International OCD Foundation

America's OCD Care Crisis

National Findings on the Failure of Effective OCD Treatment to Reach Patients

December 2025

International OCD Foundation

About the International OCD Foundation (IOCDF)

The International OCD Foundation is the leading authority on obsessive compulsive disorder (OCD) and related disorders. As a 501(c)3 nonprofit organization, the IOCDF supports a global community of people with lived experience, families, mental health professionals, and researchers. The IOCDF is committed to expanding access to effective treatment, advancing research, and ensuring that no one affected by OCD and related disorders suffers alone. Visit iocdf.org.

Authors and Contributors

Rebecca Deusser, MS, MBA
Executive Director
IOCDF

Sanjaya Saxena, MD
Director of Clinical & Research Affairs
IOCDF

Andrea McCracken, MPH
Director of Real World Evidence
Guardian Research Network

Nicolás Tentoni, MD
Director, Analytics
Resonance

Stephanie Cogen, MPH, MSW
Program Director
IOCDF

Rachel Crofut
Director of Communications & Digital Strategy
IOCDF

Boris Litvin, MA
Research Communications Specialist
IOCDF

Jordan Arfanakis
Intern & Grassroots Advocate
IOCDF

This project was developed in collaboration with

Guardian Research Network

resonance
amplifying health

Our sincere thanks to the Hyman family and the Bruce Hyman Endowment, which funded this publication.

Table of Contents

Executive Summary

Obsessive compulsive disorder (OCD) is a common and often chronic and debilitating disorder. Up to 240 million people in the world suffer from OCD at some point in their lives.[1,2,3] Fortunately, effective, evidence-based treatments are available* to help diminish OCD symptoms, greatly reduce suffering, and potentially achieve full relief. People with OCD can thrive if they receive timely and appropriate treatment; however, access remains elusive for many. Research validates what is already known anecdotally — only a tiny fraction of individuals living with OCD ever receive an accurate diagnosis and effective treatment.[4,5,6] The needless suffering of millions of people continues because of a lack of both awareness about OCD and clinicians adequately trained to diagnose and treat it properly. Stigma, shame, lack of health insurance coverage, and high costs are also significant barriers to care.[7,8]

In this debut white paper, the International OCD Foundation (IOCDF) focuses on the landscape of diagnosis and treatment of OCD in the United States. The objective was to investigate the estimated percentage of people in the U.S. who have been diagnosed with OCD, their demographics, and how many of them have received the recommended, evidence-based treatments for OCD. To do so, the IOCDF undertook a first-of-its-kind analysis — conducted in collaboration with Guardian Research Network (GRN) and Resonance — of 10 years of electronic health record (EHR) data from 10.4 million unique individuals across all 50 states. This dataset spans the entire lifespan and is approximately representative of the U.S. population, making it the largest study of people with OCD to date.

Healthcare professionals are missing or misdiagnosing an overwhelming number of individuals with OCD, with a near total failure to provide gold standard treatment.

The findings are striking: an overwhelming number of individuals with OCD are being undiagnosed or misdiagnosed by healthcare professionals. Even with a diagnosis, an astonishing treatment gap emerges, with a near total failure to provide, or even recommend, gold standard, evidence-based OCD therapy.

This white paper shares insights on the factors contributing to this issue as well as recommendations to help address them.

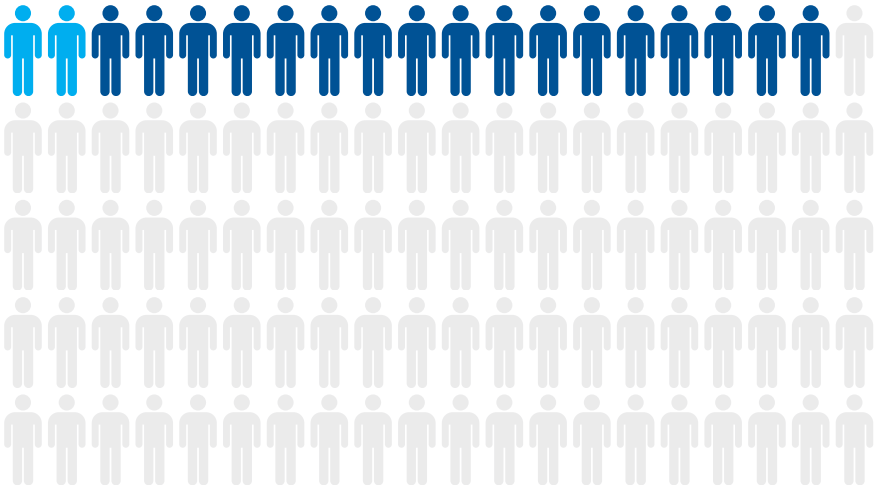
* Learn more about effective, evidence-based treatments at iocdf.org/treatment.

Key Findings

1. OCD is severely underdiagnosed in clinical settings.
Out of the more than 10.4 million unique individuals' electronic health records reviewed, only 53,316 patients (0.51%) had a formal diagnosis of OCD listed. This is well below the expected population lifetime prevalence of up to 3%, and suggests that over 80% of actual cases of OCD are not being clinically diagnosed. Analysis of EHR note content identified an additional 18,885 people whose notes indicated they either definitely or very likely had OCD, even though they had not received the formal diagnosis (see Methodology). Combined, we obtained a total sample of 72,171 patients with OCD, still comprising only 0.69% of the total population. This suggests that up to 75% of actual cases of OCD are not being detected or diagnosed by clinicians.

2. More than 80% of patients with OCD do not receive the recommended therapy for OCD.
Only 2% of the patients with OCD had documented evidence in their medical record of receiving exposure and response prevention (ERP) therapy, the specific form of cognitive behavioral therapy (CBT) that is the most effective treatment for OCD.[9] Only 19% of the OCD patients, including those receiving ERP, received any form of CBT at all. Even more concerning is that more than 72% of the patients with OCD did not even get referred for evidence-based ERP or CBT, even though more than half of them received a documented mental health assessment. This suggests that most mental health clinicians are not following the well established practice guidelines for OCD[10,11] and are failing to either provide or refer OCD patients for the most effective treatment for their condition.

The vast majority of people diagnosed with OCD are not receiving effective, evidence-based treatment.



= 10,000 individuals

Just **2%** are known to receive formal exposure & response prevention (ERP), the gold standard treatment for OCD.

Only **19%** were receiving any form of cognitive behavioral therapy, including ERP.

Between **81% and 98%** of individuals with OCD were not receiving effective, evidence-based treatment.

Recommendations

1. Conduct routine screening to detect OCD faster and with more accuracy.
Well validated, brief OCD screening tools* for adults and children exist and must be widely disseminated to all clinicians in mental health and primary care settings. Every patient should be screened for OCD and either referred to a mental health clinician upon a positive result or provided with a comprehensive assessment.

