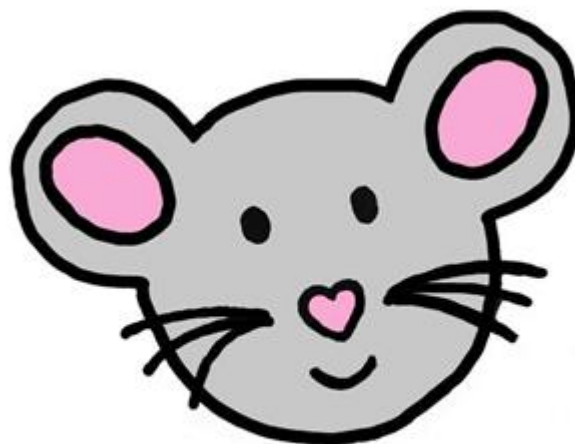


# Transforming the Mental Health of Children with Epilepsy (MICE)



MICE

Mental health Interventions for Children with Epilepsy

# Introductions



- Name
- Service/site
- Role

# Meet the Team



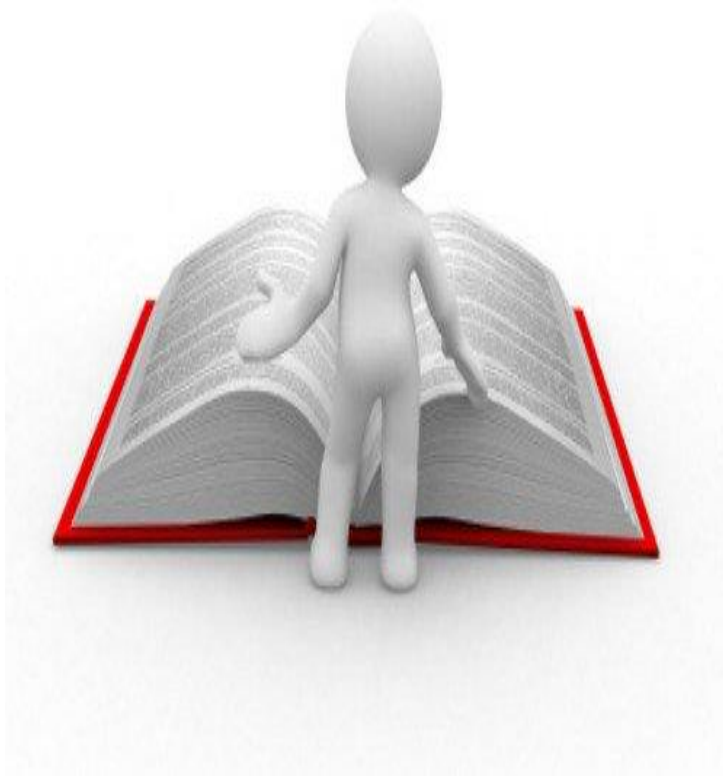
- Sophie Bennett
- Sarah Byford
- Bruce Chorpita
- Anna Coughtrey
- Helen Cross
- Emma Dalrymple
- Caroline Dore
- Peter Fonagy
- Tamsin Ford
- Isobel Heyman
- Rona Moss-Morris
- Colin Reilly
- Roz Shafran
- Jonathan Smith
- Terence Stephenson
- Sophia Varadkar

# Goals



- Building relationship
  - Site liaison link
- Understand the project
- Gain skills to deliver intervention
- Timetable at front of folder

# Contents



- Clinical contents
  - User guide
  - Therapy manual
  - Measures
- Research contents
  - Summary of study design
  - Consent sheets/info. for you to be interviewed

