

Outcomes for children and young people seen in specialist mental health services

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Key questions to address

- What are the main issues that children and young people are seeking help with from mental health services?
- How well are we currently addressing these issues?
- What does this mean for the future shape of service provision?

Plan of talk

- Overview
- Methods
- Findings
- Implications

Overview

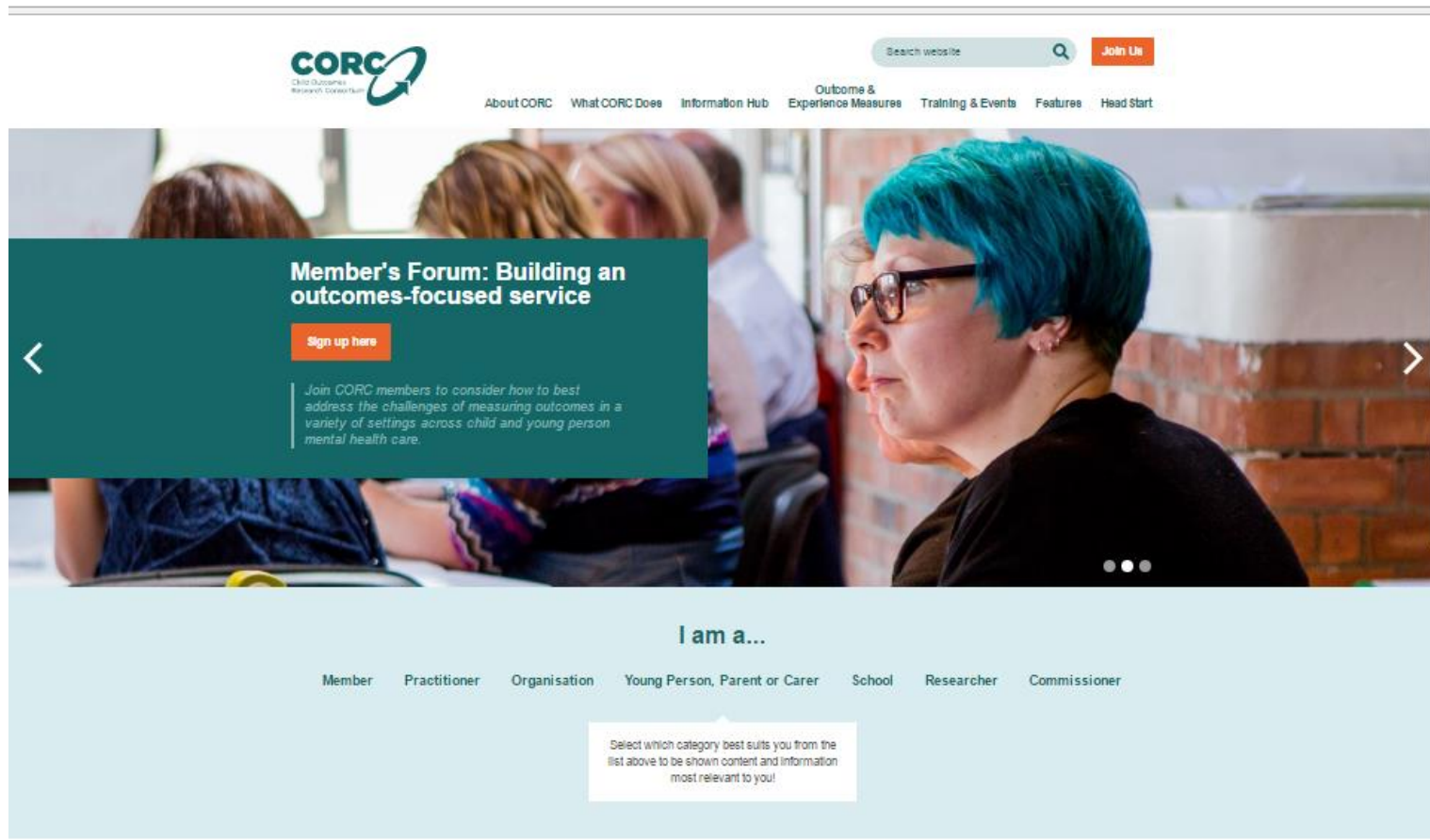
Notes on terms

- Youth shorthand for children and young people.
- Parent shorthand for parent or carer.

About CORC

- Leading membership organisation that collects and uses evidence from everyday practice to improve children and young people's mental health and wellbeing
- Members include mental health service providers, schools, professional bodies and research institutions
- CORC's **vision** is for all children and young people's wellbeing support to be informed by real-world evidence so that every child thrives
- www.corc.uk.net

WWW.CORC.UK.NET



CORC support for use of ROMS

- Annual member reports
- Practice development
 - Consultation
 - Regional meetings
 - National forums and conferences
- Programme of training & learning events
- Analysis of data & further research
- Information and guidance on www.corc.net.uk

CORC Best Practice Framework

- Developed in 2015; Piloted in 2015/16
- Structured process for working towards best practice
- Whole system self-assessment
- 4 Themes:
 - Leadership & Management
 - Staff Development
 - Infrastructure & Information Management
 - Service User Experience



Challenges for outcome collection and use in child mental health

- Diversity of
 - Population
 - Measures
 - Metrics
- Lack of
 - Control groups
 - Comparison data
 - High quality data

Measurement hard and not clear



FUPS data

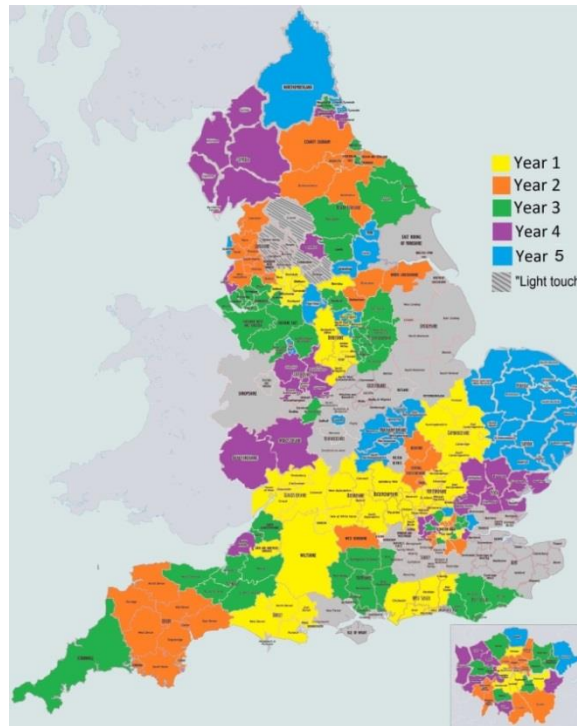
- Flawed
- Uncertain
- Proximate
- Sparse



