NICE National Institute for Health and Care Excellence

Appendix A: Stakeholder consultation comments table

2019 surveillance of Obsessive-compulsive disorder and body dysmorphic disorder: treatment (2005)

Consultation dates: 9 to 22 January 2019

Do you agree with the proposal to update the guideline?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Association for Family Therapy and Systemic Practice - UK	Yes	No comments provided	Thank you.
British Association for Psychopharmacology	Yes	A huge amount of OCD treatment trial data and a small but significant amount of BDD treatment trial data has accrued since 2006, only partly identified in the 2013 evidence update, that arguably now makes the original guidelines redundant.	Thank you for your comment. Following the evidence identified through the surveillance review and further consideration of new evidence and information from stakeholders, we have decided to fully update NICE guideline CG31 on Obsessive-compulsive disorder and body dysmorphic disorder. New evidence and intelligence identified through the surveillance review indicates a need to update the guideline so that it remains relevant to clinical practice in the UK.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

Royal College of Paediatrics and Child Health		Thank you for inviting the Royal College of Paediatrics and Child Health to comment on the Obsessive-compulsive disorder and body dysmorphic disorder: treatment surveillance consultation. We have not received any responses for this consultation.	Thank you for your comment.
Sheffield Health and Social Care NHS Foundation Trust	Yes	Since the guidelines inception, there have been significant changes in the delivery of psychological services. There has been research to support the increasing use of technology to deliver therapy. Time and practise has highlighted the benefits of the stepped care modal but also its failing to ensure people enter at the right level for there experienced OCD for treatment.	Thank you for your comment. Through the surveillance review we identified rapid advances in information technology and telecommunications and introduction of technology-enhanced cognitive behavioural therapy (CBT) intervention and also noted there is practice variation in stepped care approach particularly relating to access to specialist care services for children. Both of these issues contributed to the proposal to update the guideline.
OCD Action	Yes	Overall we feel the current guideline is comprehensive and if fully implemented would ensure the provision of a clear care pathway for individuals. Unfortunately many of the individuals we support report that often clinicians remain at best unaware and at worst dismissive of the guideline and the importance of its implementation.	Thank you for your comment. We agree that this is an important guideline and feel that updating will ensure it remains relevant to clinical practice in the UK.
Royal College of Psychiatrists	Yes	There has been a significant amount of new trail data, particularly in adult OCD that is not currently encompassed in the NICE guidance.	Thank you for your comment. Thank you for highlighting references related to the guideline. We recognise there have been advances in the evidence base which has fed into our proposal to update the guideline. We will add the

		In addition, there are lots of new BDD data mainly adults but also in children: E.g. Krebs G, Fernández de la Cruz L, Monzani B, Bowyer L, Anson M, Cadman J, Heyman I, Turner C, Veale D, Mataix-Cols D. Long-Term Outcomes of Cognitive-Behavioral Therapy for Adolescent Body Dysmorphic Disorder. Behav Ther. 2017 Jul;48(4):462-473. Mataix-Cols D, Fernández de la Cruz L, Isomura K, Anson M, Turner C, Monzani B, Cadman J, Bowyer L, Heyman I, Veale D, Krebs G. A Pilot Randomized Controlled Trial of Cognitive-Behavioral Therapy for Adolescents With Body Dysmorphic Disorder. J Am Acad Child Adolesc Psychiatry. 2015 Nov;54(11):895-904. The lack of inclusion of the evidence base for BDD makes the current guidelines and their 2013 evidence update rather lacking at present. This would particularly be the case for children and young people where there have been some important advances in the evidence base for BDD treatments.	references (Krebs et al.2017; Mataix et al. 2015) to this surveillance review. During the update of the guideline, developers may consider the highlighted studies for inclusion in the evidence reviews.
Medtronic	Yes	We believe it is important and timely to review and consider Deep Brain Stimulation (DBS) Therapy for	Thank you for your comment.

		Obsessive-Compulsive Disorders (OCD), within the guideline update. The Medtronic Reclaim DBS Therapy is indicated for bilateral stimulation of the anterior limb of the internal capsule (AIC), as an adjunct to medications and as an alternative to anterior capsulotomy for treatment of chronic, severe, treatment-resistant obsessive-compulsive disorder in adult patients who have failed at least three selective serotonin reuptake inhibitors (SSRIs). The Medtronic DBS system for OCD Therapy is an implantable multi-programmable neurostimulation system used to deliver electrical stimulation to the ventral Anterior Limb of the Internal Capsule of the brain. The system consists of the implantable neurostimulator(s) also referred to as the INS, lead(s) and extension(s) that connect the leads to the neurostimulators. There is a growing evidence base on the safety and efficacy of DBS therapy. Updated publication listing since Clinical guideline Published: 29 November 2005: 1.Raymaekers S, Vansteelandt K, Luyten L, et al. Long-term electrical stimulation of bed nucleus of stria terminalis for obsessive-compulsive disorder. Mol Psychiatry. 2017;22(6):931-934.doi:10.1038/mp.2016.124. 2.Farrand S, Evans AH, Mangelsdorf S, et al. Deep brain stimulation for severe treatment-resistant obsessive-compulsive disorder: An open-label case series. Aust N Z J Psychiatry. 2018;52(7):699-708.doi:10.1177/0004867417731819. 3.Mulders AEP, Leentjens AFG, Schruers K, Duits A, Ackermans L, Temel Y. Choreatic Side Effects of Deep Brain Stimulation of the Anteromedial Subthalamic Nucleus for Treatment-Resistant Obsessive-Compulsive disorder. World Neurosurg. 2017;104:1048.e9-1048.e13.	We recognise new developments in management of OCD via deep brain and transcranial magnetic stimulation in our proposal to update the guideline. Thank you for highlighting references related to the guideline. Opinion/narrative paper (Mian et al. 2010), single case study (Mulders et al. 2017) and a very small study (Farrand et al. 2018 n=7) are not qualified for inclusion in this surveillance however, we will add the references (Luyten et al. 2016; Raymaekers et al. 2017) to this surveillance review. During the update of the guideline, developers may consider the highlighted studies for inclusion.

		doi:10.1016/j.wneu.2017.05.067. 4.Mian MK, Campos M, Sheth SA, Eskandar EN. Deep brain stimulation for obsessive-compulsive disorder: past, present, and future. Neurosurg Focus. 2010;29(2):E10. doi:10.3171/2010.4.FOCUS10107. 5. Luyten L, Hendrickx S, Raymaekers S, Gabriels L, Nuttin B. Electrical stimulation in the bed nucleus of the stria terminalis alleviates severe obsessive-compulsive disorder. Mol Psychiatry. 2016;21(9):1272-1280. doi:10.1038/mp.2015.124. The overall amount of clinical evidence has increased, especially for long-term follow-up in a real-world clinical setting.	
Royal College of Nursing		Nurses caring for people with Obsessive-compulsive disorder and body dysmorphic disorder have reviewed the proposal and have no comments to submit at this stage.	Thank you.
Department of Health and Social Care		I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.	Thank you.
NHS England	**SC & IAPT:** Yes **CYPMH:** See comments	**CYPMH:** There is no mention of the significant transformation of mental health services for children and adolescents as one of the drivers, particularly school-based interventions and interventions from para-professionals (such as Educational Mental Health Practitioners and Children's Wellbeing Practitioners). This is a critical issue for NHSE in terms of including digitally supported low intensity psychological treatments in the training of this	Thank you for your comment. We recognise there have been advances in the evidence base which has fed into our proposal to update the guideline. Additionally, change to the service delivery landscape, including provision of Child and Adolescent Mental Health Services [CAMHS] indicates a need to update the guideline so that it remains relevant to clinical practice in the UK. This is reflected in our proposal to update the

		group or not. **IAPT:** no comments **SC:** A huge amount of OCD treatment trial data and a small but significant amount of BDD treatment trial data has accrued since 2006, only partly identified in the 2013 evidence update, that arguably now makes the original guidelines redundant.	guideline and will be passed onto the developer for consideration during the update.
OCD-UK	Yes	The guideline may benefit from updates in certain areas. However, updated or not, OCD-UK remains concerned at the general lack of implementation across mental health services for the original NICE guideline, although we recognise this may fall outside the scope of this consultation.	Thank you for your comment. Your concern about implementation is reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.