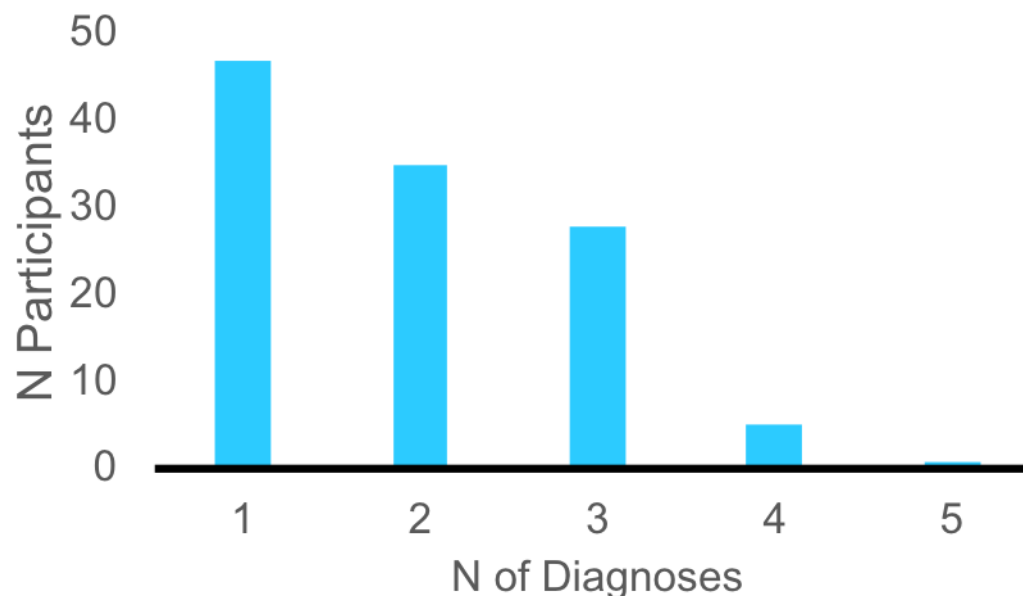
# Overview of the Programme



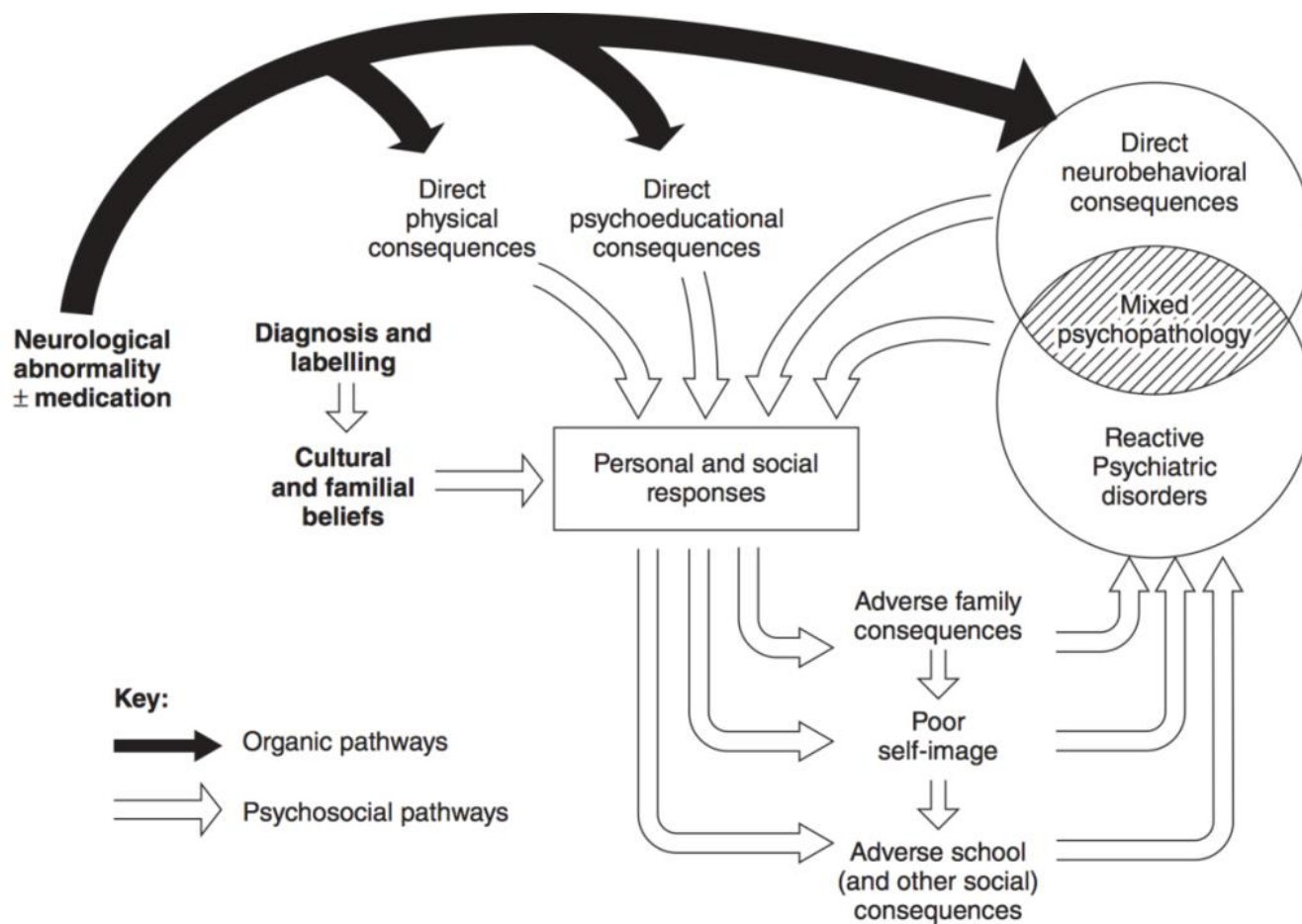
Development, trial and qualitative evaluation of modular mental health treatment in children and young people with epilepsy, delivered over the telephone from within epilepsy services.

# Background

- High rates of mental health difficulties (353 of 639; 55% in 2 previous feasibility screening studies)
- High rates of co-occurring neurodevelopmental disorders and mental health disorders



# Why?



# Current detection and treatment

- Often not picked up – lack of integrated service?
- When they are picked up, often not treated with evidence-based treatments

46 parents  
indicated impairing  
symptoms on the  
Strengths and  
Difficulties  
Questionnaire



# Access to mental health services

- Struggle to access to CAMHS, especially when comorbid long-term conditions

Young people's mental health is a 'worsening crisis'. Action is needed

*Mary O'Hara*



In both the UK and US, services for young people are being cut, leaving those from marginalised groups at greatest risk of suicide



▲ 'Whatever the language deployed to describe the scale of mental health challenges facing Britain's young people, it has to be addressed immediately.' Photograph: Alamy Stock Photo

One recent report called the problem a "**silent catastrophe**" while a survey of teachers labelled it an "**epidemic**". But, whatever the language deployed to describe the scale of mental health challenges facing Britain's young people, it has to be addressed immediately.



