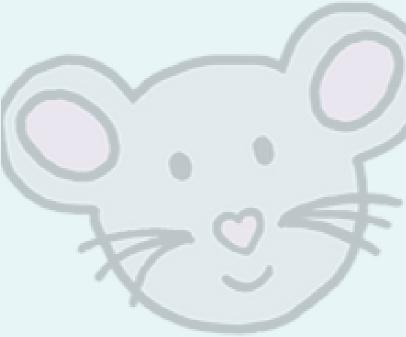
M.I.C.E — Mental Health Intervention for Children with Epilepsy

ACAMH Seminar May 2023

Sophie Bennett & Roz Shafran

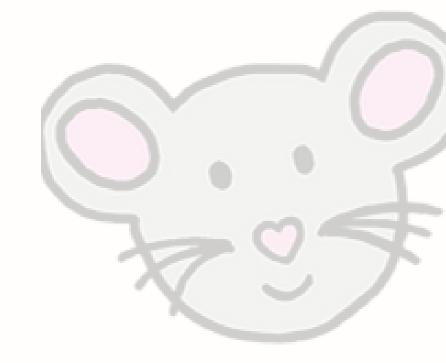
PIs: Roz Shafran & Helen Cross

[±]UCI





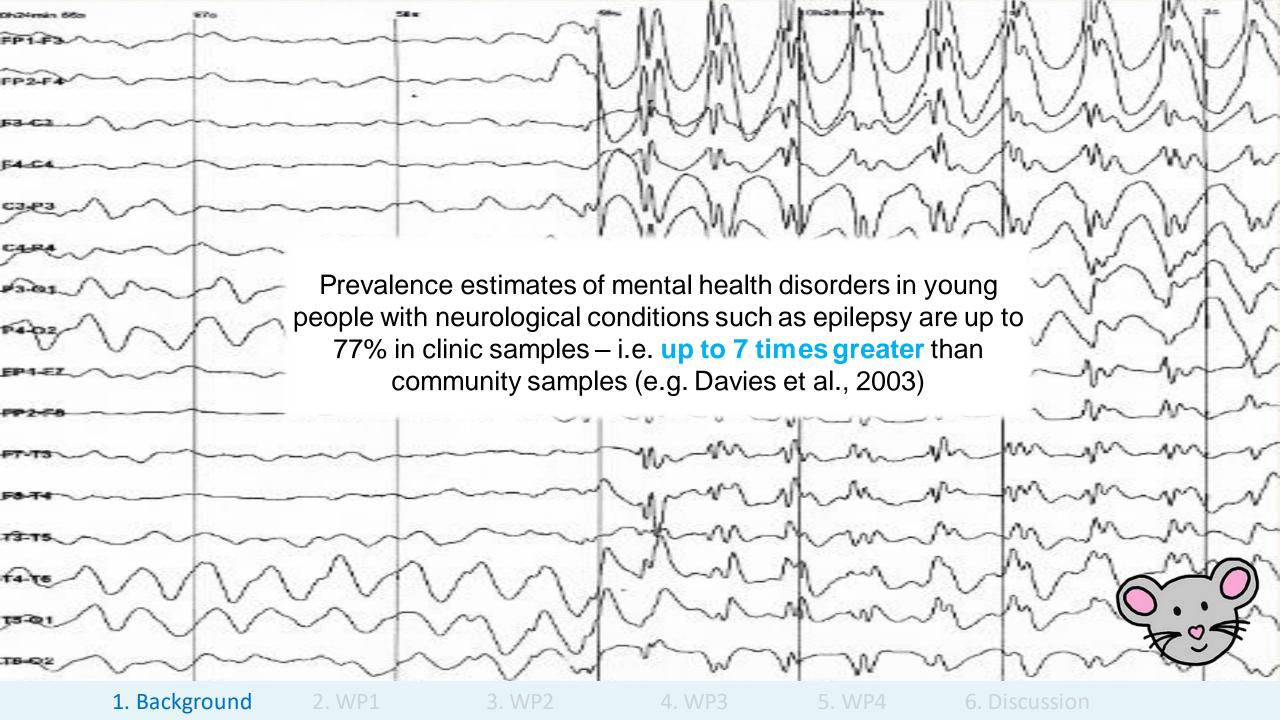
Background: mental health and epilepsy



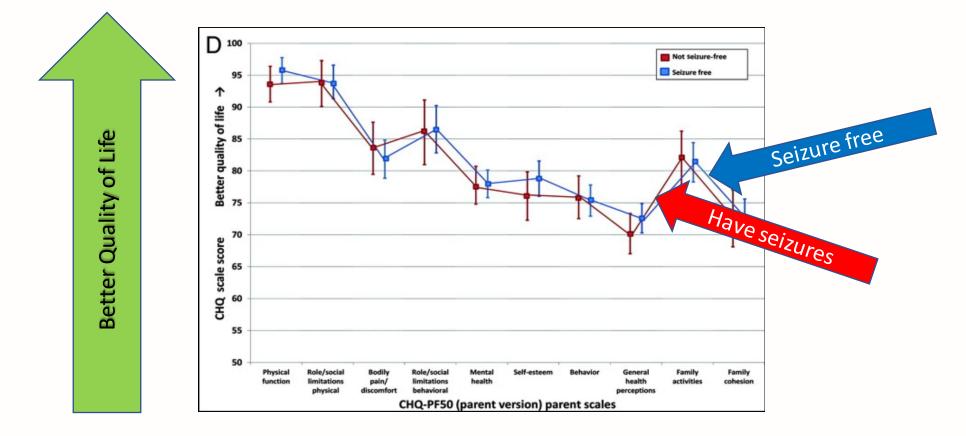
1. Background

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5. WP4



Why do we care?



Baca, C. B., Vickrey, B. G., Caplan, R., Vassar, S. D., & Berg, A. T. (2011). Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. *Pediatrics*, *128*(6), e1532-e1543.

1. Background

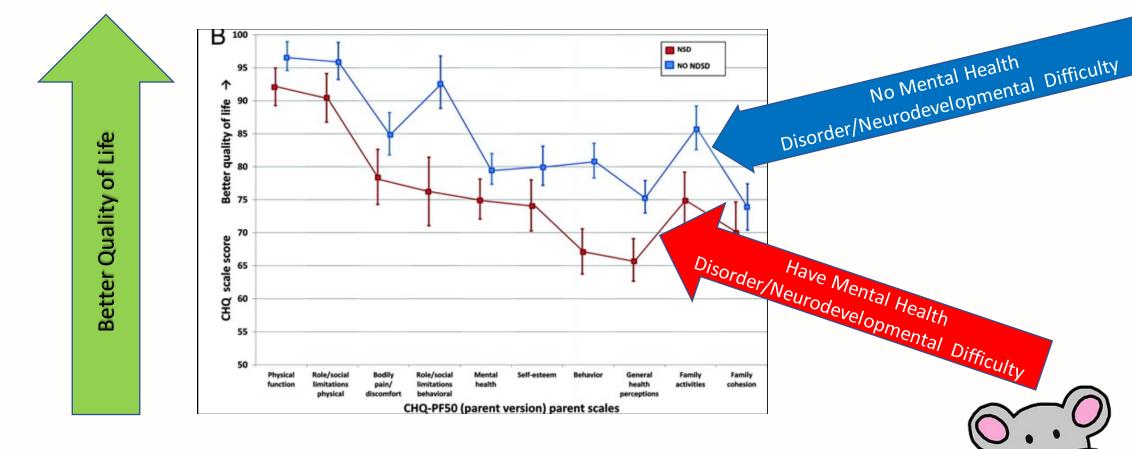
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WP2

4. WP3

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Why do we care?



Baca, C. B., Vickrey, B. G., Caplan, R., Vassar, S. D., & Berg, A. T. (2011). Psychiatric and medical comorbidity and quality of life outcomes in childhood-onset epilepsy. *Pediatrics*, *128*(6), e1532-e1543.

