

Consultation on draft scope Stakeholder comments table

08/05/2025 to 06/06/2025

### Communication about OCD/BDD stakeholder comments

Thank you for your contributions to the consultation on the scope for the Obsessive Compulsive Disorder (OCD) and Body Dysmorphic Disorder (BDD) guideline update.

We received a large number of thoughtful and constructive comments and we greatly appreciate the time, expertise, and commitment this represents. Your engagement plays an important role in shaping our work.

### Why the approach has changed

NICE's core purpose is to help practitioners and commissioners deliver the best care to patients quickly, while ensuring value for the taxpayer. To meet the changing needs of the health and care system, we are transforming how we develop guidance so that it is more relevant, timely, usable, and impactful (see NICE transformation plan | NICE).

As part of this transformation, all guideline projects now follow an 18-month maximum development timeline from the start of development to publication in order to ensure that we publish guideline updates in a timely manner. This new timeframe, combined with the volume and complexity of topics within the original scope, means we have needed to make further adjustments.

#### **Publishing in batches**

In light of these changes, and after reviewing stakeholder feedback, the guideline will be published in batches. This approach will:

- enable earlier implementation of new, evidence-based recommendations
- allow us to respond more rapidly to emerging priorities and evidence

#### The first batch will focus on:

Recognition and assessment of OCD and BDD



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- Treatment and interventions for OCD and BDD:
  - psychological interventions, for example exposure and response prevention (ERP), and cognitive behavioural therapy (CBT) with ERP,
     delivered individually or in groups, face-to-face or remotely (including digital interventions)
  - o pharmacological interventions, for example selective serotonin reuptake inhibitors (SSRIs) and clomipramine
  - o combination interventions (psychological and pharmacological)
- Accessing and engaging with treatment

#### **Future batches**

Decisions about future updates will be made after the first batch is complete. We will consider:

- insights gained during development including committee discussions on the first batch
- related work within NICE and other organisations focusing on OCD, BDD, and related mental health topics
- · input from the NHS and wider health and care system
- overall prioritisation decisions across NICE's portfolio

### Continuing to work together

We look forward to sharing the first batch of the guideline update when we plan to consult in autumn 2026. We will provide a more detailed timeline for consultation and publication shortly.



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We acknowledge that this is a narrower scope than the consultation version and understand that this may be disappointing. We remain committed to using our limited resources to prioritise those areas of guidance development that will have the greatest impact on the health and care system.

Thank you again for your continued support and for helping us ensure NICE guidance delivers maximum benefit for people affected by OCD and BDD.

ID	Type	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
						Please insert each new comment in a new row	Please respond to each comment
1	SH	Tees Esk and Wear Valleys NHS Foundation Trust	Draft scope	001	006	I have been informed that there are moves to restrict the treatment of OCD to high intensity CBT therapists. I am concerned that this will be a retrogressive step. I am currently practising as a low intensity CBT (LICBT) therapist within the context of a Mental Health Support Team and have successfully treated many young people with early onset OCD. Any move that removes the ability of young people to receive early treatment will potentially have harmful effects.  Section 1.5.1.9 of the current guidance should make reference to the treatment of OCD by all modalities or, at the very least, remain unchanged so that LICBT therapists can continue to support young people who are struggling with OCD.  There is supporting evidence to support this and can be provided if required.	Thank you for your comment. The details of the review protocols will be discussed with the committee, but it is planned that treatment intensity will be considered as part of the review of interventions for OCD and BDD. The recommendations will be drafted by the independent committee, so we cannot pre-empt their conclusions, but we will ensure that your points are raised when the relevant evidence is discussed. The outcome of this process will inform which level of CBT therapist may be most appropriate to deliver these interventions.



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2	SH	NHS England	Draft scope	001	012 - 014, 018	- The NHS follows the WHO ICD. Bodily Distress Disorder should be health anxiety/ hypochondriacal disorder. The scope must include obsessive compulsive and related disorders such as health anxiety, hoarding disorder and body focused repetitive behaviours. All the stakeholders at the consultation wanted to include related disorders defined in ICD-11, and this guidance is desperately required by Talking Therapies who receive referrals of such conditions. This is the single most important change in the scope.	Thank you for your comment. Covering all obsessive compulsive related conditions as well as other questions raised in this comment have not been added as areas to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.
3	SH	South London and Maudsley NHS Foundation Trust	Draft scope	001	012 - 014, 018	The scope must include obsessive compulsive and related disorders such as health anxiety, hoarding disorder and body focused repetitive behaviours. All the stakeholders at the consultation wanted to include related disorders defined in ICD-11, and this guidance is desperately required. This is the single most important change in the scope. Stating that the guideline needs to be completed in 18 months is inadequate when we have waited 20 years for this guideline to be updated.	Thank you for your comment. Obsessive compulsive related disorders have not been added as areas to be addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
4	SH	Orchard OCD	Draft scope	001	012 - 014, 018	The scope must include obsessive compulsive and related disorders such as health anxiety, hoarding disorder and body focused repetitive behaviours. All the stakeholders at the consultation wanted to include related disorders defined in ICD-11, and this guidance is	Thank you for your comment. Obsessive compulsive related disorders have not been added as areas to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.



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						desperately required. This is the single most important change in the scope.	
5	SH	The Body Dysmorphic Disorder Foundation	Draft scope	001	012 – 015, 022	The scope states that it is suspected to meet/or meet diagnostic criteria for OCD and BDD. We believe there is more needed in guidelines to reflect that there are unique barriers to people to getting to the point where BDD is suspected, screened and diagnosed, which may differ to OCD e.g. poorer insight into BDD, seen in cosmetic settings vs mental health settings, misdiagnosis. On line 22 it states this guidance is for all health settings and we think currently the guidelines for BDD are written for mental health settings only, however it is more likely people with BDD will be in settings where they may be trying to alter their appearance e.g. dentistry, cosmetic surgery settings etc. We believe that Bodily-Focused Repetitive Behaviours (BFRBs) should also be included in these guidelines as they affect around 20% of individuals with BDD. We also believe the sub-type of BDD, muscle dysmorphia, should be mentioned in the guidance which will help increase awareness, screening and support for sufferers with this sub-type.	Thank you for your comment. Accessing and engaging with treatments is one of the review questions that would address the topic of delay to assessment where BDD is suspected or where there is a misdiagnosis. The committee includes a co-opted role of a professional with expertise in aesthetic procedures so altering of appearance can be addressed using this expertise. With regards to additional Obsessive compulsive related disorders, these have not been included as areas to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
6	SH	Maternal OCD	Draft scope	001	015	adultsand then add (including parents) this will demonstrate the acknowledgement from NICE re the	Thank you for your comment. This section covers the population the guideline focuses on. Obsessive compulsive disorder related to antenatal and



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						higher prevalence see Fairbrother study: https://pubmed.ncbi.nlm.nih.gov/34033273/	postnatal mental health is covered in CG192 (Antenatal and postnatal mental health: clinical management and service guidance). Any updates related to assessment and identification would fall into the remit of CG192. At the time of publication of CG192 OCD was classified as an anxiety disorder and this has changed in ICD-11 we will pass this issue on to surveillance.
7	SH	Royal College of General Practitioners	Draft scope	001	015 - 016	The extension of the guideline to include children under 8 years is commendable. Early identification and intervention are crucial in this age group. However, it's important to ensure that assessment tools and interventions are developmentally appropriate for younger children.	Thank you for your comment. We will search for evidence related to interventions in this age group and recommendations could be made if evidence is identified. Identification is included in the scope and so it will be considered how this applies to this younger age group.
8	SH	Royal College of General Practitioners	Draft scope	001	022 - 023	We believe it is essential to provide guidance that is applicable across various settings, including primary care, where initial presentations often occur.	Thank you for your comment. The scope states that 'All health, mental health and social care settings in which NHS care or social care is received or commissioned' are covered.
9	SH	OCD Action	Draft scope	001, 006	011- 014	OCD Action are seriously concerned that OCD related disorders - such as Body-Focused Repetitive Behaviours (BFRBs), Hoarding Disorder, Health Anxiety (Hypochondriasis), and Olfactory Reference Disorder -	Thank you for your comment. Obsessive compulsive related disorders apart from body dysmorphic disorder have not been added as areas to be addressed in a first batch of the update,



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						have been excluded from this review based on what appear to be arbitrary timeline restrictions.  Evidence indicates that BFRBs are estimated to affect up to 1 in 5 people - potentially 4 million people in the UK. At OCD Action, 2.5% of helpline contacts are BFRB-related. Despite low public awareness of BFRBs, they still make up 2.5% of OCD Action's helpline contacts, suggesting the true scale of need may be far greater. "When I sought help for trichotillomania, my CMHT didn't know what BFRBs were. They treated it as self-harm and told me stopping might lead to "more dangerous behaviours." I was given CBT for depression, not the condition I was there for. My symptoms got worse, not better. Without clear guidelines, people like me are left with inconsistent care and no recognition that this is a legitimate mental health issue, even though effective treatments exist." (Cara, Lived experience expert)  Similarly, research indicates that Hoarding Disorder is a common condition affecting 2–5% of the population. Over 1% of OCD Action helpline contacts are from people seeking information on treatment for Hoarding Disorder, despite the stigma that often dissuades people from seeking support.	please see the stakeholder message related to the new approach NICE is taking for this guideline.



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						Following a 20 year wait for the OCRD guideline to be reviewed, at OCD Action we are very concerned that these conditions are being excluded due to timeline constraints. We are of the view that this approach risks sidelining people affected by these disorders all over again and overlooks a vital opportunity to address long-standing gaps in care.	
10	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	001	General	Bottom of page - Accessing and Engaging with Treatment: Welcome step as engagement, particularly for severe presentations, remains a significant challenge in optimal delivery of the stepped care model proposed by 2005 guidelines. For example patients unable to engage with combination treatments are unlikely to be stepped up to higher levels. It is therefore important to cover engagement across all severity levels as engagement difficulties form a significant contributor to treatment refractoriness.	Thank you for your comment in support of the inclusion of this topic.
11	SH	Orchard OCD	Draft scope	001	General	Bottom of page - Accessing and Engaging with Treatment  Welcome step as engagement, particularly for severe presentations, remains a significant challenge in optimal delivery of the stepped care model proposed by 2005 guidelines. For example patients unable to engage with	Thank you for your comment in support of the inclusion of this topic.



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						combination treatments are unlikely to be stepped up to higher levels. It is therefore important to cover engagement across all severity levels as engagement difficulties form a significant contributor to treatment refractoriness.	
12	SH	Maternal OCD	Draft scope	002	003 - 004	There is no inclusion of prevention and relapse prevention in the list	Thank you for your comment. Prevention and relapse prevention have not been added as areas to be addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
13	SH	Maternal OCD	Draft scope	002	005	Recognition & assessment is not enough – include 'diagnosis' which is particularly important for perinatal OCD when there is a perceived threat of mum and baby being separated unnecessarily	Thank you for your comment. NICE guidelines generally use the terms identification, recognition and assessment rather than diagnosis. This approach ensures the recommendations are applicable to the full range of professionals who may identify and support people with possible mental health problems, not only those in specialist roles. It also reflects a less medicalised perspective, valuing service users' experiences and avoiding unnecessary diagnostic labelling. In addition, NICE is mindful of the potential for stigma and overmedicalisation of distress; using recognition and assessment allows consideration of social,



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							psychological, and contextual factors alongside clinical ones.
14	SH	OCD-UK	Draft scope	002	005	Whilst we understand hoarding is not intended to be included within this scope, it's important that when referencing recognition and assessment of OCD, that hoarding symptoms should not be automatically excluded and should be assessed and considered as possible symptoms of OCD. The scope/guidance should look to include text to reference the fact that assessment/diagnosis should be carefully considered to understand if symptoms of hoarding are because of OCD (relevant for this guideline) or if symptoms would fall outside of a diagnosis of OCD. The clinician should then refer to treatment guidelines for hoarding disorder in such cases.	Thank you for your comment. Obsessive compulsive related disorders have not been added as areas to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
15	SH	LSCFT NHS Talking Therapies	Draft scope	002	006	To improve the usefulness of NICE guidance consideration should be given to aligning the messaging to the usual delivery of psychological treatment for most of the public via NHS Talking Therapies. The current guidance creates some confusion around the term 'low intensity treatment' for OCD, as it then then recommends up to 10 therapist hours. This is not usually available within NHS talking therapies where often the maximum low intensity treatment time is around 4 hours. Ensuring that the guidance is not misinterpreted (which	Thank you for your comment. The details of the review protocols will be discussed with the committee, but it is planned that treatment intensity will be considered as part of the review of interventions for OCD and BDD. The recommendations will be drafted by the independent committee, so we cannot pre-empt their conclusions, but we will ensure that your points are raised when the relevant evidence is discussed. The outcome of this process will inform



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						has been the case) is crucial to reduce inappropriate use	which level of CBT therapist may be most
						of a stepped care model (see below).	appropriate to deliver these interventions.
16	SH	LSCFT NHS Talking Therapies	Draft scope	002	006	The stepped care model in the current guidance can also be misinterpreted by NHS talking therapy providers to suggest that it is the usual case that psychological treatment for OCD should begin with low intensity treatment. In clinical practise, mild cases of OCD appear to be very much in the minority at the point of seeking treatment. This should be reflected in the guidance so that operational pathways to treatment are optimised to provide the best care for all service users.	Thank you for your comment. The details of the review protocols will be discussed with the committee, but it is planned that treatment intensity will be considered as part of the review of interventions for OCD and BDD. The recommendations will be drafted by the independent committee, so we cannot pre-empt their conclusions, but we will ensure that your points are raised when the relevant evidence is discussed. The outcome of this process will inform which level of CBT therapist may be most appropriate to deliver these interventions.
17	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	Draft scope	002	006	The guidance could be improved by ensuring that it takes into account how psychological therapies for OCD/BDD are usually delivered in England- often through NHS Talking Therapies for Anxiety and Depression for most members of the public. The current guidance can be confusing when it refers to 'low intensity treatment' for OCD, as it recommends up to 10 therapist hours.  In 'low intensity NHS Talking Therapies, it is unusual for people to be offered more than a total treatment investment of 8 x 30 minute sessions/ 4 hours- Since	Thank you for your comment. The details of the review protocols will be discussed with the committee, but it is planned that treatment intensity will be considered as part of the review of interventions for OCD and BDD. The recommendations will be drafted by the independent committee, so we cannot pre-empt their conclusions, but we will ensure that your points are raised when the relevant evidence is discussed. The outcome of this process will inform



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						NHS Talking Therapies is the most likely way that people will access treatment for OCD/BDD, the guidance should make clear how 10 hours of 'low intensity' therapy would be delivered- current experience suggests that the guidance can be misinterpreted, or that services do not have pathways that deliver 10 hours of low intensity therapy and this can negatively affect how stepped-care is delivered. It will be helpful in service pathways that use a stepped care model to be very clear that low intensity treatment can be suitable for people who have relatively mild symptoms, and ensure that it is clear what 'mild' means – in order to make sure that treatment is accessed at the right 'step' of care – ensuring that people whose symptoms are more severe can access the right intensity of treatment. It will be helpful to members of the public, clinicians, commissioners and service leads if this is clearly specified in the guidance so that operational pathways to treatment are optimised to provide the best care for people with OCD/BDD.	which level of CBT therapist may be most appropriate to deliver these interventions.
18	SH	NHS England	Draft scope	002	006 - 011	- The NICE Early Value Assessment for Anxiety has recommended a digitally enabled therapy for the treatment of BDD. This product is also currently being assessed against the digitally enabled therapy assessment criteria, which includes a review of the	Thank you for your comment and for highlighting this issue. Early Value Assessments are relatively new products and this has not been encountered before. We will have internal discussions about this to consider the options.



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						products' clinical content. This assessment identified that the clinical content does not include all of the elements of a high-intensity CBT intervention.  Consideration of whether psychological interventions more akin to a low-intensity intervention, and what type of clinical support is needed alongside this (e.g. support from a low- or high-intensity therapist) would help clarify whether or not this product (and potentially others in the future) are suitable for use in NHS Talking Therapies services.	The details of the review protocols will be discussed with the committee, but it is planned that treatment intensity will be considered as part of the review of interventions for OCD and BDD. The recommendations will be drafted by the independent committee, so we cannot pre-empt their conclusions, but we will ensure that your points are raised when the relevant evidence is discussed. The outcome of this process will inform which level of CBT therapist may be most appropriate to deliver these interventions.
19	SH	OCD-UK	Draft scope	002	007	Will the scope review the evidence base for the use of other third wave CBT approaches for the treatment of OCD and BDD such as Inference-based Cognitive-Behavioural Therapy (ICBT) and Acceptance and Commitment Therapy (ACT) which we know some NHS services have offered people with OCD. Understanding the evidence for effectiveness is helpful to ensure patients can be guided to effective evidence based treatments.	Thank you for your comment. The details of review protocols will be discussed with the committee, but it is planned that different types of CBT will be covered in the treatment reviews.
20	SH	OCD-UK	Draft scope	002	007	Will the scope review the evidence for the effectiveness of CBT when delivered online via Zoom/Teams, compared to face-to-face/in-person? This is important	Thank you for your comment. The details of review protocols will be discussed with the committee, but it is planned that different types of CBT including



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						at a time when many services are pushing patients to accept online appointments.	mode of delivery will be covered in the treatment reviews.
21	SH	OCD-UK	Draft scope	002	007	Will the scope review the evidence for therapy interventions delivered in a group format for OCD/BDD (group CBT) compared to therapy delivered one-to-one (face-to-face).  If the evidence supports the use of group therapy, are there recommendations for how group therapy should be delivered, no more than X people per group, how many therapists per group, how many sessions. Should the guidance consider the vast different themes in OCD and how someone with taboo intrusive thoughts may feel group therapy not helpful for them, especially if nobody else in the group appears to have a similar manifestation.  Should group therapy be considered as a patient choice only?	Thank you for your comments. The details of review protocols will be discussed with the committee, but it is planned that group versus individual CBT will feature in the review of treatments for OCD.
22	SH	Sussex Partnership NHS Foundation Trust	Draft scope	002	007 - 008	Where the scope states "psychological interventions, for example, exposure and response prevention (ERP), and cognitive behavioural therapy (CBT) with ERP." We would suggest referring to "exposure and response prevention (ERP) alone, cognitive therapy alone or their combination (i.e. CBT, or ERP with cognitive therapy.)"	Thank you for your comment. This section includes the broad areas that the review question will address. It is not a comprehensive list because the details will be discussed with the committee when a detailed protocol for the review will be developed. We have noted the reference highlighted and will



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						(see Öst, L. G., Havnen, A., Hansen, B., & Kvale, G. (2015). Cognitive behavioral treatments of obsessive—compulsive disorder. A systematic review and meta-analysis of studies published 1993–2014. Clinical psychology review, 40, 156-169.)	use this amongst other sources to develop a draft protocol for a discussion with the committee.
23	SH	OCD-UK	Draft scope	002	011	Will the scope review the evidence of other medications for the treatment of OCD, such as SNRI, especially in the event of co-existing conditions such as clinical depression.	Thank you for your comment. This section includes the broad areas that the review question will address. It is not a comprehensive list because the details will be discussed with the committee when a detailed protocol for the review will be developed. It is likely that SNRIs will feature in these discussions.
24	SH	Royal College of General Practitioners	Draft scope	002	014 - 019	We believe addressing treatment options for individuals who do not respond to initial interventions is essential. The guideline should provide clear pathways for escalation of care, including criteria for considering neuromodulation interventions.	Thank you for your comment. Treatment after a first treatment has failed is not an area to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.
25	SH	NHS England	Draft scope	002	015	- Need to provide detailed recommendations on dose and duration of augmentation strategies and their safety as these are different from use of anti-psychotics in schizophrenia (e.g. lower dose and trial duration)	Thank you for your comment. The detailed plans for the evidence review will be discussed with the committee. Unless there is clear evidence for a dose and duration that may differ from those in the BNF, it would be assumed that this is followed. If it is off label use, it would be highlighted in recommendations.



