

The Unseen Crisis: A Manifesto for OCD Awareness and Action



Introduction

Obsessive Compulsive Disorder (OCD) affects 1-2% of people in the UK. It is a powerful and destructive mental health condition. Despite its severity, OCD is treatable with the right support and evidence-based treatment. Yet, we face a crisis of neglect—OCD is invisible in our healthcare system.

The Crisis

People living with OCD in the UK face an unacceptable delay of 6-7 years from symptom onset to seeking help ¹, largely due to the pervasive lack of understanding and trivialisation surrounding the condition.

Once help is eventually sought, the path to effective treatment, specifically Cognitive Behavioural Therapy with Exposure and Response Prevention (CBT with ERP), is riddled with obstacles.

The frequent occurrence of misdiagnosis ², delayed treatment, and inappropriate therapeutic interventions is a troubling reality for too many living with OCD. These obstacles inflict unnecessary suffering and prolonged periods of illness, exacerbating the condition into a chronic cycle of relapse and remission ³. The societal impact of this is profound, with delays in treatment for OCD costing the UK an estimated £5.1 billion annually ⁴.

This highlights a critical need for immediate reform in how OCD is perceived and treated at both healthcare and policy levels.

¹ Robinson, Rose and Salkovskis, 2017

² Adult Psychiatric Morbidity Survey, 2014

³ Fineberg et al., 2019

⁴ Kocher et al, 2023

The Data Gap

Data is the bedrock of effective healthcare. Yet, our findings reveal a stark absence of OCD-specific data in secondary care.

Our research has shown that none of the main NHS planning organisations in the UK tasked with meeting the health needs of the population—be it NHS England, Integrated Care Boards (ICBs), Health Boards, or NHS Boards—systematically collect data on OCD.

Alarming, community mental health teams—which are pivotal in providing services to people who are very unwell with OCD—do not consistently collect performance or outcome data on OCD. The lack of structured data collection leaves a significant gap in our understanding of how effectively these services meet the critical needs of those with severe OCD.

This data gap indicates a healthcare system in the dark about the scale of OCD, with no clear understanding of the prevalence, treatment needs, waiting times, or treatment outcomes for those living with OCD.

Contrastingly, the NHS maintains data collection for the conditions and areas of mental health treatment it has prioritised. For example, data is collected and reported by NHS England on those treated for what they term as severe mental illness, such as schizophrenia or bipolar disorder. Such data collection ensures that service planners are informed about rising treatment needs and patient numbers⁵. Moreover, NHS England meticulously tracks specific waiting times for accessing Early Intervention in Psychosis services (psychosis can be a symptom of conditions like

schizophrenia and bipolar disorder). The rationale provided by NHS England for prioritising this data collection and monitoring is that untreated psychosis is linked to poorer recovery outcomes, higher service usage, and adverse economic impacts in both the short and long term⁶.

We are therefore left wondering: Does the prioritisation of data collection for certain conditions, and the apparent disregard for OCD within this framework, suggest that those leading the NHS are indifferent to the recovery and economic wellbeing of people living with OCD?

⁵ Mental Health Services National Statistics Dashboard (see slides 9 and 18 for regional details)

⁶ Implementing the Early Intervention in Psychosis Access and Waiting Time Standard: Guidance, page 13

Our Stance

To count is to acknowledge. The government's failure to collect and analyse data on people living with OCD is tantamount to accepting that those suffering from the condition may not receive the care they need. This oversight reflects a system dismissive of OCD, trivialising the condition and its impact on individuals and their families.

This must change. We must count every person living with OCD —because every person living with OCD matters.

Plan for Change

To address the critical issues facing people living with OCD, we present our demands to the next government, outlined with specific timelines for execution. We are calling on the next government to:



1. End trivialisation and increase understanding of OCD



2. Recognise and count people with OCD



3. Guarantee timely access to clinically recommended treatments

More on the next page >



OCD is a serious and debilitating mental health condition, but not everybody knows. Our call to action begins with government accountability in reshaping the public dialogue around OCD. To achieve change, the government must lead by example by committing to end the widespread trivialisation of OCD.

- **Immediate Action:** Within the first 100 days of the new government, the Minister for Health and Social Care, back bench ministers, and relevant officials must publicly pledge to refrain from using trivialising language and tropes about OCD.
- **Within the first year:** Prioritise the reform of the Mental Health Act to better reflect the serious nature of OCD.
- **By 2027:** Launch a funded national awareness campaign to shift public perception of OCD, emphasising its severity and treatability.