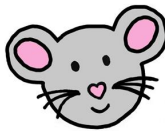
# Current detection and treatment

- Often not picked up – lack of integrated service?
- When they are picked up, often not treated with evidence-based treatments (e.g. Programme Development Grant)



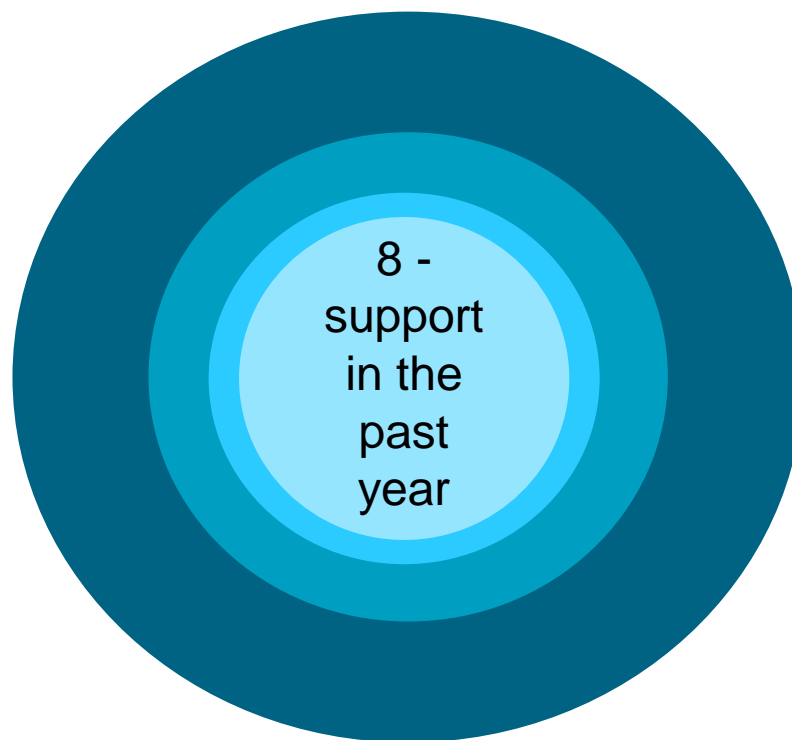
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# Current detection and treatment

- Often not picked up – lack of integrated service?
- When they are picked up, often not treated with evidence-based treatments (e.g. Programme Development Grant)



# The evidence base

- Thousands of papers demonstrate efficacy of standard evidence-based intervention for mental health intervention in children (Weisz et al., 2012)
- We don't know if evidence-based mental health treatments are safe and efficacious in children with epilepsy



Epilepsy & Behavior

Volume 56, March 2016, Pages 99-112



Review

A systematic review of psychosocial interventions for children and young people with epilepsy

Fiona M. Corrigan<sup>a</sup>, Helen Broome<sup>a, b</sup>, Liam Dorris<sup>a, b</sup> 

## **What is the effectiveness of mental health interventions for children with long term physical conditions: a systematic review**

Michael Nunns<sup>1</sup>, Darren Moore<sup>1</sup>, Obi Ukoumunne<sup>1</sup>, Liz Shaw<sup>1</sup>, Morwenna Rogers<sup>1</sup>, Sophie Bennett<sup>2</sup>, Chris Dickens<sup>1</sup>, Tamsin Ford<sup>1</sup>, Isobel Heyman<sup>1</sup>, Fiona Lockhart<sup>2</sup>, Roz Shafran<sup>1</sup>, Penny Titman<sup>3</sup>, Russell Viner<sup>4</sup>, Erin Walker<sup>3</sup>, Paula Lavis<sup>5</sup>, Rob Anderson<sup>1</sup>, Jo Thompson Coon<sup>1</sup>

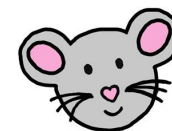
<sup>1</sup>University of Exeter Medical School, University of Exeter, St Luke's Campus, Exeter, Devon, UK, <sup>2</sup>University College London, <sup>3</sup>Great Ormond Street Hospital for Children NHS Trust, <sup>4</sup>University College London Institute of Child Health, <sup>5</sup>Children and Young People's Mental Health Coalition

Original article



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

Sophie Bennett,<sup>1</sup> Roz Shafran,<sup>1</sup> Anna Coughtrey,<sup>2</sup> Susan Walker,<sup>1,2</sup> Isobel Heyman<sup>1,2</sup>



MICE  
Mental health interventions for Children with  
Epilepsy

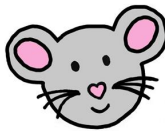
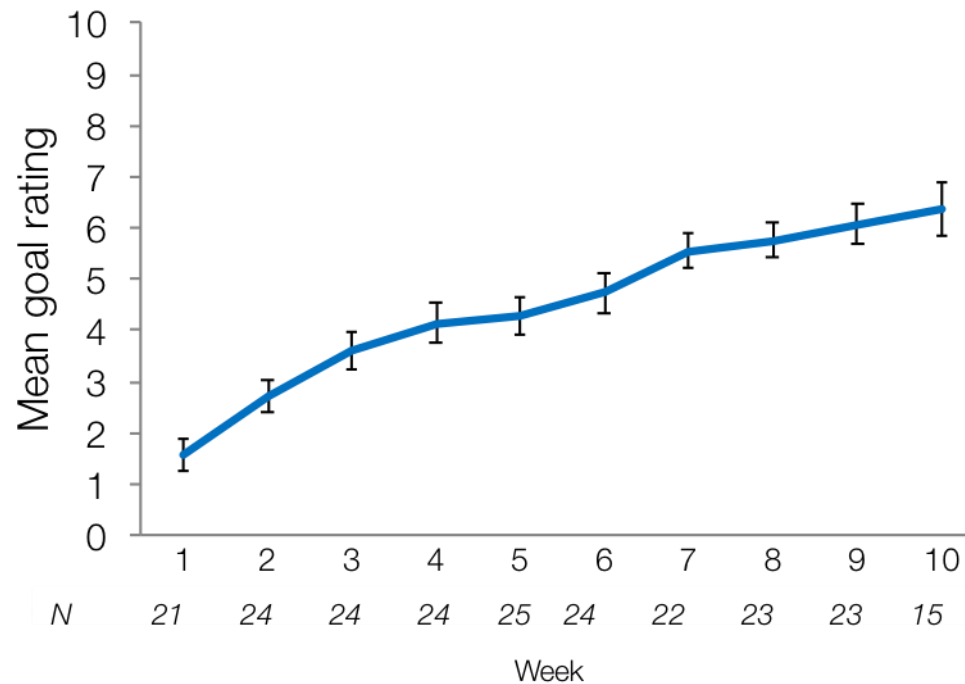
# Our view