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26	SH	South London and Maudsley NHS Foundation Trust	Draft scope	002	015	The guideline must provide detailed recommendations on dose, duration, and safety of augmentation strategies, as these differ from antipsychotic use in schizophrenia (e.g., dose and trial duration).	Thank you for your comment. The detailed plans for the evidence review will be discussed with the committee. Unless there is clear evidence for a dose and duration that may differ from those in the BNF, it would be assumed that this is followed. If it is off label use, it would be highlighted in recommendations.
27	SH	Orchard OCD	Draft scope	002	015	Need to provide detailed recommendations on dose and duration of augmentation strategies and their safety as these are different from use of anti-psychotics in schizophrenia (eg often lower dose and trial duration)	Thank you for your comment. The detailed plans for the evidence review will be discussed with the committee. Unless there is clear evidence for a dose and duration that may differ from those in the BNF, it would be assumed that this is followed. If it is off label use, it would be highlighted in recommendations.
28	SH	British Association for Behavioural and Cognitive Psychothera	Draft scope	002	015	Draft Scope Page 2. Line 14 - 18 The guidance needs to provide detailed recommendations on dose and duration of augmentation strategies and their safety - as these are different from use of anti-psychotics in schizophrenia (eg lower dose and trial duration	Thank you for your comment. The detailed plans for the evidence review will be discussed with the committee. Unless there is clear evidence for a dose and duration that may differ from those in the BNF, it would be assumed that this is followed. If it is off label use, it would be highlighted in recommendations.



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		pies – BABCP					
29	SH	University of Edinburgh - Neurodiverg ent and Learning Disabilities Research Group	Draft scope	002	020	It is good to see reference to access – a key issue facing patients with OCD in the UK is a lack of access to timely and appropriate treatment. Therapists including psychological wellbeing practitioners and mental health professionals attached to GP surgeries need more training in OCD, and how to provide therapy for a patient whose primary condition is OCD.	Thank you for your comment in support of the reference to access. Details of training are outside of the remit of NICE recommendations because this is covered by the related institutions and colleges.
30	SH	Royal College of General Practitioners	Draft scope	002	020	Understanding barriers to accessing and engaging with treatment is crucial. The guideline should offer strategies to improve engagement, particularly for populations that may be underserved or face stigma.	Thank you for your comment in support of the inclusion of this topic.
31	SH	NIHR Applied Research Collaboration (ARC) North Thames	Draft scope	002	024	Areas covered by other guidelines  The author would like to encourage reviewers to recognise the overlap between BDD and eating disorders (EDs) by including a link to Clinicial Guideline #69 (NG69: Overview   Eating disorders: recognition and treatment   Guidance   NICE)  A group of BDD experts, led by Katherine Phillips, published a statement in response to emerging issues with the potential new DSM-5 categorisation of BDD	Thank you for your comment. This section of the scope (Areas covered by other guidelines) is not an exhaustive list of related NICE guidance but outlines areas where this update will not include a specific evidence review as they are covered by other NICE guidance. Recognition and assessment of OCD and BDD will be covered as part of this update, and it is anticipated that this will include consideration of differential diagnosis and coexisting conditions. This update will cross-refer to relevant NICE guidance where appropriate.



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						(Phillips et al., 2010). They discuss Criterion C which	
						states that "the preoccupation is not better accounted for	
						by another mental disorder (e.g., dissatisfaction with	
						body shape and size in AN)", indicating that if a person's	
						symptoms meet the other diagnostic criteria for anorexia	
						nervosa, then AN – rather than BDD – should be	
						diagnosed (Phillips et al., 2010: p.574). It is recognised	
						that without this criterion, most patients with AN would	
						also be diagnosed with BDD, as they are presumably	
						preoccupied with an imagined defect in appearance.	
						Researchers also acknowledge that it can be a similar	
						case with BN (Phillips et al., 2014). However, in people	
						with potential co-morbid BDD and EDNOS, diagnostic	
						boundaries are less defined leaving it unclear where	
						BDD or EDNOS would be the more appropriate	
						diagnosis for some people (Phillips et al., 2014).	
						Despite the differences in categorisation by diagnostic	
						manuals such as DSM-5 and ICD-11, the treatment	
						pathways and stepped-care models provided by the	
						National Health Service (NHS) for both BDD and EDs in	
						the UK share similarities. The National Institute for	
						Health and Care Excellence (NICE) proposed stepped	
						care pathways for both disorders, with Cognitive	
1						Behavioural Therapy (CBT) – either in guided self-help,	



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ID	Type	Stakeholder	Document	Page no.	Line no.	Comments	Developer's response
				· ·	_	Please insert each new comment in a new row	Please respond to each comment
						group, or individual settings – being the first-line psychological treatments for adults with BDD, BN and BED (NICE 2005; NICE 2017). Whilst CBT is also the first-line psychological treatment for AN, there are additional recommended treatments such as Specialist Supportive Clinical Management (SSCM) of the likely physical health implications (NICE, 2017). For young people under the age of 18, CBT is still a first line treatment for BDD and BED, and second-line for AN and BN following Family Therapy (NICE 2005; NICE 2017). Currently, there is not yet empirical evidence for family-based interventions for BDD, therefore it is not included in the NICE Guidelines, despite researchers stating that there is 'an imperative for research [into] BDD-focused family-based interventions' (NICE, 2005; van Noppen and Sassano-Higgins, 2017).	
						This structure of service provision fails to recognise the common comorbidity and overlap of disorders related to body image disturbance, whereby an estimated third of people with BDD will also experience an ED (32.5%; Ruffolo et al., 2006), and that up to 76% of people with an ED could be diagnosed with BDD (Trott et al., 2020). For both disorders, access to treatment and support is difficult with shame and stigma being significant barriers	



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•					_	Please insert each new comment in a new row	Please respond to each comment
						(McCausland et al., 2021; Hamilton et al., 2021), which	
						emphasises the critical need for sufficient prevention	
						and early intervention strategies.	
						A narrative review conducted by Hartmann, Greenberg	
						and Wilhelm (2013) highlighted several shared clinical	
						characteristics (i.e. body image disturbance, self-	
						esteem, executive functioning, suicidality and	
						delusionality) as well as similar age of onset and illness trajectories.	
						trajectories.	
						As part of the author's PhD thesis, a systematic review	
						exploring shared psychopathology across BDD and EDs	
						was conducted. This review yielded a total of 13 studies,	
						all of which directly compared psychological traits across	
						two samples of people with EDs and BDD. To	
						summarise the narrative synthesis of studies – whilst	
						acknowledging scientific limitations – it can be	
						extrapolated that both disorders have elevated levels of	
						delusionality, body image disturbance, anxiety,	
						depression, fear of self, perfectionism, and poorer	
						executive functioning compared to healthy controls, with	
						similar levels of body image disturbance and fear of self	
						across both BDD and ED groups. Amongst this, people	
						with BDD tend to have slightly higher levels of	



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·				,		Please insert each new comment in a new row	Please respond to each comment
						delusionality, anxiety, and depression, whereas people	
						with EDs tend to have slightly higher levels of eating	
						pathology, obsessive compulsive pathology, and	
						perfectionism. Both groups displayed indicators of	
						abnormal visual processing and a lower quality of life	
						than controls. A key difference across groups is the	
						source of their body image disturbance and body	
						dissatisfaction, with ED groups tending to be	
						preoccupied with body parts pertaining to overall weight	
						and shape (lower torso, stomach, and waist), BDD	
						groups were preoccupied with more diverse body parts	
						such as facial features, skin and hair.	
						The main difference between disorders was the area of	
						appearance concern which led to body image	
						dissatisfaction and disturbance, with ED participants	
						being more preoccupied with body parts associated with	
						weight and shape (i.e. hips, waist and stomach) as	
						opposed to the BDD participants who focused on facial	
						areas, shape and symmetry (i.e. skin, nose, hair,	
						cheekbones and mouth – including lips and teeth). This	
						is consistent with the wider literature which states that "it	
						is the subject of focus that differentiates the two	
						disorders" and can explain why it is BDD which is	
						typically of "utmost concern" in the field of aesthetics due	



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						to the number of individuals with BDD who seek cosmetic help before psychiatric help (Gorbis and Jamero, 2019: p.126).	
						Traditionally, these two disorders have been distinguishable by the presence or absence of eating pathology, hence the inclusion of Criterion C ('the preoccupation is not better accounted for by another mental disorder e.g., dissatisfaction with body shape and size in AN') in the categorisation of BDD in the DSM-5 (APA, 2013). Yet, the study by Ruffolo and colleagues (2006) found that 32.5% of BDD patients had a comorbid lifetime ED, with onset of BDD usually preceding the onset of an ED. Additionally, whilst the two included studies which directly compared eating pathology in both the ED and BDD samples did illustrate higher levels in the ED than the BDD sample, both	
						samples did meet the optimal cut-off threshold (2.0) whereas the sample of healthy controls did not (Hartmann et al., 2014; Dingemans et al., 2022; Meule et al., 2024). This suggests that the traditional arbitrary presence or absence of eating pathology may not be as useful as once thought and instead, determining a continuum of disordered eating in people with body image dissatisfaction may be more clinically useful.	



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•				J	-	Please insert each new comment in a new row	Please respond to each comment
						Given the positioning of BDD as an 'Obsessive Compulsive or Related Disorder' in diagnostic manuals, it is important to examine the studies which measured obsessive-compulsive pathology as well as related traits such as fear of self and perfectionism. In this review, the one study that compared obsessive compulsive traits across groups indicated that whilst obsessive compulsive pathology was higher in both ED and BDD samples, it was in fact higher in the ED sample (Dingemans et al., 2022). The link between OCD and EDs has long been debated, with Legenbauer and colleagues (2017) accounting this to disordered eating behaviours such as body checking and food avoidance behaviours. Additionally, in the study which measured fear of self – which is a "core cognitive construct" in OCD development and maintenance – both the ED and BDD samples demonstrated higher levels than healthy controls. This was explained by fear of self being a transdiagnostic process that also applies to ED and BDD, in which obsessions are generally more ego syntonic (Aardema et al., 2017: p.e20). Moreover, the FSQ which measured fear of self in this study was able	Please respond to each comment



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						where "self-doubt, shame, guilt, and a focus on personal defects stand at the foreground of symptomatology" (Aardema et al., 2017: p.e20). Additionally, in terms of perfectionism, this review supported the notion that this was a shared trait between ED and BDD, supporting previous research (Bardone-Cone et al., 2007; Bulik et al., 2003). These findings could potentially undermine the notion that BDD and EDs are distinctly different due to the shared pathology between OCD and BDD, as evidence supports that obsessive compulsive pathology is present in ED samples also.	
32	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	002	General	Top of page - Proposed Extension to Children Under Age 8: Broadening the age range to include younger children is a positive step, though it will require careful consideration of developmental factors and the evidence base for this age group which remains sparse.	Thank you for your comment in support of broadening the age range.
33	SH	Hertfordshire Partnership University	Draft scope	002	General	Top of page - Medication Discontinuation While the draft refers to other NICE guidelines for general principles, its specific mention acknowledges a	Thank you for your comment. Relapse prevention has not been included as an area to be addressed in a first batch of the update, please see the



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		NHS foundation trust - OCD/BDS National Service				key phase of treatment. We recommend that the review explores discontinuation nuances specifically within the context of OCD and BDD, considering strong evidence for high relapse rates following discontinuation and the role of concurrent psychological therapy when medication is being used in combination.	stakeholder message related to the new approach NICE is taking for this guideline.
34	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	002	General	Middle of page - Clarification of primary outcomes: The draft scope lists "main outcomes" such as diagnostic accuracy of brief assessment tools, change in symptoms, response to treatment, discontinuation, experience of care, and cost-effectiveness (NICE, 2025, draft scope, pp. 4-5). While these are relevant, the primary outcome of a treatment guideline should arguably be effective treatment leading to meaningful clinical improvement and functional recovery. The current list feels somewhat process-oriented rather than outcome-focused in terms of patient benefit. We recommend reframing the main outcomes to prioritise: Clinically significant reduction in OCD/BDD symptom severity and frequency.  Improvement in overall functioning (social, occupational, educational) and quality of life.  Achievement of patient-defined treatment goals and recovery.  Long-term maintenance of gains and relapse prevention.	Thank you for your comment. This is not a comprehensive list of all possible outcomes. However, it includes a mixture of 'process orientated' as well as person centred outcomes because it includes 'experience of care from the perspective of service users and their families and carers'. Both sets complement each other, and further outcomes may be added when the protocols are discussed with the committee.



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35	SH	Orchard OCD	Draft scope	002	General	Top of page - Proposed Extension to Children Under Age 8:  Broadening the age range to include younger children is a positive step, though it will require careful consideration of developmental factors and the evidence base for this age group which remains sparse.	Thank you for your comment in support of broadening the age range.
36	SH	Orchard OCD	Draft scope	002	General	Top of page - Medication Discontinuation  While the draft refers to other NICE guidelines for general principles, its specific mention acknowledges a key phase of treatment. We recommend that the review explores discontinuation nuances specifically within the context of OCD and BDD, considering strong evidence for high relapse rates following discontinuation and the role of concurrent psychological therapy when medication is being used in combination.	Thank you for your comment. Discontinuation is covered in detail in other NICE guidelines (for example in NG222) and will therefore not be a topic in the OCD guideline whilst OCD is a different condition the principles apply.  Relapse prevention is not an area to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
37	SH	Orchard OCD	Draft scope	002	General	Middle of page - Clarification of primary outcomes  The draft scope lists "main outcomes" such as diagnostic accuracy of brief assessment tools, change in symptoms, response to treatment, discontinuation, experience of care, and cost-effectiveness (NICE, 2025, draft scope, pp. 4-5). While these are relevant, the	Thank you for your comment. This is not a comprehensive list of all possible outcomes. However, it includes a mixture of 'process orientated' as well as person centred outcomes because it includes 'experience of care from the perspective of service users and their families and carers'. Both sets complement each other and



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•				· ·	_	Please insert each new comment in a new row	Please respond to each comment
38	SH	Hertfordshire	Draft scope	002 - 003	General	primary outcome of a treatment guideline should arguably be effective treatment leading to meaningful clinical improvement and functional recovery. The current list feels somewhat process-oriented rather than outcome-focused in terms of patient benefit. We recommend reframing the main outcomes to prioritise: Clinically significant reduction in OCD/BDD symptom severity and frequency. Improvement in overall functioning (social, occupational, educational) and quality of life. Achievement of patient-defined treatment goals and recovery.  Long-term maintenance of gains and relapse prevention.  Bottom of page 2, continuing to page 3 - Defining	further outcomes may be added when the protocols are discussed with the committee.  Thank you for your comment. Treatment resistant
30	GIT	Partnership University NHS foundation trust - OCD/BDS National Service	Drait scope	002 - 003	General	Treatment-Resistant OCD (TR-OCD) The draft scope does not explicitly propose to define TR-OCD. This was a noted limitation in the 2005 guideline. The scope must include the development of a clear, operational definition of TR-OCD. This is fundamental for guiding recommendations on further-line and intensive treatments, standardizing patient selection for such interventions, and facilitating targeted research. The definition should consider the number/type of failed evidence-based treatments (pharmacological and psychological, delivered with fidelity), persistent	OCD is no longer an area to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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						symptom severity (e.g., Y-BOCS threshold), functional impairment, and duration of illness.	
39	SH	Orchard OCD	Draft scope	002 - 003	General	Bottom of page 2, continuing to page 3 - Defining Treatment-Resistant OCD (TR-OCD)  The draft scope does not explicitly propose to define TR-OCD. This was a noted limitation in the 2005 guideline. The scope must include the development of a clear, operational definition of TR-OCD. This is fundamental for guiding recommendations on further-line and intensive treatments, standardizing patient selection for such interventions, and facilitating targeted research. The definition should consider the number/type of failed evidence-based treatments (pharmacological and psychological, delivered with fidelity), persistent symptom severity (e.g., Y-BOCS threshold), functional impairment, and duration of illness.	Thank you for your comment. Treatment resistant OCD is no longer an area to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
40	SH	Sussex Partnership NHS Foundation Trust	Draft scope	003	001 - 025	This may be intended, but could study funding source be clearly stated in the final report and considered as a significant risk of bias where an intervention has received industry funding from the developers of an intervention that the industry in question has a vested interest in. For example, but not necessarily limited to, we would want to see that the sources of funding for studies of non-invasive neuromodulation are clearly	Thank you for your comment. Funding sources are always extracted in the evidence reviews.



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						Please insert each new comment in a new row	Please respond to each comment
						stated and potential risk of bias considered when	
						evaluating outcomes of these studies.	
41	SH	NHS England	Draft scope	003	004	- Adaptations to people with OCD and autism. ASD is extremely common in OCD and is not adequately covered by CG142. This needs to be separately covered in this guideline as it's not just about adaptation – for example separating out ASD from symptoms of OCD and deciding what is to leave alone and what is for treatment	Thank you for your comment. The adaptation of treatments for people with OCD and autism is not an area to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.
42	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	Draft scope	003	004	Draft Scope Page 3 Line 4 - Adaptations for people with OCD and autism. ASD is extremely common in OCD and is not adequately covered by CG142 - The draft guidance refers to the CG142 Autism Guidance, in which OCD is mentioned as a specific mental health disorder at 1.2.10 in the context of it being a potential disorder to screen re differential diagnosis or co-existing disorder- and in which general guidance is given on adapting CBT interventions at 1.6.3.  However, there is no detailed guidance on treatment for OCD as a specific difficulty in Guideline cg142 it therefore should be covered separately here, and within the scope of this guidance. This needs to be separately covered in this guideline as it is not just about adaptation – for example separating out ASD from	Thank you for your comment. The adaptation of treatments for people with OCD and autism is not an area to be addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.



