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.

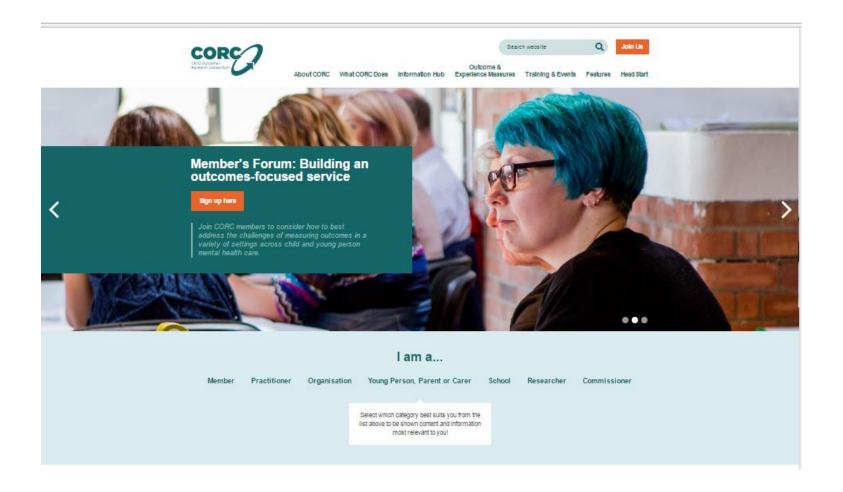


About CORC

- 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
- <u>www.corc.uk.net</u>



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







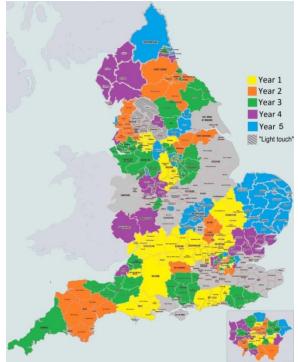


Methods



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)





Acknowledgements: Outcomes and Evaluation Group

2011		2015	
 Miranda Wolpert (Chair) David Clark Margaret Oates David Wells Bill Badham Duncan Law 	 11. Kathryn Pugh 12. Paul Wilkinson 13. Claire Maguire 14. Damian Hart 15. Paul Stallard 16. Stephen Scott 	 Miranda Wolpert (Chair) Duncan Law Cathy Troupp David Trickey Margaret Murphy Cathy Street 	 11. David Clark 12. Paul Stallard 13. Stephen Scott 14. Philippe Mandin 15. Rabia Malik 16. Anne York
7. Margaret Murphy8. Jessica Deighton9. Ann York10. Amandeep Hothi	17. Andy Fugard 18. Kevin Mullin 19. Raphael Kelvin	7. Barbara Rayment8. Margaret Oates9. Ro Rossiter10.Anne O Herlihy	 17. Emma Morris 18. Peter Stratton 19. Jessica Deighton 20. Jenna Jacob

Expertise in: outcome monitoring in CAMHS, methods of collection and collating data, analysis and review of outcome measures, data handling and management, service delivery, meaningful involvement of children and young people, use of outcome measures across range of modalities, use with a range of groups including BAME.



Acknowledgments: CORC team and colleagues

Jenna Jacob, Benjamin Ritchie, Kate Dalzell, Jenny Bloxham, Victoria Zamperoni, Elisa Napoleone, Andy Whale, Alison Ford, Sally Marriott, Meera Patel, Carin Eisenstein, Danielle Antha, Rebecca Neale and Mark Helmsley (Common Room). With thanks to past CORC team members: Isobel Fleming, Andy Fugard, Matt Barnard, Amy MacDougall, Craig Hamilton, Claudia Kanow and Lily Levy.

CORC Board

Miranda Wolpert, Ashley Wyatt, Mick Atkinson, Julie Elliott, Kate Martin, Duncan Law and Ann York. With thanks to past CORC Board members Alan Ovenden and Tamsin Ford.