Is transcranial magnetic stimulation treatment currently used in clinical practice for treatment of obsessive compulsive disorder (OCD)? Are you aware of any evidence relating to this intervention?

Stakeholder	Overall response	Comments	NICE response
Association for Family Therapy and Systemic Practice - UK		We are not aware of any evidence that TMS is effective. We think it is important that any recommendations consider both the evidence base and the potential risks of	Thank you for your comment. We have identified evidence through this surveillance review to suggest transcranial magnetic stimulation is an effective treatment for OCD, which is a trigger to suggest the guideline should be

		adverse effects, particularly in terms of neurodevelopment for children.	updated; as this intervention is not currently covered. However, the committee will consider a number of factors when making their recommendations including evidence of efficacy and any risks associated with the intervention.
British Association for Psychopharmacology	As far as I know, rTMS is not routinely used clinically in the UK. There are several individual RCTs and metaanalyses showing effectiveness for rTMS in OCD and the deep TMS approach is now FDA approved for OCD in the US.	Here are some relevant examples; 1. Dell'Osso B1, Cremaschi L1, Oldani L1, Altamura AC1 New Directions in the Use of Brain Stimulation Interventions in Patients with Obsessive-Compulsive Disorder. Curr Med Chem. 2017 May 4. doi: 10.2174/0929867324666170505113631. [Epub ahead of print] 2. Trevizol AP, Shiozawa P, Cook IA, Sato IA, Kaku CB, Guimarães FB, Sachdev P, Sarkhel S, Cordeiro Q. Transcranial Magnetic Stimulation for Obsessive-Compulsive Disorder: An Updated Systematic Review and Meta-analysis. J ECT. 2016 Dec;32(4):262-266. 3. Carmi L, Alyagon U, Barnea-Ygael N, Zohar J, Dar R, Zangen A.Clinical and electrophysiological outcomes of deep TMS over the medial prefrontal and anterior cingulate cortices in OCD patients. Brain Stimul. 2018 Jan - Feb;11(1):158-165. doi: 10.1016/j.brs.2017.09.004. Epub 2017 Sep 6.	Thank you for your comment. Thank you for the references. The highlighted studies (Dell'Osso et al. 2017; Trevizo et al. 2016; Carmi et al. 2017) were identified and assessed in this surveillance review. During the update of the guideline, developers may consider the highlighted studies for inclusion.

Royal College of Paediatrics and Child Health	Not answered	No comments provided	Thank you.
Sheffield Health and Social Care NHS Foundation Trust	No	This treatment is not available locally and we are not aware of evidence relating to it's use.	Thank you for your comment. This feedback has been added to the surveillance report.
OCD Action	No	We are only aware of it being available to those who can afford to pay privately for it and have not heard of anyone being offered or receiving such treatment under the NHS.	Thank you for your comment. This feedback has been added to the surveillance report.
Royal College of Psychiatrists	?	Not in the paediatric age range to my knowledge No RCTs in this age-group. There are several individual RCTs and metaanalyses in adults, showing effectiveness for rTMS in OCD and the deep TMS approach is now FDA approved for OCD in the US. Dell'Osso B1, Cremaschi L1, Oldani L1, Altamura AC1 New Directions in the Use of Brain Stimulation Interventions in Patients with Obsessive-Compulsive Disorder.	Thank you for your comment. This feedback has been added to the surveillance report. Thank you for the references. The highlighted studies (Dell'Osso et al. 2017; Trevizo et al. 2016; Carmi et al. 2017) were identified and assessed in this surveillance. During the update of the guideline, developers may consider the highlighted studies for inclusion.

		Curr Med Chem. 2017 May 4. doi: 10.2174/0929867324666170505113631. [Epub ahead of print] Revizol AP, Shiozawa P, Cook IA, Sato IA, Kaku CB, Guimarães FB, Sachdev P, Sarkhel S, Cordeiro Q. Transcranial Magnetic Stimulation for Obsessive-Compulsive Disorder: An Updated Systematic Review and Meta-analysis. J ECT. 2016 Dec;32(4):262-266. Carmi L, Alyagon U, Barnea-Ygael N, Zohar J, Dar R, Zangen A.Clinical and electrophysiological outcomes of deep TMS over the medial prefrontal and anterior cingulate cortices in OCD patients. Brain Stimul. 2018 Jan - Feb;11(1):158-165. doi: 10.1016/j.brs.2017.09.004. Epub 2017 Sep 6.	
Medtronic	None	No additional comments	Thank you.
Royal College of Nursing	Not answered	No comments provided	Thank you.
Department of Health and Social Care	Not answered	No comments provided	Thank you.
NHS England	**SC:** As far as I know, rTMS is not routinely used clinically in the	**IAPT:** no comments **CYPMH:** no comments	Thank you for your comment. Thank you for the references. The highlighted studies (Dell'Osso et al. 2017; Trevizo et al. 2016; Carmi et al. 2017) were identified and

	UK. There are several individual RCTs and metaanalyses showing effectiveness for rTMS in OCD and the deep TMS approach is now FDA approved for OCD in the US.	SC: Here are some relevant examples; 1. Dell'Osso B1, Cremaschi L1, Oldani L1, Altamura AC1 New Directions in the Use of Brain Stimulation Interventions in Patients with Obsessive-Compulsive Disorder. Curr Med Chem. 2017 May 4. doi: 10.2174/0929867324666170505113631. [Epub ahead of print] 2. Trevizol AP, Shiozawa P, Cook IA, Sato IA, Kaku CB, Guimarães FB, Sachdev P, Sarkhel S, Cordeiro Q. Transcranial Magnetic Stimulation for Obsessive-Compulsive Disorder: An Updated Systematic Review and Meta-analysis. J ECT. 2016 Dec;32(4):262-266. 3. Carmi L, Alyagon U, Barnea-Ygael N, Zohar J, Dar R, Zangen A.Clinical and electrophysiological outcomes of deep TMS over the medial prefrontal and anterior cingulate cortices in OCD patients. Brain Stimul. 2018 Jan - Feb;11(1):158-165. doi: 10.1016/j.brs.2017.09.004. Epub 2017 Sep 6.	assessed through our surveillance. During the update of the guideline, developers may consider the highlighted studies for inclusion.

OCD-UK	No	There remains no evidence for the long-term effectiveness of TMS to treat OCD. The studies referenced in the surveillance proposal consultation document highlighted that only short-term therapeutic effects were assessed with no evidence to demonstrate long term benefits, nor comparison to see effectiveness against existing evidence based treatments (CBT/SSRI). The research listed also highlight that larger sample sizes are fundamentally needed to clarify the precise impact of TMS in OCD symptoms. As the original 2005 NICE guidelines stated there is insufficient evidence upon which to base a recommendation for the use of transcranial magnetic stimulation in the treatment of OCD. What was true then appears to be the same at this time.	Thank you for your comment. We have identified evidence through this surveillance review to suggest transcranial magnetic stimulation is an effective treatment for OCD, which is a trigger to suggest the guideline should be updated; as this intervention is not currently covered. During the guideline update, the committee will consider the evidence base, including comparison with other established treatments, and other factors when making recommendations.

In practice, are SSRIs increasingly being used as a first-line treatment for young people with OCD?

