PROMS in Child and Adolescent Mental Health

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http://www.iapt.nhs.uk/cyp-iapt
http://www.corc.uk.net
PROMs in Child and Adolescent Mental Health Services (CAMHS)

Child Outcomes Research Consortium (CORC) [www.corc.uk.net](http://www.corc.uk.net) 2004 - present

Children and Young People Improving Access to Psychological Therapy (CYP IAPT) [www.cypiapt.org](http://www.cypiapt.org) 2011 - present
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- Neil Humprhey
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- Emma Morris
- Peter Stratton
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## Domains considered

<table>
<thead>
<tr>
<th>Goals</th>
<th>General well being</th>
<th>Symptom trackers</th>
<th>Experience of care (PREM)</th>
<th>Educational functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>What I want to achieve...</td>
<td>How things are generally...</td>
<td>I wash my hands constantly...</td>
<td>Would I recommend to a friend...</td>
<td>In school...</td>
</tr>
</tbody>
</table>
Strengths and Difficulties Questionnaire (SDQ) example items

- I try to be nice to other people. I care about their feelings
- I am restless, I cannot stay still for long
- I get a lot of headaches, stomach-aches or sickness
- I usually share with others (food, games, pens etc.)
- I get very angry and often lose my temper
- I am usually on my own. I generally play alone or keep to myself
- I usually do as I am told
- I worry a lot
### SDQ impact items

**Do the difficulties upset or distress your child?**

- **Not at all**
- **Only a little**
- **Quite a lot**
- **A great deal**

**Do the difficulties interfere with your child's everyday life in the following areas?**

- **HOME LIFE**
- **FRIENDSHIPS**
- **CLASSROOM LEARNING**
- **LEISURE ACTIVITIES**

Robert Goodman
Revised Child And Depression Checklist (RCADS) example items

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
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<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>I have trouble sleeping</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>12</td>
<td>I worry that I will do badly at my school work</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>13</td>
<td>I worry that something awful will happen to someone in my family</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>14</td>
<td>I suddenly feel as if I can’t breathe when there is no reason for this</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>15</td>
<td>I have problems with my appetite</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>16</td>
<td>I have to keep checking that I have done things right (like the switch is off, or the door is locked)</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>17</td>
<td>I feel scared if I have to sleep on my own</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>18</td>
<td>I have trouble going to school in the mornings because I feel nervous or afraid</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>19</td>
<td>I have no energy for things</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
<tr>
<td>20</td>
<td>I worry I might look foolish</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
</tr>
</tbody>
</table>
Agreeing goals
Child Outcome Rating Scale (CORS)
(Age 6 to 12)

Name ____________________ Age (Yrs) ______ Session # __________ Date: __________

Who is filling out this form? Please check one: Child __________ Caretaker ______

If caretaker, what is your relationship to the child? ______

How are you doing? How are things going in your life? Please make a mark on the scale to let us know. The closer to the happy face, the better things are. The closer to the sad face, things are not so good. If you are a caretaker filling out this form, please fill out according to how you think the child is doing.

Me
(How am I doing?)

Family
(How are things in my family?)

School
(How am I doing at school?)

Everything
(How is everything going?)

SCORING
Each line is 10 cm.
Score with ruler e.g. 3.5 cm = score of 3.5
Write the score for each of the four lines here in the white area.
Add the four scores for a total score.
Plot overall score on the graph.

The information on this page is for illustration purposes only.
Please go to http://scottmiller.com and follow the link for "Performance Metrics" to download the measure.

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CORC
Child Outcomes Research Consortium
PREMs
PROMs for practice
Advantages of PROMs for practice

- Improve clinicians ability to detect worsening of symptoms (Lambert, 2010)
- Provide information that may have otherwise been missed (Worthen & Lambert, 2007)
- Reduce drop out (e.g. Miller et al. 2006)
- Increase speed to reach good outcomes (Lambert et al. 2005)
- Improves outcomes (Bickman et al. 2011)
- Forestall drop out (Whipple and Lambert 2011)
- Enhance shared decision making (Coulter 2010)
- Ensure voice of service user is heard (Greenhalgh 2009)
Dangers of PROMs for practice

Must be:

• Meaningful to service user and practitioner
• Non burdensome
• interpreted with appropriate level of tentativeness (Wolpert et al 2012)
• introduced in context of collaborative working

• Measures plus good practice ➔ better practice
• Measures plus poor practice ➔ poor practice?
Dangers of PROMs for practice

Must not

• Be seen as trumping other forms of knowledge
• Administrative burden (Batty et al 2012)
Some Do's and Don'ts of using clinical outcome tools

1 DO Make sure you have the questionnaires you need, ready before the session
2 DO Always explain why you are asking anyone to fill out a questionnaire
3 DO Look at the answers
4 DO Discuss the answers with service users
5 DO Share the information in supervision
6 DO Always use information from outcomes in conjunction with other clinical information

1 Don’t Give out a questionnaire if you think the person doesn’t understand why they are being asked to complete them
2 Don’t Give out any outcome measure if you don’t understand why you are using it
3 Don’t Use the tools if the service users is too distressed
4 Don’t See the numbers generated from outcome tools as an absolute fact
5 Don’t See your clinical judgement as an absolute fact

Taken from CO-GP guide V1.3 Feb 2012 p.16
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
Findings in practice: young peoples’ views

Gives us a shared understanding of
...where we’re starting from.
...where we’re heading to.
...how we’re going to get there.