- No evidence that these interventions don't work in children with epilepsy and they are efficacious in a wide range of young people
- Many of the underlying causes may not be directly related to seizures
- *"The relationship between epilepsy and anxiety or depression was complex for young people; it wasn't just feeling down about their diagnosis. Most people who had had anxiety or depression said it was connected to their life situations, such as problems in the family or losing a relative"* (Health Talk)



# Previous work: feasibility of intervention

- Telephone treatment – ease of access
- Modular and evidence-based (MATCH) – comorbidity
- Not adapted for epilepsy
- Work towards specific goals



# Qualitative interviews

- *“I’d definitely prefer this sort of intervention because it’s hands on, it’s very practical and it’s in direct response to what you’re experiencing on a day to day level”*
- *“I found the phone interviews fine, it didn’t take too much time up and I could carry on with my life after”*
- *“Obviously they don’t need to know the ins and outs of epilepsy and the medical terms, but I think someone’s got to understand that having epilepsy must be like you’re walking on a frozen lake, waiting for it to crack”*



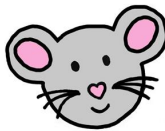
# Feasibility of recruitment

- Integrated with physical health care
- SDQ in clinic waiting room
- Bespoke algorithm
- Development And Well-Being (DAWBA) at home



# Feasibility of recruitment

- Across five London sites, including GOSH
- N = 639 completed SDQ, of which n = 353 (55%) had impairing symptoms
- N = 170 completed the DAWBA, of which N = 116 met full diagnostic criteria
- All but one found the methods acceptable



# The MICE Study

- As a result: intervention telephone based but fully integrated within epilepsy services
- Who can deliver the intervention and knows about epilepsy?
- As not previously trained in mental health intervention, need to make tailoring to epilepsy explicit – epilepsy specific module/examples