Stakeholder	Overall response	Comments	NICE response
Association for Family Therapy and Systemic Practice - UK	Not answered	No comments provided	Thank you.
British Association for Psychopharmacology	No	A published audit of specialist CAMHS OCD services showed that since the introduction of the 2006 NICE guideline there had been a reduction in the use of SSRI relative to psychological therapies in young people with OCD, while at the same the 'baseline' severity of the OCD	Thank you for your comment. The highlighted audit (Nair et al.2015) was identified and assessed through our surveillance. During the update of the guideline, developers may consider the highlighted study for inclusion.

		in young patients presenting for treatment had increased, suggesting a harmful effect of this change in practice. Please see; Nair A, Wong YL, Barrow F, Heyman I, Clark B, Krebs G. Has the first-line management of paediatric OCD improved following the introduction of NICE guidelines? Arch Dis Child. 2015 Apr;100(4):416-7. doi: 10.1136/archdischild-2014-307900. Epub 2014 Dec 30. The above change in care may relate to the following NICE recommendations that in my opinion warrant reconsideration; 1.5.5.2 Following multidisciplinary review, for a child (aged 8–11 years) with OCD or BDD with moderate to severe functional impairment, if there has not been an adequate response to CBT (including ERP) involving the family or carers, the addition of an SSRI to ongoing psychological treatment may be considered. There is a real concern that the recommendation to reserve SSRI in young people with OCD to a second line treatment, for those for whom CBT has failed, based on arguably uncorroborated data that SSRI might induce unwanted suicidal behaviour, requires urgent reconsideration as it is likely to be adversely impacting on practice, prolonging duration of illness and adversely affecting long-term outcomes.	We recognise the concern about reserving SSRI in young people with OCD to a second line treatment and also limited availability of CAMHS consultants and its impact on patients. These concerns are reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.

		1.5.6.1 An SSRI should only be prescribed to children and young people with OCD or BDD following assessment and diagnosis by a child and adolescent psychiatrist who should also be involved in decisions about dose changes and discontinuation. The general unavailability of CAMHS consultants is making this recommendation well high impossible to enact in the UK. Moreover I cannot see its justification in this group of young individuals, for whom the risk of harm from SSRI compared to benefit is relatively low. Indeed, there is a real and growing problem for those young people aged 16-18y receiving treatment in IAPTS (please see my comments below), who are often unable to access a CAMHS consultant owing to local Trust policies, and for whom GPs are no longer able to provide SSRI. These cases tend to have to wait until they reach 18y before the right treatment with SSRI can be prescribed. This prolongs the duration of untreated illness and is associated with great suffering for the patients and their families/carers.	
Royal College of Paediatrics and Child Health	Not answered	No comments provided	Thank you.

Sheffield Health and Social Care NHS Foundation Trust	Don't know	We are not aware of specific evidence on this.	Thank you for your comment.
OCD Action	Yes	This is also true of most adults who contact us and seems to be due to a lack of awareness by clinicians, particularly GPs, of the NICE guideline or the availability/benefits/effectiveness of CBT or the difficulty in accessing CBT locally.	Thank you for your comment. We have noted that adequate CBT provision for people with OCD is often not available through Improving Access to Psychological Therapies Services (IAPTS). This is despite OCD being listed as a condition that is covered by the IAPTS programme which aims to improve the delivery of, and access to, evidence-based psychological therapies within the NHS. This implementation issue is reflected in our surveillance report and contributes to our proposal to update the guideline.
Royal College of Psychiatrists	?	The intention of the original guideline was not that SSRIs should be withheld if CBT is not appropriate, not wanted or not available. SSRIs may be used first line but CBT should be offered, and guideline must make clear that this is the first line treatment of choice. However, a published audit of specialist CAMHS OCD services showed that since the introduction of the 2006 NICE guideline there had been a reduction in the use of SSRI relative to psychological therapies in young people with OCD, while at the same the 'baseline' severity of the OCD in young patients presenting for treatment had	Thank you for your comment. We recognise the concern about reserving SSRI in young people with OCD to a second line treatment and also limited availability of CAMHS consultants and its impact on patients. These are reflected in our proposal to update the guideline. Thank you for the reference. The highlighted audit (Nair et al. 2015) was identified and assessed through our surveillance and contributed to the proposal to update the guideline. During the update of the guideline, developers may also consider the result of the highlighted study.

		increased, suggesting a harmful effect of this change in practice. There was an noteworthy rise in non-NICE compliant therapies being offered to cases of OCD within the confines of this audited patient sample. In light of this, is the weighting of the current recommendations still correct and best evidence-based? Please see; Nair A, Wong YL, Barrow F, Heyman I, Clark B, Krebs G. Has the first-line management of paediatric OCD improved following the introduction of NICE guidelines? Arch Dis Child. 2015 Apr;100(4):416-7. doi: 10.1136/archdischild-2014-307900. Epub 2014 Dec 30.	
Medtronic	None	No additional comments	Thank you.
Royal College of Nursing	Not answered	No comments provided	Thank you.
Department of Health and Social Care	Not answered	No comments provided	Thank you.

NHS England	**SC:** no	**IAPT:** no comments **CYPMH:** There is a major issue in relation to SSRIs being first line treatment in terms of the context, but this is in the scope. This also has bearing on OCD being initially addressed in schools (as per NICE guideline CG31) or this is revised to make SSRIs the first line intervention which would not be compatible with how services are currently delivered. **SC:** A published audit of specialist CAMHS OCD services showed that since the introduction of the 2006 NICE guideline there had been a reduction in the use of SSRI relative to psychological therapies in young people with OCD, while at the same the 'baseline' severity of the OCD in young patients presenting for treatment had increased, suggesting a harmful effect of this change in practice. Please see; Nair A, Wong YL, Barrow F, Heyman I, Clark B, Krebs G. Has the first-line management of paediatric OCD improved following the introduction of NICE guidelines? Arch Dis Child. 2015 Apr;100(4):416-7. doi: 10.1136/archdischild-2014-307900. Epub 2014 Dec 30.	Thank you for your comment. The highlighted audit (Nair et al. 2015) was identified and assessed through our surveillance. During the update of the guideline, developers may also consider the result of the highlighted study. We recognise the concern about reserving SSRI in young people with OCD to a second line treatment and also limited availability of CAMHS consultants and its impact on patients. These are reflected in our proposal to update the guideline. Information obtained through the surveillance review, including feedback from stakeholders through this consultation, will be passed onto developers for consideration during the update of the guideline.

		The above change in care may relate to the following NICE recommendations that in my opinion warrant reconsideration; 1.5.5.2 Following multidisciplinary review, for a child (aged 8–11 years) with OCD or BDD with moderate to severe functional impairment, if there has not been an adequate response to CBT (including ERP) involving the family or carers, the addition of an SSRI to ongoing psychological treatment may be considered. There is a real concern that the recommendation to reserve SSRI in young people with OCD to a second line treatment, for those for whom CBT has failed, based on arguably uncorroborated data that SSRI might induce unwanted suicidal behaviour, requires urgent reconsideration as it is likely to be adversely impacting on practice, prolonging duration of illness and adversely affecting long-term outcomes. 1.5.6.1 An SSRI should only be prescribed to children and young people with OCD or BDD following assessment and diagnosis by a child and adolescent psychiatrist who should also be involved in decisions about dose changes and discontinuation. The general unavailability of CAMHS consultants is making this recommendation well high impossible to enact in the UK. Moreover I cannot see its justification in this group of	

		young individuals, for whom the risk of harm from SSRI compared to benefit is relatively low. Indeed, there is a real and growing problem for those young people aged 16-18y receiving treatment in IAPTS (please see my comments below), who are often unable to access a CAMHS consultant owing to local Trust policies, and for whom GPs are no longer able to provide SSRI. These cases tend to have to wait until they reach 18y before the right treatment with SSRI can be prescribed. This prolongs the duration of untreated illness and is associated with great suffering for the patients and their families/carers.	
OCD-UK	**Yes**	This question would be impossible to answer conclusively without data from CAMHS. Anecdotally 60% of people responding to our survey answered yes they felt SSRI's are increasingly being offered as a first-line treatment for young people with OCD. The majority felt SSRI's should only be offered alongside psychological therapy, and only when side effects have been adequately discussed by the prescribing doctor to child and where appropriate their parent/guardian. Attention is drawn to the following paper which concludes that in children and adolescents the risk of suicidality and aggression doubled.	Thank you for your comment. Thank you for the reference. We will add the highlighted study (Sharma et al. 2016) to this surveillance review. During the update of the guideline, developers may consider the highlighted studies for inclusion. Additionally, feedback from stakeholders through this consultation, will be passed onto developers for consideration during the update of the guideline.

