

OCD: A Silent Global Epidemic - Introduction



Dr Himanshu Tyagi

Consultant Neuropsychiatrist and Medical Psychotherapist

National Hospital for Neurology & Neurosurgery, Queen Square ·

UCLH NHS Foundation Trust

BRC Research Fellow

UCL Queen Square Institute of Neurology

Complex OCD & BDD Research & Neuromodulation Pathway

Development

h.tyagi@ucl.ac.uk · [@himanshutyagi](https://twitter.com/himanshutyagi)



Session Roadmap

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Prevalence Gap

The 1-in-50 paradox

02



Why 'Silent'

Shame, stigma, misdiagnosis

03



The Neurobiological Glitch

CSTC circuits & optogenetics

04



Treatment Limitations

The 10% ultra-refractory

05



Future Therapeutics

DBS, neuromodulation, pipeline

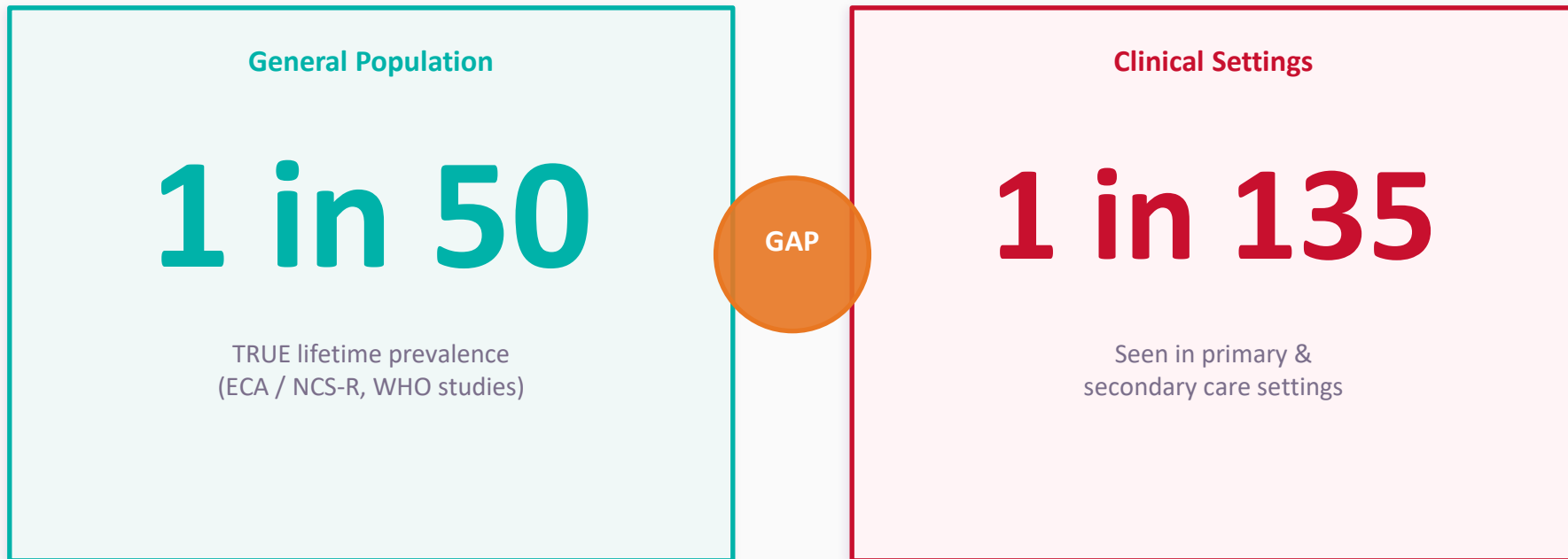
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Call to Action

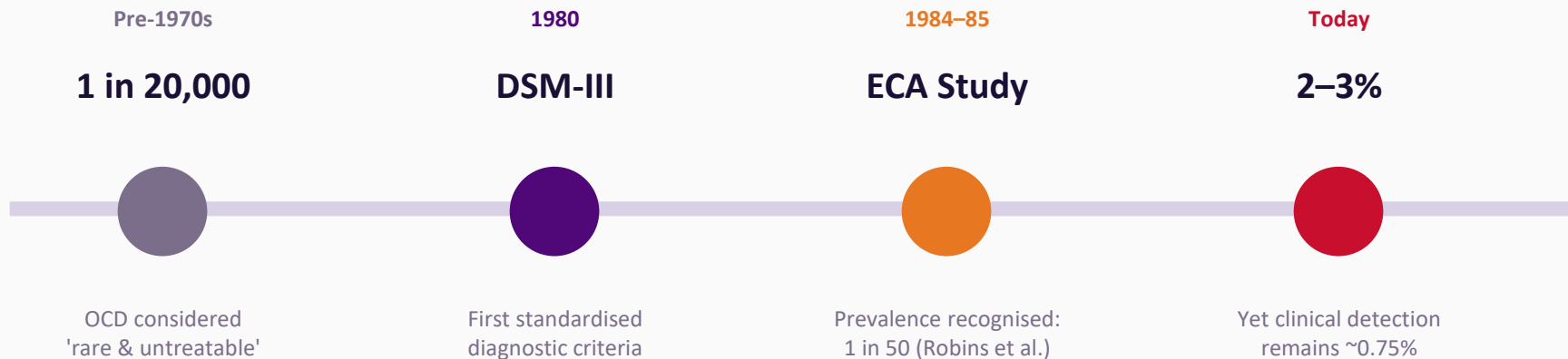
Breaking the 17-year silence

The Prevalence Paradox: The 1-in-50 Gap



Millions of patients are simply 'missing' from the healthcare system — undiagnosed, untreated, deteriorating in silence.

The 3,900% Explosion



+3,900%

Increase in recognised prevalence between 1970 and 1985.

The disease did not increase. Our recognition did — yet 'silence' persists because our clinical systems never caught up.



The Ego-Dystonic Barrier

Harm obsessions

Intrusive thoughts of harming loved ones — perceived as indicating true intent

Taboo sexual thoughts

Unwanted sexual thoughts about children, family — catastrophic shame spiral

Blasphemous thoughts

Religious intrusions — fear of being 'evil'; ostracism from community

'Pure O'

No visible compulsions — patients and clinicians both miss the diagnosis

Mental compulsions

Reassurance-seeking, neutralising — invisible to observer, exhausting to patient

17
YEARS

Patients hide symptoms not due to lack of distress, but because the content of obsessions is perceived as morally unacceptable — and because no one asks.

The Trivialisation Trap



I'm so OCD about keeping my desk tidy.

— Heard in everyday conversation, on TV, in headlines. Every. Single. Day.

Patients self-dismiss

Sufferers believe their symptoms are 'just a quirk' — seeking help feels disproportionate

Clinicians underestimate

Cultural normalisation lowers clinical index of suspicion in consultations

Policymakers deprioritise

If OCD is 'just neatness', it cannot be a public health emergency — funding follows perception

Research is defunded

OCD receives <1% of mental health research investment — trivialisation has systemic consequences

Clinical Camouflage: Misdiagnosis

19% of OCD cases misdiagnosed as GAD or Depression at first presentation in primary care

GAD / Anxiety Disorder

~47%

Intrusive thoughts misread as generalised worry; reassurance-seeking indistinguishable from anxiety avoidance

Major Depressive Disorder

~39%

Secondary depression dominates; obsessional content never directly explored by clinician

Psychosis / Schizophrenia

~18%

Overvalued ideation mistaken for delusions; ego-dystonic nature not elicited

ADHD

~12%

Ritual behaviour and inattention create superficial overlap; different cognitive substrates

Autism Spectrum Disorder

~17%

Repetitive behaviours vs compulsions; frequently co-occurring - both must be assessed and treated

Who Is Affected?