1. Background

WP1

WP2

4. WP3

The evidence base

- Thousands of papers demonstrate efficacy of standard evidence-based intervention for mental health disorders in children (Weisz et al., 2012)
- Preliminary evidence that these are effective in children and young people with Long Term Conditions (LTCs)



Original article



Psychological interventions for mental health disorders in children with chronic physical illness: a systematic review

Sophie Bennett,¹ Roz Shafran,¹ Anna Coughtrey,² Susan Walker,^{1,2} Isobel Heyman^{1,2}



1. Background

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. WP2

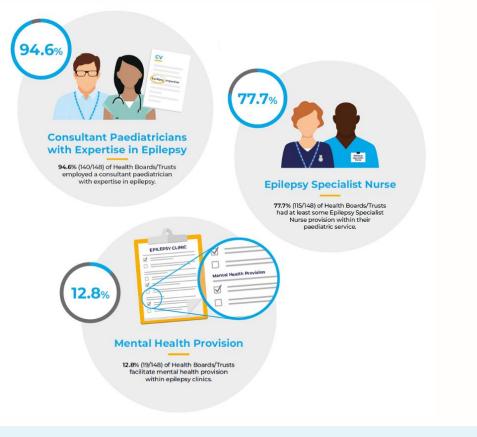
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l 6. [



- Mental health disorders in the context of neurological illnesses often remain undiagnosed and under-treated (e.g. Welch et al., 2018)
 - Diagnostic overshadowing?
 - Lack of understanding?



Welch, A., Shafran, R., Heyman, I., Coughtrey, A., & Bennett, S. (2018). Usual care for mental health problems in children with epilepsy: a cohort study. *F1000Research*, *7*.

1. Background

3. WP

4. WP3

5. WP4



Epilespsy12 Audit – NHS national data (England only) RCPCH

1. Background

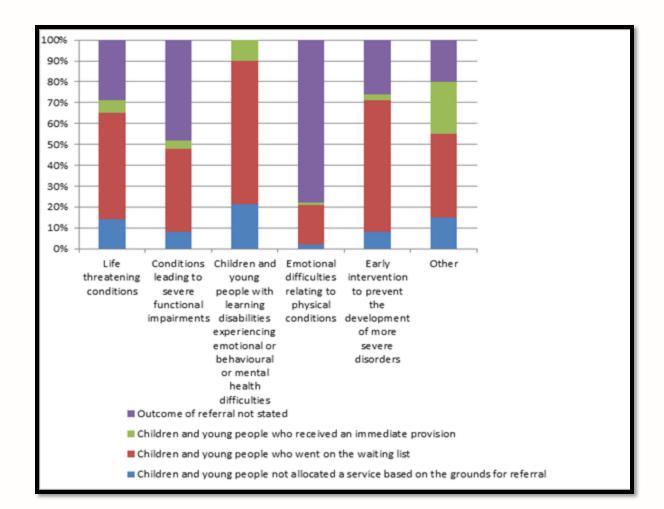
2. WP1

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But...



Children's Commissioner - Lightning review of access to CAMHS 2016



1. Background

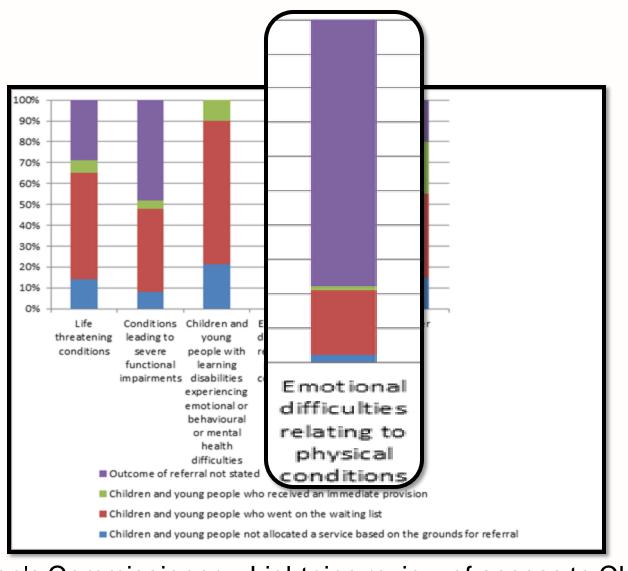


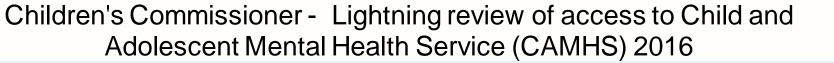
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1. WP3

/P4 6.







2. WP1

3. WP2

I. WP3

4 6. D

What happens at the moment?



...you feel like 'oh am I gonna have a seizure? I don't wanna go out because I might have a fit', like on the street. ... But I need to start to forget about it, I might go and see my, we have an Epilepsy Nurse at the hospital which I go to, and he's really lovely, he's a really nice bloke. And if I do have any problems I can always ring him, or go and see him, so I think I might go and have a chat with him soon. Book myself an appointment and go and have a chat with him about the anxiety, and whether he can suggest anything.



1. Background

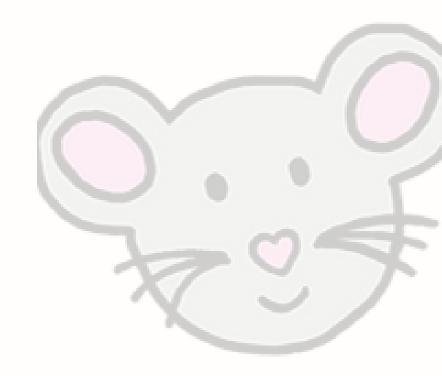
healthtalk.org

/P2

4. WP3

5. WP

Background: MICE methods



1. Background

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'P4 6

Integrated identification

Consent in clinic

Strength & Difficulties Questionnaire on tablet

> Online diagnostic assessment

> > Rate

Original article

Assessing feasibility of routine identification tools for mental health disorder in neurology clinics

Sophie D Bennett ⁽¹⁾, ¹ Isobel Heyman, ^{1,2} Anna E Coughtrey, ^{1,2} Marta Buszewicz, ³ Sarah Byford, ⁴ Caroline J Dore, ⁵ Peter Fonagy, ⁶ Tamsin Ford, ⁷ Rona Moss-Morris, ⁸ Terence Stephenson, ¹ Sophia Varadkar, ^{1,2} Erin Walker, ⁹ Roz Shafran¹

1. Background

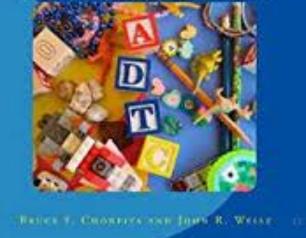
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Intervention



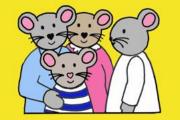
MODULAR APPROACH TO THERAPY FOR Children with Anxiety, Depression, Trauma, or Conduct Problems



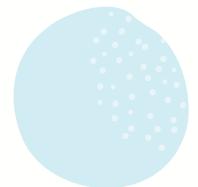
CONTRACTOR OF STREET, ST.

MICE

<u>Mental health Intervention for</u> <u>Children with Epilepsy</u>



Treatment Manual 2018





Great Ormond Street NHS Hospital for Children



1. Background

WP1

3. WP

4. WP3

5. WF



- Learning about Anxiety
- Using the Fear Thermometer
- Fear Ladder
- Practising
- Maintenance
- Cognitive STOP
- Wrap Up
- Booster (Anxiety)



- Getting Acquainted: Depression
- Learning about Depression: Family
- Problem Solving
- Activity Selection
- Learning to Relax
- Quick Calming
- Presenting a Positive Self
- Cognitive: BLUE
- Cognitive: TLC
- Plans for Coping
- Wrap Up
- Booster (Depression)



- One to one time
- Praise
- Active Ignoring
- Instructions
- Rewards
- Time Out
- Making a Plan
- Daily Report Card
- Looking Ahead
- Booster (Conduct)