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						Please insert each new comment in a new row	Please respond to each comment
						symptoms of OCD and deciding what is to left alone and what is for treatment.	
43	SH	University of Edinburgh - Neurodiverg ent and Learning Disabilities Research Group	Draft scope	003	004	Generally autistic people prefer to be referred to as "autistic people", rather than "people with autism". The wording "people with OCD and autism" could therefore be updated to "autistic people with OCD". However I understand that it may be necessary to follow typical clinical language in this guidance.	Thank you for your comment. We recognise that preferences vary regarding identity-first and person-first language. In this instance, the wording "people with OCD and autism" has been retained to avoid assuming a particular order of identity or condition, and to give equal weight to both.
44	SH	South London and Maudsley NHS Foundation Trust	Draft scope	003	004	Adaptations to people with OCD and autism need specific attention. ASD is extremely common in OCD and is not adequately covered by CG142. This guideline should go beyond adaptations to consider how to differentiate ASD traits from OCD symptoms and make appropriate treatment decisions.	Thank you for your comment. Adaptations for people with OCD and autism has not been included as an area to be addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
45	SH	OCD-UK	Draft scope	003	004	Adaptations to interventions for neurodivergent people with OCD may be covered in other guidelines, but with a significant increase in people with OCD being diagnosed with ADHD and/or Autism, the guideline should look to include at least a paragraph reference to the fact clinicians should look to make necessary and appropriate treatment adaptations where ADHD/Autism is suspected, and refer them to NICE Guideline CG142	Thank you for your comment. Adaptations for people with OCD and autism has not been included as an area to be addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.



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					_	Please insert each new comment in a new row	Please respond to each comment
						and CG170 within that text.  We have seen adaptions make a significant difference to OCD treatment outcomes for some neurodivergent people with OCD. So to ignore within any new	
46	SH	South London and Maudsley NHS Foundation Trust	Draft scope	003	004 - 006	guidelines for OCD would be a significant omission.  Propose a standalone review question on adaptations required for people with OCD and co-occurring autism, beyond referring to CG142 and CG170. The interplay of compulsions, cognitive rigidity, and treatment targeting in dual diagnosis populations warrants bespoke evidence review.	Thank you for your comment. Adaptations for people with OCD and autism has not been included as an area to be addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
47	SH	OCD Action	Draft scope	003	004 - 006	OCD Action is deeply concerned that the scope currently excludes a dedicated evidence review on how interventions should be adapted for Autistic people with OCD  This is a significant gap and it is vital that this is specifically covered in the guideline. Effective care for autistic individuals with OCD is not simply about adjusting treatment delivery - it requires informed clinical judgment. For example, clinicians must be able to distinguish between autistic traits and OCD symptoms in order to identify what should be targeted in therapy. Without this clarity, there is a risk of misdiagnosis,	Thank you for your comment. Adaptations for people with OCD and autism has not been included as an area to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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						mistreatment, and poor outcomes. This is not a small cohort. Research suggests that up to 25% of young people with OCD may also be autistic. In 2023/24, 51% of the young people who contacted OCD Action's youth helpline were seeking help with accessing appropriate treatment for OCD in the context of autism. There is a breadth of research on OCD and autism spectrum disorder. One paper (Martin, A.F., Jassi, A., Cullen, A.E. et al. https://doi.org/10.1007/s00787-020-01478-8) concluded that autistic young people with OCD "can make significant improvements in functioning with routine clinical care but are likely to remain more impaired than typically developing youth with OCD, indicating a need for longer-term support for these young people." Given this evidence, the absence of a focused review on OCD and autism in the current scope is a concerning oversight.	
48	SH	University of Edinburgh - Neurodiverg ent and Learning Disabilities	Draft scope (and EHIA)	003	004 - 006	Including guidance on autism -  The guidance notes that treating autistic people with OCD is covered in the guidance on autism. However it would be beneficial to address this in the OCD guidance as well, at the very least with a link to the guidance on treating OCD in autistic people. This is because, as	Thank you for your comment. Adaptations for people with OCD and autism, has not been included as an area to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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	Type	Research Group					
						cBT or similar is likely to worsen autistic people's mental health.  There is substantial under-diagnosis of autism,	



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Please insert each new comment in a new row especially in girls and women. Therefore it is likely that mental health professionals will encounter patients who are autistic but have not been diagnosed. Therefore it is	to each comment
mental health professionals will encounter patients who are autistic but have not been diagnosed. Therefore it is	
necessary for mental health professionals to be trained in distinguishing between OCD symptoms and autistic traits irrespective of whether the patient has a diagnosis of autism.  Some of this detail is already included in the EHIA, but it is important to ensure these considerations come under the scope as well.  49 SH Maternal OCD  Draft scope 003 007 - 008 Signposting to the AN & PN guidelines does not provide for mums with OCD. CG192 does not include identification or treatment of perinatal OCD so this OCD guideline must include otherwise HCP will not have any guidance to identify or treat perinatal OCD well enough on interventions for anxiety includes OCD (in line with to categorisations at the time of developed). This update with assessment of OCD. CG192 does not include and service guidance) includes of the original occurrence of the original occurrence of the original occurrence occu	th: clinical management ludes recommendations by disorders, which the diagnostic that guideline was will include recognition and 192 includes siderations around alth problems in the tall period to be used in



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50	SH	Maternal OCD	Draft scope	003	007 - 008	Concerning to exclude perinatal OCD – see here another example (research and meta-analysis) which puts prevalence at 9.1% in pregnancy and 6.2% postpartum https://www.sciencedirect.com/science/article/pii/S26669 1532400132X	Thank you for your comment. Perinatal OCD is not an exclusion for this update. However, this update will not include a specific evidence review on adaptations to interventions for people with OCD in the antenatal or perinatal period as this is covered by existing NICE guidance CG192 (Antenatal and postnatal mental health: clinical management and service guidance). This update will include recognition and assessment of OCD. CG192 includes recommendations on considerations around assessment of mental health problems in pregnancy and the postnatal period to be used in conjunction with condition-specific NICE guidance including this update.
51	SH	Maternal OCD	Draft scope	003	007 - 008	There are no recorded cases of a mum acting on her obsessional thoughts of harm (unintentional or intentional) to the baby however in Perinatal OCD the fear that they will harm their baby often prevents mothers from seeking treatment. This means HCPs must be trained and equipped to support the mum and avoid incorrect clinical judgements and safeguarding referrals.	Thank you for your comment. The NICE Antenatal and postnatal mental health clinical guideline CG192 (Antenatal and postnatal mental health: clinical management and service guidance) included a qualitative review on experience of care and a barrier to accessing care that emerged from that review was fear of the baby being taken away. The recommendations in CG192 on principles of care in pregnancy and the postnatal period were made based on that qualitative review and on the



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						Please insert each new comment in a new row	Please respond to each comment
							clinical and lived experience of that guideline
							committee. This update will cross-refer to relevant NICE guidance where appropriate
							Two E guidance where appropriate
52	SH	South	Draft scope	003	007 -	Recommend explicitly including OCD and BDD during	Thank you for your comment. This update will be
		London and			800	the perinatal period within this update. CG192 covers	developed to be used in conjunction with other
		Maudsley				general perinatal mental health, but lacks specificity on	NICE guidance including CG192 (Antenatal and
		NHS				intrusive thoughts, compulsive rituals, or BDD body-	postnatal mental health: clinical management and
		Foundation Trust				image issues during pregnancy and postpartum	service guidance). This update will cover recognition and assessment of OCD and BDD, and
		Trust					treatment and interventions for OCD and BDD, and treatment and interventions for OCD and BDD.
							CG192 includes recommendations on
							considerations around assessment and treatment of
							mental health problems in pregnancy and the
							postnatal period to be used in conjunction with
							condition-specific NICE guidance including this
							update.
53	SH	OCD Action	Draft scope	003	007 -		Thank you for your comment. The NICE Antenatal
					800	Data from the UK suggests that OCD affects 2 in every	and postnatal mental health clinical guideline
						100 women during pregnancy and 2–3 in every 100 in	CG192 (Antenatal and postnatal mental health:
						the year after giving birth (www.rcpsych.ac.uk).	clinical management and service guidance)
						In particular OCD assessment of the force of the first	included a qualitative review on experience of care
						In perinatal OCD, symptoms often focus on the baby. Although mothers with OCD may experience intrusive	and a barrier to accessing care that emerged from that review was fear of the baby being taken away.
					L	Authough mounters with OCD may experience intrusive	macreview was lear or the baby being taken away.



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						Please insert each new comment in a new row	Please respond to each comment
						thoughts about harming their baby, they are not at risk of acting on them. There are no recorded cases of individuals with OCD acting on these intrusive thoughts, and most mothers can care for their babies well, with appropriate support.  However, fear of being judged or misunderstood can prevent mothers from seeking help. In some cases, disclosing intrusive thoughts has led to incorrect clinical judgements or even inappropriate safeguarding referrals due to a lack of understanding among healthcare professionals.  In this context, the decision not to include a review of adaptations to interventions for people with OCD in the antenatal or postnatal period is deeply concerning, for both maternal and infant outcomes.	The recommendations in CG192 on principles of care in pregnancy and the postnatal period were made based on that qualitative review and on the clinical and lived experience of that guideline committee. This update will not include a specific evidence review on adaptations to interventions for people with OCD in the antenatal or perinatal period as this is covered by CG192. This update will include recognition and assessment of OCD. CG192 includes recommendations on considerations around assessment of mental health problems in pregnancy and the postnatal period to be used in conjunction with condition-specific NICE guidance including this update. This update will cross-refer to relevant NICE guidance, including CG192, where appropriate
54	SH	British Association for Behavioural and Cognitive Psychothera	Draft scope	003	008	The scope states that it has excluded perinatal OCD and refers to the 2014 NICE guidelines on Antenatal and Postnatal mental health, but while OCD is mentioned there as a mental health disorder, those guidelines do not cover identification or treatment of perinatal OCD in any depth.  The evidence suggests that OCD is much more common perinatally, it would be helpful to be specific in the scope	Thank you for your comment. Perinatal OCD is not an exclusion for this update. However, this update will not include a specific evidence review on adaptations to interventions for people with OCD in the antenatal or perinatal period as this is covered by existing NICE guidance CG192 (Antenatal and postnatal mental health: clinical management and service guidance). This update will be developed to



# Consultation on draft scope Stakeholder comments table

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ID	Type	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
					_	Please insert each new comment in a new row	Please respond to each comment
		pies – BABCP				of this guidance to include it, with detailed guidance on prevention, screening, identification, assessment, interventions and relapse prevention in the context of perinatal care.	be used in conjunction with other NICE guidance including CG192. This update will cover recognition and assessment of OCD and BDD, and treatment and interventions for OCD and BDD. CG192 includes recommendations on considerations around assessment and treatment of mental health problems in pregnancy and the postnatal period to be used in conjunction with condition-specific NICE guidance including this update.
55	SH	NHS England	Draft scope	003	009	- Stopping anti-depressants medication (covered in depression in adults)" OCD is a different disorder, with a different response, and stopping anti-depressants in the absence of CBT has a high rate of relapse. This needs to be tackled separately in this guideline	Thank you for your comment. Relapse prevention has not been included as an area to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
56	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	Draft scope	003	009	Draft Scope Page 3 Line 9 "Stopping anti-depressants medication (covered in depression in adults)" OCD is a different disorder, with a different response, and stopping anti-depressants in the absence of CBT has a high rate of relapse. This needs to be tackled specifically in the scope of this guideline	Thank you for your comment. Relapse prevention has not been included as an area to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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	, .				_	Please insert each new comment in a new row	Please respond to each comment
57	SH	South London and Maudsley NHS Foundation Trust	Draft scope	003	009	Stopping antidepressant medication is covered under depression in adults, but OCD is a different disorder with a different response profile. Stopping antidepressants in the absence of CBT carries a high rate of relapse. This issue needs to be addressed separately within this guideline.	Thank you for your comment. Relapse prevention has not been included as an area to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.
58	HS	Orchard OCD	Draft scope	003	009	"Stopping anti-depressants medication (covered in depression in adults)" OCD is a different disorder, with a different response, and stopping anti-depressants in the absence of CBT has a high rate of relapse. This needs to be tackled separately in this guideline.	Thank you for your comment. Discontinuation is covered in detail in other NICE guidelines (for example in NG222) and will therefore not be a topic in the OCD guideline whilst OCD is a different condition the principles apply. Relapse prevention is not an area to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.
59	SH	South London and Maudsley NHS Foundation Trust	Draft Scope	003	009 - 010	Suggest reconsidering the decision to exclude stopping antidepressant medication from this update. OCD has unique relapse risks if antidepressants are withdrawn without concurrent CBT, which differ significantly from depression. NG222 and NG215 do not adequately cover this.	Thank you for your comment. Relapse prevention has not been included as an area to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.
60	SH	NICE - Medicines	Draft scope	003	012 - 016	Should CG76: medicines adherence be linked in this section?	Thank you for your comment. This guidance has now been added to the 'Areas covered by other guidelines' section of the scope.



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						Please insert each new comment in a new row	Please respond to each comment
		Optimisation Team					
61	SH	OCD Action	Draft scope	003	012 - 016	At OCD Action we do not think that the reference to other Guidelines for improving patient experience negates the need to explore the efficacy of regular, routine outcome monitoring in treatment for OCD.  At OCD Action we are deeply concerned about the lack of regular routine outcome monitoring. There is a frequent occurrence of misdiagnosis (Adult Psychiatric Morbidity Survey 2014) and feedback through our services indicates that people regularly receive inappropriate therapeutic interventions.  Furthermore through recent FOI requests we collected data to see which ICB and mental health services were collecting outcome data on OCD and very few were. This is a particular issue in secondary mental health services where, regular, routine outcome monitoring is not standard practice for OCD.  At OCD Action we believe this not only negatively affects individual outcomes, but that it furthers the lack of	Thank you for your comment. Regular routine outcome monitoring is not an area to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
						not standard practice for OCD.	



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	''				_	Please insert each new comment in a new row	Please respond to each comment
						increases the trivialisation of the condition.  OCD Action is so deeply concerned about the lack of data available on OCD within the NHS, including routine outcome monitoring that we have an open letter to the Prime minister, that over 1700 of our community members have signed.  In this context we would ask NICE to seriously consider re-adding the review of regular, routine outcome monitoring to the Scope	
62	SH	Sussex Partnership NHS Foundation Trust	Draft scope	003	017	We suggest including a question about what works well to support family and friends of people with OCD, both in supporting their loved one's recovery and in supporting their own wellbeing and mental health as carers.	Thank you for your comment. There is NICE guidance on support for adult carers (NG150). This update will include a qualitative review on accessing and engaging with treatment which will include the perspective of parents and carers. However, the focus of that review will be on understanding the facilitators and barriers to accessing and engaging with treatment for the person with OCD and BDD.



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•					_	Please insert each new comment in a new row	Please respond to each comment
63	SH	Sussex Partnership NHS Foundation Trust	Draft scope	003 - 004	017 – 025	'Draft review questions' - The proposed questions seem broadly appropriate and address the important questions regarding assessment, and effectiveness of interventions in adults and children and young people.	Thank you for your comment in support of the review questions.
64	SH	Anglia Ruskin University	Draft scope	003	018 - 019	Draft review questions should address head on common comorbidities and their impact on assessment, treatment and effectiveness – including but not limited to depression, anxiety, and other Obsessive-Compulsive and related disorders (OCRD) such as hoarding disorder.  Generally, explicit acknowledgement and consideration for this new category should be incorporated as it influences comorbidity and treatment (relevant for assessment and also for accessing and engaging with treatment).  If resources are insufficient, alternative explicit suggestions/recommendations for addressing hoarding and other OCRD are needed.	Thank you for your comment. OCD related conditions apart form Body Dysmorphic Disorder are not topics to be addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
65	SH	PTSD UK	Draft scope	003	020	Many people living with OCD have experienced traumatic events, and research indicates a strong link between trauma exposure and the development or worsening of OCD symptoms. In some cases, trauma-	Thank you for your comment. Assessment and recognition is part of the current update but this will focus on the assessment of OCD and BDD rather than the assessment of other related conditions.



