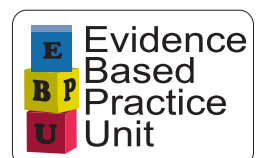




**Guide** to  
**Using Outcomes**  
and **Feedback Tools**  
with Children, Young People and Families  
*Formally known as COOP Document*

EDITED BY  
Dr Duncan Law & Dr Miranda Wolpert



Title:

*Guide to Using Outcomes and Feedback Tools with Children, Young People and Families*

Formally known as COOP (Children and Young Peoples' Improving Access to Psychological Therapies Outcomes Oriented Practice) version 2 of the above updated December 2013

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**Guide to**  
**Using Outcomes**  
**and Feedback Tools**  
**with Children, Young People and**  
**Families**

Editors:

Dr Duncan **Law** & Dr Miranda **Wolpert**

Press  
**CAMHS**

# Preface from the editors

This guide presents wisdom and learning from frontline practitioners, managers, researchers and young people with experience of service use as to how to use the outcome and feedback measures in the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) Child Outcomes Research Consortium CORC+ dataset for clinical work with children and young people with mental health issues and their families. These measures are sometimes referred to as patient reported outcome measures (PROMs) and patient reported experience measures (PREMs).

As editors we are committed to the idea of getting feedback from young people and families in order to try to track change, understand the impact of our work and to try to enhance effectiveness. We are, however, very aware of the limitations of all the current tools and approaches, and the dangers of implementation in a "reckless" fashion with no thought about "what works for whom" and "in what circumstances". We are particularly concerned that some organisations wishing to support the implementation of this approach are dictating use of tools and systems without allowing room for clinical judgement.

**The same care in choosing, using and reviewing feedback and outcome tools needs to be taken as is taken for all other aspects of therapeutic work and decision making.**

In particular we would like to highlight the following:

### **1. Curiosity**

It is early days for knowing how to best use these measures, forms and feedback approaches in ways that are clinically useful. Key questions that still need to be answered include: Should measures be used every time? Should questionnaires be given face to face or completed outside meetings? Which measures work best with whom? We are still at the start of our learning on these issues. We welcome feedback and learning from those pioneering the use of this approach and look forward to the approach being refined in the light of such learning.

### **2. Context**

All these measures are flawed; some are more flawed than others for given tasks. They should be used as a start to thinking, as guides for hypotheses or debate and need to be seen within the whole clinical picture. They are not precise tests, but rather summaries of people's answers to questions with all the limitations that entails. They should never be used as stand-alone diagnostic tools. In interpreting what responses and scores on these measures mean professionals must use their expertise and judgement.

### **3. Collaboration**

We would hope all the measures would be used in the context and ethos of collaborative working and shared decision making whereby children, young people and families are part of the process of deciding what measure to use, involved in understanding their strengths and limitations and included in any discussion of their interpretation.

The table below summarises some key dos and don'ts for how the tools/measures/forms designed to elicit outcome and experience information should be used in clinical practice:

**TABLE 0.1:** Some Dos and Don'ts of using clinical outcome tools.

<b>SOME DOS AND DON'TS OF USING CLINICAL OUTCOME TOOLS</b>	
<b>Do</b>	Make sure you have the forms you need ready before the session.
<b>Do</b>	Always explain why you are asking anyone to fill out a form.
<b>Do</b>	Look at the answers.
<b>Do</b>	Discuss the answers with service users.
<b>Do</b>	Share the information in supervision.
<b>Do</b>	Always use information from the forms in conjunction with other clinical information.
<b>Don't</b>	Give out a questionnaire if you think the person doesn't understand why they are being asked to complete it.
<b>Don't</b>	Use any form if you don't understand why you are using it.
<b>Don't</b>	Insist on someone filling out forms if they are too distressed.
<b>Don't</b>	See the numbers generated from outcome tools as an absolute fact.
<b>Don't</b>	See your clinical judgement as an absolute fact.

We welcome feedback and learning from those using any of the tools or measures in this guide. Please let us know your experience by emailing [corc@annafreud.org](mailto:corc@annafreud.org)

*Duncan Law and Miranda Wolpert, London, December 2013*

**All measures, tools, scoring advice and other resources are freely available on the CORC website [www.corc.uk.net](http://www.corc.uk.net)**

# Acknowledgements

*We would like to thank all those clinicians, young people and families who are pioneering the use of this approach and sharing their views and learning with us.*

*Thanks to all those who contributed chapters.*

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**A full list of those who have additionally contributed to this guide is given at the back.**



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# Introduction



## ABOUT THIS GUIDE

Duncan **Law**

This document combines and builds on its earlier iteration: Law, D. (Ed) (2012) 'A Practical Guide to Using Service User Feedback & Outcome Tools to Inform Clinical Practice in Child & Adolescent Mental Health'.

It has been developed from the learning, discussions and debate within the Child Outcomes Research Consortium (CORC) collaborative and Evidence Based Practice Unit (EBPU), and across Children and Young People's – Improving Access to Psychological Therapies (CYP IAPT), especially the Outcomes and Evaluation Group, and Critical Friends Forum, with input from the other CYP IAPT task and finish groups, Higher Education Institutions (HEIs), and collaborative leads.

We have tried to pay particular attention to the voice of young service users involved in the Young Minds/VIK (Very Important Kids) "Talking About Talking Therapies" and GIFT (Great Involvement, Future Thinking), and young people across the learning collaboratives, and the guide has quotes embedded in it from young people. It includes learning from clinicians and service users who have experience of using forms, feedback tools and outcome measures, to improve therapy from across the UK, Europe and USA. A big 'thank you' to all who have contributed directly and indirectly. A fuller list of contributors can be found at the back of the document.

### WHO AND WHAT IS THIS GUIDE FOR?

The main aims of this guide are twofold. Firstly, it is to provide a tool-kit setting out the forms recommended by CYP IAPT and CORC, in a coherent and structured way, setting out their uses clinically

The aim of this document is to offer guidance on how to use forms, outcome measures and feedback tools to enhance clinical practice.

This is a guide that aims to make helpful suggestions for using information from outcomes – the idea is that the suggestions are adapted to best fit with the style of the clinicians using them and context of the service users they are working with.

and as evaluation tools. Secondly, it is to provide helpful tips and advice on using the forms in everyday clinical practice. We hope the guide provides balance in setting out the problems, potential pitfalls and dilemmas in using the forms, as well as their uses and benefits. We hope the guide sparks debate and further discussion amongst practitioners and young people and families.

Primarily this document is for all who have an interest in improving clinical practice in their work with children and young people. Specifically it is aimed at those who have an interest and wish to use the information gathered from forms, feedback tools and outcome measures in clinically useful ways, either as part of CYP IAPT, or CORC, to support UPROMISE (Using Patient Reported Outcome Measures to Improve Service Effectiveness) training, or just out of curiosity. It is intended as a guide in the true sense of the word: to be used and adapted in line with clinicians' own clinical practice and in the context of the intervention with the children, young people and families with whom they are working – to give guidance, and to stimulate discussion. Its intention is to offer some helpful ideas to supervisors and clinicians who are using forms, feedback tools and outcome measures and tools in their clinical practice, to add to the full range of clinical information they routinely gather, in order to try to get better at what they do.

## A WORD ON LANGUAGE

Clearly language is important and it is easy to get paralysed by the complexity of semantics. We have tried to use language with its broadest meaning. From discussions with practitioners and young people we have found most people tend to refer to outcomes measures, feedback tools and other standardised questionnaires generically as 'forms'. In light of this we have adopted the term 'forms' as a general term to cover any 'questionnaire', 'outcome measure', 'patient reported outcomes measures (PROMs)', 'patient reported experience measures (PREMs)' or 'feedback tool'. 'Outcomes' is broadly used to mean any information gathered from using 'tools', 'measures', 'questionnaires', recommended by CYP IAPT and CORC+. Terms such as 'service users', 'clients' 'children, young people and families' (CYPFs), 'patient' are used interchangeably, as are the terms 'clinician', 'practitioner', 'therapist'. Similarly, 'intervention' is 'therapy' or 'treatment', and finally, 'information' can mean 'data'. We hope you go along with the spirit of the language – to keep things simple. Over time, in future iterations of this guide, we would hope to refine the language based on further feedback from clients, service users, children, adolescents, young people, families, carers, clinicians, practitioners, therapists...

## USING THIS GUIDE

This guide focuses on using outcomes tools to improve clinical practice. It offers suggestions for when, and when not, to use outcomes, some suggested language about how to introduce outcome measures in therapy, suggestions on how to feed back information to children, young people and families, and ideas on how to use the information from outcomes forms in supervision – along with all other clinical information – to help keep interventions on track, prevent drop-out and allow best clinical practice to be delivered whilst also attempting to improve it.

**All measures, tools, scoring advice and other resources are freely available on the CORC website [www.corc.uk.net](http://www.corc.uk.net)**

## REFERENCES

Law D., (Ed), (2012) *A practical guide to using service user feedback & outcome tools to inform clinical practice in child & adolescent mental health. Some initial guidance from the children and young people's improving access to psychological therapies outcomes oriented practice (COOP) group.* Retrieved from: [www.iapt.nhs.uk/silo/files/a-practical-guide-to-using-service-user-feedback--outcome-tools-.pdf](http://www.iapt.nhs.uk/silo/files/a-practical-guide-to-using-service-user-feedback--outcome-tools-.pdf)

# CYP IAPT TOOLS: WHAT ARE THEY, HOW WERE THEY SELECTED AND WHERE CAN YOU FIND THEM?

Miranda **Wolpert**

The approach to outcome measurement and feedback in CYP IAPT was developed by the Outcomes and Evaluation Group to support the service transformation that CYP IAPT seeks to bring about ([www.iapt.nhs.uk/CYP IAPT/](http://www.iapt.nhs.uk/CYP_IAPT/)).

The following key principles were adopted by this group (see briefing note 20 December 2011):

## KEY PRINCIPLES

### **1. This approach to use of routine outcome measurement is a new approach and is likely to benefit from refinement over time.**

The vision is that we work collaboratively and in particular that we learn from the sites that first adopt this approach and refine our thinking and practice over time.

We acknowledge up front that many aspects of this approach are new and whilst we draw on experience from earlier pilots of session-by-session monitoring in Child and Adolescent Mental Health Settings both in the UK and abroad, and from Adult IAPT, there is likely to be much for us to learn here and the approach may need refinement in light of this.

We currently invite comments; we review the approach every year (the next review is early 2014).

### **2. The views of children, young people and parents/carers are key.**

It is left to the practitioner to decide whether it is appropriate to give any individual measures to a parent/carer, a child or young person or both.

- Where only a parent/carer is involved in an intervention it may make most sense to only ask them to complete measures (and where more than one parent/carer is involved it is up to practitioner judgement if more than one parent/carer is asked to complete the measures).

- Where only a young person is in contact with services it may make most sense for only them to complete measures.
- Where both a young person and a parent/carer are involved then again it is up to practitioner judgement as to who should complete.

Most measures can be completed by a relatively able 8-year-old.

If a service user chooses not to complete a form they should not be required to do so. The practitioner should note that they have chosen not to do so. From past trials it has been found that it is very rare for service users to choose to not complete forms.

### **3. There should be no measurement without direct clinical utility.**

Any measure used as part of routine outcome monitoring should directly contribute to the clinical work. In particular, when choosing the measures for use at each meeting, practitioners should look at the specific set of items/questions being asked and choose with the relevant service user that set of items which feels most meaningful to monitor.

The potential danger of the measures being seen as a “tick box” or bureaucratic exercise, rather than a means to develop meaningful conversations, is recognised as a major risk. The vision of reviewing progress from the point of view of service users to aid direct work needs to be kept in mind by practitioners, and supported by supervisors and managers.

### **4. Good data and careful contextualized analysis are necessary for meaningful national reporting and local analysis.**

To guarantee adequate data, services need to ensure that 90% of all closed cases accepted for intervention within Tier 2 or 3 have post-assessment outcome data based on relevant service user report at at least two time points (based on the same measure and the same informant).

This completion rate should be achieved by all IAPT trainees and supervisors from April of the year they join IAPT and for those in the wider service by January of the following year.

### **5. Routine Outcome Monitoring (ROM) must be supported and resourced.**

Service managers must ensure:

- All cases have one nominated practitioner who is responsible for determining that ROM is meaningfully instituted for that case and make decisions about how this is to be managed when multiple practitioners and/or interventions are involved.
- There are appropriate systems for collection of required data in their services.

Supervisors/clinical leads must help support practitioners to:

- Determine collaboratively with service users the key things they want to work on and how to record and monitor these in each session.
- Introduce outcome evaluation to children and families and understand the rationale for the use of the measures.
- Be cognisant of the strengths and limitations of different forms of outcome data and of how best to interpret information in the light of these.
- Judge when it is appropriate for a client not to be asked to complete a scale.
- Interpret what scored questionnaire results mean including what thresholds are and what they mean, and what counts as significant improvement.
- Encourage open communication from clients including knowing how to make constructive use of negative or critical feedback.
- Be able to use outcome data along with other information to decide on whether a change of therapy or change of techniques within that therapy is needed.

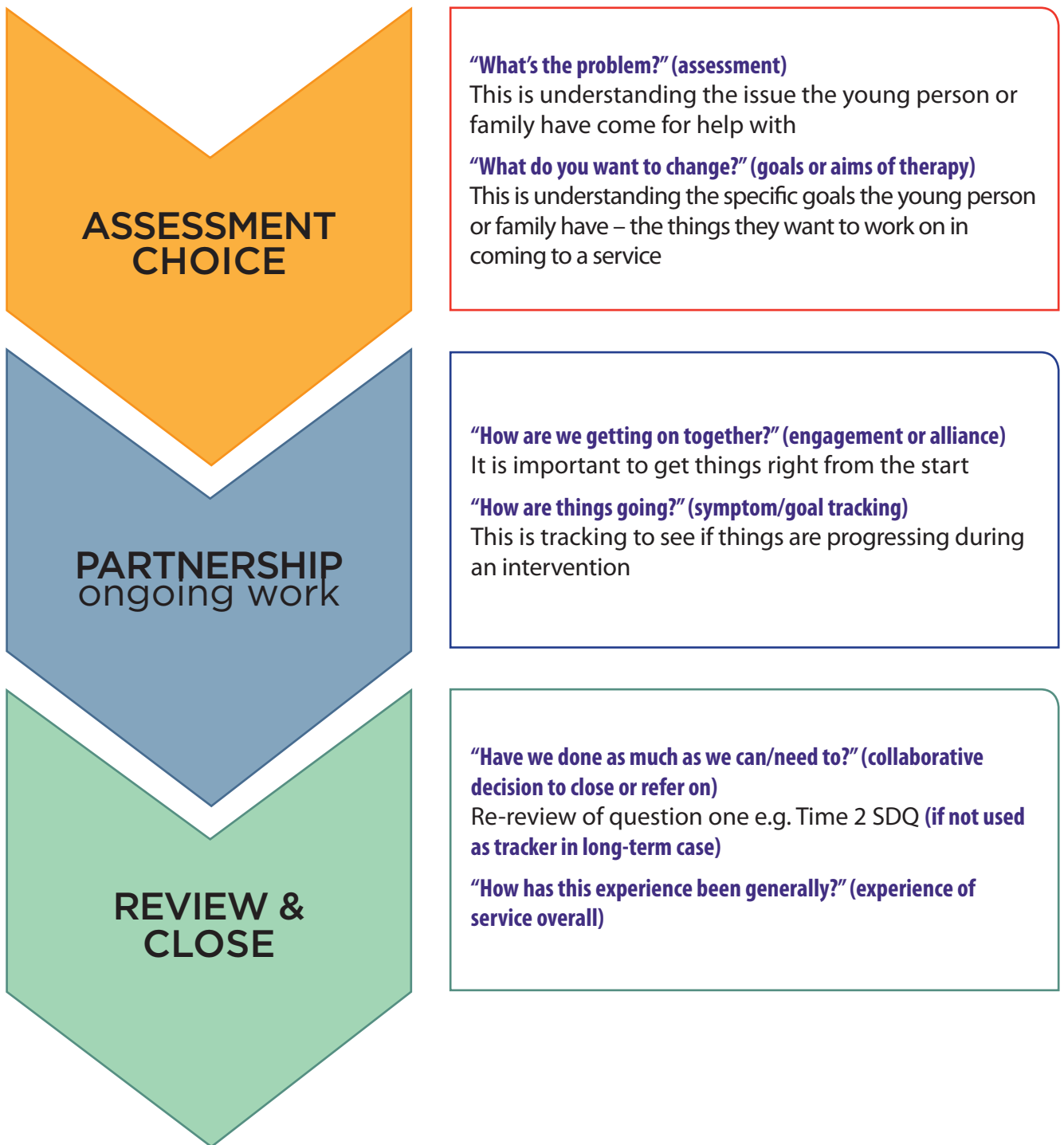
## USING THE TOOLS THROUGHOUT THE CARE PATHWAY TO ANSWER SIX QUESTIONS

Miranda **Wolpert**

The tools and approach are designed to be used at each of the three stages of the young person and family's journey through care (assessment/choice, partnership working/ongoing work and review/close), and attempts to help the clinician and those they are working with to answer six key questions (as summarised below). Note each question can be asked at different stages of the care pathway but at Figure 0.1 they are organised according to key questions for different stages just for simplicity of diagrammatic representation.

**NOTE: The tools were not selected to replace other tools or information gathering that might be crucial to care provision (such as risk management, full assessment). They are not intended to be comprehensive. They are rather the best tools the group could find that met the selection criteria, including being free at point of use and non-burdensome, that could be used for the dual purpose of clinical work and audit of services. There may be other important tools and measures not included here that may aid clinical work (such as costed measures or other tools).**

Below are outlined possible tools to answer each of the six key questions outlined below. It is advised that practitioners select the tool that is best for their client based on their judgement, informed by client choices and views.



**FIGURE 0.1:** Three Stages of Interventions and six key questions.

**TABLE 0.2:** Tools to help answer the question “What’s the problem?”

<b>BROAD FOCUS</b>		<b>AGE RANGE COVERED</b>	<b>WHOSE PERSPECTIVE THIS TOOL CAN CAPTURE</b>
Revised Children’s Anxiety and Depression Scale (RCADS)		8-18	Child, parent
Strengths and Difficulties Questionnaire (SDQ)		3-16 (self-report 11+)	Child, parent, teacher
Current View		All	Professional
Health of the Nation Outcome Scale (HoNOSCA)		3-18	Professional, child, parent
Children’s Global Assessment Scale (CGAS)		4-18	Professional
Outcome Rating Scale (ORS) or Children’s Outcome Rating Scale (CORS) or Young Child Outcome Rating Scale (YCORS)		All	Child, parent
Goals Based Outcome (GBO)		All ages	Child, parent, family, teacher, professional
Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)		13+	Child
Impact on life (impact subscale of SDQ/RMQ)		3-16 (self-report 11+)	Child, parent
<b>SPECIFIC FOCUS (SYMPTOMS, IMPACT, POPULATIONS, RELATIONSHIPS)</b>		<b>AGE RANGE COVERED</b>	<b>WHOSE PERSPECTIVE THIS TOOL CAN CAPTURE</b>
Depression	How are things? (Depression RCADS subscales)	8–18	Child, parent
	How are things? Patient Health Questionnaire – PHQ-9 (Depression)	16+	Young person
Generalised Anxiety	How are things? (Generalised anxiety RCADS subscales)	8–18	Child, parent
	How are things? Generalised Anxiety Disorder Assessment – GAD-7	16+	Young person
Separation Anxiety	How are things? (Separation anxiety RCADS subscales)	8–18	Child, parent
Social Anxiety	How are things? (Social anxiety RCADS subscales)	8–18	Child, parent
OCD	How are things? (OCD RCADS subscales)	8–18	Child, parent
Panic	How are things? (Panic RCADS subscale)	8–18	Child, parent
PTSD	How are things? Disturbed by a traumatic event (PTSD) (Impact of Events Scale)	8–18	Child, parent
Behavioural difficulties	How are things? (Me & My School – M&MS)	8–14	Child
	How are things? (Oppositional Defiant Disorder – ODDp)	All ages	Parent
Parenting	Brief Parental Self-Efficacy Scale (BPSES)	All ages	Parent
LD	Sheffield Learning Disabilities Outcome Measure (SLDOM)	All age	Parent
Eating Disorders	Eating Disorders Examination Questionnaire (EDE-Q)	14–16	Child
Family Functioning	SCORE-15	12+	Family

**TABLE 0.3:** Tools to help answer the question “What does the service user want to change/what are we going to work on?”

FOCUS	AGE RANGE COVERED	WHOSE PERSPECTIVE THIS TOOL CAN CAPTURE
Goals Based Outcome (GBO) [note: does not need to be phrased in language of goals but there should be agreement as to focus of work can draw on tools used to identify the problem]	All ages	Child, parent, family, teacher, professional

**TABLE 0.4:** Tools to help answer the question “How does the service user experience the meetings?”

SESSION FEEDBACK		
Session Feedback Questionnaire (SFQ)		
Session Rating Scale (SRS)		
Child Session Rating Scale (CSRS)		
Child Session Rating Scale (CSRS)	All ages	Child, parent
Young Child Session Rating Scale (YCSRS)		
Young Child Outcome Rating Scale (YCORS)		
Group Session Rating Scale (GSRS)		
Child Group Session Rating Scale (CGSRS)		



**TABLE 0.5:** Tools to help answer the question “How are things going week by week or at relevant regular check points?”

<b>BROAD FOCUS</b>		<b>AGE RANGE COVERED</b>	<b>WHOSE PERSPECTIVE THIS TOOL CAN CAPTURE</b>
Revised Children’s Anxiety and Depression Scale (RCADS)		8–18	Child, parent
Strengths and Difficulties Questionnaire (SDQ)		3–16 (self-report 11+)	Child, parent, teacher
Current View		All	Professional
Health of the Nation Outcome Scale (HoNOSCA)		3–18	Professional, child, parent
Children’s Global Assessment Scale (CGAS)		4–18	Professional
Outcome Rating Scale (ORS or CORS or YCORS)		All	Child, parent
Goals Based Outcome Measure (GBO)		All ages	Child, parent, family, teacher, professional
Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)		13+	Child
Impact on life (impact subscale of SDQ/RMQ)		3–16 (self-report 11+)	Child, parent

<b>SPECIFIC FOCUS (SYMPTOMS, IMPACT, POPULATIONS, RELATIONSHIPS)</b>		<b>AGE RANGE COVERED</b>	<b>WHOSE PERSPECTIVE THIS TOOL CAN CAPTURE</b>
Depression	How are things? (Depression RCADS subscales)	8–18	Child, parent
	How are things? Patient Health Questionnaire – PHQ-9 (Depression)	16+	Young person
Generalised Anxiety	How are things? (Generalised anxiety RCADS subscales)	8–18	Child, parent
	How are things? Generalised Anxiety Disorder Assessment – GAD-7	16+	Young person
Separation Anxiety	How are things? (Separation anxiety RCADS subscales)	8–18	Child, parent
Social Anxiety	How are things? (Social anxiety RCADS subscales)	8–18	Child, parent
OCD	How are things? (OCD RCADS subscales)	8–18	Child, parent
Panic	How are things? (Panic RCADS subscale)	8–18	Child, parent
PTSD	How are things? Disturbed by a traumatic event (PTSD) (Impact of Events Scale)	8–18	Child, parent
Behavioural difficulties	How are things? (Me & My School – M&MS)	8–14	Child
	How are things? (Oppositional Defiant Disorder – ODDp)	All ages	Parent
Parenting	Brief Parental Self-Efficacy Scale (BPSES)	All ages	Parent
LD	Sheffield Learning Disabilities Outcome Measure (SLDOM)	All ages	Parent
Eating Disorders	Eating Disorders Examination Questionnaire (EDE-Q)	14–16	Child
Family Functioning	SCORE-15	12+	Family

**TABLE 0.6:** Tools to help answer the question “Have we done as much as we can/need to?”

BROAD FOCUS		AGE RANGE COVERED	WHOSE PERSPECTIVE THIS TOOL CAN CAPTURE
Revised Children’s Anxiety and Depression Scale (RCADS)		8–18	Child, parent
Strengths and Difficulties Questionnaire (SDQ)		3-16 (self-report 11+)	Child, parent, teacher
Current View		All	Professional
Health of the Nation Outcome Scale (HoNOSCA)		3–18	Professional, child, parent
Children’s Global Assessment Scale (CGAS)		4–18	Professional
Outcome Rating Scale (ORS or CORS or YCORS)		All	Child, parent
Goals Based Outcome Measure (GBO)		All ages	Child, parent, family, teacher, professional
Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)		13+	Child
Impact on life (impact subscale of SDQ/RMQ)		3–16 (self-report 11+)	Child, parent

SPECIFIC FOCUS (SYMPTOMS, IMPACT, POPULATIONS, RELATIONSHIPS)		AGE RANGE COVERED	WHOSE PERSPECTIVE THIS TOOL CAN CAPTURE
Depression	How are things? (Depression RCADS subscales)	8–18	Child, parent
	How are things? Patient Health Questionnaire – PHQ-9 (Depression)	16+	Young person
Generalised Anxiety	How are things? (Generalised anxiety RCADS subscales)	8–18	Child, parent
	How are things? Generalised Anxiety Disorder Assessment – GAD-7	16+	Young person
Separation Anxiety	How are things? (Separation anxiety RCADS subscales)	8–18	Child, parent
Social Anxiety	How are things? (Social anxiety RCADS subscales)	8–18	Child, parent
OCD	How are things? (OCD RCADS subscales)	8–18	Child, parent
Panic	How are things? (Panic RCADS subscale)	8–18	Child, parent
PTSD	How are things? Disturbed by a traumatic event (PTSD) (Impact of Events Scale)	8–18	Child, parent
Behavioural difficulties	How are things? (Me & My School – M&MS)	8–14	Child
	How are things? (Oppositional Defiant Disorder – ODDp)	All ages	Parent
Parenting	Brief Parental Self-Efficacy Scale (BPSES)	All ages	Parent
LD	Sheffield Learning Disabilities Outcome Measure (SLDOM)	All age	Parent
Eating Disorders	Eating Disorders Examination Questionnaire (EDE-Q)	14–16	Child
Family Functioning	SCORE-15	12+	Family

**TABLE 0.7:** Tools to help answer the question “How has this experience been generally?”

SERVICE FEEDBACK		
CHI Experience of Service Questionnaire	All ages (self-report 9 +)	Child, parent

## WHAT YOUNG PEOPLE SAY ABOUT OUTCOMES AND FEEDBACK TOOLS

Young Sessional Workers from the **GIFT Team** (Charlotte **Green**, Bethany **Taylor**, Rhiannon **Dunlop**, Jonathan **Davies**, Rachel **Vowden** and Olivia **Stanley**) and Cathy **Street**

### YOUNG PEOPLE'S PERSPECTIVES ON THE USE OF OUTCOMES TOOLS: IDEAS AND SUGGESTIONS FROM GIFT (GREAT INVOLVEMENT, FUTURE THINKING)

Outcome measures, if used correctly and appropriately, can provide service users with a more definite goal and focus. Therapy of whatever kind can seem abstract and users can sometimes be left feeling as though their therapy is in one place and their real life another. Outcome measures and tools can help to align these by showing users and their therapists where they are heading, where they have come from and what they are achieving. They can feel tedious but they are also a great way to see how things are going and how areas of a service can be improved. From a young person's point of view, they can make them feel listened to and make the sessions feel much more worthwhile.

Most young people welcome the opportunity to complete outcomes tools – but two things are absolutely critical: they must be simple to fill in and it must be clear why a young person is filling them in. If outcome measures are going to be used, they need to be used in a positive, thoughtful and meaningful way. If the clinician doesn't feel positive about them, the client certainly won't! Also the outcome measures should be flexible and adapted according to the young person – at no point should the importance of filling in outcome measures take precedence over the young person and how they are feeling.

Our suggestion is that if you are going to use ten minutes out of each therapy session to fill in and think about outcome measures, it must feel meaningful and helpful to the young person. Outcome measures can be an extremely helpful tool for both the young person and the clinician, but not if the attitude towards them is negative and their effectiveness is not embraced.

The other thing to remember is feedback – it's all very well and good filling out the outcome measure forms and seeming positive about it, but this is all worthless if you don't follow through.

## FEEDBACK IS INCREDIBLY IMPORTANT!

### YOUNG PEOPLE'S VIEWS:

*"Make sure you listen to the young person! Some of the data may highlight things that don't feel right for the young person or things that they would like to change, make sure you listen and make sure that the young person knows that you have heard them."*

*"Knowing when and how to use the outcome measures is important. They must become an integrated part of the session – not something that is kept as an abstract form-filling exercise."*

*"The questions need to cover things about the general environment of CAMHS as well as the specific sessions..."*

*"They can consolidate a good working partnership between the clinician and the user..." "Clinicians must ensure that the feedback they give is understandable to the young person...if it feels like random form filling just for the service, tagged on at the end of each session, then this has no meaning for young people."*

*"I think maybe creating a short document to give to service users explaining how outcome measures will be used and how they will be heard is maybe important."*

*"Outcomes tools can be really useful, not only for the therapists but for the young people. They allow you to evaluate where things are going well and where they could be improved. Feedback is important for us to learn and grow. However, I do think you must use outcomes tools with the correct intention and in the right way."*

## WHAT CAN HELP ENSURE FEEDBACK AND OUTCOMES TOOLS ARE USED WELL?

- Follow up using an outcome tool with a conversation
- Make sure you emphasise how important a young person's view is – be honest!
- Ensure that both you and the young person know the purpose behind the tool
- Don't let the outcome tool cancel out how the young person is presenting

*"Whenever I was doing a questionnaire, it felt like a tick box exercise. I didn't know why I was doing it. In fact no one seemed to understand the point of the questionnaire; it was just a standard process. Eventually I stopped thinking what I wrote on it as it just seemed pointless. The questionnaire was always just whisked away from me as soon as I had finished it, never to be seen again..."*

*"It was difficult filling out the questionnaire because I filled it out according to how I felt at that moment, which could be different an hour later..."*

*"By the end of therapy, I was sick of seeing the same questionnaire over and over again"*

**TABLE 0.8:** Young people’s checklist for good practice when using tools to gather feedback.

HAVE YOU EXPLAINED?	YES	NO
What feedback you would like to gather, why and how it can improve the therapy or treatment you are offering		
That if a young person doesn’t understand a question or is unsure about it, they can ask for help... and that they don’t have to answer a question if they don’t want to		
How you will monitor feedback or outcomes data over time and how young people can be involved in this		
That if a young person has any other issues or concerns that are not covered by the feedback questionnaires, it’s fine to raise these		
If and how parents or carers might be asked for feedback too – remembering that their involvement might make it difficult for some young people to fully express themselves		
HAVE YOU CONSIDERED?	YES	NO
Using different ways of gathering and then sharing feedback (not all feedback should be gathered by questionnaires since they may not allow for qualitative or more in-depth answers)		
How to make the feedback at the end of a session personal to the young person so that it benefits them		
How to share feedback data with young people in a way that is accessible and understandable to them		
How you balance gathering feedback in the time available (it’s important young people feel listened to and that gathering feedback doesn’t dominate the session; on the other hand, young people shouldn’t feel pressured into filling in the forms quickly at the end of a session)		
How you might need to vary how and when you request or share feedback, given that every young person is different and should be treated as an individual		

## FURTHER RESOURCES

Please visit **MyAPT** at [www.myapt.org.uk](http://www.myapt.org.uk) and [www.iapt.nhs.uk/CYP IAPT/children-and- young-peoples-participation/](http://www.iapt.nhs.uk/CYP_IAPT/children-and-young-peoples-participation/)

# USING FEEDBACK AND OUTCOMES FORMS IN CLINICAL PRACTICE

Duncan Law

## TIPS FOR GETTING STARTED

For most clinicians who have not used forms in therapy before, the hardest thing is getting started – here are some tips to help:

- **Plan**
  - » Look at the tools to get the general idea about what they do.
  - » Choose just one to try.
  - » Practice what you might say to introduce the form etc.
- **Do**
  - » Try that one tool with just one young person – maybe someone you have been working with already – you might ask them to ‘help you out’ in trying it and getting their feedback.
- **Study**
  - » Reflect on what went well and what didn’t – Did you remember to take the form into the room? What did you say? Were there any difficult questions?
  - » Plan what might make things go better next time.
  - » Discuss with colleagues to get tips from them.
- **Act**
  - » Have another go, and go round the plan, do, study, act loop again and again until you feel comfortable.

- Once you have tried with one tool with one young person move to using the same tool with the next three young people you work with, then the next five, then everyone for whom it is appropriate.
- Once you are familiar with one tool introduce another.
- And repeat ...



**FIGURE 0.2:** The Plan, Do, Study, Act cycle (PDSA; Langley et al., 2009).

## REFERENCES

Langley G. L., Nolan K. M., Nolan T. W., Norman C. L., Provost L. P., (2009) *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance (2nd edition)*. Jossey Bass, San Francisco.

## WHICH TOOLS WHEN

Melanie Jones

The CYP IAPT tools provide a variety of ways of gathering a wealth of information to help clinicians understand many components of a case across all stages of the work. This is achieved through a large battery of measures covering many dimensions of symptoms, functioning and general wellbeing, with information being able to be gathered from a varying range of respondents within the network around the family. The flexibility and scope this brings can feel overwhelming when faced with the task of choosing the most appropriate set of tools that balance sufficient depth and breadth of information with minimal burden for the young person, family and clinician.

The process of selecting tools can be facilitated by thinking of the tools as being there to help you answer two questions at each of three key stages of the encounter:

**TABLE 0.9:** Questions to focus the use of CYP IAPT tool.

THE QUESTIONS	WHAT ARE YOU TRYING TO UNDERSTAND?
<b>Stage One: Choice/Assessment</b>	
1. <i>What's the problem?</i>	The issue the young person or family have come for help with.
2. <i>What do you want to change?</i>	The specific goals or aims the young person or family have for therapy (the things they want to work on in coming to a service).
<b>Stage Two: Partnership/On-going work</b>	
1. <i>How are we getting on together?</i>	The extent to which you are getting things right for the young person or family (the engagement or alliance).
2. <i>How are things going?</i>	The extent to which things are progressing as expected (symptoms and/or goal tracking).
<b>Stage Three: Review and/or Closure</b>	
1. <i>Have we done as much as we can/need to?</i>	Whether it is appropriate to end and/or refer on.
2. <i>How has this experience been generally?</i>	The young person or family's experience of the service overall.



With your question(s) in mind, your choice of tools can then be guided by the way(s) in which the different tools can contribute towards an answer to your question(s). The following table broadly clusters the CYP IAPT tools together according to their information-providing focus:

**TABLE 0.10:** CYP IAPT tools clustered according to information-providing focus.

<b>BROAD FOCUS</b>	
Revised Children’s Anxiety and Depression Scale (RCADS)	
Strengths and Difficulties Questionnaire (SDQ)	
Current View	
Health of the Nation Outcome Scale (HoNOSCA)	
Children’s Global Assessment Scale (CGAS)	
Outcome Rating Scale (ORS)	
Children’s Outcome Rating Scale (CORS)	
Young Child Outcome Rating Scale (YCORS)	
<b>SPECIFIC FOCUS (SYMPTOMS, IMPACT, POPULATIONS, RELATIONSHIPS)</b>	
Depression	How are things? (Depression)
	How are things? Patient Health Questionnaire – PHQ-9 (Depression)
Generalised Anxiety	How are things? (Generalised anxiety)
	How are things? Generalised Anxiety Disorder Assessment – GAD-7
Separation Anxiety	How are things? (Separation anxiety)
Social Anxiety	How are things? (Social anxiety)
OCD	How are things? (OCD)
Panic	How are things? (Panic)
PTSD	How are things? Disturbed by a traumatic event (PTSD)
Behavioural Difficulties	How are things? (Me & My School – M&MS)
	How are things? (Oppositional Defiant Disorder – ODDp)
Wellbeing	Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)
Parenting	Brief Parental Self-Efficacy Scale (BPSES)
Impact on Life	How are you doing? (Impact)
LD	Sheffield Learning Disabilities Outcome Measure (SLDOM)
Eating Disorders	Eating Disorders Examination Questionnaire (EDE-Q)
Family Functioning	SCORE-15
<b>GOAL-SETTING</b>	
Goals Based Outcome Measure (GBO)	
<b>SESSION FEEDBACK</b>	
Session Feedback Questionnaire (SFQ)	
Session Rating Scale (SRS)	
Child Session Rating Scale (CSRS)	
Young Child Session Rating Scale (YCSRS)	
Group Session Rating Scale (GSRS)	
Child Group Session Rating Scale (CGSRS)	
<b>SERVICE FEEDBACK</b>	
Experience of Service Questionnaire (ESQ)	

It is ultimately up to your clinical judgement to decide which forms you need to draw on to answer these questions. The following 4M principles might be helpful to bear in mind when you are considering this:

**TABLE 0.11:** Some principles to guide selection of CYP IAPT tools.

<b>THE 4M PRINCIPLES</b>	
<b><i>Minimal Burden</i></b>	No unnecessary form filling.
<b><i>Multiple Perspectives</i></b>	Consider collecting different people's views.
<b><i>Meaningful Use</i></b>	Only select forms that could provide meaningful information that will be used by somebody.
<b><i>Missing Something?</i></b>	Consider whether any of the forms could fill a gap that you may not have covered in some other way that might be useful to know about.