2. Improve clinical training in assessment, diagnosis, and treatment of OCD.
All clinical mental health training programs (i.e., psychiatry, clinical psychology, clinical social work, clinical counseling, marriage and family therapy) must provide adequate training in assessment, diagnosis, and evidence-based treatment of OCD, including ERP. Mental health clinicians who are currently practicing should also receive sufficient training and support to be able to effectively assess, diagnose, and treat people with OCD.

3. Adhere to professional standards for treating patients with OCD.
Treatment guidelines call for ERP as the first-line treatment[10,11] for patients with OCD, yet it is still very underutilized. Adherence to and enforcement of professional standards and treatment guidelines[10,11] for OCD must be strengthened among all mental health professionals.

4. Raise accurate awareness of OCD.
Inaccurate assumptions about OCD are prevalent and cause real barriers to treatment. Many individuals and providers are unaware of OCD's symptoms and effective treatments, resulting in missed diagnoses or ineffective therapies. Increased investment in initiatives that increase awareness and accurate understanding of OCD for the general public, educators, and clinicians are needed.

This white paper analyzes the largest sample of people with OCD ever studied.

* A free, ultra-brief, evidence-based OCD screening tool can be found at iocdf.org/screener for both kids and adults.

Background

Obsessive compulsive disorder (OCD) is a serious and often debilitating mental health disorder. It is an often misunderstood mental health condition in which people experience intrusive and unwanted thoughts (obsessions) and perform repetitive behaviors (compulsions) and avoidance to minimize or prevent the distress caused by obsessions. These symptoms can greatly interfere with relationships, work, school, and daily functioning, and lead to low quality of life and significant impairment and disability. Half of people with OCD in the U.S. are unable to work or continue their education at some point of time living with their illness, and 65% of adults[1] and 90% of children and adolescents with OCD[12] report impairment in at least one aspect of their lives (such as relationships, cognition, or work). In one large study, 96% of people with OCD had moderate to severe symptoms.[1] People with OCD may be 5 times more likely to die by suicide and have a 2 times increased risk of death from both natural and unnatural causes.[13,14]

OCD affects millions, but rates of diagnosis and treatment are very low.
With a lifetime prevalence rate of approximately 3%,[1,2,7] OCD will afflict up to 10 million Americans at some point in their lives. Despite its prevalence and major impact on quality of life, length of life, ability to thrive, and public health, it is seriously under-detected and under-treated in the U.S. Previous studies done in populations within more circumscribed healthcare settings, such as Kaiser,

Quick Facts

- Obsessive compulsive disorder (OCD) is a serious and often debilitating mental health disorder.
- OCD can lead to low quality of life, significant impairment, and disability.
- Nearly 240 million people worldwide suffer from OCD, including up to 10 million people in the United States alone.
- People with OCD may be 5 times more likely to die by suicide and have 2 times increased risk of death.
- Effective treatment exists to help people with OCD thrive, yet only a small proportion of patients with OCD receive appropriate, evidence-based treatment.

Exposure & Response Prevention (ERP)

Exposure and response prevention (ERP) is a form of cognitive behavioral therapy (CBT) and is the first-line psychological treatment for obsessive-compulsive disorder. It has a strong evidence base and is designed to help people reduce symptoms and improve daily functioning. ERP typically begins with education about OCD and a detailed assessment to understand a person's obsessions, compulsions, and avoidance patterns. Together with a trained therapist, individuals create a hierarchy of feared situations, thoughts, or triggers, and gradually work through them in a planned, supportive way. During these exercises, people intentionally face what causes them anxiety (exposure) while resisting rituals or avoidance (response prevention). Although anxiety often rises at first, this process teaches that distress is temporary, tolerable, and less dangerous than it feels — allowing people to regain control and participate more fully in their lives.

Veterans Administration, or Medicaid claims data, found that up to 90% of actual cases of OCD were not being diagnosed.[5,6,15,16] Comorbidity of OCD with other mental health disorders is common but is often overlooked by clinicians, families, school professionals, and even the individuals themselves.

The gold standard, most effective treatments for OCD are cognitive-behavioral therapy (CBT) using exposure and response prevention (ERP) and selective serotonin reuptake inhibitor (SSRI) medications. However, past studies have found that only a small percentage of people with OCD receive an adequate course of ERP.[8,17,18,19] Even among psychologists who correctly identified and diagnosed OCD, only half recommended ERP to their patients as the primary treatment of choice.[20]

Many people with OCD never seek treatment.[18]

The most frequently reported barriers to seeking care include stigma, shame, cost of treatment, doubt that treatment would work, and lack of insurance coverage.[7,8] Yet when people do seek treatment they often have difficulty finding any clinicians who are available, let alone those who are appropriately trained and willing to use ERP.

- More than half (51%) of all counties in the U.S. do not have a practicing psychiatrist.[21]
- At least one-third of private practice psychotherapists do not accept any form of insurance and instead rely on patients paying out of pocket.[22]

- Most clinicians are not trained in evidence-based psychotherapies like ERP,[23,24] and only 27-37% of clinicians in community mental health settings endorse routinely using exposure-based therapy with clients with anxiety-related presentations.[23,25]

Common OCD Myths

- Everyone with OCD is super neat and organized.
- OCD is all about cleanliness.
- People with OCD are uptight or neurotic.
- Everyone is a little OCD.
- OCD is a personality trait.
- OCD is helpful.

Not enough people have an accurate understanding of OCD.

Accurate public awareness about OCD is low. Notably, a 2013 survey found that more than two-thirds of respondents could not accurately identify OCD when presented with a clear description of symptoms.[26] This lack of understanding poses a significant challenge for those struggling with OCD, making it harder for them to recognize their condition, seek support, and access the life-changing treatment they need. The term "OCD" has become a common cultural catchphrase referring to quirks or preferences around cleanliness and orderliness. This casual misuse obscures the reality of OCD as a serious mental health condition.

This white paper focuses on the current landscape of diagnosis and treatment of OCD in the United States.

Prior studies have reported on the demographics of people with OCD, the types of therapy received or recommended, or the co-occurrence of OCD with other mental health disorders. Yet, all of those studies were limited by relatively small sample sizes, more constrained geographic areas, or circumscribed healthcare settings. This study analyzed a large and diverse electronic health record (EHR) database comprising data from over 10 million patients across all 50 states and all socioeconomic strata. The dataset is approximately nationally representative and spans individuals of all ages. EHR data was compiled from a variety of public and private healthcare systems across 16 states, including rural, urban, and suburban areas, allowing us to obtain the largest sample of people with OCD ever studied.