~280M

People affected
worldwide

WHO 2022

2–3%

Lifetime
prevalence

ECA / NCS-R

10th

Cause of disability
(WHO)

GBD 2019

17 yrs

Average delay
to treatment

Hollander et al.

Onset

Bimodal: peak childhood (age 10) + early adulthood (age 21); male-earlier

Paediatric

0.25–4% children/adolescents; frequently missed as anxiety or ODD

Perinatal

2–4% pregnancy/postpartum; commonest new-onset psychiatric disorder postpartum

Economic cost

~\$1.4 trillion USD/year globally in lost productivity alone



Mortal Silence: The Suicide Risk

1 in 7

patients attempt
suicide

Torres et al., 2011 · Meier et al., 2016

10×

higher mortality rate
vs. general population

Meier et al., 2016 · Fineberg et al., 2013

Why this is systematically missed:

- ▶ Suicidality attributed to comorbid depression — OCD aetiology not recognised
- ▶ Shame prevents disclosure of intrusive thoughts; clinician cannot screen for what they do not ask
- ▶ High-functioning façade maintained until catastrophic deterioration

"Dangerous" OCD: Physical Sequelae

Untreated OCD causes permanent physical damage that is systematically missed in clinical encounters.

Contamination OCD

- ▶ Dermatitis & excoriation from chronic handwashing with bleach/chemicals
- ▶ Chemical burns - undiluted cleaning agents applied directly to skin
- ▶ Contact dermatitis → open wounds, secondary infection, scarring

Hoarding

- ▶ Falls and injuries from accumulated clutter in living spaces
- ▶ Respiratory illness: dust, mould, vermin in hoarded environments
- ▶ Social isolation → cardiovascular and metabolic health deterioration

Checking / Decontam.

- ▶ Severe dehydration → acute kidney injury / renal failure (documented cases)
- ▶ Malnutrition & electrolyte disturbance from contamination food fears
- ▶ Dental erosion from repetitive mouthwashing or vomiting compulsions

Avoidance / 'Pure O'

- ▶ Extreme withdrawal → loss of employment, relationships, deconditioning
- ▶ Inadequate medical care-seeking due to healthcare contamination fears
- ▶ Delayed serious illness diagnosis when medical avoidance is a compulsion

Economic Invisibility: The £1 Million Patient



£1M+

Estimated lifetime cost
of one severe,
untreated OCD case

NHS 2014 Cost Analysis

NHS Direct Treatment

~£84,000

Hospitalisations, crisis care, outpatients over lifetime

Benefits & Welfare

~£310,000

Disability benefits, carer allowance, housing across working life

Lost Tax Revenue

~£420,000

Lost income tax & NI from inability to work (20-year working life)

Social Care & Crisis

~£190,000

A&E, police, emergency housing, voluntary sector services

The economic burden is massive — yet largely unmeasured by policymakers

OCD: Myths vs Clinical Reality

COMMON MYTH

OCD is just being 'neat and organised'



OCD is an anxiety disorder



Patients can 'just stop' rituals



OCD only involves checking or cleaning



OCD affects 'perfectionists'



CLINICAL REALITY

OCD is ego-dystonic: obsessions cause intense distress; compulsions are not pleasurable

OCD has its own DSM-5/ICD-11 chapter; overlaps with tic disorders and OCSD spectrum

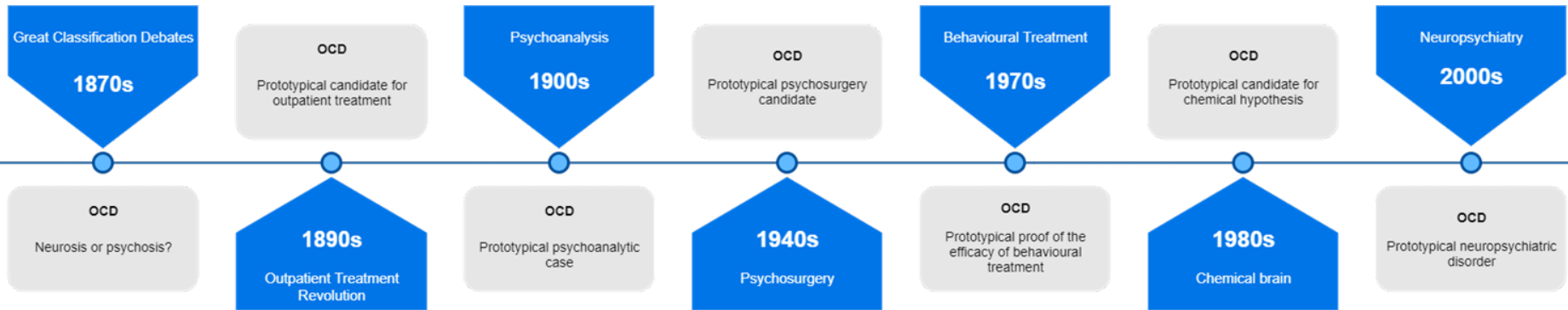
Compulsions are driven by neural circuit hyperactivity — not choice or character

Common subtypes: harm, sexual, religious, symmetry — many are completely invisible

Affects all personalities; onset from age 5; no socioeconomic or cultural boundary