Your choice of tools will also be driven by what you feel best fits with your style of working. The format of the tools varies considerably ranging from those that require integration into clinical conversation (e.g. Goals Based Outcomes) to those that, being brief questionnaire style (e.g. SDQ), could even be completed outside of the therapeutic session. Nevertheless, whatever the chosen administration method, it should be noted that information from any completed tools should always be fed back and discussed with the young person and family to some extent (as and when clinically appropriate).

You may need to spend some time familiarising yourself with each of the CYP IAPT tools in order to make best use of them and to ensure that you are really choosing what's best for the families that you are working with.

The following tables provide some brief guidance and suggestions to facilitate choice of tools using the questions and principles briefly outlined above. Table 0.11.

## CHOOSING WHAT'S BEST

**TABLE 0.12:** Choice/Assessment – Question one: What's the problem?

CHOICE/ASSESSMENT – QUESTION ONE: WHAT'S THE PROBLEM?	
<b>Some dimensions to help you determine how you need to answer the question</b>	<p>Reflect on what you need to know about the presenting problems.</p> <p><b>Overview of symptoms</b></p> <ul style="list-style-type: none"> <li>• Would it be good enough to just use a measure that provides an overview of functioning/difficulties?</li> </ul> <p><b>Specific symptoms</b></p> <ul style="list-style-type: none"> <li>• Do you also need a measure of the frequency and/or severity of specific symptoms?</li> <li>• If you are measuring specific symptoms, do you also need the general overview measure?</li> </ul> <p><b>Impact</b></p> <ul style="list-style-type: none"> <li>• Do you need a measure that more directly considers the impact of symptoms on functioning, or is frequency/severity good enough?</li> <li>• Are there specific aspects of impact that you want to reflect on, e.g. education, employment &amp; training (EET)?</li> </ul> <p><b>Well-being</b></p> <ul style="list-style-type: none"> <li>• Would it be useful to include a measure of general well-being? Could this best be used before/after/alongside any measures of symptoms?</li> </ul> <p><b>Supportive/protective factors</b></p> <ul style="list-style-type: none"> <li>• Would it be useful to include a measure of something that might help with assessment of supportive and/or protective factors, e.g. self-identity, resilience, self-efficacy, strength of support network, relationships?</li> </ul>
<b>Consider the 4Ms</b>	<p><b>Minimal burden</b></p> <ul style="list-style-type: none"> <li>• Selecting at least one measure of general symptomatology is usually a good starting place (the exception to this might be when this would be too burdensome if also using several measures of specific symptoms).</li> </ul> <p><b>Multiple perspectives</b></p> <ul style="list-style-type: none"> <li>• Whose perspectives do you need to know? Have you included everyone who you might need to give you this information?</li> <li>• It is generally useful to consider gaining ratings from different perspectives where appropriate and possible (e.g. both self-report and parent report...do you need to know both parents' views?).</li> </ul> <p><b>Meaningful use</b></p> <ul style="list-style-type: none"> <li>• Consider whether you need to understand about the frequency or severity of specific symptoms, (e.g. frequency of purging for eating disorders) or whether a more general measure of symptomatology would be sufficient and of more meaningful use.</li> </ul> <p><b>Missing something?</b></p> <ul style="list-style-type: none"> <li>• Consider completing one of the practitioner forms (e.g. Current View) as a way of focusing on which self and parent report measures may be most helpful. This sort of tool may help clarify where depth and breadth of further information gathering is necessary and can sometimes also provide a means of logging and tracking aspects of a presentation that are not covered by other measures used (e.g. EET).</li> </ul>
<b>Once you have made your choice...</b>	<ul style="list-style-type: none"> <li>• Reflect on how you will use the information from each of the tools you have chosen to use.</li> <li>• Plan how you will administer and feedback this information.</li> </ul>

**TABLE 0.13:** Choice/Assessment – Question two: What do you want to change?

<b>CHOICE/ASSESSMENT – QUESTION TWO: WHAT DO YOU WANT TO CHANGE?</b>	
<b><i>Some dimensions to help you determine how you need to answer the question</i></b>	<p>Reflect on what you need to know to help the young person or family to become clearer about specific goals or aims for the work.</p> <p><b>Consider exploring symptoms</b></p> <ul style="list-style-type: none"> <li>• Would exploring the severity and/or frequency of symptoms help with thinking about focus for the work?</li> <li>• Would an overview of functioning/difficulties be enough and/or would it be useful to understand specific types of difficulties?</li> <li>• If you are measuring specific symptoms, do you also need the general overview measure for identifying goals?</li> </ul> <p><b>Consider exploring impact</b></p> <ul style="list-style-type: none"> <li>• Would a measure that considers the impact of symptoms on functioning be helpful in identifying focus for this young person or family?</li> <li>• Are there specific aspects of impact that you think might be most helpful, (e.g. EET)?</li> </ul> <p><b>Consider exploring supportive/protective factors</b></p> <ul style="list-style-type: none"> <li>• Would a more solution-focused approach be most helpful – some young people and families might find goal-setting is facilitated by completion of a measure that considers supportive and/or protective factors (e.g. self-identity, resilience, self-efficacy, strength of support network, relationships).</li> </ul>
<b><i>Consider the 4Ms</i></b>	<p><b>Minimal burden</b></p> <ul style="list-style-type: none"> <li>• Consider whether additional forms are even necessary for goal-setting – could you help the young person or family to identify goals simply through clinical conversation?</li> </ul> <p><b>Multiple perspectives</b></p> <ul style="list-style-type: none"> <li>• Whose perspectives might be helpful in thinking about areas for change? Have you included everyone who you might need to give you this information?</li> <li>• Consider whether and where it is most appropriate to set shared goals and individual goals – and then reflect on the range of perspectives that would facilitate this process.</li> </ul> <p><b>Meaningful use</b></p> <ul style="list-style-type: none"> <li>• Reflect on whether knowing more about general and/or specific symptoms, impact and strengths would really be information that you could use in goal-setting. If you decide to collect the information for this purpose, then make sure you explain this rationale to the family and then consider the information they provide with goal-setting in mind.</li> </ul> <p><b>Missing something?</b></p> <ul style="list-style-type: none"> <li>• Consider completing one of the practitioner forms (e.g. Current View) as a way of focusing your ideas on which goals may be most relevant and helpful for this young person/family. This sort of tool may help your developing formulation and clarify where you think the focus of the work could/should be.</li> </ul>
<b><i>Once you have made your choice...</i></b>	<ul style="list-style-type: none"> <li>• Reflect on how you will use the information from each of the tools you have chosen to use.</li> <li>• Plan how you will administer and feed back this information.</li> </ul>

**TABLE 0.14:** Partnership/On-going – Question two: How are we getting on together?

<b>PARTNERSHIP/ON-GOING – QUESTION ONE: HOW ARE WE GETTING ON TOGETHER?</b>	
<i>Some dimensions to help you determine how you need to answer the question</i>	<p>Reflect on what you need to know to understand how well you are meeting the needs of the young person or family.</p> <p><b>Consider different formats for feedback</b></p> <ul style="list-style-type: none"> <li>• There are a few choices of format for young people and families to provide feedback on how they have found the session – consider which of these you think they would find most helpful.</li> <li>• Would this young person/family be best suited to a questionnaire-style tick box method or do you think they would find it easier to feed back by placing a mark on a line?</li> </ul>
<i>Consider the 4Ms</i>	<p><b>Minimal burden</b></p> <ul style="list-style-type: none"> <li>• Consider whether the feedback might feel more or less burdensome when administered in paper form. Are there circumstances where collecting this information verbally might reduce the perceived burden of paperwork in the session? Consider how this format might affect the information you receive.</li> </ul> <p><b>Multiple perspectives</b></p> <ul style="list-style-type: none"> <li>• Whose perspectives might be helpful in thinking about how useful the session was? Have you included everyone who you might need to give you this information? Consider how useful information around differing experiences of usefulness might be and ensure you leave enough time in the session for any resulting discussions.</li> </ul> <p><b>Meaningful use</b></p> <ul style="list-style-type: none"> <li>• Explaining the rationale for asking for feedback on session experience is an important component. Ensure that you explain this rationale to the family and allow the opportunity for any questions around this.</li> <li>• Once you have introduced this way of working, it is then important to make sure that you follow this up with actually asking for and discussing this feedback (where clinically appropriate).</li> <li>• Consider how prepared you are to adapt your ways of working in response to feedback from the families you work with.</li> </ul> <p><b>Missing something?</b></p> <ul style="list-style-type: none"> <li>• Try to step back and reflect on whether your proposed frequency and format of gathering feedback will allow this family to let you know how well things are going in a way such that you could, if necessary, adapt your ways of working with them.</li> </ul>
<i>Once you have made your choice...</i>	<ul style="list-style-type: none"> <li>• Reflect on how you will use the information from each of the tools you have chosen to use.</li> <li>• Plan how you will administer and feed back this information.</li> </ul>

**TABLE 0.15:** Partnership/On-going – Question two: How are things going?

<b>PARTNERSHIP/ON-GOING – QUESTION TWO: HOW ARE THINGS GOING?</b>	
<b>Some dimensions to help you determine how you need to answer the question</b>	<p>Reflect on what you need to know about in order to sufficiently understand progress.</p> <p><b>Effectiveness</b></p> <ul style="list-style-type: none"> <li>• Which measures could you use to understand more about the on-going effectiveness of the intervention being provided?</li> </ul> <p><b>Frequency of measurement</b></p> <ul style="list-style-type: none"> <li>• Consider how often measurements would need to be taken to be sufficiently informative and useful? What speed of change are you expecting to/hoping will occur?</li> </ul> <p><b>Unit(s) of progress</b></p> <ul style="list-style-type: none"> <li>• Consider which unit(s) of progress would be most useful both for understanding change and for making use of the information to guide the on-going work.</li> <li>• <b>General symptoms</b> Consider whether it is good enough to track progress by measuring changes in overall functioning.</li> <li>• <b>Specific symptoms</b> Would it be more useful to track changes in the frequency and/or severity of specific symptoms?</li> <li>• <b>Impact</b> Consider whether it might be more useful to track the impact of symptoms on functioning and/or whether there are specific aspects of impact that you want to be able to reflect on, e.g. attendance or attainment with regard to EET?</li> <li>• <b>Well-being</b> Would the young person/family find it more meaningful and motivating to track levels of well-being? Could this be enough or would you also need to consider tracking of symptoms alongside?</li> <li>• <b>Supportive/protective factors</b> Would tracking scores on a measure of supportive and/or protective factors (e.g. self-identity, resilience, self-efficacy, strength of support network, relationships) be meaningful and motivating for some young people and families?</li> </ul>
<b>Consider the 4Ms</b>	<p><b>Minimal burden</b></p> <ul style="list-style-type: none"> <li>• Consider the balance between sufficiently monitoring progress in order to notice change with not introducing unnecessary burden or measurement fatigue.</li> <li>• If forms are long, would infrequent time points (e.g. four–six monthly intervals) be sufficient for tracking progress? Would it be more appropriate/informative to choose briefer measures that could be used at more frequent intervals?</li> </ul> <p><b>Multiple perspectives</b></p> <ul style="list-style-type: none"> <li>• Whose perspectives will be most important in understanding progress? Have you included everyone who you might need to give you this information? Consider whether you want to use forms to consult respondents who you are not directly meeting with – their perceptions of progress could be a useful part of the process.</li> </ul> <p><b>Meaningful use</b></p> <ul style="list-style-type: none"> <li>• Consider the potential purpose of the information you are collecting and keep that purpose in mind as the information comes in over time. Are you hoping things will improve, wanting to check they don't worsen or demonstrate an unrecognized strength? Reflect on whether the information you are collecting is really serving the purpose you hoped – if it isn't, then consider whether you need to keep collecting it, and whether there might be some other more meaningful information you could be gathering.</li> </ul> <p><b>Missing something?</b></p> <ul style="list-style-type: none"> <li>• Reflect on the information you are gathering and the purpose(s) for collection. Consider this information in the context of your overall developing clinical impression. Is this tracking information still providing all you need to know, or are there other components of the young person's presentation that you might usefully consider through form measurement?</li> </ul>
<b>Once you have made your choice...</b>	<ul style="list-style-type: none"> <li>• Reflect on how you will use the information from each of the tools you have chosen to use.</li> <li>• Plan how you will administer and feed back this information.</li> </ul>

**TABLE 0.16:** Review/Closure – Question one: Have we done as much as we can/need to?

<b>REVIEW/CLOSURE – QUESTION ONE: HAVE WE DONE AS MUCH AS WE CAN/NEED TO?</b>	
<b><i>Some dimensions to help you determine how you need to answer the question</i></b>	<p>Reflect on what you need to know about in order to sufficiently understand whether the work has reached an appropriate end-point.</p> <p><b>Unit(s) of clarification</b></p> <ul style="list-style-type: none"> <li>Consider whether it would be appropriate to repeat all measures used at the assessment stage (and at any previous review stages), or whether the collection of all this information would now not be meaningful and/or would introduce unnecessary burden.</li> </ul> <p><b>Evaluating proposed pathways</b></p> <ul style="list-style-type: none"> <li>Which measures might provide information about whether it could be beneficial to continue with the proposed pathway of care (whether that be continuation of current work and/or referral on to a different professional/service)?</li> <li>Which measures might provide information that could facilitate any decisions/discussions around ending the work/discharge?</li> </ul>
<b><i>Consider the 4Ms</i></b>	<p><b>Minimal burden</b></p> <ul style="list-style-type: none"> <li>What do you minimally need to know about in order to understand whether the work could most usefully end at this point?</li> </ul> <p><b>Multiple perspectives</b></p> <ul style="list-style-type: none"> <li>Whose perspectives will be most important in understanding decisions to end/refer on? Have you included everyone who you might need to give you this information? Consider whether you want to use forms to consult respondents who you are not directly meeting with – their experiences could be an important part of the decision-making process.</li> </ul> <p><b>Meaningful use</b></p> <ul style="list-style-type: none"> <li>Be clear about what information you might need in order to gain a shared understanding of progress and consideration of next steps. Only gather information that will serve some clinical purpose – and be clear about that purpose with those you are asking for information from.</li> </ul> <p><b>Missing something?</b></p> <ul style="list-style-type: none"> <li>Reflect on the information you are gathering and the purpose(s) for collection. Consider this information in the context of your overall formulation of where the work has got to. Are there other components of the young person’s current presentation that you might usefully consider through form measurement that could feed into understanding and decision-making around ending?</li> </ul>
<b><i>Once you have made your choice...</i></b>	<ul style="list-style-type: none"> <li>Reflect on how you will use the information from each of the tools you have chosen to use.</li> <li>Plan how you will administer and feed back this information.</li> </ul>

**TABLE 0.17:** Review/Closure – Question two: How has this experience been generally?

<b>REVIEW/CLOSURE – QUESTION TWO: HOW HAS THIS EXPERIENCE BEEN GENERALLY?</b>	
<b><i>Some dimensions to help you determine how you need to answer the question</i></b>	<p>Reflect on what you need to know about in order to sufficiently understand how the experience of being in contact with your service has been for this young person and their family.</p> <p><b>Unit(s) of clarification</b></p> <ul style="list-style-type: none"> <li>• Consider when it would be most useful to collect this information.</li> <li>• Consider different formats for feedback – reflect on which formats would be most likely to yield useful information from this particular young person and their family (e.g. tick box, free text, structured telephone interview.)</li> </ul>
<b><i>Consider the 4Ms</i></b>	<p><b>Minimal burden</b></p> <ul style="list-style-type: none"> <li>• What do you minimally need to know about in order to understand the family's experience of your service?</li> </ul> <p><b>Multiple perspectives</b></p> <ul style="list-style-type: none"> <li>• Whose perspectives do you need to gather in order to understand this information? Consider whether you always need to ask everyone or whether some perspectives are more meaningful than others.</li> </ul> <p><b>Meaningful use</b></p> <ul style="list-style-type: none"> <li>• Consider how this information will be used above and beyond service-level reporting. How could this information (and the use it is put to) be fed back to those leaving and coming into the service?</li> </ul> <p><b>Missing something?</b></p> <ul style="list-style-type: none"> <li>• Reflect on the information you are gathering and the purpose(s) for collection. Consider this information in the context of your overall understanding of the experience of those coming to your service. Are there other bits of information that you could routinely ask for that would allow you to further improve the experience of your service users?</li> </ul>
<b><i>Once you have made your choice...</i></b>	<ul style="list-style-type: none"> <li>• Reflect on how you will use the information from each of the tools you have chosen to use.</li> <li>• Plan how you will administer and feed back this information.</li> </ul>



# Section One - General issues

## WHY BOTHER?

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The aim of CYP IAPT (Children and Young People's – Improving Access to Psychological Therapies) and CORC (Child Outcomes Research Consortium) is to improve both the effectiveness and service user experience of child mental health services in all their settings. A major part of achieving this aim is to embed evidence based practice and the use of service user feedback and outcome measures in CAMHS (Child and Adolescent Mental Health Services) in order to improve clinical practice and, in turn, get better service user experience and clinical outcomes. There is good evidence that the model of therapy used in an intervention has a significant effect on clinical outcomes (Fonagy et al., in press; Kazdin and Weisz, 2010), and there is a well-developed curriculum to provide training in evidence-based interventions, relating to particular models of intervention. Outcomes, and outcomes-oriented practice, are equally embedded in the CYP IAPT programme. However, there is a less well-developed curriculum for the implementation of this aspect of the CYP IAPT model. There is a particular need to develop the therapeutic and supervision processes, and language, to use outcomes informed practice in everyday clinical practice, in real world CAMHS settings, embedded in supervision, and across all therapeutic modalities. The task of the CYP IAPT Outcomes and Evaluation Task and Finish Group (OEG) and learning collaborations such as CORC, is to work with others to produce information and guidance that will enable clinicians to use forms in ever more practical and effective ways.

## WHY USE FORMS TO MEASURE OUTCOMES AND GET SERVICE USER FEEDBACK?

### **1. It is what young people, families and carers, who use services, want.**

Young service users, and carers, quite rightly, want their voice heard in intervention decisions, and therapy, and to collaborate in service development. They see the use of feedback and outcomes tools as an important aspect of this process (Badham, 2011). Used properly, forms should support the voice of service users as part of collaborative practice and shared decision making. Young people have talked about how difficult it is to really get their views across to practitioners in a way that feels safe and respected – even in therapy with practitioners they experience as helpful and who listen. Forms are not the only or best route, but what they do provide is another

avenue for young people and families to share their views, in ways that they may not have shared if this route was not made available to them.

## 2. To provide better therapy

One important reason for using outcome measures must be to improve the relationship between service users and therapists and, in turn, to enhance clinical practice. There is good evidence that the relationship between practitioners and the children and families they work with contributes significantly to clinical outcomes, regardless of the model of therapy that is used in the intervention (Lambert, 2007). This relationship relies on good feedback from children, young people and families to the therapist working with them. There is positive emerging evidence that good collaborative practice between service users and clinicians can be significantly supported by feedback from frequent outcome monitoring (Miller et al., 2006) reducing drop-out and improving outcomes. Furthermore, these improvements in outcomes can occur across the broad spectrum of CAMHS regardless of the therapeutic model

(Bickman et al., 2011). Simply put: using questionnaire based outcomes and feedback tools can help us do better therapy. However, the information from forms is only effective if it is used to feed back into the therapy and to make changes where helpful to keep things 'on-track'. Just monitoring without using the information to change the intervention is not effective as this cartoon from a young person clearly demonstrates. The cartoon shows

Young person's view:

"Sometimes it feels as though we are not being listened to because of our illness. It feels like people don't consider what we have to say as worth anything because we are 'ill', implying we are incapable of having input into decisions etc."

"Although we may not always make the right decisions regarding our illness, it is important to listen to what we want and what we have to say because ultimately we know best what we are going through and therefore know best what may help us."



**FIGURE 1.1:** Why just monitoring outcomes is not enough. A cartoon by Julia, 16.

Young person's view:

"[It is important to] monitor outcomes to make sure person feels better not worse."

"[The] therapist needs to know from [the] patient if they have done a good job otherwise they may just think they have done well even if they haven't."

"[It is important] to check that the patient and the services definitely see the patient's needs in the same light and if not, being able to talk about it."

Outcomes monitoring is important for service evaluation but the needs of the client should always take precedence over the wishes of the service to collect data.

a medic who has perfectly monitored his patient (every change in temperature, heart rate, blood pressure) but, because he has not used the information to change his intervention the patient has died.

### 3. To ensure we continue to have appropriate services

Over the past decade clinical outcome monitoring in CAMHS has become part of the therapy landscape. Its importance has grown due to political drivers to monitor and evaluate services and new initiatives. Commissioners have increasingly been interested in receiving evidence that the services they commission provide good value and are effective, and supervisors and managers have encouraged clinicians to produce more objective information to evidence their practice. Measures are also helpful in guiding us to ensure the level of service provided matches with the severity of the client's problems. The question of whether to monitor outcomes, or not, is no longer in debate – we must use them to ensure good services continue to be commissioned and to support arguments to bring new money into CAMHS – but we must use them in ways that are meaningful to practitioners and young people alike. If used well, the data for evaluation will drop out from good clinical practice with outcomes forms.

All three reasons for using outcomes tools are vital, and CORC and the CYP IAPT outcomes framework (see OEG briefing paper <http://www.iapt.nhs.uk/silo/files/rom-dec11-03.pdf>) has had the challenge of producing measures that achieve all of these aims in the most practical and effective way possible, within the limits of the

resources available. But the use of outcomes tools to inform commissioners, service managers or the Department of Health (DH) must always be secondary to what helps improve practice, and if there is a conflict between the two that would negatively affect clinical practice, the needs of the clinical intervention must always win out.

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# GENERAL GUIDANCE ON USING FORMS IN THERAPY

Duncan Law

When used well outcome and feedback forms support and enhance clinical practice. Forms can be used to help answer six questions vital to any therapeutic encounter, alongside the usual clinical information you would get from talking and observing (more information on the specific tools that can help facilitate the answers to these questions can be found in Section Three).

## AT CHOICE/ASSESSMENT APPOINTMENT

1. **“What’s the problem?”** (assessment) This is understanding the issue the young person or family have come for help with.
2. **“What do you want to change?”** (goals or aims of therapy) This is understanding the specific goals the young person or family have – the things they want to work on in coming to a service.

### During partnership/on-going work

3. **“How are we getting on together?”** (engagement or alliance) It is important to get things right from the start when working with children, young peoples and their families, but also to ensure that you continue to work well together.
4. **“How are things going?”** (symptom/goal tracking) This is tracking to see if things are progressing during an intervention.

### At review and closure

5. **“Have we done as much as we can/need to?”** – This is making collaborative decision to close or refer on.
6. **“How has this experience been generally?”** – This is understanding and learning from the young person or family’s broad experience of the service overall.

These six questions are largely inter-related and mostly rely on good clinical skills to get right – but specific tools can help. Section Three of this document, which deals more with specific tools, is set out around these helpful therapeutic questions.

Young person's view:

“I think it is really important to understand the points of view of all people involved in the young person's recovery. The young person's views should not be overlooked just because they are considered ‘ill’ and therefore may be thought of as not thinking straight.”

Young person's view:

“Establishing a good working relationship is so important and I think is the key to successful recovery. If a relationship doesn't work it can sometimes drive the young person in the opposite direction away from recovery.

Young people need to feel understood and valued.”

Young person's view:

“I think sometimes involving parents and asking them of the difficulties makes it hard for the young person because often parents will hold very different views and may try to create a picture that focuses on the negatives of the young person without addressing maybe family problems or the way the young person sees things. I found often clinicians will listen more to what parents say because they are not the ones that are ‘ill’. But parents can be very biased and doing this makes the young person feel as though they are not being heard or what they say is not being valued. Ultimately the young person experiencing the problems should be at the centre of treatment.”

## AT ASSESSMENT/CHOICE

### Understanding the problem: “What's the problem?”

It is important to get things right from the beginning (aims), and getting on well enough together (engagement or alliance) to be able to do the agreed work (intervention).

One of the most important things at the start of any good intervention is to give time to hear from the family, in their own words, about the difficulties they are experiencing and how they understand them.

Different measures can help collect certain different information to add to an understanding of the person's difficulties. However, collecting information in such a way is contentious; there are strong opposing ideas that range from:

- A view that it is essential to collect good, standardised assessment information about symptoms and presenting problems to the start when working with children, young people and their families. There are three elements to this: understanding the problem (assessment), agreeing how and what to work together on goals or
- A view that even asking such questions imposes a narrow cultural definition of the problem, which is unhelpful to families and clinicians' ways of working.

Most clinicians seem to take a moderate stance somewhere between these two views.

The SDQ (Strengths and Difficulties Questionnaire) and the RCADS (Revised Children's Anxiety and Depression Scale) are the tools recommended for use to help understand a family's difficulties (and are also an important part of the evaluation of the CYP IAPT programme), but services and clinicians are encouraged to use other assessment tools as they see fit. They both have good psychometric properties and norms that allow some guide to the severity of the problems as well as a description of them.

Many services find it helpful to either send out the SDQ and the RCADS to clients and families prior to a first appointment or to ask the client and/or family to fill the questionnaires out in clinics prior to the first meeting. Either way it is important to accompany the questionnaires with a clear letter that:

- sets out who is being asked to fill out the form
- sets out why they are being asked
- sets out how the information will be used
- sets out how the information will be useful for that

family and possibly subsequent families

- is clear that it is optional
- takes into account literacy and language difficulties
- is clear that there will be an opportunity to discuss the measure with the clinician at the first and any subsequent meeting.

### **Agreeing the shared aims or goals of the work: “What do you want to change?”**

Understanding the problem includes understanding what a person wants to change and having a clear understanding of what their aims or goals of coming to a service are. Without this interventions can be vague and unfocused making it hard to be clear about what is being agreed to work on together. Tools such as the goals based outcomes (GBO) or the (Children’s) Outcomes Rating Scale – (C)ORS, when used clinically, can help bring some clarity to the aims of the intervention. Getting to the stage of writing down a goal or aim means there is some agreement at least about the focus of the work – if you can’t write the goal down then it suggests you need to do a bit more work. Having an agreed goal is good clinical practice and helps create a better working relationship. Scoring progress towards the goal at the start of an intervention gives a baseline – this can be used as a clinical guide to track progress. Similar baselines can be achieved with the (C)ORS baseline scores – but it is important to remember that these are subjective tools and do not have the robust psychometric properties and norms of standardised outcome measures. Feedback from young people shows they value clinicians taking time to understand their personalised and specific wishes for therapy and do not like being treated just as a ‘diagnosis’ or a ‘symptom’.

Once a problem is understood well enough, the symptoms checklist or measure should be selected – ideally this should be a collaborative process with the clinician guiding the young person to the measures that best fit with the problem description they have heard.

*“...OK, from what I have heard so far it seems that the main thing you want to change is around worries? One of the things that can be helpful is to check how your worries are doing over time, to see if they are getting better or not, one way we can do this is to ask you some questions about worries each time we meet...”*

The therapist may want to show the young person a couple of the symptom trackers that relate to worries and ask:

*“... out of the checklists we have just looked at now, which set of questions would make most sense to you to ask each time we meet?”*

It is important that the checklist makes sense to the young person, and fits with their understanding of the difficulties they want to work on.

## **DURING PARTNERSHIP/ON-GOING WORK**

### **Working well together: “How are we getting on together?”**

There is very good evidence that how well a clinician and service user work together in therapy has a big impact on the outcomes of the work. Working together well reduces early drop-out from treatment and increases the chances of a person significantly improving. This is a particular kind of ‘working well’ – we know that if certain aspects of the therapeutic relationship are right, the therapy is more likely to go well; these

#### Young person’s view

“It’s important to introduce measures in a way that is ‘friendly’ and ‘approachable’, to assist young people in feeling comfortable to answer.... Appropriate font, style and layout should be considered... it’s important to have questions that reflect on the ‘journey’ a young person is making.”

“Measures should be introduced to the client so that they know what they are about and what they are for and how you are going to use them together. No-one wants to fill in forms when they are unsure of their purpose and nothing would be worse than a young person feeling pressured to fill them in and then doing so in a way that gives inaccurate and unhelpful data.

The frequency, nature and what they are going to be used for should be established outright.

include: feeling listened to or heard, working on the right things together, feeling you are getting something useful from the sessions, and working in the right way together. Research also tells us that clinicians find it difficult to predict accurately how well they are working together with service users. Using outcome tools can aid this important feedback process – but even then clinicians need to find ways of genuinely encouraging both positive and helpful negative feedback from clients. How we introduce the measure will make a big difference to how helpful the feedback we get back might be, for example:

Young person's view:

"I felt that my therapist didn't know how to help me and felt I didn't engage well enough with her and so she gave up on me. She said things like 'I can't help you if you don't talk to me' but I genuinely didn't know how to answer some of her questions and I couldn't help saying 'I don't know' which frustrated her and she said she was going to ban the phrase 'I don't know'. She then told me that maybe I needed a break from therapy and asked me if I wanted to live with 'chronic anorexia' because if I didn't work with the therapists, then that was the reality I had to face. This made me give up hope and I felt as though there was no one who could help me and all I wanted was to get better."

*"...one of the things that is really important is making sure that we work together well and feel OK to let each other know how things are going. Sometimes that might be easy – if things are going well it is usually easier to let someone know – but sometimes that might be more difficult, particularly if things don't seem to be going so well. I will try and get things right, so we can work together well, but I know that sometimes I will get it wrong; towards the end of each session I want us to check how well we are working together (or not) – I really want to hear from you if things are going well so we can carry on doing what works, and I really, really want to hear from you if you think things aren't going so well, so we can work to improve things..."*

Some clinicians choose to add at this point that the young person won't be in trouble if they give negative feedback – and stress that they will be thanked for it, as it will help both do a better job together.

*"...I have a few short questions for us to look at together towards the end of each time we meet which might help with this..."*

Use your judgement to decide how much time might be needed to review the questions; this will vary – particularly if things are going less well. Sometimes even with planning there may not be enough time to discuss all that is helpful. If this is the case agree to give time in the next session to discuss more fully. In some sessions the scoring and discussion may only take seconds, whereas in others a significant part of the session might be about working to get the alliance back on track.

The (Children's) Session Rating Scale ((C) SRS) or the four alliance questions in the session feedback questionnaire (SFQ) are recommended to help with this feedback. Again the scores can provide a useful clinical baseline to track the alliance in therapy.

Once enough information is gathered it should be all put together into a coherent story or narrative that combines all the clinical information: from talking, and forms, and other information sources. This narrative should be checked out with the family to ensure it forms a shared understanding of the problem and its context, and takes into account the needs and wishes of the family (some may call this a co-construction, formulation, or multi-axial diagnosis). From this shared understanding should come the shared agreement of the way forward. It is important to check that the understanding of the problem remains shared and both family/young person remain agreed that the work is progressing in a helpful direction (within the usual messy bounds of therapy).

Use session-by-session information to check if the intervention is 'on track.'

Staying on track – "How are things going?" Session-by-session, or frequent outcome monitoring, allows for the potential to pick up subtle and rapid changes that might begin to move an intervention off-track, leading to potential drop-out, or poor outcomes. As ever, outcomes tools are not the only way to monitor trajectories, but evidence suggests they are an important part of the monitoring process.



When you spot an 'off-track' clue remember that there is nothing magical about numbers. They may provide helpful hints and clues that something may not be going to plan, the tools can help clients hint at problems that they may not be able to say outright, but these are only indicators (not facts). Like any clue it needs to be examined and discussed to understand it more fully – so discuss the change with the client:

*"...from the answers you have given on the session feedback questionnaire it looks like the score for 'listening' is a bit lower than usual? Let's spend a minute or two understanding that and see if we can figure out if there is something I need to do differently next time... Is it OK to talk about it now? ..."*

It is also good to discuss changes in supervision, understand what lies behind them, come up with a plan to get things back on track, try out the plan, and continue to monitor progress. This cycle (set out in the diagram below) may seem simple in theory, but to achieve it requires very good clinical skills.

Young person's view:

"Talking to the young person about the questionnaire makes it seem more important and increases understanding of what it is for making service users more likely to take time over it and answer it properly. Often questionnaires are just handed to the individual or left in the inpatient room if the young person is in hospital but never is it ever explained what it is for."



**FIGURE 1.2:** Getting things back on track.

## REVIEW AND CLOSE

### “Have we done as much as we can/need to?” and “How has this experience been generally?”

Towards the end of an intervention it is important to decide together when the right time to stop the intervention might be: “Have we done as much as we can/need to?” and to reflect on the overall experience of the therapy “How has this experience been generally?” Clinical discussion is a vital element to help make the clinical judgement needed to make the decision about when to stop, but again outcomes information can help. Sharing goals with young people and families and symptom trackers such as the subsections of the RCADS can help review progress and aid decision making. Tools such as the CHI-ESQ (Commission for Health Improvement-Experience Service Questionnaire) are helpful for reviewing the experience of therapy and help clinicians review their own and their service’s practice, to improve what they do. The table below sets out some of the clues that an intervention may be starting to go off track, and suggests some things to consider.

**TABLE 1.1:** Clues that an intervention may be starting to go off track, possible problems and solutions.

CLUE	POSSIBLE PROBLEM	POSSIBLE SOLUTION
A sudden drop in the working well together (alliance) scores or SRS.	Might suggest a difficult session or early indicator of an alliance problem?	Discuss changes – was it a ‘one-off’? Decide if anything needs to change for next session.
A general decline in working well together (alliance) scores or SRS over a number of sessions.	Problem with alliance?	Discuss changes – are you still working on the important goals? Have problems/symptoms got worse? – review symptoms checklist. Is there an issue outside of therapy?
Sudden decline in goals score.	Have goals changed? Have problems got worse? Is there an issue outside of therapy?	Review goals with young person. Check to see if there are other external issues that need to be discussed.
A general decline in goal scores over a number of sessions.	Have goals changed? Have problems got worse? Is there a problem with the therapeutic approach? Is there an issue outside of therapy?	Review goals with young person. Check to see if there are other external issues that need to be discussed. Discuss therapy model – does it need to change? Consider change of therapist?
Sudden decline in the ORS.	Have problems got worse? Is there a problem with the therapeutic approach? Is there an issue outside of therapy?	Check to see if there are other external issues that need to be discussed. Discuss therapy model – does it need to change? Consider change of therapist?
Sudden decline in symptom scores.	Have problems got worse? Is there a problem with the therapeutic approach? Is there an issue outside of therapy?	Check if significant event has happened in between sessions. Check if scores match real experience – does the client subjectively feel things are much worse?
A general decline in ORS scores over a number of sessions.	Have problems got worse? Is there a problem with the therapeutic approach? Is there an issue outside of therapy?	Check to see if there are other external issues that need to be discussed. Discuss therapy model – does it need to change? Consider change of therapist?
A general decline in symptom scores over a number of sessions.	Have problems got worse? Is there a problem with the therapeutic approach? Is there an issue outside of therapy?	Review goals with young person. Check to see if there are other external issues that need to be discussed. Discuss therapy model – does it need to change? Consider change of therapist?

### **How often to use feedback and outcomes forms**

The CYP IAPT and CORC model incorporates both frequent (session-by-session) measures and less frequent (six-monthly or at the end of the intervention). Both have their value and challenges. Less frequent tools can be longer and arguably more psychometrically robust measures of outcome but demand operational challenges (not least remembering to give them out!). Session-by-session measures are, by their nature, more routine and therefore more likely to be used, but need to be kept brief and focused. They provide vital information to help keep interventions on track, reducing drop-out, and can have a significant effect on outcomes. Section Three of this guide provides more detail of the forms and how and when best to use them.

### **BUT...Could use of forms be harmful?**

Both clinicians and service users have expressed concerns that PROMs (Patient Reported Outcome Measures) use, poorly implemented, could damage patient-clinician relationships (Badham, 2011; Curtis-Tyler et al., 2012; Moran, Kelesidi, Guglani, Davidson & Ford, 2012).

The administrative burden of form filling may unhelpfully reduce consultation time; this is a particular problem if the PROMs are not felt to add information that aids the clinical care (Jacobs, 2009).

If PROMs are perceived or experienced as part of a 'top down' or tick box culture they may undermine or even harm collaborative working (Badham, 2011; Curtis-Tyler et al., 2012; Moran et al., 2012).

If clinicians do not know how to interpret data from PROMs or do not reflect on it with their clients, it may reduce their impact and leave clients feeling more unheard than before (Curtis-Tyler et al., 2012; Greenhalgh, 2009).

A concern for service users and clinicians alike is that without appropriate support on meaningful interpretation and use, managers and commissioners might use the limited information derived from PROMs to make misjudgements such as ending care prematurely if scores are seen as "positive enough" or closing services if scores are "not positive enough" (Moran et al., 2012).