The IOCDF intends to develop a series of white papers in the coming years to explore more questions with the goal of better serving and supporting the OCD community and to help inform decision makers about the unique challenges and opportunities related to OCD. In the future we plan to focus on topics including children and adolescents with OCD, older adults with OCD, obsessive compulsive-related disorders, and global perspectives.

Youth and OCD

Children and adolescents are just as likely as adults to experience OCD, with a prevalence rate of up to 3%. OCD usually begins in childhood or adolescence and can start as early as age 6.* Nearly 14% of the OCD patients in this study (9,730 individuals) were children age 18 or younger. Many children may be embarrassed about their symptoms or unaware that what they are experiencing isn't typical, which can make them hesitant to speak up about them. Parents and family members often sense something is wrong but may not know how to identify the symptoms or how to help. OCD symptoms can overlap and coexist with other mental health disorders, which can make it harder to receive an accurate diagnosis or appropriate care. OCD can significantly impact a child's quality of life, with 90% of children and adolescents with OCD reporting impairment in at least one aspect of their lives such as relationships, cognition, or school.[12]

* 25% of cases start by age 14, 50% by age 19, and 64% by age 25.[1]

Findings

An unacceptable diagnosis and treatment gap exists for people suffering from OCD.

OCD is severely under-diagnosed in clinical settings.
Out of 10.4 million patient records reviewed, only 53,316 patients — one half of one percent (0.51%) — received a formal diagnosis of OCD, which is only one-sixth of the expected lifetime prevalence rate of 3%. This means that hundreds of thousands of people in the overall sample were suffering from OCD but were missed, making them unlikely to receive treatment. A natural language processing analysis of key terms listed in EHR notes (see Methodology, page 15) identified an additional 18,855 patients (0.18% of the total database population) whose note content indicated that they either definitely or very likely had OCD, even though they had not received the formal diagnosis. The two groups were then combined, creating a total sample of 72,171 patients with OCD — just 0.69% of the total database population, which suggests that up to 75% of actual cases of OCD are not being detected or diagnosed by clinicians.

Deeper diagnosis gaps exist for men and people of color.
OCD affects people of all sexes, races, and income levels at similar rates.[1,27] The prevalence of diagnosed OCD in this study was equally distributed across all socioeconomic statuses, measured by Area Deprivation Index.[28] Yet, certain demographic groups were significantly underrepresented in the OCD patient sample (see Table 1).

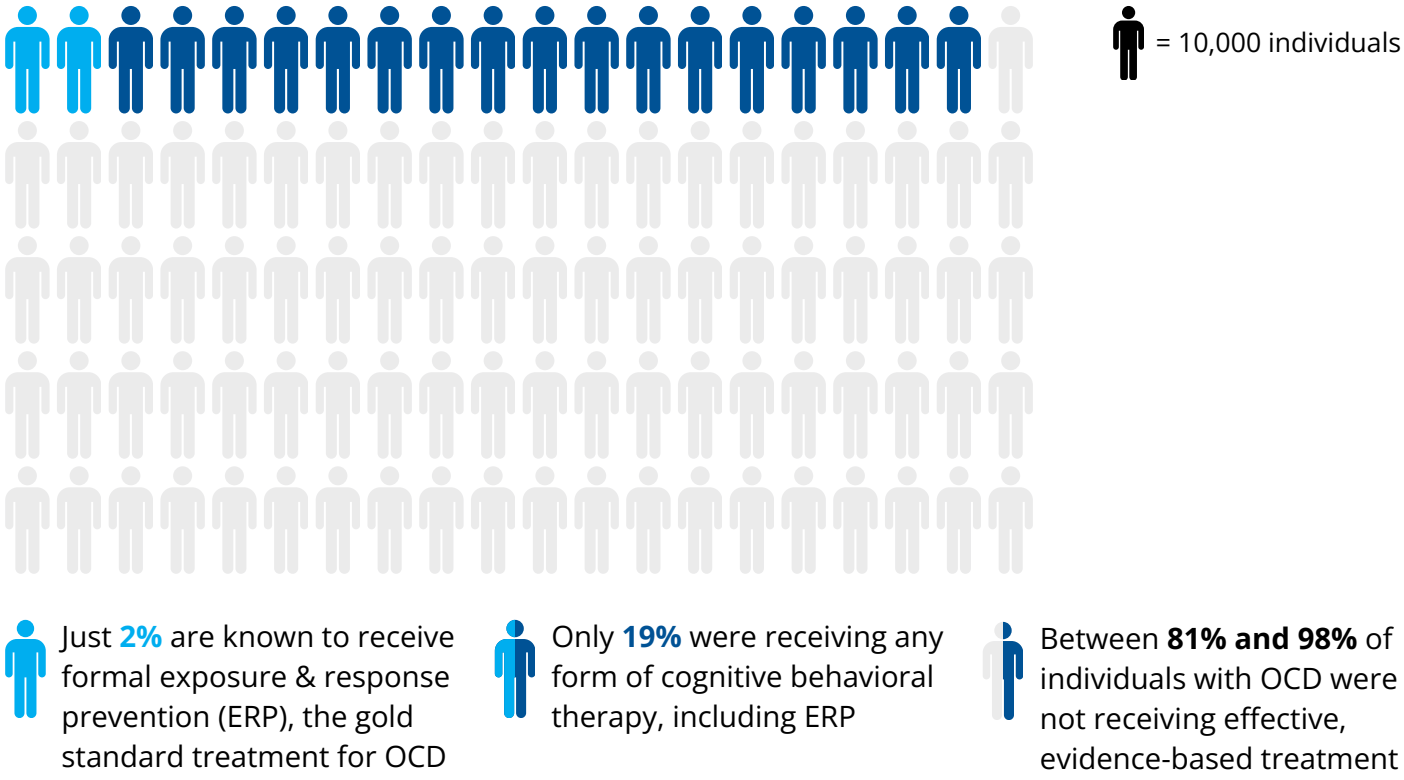
- **Men.** Nearly double the number of women than men were in the OCD patient sample (63.4% versus 36.6%), while the overall EHR database population consisted of 54.2% women and 45.7% men. The observed female to male ratio in the OCD patients was far greater than the gender ratio found in epidemiological studies of OCD,[1,2,3] suggesting that factors other than relative prevalence influenced the striking gender disparity found in this sample of patients with OCD. Research consistently shows that men are less likely than women to seek mental health support, despite facing similar psychological challenges.[29,30] General factors precluding men from diagnosis and treatment include a reluctance to talk about one's feelings, viewing symptoms as minor or insignificant, embarrassment, anxiety about using health services, and poor communication with health care providers.[31]

