



**Barn- och ungdomspsykiatri**

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**Karolinska  
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*OCD and related disorders in young people:  
Innovation and consolidation*

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# Disclosures



- I have no relevant financial or nonfinancial relationships to disclose

# Funders



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tourette syndrome association



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# Child and Adolescent Psychiatry Research Centre



- Official opening: Sept 2013



# OCD and related disorders at KI/SLL



**Karolinska  
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## Research group

- Clinical research
- Genetic epidemiology
- Neuroscience



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## Specialist clinic

- Regional and national referrals
- Multiple packages of care
- Treatment development/testing

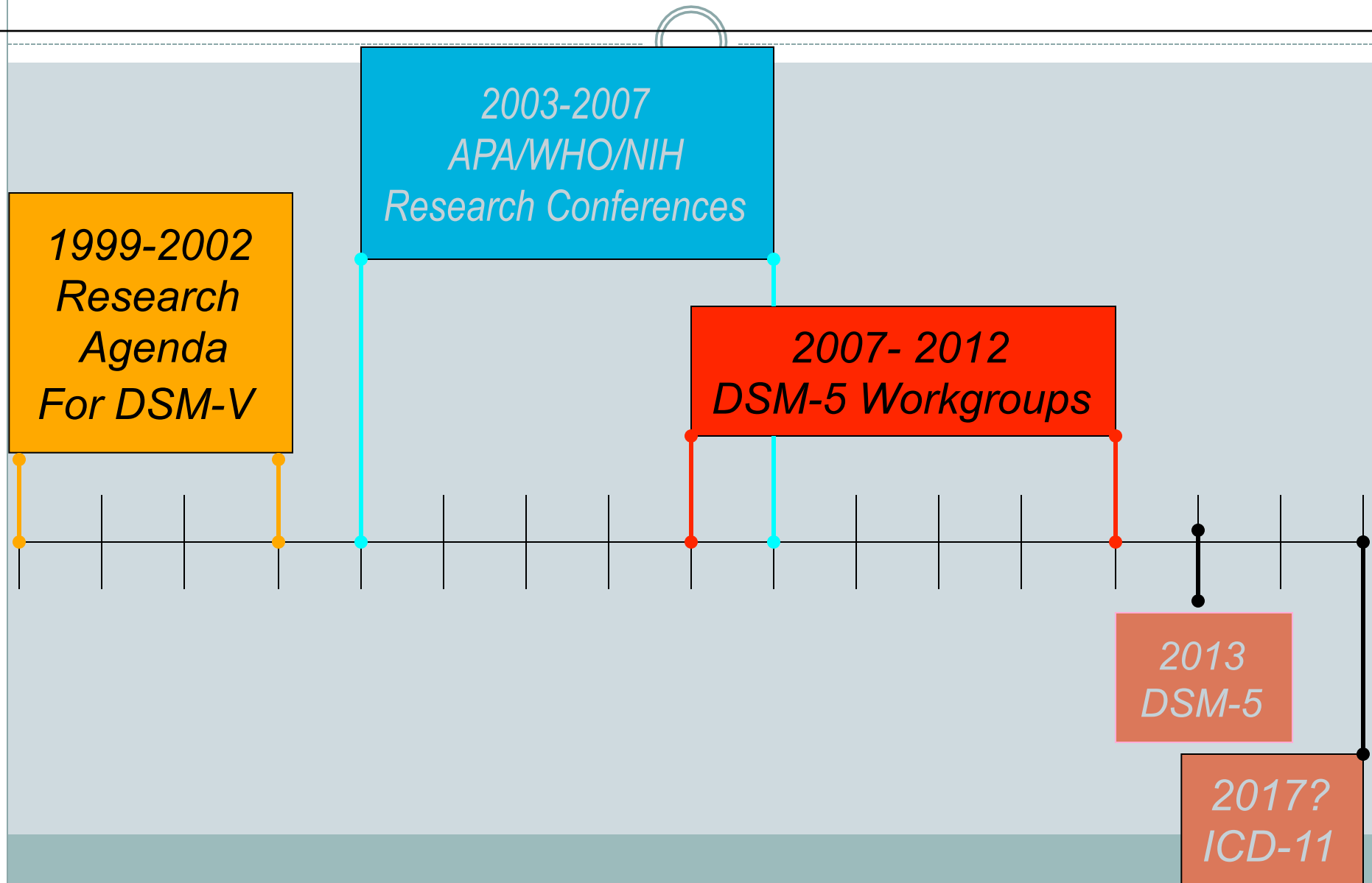
*Full integration of  
clinic and research*

# Overview of this lecture



- OCD-RDs chapter in DSM-5/ICD-11
- Evidence-based treatments
- Unmet needs and challenges
- Improving outcomes through innovation and consolidation

# DSM-5/ICD-11 Timeline



# New 'OCD and Related Disorders' Chapter in DSM-5



## ***OBSESSIVE-COMPULSIVE AND RELATED DISORDERS***

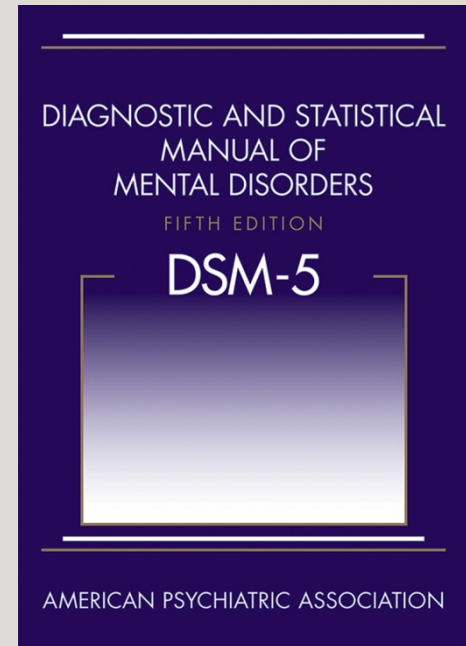
*OBSESSIVE-COMPULSIVE DISORDER*

*BODY DYSMORPHIC DISORDER*

*HOARDING DISORDER*

*TRICHOTILLOMANIA (HAIR-PULLING DISORDER)*

*EXCORIATION (SKIN-PICKING) DISORDER*



*American Psychiatric Association, 2013*

- *Chronic Tic Disorders remain in Childhood Disorders*
- *Hypochondriasis remains in Somatic Disorders*



# ICD-11 (due 2017)



## ICD-11 Beta Draft (Foundation)

Search



▼ Obsessive-compulsive and related disorders



Tourette syndrome

Idiopathic chronic motor or phonic tics

▶ Obsessive-compulsive disorder

▶ Body dysmorphic disorder

▶ Olfactory reference disorder

▶ Hypochondriasis

▶ Hoarding disorder

▶ Body-focused repetitive behaviour disorders

Secondary obsessive-compulsive or repetitive habit

# DSM-5 Obsessive-Compulsive and Related Disorders SubWorkgroup: Main issues



- What refinements are needed to the diagnostic criteria?
- How strong is the evidence for specific OCD subtypes and symptom dimensions?
- Should OCD leave the Anxiety Disorders grouping?
- Should an Obsessive-Compulsive Spectrum Grouping of Disorders Be Included in DSM-5?
- If so, what disorders should be included?

# Refinements to the OCD criteria in DSM-5



- Word ‘impulse’ changed to ‘urge’
- Obsessions and compulsions are ‘time consuming’ (from 1h to e.g. 1 hour)
- Expand insight specifier to 3 categories:
  - Good or fair insight
  - Poor insight
  - Absent insight (delusional beliefs)
- Add tic-related specifier

# OCD subtypes



- Tic-related OCD
  - Highly familial, specific characteristics (sensory phenomena), course and differential response to SRIs (but not CBT!)
  - Most experts agree it's a valid subtype
- Early-onset OCD
  - Some special features but evidence is less compelling. One problem is the definition of 'early onset'
- PANDAS/PANS
  - Some supporting evidence but remain controversial
  - 53% of OCD experts do not agree (Mataix-Cols et al 2007)

**Recommendation: add tic-related OCD as specifier in DSM-5**

# OCD is clinically heterogeneous



Contamination/  
Washing



Obsessions/ Checking



Hoarding/Saving



Symmetry/  
Order/" Just



# OCD dimensions

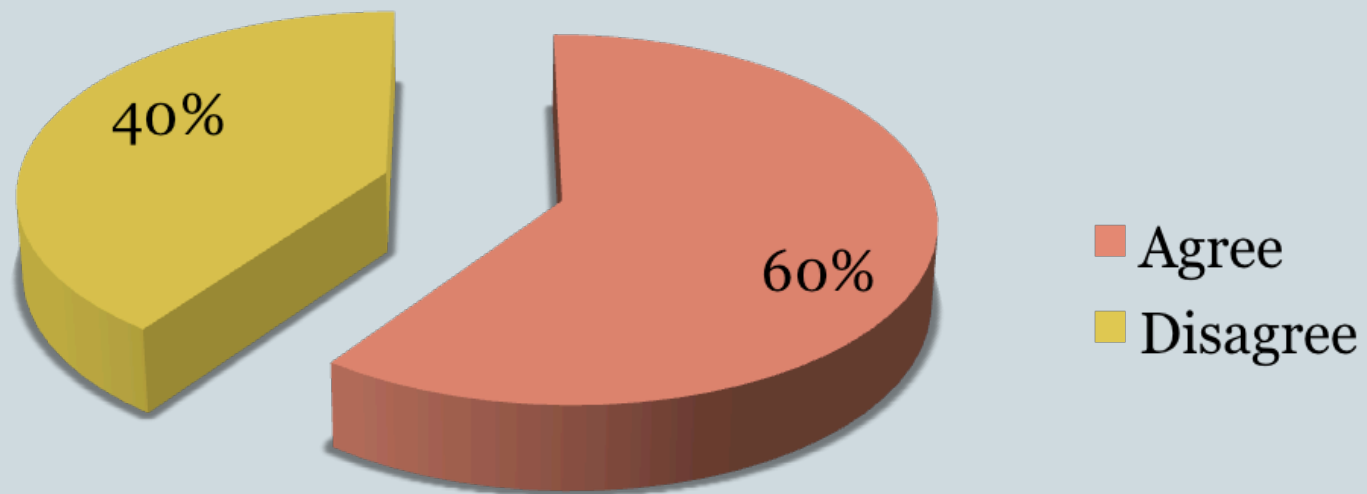


- OCD is clearly clinically and etiologically heterogeneous
- There may be clinical value in identifying main OCD dimensions to guide treatment
- Wide support from experts
- However, not needed to establish diagnosis
- Additional burden for clinicians
- Recommendation: to list them in the text

# Should OCD leave the Anxiety Disorders grouping?



*EXPERTS: NO CONSENSUS!!*



# Initial recommendation (some time in 2010)



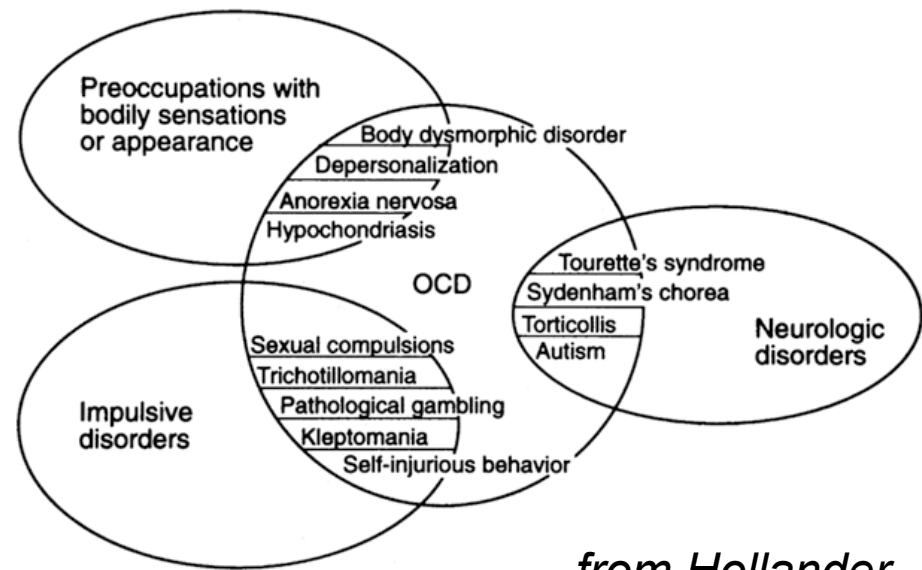
- OCD to be retained in the category of anxiety disorders, but that the name of this category be changed to reflect the uniqueness of OCD
- Some options are:
  - “Anxiety and Obsessive-Compulsive Disorders”, or
  - “Anxiety, Posttraumatic and Obsessive-Compulsive Disorders”
- Compromise option that would acknowledge similarities and differences
- Would bring DSM and ICD closer together
- **Eventually OCD was separated from anxiety disorders**



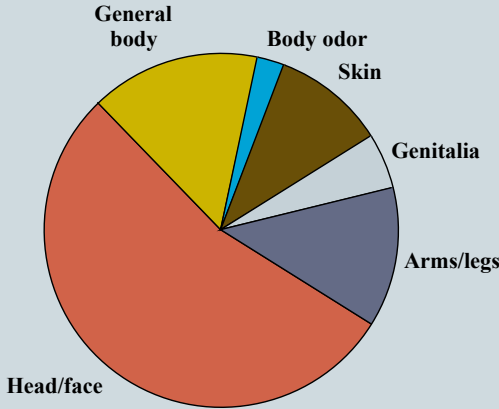
# OCD 'Spectrum'



- An OC-spectrum grouping of disorders should be included in DSM-5
- This should be narrow and only include a few disorders



# Body Dysmorphic Disorder



## DSM-5 Diagnostic Criteria for Body Dysmorphic Disorder (© APA 2013)

- A. **Preoccupation with one or more perceived defects or flaws in physical appearance** that are not observable or appear slight to others.
- B. At some point during the course of the disorder, **the individual has performed repetitive behaviors** (e.g., mirror checking, excessive grooming, skin picking, reassurance seeking) **or mental acts** (e.g., comparing his or her appearance with that of others) in response to the appearance concerns.
- C. The preoccupation causes clinically **significant distress or impairment** in social, occupational, or other important areas of functioning.
- D. The appearance preoccupation is **not better explained by concerns with body fat or weight** in an individual whose symptoms meet diagnostic criteria for an eating disorder.

*Specify if:*

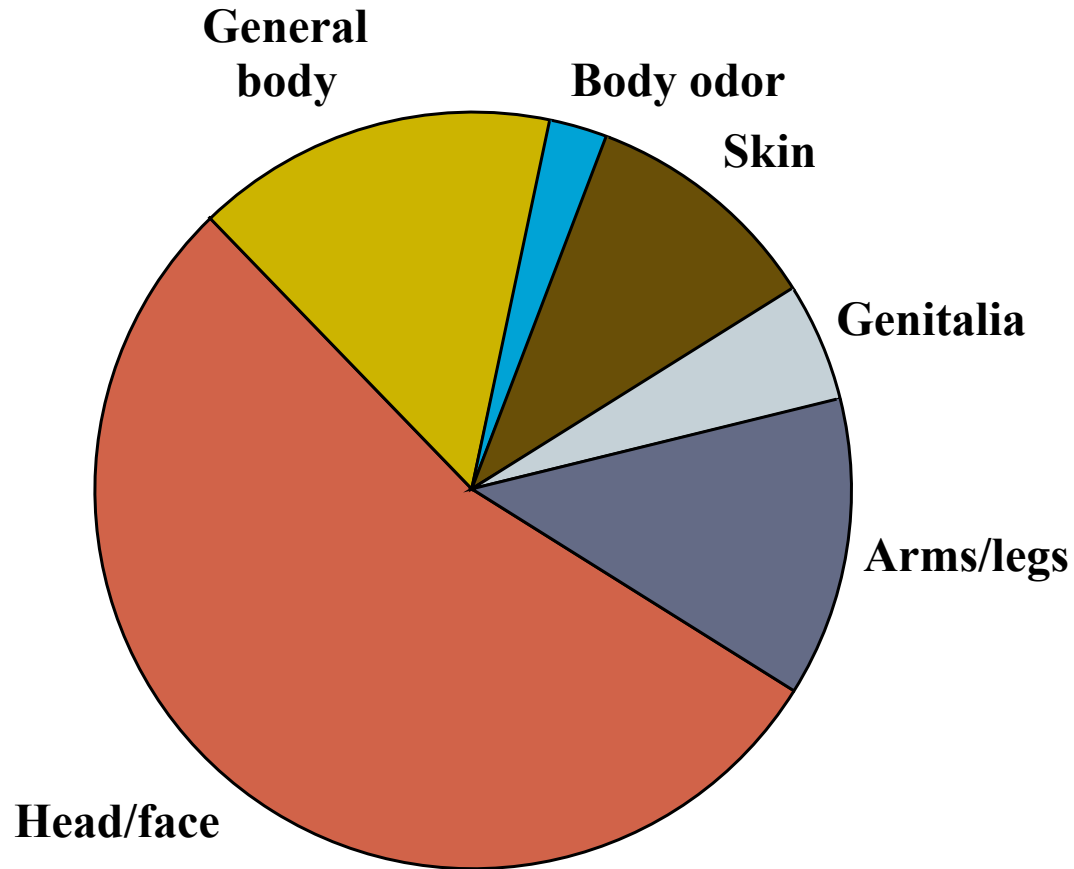
**With muscle dysmorphia:** The individual is preoccupied with the idea that his or her body build is too small or insufficiently muscular. The specifier is used even if the individual is preoccupied with other body areas, which is often the case.

*Specify if:*

Indicate degree of **insight regarding BDD beliefs** (e.g., "I look ugly" or "I look deformed").

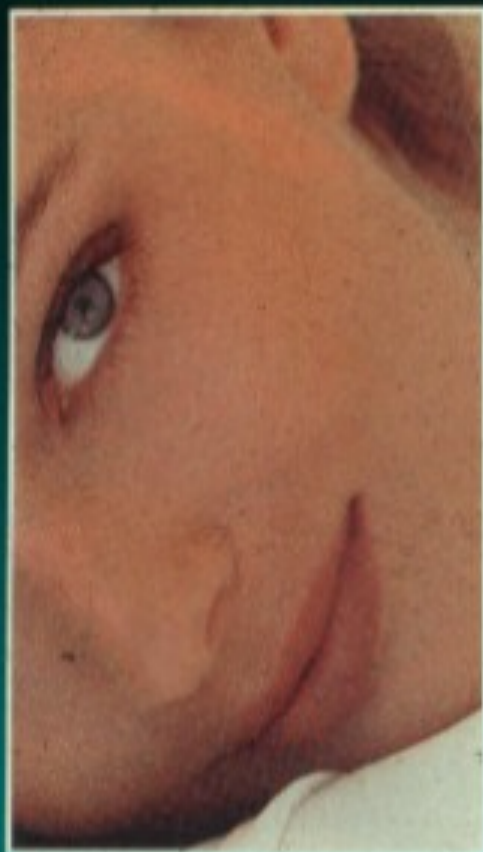
With good or fair insight | With poor insight | With absent insight/delusional beliefs.