We believe that there is a potential risk that inappropriately used outcomes and feedback forms, and data derived from them, may be unhelpful or even harmful. It is vital that the forms are used thoughtfully and with clinical judgement and embedded in well-supported, well-supervised environments to mitigate against the risk of harm.

What we all must keep clear in our minds is that we are at the start of a journey in using feedback and outcomes tools on this scale. In using them we must always be mindful of the balance between their usefulness clinically and in service evaluation, and their potential misuses and possible harm.

Young person's view:

"Young people never get any feedback about what the information they have given has been used for or how it has been implemented in services. This makes it seem like the questionnaires are just so that they can tick a box to say they have used outcome tools without actually using the information given."

Young person's view:

"[w]henever I was asked to fill in a form, it wasn't explained to me – this can make young people feel as if they are just a 'number' or a figure... clinicians must remember that it's equally important to focus on what a young person has to say during a session."

Young person's view:

"I've seen people become overly reliant on the use of outcomes tools and to make judgements or decisions purely on the scores. This can lead to young people's views being dismissed and can lead to young people wondering if it's worth attending if what is said during an appointment is ignored..."

Young person's view:

"I think it is important to not rely too heavily on questionnaires because they can be interpreted differently by different people and they don't always give you the full picture because they don't allow for qualitative answers."

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## MAKING SENSE OF THE INFORMATION FROM THE FORMS

Duncan Law

### LEARNING FROM FEEDBACK

#### LEARNING WITHIN INTERVENTIONS

##### ***The two minute review: Look for surprises***

If all you have is two minutes to review the information from the outcomes in the sessions (which in many cases will be all clinicians have between sessions) have a quick scan of the answers on the outcome tools – look for Surprises. Is there anything on the questionnaires that doesn't fit with what you heard in the session? Did you hear that everything was fine but the symptoms checklist scores are very high? Did you hear that things were going well but the goals measure is scored very low? Or maybe you heard that it had been a very bad week but the ORS scales are rated quite high. If you didn't already discuss these in the session you just had, make a note to ask next time.

##### ***The ten minute Review: Create a 'story' or narrative of the case***

With a little more time, it is helpful to do more than a quick scan of the information from outcomes. A useful exercise is to create a story or narrative that includes all the clinical information about the case (presenting problem, formulation, motivation, contextual

Remember there is nothing magical about scores on a questionnaire or outcome tool. The information is no better or worse than what clients tell us verbally in a session – it is just different. Both are useful in their own right, but used together they can really complement each other.

If you have slightly longer you can create a story or narrative about the data – challenge yourself, with your supervisor, to come up with alternative explanations of the data.

factors etc.) and includes the information gathered from the outcomes tools. It should be possible to tell a story in which all the information hangs together – the outcomes run in a ‘positive’ direction (if you have information from a number of Sessions). What was it about the factors of the case that explain that? Similarly, if they run in a negative direction, what factors might account for that? Try and make the story as coherent as possible (make sure the story is logical and accounts for the changes and any anomalies – the more all the information hangs together the more coherent the narrative).

You may find that the stories you create tend to attribute clinical success to your own good clinical skill, and that you tend to attribute less good outcomes to factors outside of therapy – contextual factors! (Some practitioners will tend to make attributions in the opposite direction). Your initial attributions may well be true in some cases, but we know clinicians tend to overestimate their abilities (Norcross, 2010) and have a tendency to view things either overly positively or overly negatively – to improve our practice we need to be a bit more reflective and objective. One way is to try and create an alternative account of the information you have. Play ‘devil’s advocate’; challenge yourself to find alternative explanations to the outcome. Creating two alternative narratives gives you a kind of binocular view of the outcomes (rather than the usual one dimension we tend to create). This gives the outcomes data a depth in which to explore and reflect on our practice.

Using supervision to create the narratives can be extremely fruitful – the colleague or supervisor can take the ‘devil’s advocate’ role which can make it easier to create the alternative view.

### ***The six-month review***

It is helpful to do a more in-depth review of a case at six months including the information from the second SDQ, RCADS.

Both the RCADS and the SDQ will be given out again after six months (if the case is still open; some services may choose to send out these questionnaires even if the case is closed to see if progress has been sustained) and the CHI-ESQ may also be given out then. This is a good opportunity to do a more in-depth review of a case. Review the results of the SDQ and RCADS in conjunction with the session-by-session data and other clinical information about the case. Take it to individual supervision and/or peer group supervision to get a range of views. Are the goals still clear and appropriate? Are you

working well enough with the child or family? Are symptoms showing signs of improvement? Is the intervention still the most appropriate one for the case? Consider whether change of therapist or therapeutic approach might be indicated.

## **LEARNING ACROSS A NUMBER OF INTERVENTIONS**

### **LOOK OUT FOR ‘THEMES’ ACROSS THE INFORMATION**

Once you have information over a number of cases it can be helpful to look for themes in the information – it helps to set out information in a table so that you can easily scan the data across clients, rather than trying to look at one case at a time. The themes might relate to particular presenting problems: do you tend to get better outcomes with one particular client group (e.g. Obsessive Compulsive Disorder (OCD)) than another (e.g. eating disorders).

Do you tend to get high scores on certain items on the CHI-ESQ (e.g. “listens well”) and do less well on others (e.g. “explained clearly”)? Are there many service related themes e.g. “convenient appointments”, “surroundings”? Look at the qualitative comments from the SDQ and especially the CHI-ESQ. What can you do to improve things? Do they point to any further training or issues to discuss in supervision?

When you have outcomes information on a number of clients you can start looking for themes across the cases. What do you do well at? What areas of development can you identify?

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# THE SERVICE STRUCTURES TO SUPPORT THE EFFECTIVE USE OF OUTCOMES

Duncan Law

## GETTING THE SERVICE STRUCTURE RIGHT

The CYP IAPT programme clearly acknowledges the vital importance of service structures to enable and support excellent clinical practice. This is certainly true for any service seriously wanting to use clinical outcomes to improve practice – before it is possible to collect any information around outcomes there needs to be reasonable service structures to support it. The development and sustainability of these structures relies on effective and committed clinical and operational leadership.

## FACILITATING THE RIGHT CULTURE

To enable the effective use of feedback from clinical interventions requires a certain mindset that embraces a reflective stance on clinical practice, and uses information, from a variety of sources, to facilitate such reflection. For some individual clinicians outcome evaluations are already a part of their practice, and for others not. Within CAMHS there is great variety of opinion amongst clinicians as to how big a shift it would be to adopt a reflective practice based on outcome measures. This change would need support to embed any routine system of evaluation fully. But most importantly, clinicians must have ownership of the information and models, and see the benefits, for there to be any improvement in service quality. Such cultural change needs to flourish in a learning organisation with a supportive management environment that allows clinicians to explore their successes, and do more of what works, but more importantly, feel confident that they can explore their 'failures' and learn from them, and improve their practice – this is a particular challenge given the understandable anxieties associated with shrinking services and potential job losses.

There is a need for a supportive management environment that allows clinicians to explore their successes, and feel more confident that they can explore their 'failures' to learn from them, and improve their practice.



Creating the right culture needs to come from the top down (commissioners, chief executives, managers, service leads, supervisors) as well as from the bottom up (clinicians and practitioners). It is also important to recognise what is realistic and possible within CAMHS, given the current clinical and scientific knowledge and resources available.

## INFRASTRUCTURE

The learning from other programmes where routine outcomes have been introduced shows that successful implementation of evaluations systems requires a supportive infrastructure. The requirements need not be costly but require, as a minimum, reasonable IT systems and good administrative support, reducing the burden on clinicians' time.

Without sustainable infrastructure in place, the implementation of outcomes monitoring fails.

## COSTS AND POTENTIAL SAVINGS

Implementing good systems of evaluation always have a cost – financial costs: setting up IT infrastructures to support the process, extra administrative personnel, licensing and so on. But often the most expensive deficits come from hidden costs: shrinking capacity for clinicians where clinical contact time is reduced due to increased burdens of administration. A helpful consideration is to weigh up the cost of the system with the benefits it may bring – both in terms of better quality patient care but also real economic savings. American colleagues (whose services have always been driven by results and the demands to reduce health insurance costs) have demonstrated that effective clinical monitoring systems can lead to more effective and efficient interventions (Lambert et al., 2001), leading to cost saving across the board.

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# SUPERVISION

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## THE SPECIFIC ROLE OF SUPERVISORS

The routine and frequent use of clinical outcome tools in CYP IAPT and CORC+ is one of the key strands of the programme, leading to improved and efficient practice across child and adolescent mental health services. It can also be an anxiety-provoking and exposing practice for clinicians using the forms in their work. For the forms to be useful, clinicians need to understand their purpose and feel comfortable in sharing the information produced, and to reflect on and challenge their practice – in order to learn and improve what they do. Supervisors have a particularly important role in enabling this by:

### Young person's view:

“I think clinicians sometimes feel they have to go by the book and tend to generalise patients to a stereotypical diagnosis. It is important to recognise that everyone is different and should be treated as an individual. What works for one person may not work for another and so shared decision making between the young person and clinician is important and the young person should be listened to.”

- creating the right culture to help clinicians to use and share outcome information in a productive, co-operative environment
- encouraging clinicians to use the measures to aid shared decision making with the young people and families
- helping clinicians to review and reflect on the information from outcomes tools in the context of other clinical information and with a focus on keeping interventions on track.

It is important that supervisors and supervisees work together to understand the outcomes and feedback. It is likely that a range of supervision structures will be effective in helping create the best environment for the above tasks: individual, group, and peer supervision. Supervisors should model openness and feedback with supervisees by sharing their own outcome data and

introducing feedback at the end of supervision along the lines of the Session Rating Scale (SRS).  
The next part of this section explores the use of forms in supervision in more depth.

# OUTCOME TOOLS IN SUPERVISION: USING FEEDBACK AND OUTCOMES

Emma **Karwatzki**, Sally **Westwood** and Gill **Walker**

## WHY BRING SERVICE USER FEEDBACK AND OUTCOMES TOOLS TO SUPERVISION?

Ultimately, the practice of incorporating service user feedback and outcomes tools in supervision allows service users' voices to be represented within supervision case discussions. It is a reminder to place the service user at the centre of supervision.

The availability of these tools can influence the types of cases that are brought to supervision for discussion. Previously, cases may have been prioritised for a range of reasons – from risk issues through to perceived “stuckness”. Of course, this does not, and should not, stop. However, the availability of service user feedback and outcomes tools can lead supervisees to pick up on new information about a case, which may be helpfully supported within a supervision framework.

The use of service user feedback and outcomes tools in supervision also provides huge amounts of potential for both the supervisee and supervisor to be curious, about both the content and the process of therapy, and, due to the availability of specific information, it's hard to stay vague.

*Supervisor:*

*“It's really interesting that the goals have been set by the parents. How might you describe the processes that brought about this decision?”*

## WHO IS RESPONSIBLE FOR BRINGING SERVICE USER FEEDBACK AND OUTCOMES TOOLS TO SUPERVISION?

As with any supervision relationship, it is important to be clear about the boundaries of the relationship, and the aims of supervision. Supervision incorporating service user feedback and outcomes tools should be no different.

Therefore, depending on your supervision boundaries, there will be varying levels of responsibility that the supervisee or supervisor takes on.

The key principles of good clinical supervision such as collaboration, openness, respect, reflection, challenge and skills development (i.e. Scaife, 2001) can be enhanced by the appropriate discussion of service user feedback and outcomes tools. However, the supervisor and supervisee need to work hard to maintain these principles as understandable anxiety and uncertainty about using these tools in supervision can have an impact. It is invariably beneficial for both the supervisor and the supervisee to take shared responsibility, to prevent the incorporation of service user feedback and outcome tools seeming like a management imposition, which would be in stark contrast to the philosophy behind their use.

#### Active supervision

Supervisors and supervisees may wish to use “Active Supervision” processes within their supervision, in which the supervisor contributes to agenda setting, having reviewed the supervisee’s service user feedback and outcome tools (see Bickman’s Contextualised Feedback System for a similar approach). It is important to set up this type of supervision carefully, to prevent the process becoming a case management exercise.

## WHAT MIGHT THE SUPERVISOR TAKE RESPONSIBILITY FOR?

### LIVING THE PHILOSOPHY

Depending on the supervision arrangements that have been negotiated between the supervisor and the supervisee, there are a variety of responsibilities that the supervisor may adopt. Ultimately, it is important that the supervisor “lives” the philosophy of curiosity, shared decision making, openness and collaboration with their supervisee. It is also paramount that the supervisor provides a safe and reflective space, which enables therapists to consider and explore ideas.

*Supervisor:*

*“Can I ask a bit more about your response to the ‘did you talk about what you wanted to talk about’ item? I’d be interested in reflecting on this further.”*

#### Supervision feedback

One way in which the supervisor can “live the philosophy” is to obtain feedback from the supervisee about their experience of supervision, for example, by using the Session Feedback Questionnaire or the Session Rating Scale. This can be negotiated when setting up or reviewing a supervision contract.

### SUPPORTING THE USE OF TOOLS

The supervisor can help to support the supervisee at various points along the therapy journey. For example, they may help the supervisee to consider how to select appropriate tools in collaboration with the service user, they may help the supervisee to consider how to make sense of service user feedback and outcome tools when they are in use, and can work together with the supervisee when considering how to offer feedback to the service user.

*Supervisor:*

*“It sounds like the use of the feedback tools has helped you to tease out a shared understanding of Harry’s low mood. How might you be able to use the feedback tools to help identify a focus for moving forwards?”*

### EXPLORING MEANING

The supervisor can helpfully encourage the supervisee to incorporate the available information with the information provided in the feedback tools, asking about the ways in which the feedback may be understood in the context of this information, from a number of perspectives. The supervisor may ask questions to establish the practitioner’s current view, to generate alternative hypotheses, and to evaluate whether there is any evidence to

support these ideas. It is especially important that the supervisor encourages the supervisee to look beyond the “face value” content, to consider the multiple meanings that the feedback could represent. It can be helpful to view service user feedback and outcomes tools as one of many important pieces of the puzzle.

*Supervisor:*

*“It seems as though Lauren has moved from a passive stance to a more active stance, as her mood has started to improve... How might this influence the way in which you encourage feedback on the How Was This Meeting tool?”*

## REMEMBERING THE CONTEXT

It is important that service user feedback and outcome tools are considered in conjunction with contextual and complexity factors, family functioning, education and employment issues. It is important not to fall into a reductionist position, maintaining a broad view of complexity.

*Supervisor:*

*“Taya reports that she is well on her way to reaching her goals. What conversations have you had together about what this represents?”*

## SPOTTING “OFF TRACK” INTERVENTIONS

The supervisor is usefully positioned to help the supervisee to identify when interventions appear to be on or off track, by referring to reliable change indices and clinical cut-offs (as described elsewhere in this guide). This should be done carefully, to avoid the practitioner feeling judged or criticised for their practice, which is likely to impact on their openness and ability to be curious. Other explanations for apparent “off track” interventions will also need to be considered. As a way to demonstrate the value of learning and development, the supervisor should demonstrate a commitment to collecting and using service user feedback and outcomes tools in their own practice, and model a philosophy of curiosity and openness with respect to this.

*Supervisor:*

*“David scored his symptoms quite high on his tracker initially and his last two scores suggest that he feels his symptoms are getting worse. His mum has scored his functioning as much better. Shall we see if we can make sense of all the things that might account for David and his Mum’s differing views?”*

## THE ROLE OF THE SUPERVISEE

### STAYING OPEN-MINDED AND CURIOUS

Bringing service user feedback and outcome tools to think about in supervision might be a daunting prospect and is potentially exposing as a practitioner. It is a new way of working and practitioners may be sceptical or unsure about how helpful it might be.

Done in the right way it potentially brings opportunities as a supervisee for enriching supervisory discussions and offering fresh insights into one’s practice. To get the most out of it both supervisor and supervisee need to keep an open mind and maintain a stance of curiosity.

### BRINGING SPECIFIC QUESTIONS

Supervision time may be limited and as a supervisee it is important to think about how to get the most out of the time you have. Taking some time in advance of supervision to think about the cases you want to bring and

particular questions you want to consider in relation to a case means you can feel prepared, have the measures or equipment you need ready and can focus the discussion to get what you want out of it. Supervision might be used to think about a whole range of issues related to the use of tools in your work for example:

- Choosing the most relevant tools for a particular young person and their parent/carer
- The content of feedback from everyone's perspective and what it means
- Process issues which are highlighted by feedback or around how to integrate tools into your practice
- What gets in the way of using a particular tool
- Trends in the data collected

*Supervisee:*

*"I've been thinking that the impact tracker would be a tool that could be useful, but I'm struggling with how to introduce it. I'm worried that it won't flow naturally in the session, so I've been holding back from introducing it."*

*Supervisor:*

*"Would it help if we have a look at the tool together, to see what relevance we think it may have for Jo at the present time?"*

## WORKING TOGETHER

Supervision can be seen as a collaborative space which models the collaborative therapeutic relationship. The tools which are used with children and young people and families need to be meaningful to them and selected in a collaborative way. Talking through ideas about this in supervision can help to narrow down which ones to take into the session and how to present them so that they make sense to the particular individual. After feedback has been collected from a young person, the supervisor and supervisee can work together to think about how it fits with the therapeutic story, generate hypotheses about what the feedback may mean, and consider how to test out these hypotheses in future sessions.

*Supervisor:*

*"If our hypotheses about Robert and his family are accurate, what might we predict would happen to the symptom tracker over the next few sessions?"*

## CONSIDERATIONS FOR MANAGERS/LEADS/COMMISSIONERS

Supervision will be an integral part of supporting whole service transformation and consideration will need to be given to how systems are set up for this, depending on the local picture (which might include staff within a range of settings including the NHS, local authority, and independent/third sector providers). Organisational arrangements will be needed to effectively guide practice to support the development of successful practitioners. Services need to be realistic about resources needed. These resources can include release of time and availability of skilled supervisors. The following are some key considerations for managers/leads/commissioners of services:

### POTENTIAL PITFALLS

Practice around the use of session-by-session feedback and tools is developing and there is still a lot to be learnt. However, there are a number of potential pitfalls to be mindful of:

The tendency to see the measures as being the "truth" and using them to confirm your narrative about a case rather than allowing yourself to be curious about their meaning; remember they are only one piece of information.

The risk that supervision becomes purely case management rather than a reflective space.

Taking the feedback at face value, for example feedback about not being listened to might actually be a communication about not being heard in other relationships.

Some of the measures used are standardised on an American population. You therefore need to be cautious in interpreting what they mean.

The measures have not been used to collect session-by-session data in a systematic way before, therefore we do not know what a typical trajectory would look like and this presents challenges in thinking about what the information means.

- **Commitment**

Ensure the service has a supervisory infrastructure (including governance, local policies and professional guidance) that supports the incorporation of service user feedback and outcome data into supervisory practice. Data collection tools and reports needs to be made available to the supervisee and supervisor as needed and both need to be able to understand them. A service training needs analysis might be required in order to identify any issues and needs that arise from this new way of working which can feed into training and development plans.

- **Concerns**

The use of session-by-session tools should help to identify issues within therapy sooner, such as lack of progress, going off track, ruptures in the therapeutic alliance and risk of DNA (Did Not Attend) or drop-out. Ensure the service has structures and policy for addressing the needs of those who are not progressing. This could include a review meeting, change of therapist or change of approach.

- **Culture**

Ensure that the right culture is created to facilitate use of service user feedback and outcome information in an ethical, values-based and meaningful way within sessions and supervision. This can be encouraged by focusing on the philosophy behind the use of the tools and encouraging curiosity and learning together.

- **Care**

Looking after the workforce (supervisors and supervisees) can help with job satisfaction, support retention and recruitment, and improve the care experience for service users. Ensure that formats of supervision can be provided that are sensitive to the needs of the supervisee: this can include group or individual, with agreed goals and boundaries defined at the start of the process.

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# CAPA – THE CHOICE AND PARTNERSHIP APPROACH, AND SERVICE USER FEEDBACK TOOLS AND OUTCOMES MEASURES

Steve **Kingsbury** and Ann **York**

CAPA is a clinical service transformation model that brings together:

- **Collaborative practice:** active involvement of service users and Shared Decision Making
- **Demand and capacity:** ideas and Lean Thinking
- **Skill mix layering:** a new approach to clinical skills and job planning.

It was designed by Dr Ann York and Dr Steve Kingsbury and developed in Richmond and East Herts CAMHS – both teams have now run CAPA for many years. Wider implementation began in 2005 and CAPA is now used all over the world in many settings and client groups. It is used in CAMHS in many countries as well as in adult mental health in New Zealand and is beginning to be implemented in adult mental health in England and Canada.

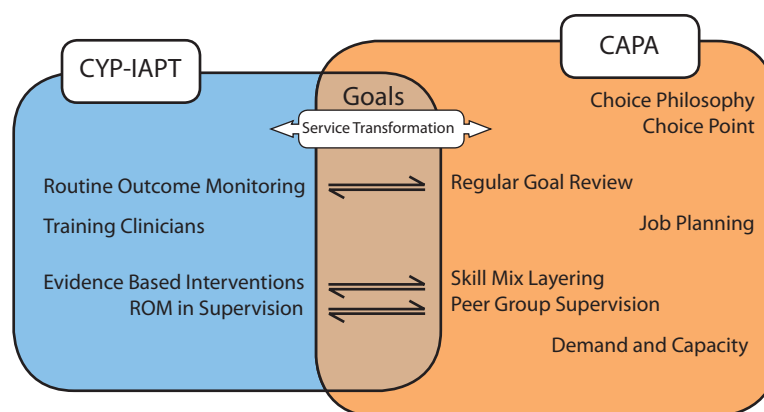
CAPA combines processes that enhance effectiveness and efficiency of service delivery. It is informed by demand and capacity theory (The Seven HELPFUL Habits of Effective CAMHS) and has links with Lean Thinking, New Ways of Working, Our Choices in Mental Health, Recovery Principles, You're Welcome Standards, Shared Decision Making and CYP IAPT.

CAPA and CYP IAPT

CAPA is an example of service improvement that may be chosen to facilitate CYP IAPT implementation and is part of the service development curriculum. CAPA has a strong focus on clinical supervision that incorporates goal and outcome monitoring.

CAPA and CYP IAPT are closely linked:

- Share the same values and philosophy: service user at the centre of everything we do.
- Focus on collaborative practice.
- Focus on goals and outcomes.
- Focus on skills and matching these to the goals of the service user.
- Smooth processes and easily accessible services.



**FIGURE 1.3:** Relationship between CYP IAPT and CAPA. Diagram created by Steve Kingsbury.

In addition, CAPA also:

- uses demand and capacity techniques to increase capacity and efficiency
- promotes a team culture of flexibility and continuous service improvement
- promotes development of extending skills in staff.

## WHY HAS CAPA SPREAD AS A USEFUL MODEL?

Spread has been by word of mouth. It has been replicated in many countries, cultures and differing health systems, testimony to its flexibility within its key components:

- It is collaborative at its heart, working in a flexible, outcome focussed way with clients, offering choice and building on their strengths.
- It incorporates factors that increase therapeutic effectiveness.
- It is efficient, with a focus on adding value, reducing waste and maximising capacity.
- It has a language that allows the service to describe themselves.
- It fits with people's values – clients and staff.
- It brings clarity to what is done, by whom and how much, facilitating the dialogue between commissioner and providers.

Sometimes CAPA is viewed purely as a waiting list management system or demand and capacity tool. This is not the main focus. Of primacy is the philosophy of the client being at the centre of everything we do, the processes we have around them are to enhance their experience. It is a 'pull' system, rather than 'push' in lean thinking terminology. For the clinician there is a shift in position from an 'expert with power' to a 'facilitator with expertise'. There are 11 key components, including a change in language, team job planning, goal setting, care planning and peer supervision.

The focus on extending skills in staff is key. This involves mapping staff skills and enhancing their ability to provide a wider range to higher competency levels than has been traditional in services. There is a focus on skill rather than profession when thinking of competency. Core CAPA skills are higher level than many existing staff have in services – there is usually a pattern of staff having advanced skills in only one area, often defined by their profession. This focus on extending skills results in extended capacity, better matching of goal and intervention,

and a learning environment for staff. In terms of CYP IAPT, therapy skills gained on the CYP IAPT courses equate to Core CAPA skills.

## THE CAPA CLIENT PATHWAY

### THE CHOICE APPOINTMENT

When their referral is accepted, the young person and their family are given the opportunity to book an appointment at a time (and ideally place) to suit them. The first clinical contact is in a Choice appointment. During the Choice appointment they may choose:

- that they can get back on track and do not need to return
- to be put in contact with a different agency more suited to help
- to return to the service.

If they decide to return, they will be able to choose an appointment with a clinician in the service who has the right skills to help them. This next appointment will be the start of Core Partnership work with one or more clinicians with extended threshold clinical skills. Most people will find this is enough to achieve their goals. For some, more specific work with additional specialist skills may be added to the core work.

### THE KEY TASKS IN CHOICE

Curiosity in the young person's and family's view and reflecting of our opinion; evolving a joint Formulation followed by a discussion of Alternatives (not all involving CAMHS) ending in the Choice Point maximised by their engagement tasks.

Choice appointments aim to combine:

- assessment
- motivational enhancement
- psycho-education
- goal setting
- things to try at home/ 'homework' or Pre-Partnership work.

The style is conversational, collaborative and strengths based. Baseline measures are used in the Choice appointment, linking with CYP IAPT.

### PARTNERSHIP

Core Partnership is where the majority of intervention work occurs. It can be done by most clinicians who have **extended core clinical skills**. Extended core clinical skills means having a core level of competency to deliver a range of common CAMHS assessments and interventions. Core Partnership work can involve single method or integrative, multimodal work to help the client meet agreed goals. The Core Partnership worker remains the Key Worker during the pathway.

Assessment and reformulation continue throughout contact with the service. Routine Outcome monitoring is embedded. Some clients will need additional Specific Partnership work, alongside the Core work. This type of work may be delivered at higher intensity or use more advanced skills and techniques than at core level. Examples could be individual psychodynamic psychotherapy in conjunction with Core family work, systemic therapy using a one-way screen alongside core individual work or additional Specific assessments e.g. psychometry or ASD (Autistic Spectrum Disorder) assessment.

Partnership work can be as many or as few appointments as are needed. Feedback tools and outcome measures can facilitate the choice and partnership process. The work must be regularly reviewed against clear goals, through the use of care planning and on-going outcome measurement. Contact with the client ends when a review concludes that goals have been met. Ending outcome measures are used.

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## FURTHER READING

For more information visit: [www.capa.co.uk](http://www.capa.co.uk)

# CORC: MAKING PROMS AND PREMS PART OF ROUTINE PRACTICE - DRAWING ON A DECADE OF LEARNING

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## BACKGROUND AND CHALLENGES

Historically, the use of Patient Reported Outcome and Experience Measures (PROMs and PREMs) in Child and Adolescent Mental Health Services (CAMHS) has been sporadic. A review by Johnston & Gowers (2005) of CAMHS found only 29% of services reported engaging in routine outcome monitoring (ROM) generally and even less routinely collected feedback direct from those using the service. Clinicians and services are now recognising the value of using outcome measures and the benefits using client feedback can bring such as: reducing the likelihood of dropout; improving the speed with which good outcomes are achieved; improving the quality of information gained by covering potential gaps in assessment and/or review; and, improving identification of worsening of symptoms (Bickman et al., 2011; Lambert et al., 2003; Lambert & Shimokawa, 2011; Miller et al., 2006; Worthen & Lambert, 2007). Encouragingly, recent consideration of implementation reflects the benefits of these positive advances in understanding around outcomes. For example, Hall et al. (2013) have shown increases in use of outcome measures across different types of services.

CAHMS services are undergoing a major period of change and service transformation with programmes such as Children and Young People Improving Access to Psychological Therapies (CYP IAPT) and The Choice and Partnership Approach (CAPA; Kingsbury & York, 2014; York & Kingsbury, 2013). Despite the focus on the service transformation it is hard to make changes in organisations even when those changes are recognised as beneficial and necessary. Organisational research suggests that existing routines and current practices can be powerful barriers to change with staff being trapped by current competencies (Edmondson, Bohmer & Pisano, 2001). The introduction of routine outcome monitoring to a service unfamiliar with routinely using such tools and processes is a particularly complex implementation challenge as it requires not just the setting up of the administrative and technological infrastructure to support the necessary data collection, but also training for clinical staff, along with ongoing support and supervision to enable them to embed these new processes in their routine practice. Certainly, previous literature considering the implementation of PROMs reflects the complexity of this task with

studies indicating relatively poor consistency in measures use across services and that completion rates are still relatively low, particularly in the repeated administration of measures to assess progress (Batty et al., 2013; Johnston & Gowers, 2005).

The many reasons for poor completion are well-known to anyone who has been involved in any part of the process of implementation of ROM. Common barriers to success include: concerns about time pressure (ranging from the perception that the introduction, administration and feedback of measures means less time for the “real therapeutic work” to accommodating the inevitable duplication of data entry), resistance to changing current practice (ranging from perceived incompatibility with therapeutic approach to lack of confidence in choosing and using measures), training issues (such as confusion over which measures to use, when and with whom) and, perhaps most significantly, resource issues (ranging from insufficient funding to support increased administrative demands to inadequate data systems to support the collection of considerable amounts of additional data fields).

There is a balance that must be sought between the clinical meaningfulness of measures and collating data for service evaluation. Data is only worth collecting and analysing if it is something you want to know about (Kennedy, 2010). Many clinicians may find that measures that are most useful clinically are not as useful for service evaluation and vice versa (Wolpert, 2013). We believe priority should be given to the clinical meaningfulness and relevance to the individual patient care. If these measures are supplemented by more generic tools, which can be used for service evaluation their different purpose and use should be made clear to service users and others.

## **RISING TO THE CHALLENGE: THE CORC APPROACH**

The Child Outcomes Research Consortium (CORC<sup>1</sup>), a not-for-profit learning collaboration, was formed in 2002 by a group of child mental health clinicians, managers and funders working across five different service providers across the country. They shared a mutual curiosity as to the effectiveness of their and colleagues’ practice and how to improve it. They felt that one way to find out about the impact of their work was to ask those they worked with and thus set about finding appropriate PROMs and PREMs to try to access these views in a systematic way (Wolpert et al., 2012). Interest grew amongst other services and the founding group were also joined by interested academics. The collaboration opened to wider membership in 2004 and was formalised as a not-for-profit learning consortium in 2008 (see [www.corc.uk.net](http://www.corc.uk.net)). CORC members are professionals providing mental health provision to children, young people and their families across the UK, Scandinavia and Australia. Membership has grown via word of mouth to approximately 70 mental health providers and includes members from over half of UK CAMHS, with an increasing cohort of voluntary sector members (see [www.corc.uk.net](http://www.corc.uk.net)). Being part of the collaboration means membership of an international network of professionals facing similar challenges, with a willingness to share ideas and learning through facilitated peer-support.

Members collate outcome information from children and their families, primarily from questionnaires focused on symptomology, general wellbeing, impact and therapeutic relationships. These are completed at specified time points throughout the therapeutic process. Until recently, the majority of members have followed the ‘Snapshot’ approach, which involves collecting information at the beginning of treatment and approximately six months later. In the last two years CORC has shifted to support a more continual approach (CORC+) of tracking progress more frequently (e.g. every session).

CORC members are supported by a Central Team which includes performance analysts, researchers and support staff. These main objectives are to provide assistance and training on all aspects of outcome monitoring and to centrally analyse aggregated data, providing bespoke ‘Rest of CORC’ comparisons in reports to services. One of the main roles of the Central Team is to provide best practice advice about the interpretation and use of data. CORC recommends a ‘Mindful approach’ to the use of data (Wolpert et al., 2014), including multiple perspectives and harnessing the strength of a learning collaboration.

Members commit to focus on outcomes that:

- Directly inform clinical work
- Are important to children

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<sup>1</sup> Formerly known as the CAMHS Outcomes Research Consortium; the name changed in 2014 in recognition of the widening scope of the work of the collaboration.

- Contribute towards performance management
- Promote reflective practice.

**Outcomes that directly inform clinical work:** CORC emphasises that the tools should be used in the context of collaborative working and shared decision making (Law, 2012; Law & Wolpert, 2014). Service users themselves have encouraged outcome monitoring on the premise that clinicians explain its purpose well, providing a collaborative sense, with opportunities for questions (MyAPT, 2014). Thus CORC suggests that use of PROMs and PREMs should be embedded in the five steps of shared decision making (as defined by the Health Foundation Closing the Gap project in which CORC was a partner collaborator alongside the Evidence Based Practice Unit (EBPU) at the Anna Freud Centre and UCL and YoungMinds):

1. Young people and those working with them agree key problems and goals together
  2. Those working with young people support them to understand the options available to them
  3. Young people and those working with them agree which options for help they will try
  4. Young people and those working with them review progress
  5. Young people and those working with them discuss options and make any changes as necessary.
- (Law, 2011)

**Outcomes that are important to children:** CORC emphasises that the use of PROMs should always include providing the child with good information on what measures are being used as part of their treatment and why these are suitable. Gathering children's views through the use of PREMs may be crucial to ensure the voice of the child influences review of services, and there is evidence that children as young as eight years old can reliably comment on their experience and outcomes (e.g. Deighton et al. 2013; Riley, 2004). CORC members collect feedback which is analysed as part of their reports. Some services have developed bespoke surveys to encourage feedback on specific aspects. In support of promoting children's views within ROM, CORC also recognises and promotes recent improvements in the online information available to children and their families. For example, the Youth Wellbeing Directory with ACE-V quality standards ([www.youthwellbeingdirectory.co.uk](http://www.youthwellbeingdirectory.co.uk)) provides a tool for raising awareness of the usefulness of outcomes, whilst various social media/websites such as MyCAMH-SChoices ([www.mycamhschoices.org](http://www.mycamhschoices.org)) provide information for young people around how outcomes are being used in services.

**Outcomes that contribute towards performance management:** CORC suggests adopting a 'MINDFUL' approach which consists of the following aspects:

**M**ultiple perspectives: child, parent, practitioner should all be considered separately.

**I**nterpretation: this should be at the most meaningful level e.g. team or individual level or care pathway where possible.

**N**egative differences: where unit under consideration appears worse than others, this should be a starting point for discussions.

**D**irected discussions: focus on what one would do if negative differences were real (75% discussion time) rather than examining reasons for why they might be not real (25% discussion time).

**F**unnel plots: a good way to present data to reduce risk of over-interpretation but still only a starting point.

**U**ncertainty: important to remember that all data are flawed and there is a need to triangulate data from a variety of sources.

**L**earning collaborations: CORC supports local learning collaborations of service users, commissioners and providers to meaningfully interpret data.  
(Wolpert et al., 2014)

**Outcomes that promote reflective practice:** To enable services to be supported in their transformational journey in the use of PROM and PREM to support direct clinical work, children's views and performance management, CORC has developed the potential for accreditation of members against their ability to support and embed the principles outlined above using a stepping stones approach. For further details of accreditation please contact [corc@annafreud.org](mailto:corc@annafreud.org).

## LEARNING FROM MEMBERS' EXPERIENCE: ASPECTS TO CONSIDER IF YOU ARE JUST STARTING OUT

### SHARING A VISION

A clear vision of what the service wants to achieve and a plan of how to achieve it needs to be in place. One of the first considerations should be to create a solid foundation to build from. It seems to be important to consider carefully how the rationale for ROM is to be understood within the service. Teams with greater success in winning over hearts and minds have been able to share the understanding that ROM is not just about learning new techniques but is, for many services, a paradigm shift, a new way the service practices. The way in which this message is delivered can be the difference between the move to ROM being seen as an exciting opportunity or an imposing threat. The strategic vision and support from the senior leadership is critical to success when implementing any new initiative. This should be at the heart of the initiative. How this will be communicated should be considered before implementation starts: How will this vision be shared across all staff, children and their families? Does this match not only the need but the aspiration of your service user? How are you going to ensure all staff are committed to delivering this?

During any change or transformation process it is essential to keep all staff engaged with the process. The value of internal communication and support cannot be underestimated in keeping momentum. This could include: information-providing presentations/workshops; database training sessions; practitioner training in making best use of measures; dissemination of learning about process, data quality, effectiveness and service user experience of the change to ROM; reports or internal newsletters.

CORC runs implementers' meetings every six months for those new to CORC or implementing CORC protocols. Attendances at these meetings show the role of keeping the implementation going is delegated to a junior staff member, usually an Assistant Psychologist. Leadership support is often cited as the key to success during the process, particularly when working with senior colleagues resistant to change. Informal measures such as 'taking the temperature' of the service during staff briefings can help maintain the journey and when the inevitable dips in performance occur, these should be swiftly counterbalanced. As a member of CORC one of the key feedbacks from services is the opportunity to share experiences with other services who have undertaken this process and have achieved success

### STARTING SMALL

Many services have found it beneficial to start by trialling something small with a few clinical staff so as to have the opportunity to "work through the bumps" in the processes, and then consider scaling up to implementation across the larger team or service. There may be a necessary stage of "feeling clunky" that clinicians have to work through (Abrines et al., 2014). Some members have opted for a staged rollout within and across teams supported by the identification of local champions, supervision/peer support and working groups to enable expertise to be shared and passed on.