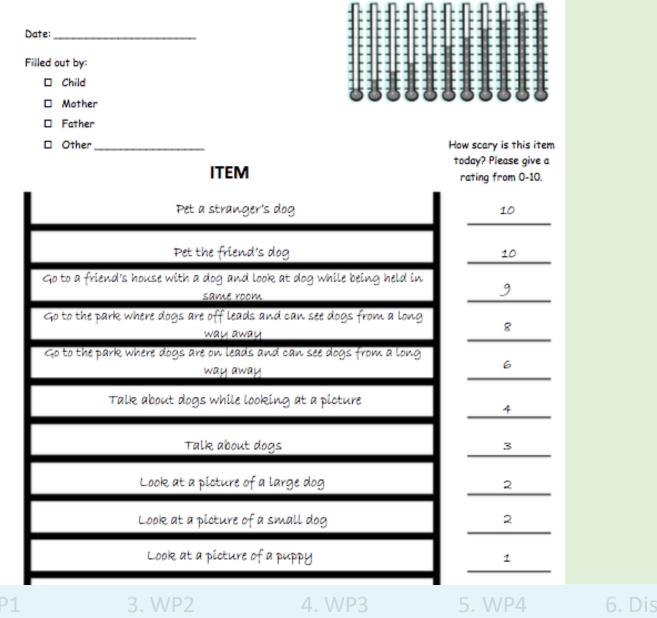
3. WP2

4. WP3

5. WP4

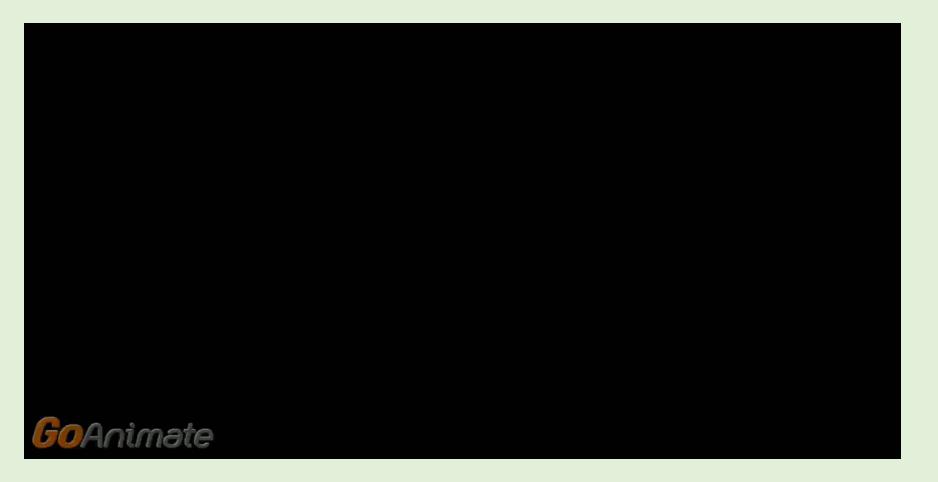


Fear Ladder (example)



1. Background





. WP1

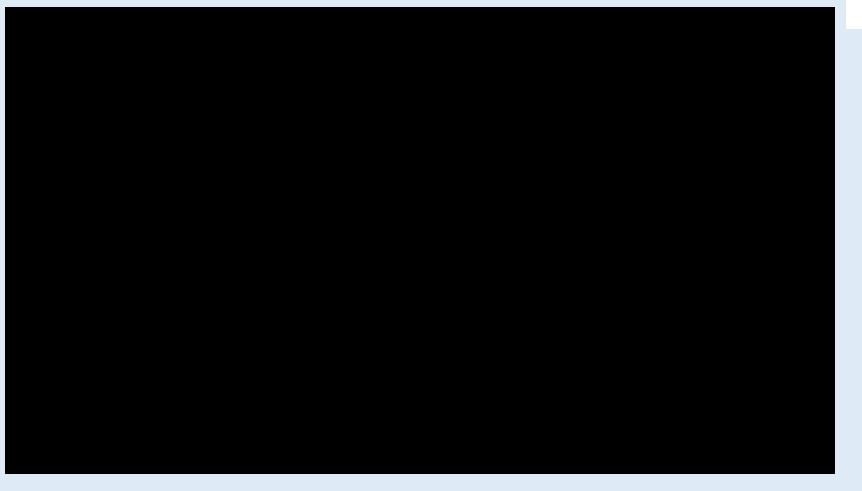
3. WP2

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WP1

3. WP2

4. WP3

5. WP4







VP1

3. WP2

4. WP3

5. WP4

Personalising

 Review
 > Curr Opin Psychiatry. 2023 Jan 1;36(1):28-33. doi: 10.1097/YCO.0000000000834.

 Epub 2022 Oct 22.

Adaptation, personalization and capacity in mental health treatments: a balancing act?

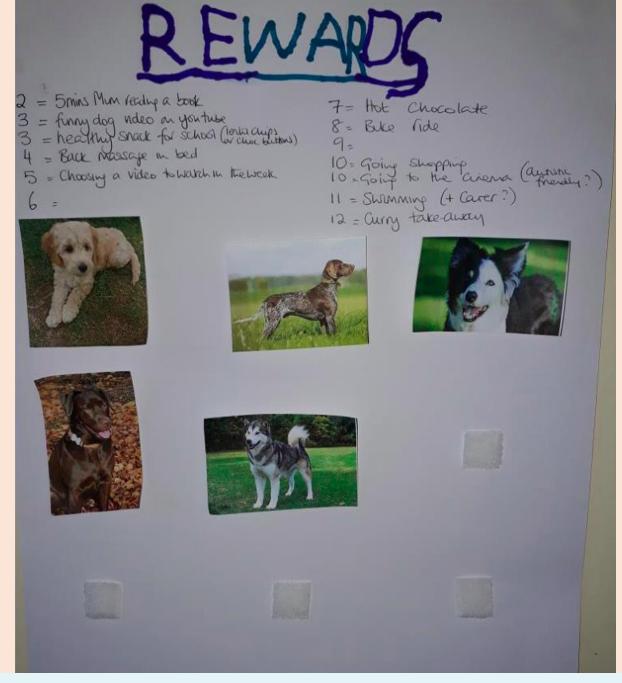
Sophie D Bennett ¹, Roz Shafran

Editorial > J Child Psychol Psychiatry. 2023 Feb;64(2):213-216. doi: 10.1111/jcpp.13732.

Editorial: Therapies for mental health difficulties: finding the sweet spot between standardization and personalization

Alice M Gregory ¹, Martin K Rutter ² ³, Juan J Madrid-Valero ⁴, Sophie D Bennett ⁵, Roz Shafran ⁵, Daniel J Buysse ⁶

Affiliations + expand PMID: 36636905 DOI: 10.1111/jcpp.13732



1. Background

WP1

3. WP2

4. WP

5. WP





3. WP2

4. WP3

5. V

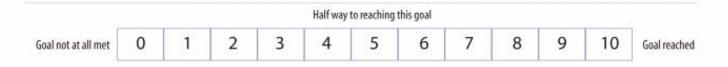
Goals and goal-based outcomes (GBOs) Goal rating sheet

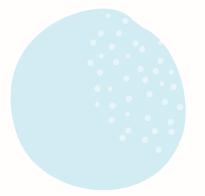
How close are you to the goals you want to get to?

On a scale from zero to ten, please circle the number below that best describes how close you are to reaching your goal today. Remember a score of zero means no progress has been made towards a goal, a score of ten means a goal has been reached fully, and a score of five is exactly half way between the two

YOUR FIRST GOAL

Enter brief description of goal and goal number as recorded on the Goals Record Sheet

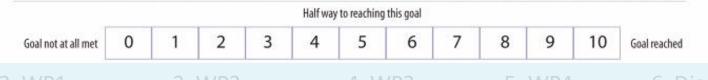




1. Background

YOUR SECOND GOAL

Enter brief description of goal and goal number as recorded on the Goals Record Sheet