# Areas of perceived defect

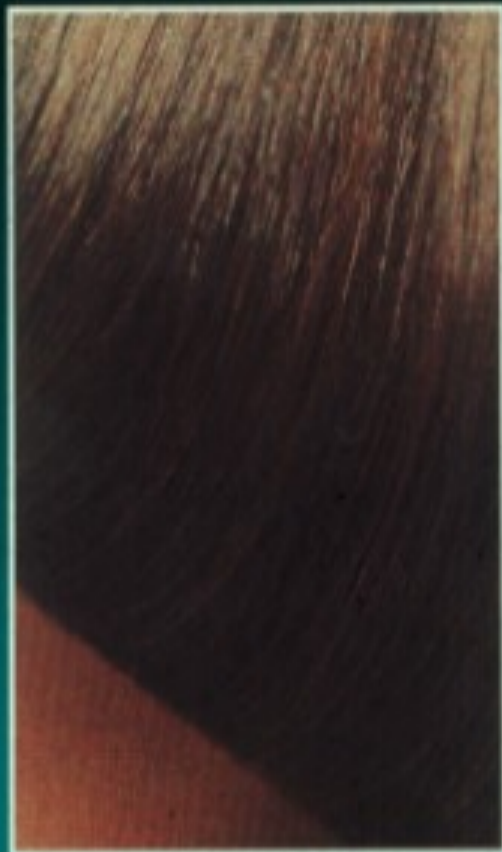


# Focus of Concern

**Skin: 65%**



**Hair: 50%**



**Nose: 38%**



# Phenomenology: 'Obsessions'

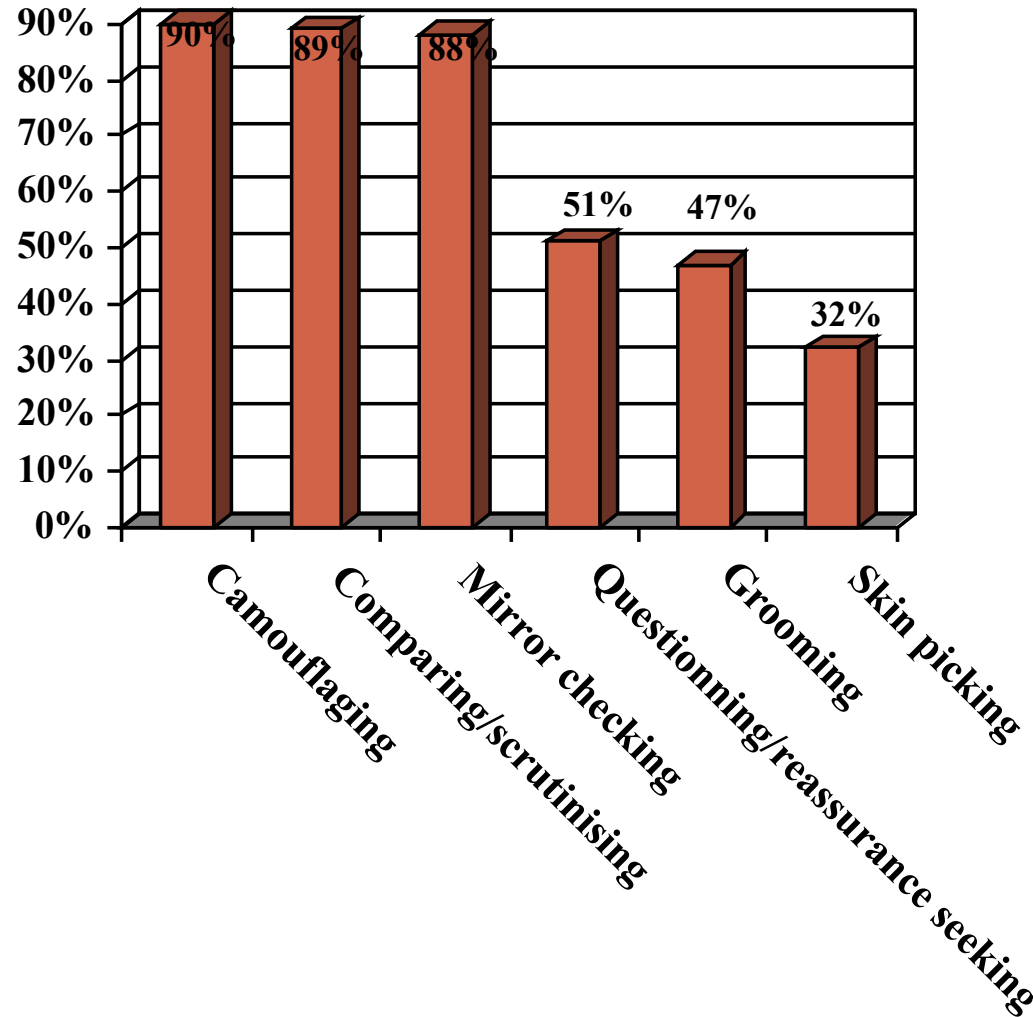
## Like OCD

- Intrusive, persistent, repetitive, unwanted thoughts
- Usually recognized as excessive (in terms of time spent)
- Recognized as own thoughts
- Cause anxiety and distress
- Usually resisted
- Sometimes similar content and core beliefs (e.g., symmetry)

## Unlike OCD

- BDD patients have poorer insight. ~2% of OCD patients are currently delusional vs 27%-39% of BDD patients.
- Underlying core beliefs in BDD focus more on unacceptability of the self -- e.g., being unlovable, inadequate, worthless. Moral repugnance is unusual.

# Phenomenology: Ritualistic behaviours



# BDD

- Estimated prevalence of approximately 2% in community samples of adults.
- Associated with high levels of occupational and social disability, including absenteeism, unemployment, marital dysfunction, and reduced quality of life.
- Adolescent onset reported in 70% of cases...
- ... but has received little empirical attention in this age group.



## BDD in adolescents

- Results in major functional impairment (e.g., reduced academic performance, social withdrawal, dropping out from school).
- High suicidality rates (reported 21-44% of patients attempting suicide).

# Why is BDD under-diagnosed?



- Patients often seek non-psychiatric treatment
- Some mental health clinicians are unfamiliar with BDD
- Patients are secretive about the condition
- Young people: Symptoms are often mistaken as normal developmental concerns

*Often, to make the diagnosis, BDD symptoms have to be specifically asked about*

# Simple BDD screening questions



- *Concern with appearance:* Are you very worried about your appearance in any way? (OR: Are you unhappy with how you look?) If yes, What is your concern?
- *Preoccupation:* Does this concern preoccupy you? That is, do you think about it a lot and wish you could think about it less? (OR: How much time would you estimate you think about your appearance each day?)
- *Distress or impairment:* How much distress does this concern cause you? Does it cause you any problems socially, in relationships, or with school/work?

# Cosmetic treatments: Bad idea!



- 76% sought non-psychiatric treatment
- Received treatment: 60% (45% dermatological; 23% surgical)
- Surgeries per patient: mean=2, SD=1.4, range: 1-8
- Outcome
  - No change or worse: 69%
  - New appearance preoccupations can develop
  - Spiral of multiple procedures
  - Doctors can be sued and even attacked by dissatisfied clients!

# Hoarding Disorder:

## A new mental disorder in DSM-5



*The majority report that their problems began in the teenage years*

*Approx 2% of Swedish teenagers report difficulties discarding (Ivanov, 2013)*



*Substantial health risks*

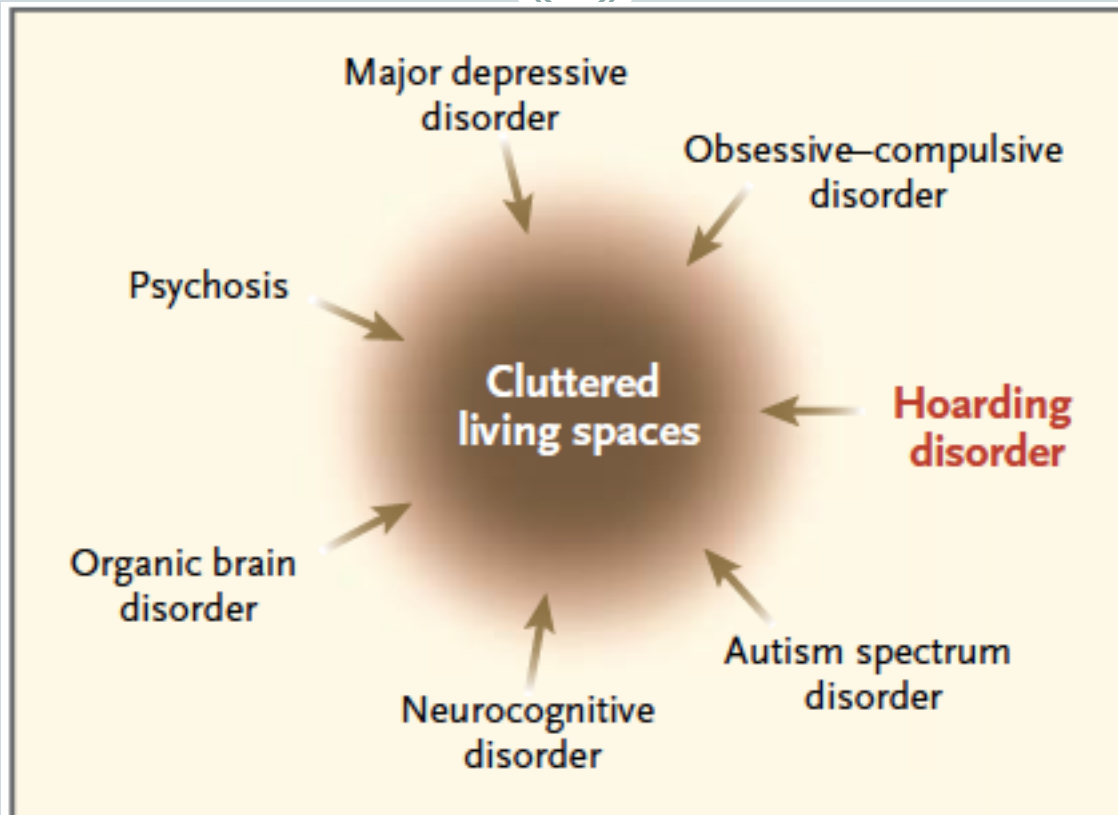
*Most sufferers are diagnosed as adults*

# Hoarding Disorder: Diagnostic criteria



- A. Persistent difficulty discarding or parting with possessions, regardless of their actual value.
- B. The difficulty is due to a perceived need to save items and to distress associated with discarding them.
- C. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If all living areas are uncluttered, it is only because of the interventions of third parties (e.g. family members, cleaners, authorities).
- D. The hoarding causes clinically significant distress or impairment in social, occupational or other important areas of functioning (including maintaining a safe environment for self and others).
- E. The hoarding is not attributable to another medical condition (e.g. brain injury, cerebrovascular disease, Prader-Willi syndrome).
- F. The hoarding is not better explained by the symptoms of another mental disorder (e.g. obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

# Differential Diagnoses



**Figure 2. Differential Diagnosis of Hoarding Disorder.** A careful psychopathological interview is necessary to establish the differential diagnosis of hoarding disorder.

# Collecting: a widespread human activity



- Up to 70% of children own a collection (Evans et al 1997)
- 30% of British adults have a collection at any given time (Pearce, 1998)
- Regarded as normative and benign





# Hoarding Disorder: Specifiers



## **1 - Specify if:**

*With Excessive Acquisition: If difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space.*

## **2 - Specify if:**

*With good or fair insight: The individual recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter or excessive acquisition) are problematic.*

*With poor insight: The individual is mostly convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter or excessive acquisition) are not problematic despite evidence to the contrary.*

*With absent insight/delusional beliefs: The individual is completely convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter or excessive acquisition) are not problematic despite evidence to the contrary.*

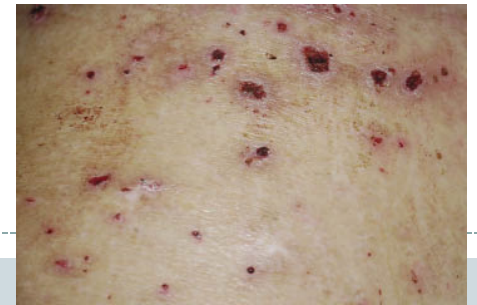


# Trichotillomania (Hair-Pulling Disorder)

Diagnostic Criteria

**312.39 (F63.2)**

- A. Recurrent pulling out of one's hair, resulting in hair loss.
- B. Repeated attempts to decrease or stop hair pulling.
- C. The hair pulling causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The hair pulling or hair loss is not attributable to another medical condition (e.g., a dermatological condition).
- E. The hair pulling is not better explained by the symptoms of another mental disorder (e.g., attempts to improve a perceived defect or flaw in appearance in body dysmorphic disorder).



## Excoriation (Skin-Picking) Disorder

Diagnostic Criteria

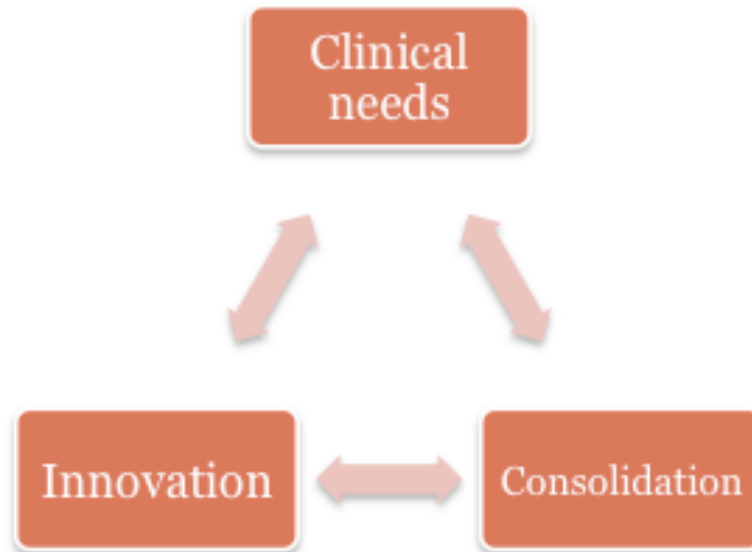
698.4 (L98.1)

- A. Recurrent skin picking resulting in skin lesions.
- B. Repeated attempts to decrease or stop skin picking.
- C. The skin picking causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The skin picking is not attributable to the physiological effects of a substance (e.g., cocaine) or another medical condition (e.g., scabies).
- E. The skin picking is not better explained by symptoms of another mental disorder (e.g., delusions or tactile hallucinations in a psychotic disorder, attempts to improve a perceived defect or flaw in appearance in body dysmorphic disorder, stereotypies in stereotypic movement disorder, or intention to harm oneself in nonsuicidal self-injury).

# Treatment of OCD-RDs: MAIN CHALLENGES

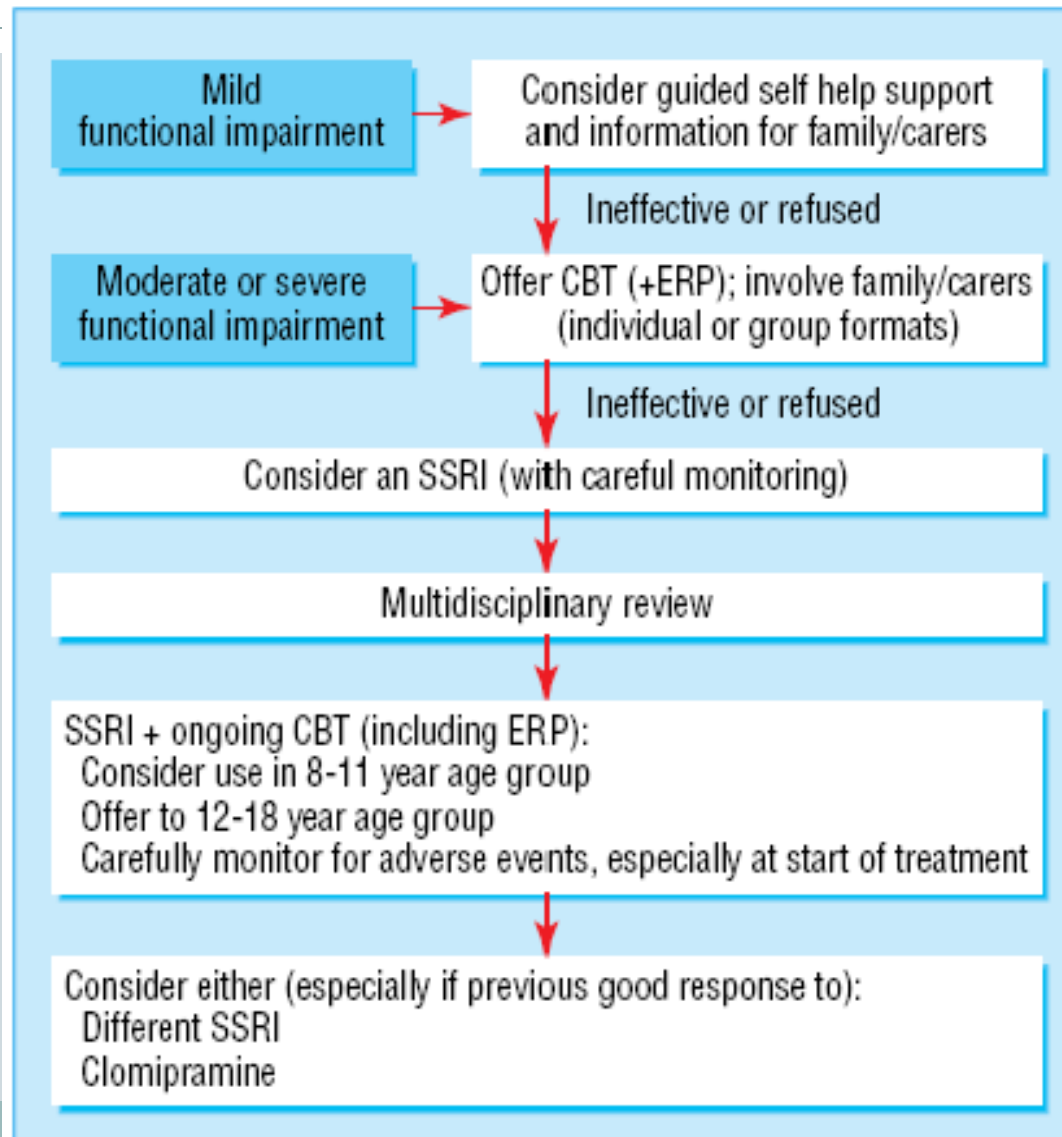
*SOME OCD  
PATIENTS DO NOT  
RESPOND TO TR*