Methods

Where data came from

- Analysis of routinely collected outcomes and experience data from 75 mental health services in England 2011-15 which were part of best practice service transformation (CYP IAPT)



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2011		2015	
1. Miranda Wolpert (Chair)	11. Kathryn Pugh	1. Miranda Wolpert (Chair)	11. David Clark
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CORC Board

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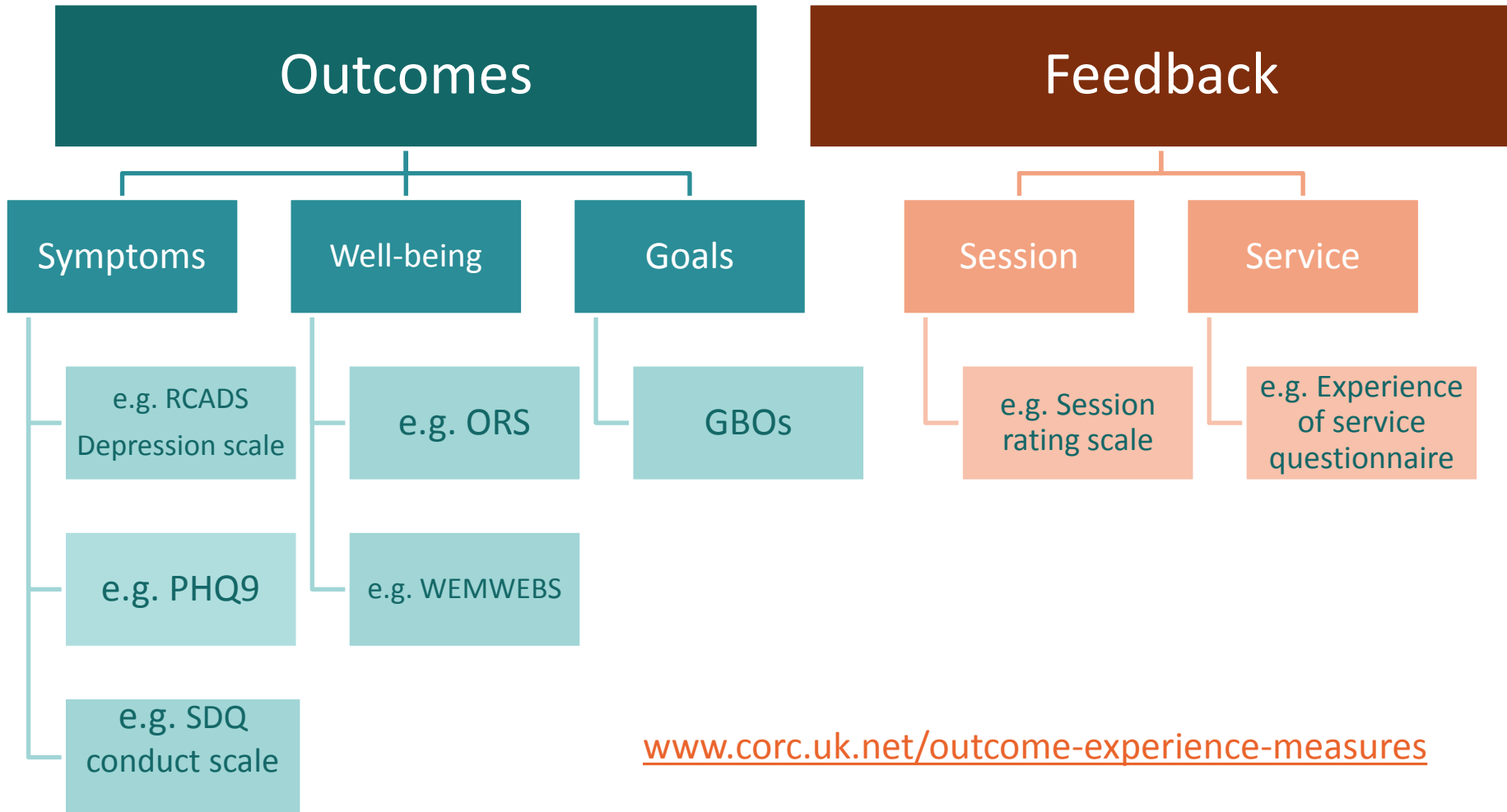


In collaboration with

Evidence Based Practice Unit (UCL & Anna Freud National Centre for Children and Families): Julian Edbrooke-Childs, Peter Martin, Ana Calderon, Dan Hayes and Jessica Deighton

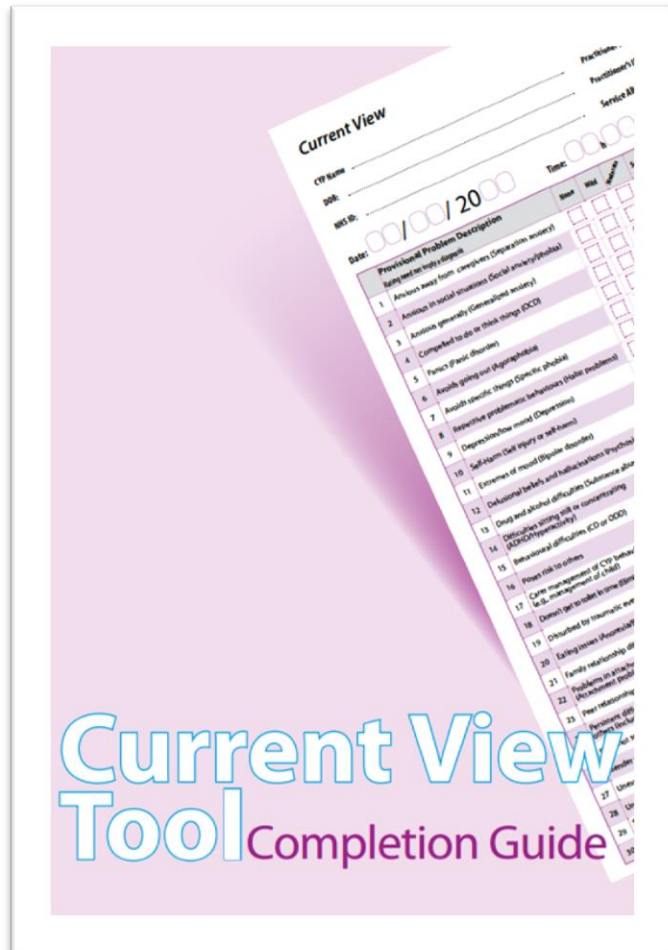
With thanks to: Lee Murray, Ailin Tarbinian and Dan Brown of MegaNexus, Tim Patterson at Click Databases, Kate Martin of Common Room