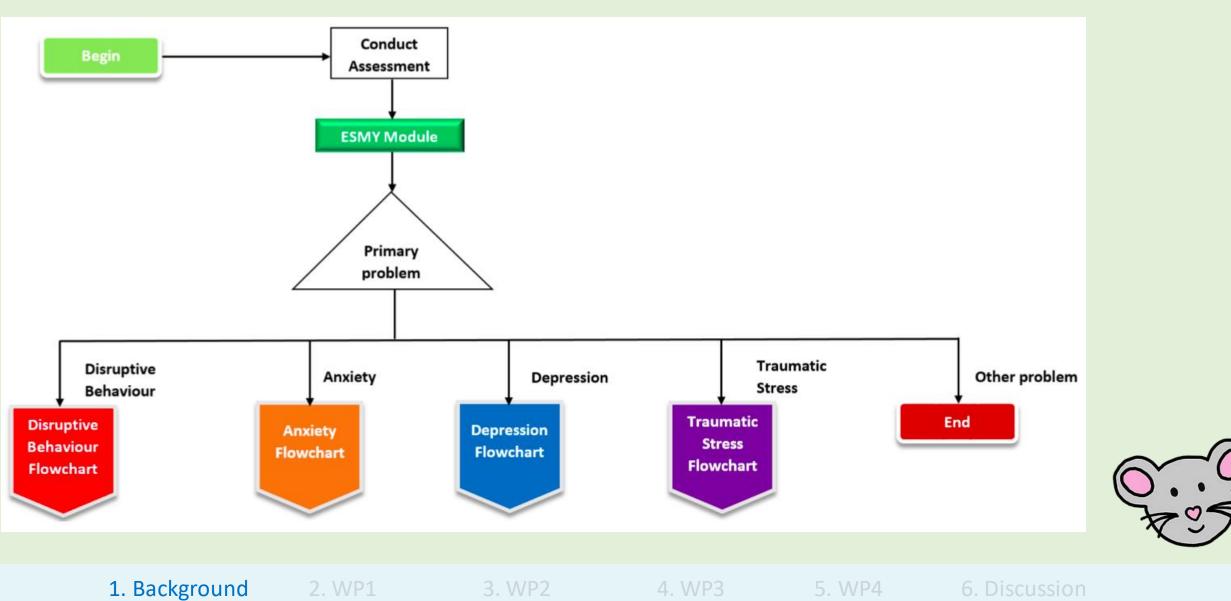




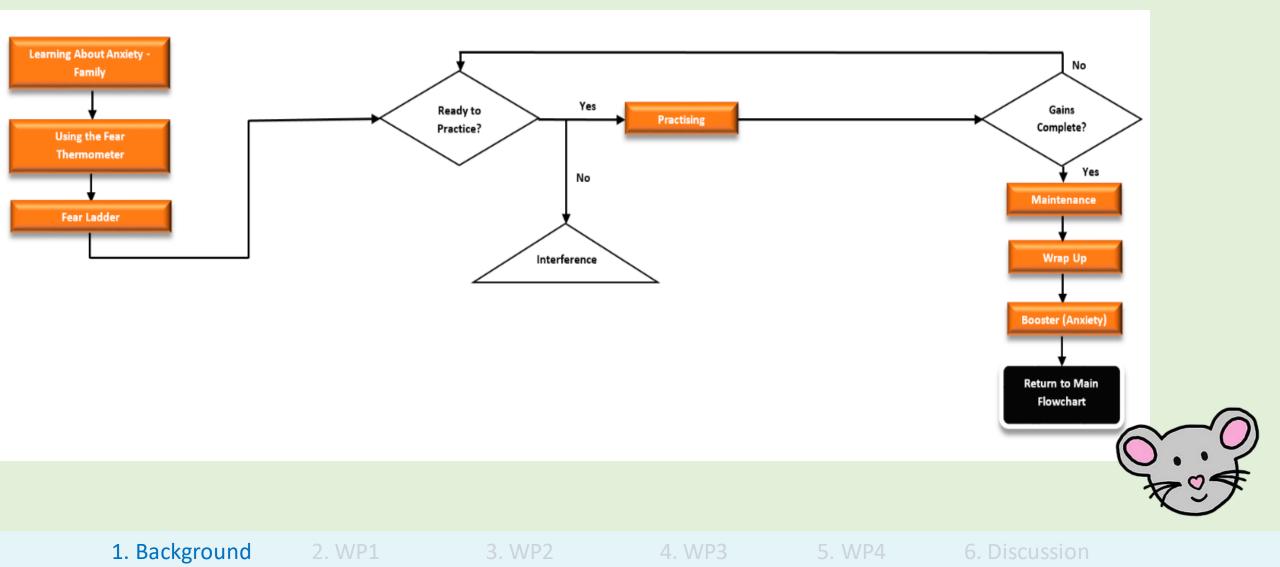
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Intervention



Intervention - Anxiety no interference





Development of epilepsy- specific module (n=12)	Training services and pilot intervention (n=2 per therapist)	Randomised Controlled Trial (n=334)	Qualitative outcome and process evaluation (n=24)	
WP1	WP2	WP3	WP4	
2018	2019	2019 - 2023	2019 - 2023	

2. WP1

WP3

WP4 6.

MICE Programme: Work Package 1

Development of epilepsyspecific module (n=12) WP1



1. Background

2. WP1

VP2

4. WP3

5. WP4

Optimising MATCH-ADTC with Implementation Science

"the study of methods and strategies to promote the uptake of interventions that have proven effective into routine practice, with the aim of improving population health"





1. Background

2. WP1

3. WP2

4. WP3

5. WP4



- 1. Literature review
- 2. Focus groups of patients and professionals
- 3. Plan do Study Act cycles (n=12 patients)
- 4. Qualitative interviews (n=7 families)

. WP2

4. WP3

5. WP4

Results: overall changes to intervention

- 1. High level of consensus and substantial overlap
- 2. Need to personalise the intervention for the individual and context by:
 - 1. Anglicising the language
 - 2. Using epilepsy-specific examples where possible
 - 3. Making it explicit that the pace of the intervention and delivery may need to be adjusted on a case-by-case basis depending on the child's intellectual ability and mode of delivery (telephone vs. face-to-face)



1. Background

2. WP1

. WP2

. WP3

5. WP4

Results: additional modules

 A core module for everyone that provides education about mental health disorders and their relationship with epilepsy, enables a formulation of the maintenance of mental health disorders within epilepsy and provides links to additional resources.

If epilepsy and mental health difficulties are related, how will it get better? Will anything make a difference?

Epilepsy and mental health problems have different treatments, which can be used at the same time. Mental health problems can get better, even if the epilepsy doesn't.

My child's epilepsy is just one of many problems e.g. ADHD, Autism, learning difficulties, physical disability, a genetic condition. Will this programme still work?

Yes! Most children who have used this programme have many additional difficulties. Research has shown that these strategies work for children with many problems. Your therapist will work with you to make sure the programme suits your child's individual needs.

Is the medicine that my child is taking responsible for their low mood, challenging behaviour or worries?

It is important to discuss this with your child's epilepsy nurse/team. Some epilepsy medicines might have an effect on mood and behaviour, especially when the medicine, or the dosage, is changed.

It does not matter what the cause of the challenging behaviour or low mood is, we still have the strategies to help. In the same way, it does not matter whether your headache was caused by a noisy room or because you banged your head, Paracetamol works just as well.



1. Background

2. WP1

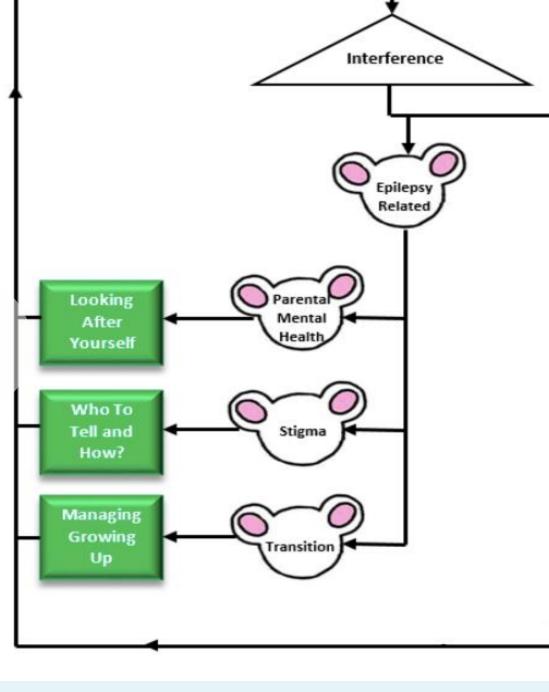
WP2

WP3

5. WP4

Results: additional modules

- Additional 'interference' modules in keeping with the structure of MATCH-ADTC:
 - Stigma
 - Parental mental health
 - Transition to adulthood



4. WP3

5. WF

Results: training

- 1. A 5-day training course accompanied by a minimum of monthly supervision was therefore developed to ensure fidelity to the MATCH-ADTC model as well as facilitating delivery within busy services
- 2. A 'user-guide' was also developed that makes it explicit how to use the manual for nurses and other health professionals unfamiliar with the delivery of mental health interventions
- 3. The training course was video-taped