Understanding the scope of OCD is fundamental to improving services. The government must recognise the needs of the 750,000 people living with OCD in the UK.

- **Immediate Action:** Initiate a comprehensive national needs assessment within the first 100 days post-election to determine the precise treatment needs for people living with OCD.
- **Within the first year:** Host a summit for key ministers and people affected by OCD, informed by the needs assessment, and establish an All-Party Parliamentary Group (APPG) to ensure long-term oversight and action.
- **By 2027:** Mandate all NHS Trusts to track and report the number of individuals receiving OCD treatment within secondary care, establishing nationally set performance targets and service waiting time targets. Additionally, ensure NHS England, every health board, NHS Trust, and Integrated Care Board (ICB) receives detailed reports on the number of individuals receiving OCD treatment, enabling them to effectively plan for the care of people with OCD.

Nobody living with OCD should face unnecessary delays in receiving the care they need.

- **Immediate Action:** Within the first 100 days of the formation of the new government, the Minister for Health and Social Care must commit to ring-fencing funding specifically for OCD treatment.
- **By 2027, we expect the government to:**
- **Utilise Data Driven Planning:** Implement comprehensive service and workforce development plans across all trusts, tailored to meet the specific needs of those affected by OCD.
- **Establish New Specialist OCD Services:** Secure funding for and establish new regional specialist OCD services, ensuring regional OCD specialist services are funded and functioning to complement existing national specialist services.

Why It Matters

The Personal Cost of a Broken System

Every person with OCD has a story that deserves to be heard. The stories of Michelle and Annabel bring to light the often-overlooked struggles of those dealing with OCD in a system that fails to consistently monitor the quality and effectiveness of treatment and understand the extent of service requirements, particularly in community mental health teams, where many of those who are severely affected by OCD are treated. Michelle and Annabel's experiences, representative of many, demand our immediate attention and action.

Michelle's Story

My son Liam's deep fear of contamination wasn't just a quirk – it was a prison that stripped away his basic comforts, from touching a phone to the simple act of drinking water. His OCD led him to worry that everything around him was contaminated, a fear so strong it left him malnourished, isolated, and trapped in a room he couldn't bear to let me clean.

For six years, as Liam battled severe OCD, we faced a relentless cycle of bureaucracy, misunderstandings, and delays. Treatment was withheld by his community mental health team because his battle with OCD had left him too frail—his BMI had plummeted due to compulsive eating restrictions, the very issue that necessitated the treatment.

The most devastating blow came when Liam was denied access to the specialist OCD unit because he couldn't take his medication. Labelled noncompliant, the reality was his OCD around contamination was so intense it stopped him from ingesting food and pills—an issue that the specialist care should have been ready to navigate and support.

Ultimately, the delay in receiving the right treatment culminated in my son taking his own life in May last year. A system that was supposed to protect and heal him contributed to his sense of despair. My heart is shattered.

I share Liam's story because we need something to change. I cannot bear the thought of another family enduring this pain. The mental health care system's failings are not just statistics - they represent real lives destroyed by inaction and neglect. No other mother should have to face this agony. We need systemic change now, to ensure that OCD is treated with the seriousness and urgency it demands, and that no one else slips through the cracks as Liam did.

Annabel's Story

Last year, I was so unwell with my OCD that I took an overdose. It was a full three months before I heard from the community mental health team. When I finally had my assessment in September, the nurse's words stunned me: "Everyone has a little bit of OCD." No treatment was suggested; instead, I received infrequent and brief phone calls, about once a month, where the nurse would simply ask how I was. On my birthday, amidst tears and after confessing I had spent five hours on compulsions, the nurse's advice was to "have a big smile and be grateful it's your birthday." These interactions left me feeling unseen and unheard, with my OCD completely trivialised.

By February of this year, my situation hadn't improved, but the nurse decided to discharge me, due to a two-year waiting list for 'talking therapy'—a vague term which didn't make it clear if it was even the recommended treatment I needed. She told me that I'd find being on a waiting list for two years too difficult, and recommended I seek low cost therapy instead. Exhausted and without the strength to fight anymore, I consented to the discharge. The calls didn't offer support; they amplified my distress and reinforced the notion that help was out of reach, and that my condition was misunderstood, even by mental health professionals. Left with no choice, I've had to turn to private CBT with ERP therapy, despite being unemployed, because the support I needed from my community mental health team was inaccessible.