*WE DO NOT HAVE  
TREATMENTS FOR  
OCD-RDS*



*WE HAVE GOOD  
TREATMENTS FOR  
OCD BUT MOST  
CHILDREN ARE  
NOT RECEIVING  
THEM*

# NICE guidelines for OCD: Children

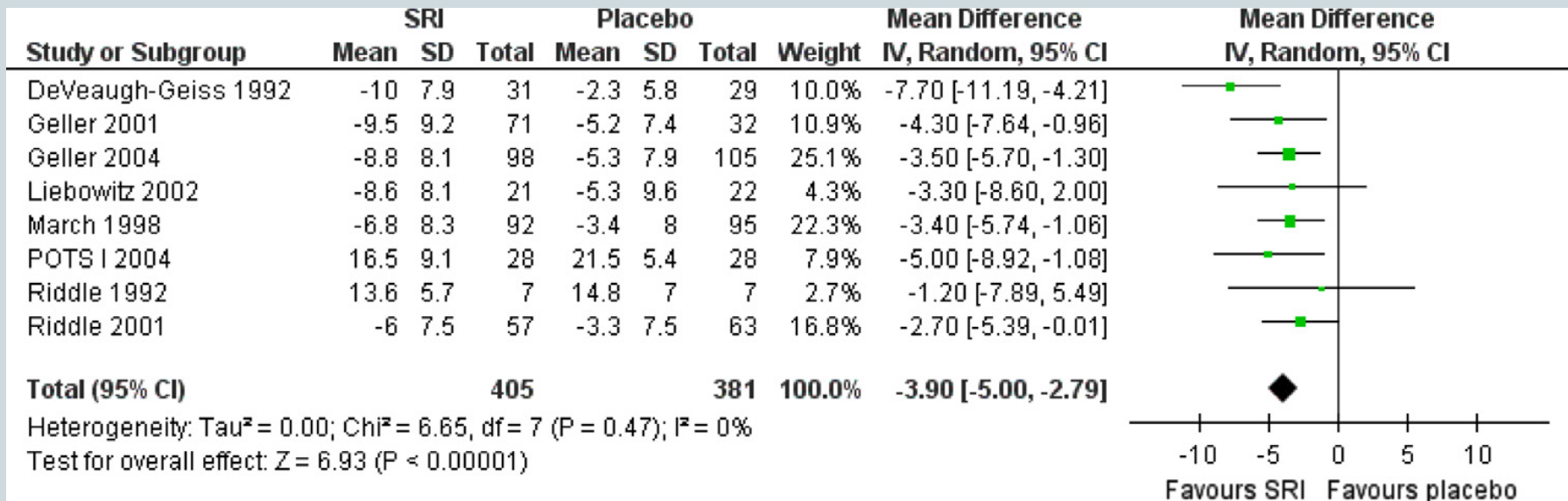


# OCD: Evidence-based treatments **Work!**



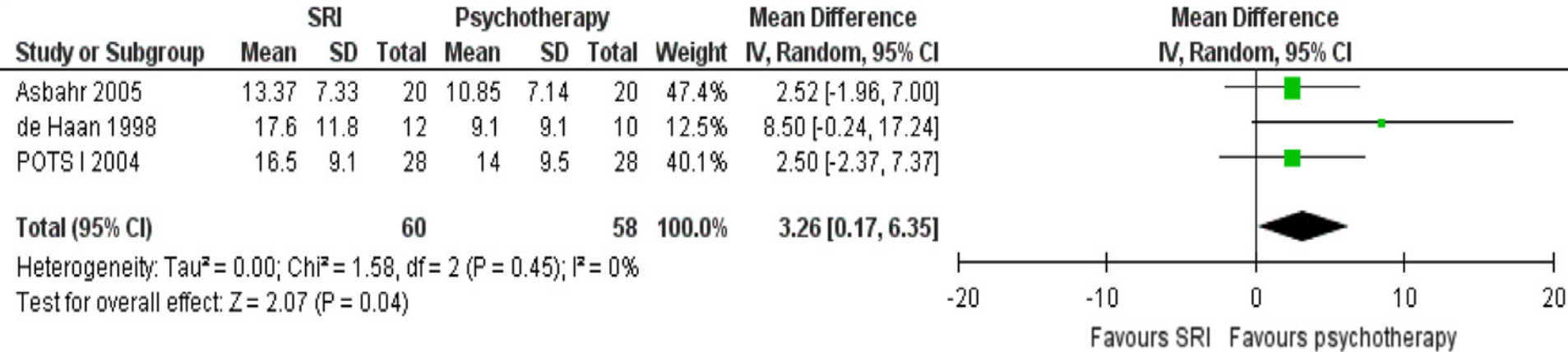
- Cognitive behaviour therapy (ERP) +/- medication (SRI) are effective treatments in 60-70%: (Heyman et al, 2006; Turner, 2005; POTS, 2004)
- Unclear if combining CBT and medication is superior to CBT alone; probably not (POTS, 2004; Ivarsson et al 2015)
- Individual or group + family therapy (Barrett et al 2004)
- ERP or CBT (Bolton et al 2011)
- Long or short duration (12 sessions vs 5 sessions) (Bolton et al 2011)
- Very early age of onset vs later age of onset (Nakatani et al 2011; POTS Jr)

# Meta-analysis of SRI trials: Effective but effect sizes are modest



Ivarsson et al (2015), *Psychiatry Res*

# CBT probably superior to SRIs



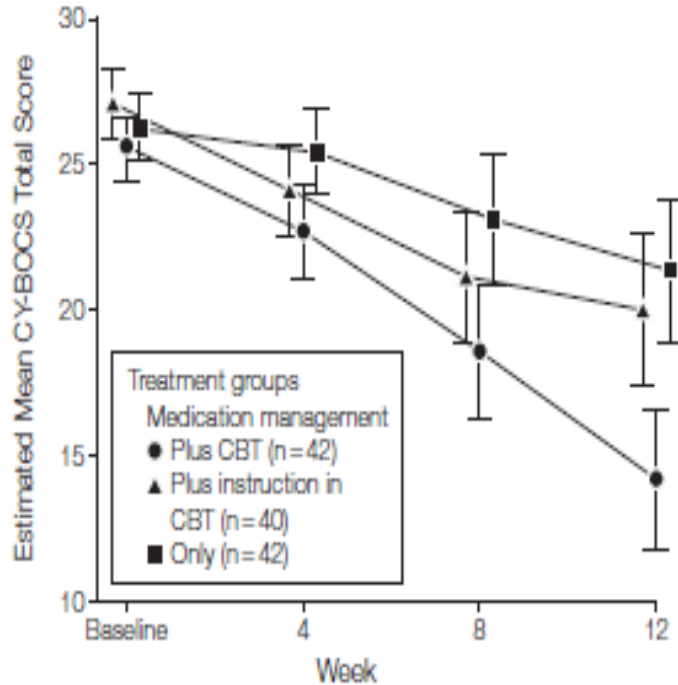
*Ivarsson et al (2015), Psychiatry Res*



# SRI non-responders (POTS II study)



**Figure 2.** Children's Yale-Brown Obsessive Compulsive Scale (CY-BOCS) Scores During 12 Weeks of Acute Treatment



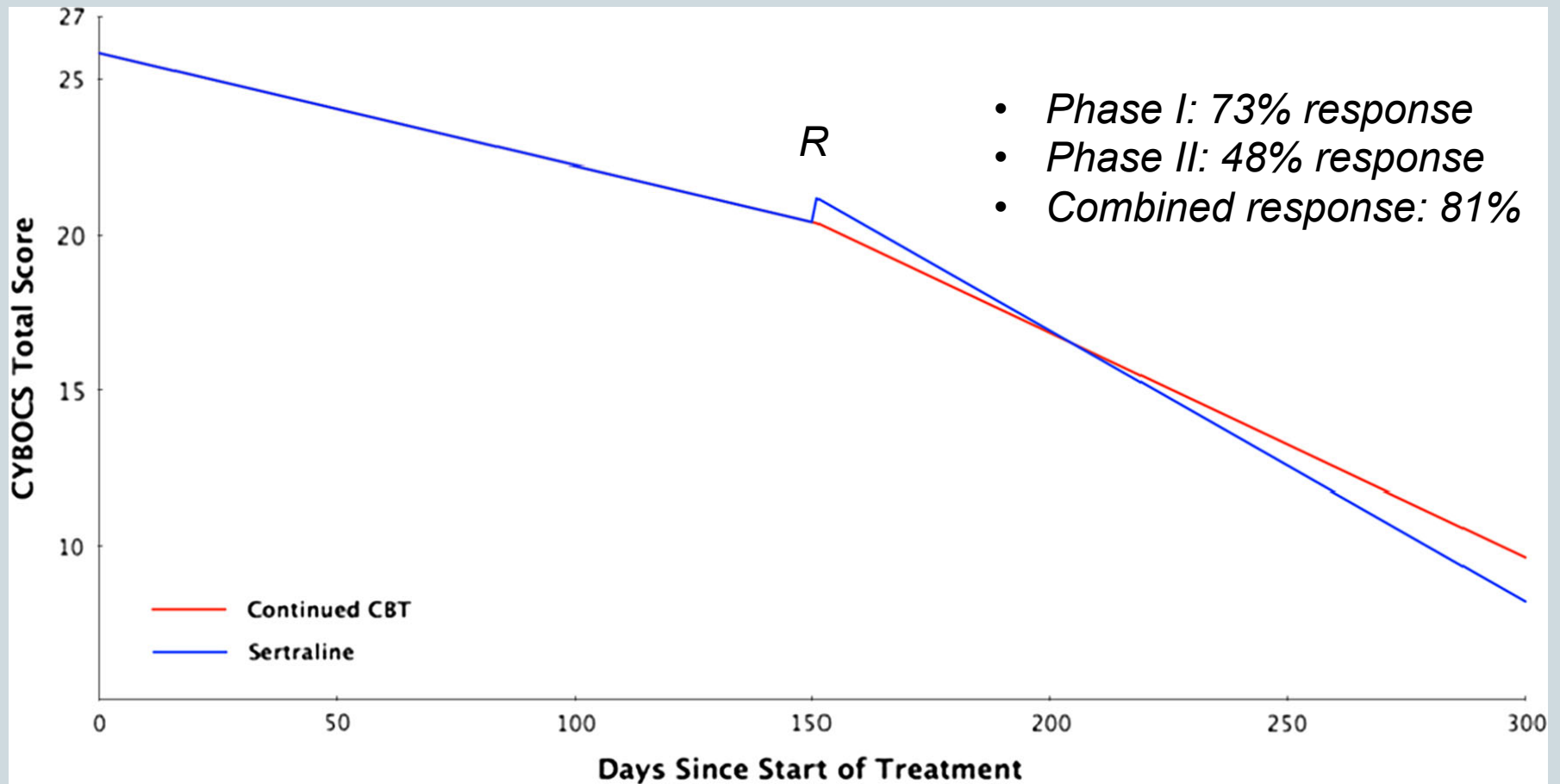
Responders

Medication: 30%

CBT instructions: 34%

CBT: 68%

# CBT non-responders (NordLOTS study)



# The many challenges of OCD

*The Secret Problem*

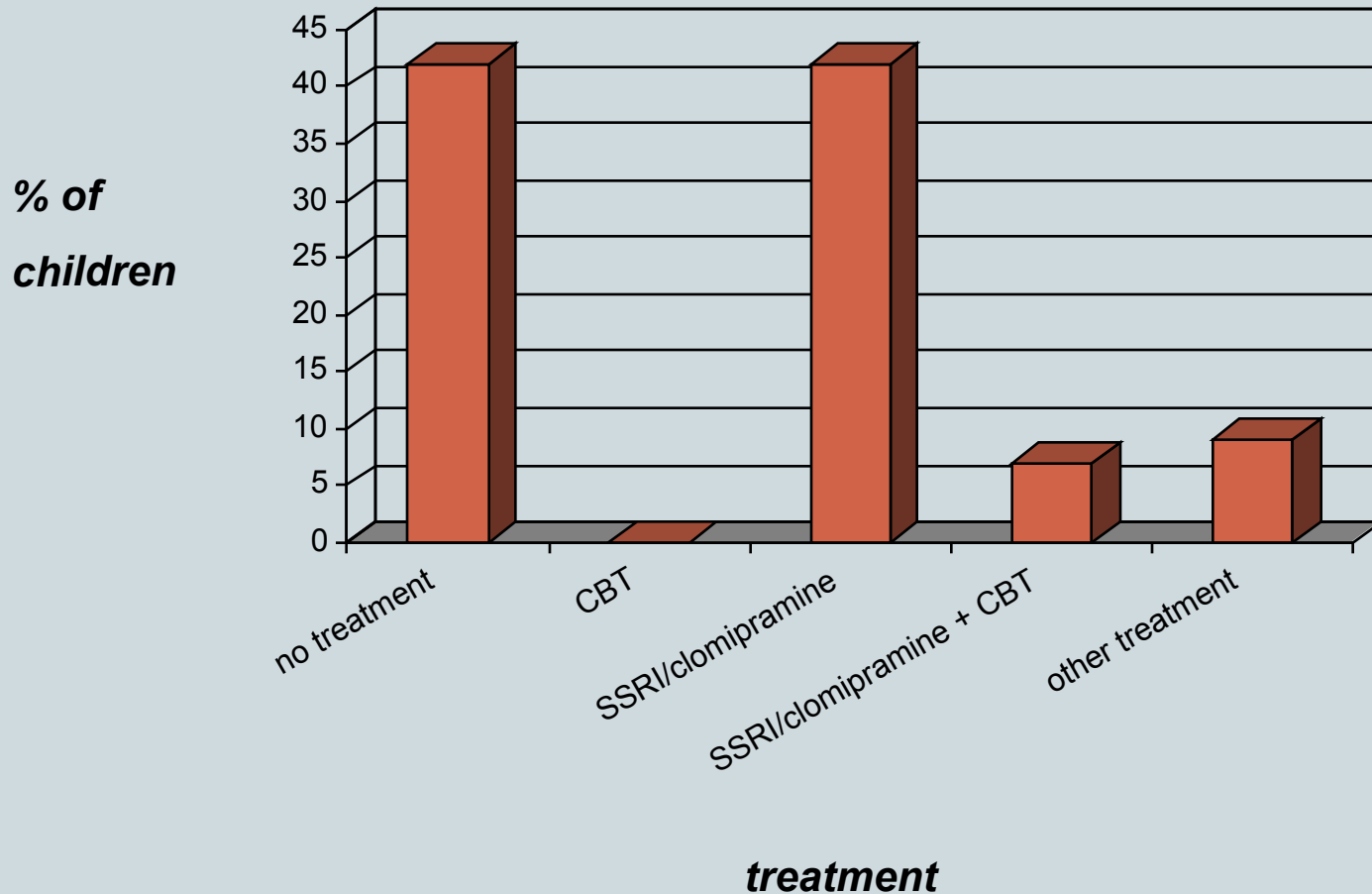


Written by Chris Weaver  
Drawn by Neil Phillips

A Skunk-Top Press Book

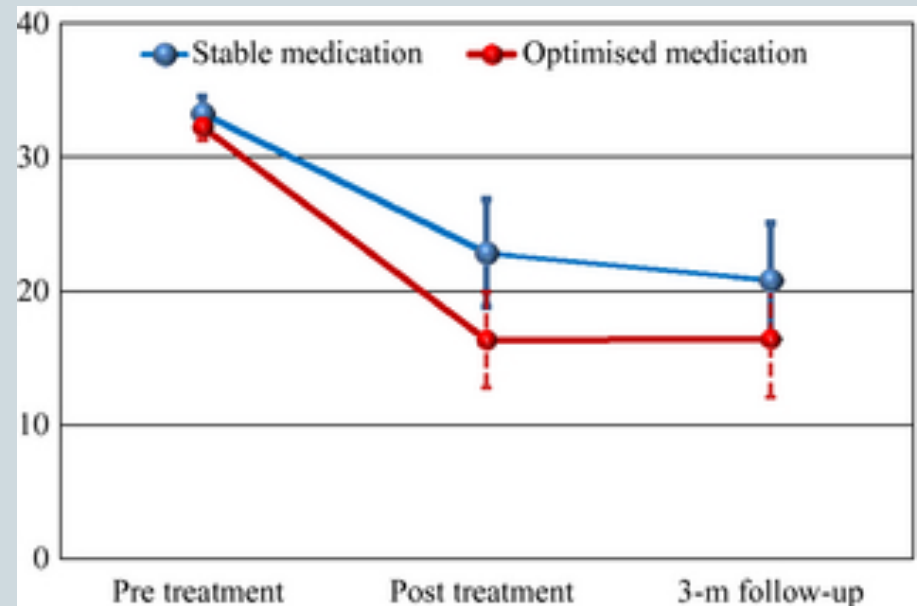
- Some patients (1/3) do not respond sufficiently
- Long delays in the detection of OCD
  - 17 years on average in adults (Hollander et al., 1998)
  - 3 years on average in children (Chowdhury et al., 2004)
- Misdiagnosis is not uncommon
- Need for increased recognition at the earliest stages of the disorder (Micali et al., 2010) → BETTER OUTCOMES
- Once diagnosed, patients not always getting the right treatments, particularly CBT (e.g., Choddhury et al 2004)
- Ethnic inequalities (Williams et al., 2010; Fernández de la Cruz et al., in press)

# Maudsley clinic: young people with OCD had rarely received CBT before assessment



# How resistant is 'treatment-resistant' OCD?

- *CYBOCS >30*
- *Previous failure*
  - ✦ *CBT \**
  - ✦ *SSRI*
- *58% responded to treatment*
- *22% in remission*
- *Medication group tended to do better (non-sign)*



*\* CBT inadequate in 95.5% of cases  
(insufficient focus on ERP)*

# Pharmacoepidemiology of pediatric OCD (N=905)



- 85% RECEIVE AN SSRI
- **ONLY 53% RECEIVE ADEQUATE DOSE!**
- **ONLY 43% RECEIVE AN ADEQUATE DOSE FOR ONE YEAR OR LONGER**