Obsessive Compulsive Disorder

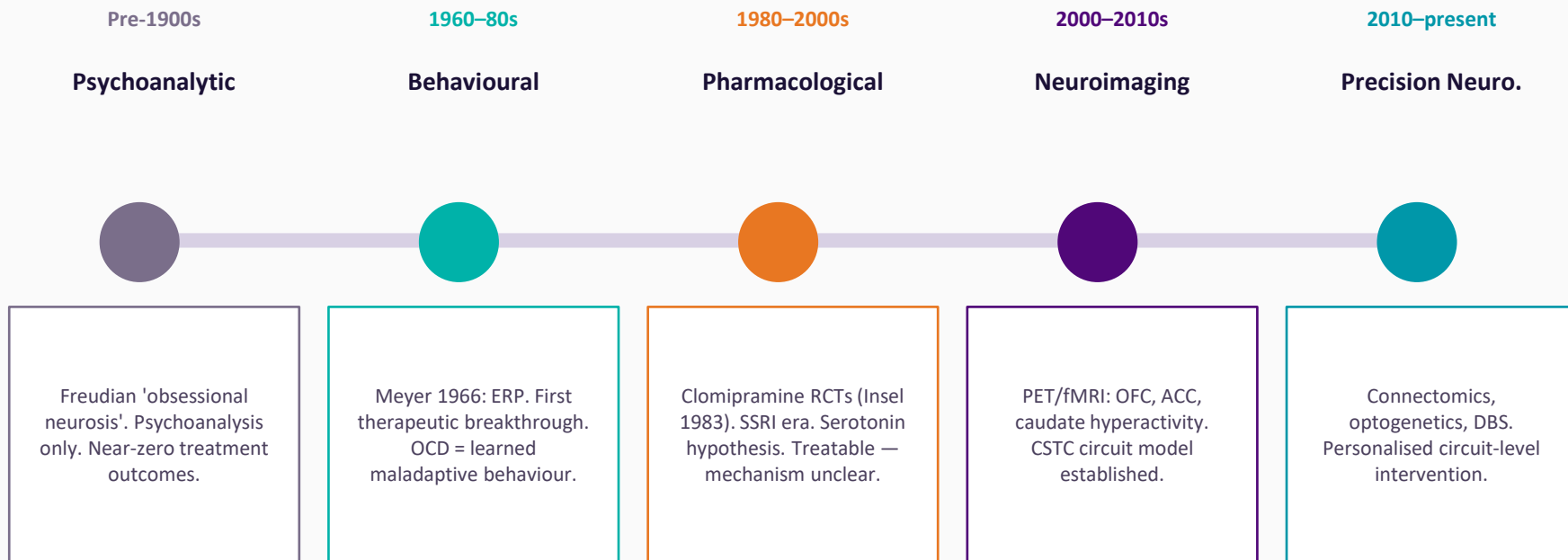
A Prototypical ___ Disorder



Fascinating co-evolution of psychiatry as a discipline and OCD as an illness

A Prototypical Neuropsychiatric Disorder

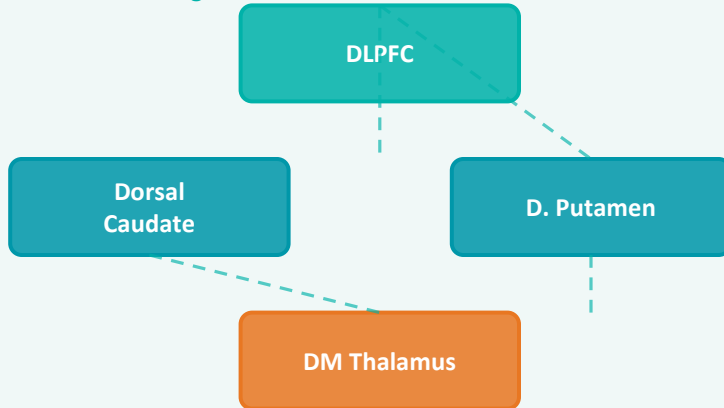
The evolution from psychoanalytic curiosity to circuit-based pathology



The CSTC Matrix: Two Pathological Loops

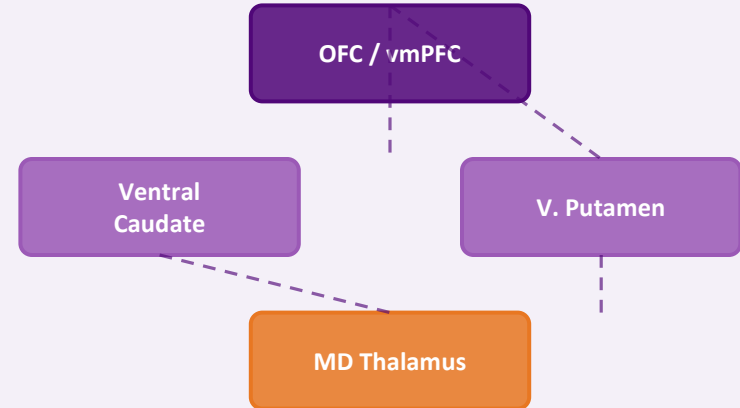
Cognitive Loop (Dorsolateral)