- **People of Color.** OCD is equally prevalent in Asian, Black, Latino, and White populations.[32] However, the percentage of non-white people — Black, Latino, and Asian — was significantly lower in the OCD sample than in the entire EHR database population, while white people were overrepresented (see Table 1). This discrepancy suggests a systematic underdiagnosis of OCD in non-white populations, which is concerning and deserves further study. Our findings in the U.S. are similar to those of a U.K. study that also found severe underrepresentation of ethnic minorities with OCD in mental health services.[33] Previous studies have found that African-Americans with OCD rarely seek treatment for their OCD symptoms.[34] African-Americans and Latinos also face numerous barriers to treatment[35] and have difficulty accessing mental health care.[36]

Table 1. Percentage of People by Race, Ethnicity in EHR Database Population

Race / Ethnicity Categories Available	% Overall Database Population (n=10,425,857)	% OCD Sample (n=72,171)
White	77.8%	89.6%
Black or African American	16.3%	6.2%
Race not reported	0.0%	0.2%
Two or more races	1.4%	1.6%
Asian	2.2%	1.0%
Other race	1.6%	0.7%
American Indian or Alaska Native	0.5%	0.5%
Native Hawaiian or other Pacific Islander	0.2%	0.1%
Not Hispanic or Latino	92.9%	96.1%
Hispanic or Latino	7.1%	3.9%

Graphic 1. The vast majority of people diagnosed with OCD are not receiving effective, evidence-based treatment.



More than 80% of patients with OCD do not receive the recommended OCD therapy. Remarkably, only 2% of the OCD patients had documented evidence in their EHR of receiving ERP, the specific form of CBT that is the gold standard, most effective treatment for OCD, and only 19% received any type of CBT (which may or may not have included ERP; the specific type of CBT provided was not always described in the EHR notes). Even more concerning was that over 72% of the patients with OCD did not get referred for ERP or CBT at all, even though more than half of them received a documented mental health assessment. This finding suggests most mental health clinicians are not following the well-established practice guidelines for OCD,[10,11] and are failing to either provide or refer OCD patients for the most effective treatment for their condition.

About 66% of the OCD patients in this study received selective serotonin reuptake inhibitors (SSRIs) or clomipramine — the evidence-based, frontline medications proven to be effective for OCD. Half of the patients with OCD received only these medications,

without CBT or ERP. However, SSRI medication treatment alone does not typically result in remission of OCD symptoms.[37] Combining medication with CBT is often necessary to achieve lasting relief or remission of OCD symptoms and to restore functioning, particularly for patients with more severe symptoms and comorbid mental health disorders.[10,11] Yet, only 16% of the OCD patients in this study received this treatment combination. It is unknown how many individuals with OCD in this sample received treatment outside of the healthcare settings included in our EHR database.

OCD-Related Disorders are dramatically underdetected, even by mental health clinicians.

82% of the OCD patients in the EHR database were also diagnosed with another anxiety disorder, including 51% diagnosed with generalized anxiety disorder and 18% with panic disorder. Comorbid mood disorders were also very common, with 68% of the OCD patients diagnosed with major depressive disorder and 19% with bipolar disorder. These comorbidity rates are generally consistent with expected lifetime prevalence rates in clinical OCD populations.[1,38,39] However, diagnosis rates within this study of comorbid obsessive compulsive-related disorders (OCRDs), which include body dysmorphic disorder (BDD), hoarding disorder, and the body-focused repetitive behaviors (BFRBs) including excoriation (skin-picking) disorder and trichotillomania (hair-pulling disorder) were far lower than previously documented comorbidity rates.

- Only 0.4% of the OCD patients in our sample were diagnosed with comorbid BDD, far lower than the 10% found in prior studies.[40]
- Only 0.8% were diagnosed with hoarding disorder, a small fraction of the 18-38% expected based on previous studies.[41,42,43,44]
- Previous studies have found that 15-20% of people with OCD also have a BFRB,[45] yet excoriation disorder and trichotillomania were only diagnosed in 1.5% and 0.9% of our OCD patient sample, respectively.

Although the rate of diagnosis of comorbid OCRDs was higher for OCD patients who received a mental health assessment than for those who did not, they were still far below the rates found in previous studies.

These findings indicate that OCRDs are dramatically under-detected in U.S. healthcare settings. Considering OCRDs affect up to 1 billion people worldwide, it is clear a major gap exists. The IOCDF plans to share more findings on this topic in the future.

Recommendations

Despite the enormous gap for diagnosis and treatment for OCD that currently exists, there is hope. People living with OCD can thrive with effective treatment that is available today. Decision makers from government, accrediting bodies, academic institutions, and mental health professional and advocacy organizations, as well as clinicians and school professionals, can take action to help close the concerning gap in diagnosis and treatment revealed by this study.

Provide routine screenings to detect OCD sooner and with more accuracy.

Brief, well validated OCD screening tools*[46,47] must be widely disseminated to all clinicians in mental health and primary care settings to address the 7 years on average it takes for an individual with OCD to receive a clinical diagnosis.[48] Many factors likely play a role in this issue, but helping health professionals recognize the signs of OCD and making screening tools more available can lead to earlier detection and more accurate diagnoses that get people on a path to treatment and recovery. Every patient should be screened for OCD and upon a positive result either referred to a mental health clinician or provided with a comprehensive assessment.

Scalable Solutions You Can Support:

Those in charge of decision making, policy setting, and/or compliance tracking in health settings:

- Make OCD screening tools* widely available to first-line clinicians, such as pediatricians and primary care providers, as well as school professionals and mental health clinicians.
- Mandate routine screening for OCD during assessment for any mental health disorder. Requiring screenings for children and adults in these settings will help uncover underlying OCD in those affected.

For everyone:

- Support funding for the dissemination of resources and tools to help school professionals identify the signs of OCD, screen effectively, and refer individuals to clinicians trained to treat it.**

---

* Visit IOCDF's OCD screening tool at iocdf.org/screener.

** Anxiety in the Classroom is the IOCDF's initiative for how to spot symptoms of anxiety and OCD in classroom settings, for students, parents/caregivers, and teachers/school staff. Please visit anxietyintheclassroom.org to learn more.

Train clinicians comprehensively in OCD and its effective, gold-standard treatments.

Mental health clinicians need training and support to treat people with OCD appropriately and effectively, yet often receive minimal education in how to diagnose or treat OCD.[20] ERP has been well established as the gold standard treatment for OCD for decades and is regarded as the first-line treatment by clinical practice guidelines for its ability to produce lasting relief or remission of OCD symptoms.[10,11] Yet, there is very low usage of ERP in clinical settings,[49] in part due to a fear that exposures will upset or harm their patient, a lack of training, concerns about using standardized treatments, and lack of funding for institutions/clinics to offer more training.[49,50,51] Widely available training and support for clinicians will dramatically increase use of ERP. Most mental health training programs provide minimal education on OCD or ERP, leaving many clinicians without the knowledge or confidence to use it effectively. While some strong training programs and professional supports exist,* access and awareness remain limited. Increasing both training opportunities and ongoing clinical support is essential to expanding effective OCD treatment.