### LEARNING TOGETHER

Successful teams have been the ones that have put thought into planning the process of "learning from doing" at the team or service-level, in particular, making sure that processes are in place for on-going support and feedback. They have established processes for raising awareness of the benefits of ROM, and some way to facilitate regular sharing of the on-going learning and utility of using measures both in terms of local and national goals.

Edmondson et al. (2001) discuss how successful implementation of new innovative technologies can be dependent on the way in which learning happens and it seems that collective learning processes are a key part of whether or not new routines take hold. They found that early practice opportunities and trials were motivating and encouraged confidence to adopt new behaviours. Likewise, the opportunity for peer reflection about experience and process were also beneficial in encouraging adoption. These facilitative practices can be seen in those CORC members where implementation appears to have been more successful.



Fullan (2009) discusses how purposeful peer interaction can encourage better community learning for organisations and explains that this can be facilitated when knowledge of effective practices are widely and openly shared and when there is transparency towards ongoing consideration of data to inform this. As a member of CORC all services can submit their pseudonymised data for bespoke analysis and comparison against the data held in the central records of all services. However, to have impact, the reports created must be shared and acted upon. Creating reports that are meaningful to the audience is important, and scheduling in time for consideration of learning at team meetings is a good way of keeping ROM on peoples' minds. All staff need to understand why the collecting and analysis of data is relevant to their role and the impact it can have on service development.

Service discussions around data quality impacting on performance information or lack of appropriate case complexity control skewing figures may be presented as barriers to moving past data issues. To contract this human tendency, CORC promotes spending 25% of discussion time on looking at practical issues and 75% of time on a thought experiment considering: "if these data were showing up problems in our practice what might they be and how might we investigate this and rectify these issues" (Wolpert et al., 2014).

Clarity over roles and responsibilities, in particular in relation to data collection, collation and feedback, seems to be key. Some members have found that assigning responsibility to administrative staff was most effective. A few services have found it motivating to incorporate a competitive edge to the process (e.g. having small monthly prizes for the highest return rates). Many services stress that simple acknowledgement of the additional burden that ROM brings can be engaging and motivating as are demonstrated attempts to overcome unnecessary duplication in planning around data entry and recording processes.

## TRAINING STAFF

Visible and regular opportunities for training (including new staff and refresher training) in all aspects of the process (data entry, rationale, introducing and feeding back to families, scoring and interpreting responses) also seems to be key. Likewise, having an identified multi-disciplinary working group (e.g. representatives from CAMHS management, informatics, CAMHS practitioner champions, administration) to meet and consider progress, hold the bigger picture across teams within a service, communicate learning across the site, and to be responsible for feeding back in any learning from correspondence with other CORC sites. Having a whole-team approach with clarity over roles and responsibilities is crucial to avoid both situations where ROM might be seen as just one person's job rather than a shared responsibility and those where work is unnecessarily being duplicated by both clinical and administrative staff.

CORC accredits UPROMISE (Using Patient Reported Outcome Measures to Improve Service Effectiveness), a training package developed in collaboration with the EBPU. The training is run by service providers and service user experts and consists of three face-to-face training days spaced apart to allow for practice and including accreditation of practitioners based on videotaped examples of their use of PROMs. Two versions of the course currently exist; one for clinicians/front line practitioners and one for supervisors. Clinicians who have completed this course demonstrated more positive attitudes to using PROMs and PREMs and higher levels of PROM and PREM self-efficacy, after training (Edbrooke-Childs, Wolpert & Deighton, 2014).

## CLARITY ON USE OF DATA

Clarity around managerial expectations with regard to completion rates can be important. This involves having clearly stated roles and responsibilities, clarity around deadlines for data entry and submissions to the central system and clear processes for monitoring completion rates and for managing and supporting non-compliance. This process needs to be set up in a context where there is acknowledgement of the need for careful consideration of datasets and reassurance that data will not be used to influence staffing or service change without due consideration. It can also be helpful to have planned feedback opportunities for staff to voice reservations and challenges.

## ESSENTIAL IT

Shortfalls in the IT systems have repeatedly been reported as a limiting factor for some time (Johnston & Gowers, 2005) and, more recently, the CORC member survey (2013) again highlighted this central challenge. Although

CORC does not endorse any single IT system, CORC members are able to gain access to 'free' or reduced cost IT systems to support their services, although it is recognised the challenges in this regard remain substantial! CORC can support members to review their systems and processes. An effective IT infrastructure should support and be seamlessly integrated into practise. Members have raised if it is seen as an additional administrative burden this can negatively impact on the value of data collected and potentially even restrict the use of clinically meaningful measures should they not be available within the main system.

## **FUTURE OF PROMS AND PREMS**

Over the past decade there have been important advances in the field of ROM: significant growth in the evidence base unpinning outcome use, a growing body of practical experience as teams across the UK become more knowledgeable and skilful and, through CORC and CYP IAPT, more agreement and clarity at a national level about what the most appropriate measures and informative datasets are for the purposes of good clinical practice, standardisation, benchmarking and policy-making.

The current national funding for the CYP IAPT will end in 2015, however the focus on the use of ROM and PROM will not. Services who have taken part in this transformation project should have embedded the use of outcome and session by session measures within their practice. It is important to remember that all change takes time. Groark & McCall (2008) estimate three years to embed a new practice and research evidence (e.g. Balas & Boren, 2000) suggests 17 years from research finding to practice. CORC has and will continue to support services and share learning at all stages of their transformational journey.

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## A STATISTICAL INTERLUDE...

# UNDERSTANDING UNCERTAINTY IN MENTAL HEALTH QUESTIONNAIRE DATA

Andy **Fugard**

## INTRODUCTION

This chapter provides a brief overview of issues to consider when interpreting mental health questionnaire data from service users. I have focused on what I think are topical areas of uncertainty. Suggestions for further reading are provided at the end.

## THE KEY IDEA: REASONING FROM SAMPLE TO POPULATION

One of the key problems statistical methods solve is how to reason from your sample, for instance average changes in scores over time for a selection of service users, to the population, for example people who are likely to attend your service in future. Figure 1.4 illustrates this pictorially.

Intuitively, the larger your sample, the better you can estimate the population effect. How you sample is also important; for instance people who drop out of treatment have been shown to have worse outcomes than those who complete. This leads to a common sample bias: people who drop out are also less likely to complete follow-up questionnaires, which artificially inflates the estimated average outcome.

## UNDERSTANDING SCORES FROM INDIVIDUALS

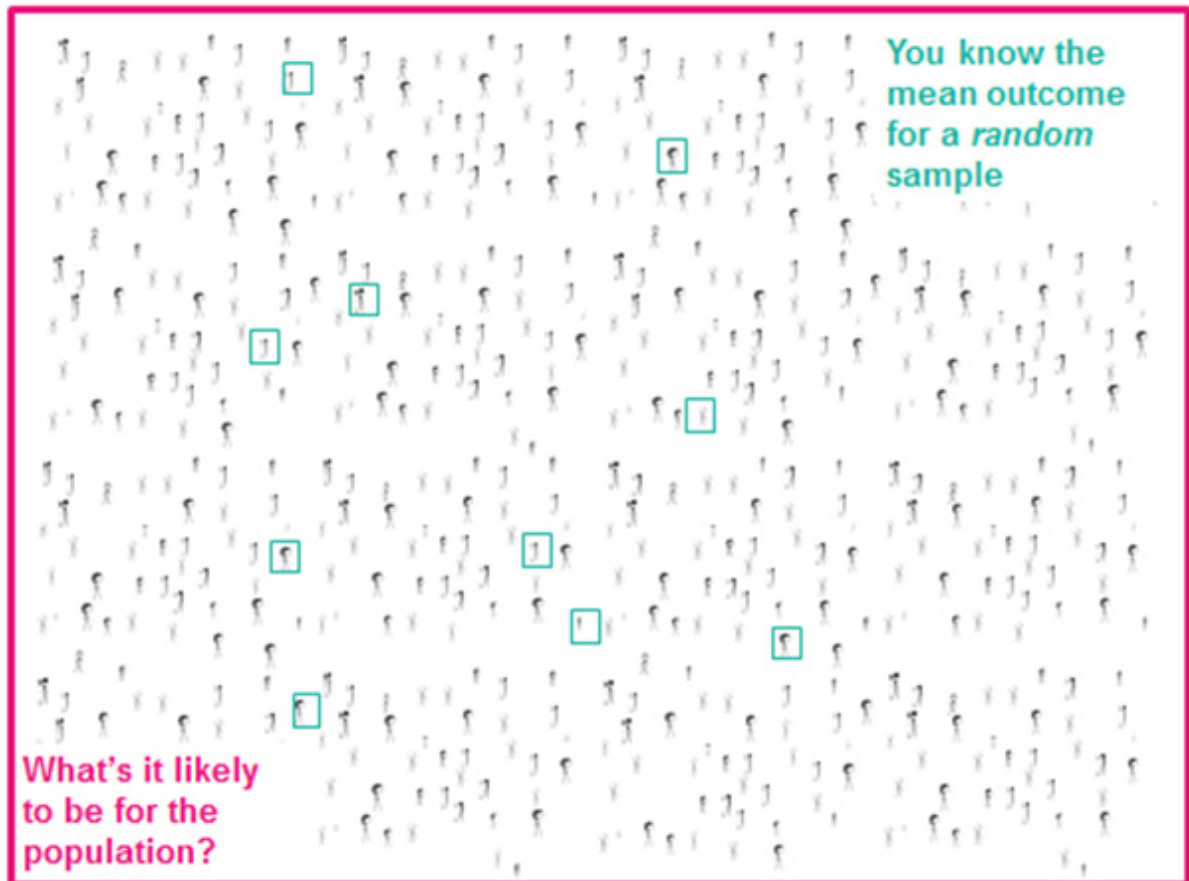
Consider a measure of symptom severity such as the difficulties subscores of the Strengths and Difficulties Questionnaire (SDQ) or from the Revised Children's Anxiety and Depression Scale (RCADS). A particular score will be the result of severity, plus noise due to factors such as:

- The complicated processes required to translate feelings into ticks on a page

- Moment-by-moment variation in feelings due to particular events that have occurred close to the time of completing the questionnaire.

Statistical methods, usually relying on analyses of large norm samples, can be used to help safely interpret scores. In all cases, clinical judgement should be central and scores triangulated with others sources of information.

The following sections illustrate some useful ideas.



**FIGURE 1.4:** An illustration of the sample-to-population inference problem. Image created using stick people from XKCD ( [xkcd.com](http://xkcd.com)), which is licensed under a Creative Commons Attribution-NonCommercial 2.5 License.

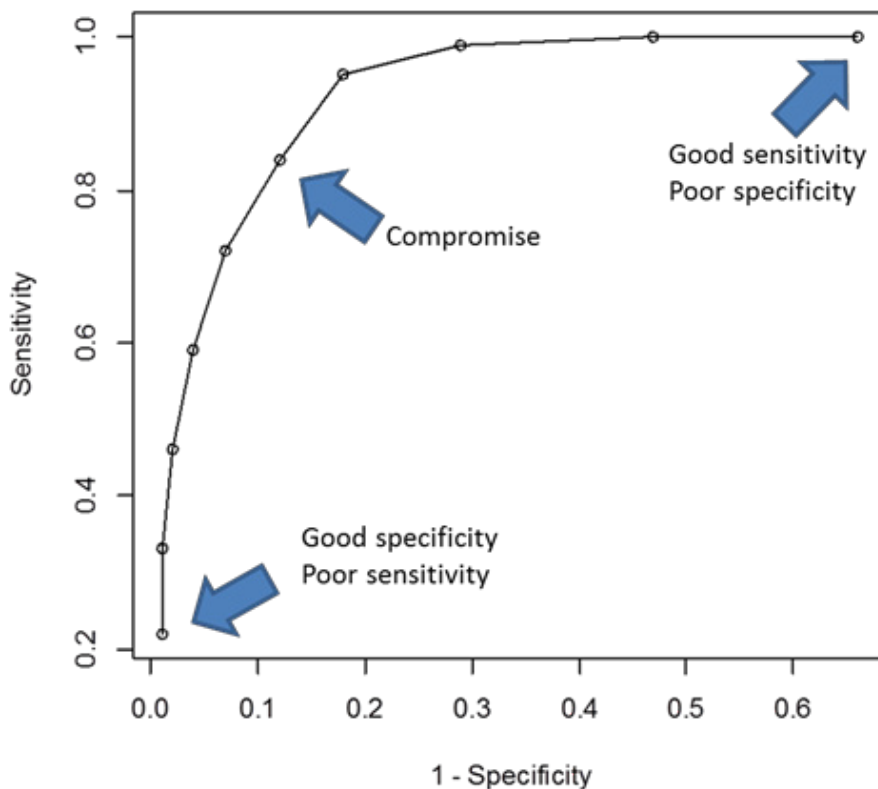
## CLINICAL CUT-OFFS

Some measures provide clinical cut-offs or clinical bands which can be used to help interpret scores. A score in the clinical band indicates levels of symptoms which would benefit from therapeutic input. These cut-offs are found via some kind of “gold-standard” of clinical “caseness”, for instance agreement between a number of clinicians who have assessed a young person’s levels of difficulties – perhaps using a structured assessment tool. In large samples where both structured assessments have taken place and measures have been completed, it is then often possible to find a score which distinguishes between people who are and those who are not experiencing clinical levels of difficulties.

For a given score, two quantities can be calculated and are often reported in test manuals:

- Sensitivity. Take all those people who were assessed to have clinical levels of difficulties by the gold standard. What proportion of these score in the clinical band on the questionnaire?
- Specificity. Take all of those people who were assessed not to have clinical levels of difficulties. What proportion of these score in the non-clinical band on the questionnaire? The quantity  $1 - \text{Specificity}$  is also often used – known as the *false alarm rate*. This is how many people who are non-clinical are incorrectly classified as clinical according to the questionnaire.

Each cut-off score chosen leads to different sensitivities and specificities. Figure 1.5 below shows an example. Note how as the sensitivity improves from around 0.2 at one extreme to 1.0 at the other (i.e. we get better at detecting people with clinical problems), the specificity becomes correspondingly worse (we over-diagnose). The best cut-offs are compromises between missing possible problems and wrongly suggesting someone has a problem when they do not.



**FIGURE 1.5:** Sensitivity and  $1 - \text{Specificity}$  for all possible cut-offs on a measure.

## PERCENTILES

Suppose a large sample of people have completed a questionnaire, and their scores are sorted into ascending order. Percentiles provide a way to pick out individual scores along this list and are helpful landmarks to interpret symptom severity. The 0<sup>th</sup> percentile is the minimum score, the 100<sup>th</sup> percentile the maximum, and the 50<sup>th</sup> percentile is in the middle (also known as the median). So if a young person scores on the 82<sup>nd</sup> percentile of a test, then it means that their score is greater than or equal to 82% of similar young people used to calculate the norms.

Many measures provide percentiles. For example for the SDQ, these are available at <http://www.sdqinfo.com/UKNorm.html> from a large community sample.

## STATISTICALLY RELIABLE CHANGE

Various tests such as t-tests and ANOVA can be applied to test changes in averages of groups of clients, but how about individual change?

One useful tool is the *reliable change index* and its close relation the *reliable change criterion*. The general idea is that scores consist of two main components: the true score reflecting whatever dimension we want to measure, and a noise component, due to reasons explained above. A change in scores over time – for instance between first and last score – is said to be reliable change at some level of confidence if it is greater than would be expected by the noise component.

The reliable change index is simply the difference between two scores (let's call them x and y) divided by the standard error of the difference ( $SE_{diff}$ ):  $RCI = \frac{x-y}{SE_{diff}}$

The standard error of the difference requires the following information from a large sample, for example published norm data:

- The *standard deviation* of scores at the beginning of treatment.
- A measure of the questionnaire's *reliability*: either Cronbach  $\alpha$  ("alpha"), which summarises the extent to which items measure the same thing, or test-retest reliability, typically a correlation in scores measured a short time apart so that little or no "real" change would have been expected.

The formula is as follows:  $SE_{diff} = SD \times \sqrt{2} \times \sqrt{1-r}$

where SD is the standard deviation and r is the reliability. The resulting RCI is a z-score, i.e. it is normally distributed (bell curve) with a mean of 0 and an SD of 1.

This information is available for all CYP IAPT measures on the ROM web page:

<http://www.cypiapt.org/routine-outcome-monitoring/routine-monitoring-outcome.php>

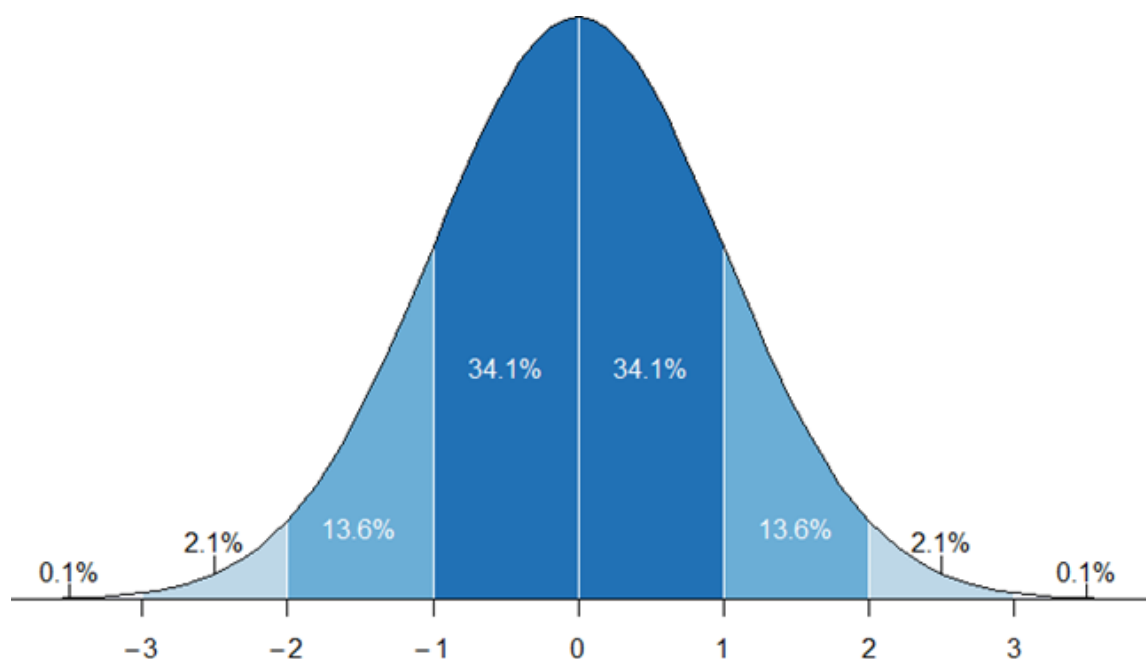
### **A recap on z-scores**

What do these RCI values mean? One rule of thumb is that if it is over 1.96 or less than -1.96, then you can be confident (95% level) that change was statistically reliable. Figure 1.6 shows the z-score distribution pictorially. For RCI, this illustrates the likely pattern of change due to chance *alone assuming there was no change in the true score*. So, for instance, around 68% of people will have scores fluctuating around -1 to +1 even if the true score has not changed.

### **Example**

Let's use one of the CYP IAPT measures, the depressive symptoms subscore of the RCADS. The norms for the RCADS depend on age and gender; suppose the service user is 13 years old and female. The SD is 6.26 and Cronbach  $\alpha$  is 0.87. The standard error of the difference is then  $6.26 \times \sqrt{2} \times \sqrt{(1-0.87)} = 3.2$ . Table 1.2 shows the computed RCIs for a range of changescores.





**FIGURE 1.6:** Distribution of z-scores. For the RCI, approximately 68% of scores will be between -1 and +1, and 95% of scores between -2 and +2 if there has been no change in the “true” score.

**TABLE 1.2:** Reliable change indices for a range of changescores for the RCADS depressive symptoms subscore (using norms for a 13-year-old female).

CHANGESCORE	RCI
0	0.00
1	0.31
2	0.63
3	0.94
4	1.25
5	1.57
6	1.88
7	2.19
8	2.51
9	2.82

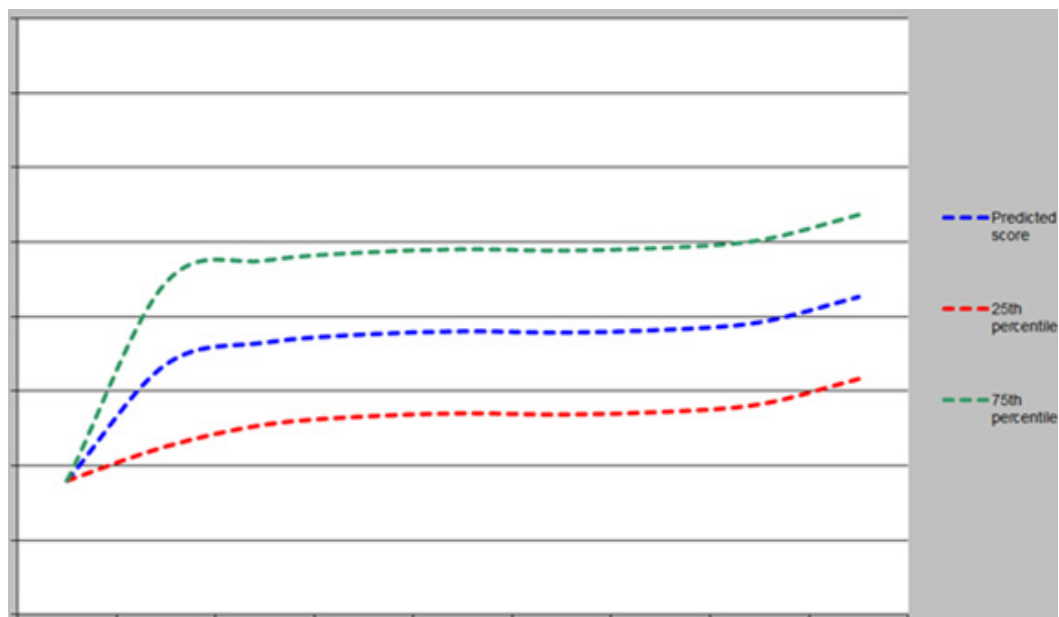
A (95%) *reliable change criterion* is just  $1.96 \times SE_{diff}$ . For this measure this will be approximately 6, i.e. a score of 6 or more would be considered reliable change, and a score of less than 6 could well be due to measurement error. Other levels may be computed based on the z-distribution. Some examples (two-tailed) are shown in Table 1.3, for example the 90% criterion for this RCADS subscale is approximately  $1.64 \times 3.2 = 5.2$ .

**TABLE 1.3:** Multipliers for reliable change criteria for levels of confidence from 50% to 95%.

CONFIDENCE	MULTIPLIER
0.50	0.67
0.55	0.76
0.60	0.84
0.65	0.93
0.70	1.04
0.75	1.15
0.80	1.28
0.85	1.44
0.90	1.64
0.95	1.96

## EXPECTED RECOVERY CURVES

Session-by-session measure developers are also providing curves of change over time. As more data are collected in the UK, this will be possible for CYP IAPT measures too. The idea is then that it's possible to predict the distribution of change over time and see how well a particular service user is progressing compared to others with similar problem severity. See Figure 1.7 for an illustration of how this looks.



**FIGURE 1.7:** Expect recovery curve example for a session-by-session measure showing the 25<sup>th</sup> percentile, 75<sup>th</sup> percentile, and prediction for the average.

## INSTITUTIONAL COMPARISONS

Up until now we have focused on interpreting individual scores. Increasingly outcome measures are used for team and service provider comparisons too. For some years now, Adult IAPT outcomes have been published by (what is now) the Health & Social Care Information Centre (HSCIC; see <http://www.hscic.gov.uk/>). Anyone can see “recovery rates” for their local adult IAPT service.

When estimating a population quantity, such as an average outcome, based on a sample, two main factors affect the precision:

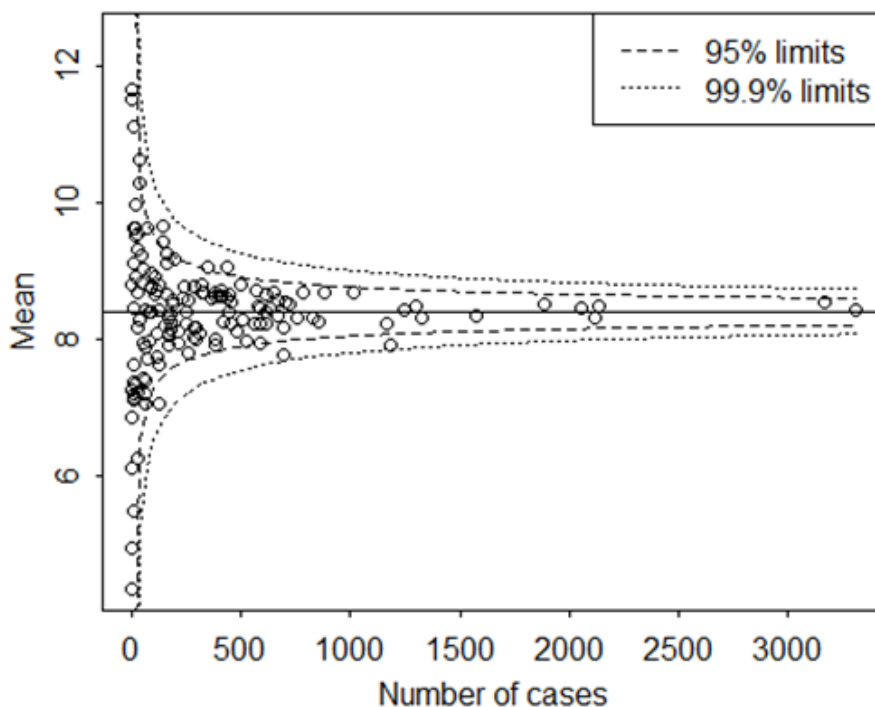
1. The number of cases included in an analysis, i.e., the sample size. The larger the sample size then the more precise the estimate.
2. The spread of values, i.e., the variance or standard deviation. Greater spread means less precision.

This impact is summarised by the equation for the standard error of the mean for normally distributed (bell curve) data:  $SEM = \frac{SD}{\sqrt{N}}$  where SD is the standard deviation and N is the sample size. (This, as an aside, is an example of one of the wondrous things about statistics: it’s possible to come up with simple formulas which quantify best guesses about how sure one can be about the precision of inferences.)

Note that the standard deviation will tend not to change so much as the sample size increases. This gives the overall spread of values in the data. The standard error of the mean depends on the standard deviation, but it represents a level of uncertainty about what the mean is likely to be in the population based on what it is in the sample. (And recall, you always know for certain what a sample-quantity is – you just compute it.)

Figure 1.8 illustrates the implications of this for outcomes. Each point represents a service. The position on the horizontal axis shows how much data the service provides and the vertical axis is the average improvement in symptoms.

Importantly, this data is all simulated and designed so that at the population-level, there is no difference between the services’ outcomes. It’s clear that mean outcomes are more varied for smaller datasets than for larger ones.



**FIGURE 1.8:** A “funnel plot” illustrating how sample size affects average outcomes.

This is as predicted by the standard error of the mean equation above. This equation was also used to calculate 95% and 99.9% confidence intervals for the mean. As may be seen, all points are within the 99.9% limits and most within the 95% limits. It's notable that not all are in the 95% limits – especially as this is the criterion often used to test whether there are “statistically significant” differences in data.

## HELP – NONE OF THIS MADE ANY SENSE !

What if you didn't study statistics, or aren't a fan of maths? Fear not – colleagues will be able to assist! You could try asking:

- **Recent psychology graduates**, perhaps working as assistant psychologists. Graduates of UK programmes accredited by the British Psychological Society study a range of approaches. All are essential for analysing questionnaire data. Arguably analysing data is a better use of graduates' time than is data entry – a task they often seem to perform at services.
- **IT professionals** have extensive experience developing software and a strong background in mathematics. They are less likely to have an applied statistics background, however often will be able to pick it up quickly with the help of intensive one or two day courses. The statistical package R ([www.r-project.org](http://www.r-project.org)), free and driven by a powerful programming language, might be a way to entice them.
- **Other colleagues** who use terms like “regression to the mean” or “precision” in conversation. Keep an eye out. You never know who you might find. Some services have undercover physicists now working as clinical psychologists, ecologists with a knack for stats working as senior managers.

## ACKNOWLEDGEMENTS

Thanks to David Trickey for helpful comments.

## FURTHER READING

General introductions/refreshers to statistics

**Crawley** M. J., (2012) *The R book*. Wiley, Chichester.

This is the textbook to read about R and a wide range of statistical methods. Probably one for the IT professionals.

**Field** A., (2013) *Discovering statistics using IBM SPSS Statistics (4th edition)*. SAGE Publications, Los Angeles, London, New Dehli, Singapore, Washington D. C.

A leisurely introduction to statistics through SPSS, much loved by undergraduate psychology students.

**Field** A., Miles J., Field Z., (2012) *Discovering statistics using R*. SAGE Publications, Los Angeles, London, New Dehli, Singapore, Washington D. C.

As above, using R rather than SPSS for its examples.

**Howell** D. C., (2010) *Fundamental statistics for the behavioral sciences (8th edition)*. Wadsworth, Belmont.

Suitable for more advanced psychology graduates.

## RELIABLE CHANGE

**Evans C., Margison F., Barkham M.,** (1998) The contribution of reliable and clinically significant change methods to evidence-based mental health. *Evidence-Based Mental Health*, 1, 70–72.

See also Chris Evans' very helpful webpage at <http://www.psych.org/stats/rcsc.htm>

## RUNS CHARTS AND CONTROL CHARTS

**Caulcutt R.,** (2004) Managing by fact. *Significance*, 1, 36–38.

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## REGRESSION TO THE MEAN

**Ford T., Hutchings J., Bywater T., Goodman A., Goodman R.,** (2009) Strengths and Difficulties Questionnaire Added Value Scores: Evaluating effectiveness in child mental health interventions. *British Journal of Psychiatry*, 194, 552–558.

## COMPARING INSTITUTIONAL PERFORMANCE

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# Section Two - Specific populations

# LONGER TERM THERAPY: USING FEEDBACK AND OUTCOMES TOOLS

Cathy **Troupp**, Susannah **Marks**, Nick **Waggett**, Nick **Midgley** and Karl **Huntbach**

## A BRIEF OUTLINE OF THE AREA BEING COVERED

This contribution is prepared by a small group of Child and Adolescent Psychotherapists (CPTs).

The majority of CAMHS (Child and Adolescent Mental Health Services) casework is brief or time-limited. There have been no difficulties in incorporating the range of CYP IAPT (Children and Young People's Improving Access to Psychological Therapies) outcome monitoring tools into this work. However, a significant minority of children and young people presenting to CAMHS require a longer term therapeutic intervention. They often have complex, multi-layered, multi-faceted health and social care needs.

The following guidance gives a description of what constitutes longer term therapy, the likely profile of a child or young person who may access longer term therapy and the features of the settings in which longer term therapy takes place. It provides a description of how feedback and outcomes tools may be used in longer term therapy and notes important areas for clinicians to consider when using such measures.

## A DEFINITION OF LONGER TERM THERAPY

For the purpose of this document the definition of longer term therapy is therapy which is recommended after a careful assessment and which lasts 12 months or longer. Longer term therapy usually takes place weekly. In some instances it may be deemed clinically appropriate for some children and young people to be seen more frequently, for example twice or three times weekly.

## THE PROFESSIONALS WHO MAY PROVIDE LONGER TERM THERAPY

Longer term therapy may be provided by child and adolescent psychotherapists, art therapists, drama therapists, clinical psychologists, child and adolescent psychiatrists and others. Longer term therapy is usually supported by core training (as in CPT) or by additional training and supervision.

## THE SETTING LONGER TERM THERAPY TAKES PLACE IN

Longer term therapy usually occurs at the same time(s) on the same day(s) of the week with minimum disruption to the routine. The significance of the room, or therapeutic setting, is important as it supports the establishment of a stable and reliable framework.

Often, when a child or young person is attending longer term therapy, the parent or carer is offered regular sessions in parallel.

## THE CONTEXT OF CHILDREN AND YOUNG PEOPLE WHO MAY ACCESS LONGER TERM THERAPY

In some cases, a child or young person's mental health difficulties require a longer term therapy. Mental health needs may only be one area of need in a complicated set of circumstances; often these children have complex familial, social and educational problems.

Initial assessment and informed consent from a child or young person when longer term therapy is being considered is crucial in order that the therapy be sustainable. The assessment phase is also important for establishing a relationship with a child, young person and their family. Shared decision making is vital in reaching an agreement to pursue longer term therapy.

Children and young people for whom longer term therapy is considered appropriate may have experienced significant and repeated traumas which have impacted on their development, their relationships and their capacity to make use of the opportunities available to them. They may have severe and enduring mental health difficulties such as complex trauma, depression, eating disorders, autistic spectrum disorders, ADHD or attachment disturbance. It may also be the case that a child or young person has emotional and behavioural difficulties which are deeply rooted and resistant to change.

## USING THE CYP IAPT FEEDBACK TOOLS IN LONGER TERM THERAPY

A longer term therapy may not be directly problem solving or solution focused in the same way as Cognitive Behaviour Therapy (CBT) for instance. Many of the routinely used outcome measures tend to focus on specific symptoms (symptom trackers such as RCADS (Revised Children's Anxiety and Depression Scale)), specific goals (Goals Based Outcome (GBOs)) and therapeutic alliance measures. A therapy which focuses on allowing a child or young person time and space to find ways of communicating and experimenting with ideas in the therapeutic relationship, does not necessarily lend itself to session-by-session review.

1. Goal Based Outcomes: The roll-out of GBOs across CAMHS starting in 2007 was welcomed by many as providing focus to treatment and the clinical experience has been described recently in the literature (Emanuel et al., 2013; Law, 2013a; Troupp, 2013). However, few therapists doing longer term work have yet trialed the use of GBOs on a session-by-session basis.

In setting the frequency of goal reviews, clinicians may need to consider the following points:

- Reviewing the achievement of goals too frequently could give the child or young person the impression that the therapist was not interested in them as a whole person, but rather as a measure of the therapist's own success. Young people who have good reason to be cynical about adults/professionals often voice the belief that the therapist's status is contingent on their 'getting better'. Session-by-session goal rating might not help to dispel this belief.
- There is an attrition factor. The goals could become increasingly meaningless and rating done by rote, if reviewed too frequently.



- It is in the nature of long term therapeutic relationships for there to be periods in which the child or adolescent feels that no progress is being made. They may or may not express anger and frustration openly but their hostility is often known by both parties. At other times, children feel optimistic and appreciative. Goal reviews need to be frequent enough to capture these fluctuations but not so frequent as to be confusing or misleading. Progress needs to be evaluated over time.
  - Reviewing of goals may most usefully take place at treatment reviews or at points of change in the treatment package. The regularity of such reviews would be at the discretion of the child/young person and therapist, but would need to be at least termly.
2. Symptom trackers (for example, RCADS): Routine monitoring of symptom outcomes is a regular part of longer term therapy. Using them at assessment and review is embedded in practice but to date there is little reported experience of using session-by-session symptom trackers. Again, it seems that directing the child or young person's attention to their symptoms at every session could be experienced by them as irksome and too narrow a focus. Again, we suggest that guidance be amended to allow for frequent rather than session-by-session symptom tracking.

Clinical experience suggests that patients do not necessarily report spontaneously about changes in symptoms, either positive or negative. Symptom tracking needs to be built in to longer term therapy in order for therapists to remain alert to changes in patients' symptoms as there is a risk that therapists believe that symptoms are ameliorating simply as a consequence of on-going therapy (see, for example, Hatfield, 2010).

As with all outcome measurement, enough time needs to be built in to a session to allow discussion of symptom change.

3. The Session Rating Scale (SRS) is new to many therapists. Measuring therapeutic alliance has long been part of research into psychotherapy generally, and the concept originates in the psychodynamic field (Bordin, 1979), but it has not generally been used in a routine way in CAMHS. Research into its relation to therapeutic outcome has mostly been conducted in therapy with adults (but see Shirk et al., 2011) and there has been recent research to suggest that the earlier belief that therapeutic alliance strongly predicts outcome is not founded in evidence, and that many factors interact.

SRS has the potential to be a useful source of clinical information (see case scenario two, at the end of this chapter), and a prompt to clinical conversations about how the young person experiences therapy, prompting adjustments in approach. In the limited experience thus far, it has been found to be a valuable source of information about how the session was received by the client, what was felt to be valuable and what could not be talked about. The SRS has identified important topics for further discussion, allowing as it does an impromptu 'review' of the difficulties and strengths of the session. There is therefore the potential for addressing any misunderstandings at the time, rather than in a subsequent session, and thereby strengthening the therapeutic alliance.