Doubt · Checking · Indecision

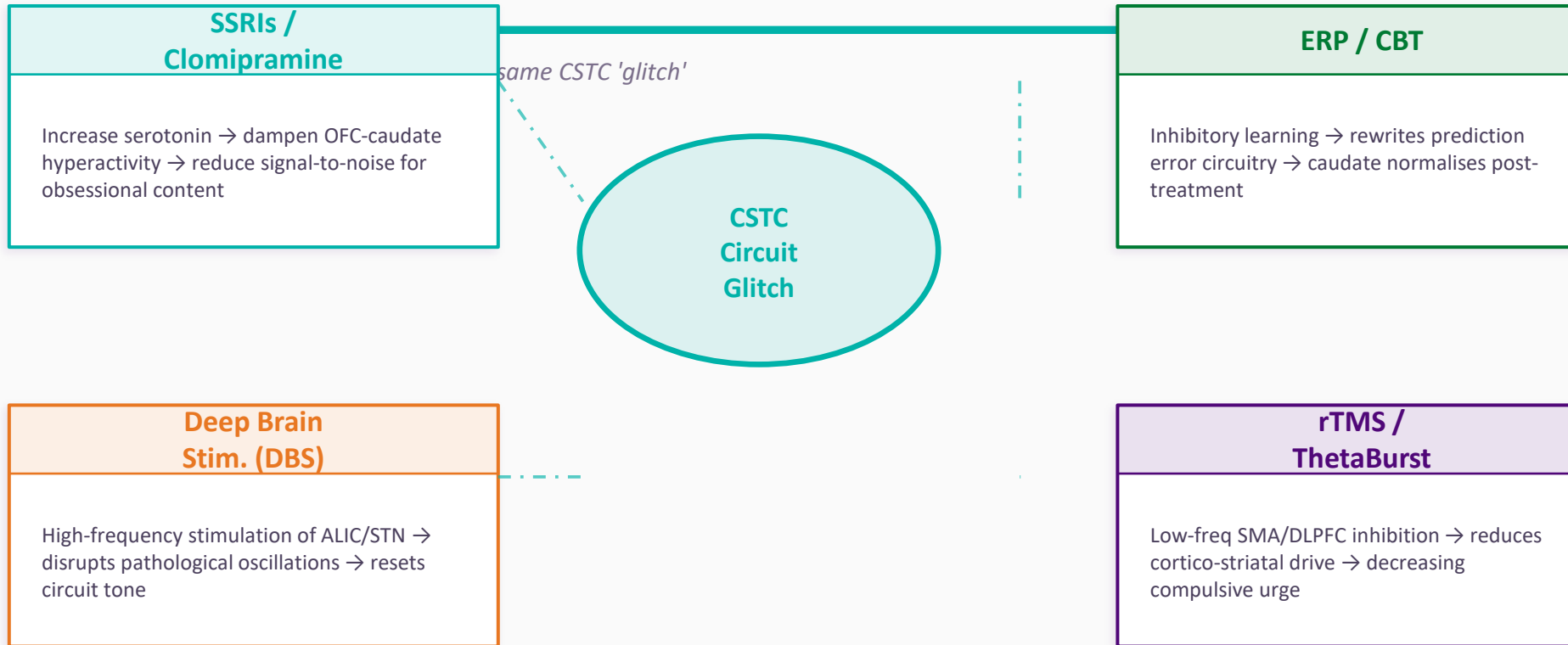


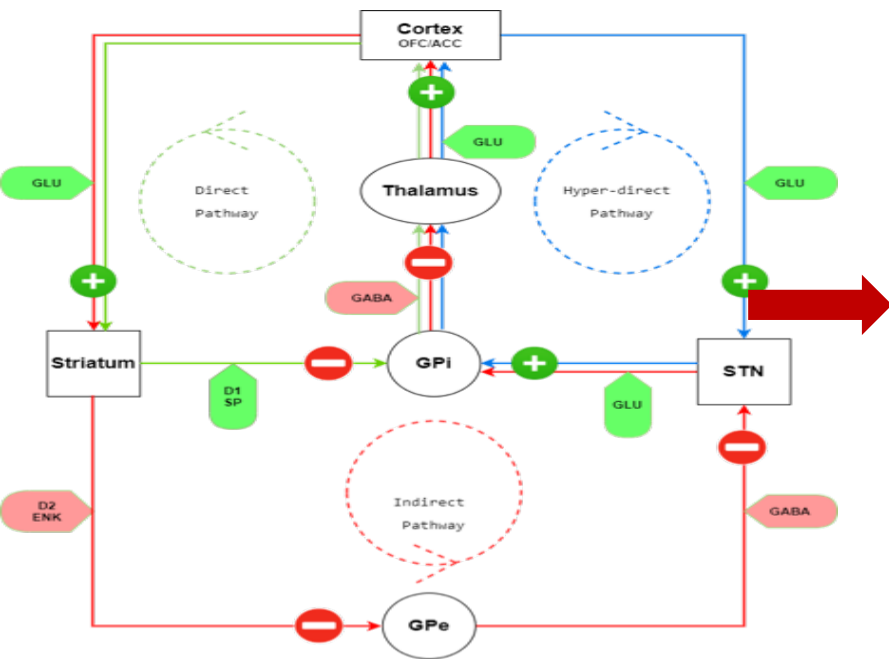
Affective Loop (Ventromedial)

Contamination · Harm · Fear



One Circuit, Many Interventions





Every effective OCD intervention is based on modulating this circuit

- SRI/SSRI
- Dopamine augmentation of SRI
- Exposure based CBT
- Magnets
- ABI
- Brain stimulation treatments
- Lesioning

Broad aim: inhibition, not stimulation*.



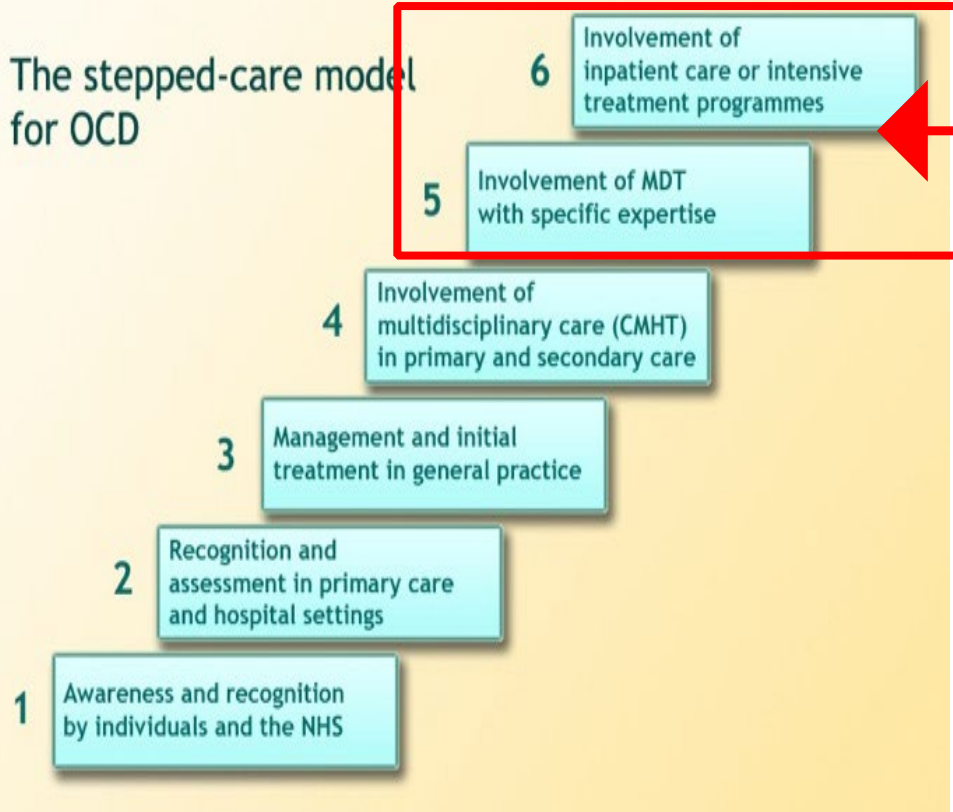
*National Institute for
Health and Clinical Excellence*

Issue date: November 2005

Obsessive-compulsive disorder