*SRI prescription guidelines  
American Academy of Child and  
Adolescent Psychiatry (2012)*

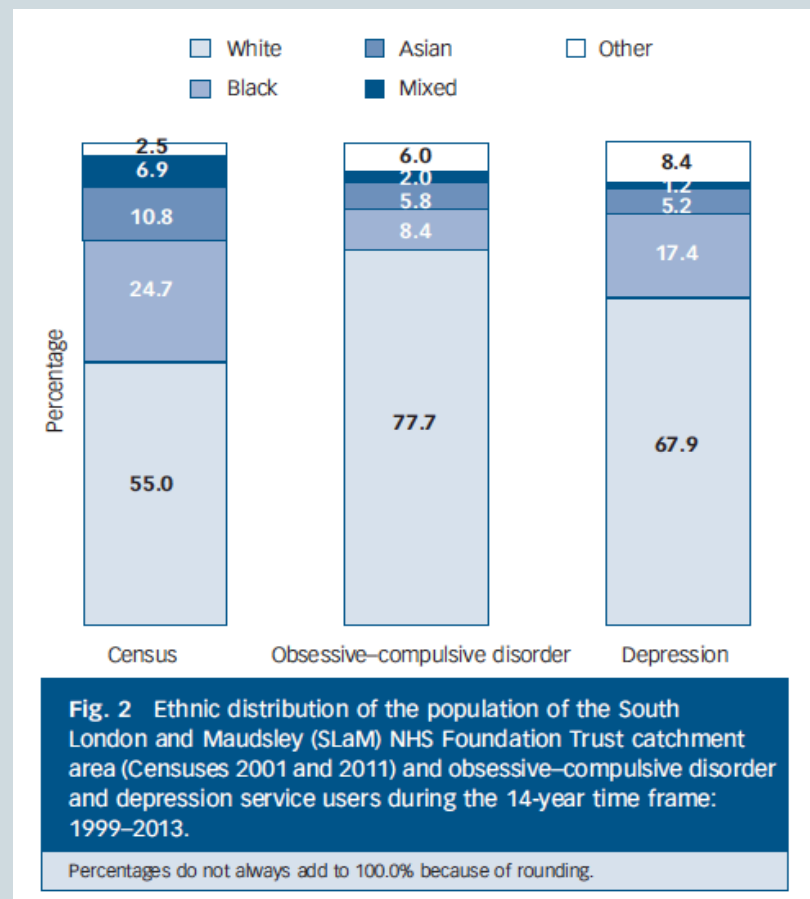
	<b>Dosage range</b>
Citalopram	10-60
Clomipramine	50-300
Escitalopram	-
Fluoxetine	10-80
Fluvoxamine	50-300
Paroxetine	10-60
Sertraline	50-200

*Swedish National Patient Register  
Swedish Prescriptions Register*

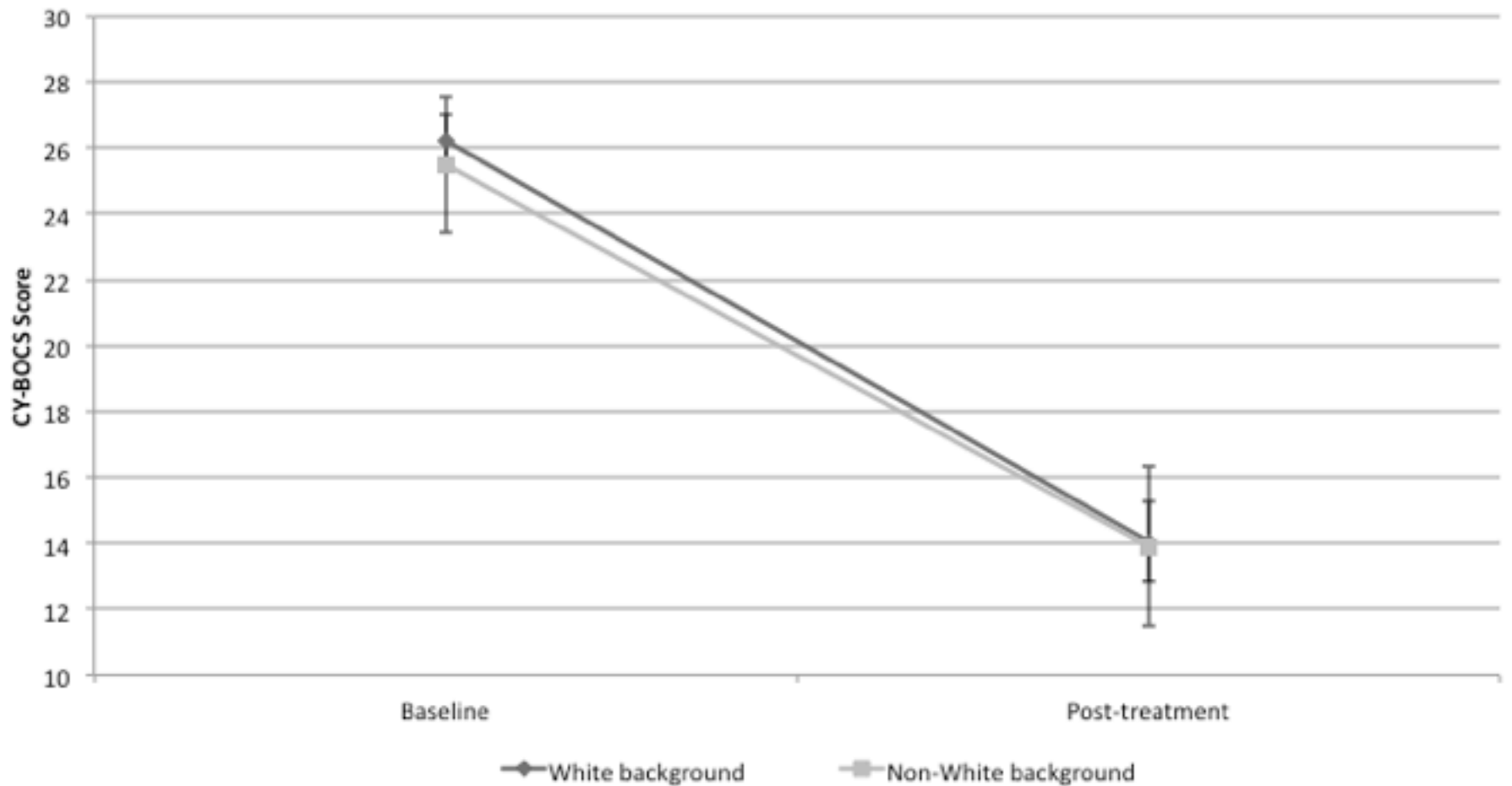
*Isomura et al, in preparation*

# Ethnic inequalities in the use of secondary and tertiary mental health services among patients with obsessive-compulsive disorder

Lorena Fernández de la Cruz, Marta Llorens, Amita Jassi, Georgina Krebs, Pablo Vidal-Ribas, Joaquim Radua, Stephani L. Hatch, Dinesh Bhugra, Isobel Heyman, Bruce Clark and David Mataix-Cols



# Outcomes in white vs non-white patients



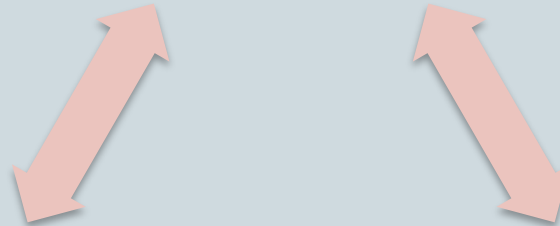


# Improving outcomes

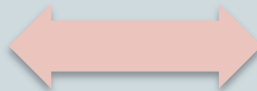


Clinical  
needs

- *Development of better treatments*
- *Adapting treatments for particular populations*



Innovation



Consolidation

# OCD in Autism Spectrum Disorder



- High rates of anxiety disorders in ASD

- Child and Adult Studies (Kim et al, 2000; Ghaziuddin, 2005)
- 11 to 84% ( White, Oswald, et al. 2009)

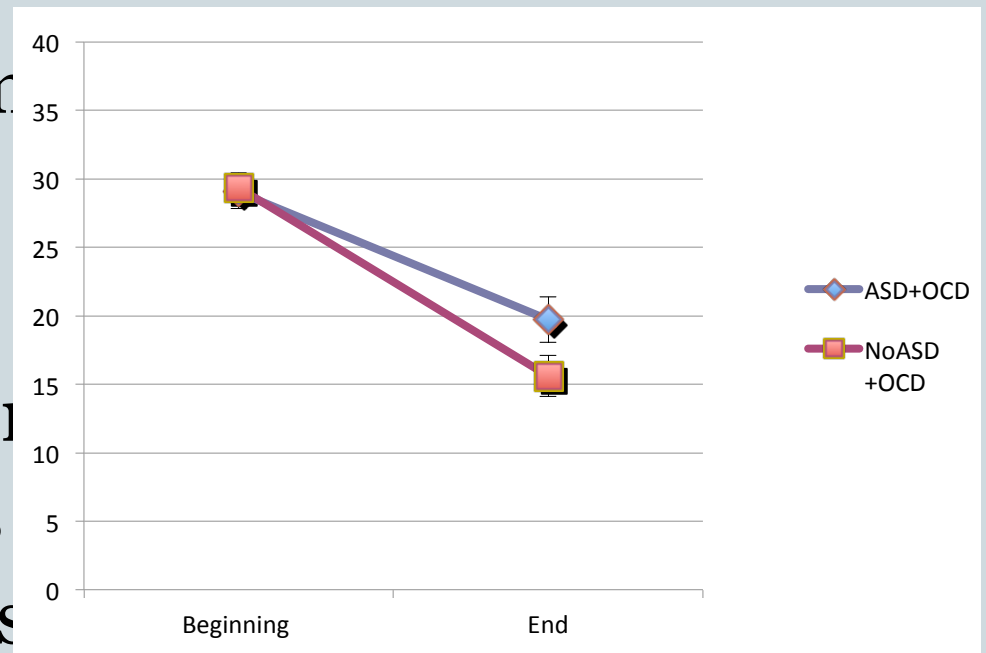
- OCD particularly common in ASD

- South et al. (2005)
- McDougle et al.(1995)
- Russell et al (2005)

- Often untreated (“passive”)

- Unnecessary distress

- Predicts poor response to treatment



*Murray et al, 2015, Psych Res*

# ASD+OCD project



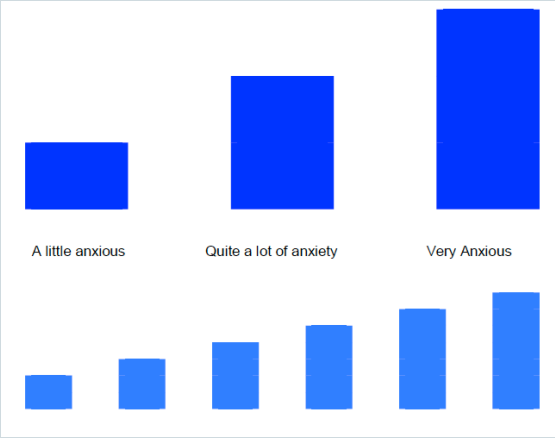
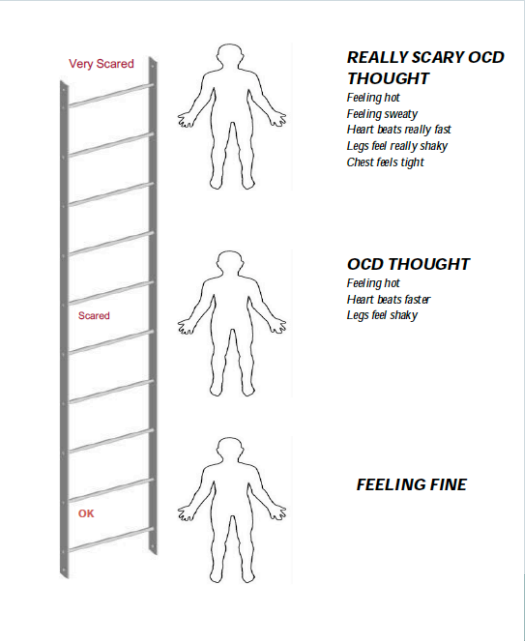
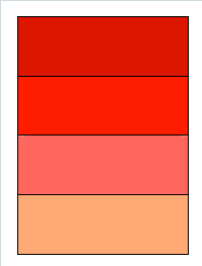
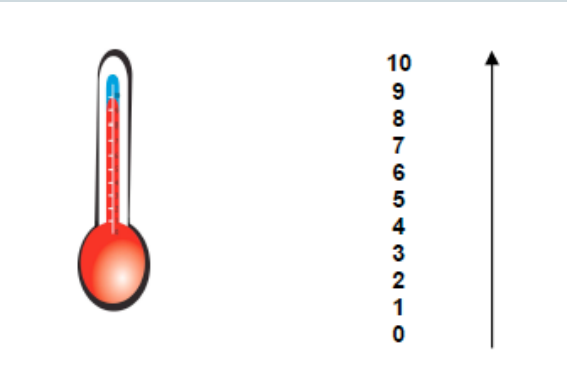
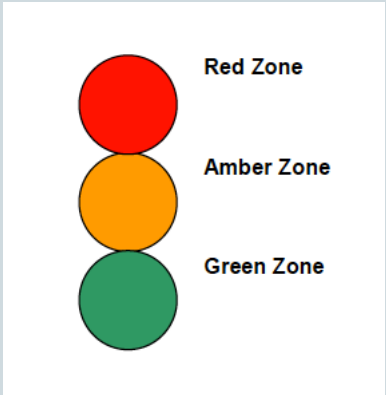
- Develop and manualise a CBT protocol for OCD in this particular population
- Systematically evaluate it via a RCT
  - Adapted CBT for OCD vs a credible control treatment

# Adapted CBT protocol



- **Manual: CBT for OCD with adaptations for ASD**
  - Expert recommendations (Attwood, 1999; Anderson & Morris, 2006)
  - Experience from pilot study
  - Theoretical literature
- **Up to 20 sessions (mean 17 sessions)**
- **Longer period of assessment/formulation (4 sessions or more if needed)**
- **Education about anxiety and OCD**
  - Visual aides
  - Special interest/concrete analogy
- **Exposure & Response Prevention (ERP)**
  - Graded hierarchy
  - Therapist modelling/direction
- **Cognitive elements**

# Use of visual aides



# Capitalising on 'special interests'



*Harry Potter  
hierarchy*

Voldemort

Wormtail

Lucius

Draco

Professor Snape

The Dursley

Professor Telawny

Hagrid

Neville






Hermione

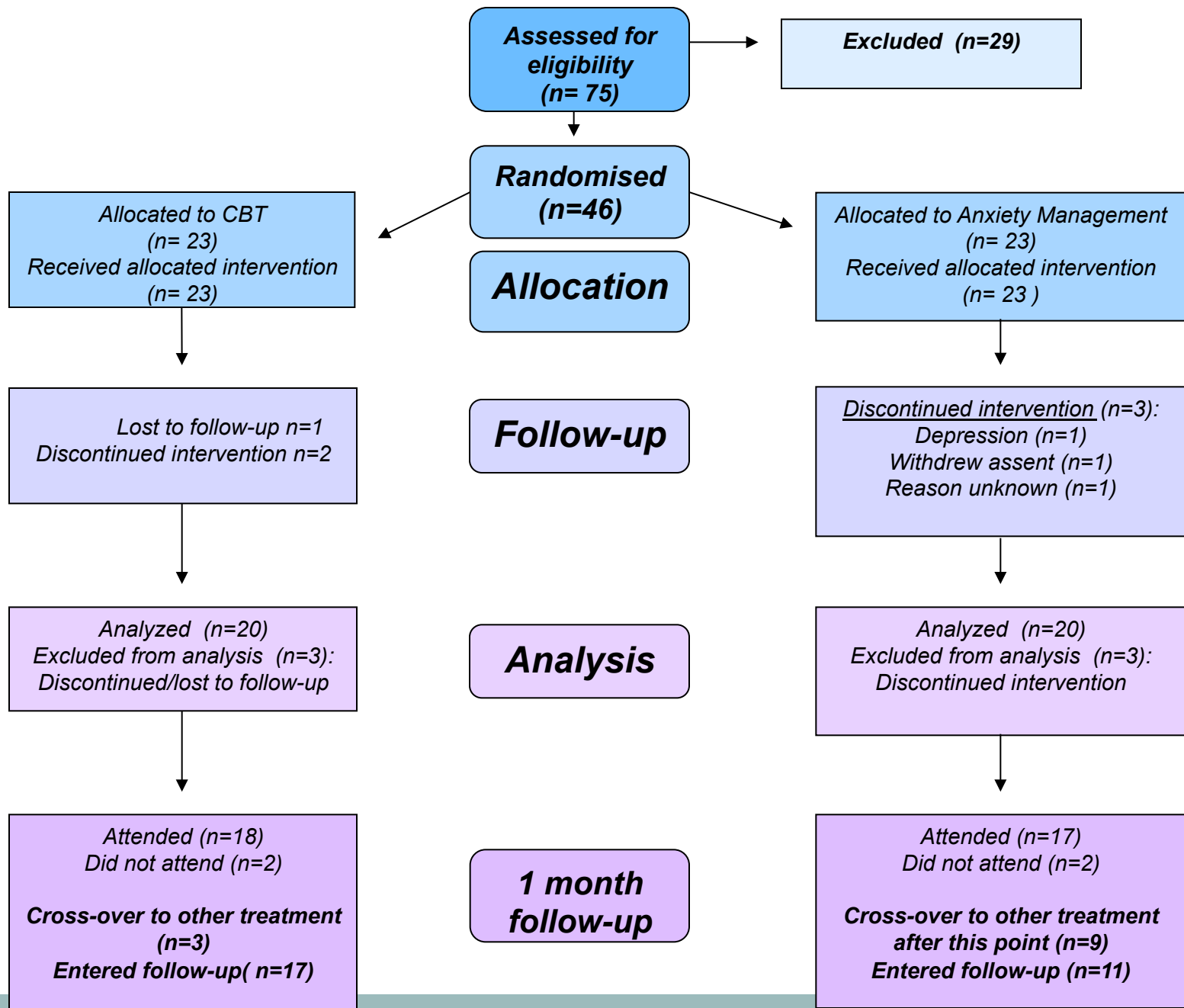
Ron

Harry



Example: Anchoring feelings with visual symbol and special interest in football

<b>Very Good</b>		<b>Barcelona have won a match</b>
<b>Good</b>		<b>Barcelona have drawn a match</b>
<b>Okay</b>		<b>Barcelona have lost 1-0.</b> I keep thinking about it I want to punch the air
<b>Not So Good</b>		<b>Barcelona have lost 5-0</b> I keep thinking about it I want to punch the air
<b>Very Bad</b>		<b>Barcelona have lost 10-0 (and their best player was injured)</b> I keep thinking about it I want to punch the air I want to swear