Self and parent report measures



www.corc.uk.net/outcome-experience-measures

Clinician measure of youth seen



Current View

CYP Name _____ Practitioner's Name _____
 DOB: _____ Practitioner's ID _____
 NHS ID: _____ Service Allocated Case Id _____

Date: / / 20 Time:

Please indicate your reason for completing this form:

First Contact	<input type="checkbox"/>
Changed Situation	<input type="checkbox"/>
Changed Understanding	<input type="checkbox"/>

Provisional Problem Description	None	Mild	Medium	Severe	Not known
1 Anxious away from caregivers (Separation anxiety)					
2 Anxious in social situations (Social anxiety/phobia)					
3 Anxious generally (Generalized anxiety)					
4 Compelled to do or think things (OCD)					
5 Panics (Panic disorder)					
6 Avoids going out (Agoraphobia)					
7 Avoids specific things (Specific phobia)					
8 Repetitive problematic behaviours (Habit problems)					
9 Depression/low mood (Depression)					
10 Self-Harm (Self injury or self-harm)					
11 Extremes of mood (Bipolar disorder)					
12 Delusional beliefs and hallucinations (Psychosis)					
13 Drug and alcohol difficulties (Substance abuse)					
14 Difficulties sitting still or concentrating (ADHD/Hyperactivity)					
15 Behavioural difficulties (CD or ODD)					
16 Poses risk to others					
17 Carer management of CYP behaviour (e.g., management of child)					
18 Doesn't get to toilet in time (Elimination problems)					
19 Disturbed by traumatic event (PTSD)					
20 Eating issues (Anorexia/Bulimia)					
21 Family relationship difficulties					
22 Problems in attachment to parent/carer (Attachment problems)					
23 Peer relationship difficulties					
24 Persistent difficulties managing relationships with others (includes emerging personality disorder)					
25 Does not speak (Selective mutism)					
26 Gender discomfort issues (Gender identity disorder)					
27 Unexplained physical symptoms					
28 Unexplained developmental difficulties					
29 Self-care issues (includes medical care management, obesity)					
30 Adjustment to health issues					

SELECTED COMPLEXITY FACTORS	Yes	No	Not known
1 Looked after child			
2 Young carer status			
3 Learning disability			
4 Serious physical health issues (including chronic fatigue)			
5 Pervasive Developmental Disorders (Autism/Asperger's)			
6 Neurological issues (e.g. Tics or Tourette's)			
7 Current protection plan			
8 Deemed 'child in need' of social service input			
9 Refugee or asylum seeker			
10 Experience of war, torture or trafficking			
11 Experience of abuse or neglect			
12 Parental health issues			
13 Contact with Youth Justice System			
14 Living in financial difficulty			

CONTEXTUAL PROBLEMS	None	Mild	Medium	Severe	Not known
HOME					
SCHOOL, WORK or TRAINING					
COMMUNITY					
SERVICE ENGAGEMENT					
EDUCATION/EMPLOYMENT/TRAINING					
ATTENDANCE DIFFICULTIES					
ATTAINMENT DIFFICULTIES					

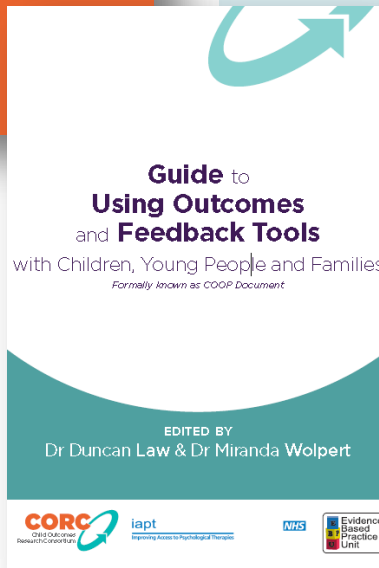
Presenting Problems: Current View

1. Anxious away from care givers (Separation anxiety)	11. Extremes of mood (Bipolar disorder)	21. Family relationship difficulties
2. Anxious in social situations (Social anxiety/phobia)	12. Delusional beliefs and hallucinations (Psychosis)	22. Problems in attachment to parent/carer (Attachment problems)
3. General anxiety (generalised anxiety)	13. Drug and alcohol difficulties (Substance abuse)	23. Peer relationship difficulties
4. Compelled to do or think things (OCD)	14. Difficulties sitting still or concentrating (ADHD/Hyperactivity)	24. Persistent difficulties managing relationships with others (includes emerging personality disorder)
5. Panics (Panic Disorder)	15. Behavioural difficulties (CD or ODD)	25. Does not speak (selective mutism)
6. Avoids going out (Agoraphobia)	16. Poses risk to others	26. Gender discomfort Issues (GID)
7. Avoids specific things (Specific phobia)	17. Carer management of CYP behaviour (e.g. management of child)	27. Unexplained physical symptoms
8. Repetitive problematic behaviours (Habit problems)	18. Doesn't go to the toilet in time (Elimination problems)	28. Unexplained developmental difficulties
9. Depression/low mood (Depression)	19. Disturbed by traumatic event (PTSD)	29. Self-care issues (includes medical care management, obesity)
10. Self-harm (Self injury or self-harm)	20. Eating issues (Anorexia/Bulimia)	30. Adjustment to health issues

Training in use of “patient-reported” outcome measures

Dr Duncan Law and Jenna Jacob
**GOALS AND GOAL BASED
OUTCOMES (GBOs)**
Some Useful Information

Third Edition



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Training Videos: Use of outcome measures



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CORC have developed the following videos to be used in training on the use questionnaire outcome measures used in CORC+ and CYP IAPT. They are not intended to present perfect practice but rather to stimulate discussion. How might you do it differently or better? The scenarios are based on real clinical examples although the young people are played by actors in the videos. Copyright is owned by CORC and the therapists jointly who all give permission for the videos to be used in non-commercial training and CPD events.