However, this positive effect may not always be the case. Very disturbed children and young people usually have very strong feelings about the relationships that they develop with their therapists, including negative feelings such as anger, hostility and frustration, which are usually understood as relating not only to the therapist but also to significant figures in their lives. When angry or frustrated, children and young people with complex difficulties may give negative feedback on scales such as the SRS which may not necessarily be indicative of negative treatment outcomes.

It is important to stress that as yet it is not known if the SRS has any psychometric properties over the longer-term, and that data returns for the SRS may or may not turn out to be meaningful in global terms. Currently, the SRS is primarily valuable as a tool for eliciting clinical feedback and for discussion in supervision.

## FURTHER ISSUES FOR PRACTITIONERS TO CONSIDER

Experience to date suggests that many of the children and young people seen for longer term therapy are able and willing to engage with session-by-session outcome monitoring. However, there are certain groups of children and young people who find this way of working challenging. Many children seen in longer term therapy have severe difficulty in ordering their thoughts and are not able to reflect on themselves or on others. They may also have conduct disorders which lead them to see any such request as provocative and reason for further acting out. Outcome monitoring with this group of children and young people may therefore at times be counter-indicated. Asking these children to reflect on the session, especially early in the treatment, may be too difficult for them. One option with these cases is to find other ways of incorporating outcome measures without facing the child or young person with their difficulty. Alternatives include:

- Reviewing goals termly instead of session-by-session. If setting goals is a challenge, the first set of goals may need to be focused on building trust in the therapeutic relationship, as basic trust is often very fragile with this group of children and young people. This kind of goal should be revised at reviews so that the therapeutic relationship itself does not remain the primary goal of therapy in the long term.
- Reviewing goals with the parents only if review with the child or young person proves too difficult.
- Using one of the younger child measures of therapeutic alliance may prove appropriate for children and young people who find verbalising too challenging.

Whilst children and young people have shown interest in using these measures in therapy, there is as yet no clear evidence as to what would be the impact of being asked to complete the measures very regularly over a long period of a year or more. This is an area that will need some careful consideration and further discussion and review once therapists have had more experience.

## TIPS ON USING THE MEASURES

One of the challenges has been how to incorporate session-by-session routine outcomes measures into therapy that is not directive but follows the young person's lead. There are a number of ways of doing this:

- Explain to the child or young person that the therapeutic session, which is usually 50 minutes long, will finish after 40–45 minutes and that the last 5–10 minutes of the time will be used to explore the routine outcome measures. In practice, the session can be extended to allow for discussion of the patient's scores or ratings, in keeping with the emphasis in CYP IAPT on clinician feedback.
- Some clinicians prefer to incorporate the outcome measurement into the session and make them an explicit part of the work.
- Some clinicians prefer to separate outcome measurement entirely from the therapeutic session and may choose to use another setting for this part of the work, or ask another team member to undertake it on their behalf.

## CASE SCENARIOS SHOWING GOOD PRACTICE OF THE USE OF THE TOOL-KIT IN THIS SETTING

### CASE SCENARIO ONE

A 13-year-old girl, M, in long-term therapy for anorexia nervosa talked about her anxiety about being away from her mother, even during the school day, when she felt the need to text her mother many times for reassurance. She doubted that she would ever manage a sleepover at a friend's house, though quickly justified this by saying that she could not eat without her mother's total mealtime supervision, as was well known in the therapy team at this time.

Although separation anxiety is a familiar co-morbid feature of eating disorders, the therapist decided to administer the RCADS to track more closely the separation anxiety symptom in isolation. As expected, M scored well above the clinical cut-off range for separation anxiety, as well as social phobia (this was more of a surprise) as well as

at the clinical cut-off for depression. The results of this intervention were ultimately far-reaching. They allowed the initiation of a conversation with M that focused on her developmental difficulties and fears of growing up, as opposed to her preferred frame of an 'eating disorder'. They also allowed new conversations with her parents in family therapy about the requirements of parenting a teenager. The result ultimately was that M embraced the difficulties of the tasks of adolescence and separation with awareness and a desire to overcome them.

## CASE SCENARIO TWO

A 14 year old girl, S, with anorexia nervosa and co-morbid depression, filled in the Session Rating Scale at every session. After one reflective session, S rated the 'Goals and Topics' item around 75%, then seemed to change her mind and crossed it out and moved it back to 60%, and then again back to 50%. The therapist on this occasion had not left enough time for discussion and hesitated as to whether to elicit feedback but decided to do so, asking what had prompted her to re-rate the item twice: 'Have I missed something? Was there something on your mind today that you didn't get to talk about?' S hesitated, began to speak, and fell silent again, looking away. The therapist encouraged her to say what she was thinking of. S said, 'It's the thing about self-harm...'

This resulted in the therapist inquiring and inspecting fresh and quite serious cuts on S's arm, asking whether her parents knew, whether she had been able to use previous self-care advice, and having a conversation about the context for the cutting. S described needing to show that despite her recent weight gain, she still had problems and needed to elicit care. The therapist then took her to join her parents who were in a family therapy session, informed her parents and the family therapist about what had transpired, and fetched a doctor to look at the cuts, partly for safety and partly in a spirit of responding to the explicit request for enhanced care. The session ran over by approximately 20 minutes (another example of eliciting extra care).

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# YOUTH INFORMATION, ADVICE AND COUNSELLING SERVICES (YIACS): OPPORTUNITIES AND CHALLENGES

Barbara **Rayment** with Barry **McInnes**, Bodhakari **Hurd**, Keith **Coulston**, Mike **Lawley**, Rhona **Kenney**, Wendy **Traynor**, Sam **Baker**

Largely found in the voluntary sector, youth counselling services or YIACS (Youth Information, Advice and Counselling Services) have an important contribution to make to the CYP IAPT programme. Their inclusion in partnerships will strengthen local capacity to meet young people's needs and increase the service choices available to them. While facing some of the same challenges as statutory CAMHS in implementing the CYP IAPT approach to outcome measurement, youth counselling providers also face specific challenges due to their own organisational history, culture and purpose.

## WHAT ARE YIACS?

Youth counselling has its origins in the voluntary youth and community sector and in many ways has grown out of a need to respond to both the gaps and, sometimes, the failings of statutory mental health services. While the roots of youth counselling may lie in 'youth work' traditions, these services have evolved their own distinctive values, principles and standards. Youth counselling providers may vary according to local needs, but typically share some common features:

- **'Under one roof' service model:** most providers offer counselling alongside a range of other information, advice and support activities.
- **Range of help and support:** they offer help not only for mental and emotional health issues, but also offer information and advice on, for example, sexual health or housing, or provide support groups for particular groups, such as young carers.
- **Wide age range:** generally open to 13–25-year-olds and some 10–12-year-olds, few services have contact with or support parents or carers.
- **Highly accessible:** services promote self and supported referral via drop-in or appointment, and are generally delivered in dedicated young people-friendly community-based settings, with provision also offered within schools.

- **Diverse range and level of needs:** as universal access points to targeted and specialist provision, young people approach youth counselling services with varying degrees of need: from 'everyday' life challenges to complex and multiple difficulties.
- **Multiple funding streams:** most services rely on a mix of funding from statutory and voluntary sources, often demanding different reporting requirements.

## VALUES, PRINCIPLES AND STANDARDS

The YIACS model has developed out of a social developmental approach to young people's needs and thus the ethos and culture is different to that of the medical model of statutory CAMHS. Youth Access, the national membership body for YIACS, has nationally agreed core values, principles and quality standards, which members agree to abide by in their work with young people (see [www.youthaccess.org.uk](http://www.youthaccess.org.uk)).

## CHALLENGES

- The internal infrastructure of many services is limited and often underpinned by a web of small project funding streams. Few funders recognise management and administrative costs, and services may invest considerable time fundraising basic levels of frontline provision.
- Most services cut across children and adult services, as well as different statutory and voluntary funding streams, creating multiple and sometimes complex monitoring and reporting requirements.
- Local agencies need to implement a variety of measures, due to the varied age range and also the range of services that are often available.
- A number of services will have established systems for outcome measurement, which may or may not be CYP IAPT 'compliant', but will have met their services' needs to date.
- Traditionally, the informal young people-friendly ethos of services has been supported by reducing bureaucratic barriers to service access.
- Confidentiality and informed consent are cornerstones of delivery. Service users' names have not been revealed to funders or other external bodies without consent or where this is overridden by child protection and safeguarding issues.

## SUGGESTIONS FOR MANAGING THE CHALLENGES

YIACS need to work with CAMHS partners to:

- Identify possible solutions to practical administrative and IT system needs.
- Raise the local profile of CYP IAPT outcome measures with adult mental health commissioners.
- Promote better understanding of the services they offer and how the different ethos and culture can be sustained to provide continuity and choice in service provision, whilst remaining part of the local CYP IAPT offer.

## IMPLEMENTING OUTCOME MEASUREMENT IN YOUTH COUNSELLING

The implementation of routine outcome measurement is likely to provide even the most well-organised counselling service with significant challenges. There are likely to be a variety of responses from practitioners: from the pragmatic to outright hostility. Unlike psychologists, the majority of counsellors and psychotherapists are unlikely to have received any training in the use of measures as part of their professional preparation. Some counsellors may see outcome measurement as bureaucratic: a threat to their service ethos and/or the therapeutic relationship with young people. Local services need to invest time in creating a plan for preparing and supporting their workforce, not only for the practical challenges of implementing outcome measures, but also to give time to addressing any fears and concerns about its impact on the agency's culture and established ways of working.

## CHALLENGE: PREPARING A YOUTH COUNSELLING STAFF TEAM OF PART-TIME AND VOLUNTEER WORKERS

Many YIACS employ a mix of paid and volunteer staff to provide counselling services to young people. Depending on the size of the organisation, paid staff can include counselling service managers, senior practitioners and sessional counsellors. The often small core of paid staff is frequently boosted by the services of volunteers in most local agencies. Volunteers and sessional staff will have limited capacity beyond their face-to-face work to meet the additional demands of implementing outcome measures.

## CHALLENGE: ENSURING A YOUNG PERSON-FRIENDLY COUNSELLING ASSESSMENT FRAMEWORK REMAINS AT THE HEART OF THE CYP IAPT COLLABORATION AND THE MEASUREMENT OF OUTCOMES

Most youth counselling services operate some form of assessment process, though not all will call the process an assessment, choosing instead to call it an initial or introductory session. Agencies aim to offer these sessions as soon as possible after a young person first makes contact, ideally within two to four weeks or sooner. Assessments are generally carried out by senior counsellors and conducted in a supportive and relaxed manner to allow time for the exchange of information and for the young person to adjust to the notion of being in control and able to make choices. Ideally the focus is on setting goals or is solution focussed. They should also include risk assessment, including risks to self and others, self-harm, suicidal thoughts and safeguarding. Where there are risks and it is possible and appropriate, the counsellor and young person will also determine sources of support, and agree who the young person will ask for help if they feel themselves to be at risk of harm.

Young people will arrive in youth counselling with a range of experiences of past assessment processes and previous therapeutic interventions. They may have referred themselves having had little or no previous contact with any other service or will have been referred or signposted to the service by CAMHS, a GP or other professional. Initial counselling assessments are not prescriptive, diagnostic or interpretative although there are expected standards of practice. While some young people are referred following a CAMHS assessment and the young person may inform the counsellor they have a diagnosed condition, this may or may be only part of the reason they are seeking counselling. Counselling assessments should note any diagnoses, medication and/or any previous therapeutic interventions, but these will only become the focus of the counselling where the young person specifies.

Following the assessment, next steps are agreed. While not all young people choose to go further than the assessment, those that do are referred to an individual counsellor, where possible given the choice of who they see and when.

## CHALLENGE: USING OUTCOME MEASUREMENT DATA IN THE COUNSELLING SUPERVISION PROCESS

Clinical supervision has long been at the heart of counselling practice with clear standards of practice and clarity about the different definitions and purpose of clinical supervision and management supervision processes and the links between the two. Depending on the local context, youth counselling agencies use a variety of contracts with supervisors, including in-house employed supervisors and independent external supervisors, as well as CAMHS clinicians. One of the issues for consideration in the counselling supervision process is assessing and monitoring individual counsellors' fitness to practice. While supervisors will be experienced practitioners and often trained and qualified in supervision, they are generally unlikely to have any training or experience of outcome measurement in their own practice. While a number of agencies may have previous experience of implementing outcome measures, though not necessarily those recommended by CYP IAPT, this data may not have been used within the supervision process.

## SUGGESTIONS FOR MANAGING THE CHALLENGES

- Develop a plan for introducing CYP IAPT outcome measurement to the whole agency. Taking into account their different needs, think about how to include not only counselling staff and counselling supervisors,

but also non-counselling staff and management committee members. Are there lessons to be drawn from any past experience of using outcome measures elsewhere in your agency?

- Think about the impact on your future recruitment and selection processes for volunteer and other paid staff and how outcome measurement will fit into any future formal agency induction programmes.
- Plan and consult with young people on the information they need to help them understand the purpose of outcome measurement and develop a plan for how the information will be communicated to young people seeking counselling in the future.
- Be clear about how outcome measurement will work within the agency's overall quality assurance processes, including clinical and line management supervision. How will the data inform on-going service development?
- Consider how the CYP IAPT measures will work alongside any other outcome measures used within the agency whether for counselling or any other interventions offered. Are there opportunities for streamlining your systems?
- Appoint a senior member of staff to lead the agency's implementation plan and provide on-going support to staff. They will also need to regularly monitor the delivery of the plan and be alert to problems with data completion and have the ability to respond quickly if gaps and problems do emerge.
- If you use key staff to provide initial counselling assessment and then refer onwards to other counsellors, such as volunteers, consider how you might use this process to identify and agree the range of measures to be used with the young person as a way to reduce the administrative burden on volunteers.



# BLACK AND MINORITY ETHNIC (BME) FAMILIES: THE USE OF FEEDBACK AND OUTCOME FORMS

Emma **Morris**, Rabia **Malik** and Philippe **Mandin**

## ESTABLISHING AND EMBEDDING POSITIVE PRACTICE

These guidelines are not tailored to cultures associated with specific ethnic groups. Rather they aim to support the development of reflexive thinking when using ROM (Routine Outcome Monitoring) with BME (Black and Minority Ethnic) families where there might be issues around their validity. It is recognised that the degree to which services engage with parents varies, and that some services work with particular age groups. Within this section we have used the term 'families' to refer to children, young people and parents.

In relation to specific cultural knowledge, different boroughs have different training needs linked to their local demographic. For example, some areas are characterised by a large population of one ethnic group, whereas others are characterised by a wide range of ethnic diversity.

There are various resources available to help services understand the needs of their local communities, and details of some of these are given below.

In order for the type of reflexive practice described in this section to be sustained and embedded, it is suggested that an identified lead for cross-cultural work of this kind is identified for each service within partnerships. As well as helping to identify the local demographic and co-ordinate thinking and resources, they can link in with the national network of cultural leads.

## POSITIVE PRACTICE IN CLINICAL WORK

As a clinician, there are useful questions you can ask yourself, or within your team, at every stage of therapy in order to ensure that the ROM being used with some BME families:

- is valid, in that it measures a construct that both clinician and the family can relate to; and
- does not impact negatively on engagement, either because of the meaning of form filling for the family, or because of a difference between the language used by some ROM and the families' understanding of the problem.

## BEFORE THE SESSION

- How does my own culture fit with or differ from the culture of the family I am about to see?  
*Example: some cultures have a more individualistic way of constructing mental health, likely to be based on individual symptomatology, whilst others might have a more collective perspective, understanding difficulties in the context of family relationships, and/or the impact of behaviour. In these cases a symptom-based measure may not be valid. For example, there is not a specific word that means 'depression' in certain languages, including Punjabi, Urdu and Hindi.*
- What do I need to know about the culture of this particular family?  
*Example: contact the cultural lead and seek cultural consultation from colleagues from that background with regard to accessing resources and knowledge. Bear in mind that in different cultures there are different constructions of mind, body and spirit; causes of illness; parenting; and treatment. They may also have a different view on professionals' role and the role of the state in family life. Children may be navigating multiple cultural contexts, which might add to their anxiety and confusion.*
- Might I need to tailor my practice at this stage?  
*Example: if there is a possibility the family have a more collective or relational construction of problems, think about different ways their progress could be measured. In cases where you think there might be a difference between the way the family construct problems, and the way they are constructed by ROM, do not send forms out by post/ give them prior to the session. Spend some time with the family before making decisions about which measures to use.*
- Is it possible that there is some difference in the way the problem is constructed across generations?  
*Example: children born in the UK may be able to relate to symptom measures such as the RCADS in a way their parents, born elsewhere, do not. Be aware that, because of this difference, it might be difficult for parents and children to share a conversation about their problem. In such cases special attention may need to be given to keeping the parents involved and co-constructing a formulation of the problem that is meaningful to the family.*
- Based on what I know from the referral, what is the family's likely relationship to authority/professional figures, and what is their experience of form filling?  
*Example: for those families with a history of migration, form filling with a professional thought to be in a position of authority may hold a different meaning and provoke some anxiety.*

## PRACTICAL CONSIDERATIONS BEFORE THE SESSION

- What language does the form need to be in?  
*Example: some ROM are available in different languages. Where appropriate and possible print these out prior to the session.*
- Do I need an interpreter, and have I prepared them to use ROM?  
*Example: book an interpreter for a longer period of time where necessary so that you can prepare them. Explain the rationale behind ROM, ask them to read through it first and clarify any items that do not translate easily or which the interpreter needs clarification on. Ask the interpreter to refer queries the family have with regard to the meaning of items to you, so that you can enter in to a discussion with them about meaning, and assess the impact of completing the measures.*
- Might I need to bring an additional alternative to symptom measurement to the first session?  
*Example: bring measures of functioning, such as the ORS (Outcome Rating Scale) and CORS (Children's Outcome Rating Scale), or measures of relating, such as the SCORE-15 (Systemic Clinical Outcome and Routine Evaluation).*
- Will the first session need to be longer in order for me to be able to complete the forms?

## IN THE SESSION

- EXPLORE: How can I explore this family's construction of the problem in a way that we can develop a shared understanding?  
*Example: this is something all clinicians do anyway. Common questions include: How would you describe the problems that have brought you here today (asked from the perspective of different members of the family)? What do you think has led to these problems? What sort of solutions/ support has helped in the past (signalling that you are open to cultural, spiritual, physical and relational understanding)? Use their language to help guide selection and discussion of ROM.*

Some useful questions in relation to ROM:

*“The questions that you just answered... Do you feel as though those describe the type of problems that brought you here today?”*

*“(example of an item from ROM used) Are these the sort of words you would use to describe your problems, or would you use different words?”*

*“Do you think I would have some idea of the sorts of problems you have been having if I just looked at the scores on these measures before I spoke to you?”*

- **ACKNOWLEDGE:** How can I acknowledge differences in the way problems are constructed and empower families to say in cases where ROM might not ‘fit’?

*Example: in all cultures there are different explanations about the interaction between mind, body and spirit and so be prepared to explain that some of the questionnaires relate to a Western way of understanding mental health problems. For example “Different cultures understand their problems differently. Some of the measures we use here might be more familiar to those who come from a Western background. Some questions might feel like they don’t ‘fit’ with your understanding of your difficulties”; “We are most interested in finding out how you understand your difficulties, and finding ways of monitoring these that suit you. In order to do this we might have to try a few different measures out...”*

- **ADDRESS:** How can I address issues of power and authority?

*Example One: Check out the family’s understanding of your role and how the forms/ data are used, knowing that they may be suspicious due to negative past experiences. Be ready to talk about people’s anxiety about how the data is used. Be aware that young people, for example asylum seekers, may be reluctant to talk in the presence of interpreters. The consent form may also raise particular issues for some groups for whom these forms have to be introduced with sensitivity.*

*Example Two: in families where there is a strong culture of hierarchy across generations, ask the parents before completing the forms with the children.*

- **BRIDGING:** How can I find a shared language or understanding that will facilitate completion of the forms?

*Example: try and identify language used by the family that links concepts identified on the ROM with the family’s construction. For example, if a young person has rated high on the depression subscale of the RCADS, and you have subsequently decided to track this symptom with them, you might choose to use their mother’s description of depression (for example, being ‘distant’) in sharing feedback from ROM with the family, having established that this relates to the same problem.*

- **FLEXIBILITY:** Introduce the idea of measurement.

However, if it is likely that completing ROM might impact on engagement, do them in the next session. Be prepared to complete ROM over more than one session if need be. Prioritise engagement and building a shared narrative with the family when selecting which ROM to use. If your clinical judgement is that using ROM will have a significant negative impact on treatment, do not use it– but be sure to discuss this in supervision and with the cultural lead so that they are aware of issues within the service and can feed this back to the broader network.

## AFTER THE SESSION

Discuss in supervision any challenges in engaging across cultures. With the information you now have, you can go back to the ‘before session’ questions and develop your understanding of the use of ROM with this family.

## BRINGING IT ALL TOGETHER

These stages of positive practice when using ROM with BME families can be brought together within services and partnerships, as depicted by the diagram below. However, be aware that we all have a culture but that culture is dynamic and negotiated differently by different individuals. Clinicians should be curious about the particular meanings that culture holds for the individual clients they are seeing and what they choose to conform to and contest.

## CASE EXAMPLE

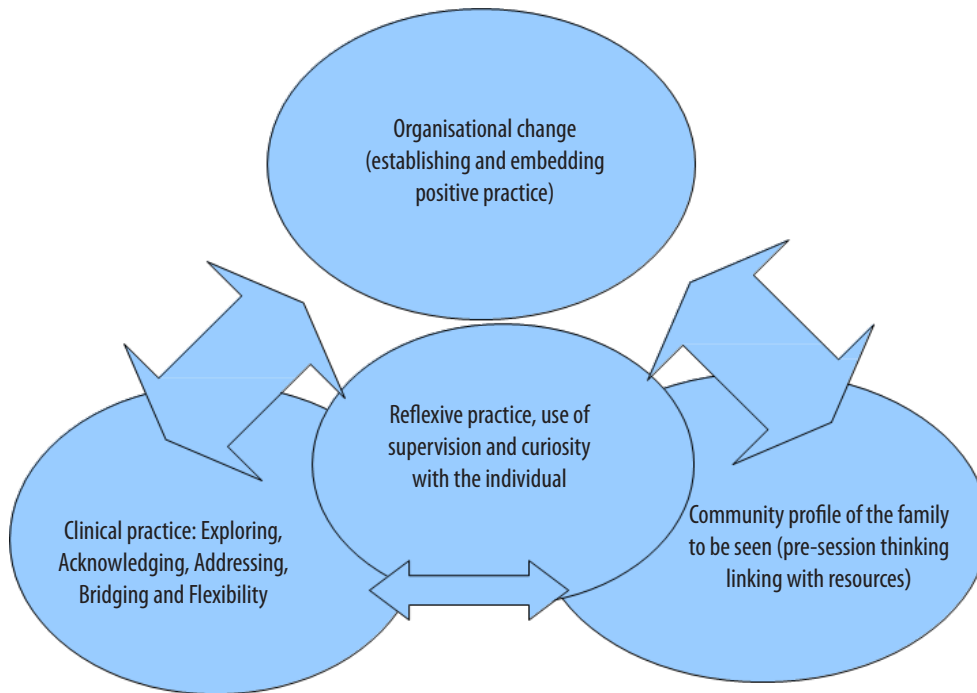
A 14-year-old girl, born in the UK, whose parents are originally from Bangladesh, was referred to a CAMHS. The GP and school's construction of the problem was depression and they requested individual therapy to give the young person some 'space'.

The young person's construction of the problem was mood swings and angry outbursts at home and school: 'I don't know what is happening to me'. She is worried about her mum who has been very ill, but is also keeping secrets and breaking cultural rules that she knows her family will not approve of.

Her mother's construction of the problem is relational. She knows her daughter 'worries' about her health, and has been quiet recently, but can't understand why she is still worrying when she is now better. Her mother states that they are 'good parents', taking care of things and providing for their daughter. Mum thinks her daughter has bad friends who are leading her astray and is worried about her having a boyfriend.

The aim of the intervention, agreed with the family, was to help the young person to bridge the individualistic and collectivist explanatory models – to understand the young person's mental and emotional state but also to fit and negotiate within her family and cultural context. This will require the family to understand the young person's emotional state but from within their cultural context where individual 'space' and emotions may not be given precedence, but rather greater emphasis may be given to performing functional roles and keeping harmonious relationships in the group by being obedient to parents and cultural expectations.

In this case it is important that ROM are used to facilitate understanding between the young person and the context they live in, rather than to isolate the young person further by focusing on the individual and not engaging the parental viewpoint. The RCADS was given to the young person in an individual session during the



**FIGURE 2.1:** The relationship between elements of positive practice when using ROM with BME families.

assessment phase. The young person scored highly for depression and generalised anxiety. However, both the parents and the young person felt that individual goals for the child, in addition to the ORS, completed by parent and child, was a better tool for tracking progress in this case.

## FURTHER RESOURCES

Resources available to help partnerships identify the needs of their local communities: The 2011 Census provides some data about BME communities in the local area but these communities tend to change rapidly, so further analysis is essential to understand the range and number of BME communities within the local area. There are a number of sources that this information can be obtained from, such as:

[www.ons.gov.uk/ons/dcp171776\\_290558.pdf](http://www.ons.gov.uk/ons/dcp171776_290558.pdf) <http://www.ethnicity.ac.uk/census/>

[www.runnymedetrust.org/blog/188/359/Who-are-we-Census-2011-reports-on-ethnicity-in-the-UK.html](http://www.runnymedetrust.org/blog/188/359/Who-are-we-Census-2011-reports-on-ethnicity-in-the-UK.html)

The regional public health observatory [www.apho.org.uk](http://www.apho.org.uk)

The Equality and Human Rights Commission website [www.equalityhumanrights.com/pages/eocdrccre.aspx](http://www.equalityhumanrights.com/pages/eocdrccre.aspx)

There are also resource available from Adult IAPT including the BME Positive Practice Guide ([www.iapt.nhs.uk/silo/files/black-and-minority-ethnic-bme-positive-practice-guide.pdf](http://www.iapt.nhs.uk/silo/files/black-and-minority-ethnic-bme-positive-practice-guide.pdf)) and the IAPT Equality and Diversity Toolkit ([www.iapt.nhs.uk/2008/10/equality-and-diversity-toolkit](http://www.iapt.nhs.uk/2008/10/equality-and-diversity-toolkit)), for more information on gathering data about the local community.

## ADMINISTERING MEASURES TO FAMILIES

Prepared by the Family Therapy Outcomes Advisory Group, Convener Peter **Stratton** with Marcus **Averbeck**, Iris **Corrales**, Liz **Forbat**, Gill **Goodwillie**, Judith **Lask**, David **Low**, Nicola **McCarry**, Lynne **McCandless**, Jeanette **Neden**, Jan **Parker**, Gary **Robinson**, Reenee **Singh** and Teh **Yang Yang**

### INTRODUCTION

Measuring progress and outcomes of therapy raises a number of specific issues when the therapist is working with families and other networks of care. This guidance is primarily for measurement when a number of family members are present in the session. It is also relevant when working systemically with an individual, in relation to their significant relationships, when working with members of more than one family (multi-family work), and in sessions involving family member(s) and professionals.

Most measures used in CYP IAPT and CORC+ (Child Outcomes Research Consortium +) are designed for administration to individuals who have been referred for treatment and may be being seen on their own in therapy. Sometimes an individual child or young person is receiving individual-focused treatment for their diagnosed condition in the presence of other family members, so we need to know how to use these measures when several members of a family are present.

However, we are restricting our interest to cases in which the functioning of a number of family members is of interest. The case in which an individual child or young person is receiving treatment for their diagnosed condition in the presence of other family members, will usually be processed in the same way as individual therapy. So we are concerned with the situations when the therapeutic focus includes the family's relationships, context and functioning as relevant to the referral problems and/or to the effectiveness of therapy, i.e. when children and young people's important relationships are particularly relevant to the difficulties they are experiencing and/or to their recovery and to our therapeutic work together.

An alternative to using measures developed for use with individuals is to use one that is specifically designed for use with families. Several measures have been designed for use with families and other groups. Some, primarily those developed in the USA during the 1970s and 1980s, reflect the understanding of families and of outcome measures of that time and context. More recent measures include the STIC (Pinsof et al.) in the USA and the SCORE in the UK. Where this guidance refers to family measures, we are referring to SCORE and specifically its newer and shorter version, the SCORE-15.

Systemic family therapy works with the complexity and recursive influence of people's relationships, contexts, beliefs and experiences over generations. As such, it is often used with families experiencing serious and/or multiple problems, often over many years and/or for whom other interventions have not brought change.

While non-attendance (Did Not Attend; DNAs) are sometimes construed as an indication of a poor therapeutic alliance, there may be many more factors at play in the case of family attendance. Arrangements for getting everyone present are likely to be more complicated both in terms of practicality of fitting around other commitments, and of the expense and time demands of transport. By the time a family is referred for therapy they may be already receiving help from a number of other agencies and needing to balance these appointments with other aspects of their lives, which may well include insecurity about employment or problems with schools.

## INTRODUCING THE MEASURES

While this chapter is intended to be useful when using any outcome measure while working with families, the SCORE-15 is specifically designed for the purpose and the ORS and SRS are readily usable in a family context.

## PRACTICAL GUIDANCE

It is important that practitioners use their clinical judgement about whether it is useful and safe for the family to complete the measures in each others' presence or separately, and if, when and how their responses will be shared with other family members. Factors influencing clinical judgement include the developmental and cognitive abilities of persons answering the question, therapeutic alliance, confidentiality or safeguarding issues.

All family members, especially children and young people, may need clear and repeated assurances about the parameters of confidentiality; what is to be shared with whom. The therapist must decide beforehand whether and how the information from the measure will be used with the family so that assurances about privacy will not conflict with clinical needs.

## TALKING ABOUT TALKING

In some families and in some cultures, and in some families sometimes, it is considered insulting for a child to talk about their parents with anything but praise, or to ask a child to talk about their family members. Is it OK to ask these family members to complete a questionnaire about the family, or might it be felt as disrespectful, unsafe, or blaming?

*Would you feel OK about answering these questions now?*

*Would you still feel OK if your answers are seen by other family members?*

*If you have open talks as a family now, how do you imagine things might be between you after the session has finished?*

*What might help talking together feel more easy/possible/less risky?*

*If it feels tricky to talk together at the moment, is that a useful focus of our work together? /might an aim of our work together be to get to a point when talking as a family feels OK?*

*If open talk were possible, what difference might that make to you/your family?*

This child, young person, family may need a clear reassurance that you don't have to answer any questions you don't want to. If the agency is paid according to the number of completed assessments, can this assurance be freely given? This may be one area in which routine research ethics operate to a higher standard than (monetised) clinical practice.

Specific expertise for talking with children of different ages is available especially in the literature of systemic family therapy. A sample of the literature that contributors to this chapter have found helpful is included in the references for this chapter.

## WHO COMPLETES THE MEASURES

*Everybody with the capabilities to do so?* The questionnaires should be completed routinely and given to all members of the family group taking part in a therapy session. Some measures have versions for different age groups, e.g. SRS/ORS and so the relevant measure would be used. Where available, clinicians could consider using the measures that have been designed for younger children with the older age group/adults if this is likely to be more accessible for them.

Each family member would be given their own questionnaire. Be sensitive to how much help parents are giving their children in completing the questionnaires. Their expertise on their children means that they are likely to know how much help they need to understand what is being asked of them. However, it is important that the response is from the child/young person and not from the parent; they will have their own measure to complete.

### ***Measures for Younger Children***

Most CYP IAPT recommended measures are currently validated for use with children 8 years or above, and measuring behavioural or emotional changes within the children. For younger children, especially age 5 and below, their presenting problems are usually more relational, even though problems are often located in the child at the point of referral. As such, parental change measures such as attributions and parenting style rather than/as well as child symptom change would be more helpful.

Our colleagues in the Oxleas Greenwich SureStart programme are piloting Spence Preschool Anxiety and Parenting Daily Hassles Scales in 2013. This could change based on subsequent feedback from the parents. Parent Stress Index (PSI) has been found to be very helpful for complex cases, but not as an initial assessment tool as, as the name suggests, it has over 100 questions. Beck's Depression Index (BDI) is a worthwhile tool in cases with parents presenting with depression. The problem, however, is that both PSI and BDI currently do not have weekly symptoms tracking components. The team is considering adapting Spence for this purpose. As for the goals tracking measures, the team and their service users have found them very useful. However, goal setting may not always be appropriate for very sensitive cases such as little children with a brain tumour or with parents with serious head injuries.

### ***Issues of handling non-literacy***

Clinicians may need to read the questionnaires to family members where there are literacy challenges and take care to check that the meaning of questions is understood. For example, with scaling questions it is important to check that the family member understands which end of the scale represents a positive and which a negative response.

The issue of language is difficult; some interpreters may offer to translate the questionnaires on the spot but evidence suggests that this is rarely effective. A pre-arranged translation of the questionnaires is most likely to work.

## MINDFULLY NOT USING THE MEASURES

In some situations it may be wholly inappropriate to introduce measures, for example where young people/parents are extremely distressed and emotionally deregulated. The clinician will use their clinical judgement to assess the situation and may decide to delay doing the measures until a later session. The reasons for not using the questionnaires should be documented and consideration given to when would be an appropriate time to introduce them to the family members. The therapeutic needs of the child/young person will be the main focus of the session; if the clinician judges that to use the measures is likely to increase distress or disrupt therapy, and thereby outweigh any clinical benefit to using them, then it would be appropriate to postpone seeking the information.



## DISCUSSING THE RESULTS AND USING THEM TO INFORM THE THERAPY

Distinguish discussing results for clinical purposes from audit or research. And the issues this raises about any offering of privacy in relation to each other. Solutions include e.g. phrasing of general statements that identify hot issues but do not identify who raised them. *"An impression I get . . . . does this seem worth discussing?"*

How to raise the issue if results show therapy is not progressing.

1. A focus on the special issue when it is going badly for one or more family members but well for others.
2. Some suggestions for productive discussions when the whole family indicates lack of progress, with ideas for ways of changing tack.

Whether the written answers and discussions would be best conducted separately with individuals or with a constellation of family members and/or professionals is a matter for clinical judgement. Influencing factors to consider include developmental and cognitive abilities of persons answering the question, therapeutic alliance, confidentiality or safeguarding issues. The clinician could cross-examine the answers given with those from other questionnaires. For example, consider answers to SCORE-15 with scores of depression in RCADS by the child/young person and parents.

Consider creatively adapting measures to match clinical needs. For example, the use of drawings, play or sculpting may enhance therapeutic engagement and understanding for some clients and families.

The assessment or reviews could either take a single or multi focus lense that would capture the background context (silent concerns) that comes along with the referred child/young person. This might include an additional component/element of the assessment or reviews, which would make visible the associated concerns that other family members bring forth at the assessment/review stage that the clinician has to work with.

## QUALITATIVE FEEDBACK

While tracking quantitative aspects of the outcome measures are strengths in CYP IAPT, it is important those working with families and other networks of care invite and incorporate qualitative information where helpful. Participants' words and other communications can alert us to thicker descriptions of their experiences, struggles and resources. For example, the child/young person, siblings and parents could be invited to insert additional comments in their Session Rating Scale (SRS) or Session Feedback (four questions). Besides using the descriptive comments clinically, where resources are available, the descriptions could be invaluable for services to invest in qualitative analyses, which could also be shared with families and partnering professionals as additional levels of feedback.

## EXPLORING AND MANAGING THE MEANINGS OF DIFFERENCE

The same event, even the same word, can mean very different things to different people. It can often be helpful to look at those differences, as often they can help us understand each other better and find ways forward. But it can also feel tricky or risky if people believe that someone having a different view means that person doesn't love or respect them... Who could help me understand what beliefs you hold in your family about different opinions?

## MANAGING DIVERSITY

The social GRRRAACCEESS (Burnham, Palma and Whitehouse, 2008). The acronym draws attention to issues of Gender, Race, Religion, Age, Ability, Class, Culture, Ethnicity, Education, Sexuality, Spirituality, not as an obligatory list but a systemically interacting framework which demands attention of different aspects at different times in therapy and training.

## INTERPRETING THE FEEDBACK

How to feed back to colleagues and managers. Are there specific issues in relation to families? What if any of the measures used reveal abuse especially by a member of the family who is present?

## NOTE

Even though this chapter concentrates on therapist activities with a family, we recommend that systemic clinicians extend its use to gather multiple perspectives. This can be done by inviting different partnering professionals, the child/young person and their family members to answer the form based on their respective views about Johnny's presenting problems. This could be done at a family session, a professional's meeting, or a TAC (Team Around the Child) meeting could be convened to facilitate better understanding and clarify different persons' rating of the various levels of functioning and distress.