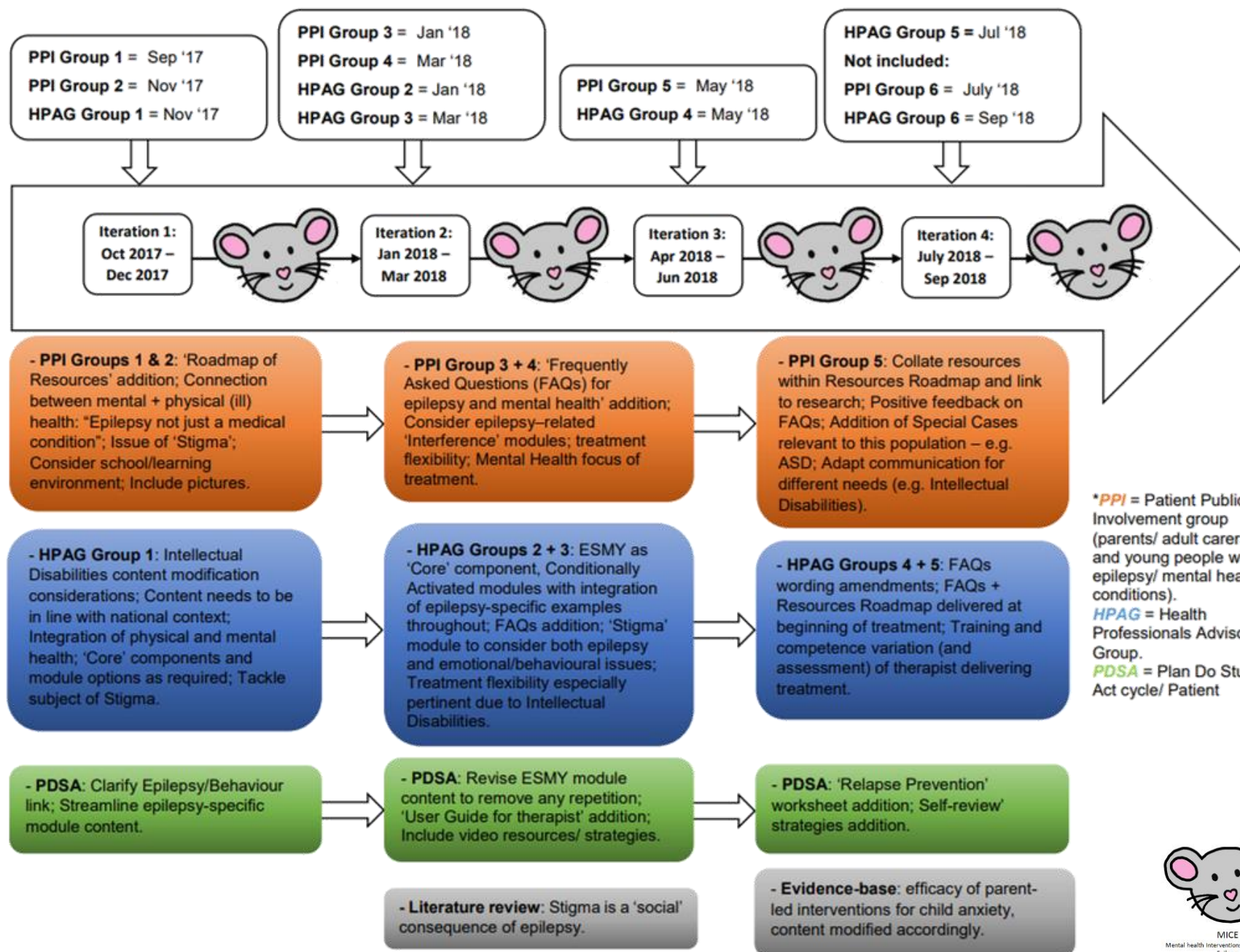
# Design

## 4 phases:

- 1. Development of epilepsy-specific module (n=12)
- 2. Training services in intervention (n=2 per therapist)
- 3. Randomised Controlled Trial, with quantitative and health economic evaluation (n=1195 screened, n=334 randomised to intervention)
- 4. Qualitative outcome and process evaluation (n=24)

## Work Package 1 (Oct 2017-18):

- Develop Multicomponent Epilepsy-Specific Module for Youth (ESMY)
- Developed iteratively with significant input from patients, carers and professionals via repeated focus groups

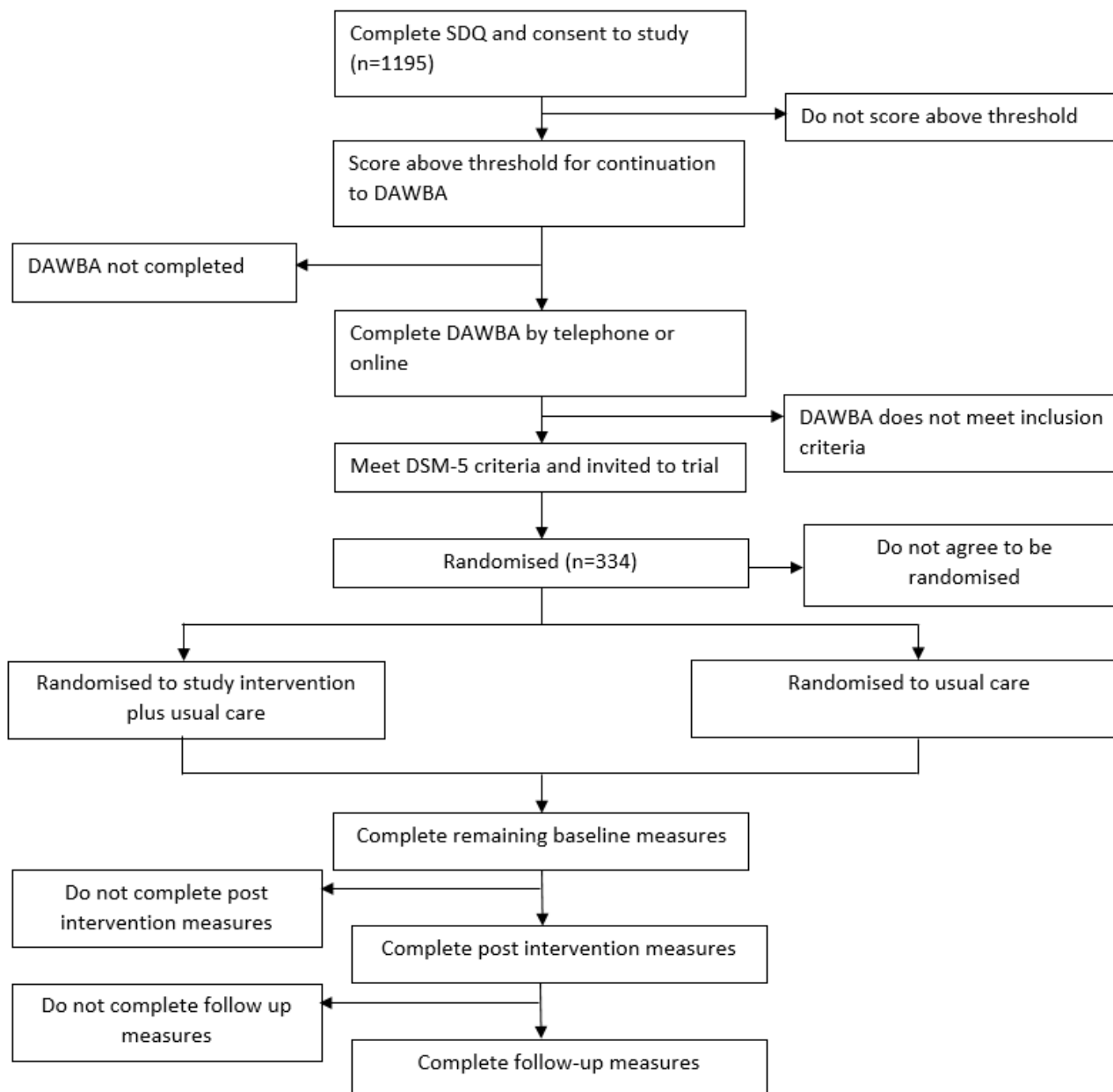


## Work Package 2: Oct 2018-April 2019

- Train therapists and their clinical supervisors across sites to deliver MATCH
- Use MATCH portfolio system to ensure therapist competence and adherence
- Therapist and patient perspectives on the intervention assessed using qualitative interviews