		Suicidality and aggression during antidepressant treatment: systematic review and meta-analyses based on clinical study reports BMJ 2016; 352 doi: https://doi.org/10.1136/bmj.i65 (Published 27 January 2016) Cite this as: BMJ 2016;352:i65 Tarang Sharma, Louise Schow Guski et al. **So we would like the NICE Guidelines to be clear that prescribing health professionals should take time to inform of potential side effects and offer guidance to parents/guardians on monitoring.**	

How often people with OCD are referred to IAPTS (improving access to psychological therapies services) and are there any barriers with access to treatment offered through IAPTS?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Association for Family Therapy and Systemic Practice - UK		IAPT for children and young people includes therapists trained in systemic practice who can offer interventions other than CBT. Clinical practice includes more therapeutic models than solely CBT and we feel the NICE guidelines should include these. RCT study evaluating Individual Cognitive Behavioral Therapy (ICBT) vs. Family Based Cognitive Behavioral Therapy vs. Family based Education, Support and Attention	Thank you for your comment and highlighting that treatment options go beyond CBT. We recognise there have been advances in the evidence base around psychological treatment options which has fed into our proposal to update the guideline. Thank you for the references. We will add the highlighted ongoing study (Pietrabissa et al.) to the issues log for this guideline. During the update of the guideline, developers may consider the results the

		therapy (FESA) for young people with anxiety disorders. ICBT, FCBT and FRSA shown to be equally effective in treating factors and adaptive functioning deficits associated with anxiety. Suveg, Hudson et al.(2009) Cognitive-behavioral therapy for anxiety-disordered youth: Secondary outcomes from a randomized clinical trial evaluating child and family modalities. Journal of Anxiety Disorders 23 (2009) 341–349 Banting & Lloyd (2017) A case study integrating CBT with narrative therapy externalizing techniques with a child with OCD: How to flush away the Silly Gremlin. A single-case experimental design J. Child and Adolescent Psychiatric Nursing https://doi.org/10.1111/jcap.12173 this documents the use of an effective narrative therapy practice of externailising, integrated with CBT in OCD. Alan McLuckie (2006) Narrative Family Therapy for Paediatric Obsessive Compulsive Disorder, Journal of Family Psychotherapy, 16:4, 83-106, DOI: 10.1300/J085v16n04_07 A meta-analysis showed systemic therapies are effective in various conditions in adults, including OCD: Martin Pinquart, Barbara Oslejsek & Daniela Teubert (2016) Efficacy of systemic therapy on adults with mental disorders: A meta-analysis, Psychotherapy Research, 26:2, 241-257, DOI: 10.1080/10503307.2014.935830 There is an ongoing study looking at the effectiveness of Brief Strategic Therapy (a systemic therapy) for OCD: Pietrabissa G, Manzoni GM, Gibson P, et al Brief strategic therapy for obsessive–compulsive disorder: a clinical and research protocol of a one-group observational study BMJ Open 2016;6:e009118. doi: 10.1136/bmjopen-2015-009118	highlighted study if results are published. We will include the meta-analysis (Pinquart et al. 2016) to this surveillance review. A single case study (Banting & Lloyd, 2017) and studies before 2013 (date of Evidence Update) (McLuckie et al.2006; Hudson et al, 2009) are not qualified for inclusion in this surveillance. However, the developers may include these studies in the evidence reviews conducted for the update of the guideline. Finally, feedback from stakeholders through this consultation, will be passed onto developers for consideration during the update of the guideline.

British Association for Psychopharmacology	Almost always and there are huge barriers related to service configuration (limited number of therapy sessions available, unavailability of a psychiatrist to prescribe medication) and staff competencies.	The recent introduction of the IAPTS services have changed service provision universally that affects the level of care at which adults and in many areas young people with OCD aged 16-18y are now receiving treatment. As the level of 'risk' is viewed as low, most people with OCD are being referred to IAPTS instead of secondary care mental health services, where medication management (optimised (often high) dose SSRI or augmentation with antipsychotic) or adequate CBT provision for OCD (at least 16 hours face to face individual CBT involving exposure and response prevention, home-based therapy) is often not available.They often 'drop out' of care as a result. IAPTS, while providing good access for some forms of CBT, may have the unintended effect of denying people with OCD the most effective form of treatment in terms of labour intensive CBT and /or medication for the OCD. As a consultant psychiatrist working both in a highly specialised OCD service and as a consultant in IAPTS, I see many people 'falling through the gaps" in services as a result of being referred to iapts. As medical adviser of an OCD charity, I hear of cases such as these approaching the charity's advocacy service asking for help to navigate NHS services to get the care they need.	Thank you for your comment. We recognise the concern that people with OCD are being referred to IAPTS instead of secondary care mental health services, where medication management or adequate CBT provision for OCD is often not available. The surveillance review of the guideline has also indicated that the stepped care model needs to be adjusted to take account of the introduction of IAPTS services and the needs of young people with OCD. These issues have been captured in the surveillance review and have contributed to our proposal to update the guideline.
Royal College of Paediatrics and Child Health	Not answered	No comments provided	Thank you.
Sheffield Health and Social Care NHS Foundation Trust	Yes	People with OCD are referred to and able to access evidence based treatment in our local IAPT service. We do not have data on numbers of people. In practice some patients report difficulties in access.	Thank you for your comment. This stakeholder consultation has raised mixed views about access to IAPTS services therefore it is proposed to update the guideline to

			ensure the recommendations take account of current service delivery and provision of mental health.
OCD Action	Yes, very often.	Common barriers cited by individuals include long waiting times – reports to us of individuals waiting longer than 8 months to start treatment despite waiting time targets being in place; inaccessibility of IAPTS for some individuals due to the severity or nature of their OCD and a failure of IAPTS to make reasonable adjustments under the Equality Act 2010. For example many individuals struggle to attend appointments in the morning or at any time out of their home; often individuals are offered no choice as to mode of assessment with some people offered only telephone assessments when they would prefer face-to-face. Often individuals report being offered trainee therapists or therapists with no relevant experience in OCD (or related conditions). In addition, individuals are still not always provided with OCD-specific CBT with Exposure Response Prevention (ERP) (IAPTS do not record this data) sometimes because OCD is not specifically diagnosed/looked for which may possibly be linked to the over use of GAD-7 & PHQ-9 rather than the OCI as a diagnostic tool/outcome measure. No IAPTS or equivalent services are available outside England.	Thank you for your comment and for highlighting barriers with access to treatment through local IAPTS. These barriers have been captured in the surveillance report and contribute to the proposal to update the guideline.

Royal College of Psychiatrists	Yes	CBT for OCD is in the curriculum for CYP IAPT. CY-IAPT and IAPT services have been introduced with significant national roll-out since the original NICE guidance was published. This has important implications. Given the points made at 5 below , regarding the current stepped care model, it seem appropriate that the NICE recommended model of care, is given very careful thought in the context of IAPT and CY-IAPT services i.e. is the current emphasis on CY-IAPT and IAPT services, perhaps delaying the commencement of drug based therapies and in turn are medication based therapies given the correct level of emphasis in the current NICE guidance for OCD.	Thank you for your comment. We recognise that the service delivery and provision of mental health (including Child and Adolescent Mental Health Services [CAMHS]) has changed since the guideline was developed indicating a need to update the guideline so that it remains relevant to clinical practice in the UK.
Medtronic	None	No additional comments	Thank you.
Royal College of Nursing	Not answered	No comments provided	Thank you.
Department of Health and Social Care	Not answered	No comments provided	Thank you.
NHS England	**SC:** Almost always and there are huge barriers related to service configuration (limited number of therapy	**CYPMH:** no comments **IAPT:** NHS Digital's latest Annual IAPT report, which covers the 2017/18 financial year, indicated that of all the people who were assessed in IAPT, 16716 had OCD as their main problem descriptor. 11,665 had a course of treatment in IAPT. The mean recovery rate for treated cases was 50.2% and 65.3 % were coded as reliably improved.	Thank you for your comment. We recognise the concern that people with OCD are being referred to IAPTS instead of secondary care mental health services, where medication management or adequate CBT provision for OCD is often not available. The surveillance review of the guideline has also indicated that the stepped care model needs to be adjusted to take