Obsessive-compulsive disorder: core interventions in the treatment of obsessive-compulsive disorder and body dysmorphic disorder

The stepped-care model for OCD



Evidence-Based Treatments: What We Have



SRIs / SSRIs

First-Line Pharmacotherapy

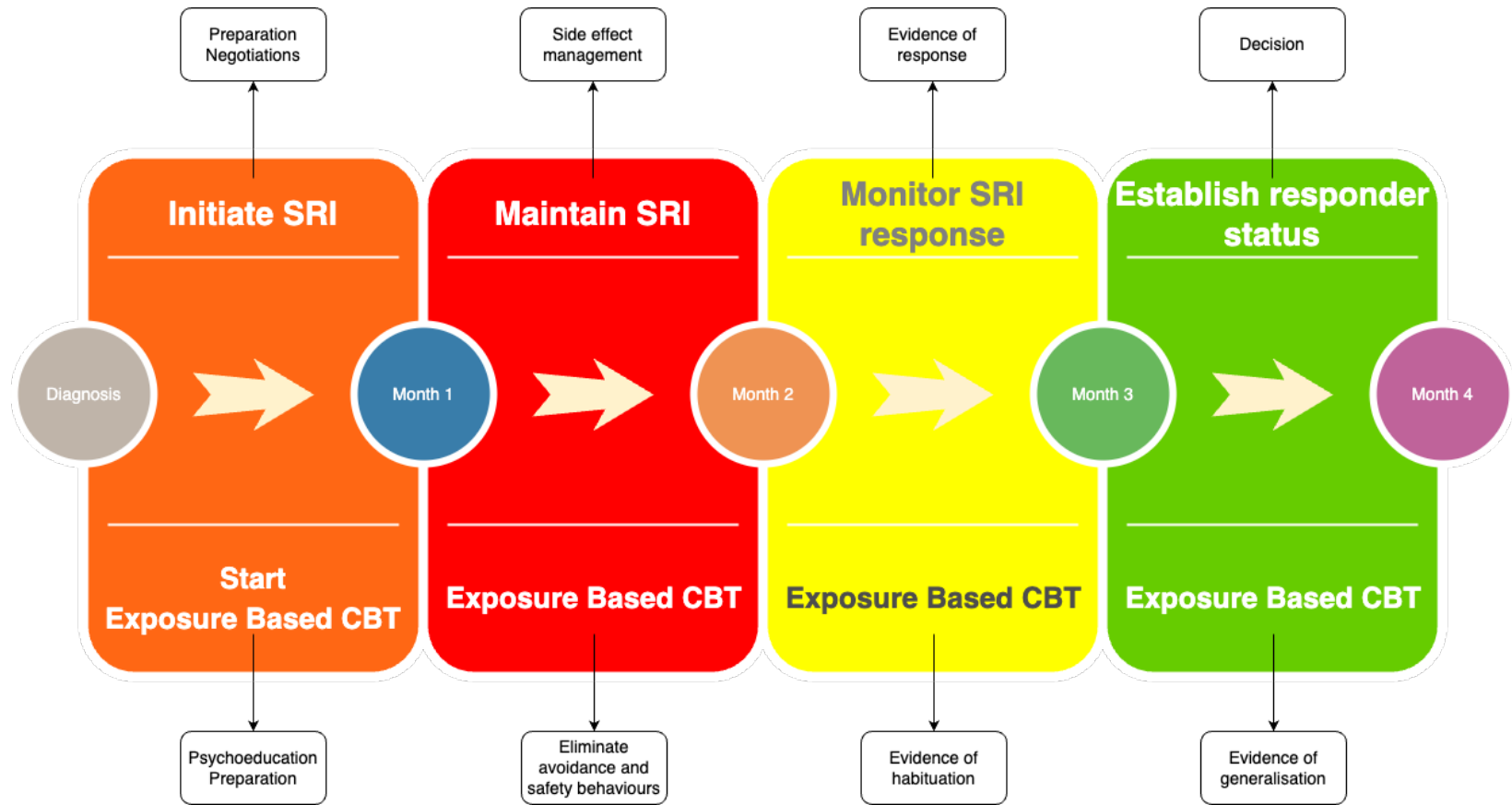
- SSRIs: fluoxetine, sertraline, fluvoxamine, escitalopram, paroxetine
- Clomipramine: most efficacious SRI — tolerability limits use
- Higher doses than depression: fluoxetine 60–80 mg (NICE)
- Minimum trial: 10–12 weeks at therapeutic dose
- 40–60% meaningful response; ~25% full remission
- Augmentation: aripiprazole or risperidone for partial response