# Work Package 3: April 2019-April 2021

- Full Scale Randomised Controlled Trial (n=334)
- 12-16 sessions MATCH + TAU vs. TAU
- Clinical and cost-effectiveness
- 1195 children and young people across 10 sites complete SDQ
- Above threshold complete DAWBA (as in PDG)
- Those meeting DSM-5 threshold invited to trial
- Primary outcome: SDQ



## Work Package 4:

- Qualitative outcome and process evaluation
- 24 participants from WP3 (purposive sampling)
- Framework Analysis and Interpretative Phenomenological Analysis

# Consultation/support





- Complete TAU form and consent forms for interviews
- Go through manual in sites
- Ask Questions!

# BREAK



10:45 – 11:15

# The user guide

- Setting the agenda....
- A brief overview
- Time to look through
- Rating adherence



## What is it?

- ‘How to’ use the manual, with hints and tips we have learned from our previous studies and clinical experience

# Philosophy of the treatment

- Flexible
- Non-blaming – there are brain differences
- Collaborative

# Practical issues

- Route to treatment: SDQ and DAWBA.
- Session timings – ideally at least weekly
- Telephone – need to make sure materials ready
- Who?
- Therapist stance – empowering and understanding – look for positives
- Homework and barriers to completion
- Help for other problems
- Further help/onward referrals



## Working over the telephone

- Ideally meet face-to-face first
- Discuss concerns
- Use verbal indications of listening and explain pauses



# Measures

- To be discussed in detail later
- Weekly measures of goals and symptoms that will be emailed before each session
- Also measures before and after the therapy and at follow-ups



# Session timing

- 10-22, average of 16
- Delivered over 6 months including boosters
- 50 minutes
- Booster sessions at 1 month and 3 months after final treatment session



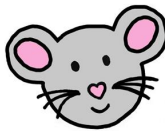
# Session content

- Structure:
  - Setting an agenda
  - Questionnaires and goal review (to be discussed later)
  - Monitoring review
  - Review homework
  - Key concepts
  - Other issues
  - Setting homework
  - Summarise




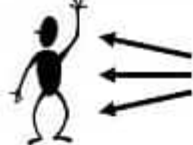



# Agenda setting

- A collaborative process
- Prioritise items
- Questions to help:
  - *What items would you like to place on the agenda for today's session?*
  - *What topics do you think are important to discuss today?*
  - *What would you like to have achieved by the end of today's session?*



# Session content: Monitoring

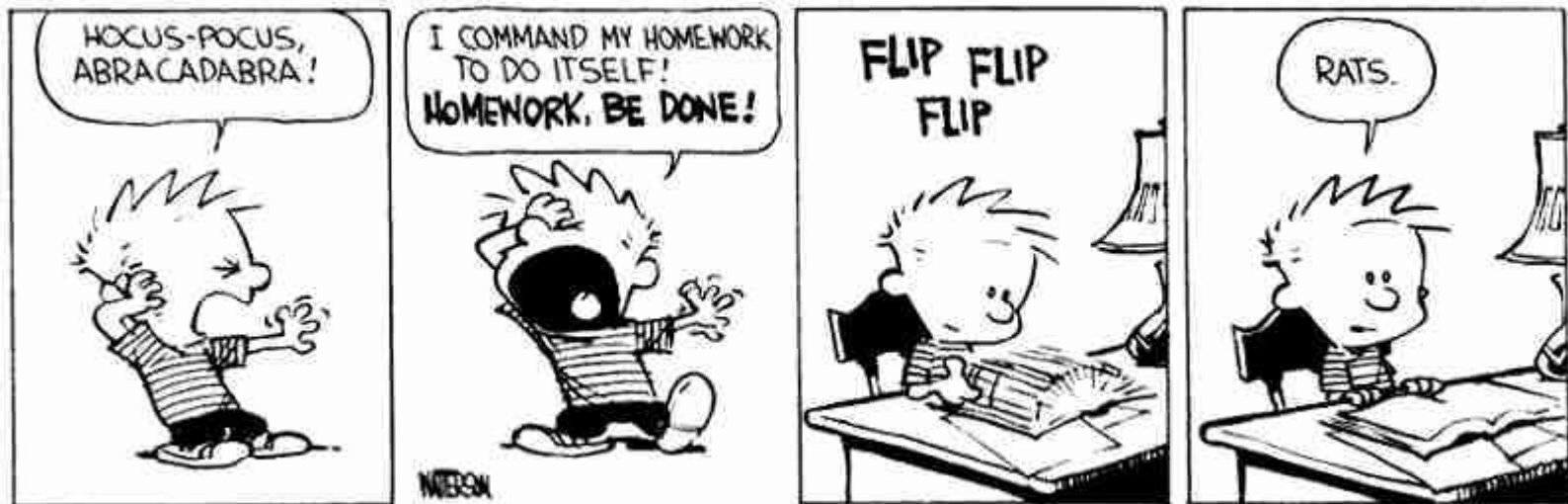
- Important but be flexible

 <b>What was going on around me?</b>	 <b>How was I feeling?</b>	 <b>What was I thinking?</b>	 <b>What did I do?</b>	<b>Did it work?</b>	 <b>What else could I have done?</b>