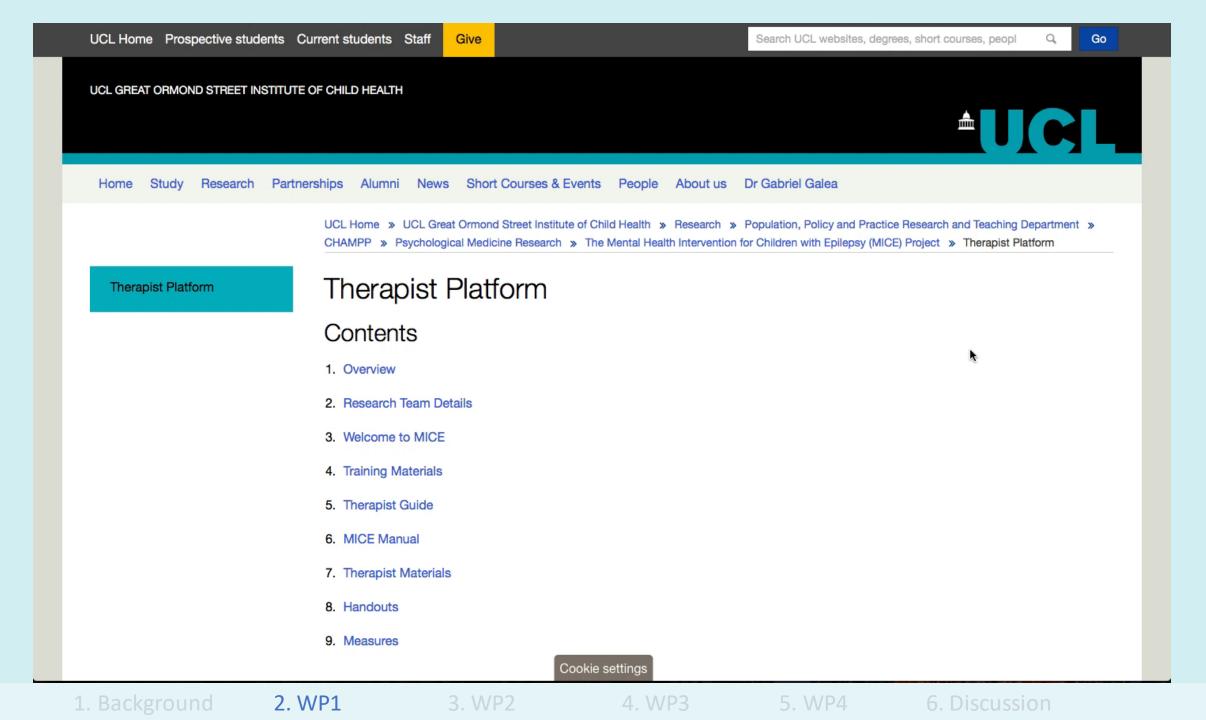
Optimising Evidence-Based Psychological Treatment for the Mental Health Needs of Children with Epilepsy: Principles and Methods

2. WP1

Roz Shafran^{1,2} • Sophie Bennett^{1,2} • Anna Coughtrey^{1,2} • Alice Welch^{1,2} • Fahreen Walji^{1,2} • J. Helen Cross^{1,2} • Isobel Heyman^{1,2} • Alice Sibelli³ • Jessica Smith⁴ • Jamie Ross⁵ • Emma Dalrymple¹ • Sophia Varadkar² • MICE Research Study Team • Rona Moss-Morris³



1. Background



MICE Programme: Work Package 2

Development of epilepsy- specific module (n=12)	Training services and pilot intervention (n=2 per therapist)	
WP1	WP2	



1. Background

2

3. WP2

4. WP3

5. WP4

Training the therapists: methods

- 27 Health Care Professionals (HCPs) from six different NHS trusts across England attended the first 5 days of training workshops
- 5 paediatricians, 5 specialist epilepsy nurses, 3 paediatric nurses, 2 mental health workers, 1 educational psychologist, and 4 assistant psychologists
- All HCPs then completed at least 1 training case of the expanded telephone delivered treatment, supported by weekly clinical consultation by a qualified clinical psychologist from the research team
- Parent reported measures of child's mental health and quality of life
- Qualitative interviews with HCPs at the start (n = 23) and end (n = 15) of the 6-month training period

3. WP2



Training the therapists: 6-month outcomes

- All therapists deemed competent
- Statistically significant improvements in: symptoms of mental health problems (p = 0.01; Cohen's d = 0.62), total impact of mental health problems (p = 0.03; Cohen's d = 0.52), anxiety and depression symptoms (p = 0.02; Cohen's d = 0.57) and quality of life (p = 0.01; Cohen's d = 0.57)

Feasibility of telephone-delivered therapy for common mental health difficulties embedded in pediatric epilepsy clinics



Sophie D. Bennett *, Christy Au, Sarah Byford, Bruce Chorpita, Anna E. Coughtrey, J. Helen Cross, Emma Dalrymple, Peter Fonagy, Tamsin Ford, Isobel Heyman, Amy Lewins, Rona Moss-Morris, Colin Reilly, Laila Xu, Roz Shafran

Great Ormond Street Hospital for Children NHS Foundation Trust, UK

. Background

3. WP2

4. WP3

5. WP4

Training the therapists: 6-month outcomes

I think it's a really good, obviously highquality, well researched giftbox, almost. It's like a greatest hits compilation of mental health support and psychological therapies which can be used interchangeably. So yes, it's like having your favourite CD in your car."

(Therapist)

"Yes, the sessions feel completely relevant. I mean, things that we're talking about are completely relevant to what we're dealing with and going through."

(Parent)

"A greatest hits compilation of mental health support": A qualitative study of health professionals' perceptions of modular CBT in pediatric epilepsy services



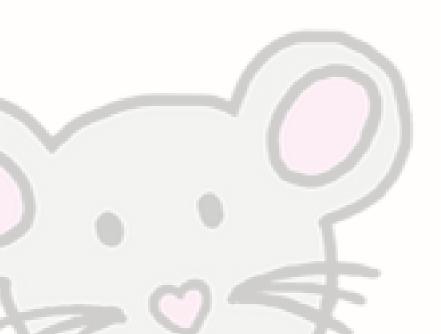
Anna E. Coughtrey^{a,b,*}, Sophie D. Bennett^{a,b}, Alice Sibelli^c, Bruce Chorpita^d, Emma Dalrymple^a, Peter Fonagy^e, Tamsin Ford^{f,g}, Isobel Heyman^{a,b}, Rona Moss-Morris^c, MICE Study Team^{a,b}, Brian C.F. Ching^{a,b}, Roz Shafran^{a,b}

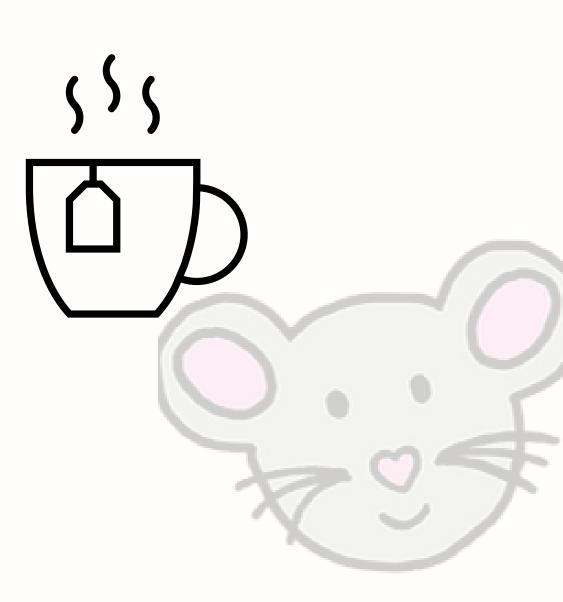






Mini-Break





MICE Programme: Work Package 3

Development of epilepsy- specific module (n=12)	Training services and pilot intervention (n=2 per therapist)	Randomised Controlled Trial (n=334)	
WP1	WP2	WP3	



1. Background

P1

3. WP2

4. WP3

Work Package 3: the trial

- Randomised Controlled trial
- MICE + Usual Care versus Assessment Enhanced Usual Care (Control)
- Primary outcome: Strengths and Difficulties Questionnaire
- Secondary outcomes: Quality of Life, Mental Health of child and parent
- Safety data
- Acceptability Experience of Service Questionnaire

Sites:

- Great Ormond Street
- Barnet
- Lewisham and Greenwich
- NELFT
- UCLH
- Whittington

Patient Identification

- Centres (PIC):
- Sherwood Forest
- Cambridge
- Northern Ireland
- Mid Yorkshire
- Surrey
- Suffolk
- Belfast



1. Background

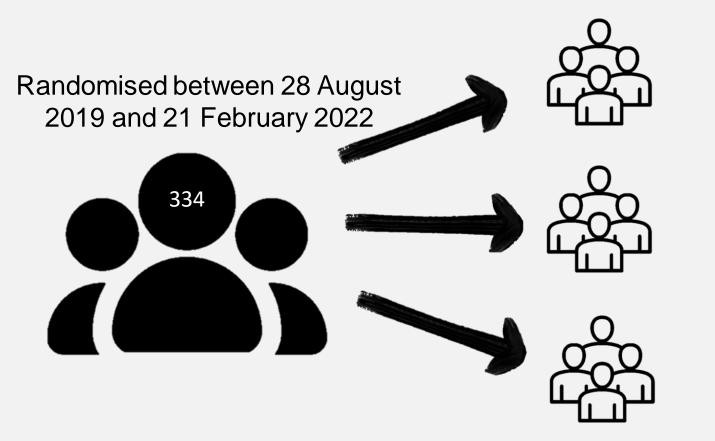
WP2

4. WP3

5.