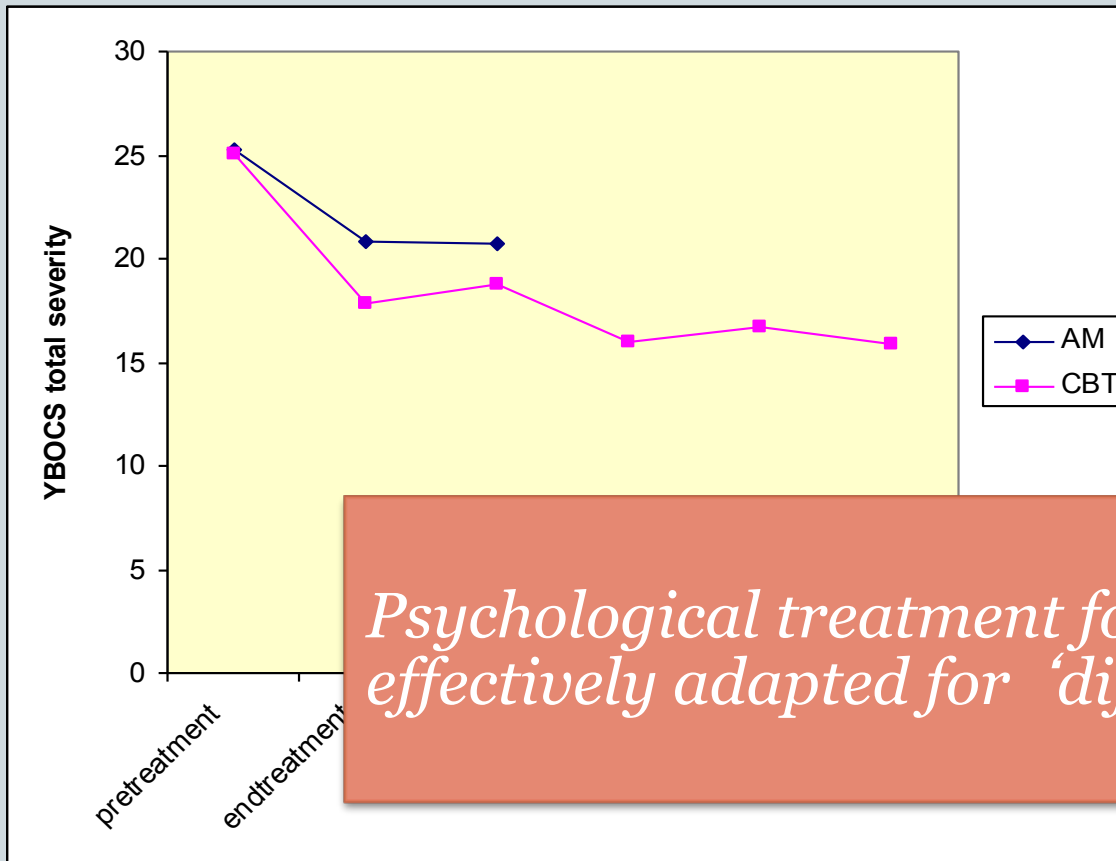


# Anxiety Management (control)



- Based on previous studies with some ASD adaptations (Cautela & Groden, 1978, Schneider et al, 2006)
  - Anxiety education
  - Breathing practice
  - Relaxation training and practice
  - Mood monitoring
  - Healthy Habits
  - Problem solving
- No ERP or cognitive techniques
- Up to 20 sessions (Mean 16 sessions)

# Main results: YBOCS severity



- *Both groups improve significantly, with a slight advantage of CBT > AM*

- *Treatment responders:*

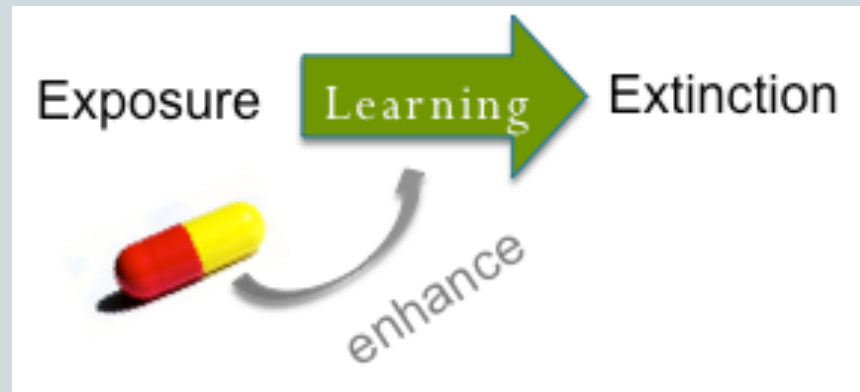
45% CBT

*Psychological treatment for OCD can be effectively adapted for 'difficult' populations*

# Augmenting CBT with fear extinction enhancers



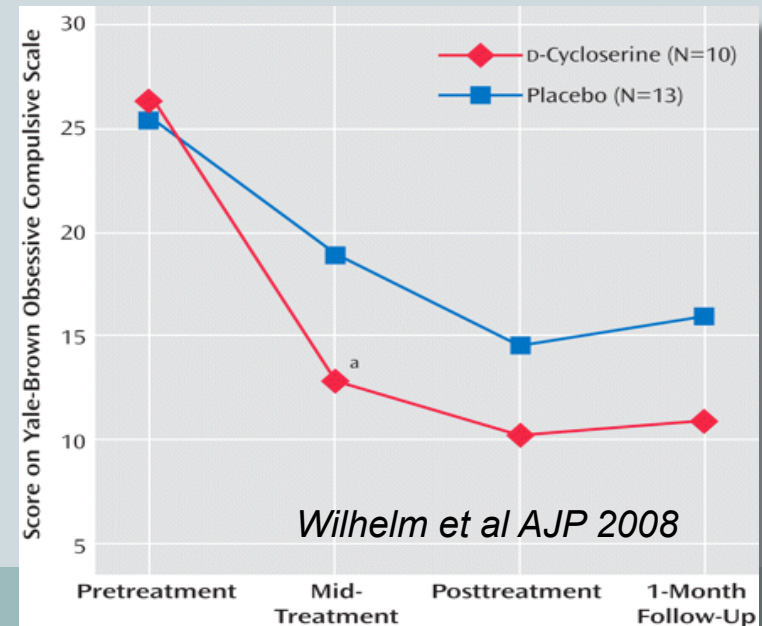
- No clear benefit of combining CBT with SRIs
- Novel treatment combinations, e.g. use of fear extinction enhancers to augment CBT
- D-Cycloserine is a partial NMDA-agonist



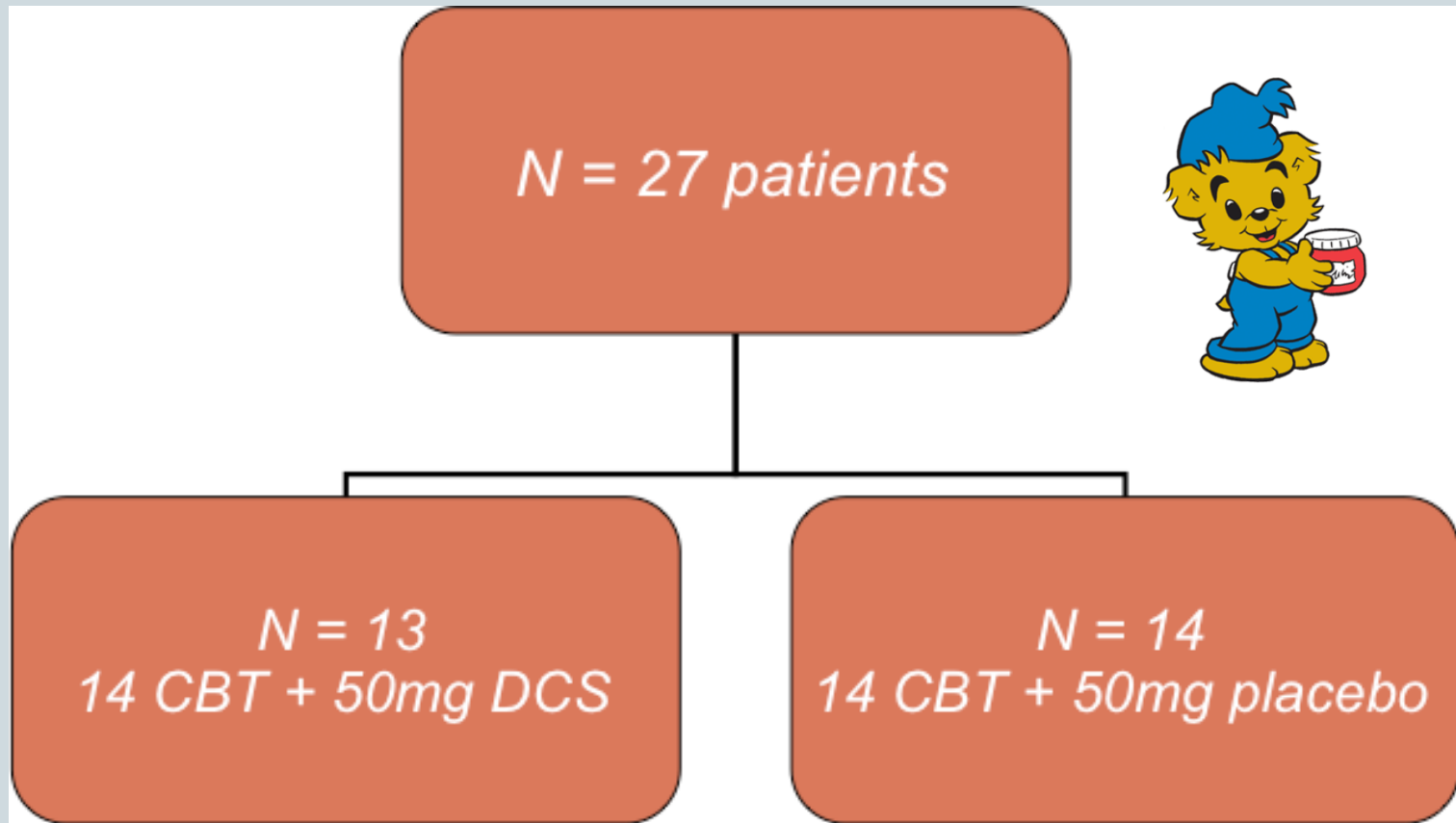
# DCS in various anxiety disorders



- Promising trials
  - Fear of heights (Ressler et al., 2004)
  - Social phobia (Hoffman et al., 2006; Guastella et al., 2008)
  - Panic disorder (Otto et al., 2009)
  - OCD (Kushner et al., 2007; Wilhelm et al., 2008; Storch et al., 2010)
- Negative trials (adults)
  - Spider phobia (Guastella et al., 2007)
  - OCD (Storch et al., 2007)
- Many more ongoing trials in adults as well as children



# Maudsley pilot double blind RCT in adolescents with OCD



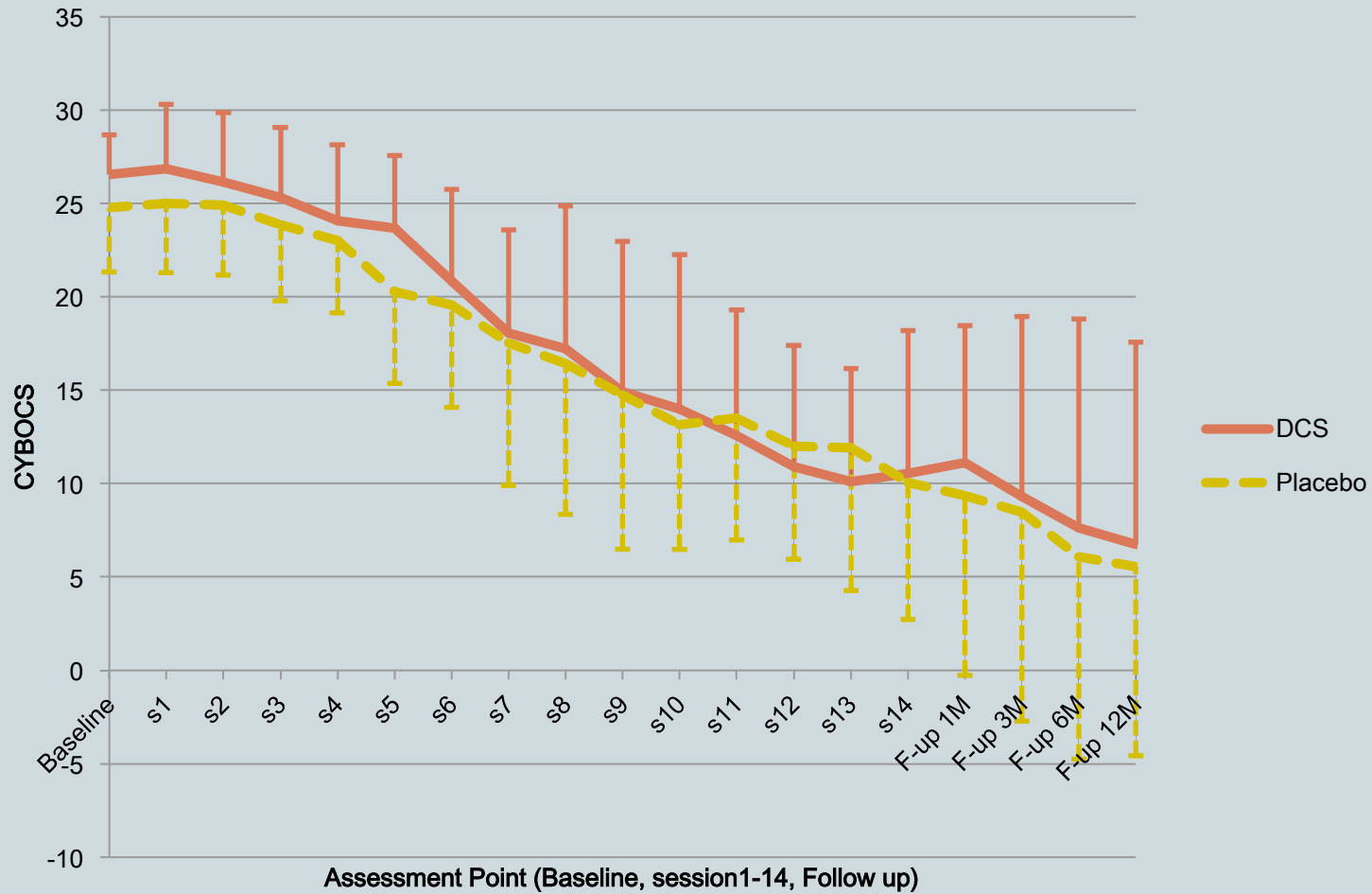
*Funded by: NIHR Biomedical Research Centre for Mental Health*

# Standard clinic protocol

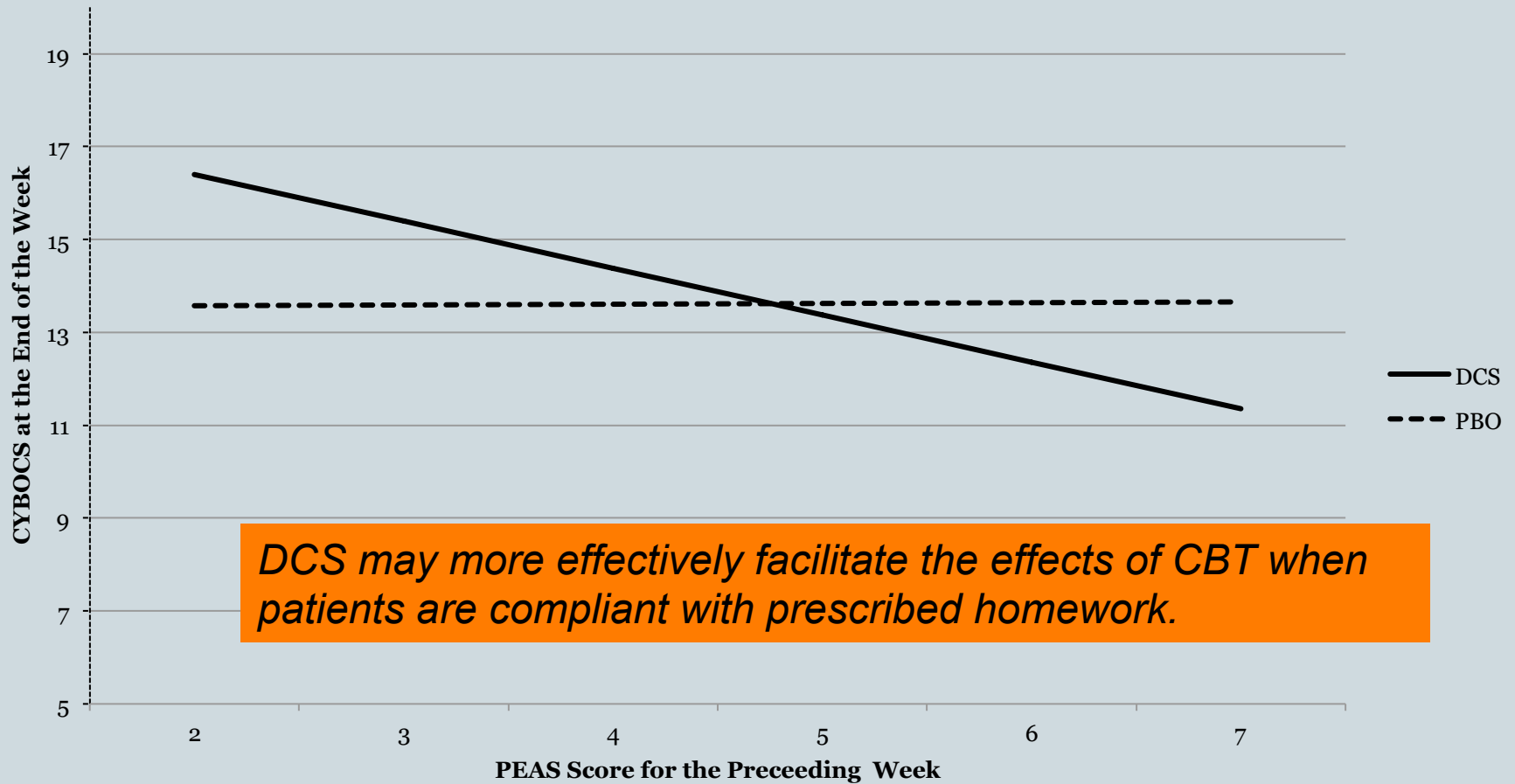


- 14 sessions on a weekly basis (within 17 weeks)
  - Session 1-2 : education about anxiety and OCD
  - Session 3-12: E/RP *Followed by 50mg DCS or placebo*
  - Session 13-14: Relapse prevention
  - Standard follow-up: 1, 3, 6 and 12 months