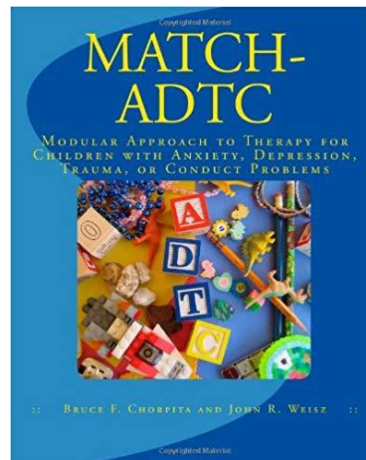
# Session content: Review homework

- Really important
- Don't move on to another strategy if not understood or not done



# Session content: The main content

- Will be discussed in more detail on other days
- Example scripts – don't need word for word
- Exercises are important
- Flexibility
- Initial sessions may progress more slowly



# Session content: Role plays

- Don't skip
- Adapt
- Verbalise
- Face-to-face is possible



# Session content: Summarise



## After the session

- **Email:** typed summary, blank measures, homework sheet, reminder of materials
- **Notes** are logged on your clinical systems
- **Measures** to be updated and saved (this will be covered later)
- **Letters** – after assessment, mid treatment, end of therapy, each booster. Templates in pack.



# Tailoring

- Flexible
- Intellectual Disability/ASD/ADHD
- Involve parents, simplify language, use pictures, have breaks



# Working with schools

- Parents can share materials



# Using consultation

- To be discussed
- Site supervisors should be informed about risk
- Please get in touch if you have questions!



# Example of homework review

- <http://www.iapt.nhs.uk/workforce/low-intensity/reach-out--students-menu/>



# LUNCH



12:45 – 13:30

# Clinical and research skills training

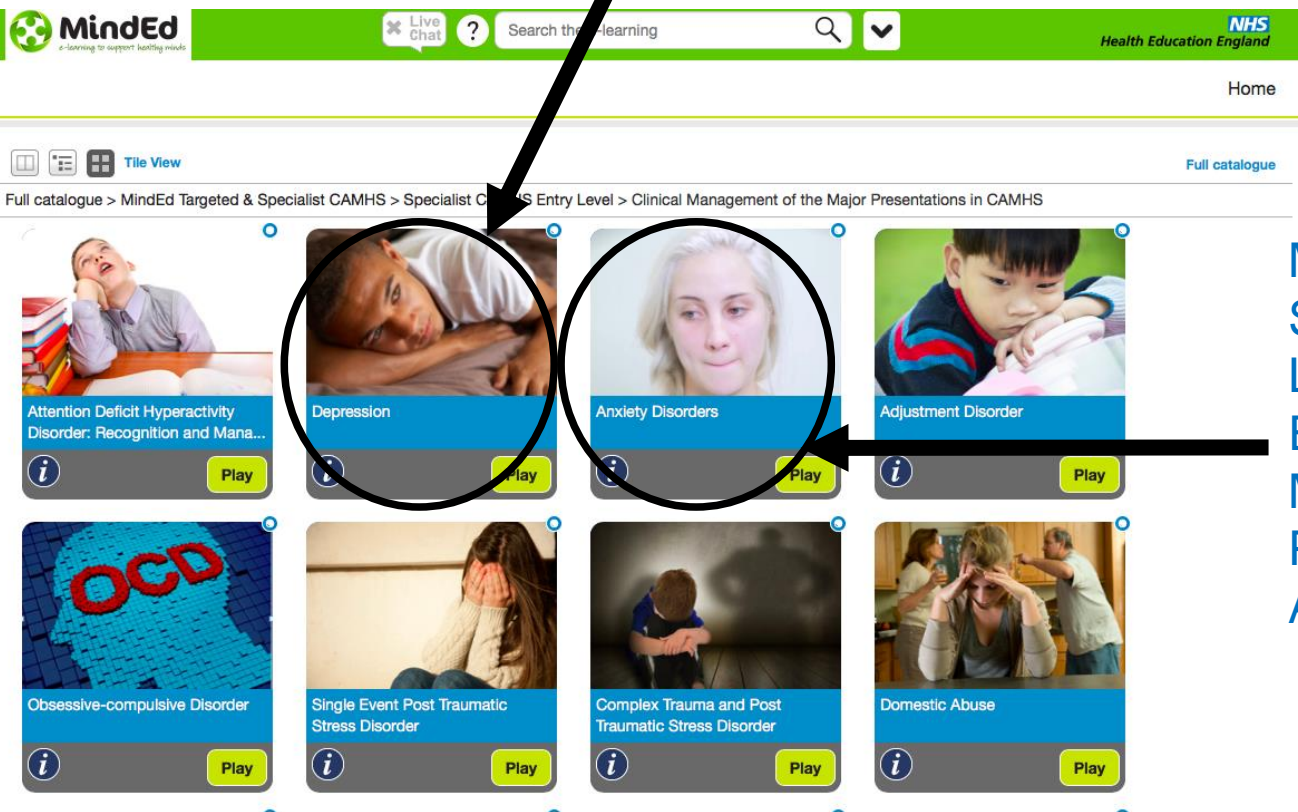
Three MindEd Sessions:

1. Depression
  2. Anxiety Disorders
  3. Oppositional Defiant Disorder and Conduct Disorder 1
- Please create an account so that your certificates can be saved!