For example, 15-year-old Johnny, known to Social Care, was referred by the school to CAMHS for self-harming behaviour. The systemic clinician convenes an assessment session, inviting the following people to answer ... from their own perspective:

- School teacher (referrer)
- Parents
- Allocated social worker
- 18-year-old sister
- Johnny himself

Variations to this could be incorporating circular questioning within the answers by having everyone answering the current view from another perspective:

*"I would like each of you to each imagine you are answering the questions as if you are the person sitting on your left, for example, Johnny, you will imagine you are your sister. How severe would she rate your self-harm, and Mr. Henderson (father), how would you rate Johnny's low mood if you were your wife? As for June (school teacher), could you answer it from the Social Services' point of view, and Anita (social worker), answer it from the school's view?"*

We suggest that it can be used at both assessment and six-monthly reviews, alongside SCORE-15 and other relevant symptom measures, as together they give a broader and relational lens compared to what symptom-specific questionnaires alone could provide. Overtime, the systemic clinician would be able to weave the multiple perspectives (including the clinician's personal clinical judgement) into a coherent narrative, not just around the presenting problems located within the referred child/young person, but also those located within or between the family and other contexts as well. This can then be fed back to the family and professionals to further build on the circular hypothesis. However, we need to, bear in mind that the map is not the territory; the information is just a tool to guide us to see the problems, relationships and situations in various ways, but it would not represent the entire picture of what is happening within the family, professional systems or between the systems.

While tracking quantitative aspects of the outcome measures are the strengths in CYP IAPT, we invite systemic clinicians to creatively incorporate qualitative inputs where deemed helpful, so as to bring to the foreground thicker descriptions of the contextual issues. For example, the child/young person, siblings and parents could be invited to insert additional comments in their Session Rating Scale (SRS) or Session Feedback (four questions). Besides using the descriptive comments clinically, where resources are available, the descriptions could be invaluable for services to invest in qualitative analyses, which could also be shared with families and partnering professionals, as an additional level of feedback.

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## LEARNING DISABILITIES: COLLECTING AND USE OF FEEDBACK WITH CHILDREN AND YOUNG PEOPLE WITH LEARNING DISABILITIES AND THEIR FAMILIES

Collated by Rowena **Rossiter** with contributions from: Heather **Armstrong**, Eddy **Draper**, Robert **Goodman**, Sally **Morgan**, Neil **Phillips**, Julie **Pill**, Caroline **Reid**, Catherine **Sholl**, Sam **Shrubsole**, Jeremy **Turk**, Orlee **Udwin**

This section offers some practice-based reflections, consensus and tips to help practitioners. It mirrors the BME guidance in aiming to support the development of “reflexive thinking” around feedback and outcome measurement, where difference and diversity may challenge their use and validity. As Pill and colleagues (2013) helpfully summarise in their CYP IAPT Leadership Project investigating: Can CYP IAPT Routine Outcome Measures be used in a meaningful way with Children and Young People with a Learning Disability and their Families? “ROMS [Routine Outcome Measures] need to be meaningful for the child/young person with LD [learning difficulty/disability], their family and clinicians. ROMS must form part of the therapeutic relationship and help to inform clinical practice through interpretation and discussion. They need to be fit for purpose and accessible to everyone who is asked to use them to promote a genuine appreciation of the partnership with service users. Consideration needs to be given to the individual’s ability (disability) and culture.

Parents must be given the choice to complete the measures or not and practitioners are encouraged to use their clinical judgement around when it’s appropriate not to ask a service user to complete them”.

Revised guidance will develop as the evidence base increases and incorporates more views of children and young people with learning disabilities and their families.

This section is not only for specialist CYP LD practitioners. Disability awareness and skills are relevant for all CYP practitioners. Learning difficulties/disabilities are often unrecognised, for example:

- Simonoff et al. (2006) found only 15% of those with IQ < 70 had a statement of special educational needs or attended a school for children with moderate learning difficulties in a sample of 2,730 school children in years eight and nine.
- Talbot (2007) and Emerson & Baines (2010) found lack of recognition of learning difficulties/disabilities in mental health, care, education and criminal justice settings meant children and young people’s needs are not met and contributes to health inequalities.
- Falconbridge et al. (2012) identified “Undiagnosed Developmental Disorders in Secondary Age Group” as one of the features of their work in schools with “a surprisingly high number referred for specialist

assessment for suspected developmental disorder” which in the “majority of cases this has proved correct”.

- The prevalence of children with Complex Learning Difficulties and Disabilities, CLDD, is increasing (Blackburn et al., 2010; DCFS, 2010; Carpenter et al., 2010; see <http://complexld.ssatrust.org.uk>, reflecting increased survival of premature babies and/or with complex health needs which can be associated with parental alcohol and drug misuse).

Factors that may impair or reduce cognitive functioning and affect accessibility to psychological interventions include pervasive developmental disorders (such as Autistic Spectrum Disorders or Asperger’s Syndrome); learning disabilities; generic or specific learning difficulties; neurological disorders (such as epilepsy, tumours, head injury, ADHD); sensory impairments; effects of medication, literacy and/or language difficulties and mental health problems such as psychosis with associated reasoning biases, attention and working memory problems (Rossiter and Holmes, 2013). Parents may have learning difficulties or disabilities and other cognitive impairments.

Practitioners already have many relevant core skills such as working across the developmental range from very young children, with those for whom English is not a first language, as well as those with other “atypical” development and/or neurodevelopmental disorders. It forms part of the broader diversity and equalities agenda (race and culture, socioeconomic status etc.).

## ISSUES

There is a wide range of learning ability/disability from specific learning difficulties to severe/profound learning disability across the age range. This affects development and presentation of emotional, social and behavioural problems associated with mental health issues. Often communication issues, neurodevelopmental disorders, physical and sensory impairments are associated.

Limitations with collecting and using feedback from standard CYP IAPT ROMS and toolkit include:

- Difficulties with reliability and validity with measures developed with “typically-developing” populations. Any adaptations (e.g. wording, presentation) may create issues for validity, whereas psychometric properties of existing measures may be unsatisfactory for people with LD.
- Measures for “typically-developing” children may pose difficulties with self-report, appropriateness and comprehensibility of language and concepts within items.
- “Steps” for items within norm-referenced measures or “symptom change” measures may not be sensitive to any relevant change that occurs during intervention.

Development of, or change in, adaptive behaviour can be very small, especially for CYP with severe learning disabilities or profound and multiple disabilities.

- CYP LD are very diverse and complex (Paddington Complexity scores (Yates, 1999) for CYP LD were equivalent or higher than mean in-patient psychiatric case scores).
- Limitations of measures which focus on “symptoms” and behaviours, rather than adaptation and adjustment of the child/young person, or by focusing on the child or young person rather than those around them such as parents and carers. The acceptance or adjustment of families/carers may be a more crucial variable than the behaviour of the child or young person.
- Issues of “acquiescence” or response bias, with CYP LD possibly at greater risk of trying to “please” clinicians perceived as more powerful.
- Inappropriate timing, measures and/or “over-evaluation” may affect engagement and validity of evaluation.

Hence, the Positive Practice stages (Before and After the Session, bringing it all together) and questions e.g. about timing (when, how much time is needed, understanding, flexibility) in the BME section, and issues covered in the Families section (especially measures for younger children, mindfully not using measures) are relevant and helpful.

## COMMENTS ON SPECIFIC TOOLS

**Strengths and Difficulties Questionnaire:** is not standardised with CYP LD. The self-report version can have limited scope for some CYP LD. The items are “gross” rather than “fine grained” so may not measure any change. Parents and professionals have found the parent version useful with milder, but not more significant/severe learning disabilities for measuring change. The impact rating can be useful considering the effect of the child’s behaviour on the family and other areas of life such as school and peers.

Emerson (2005) explored validity of the child, carer and parent forms for a CYP LD sample with less severe intellectual disabilities, concluding the SDQ (Strengths and Difficulties Questionnaire ) appears, in general, to provide a robust measure for this group. CORC (Child Outcomes Research Consortium) recommend its use with children and young people with mild learning disabilities. Robert Goodman recently advised his experience that the SDQ generally works well for mild intellectual disability but not severe/profound intellectual disability “... at least in part because the high rate of self-injurious behaviour and autistic features is not well covered”.

Therefore, SDQ may be appropriate for mild LD but not more severe.

**RCADS:** Use of RCADS with CYP LD and their families to date indicates difficulties. Feedback from families and clinicians indicates lack of relevance/meaningfulness of items for CYP LD. Partly this reflects it being too developmentally advanced (basal age of Grade Three, i.e. 7–9 years). Also, RCADS is based on “typical” presentations of/difficulties with mental health issues which often present differently in CYP LD. Particular issues arise with CYP with ASD (Autistic Spectrum Disorder) and associated anxiety, rather than an “anxiety disorder” as the questions in RCADS do not map an ASD profile.

RCADS has been found useful directly with some CYP with mild learning disabilities to help think about and explore thoughts and feelings.

More feedback and a systematic project using RCADS with CYP LD and families is needed to clarify the appropriate developmental level required and whether using visual supports/symbols for RCADS items and scoring to support comprehension increases utility (Considering Spence Anxiety–Preschool parents version as possibly more appropriate).

Suggest: use RCADS with CYP with mild LD and their families only.

**Sheffield Learning Disability Outcome Measure (SLDOM, Sheffield Children’s NHS Foundation Trust/ CORC):** looks at parent/carer’s feelings about their child, their family, their ability to care for their child and the family’s experience with the service. The post-form also includes the CHI experience of the service questionnaire. Feedback on SLDOM indicates it is an easy questionnaire for parents to complete (although the negative wording of some items can be difficult), can provide helpful clinical information, works well, appears to measure parental confidence/understanding of child’s needs/self- efficacy, and has good face validity.

Some feedback indicates the SLDOM may not be very sensitive to change as an outcome measure and may best be used qualitatively or providing a “snapshot”. Parents initially may indicate they understand their child very well, despite clinical observations indicative of poor attunement. After interventions focusing on developmental awareness, parents may realise their expectations do not match their child’s abilities and/or motivations. Progress can result from parents re-aligning their understanding and then their relationship with their child improves. However, the scale may show no change, or worsening, in the scores of self-rated understanding of the child as parents become more realistic.

Other parenting-related measures practitioners reported as useful with parents and carers of CYP LD include Parenting Stress Index (PSI, Abidin, 1995) though it is not normed on CYP LD: Questionnaire on Resources and Stress (short form, Friedrich et al., 1983) as being more “learning disabilities friendly” than the PSI and free; systemic change measures such as the Challenging Behaviour Attributions Scale (Hastings, 1997); or family quality of life measures such as the Family Quality of Life Scale (Park et al., 2003).

Whilst the SLDOM appears a useful measure for change in parents’ understanding and parenting ability, it does not focus on behavioural, emotional or social aspects of a child or young person’s functioning in a way that would help a broader assessment, formulation, goal setting and evaluation of change in a standardised way that would then triangulate with individual goal based outcome measures. Possible standardised measures include:

**Nisonger Child Behaviour Rating Form (NCBRF):** Previously recommended by CORC for use with children and young people with more severe learning disabilities, it does not seem widely used. Feedback indicated criticism of items less appropriate to children with severe LD, negative language and complicated scoring.

**Developmental Behaviour Checklist (DBC, Enfield & Tonge, 1995):** designed specifically to assess behavioural and emotional problems in young people aged 4 to 18 years. Feedback suggests the DBC is fairly widely used with CYP LD with advantages of being developed with CYP LD, being comprehensive (can lead consideration of behaviours of which parents may not have been aware of). The total score appears a good measure of level of need and “caseness”. Drawbacks include its length, which can be off-putting for parents, particularly those for whom English is a second language.

## SESSION BY SESSION MEASURES

**Goals Based Outcome measures:** have the advantages of being individualised and quick to administer. They can focus on child, young person, parents and carers, other people or settings. Feedback indicates experience of their use as mixed, with some clinicians finding them a useful way to engage families and track progress, and others less so.

The current CYP IAPT support tools “Short problem specific checklist” and “symptom trackers” (including the general tracker) do not appear suitable for most CYP LD. They are very “mental health” rather than behavioural, developmental, social/emotional and not appropriate for many CYP LD presentations.

More helpful seems an individualised approach with goals which are concrete i.e. “what would it look like if it were better/worse?”, “what would be happening when..?” These can be for more subjective and/or feelings-related goals, objective “behavioural” goals or both.

Individualised behaviour/emotions measures: of frequency, duration, intensity, latency and/or settings etc. may be effective in measuring relevant aspects which are targets of interventions. Goals should be set and tracked as in the main CYP IAPT approach with parents, and may be adapted to use with children and young people. Scales may need personalising and for some a 1–10 scale may be too great. Use of visual supports can help e.g. ladders, thermometers, floor mats, individualised approaches, with concrete markers (symbols or pictures) of what would be happening if the goal was or was not achieved.

Other tools which may help identify goals and measure change include:

- For emotions/feelings – “P levels” from the National Curriculum for Personal, Health, Social and Relationship education (QCA, 2007).
- Measures developed with adults with LD as their format is accessible and they are developed and standardised with people with learning disabilities. Examples include:
  - \* The Behaviour Problems Inventory (BPS-01 Rojahn et al., 2001) and the Challenging Behaviour Interview (CBI; Oliver et al., 2002) as recommended by the BPS/DCP LD Faculty.
  - \* Glasgow Anxiety Scale (Mindham & Espie, 2003), Glasgow Depression (Cuthill et al., 2003), Profile of Anger Coping Skills (Willner et al., 2005) and CORE LD (CORE).

Content may be appropriate but as these scales are not developed with CYP LD issues may arise with validity and reliability.

**ORS/CORS/YCORS & SRS/CSRS/YCRS:** feedback indicates some benefits e.g. visualising change and difference as helpful, lines better than verbal description...

“Good basis for discussion” for both CYP LD and their families. Feedback also indicates it was less useful for some young people; eg. “YP refused to complete”, “too hard for YP, struggled to verbalise”.

General comments... “feels like a lot of information to be gathered each session!” along with comments about appropriateness, timing, burden.

## HOW WAS THIS MEETING?

Feedback mixed e.g. concerns about honesty, depend on child's ability, helpful.

## HOW ARE YOU DOING?

Feedback mixed e.g. "many children did not understand"; "depend on child's ability"; "good to focus on current and get client's subjective interpretation".

## HOW IS YOUR CHILD DOING?

Feedback mixed e.g. "Some questions helpful, some questions parents felt did not apply and left them"; "Helpful to gain insights into parents' issues".

Feedback on concerns regarding "session-by-session" monitoring includes:

- Change in the LD population happens slowly, over many months so it can be very depressing/inappropriate for parents to be ticking the same boxes week after week.
- Issue of timing – two or more sessions may be needed for engagement and preliminary assessment before goals can be set. Where practitioners have tried this, parents have questioned the value of this form in the very beginning stages of therapy.
- Every session may not generate measures as a significant number of clinical contacts are not "face-to-face therapy" but "indirect" and include liaison and consultation.

It is therefore recommended that, with CYP LD, there is some flexibility on the frequency of monitoring so it does not have to be session by session.

Professor Turk and team have investigated outcome measures for CYP LD and or neurodevelopmental disorders over a number of years. Ezer and Turk (2012) reported parental and clinician views of global assessment scales (Children's Global Assessment Scale (CGAS)), symptom checklists (DBC) and a quality of life measures (Kindl) with parents of 30 children and young people, aged 8–16 years, who met ICD-10 criteria for diagnosis of a neurodevelopmental disorder randomly selected from those who had received a service. The measures are listed below, in order of most to least preferred, along with qualitative comments:

- Developmental Behaviour Checklist (DBC) preferred by 63.3%. "More detailed, Relates best to child, In-depth, Hard to face the fact that child has these symptoms, Depressing".
- Quality of Life Questionnaire (KINDL-R) preferred by 26.7%. "Cares for the quality of the child's life, Less time consuming, Easy to understand, Only asks about past week, Less depressing".
- Children's Global Assessment Scale (CGAS) preferred by 10%. Generally comments were negative "Subjective, Doesn't relate to a child with this condition, Not useful, Cannot put a child into a box, Not good, Less time consuming, Easier to score, Shouldn't be used, Dislike the idea of giving a child a number".

Professor Turk and team are trying to develop systematic use of the DBC (Einfeld & Tonge), DDCGAS, KINDL ([www.kindl.org](http://www.kindl.org)) and SLDOM as a possible appropriate package of measures for CYP LD and/or neurodevelopmental disorders.

## RECOMMENDATIONS

Collecting and using feedback with children and young people with learning disabilities and their families can assist engagement, assessment and formulation and evaluation. Given the diverse range of abilities and needs, a more individualised approach may be needed including:

- Use of accessible supports such as visual "prompts" to aid comprehension, engagement and "scoring" and ensure any language and visuals are able to be processed by the child e.g. variations on the ROMS Young Children's SRS, ladders, thermometers; use of card sort or "Talking Mat" type supports.



- Being aware of the research on outcome measures with adults with LD which showed developments or adaptation of measures specifically for people with learning disabilities can be needed e.g. Mindham and Gillespie's (2005) anxiety measure; whilst others showed "mainstream measures" can be used with where items are read out and occasional simplification of wording made to enhance comprehension (Lindsay and Skene, 2007; Oathamshaw et al. 2006).
- Being aware of limitations and strengths of measures and being supported to use clinical judgement in what measures are used/reported for what, with whom and when, within the limits of a "core set" of ROMS plus additional appropriate measures.

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# Section Three - Specific measures

[NB The following measure-specific guidance is currently only available for some of the CYP IAPT measures. We are keen to extend this information to cover a wider range of measures in future versions of this document so all offers to contribute guidance documents are welcome!]

# RCADS: THE REVISED CHILDREN’S ANXIETY AND DEPRESSION SCALE (RCADS) AND THE REVISED CHILDREN’S ANXIETY AND DEPRESSION SCALE – PARENT VERSION (RCADS-P)

David **Trickey**

## INTRODUCTION

The RCADS and the RCADS-P are 47-item questionnaires that measure the reported frequency of various symptoms of anxiety and low mood. The RCADS can be completed by young people aged from 8 to 18 years and the RCADS-P can also be completed by the parent or carer of young people aged from 8 to 18 years. The person completing the questionnaire rates each of the items according to its frequency e.g.:

I worry that something bad will happen to me                      Never                      Sometimes                      Often                      Always

Responses can be scored to produce a value for each of the following scales:

- Separation anxiety
- Social phobia
- Generalised anxiety
- Panic
- Obsessive compulsive
- Total anxiety
- Low mood
- Total anxiety and low mood (sometimes known as “internalising”)

At the time of writing, the RCADS is available in English, Spanish (US), Chinese, Dutch, Danish, French and Korean; and the RCADS-P is available in English, Spanish (US), Dutch, Danish and Korean.

More information can be found in the User’s Guide, which is available together with copies of the different questionnaires and MS Excel Scoring Spreadsheets at [www.childfirst.ucla.edu/Resources.html](http://www.childfirst.ucla.edu/Resources.html)

## WHEN TO USE THE RCADS AND THE RCADS-P

The information generated by using the RCADS and the RCADS-P can be hugely helpful in understanding the difficulties with which the young person is struggling. For example, they may seem to be having problems with generalised anxiety, but the results of the RCADS might raise the possibility that in fact they are struggling specifically with separation anxiety. Or they may appear to have a very low mood, but the results of the RCADS may raise the possibility that their low mood is the result of being fed up with symptoms of obsessive compulsive disorder. Such alternative possibilities can be raised with the young person as hypotheses with a view to seeking their opinion.

Using both the RCADS and the RCADS-P may also highlight clinically important differences in how the young person and the parent or carer see the difficulties. If there are noticeable differences in the scores generated by the young person on the RCADS and the parent or carer on the RCADS-P, then this could be raised in a session by the clinician with an air of genuine curiosity. The young person and the parent or carer could then be invited to help you to understand the differences.

As such the RCADS and the RCADS-P can be used routinely as part of an assessment. There may be occasions when using the RCADS or the RCADS-P may be considered clinically inappropriate. For example, if a client is very distressed, asking them to complete a 47-item questionnaire might be overwhelming or have a negative impact on the development of a therapeutic alliance.

The RCADS and the RCADS-P, and the individual symptom trackers based on the subscales, can also be used to track change over the course of an intervention. They could, therefore, be used at review appointments to help guide decisions about continuing, changing or ending an intervention.

## ADMINISTERING

Both questionnaires can be given to the appropriate respondent to complete themselves. Alternatively, in order to ensure that each item is understood by the respondent, or to gain additional information about each response, the questionnaires can be administered directly by the clinician who can ask follow-up questions.

The RCADS and the RCADS-P could be introduced in the following way:

*“To help me to understand more about how you are doing, it would be really helpful if you could fill in a questionnaire or two. Partly this makes sure that I don’t forget to ask important questions, but it also means that I can compare how much you worry or how sad you are, to other people of your age. If you fill in the questionnaire on another day as well, then we can see if you are getting more worried and sad over time, or less. This questionnaire has a list of different sentences about how people feel, and all you have to do is circle one of these words to show how often it’s true for you – never, sometimes, often or always. If you are not sure what any of the questions mean, do please ask me and I’ll try to explain it.”*

It is worth noting, that there are a number of very similar items, and some young people (particularly those that have a good relationship with the clinician and feel able to question things, or those that have a difficult relationship and want to raise problems), may point this out. Some young people may worry that the questions are trying to catch them out, others may feel irritated by the perceived repetition. The clinician can respond to such questions in whatever way they feel is most helpful; but one option would be to say that by asking the same sort of question in slightly different ways, it helps us to really understand the nature of the difficulties.

## SCORING

### COMPUTERISED

The easiest way to score the RCADS and the RCADS-P is to download the MS Excel spreadsheets available from [www.childfirst.ucla.edu/Resources.html](http://www.childfirst.ucla.edu/Resources.html), and then enter the responses into the spreadsheet. You will need to

enter the young person's US School Grade and not the UK School Year or age. This is easy to work out if you remember that UK children start education a year earlier than in the US, so the UK Year Two = US First Grade etc.

The spreadsheet then produces a graph showing the scores for the various scales. These are calculated as "T-Scores". T-scores are standardised scores, which are adjusted to take into account how other un-referred young people of the same age have responded to the items. A T-score of 65 means that the score is roughly in the top 7% of scores of un-referred young people of the same age (statistically it actually means that the score is 1.5 standard deviations above the mean). A T-score of 70 means that the score is roughly in the top 2% of scores of un-referred young people of the same age (statistically it means that the score is two standard deviations above the mean).

## BY HAND

Simply follow the instructions on the Scoring Aids for the RCADS and RCADS-P on the CORC website ([www.corc.uk.net](http://www.corc.uk.net)). Previous versions of tables of bands have used ages rather than school year groups. The current tables have reverted to using school year groups. Although this is a little more difficult because you have to know or work out what school year they are in (or would be in), it does mean that the interpretation will be more accurate because the standardisation sample on which the tables are based was split by year groups rather than ages.

## INTERPRETING

The "clinical thresholds" should not be considered as cut-off scores. They are not magic numbers which indicate a particular difference between those young people that score above and those that score below. As stated above, they do have a very precise statistical meaning, but from a clinical point of view they are just rough guides to help us understand whether, compared to other young people of the same age, a score is a bit raised or high. Clinical opinion and what the clients tell us directly are hugely important.

## FEEDING BACK

Feeding back the results of the RCADS and the RCADS-P can be very useful. Firstly, it may strengthen the therapeutic rapport as it increases the transparency of the clinician's work and increases the involvement of the client(s). It also allows the client(s) to comment on the results and endorse or question them. Some might find the results surprising, and some might disagree vehemently with them. Both of these are opportunities for discussion; the clinician can go through the client's responses to the items picking out those that lead to the particular score and inviting them to comment. Clients that are concerned or frustrated can be re-assured that the scores are just a small part of the information on which your assessment is based.

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## SCORE: SYSTEMIC CLINICAL OUTCOME AND ROUTINE EVALUATION INDEX OF FAMILY FUNCTIONING AND CHANGE USING THE SCORE-15

Peter **Stratton**, with contributions from Judith **Lask**, Gary **Robinson**, Marcus **Averbeck**, Reenee **Singh**, Julia **Bland** and Jan **Parker**

The SCORE-15 is one of a group of self-report measures of family processes derived from the original SCORE-40 (Stratton et al., 2010). These measures are designed to indicate crucial aspects of family life that are relevant to the need for therapy and for therapeutic change.

The SCORE-15 has 15 Likert scale items and six separate indicators, three of them qualitative, plus demographic information. It records perceptions of the family from each member over the age of 11 years. Versions for younger children (8 years upwards) and translated versions have been developed and are being tested. Alternative versions suitable for administration at consecutive sessions are in preparation.

The SCORE-15 was created through a data-driven process integrating psychometrics with clinical judgement. It is designed to enable family members to report on aspects of their interactions which have clinical significance and are likely to be relevant to therapeutic processes. Extensive consultations with therapists, service users and researchers were undertaken to obtain simple and unambiguous items that would be meaningful to families from a wide variety of cultural, ethnic and socioeconomic backgrounds.

Use within CORC (Child Outcomes Research Consortium [www.corc.uk.net](http://www.corc.uk.net)) is expected to follow standard CORC protocol. The main difference from the validation study protocol (Stratton et al., 2013) is that that study, funded through the Association for Family Therapy and a research grant from South London and Maudsley Trust (SLAM), specified the first follow-up at the fourth session whereas CORC specifies a six-month follow-up.

SCORE will be a helpful complement to CORC measures focusing just on the child or a parent. It will be of obvious value where there is any element of intervention with or support of the family system or subsystems, and provide both an indication of problems and of change in the family. Furthermore, and in this it differs from measures that focus on individuals, it can highlight differences between family members in their views of the family.

We have now completed the phase to test whether it is valid as a measure of therapeutic change. The 15-item version (SCORE-15) was administered to 584 individual family members at the start of therapy. A sample of 239 participants provided data at first and fourth therapy sessions. Consistently statistically significant change ( $p < .001$ ) was found in the overall score using a variety of statistical analyses. Amount of change correlated with



therapist judgement and independent rating by family members of their problems (Stratton et al., 2013). It is now offered as a comprehensively validated measure.

We are proceeding with recruiting a non-clinical sample to establish norms, and analysing the descriptive data provided by family members on the forms. We have verbatim descriptions of close relationships and of the clients' description of the problems they want help with, which we have grouped according to the quantification of the kind of relationship difficulty. Then, the descriptive accounts are used to identify salient items in the quantitative record. We are also conducting a survey by which therapists who have used SCORE in any way can report their experiences.

We conclude that SCORE is an effective indicator of close relationships and of change at an early stage of systemic therapy. We have a version for children aged 8 to 11 and are working on one for adults with learning difficulties; and we have translated versions being applied in several European countries and with ethnic minorities in the UK.

## RELATIONSHIPS WITH OTHER MEASURES

SCORE does not duplicate any of the child focused individual measures recommended by CORC nor will it clash in any way with any of them. What it offers is the crucial addition of ratings of the family for overall scoring and differences. As noted above, this fills a gap in the coverage individual focused measures offer, when problems and/or interventions and recovery are linked to the family not just the individual child.

## ADMINISTRATION OF THE SCORE-15

The SCORE is appropriate for use with individuals, couples and full families when the operation of relationships within the family is relevant. It is completed by each person aged 12 years or over privately at the start of sessions. For children aged 8 to 11 years the Child SCORE (Jewell et al., 2013) should be used. The current validation study, funded by South London and Maudsley NHS Trust and the Association for Family Therapy, can provide a detailed protocol. For participation in our projects or to obtain the more extensive background information for CORC purposes, please contact Peter Stratton at [p.m.stratton@ntlworld.com](mailto:p.m.stratton@ntlworld.com)

Translated versions of SCORE-15 following a standard protocol are now available and can be obtained from Peter Stratton. Versions are currently available in Finnish; Polish; German; French; Hindi; Greek; Norwegian; Italian; Hungarian; Spanish; and Turkish. There is a Portuguese translation of the SCORE-29 which incorporates the SCORE-15. Further translations into Swedish; Sylheti; Dutch and Flemish; Arabic; and Bengali are currently being undertaken.

The SCORE-15 should be administered to each family member individually at or just before the start of the relevant sessions. Arrangements should be made so that each person fills it in privately and their completed SCORE is not seen by other family members. It is usually presented by the therapist at the start of the session but could also be while waiting just before the session, and by another member of the therapeutic team, a researcher, or an appropriately trained administrator. Help can be offered for people who have difficulty with the written text, but the items themselves should not be elaborated. For CORC the SCORE should be administered at the start of the first session, a session at six months and the final session (see 'information sheet on when time one and time two should be' on the CORC website).

## PRACTICALITIES OF ADMINISTRATION

A more general discussion of issues in administering measures to families is provided in 'Administering measures to families'.

Systemic family psychotherapists recognise that different cultures and groups have different ideas of what 'family' means. We take 'family' to describe any group of people who care about each other and define themselves as such. As well as parents and children of all ages, we may work with grandparents, siblings, uncles and aunts, cousins, friends, carers, other professionals – whomever people identify as important to their lives. The SCORE questionnaires orient respondents towards thinking of their household but then invites them to choose who they want to include.

Based on our clinical experience of using SCORE-15, you may find it useful for the family to each list in the empty space just below “For each line, would you say this describes our family” the constellation of family they are thinking of when answering the 15 questions:

*“Before you start, it might be helpful if you could list down who in your family you are thinking of when answering the questions. For example, Ann (mother) you may be thinking of yourself, your partner Marie and Jack (son), while Jack you may include your mother and your biological father. It is totally fine if each of you include or exclude different people as we all define family in different ways. Writing it down will help you and me remember who you were thinking of at the end of the treatment when we compare the before and after. Who knows, you may be thinking of slightly different people before and after, for example, Jack you may end up including your dog and iPad at the end of treatment when answering it again!”*

Here we offer some samples of ways to introduce the SCORE to family members. They are not intended as a fixed script, but as ideas from which you can construct your own introductions, adapted to the family and your relationship with them.

## FIRST MEETING

### **Therapist**

*In agreeing to work together to see if we/I can be helpful to you and your family it might be helpful to have a think about how you see things within your family at the moment. To help us to do this we have a short questionnaire which gives everyone an opportunity to rate how you think things are going at the moment for your family. If it is OK with you, we will spend the first part of today's meeting having a look at these questions and giving you all an opportunity to individually rate your answers about how you see things. Families usually find it is best for each person in the family to complete these on your own and I will be here to help you if you have any questions about the form. So it is probably best if you don't discuss it yet, but just each give us your first thoughts on the form. Then when you have all completed the form we can decide together whether or not you want to share your answers or just let me/us see them to help me/us think about how I/we might be most helpful to you. There are no right or wrong answers; however, completing the form will help us think about what areas we might want to focus on together. It will also give us a chance in a few weeks' time to perhaps revisit the form and see what, if anything, has changed and to view how things are going together. Here is a pen and a form for each of you and as we/I said we/I will be here if you want to ask me/us anything about the questions.*

## SCORE TWO

### SIXTH OR LATER, AND REVIEW MEETING

### **Therapist**

*Do you remember that form we filled in when we began work together four or five meetings ago called SCORE? I/we thought it might be helpful to review where we are at now and think about what, if anything, has changed for you all as a family. To help us with this I/we thought we might fill in the form again to see what changes have occurred and to see if things are the same, better or worse. This will then help us think about how I/we might be most helpful if we decide to continue meeting together. As before, it would be helpful if you complete the form individually and I/we will be here again to help you with any of the questions if anything is unclear. When everyone has filled in their form we can decide together whether we should keep them privately or if you would like to share them as a family as we plan for the future.*

## SCORE THREE FINAL SESSION

### **Therapist**

*In agreeing to end our work together (/as it looks as if we may be coming towards ending our work together) I/we thought it might be helpful to complete the SCORE form one last time to see what has changed and to help you as a family think about anything you might want to continue to change in the future beyond our meetings together. Again it would be helpful if everyone could complete a form individually and we can then decide whether or not to share the answers or keep them private. It will also be very helpful for me/us to think about what has been helpful and what we might do similarly or differently in our work with families in the future.*

### **SOME SUGGESTIONS FOR CLINICAL USE**

Before introducing SCORE, make all of your decisions about whether and how the information acquired from the family will be used clinically. In some contexts you may guarantee privacy so that family members will not know each other's ratings. But this offer will severely limit the open discussion of tendencies and differences in family ratings. Usually, clinical usefulness will override 'purity' of the data.

*"Ann (mother), you rated 'all' for item six 'we trust each other' and Jack (son) you rated 'not at all' for the same item. Could you help each other understand what trust means to you that could be so different? What particular incident could you think of that might help us understand how differently you see this?"*

*"I know Chris (brother) is not here with us today. What do you, Ann (mother) and Jack (son), think he would rate item 11 'things always seem to go wrong for my family'? What do you think he observes between you that he based his rating on?"*

*"If you were to answer SCORE-15 in six months' time, what would be one thing that you hope to see yourself and other family members give a better rating? What would things be like in your family then for you to be able to rate it that way?"*

*"It's amazing to see that all of you rated item 15 'we are good at finding new ways to deal with things that are difficult' rather highly even though you have been arguing a lot in sessions. I wonder if my presence or involvement make a difference to your interaction? What are some new ways you have found as a family outside of sessions that you could remember?"*

*"What words would best describe a family like yours where most family members rate item nine on crisis to be high and item five finding it easy to deal with everyday problems?"*

*"Jack, you found it hard to answer item three 'each of us gets listened to in our family' as some of you do and some don't, so in the end you rated it as 'partly'. Could you help your family understand more what you have noticed so far about these differences?"*

### **DISCUSSING THE RESULTS AND USING THEM TO INFORM THERAPY – WORKING WITH COMPLEXITY**

Time to provide therapy is often limited by the session (half a day) employment practices of the NHS. We tend to split things into half days whether with staff who are paid or those who are on honorary contracts. Additionally, demand for the limited resources of therapy staff and rooms leads to the (i) pre-session, (ii) session and (iii) post-session consideration being divided something like (i) 25 minutes, (ii) one hour and (iii) 15 minutes. Under these constraints, the therapist's time may be used for being with the family when they fill in the SCORE or she may

wish to spend the time preparing for the session. But if she can take the filled-in SCORE into the pre-session, the therapy may more easily integrate both the written and the spoken words. That is, the hypothesising before the session can be enriched by looking at the SCORE. For example, an issue of race was written about very briefly in the ('What is the problem/challenge' section at the top of SCORE-15 side two) by a parent of an African/Caribbean/white mixed race 12-year-old girl. This then enabled the therapist to hear conversation during the session, maybe 10-15 minutes later, with this comment (written) in mind. So when she heard about hair care for the girl there was an opportunity to explore the stories behind this and connect it with the problem in the referral. The hair care could have been left uncommented on if the SCORE hadn't been read beforehand and the connection with race not made.

## INTEGRATING THE 'MAPS' FOR ASSESSMENT, REVIEWS AND CLINICAL USE

Clinical judgement over influencing factors such as developmental and cognitive abilities of persons answering the question, therapeutic alliance, confidentiality or safeguarding issues needs to be made on whether the written answers and discussions would be best conducted separately with individuals, or with a constellation of family members and/or professionals. The clinician could cross-reference the answers from other questionnaires with SCORE-15 and Current View, such as scores of depression in RCADS by the child/young person and parents could be compared with the severity rating of depression rated by various persons in the Current View.

The assessment or reviews could either take a single focus or multi focus lense that would capture the background context (silent concerns) that comes along with the referred child/young person. This might include an additional component/element of the assessment or reviews, which would make visible the associated concerns that other family members bring forth at the assessment/review stage that the clinician has to work with – this could be done by having each family member answering the Current View questionnaire as suggested above. This also reinforces the methodological position from which a systemic family therapist gets engaged.

Below are some examples of questions that could be asked to help integrate and clarify information collected from various outcome measures:

*"I notice that your mother rated family relationship difficulties as mild while you rated it as severe in this Current View questionnaire. I also noted that your mother's rating of family strength in SCORE-15 is better at 2.0 than your rating at 3.4. What strengths in your family do you think she sees that you might not at this moment?"*

*"I'm struck by how similar the family and I see the father's depression as more severe than the behavioural difficulties of the child. Could you help us understand how you (social worker) see it, which is the other way round?"*

*"Mr James (teacher), you rated Andy (identified patient) to be severe for depression, while Andy and his father rated it mild, which is consistent with the results of their RCADS rating (show the summary tables of RCADS score). All of us, however, rated school problems to be severe and home mild. Could you tell us more about what you observed about his mood in school which might be different when he is at home?"*

Examples of how to make use of outcome information with families: restoring multiple perspectives and constructing stories about the wider system.

A family with a 13-year-old white girl who had suicidal ideation and an Asian/white mixed race 15-year-old boy with their white in-house parents were in their first session of therapy in CAMHS. The white half-sister of the boy had a chronic and serious anxiety problem. The therapist was getting rather preoccupied with the boy and when the therapist prompted himself with what was in the SCORE, that is thinking about the effect of relationships on problems, he moved to a more multi perspective way of working with the family. This meant that the mixed race boy was not the focus of the problem talk.

The SCORE can often provide a historical context when preparing to see a family. In the preparation time for the fourth session the therapist reviewed the SCORE filled in before the first session. This helped him to pick up on a remark (mention of a first name) of someone (in this case an outreach worker) who was helping the 15- year-old boy. This then led to opportunities of more talk about helpful and unhelpful people for other members of the family.