Scalable Solutions You Can Support:

Clinical mental health training programs (i.e., psychiatry, clinical psychology, clinical social work, clinical counseling, marriage and family therapy):

- Provide comprehensive training in assessment and diagnosis of OCD as well as treatment using evidence-based treatment, including ERP. These trainings should be available for students, pre-licensed trainees, and currently practicing mental health clinicians.

Those in charge of licensure:

- Include demonstrated competency in assessment, diagnosis, and treatment of OCD as part of licensure requirements.
- Enforce adherence of professional standards and treatment guidelines[10,11] for OCD across all mental health professionals.

Increase affordable access to effective care.

In addition to important cost considerations related to affordability and health insurance coverage, the dire shortage of mental health professionals in the U.S. must also be addressed, especially of pediatric mental health professionals.

---

* For example, the IOCDF Training Institute provides training for clinicians about OCD and related disorders. Please visit iocdf.org/training.

Scalable Solutions You Can Support:

Insurance companies:

- Increase reimbursement rates for mental health professionals.
- Reduce restrictions on the number of sessions allowed to be covered by health insurance.
- Ensure that evidence-based treatments are billable and reimbursed appropriately for necessary durations and intensities (e.g. home visits, intensive treatment programs).

For graduate programs and government officials:

- Promote programs that incentivize an increased mental health workforce in the U.S., such as increasing graduate training slots, scholarship availability, loan forgiveness programs, mentorship opportunities, etc.

Increase accurate awareness of OCD and its treatment options.

Awareness and accurate understanding of OCD, its symptoms, and effective treatments are low, both in the general public and amongst clinicians. Without increased awareness, stigma against people with OCD and barriers to treatment will remain.

Scalable Solutions You Can Support:

For everyone:

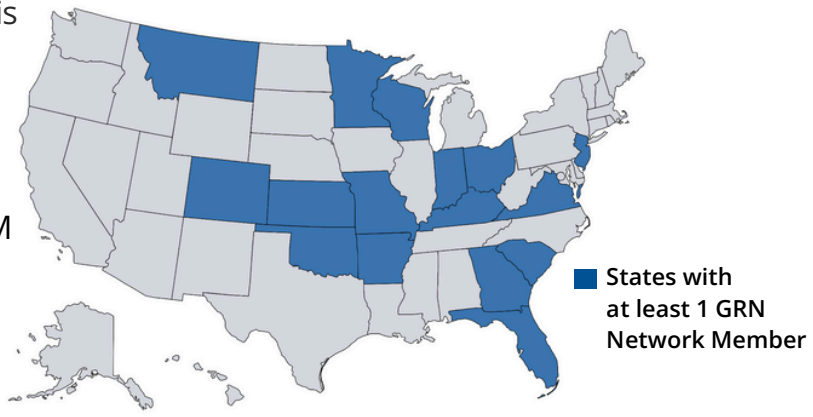
- Share the data in this white paper.
- Share your OCD story. OCD affects millions of Americans, but too many suffer in silence. Courageous individuals who speak openly about their lived experience of OCD, including their treatment journey, bring hope and healing to many others.
- Speak up about OCD as a topic of importance for workplace and school mental health initiatives.
- Advocate for your local, state, and federal governments to recognize the annual OCD Awareness Week the second full week of each October.
- Increase awareness by disseminating information to legislators and policy makers, conducting public service announcements, sharing social media posts, engaging in awareness and fundraising campaigns, and working with local and regional advocates and volunteers.

Methodology

This was a retrospective, population-based, cohort study designed to estimate the prevalence of diagnosed OCD, characterize the affected population, and analyze patterns of diagnosis and treatment over a 10-year period, from January 1, 2015, to January 1, 2025. The study utilized de-identified Electronic Health Record (EHR) data from the Guardian Research Network (GRN),[52] a consortium of 14 integrated health delivery networks (IDNs) across 16 states within the United States. Thirteen of the 14 health systems are community-based IDNs, while one is an academic medical center. The GRN database contains longitudinal EHR data for approximately 18 million adult and pediatric patients, residing in all 50 states. The database contains complete patient records, including inpatient and outpatient encounters, encounters with specialists and primary care providers, as well as urgent care and emergency department visits.

The GRN database reflects a diverse population in terms of age, gender, geography, socioeconomic status, insurance coverage, and racial/ethnic distribution. Patients in the GRN may be insured by private insurance, Medicaid, Medicare, Tricare, or may be uninsured. The database population aligns very closely with U.S. Census data in terms of gender, urban vs. rural distribution, percentage who are Black, Native American or Pacific Islander. However, it under-represents Hispanics, Asians, multiracial persons, and children (0-19 years of age) but over-represents Whites and people over 65. The database is linked to the Area Deprivation Index (ADI),[28] which allows for grouping by socioeconomic status.

To help ensure as many cases of OCD were found in the EHR records, a dual-method algorithm was used. OCD diagnoses were identified by either the presence of at least one International Classification of Diseases, Tenth Revision (ICD-10) code for OCD or through a Natural Language Processing (NLP) analysis of clinical progress notes. A proprietary Large Language Model (LLM) was used to detect key terms and clinical narratives consistent with an OCD diagnosis (e.g., intrusive thoughts, compulsions, ERP). LLM analysis of EHR notes was also used to identify referral, recommendation, and receipt of CBT, ERP, and other therapies.



Key Terms

Cognitive-Behavioral Therapy (CBT): A form of therapy that focuses on addressing the ways we think and behave. Exposure and response prevention (ERP) is the specific type of CBT that is the gold standard, evidence-based therapy for OCD. Other forms of CBT may have differential efficacy relative to ERP.

Comorbidity / Comorbid ("Co-occurring") Disorder(s): Having more than one condition or being diagnosed with more than one disease/ disorder. It means that both conditions exist and may interact within the same person at the same time. Comorbidity is the rule, not the exception.

Electronic health record (EHR): Electronically stored medical and health information from visits to medical centers, clinicians, hospitals, and other healthcare settings.

Exposure and response prevention (ERP): ERP involves having a person with OCD intentionally trigger an obsession through an "exposure" activity, and then resist the urge to engage in compulsions ("response prevention"). This causes an initial burst of anxiety, but gradually, there is a natural decrease in that anxiety, called habituation. Repeated exposures eventually extinguish obsessional fears, eliminate compulsions and avoidance behaviors, and promote learning. ERP assignments usually proceed along a hierarchy of progressively more distressing exposures. ERP is initially done with a therapist, who develops the ERP hierarchy and guides the person with OCD through their ERP assignments. Eventually the person with OCD becomes more able to resist rituals on their own. ERP is considered a first-line treatment for OCD, something to try first when beginning an OCD treatment journey.