6. Discussion





Around 25% with Austism Spectrum Disorder (ASD) diagnoses

Around 40% with intellectual disability diagnoses

Around 65% reported having a seizure in the past three months

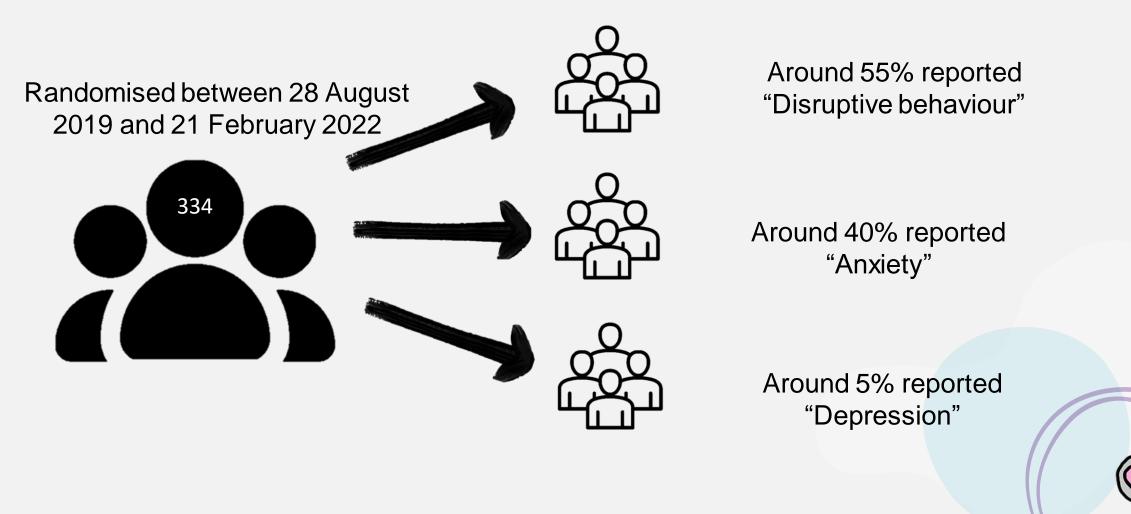
1. Background

P1

3. WP2

4. WP3





1. Background

P1

3. WP2

4. WP3

5. WP4

6. Discussion

MICE Intervention: therapy sessions

- Of the 166 participants randomised to the MICE arm, 164 had at least 1 therapy session
- Number of therapy sessions ranged between one to 22 median n=16
- 21 therapists provided therapy sessions as a main therapist on the trial



1. Background 2.

WP2

4. WP3

5. WP

6. Discussion

What does this look like in real life?

1. Background

/P1

3. WP2

4. WP3

Meet Alex: Anxiety



- 9-year-old
- Female
- No seizure activity at baseline
- SDQ Total: Very High (24)
- SDQ Impact: Very High (10)
- Diagnosis on the Development And Well Being Assessment: Social Phobia

1. Background

1

4. WP3

5

WP4 6.

Presenting difficulties



- Alex was struggling in new social situations:
 - For example, making new friends that are loyal or speaking in front of her peers
- Alex was struggling being in crowded spaces:
 - For example, going on trains or in busy places
- This led to withdrawing and avoidant behaviour, for example choosing to stay home when possible
- This also led Alex to get upset, for example: becoming irritable or tearful

1. Background

WP2

4. WP3

SMART Goals

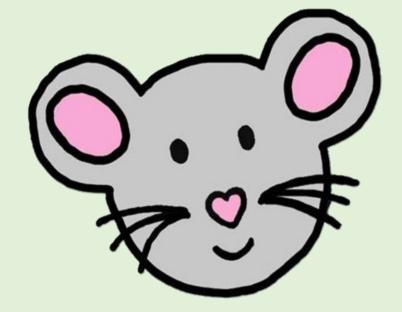


- 1. To talk to a new friend at school
- 2. To visit a busy place (e.g. a concert, restaurant, shop etc.) and feel calm (i.e. without feeling anxious or panicked)
- 3. To fall asleep every week day without needing to use an iPad to distract from anxiety

1. Background

2

4. WP3



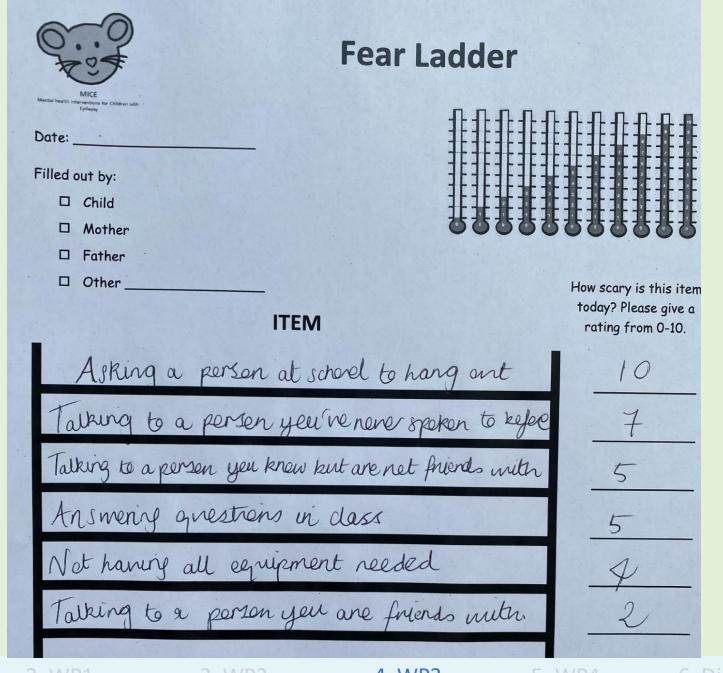
- Alex completed 21 sessions of only anxiety module:
 - Assessment
 - Epilepsy Specific Module for Youth (ESMY)
 - Learning about anxiety
 - Using the Fear Thermometer
 - Fear ladder
 - Practicing
 - Maintenance
 - Cognitive STOP
 - Wrap Up
 - X2 Boosters
 - X3 Review
- Alex and her mother were primarily present during sessions
- No interference throughout treatment

1. Background

P<u>1</u>

3. WP2

4. WP3



1. Background

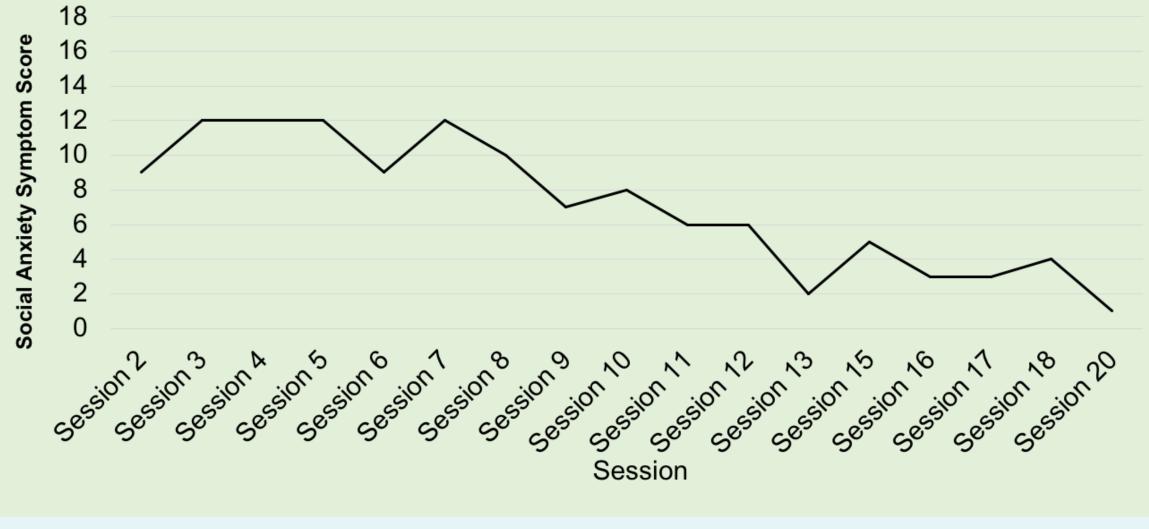
WP1

2

4. WP3



Social Anxiety Symptoms



1. Background

10 9 8 Score 7 **Goal Based Outcome** 6 5 4 3 2 1 0 $A^{\text{seesenent}} = 5^{\text{esenent}} = 5^$ Session