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					_	Please insert each new comment in a new row	Please respond to each comment
66	SH	Royal	Draft scope	003	020 -	related intrusive thoughts may be misinterpreted as OCD-related obsessions. Without proper traumainformed assessment, this can lead to: Misdiagnosis, where trauma-related symptoms are mistaken for OCD Missed diagnosis of co-occurring PTSD or C-PTSD Ineffective treatment, as the underlying trauma is not addressed We recommend that the guideline includes a clear prompt for clinicians to ask about trauma and consider PTSD/C-PTSD as part of the assessment process for OCD. Early identification of trauma history is vital to ensuring the right diagnosis and treatment pathway. Focusing on the accuracy and effectiveness of brief	The intention is that if features of these conditions are identified in a timely way it may also be easier to differentiate comorbid conditions.  Thank you for your comment. Accuracy and
		College of General Practitioners			026	assessment tools is valuable. In primary care, time constraints necessitate efficient screening methods. The guideline should recommend validated tools suitable for use in primary care settings.	effectiveness of screening tools are no longer addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
67	SH	British Association for Behavioural and Cognitive	Draft scope	003	021	Draft Scope Page 3 Line 21-26  — while accuracy and effectiveness of screening tools is important, we would not expect them to be prioritised over inclusion of related disorders such as illness	Thank you for your comment. Accuracy and effectiveness of screening tools are no longer addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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•					_	Please insert each new comment in a new row	Please respond to each comment
		Psychothera pies – BABCP				anxiety and hoarding if there are time constraints.	
68	SH	Sussex Partnership NHS Foundation Trust	Draft scope	003	021 - 026	Regarding questions 1-3 (assessing the accuracy and effectiveness of brief identification tools) we have the following comments:  It isn't clear why this question is separated out for children/young people (Q1) and adults (Q2) for OCD but not for BDD (Q3), unless there's a good reason for this could this question also be separated into two questions for BDD.  We would suggest rephrasing the questions, in particular it isn't clear what is meant by 'effectiveness' of assessment tools. We would suggest rephrasing to something such as "What is the sensitivity and specificity of brief assessment tools for" as a more precise marker of accuracy (i.e. in order to highlight and allow comparison between measures of false positives and false negatives as this seems most pertinent to the question of accuracy).  We would suggest separating out self-rated assessment tools and clinician-rated assessment tools when	Thank you for your comment. Accuracy and effectiveness of screening tools are no longer addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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						reporting on these questions as self-rated tools (e.g. OCI-R) have advantages in terms of reduced clinician time whereas clinician-rated tools (e.g. YBOCS) may have advantages in terms of improved sensitivity/specificity but are more time-consuming for clinicians.	
						In addition to reporting on sensitivity/specificity, we would suggest reporting on user experience for each reported assessment tool (perhaps seeking feedback from lived experience members on the panel) as some tools are very long and can be particularly challenging for people with OCD (e.g. 42 items on the full OCI). There is perhaps a balance to be struck between sensitivity/specificity and user experience to ensure that the process of completing any brief assessments is a good experience for users.	
69	SH	NHS England	Draft scope	003	021 - 026	<ul> <li>accuracy and effectiveness of screening tools. If you need to cut the scope to make time more related disorders like health anxiety and hoarding disorder, then this section is the least priority</li> </ul>	Thank you for your comment. Accuracy and effectiveness of screening tools are no longer addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
70	SH	South London and	Draft scope	003	021 - 026	Accuracy and effectiveness of screening tools may be considered lower priority. If scope reduction is necessary	Thank you for your comment. Accuracy and effectiveness of screening tools are no longer



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						Please insert each new comment in a new row	Please respond to each comment
		Maudsley NHS Foundation Trust				to include related disorders like health anxiety and hoarding disorder, this section could be considered for de-prioritisation.	addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
71	SH	Orchard OCD	Draft scope	003	021 - 026	Accuracy and effectiveness of screening tools  If you need to cut the scope to make time more related disorders like health anxiety and hoarding disorder then this section is the least priority	Thank you for your comment. Accuracy and effectiveness of screening tools are no longer addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
72	SH	The Body Dysmorphic Disorder Foundation	Draft scope	003	025 - 026	We are pleased screening measures for BDD are across the lifespan are included in draft. We feel for BDD there needs to be an expansion to share how four screening questions (Body Dysmorphic Disorder Questionnaire) can be a starting point across settings and then fuller screening tools could be employed.	Thank you for your comment. Accuracy and effectiveness of screening tools are no longer addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
73	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	003	General	Middle of page - Neuromodulation The draft scope limits further-line neuromodulation to "non-invasive" techniques (e.g., rTMS) and refers Deep Brain Stimulation (DBS) to a separate Interventional Procedures Guidance (IPG693). This is overly restrictive. The scope should be broadened to comprehensively review the evidence for relevant invasive neuromodulation techniques, particularly DBS, integrating with IPG693 to provide holistic clinical	Thank you for your comment. Further line treatment is no longer in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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					_	Please insert each new comment in a new row	Please respond to each comment
						pathway guidance (patient selection, pre- and post- procedure care, long-term management) which an IPG alone does not cover. The guideline should also acknowledge and consider the evidence for emerging "borderline invasive" techniques (e.g., focused ultrasound, radiofrequency ablation) if sufficient data exist. The issue of patients travelling abroad for treatments like DBS underscores the need for clear UK guidance.	
74	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	003	General	Bottom of page - Comorbidities The draft scope lacks explicit focus on integrated treatment strategies for high-frequency comorbidities such as depression, generalized anxiety disorder (GAD), trauma-related disorders, and particularly tic disorders. Relying solely on cross-referral to other guidelines is often insufficient for complex presentations. The scope must include dedicated review questions to develop recommendations for:  Routine assessment of common comorbidities.  Evidence-based strategies for sequencing or integrating treatments for OCD/BDD alongside these comorbidities.  Specific guidance on the OCD-tic disorder overlap is urgently needed due to shared neurobiology, treatment implications (e.g., role of antipsychotics), and the current lack of dedicated NICE guidance for tics.	Thank you for your comment. Assessment and treatment of comorbidities are not areas that are addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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ID	Type	Stakeholder	Document	Page no.	Line no.	Comments	Developer's response
,					_	Please insert each new comment in a new row	Please respond to each comment
						The OCD-Autism Spectrum Disorder (ASD) overlap: While primary ASD management is in other guidelines, the scope should address adaptations and specific considerations for assessing and treating OCD/BDD in individuals with co-occurring ASD who present to OCD/BDD services, as their needs and treatment responses can differ significantly.	
75	SH	Orchard OCD	Draft scope	003	General	Middle of page - Neuromodulation  The draft scope limits further-line neuromodulation to "non-invasive" techniques (e.g., rTMS) and refers Deep Brain Stimulation (DBS) to a separate Interventional Procedures Guidance (IPG693). This is overly restrictive. The scope should be broadened to comprehensively review the evidence for relevant invasive neuromodulation techniques, particularly DBS, integrating with IPG693 to provide holistic clinical pathway guidance (patient selection, pre- and post-procedure care, long-term management) which an IPG alone does not cover.  The guideline should also acknowledge and consider the evidence for emerging non-invasive techniques (e.g., transcranial focused ultrasound) or "borderline invasive (e.g., radiofrequency ablation) if sufficient data exist. The	Thank you for your comment. Further line treatment is no longer in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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						Please insert each new comment in a new row	Please respond to each comment
						issue of patients travelling abroad for treatments like	
						DBS underscores the need for clear UK guidance.	
76	SH	Orchard	Draft scope	003	General	Bottom of page - Comorbidities	Thank you for your comment. Assessment and
		OCD				The draft scope lacks explicit focus on integrated	treatment of comorbid conditions are not areas that
						treatment strategies for high-frequency comorbidities	are addressed in a first batch of the update, please
						such as depression, generalized anxiety disorder (GAD),	see the stakeholder message related to the new
						trauma-related disorders, and particularly tic disorders.	approach NICE is taking for this guideline.
						Relying solely on cross-referral to other guidelines is	
						often insufficient for complex presentations. The scope	
						must include dedicated review questions to develop	
						recommendations for:	
						Routine assessment of common comorbidities.	
						Evidence-based strategies for sequencing or integrating	
						treatments for OCD/BDD alongside these comorbidities.	
						Specific guidance on the OCD-tic disorder overlap is	
						urgently needed due to shared neurobiology, treatment	
						implications (e.g., role of antipsychotics), and the current	
						lack of dedicated NICE guidance for tics.	
						The OCD-Autism Spectrum Disorder (ASD) overlap:	
						While primary ASD management is in other guidelines,	
						the scope should address adaptations and specific	
						considerations for assessing and treating OCD/BDD in	
						individuals with co-occurring ASD who present to	



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						Please insert each new comment in a new row	Please respond to each comment
						OCD/BDD services, as their needs and treatment responses can differ significantly. ASD is extremely common in OCD and is not adequately covered by CG142. This needs to be separately covered in this guideline as it's not just about adaptation – for example separating out ASD from symptoms of OCD and deciding what is to left alone and what is for treatment	
						The overlap between OCD/BDD and Eating disorders: The guideline should explicitly address the overlap with eating disorders, particularly anorexia nervosa, due to their shared psychopathological features and high comorbidity. Individuals with OCD or BDD often present with rigid compulsions, perfectionism, and intrusive thoughts that mirror the obsessive concerns and ritualistic behaviors seen in eating disorders. In anorexia nervosa, for example, compulsive weighing, checking, and strict control over food intake can resemble OCD-like rituals, complicating diagnosis and treatment. On occasion OCD is first diagnosed in specialist eating disorder units – while this is rare, recognizing this overlap is essential for accurate assessment, preventing misdiagnosis, and ensuring that treatment approaches	



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·					_	Please insert each new comment in a new row	Please respond to each comment
						are appropriately adapted to address both sets of	
						symptoms in an integrated manner.	
77	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	003	General	Top of page - Ablative Neurosurgery (Capsulotomy/Cingulotomy): The draft scope omits explicit review of ablative neurosurgical procedures (anterior capsulotomy, anterior cingulotomy). These are established, albeit last-resort, operational pathways within the NHS for severe TR-OCD and were discussed in CG31. We recommend that the scope must include a critical review of the current pathways and evidence (efficacy, safety, patient selection, long-term outcomes, ethical considerations)	Thank you for your comment. Further line treatment is no longer in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
78	SH	Orchard	Draft scope	003	General	for these ablative procedures in the UK context.  Top of page - Ablative Neurosurgery	Thank you for your comment. Further line treatment
	611	OCD	Brait scope	000	Control	(Capsulotomy/Cingulotomy)  The draft scope omits explicit review of ablative neurosurgical procedures (anterior capsulotomy, anterior cingulotomy). These are established, albeit last-resort, operational pathways within the NHS for severe TR-	is no longer in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
						OCD and were discussed in CG31. We recommend that the scope must include a critical review of the current pathways and evidence (efficacy, safety, patient selection, long-term outcomes, ethical considerations) for these ablative procedures in the UK context.	



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79	SH	PTSD UK	Draft scope	004	001	PTSD and OCD frequently co-exist, and this co- occurrence is associated with more severe symptoms, poorer treatment outcomes, and increased distress.  Many people with both conditions may experience intrusive thoughts, hypervigilance, and compulsive behaviours, making it challenging to separate the two without a trauma-informed lens.  It is crucial that the updated guideline acknowledges this overlap and provides specific recommendations on how to assess for, and manage, co-occurring PTSD and OCD.	Thank you for your comment. Assessment and treatment of comorbid conditions are not areas that are addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
80	SH	PTSD UK	Draft scope	004	001	Standard OCD treatments may need adaptation when used with people who have a history of trauma or co-occurring PTSD. In some cases, these interventions can risk re-traumatisation or lead to disengagement from treatment if trauma is not also addressed.  We recommend that the guideline: Includes guidance on adapting psychological interventions to be trauma-informed Encourages a phased or integrated approach where trauma-focused work can be incorporated alongside OCD treatment Highlights the importance of clinician training on how to deliver adapted, sensitive interventions	Thank you for your comment. Assessment and treatment of comorbid conditions are not areas that are addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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81	HS	South London and Maudsley NHS Foundation Trust	Draft scope	004	001 - 003	Consider adding long-term follow-up outcomes (e.g., relapse rates, functional recovery) to all intervention questions to ensure sustainable treatment models are evaluated.	Thank you for your comments. The outcomes referred to in the review questions as well as in the outcome section of the scope are not comprehensive and the list depends on the discussion of the committee and the outcomes they prioritise when the review protocol is finalised. We will raise your comment when this will be discussed.
82	SH	Sussex Partnership NHS Foundation Trust	Draft scope	004	001 - 010	It isn't clear why the evaluation of effectiveness for BDD isn't separated out for children/young people and adults as it is for OCD. If warranted by the evidence, could this be reported separately, or if not warranted, explained when the guideline is published.	Thank you for your comment. The evidence review for BDD is not separated by age based on the limited evidence base that is anticipated for children and young people. If the evidence allows, sensitivity analyses by age will be considered for this review question.
83	SH	Sussex Partnership NHS Foundation Trust	Draft scope	004	001 - 010	When reviewing evidence for the effectiveness of psychological interventions we suggest separating out evidence for and clearly stating whether interventions are delivered by an expert psychological therapist (e.g. CBT therapist, clinical psychologist) or by a psychological practitioner (e.g. a Psychological Wellbeing Practitioner) and drawing out implications of these findings for practice.	Thank you for your comment. Decisions about the categorisation and grouping of interventions will be based on the evidence and the expertise of the guideline committee. When making recommendations, implementation factors will also be taken into account.
84	SH	Sussex Partnership	Draft scope	004	001 - 010	For questions 4-6, in addition to reporting on effectiveness of interventions, we suggest highlighting	Thank you for your comments. Any potential subgroup analyses in the review questions depends



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		NHS Foundation Trust				any moderators of intervention outcome, i.e. if there are certain factors that increase or decrease the likelihood of recovery (e.g. OCD subtype) and any evidence suggesting what can be done to address these factors to improve recovery rates.	on the discussion of the committee and the outcomes they prioritise when the review protocol is finalised. We will raise your comment when this will be discussed.
85	SH	Anglia Ruskin University	Draft scope	004	001 - 010	Top of page - Interventions – the scope should be broader given advances in therapeutic options. Further, explicit consideration of the diverse delivery within the NHS and divergence from recommended therapies in practice given practice constraints, either in content or in form (e.g., digital delivery, average number of sessions in Talking Therapies, lines 5-10).	Thank you for your comment. The list of interventions included in the scope is not an exhaustive list. Review protocols are being developed with the guideline committee and the range of interventions for which RCT evidence will be searched, is fairly broad, including digital interventions, intensive short-term CBT, and third-wave cognitive behavioural therapies
86	SH	Sussex Partnership NHS Foundation Trust	Draft scope	004	001 - 010	We suggest including a separate review of evidence evaluating the effectiveness of interventions involving family and friends in interventions for OCD and BDD.	Thank you for your comment. Review protocols for the OCD and BDD treatment review questions are being developed with the guideline committee and the range of interventions for which RCT evidence will be searched includes family-based interventions and systemic therapy, and parent training.
87	SH	Sussex Partnership NHS	Draft scope	004	001 - 015	We would welcome if the final guideline could explicitly recommend against offering interventions as a first-line treatment that are found to lack sufficient evidence for superiority or non-inferiority over well-established	Thank you for your comment. It is anticipated that the OCD and BDD treatment review questions will be addressed using network meta-analyses (NMAs). This will allow the update to examine the



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#### 08/05/2025 to 06/06/2025

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						Please insert each new comment in a new row	Please respond to each comment
		Foundation Trust				evidence-based interventions, even if they have some evidence for effectiveness in comparison to, for example, treatment as usual. This is because whilst such interventions may be more effective than notreatment, they could be less effective than the best treatments. We feel that recommending against such treatments as first line interventions would ensure that people living with OCD are offered the interventions with the best evidence for effectiveness first.  We would of course welcome the final guideline explicitly recommending against any interventions that are found to lack sufficient evidence for effectiveness (i.e. not just recommending what should be made available to people living with OCD, but also recommending what shouldn't routinely be made available).	relative effectiveness of different interventions.  NMAs have the advantage of combining evidence from RCTs on multiple interventions in connected networks and providing internally coherent estimates of relative intervention effectiveness for any pair of interventions in the network including compared to a common reference condition. This should address your concern as we should be able to rank the interventions in order of effectiveness and to recommend the best treatment. The committee may make recommendations against an intervention if: potential harms outweigh potential benefits; good quality evidence shows lack of effectiveness; there is limited, low quality or uncertain evidence of effectiveness; there is no reasonable prospect of cost-effectiveness; or there are safety concerns.
88	SH	Maternal OCD	Draft scope	004	007	Add 'including parents' to be in line with page 3 lines 7 & 8	Thank you for your comment. This update will include a qualitative review on accessing and engaging with treatment which will include the perspective of parents and carers. However, the focus of that review will be on understanding the facilitators and barriers to accessing and engaging with treatment for the person with OCD and BDD.



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						Please insert each new comment in a new row	Please respond to each comment
							Review protocols for the OCD and BDD treatment review questions are being developed with the guideline committee and the range of interventions for which RCT evidence will be searched includes family-based interventions and systemic therapy, and parent training. However, the outcomes for the OCD and BDD treatment review questions will not include parent outcomes so it was not considered appropriate to make the suggested change.
89	SH	South London and Maudsley NHS Foundation Trust	Draft scope	004	012 - 015	Encourage clearer breakdown of augmentation strategies for treatment-resistant OCD (e.g. SSRIs with antipsychotics). The review should specify dose ranges, duration thresholds, and safety/tolerability differences from schizophrenia treatment contexts.	Thank you for your comment. Further-line treatment is no longer in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
90	SH	Anglia Ruskin University	Draft scope	004	016	Accessing and engagement with treatment – as encompassing both child and adolescent and adult treatment, include treatment recommendations when shifting from one to the other. Complementary research evidence indicates a drop in access at this nexus point.	Thank you for your comment. This review question will examine the qualitative experience of accessing and engaging with treatment. Barriers including breakdown in continuity of care when moving from child to adult services may emerge as a theme from this analysis, but it was not considered appropriate to add this to the review question.



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91	SH	Sussex Partnership NHS Foundation Trust	Draft scope	004	016 - 018	We welcome question 8 "What works well, and what could be improved, in terms of accessing and engaging with treatment for OCD and BDD?". In our experience this is a critical question. We suggest that particular attention is paid to any specific barriers to accessing and engaging with treatment for people from under-served communities or other groups who may struggle to access and/or engage with treatment for practical reasons (e.g. mothers with young children).	Thank you for your comment in support of the inclusion of this topic.
92	SH	University of Edinburgh - Neurodiverg ent and Learning Disabilities Research Group	Draft scope	004	016 - 018	Engaging with treatment –  The therapeutic relationship is very important for the success of treatment (irrespective of what intervention is being delivered). Therefore if a patient appears not to be engaging with treatment, it may be beneficial to transfer them to a different therapist. It is important to be aware that disengagement from therapy could be due to a range of factors, not just the patient themselves.	Thank you for your comment. This review question will examine the qualitative experience of accessing and engaging with treatment. Themes around the therapeutic relationship in the context of engaging with treatment may emerge from this analysis, but it was not considered appropriate to add this to the review question.
93	SH	Surrey and Borders Partnership NHS Foundation Trust	Draft scope	004 - 005	016, 003 - 004	Concerning either Accessing and engaging with or Main outcomes for this update around response to treatment and discontinuation, I think that 'Review of clinical priority' is something that is very important to me as a Practitioner Psychologist working with OCD. Quite often we see that OCD symptoms may be a displacement of	Thank you for your comment. Recognition and assessment of OCD and BDD will be covered as part of this update, and it is anticipated that this will include consideration of differential diagnosis and coexisting conditions. This update will cross-refer to relevant NICE guidance where appropriate.



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						underlying Generalised Anxiety and focusing on OCD symptoms may only have temporary effectiveness. Quite often people can re-present quite quickly with a different combination of compulsions or obsessive thoughts after an initial treatment of OCD. Reviewing the clinical priority and instead treating generalised anxiety or using a metacognitive therapy model for OCD has then often been an effective tack.	
94	SH	PTSD UK	Draft scope	004	017	People with co-occurring trauma and OCD symptoms often struggle to access appropriate support, especially when services focus on only one condition. We would welcome the inclusion of recommendations on how to improve access to joined-up care, and how services can better support engagement when trauma has impacted trust, safety, or capacity to participate in therapy.	Thank you for your comment. Assessment and treatment of comorbid conditions are not areas that are addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
95	SH	NIHR Applied Research Collaboration (ARC) North Thames	Draft scope	004	017	Accessing and engagement with treatment  The author would like to draw the reviewers attention to the current inaccessibility of treatment for people with BDD:  Currently in the UK, BDD is treated with CBT (with Exposure and Response Prevention) largely from general mental health primary care services, such as 'Talking Therapies' services (formerly known as	Thank you for your comment and for drawing our attention to this evidence. This review question will examine the qualitative experience of accessing and engaging with treatment and will include experiences of people with BDD if there is available eligible evidence. When making recommendations, the committee will consider the evidence together with their clinical and lived experience and will also take implementation factors into account.