Introducing measures

- Introducing measures (example of Goals and RCADS with a young person with eating difficulties; introducing the measures, using the tools to find other information that might not have emerged from the clinical discussion and explaining what the measures are used for)
- Introducing measures and selecting symptom trackers (example of introducing Goals and RCADS and selecting symptom tracking measures with a young person with difficulties with mood)

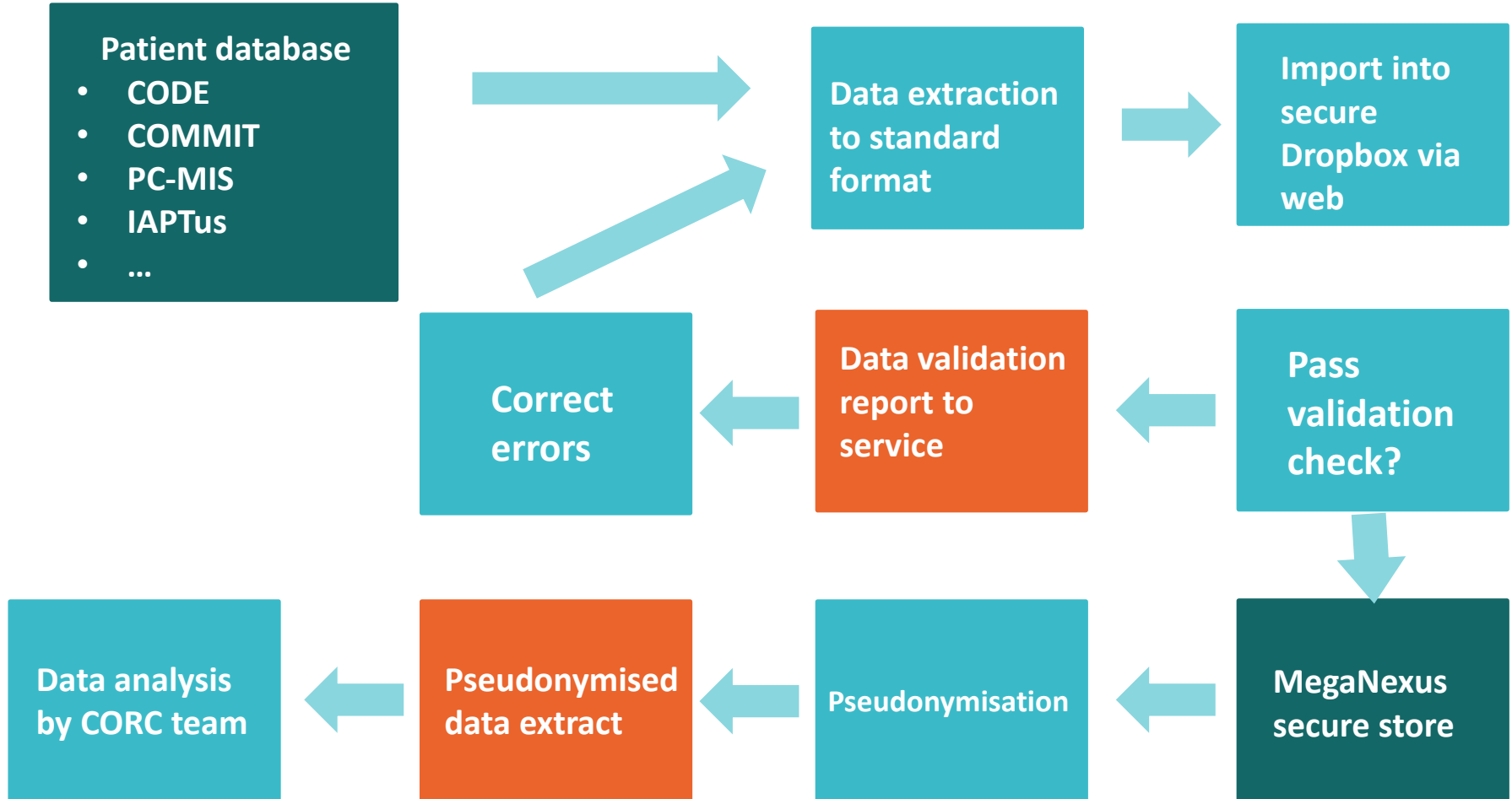
Choosing measures

- Choosing a tracking measure (example with a young person with mood and sleep difficulties and self-harming)

Scoring/completing measures with young people

- Completing questionnaires with young people (example of RCADS and SDQ with a young person with mood and sleep difficulties and self-harming)
- Using measures to help focus the session (example of using the symptom trackers with a young person with anxiety difficulties)