 To talk to a new friend at school

To visit a busy place (e.g. a concert, restaurant, shop etc.) and feel calm (i.e. without feeling anxious or panicked)

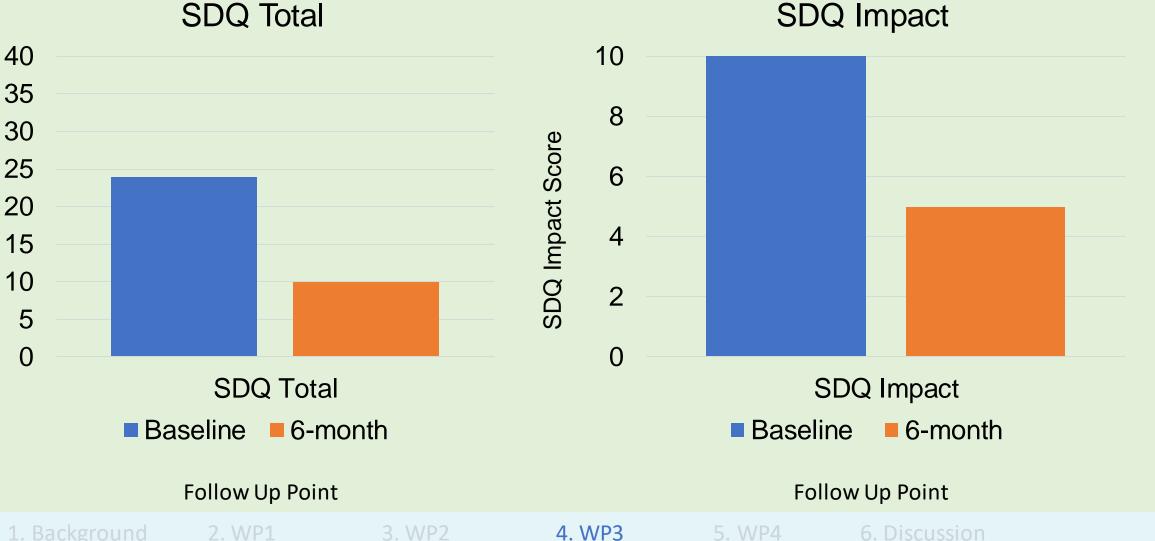
To fall asleep every week day
without needing to use an iPad to distract from anxiety

Goals Over Time



SDQ Total

SDQ Total Difficulties



Alex can see a brighter future for herself and we can see a brighter future for us as a family

...once again from Alex and the whole family THANK YOU SO MUCH

...without your understanding, patience and professionalism and the advice and tools you gave her to success

3. WP2

4. WP3

But my patient is anxious because of Seizures... what do I do?

1. Background

4. WP3

Meet Jo: Anxiety about epilepsy



- 16-year-old
- Female
- Seizure activity at baseline
- SDQ Total: Very High (26)
- SDQ Impact: Very High (6)
- Diagnosis on the DAWBA: Separation and Generalised Anxiety Disorder

1. Background

P1

3. WP2

4. WP3

Presenting difficulties



- Jo would become very anxious when separated from her mother
 - Particularly she would worry about having a seizure when alone
- Jo worries about a range of topics including:
 - Catching COVID-19
 - Having seizures in public
 - Being in crowded places
 - Travelling by bus
 - Socialising with others
- Jo would be overactive and struggle to concentrate so would find it hard to calm down

4. WP3

SMART Goals



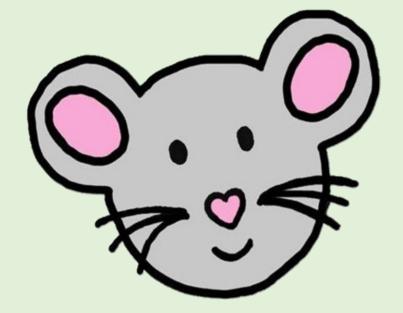
- 1. For Jo to talk with her friends about her epilepsy
- 2. For Jo to worry less about doing things on her own in public, meaning she can be more independent and do things on her own (e.g. walk to see her friends in the park on her own, go shopping on her own)
- 3. For Jo to feel more confident, meaning she can get a bus on her own (to visit friends/family/go shopping)

1. Background

4. WP3

5.

6. Discussion



- Jo completed 19 sessions of the Anxiety module:
 - Assessment
 - ESMY
 - Learning about anxiety
 - Fear Thermometer
 - Fear Ladder
 - Practicing
 - Cognitive STOP
 - Problem solving
 - Learning to relax
 - Wrap Up
 - X2 Boosters
 - X1 Review
- Jo and her mother were primarily present during sessions

1. Background

4.

Date:	
Filled out by:	
C Child	
□ Mother 55555	******
🗆 Father	
Other	How scary is this item
ITEM	today? Please give a rating from 0-10.
Going to a kusy supermarket by myself and staying there for three ninutes	10
Messaging a friend mho doesn't knew I have epilepsy, to fell men abent it	9
Hanging ont nutr a greup of friends and talk about epilepsig	8
Craing to the supermarket in a quiet aide by myself fer tunee minutes	7
Greing to the park with my friends and Helling them about my epilepsy medication	6
Crang to be supermarket with mun	5
Go to the corner shep miter a few people in it	4
Go to bre comer shep miler a few people in it milerorate mun per proce minutes	3
Message a friend about something unrelated	2
faretime a finiend to shat (wroteled to epilops)	1

1. Background

WP1

. WP2

4. WP3



STOP

STOP will be an important part of getting braver. When we talk about STOP, S stands for *scared*, T stands for *thoughts*, O stands for *other thoughts*, and P stands for *praise*. Let's learn more about STOP.



S is the first letter in the word scared. Let's learn more about feeling scared.

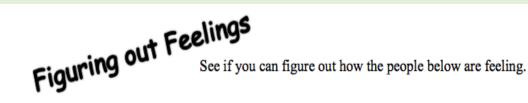
Scared Scramble Unscramble the letters below to find other words for feeling scared.



DAARIF

IERWROD

ERVOUNS











This person feels	This person feels	This person feels	This person feels
How do you know?			