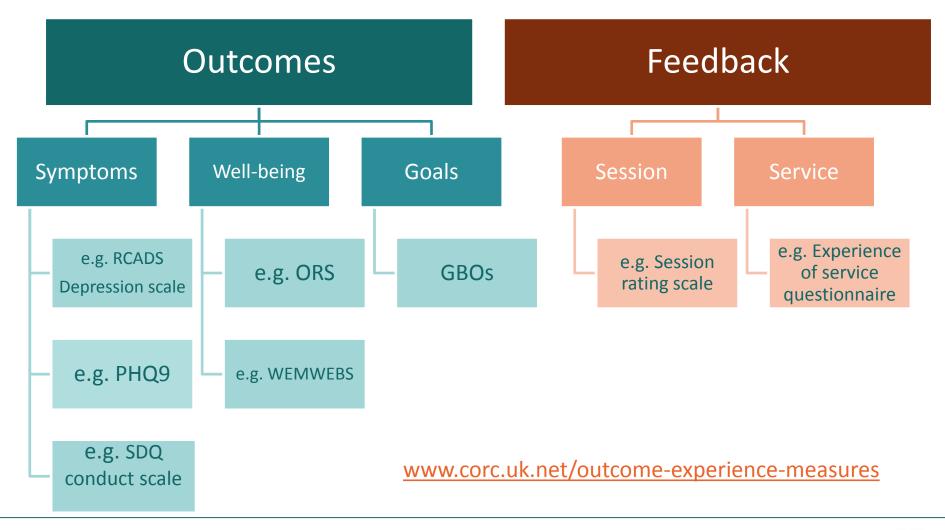
In collaboration with

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





Clinician measure of youth seen

Current View Toolcompletion Guide

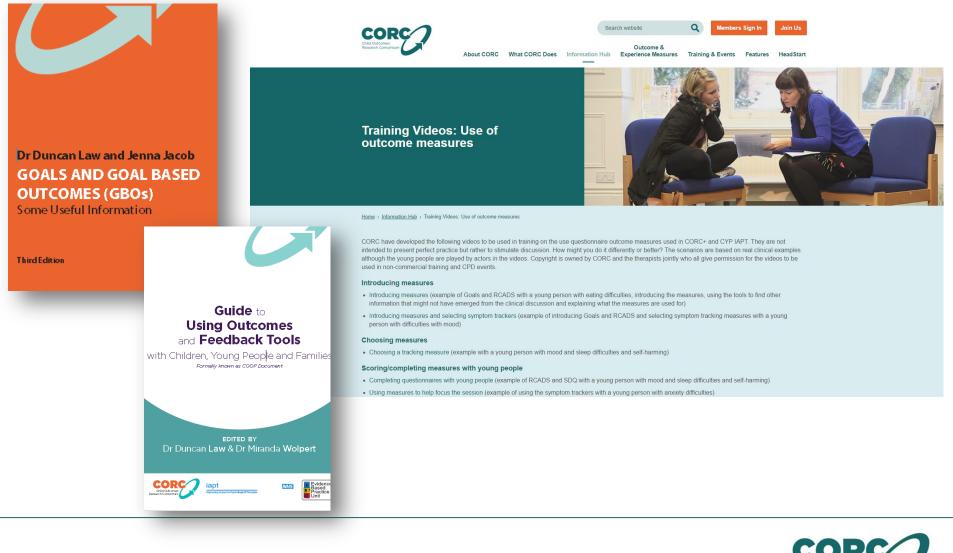
CYP Na	P Name Practitioner' Practitioner' Practitioner' Practitioner'				oner's N	lame	Please indi for comple	icate your	r reaso form:	
DOB:					Practitioner's ID					1
NHS IC			~		Servic	e Allocat	ted Case Id	Change Situatio Change	n d	
Date:	00/00/2000	Time:	Ų	JL	J	_		Underst	anding	-
	Provisional Problem Description Rating need not imply a diagnosis	None	Mild	and the second	Severe	Not known	SELECTED COMPLEXITY FACTORS	Yes	No	Not known
1	Anxious away from caregivers (Separation anxiety)						1 Looked after child			
2	Anxious in social situations (Social anxiety/phobia)						2 Young carer status			1
3	Anxious generally (Generalized anxiety)		[]]			\Box	2 Today Carel status			L
4	Compelled to do or think things (OCD)						3 Learning disability			I
5	Panics (Panic disorder)						4 Serious physical health issues (including chronic fatigue)			Ľ
6	Avoids going out (Agoraphobia)						5 Pervasive Developmental Disorders (Autism/Aspergers)			-
7	Avoids specific things (Specific phobia)						Neurological Issues			
8	Repetitive problematic behaviours (Habit problems)			[]]			6 (e.g. Tics or Tourette's)			
9	Depression/low mood (Depression)						7 Current protection plan			1
10	Self-Harm (Self injury or self-harm)						8 Deemed "child in need" of social service input			1
11	Extremes of mood (Bipolar disorder)							-		1
12	Delusional beliefs and hallucinations (Psychosis)							-		-
13	Drug and alcohol difficulties (Substance abuse)						10 Experience of war, torture or trafficking			[
14	Difficulties sitting still or concentrating (ADHD/Hyperactivity)						11 Experience of abuse or neglect			1
15	Behavioural difficulties (CD or ODD)						12 Parental health issues			1
16	Poses risk to others						Contact with		frame.	
17	Carer management of CYP behaviour (e.g., management of child)						13 Youth Justice System			L
18	Doesn't get to toilet in time (Elimination problems)						14 Living in financial difficulty			L
19	Disturbed by traumatic event (PTSD)	[1]	[]]			\square	CONTEXTUAL PROBLEMS			
20	Eating issues (Anorexia/Bulimia)						None Mild o	olenes s	evere	Not
21	Family relationship difficulties		[]]				номе	100		(CONTRACTOR OF CONTRACTOR OF C
22	Problems in attachment to parent/carer (Attachment problems)						SCHOOL	-		
23	Peer relationship difficulties	[]]	[]]			\square	WORK or TRAINING			
24	Persistent difficulties managing relationships with others (includes emerging personality disorder)									
25	Does not speak (Selective mutism)									
26	Gender discomfort issues (Gender identity disorder)						ENGAGEMENT	-	-	herene
27	Unexplained physical symptoms						EDUCATION/EMPLOYM	NT/TRA	INING	
28	Unexplained developmental difficulties						ATTENDANCE DIFFICULTIES			
29	Self-care Issues (includes medical care management, obesity)		[[]]				
30	Adjustment to health issues					Twitt	ATTAINMENT DIFFICULTIES			