Obsessive Compulsive Disorder (OCD): A disorder of the brain and behavior, causing distress and impairment in those affected. OCD involves both obsessions and compulsions that take a lot of time and get in the way of important activities the person values. People diagnosed with OCD experience repetitive, intrusive thoughts or fears that cause anxiety or distress. They try to reduce the distress caused by their obsessions by doing compulsive behaviors (rituals), including avoidance.

Obsessive Compulsive-Related Disorders: A category of mental health disorders that are related to OCD, as described in the DSM-5. These include body dysmorphic disorder (BDD), hoarding disorder (HD), and body-focused repetitive behaviors (BFRBs) such as skin picking (excoriation) and hair pulling (trichotillomania). Tic Disorders and Tourette Syndrome and certain Eating Disorders are also strongly related to OCD.

Prevalence: The sample analyzed in this paper covers the 10-year timeframe between 2015 and 2025. Comparisons made to other prevalence rates are lifetime prevalence rates (the percentage of cases in a population with a particular condition/disorder at any point in their lifetime).

Selective serotonin reuptake inhibitor (SSRI): A class of medication that works by blocking the reabsorption of serotonin, a neurotransmitter, from the synapse. SSRIs are the first-line, evidence-based medication treatments for OCD.

References

1 Ruscio, A. M., Stein, D. J., Chiu, W. T., & Kessler, R. C. (2010). The epidemiology of obsessive-compulsive disorder in the National Comorbidity Survey Replication. *Molecular Psychiatry, 15*(1), 53-63. https://doi.org/10.1038/mp.2008.94

2 Stein, D. J., Ruscio, A. M., Altwaijri, Y., Chiu, W. T., Sampson, N. A., Aguilar-Gaxiola, S., Al-Hamzawi, A., Alonso, J., Chardoul, S., Gureje, O., Hu, C., Karam, E. G., McGrath, J. J., Navarro-Mateu, F., Scott, K. M., Stagnaro, J. C., Torres, Y., Vladescu, C., Wciórka, J., Xavier, M., … Kessler, R. C. (2025). Obsessive-compulsive disorder in the World Mental Health surveys. *Research Square,* rs.3.rs-6090427. https://doi.org/10.21203/rs.3.rs-6090427/v1

3 Ringeisen, H., Edlund, M., Guyer, H., Dever, J., Carpenter, L., Olfson, M., First, M., Geiger, P., Liao, D., Peytchev, A., Carr, C., Chwastiak, L., Dixon, L. B., Monroe-Devita, M., Scott Stroup, T., Swanson, J., Swartz, M., Gibbons, R., Stambaugh, L., Bareis, N., … Mental Health and Substance Use Disorders Prevalence Study Consortium (2025). Prevalence of past-year mental and substance use disorders, 2021-2022. *Psychiatric Services (Washington, D.C.), 76*(8), 720–728. https://doi.org/10.1176/appi.ps.20240329

4 Baweja, R., Waschbusch, D. A., Rajalakshmi, A. K., Petrovic-Dovat, L., & Waxmonsky, J. G. (2025). National trends in pediatric obsessive compulsive disorder management: Insights from a retrospective cohort study. *Journal of Child and Adolescent Psychopharmacology,* 10.1089/cap.2025.0049. (Advance online publication.) https://doi.org/10.1089/cap.2025.0049

5 Fireman, B., Koran, L. M., Leventhal, J. L., & Jacobson, A. (2001). The prevalence of clinically recognized obsessive-compulsive disorder in a large health maintenance organization. *The American Journal of Psychiatry, 158*(11), 1904–1910. https://doi.org/10.1176/appi.ajp.158.11.1904

6 Patel, S. R., Messner, G. R., Radigan, M., Sang, Y., Wang, R., Gu, G., Myers, R. W., Dixon, L. B., & Simpson, H. B. (2023). Retrospective state Medicaid claims analysis of children and adults with obsessive-compulsive disorder. *Psychiatric Services (Washington, D.C.), 74*(11), 1185–1188. https://doi.org/10.1176/appi.ps.20220152

7 García-Soriano, G., Rufer, M., Delsignore, A., & Weidt, S. (2014). Factors associated with non-treatment or delayed treatment seeking in OCD sufferers: A review of the literature. *Psychiatry Research, 220*(1-2), 1–10. https://doi.org/10.1016/j.psychres.2014.07.009

8 Marques, L., LeBlanc, N. J., Weingarden, H. M., Timpano, K. R., Jenike, M., & Wilhelm, S. (2010). Barriers to treatment and service utilization in an internet sample of individuals with obsessive-compulsive symptoms. *Depression and Anxiety, 27*(5), 470–475. https://doi.org/10.1002/da.20694

9 Olatunji, B. O., Davis, M. L., Powers, M. B., & Smits, J. A. (2013). Cognitive-behavioral therapy for obsessive-compulsive disorder: A meta-analysis of treatment outcome and moderators. *Journal of Psychiatric Research, 47*(1), 33–41. https://doi.org/10.1016/j.jpsychires.2012.08.020

10 Koran, L. M., Hanna, G. L., Hollander, E., Nestadt, G., Simpson, H. B., & American Psychiatric Association (2007). Practice guideline for the treatment of patients with obsessive-compulsive disorder. *The American Journal of Psychiatry, 164*(7 Suppl), 5–53.

11 Koran, L. M. & Simpson, H. B. (2013). *Guideline Watch (2013): Practice Guideline for the Treatment of Patients with Obsessive-Compulsive Disorder.* Arlington, TX, USA: American Psychiatric Association.

12 Piacentini, J., Bergman, R. L., Keller, M., & McCracken, J. (2003). Functional impairment in children and adolescents with obsessive-compulsive disorder. *Journal of Child and Adolescent Psychopharmacology, 13 Suppl 1*, S61–S69. https://doi.org/10.1089/104454603322126359

13 Fernández de la Cruz, L., Isomura, K., Lichtenstein, P., Larsson, H., Kuja-Halkola, R., Chang, Z., D'Onofrio, B. M., Brikell, I., Rück, C., Sidorchuk, A., & Mataix-Cols, D. (2024). All cause and cause specific mortality in obsessive-compulsive disorder: Nationwide matched cohort and sibling cohort study. *BMJ (Clinical research ed.), 384,* e077564. https://doi.org/10.1136/bmj-2023-077564

14 Fernández de la Cruz, L., Isomura, K., Lichtenstein, P., Rück, C., & Mataix-Cols, D. (2022). Morbidity and mortality in obsessive-compulsive disorder: A narrative review. *Neuroscience and Biobehavioral Reviews, 136,* 104602. https://doi.org/10.1016/j.neubiorev.2022.104602