MICE Worksheet - STOP / 1 of 7

334

1. Background

VP1

3. WP

4. WP3

5. N

6. Di



1. Background

WP1

2

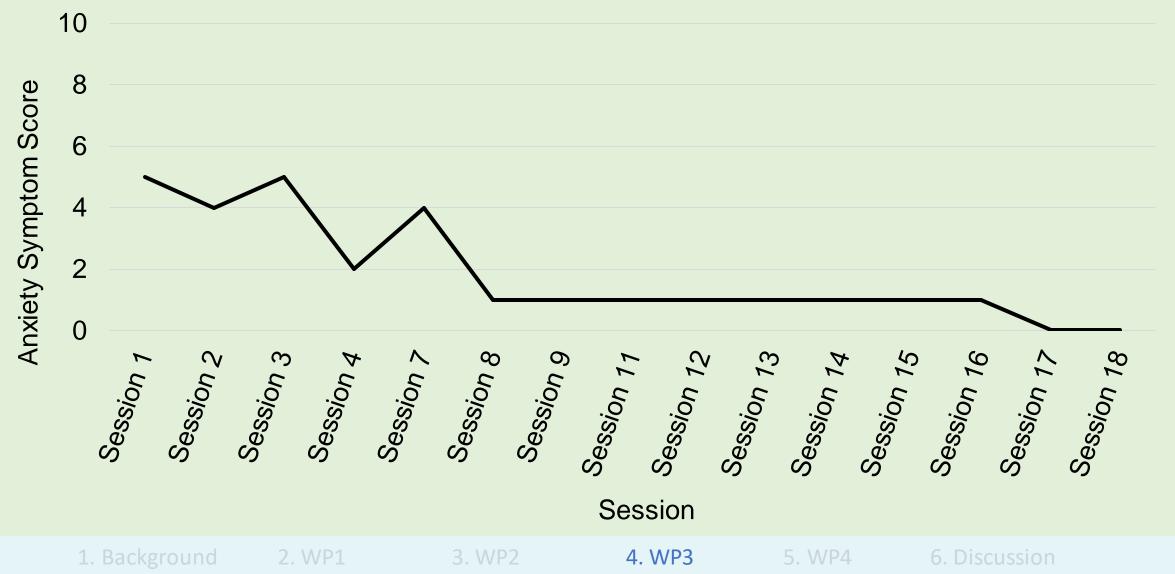
4. WP3

5. W

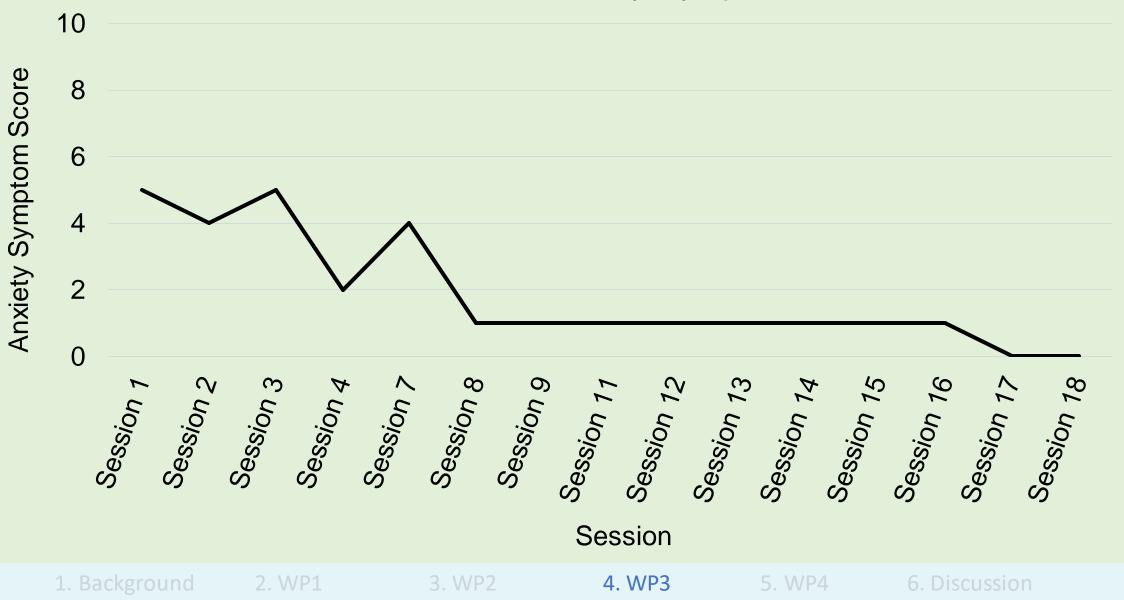
6. Discussion



Separation Anxiety Symptoms



Generalised Anxiety Symptoms



Goals Over Time



To talk with her friends about her epilepsy

To worry less about doing things on her own in public, meaning she can be more independent and do things on her own (e.g. walk to see her friends in the park on her own, go shopping on her own)

To feel more confident, meaning she can get a bus on her own (to visit friends/family/go shopping

Pre-Post Outcomes



Meet Henry: Behaviour and Anxiety



- 13-year-old
- Male
- Very severe seizure activity at baseline
- SDQ Total: Very High (27)
- SDQ Impact: Very High (9)
- Diagnosis on the DAWBA: ASD, Generalised Anxiety

1. Background

P1

WP2

4. WP3

Presenting difficulties



- Henry was experiencing symptoms of anxiety, disruptive behaviour and hyperactivity
- Henry expressed a fear of dogs

- Henry demonstrated challenging behaviours
 - Harming himself in response to change or loud unpredictable noises
- Henry was becoming increasingly withdrawn

SMART Goals



- 1. For Henry to be able to get ready for school in the morning without hitting, spitting, hair pulling or asking repeatedly if he's going to school
- 2. For Henry to be able to interact with his support assistant at school in the mornings (or when people visit, or going to somebody else's house)
- 3. For Henry to be able to go shopping (in a small shop) with mum at least once a week without asking whether or not there will be other children more than three times

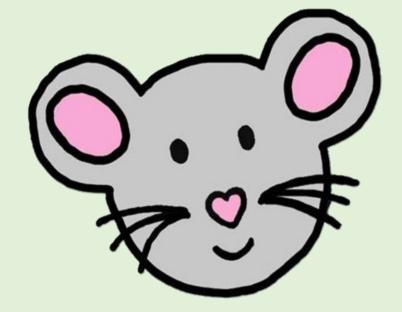
1. Background

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4. WP3

5. \

6. Discussio



- Henry completed a total of 20 sessions of the anxiety module followed by the behavioural module:
 - Assessment
 - ESMY
 - Learning about anxiety
 - Fear Thermometer
 - Fear Ladder
 - Practising
 - One to one time
 - Praise
 - Active ignoring
 - Instructions
 - Rewards
 - Problem solving
 - X2 Boosters
 - X1 Review
- Henry's mother was primarily present during sessions

1. Background

21

3. WP2

4. WP3



- —To be able to get ready for school in the morning without hitting, spitting. hair pulling or asking repeatedly if he's going to school
 - To be able to interact with his support assistant at school in the mornings (or when people visit, or going to somebody else's house)
- —To be able to go shopping (in a small shop) with mum at least once a week without asking whether or not there will be other children more than three times

1. Background



. WP2

4. WP3

Pre-Post Outcomes



(MICE was) excellent in general, has been super helpful with my daughter who had quite complex physical and behavioural needs

It is not a one-size-fits-all programme and is really tailored to my child

Being fixed isn't the objective, but changing the scale of intensity of impact is

With the techniques I have learnt in therapy, I have a tool kit to make things I find difficult more manageable MICE treatment had given me hope and a sense of accomplishment

1. Background

3. WP2

4. WP3

MICE Programme: Work Package 4

Development of epilepsy- specific module (n=12)	Training services and pilot intervention (n=2 per therapist)	Randomised Controlled Trial (n=334)	Qualitative outcome and process evaluation (n=24)
WP1	WP2	WP3	WP4



1. Background

4. WP3

MICE Programme: Work Package 4

Qualitative outcome and process evaluation (n=24)

WP4



1. Background

P1

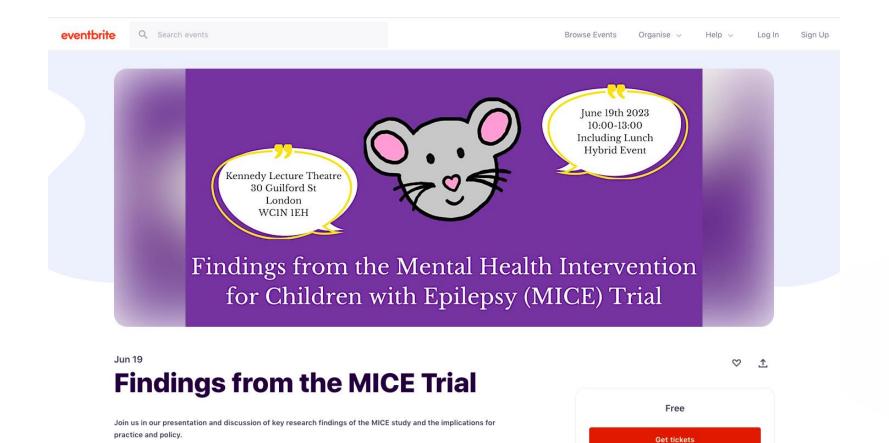
3. WP2

4. WP3

5. WP4

6. Discussion

Work Package 4 and beyond





1. Background



. WP3



Discussion

- Positive effect on children and young people
- And their families
- Model for other chronic illnesses?
- How do we implement it in clinical practice?
- How do you get trained in MICE?
 Gos-tr.mice@nhs.net

https://forms.office.com/e/Babnv5xhun





1. Background

WP1

3. WP2

. WP3

5. WP4

6. Discussion

Acknowledgements



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MICE co-investigators and Team: J. Helen Cross (co-CI), Kashfia Chowdhury, Tamsin Ford, Isobel Heyman, Anna E. Coughtrey, Emma Dalrymple, Sarah Byford, Bruce Chorpita, Peter Fonagy, Rona Moss-Morris, Colin Reilly, Jonathan Smith, Terence Stephenson, Sophia Varadkar, James Blackstone, Harriet Quartly, Tyler Hughes, Amy Lewins, Elana Moore, Fahreen Walji, Alice Welch, Emily Whelan, Alice Zacharia, Anais D'Oelsnitz, Mariam Shah, Laila Xu, Aikaterini Vezyroglou