Collection and collation of data

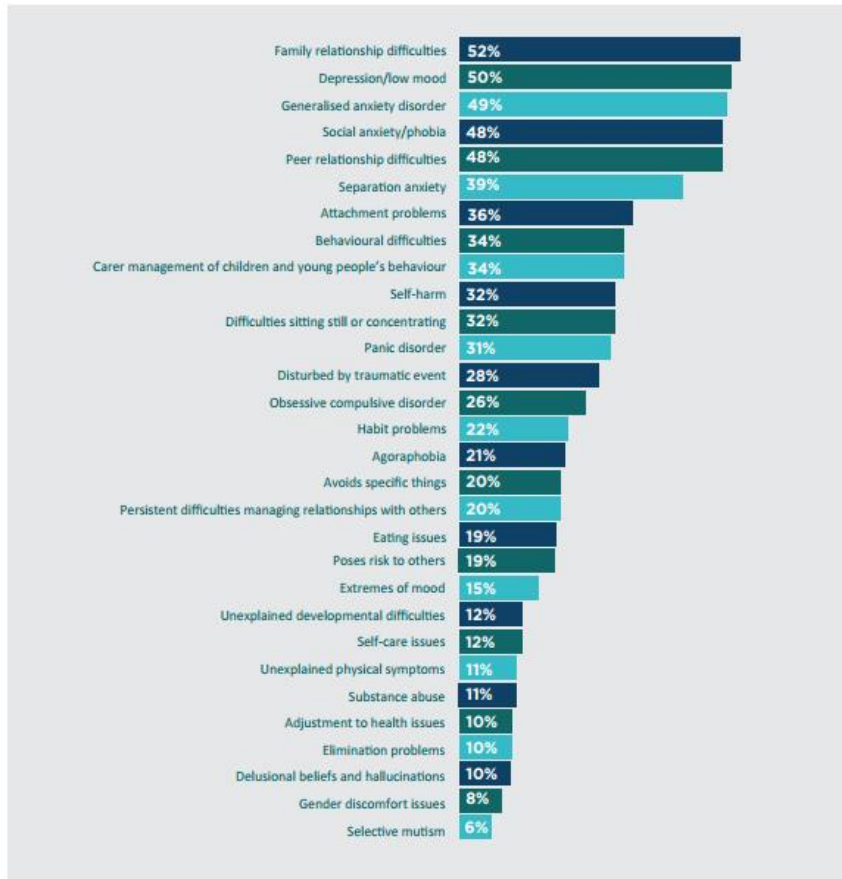


Sample

- 96,325 records of care
- 81 (out of 82) partnerships
- Represent 91,503 youth because each separate episode of care creates a different case record

Findings

Who was seen: Presenting Problems

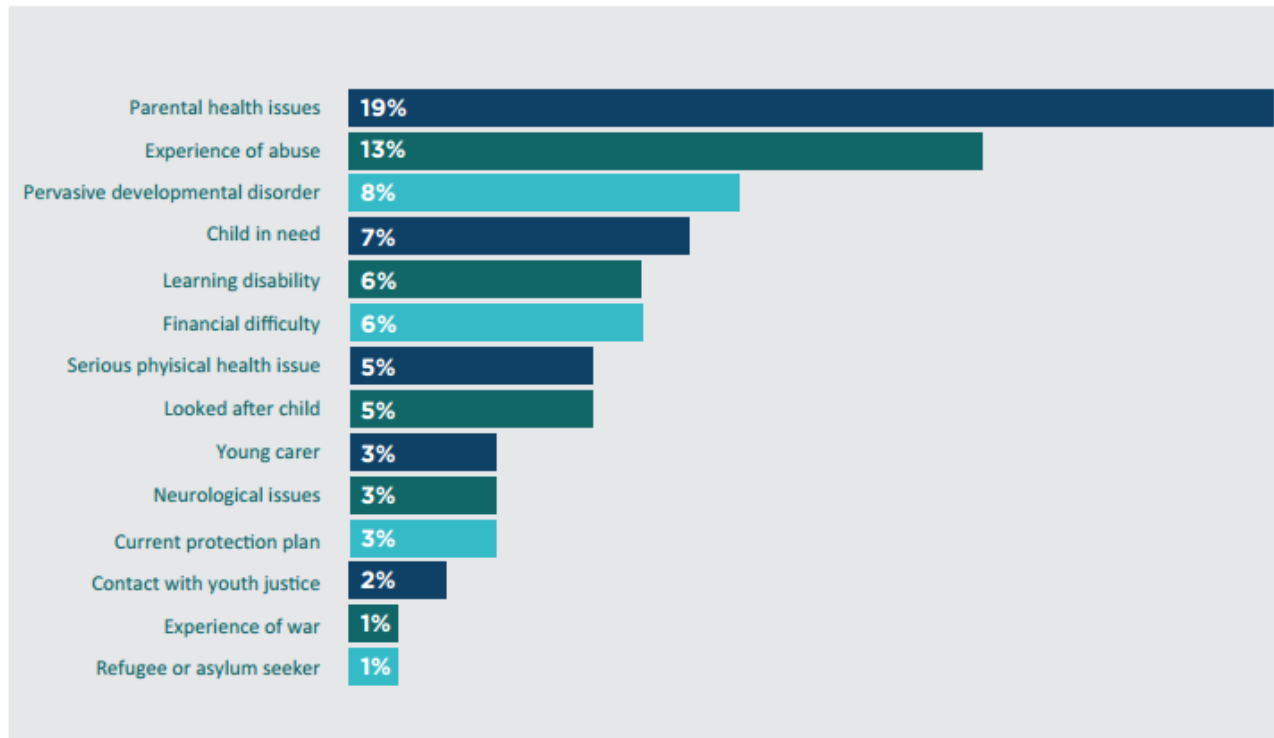


N = 42,798 (44% of the sample)

Percentages are out of those with a completed Current View form; categories are not mutually exclusive

Figure 3: Percentage of cases with a provisional problem descriptor endorsed as mild or above in the first recorded Current View.

Who was seen: Complexity factors



n = 42,798 (44% of the sample); percentages are out of those with a completed Current View form; categories are not mutually exclusive

Figure 4: Percentage of cases with a complexity factor endorsed in the first recorded Current View.