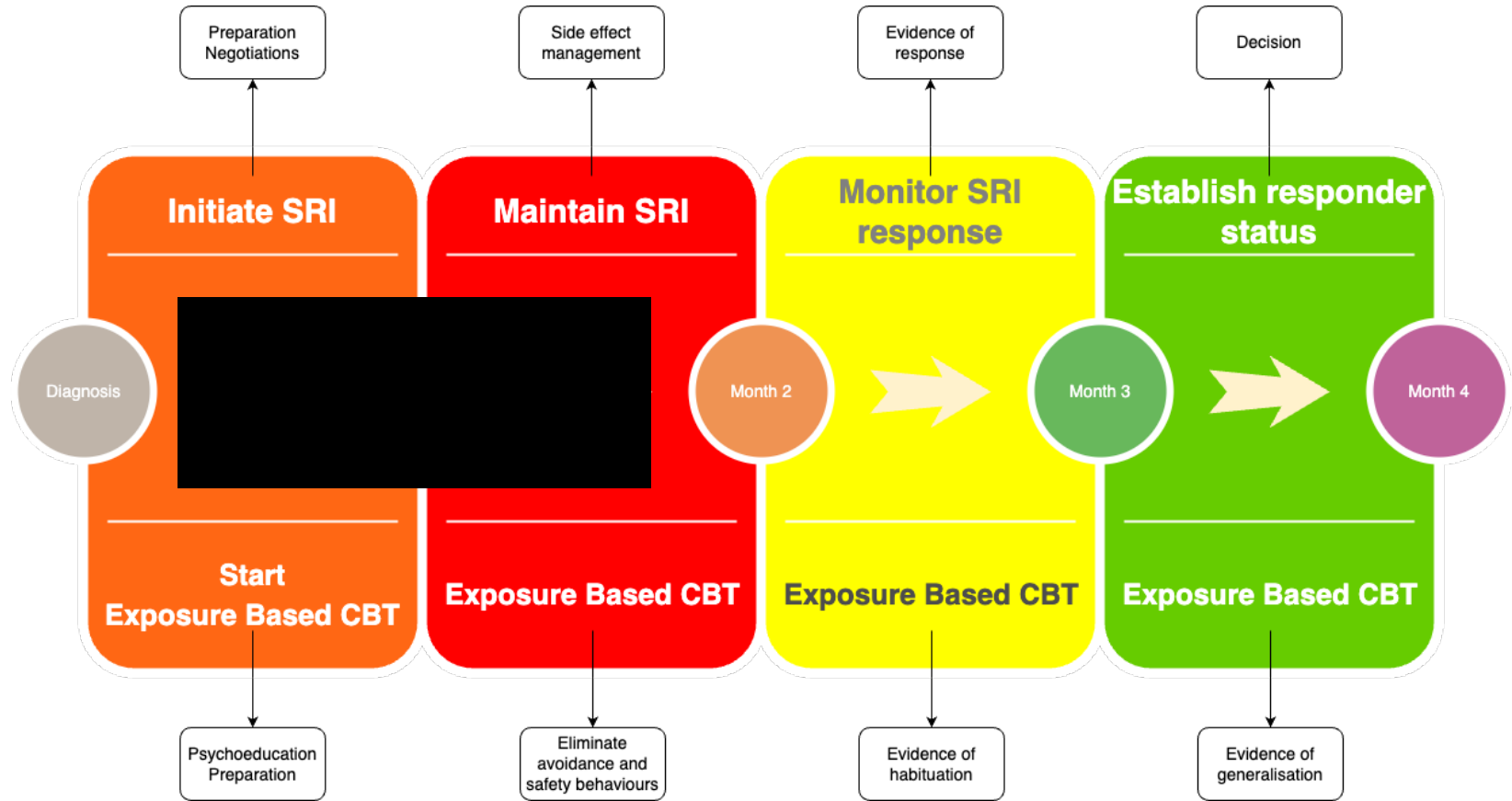


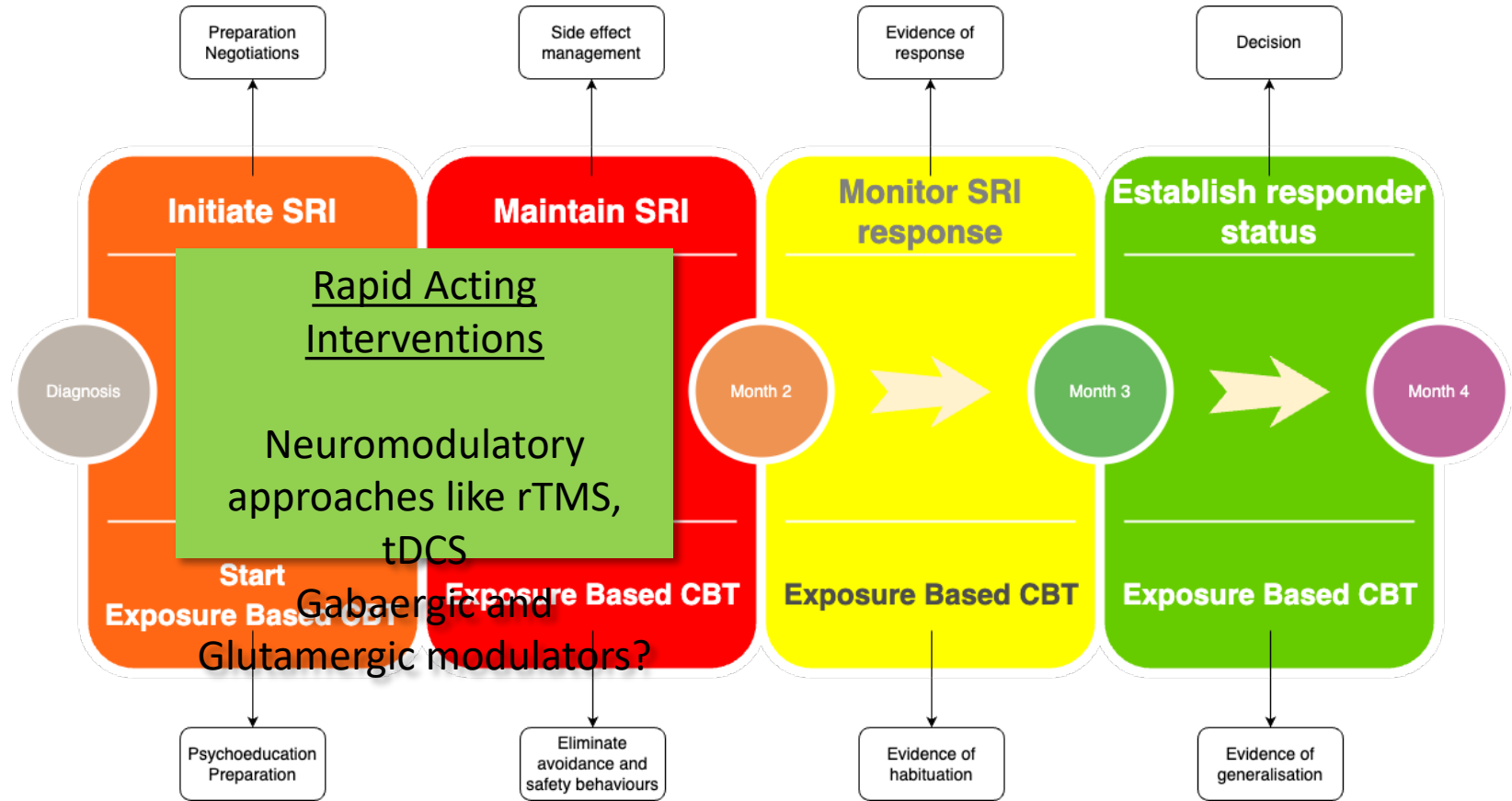
ERP / CBT

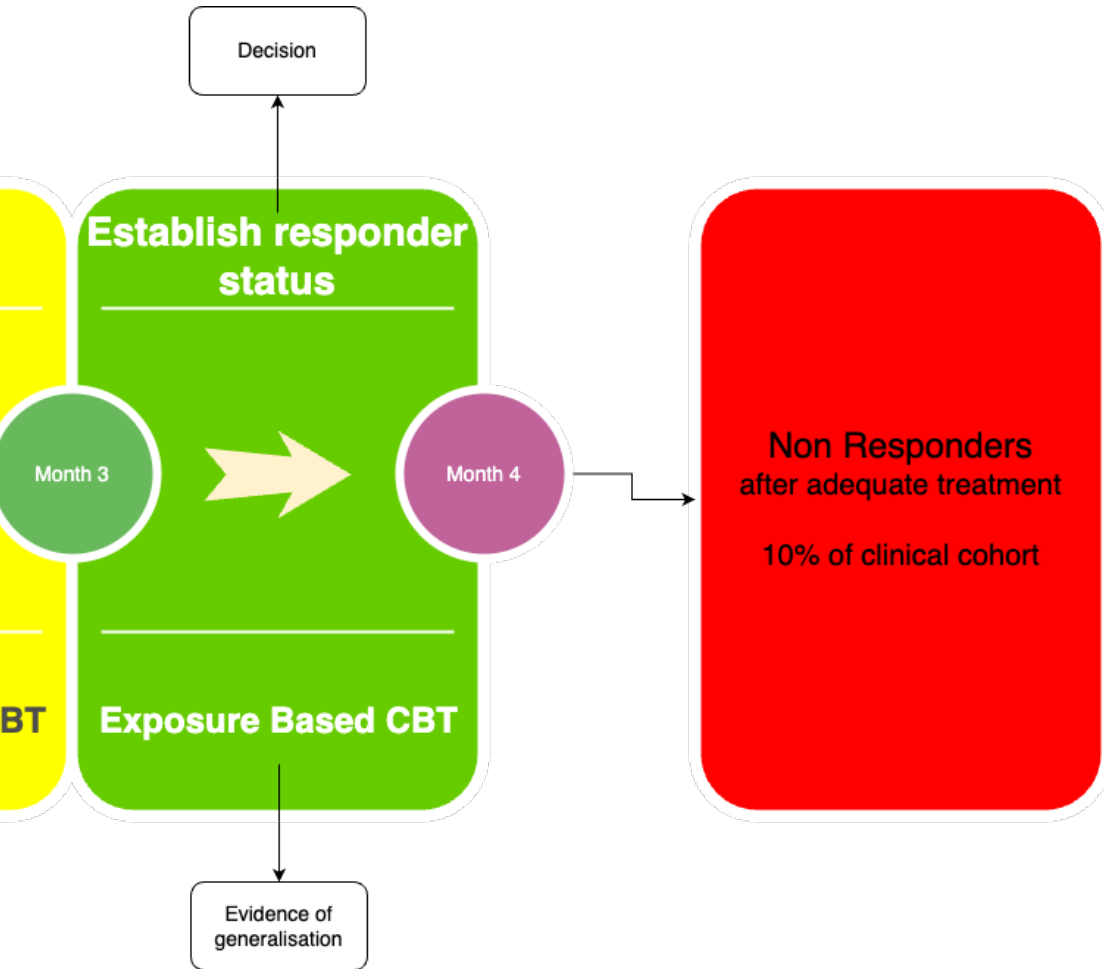
Gold Standard Psychological Therapy

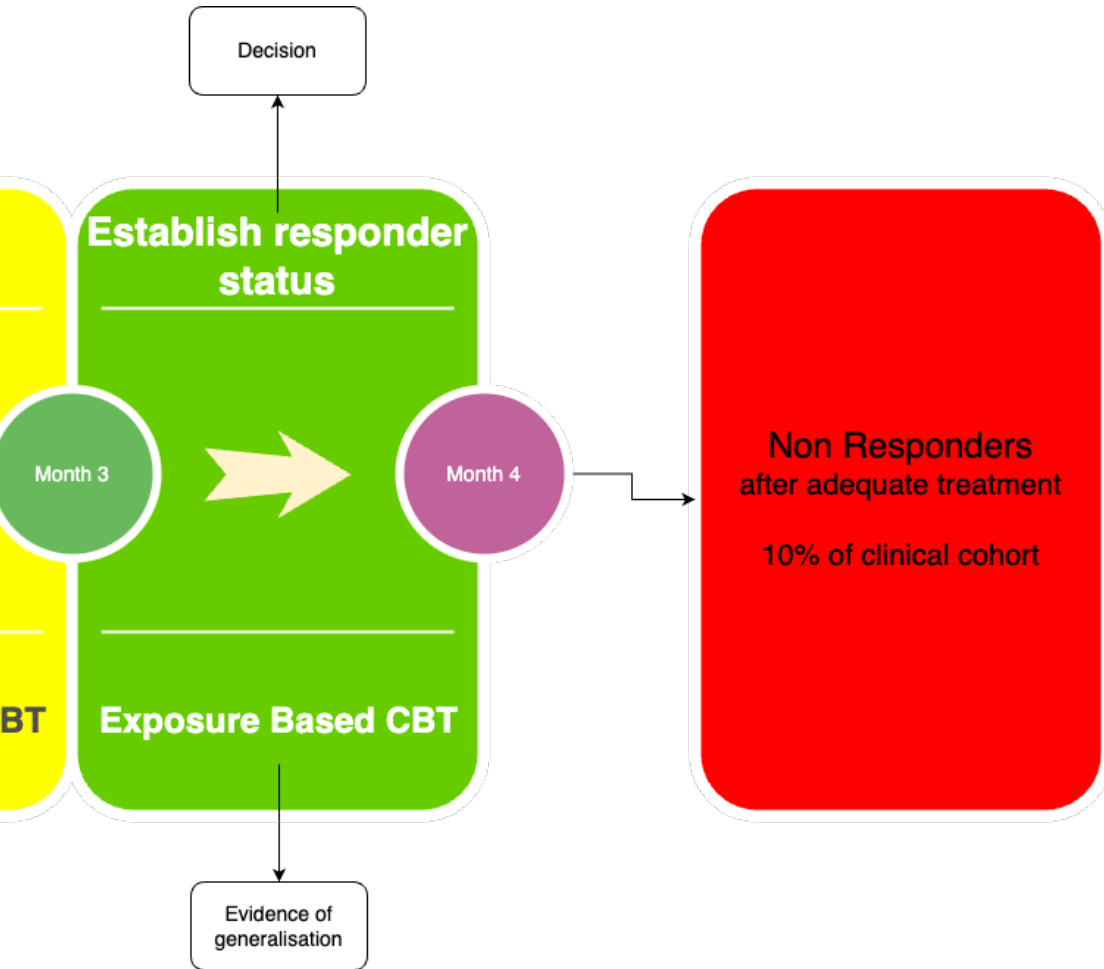
- Exposure & Response Prevention: graded exposure + urge habituation
- Inhibitory learning model: new non-threat associations override OFC fear
- Response rates: 60–80% with intensive fidelity-delivered ERP
- 12–20 sessions; intensive residential format for severe OCD
- ICBT: comparable efficacy with substantially improved access
- Combination SRI + ERP superior to either alone











Advanced treatments

- Deep Brain Stimulation
- Adaptive Deep Brain Stimulation
- Cingulotomy
- Capsulotomy
- Future approaches

The Solution-Refractory Problem

~40%

No response to first-line SRI

Fail to achieve clinically meaningful response after adequate SRI trial at optimal dose

~25%

SRI partial responders

Some improvement but persist with significant symptoms; require augmentation strategies

~10%

"Ultrapotent" non-responders

Fail ≥ 3 adequate SRI trials AND ERP — meet criteria for treatment-resistant OCD (TR-OCD)

<1%

Access advanced neuromodulation