Presenting Problems: Current View

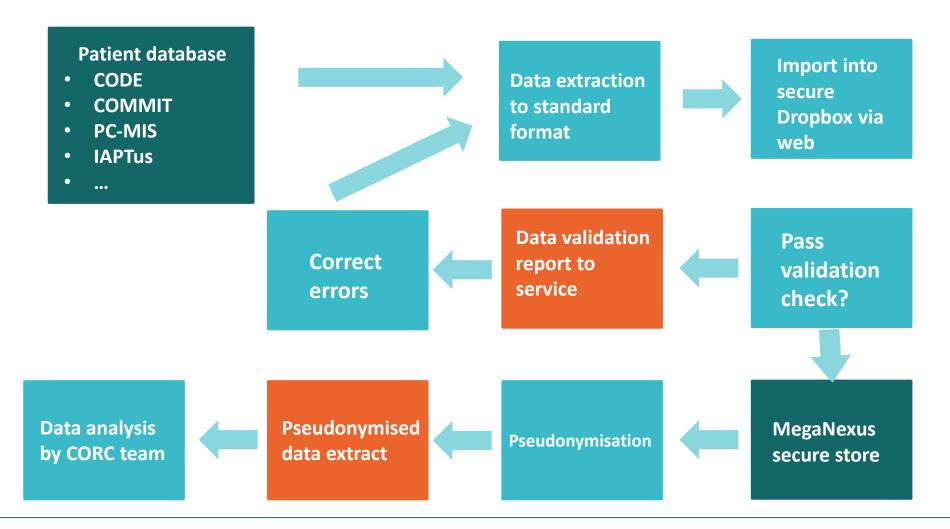
1. Anxious away from care givers (Separation anxiety)	11.Extremes of mood (Bipolar disorder)	21.Family relationship difficulties
2. Anxious in social situations (Social anxiety/phobia)	12. Delusional beliefs and hallucinations (Psychosis)	22. Problems in attachment to parent/carer (Attachment problems)
3. General anxiety (generalised anxiety)	13. Drug and alcohol difficulties (Substance abuse)	23. Peer relationship difficulties
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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



Research Consortium

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

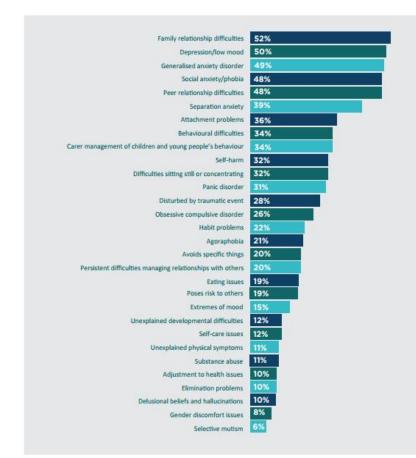
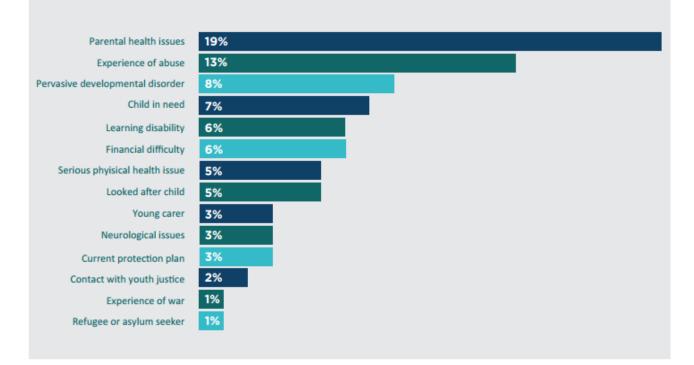