## SCORING AND DATA RECORDING

The SCORE-15 can be interpreted very quickly during the session or when writing up the session notes. The instructions that follow enable computation of the overall total and, if wanted, the subtotals for the SCORE's three dimensions.

### SCORING BY HAND

#### **Calculating the total score**

The SCORE-15 for each person who completes it can be calculated very simply by hand by working through the following instructions line by line. For the 15 Likert scale items (this method does not require reversing of scores for negative items):

Total all negative items – Qs 2+4+5+7+8+9+11+12+13+14 (with 'very well' as 1 and 'not at all' as 5)

Subtract this total from 60

Add the remainder to the total of positive items Qs 1+3+6+10+15

This gives a total score for each person. Divide by 15 for the average.

For more detail you may wish to calculate each of the three dimensions that make up the total SCORE.

#### **Scoring dimensions**

The SCORE generates three dimensions which can be calculated as follows. In each case the total is divided by five to give the average, and the lower the score, the higher the functioning.

For Dimension One, **Strengths and adaptability** As all of the questions are positive, simply add the scores (Qs 1+3+6+10+15).

For Dimension Two, **Overwhelmed by difficulties** Add all the scores (Qs 5+7+9+11+14) and then subtract from 30, the remainder is the dimension score.

For Dimension Three, **Disrupted communication** Add all the scores (Qs 2+4+8+12+13) and then subtract from 30, the remainder is the dimension score.

The qualitative items can be listed as text as Q16description and Q17problem.

The three analogue scales are Severity of problem Q17rate\_a

Managing as a family Q17rate\_b

Helpfulness of therapy Q17rate\_c

We have also developed a facility for entering data from one person into a simple Excel sheet which then calculates the averages automatically. See "SCORE-15 individual scoring template guide" and the "SCORE-15 individual data SCORING TEMPLATE"

([www.corc.uk.net/resources/additional-information-about-the-measures/family/](http://www.corc.uk.net/resources/additional-information-about-the-measures/family/)).

#### **Recording group data**

Data from a series of cases should be recorded with unique identifiers of the clinic (the site code), and a code that uniquely identifies the family, followed by digits or labels for successive family members. So 'MAU008male partner' records the eighth Maudsley family data provided by the male partner.

To record data from a number of clients and to have the totals calculated automatically, please follow these instructions using the Excel spreadsheet. When submitting data it is important to provide any parallel measures that have been taken at the same time.

## SCORE-15 INDEX OF FAMILY FUNCTIONING AND CHANGE

### **Excel data entry**

This set of instructions, and the Excel file called "SCORE-15 data entry Excel97 301013", are for collecting data from a series of people ('cases') so that the whole group can be examined together ([www.corc.uk.net/resources/additional-information-about-the-measures/family/](http://www.corc.uk.net/resources/additional-information-about-the-measures/family/)). A group may be all the cases of a particular clinic, or a selection of particular types of family. It automatically calculates various averages for each person, for example their average SCORE on each occasion and, if you have data from a first and later session, how much each aspect has changed. Then, when you have finished, it calculates the averages for each aspect of your data.

The instructions here are designed so that anyone, even with no previous experience of using Excel, will be able to process their own data. They may look rather elaborate but that is because I have attempted to explain every aspect. If you work through them one step at a time, you should have no problem. If you are familiar with Excel a quick scan of these instructions will probably be all you need.

The Excel file: SCORE-15 Data Entry has been set up to enter data at up to two points in therapy and calculate totals and averages within the spreadsheet

([www.corc.uk.net/resources/additional-information-about-the-measures/family/](http://www.corc.uk.net/resources/additional-information-about-the-measures/family/)).

Each line from top to bottom is numbered as a row. The first row contains the titles of the columns. Many are abbreviated to fit but if you click on one the full title will appear in the slot above the sheet.

The second line is an example so that you can see the required format. Once you are entering your own data, please remember to delete this row.

### **Entering the data**

Use one row for each respondent. In the first four columns enter their:

Identifier Age Gender Other

Identifier should be as filled in on their SCORE data sheet. 'Other' is for one other item of information if needed but can be left blank.

You should enter the raw scores as they are ticked on the SCORE-15 form (some items are negatively phrased but that will be dealt with within the Excel calculations).

**From the first page.** Enter the fifteen ratings of one (describes us very well) to five (describes us not at all) into 1talk1, 2-truth1 etc. The first number in the column heading is the number of the item; – (minus) indicates a negatively phrased item and the final 1 indicates that it is the first administration. So '2-truth 1' is the second item, which is negative (so scoring it as 'describes us very well' is not a good thing), this is the item: 'people often do not tell each other the truth in my family', so is summarised as 'truth' and at this point under the column that Excel labels as 'F', is the first time of administering the SCORE to this person.

When entering the data, if someone fails to tick one of the items, leave the space in the relevant column blank.

**Now for Page two.** Once you have entered the fifteen ratings, enter as text what they have said as a description of their family, and what they say their main problem is. Don't worry if your typing seems to go over the next cells. Excel only does that when the next cell is empty, and when you put information into the next cell, the text will be cut to the size of the cell. But the full text appears in the top space if you click on the cell.

Now enter the ratings 0–10 where they have put their X along the line. We would not usually bother with decimal points so put the nearest whole number. If it is halfway between five and six (say), then record it as a six (i.e. rounding up). There are three ratings: of severity of the problem; how they are managing as a family; and whether they think family therapy will be (/ has been at the second and later administration) helpful.

Then the demographic information. This only goes in once.

Excel will now calculate for that person the averages for each dimension, the total SCORE and the average SCORE.

The three dimensions are: 1. Strengths and adaptability; 2. Overwhelmed by difficulties; and 3. Disrupted communication. Each dimension is based on five of the items.

**NOTE:** If any scores are missing, the TOTAL is an estimate based on the items that were rated. This estimate becomes unreliable if more than one item is missed as we don't really know whether they were left out for a reason (e.g. too revealing about a major problem).

The sheet is set up to record 30 cases. If you have less, simply delete the rows up to number 31. If you have more than 30, click on row 31, click on 'Insert' on the top menu, then 'insert sheet rows' for as many rows as you need. Make sure you insert the extra rows while you are within the first 30 rows otherwise the column averages will be incorrect.

Good luck, and please tell us how you got on in the SCORE list at [aftSCORE@googlegroups.com](mailto:aftSCORE@googlegroups.com) Please also feed back suggestions for improving this process to Peter Stratton [p.m.stratton@ntlworld.com](mailto:p.m.stratton@ntlworld.com)

For further detail see References below.

Current updates are on the research page of the AFT website: [www.aft.org.uk](http://www.aft.org.uk)

#### **A rough idea of what the total and average scores mean**

The total score could, in theory, be 15 if they rated every question was rated absolutely positively and 75 if every question absolutely negatively. So, the higher the total, the worse the person is rating their family. On our first samples we found that families at the start of therapy averaged 39, and non-clinical families averaged 26. Looking at the average score for someone lets you relate their score to a position on the scale of one to five that they were using. If all questions were phrased positively, full agreement is positive and would score one, while full negative ('not at all') would score five. Excel converts them in this direction for you. An average of 2.67 (equivalent to a total of 40) would be just more than halfway from 'describes us well' to 'describes us partly'.

The dimensions range from 5 to 25 as totals but are calculated here as averages so can be interpreted in the same way as the overall SCORE. At the second administration, start entering the data at the column AH, labelled 1talk2 (the 1 as it is the first item, the 2 because it is the second administration) and continue as above.

#### **Data from second (follow-up) administration**

After the calculations for time two, it will then calculate the change from first to later session, with a positive score being the preferred change in each case, as it means the SCORE average has dropped. There is space to record the two therapist ratings (see "therapists scale"). The changes in the Page Two, 10-point ratings are then calculated.

When you have all your data, delete any unwanted rows and let Excel calculate averages for each column. These numbers show what the average of that item is across the whole set of scores that you have entered. They will tell you the overall average for the data in that column. For example, the column average for column AF, (TOTAL SCORE) tells you the average of the totals across all the cases you have entered. Statistical calculations such as standard deviations, the significance of any change, and correlations between different measures can be carried out in Excel or the data can be read in by PASW (SPSS) for analysing there. An SPSS file and syntax are available on request.

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# GOAL BASED OUTCOMES (GBOS)<sup>1</sup>

Duncan **Law** and Jenna **Bradley**

## WHAT ARE GOAL BASED OUTCOMES (GBOS)?

Goal based outcomes (GBOs) are a way to evaluate progress towards a goal in clinical work with children and young people, and their families and carers (but the ideas can equally be adapted to work in adult mental health or learning disability settings). They simply compare how far a young person feels they have moved towards reaching a goal they set at the beginning of an intervention, compared to where they are at the end of an intervention (or after some specified period of input). GBOs use a simple scale from 0–10 to capture the change; the outcome is simply the amount of movement along the scale from the start to the end of the intervention. (See Examples section below).

## IT IS A TOOL TO TRACK THE PROGRESS OF WHAT THE SERVICE USER WANTS TO ACHIEVE

Goals should be those that the young person (and/or their family/carers) themselves want to reach from coming to a particular service – not the goals a clinician or practitioner might wish to see them achieve (although there is often need for some negotiation – see the next part of this chapter on goal setting and negotiating). The goals should be set in collaboration between the child/young person, their family and the clinician, wherever relevant. As such it gives a different perspective to clinical outcome measures and can measure different sorts of change that might not always be captured using only behavioural or symptom based outcome measures. For example, let's say a goal of parents of a

### Young Person's View:

“I think it is really important to establish goals at the start of a treatment programme because it gives the young person something to work towards and makes them feel as though recovery is worth something and they are achieving something. For me, knowing that if I started to recover I would be able to go back to school and do my exams and take part in all the sport I once enjoyed was key in my determination and motivation to recover.”

<sup>1</sup> Adapted from: Law D. (2013)

young child with autism and challenging behaviour is to “cope with tantrums”; an intervention might help the parents feel more confident about dealing with the tantrums, e.g. by working on ways of helping them to keep calm at the time. Such an intervention may not necessarily have much of an impact on the child’s behaviour (in the short term at least), but despite this, it is clearly an important and successful intervention for the family, if they feel more confident in dealing with their child’s tantrums.

## **THEY ALLOW MEASUREMENT ACROSS A BROAD SPECTRUM OF INTERVENTIONS**

GBOs enable us to measure the effectiveness of an intervention across the whole spectrum of work we do, across a variety of settings, and with a variety of service users. The goals could be those of a young person in individual therapy or a family in a systemic intervention. Similarly, they can be used to track progress towards the goals through a staff team in a care home receiving consultation from a service, or a teacher implementing a new class based approach to managing behaviour. In this sense the ‘service user’ is the person involved in the intervention (not always the child) and the goals that are set should be the goals of the person doing the work. Goals are, by their nature, varied and subjective. In GBOs what is important to measure is the amount of movement towards a goal, and not the goal itself.

## **DO GBOS DICTATE A WAY OF WORKING?**

Once a goal has been set it is possible to use any suitable intervention to collaborate to reach it. GBOs should not dictate any particular way of working or therapeutic approach – they are merely another piece of information to help assess the success of an intervention. They work on the principle that there are many potential routes to the same destination. Having said that, there are many approaches that use goals as part of the work: CBT, Solutions Focused Therapy, CAT, Personal Construct Psychology and many more. Equally the goals set as part of GBO measures can be used in the work if this is helpful.

## **WHAT SORTS OF GOALS DO CHILDREN AND YOUNG PEOPLE SET FOR THEMSELVES IN CAMHS?**

In thematic analysis of the CORC data, a wide range of goals were found to be set by children and young people (Bradley, Murphy, Fugard, Nolas and Law, 2013). The child-rated goals (age range 4–17 years) mapped broadly onto three overarching themes, which related to: coping with symptoms or specific problems; personal growth; and relationships. The goals were also organised into 25 sub-themes, of which the top five goals mainly concerned: coping with specific symptoms; feeling more confident; goals relating to hobbies; being responsible for oneself; and controlling or managing anger. There was a range of positively and negatively worded goals. A substantial number of goals set related to a specific hobby or achievement that at first appearances seems to be outside of the remit of CAMHS. It’s not obvious what to do with these sorts of goals, but it is desirable that the clinician makes clear to the child/young person what goals it is possible to work on in CAMHS. However, for engagement purposes, it makes sense to acknowledge goals that are important to the child/young person. It may also be that phrasing the question in the positive (“What would you like to achieve?” as opposed to “What would you like to move away from?”) may subtly change the focus of the goals set.

## **PERCEIVED BENEFITS OF GOAL SETTING**

Goal setting and tracking in CAMHS has good face validity amongst CAMHS users, with advocates of CAMHS users liking the idiosyncratic nature of goals (Moran et al., 2012). One aspect of goals that children/young people have also said is useful is that goals can help to focus treatment, e.g. “Setting goals makes you see where you need to go, makes you see what you are working on and what still needs to be worked on.” (Bromley & Westwood, 2013, 43). Pender et al. (2013) also found that clinicians found goals easier than other measures to use and the majority of clinicians also said that the changes they needed to make in order to start using goals in their practice was either small or very small. Further, preliminary analysis of the CORC data suggests that goal setting may lead to

higher rates of retention and perceived satisfaction in particular reference to aspects of the therapeutic relationship (Bradley, 2013).

## GOAL SETTING AND NEGOTIATING

### HELPING TO SET GOALS

Some service users are very clear about the goals they want to achieve and others are more vague, and some have very little idea of what they want to achieve other than a notion that 'something must change'. For many people the first step is identifying some potential goals. There are many ways of facilitating this process and these depend on the particular context of the work. It is important to hear from the service user what has brought them to the service – to hear their story. At the point where you feel the family have told you enough initial information it can be helpful to start to introduce goals along the lines of:

*"That has been really useful in helping me understand a little about what has brought you here today, next it might be helpful for us all to think together about what your hopes for the future might be."*

What comes out of the following discussion can begin to be shaped into goals,

*"So, from what you have told me so far, what would you say your main goals are from coming to this service? If we were to work together in a very helpful way, what things would you hope to be different in the future, when we agree to stop meeting, from how things are now?"*

Sometimes it is easier for families to start with what they know they don't want: "I don't want to be depressed", "I don't want to get into fights," "I don't want to feel so scared all the time". In some cases these statements can be good enough to start work (the "anywhere but here" goal). However, if a family or CYP can be helped to think more specifically about where they want to get to – rather than where they don't want to be – it helps bring a focus to the goal, making it clearer to therapist and client where they are both heading, and it can help the process become more collaborative.

One way of turning a problem into a goal can be simply to turn the problem on its head by asking,

*"When you are no longer depressed, what would you want life to look like then?"*, or

*"When you are no longer getting into fights, what do you want to be doing instead?"*

With more entrenched problems some of the more solution focused techniques can help with goal setting. Good examples are the 'miracle question' used in solution focused therapy,

*"Imagine when you go to bed tonight a miracle happens that makes all the difficulties you have go away. When you wake up in the morning, what will you notice is different ..."*

Or by asking what a person might change if they were given three wishes:

*"If you had three wishes, what are the things you would wish to change that would make life better for you than it is now?"*

Once a goal has been agreed it is useful to find a sentence that summarises the goal:

*"OK, so we have agreed that one of your goals is to 'get back into school full time'."*

This helps make reference to goals easier – the summary sentence can then be recorded on the GBO record sheet. At this point some choose to make the goals SMART – Specific, Measurable, Attainable, Realistic and Timely, to really tie down the focus, but this is not always necessary or indeed desirable in some aspects of clinical work.

## GOALS CAN BE PROBLEM FOCUSED

Having said all that, some families and clinicians prefer to keep the goal identified as what the family does not want – to be more problem focused rather than solution focused. For some people to work away from a problem makes more intuitive sense. This is fine, as the key to using goals is to help work with people in a way that is most helpful to them. When scoring these problem focused goals the scale needs to run from zero = the problem has not even started to shift, to ten = the problem has gone. Whether a goal is problem focused or solution focused depends on what works best for that particular young person or family working in collaboration with the clinician.

## GOAL SETTING SHOULD BE COLLABORATIVE

Goals should always reflect the wishes of the service user. This doesn't mean the clinician is a passive recipient in the process. It is often helpful and necessary for clinicians to be active in making suggestions of possible goals. Troupp (2013) quotes a young person declaring: "sorry but how are people like us meant to know our goals..." This is an invitation for the clinician to bring their clinical skills and experience to suggest goals based on what the young person or family have said. The vital collaborative next step is then to check back with the family if the suggestions are helpful and meet with the wishes and unique context of the family.

There also needs to be some collaboration between the clinician and the service user to ensure that the service is the right place to help with an intervention. It is also helpful to guide users towards goals that are more focused and achievable, whilst still keeping to the spirit of what they want. If say an adolescent wanted to "be happier" it might be helpful to think about what the markers might be for them in being 'happier'. Similarly, carers of a looked after child wanting to "cope better", might need some input to unpick what 'coping better' might look like, and to break this broad statement down into some smaller focused goals. We would expect this process to be achieved within the first three meetings.

## THE GOAL MUST BE AGREED ON, AND OWNED BY THE PERSON ASKING FOR HELP

The key rule is that the person setting the goal is the person doing the work. So, in the care home example an appropriate goal would be for the staff team to set goals on managing the behaviour of a child if the work is with a team on what they can do differently, but it is not appropriate for the team to set a behaviour change goal if the focus of the work is individual therapy with the child in question. The reason for this is that the person working towards the goal needs to agree and own it themselves – otherwise you are measuring someone else's outcome!

## HOW MANY GOALS AND RANKING OF GOALS

The CORC protocols allow for up to three goals to be scored and rated. Sometimes families come with long lists of things they want to be different. This is fine and suggests motivation to really make big changes to their lives; however, too many goals can be distracting. Trying to do everything at once can result in very little focus to the work. For this reason, asking a service user for their top three goals brings a focus to the intervention. Taking it a step further and asking service users to rank their top three goals can help bring further focus. You may agree together that, for practical reasons, you don't always choose to start with tackling the top ranked goal.

For families with certain presenting difficulties, picking only one goal to work on might be the most helpful strategy – this is particularly useful in work around conduct and behaviour difficulties. For other families, acknowledging a long list of goals can be helpful and validating, but by agreeing up to three goals to focus on gives a clear focus as to what the shared agreement for the intervention is from the start.

## SCORING GOALS

Once a goal has been set the next step is to get the initial (time one) score for the goal. You may want to say something like:

*"OK, now we have agreed the goals you want to work on, it would be helpful to get an idea of where you are now with each of the goals. This will help us get an idea of where we are starting from, and what you*

*have already managed to achieve, and it can help us keep track of how far you have moved on at a later date" (you may want to specify at this point how often you would expect to review progress towards the goal – every session, at the end of the intervention etc.). "Taking your first goal: 'To get back into school full time'. On a scale from nought to ten, where ten means that you have fully reached your goal, and nought means you haven't even begun to make progress towards it, and a score of five is exactly half way between the two, today what score would you give your progress towards 'getting back into school full time'?"*

It can help to make the scale visual by showing the service user the GBO score sheet with the numbers on, or by drawing a line on a white board. Younger children might prefer a visual metaphor such as a ladder with the numbers 0–10 on the rungs, or (if you have the space) you can have squares set out on the floor and children can walk or jump to the relevant square.

## DANGEROUS AND 'UNACCEPTABLE' GOALS

In most cases the clinician should take on the role of facilitator to help shape and guide a young person in setting goals they chose to work on. However, there are occasions where a client may choose a goal that is unacceptable – either because it is dangerous (e.g. an teenager with anorexia wanting to set a goal to lose 10kgs, or someone with depression wanting to be helped to end their life), or because a goal is so unrealistic that it may be unethical to try to work towards it (e.g. a child with a physical disability wanting to be a professional footballer), or where a goal simply does not fit with what a service is able to provide (e.g. a parent who wants an assessment for dyslexia in a service that is not able to provide such an assessment). In each of these cases, even though the goals may be judged unacceptable, they should not be simply dismissed, but there needs to be more careful negotiation, to either steer a goal to a place of overlap between what the young person wants and what the service feels able to provide – safely and ethically – or to signpost a family to another service that may be better placed to help.

Even the most seemingly unacceptable goals can yield acceptable goals if the time is taken to ask a young person more about they want. By understanding what is hidden behind an initially stated goal, it is usually possible to find some point of overlap to agree goals and begin a collaborative intervention. It is often helpful to ask,

*"What would you hope to be different if you lost the 10kgs?"*

This gives the young person the opportunity to talk about their hopes, "I would hope I'd feel more confident if I was thinner" or "I would feel I had achieved something." This then opens the door to negotiating goals that both therapist and service user can agree to work together on: building confidence, being successful. But, beware 'perverse' goal setting (see the next section on Cautions).

## 'STUCK' GOALS

Sometimes families and young people come to child services "stuck" in their attempts to reach a goal – in such cases it may be helpful to move away from goal focused talk to "un-stick" the problem before moving on. The goal might always be in the mind of the therapist but not always the direct focus in the room. Taking a sailing analogy – it might be thought of as similar to 'tacking' – depending on the direction of the wind, it is quicker and easier to divert away from the direct route you are heading in but still know where you want to get to in the end.

## WHAT IF GOALS CHANGE?

Goals often do change during the course of an intervention and the work should change focus accordingly if this is helpful – although you may want to question how helpful it is if goals change regularly throughout an intervention. And, depending on the type of intervention you are working on with a young person, you may want to formally reset the goals. But, if you are using GBOs as part of the CORC collaboration, when it comes to scoring the GBOs to submit to CORC you must only record the scores of the original goals set at the start of the intervention – in the first three sessions. For your own records you might find it helpful to keep a note of those cases where the goals changed mid-intervention, and those that did not. This may help in interpreting the data in a more meaningful way if you choose to dig deeper into the GBOs data.

## CAUTIONS WHEN USING GBOS

### SUBJECTIVITY – “A DOUBLE EDGED SWORD”

Goals, by their nature, are subjective – this gives them strengths as well as weaknesses. The difficulty with such subjective measures is that their scientific validity is difficult to establish – as a young person moves towards a goal it is difficult to be sure that what they rate on the 11-point scale reflects a “true” shift. The strength is that in much work with young people it is their subjective view of change that is arguably a vitally important measure of success.

### BEWARE ‘PERVERSE’ GOAL SETTING

Remember the aim of using any outcome measure is to gain useful feedback on our work to improve services we and our teams provide. However, it is easy to be seduced into ‘collaborating’ with clients in perverse ways, to set ‘easy’ goals that are more achievable – not to help provide users with a sense of achievement, but to make our outcomes look good! Watch out, and question yourself, “is this refinement in goal for my benefit or the client’s?”

This process can equally be at play from the young person’s side; if they feel that setting complex goals may lead to their receiving a ‘better’ service, or if they fear that showing progress towards a goal may lead to a useful service being stopped.

### GUARDING AGAINST GBOS PROBLEMS

Transparency and dialogue are very helpful tools to help guard against the potential pitfalls in collaborating to set goals. Discussions with the goal setter about their choice, and scoring, of the goals, and from the practitioner’s perspective help towards this also, using supervision structures to explore any possible unspoken motivation that might be at work. However, as with most other outcome measures, we can never be entirely confident that the goals and their scoring are representations of the ‘truth’. For this reason, as with all outcome measures, the gold standard is to not rely on just one measure of change, but to gather information from more than one source to help provide a more detailed picture.

## USING GOALS IN CLINICAL PRACTICE

### TRACKING PROGRESS

#### ***Regular and session-by-session monitoring of goals***

Although originally GBOs were adopted to use as an outcome tool: to track the amount of change towards a goal at the end of an intervention compared with where things were at the start of an intervention, it is possible to use the GBOs rating more frequently throughout an intervention, to track progress as an intervention proceeds.

CORC will now collect data on frequent GBO scores. The chart in the Goals and Goal Based Outcomes booklet (Law, 2013, 27) can be used to track GBOs regularly or every session if required. It is written in a way that allows progress to be monitored and shared with the service user and/or with a supervisor, as well as being useful for clinicians and practitioners to use themselves to reflect on progress.

Tracking progress regularly allows the therapist and service user to monitor progress together. Sharing the information in sessions can lead to helpful discussions about what is helping a goal to be reached and how this progress can be maintained, or, conversely, can flag if progress appears to be moving away from a goal. This can be the basis of a useful shared discussion between therapist and service user about why the progress may be heading in a particular direction and can allow any necessary issues to be addressed, such as: how well the therapist and service user are working together; if the model is still the most appropriate for the intervention; if

there are any external factors that need addressing; or to review the client's motivation. It may be helpful to score the GBOs early in a session to allow for discussion and for issues to be addressed quickly where necessary.

The idea of regular monitoring should be introduced at the first therapy session. Each subsequent session might helpfully be introduced by saying:

*"OK, let's have a look at where you feel you are at with the goals we agreed on at the start of the work together. Let's look at goal one first which was to... (insert goal summary sentence)" – on a scale from nought to ten... etc. ..., today how would you rate your progress on that goal?"*

Once the rating has been obtained it may be helpful to compare it to last week's score and discuss as appropriate:

*"OK, it looks like you have moved three points towards that goal – what do you think has helped?" Or "OK, it looks like you have moved back three points – what do you think might be the reasons?"*

It might be necessary to guide a young person to think what the reasons may be: with the external context:

*"Has anything particular happened this week that might have affected progress... at home, school etc..."*

Or with the therapeutic alliance:

*"Is there anything that we could do differently in this session which might help things move forward? Is there anything I could do that would make things more helpful?"*

Or with the model:

*"Does the way we have been working still seem to be helpful – or do you have some thoughts on what might be a more useful way of doing things?"*

Or with the service user's motivation:

*"Do the goals we set at the beginning of the intervention still feel the right ones that you want to work towards? ... how much do you feel you want to work towards the goals we agreed?"*

Clearly these questions, and the phrasing of the questions, would be adapted to fit the client and based on the clinical judgement of the therapist – but it is always helpful to keep these four broad areas in mind.

## SOME EXAMPLES OF SCORING GOALS

### EXAMPLE ONE

Sally is a 17 year old who was referred by her GP with concerns about possible depression and self-harm. At the first appointment she was clear that one of her goals was "to feel less down". She rated herself on this first goal (goal one) as currently 2/10 – as she had been feeling down much of the time recently. In the next session there was more time to talk about the self-harm. Sally said she had been frightened to give it up but as there had now been some chance to discuss alternative coping styles she wanted to stop cutting herself. This became her second goal (goal two) which she rated at 3/10 – she said she had already tried stopping cutting and was having some success, even if it was only delaying the harm rather than stopping it completely.

Sally's progress towards these goals was rated each session – at the end of the intervention Sally did a final rating of the goals :

Goal one (feeling low) she now rated at 7/10 – she felt less low much of the time.

Goal two (self-harm) she now rated at 5/10 – despite a lot of effort she still found it difficult at this stage to stop.

So her outcomes were:

Goal one (low mood) T1 = 2/10, T2 = 7/10, therefore GBO score = 7 – 2 = 5

Goal two (self-harm) T1 = 3/10, T2 = 5/10, therefore GBO score = 5 – 3 = 2

## EXAMPLE TWO

David is a ten year-old-referred due to, “difficult behaviour at home”. He attended with his parents. All agree to work to try and find better ways for David to manage. Part of this work will be individual work with David, to develop some strategies to control his aggression when he gets upset – this is the first goal (goal one) and David scores himself 1/10. As David’s parents are also going to do some work around this, they set the same goal for themselves – they score this (goal two) as 3/10.

The goals were rated each session to track progress. After four months all agree that things are going well and it is agreed to end the intervention at this stage. All agree there have been great improvements. David now rates himself 7/10 (goal one) and his parents rate things 9/10 (goal two).

So the outcomes here are:

Goal one (David) T1 = 1/10, T2 = 7/10, therefore GBO score = 7 – 1 = 6

Goal two (Parents) T1 = 3/10, T2 = 9/10, therefore GBO score = 9 – 3 = 6

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# THE OUTCOME RATING SCALES (ORS) & SESSION RATING SCALES (SRS): FEEDBACK-INFORMED TREATMENT IN CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)

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## INTRODUCTION

Monitoring the young person's and carer's feedback on progress with the Outcome Rating Scale (ORS) and the alliance with Session Rating Scales (SRS) is a natural fit for clinicians who strive for a collaborative clinical practice. The ORS and SRS gives young people and carers a voice in treatment as it allows them to provide immediate feedback on what is working and what is not. This section details how clinicians can use the ORS and SRS for real time feedback to inform treatment thereby improving the outcome of services they offer to young people and families. A brief overview of the empirical evidence of both scales, and the research of their combined use will be provided. In addition, the majority of this section will be practical and provide an introductory illustration to the use of the ORS and SRS throughout the therapy process. At the end you will be signposted to how to access the measures and resources available to support your use of them.

## KEY EVIDENCE BASE FINDINGS

Since the introduction of the ORS and SRS in 2000, research has progressed from instrument validation to randomized control trials (RCTs).

- Research on the ORS and SRS demonstrates impressive internal consistency and test-retest reliability (Miller et al., 2003; Duncan et al., 2003; Bringham et al., 2006; Duncan et al., 2006; Campbell & Hemsley, 2009).
- In those studies the ORS and SRS show moderately strong concurrent validity with longer, more established measures of treatment outcome and therapeutic alliance.
- Feasibility (i.e. the degree to which it can be explained, completed, and interpreted quickly and easily) of the ORS and SRS is high as they are ultra-brief. As a result clinicians and clients don't mind using them and so their utilisation rates are higher than other measures (Miller, et al., 2003; Duncan et al., 2003). If session-by-session measures do not meet the time demands of real clinical practice, clinicians and clients alike

may use them with reluctance at best, and resistance at worse. Much of the fear and loathing involved in doing session-by-session measures is not there with the Outcome and Session Ratings Scales as they usually take on average a minute for administration and scoring.

- Over 3000 young people participated in the four-year validation study of the ORS with adolescents aged 13–17, and the Child Outcome Rating Scale (CORS) for children aged 6–12 (Duncan et al., 2006). The ORS with the adolescents and CORS significantly correlated with the Youth Outcome Questionnaire (YOQ 30), and both showed robust reliability, validity and feasibility.
- Four studies, including three RCTs, support the efficacy of using the ORS and SRS as a client feedback intervention across various treatment approaches (Miller et al., 2006; Anker et al., 2009; Reese et al., 2009a & 2009b).

The three RCTs and several quasi-experimental studies to date provide ample evidence that routine use of the scales improves retention and outcome (in terms of functioning) while decreasing deterioration, length of stay and costs. Shortly, the ORS and SRS: Feedback Informed Treatment (FIT) will receive designation as an evidence-based practice by the US federal government.

## ORS AND CORS

The ORS is a simple, four-item session by session measure designed to assess areas of life functioning known to change as a result of therapeutic intervention. To encourage a collaborative discussion of progress with clients, Miller and Duncan (2000) developed the ORS as an ultra-brief alternative to longer measures whose length of administration, scoring, and interpretation made them less practical. The ORS assess four dimensions of client functioning that are widely considered to be valid indicators of successful outcome (Lambert et al., 1996):

1. Personal or symptom distress (measuring individual well-being)
2. Interpersonal well-being (measuring how well the client is getting along in intimate relationships)
3. Social role (measuring satisfaction with work/school and relationships outside of the home)
4. Overall well-being.

The ORS translates these four dimensions of functioning into four visual analogue scales which are 10cm lines, with instructions to place a mark on each line with low estimate to the left and high to the right. The ORS rates at a 13-year-old's reading level, making it feasible for adolescents and adults. Clients are asked to fill in the ORS at the beginning of each session.

The Child ORS (CORS) was developed for children age 6–12. It has the same format as the ORS but with more child friendly language and smiley and frowny faces to facilitate the child's understanding when completing the scales (Duncan et al., 2003). Some young teens might prefer the CORS format over the ORS. You can use your clinical judgement here to consider which version will engage the young person the best. So, some teenagers might fill in the CORS and some older children may fill in the ORS.

For children 5 or under there is also Young Child Outcome Rating Scale (YCORS), which has no psychometric properties, but can be a useful way of engaging small children regarding their assessment of how they are doing.

## OTHER WAYS THE ORS IS DIFFERENT

- One source of potential confusion is that the ORS/CORS, unlike other measures, is not designed to predict what diagnosis a young person is likely to have, nor is it measuring symptom reduction. The research makes it clear that people do not seek or stay in services when they experience symptoms, but rather when those symptoms begin to impact on their functioning (Hill & Lambert, 2004). The purpose of the ORS/CORS is to provide real time feedback on progress in client functioning.
- The ORS also has a Reliable Change Index (RCI) that provides a useful guide to help identify when change is clinically significant and attributable to therapy rather than chance. On the ORS the RCI = 5 points. So, change that exceeds the RCI and crosses the clinical cut-off scores can be considered reliable change.

- Most important, unlike other existing measures, the ORS provides session-by-session predictive trajectories to let clinicians know at a given session if their client is at risk of drop-out or negative outcome. To help make this clinical judgement, the client's current ORS scores can be compared to similarly scoring individuals in treatment.

## DECIDING WHO FILLS OUT THE ORS/CORS

If two clinicians from a multi-disciplinary team are separately seeing the young person and carers within the same week, you will need to decide between you who will be administering the ORS/CORS.

### “WHERE IS THE DISTRESS?”

The ORS/CORS is designed to assess distress and help measure progress. So in deciding who in the family is to fill out the ORS/CORS, ask yourself: Where is the distress? In most first interviews you won't know where the distress is, so you can ask all family members to complete the measures on themselves to see who is distressed.

## CHILD AND YOUNG PERSON

The young person who is referred or is seeking help, is always asked to fill out the ORS (ages 13–18) or CORS (ages 6–12) on themselves.

## CARER

The carer is always asked to complete the ORS/CORS on the young person. For instance, if the young person is 13 or over and fills out the ORS, the carer fills out the ORS on how they perceive the young person doing. Similarly, if the young person is 12 and under and fills out the CORS, then the carer fills out the CORS on the young person.

N.B. Even if the carer is invited to fill out the ORS on themselves, they still fill out the ORS or CORS on the young person.

## CARER AND/OR OTHER FAMILY MEMBERS WHO ARE DISTRESSED

If it turns out that the carer and/or other family members are distressed, and the distress is related to problems in the family (including the child), then you can continue to have the carer and family members filling out the ORS/CORS on themselves. Your plan and approach should consider how those individual family members' needs will be met.

If the distress of a carer seems separate and/or beyond what your service can provide, discuss and plan with the carer which individual services they would find beneficial.

## TEACHERS AND OTHER PROFESSIONALS

Teachers or other professionals closely involved, and who can attend periodic meetings, can also be asked to fill out the ORS/CORS on the young person.

## MANDATED OR INVOLUNTARY CLIENTS

Mandated or involuntary clients, who frequently present as not distressed or report they have no problem, can be asked to fill out the ORS/CORS from the point of view of the person who is distressed and who has concerns for them. Similarly, you can ask them to fill the ORS/CORS from the perspective of the referrer who has concerns about how they are doing. At the same time, ask the client to fill out the ORS/CORS on themselves, with the rationale that you want to make sure that whatever you do together doesn't impact their stated functioning negatively.

## INTRODUCING THE ORS/CORS AT THE FIRST SESSION

Avoid clinical jargon and explain the purpose of the ORS or CORS and its rationale in a common sense way. For instance, you can introduce the ORS/CORS by saying that it is designed to assess distress and help measure progress. The specific wording is not important. When administering the ORS and CORS it is useful to read the instructions out to the clients and ask if they have any questions before they start. The following are a couple of examples:

To young person and carer: Before we get started I would be grateful if you could help me out by taking a minute to fill out a very brief questionnaire to help me understand how things are going for (young person's name). Every time we meet I will ask you to fill the form again to help us track progress. Are you ok with that? OK, so let me go over the instructions with you.

However, at most first interviews you won't know where the distress is, so you can ask **all** family members present to complete the ORS on themselves. This allows you to "see" who is distressed.

To carer and other family members present: I would also be grateful if all of you can fill the form out on yourselves to help me understand how things are going for you too. Even if things are going ok with you, I would be grateful if you could do this today and on a periodic basis, to ensure that whatever we do together doesn't impact you negatively.

When the carer is asked to fill out the ORS on themselves, they are still asked to complete the ORS about the young person. This may sound cumbersome, but remember the measure is ultra-brief and takes a minute to do.

## DISCUSSING THE ORS/CORS RESULTS

You can ask family members to feel free to talk amongst themselves for a couple minutes while you score the ORS. Scoring is done in front of the client using a centimeter ruler. Each of the four visual analogue scales is 10cm, so the score for each of the four visual analogue scales is the measurement length on the ruler (e.g. 3.3cm = score of 3.3) with 10 being the highest score for each scale. You simply write the score in the right margin, and then add the four scores for the overall score. The total possible score is 40. If working with families, you can teach family members how to do the scoring to help save time and as a way of engaging them in the process.

Next, plot each person's overall score on a graph or enter into an electronic database to monitor the trajectory of progress.