Who was seen: contextual factors

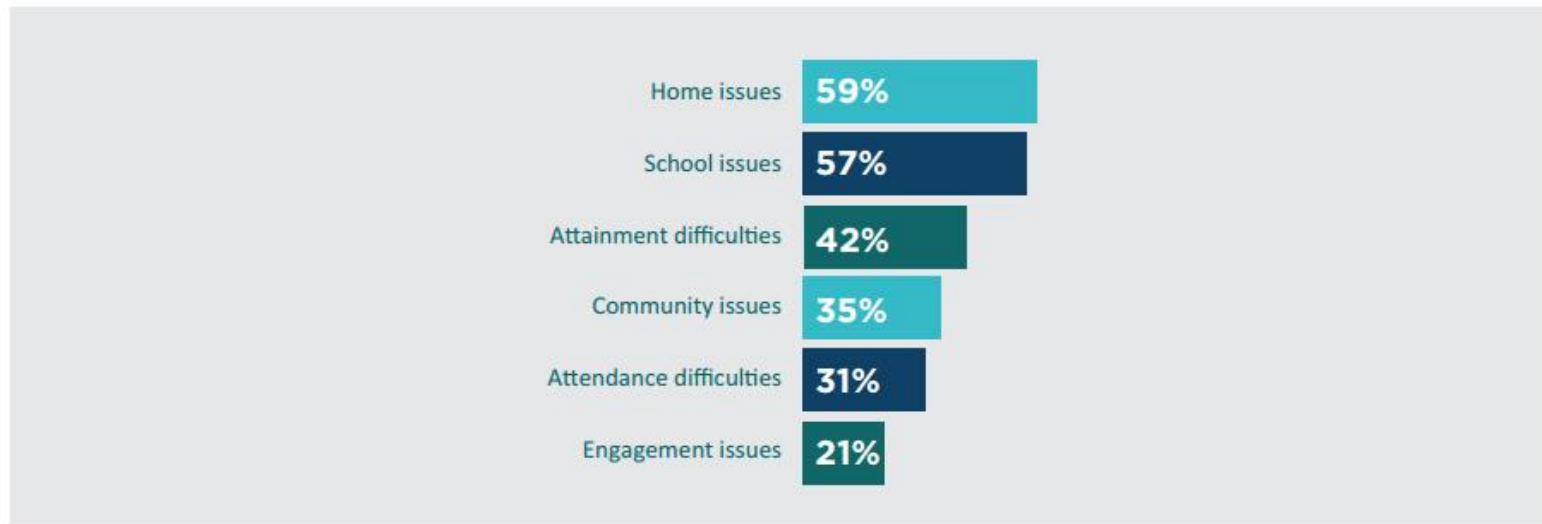


Figure 5: Percentage of cases with a contextual or attainment factor endorsed as mild or above in the first recorded Current View

n = 42,798 (44% of the sample); percentages are out of those with a completed Current View form; categories are not mutually exclusive

Who was seen in terms of presenting problems with NICE guidance for children and young people

1. Anxious away from care givers (Separation anxiety)	11. Extremes of mood (Bipolar disorder)	21. Family relationship difficulties
2. Anxious in social situations (Social anxiety/phobia)	12. Delusional beliefs and hallucinations (Psychosis)	22. Problems in attachment to parent/carer (Attachment problems)
3. General anxiety (generalised anxiety)	13. Drug and alcohol difficulties (Substance abuse)	23. Peer relationship difficulties
4. Compelled to do or think things (OCD)	14. Difficulties sitting still or concentrating (ADHD/Hyperactivity)	24. Persistent difficulties managing relationships with others (includes emerging personality disorder)
5. Panics (Panic Disorder)	15. Behavioural difficulties (CD or ODD)	25. Does not speak (selective mutism)
6. Avoids going out (Agoraphobia)	16. Poses risk to others	26. Gender discomfort Issues (GID)
7. Avoids specific things (Specific phobia)	17. Carer management of CYP behaviour (e.g. management of child)	27. Unexplained physical symptoms
8. Repetitive problematic behaviours (Habit problems)	18. Doesn't go to the toilet in time (Elimination problems)	28. Unexplained developmental difficulties
9. Depression/low mood (Depression)	19. Disturbed by traumatic event (PTSD)	29. Self-care issues (includes medical care management, obesity)
10. Self-harm (Self injury or self-harm)	20. Eating issues (Anorexia/Bulimia)	30. Adjustment to health issues

Findings: who was seen- allocations to NICE-guided treatment

Table 5: Potential allocation to support guided by NICE guidelines

Index difficulties as indicated on current view	Percentage in CYP IAPT dataset	Relevant NICE guideline (at time of development of algorithm 2014)
Difficulties sitting still or concentrating (ADHD)	6%	ADHD NICE guideline 72
Pervasive developmental disorder (autism)	2%	Autism spectrum NICE guideline 170
Behavioural difficulties (conduct disorder or oppositional defiant disorder)	4%	Anti-social behaviour and conduct disorders NICE guideline 158
Extremes of mood (bipolar disorder)	1%	Bipolar disorder NICE guideline 185
Depression/low mood (depression)	5%	Depression NICE guideline 28
Anxious generally (generalised anxiety disorder, GAD) and/or panics (panic disorder)	5%	GAD and/or panic disorder NICE guideline 113
Compelled to do or think things (obsessive compulsive disorder, OCD)	1%	OCD NICE guideline 31
Disturbed by traumatic event (post traumatic stress disorder)	2%	PTSD NICE guideline 26
Self-harm (self-injury or self-harm)	6%	Self-harm NICE guidelines 16 and/or 133
Anxious in social situations (social anxiety or phobia)	2%	Social anxiety disorder by NICE guideline 159
Eating difficulties (anorexia, bulimia)	2%	Eating disorders NICE Guideline 9
Delusional beliefs and hallucinations (psychosis)	1%	Psychosis NICE guidelines 155 and/or 185
Co-occurring emotional problems	10%	One or more of NICE guidelines above
Co-occurring emotional and behavioural difficulties	2%	One or more of NICE guidelines above

n = 31,037 cases ; current view completed within 56 days of the recorded start of therapy .

Categories are mutually exclusive

Findings: who was seen- not possible to allocate to evidence based guided treatment

28% Potentially assignable to “advice/signposting”

- Doesn't fit into any of the groupings
- No indication of significant problems i.e. all mild or only 1 moderate
- If moderate this not one of the “index” problems associated with the “NICE informed Groupings”

n = 42,798 (44% of the sample); categories are mutually exclusive

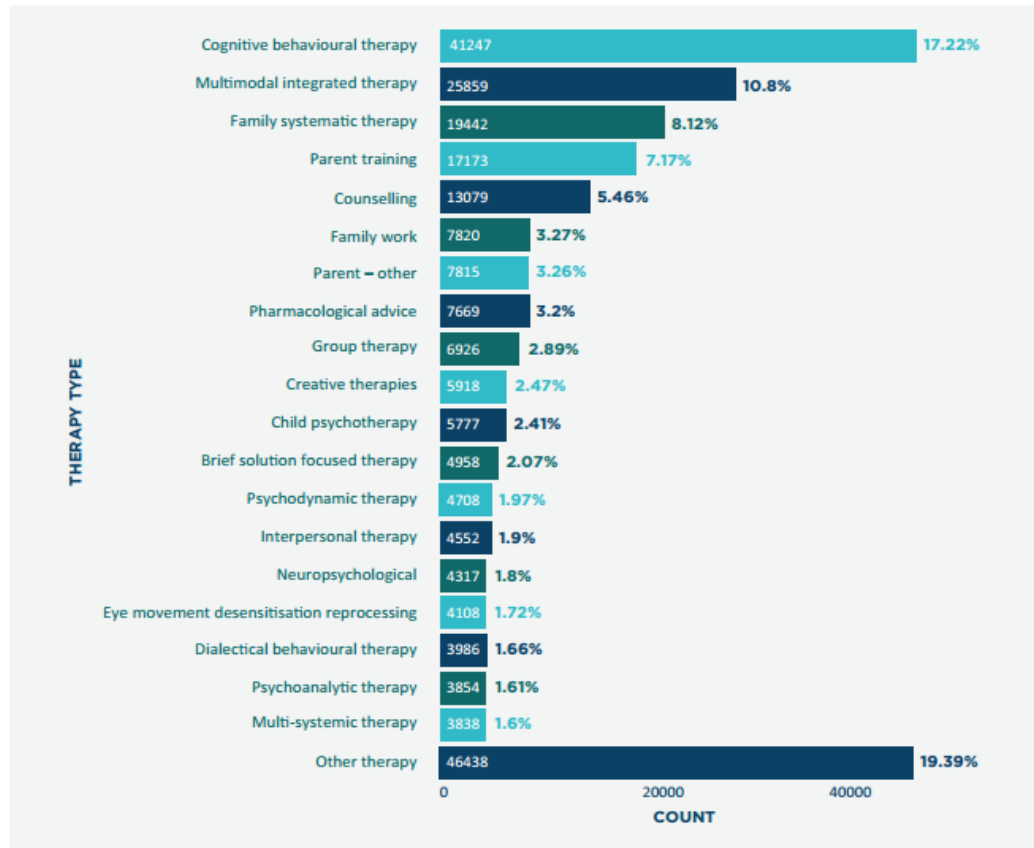
Findings: who was seen- not possible to allocate to NICE- guided treatment