15 Hankin, C. S., Koran, L. M., Bronstone, A., Black, D. W., Sheehan, D. V., Hollander, E., Dunn, J. D., Culpepper, L., Knispel, J., Dougherty, D. D., & Wang, Z. (2009). Adequacy of pharmacotherapy among medicaid-enrolled patients newly diagnosed with obsessive-compulsive disorder. *CNS Spectrums, 14*(12), 695–703. https://doi.org/10.1017/s1092852900023956

16 Barrera, T. L., McIngvale, E., Lindsay, J. A., Walder, A. M., Kauth, M. R., Smith, T. L., Van Kirk, N., Teng, E. J., & Stanley, M. A. (2019). Obsessive-compulsive disorder in the Veterans Health Administration. *Psychological Services, 16*(4), 605–611. https://doi.org/10.1037/ser0000249

17 Mancebo, M. C., Eisen, J. L., Sibrava, N. J., Dyck, I. R., & Rasmussen, S. A. (2011). Patient utilization of cognitive-behavioral therapy for OCD. *Behavior Therapy, 42*(3), 399–412. https://doi.org/10.1016/j.beth.2010.10.002

18 Schwartz, C., Schlegl, S., Kuelz, A. K., & Voderholzer, U. (2013). Treatment-seeking in OCD community cases and psychological treatment actually provided to treatment-seeking patients: A systematic review. *Journal of Obsessive-Compulsive and Related Disorders, 2*(4), 448–456. https://doi.org/10.1016/j.jocrd.2013.10.006

19 Senter, M. S., Patel, S. R., Dixon, L. B., Myers, R. W., & Simpson, H. B. (2021). Defining and addressing gaps in care for obsessive-compulsive disorder in the United States. *Psychiatric Services (Washington, D.C.), 72*(7), 784–793. https://doi.org/10.1176/appi.ps.202000296

20 Weinberg, L., Martin, L. A., Post, K. M., & Ricketts, E. J. (2025). Psychologists' diagnostic accuracy and treatment recommendations for obsessive-compulsive disorder. *Journal of Clinical Psychology, 81*(5), 324–333. https://doi.org/10.1002/jclp.23775

21 Andrilla, C. H. A., Patterson, D. G., Garberson, L. A., Coulthard, C., & Larson, E. H. (2018). Geographic Variation in the Supply of Selected Behavioral Health Providers. *American Journal of Preventive Medicine, 54*(6 Suppl 3), S199–S207. https://doi.org/10.1016/j.amepre.2018.01.004

22 Zhu, J. M., Huntington, A., Haeder, S., Wolk, C., & McConnell, K. J. (2024). Insurance acceptance and cash pay rates for psychotherapy in the US. *Health Affairs Scholar, 2*(9), qxae110. https://doi.org/10.1093/haschl/qxae110

23 Hipol, L. J. & Deacon, B. J. (2013). Dissemination of evidence-based practices for anxiety disorders in Wyoming: A survey of practicing psychotherapists. *Behavior Modification, 37*(2), 170–188. https://doi.org/10.1177/0145445512458794

24 Weissman, M. M., Verdeli, H., Gameroff, M. J., Bledsoe, S. E., Betts, K., Mufson, L., Fitterling, H., & Wickramaratne, P. (2006). National survey of psychotherapy training in psychiatry, psychology, and social work. *Archives of General Psychiatry, 63*(8), 925–934. https://doi.org/10.1001/archpsyc.63.8.925

25 Becker-Haimes, E. M., Okamura, K. H., Wolk, C. B., Rubin, R., Evans, A. C., & Beidas, R. S. (2017). Predictors of clinician use of exposure therapy in community mental health settings. *Journal of Anxiety Disorders, 49,* 88–94. https://doi.org/10.1016/j.janxdis.2017.04.002

26 Coles, M. E., Heimberg, R. G., & Weiss, B. D. (2013). The public's knowledge and beliefs about obsessive compulsive disorder. *Depression and Anxiety, 30*(8), 778–785. https://doi.org/10.1002/da.22080

27 Horwath, E. & Weissman, M. M. (2000). The epidemiology and cross-national presentation of obsessive-compulsive disorder. *The Psychiatric Clinics of North America, 23*(3), 493–507. https://doi.org/10.1016/s0193-953x(05)70176-3

28 Kind, A. J. H. & Buckingham, W. (2018). Making neighborhood disadvantage metrics accessible: The Neighborhood Atlas. *New England Journal of Medicine, 378,* 2456-2458. https://doi.org/10.1056/NEJMp1802313

29 Blumberg, S. J., Clarke, T. C., & Blackwell, D. L. (2015). *Racial and ethnic disparities in men's use of mental health treatments (NCHS data brief, no 206.)* National Center for Health Statistics. https://www.cdc.gov/nchs/products/databriefs/db206.htm

30 National Institute of Mental Health. (2024, September). *Mental illness.* Retrieved October 9, 2025, from https://www.nimh.nih.gov/health/statistics/mental-illness

31 Yousaf, O., Grunfeld, E. A., & Hunter, M. S. (2015). A systematic review of the factors associated with delays in medical and psychological help-seeking among men. *Health Psychology Review, 9*(2), 264–276. https://doi.org/10.1080/17437199.2013.840954

32 Katz, J. A., Rufino, K. A., Werner, C., McIngvale, E., & Storch, E. (2020). OCD in ethnic minorities. *Clinical and Experimental Psychology, 6*(1), 01-06. https://www.iomcworld.org/open-access/ocd-in-ethnic-minorities-53125.html

33 Fernández de la Cruz, L., Llorens, M., Jassi, A., Krebs, G., Vidal-Ribas, P., Radua, J., Hatch, S. L., Bhugra, D., Heyman, I., Clark, B., & Mataix-Cols, D. (2015). Ethnic inequalities in the use of secondary and tertiary mental health services among patients with obsessive-compulsive disorder. *The British Journal of Psychiatry: The Journal of Mental Science, 207*(6), 530–535. https://doi.org/10.1192/bjp.bp.114.154062

34 George, J. R., Taylor, R. J., Rouleau, T. M., Turner, E. D., & Williams, M. T. (2025). Seeking care for obsessive-compulsive symptoms among African Americans: Findings from the National Survey of American Life. *Behavior Therapy, 56*(1), 1-15. https://doi.org/10.1016/j.beth.2024.08.002

35 Williams, M. T., Domanico, J., Marques, L., Leblanc, N. J., & Turkheimer, E. (2012). Barriers to treatment among African Americans with obsessive-compulsive disorder. *Journal of Anxiety Disorders, 26*(4), 555–563. https://doi.org/10.1016/j.janxdis.2012.02.009

36 Cabassa, L. J., Zayas, L. H., & Hansen, M. C. (2006). Latino adults' access to mental health care: a review of epidemiological studies. *Administration and Policy in Mental Health, 33*(3), 316–330. https://doi.org/10.1007/s10488-006-0040-8