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						'Improving Access to Psychological Therapies (IAPT)'). However, in 'Talking Therapies' services, training for BDD is stated as 'optional' in the training curriculum (NHS England & IAPT, 2019). These inconsistencies in training can lead to disparities in care and service provision, resulting in people falling through the gaps between IAPT and secondary care – often deemed too complex for IAPT services, but without the 'severe mental illness (SMI)' diagnosis needed to access secondary care services (BDD Foundation, 2022). As people with BDD become more chronic and severe, demand for under-resourced tertiary services increases, For example, at the point when people do access the consortium of national specialist services, approximately 67.5% of patient with BDD would have received treatment for a misdiagnosed anxiety disorder (BDD Foundation, 2022; Krebs et al., 2023).	
96	SH	Maternal OCD	Draft scope	004	017 - 018	Be explicit so it states for all patients i.e. adults (inc parents) children and young people	Thank you for your comment. This qualitative review on accessing and engaging with treatment will include the perspective of parents and carers. However, the focus will be on understanding the facilitators and barriers to accessing and engaging with treatment for the person with OCD and BDD. For this reason, it was not considered appropriate to add parents to this review question. This review



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							will include evidence from children and young people, and adults, where available. The draft questions in the scope will be used to develop detailed review plans (protocols) which will make explicit the population included in the review.
97	SH	South London and Maudsley NHS Foundation Trust	Draft scope	004	017 - 018	Add a draft review question on the experience of people with taboo-themed OCD (e.g. paedophile OCD, sexual orientation fears), with specific consideration of safeguarding misinterpretation. This group faces distinct access barriers due to stigma and clinician discomfort.	Thank you for your comment. The review protocol (detailed review plan) for the experience of accessing and engaging with treatment is being developed with the guideline committee. Formal subgroup analyses are not appropriate for this question due to qualitative data, but it is anticipated that where evidence allows, similarities and differences in views and experiences based on OCD subtype (including taboo-related) will be explored.
98	SH	Maternal OCD	Draft scope	004	026	Include prevention and relapse prevention as part of the main outcomes of the update to help prevent suffering further along the treatment pathway	Thank you for your comment. Relapse prevention is not an area to be addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
99	SH	Hertfordshire Partnership	Draft scope	004	General	Top of page - Psychological Therapies The draft scope's examples ("ERP, and CBT with ERP")	Thank you for your comment. The list of interventions included in the scope is not an



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		University NHS foundation trust - OCD/BDS National Service				are foundational but too narrow, not reflecting the evolution of psychological treatments. We recommend that the scope should explicitly include reviewing evidence for:  Digitally-enhanced CBT (dCBT): Internet-delivered, app-based interventions, and virtual reality exposure, which have significantly advanced since 2005.  Adaptations and Adjuncts to CBT/ERP: Such as Acceptance and Commitment Therapy (ACT) principles, mindfulness-based interventions, schema-informed approaches, and imagery rescripting, particularly for engagement, emotion regulation, or specific presentations.  Other Specific Therapies: Habit Reversal Training (HRT) for tic-related compulsions, body-focused repetitive behaviours (often comorbid or overlapping); Danger Ideation Reduction Therapy (DIRT) for specific OCD presentations.  The guideline should address the practicalities of delivering effective ERP, acknowledging it is not a "one-size-fits-all" approach and requires skilled adaptation.	exhaustive list. Review protocols are being developed with the guideline committee and the range of interventions for which RCT evidence will be searched, is fairly broad, including digital interventions, and third-wave cognitive behavioural therapies.
100	SH	Hertfordshire Partnership University NHS	Draft scope	004	General	Middle of page - Pharmacological Treatments While SSRIs and clomipramine are mentioned, additional detail is needed for complex scenarios. The scope should include a detailed review of:	Thank you for your comment. Further-line treatment is no longer in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.



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		foundation trust - OCD/BDS National Service				Evidence-based augmentation strategies for TR-OCD (e.g., specific atypical antipsychotics, glutamatergic agents if evidence matures).  Optimal medication switching strategies.  Specific guidance on medication discontinuation in OCD/BDD, considering higher relapse risks and the role of concurrent psychological therapy, beyond general antidepressant withdrawal advice.	
101	SH	Orchard OCD	Draft scope	004	General	Top of page - Psychological Therapies  The draft scope's examples ("ERP, and CBT with ERP") are foundational but too narrow, not reflecting the evolution of psychological treatments. We recommend that the scope should explicitly include reviewing evidence for:  Digitally-enhanced CBT (dCBT): Internet-delivered, appbased interventions, and virtual reality exposure, which have significantly advanced since 2005.  Adaptations and Adjuncts to CBT/ERP: Such as Acceptance and Commitment Therapy (ACT) principles, mindfulness-based interventions, schema-informed approaches, and imagery rescripting, particularly for engagement, emotion regulation, or specific presentations.  Other Specific Therapies: Habit Reversal Training (HRT)	Thank you for your comment. The list of interventions included in the scope is not an exhaustive list. Review protocols are being developed with the guideline committee and the range of interventions for which RCT evidence will be searched, is fairly broad, including digital interventions, and third-wave cognitive behavioural therapies



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						for tic-related compulsions, body-focused repetitive behaviours (often comorbid or overlapping); Danger Ideation Reduction Therapy (DIRT) for specific OCD presentations.  The guideline should address the practicalities of delivering effective ERP, acknowledging it is not a "one-size-fits-all" approach and requires skilled adaptation.	
102	SH	Orchard OCD	Draft scope	004	General	Middle of page - Pharmacological Treatments While SSRIs and clomipramine are mentioned, additional detail is needed for complex scenarios. The scope should include a detailed review of: Evidence-based augmentation strategies for TR-OCD (e.g., specific atypical antipsychotics, glutamatergic agents if evidence matures). Optimal medication switching strategies. Specific guidance on medication discontinuation in OCD/BDD, considering higher relapse risks and the role of concurrent psychological therapy, beyond general antidepressant withdrawal advice.	Thank you for your comment. Further-line treatment is no longer in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
103	SH	Hertfordshire Partnership University NHS foundation trust -	Draft scope	004 - 005	General	Bottom of page 4, leading into page 5 - "Off-Label" Prescribing The draft scope notes: "guideline recommendations for medicines will normally fall within licensed indications; exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended"	Thank you for your comment. The guideline systematic reviews will consider off-label medications. Recommendations will be informed by the findings of the clinical and economic reviews and the guideline economic analyses. Available evidence on the clinical and cost effectiveness for



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ID	Туре	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
•	'			J	_	Please insert each new comment in a new row	Please respond to each comment
		OCD/BDS National Service				(NICE, 2025, draft scope, p. 4). This is standard. However, as highlighted in expert discussions, much of the pharmacological treatment for OCD/BDD, especially in children and adolescents, and many augmentation strategies in adults, are "off-label." The guideline update must grapple with this reality transparently and provide clear, evidence-based recommendations even for off-label use where the evidence supports it and it represents established best practice, rather than shying away from it. This is critical for child and adolescent populations.	licensed medications will be considered alongside respective evidence for off-label medications when updating recommendations.
104	SH	Orchard OCD	Draft scope	004 - 005	General	Bottom of page 4, leading into page 5 - "Off-Label" Prescribing The draft scope notes: "guideline recommendations for medicines will normally fall within licensed indications; exceptionally, and only if clearly supported by evidence, use outside a licensed indication may be recommended" (NICE, 2025, draft scope, p. 4). This is standard. However, as highlighted in expert discussions, much of the pharmacological treatment for OCD/BDD, especially in children and adolescents, and many augmentation strategies in adults, are "off-label." The guideline update must grapple with this reality transparently and provide clear, evidence-based recommendations even for off-label use where the evidence supports it and it	Thank you for your comment. The guideline systematic reviews will consider off-label medications. Recommendations will be informed by the findings of the clinical and economic reviews and the guideline economic analyses. Available evidence on the clinical and cost effectiveness for licensed medications will be considered alongside respective evidence for off-label medications when updating recommendations.



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						represents established best practice, rather than shying away from it. This is critical for child and adolescent populations.	
105	SH	NICE - Medicines Optimisation Team	Draft scope	005	001 - 008	Should 'adverse events' and 'withdrawal effects' be listed as outcomes? I can see that discontinuation due to adverse events is listed, but not adverse events alone. Withdrawal effects can be an issue with SSRIs and so it could be relevant to consider these in the outcomes	Thank you for your comment. Withdrawal effects are indeed an issue with SSRIs. NICE has already published guidance on safe prescribing and withdrawal management relating to antidepressants, see NG215 (Medicines associated with dependence or withdrawal symptoms). This guidance is also relevant to the OCD guideline, therefore no new reviews will be conducted on this issue. The OCD updated guideline may cross-refer to the NG215 guideline, if this is considered appropriate and relevant by the committee.
106	SH	NICE - Medicines Optimisation Team	Draft scope	005	001 - 008	The scope for depression (NG222) contains outcomes that may be relevant for this scope such as adaptive functioning (for example, employment, social functioning, ability to carry out activities of daily living and quality of life), and carer wellbeing. Do these need adding?	Thank you for your comment. Although we acknowledge that these outcomes are very important, our experience is that they are not consistently reported in the literature compared with, for example, change in symptom severity or discontinuation (for any reason or due to side effects) following treatment, and for this reason they are not particularly informative when assessing the relative clinical effectiveness across treatments of interest. For this reason they have not been



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							considered as outcomes of the review questions covered in this batch, although such issues will be considered by the committee when updating recommendations.
107	SH	NICE - Medicines Optimisation Team	Draft scope	005	001 - 008	As there is a potential increased risk of suicidal thoughts and self-harm in children, young people and young adults using SSRIs (especially in the early stages of treatment), should the outcome of mortality (including all-cause and suicide) be included as an outcome as it has been in the depression (NG222 scope)?	Thank you for your comment. Although consideration of mortality is crucial when making recommendations, it is rarely reported in RCTs and, where reported, it is a rare event that is usually less informative in guiding treatment recommendations on its own. For this reason it was also not an outcome included in the Depression guideline treatment reviews, although issues around mortality were considered by the Depression guideline committee when making recommendations. The Depression guideline has made cross-reference to the NICE guideline on self-harm and has also included recommendations on antidepressant medication for people at risk of suicide, which acknowledge the possible increased prevalence of suicidal thoughts, self-harm and suicide in the early stages of antidepressant treatment. The OCD guideline committee will consider the issues around mortality relevant to this population and may cross-



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							refer to relevant NICE recommendations, where appropriate.
108	SH	OCD Action	Draft scope	005	001 - 008	We would ask that strong consideration is given to the inclusion of prevention and early intervention, as well as relapse prevention as part of the main outcomes of the update to help prevent significant suffering further along the treatment pathway.  This is key as at OCD Action a significant number of the people we work with experience relapse and there is notable data that indicates that many of the people who have OCD have waited on average 7 years between onset of symptoms and access to treatment (Robinson et al, 2017), highlighting how many years of suffering could be prevented by earlier identification of OCD and BDD.	Thank you for your comment. Prevention and relapse prevention are not in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
109	SH	EMDR UK Association	Draft scope	005	004 - 007	Acceptability of treatment is key. Discontinuation is not an ideal proxy for acceptability, so it may also be covered by the experience of care outcome. However, we recommend that it is critical for service users and therefore should be listed as a distinct outcome.	Thank you for your comment. We agree that acceptability of treatment is key. Issues on acceptability will be covered in the question covering access and engagement with treatment.
110	SH	NHS England	Draft scope	005	006	- Experience of care from the perspective of service users This needs to include experience of care in Paedophile	Thank you for your suggestion, the committee will consider relevant issues around risk assessment for people with OCD when updating recommendations.



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						Please insert each new comment in a new row	Please respond to each comment
						OCD and stronger recommendations on not referring to Safeguarding	
111	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	Draft scope	005	006	Draft Scope Page 5. Line 6. Experience of care from the perspective of service users It is particularly important that the experience of care includes overtly and specifically the experience of care in in people who have Paedophile OCD or other violence or sexual content related OCD which can trigger safeguarding concerns  — there should be clear recommendations and guidance for clinicians on understanding how this relates to actual (and lack of) risk and there need to be careful, evidence-based decision-making processes to follow in relation to these forms of OCD- in order to ensure appropriate risk and safety management, and decisions on whether a referral to Safeguarding is in fact indicated.	Thank you for your comment, the review questions on experience of care will be broad enough to cover evidence from the whole population of people with OCD. Relevant issues around risk assessment will be considered by the committee when updating recommendations.
112	SH	South London and Maudsley NHS Foundation Trust	Draft scope	005	006	The section on service user experience must include those with Paedophile OCD, with stronger recommendations on not making automatic safeguarding referrals in such cases where risk is not present.	Thank you for your comment, the review questions on experience of care will be broad enough to cover evidence from the whole population of people with OCD. Relevant issues around risk assessment will be considered by the committee when updating recommendations.



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113	SH	South London and Maudsley NHS Foundation Trust	Draft scope	005	006	Request that 'experience of care' outcomes include the perspective of young people and neurodivergent individuals, who may interpret therapeutic alliance, flexibility, and autonomy differently from neurotypical adults.	Thank you for your suggestion. These perspectives will be considered when reviewing access and engagement with treatment of people with OCD and BDD.
114	SH	Orchard OCD	Draft scope	005	006	Experience of care from the perspective of service users  This needs to include experience of care in Paedophile OCD and stronger recommendations on not referring to Safeguarding	Thank you for your suggestion, the committee will consider relevant issues around risk assessment for people with OCD when updating recommendations.
115	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	005	General	Top of page - Long term follow up The draft scope mentions "longer-term follow-up" but lacks an explicit focus on proactive long-term management models, reflecting the often chronic or relapsing nature of OCD/BDD. The scope must include dedicated review questions to develop recommendations on: Models of long-term recovery and stepped-down care. Evidence-based relapse prevention strategies (psychological, pharmacological, self-management). Recognizing OCD/BDD as conditions that may require lifelong management or accessible re-entry into services for many.	Thank you for your comment. Models of long-term recovery, relapse prevention and lifelong management are not areas covered in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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116	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	005	General	Middle of page - Family, Carer Involvement, and Culturally Competent Care While "experience of care" is an outcome, proactive strategies are not scoped for review. The scope must include review questions to develop actionable recommendations on how to effectively involve and support families/carers, and how to ensure culturally sensitive and competent assessment and treatment adaptations.	Thank you for your comment. The committee will consider inclusion of issues around family involvement and support as well as cultural issues when developing review questions around experience of care and when updating relevant recommendations.
117	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	005	General	Middle of page - Suicidality No specific review question on this critical issue which has undergone a major update of evidence base since 2005. Given the significantly elevated risk of suicidal ideation and attempts, particularly in BDD and severe OCD, the scope must include developing specific guidance on routine screening, comprehensive risk assessment protocols tailored to these conditions, and evidence-based management strategies for those at risk.	Thank you for your comment. These issues will be considered when updating recommendations around risk assessment. The guideline may also cross-reference the recently updated guideline on self-harm (NG225) if this is considered appropriate and relevant.
118	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS	Draft scope	005	General	Bottom of page - Disability Assessment and Functional Outcomes Focus is on symptom tools; disability assessment tools are absent. The scope should include guidance on using standardized tools to assess functional disability (e.g., WHODAS 2.0, specific OCD/BDD functional scales) to inform holistic care, measure broader recovery, and	Thank you for your comment. This section describes outcomes that will be assessed in the guideline, as part of the evidence base. Although we acknowledge that functional outcomes are very important, our experience is that they are not consistently reported in the literature compared with change in symptom severity following treatment,



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		National Service				support access to wider disability/social support services.	therefore they are not particularly informative when assessing the relative clinical effectiveness across treatments of interest. For this reason, they have not been considered as outcomes of the review questions covered in this batch, although issues around functional disability will be considered when updating recommendations. Guidance on the use of tools to routinely assess functional disability was not part of the previous guideline and is not part of the current scope, which partially updates the previous guideline, either.
119	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	005	General	Bottom of page - Standardization of Outcome Measures The guideline should explicitly recommend a core set of validated outcome measures for routine use in both clinical practice and research, encompassing symptoms, function, quality of life, and patient-reported experiences, to improve consistency and data quality.	Thank you for your comment. Assessment tools which can also be used to measure outcomes was a topic in the consultation version of the guideline but is no longer included as an area to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.
120	SH	Orchard OCD	Draft scope	005	General	Top of page - Long term follow up  The draft scope mentions "longer-term follow-up" but lacks an explicit focus on proactive long-term	Thank you for your comment. Models of long-term recovery, relapse prevention and lifelong management are not areas covered in a first batch of the update, please see the stakeholder message



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						management models, reflecting the often chronic or relapsing nature of OCD/BDD. The scope must include dedicated review questions to develop recommendations on:  Models of long-term recovery and stepped-down care.  Evidence-based relapse prevention strategies (psychological, pharmacological, self-management).  Recognizing OCD/BDD as conditions that may require lifelong management or accessible re-entry into services for many.	related to the new approach NICE is taking for this guideline.
121	SH	Orchard OCD	Draft scope	005	General	Middle of page - Family, Carer Involvement, and Culturally Competent Care While "experience of care" is an outcome, proactive strategies are not scoped for review. The scope must include review questions to develop actionable recommendations on how to effectively involve and support families/carers, and how to ensure culturally sensitive and competent assessment and treatment adaptations.	Thank you for your comment. The committee will consider inclusion of issues around family involvement and support as well as cultural issues when developing review questions around experience of care and when updating relevant recommendations.
122	SH	Orchard OCD	Draft scope	005	General	Middle of page - Suicidality  No specific review question on this critical issue which has undergone a major update of evidence base since 2005. Given the significantly elevated risk of suicidal ideation and attempts, particularly in BDD and severe	Thank you for your comment. These issues will be considered when updating recommendations around risk assessment. The guideline may also cross-reference the recently updated guideline on <a href="mailto:self-harm">self-harm</a> (NG225) if this is considered appropriate and relevant.