Enables us to get an in-depth understanding of what we’re feeling, why we’re feeling it and what we can do about it.

Makes us feel like it’s a shared experience between us and the clinician... like we’re in this together.

PROMs help make the balance of power more equal.

It means if we go off track or get a bit lost along the way, we can both figure out how to find the way back again.

It is important to monitor outcomes to make sure the person feels better not worse.

It makes us feel like there is a point to our therapy.

Quotes from young people from YoungMinds consultation in Devon. Reference: Talking About Talking Therapies/Devon CAMHS Views of members of VIK Young Minds
Impact of organisational context

- Practitioners are more positive towards feedback when they feel a good fit between their own focus on success or failure and the perceived focus of the organization (Dikkentman 2009).
- Use may be influenced by the amount of demoralization (Simon et al. 2012).
Impact of therapist factors
de Jong et al. 2012

- Feedback less likely to be used by clinicians when they had a more negative attitude towards getting feedback.
- Women were more likely to use feedback than men. The design of the feedback, in terms of content
- After receiving feedback clinicians with higher self-efficacy are better at improving outcomes for at risk cases.
PROMs in Practice - uptake

• 67% of clinicians would be unwilling to implement outcome measures even if it improved patient care (Walter, Cleary, & Rey, 1998).
• Clinician survey and case note audit studies have found the use of measures at one time point to range from 65-87% but at more than one time point from only 16-40% (Batty et al., 2013).
• audit in two child mental health services found that routine administration of outcome measures increased from 30% to 60% one year later when supported by an active learning collaboration (Hall et al., 2013).
• had more positive attitudes to PROMs and feedback, and higher levels of PROM and feedback self-efficacy, before and after training than clinicians who attended the one-day training. (Edbrooke-Childs et al 2014)
Implementation states (Abrines et al 2014)
PROMs outside practice

- The way forward?
  - http://www.youthinmind.info/py/yiminfo/YouthSDQ3.py
  - https://www.buddyapp.co.uk/
  - https://www.mindfull.org/more-about-mindfull/#self-help
PROMs for evaluation
## CORC service level dashboard - domains covered

<table>
<thead>
<tr>
<th>1. Who is my service seeing?</th>
<th>2. How well are we addressing their needs?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Demographics</td>
<td>• Change over time</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. What do service-users think of their support?</th>
<th>4. How good is our evidence?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Quantitative service feedback analysis</td>
<td>• What could we be doing better?</td>
</tr>
<tr>
<td>• Qualitative service feedback analysis</td>
<td></td>
</tr>
</tbody>
</table>
3. What do service users think of their support?

Children & Parents’ comment on the service:

The above text cloud has been created using the free text comments from the CHI-ESQ. The size of the text represents the frequency of each word in the sample, with the most common words being largest. For further information: http://wordle.net (Your CHI-ESQ comments are not saved or stored online)
Outcomes for evaluation
MINDFUL approach

- **Multiple perspectives**: child, parent, practitioner considered separately.
- **Interpretation**: team or individual level or care pathway.
- **Negative differences**: as starting point.
- **Directed 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).
- **Funnel plots**: a good way to present data to reduce risk of over-interpretation but still only a starting point.
- **Uncertainty**: important to remember that all data are flawed and there is a need to triangulate data from a variety of sources.
- **Learning collaborations**: of service users, commissioners and providers to meaningfully interpret data.

7 steps to MINDFUL use of PROMs for performance management - CORC approach

1. Once a year commissioners and providers and service user reps would jointly agree high level KPIs in areas that had been indicated to be weaknesses or areas of concern in the service - this could be facilitated by CORC as relevant (see step 7 below).
7 steps to MINDFUL use of PROMs for performance management

2. Data about assessment, activity and outcomes would be collected routinely by the service to help direct work with clients, with a particular emphasis on ensuring that the client voice was heard in relation to progress, experience and outcomes. CORC can advise on particular measures, tools and approaches to support this and to ensure that all direct client work is outcomes-focused and informed.
7 steps to MINDFUL use of PROMs for performance management

3. Service managers collate information against relevant to the KPIs regularly (e.g. monthly) and feed this information back to teams. Data will be considered relative to other teams taking artefacts of measurement using statistical analysis and where relevant funnel plots. CORC central team can answer any general queries about how to interpret data and factors to take into consideration drawing on our understanding and research in this area.
7 steps to MINDFUL use of PROMs for performance management

4. Where a team is performing significantly worse than others on a particular indicator, the team can be supported by their quality improvement lead or relevant others in the service to explore whether the variation is warranted or not. These explorations should include directed discussions in which the team are invited to consider if these differences were unwarranted and what they would do differently. CORC can facilitate these discussions if required.
7 steps to MINDFUL use of PROMs for performance management

5. Teams are encouraged to trial improvements aimed at addressing unwarranted variation and enhancing service quality. This may involve use of statistical process control methodology such as run charts to consider and review improvements and impact on patient care and use of PDSA cycles and learning sets. CORC has materials to support this
7 steps to MINDFUL use of PROMs for performance management

6. Quarterly joint meetings of users, commissioners and providers will meet to review progress against KPIs and any learning and improvements across the service. CORC can facilitate or provide input as required.
7 steps to MINDFUL use of PROMs for performance management

7. The annual report produced by CORC will allow the service as a whole to benchmark against other similar services and CORC team are on hand to help facilitate consideration of the findings by all stakeholder groups and plans for future KPIs and QI initiatives.
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Websites

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http://www.corc.uk.net
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