	sessions available, unavailability of a psychiatrist to prescribe medication) and staff competencies.	**SC:** The recent introduction of the IAPTS services have changed service provision universally that affects the level of care at which adults and in many areas young people with OCD aged 16-18y are now receiving treatment. As the level of 'risk' is viewed as low, most people with OCD are being referred to IAPTS instead of secondary care mental health services, where medication management (optimised (often high) dose SSRI or augmentation with antipsychotic) or adequate CBT provision for OCD (at least 16 hours face to face individual CBT involving exposure and response prevention, home-based therapy) is often not available.They often 'drop out' of care as a result. IAPTS, while providing good access for some forms of CBT, may have the unintended effect of denying people with OCD the most effective form of treatment in terms of labour intensive CBT and /or medication for the OCD. As a consultant psychiatrist working both in a highly specialised OCD service and as a consultant in IAPTS, I see many people 'falling through the gaps" in services as a result of being referred to iapts. As medical adviser of an OCD charity, I hear of cases such as these approaching the charity's advocacy service asking for help to navigate NHS services to get the care they need.	account of the introduction of IAPTS services and the needs of young people with OCD. These issues have been captured in the surveillance review and have contributed to our proposal to update the guideline.
OCD-UK	Yes	This question would be impossible to answer conclusively without data from NHS England. Anecdotally, the majority of our users self-refer, or when seeking help through a GP are given the telephone number to self-refer to local IAPT	Thank you for your comment. Your concern about access to IAPTs and the identified barriers are reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.

		services. This is backed up with data from a survey with almost 58% of responders saying they went through an IAPT service and 18% unsure which service they had accessed. It is our belief that that there remains significant barriers to access treatment through local IAPT services. These include: - Significant wait times - GPs not helping patients make the referral - Limited amount of treatment sessions, then being told they're not eligible for more therapy sessions for 3 months - Offered non evidence based treatment through IAPT - Lack of sensitivity from telephone assessment practitioners. - Being told to confirm first appointment by telephone within a few days of being offered or lose appointment (hard to do with anxiety problems) - Being offered group therapy when preference individual - Being assigned a therapist with absolutely no understanding of OCD - Failure to access OCD correctly during telephone assessment and inaccurately being diagnosed with GAD or similar - Limited access to treatment out of regular working hours.	

		At this time it is our belief that far too many IAPT service therapists have insignificant knowledge and understanding of OCD to offer treatment to patients with moderate to severe OCD. (see below).	

Does the stepped care pathway in CG31 need reconsideration? If so, why?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Association for Family Therapy and Systemic Practice - UK	Not answered	No comments provided	Thank you.
British Association for Psychopharmacology	Yes	1.3 Step 1: awareness and recognition Since 2005 there has been considerable research interest in the 'toxic' effect of the very long duration of untreated OCD (still @10 y in adults despite NICE 2006) e.g. Rapoport JL, Inoff-Germain G, Weissman MM, Greenwald S, Narrow WE, Jensen PS, et al. Childhood obsessive–compulsive disorder in the NIMH MECA study: Parent versus child identification of cases. J Anxiety Disord 2000; 14: 535–48 Dell'Osso B, Camuri G, Benatti B, Buoli M, Altamura AC. Differences in latency to first pharmacological treatment (duration of untreated illness) in anxiety disorders: a study on patients with panic disorder, generalized anxiety disorder and obsessive-compulsive disorder. Early intervention in psychiatry 2013b:7(4), 374–80. Poyraz CA, Turan Ş, Sağlam NG, Batun GÇ, Yassa A, Duran A. Factors associated with the duration of untreated illness	Thank you for your comment. We recognise the concerns about reserving SSRI in young people with OCD to a second line treatment and also limited availability of CAMHS consultants and its impact on patients. These are reflected in our proposal to update the guideline. Thank you for the references. The highlighted studies were all identified and assessed through surveillance review. Studies not specific to OCD (Dell'Osso et al. 2013c), and out of date for this surveillance (Rapoport et al.2000) were not qualified for inclusion. Note that feedback from stakeholders through this consultation will be passed onto developers for consideration alongside the evidence during the update of the guideline. Your concern about stepped care pathway is reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.

		among patients with obsessive compulsive disorder. Compr Psychiatry. 2015;58:88-93. Dell'Osso B, Glick ID, Baldwin DS, Altamura AC. Can long-term outcomes be improved by shortening the duration of untreated illness in psychiatric disorders? A conceptual framework. Psychopathology. 2013c;46(1):14-21. Vigne P, Fortes P, Dias RV, et al. Duration of untreated illness in a cross-diagnostic sample of obsessive-compulsive disorder, panic disorder, and social anxiety disorder. CNS Spectr. 2018:(in press) Beyond recognition, the stepped care model is based on offering CBT as a first line treatment. However, a recent NIHR-funded meta-analysis (ref below) cast serious questions on the 2006 recommendations that CBT with ERP was the most effective form of CBT and drew attention to the serious limitations inherent in the published CBT studies upon which this recommendation was based, as the RCTS mainly included patients also taking SSRI. This was not taken into account in the original NICE guidelines and arguably now needs reconsideration. Skapinakis P, Caldwell DM, Hollingworth W, Bryden P, Fineberg NA, Salkovskis P, Welton NJ, Baxter H, Kessler D, Churchill R, Lewis G. Pharmacological and psychotherapeutic interventions for management of obsessive-compulsive disorder in adults: a systematic review and network meta-analysis. Lancet Psychiatry. 2016;3(8):730-739. In addition, NICE found some health economic evidence for greater cost effectiveness associated with SSRI versus CBT in adults with OCD, but chose to recommend in the stepped care pathway either SSRI or CBT as equivalent first line treatments, with the combination of SSRI with CBT	

		reserved for those who fail first line treatments, as the evidence at the time was relatively slim. A recent study comparing CBT, SSRI and the combination of SSRI with CBT produced a health economic evaluation that showed a health economic advantage for SSRI over CBT with a large effect size (see ref below). This finding adds weight to the original NICE health economic evaluation and adds to the argument for a reconsideration of the original recommendations for first line care. Fineberg NA, Baldwin DS, Drummond LM, Wyatt S, Hanson J, Gopi S, Kaur S, Reid J, Marwah V, Sachdev RA, Pampaloni I, Shahper S, Varlakova Y, Mpavaenda D, Manson C, O'Leary C, Irvine K, Monji-Patel D, Shodunke A, Dyer T, Dymond A, Barton G, Wellsted D. Optimal treatment for obsessive compulsive disorder: a randomized controlled feasibility study of the clinical-effectiveness and cost-effectiveness of cognitive-behavioural therapy, selective serotonin reuptake inhibitors and their combination in the management of obsessive compulsive disorder. Int Clin Psychopharmacol. 2018 Nov;33(6):334-348. doi: 10.1097/YIC.0000000000000237 For the reasons discussed in point 4 and 5, the stepped care model needs to be adjusted to take account of the introduction of IAPTS services and the needs of young people with OCD.	
Royal College of Paediatrics and Child Health	Not answered	No comments provided	Thank you.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