25% require clinician judgment as don't fit into any of the groupings but have:

- **19%** 2+ moderate or 1 severe (not assignable to NICE guideline suggested cluster)
- **9%** 2+ severe, and/or moderate or severe Delusional and/or Eating Issues and/or severe Extremes of Mood

n = 42,798 (44% of the sample); categories are mutually exclusive

Findings: treatment provided



N=62,611 (65% of full sample)

Figure 6: Therapy types for events attended for all cases

Notes: Categories are not mutually exclusive.

Treatment length

- 41,068 closed cases with at least 1 recorded event
- Mean no of events= 5.3 (SD = 7.8)
- Median = 3
- Range 1 – 268 events

Self reported experience of care



**4 in 5 strongly agreed
“good help”
82%**



**3 in 5 strongly agreed
“convenient appointments”
62%**

N= 3196 (12% of closed treatment cases)

Parent reported experience



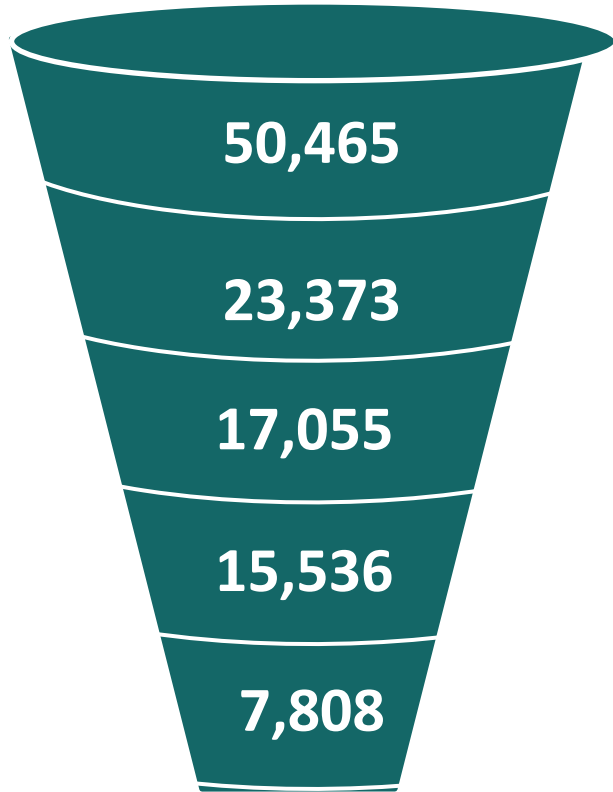
**9 in 10 strongly
agreed “good help”
88%**



**7 in 10 strongly agreed
“convenient appointments”
69%**

N= 2698 (12% of closed treatment cases)

Sample for considering outcomes



Ended referrals

Closed treatment cases

Measured closed treatment cases sample

Above threshold closed treatment sample

Paired outcomes for above threshold

FUPS data

- Flawed
- Uncertain
- Proximate
- Sparse



Demographics

Self-reported outcomes were more likely to be from older and female respondents than being representative of the full sample.

Mean age 14, 72% female .



Parent-reported outcomes were more likely to relate to younger and male children than being representative of the full sample.

Mean age 11, 54% female.



“Recovery” (crossing threshold/symptom free)

- Scores having moved from above the threshold on a measure to below the threshold on a measure.
- “recovery” referred to in inverted commas to differentiate from broader concept as reflected in the lived experience (e.g. Leamy, et al 2011).

Note on “recovery”/symptom free

- Different measures used different ways to establish thresholds
- Where multiple measures used (mean = 4), no measure at end scored above threshold to be categorised as “recovered” (symptom free)

Reliable change/measurable change

- Amount of change in scores on a scale
- Amount of change needed to be confident change is unlikely due to measurement fluctuation
- It tells us whether change reflects more than the fluctuations of an imprecise measuring instrument (Jacobson & Truax, 1991).

Reliable recovery

- Combines recovery and reliable change
- Score needs to
 - Cross cut-off threshold
 - Change by a reliable amount
- Need to be careful about definition when you have more than one measure

Movement towards goals

- 10 pt scale
- How close are you to reaching your goals
- 0= nowhere, 10=completely

Self-reported “recovery”/symptom free



1 in 3

Scores below threshold on all measures

36% (95% CI 35% – 37%)

Mean no of measures = 4 (SD 2.5 range 1-13)

N= 5896 (25% of closed treatment cases)

Self reported reliable improvement



1 in 2

Scores improved more than likely due to measurement error on at least one measure and on no measure reliably deteriorated

52% (95% CI 51.7-52%)

Mean no measures = 4 (SD 2.5 range 1-13)

N= 5896 cases (25% of closed treatment cases)

Self reported reliable deterioration



1 in 10

Scores deteriorated on at least one measure more than likely due to measurement error (may have improved on others)

9% (95% CI 8.5%-9%)

Mean no of measures= 4 (SD 2.5, range 1-13)

N= 5896 cases (25% of closed treatment cases)