# Anxiety disorders and depression

MindEd Targeted & Specific CAMHS Entry Level > Specialist  
CAMHS Entry Level > Clinical Management of the Major  
Presentations in CAMHS > Depression

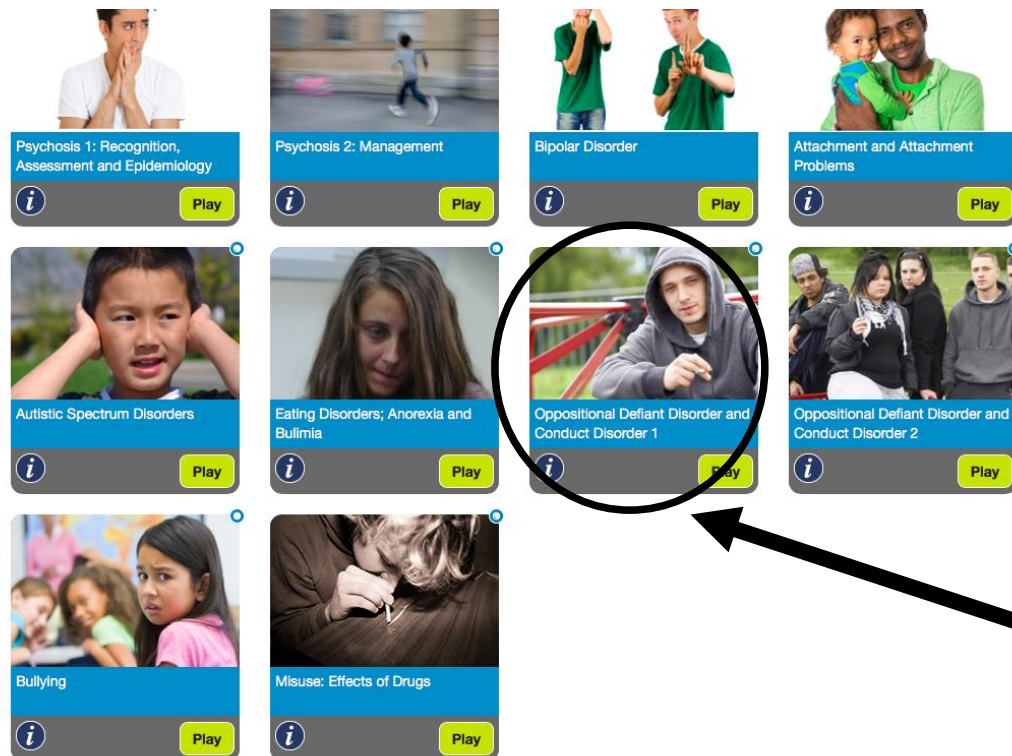


The screenshot shows the MindEd website interface. At the top, there is a green header with the MindEd logo, a search bar, and the NHS Health Education England logo. Below the header, there is a navigation bar with 'Home' and 'Full catalogue' links. The main content area displays a grid of eight tiles, each representing a mental health topic. The tiles are arranged in two rows of four. The first row includes 'Attention Deficit Hyperactivity Disorder: Recognition and Mana...', 'Depression', 'Anxiety Disorders', and 'Adjustment Disorder'. The second row includes 'Obsessive-compulsive Disorder', 'Single Event Post Traumatic Stress Disorder', 'Complex Trauma and Post Traumatic Stress Disorder', and 'Domestic Abuse'. Each tile features a representative image, the topic name, an information icon (i), and a 'Play' button. A large black arrow points from the text above to the 'Depression' tile. A smaller black arrow points from the 'Anxiety Disorders' tile to the text on the right.

MindEd Targeted &  
Specific CAMHS Entry  
Level > Specialist CAMHS  
Entry Level > Clinical  
Management of the Major  
Presentations in CAMHS >  
Anxiety Disorders



# Behavioural difficulties



MindEd Targeted & Specific  
CAMHS Entry Level > Specialist  
CAMHS Entry Level > Clinical  
Management of the Major  
Presentations in CAMHS >  
Oppositional Defiant Disorder  
and Conduct Disorder 1

# Good clinical practice

- Good clinical practice e-learning (secondary care)

## Introduction to Good Clinical Practice eLearning (Secondary Care)

### OCTOBER 2017 RELEASE

This is the latest version of the e-learning course which provides an introduction to GCP in a secondary care setting.

This course is now open to all users of NIHR Learn with a verified system account. To access the course, click the course title above and then click 'Enrol me' at the bottom of the next page.

For face to face workshops see the [Local Learning](#) section.



<https://learn.nihr.ac.uk/course/index.php?categoryid=38>

# Information governance

- Data security level 1

## About the Data Security Awareness programme

The Data Security e-learning programme has been designed to support staff in health and social care Level 1 – Data security awareness:

This course is mandated for everyone working in health and care. It has been designed to inform, educate and upskill staff in data security and information sharing. It provides an understanding of the principles and importance of data security and information governance. It looks at staff responsibilities when sharing information and includes a section on how to take action to reduce the risk of breaches and incidents.

This training has been produced by the NHS Digital and the External Information Governance Delivery team, in collaboration with partners across health and care.



## Level 1 - content

Welcome Module

This is an overview of navigation through the eLearning modules and the overall training requirements and course structure.

A certificate will be produced for those who pass all the assessments. The pass mark for the course is 80%.

This course will take approximately one hour to complete.

**Module 1 - Introduction to Data Security Awareness**  
Aims and Objectives

**Module 2 -Introduction to the Law**  
Aims and Objectives

<https://www.e-lfh.org.uk/programmes/data-security-awareness/>