Sheffield Health and Social Care NHS Foundation Trust	Yes	The nature of OCD is that it is a spectrum of presentations. Its presentation is ranges from problems associated with checking and overt behaviours to pure thought based obsessions. Identification at an early stage could enable the person to have the best targeted treatment in line with the present research and recent developments in how therapy can be delivered. The stepped care model itself is not a potential barrier, but how it's operated within the system e.g. you have to go through the steps. This is in contrast to the original M.A.P.L.E. paper which is about levels of entry, appropriate to need rather than steps a person has to go through.	Thank you for your comment. We recognise that service delivery and provision of mental health (including Child and Adolescent Mental Health Services [CAMHS]) has changed since the guideline was developed indicating a need to update the guideline so that it remains relevant to clinical practice in the UK.
OCD Action	Yes	Currently there is no provision for those individuals who remain treatment resistant at the end of the existing stepped care pathway. The guideline assumes that an intervention has been offered and/or attempted before an individual's treatment is stepped up but it is essential that the individual should be treated at the most appropriate step for the severity of their condition.	Thank you for your comment. Your concern about a gap in the stepped care pathway for individuals who are treatment resistant is reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.
Royal College of Psychiatrists	?	A recent important NIHR funded metanalysis of treatment in adult patients puts into serious question the current NICE recommended emphasis on CBT treatments. It draws attention to the fact that many of the subjects included in the influential trails were in fact on SSRI medications and therefore brings into questions the conclusions drawn. This merits careful review and reconsideration, in light of this study. Skapinakis P, Caldwell DM, Hollingworth W, Bryden P, Fineberg NA, Salkovskis P, Welton NJ, Baxter H, Kessler D, Churchill R, Lewis G. Pharmacological and psychotherapeutic interventions for management of	Thank you for your comment. Introduction of new pharmacological interventions and new augmentation therapies were identified through the surveillance review and contributed to our proposal to update the guideline. Thank you for the reference. The highlighted references including NIHR funded meta-analysis (Skapinakis et al. 2016; Fineberg et al. 2018) were identified and assessed in this surveillance review. Finally, We recognise the concern about reserving SSRI in young people with OCD to a second line treatment and this is reflected in our proposal to update the guideline.

		obsessive-compulsive disorder in adults: a systematic review and network meta-analysis. Lancet Psychiatry. 2016;3(8):730-739. Also, at the time of writing of the current recommendations. NICE found some health economic evidence for greater cost effectiveness associated with SSRI versus CBT in adults with OCD, but chose to recommend in the stepped care pathway either SSRI or CBT as equivalent first line treatments, with the combination of SSRI with CBT reserved for those who fail first line treatments, as the evidence at the time was relatively slim. A recent study comparing CBT, SSRI and the combination of SSRI with CBT produced a health economic evaluation that showed a health economic advantage for SSRI over CBT with a large effect size (see ref below). This finding adds weight to the original NICE health economic evaluation and adds to the argument for a reconsideration of the original recommendations for first line care. Fineberg NA, Baldwin DS, Drummond LM, Wyatt S, Hanson J, Gopi S, Kaur S, Reid J, Marwah V, Sachdev RA, Pampaloni I, Shahper S, Varlakova Y, Mpavaenda D, Manson C, O'Leary C, Irvine K, Monji-Patel D, Shodunke A, Dyer T, Dymond A, Barton G, Wellsted D. Optimal treatment for obsessive compulsive disorder: a randomized controlled feasibility study of the clinical-effectiveness and cost-effectiveness of cognitive-behavioural therapy, selective serotonin reuptake inhibitors and their combination in the management of obsessive compulsive disorder. Int Clin Psychopharmacol. 2018 Nov;33(6):334-348. doi: 10.1097/YIC.0000000000000237	

		Only commenting on child – it should be perhaps be clear that a child may start an SSRI before CBT if appropriate – but not a permission to let services underprovide CBT.	
Medtronic	None	No additional comments	Thank you.
Royal College of Nursing	Not answered	No comments provided	Thank you.
Department of Health and Social Care	Not answered	No comments provided	Thank you.
NHS England	**SC:** yes	**IAPT:** no comments **CYPMH:** no comments **SC:**1.3 Step 1: awareness and recognition Since 2005 there has been considerable research interest in the 'toxic' effect of the very long duration of untreated OCD (still @10 y in adults despite NICE 2006) e.g. Rapoport JL, Inoff-Germain G, Weissman MM, Greenwald S, Narrow WE, Jensen PS, et al. Childhood obsessive–compulsive disorder in the NIMH MECA study: Parent versus child identification of cases. J Anxiety Disord 2000; 14: 535–48 Dell'Osso B, Camuri G, Benatti B, Buoli M, Altamura AC. Differences in latency to first pharmacological treatment (duration of untreated illness) in anxiety disorders: a study on patients with panic disorder, generalized anxiety	Thank you for your comment. Introduction of new pharmacological interventions and new augmentation therapies were identified through the surveillance review and contributed to our proposal to update the guideline. Thank you for the references. The highlighted studies were all identified and assessed through surveillance review. Studies not specific to OCD (Dell'Osso et al. 2013c), and out of date for this surveillance (Rapoport et al.2000) were not qualified for inclusion.

		disorder and obsessive-compulsive disorder. Early intervention in psychiatry 2013b:7(4), 374–80. Poyraz CA, Turan Ş, Sağlam NG, Batun GÇ, Yassa A, Duran A. Factors associated with the duration of untreated illness among patients with obsessive compulsive disorder. Compr Psychiatry. 2015;58:88-93. Dell'Osso B, Glick ID, Baldwin DS, Altamura AC. Can long-term outcomes be improved by shortening the duration of untreated illness in psychiatric disorders? A conceptual framework. Psychopathology. 2013c;46(1):14-21. Vigne P, Fortes P, Dias RV, et al. Duration of untreated illness in a cross-diagnostic sample of obsessive-compulsive disorder, panic disorder, and social anxiety disorder. CNS Spectr. 2018:(in press) Beyond recognition, the stepped care model is based on offering CBT as a first line treatment. However, a recent NIHR-funded meta-analysis (ref below) cast serious questions on the 2006 recommendations that CBT with ERP was the most effective form of CBT and drew attention to the serious limitations inherent in the published CBT studies upon which this recommendation was based, as the RCTS mainly included patients also taking SSRI. This was not taken into account in the original NICE guidelines and arguably now needs reconsideration. Skapinakis P, Caldwell DM, Hollingworth W, Bryden P, Fineberg NA, Salkovskis P, Welton NJ, Baxter H, Kessler D, Churchill R, Lewis G. Pharmacological and psychotherapeutic interventions for management of obsessive-compulsive disorder in adults: a systematic review and network meta-analysis. Lancet Psychiatry. 2016;3(8):730-739.	

		In addition, NICE found some health economic evidence for greater cost effectiveness associated with SSRI versus CBT in adults with OCD, but chose to recommend in the stepped care pathway either SSRI or CBT as equivalent first line treatments, with the combination of SSRI with CBT reserved for those who fail first line treatments, as the evidence at the time was relatively slim. A recent study comparing CBT, SSRI and the combination of SSRI with CBT produced a health economic evaluation that showed a health economic advantage for SSRI over CBT with a large effect size (see ref below). This finding adds weight to the original NICE health economic evaluation and adds to the argument for a reconsideration of the original recommendations for first line care. Fineberg NA, Baldwin DS, Drummond LM, Wyatt S, Hanson J, Gopi S, Kaur S, Reid J, Marwah V, Sachdev RA, Pampaloni I, Shahper S, Varlakova Y, Mpavaenda D, Manson C, O'Leary C, Irvine K, Monji-Patel D, Shodunke A, Dyer T, Dymond A, Barton G, Wellsted D. Optimal treatment for obsessive compulsive disorder: a randomized controlled feasibility study of the clinical-effectiveness and cost-effectiveness of cognitive-behavioural therapy, selective serotonin reuptake inhibitors and their combination in the management of obsessive compulsive disorder. Int Clin Psychopharmacol. 2018 Nov;33(6):334-348. doi: 10.1097/YIC.0000000000000237 For the reasons discussed in point 4 and 5, the stepped care model needs to be adjusted to take account of the introduction of IAPTS services and the needs of young people with OCD.	