# Sometimes you lose...



# ...but homework compliance matters



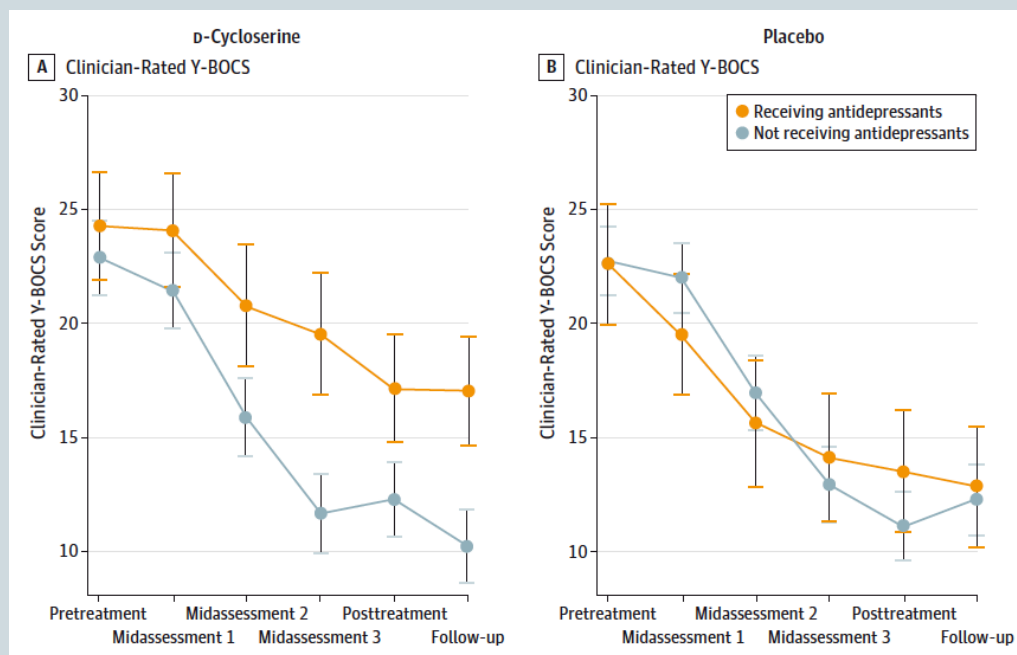
*DCS may more effectively facilitate the effects of CBT when patients are compliant with prescribed homework.*



# D-Cycloserine vs Placebo as Adjunct to Cognitive Behavioral Therapy for Obsessive-Compulsive Disorder and Interaction With Antidepressants

## A Randomized Clinical Trial

Erik Andersson, PhD; Erik Hedman, PhD; Jesper Enander, MSc; Diana Radu Djurfeldt, MD, PhD; Brjánn Ljótsson, PhD; Simon Cervenka, MD, PhD; Josef Isung, MD; Cecilia Svanborg, MD, PhD; David Mataix-Cols, PhD; Viktor Kaldo, PhD; Gerhard Andersson, PhD; Nils Lindefors, MD, PhD; Christian Rück, MD, PhD



# Developing treatments for pediatric BDD



## BACKGROUND

- CBT efficacious for adults with BDD
- No evidence in pediatric populations (case series)



## AIMS

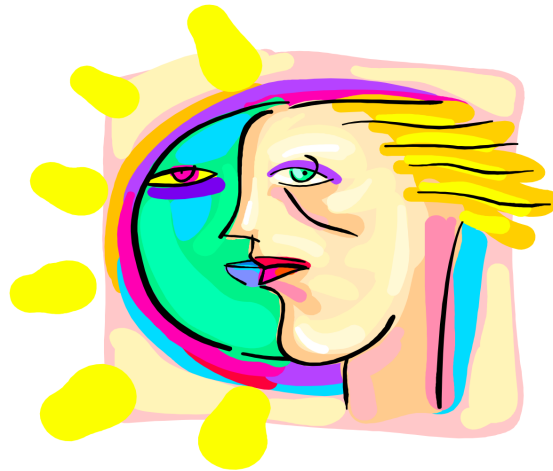
- Develop a **developmentally tailored CBT protocol for young people with BDD**, involving family when appropriate.
- Evaluate its efficacy in a pilot **randomized controlled trial**.

# CBT for pediatric BDD

London and Maudsley  
NHS Foundation Trust



## Reflecting on your Reflection: A Treatment Manual for BDD

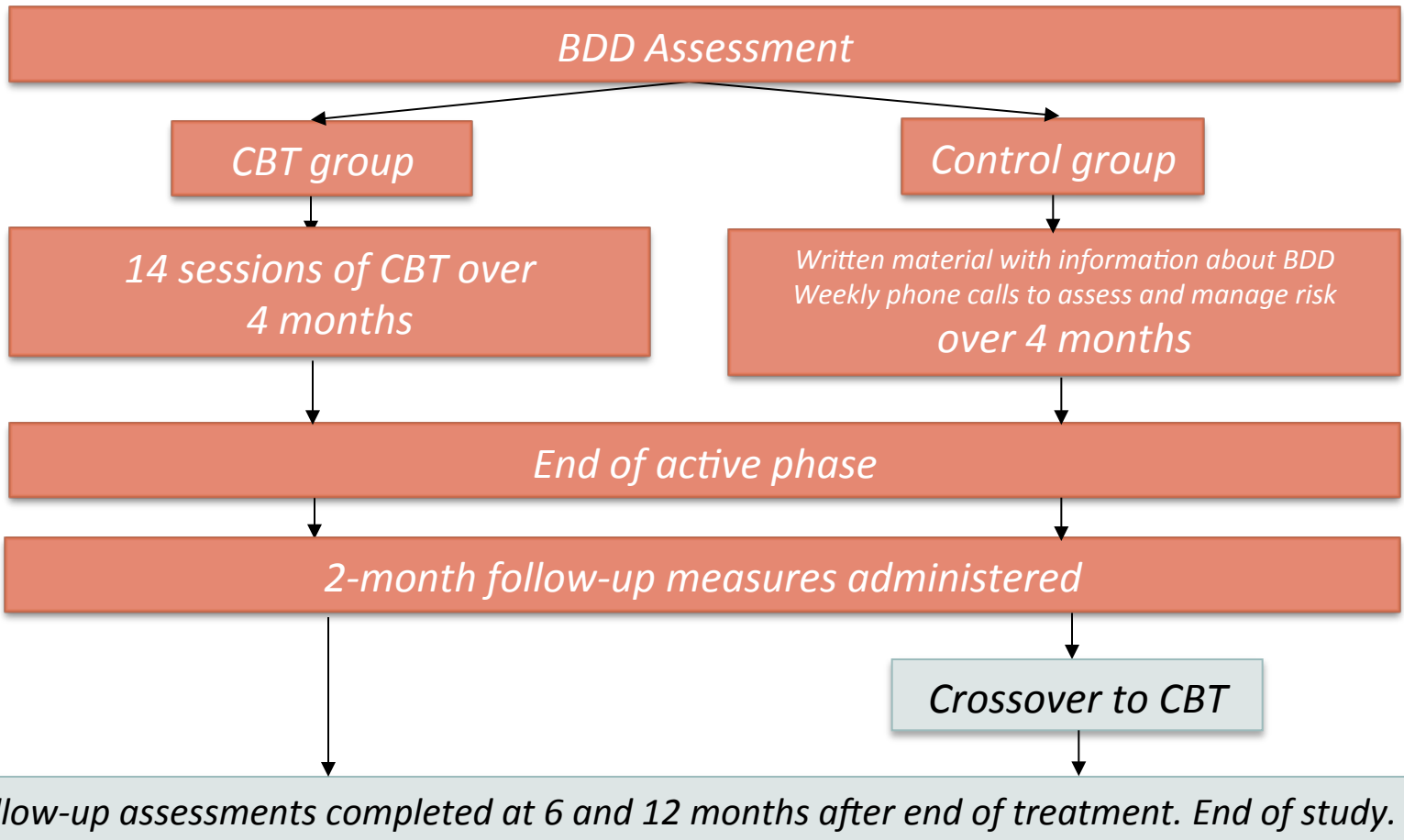


# Protocol

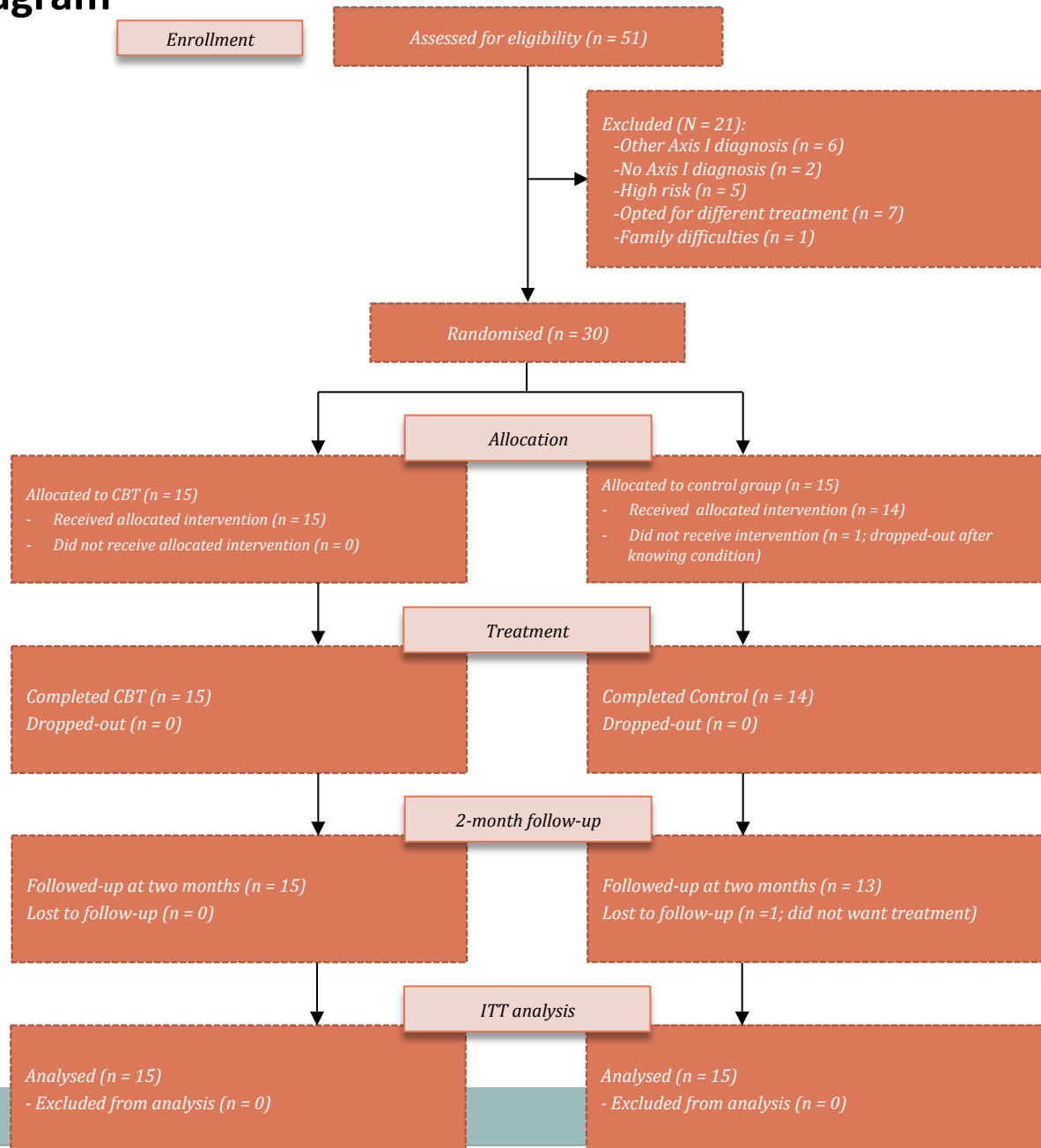


- *CBT: 14 sessions offered flexibly over 4 months*
  - ✦ *Sessions 1-2 (90 minutes): Psychoeducation, resolve ambivalence, case formulation, goal setting, ERP rationale.*
  - ✦ *Sessions 3-12 (60 minutes): Exposure and response prevention (ERP). Other optional modules to promote engagement with ERP (mainly: mirror retraining and attention training).*
  - ✦ *Sessions 13-14 (60 minutes): Relapse prevention.*
- *Developmentally appropriate content*
- *Strong parental involvement, depending on individual formulation (e.g., more accommodation = more parental involvement)*

■ **Trial design:**

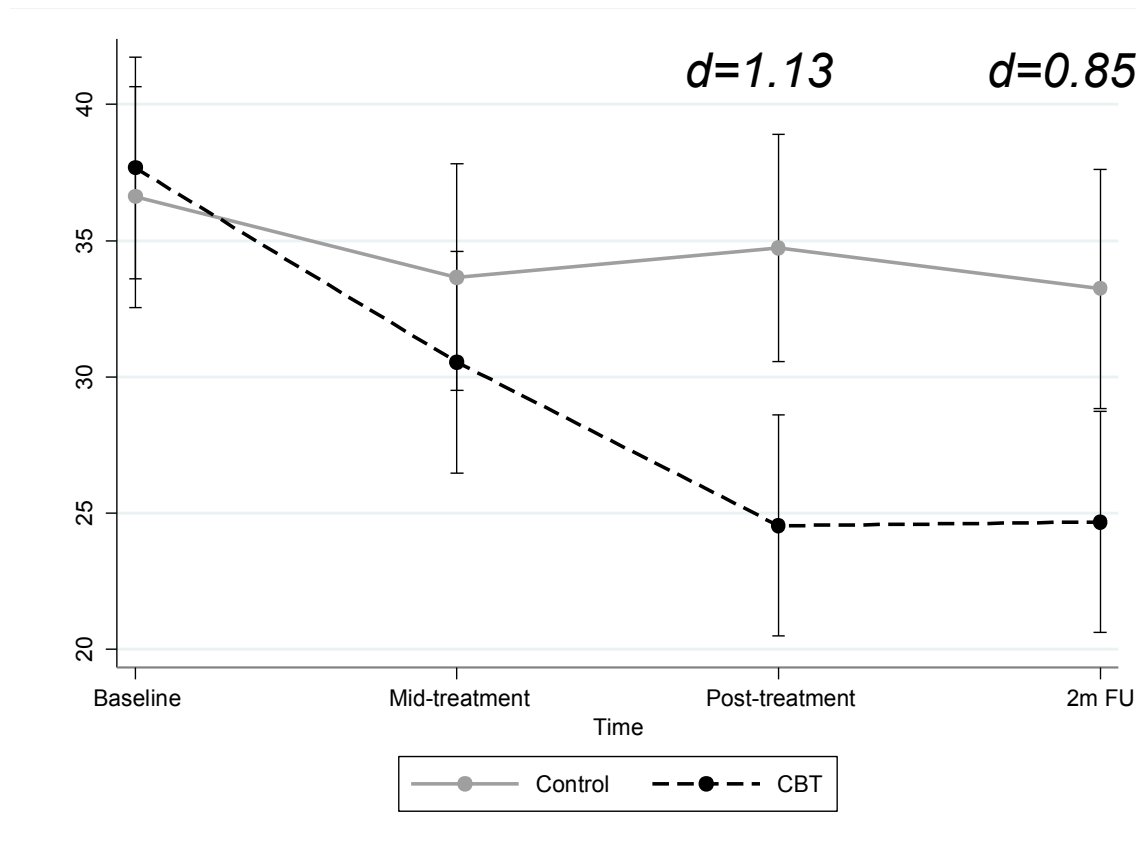


# CONSORT Diagram



## Results

- **Primary outcome:** interaction time x group is sign at post-treatment and at 2m FU.



## Results

- Treatment response ( $\geq 30\%$  reduction in the BDD-YBOCS) at post-treatment and at FU:

- 40% (n=6) in the CBT group
- 6.7% (n=1) in the control group

- CGI  
impr

- 53%
- 0%

- *Developmentally tailored CBT is a promising intervention for youths with BDD*
- *There is substantial room for improvement*
- *Pressing need to compare CBT, SSRIs and their combination in pediatric BDD*

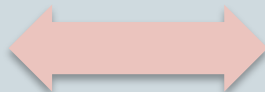




Clinical  
needs



Innovation



Consolidation

- *Dissemination*
- *Training*
- *Specialist services*

# ‘Consolidation’



- After decades of evidence-based treatments for OCD...
  - the majority of patients remain untreated...
  - or receive the wrong treatment!
- Still poor awareness
- Lack of expertise (particularly CBT)
- Difficult to access remote areas
- Ethnic minorities underserved
  
- = HUGE UNMET NEED!! WHAT CAN WE DO?

Obsessive Compulsive Disorder - Mozilla Firefox

File Edit View History Bookmarks Tools Help

http://www.ocdyouth.info/

HOME | CONTACT US | SITE MAP

## Obsessive Compulsive Disorder

WHAT IS OCD? | YOUNG PEOPLE WITH OCD | GETTING HELP | GETTING BETTER | NEWS & RESOURCES

### Things you need to know about OCD: Information for young people

- Find out you are not the only one with OCD
- Learn how to fight back and overcome OCD
- Discover the science behind OCD
- Explore how families, teachers and adults can help
- Hear from young people about their experiences of OCD

Fighting OCD posters, made by young people from the Maudsley OCD clinic:

NHS choices Your health, your choices

Site search GP Hospital De

Enter a search term

Medical advice Find services Health A-Z Live Well Carers Direct News Tools Video Blogs

## Obsessive compulsive disorder

Overview Expert View Lifestyle Real stories Map of Medicine Medicine Guides

Introduction Symptoms Causes Diagnosis Treatment Complications References NICE guidelines

### Introduction

Watch this...

Danielle, 11, has obsessive compulsive disorder. An expert describes the most common symptoms and the treatment for children.

Obsessive compulsive disorder (OCD) is a chronic mental health condition that is usually associated with both obsessive thoughts and compulsive behaviour.

**Obsessions**

An obsession is defined as an unwanted thought, image or urge that repeatedly enters a person's mind.

**Compulsions**

A compulsion is defined as a repetitive behaviour or mental act that a person feels compelled to perform.