## Consultation on draft scope Stakeholder comments table

#### 08/05/2025 to 06/06/2025

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ID	Type	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
						Please insert each new comment in a new row	Please respond to each comment
100						OCD, the scope must include developing specific guidance on routine screening, comprehensive risk assessment protocols tailored to these conditions, and evidence-based management strategies for those at risk.	
123	SH	Orchard OCD	Draft scope	005	General	Bottom of page - Disability Assessment and Functional Outcomes Focus is on symptom tools; disability assessment tools are absent. The scope should include guidance on using standardized tools to assess functional disability (e.g., WHODAS 2.0, specific OCD/BDD functional scales) to inform holistic care, measure broader recovery, and support access to wider disability/social support services.	Thank you for your comment. This section describes outcomes that will be assessed in the guideline, as part of the evidence base. Although we acknowledge that functional outcomes are very important, our experience is that they are not consistently reported in the literature compared with change in symptom severity following treatment, therefore they are not particularly informative when assessing the relative clinical effectiveness across treatments of interest. For this reason they have not been considered as outcomes of the review questions covered in this batch, although issues around functional disability will be considered when updating recommendations. Guidance on the use of tools to routinely assess functional disability was not part of the previous guideline and is not part of the current scope, which partially updates the previous guideline, either.



## Consultation on draft scope Stakeholder comments table

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ID	Type	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
						Please insert each new comment in a new row	Please respond to each comment
124	HS	Orchard OCD	Draft scope	005	General	Bottom of page - Standardization of Outcome Measures The guideline should explicitly recommend a core set of validated outcome measures for routine use in both clinical practice and research, encompassing symptoms, function, quality of life, and patient-reported experiences, to improve consistency and data quality.	Thank you for your comment. Assessment tools which can also be used to measure outcomes was a topic in the consultation version of the guideline but is no longer included as an area to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.
125	SH	The Body Dysmorphic Disorder Foundation	Draft scope	006	008 - 010	We feel there needs to be further details of how an exposure-based treatment is augmented for BDD with other techniques to address high levels of shame, poor insight and trauma including motivational interviewing, compassion focussed therapy and imagery rescripting.	Thank you for your comment. Available evidence of treatments for people with BDD and any required adjustments will be reviewed and considered by the committee when updating recommendations for this population.
126	SH	The Body Dysmorphic Disorder Foundation	Draft scope	006	008 - 010	It is important to highlight that with BDD there are high levels of risk in terms of suicidality, self-harm and substance misuse and how that is considered when embarking on treatment.	Thank you for your comment. These issues will be considered when updating treatment recommendations. Cross references to respective NICE guidelines will be made, as appropriate and relevant.
127	SH	The Body Dysmorphic Disorder Foundation	Draft scope	006	008 - 010	We would also like to see treatments for young people and adults separated out in BDD as we now have more evidence across the lifespan for psychological interventions.	Thank you for your suggestion. We will consider treatments for children, young people and adults with BDD and do separate analyses by age group if availability of data permits.



## Consultation on draft scope Stakeholder comments table

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ID	Type	Stakeholder	Document	Page no.	Line no.	Comments	Developer's response
				· ·	_	Please insert each new comment in a new row	Please respond to each comment
128	SH	The Body Dysmorphic Disorder Foundation	Draft scope	006	016 - 018	We believe in the section of what works well and what could be improved in terms of accessing and engaging for treatment for OCD and BDD, it is vital these conditions are separated. There are unique challenges to people with BDD access mental health support, including poorer insight, seeking cosmetic remedies, misdiagnosis of they are in mental health services and treatments for BDD not being as available outside of specialist services. The stepped approach is not the same for BDD as it is for OCD e.g. CY-IAPT does not teach on BDD, clinicians in secondary mental health services are not trained in BDD.	Thank you for your comment. Views and experiences of people with OCD or BDD, their parents, family or carers, and healthcare professionals involved in their care will be considered separately by diagnosis (OCD or BDD).
129	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	006, 007, 008	General	Bottom of page 6 continuing onto pages 7 and 8 - Comments on Draft Review Questions The eight draft review questions provided in the scope document (NICE, 2025, draft scope, pp. 3-4) are a starting point but require refinement and expansion to address the gaps identified: Questions 1, 2, 3 (Assessment Tools): While important, limiting the review to "brief assessment tools" may be too narrow. The guideline should also consider comprehensive assessment strategies for confirming diagnosis and informing treatment planning across the full population, not just initial identification. Questions 4, 5, 6 (Effectiveness of Interventions): These	Thank you for your comment. Further-line treatment is no longer in a first batch of the update nor have any further areas been added, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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#### 08/05/2025 to 06/06/2025

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						Please insert each new comment in a new row	Please respond to each comment
						are core but need to be broken down further to reflect	
						the breadth of psychological, pharmacological, and	
						combination interventions discussed above (e.g.,	
						different types of psychological therapies, dCBT, specific	
						augmentation strategies, neuromodulation). "Longer-	
						term follow-up" must be robustly defined.	
						Question 7 (Further-line Treatment): This is critical but,	
						as noted, must expand beyond "non-invasive	
						neuromodulation" to include ablative surgery and	
						invasive neuromodulation like DBS. "Switching and	
						augmentation strategies" needs detailed exploration of	
						specific options.	
						Question 8 (Accessing and Engaging): A good question,	
						but ensure it covers all severity levels and diverse	
						populations.	
						Missing Review Questions (Examples based on	
						critique):	
						What are the optimal criteria for defining Treatment-	
						Resistant OCD (TR-OCD)?	
						What is the efficacy and safety of [specific ablative	
						procedure, e.g., anterior capsulotomy] for TR-OCD in	
						adults?	
						What is the efficacy and safety of Deep Brain	
						Stimulation for TR-OCD in adults?	
						What are the optimal patient selection and care	



## Consultation on draft scope Stakeholder comments table

#### 08/05/2025 to 06/06/2025

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ID	Type	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
						Please insert each new comment in a new row	Please respond to each comment
						pathways? What are effective strategies for managing [specific comorbidity, e.g., tic disorders/depression] in individuals with OCD/BDD? What is the effectiveness of [specific psychological therapy, e.g., ACT-informed ERP/dCBT/HRT] for OCD/BDD? What are effective long-term management and relapse prevention strategies for individuals with OCD/BDD following initial treatment response? How can assessment and treatment for OCD/BDD be best adapted for [specific diverse group, e.g., individuals with co-occurring ASD/specific cultural groups]? What are effective methods for assessing and managing suicidality in individuals with OCD/BDD? The update to the NICE OCD/BDD guideline is a vital opportunity to ensure that clinical practice in the UK reflects the substantial progress made in understanding and treating these complex disorders in the past two decades. While the initial draft scope provides a basic framework, it currently falls short of the breadth and depth required to address the multifaceted nature of OCD and BDD, the diversity of patient needs, and the full spectrum of evidence-based and emerging interventions.	



## Consultation on draft scope Stakeholder comments table

#### 08/05/2025 to 06/06/2025

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ID	Type	Stakeholder	Document	Page no.	Line no.	Comments	Developer's response
•	, ,			ŭ	_	Please insert each new comment in a new row	Please respond to each comment
130	SH	Orchard OCD	Draft scope	006, 007, 008	General	Comments on Draft Review Questions  The eight draft review questions provided in the scope document (NICE, 2025, draft scope, pp. 3-4) are a starting point but require refinement and expansion to address the gaps identified:  Questions 1, 2, 3 (Assessment Tools): While important, limiting the review to "brief assessment tools" may be too narrow. The guideline should also consider comprehensive assessment strategies for confirming diagnosis and informing treatment planning across the full population, not just initial identification.  Questions 4, 5, 6 (Effectiveness of Interventions): These are core but need to be broken down further to reflect the breadth of psychological, pharmacological, and combination interventions discussed above (e.g., different types of psychological therapies, dCBT, specific augmentation strategies, neuromodulation). "Longerterm follow-up" must be robustly defined.  Question 7 (Further-line Treatment): This is critical but, as noted, must expand beyond "non-invasive neuromodulation" to include ablative surgery and invasive neuromodulation like DBS. "Switching and augmentation strategies" needs detailed exploration of specific options.	Thank you for your comment. Further-line treatment is no longer in a first batch of the update nor have any further areas been added, please see the stakeholder message related to the new approach NICE is taking for this guideline.



## Consultation on draft scope Stakeholder comments table

#### 08/05/2025 to 06/06/2025

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·				•	1	Please insert each new comment in a new row	Please respond to each comment
						Question 8 (Accessing and Engaging): A good question,	
						but ensure it covers all severity levels and diverse	
						populations.	
						Missing Review Questions (Examples based on	
						critique):	
						What are the optimal criteria for defining Treatment-	
						Resistant OCD (TR-OCD)?	
						What is the efficacy and safety of [specific ablative	
						procedure, e.g., anterior capsulotomy] for TR-OCD in	
						adults?	
						What is the efficacy and safety of Deep Brain	
						Stimulation for TR-OCD in adults?	
						What are the optimal patient selection and care	
						pathways?	
						What are effective strategies for managing [specific	
						comorbidity, e.g., tic disorders/depression] in individuals	
						with OCD/BDD?	
						What is the effectiveness of [specific psychological	
						therapy, e.g., ACT-informed ERP/dCBT/HRT] for	
						OCD/BDD?	
						What are effective long-term management and relapse	
						prevention strategies for individuals with OCD/BDD	
						following initial treatment response?	
						How can assessment and treatment for OCD/BDD be	
						best adapted for [specific diverse group, e.g., individuals	



# Consultation on draft scope Stakeholder comments table

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ID	Type	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
·						Please insert each new comment in a new row	Please respond to each comment
						with co-occurring ASD/specific cultural groups]? What are effective methods for assessing and managing suicidality in individuals with OCD/BDD?	
						The update to the NICE OCD/BDD guideline is a vital opportunity to ensure that clinical practice in the UK reflects the substantial progress made in understanding and treating these complex disorders in the past two decades. While the initial draft scope provides a basic framework, it currently falls short of the breadth and depth required to address the multifaceted nature of OCD and BDD, the diversity of patient needs, and the full spectrum of evidence-based and emerging interventions.	
131	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	006	General	Top of page - Early Detection, Under Detection, Clinician Awareness, and Stepped Care Pathways "Recognition and assessment" is included, but a more proactive focus on overcoming under-detection is needed. The draft mentions stepped care but has not explicitly proposed an in-depth review of stepped care pathway review is proposed which is vital to incorporate learning from operational use of such pathways for 20 years. The scope should aim to develop recommendations for:  Proactive screening and awareness-raising strategies	Thank you for your comment. The committee will consider the issues you raise when updating recommendations. Interventions for patients who have not responded to previous treatment will not be considered in this update batch, but may be considered in a future batch of the guideline update.



## Consultation on draft scope Stakeholder comments table

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ID	Туре	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
						Please insert each new comment in a new row	Please respond to each comment
						for frontline clinicians (GPs, school staff, dermatologists, pediatricians). Clearer, more detailed care pathways that operationalize the stepped-care model across different service tiers and severities, including criteria for stepping up/down and introducing a newer step for exceptional interventions (Step 7) for multi-treatment resistant patients who have not achieved response to Step 6 interventions.	
132	SH	Hertfordshire Partnership University NHS foundation trust - OCD/BDS National Service	Draft scope	006	General	Middle of page - Intensive Care Settings Intensive/inpatient/residential care and intensive home- based treatment are not explicitly singled out for detailed review. The scope should include a dedicated review of indications, characteristics, minimum standards, and integration of specialized intensive services (inpatient, residential, and intensive home-based treatment via CMHTs or specialist outreach).	Thank you for your comment. Although it is acknowledged that this level of care has a crucial role in the management of people with more severe OCD and BDD, it will not be covered at this batch of the guideline update, which aims to cover interventions and care pathways for a broader population of people with OCD and BDD.  Nevertheless, issues around criteria for referral to specialist care may be considered by the committee when making recommendations, as appropriate.
133	SH	Hertfordshire Partnership University NHS foundation	Draft scope	006	General	Middle of page - Broader Public Health and Societal Issues Areas like stigma, very early (preventative) interventions, body image awareness campaigns, and school liaison are important. The scope should consider including	Thank you for your comment. This is a clinical guideline, therefore it will not cover areas related to public health, for example body image awareness campaigns. As stated, the guideline will cover any health, mental health and social care settings in



## Consultation on draft scope Stakeholder comments table

#### 08/05/2025 to 06/06/2025

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ID	Type	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
					_	Please insert each new comment in a new row	Please respond to each comment
		trust - OCD/BDS National Service				principles or recommendations relating to: Guideline language and dissemination strategies that actively combat stigma. The role of services in promoting positive body image and media literacy (especially for BDD). Supporting educational institutions in identifying and appropriately supporting students with OCD/BDD.	which NHS care or social care is received or commissioned. Primary prevention will also not be covered, although secondary prevention (i.e. prevention of relapse) may be considered in a future batch of the guideline update. Issues around stigma will be considered by the committee in the context of experience of care and barriers to accessing and engaging with treatment.
134	SH	Orchard OCD	Draft scope	006	General	Middle of page - Intensive Care Settings Intensive/inpatient/residential care and intensive home- based treatment are not explicitly singled out for detailed review. The scope should include a dedicated review of indications, characteristics, minimum standards, and integration of specialized intensive services (inpatient, residential, and intensive home-based treatment via CMHTs or specialist outreach).	Thank you for your comment. Although it is acknowledged that this level of care has a crucial role in the management of people with more severe OCD and BDD, it will not be covered at this batch of the guideline update, which aims to cover interventions and care pathways for a broader population of people with OCD and BDD.  Nevertheless, issues around criteria for referral to specialist care may be considered by the committee when making recommendations, as appropriate.
135	SH	Orchard OCD	Draft scope	006	General	Middle of page - Broader Public Health and Societal Issues  Areas like stigma, very early (preventative) interventions, body image awareness campaigns, and school liaison	Thank you for your comment. This is a clinical guideline, therefore it will not cover areas related to public health, for example body image awareness campaigns. As stated, the guideline will cover any health, mental health and social care settings in



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ID	Type	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
•				•	_	Please insert each new comment in a new row	Please respond to each comment
						are important. The scope should consider including principles or recommendations relating to: Guideline language and dissemination strategies that actively combat stigma. The role of services in promoting positive body image and media literacy (especially for BDD). Supporting educational institutions in identifying and appropriately supporting students with OCD/BDD.	which NHS care or social care is received or commissioned. Primary prevention will also not be covered, although secondary prevention (i.e. prevention of relapse) may be considered in a future batch of the guideline update. Issues around stigma will be considered by the committee in the context of experience of care and barriers to accessing and engaging with treatment.
136	SH	Orchard OCD	Draft scope	006	General	Top of page - Early Detection, Under Detection, Clinician Awareness, and Stepped Care Pathways  "Recognition and assessment" is included, but a more proactive focus on overcoming under-detection is needed. The draft mentions stepped care but has not explicitly proposed an in-depth review of stepped care pathway review is proposed which is vital to incorporate learning from operational use of such pathways for 20 years. The scope should aim to develop recommendations for:  Proactive screening and awareness-raising strategies for frontline clinicians (GPs, school staff, dermatologists, pediatricians).  Clearer, more detailed care pathways that operationalize the stepped-care model across different service tiers	Thank you for your comment. The committee will consider the issues you raise when updating recommendations. Interventions for patients who have not responded to previous treatment will not be considered in this update batch but may be considered in a future batch of the guideline update.



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						Please insert each new comment in a new row	Please respond to each comment
						and severities, including criteria for stepping up/down and introducing a newer step for exceptional interventions (Step 7) for multi-treatment resistant patients who have not achieved response to Step 6 interventions.	
137	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	Draft scope	General	012 – 014, 018	Draft Scope Page 1, Line 12-14, Line 18.  The NHS follows the WHO ICD 11. The scope should include obsessive compulsive and other related disorders, not only OCD and BDD.  We have noted that the consultation specifies that only OCD and BDD will be covered due to time constraints – however, all the stakeholders at the scoping consultation wanted to include related disorders as defined in ICD-11, and guidance is desperately required on these disorders – it is not clear why this is not included here, and it would be a particularly important area to include in the scope of the guidance.  It is important to have guidance to cover disorders related to OCD, including Illness Anxiety and hypochondriacal disorder, hoarding disorder and body focused repetitive behaviours. Inclusion of Bodily	Thank you for your comment. Obsessive compulsive related disorders apart from body dysmorphic disorder have not been added as areas to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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						Please insert each new comment in a new row	Please respond to each comment
						Distress Disorder should be considered rather than excluded.	
138	SH	NICE - Medicines Optimisation Team	Draft scope	General	General	Is safety sufficiently covered in the scope? In other mental health topics such as depression (NG222), the draft review questions in the scope use the phrase 'what are the relevant benefits and harms of xxxxx'. Would it be more appropriate to use similar wording for the review questions in this scope?	Thank you for your comment. By 'effectiveness' we refer to the overall treatment effects, including benefits and harms. Harms related to treatment will be covered by the outcome 'discontinuation due to side effects'.
139	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	Draft scope	General	General	It is particularly important that expertise in CBT is represented in the development of the guidance - as it is one of the key current evidence-based psychological approaches to OCD/BDD, it is important that there are stakeholders in the group who are specifically clinicians and researchers recognised for their expertise in CBT – and CBT for OCD, BDD and related disorders specifically.	Thank you for your suggestion. Expertise in CBT will be taken into account when forming the guideline committee.
140	SH	British Association for Behavioural and Cognitive Psychothera	Draft scope	General	General	Overall the guidance is focussed on identification and treatment – It does not appear to include recommendations and guidance on prevention or relapse prevention, - both of which should be included and regarded as important	Thank you for your comment. Prevention and relapse prevention have not been added as areas to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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						Please insert each new comment in a new row	Please respond to each comment
		pies – BABCP					
141	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	Draft scope	General	General	The guidance mentions autism – see comment belowbut does not refer to ADHD or other neurodiversity.  Given the relatively high comorbidity of ADHD and OCD and potential for misdiagnosis, the guidance should address this.	Thank you for your comment. The section of the scope (Areas covered by other guidelines) is not an exhaustive list of related NICE guidance but outlines areas where this update will not include a specific evidence review as they are covered by other NICE guidance. Recognition and assessment of OCD and BDD will be covered as part of this update, and it is anticipated that this will include consideration of differential diagnosis and coexisting conditions. This update will cross-refer to relevant NICE guidance where appropriate
142	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	Draft scope	General	General	The draft scope should include recommendations on risks specifically associated with OCD and related disorders and ensure these are included in the guidance, as well as reference linking to staying safe from self-harm and suicide. Risk, safety and safeguarding are not referred to in the scope. Please see also comment below on the potential for inappropriate referrals for safeguarding in paedophile OCD and similar situations	Thank you for your comment. Issues around risk, safety and safeguarding will be considered by the committee when updating recommendations.
143	SH	British Association	Draft scope	General	General	It may be helpful to be more specific on how the draft scope will tackle equality issues that can arise when	Thank you for your comment. Equality issues and groups (including religious groups) are captured in



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						Please insert each new comment in a new row	Please respond to each comment
		for Behavioural and Cognitive Psychothera pies – BABCP				working with (for example) particular faith groups or communities where cultural or religious practices may be particularly affected by OCD or its treatment, and including recommendations about collaboration with religious leaders for example.	our Equality and Health Inequalities Assessment (EHIA), which outlines issues that need to be considered throughout guideline development.
144	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	Draft scope	General	General	As psychological treatment for OCD- exposure and response-prevention E/RP in particular- can be distressing, the scope could include consideration of acceptability of evidence-based treatment, and how to enhance engagement and motivation as an important aspect of interventions - building on the current guidance which does mention refusal or inability to engage with treatment, but not how to enhance engagement and motivation (the current guidance is more that the response to inability to engage or refusal is to offer more intensive/add pharmacological interventions).	Thank you for your comment. Issues relating to acceptability and engagement with interventions will be covered in the qualitative review question on access and engagement with treatment, with a view to understanding the factors that can improve engagement.
145	SH	University of Edinburgh - Neurodiverg ent and Learning Disabilities	Draft scope	General	General	Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline? Innovative approaches: Medication that acts on glutamate Evidence is currently being collected for the use of	Thank you for your comment and the associated references. The details of treatments in review protocols will be discussed with the committee. We can raise this issue and the associated references when the protocol for this topic is being discussed.