OCD-UK	Yes	The NICE guidelines should reference IAPT services within the stepped care model to help patients understand the model better. However, with each IAPT service having it's own regional name this can be confusing for patients to even know what IAPT is. By the time most patients with OCD seek help, they're beyond the clinical definition of 'mild' and closer to 'moderate'. As mentioned above, many patients will enter the pathway too severe for many IAPT services, yet are forced to go through an IAPT pathway. The OCTET research highlighted that there is no benefit in offering a low-intensity therapy as a standalone treatment for OCD. Significantly, and of concern was they also reported that people who had received a low-intensity therapy were less likely to go on to receive higher-intensity CBT. The OCTET research also reported those who received computerised CBT received no added benefit (in terms of their OCD symptoms) compared to those on the waiting list.	Thank you for your comment. Your concern about stepped care pathway is reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update. The highlighted study 'OCTET' (Lovell et al. 2017) was identified and assessed through the surveillance review. During the update of the guideline, developers may consider the highlighted study for inclusion.

Is ego-dystonic paedophilic or violent thoughts and images a reasonable consideration in risk assessment for individuals with OCD?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Association for Family Therapy and Systemic Practice - UK	Not answered	No comments provided	Thank you.
British Association for Psychopharmacology	Not sure how best to answer this- see comments	These kinds of aggressive obsessions should always be fully assessed, but if found to be ego-dystonic should not be used as evidence that the individual is at increased risk of enacting harm. In my experience, clinicians are unaware of this and are unfairly attributing risk to this kind of obsessional thought where none exists. The effect of inappropriately attributing such risk can be very harmful for the patient, as it reinforces their pathological fear that they are a risky person and acts as a barrier to treatment.	Thank you for your comment. Your concern about inappropriately attributing ego-dystonic paedophilic or violent thoughts risk in the OCD assessment is reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.
Royal College of Paediatrics and Child Health	Not answered	No comments provided	Thank you.
Sheffield Health and Social Care NHS Foundation Trust	Yes	The impact of these thoughts can be devastating on an individual fuelling depressive responses and suicidal thoughts. The patient has to endure these due to difficulties accessing appropriate treatment.	Thank you for your comment. Your concern about inappropriately attributing ego-dystonic paedophilic or violent thoughts risk in the OCD assessment and the potential impact this can have as a barrier to treatment is reflected

			in our proposal to update the guideline and will be passed onto the developer for consideration during the update.
OCD Action	No	There is no evidence that individuals with paedophilic or violent intrusive thoughts ever act on those thoughts as the thoughts more often focus on what the individual values most. Therefore, individuals with such thoughts do not pose a risk to those around them. Where the nature of intrusive thoughts means safeguarding protocols are triggered, thoughts are often misinterpreted by health or social care practitioners due to a lack of knowledge and understanding that these are simply symptoms of OCD. Additionally individuals are not kept well informed as to the reasons for safeguarding processes or provided with reassurance that their thoughts are normal and an integral part of OCD. Safeguarding processes are not always transparent and the individual is not always kept informed as to the details and progress of the process. We are regularly contacted by individuals who have been subjected to safeguarding action as a result of disclosing their intrusive thoughts (often in an attempt to secure appropriate diagnosis and treatment) resulting in severe distress to them and their families. The fear of safeguarding action can pose a significant barrier to individuals seeking help, particularly parents where their intrusive thoughts focus on their children.	Thank you for your comment. Your concern about inappropriately attributing ego-dystonic paedophilic or violent thoughts risk in the OCD assessment is reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.
Royal College of Psychiatrists	Yes	Veale, D., Freeston, M., Krebs, G., Heyman, I., & Salkovskis, P. (2009). Risk assessment and management in obsessive–compulsive disorder. Advances in Psychiatric Treatment, 15(5), 332-343. doi:10.1192/apt.bp.107.004705	Thank you for your comment. Thank you for the references. The highlighted study (Veale et al. 2009) was out of date for this surveillance and not qualified for

			inclusion in the surveillance report. However, it may be considered by developers during the update to the guideline.
Medtronic	None	No additional comments	Thank you.
Royal College of Nursing	Not answered	No comments provided	Thank you.
Department of Health and Social Care	Not answered	No comments provided	Thank you.
NHS England	**SC:** Not sure how best to answer this- see comments	These kinds of aggressive obsessions should always be fully assessed, but if found to be ego-dystonic should not be used as evidence that the individual is at increased risk of enacting harm. In my experience, clinicians are unaware of this and are unfairly attributing risk to this kind of obsessional thought where none exists. The effect of inappropriately attributing such risk can be very harmful for the patient, as it reinforces their pathological fear that they are a risky person and acts as a barrier to treatment.	Thank you for your comment. Your concern about inappropriately attributing ego-dystonic paedophilic or violent thoughts risk in the OCD assessment is reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.
OCD-UK	Yes	OCD-UK believe the advice offered by the current NICE Guidelines is sufficient, however, as highlighted above we remain concerned that the NICE Guidelines are simply not implemented and clinical teams lack knowledge and understanding of the NICE Guidelines for the Treatment of OCD. For this specific area of OCD, this lack of understanding of the NICE guidance causes significant consequence if a mental health professional involves other	Thank you for your comment. Your concern about implementation being an issue is reflected in our proposal to update the guideline. Additionally, new evidence and intelligence identified through the surveillance review indicates a need to update the guideline so that it remains relevant to clinical

		agencies because they misunderstood the risk associated with OCD. This can be evidenced by a recent report from the health ombudsman which concluded in support of OCD-UK against an IAPT service for this failing. To partly address this in addition to heightened awareness around this specific text in the guidelines, it could be worth reviewing the existing NICE Guidelines to add a specific question about this aspect of OCD into the list of 'Recognition and assessment questions' to help health professionals further understand this type of thought is a recognised unwanted and intrusive thought associated with Obsessive-Compulsive Disorder. We would like to see greater awareness amongst health professionals about this specific NICE recommendation, particularly amongst IAPT services. Some mental health services send patients referral forms with questions including: Do you care for, look after or have significant contact with children, including asking for names and addresses of those children. NICE may need to consider recommending mental health services use appropriate referral forms for patients with OCD, specifically patients with these types of unwanted obsessive thoughts may find such questions on the referral forms distressing and prevent patients completing the referral form.	practice in the UK. Feedback from stakeholders will be passed onto the developer for consideration during the update.

Do you have any comments on areas excluded from the scope of the guideline?			
Stakeholder	**Overall response**	**Comments**	**NICE response**

Association for Family Therapy and Systemic Practice - UK		For children and young people the family and school context should be included in any psychological intervention. Systemic family therapy can be a useful and effective way of moving forwards with OCD and BDD by resourcing the child and the system in which the child is. This kind of intervention is different from CBT involving the family, particularly because it avoids locating blame or responsibility in any one part of a system. Treatments (including psychological, pharmacological and other) which focus on individualistic constructions of mental health risk iatrogenic harm whereby the child can internalise difficulties and find it more difficult to access positive internal and external resources.	Thank you for your comment. We recognise there have been advances in the evidence base around psychological and pharmacological treatment options which has fed into our proposal to update the guideline.
British Association for Psychopharmacology	Yes. Third line treatments for OCD. Somatic treatments for OCD (including rtms- covered above, other forms of non invasive neurostimulation, deep brain stimulation).	Third line treatments are not covered in the original guideline. This is what the guideline currently says for patients who fail to respond to first or second line treatments; 1.5.4.7 Following multidisciplinary review, for adults with OCD if there has been no response to a full trial of at least one SSRI alone, a full trial of combined treatment with CBT (including ERP) and an SSRI, and a full trial of clomipramine alone, the following treatment options should also be considered (note, there is no evidence of the optimal sequence of the options listed below): • additional CBT (including ERP) or cognitive therapy • adding an antipsychotic to an SSRI or clomipramine • combining clomipramine and citalopram. Since the 2006 guideline (and the 2013 evidence update) there has been publication of very many RCTS of different pharmacological treatments that have a role as third line	Thank you for your comment. Thank you for the references. All highlighted studies were identified and assessed in the current surveillance review. Studies before 2013 (date of Evidence Update) were not qualified for inclusion in this surveillance. During the update of the guideline, developers may consider the highlighted studies for inclusion. Your concerns about third line and somatic treatments are reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.