Unlike some other types of compulsive behaviour, such as an addiction to drugs or gambling, a person with OCD gets no pleasure from their compulsive behaviour. They feel that they need to carry out their compulsion to prevent their obsession becoming true. For example, a person who is obsessed with the fear that they will catch a serious disease may feel compelled to have a shower every time they use a public toilet.

Useful  
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Adobe Reader - [TES article on OCD and schools May 2008.pdf]

File Edit View Document Tools Window Help

Save a Copy Search Select 77% Help Search Web Embed video and audio in Adobe PDF

# Breaking the ritual

personal brain & behaviour

Pupils who display repetitive behaviour or seem distressed may be suffering from obsessive compulsive disorder. **Rebecca Heyman** and **Chloe Volz** explain what you can do to help them

The child who is always last back from lunch, the child sitting and re-writing a piece of work, or the teenager who seems to spend an inordinate amount of time in the toilets. All of these pupils may have obsessive compulsive disorder (OCD). OCD is an anxiety problem that affects up to 1 per cent of under-18s, so a large secondary school might have 10 to 20 affected pupils. Although it can start in children as young as six or seven, it is more common in teenagers.

The characteristic symptoms are obsessions and compulsions. Obsessions are unwanted, repetitive, unpleasant thoughts. Typically they may be unrealistic worries about things being contaminated or fears of bad things happening to loved ones. Compulsions are repetitive, unnecessary and unwanted behaviours. Sometimes they are clearly associated with particular obsessions, such as repeated and excessive hand washing, which is linked to fears of contamination, but they can be more "magical", such as tapping objects or walking in a particular way, which the child may feel prevents their mother from an accident.

If teachers see a pupil with symptoms, they should gently ask about them. Depending on their age, the teacher should find out if the parents are aware of the problem and perhaps advice seeking help from a GP.

Once a diagnosis of OCD has been made it is very treatable, but unfortunately it often goes undiagnosed for years. One reason for this is that those with OCD are embarrassed about their symptoms, and they are the ones with full insight into the unnecessary and time-consuming nature of the unwanted thoughts or rituals. If a child approaches the teacher about their problem, the teacher should treat the disclosure sensitively, make it clear they should not be ashamed, and wish help they will receive.

The UK National Institute for Health and Clinical Excellence has published guidelines on the assessment and treatment of OCD throughout the lifespan (www.nice.org.uk). Treatment of mild cases may be possible with self-help books, or via a GP, but most children will need to be referred to child mental health services. The treatment includes cognitive behavioural therapy. A specific technique is recommended called "response prevention", where the child works closely with their therapist and family to gradually face their fears, one by one and eventually many rituals. Occasionally schools might be invited to help with the programme. For example, if a child has a fear of chemicals and has dropped out of science, their treatment might include gradually building confidence to step inside the science lab, touch a bench or pick up a bottle of chemicals. It helps if a school understands and cooperates with this type of intervention.

Some children with OCD are helped by specific medication. However, it does not usually need to be dispensed in school time and is unlikely to affect the child's ability in school. The impact on school can be variable, from no impact to complete school refusal. Even if attendance is not a problem, OCD can sometimes make it hard for young people to concentrate, particularly if obsessions trouble them at school, or if they are tired from carrying out rituals, such as washing, throughout the night. Rituals may also make it hard to complete certain pieces of work. For instance, if sufferers have an urge to sit or stand or re-erase, the need for reassurance can mean that they repeatedly ask the teacher questions.

**Dr Isabel Heyman** is consultant child and adolescent psychiatrist and Chloe Volz clinical psychologist in the service for young people with OCD at the Maudsley Hospital, London. Their website, [www.ocdyouth.info](http://www.ocdyouth.info), has advice, links, books, information and other resources about OCD for children, parents, teachers and other professionals.

**Time consuming:** fear of contamination can urge a pupil with OCD to repeatedly wash their hands



## Sufferers of body dysmorphic disorder see only distorted and grotesque versions of themselves in the mirror; the condition affects one in 100 people. So why are diagnosis and treatment so difficult to get? Sally Williams meets a family whose lives were turned upside down by the illness. Illustrations by Wesley Allsbrook

Samantha Davies was 13 when she began to develop the deformities that would transform her into what she described as "the most ugly person in the world". Her nose began to grow into a formless lump across her face, her cheeks inflated to three times their normal size and her head became square and misshapen.

First, she tried hiding behind make-up. She would use so much foundation that "her face was just orange like a mask", her mother says. She would apply six or seven layers of mascara. She would straighten her hair (to cover her face) with hair iron to the point of singeing it. Her three months she decided she was too unattractive to wear. She confined herself to her bedroom and refused to go to school. She would agree to be taught at home only if the tutor couldn't see her face. "She would sit on the bed with a quilt over her head. The women would laugh her through the quilt", her mother remembers. Finally, aged 17 and a half, Samantha had had enough. She took an overdose. And if this weren't evidence enough of her state of mind at that point, her reaction when she came to hospital undermined it. "My first thought was, 'What do I look like?'" And the feeling of self-loathing returned.

The strange thing is that Samantha looks perfectly normal. It was all her head. In October 2000, after months of anguish and three suicide attempts, she was finally treated for severe body dysmorphic disorder. Body dysmorphic disorder (BDD) is driven by intense anxiety about appearance, and its exceptional focus lies in its delusional quality. The focus can be any body part, but typically it is the head - hair, nose, ears, skin, the size and shape of the jaw - which sufferers see as ugly, "not right".

I remember a colleague from the States who was training a soldier in the American Army. He had been on the front line in Iraq and had been shot at and all he could think about was the size of his nose; that he was intense and consuming the preoccupation can be, says Dr David Mataix-Cols, a professor and consultant clinical psychologist at the Institute of Psychiatry and at the Maudsley Hospital, London, which has ramped up its services for young people with BDD in the past year. BDD is relatively common - it affects about one in 100 people (significantly more than schizophrenia, slightly more than anorexia). It typically starts in early teens and affects boys as frequently as girls. The cause of BDD are still unknown. "We know it runs in families and that it

At her worst, Samantha was checking her face in the mirror 80 times a day, sometimes for up to two hours at a time

TELEGRAPH MAGAZINE 25

# *Channel 4 Documentary*

*2006*

*“Help me, help my child”*

*4 on Demand*

*[www.channel4.com](http://www.channel4.com)*



# Dissemination of evidence-based treatments



- Training of clinicians
- Self-help (e.g., bibliotherapy)
- Telephone treatment
- Internet treatment
- Reaching disadvantaged groups (e.g., ethnic minorities)

# Telephone treatment for youth with OCD

- Improve access to and availability of CBT
- Establish efficacy
- Establish feasibility
- Determine acceptability



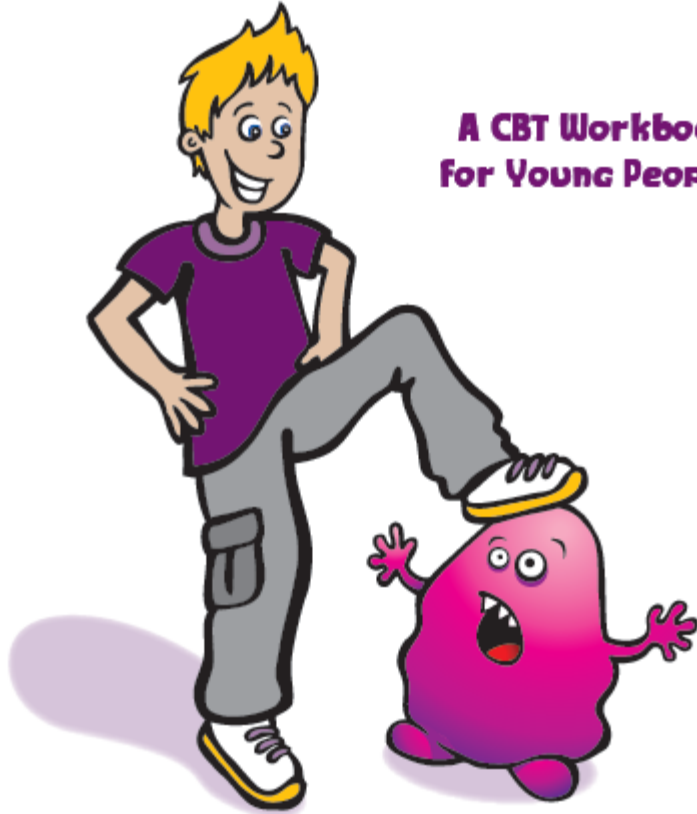
# Standard clinic protocol



- 14 sessions on a weekly basis (within 17 weeks):
  - Session 1-2 : education about anxiety and OCD
  - Session 3-12: E/RP
  - Session 13-14: Relapse prevention
  - Standard follow-up: 1, 3, 6 and 12 months

# Learning about OCD and **FIGHTING BACK!**

**A CBT Workbook  
for Young People**



Written by Cynthia Turner  
Illustrated by Lisa Jo Robinson



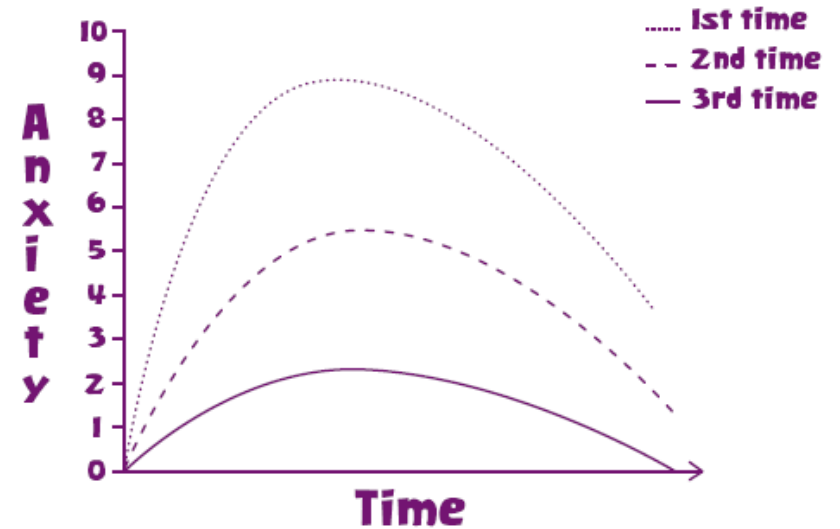
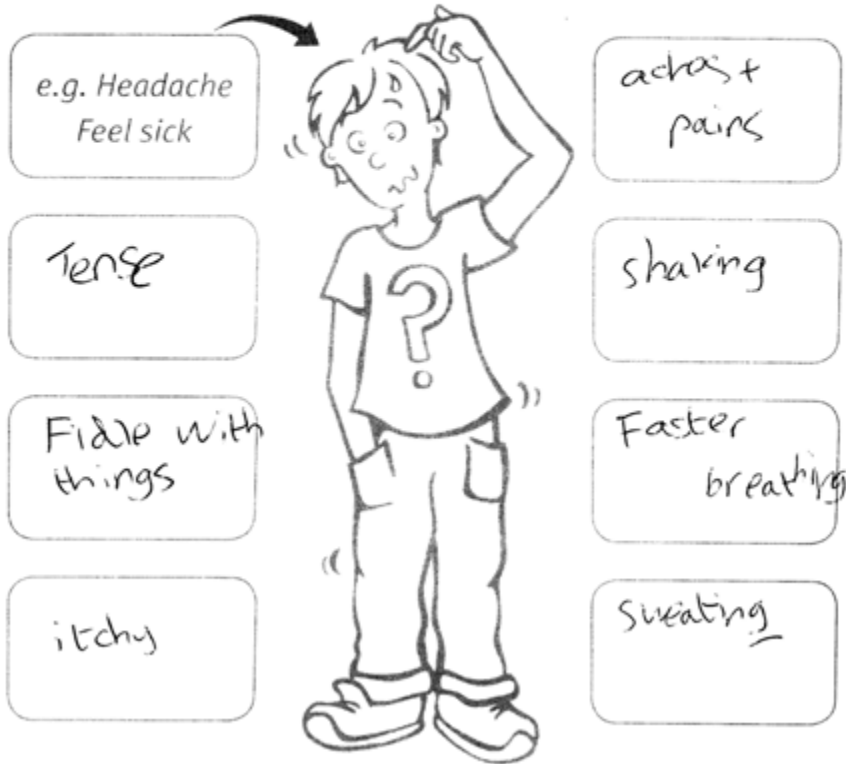


## Tool 1: Understanding Anxiety

Anxiety is a normal feeling that everyone has from time to time. When we feel anxious, we usually get changes in our body to help us understand how we are feeling.



What happens to your body when you feel anxious or worried about something? Let's make a list of how you feel anxiety affects you:



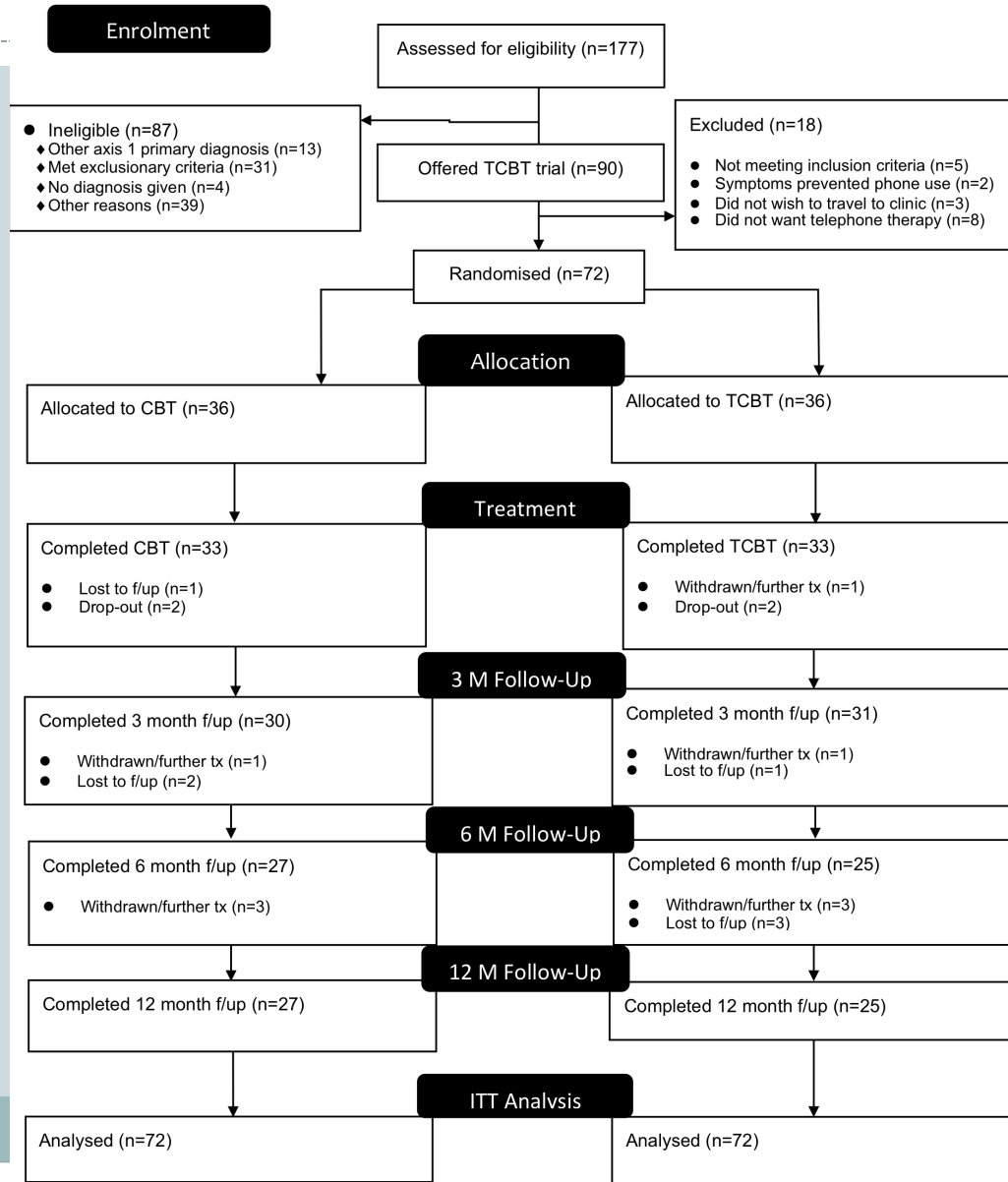
**1st time** The first time we do it, we feel really anxious!

**2nd time** The second time, our feelings are not quite so bad

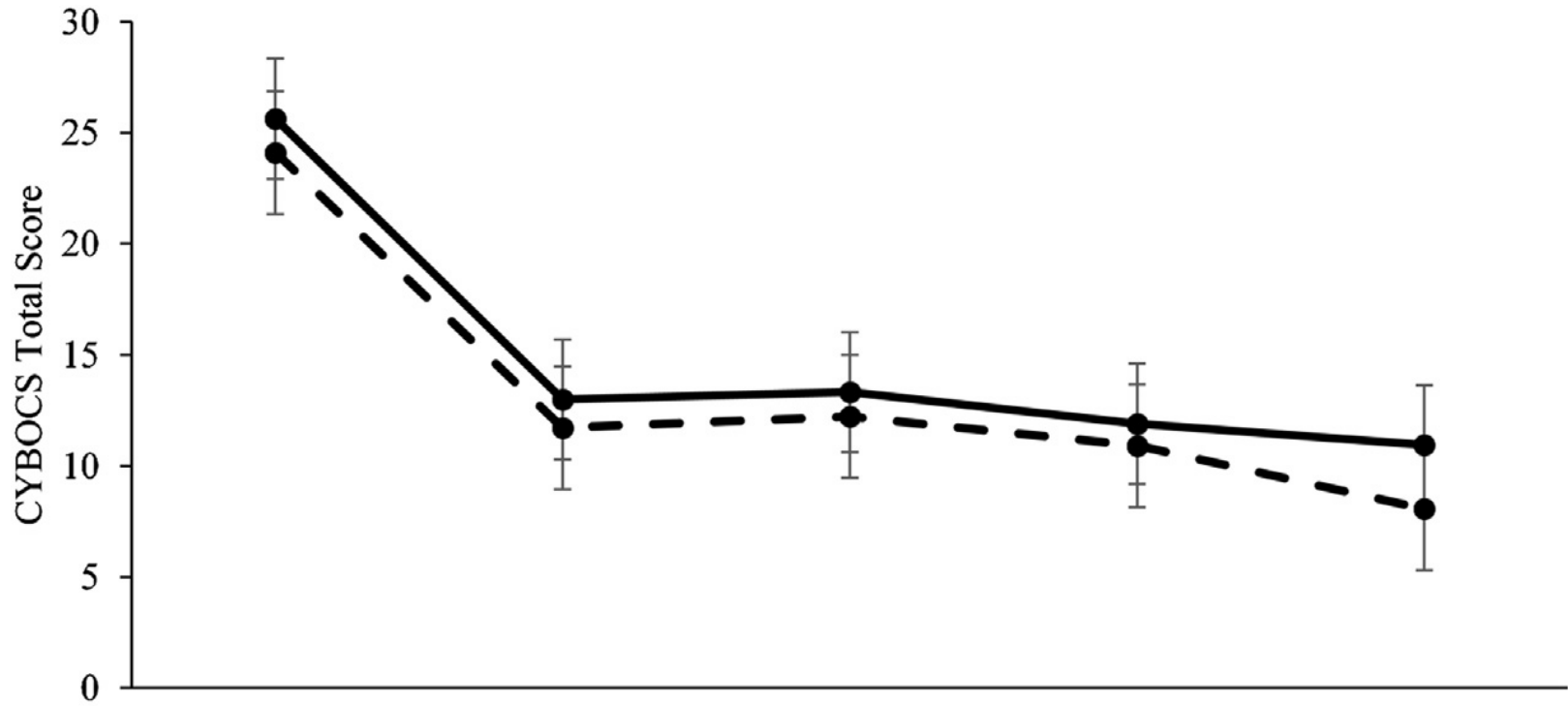
**2nd time** The third time, they are not quite so bad again!  
If we keep going, the feelings keep getting smaller and smaller, and then we don't feel anxious at all!