Of those eligible for DBS or specialist neuromodulation, only a fraction access it globally

Defining Treatment-Resistant OCD:

Failure of adequate trials of ≥ 3 different SRIs (including clomipramine) at maximum tolerated dose for ≥ 12 weeks each, PLUS failure of therapist-delivered ERP. Approximately 10% of all OCD sufferers.



Treatment Limitations: The Unmet Need

<10%

ERP Access Crisis

receive evidence-based ERP; most CBT therapists lack OCD-specific training

25–30%

Dropout from ERP

dropout due to anxiety, shame, or poor fidelity of exposures

>60%

Paediatric Gap

child/adolescent OCD goes unrecognised in CAMHS

<5%

Perinatal Invisibility

of perinatal OCD is correctly identified at presentation

>85%

Global Inequity

LMIC patients have no specialist access whatsoever

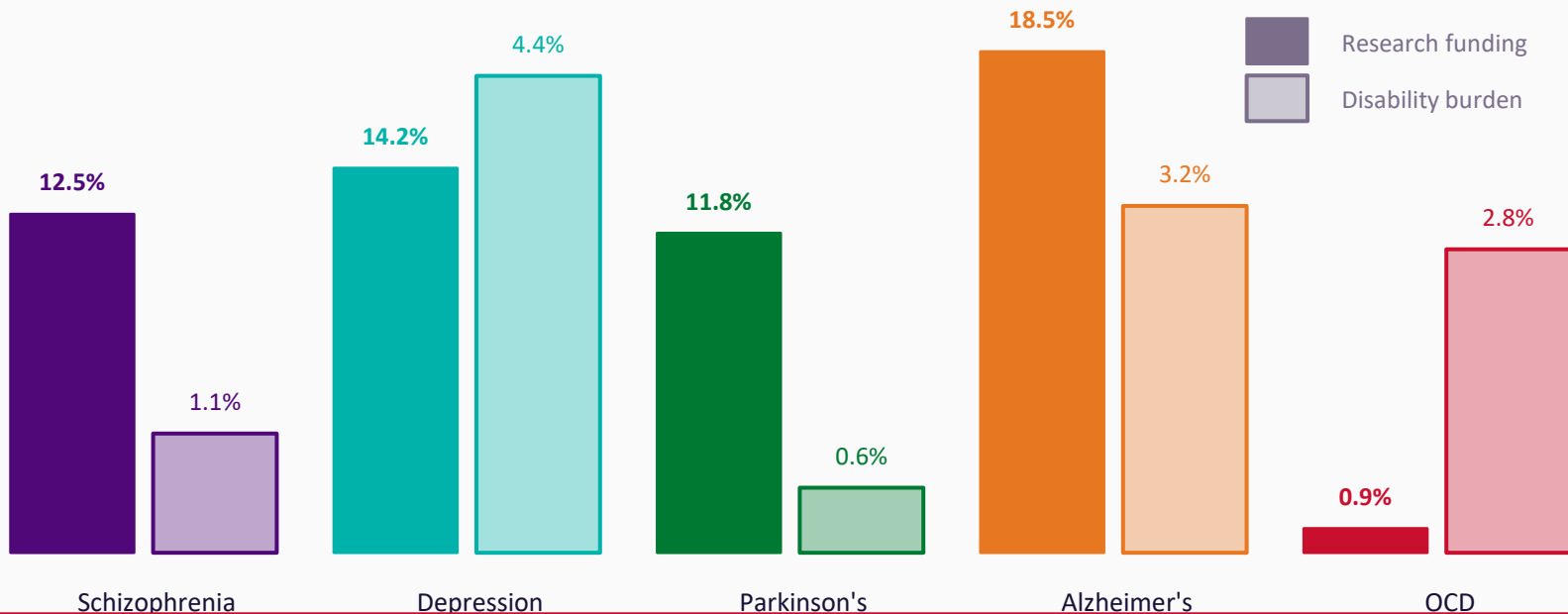
<1%

Research Neglect

of total MH research funding allocated to OCD globally

Structural Neglect: The Research Funding Gap

UK NIHR/MRC Mental Health Research Investment (%) vs Global Disability Burden (%)



OCD: 0.9% of funding, 2.8% of burden. Schizophrenia receives 14x more research investment. Structural neglect keeps the epidemic silent.