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ID	Type	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
·					_	Please insert each new comment in a new row	Please respond to each comment
		Research				troriluzole for treatment-resistant OCD. Troriluzole is a	
		Group				formulation of riluzole. Riluzole is currently used to treat	
						amyotrophic lateral sclerosis (ALS). The Greater	
						Manchester NHS Foundation Trust has recently	
						collected data on the use of troriluzole for OCD, as part	
						of a wider international trial. The person leading this is	
						Prof Damien Longson, Associate Director for Research	
						and Innovation at Greater Manchester Mental Health	
						(GMMH) NHS Foundation Trust, and I would	
						recommend contacting him for further details on this	
						specific trial.	
						Troriluzole and riluzole are thought to act on the	
						neurotransmitter glutamate. This fits with prior research	
						suggesting the importance of glutamate in OCD. I am	
						aware that troriluzole may be considered too	
						experimental to recommend at this stage. However,	
						there is relatively convincing evidence for the role of	
						glutamate in OCD, and as such other medications which	
						act on this neurotransmitter (such as memantine,	
						topiramate or lamotrigine) may be important to consider.	
						This is particularly important given this area of medicine	
						has advanced since the last guidance on OCD was	
						written (e.g. Karthik, Sharma & Narayanaswamy, 2020;	
						Marinova, Chuang & Fineberg, 2017).	



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i ype	Stakeholder	Document	Page no.	Line no.	Comments	Developer's response
,,			J	_	Please insert each new comment in a new row	Please respond to each comment
					References: Karthik, S., Sharma, L. P., & Narayanaswamy, J. C. (2020). Investigating the Role of Glutamate in Obsessive-Compulsive Disorder: Current Perspectives. Neuropsychiatric Disease and Treatment, 16, 1003–1013. https://doi.org/10.2147/NDT.S211703  Marinova Z, Chuang DM, Fineberg N. Glutamate- Modulating Drugs as a Potential Therapeutic Strategy in Obsessive-Compulsive Disorder. Curr Neuropharmacol. 2017;15(7):977-995. doi: 10.2174/1570159X15666170320104237. PMID: 28322166; PMCID: PMC5652017.  Psychological interventions  Therapies such as acceptance and commitment therapy (ACT) and dialectical behaviour therapy (DBT) may be beneficial for people with OCD. In addition, there is some evidence that eye movement desensitization and reprocessing (EMDR) could be helpful.	
	уре	ype Stakenolder	ype Stakeholder Document	ype Stakenolder Document Page no.	ype Stakeholder Document Page no. Line_no.	References: Karthik, S., Sharma, L. P., & Narayanaswamy, J. C. (2020). Investigating the Role of Glutamate in Obsessive-Compulsive Disorder: Current Perspectives. Neuropsychiatric Disease and Treatment, 16, 1003–1013. https://doi.org/10.2147/NDT.S211703  Marinova Z, Chuang DM, Fineberg N. Glutamate- Modulating Drugs as a Potential Therapeutic Strategy in Obsessive-Compulsive Disorder. Curr Neuropharmacol. 2017;15(7):977-995. doi: 10.2174/1570159X15666170320104237. PMID: 28322166; PMCID: PMC5652017.  Psychological interventions  Therapies such as acceptance and commitment therapy (ACT) and dialectical behaviour therapy (DBT) may be beneficial for people with OCD. In addition, there is some evidence that eye movement desensitization and



## Consultation on draft scope Stakeholder comments table

#### 08/05/2025 to 06/06/2025

Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.

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					_	Please insert each new comment in a new row	Please respond to each comment
						The importance of early intervention following initial onset is becoming widely recognised – however the principle of early intervention should also be applied to the interruption of relapse for patients whose OCD has been treated previously. Relapse is very common is OCD, especially if a patient has only achieved partial recovery following a course of treatment. Therefore occasional "check-ins" with a mental health professional following a course of treatment (e.g. once every 3 months) would help with relapse prevention. This in turn could save money because the more ill a patient becomes, and the more full courses of treatment they need, the more expensive it is to treat them.	
146	SH	University of Edinburgh - Neurodiverg ent and Learning Disabilities Research Group	Draft scope	General	General	Logistical processes following ineffective first-line intervention -  It is important that there are clear mechanisms in place for patients who have not seen a substantial improvement in their OCD symptoms following first-line interventions, and that these are accessible and visible to patients. For example, patients who have seen a mental health specialist attached to a GP may be	Thank you for your comment. Further-line treatment is no longer in a first batch of the update nor have any further areas been added, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.



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						nervous to go back to that GP to report that the therapy was not successful (either because they don't want to appear dismissive of the mental health specialist's intervention or they are unaware that any further treatment is available). In addition, the mental health professional who carried out the intervention should not be the only person involved in the decision to (not) refer the patient for further treatment. This is because therapists may (despite the best of intentions) find it difficult to acknowledge that the patient has not seen substantial improvement while under their care. Any targets around achieving a successful treatment outcomes for a specific number of patients may also have a negative impact on this process.  One way to approach this issue this may be for a different professional to administer an OCD questionnaire 3 months after the first-line intervention	
						ends, and to use this to guide decisions on whether the patient needs further treatment.	
147	SH	University of Edinburgh - Neurodiverg ent and Learning	Draft scope	General	General	OCD is best seen as a chronic condition, as full and sustained recovery is relatively rare. For example, Eisen et al. (2013) looked at the five-year outlook for 213 treatment-seeking adults with OCD. Of these, 61% saw no measurable improvement, and of the 39% who had	Thank you for your comment. Relapse prevention or monitoring have not been included as areas to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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		Disabilities Research Group				made a partial or full recovery, more than half had relapsed by the end of the five-year period.  Patients who respond well to a first-line intervention are unlikely to stay clinically well indefinitely. The guidance should reflect this, for example by including information	
						on monitoring patients with OCD who are not currently receiving treatment (relapse prevention).  It may be that some patients require first-line interventions on multiple separate occasions throughout their life, whereas other patients may not respond to first-line interventions and require further interventions immediately afterwards. Both these potential courses of illness should be accounted for in the guidance.	
						Reference: Eisen, J. L., Sibrava, N. J., Boisseau, C. L., Mancebo, M. C., Stout, R. L., Pinto, A., & Rasmussen, S. A. (2013). Five-Year Course of Obsessive-Compulsive Disorder: Predictors of Remission and Relapse. Journal of Clinical Psychiatry, 74(3), 233-239. https://doi.org/10.4088/JCP.12m07657	
148	SH	OCD-UK	Draft scope	General	General	Can the scope review if there is any evidence that supports patients being made to wait at least 3-6 months before they can seek further therapy.	Thank you for your comment. Further-line treatment is no longer in a first batch of the update nor have any further areas been added, please see the



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						This routinely happens where patients continue to be impacted by OCD and treatment has not helped, and are told to work on their techniques learned in the previous course of therapy before they re-refer. Such practice does not seem to be supported by evidence.	stakeholder message related to the new approach NICE is taking for this guideline.
149	SH	Orchard OCD	Draft scope	General	General	Any thought about including some comment about PANDAS and whether it should be explicitly excluded (e.g. as per autism and OCD).	Thank you for your comment. Paediatric Acute- onset Neuropsychiatric Syndrome, including Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections, are neither included nor excluded because they are separate conditions with distinct aetiologies.
150	SH	EMDR UK Association	Draft scope	General	General	Based on our representative's attendance at the scoping workshop, we understand that the guideline will reflect the ICD classification of OCRD (Obsessive Compulsive & Related Disorders). As well as OCD and BDD, this would include Health Anxiety, Hoarding Disorder, Trichotillomania, Skin Picking, Olfactory Reference Disorder etc. This is not currently reflected in the draft scope document.	Thank you for your comment. Obsessive compulsive related disorders apart from body dysmorphic disorder have not been added as areas to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
151	SH	Paediatric mental Health Association	Draft scope	General	General	Pleased to see scope expanding to include children under 8 years old. Most OCD/BDD management is CAMHS-led, we await the revised guidance with interest.	Thank you for your comment in support of the wider age inclusion.



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152	SH	NHS England	Draft scope	General	General	I note this guidance will cover adults but I would suggest that older adults can not be grouped under adults and will need specific mention for the following reasons	Thank you for your comment. We aim to include representation from people with experience of working with older adults on the committee because we agree that this is an important consideration.
						Re prevalence of Obsessive-Compulsive Disorder (OCD) in older adults is lower than in younger populations, but is clinically significant and often under-recognised compared with adults .Late-onset OCD can occur in association with neurological changes (e.g., stroke, Parkinson's, or dementia).	
						In older adults like OCD Body dysmorphic disorder (BDD) is also unrecognized or misdiagnosed as depression, anxiety, or delusional disorder, especially if the body image concerns focus on signs of ageing Re assessment  Most tools were developed and validated with adults/younger people and so have not got validated older adults norms. Cognitive impairment and sensory deficits may interfere with self-report accuracy and indeed their ability to complete the assessment. Older adults may also present with more somatic or religious obsessions and fewer overt compulsions.	
						In BDD older adults may have different focuses of	



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						concerns eg Ageing signs (wrinkles, sagging skin) vs. features like acne or nose shape in younger adults and these concerns may be missed. The overlap with somatic symptoms, depression, or mild cognitive impairment may also complicate interpretation.	
						Re Treatment Again highlighting adaptations for older adults would be useful Rule out co morbidities and other differential diagnosis as very common in older adults CBT for older adults might include: Slower pacing Memory aids or written materials Shorter appointment etc Drugs - Higher risk of side effects in older adults (e.g., GI issues, hyponatremia, , falls) Potential drug interactions with medications for physical health conditions more likely in older adults The setting and delivery – may need adaptation	
153	SH	Hertfordshire Partnership University NHS	Draft scope	General	General	We, as a group of clinical and academic experts working in highly specialised services for the treatment of OCD and BDD across five centres and incorporating erstwhile NHS England's Severe OCD and BDD Specialist	Thank you for your comment. Further-line treatment is no longer in a first batch of the update nor have any further areas been added, please see the



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Type Stakeholder	Comments Developer's response	Page no. Line_no.	Documo	Stakeholder	Type	ID
	Please insert each new comment in a new row Please respond to each comment					
foundation trust - OCD/BDS National Service	Please insert each new comment in a new row Services, welcome the long-awaited revision to NICE 2005 guidelines on the topic but strongly urge NICE to revise and significantly expand the scope to explicitly include: A clear operational definition of TR-OCD. A thorough review of all relevant further-line treatments, including ablative neurosurgery and a wider range of neuromodulation techniques. Comprehensive strategies for managing common and impactful comorbidities. A broader consideration of psychological therapies, including technological advancements and specific approaches for varied presentations. Dedicated focus on long-term management, recovery imodels, relapse prevention, cultural factors, suicidality, functional outcomes, and disability. Actionable recommendations for service delivery improvements, including early detection, care pathways, and intensive treatment models. Acknowledgement that Obsessive-Compulsive and related disorders (OCRDs) is now a separate category amongst both leading diagnostic classification systems. This can be done by: Reclassifying NICE guidance on OCD & BDD outside			trust - OCD/BDS National		
Service	A thorough review of all relevant further-line treatments, including ablative neurosurgery and a wider range of the neuromodulation techniques.  Comprehensive strategies for managing common and impactful comorbidities.  A broader consideration of psychological therapies, including technological advancements and specific approaches for varied presentations.  Dedicated focus on long-term management, recovery models, relapse prevention, cultural factors, suicidality, functional outcomes, and disability.  Actionable recommendations for service delivery including early detection, care pathways, and intensive treatment models.  Acknowledgement that Obsessive-Compulsive and related disorders (OCRDs) is now a separate category amongst both leading diagnostic classification systems.  This can be done by:			Service		



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IC	Туре	Stakeholder	Document	Page no.	Line_no.	Comments	Developer's response
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						congruence with ICD-11 and DSM-5 with classification under its own category of OCRDs.  By including other OCRDs like Hoarding Disorder, Trichotillomania (hair-pulling disorder), and Excoriation (skin-picking) disorder in the scope as these disorders share common features with similar treatment strategies.	
15	4 SH	Orchard OCD	Draft scope	General	General	We, as a charity composed by people with lived experience of OCD, clinical and academic experts welcome the long-awaited revision to NICE 2005 guidelines on the topic but strongly urge NICE to revise and significantly expand the scope to explicitly include: A clear operational definition of TR-OCD.  A thorough review of all relevant further-line treatments, including ablative neurosurgery and a wider range of neuromodulation techniques.  Comprehensive strategies for managing common and impactful comorbidities.  A broader consideration of psychological therapies, including technological advancements and specific approaches for varied presentations.  Dedicated focus on long-term management, recovery models, relapse prevention, cultural factors, suicidality, functional outcomes, and disability.  Actionable recommendations for service delivery improvements, including early detection, care pathways,	Thank you for your comment. Further-line treatment is no longer in a first batch of the update nor have any further areas been added, please see the stakeholder message related to the new approach NICE is taking for this guideline.



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						and intensive treatment models. Acknowledgement that Obsessive-Compulsive and related disorders (OCRDs) is now a separate category amongst both leading diagnostic classification systems. This can be done by: Reclassifying NICE guidance on OCD & BDD outside the category of anxiety disorders. We recommend congruence with ICD-11 and DSM-5 with classification under its own category of OCRDs. By including other OCRDs like Hoarding Disorder, Trichotillomania (hair-pulling disorder), and Excoriation (skin-picking) disorder in the scope as these disorders share common features with similar treatment strategies.	
155	SH	Royal College of General Practitioners	Draft scope	General	General	We believe that the guideline should provide clear guidance for primary care practitioners on when to refer patients to specialist services.	Thank you for your comment. Referral and service organisation have not been included as areas to be addressed in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
156	SH	South London and Maudsley NHS Foundation Trust	EHIA	003	2.2	Note that ICD-11 classifies hoarding disorder, health anxiety, and body-focused repetitive behaviours alongside OCD. Request these be included or scoped for parallel guideline development to avoid equity gaps.	Thank you for your comment. Obsessive compulsive related disorders apart from body dysmorphic disorder have not been added as areas to be addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.



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157	SH	South London and Maudsley NHS Foundation Trust	EHIA	003	2.3	Propose an explicit review question on safeguarding and misinterpretation of taboo-themed OCD (e.g., paedophile OCD) to reduce inappropriate safeguarding referrals and stigma.	Thank you for your comment. While your suggested topic will not be a particular review question, it may be addressed during work on assessment. The qualitative review on access and engagement with treatment is also expected to include issues relating to taboo-themed OCD and stigma.
158	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	EHIA	004	2.2	Under 'autism' — While some are, not everyone with autism is disabled by this, or identifies as disabled, and this is listed under disability.  Other forms of neurodiversity are not mentioned, and given the co-morbidity and potential for misdiagnosis, it may be useful to include this in the equalities impact assessment.	Thank you for your comment. We recognise that not all autistic people are disabled or identify as disabled, although some do experience significant disabilities. For the purposes of the Equality and Health Impact Assessment (EHIA), autism is included under the disability category to ensure that the need for reasonable adjustments under the Equality Act 2010 is clearly recognised. We have also amended the EHIA to include other forms of neurodiversity.
159	SH	South London and Maudsley NHS Foundation Trust	EHIA	004	2.2	Recommend broadening the pharmacological guidance to consider first-line SSRIs for children and young people in the presence of severe symptoms, given that restriction to second-line only may delay treatment. Explicitly address diagnostic misclassification issues that delay referrals to appropriate services.	Thank you for your comment. The evidence review on the effectiveness of interventions for the treatment of OCD in children and adolescents will include SSRIs as first line treatment. We anticipate that issues relating to diagnostic misclassification will likely be addressed in the qualitative review of



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							barriers and facilitators to access and engagement with treatment.
160	SH	South London and Maudsley NHS Foundation Trust	EHIA	004	2.2	Propose a dedicated review question on diagnostic differentiation between ASD and OCD symptoms and their treatment prioritisation, as current cross-reference to CG142 and CG170 lacks specificity for OCD treatment planning.	Thank you for your comment. Adaptations for people with OCD and autism, has not been included as an area to be addressed in a first batch of the update, please see the stakeholder message related to the new approach NICE is taking for this guideline.
161	SH	South London and Maudsley NHS Foundation Trust	EHIA	004	2.2	Request that review questions or evidence tables address intersectional inequalities (e.g., ethnicity and age or neurodiversity), as current sections treat these in isolation and risk missing compounded effects.	Thank you for your comment. We will aim to do this for all reviews, where possible and depending on the availability of evidence to do so.
162	SH	South London and Maudsley NHS Foundation Trust	EHIA	005	2.3	Encourage a more detailed pharmacological review of augmentation strategies for treatment-resistant OCD, including dose, duration, and relapse prevention, beyond generalised pharmacological advice.	Thank you for your comment. Further-line treatment is no longer in a first batch of the update, please see the <u>stakeholder message</u> related to the new approach NICE is taking for this guideline.
163	SH	University of Edinburgh - Neurodiverg	EHIA	005	General	I agree that parent training is important regarding the treatment of OCD in children and young people. Family accommodation (when members of the family make	Thank you for your comment in support of the inclusion of this topic.