# Non-inferiority RCT

Figure 1. CONSORT Diagram.



# Telephone vs face to face CBT results



- *Non-inferiority demonstrated*
- *Highly acceptable for patients*
- *No savings in clinician time*

# Internet CBT for young people with OCD with minimal therapist backup: BIP OCD



**BIP** Kapitel 1: Vad är tvång? Startside

STEG 5 AV 17 FILM

## Om tvång

◀ Tillbaka Nästa steg ▶

**BIP** Kapitel 2: Vi knäcker koden\* Startside

STEG 13 AV 16

## Övning: ett eget tvång

Försök nu att fylla i tvångscirkeln som den ser ut för ett eget tvång. Du har ju precis lärt dig tvångscirkeln, så tänk på att det inte behöver bli perfekt. Gör så gott du kan och försök att fylla i så mycket som du vet om tvånget. Din psykolog kan hjälpa dig med de rutor som känns svåra.

◀ Tillbaka Nästa steg ▶

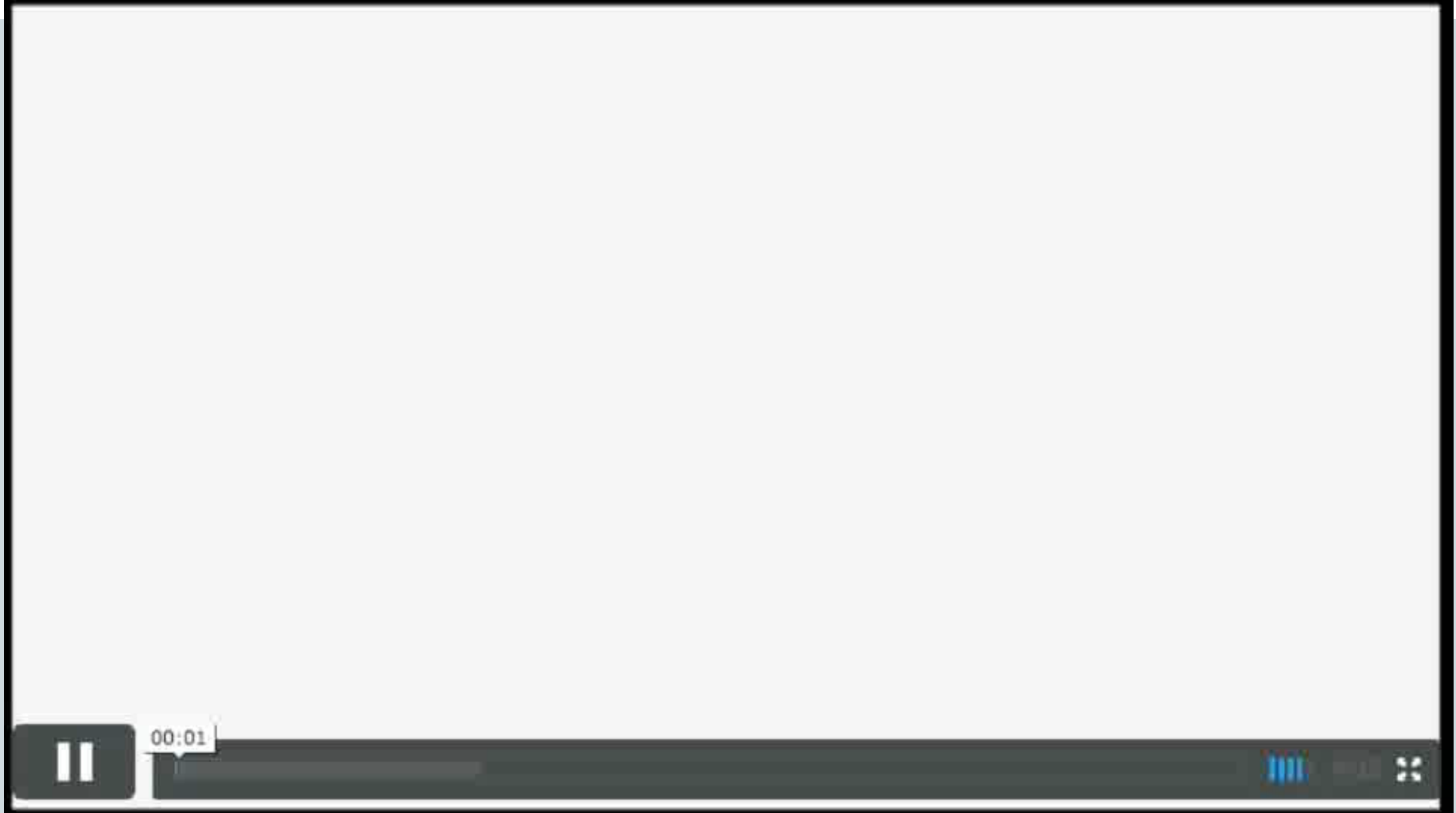
# BIP OCD chapters



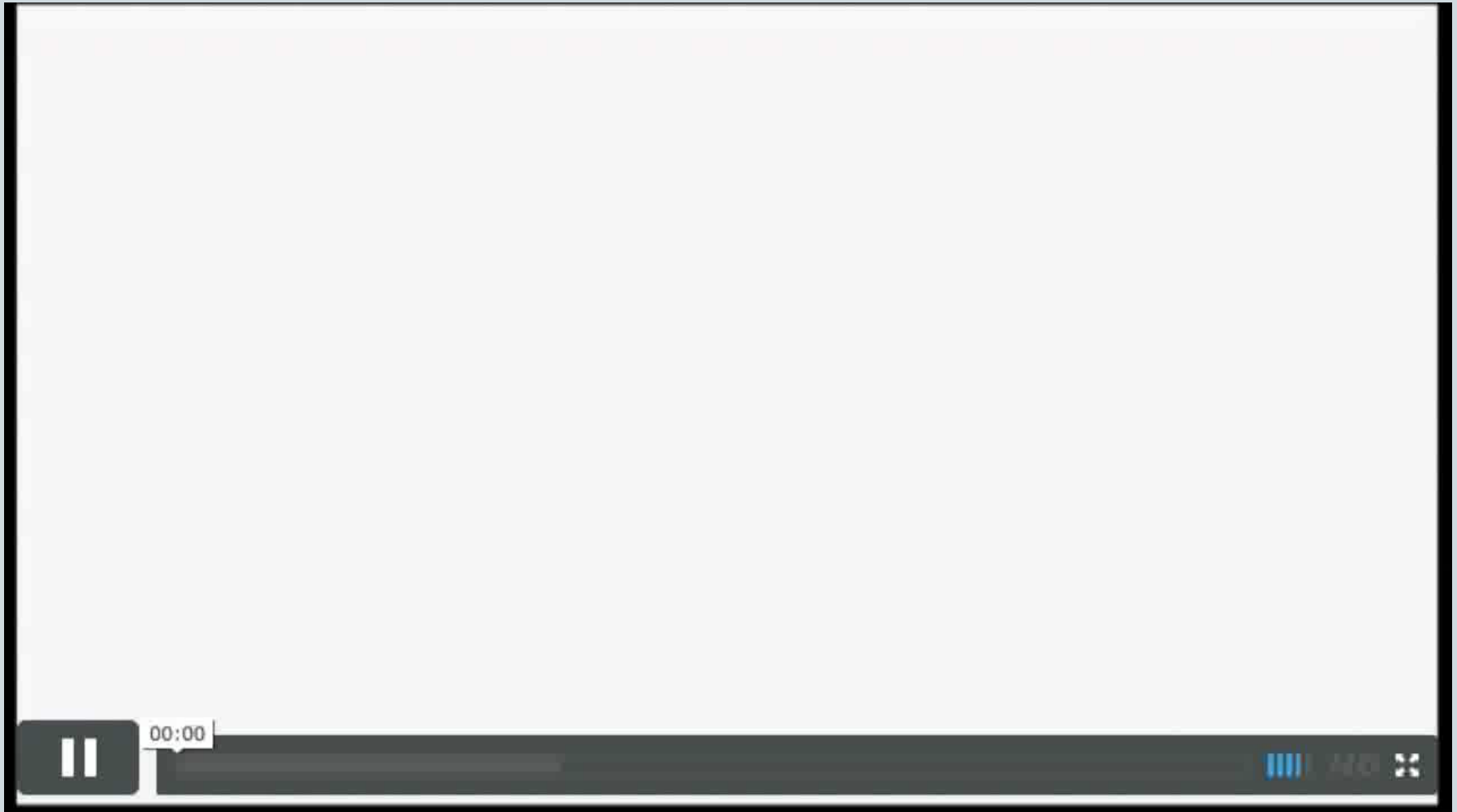
<b>Treatment phase</b>	<b>Chapter</b>	<b>Parent chapters</b>	<b>Adolescent chapters</b>
<b>Psychoeducation</b>	1	Introduction to ICBT	Introduction to ICBT
	2	About OCD	What is OCD?
	3		We are cracking the code: The OCD circle
	4	Exposure and response prevention	Building a hierarchy
<b>Exposure with response prevention (ERP)</b>	5		Testing exposure
	6	Being an exposure coach	Planning your ERP training
	7		New steps with ERP
	8	When the family has OCD	ERP – frequent problems and solutions
	9		More new steps with ERP
	10		Talking back to OCD - Coping with obsessions
<b>Relapse prevention</b>	11		The final sprint
	12		Your treatment in the rear-view mirror

doi:10.1371/journal.pone.0100773.t002

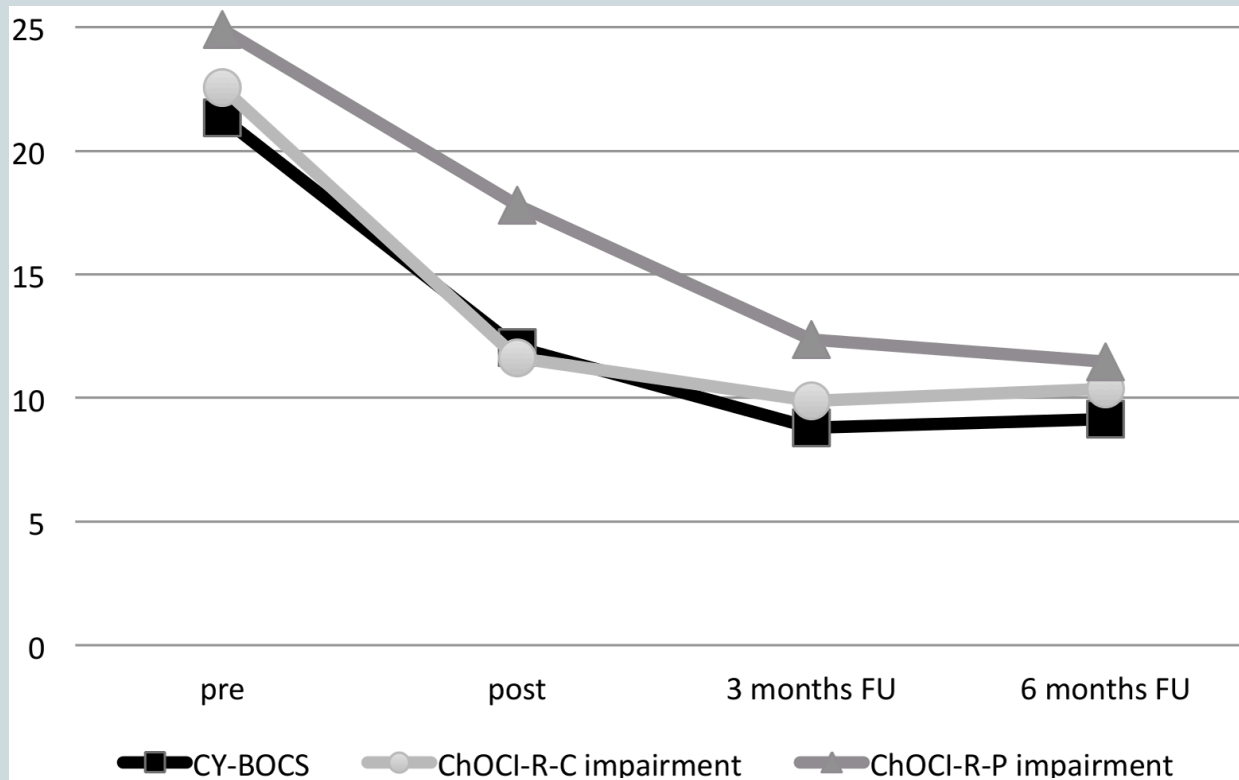
# BIP OCD clip I (psychoeducation)



# BIP OCD clip II (ERP)



# Internet CBT for young people with OCD with minimal therapist backup: BIP OCD



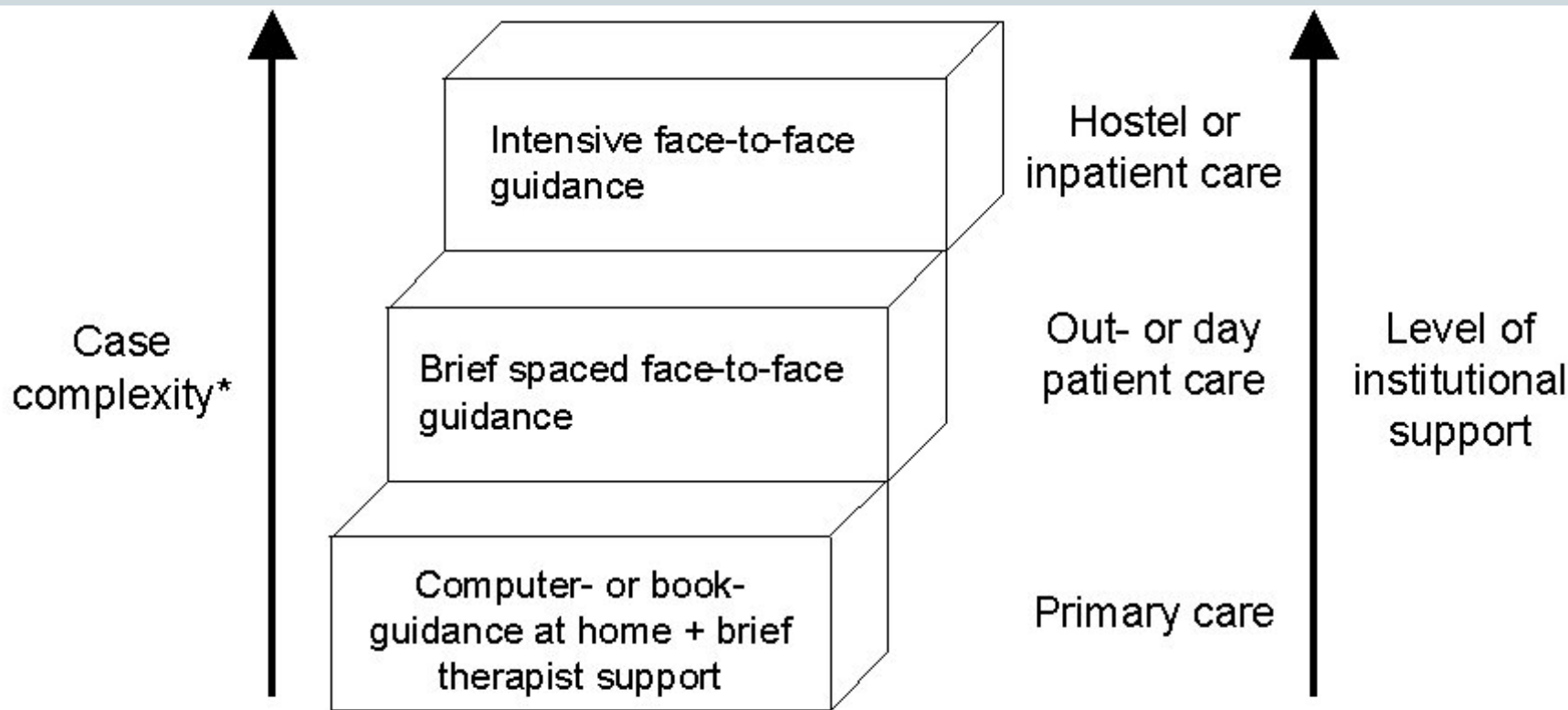
*d = 2.29*

*Clinician time:*

*About 20  
minutes per  
patient per  
week!!*



# Towards a stepped care model



\* > co-morbidity, < insight, < motivation

# Conclusions



- OCD-RDs are prevalent and there is a huge unmet need
- Treatments for OCD are pretty good but there is room for improvement
- Biggest challenge: to disseminate existing evidence-based treatments
- Much work needs to be done for the other OCD-RDs
- This work would be optimally orchestrated from specialist centres, where clinical work and research go hand in hand

# Acknowledgements



OCD/ASD	BDD	Hoarding	Tic Disorders	Trich/Excor
I Heyman	G Krebs	A Nordsletten	P Andren	B Monzani
G Krebs	D Veale	A Pertusa	M Boman	P Andren
L Fernandez	J Cadman	L Fernandez	C Ruck	C Ruck
A Jassi	L Bowyer	D Billotti	E Serlachius	K Aspvall
A Russell	B Monzani	D Landau	F Lenhard	
E Serlachius	L Fernandez	A Iervolino	M Silverberg	
F Lenhard	J Enander	V Ivanov		