Figure 3: Percentage of cases with a provisional problem descriptor endorsed as mild or above in the first recorded Current View. N = 42,798 (44% of the sample)

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



Who was seen: 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

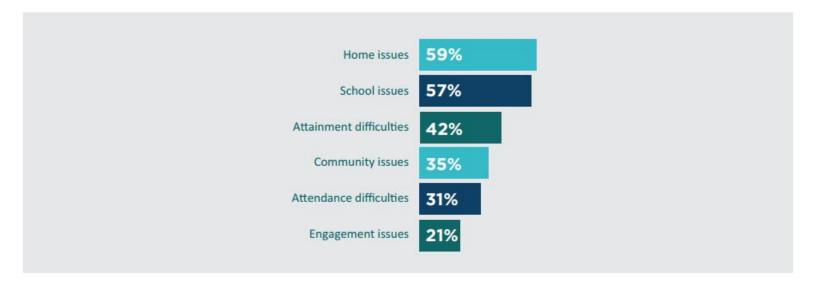


Figure 5: Percentage of cases with a contextual or attainment factor endorsed as mild or above in the first recorded Current View

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)
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10.Self-harm (Self injury or self-harm)	20.Eating issues (Anorexia/Bulimia)	30. Adjustment to health issues

Findings: who was seen- allocations to NICEguided 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

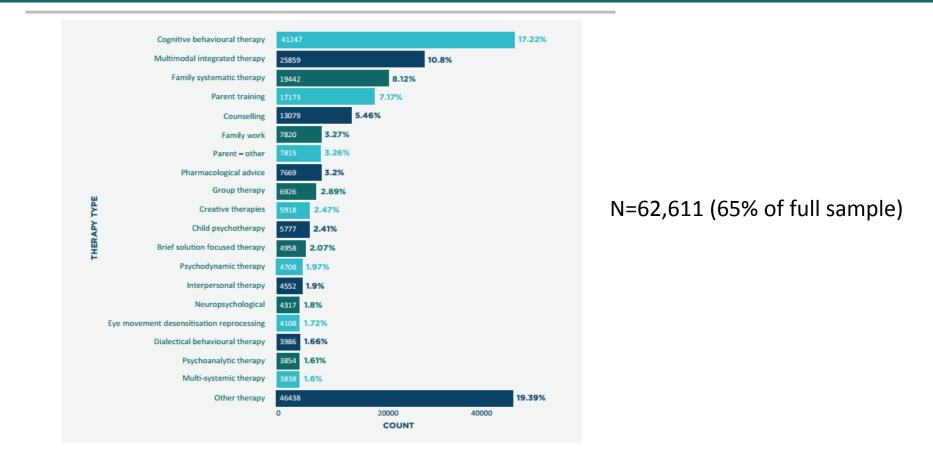


Figure 6: Therapy types for events attended for all cases

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)



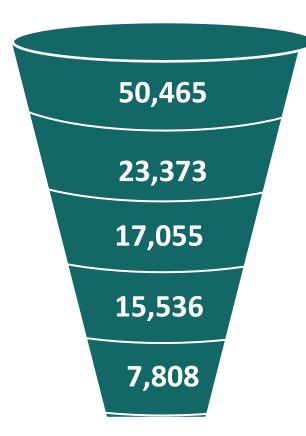
Parent reported experience

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









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

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 fre



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:



Norway



Paediatric diabetes



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

'relatively few children and youth with emotional disorders experience clinical significant and statistical reliable change' 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.



Publish: Dr Rousmaniere <u>www.drtonyr.com/</u>

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%)



Publish: Dr Rousmaniere www.drtonyr.com/

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



Publish: Dr Rousmaniere <u>www.drtonyr.com/</u>

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)



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





Consider trajectories and end points from the outset







Consider trajectories and end points from the outset

http://www.corc.uk.net/media/1490/trajectorie s_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





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