Beyond Chemistry: The Electrical Approach

40% of patients do not achieve adequate response with best pharmacological and psychological therapies. For this group, we need tools that act directly on the circuit — not indirectly through synaptic pharmacology.

Targeted

Stimulation delivered directly to specific CSTC nodes (ALIC, STN, NAc) — bypasses systemic off-target effects of drugs

Programmable

Stimulation parameters (frequency, amplitude, pulse width) adjusted non-invasively after implant based on biomarkers

Reversible

Device can be switched off or removed if adverse effects occur or remission achieved — unlike ablative capsulotomy

Biomarker-driven

Closed-loop DBS: neural biomarkers (beta oscillations, LFPs) trigger stimulation only when circuit dysfunction is detected

Precision Targets: ALIC vs STN vs NAc

Matching stimulation site to symptom cluster — network-based targeting



ALIC / VC-VS

Symptom cluster:

Anxiety-dominant OCD: harm, contamination, checking

Mechanism:

Disrupts OFC-caudate & OFC-thalamic afferents; reduces threat appraisal

Key evidence:

Nuttin 1999; Greenberg 2010 HDE trial; ~50% ≥35% Y-BOCS reduction



vm-STN

Symptom cluster:

Compulsion-dominant: symmetry, 'just right', tics

Mechanism:

Modulates indirect pathway inhibition; reduces compulsive motor output

Key evidence:

Mallet et al., 2008 NEJM double-blind crossover; ~50% response



Nucleus Accumbens

Symptom cluster:

Anhedonic/avoidant OCD with severe depression

Mechanism:

Dopaminergic reward circuit modulation; dual OCD+MDD effect

Key evidence:

Denys et al., 2010; preferred where severe depression co-exists

Emerging Translational Approaches



rTMS & ThetaBurst

SMA target (low-freq)

Multiple RCTs; reduces compulsive urge; non-invasive; outpatient

DLPFC protocol

Augments ERP cognitive reappraisal; combined neuromodulation+therapy

Intermittent TBS

5-min sessions; equivalent to 40-min rTMS; dramatically improves scalability



Glutamate Modulators

N-Acetylcysteine

Positive augmentation RCTs (Afshar et al.); well-tolerated; accessible

Riluzole

Glutamate release inhibitor; open-label series; ongoing Yale RCT

Ketamine IV

Rapid transient anti-OCD response; provides mechanistic translational window



Psychedelic-Assisted

Psilocybin (OCD RCT)

Moreno 2006; UCL/JHU RCT underway; 5HT2A serotonergic reset hypothesis

MDMA-assisted

Facilitates emotional processing; PTSD-comorbid OCD evaluation underway

D-cycloserine

NMDA partial agonist; timing-sensitive ERP augmentation; 3 positive RCTs



Immunotherapy & Novel

PANDAS/PANS: rapid reversal in autoimmune-mediated OCD (Perlmutter 1999)

Anti-inflammatory

Microglial PET: neuroinflammation in OCD; potential anti-inflammatory trials

Gut-brain axis

Preclinical microbiome disruption → OCD-like behaviour; human trials in design

Rapid-Acting Interventions & The Pipeline

Ketamine & Glutamatergic Modulators

- ▶ IV ketamine (0.5 mg/kg): rapid (hours) anti-OCD response — open-label series (Rodriguez et al., 2013)
- ▶ Mechanism: NMDA blockade → disrupts glutamatergic CSTC hyperactivity → transient normalisation
- ▶ Duration: 1–2 weeks — insufficient standalone; opens mechanistic window
- ▶ Therapeutic window hypothesis: ketamine augments subsequent ERP by reducing compulsive drive
- ▶ Esketamine (nasal): approved for TRD; OCD-specific RCT evidence lacking
- ▶ NAC, riluzole: longer-lasting circuit stabilisation; fewer dissociative side effects

THERAPEUTIC PIPELINE

Preclinical	Gene therapy (OFC); microbiome; NMDA antagonists
Phase I	tDCS OFC; MDMA-assisted; 5-HT2A ligands
Phase II	Psilocybin RCT; riluzole RCT; ketamine + ERP
Phase III / HDE	ThetaBurst TMS; DCS + ERP; STN-DBS trial
Licensed / HDE	DBS (ALIC — FDA HDE); SSRIs; clomipramine; ERP

Reframing OCD for the 21st Century

Niche anxiety disorder

Classified under anxiety for decades; clinicians deprioritise



Major neuropsychiatric disorder

Circuit-based pathology; equal to Parkinson's in biological complexity

'Difficult' patient group

Treatment resistance framed as patient failure



Precision medicine opportunity

Circuit biomarkers enabling personalised intervention selection

Psychological curiosity

Freudian legacy; 'talk therapy'



Translational neuroscience priority

Optogenetics, connectomics, DBS — a neuroscience research frontier

Policy footnote

<1% of MH research funding; absent from WHO priority lists



Global public health emergency

280M affected; 10th disability cause; \$1.4T economic burden

The science is ready. The gap is structural, political, and economic — not biological.

Breaking the 17-Year Silence

1

Active Screening

Embed OCD screening in ALL new GP, CMHT, IAPT, perinatal assessments. Ask directly. Use OCI-R or Y-BOCS. Do not wait for disclosure.

2

Specialist Referral Pathways

Nationally commissioned OCD specialist pathways (NHS England). Every region should have direct-access OCD clinic. Stop referring to generic CBT.

3

Clinician Training

Mandatory ERP competency in all CBT programmes. OCD-specific modules in undergraduate psychiatry and GP training. OCARD educational programme.

4

Research Investment

Increase NIHR/MRC OCD allocation to $\geq 3\%$ (in line with disability burden). Fund psilocybin, TMS, immunotherapy RCTs. National OCD biobank.

5

Policy Advocacy

Name OCD as a national NHS priority (as gambling disorder was in 2022). Lived experience + specialist voices in NICE guideline refresh.

The Framework for Change

1

Research Investment

- ▶ Fund OCD to burden parity ($\geq 3\%$ MH research)
- ▶ Biomarker & stratification trials
- ▶ National OCD genomic & imaging biobank

2

Clinical Training

- ▶ Mandatory ERP competency in all CBT programmes
- ▶ OCD modules in GP & psychiatry curricula
- ▶ Peer supervision networks nationally

3

Service Innovation

- ▶ NHS England national stepped-care OCD pathway
- ▶ Integrated ICBT + specialist escalation model
- ▶ Perinatal OCD screening in all antenatal settings

4

Advocacy & Destigmatisation

- ▶ Campaign against 'I'm so OCD' trivialisation
- ▶ Lived experience in guideline and research design
- ▶ OCD on NHS Long Term Plan as named priority

OCD is not a niche.

OCD is not trivial.

**OCD is a silent global epidemic —
and silence costs lives.**

Key messages:

The 1-in-50 paradox is a clinical failure, not an epidemiological artefact

OCD is a neuropsychiatric disorder: the circuit is the target

1 in 7 attempt suicide - yet the risk is systematically misattributed

DBS, TMS, Ablative neuromodulation: precision neuromodulation is the next frontier

Structural change needed: funding, training, services, and policy advocacy