37 Soomro, G. M., Altman, D., Rajagopal, S., & Oakley-Browne, M. (2008). Selective serotonin re-uptake inhibitors (SSRIs) versus placebo for obsessive compulsive disorder (OCD). *The Cochrane Database of Systematic Reviews, 2008*(1), CD001765. https://doi.org/10.1002/14651858.CD001765.pub3

38 Brakoulias, V., Starcevic, V., Belloch, A., Brown, C., Ferrao, Y. A., Fontenelle, L. F., Lochner, C., Marazziti, D., Matsunaga, H., Miguel, E. C., Reddy, Y. C. J., do Rosario, M. C., Shavitt, R. G., Shyam Sundar, A., Stein, D. J., Torres, A. R., & Viswasam, K. (2017). Comorbidity, age of onset and suicidality in obsessive-compulsive disorder (OCD): An international collaboration. *Comprehensive Psychiatry, 76,* 79–86. https://doi.org/10.1016/j.comppsych.2017.04.002

39 Sharma, E., Sharma, L. P., Balachander, S., Lin, B., Manohar, H., Khanna, P., Lu, C., Garg, K., Thomas, T. L., Au, A. C. L., Selles, R. R., Højgaard, D. R. M. A., Skarphedinsson, G., & Stewart, S. E. (2021). Comorbidities in obsessive-compulsive disorder across the lifespan: A systematic review and meta-analysis. *Frontiers in Psychiatry, 12,* 703701. https://doi.org/10.3389/fpsyt.2021.703701

40 Frías, Á., Palma, C., Farriols, N., & González, L. (2015). Comorbidity between obsessive-compulsive disorder and body dysmorphic disorder: Prevalence, explanatory theories, and clinical characterization. *Neuropsychiatric Disease and Treatment, 11,* 2233–2244. https://doi.org/10.2147/NDT.S67636

41 Lochner, C., Kinnear, C. J., Hemmings, S. M., Seller, C., Niehaus, D. J., Knowles, J. A., Daniels, W., Moolman-Smook, J. C., Seedat, S., & Stein, D. J. (2005). Hoarding in obsessive-compulsive disorder: Clinical and genetic correlates. *The Journal of Clinical Psychiatry, 66*(9), 1155–1160. https://doi.org/10.4088/jcp.v66n0911

42 Samuels, J. F., Bienvenu, O. J., Grados, M. A., Cullen, B., Riddle, M. A., Liang, K. Y., Eaton, W. W., & Nestadt, G. (2008). Prevalence and correlates of hoarding behavior in a community-based sample. *Behaviour Research and Therapy, 46*(7), 836–844. https://doi.org/10.1016/j.brat.2008.04.004

43 Mathews, C. A., Delucchi, K., Cath, D. C., Willemsen, G., & Boomsma, D. I. (2014). Partitioning the etiology of hoarding and obsessive-compulsive symptoms. *Psychological Medicine, 44*(13), 2867–2876. https://doi.org/10.1017/S0033291714000269

44 de Mattos, C. N., Cooke, M. E., Whiteman, C., & Pato, M. (2025). Obsessive-compulsive disorder with hoarding behavior: Unravelling key differences. *Psychiatry Research, 351,* 116640. https://doi.org/10.1016/j.psychres.2025.116640

45 Lovato, L., Ferrão, Y. A., Stein, D. J., Shavitt, R. G., Fontenelle, L. F., Vivan, A., Miguel, E. C., & Cordioli, A. V. (2012). Skin picking and trichotillomania in adults with obsessive-compulsive disorder. *Comprehensive Psychiatry, 53*(5), 562–568. https://doi.org/10.1016/j.comppsych.2011.06.008

46 Abramovitch, A., Abramowitz, J. S., & McKay, D. (2021). The OCI-4: An ultra-brief screening scale for obsessive-compulsive disorder. *Journal of Anxiety Disorders, 78,* 102354. https://doi.org/10.1016/j.janxdis.2021.102354

47 Abramovitch, A., Abramowitz, J. S., McKay, D., Cham, H., Anderson, K. S., Farrell, L.J., Geller, D.A., Hanna, G.L., Mathieu, S., McGuire, J. F., Rosenberg, D. R., Stewart, S. E., Storch, E. A., & Wilhelm, S. (2022). An ultra-brief screening scale for pediatric obsessive-compulsive disorder: The OCI-CV-5. *Journal of Affective Disorders, 312,* 208–216. https://doi.org/10.1016/j.jad.2022.06.009

48 Dell'Osso, B., Benatti, B., Grancini, B., Vismara, M., De Carlo, V., Cirnigliaro, G., Albert, U., & Viganò, C. (2019). Investigating duration of illness and duration of untreated illness in obsessive compulsive disorder reveals patients remain at length pharmacologically untreated. *International Journal of Psychiatry in Clinical Practice, 23*(4), 311–313. https://doi.org/10.1080/13651501.2019.1621348

49 Gunter, R. W. & Whittal, M. L. (2010). Dissemination of cognitive-behavioral treatments for anxiety disorders: Overcoming barriers and improving patient access. *Clinical Psychology Review, 30*(2), 194–202. https://doi.org/10.1016/j.cpr.2009.11.001

50 Wolitzky-Taylor, K., Fenwick, K., Lengnick-Hall, R., Grossman, J., Bearman, S. K., Arch, J., Miranda, J., & Chung, B. (2018). A preliminary exploration of the barriers to delivering (and receiving) exposure-based cognitive behavioral therapy for anxiety disorders in adult community mental health settings. *Community Mental Health Journal, 54*(7), 899–911. https://doi.org/10.1007/s10597-018-0252-x

51 Frank, H. E., Woodard, G. S., & Martinez, R. G. (2025). Supporting clinicians in implementing exposure therapy for anxiety and related disorders. *Current Psychiatry Reports, 27*(7), 417–428. https://doi.org/10.1007/s11920-025-01612-w

52 McCracken, A., Heidt, J., Eldridge, E., Hurmiz, C., Duran, N., Reich, A., & Eworuke, E. (2025). The Guardian Research Network: A real-world data source for pharmacoepidemiologic research and regulatory applications. *Pharmacoepidemiology and Drug Safety, 34*(9), e70202. https://doi.org/10.1002/pds.70202

International OCD Foundation

Our Mission
The mission of the IOCDF is to ensure that no one affected by OCD and related disorders suffers alone. Our community provides help, healing, and hope.

Our Vision
Our vision is that everyone impacted by OCD and related disorders has immediate access to effective treatment and support.

Make a difference. Donate to the International OCD Foundation at iocdf.org/donate.

iocdf.org | 617-973-5801 | PO Box 961029, Boston, MA 02196 | EIN: 22-2894564