Self reported movement towards goals



9 in 10

Moved towards goals by at least 1 point on a 10 point scale

86%

Mean change= 4 points

NB 5% moved away from goals

2784 cases (12%)

Parent reported youth “recovery”/symptom free



1 in 4

Scores below threshold on all measures

26% (95% CI 25%-27%)

N= 3707 (6% of closed treatment cases)

Parent reported reliable improvement



4 in 10

*Scores improved more than likely due to measurement error
and on no measure reliably deteriorated*

40 % (95% CI 51.7-52%)

N= 3707 (6% of closed treatment cases)

Parent reported reliable deterioration



1 in 10

Scores deteriorated on at least one measure more than likely due to measurement error (may have improved on others)

9% (95% CI 8.6%-9%)

Mean no of measures= 4 (SD 2.5, range 1-13)

N= 3707 (6% of closed treatment cases)

Parent reported movement towards goals



9 in 10

Moved towards goals by at least 1 point on a 10 point scale

87%

Mean move in scales= 4 points;

NB 3% reported movement away from their goals

N= 686 (3% of closed treatment cases)

Comparison with other findings

Consistent with findings from other countries and with “recovery” or change rates in areas of physical health:

USA



29/32% reliable improvement,
15%/30% “recovery”
13/19% reliable deterioration

Norway



‘relatively few children and youth with emotional disorders experience clinical significant and statistical reliable change’

Paediatric diabetes



Control of blood sugar has moved from nearly **15%** of cases to nearly **24%** of cases over the last 5 years

Implications

Provocations

- How do we acknowledge and discuss the findings as a sector and as a society?
- Do we have realistic expectations for mental health outcomes?
- Is a key component of evidence based practice being limitation-aware?
- If someone says their approach always works they are unlikely to be an evidence based practitioner?

Implications

- Three pronged approach to precision mental health and prognostic focus in practice
 1. Publish
 2. Practice
 3. Learn

1) Publish

- Publish failure and success rates and make these available to potential clients, funders and others.
- Include key metrics e.g. % symptom free, % with measurable improvement, % with measurable deterioration and % moved towards goals.

2011 Private Practice data (San Francisco & Palo Alto, California) (accessed 12th March 2017)

- Total # of clients in dataset: 42
- Avg # of sessions: 8.58
- Total # of clients with more than one session: 38 (90%)
- Single session clients: 4 (10%)
- Start in clinical range (of clients with 2+ sessions): 25 (66%)



2011 Private Practice data (San Francisco & Palo Alto, California) (accessed 12th March 2017)

Duration of Treatment

- Avg # of sessions for low distress clients: 5.27
- Avg # of sessions for high distress clients: 10.74
- Avg # of sessions for clinical change to occur: 3.27

2011 Private Practice data (San Francisco & Palo Alto, California) (accessed 12th March 2017)

Clinical Outcomes

- Ended Year in Clinical Change: 22 (88% of clients starting in clinical range)
- Ended Year in Clinical Recovery: 20 (80% of clients starting in clinical range)
- Ended Year in Clinical Deterioration: 2 (8% of clients starting in clinical range)
- Average change in ORS score: 7.52 (clients starting in clinical range)
- Cohen's D effect size for clients starting in clinical range: 1.22. (Pre-tx std dev=6.14, mean intake ORS=22.27, mean last session ORS=29.79, n=38)

Publish: outcomes CYP

Use clear lay language to report outcomes (separately for parent and youth perspectives):

- % symptom free (having had symptoms at outset)
- % with substantial improvement and no substantial deterioration
- % with substantial deterioration in any one area (even if substantial improvement in some areas)
- % moved towards their goals by at least one point

2) Practice

- Be open from outset with clients, colleagues and funders about the limitations of treatment and likely end points given their level of difficulties
- Focus on self management and ongoing sustainable solutions from the start

Practice

Consider trajectories and end points from the outset



Practice

Consider trajectories and end points from the outset

http://www.corc.uk.net/media/1490/trajectories_torch.pdf

3) Learn

- Commit to learn from failures and consider what might do differently
- Benchmark against others and use supervision and research to build improved practice
- Be curious
- Guard against biases
- Use FUPS use of data approach

Learn: supporting use of FUPS data

- Challenge our biases
- Maintain curiosity
- Scrutinise findings that support our assumptions as well as those that don't
- Consider if any actions need to be taken in terms of quality assurance
- Consider possible initiatives that even if not definitively indicated may do more good than harm
- Challenge the assumption that change is always more risky than status quo
- Help ensure agreed rules of engagement are adhered to

Contact details

corc@annafreud.org

Spare slides

Measures

	Measure	Example questions
Goals	GBQ	We agreed to work on... How would you score this today on a scale of 0–10 where 0 is not begun to achieve goal and 10 is really good/goal achieved
Anxiety	RCADS (5)	“I worry about things; I worry that something awful will happen to someone in my family; I worry that bad things will happen to me; I worry about what is going to happen; I think about death” Responses: Never; Sometimes; Often; Always (generalized anxiety)
	GAD7	“Not being able to stop or control worrying” over last 2 weeks Responses: Not at all; Several days; More than half the days; Nearly every day
Depression	RCADS	“Nothing is much fun anymore; I have trouble sleeping; I have problems with my appetite; I have no energy for things; I am tired a lot; I cannot think clearly” Responses: Never; Sometimes; Often; Always
	PHQ9	“Thoughts that you would be better off dead or of hurting yourself in some way “ Responses: Not at all; Several days; More than half the days; Nearly every day

Measures

	Measure	Example question
Behaviour problems	M&MS	<p>"I get very angry, I hit out when I am angry, I lose my temper, I do things to hurt people, I break things on purpose"</p> <p>Responses: Never; Sometimes; Always</p>
	SDQ	<p>Over last 6 months</p> <p>"I fight a lot. I can make other people do what I want"</p> <p>Responses: Not true; Somewhat true; Certainly true</p>
PTSD	CRIES	<p>Thinking of stressful life event over last 7 days</p> <p>"Do you think about it even when you don't mean to?"</p> <p>Responses: Not at all; Rarely; Sometimes; Often</p>
Impact on life	SDQ/RMQ	<p>Thinking of last 6 months/since most recent visit how much have your difficulties been interfering with your....Ability to learn or work</p> <p>Responses: Not at all; A little; A medium amount; A great deal</p>