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		ent and Learning Disabilities Research Group				changes in response to the child's OCD) is a major concern when treating OCD in children and young people.	
164	SH	Maternal OCD	EHIA	005	Review question 1b	Breast-feeding can impact decisions for pharmacological treatment and nearly 25% of pregnancies are to young mums so would fall into this category	Thank you for your comment. For all medicines related recommendations, it is expected that the prescribing clinician would take factors such as breastfeeding into account, so this would not need to be explicitly addressed in the evidence review or recommendations.
165	SH	British Association for Behavioural and Cognitive Psychothera pies – BABCP	EHIA	005	Review question c	In addition to remotely delivered psychological interventions, perhaps overtly including computerassisted delivery would be useful as it impacts people differently (e.g. according to age, intellectual ability)	Thank you for your comment. Computer-assisted delivery has been added as an example of remotely delivered psychological interventions. It was also added that this may address geographical inequalities but could disadvantage people with learning disabilities and older people who may be less computer literate.
166	SH	British Association for Behavioural	EHIA	006	2.4	Including stakeholder groups specifying religious organisations is particularly important for OCD in particular as a disorder – see general comment above	Thank you for your comment. We have encouraged stakeholders representing various religious practices to register.



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		and Cognitive Psychothera pies – BABCP					
167	SH	South London and Maudsley NHS Foundation Trust	EHIA	006	2.4	Suggest that LGBTQ+ representation be paired with specific experiences in taboo OCD subtypes (e.g., sexual orientation fears) to ensure tailored insights in consultation.	Thank you for your comment. We do not think that it is appropriate to list any groups of people with experience in taboo OCD subtypes with LGBTQ+ groups. The stakeholder list already contains OCD specific stakeholder groups which could advocate for these subtypes.
168	SH	University of Edinburgh - Neurodiverg ent and Learning Disabilities Research Group	EHIA	006	General	Given that autism is raised on multiple occasions in the EHIA, it would be good to include autistic individuals or representatives of autism organisations in the list of stakeholders to be approached/included.	Thank you for your comment. We have added 'organisations representing neurodivergent people' to the list and will invite relevant stakeholders to register.
169	SH	NIHR Applied Research Collaboration	EHIA	General	General	Acknowledging the inequalities at play in the various stages of assessment and treatment of BDD is welcome. The author would like to emphasise some further inequalities and invite reviewers to draw attention to these in the guideline update:	Thank you for your comment. We have added the information about age and BDD prevalence to the relevant section of the EHIA.



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		(ARC) North Thames				Age: It is estimated that 1% of children and young people are living with BDD in the UK, and that it is most prevalent (5.6%) in girls aged 17-19 years old (Veale et al., 2016; NHS Digital, 2017). However, this prevalence is thought to be underestimated due to the stigma and shame internalised by people with the condition acting as a barrier to help-seeking. This stigma and shame also contribute to a delay of several years from symptom onset to help seeking, where people will often present in dermatology or cosmetic settings repeatedly before entering psychiatric settings (Herbst and Jemec, 2020; Dogruk et al., 2014). Gender: In a UK based prevalence survey conducted as part of the parliamentary committee on Women and Equalities (n=7878), it was reported that 61% of adults and 66% of children experienced body dissatisfaction – a core component of BDD – most of the time, with 62% of women feel negatively about their body image compared with 57% of non-binary respondents and 53% of men (HC 359,2021). A sub-type of BDD is muscle dysmorphia (MD), where	Trease respond to each comment



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						the body dissatisfaction and pre-occupation is focused specifically on "insufficient muscularity" (Tod, Edwards and Cranswick, 2020: p.179). Whilst symptoms of MD align with repetitive checking and compulsive safety behaviours similar to that of BDD, these behaviours predominantly centre around pathological and compulsive exercise behaviours, with dietary concerns a secondary feature (Murray et al., 2010). MD was first recognised in the 1990s from a study of bodybuilders where it was termed 'reverse anorexia' due to its behavioural and cognitive similarities to anorexia nervosa (AN) except the core body image distortion manifested as a belief in oneself appearing too small and too skinny despite often being large and muscular (Murray et al., 2010). However, a seminal paper by Pope and colleagues (2005: p.395) positioned MD as a form	Please respond to each comment
						of BDD in which people become "pathologically preoccupied with their degree of muscularity".  Ethnicity In a study by Marques and colleagues (2011), it was highlighted how Asian participants reported more than twice as many hair concerns and four times as many skin concerns when compared with White participants yet were much less likely to report concerns about other	



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						body areas such as the stomach. In addition, Asian	
						participants were nearly three times more likely to	
						engage in excessive and compulsive exercise, yet were	
						significantly less likely to engage in grooming,	
						camouflaging, and touching behaviours when compared	
						to White participants (Marques et al., 2011). This is an	
						important revelation, as previous studies have found that	
						symptoms were generally similar across ethnic groups,	
						and that most BDD behaviours and body parts of	
						concern were not statistically different between Asian-	
						American and White-American participants (Marques et	
						al., 2011; Bohne et al., 2002; Cansever et al., 2003;	
						Fontenelle et al., 2006). This lends support to the current	
						conception of BDD as a universal disorder that may vary	
						slightly in presentation across racial and ethnic groups,	
						however, this still ought to be explored in a UK context	
						and in light of body dissatisfaction prevention strategies.	
						As part of the author's PhD thesis, a qualitative	
						exploration of culturally-specific risk factors for body	
						dissatisfaction. The majority of participants identified	
						how early experiences of racism – which often included	
						discrimination based on not just the colour but the shade	
						of their skin – negatively affected their self-perception	
						and consequently became a risk factor for body	



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						dissatisfaction and compulsive use of skin lightening cosmetic products and procedures.	
						Prognosis A study in the US reported that 77% of people with BDD reported that their BDD symptoms had interfered moderately, severely, or extremely with occupational, academic, or role functioning over the course of their illness (Phillips and Diaz, 1997) whilst a UK-based study demonstrated that 50% of people with BDD were currently unemployed (Veale et al., 2018). Individuals with BDD may at times be housebound or have needless cosmetic and dermatological treatments (Phillips and Menard, 2006; Dogruk et al., 2014). The symptoms cause significant distress or handicap and there is an increased risk of suicide and attempted suicide, with it being reported that suicidality is 45 times higher than that of the general population (Phillips and Menard, 2006).	
170	SH	Maternal OCD	Question 1	General	General	See here intensive CBT for perinatal OCD: https://pubmed.ncbi.nlm.nih.gov/21489404/	Thank you for your comment. This update will not include a specific evidence review on adaptations to interventions for people with OCD in the antenatal or perinatal period as this area is covered by the NICE guideline on Antenatal and postnatal mental



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							health (CG192). This update may cross-refer to other relevant NICE guidance. However, people in the antenatal or perinatal period will not be excluded from this update. Review protocols for the OCD treatment questions are being developed with the committee and the list of interventions for which RCT evidence will be sought includes intensive short-term CBT
171	SH	Maternal OCD	Question 1	General	General	As a principle, investing in services / integrating care is cheaper than problems left untreated / long waiting times – note the following:  https://maternalmentalhealthalliance.org/campaign/count ing-costs/	Thank you for your comment. The reviews on treatment for OCD and BDD will consider evidence for both clinical and cost effectiveness. When making recommendations, the committee will also take implementation factors into account
172	SH	EMDR UK Association	Question 1	General	General	Are there any cost saving interventions or examples of innovative approaches that should be considered for inclusion in this guideline?  Eye Movement Desensitization and Reprocessing (EMDR) was assessed in a systematic review conducted by the University of Sheffield (in press, protocol can be found here:  https://www.crd.york.ac.uk/PROSPERO/view/CRD42023 463360) to be the most-cost effective treatment in adults with PTSD. This is based on evidence regarding the	Thank you for your comment. EMDR will be included in the guideline treatment reviews, in order to assess its clinical and cost effectiveness in populations with OCD and BDD, depending on available data in this population.



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						number of sessions required compared with trauma- focused CBT. This may suggest, particularly where trauma is linked to the onset or worsening of OCD symptoms, that it would be similarly cost-effective for obsessive compulsive and related disorders. In terms of innovative approaches, EMDR could be explored for OCRD conditions such as hoarding disorders, as the recovery rate with CBT for hoarding is reported to be 25%. See: Ivanov, Volen Z., et al. "Enhancing group cognitive-behavioral therapy for hoarding disorder with between-session internet-based clinician support: A feasibility study." Journal of clinical psychology 74.7 (2018): 1092-1105. https://doi.org/10.1002/jclp.22589	
173	SH	Anglia Ruskin University	Committee membershi p list	003	General	Membership would benefit from primary care representation (e.g., GP), and possibly also from someone with a research background with a track-record in OCD research (e.g., academic pertaining to assessment, formulation, intervention etc.).	Thank you for your comment. We have advertised and appointed a primary care professional.
174	SH	The Body Dysmorphic Disorder Foundation	Committee membershi p list	004	Co- opted member s	To ensure the guidelines reflect the experiences of a diverse group of service users, we suggest our organisation be considered for co-opted membership. This would allow us to be consulted as needed and help identify relevant lay member representation - particularly to inform complex aspects of BDD.	Thank you for your comment. Committee members are appointed as individual rather than representatives to speak on behalf or organisations. However, experience of such work would contribute to their individual knowledge and experience informing the discussions.



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175	SH	OCD Action	Committee membershi p list	004	Co- opted member s	We would ask that significant consideration is given to the inclusion of lived experience in the development of these guidelines. The experience of shame in those impacted by OCD, coupled with the significant misunderstanding and trivialisation of the condition, has a significant effect on people's experience of seeking and receiving treatment for OCD. OCD Action would be happy to support the committee with engaging lived experience expertise to help inform the development of the guidelines from this perspective.	Thank you for your comment and offer of help in involving people with lived experience.
176	SH	Maternal OCD	Committee membershi p list	004	General	Add a HCP from either a perinatal mental health service or a HCP with an interest in perinatal mental health	Thank you for your comment. It was not considered appropriate to add a HCP with experience or interest in perinatal mental health to the committee membership list. This update will not include a specific evidence review on adaptations to interventions for people with OCD in the antenatal or perinatal period as this area is covered by the NICE guideline on Antenatal and postnatal mental health (CG192)
177	SH	British Association for	Draft Scope	003	020	Recognition and assessment of OCD and BDD. There needs to be mention of considering these in neurodivergent people, and of considering neurodivergence in people with OCD and BDD.	Thank you for your comment. Recognition and assessment of OCD and BDD will be covered as part of this update, and it is anticipated that this will include consideration of differential diagnosis and



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						Please insert each new comment in a new row	Please respond to each comment
		Neurodiversit y (B4ND)					coexisting conditions. This update will cross-refer to relevant NICE guidance where appropriate
178	SH	British Association for Neurodiversit y (B4ND)	Draft Scope	004	001	Interventions for OCD and BDD – again, there needs to be mention of neurodivergence; interventions should be neuro-affirmative (i.e. considering the sensory, movement, ritualistic, communication and attentional etc needs of patients). There should also be mention of MDT working with Neurodevelopmental clinicians & teams.	Thank you for your comment. This update will not include a specific evidence review on adaptations to interventions for people with OCD and autism as this area is covered by the NICE guidelines on autism (CG142 and CG170). This update may cross-refer to other relevant NICE guidance. However, people with neurodiversity will not be excluded from this update. The review protocol (detailed review plan) for the experience of accessing and engaging with treatment is being developed with the guideline committee. Formal subgroup analyses are not appropriate for this question due to qualitative data, but it is anticipated that where evidence allows, similarities and differences in views and experiences based on presence of neurodiversity will be explored
179	SH	British Association for Neurodiversit y (B4ND)	Draft Scope	004	016	Accessing and engaging with treatment – again, there needs to be mention of neurodivergence; access and engagement strategies should be neuro-affirmative (i.e. considering the sensory, movement, ritualistic, communication and attentional etc needs of patients).	Thank you for your comment. The review protocol (detailed review plan) for the experience of accessing and engaging with treatment is being developed with the guideline committee. Formal subgroup analyses are not appropriate for this question due to qualitative data, but it is anticipated that where evidence allows, similarities and



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							differences in views and experiences based on
400	011	000 4 11	D (10	004 000	044	NA 1	presence of neurodiversity will be explored
180	SH	OCD Action	Draft Scope	001 – 006	011 -	We have worked as a collective of Charities and NHS	Thank you for your comment. Obsessive
		(collated			014	professionals who support people with OCD, BDD and	compulsive related disorders apart from body
		response)				related conditions to review this scope and we are	dysmorphic disorder have not been added as areas
						seriously concerned that OCD related disorders - such	to be addressed in a first batch of the update,
						as Body-Focused Repetitive Behaviours (BFRBs),	please see the stakeholder message related to the
						Hoarding Disorder, Health Anxiety (Hypochondriasis),	new approach NICE is taking for this guideline.
						and Olfactory Reference Disorder - have been excluded	
						from this review based on what appear to be arbitrary	
						timeline restrictions.	
						Evidence suggests that BFRBs are estimated to affect	
						up to 1 in 5 people - potentially 4 million people in the	
						UK. This estimate is supported by unpublished	
						prevalence data from Prof. Clare Mackay. Clinical	
						research also highlights the distress and functional	
						impairment these conditions cause (e.g. Grant et al.,	
						Psychiatry Research 2020; Woods et al., J Clin Psych	
						2006; Tucker et al., <i>J Anxiety Disord</i> 2011). At OCD	
						Action, 2.5% of helpline contacts are BFRB-related.	
						Despite low public awareness of BFRBs, they still make	
						up 2.5% of OCD Action's helpline contacts, suggesting	
						, , , , , , , , , , , , , , , , , , , ,	
						the true scale of need may be far greater.	



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						BFRB UK & Ireland is a charitable organisation that has supported people with BFRBs and their loved ones since 2015. In their support communities, it's common to hear that most healthcare professionals are unaware of BFRBs, leading to poor or even misleading advice when people seek help. When conditions are lesser known, it's especially important that clinicians have access to clear, reliable guidance.	
						"On the two occasions that I have been to the GP about my hair-pulling (to ask for a referral to a psychologist) I have had to educate them about BFRBs in order to access support. This adds to feelings of unworthiness and 'otherness' and is a major barrier to asking for help". (Clare Lived experience expert)	
						"When I sought help for trichotillomania, my CMHT didn't know what BFRBs were. They treated it as self-harm and told me stopping might lead to "more dangerous behaviours." I was given CBT for depression, not the condition I was there for. My symptoms got worse, not better. Without clear guidelines, people like me are left with inconsistent care and no recognition that this is a legitimate mental health issue, even though effective treatments exist." (Cara, Lived experience expert)	



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						Similarly, research indicates that Hoarding Disorder is a common condition affecting 2–5% of the population.  Over 1% of OCD Action helpline contacts are from people seeking information on treatment for Hoarding Disorder, despite the stigma that often dissuades people from seeking support.  Following a 20 year wait for the OCRD guideline to be reviewed, it is deeply concerning that these conditions are being excluded due to timeline constraints. We believe this risks sidelining people affected by these disorders all over again and overlooks a vital opportunity to address long-standing gaps in care. It also calls into question NICE's duty to represent and respond to commonly occurring, yet consistently overlooked, conditions.	
181	SH	OCD Action (collated response)	Draft Scope	003	004 -	As a collective, we are concerned that the scope currently excludes a dedicated evidence review on how interventions should be adapted for people with OCD and autism.  This is a significant gap and it is vital that this is specifically covered in the guideline. Effective care for	Thank you for your comment. The adaption of and treatment for people with OCD and autism is not an area that is addressed in a first batch of the update, please see the <a href="stakeholder message">stakeholder message</a> related to the new approach NICE is taking for this guideline.



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						adjusting treatment delivery - it requires informed clinical judgment. For example, clinicians must be able to distinguish between autistic traits and OCD symptoms in order to identify what should be targeted in therapy. Without this clarity, there is a risk of misdiagnosis, mistreatment, and poor outcomes.	
						It is vital that this is specifically covered in the guideline. Ensuring that autistic people receive appropriate treatment is not simply a matter of adapting therapy - it depends on informed clinical judgment. For example, understanding how to separate traits associated with autism from OCD symptoms is essential in determining what should be targeted in therapy.	
						This is not a small cohort. Research suggests that up to 25% of young people with OCD may also be autistic. In 2023/24, 51% of the young people who contacted OCD Action's youth helpline were seeking help with accessing appropriate treatment for OCD in the context of autism.	
						There is a breadth of research on OCD and autism spectrum disorder. One paper (Martin, A.F., Jassi, A., Cullen, A.E. et al. https://doi.org/10.1007/s00787-020-01478-8) concluded that autistic young people with OCD	



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						"can make significant improvements in functioning with routine clinical care but are likely to remain more impaired than typically developing youth with OCD, indicating a need for longer-term support for these young people."  Given this evidence, the absence of a focused review on OCD and autism in the current scope is a concerning oversight.	
182	SH	OCD Action (collated response)	Draft Scope	003	007 - 008	Data from the UK suggests that OCD affects 2 in every 100 women during pregnancy and 2–3 in every 100 in the year after giving birth (www.rcpsych.ac.uk). However, a recent global meta-analysis found higher rates—9.1% during pregnancy and 6.2% postpartum (https://www.sciencedirect.com/science/article/pii/S2666 91532400132X).  In perinatal OCD, symptoms often focus on the baby. Although mothers with OCD may experience intrusive thoughts about harming their baby, they are not at risk of acting on them. There are no recorded cases of	Thank you for your comment. The NICE Antenatal and postnatal mental health clinical guideline (CG192) included a qualitative review on experience of care and a barrier to accessing care that emerged from that review was fear of the baby being taken away. The recommendations in CG192 on principles of care in pregnancy and the postnatal period were made based on that qualitative review and on the clinical and lived experience of that guideline committee. This update will not include a specific evidence review on adaptations to interventions for people with OCD in the antenatal or perinatal period as this is covered by CG192. This update will include recognition and assessment of OCD. CG192 includes recommendations on considerations around



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						individuals with OCD acting on these intrusive thoughts, and most mothers can care for their babies well, with appropriate support.	assessment of mental health problems in pregnancy and the postnatal period to be used in conjunction with condition-specific NICE guidance including this update. This update will cross-refer to relevant NICE guidance, including CG192, where appropriate
						However, fear of being judged or misunderstood can prevent mothers from seeking help. In some cases, disclosing intrusive thoughts has led to incorrect clinical judgements or even inappropriate safeguarding referrals due to a lack of understanding among healthcare professionals.	
						In this context, the decision not to include a review of adaptations to interventions for people with OCD in the antenatal or postnatal period is deeply concerning, for both maternal and infant outcomes.	
183	SH	OCD Action (collated response)	Committee membershi p list	004	Co- opted member s	To ensure the guidelines reflect the experiences of a diverse group of service users, we suggest that this coalition of organisations be considered for co-opted membership. This would allow us to be consulted as needed and help identify relevant lay member representation - particularly to inform complex areas	Thank you for your comment. Committee members are appointed as individual rather than representatives to speak on behalf or organisations. However, experience of such work would contribute to their individual knowledge and experience



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						such as taboo intrusive thoughts, including thoughts of	informing discussions and are likely to be able to
						harming a child or sexually intrusive thoughts.	appoint several to the committee.

**Registered stakeholders**