The ORS/CORS cut-off scores between the clinical population and the non-clinical population are different depending on the age of the client:

- 13–17 year olds (self-reporting and carer reporting on teen) = 28
- 18 and over = 25

The CORS (ages 12 and under) cut-off scores are:

- Child Self Reporting = 32
- Carer Reporting on Child = 28

It is important to explain these cut-off scores to the young people and carers.

To young person and carer: Great, thanks. Let me show you what I have done. The four lines on the form are each 10cm. I have used the ruler to come up with a score for each line. I then have added the numbers for a total score and plotted them on this graph.

(Young person's name) I have put your score here and (mum's name) I have placed your score here. Scores above this line represent young people who seem to be plodding along all right in life and don't seek help. Scores below this line, like yours, are typically young people who are having problems and wanting help to make some changes. Is that true for you?

OK, so when we fill out this form each time we meet I will be putting your scores on the graph and connect the dots, and hopefully we will soon see a line going up which will tell us we are on the right track. If it does not go

up, or goes down, we will know about it right away and we can talk about it, and together work out what might need to be different and what might be more helpful.

## COLLABORATIVE FORMULATIONS AND THE ORS/CORS SCORES

It is important to help the young person and carer connect the problems that brought them to you with their ORS and CORS scores. You can incorporate this within your usual style of doing assessments and/or how you construct collaborative formulations with young people and carers.

To young person and carer (laying out the ORS or CORS in front of them): I would be grateful if you both tell me a bit about why you put the marks where you placed them so I can better understand the problems that brought you here.

This will often end up with a narrative about the problem, which is fine. Such discussions can be a part of your normal interviewing style and how you come up with shared formulations with clients. For example:

To the young person: It sounds like you are spending a lot of your day worrying and avoiding places out of fear, does that explain your mark here on the Me (How am I doing?) scale?

To the parent: It sounds like there is a lot of arguing and anger amongst family members including (young person's name), does that explain your mark here on the Family (How are things in my family?) scale?

To the teacher: It sounds like running out of class and not knowing where he is going is your biggest concern for Kevin. Does that explain your mark here on the School (How am I doing at school?) scale? Is there anything else that helps explain your mark?

## EXPLORE DIFFERENCES IN PERCEPTIONS

It is common for the young person and carer to have very different scores on the different scales, which can be useful perceptual differences to explore:

*“Sebastian, I noticed you rated how things are going in the family closer to the frowny face, and Emma (mother) you rated your son closer towards the smiley face. What do you both make of that?”*

*“Lucy, I noticed that you rated yourself high on Individual (Personal well-being), and Sarah (mother) you rated her quite low. Lucy, what do you suppose you know about yourself and what has changed that your mother doesn't know?”*

## WORKING OUT SHARED GOALS AND EXPLORING STRONG PREFERENCES

You can use the scales to help establish what kind of changes and goals the young person and carers want from your help. If they have any strong preferences and ideas about treatments, try to accommodate their preferences.

To young person or carer: a) What will you and others notice that will be different when your marks on this line move from where you placed it to over here at this end near the smiley face? b) What ideas do you have about what needs to happen to move your mark from here to there (pointing at the smiley face)?

## CARER'S DISTRESS AND NEEDS

In situations where it seems the carer's distress goes beyond the problems related to the young person, and you are concerned it is negatively impacting the young person's ORS/CORS scores, consider meeting with the carer separately to help them explore how to have their needs met e.g. using their own network of family and friends, parenting groups, couple therapy, individual therapy and doctor etc.

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## SESSION RATING SCALE (SRS) AND CHILD SESSION RATING SCALE (CSRS)

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Researchers have repeatedly found that the therapeutic alliance – i.e. agreement on goals, agreement on tasks in therapy and emotional bond (Bordin, 1979) – is one of the best predictors of outcome across different types of therapy including psychopharmacology (Martin et al., 2000; Wampold, 2001; Norcross, 2010). Evidence regarding an alliance's contribution to outcome is reflected in more than 1,000 studies (Orlinsky, Ronnestad, & Willutzki, 2004). A strong therapeutic alliance may be even more critical for youth psychotherapy than adult therapy, given that the child and young people are typically not self-referred, and the carers or extended family usually play a vital role in treatment (Shirk & Karver, 2003).

The quality of the therapeutic alliance with the carer impacts treatment outcome for the young person. (Kelley, Bickman and Norwood, 2010). For instance, a strong therapeutic alliance with the carer will be critical when treatment requires a focus on the carer making some direct changes to positively impact the young person. In individual therapy that is focused on the young person, a strong therapeutic alliance with the carer will be important because it is the carers who schedule and keep the appointments, provide information needed about the young person, and encourage the young person's treatment adherence in between therapy sessions (Fields et al., 2004). Further, a strong therapeutic alliance with a carer is likely to convey hope and other positive attitudes about treatment that may encourage the young person's participation in treatment, which then in turn will positively influence youth outcomes (Kelley et al., 2010).

In family work, establishing multiple alliances simultaneously with each individual can be a formidable task (Friedlander, Escudaro & Heatherington, 2006). Even agreeing with one family member on the need for therapy can alienate another family member who may have come to the session unwillingly. Gaining shared agreements on the goals and tasks of therapy is an enormous challenge when family members have differing developmental needs, hidden agendas, highly variable motivations for treatment, are in conflict with one another, or have contrasting views of the problem and differing views about who and what needs to change. For instance, validating the goal of one party can alienate another. The challenge is to try to align simultaneously with all members in the pursuit of a common goal (Friedlander, Lambert, Muniz de la Pena, 2008).

Research has shown that clinicians are poor at gauging their client's experience of the alliance (Norcross, 2010) and they need to request real time alliance feedback. The benefits of requesting real time feedback on the therapy alliance include: empowering clients, promoting collaboration, making necessary adjustments to therapy, and enhancing outcomes (Lambert, 2005).

The Session Rating Scale (SRS) was developed for exactly these reasons. The SRS is a simple, four-item pencil-and-paper alliance measure designed to assess key dimensions of effective therapeutic relationships. The SRS is administered, scored and discussed at the end of each session to get real time alliance feedback from young people and carers so that alliance problems can be identified and addressed (Miller et al., 2002).

The SRS translates what is known about the alliance into four visual analogue scales to assess the clients' perceptions of:

- Respect and understanding
- Relevance of the goals and topics
- Client-practitioner fit
- Overall alliance.

The SRS is used with young people aged 13 to adults. The Child Session Rating Scale (CSRS) is for young people aged 6-12 (Duncan, et al. 2003). There is also a Group Session Rating Scale (GSRS) for ages 13 to adults, and Child Group Session Rating Scale (CGSR) for ages 6-12.

The cut-off score on the SRS, CSRS and GSRS is 36 out of a possible 40.

For children 5 or under there is also the Young Child Session Rating Scale (YCSRS), which has no psychometric properties, but can be a useful way of engaging small children regarding their assessment of the alliance.

## **INTRODUCING THE SRS/CSRS AT THE FIRST SESSION**

Everyone who attended the session is invited to fill out an SRS or CSRS. In introducing the SRS/CSRS you want to convey that you are really interested in everyone's feedback about how the session went for each of them. You can explain that scores on the forms provide an opportunity for you to learn what to keep doing that is useful and, importantly, what you might need to do different next time to make it better for them.

To young person and carer: OK, we need to end, but before we do I would be grateful if you would take a minute to fill out this form which asks your opinion about our work together today. Now, I rely on this feedback to keep me on track, and let me know when I am off track and need to make some changes for you. So, please give me your honest opinion when filling this out. OK?

NB Recall that when giving the SRS to young people you also give CSRS to the carer. Here when you give the CSRS to young people, you give the SRS to those 13 and over. If you are working with a family, have everyone fill out the SRS or CSRS as your alliance with each of them is important.

## **DISCUSSING THE SRS/CSRS RESULTS**

Score the SRS/CSRS in front of the client. If you are working with more than one person in a session, to save time you can teach the family to score their SRS/CSRS so there is more time for discussion about the scores and address any difficulties in the alliance.

Positive feedback is valuable as it helps you know what to do more of that matches the sensibilities of a specific client and family. Although we all prefer positive feedback as it feels nice, you have to convey to clients that negative feedback is like gold to you, as it gives you a chance to make adjustments to make a better fit for them.



## WHEN SCORES ARE AT THE CUT-OFF SCORE OF 36 AND ABOVE

*“These marks are way over to the right, which suggests you are feeling understood and that we are working on the right things that are important for you, and how we are doing seems to fit for you. Is that right? Can you think of anything at all that I might be able to do differently to make these meetings even better for you?”*

Scores that go down even a single point are significant and should be checked out with the clients. It is important to discuss any downturn on the SRS even when scores are above the cut-off. Any scores less than nine on the four scales is an invitation for you to check out if you might have done or said something that did not sit well with them and/or how you can improve the sessions for that young person or family member.

## WHEN SCORES ARE BELOW 36 (OR ONE SCALE IS SIGNIFICANTLY BELOW NINE)

When you are getting scores below 36 it helps to adopt a posture of gratitude versus disappointment. Treat low SRS scores as a gift from your clients as they allow you the opportunity to repair ruptures to the alliance, and make the necessary adjustments in therapy to help improve your clients' outcomes.

OK, it seems that I could be doing better. I am grateful for you being honest and giving me a chance to try to make some changes. What could I do differently next time to make things better for you?

## SUBSEQUENT SESSIONS

Each session the ORS or CORS is given out at the beginning of the session to compare current ORS and CORS scores with previous ratings. If individual therapy is being offered to the young person, it is still important to try to capture the carer's scores by having a few minutes before each session. It can be very useful to have periodic review sessions where the carers (e.g., parent or teacher) and possibly other family members can fill out the ORS or CORS.

In each session the SRS or CSRS is given at the end of the session. It is important to leave yourself enough time for the clients to fill it out and pick up on any alliance difficulties. In many cases there might not be a next time as, if there is a poor alliance, the clients are likely to not attend, or come back with no change as what you are doing together is not a good fit.

To the young person and/or carer: These scores suggest that for the past few weeks I have not been getting things quite right for you? Can you help me understand what I need to do differently to make these sessions fit better for you?

## ROLE OF SUPERVISION AND TEAM/PEER REVIEWS

Supervision is a key mechanism for supporting a supervisee's integration of feedback into their clinical practice. Supervisees should bring the clients' ORS/CORS and the SRS/CSRS and graphs to supervision. The measures and the graphs bring the feedback and voice of the young person and carer directly into the supervisory session, which is an invaluable addition to the clinician's perceptions of progress and the alliance. The measures can be used in a similar way in multi-disciplinary team/peer reviews and Care Plan Approach (CPA) reviews.

Further, supervisors can also utilise the measures and graphs across multiple cases to incorporate the voice and feedback of young people and carers to help the supervisee reflect on patterns of strengths and shortcomings to assist in the targeting of areas for professional growth and development.

## ORS/CORS SCORES INCREASE

When scores increase we can help clients see their hand in the changes.

To the young person: That is encouraging: your total score increased four points! What did you do differently to make that happen? What have you learned about yourself?

To the carer: Your rating of (young person's name) has gone up. What have you and/or others been doing different to make things better (young person's name)? What have you noticed (young person's name) doing different that is helping?

Young people with complex problems might only make slight improvements and need longer interventions, but a discussion of alternatives remains an important intervention at recurrent stages.

ORS/CORS scores that exceed the RCI (five points) and cross the clinical cut-off scores can be considered reliable change. This is a good time to review the progress towards the therapeutic goals with the young person and carer, and consider starting some consolidation and response prevention and end therapy.

## ORS/CORS SCORES DON'T IMPROVE OR GO DOWN

In general, discuss any lack of progress or downturn on the ORS/CORS with the clients.

Look closely at the SRS/CSRS scores

The following are possible things to consider with clients, supervisors and multi-disciplinary/peer and CPA reviews:

- Is there a problem in the alliance with the young person or carer that is getting in the way of progress?
- Review the treatment goals to see if they still fit. Are you working on the clients' goals versus the referrer's? Do the goals need to be revised from the absence of symptoms (e.g. less depressed) to improvement in functioning (e.g. going out with friends and doing usual pleasurable activities).
- If you are working with more than one member of the family and there is blaming and conflict, consider using empathic messages to both sides of a conflict along with pointing out everyone's good intentions. You may also want to transform individual goals that involve others changing to common shared goals involving improved family relationships (e.g. "to get the family back on track" or "to restore intimacy, closeness or trust") emphasising mutual collaboration.
- Check out that the approach is fitting and whether you need to adjust, or change to another approach.
- If there is a rupture in the alliance that you don't seem able to overcome, consider referring to a colleague.

## ORS/CORS SCORES SHOW NO PROGRESS AFTER THIRD SESSION

When you have had no progress on the ORS/CORS after the third session, discuss this with the client and carers, and with supervisor.

To the young person and carer: The scores have not gone up. What are your hunches about why that is? These scores indicate we might need to try to do something quite different as you don't seem to be benefitting. What are your thoughts about that? What do you think we need to do differently to increase the chances of this line moving in an upward trend?

At this point you might consider:

- Do you need to expand the work to include different members of the family and/or school?
- Do you need to meet with the carer (e.g. parent and/or school) to ensure they understand how they can best help the young person, and/or better understand what support and help they need?

## ORS/CORS SCORES SHOW NO PROGRESS AFTER FIFTH OR SIXTH SESSION

If there is no improvement by the fifth or sixth visit consider adding additional services with the young person, carer, and supervisor. This may involve a referral to another agency.

## ORS/CORS SCORES SHOW NO PROGRESS AFTER EIGHTH, NINTH OR TENTH SESSION

If there is no progress by the 8th–10th visit discuss with the client and carer whether they need to see someone else such as another clinician with a different approach and/or a higher level of care.

To the young person and/or carer: I am wondering if I might not be the best person to help with this problem. Would it be useful for me to go over different types of therapies and clinicians we have and maybe what one of them has to offer might be a better fit with you than what I can offer?

## ORS AND SRS TOGETHER FACILITATE BETTER OUTCOMES IN CAMHS

Using the ORS and SRS provides an outcome management process to monitor and adjust treatment as a result of client feedback. The ORS/CORS and SRS/CSRS measures are clinical tools that both facilitate better outcomes if used together to enhance engagement and participation in the care provided as the measures are discussed with young people and carers. The following is how CAMHS clinicians from different disciplines have found using the ORS/CORS and SRS/SRS to help their clinical practice:

*“The ORS/SRS measures fit incredibly well into the Cognitive Behaviour Therapy (CBT) model of working, allowing monitoring of progress in functioning in a measurable way, which is explicit to clients, and also enabling monitoring of the therapeutic alliance as part of the process of obtaining feedback from clients. The young people I work with have engaged well in adopting these measures as part of the work, and have benefited from the opportunity for self-reflection and celebration of progress which these measures facilitate. For me, as a clinical psychologist, the measures have furthered my self-reflection, enabling me to better tailor my work to the needs’ of my clients on the basis of their feedback, thus promoting the client-centred, idiosyncratic approach.” – Maria Loades, Clinical Psychologist, CAMHS, Suffolk.*

*“I have been using the ORS and SRS in both my Cognitive Behaviour Therapy work and in my role as a primary mental health worker. In both roles it gives me a true sense of how the client is finding our work, rather than my best (and usually inaccurate) guess. In the PMHW role, where work is often brief, the ORS has the added benefit of helping to quickly identify which areas the client is finding most difficult so that intervention can be targeted to this. I have found both measures easy to use and that they can quickly be adopted into my routine with clients. Parents and children find the visual representation of progress on the ORS very useful, and combining this with monitoring the therapeutic relationship through the SRS can give great clarity on what to do when therapy runs into problems. It is also a great aid for supervision discussions, helping aid reflection on factors affecting progress.” – Rebecca Light, Primary Mental Health Worker and Cognitive Behavioural Therapist, CAMHS, Suffolk.*

*“I have found the ORS and SRS really useful in my Specialist Nurse practice. The measures have been a significant aid in supporting me with keeping client focused and this has had the knock-on effect of enhancing client motivation and engagement. The measures have also been useful in facilitating conversations about what’s not been quite right in sessions and challenged unhelpful assumptions that I have made within sessions in a non-confrontational manner. The measures are also great for clinicians’ self-esteem as they provide ‘evidence’ of when you have done a cracking job, or are simply needing reassurance that you are doing ‘OK’ with a case.” – Rachael Ewan, Specialist Nurse, CAMHS, Suffolk.*

*“The ORS and SRS fit very well with family work. The ultra-brief design and formats for different age groups including small children, allows all members of the family an important feedback voice into the therapeutic system, and enhances everyone’s engagement and participation in family work. As the measures are ultra-brief they do not take much time out of the session. Families are generally curious about each other’s ORS scores. Where differences of opinion exist, a graph on which each family member’s outcome score is plotted in different colours provides a useful structure for a manageable inclusive discussion about the problem and its resolution from different perspectives. The feedback from the SRS helps clinicians make the necessary adjustments to align simultaneously with all family members in the pursuit of common agreement on goals and tasks in therapy.” – David C. Low, Family and Systemic Psychotherapist, CAMHS, Suffolk.*

*“I’ve been using the ORS/CORS and SRS/CSRS in my day-to-day clinical practice for many years now. It’s hard for me to imagine practice without using them these days. There is no magic about them of course, but they have really helped me think a lot more carefully about what I do and how I do it. Whether in*

*short term work or longer term treatment, from the very first meeting the young people and their families are being included in an active way giving me feedback about what is important to them and teaching me about what I need to reconsider. It is a bit daunting at first, particularly getting the feedback through the SRS/CSRS. Not many of us like to be confronted with feedback about what our patients see needs to change with what we are doing, but this is the aspect of using feedback that has most influenced and challenged my practice. Whether using individual or family meetings, prescribing medication, liaising with other agencies, or deciding on frequency of meetings, the feedback you get about what works and what is helpful is invaluable: In fact so inspired I have incorporated the rating scales and the philosophy around them into a whole service model for Lincolnshire CAMHS known as the Outcome Orientated CAMHS (OO-CAMHS) Project.” – Sami Timimi, Consultant Child and Adolescent Psychiatrist, CAMHS, Lincolnshire.*

*“The introduction of the ORS (CORS) and SRS (CSRS) in the Cambridgeshire Early Intervention Service in CAMH enthused clinicians as it enriched their practice by obtaining so much more relevant information about their clients. Children and young people made it their own story of what was upsetting for them, which could not be captured by a symptom measure. They were able to express what they like or not like about the session and the therapists were very positive about any negative feedback as they change their approach. Clinicians want to continue using the measures because of their clinical significance.” Brigitte Squire, Clinical Psychologists and MST Programme Manager, Cambridgeshire.*

## **ADDITIONAL GUIDELINES AND EXAMPLES**

- Additional guidelines and examples can be found in the ORS/SRS manual (Miller & Duncan, 2004).
- There are also six newly developed manuals covering every aspect regarding the use of the ORS and SRS measures in clinical practice. These were developed as part of the International Center for Clinical Excellence’s (ICCE) application to the National Registry of Evidence Based Programs and Practices (NREPP) in the United States. Each service will find the manuals a valuable resource.
- These manuals and other resources are available at [www.scottdmiller.com](http://www.scottdmiller.com).

## **HOW TO GET THE MEASURES FREE**

The ORS/CORS and SRS/CSRS measures are licensed for members of CORC and CYP IAPT by Scott D. Miller and ICCE ([www.centerforclinicalexcellence.com](http://www.centerforclinicalexcellence.com)). CORC and IAPT may distribute the measures to their practitioners. Users may also obtain the measures in English and languages other than English at [www.scottdmiller.com](http://www.scottdmiller.com).

Note: When downloading the measures for the first time, you may need to adjust the analogue scales to make sure they are exactly 10cm. Beyond that adaptation the licence agreement involves no alterations to the ORS/CORS and SRS/CSRS.

## **FOR COMMENTS, OR INFORMATION ON TRAINING IN USING THE ORS/CORS AND SRS/CSRS**

For comments, or information about training on skills for improving client engagement in treatment services, and how to integrate real time outcome and alliance feedback using the ORS & SRS to improve clinical effectiveness with young people and families, contact:

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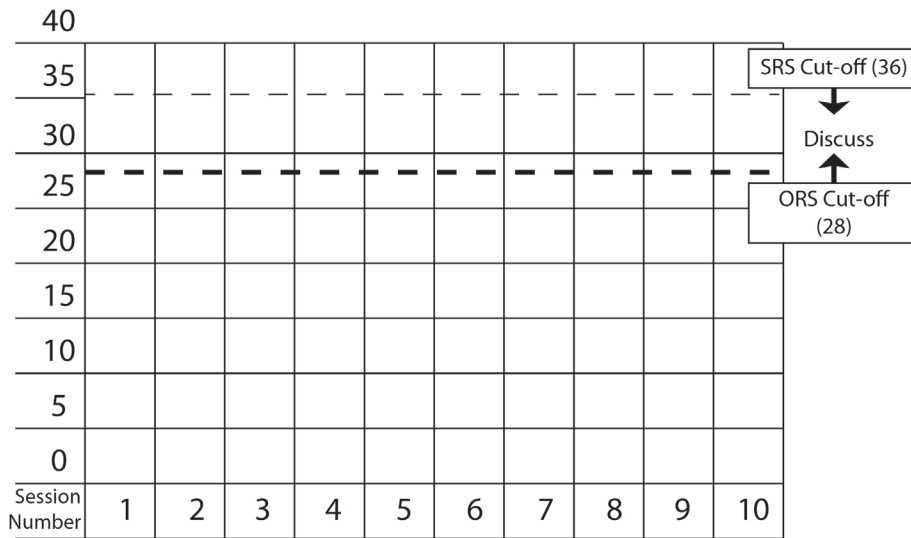
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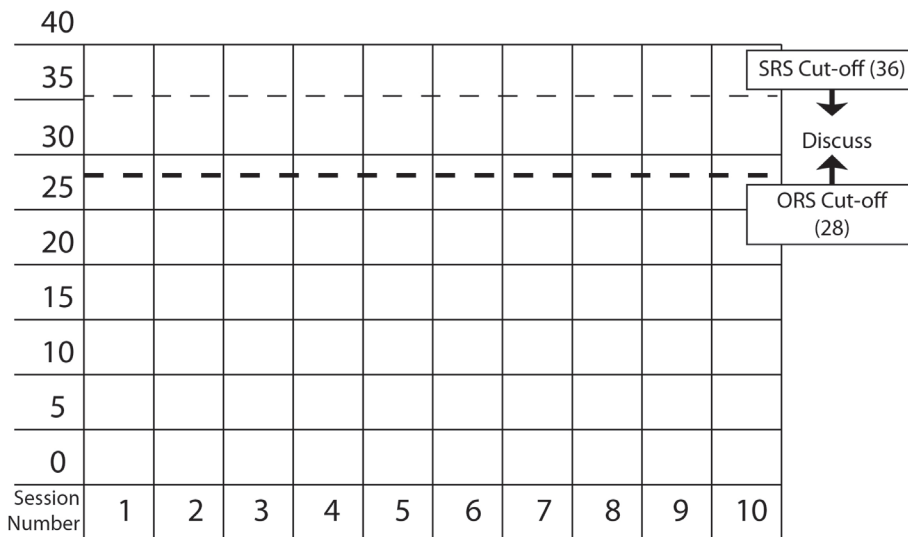
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### ORS/SRS Graphs

Young Person Scale (Age 13 –17)

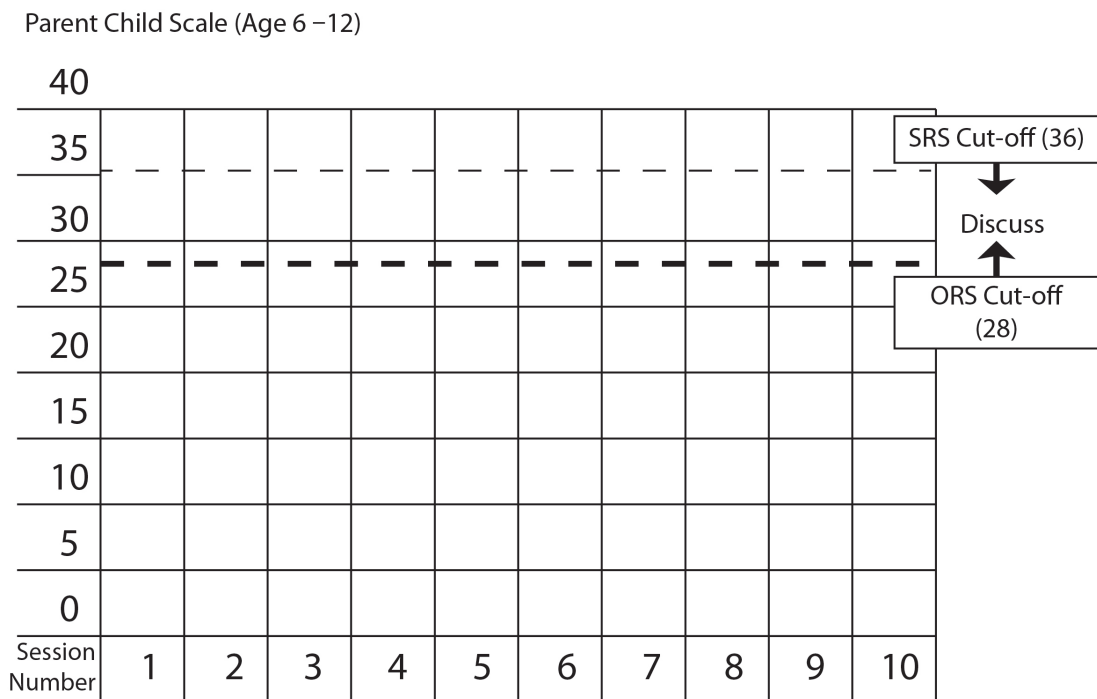
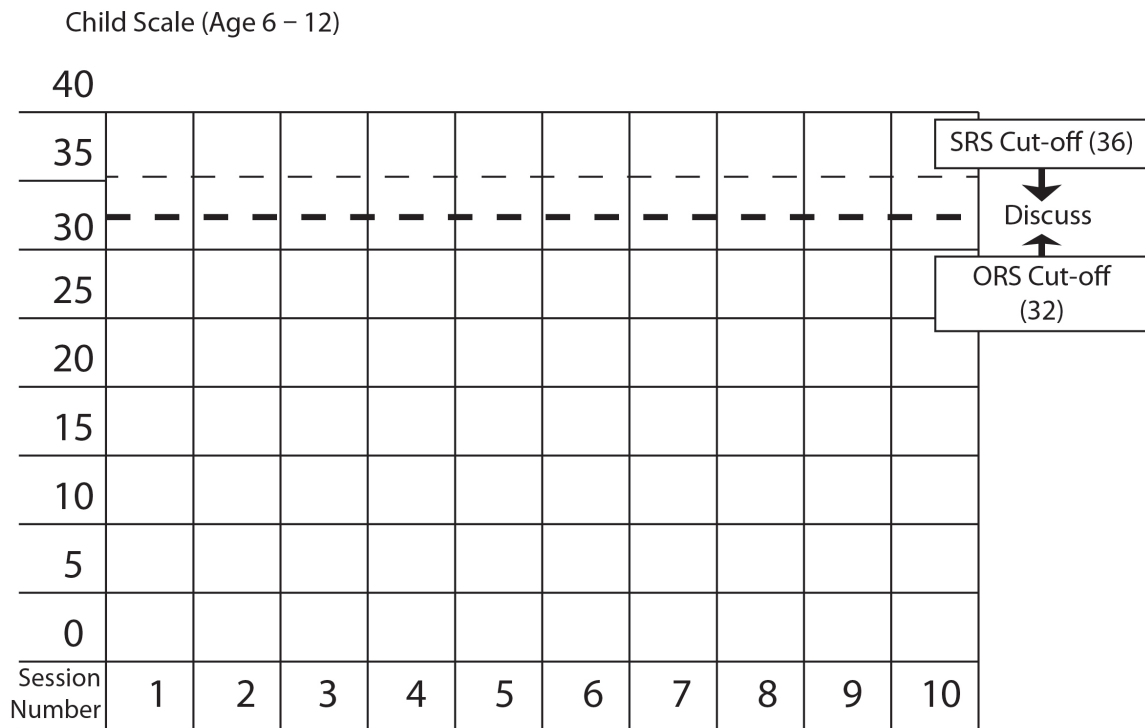


Parents Young Person Scale (Age 13 –17)



**FIGURE 3.1:** ORS/SRS Graphs.

## CORS/CSRS Graphs



**FIGURE 3.2:** CORS/CSRS Graphs.

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## ADMINISTERING CLIENT-RATED HONOSCAS

Simon Gowers

The client-rated version of HoNOSCA has been developed using the 13 scales in Section A of the clinician-rated HoNOSCA. This consists of an administered questionnaire based on the main statement for each scale worded in the form of a question. For example, scale one of the clinician-rated HoNOSCA “Disruptive, anti-social or aggressive behaviour” became “Have you been troubled by your disruptive behaviour, physical or verbal aggression?”

The client-rated HoNOSCA is completed with minimal assistance from an independent person (i.e. not a clinician). This assistant explains the purpose of HoNOSCA (i.e. to measure outcome) and gives a few brief guidelines, which consist of :

- Answer questions with last two weeks in mind.
- Try to be honest.
- Try to answer all 13 questions.
- Please tick one box for each question.
- Try to rate the most severe difficulty mentioned in a question.
- Take as long as necessary to answer questions.

The client then completes the questionnaire with the assistant still present, so that help can be given in answering the questions if difficulties arise.

If it is not possible for an assistant to be available to administer the questionnaire, the client is given a “guidance sheet”, which consists of the brief guidelines given above as well as an example which goes through a specific question and possible responses.

The client-rated HoNOSCA should be administered every time a clinician-rated HoNOSCA is completed, to act as a comparison. This would usually be at assessment, six-weekly review and discharge.



## USEFUL LINKS

**Click Databases:** [www.clickdatabases.co.uk](http://www.clickdatabases.co.uk)

**Child Outcomes Research Consortium (CORC):** [www.corc.uk.net](http://www.corc.uk.net)

**CORE Information Management Systems:** [www.coreims.co.uk](http://www.coreims.co.uk)

**CYP IAPT YouTube channel:** [www.youtube.com/channel/UCVr\\_XGnjA229P5bUgfZ-y3w](http://www.youtube.com/channel/UCVr_XGnjA229P5bUgfZ-y3w)

**FAQs on the CYP IAPT website:** [www.iapt.nhs.uk/CYP\\_IAPT/children-and-young-peoples-project-faqs](http://www.iapt.nhs.uk/CYP_IAPT/children-and-young-peoples-project-faqs)

**Health and Social Care Information Centre (HSCIC):** [www.hscic.gov.uk](http://www.hscic.gov.uk)

**IAPTus:** [www.iaptus.co.uk](http://www.iaptus.co.uk)

**MegaNexus:** [www.meganexus.com](http://www.meganexus.com)

**My Access to Psychological Therapies (MyApt):** [www.myapt.org.uk](http://www.myapt.org.uk)

**Outcome Orientated CAMHS (OO-CAMHS):** [www.oocamhs.com](http://www.oocamhs.com)

**Patient Case Management Information System (PC-Mis):** [www.pc-mis.co.uk](http://www.pc-mis.co.uk)

**The International Center for Clinical Excellence (ICCE):** [www.centerforclinicalexcellence.com](http://www.centerforclinicalexcellence.com)

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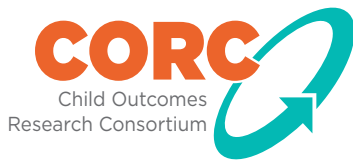
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## ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autistic Spectrum Disorder
BDI	Beck's Depression Index
BME	Black and Minority Ethnic
BPS	Behaviour Problems Inventory
BPSES	Brief Parental Self-Efficacy Scale
CAMHS	Child and Adolescent Mental Health Services
CAPA	Choice and Partnership Approach
CBI	Challenge Behaviour Interview
CBT	Cognitive Behaviour Therapy
CGAS	Children's Global Assessment Scale
CGSRS	Child Group Session Rating Scale
CHI	Commission for Health Improvement
CHI-ESQ	CHI- Experience Service Questionnaire
COOP	CYP IAPT Outcomes-Orientated Practice
CORC	CAMHS Outcomes Research Consortium
CORC +	CAMHS Outcomes Research Consortium +
CORE	Clinical Outcomes in Routine Evaluation
CORS	Children's Outcome Rating Scale
CPA	Care Plan Approach
CSRS	Child Session Rating Scale
CYP IAPT	Children and Young People's – Improving Access to Psychological Therapies
CYP	Children and Young People
CYPFs	Children, Young People and Families
DBC	Developmental Behaviour Checklist
DNA	Did Not Attend
EBPU	Evidence Based Practice Unit
EDE-Q	Eating Disorders Examination- Questionnaire
EET	Education, Employment & Training
FIT	Feedback Informed Treatment
GAD	Generalised Anxiety Disorder
GBO	Goals Based Outcome
GIFT	Great Involvement, Future Thinking
GRRACCEESS	Gender, Race, Religion, Age, Ability, Class, Culture, Ethnicity, Education, Sexuality, Spirituality
GSRS	Group Session Rating Scale
HEIs	Higher Education Institutions
HoNOSCA	Health of the Nation Outcome Scales for Children and Adolescents
HSCIC	Health and Social Care Information Centre
ICCE	International Center for Clinical Excellence

## ABBREVIATIONS

LD	Learning Difficulty/Disability
M&MS	Me and My School
MyAPT	My Access to Psychological Therapies
NHSE	National Health Service England
NREPP	National Registry of Evidence Based Programs and Practices
NCBRF	Nisonger Child Behaviour Rating Form
OCD	Obsessive Compulsive Disorder
ODD	Oppositional Defiant Disorder
OEG	Outcomes and Evaluation Task and Finish Group
OO-CAMHS	Outcome Orientated CAMHS
ORS	Outcome Rating Scale
PC-Mis	Patient Case Management Information System
PDSA	The Plan, Do, Study, Act cycle
PHQ-9	Patient Health Questionnaire
PREMS	Patient Reported Experience Measures
PROMS	Patient Reported Outcome Measures
PSI	Parent Stress Index
PTSD	Post-Traumatic Stress Disorder
RCADS	Revised Children's Anxiety and Depression Scale
RCADS-P	Revised Children's Anxiety and Depression Scale – Parent Version
RCI	Reliable Change Index
RCPCH	Royal College of Paediatrics & Child Health
RCT	Randomized Control Trials
RMQ	Regular Monitoring Questionnaire
ROM	Routine Outcome Monitoring
ROMS	Routine Outcome Measures
SCORE	Systemic Clinical Outcome and Routine Evaluation
SDQ	Strengths and Difficulties Questionnaire
SFQ	Session Feedback Questionnaire
SLDOM	Sheffield Learning Disabilities Outcome Measure
SRS	Session Rating Scale
SWEMWBS	Short Warwick-Edinburgh Mental Well-being Scale
U-PROMISE	Using Patient Reported Outcome Measures to Improve Service Effectiveness
VIK	Very Important Kids
YIACS	Youth Information, Advice and Counselling Services
YCORS	Young Child Outcome Rating Scale
YCSRS	Young Child Session Rating Scale



## **CORC**

The Child Outcomes Research Consortium (CORC) is a learning collaboration of mental health professionals dedicated to improving the quality of Child and Adolescent Mental Health Services (CAMHS) nationwide. Every year over a quarter of a million children, young people and their carers attend CAMHS in the UK. CORC wants to understand what helps them best. Over 70 member services across the UK and Scandinavia are committed to ensuring that young people and their families receive the best help possible. CORC trains CAMHS professionals in how to use outcome data by offering free training to members, consultancy to interested parties and advice to government.

Contact CORC by email: [CORC@annafreud.org](mailto:CORC@annafreud.org)  
CORC website: [www.corc.uk.net](http://www.corc.uk.net)

**iapt**

**Improving Access to Psychological Therapies**



## **CYP IAPT**

The Children and Young People's Improving Access to Psychological Therapies Project is an exciting programme working with existing Child and Adolescent Mental Health Services (CAMHS) to:

- improve access to CAMHS, and the partnership with children, young people, families, professional and agencies
- build capability to deliver positive and measurable outcomes for children, young people and families
- increase choice of evidence based treatments available.

The information on this website is aimed at professionals and commissioners.

If you are a young person or parent, or want to know more detail about participation, you may find the MyAPT website more helpful.

More information is available from the CYP key facts document.

**Press**  
**CAMHS**

## **CAMHS Press**

CAMHS Press is the publishing arm of the Evidence Based Practice Unit and is placed at the Anna Freud Centre, North London. CAMHS Press brings to you the worlds of academic research and mental health practice, through series of booklets, leaflets and other forms of publications related to mental health in support of children, young people and mental health practitioners. CAMHS Press publications are free of charge. CAMHS Press is proud to work with front line practitioners, service users and policy makers to share knowledge and information and is committed to serving its readership.

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EBPU website: [www.ucl.ac.uk/EBPU](http://www.ucl.ac.uk/EBPU)



## CORC

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