		treatments for OCd that were not covered at all in the original guidelines. These pharmacological compounds are now being used in clinical practice but were not considered in the existing guideline or evidence update and therefore changes to the recommendations in this section are now needed. EG Riluzole Pittenger, C.; Bloch, M.H.; Wasylink, S.; Billingslea, E.; Simpson, R.; Jakubovski, E.; Kelmendi, B.; Sanacora, G.; Coric, V. Riluzole augmentation in treatment-refractory obsessive-compulsive disorder: a pilot randomized placebo-controlled trial. J. Clin. Psychiatry, 2015, 6, 1075-1084. Emamzadehfard, S.; Kamaloo, A.; Paydary, K.; Ahmadipour, A.; Zeinoddini, A.; Ghaleiha, A.; Mohammadinejad, P.; Zeinoddini, A.; Akhondzadeh, S. Riluzole in Augmentation of Fluvoxamine for Moderate to Severe Obsessive Compulsive Disorder: Randomized, Doubleblind, Placebo-Controlled Study. Psychiatry Clin. Neurosci., 2016 Apr 23,. doi: 10.1111/pcn.12394. Memantine Kavirajan, H. Memantine: a comprehensive review of safety and efficacy. Expert Opin. Drug Saf., 2009, 8, 89-109. Pasquini, M.; Biondi, M. Memantine augmentation for refractory obsessive-compulsive disorder. Prog. Neuropsychopharmacol. Biol. Psychiatry, 2006, 30, 1173-1175. Hezel, D.M.; Beattie, K.; Stewart, S.E. Memantine as an augmenting agent for severe	

		pediatric OCD. Am. J. Psychiatry, 2009, 166, 237. Aboujaoude, E.; Barry, J.J.; Gamel, N. Memantine augmentation in treatment-resistant obsessive-compulsive disorder: an open-label trial. J. Clin. Psychopharmacol., 2009, 29, 51- Ghaleiha, A.; Entezari, N.; Modabbernia, A.; Najand, B.; Askari, N.; Tabrizi, M.; Ashrafi, M.; Hajiaghaee, R.; Akhondzadeh, S. Memantine add-on in moderate to severe obsessivecompulsive disorder: randomized double-blind placebo-controlled study. J. Psychiatr. Res., 2013, 47, 175-180. Haghighi, M.; Jahangard, L.; Mohammad-Beigi, H.; Bajoghli, H.; Hafezian, H.; Rahimi, A.; Afshar, H.; Holsboer-Trachsler, E.; Brand, S. In a double-blind, randomized and placebocontrolled trial, adjuvant memantine improved symptoms in inpatients suffering from refractory obsessive-compulsive disorders (OCD). Psychopharmacology (Berl.), 2013, 228, 633-640. <u>Ketamine</u> Rodriguez, C.I.; Kegeles, L.S.; Levinson, A.; Feng, T.; Marcus, S.M.; Vermes, D.; Flood, P.; Simpson, H.B. Randomized controlled crossover trial of ketamine in obsessive-compulsive disorder: proof-of-concept. Neuropsychopharmacology, 2013, 38, 2475-2483. Bloch, M.H.; Wasylink, S.; Landeros-Weisenberger, A.; Panza, K.E.; Billingslea, E.; Leckman, J.F.; Krystal, J.H.; Bhagwagar, Z.; Sanacora, G.; Pittenger, C. Effects of ketamine	

		in treatment-refractory obsessive-compulsive disorder. Biol. Psychiatry, 2012, 72, 964-970. <u>Topiramate</u> Mowla, A.; Khajeian, A.M.; Sahraian, A.; Chohedri, A.H.; Kashkoli, F. Topiramate Augmentation in Resistant OCD: A Double-Blind Placebo-Controlled Clinical Trial. CNS Spectr., 2010, 15, 613-617. Berlin, H.A.; Koran, L.M.; Jenike, M.A.; Shapira, N.A.; Chaplin, W.; Pallanti, S.; Hollander, E. Double-blind, placebo-controlled trial of topiramate augmentation in treatment-resistant obsessive-compulsive disorder. J. Clin. Psychiatry, 2011, 72, 716-721. Afshar, H.; Akuchekian, S.; Mahaky, B.; Zarean, E. Topiramate augmentation in refractory obsessive-compulsive disorder: A randomized, double-blind, placebo-controlled trial. J. Res. Med. Sci., 2014, 19, 976-981. <u>Lamotrigine</u> Arrojo-Romero, M.; Tajes Alonso, M.; de Leon, J. Lamotrigine augmentation of serotonin reuptake inhibitors in severe and long-term treatment-resistant obsessive-compulsive disorder. Case Rep. Psychiatry, 2013, 2013:612459. Uzun, O. Lamotrigine as an augmentation agent in treatment-resistant obsessive-compulsive disorder: a case report. J. Psychopharmacol., 2010, 24, 425-427. Bruno, A.; Mico, U.; Pandolfo, G.; Mallamace, D.; Abenavoli, E.; Di Nardo, F.; D'Arrigo, C.;	

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

		Spina, E.; Zoccali, R.A.; Muscatello, M.R. Lamotrigine augmentation of serotonin reuptake inhibitors in treatment-resistant obsessive-compulsive disorder: a double-blind, placebocontrolled study. J. Psychopharmacol., 2012, 26, 1456-1462. Poyurovsky, M.; Glick, I.; Koran, L.M. Lamotrigine augmentation in schizophrenia and schizoaffective patients with obsessive-compulsive symptoms. J. Psychopharmacol., 2010, 24, 861-866. <u>N Acetyl cysteine</u> Lafleur, D.L.; Pittenger, C.; Kelmendi, B.; Gardner, T.; Wasylink, S.; Malison, R.T.; Sanacora, G.; Krystal, J.H.; Coric, V. N-acetylcysteine augmentation in serotonin reuptake inhibitor refractory obsessive-compulsive disorder. Psychopharmacology (Berl.), 2006, 184, 254-256. Afshar, H.; Roohafza, H.; Mohammad-Beigi, H.; Haghighi, M.; Jahangard, L.; Shokouh, P; Sadeghi, M.; Hafezian, H. N-acetylcysteine add-on treatment in refractory obsessivecompulsive disorder: a randomized, double-blind, placebo-controlled trial. J. Clin. Psychopharmacol., 2012, 32, 797-803. Sarris, J.; Oliver, G.; Camfield, D.A.; Dean, O.M.; Dowling, N.; Smith, D.J.; Murphy, J.; Menon, R.; Berk, M.; Blair-West, S.; Ng, C.H. N-Acetyl Cysteine (NAC) in the Treatment of Obsessive-Compulsive Disorder: A 16-Week, Double-Blind, Randomised, Placebo-Controlled Study. CNS Drugs, 2015, 29, 801-809.	

		Paydary, K.; Akamaloo, A.; Ahmadipour, A.; Pishgar, F.; Emamzadehfard, S.; Akhondzadeh, S. N-acetylcysteine augmentation therapy for moderate-to-severe obsessive-compulsive disorder: randomized, double-blind, placebo-controlled trial. J. Clin. Pharm. Ther., 2016, 41, 214-219. There also have been additional RCTS as well as scholarly metaanalyses and analyses of moderators of effect relating to the use of antipsychotic augmentation in OCD that need to be added to update and refine this part of the guideline, as they will provide greater clarity for the clinician on which specific antipsychotic agents are effective and which patients are more likely to respond to this strategy e.g. Dold M, Aigner M, Lanzenberger R, Kasper S. Int J Neuropsychopharmacol. 2015 May 4;18(9). pii: pyv047. doi: 10.1093/ijnp/pyv047. PMID: 25939614 Antipsychotic Augmentation of Serotonin Reuptake Inhibitors in Treatment-ResistantObsessive-Compulsive Disorder: An Update Meta-Analysis of Double-Blind, Randomized, Placebo-Controlled Trials. Veale D, Miles S, Smallcombe N, Ghezai H, Goldacre B, Hodsoll J. Atypical antipsychotic augmentation in SSRI treatment refractory obsessive-compulsive disorder: a systematic review and meta-analysis. BMC Psychiatry. 2014 Nov 29;14:317. doi: 10.1186/s12888-014-0317-5. Review. PMID: 25432131 Dold M, Aigner M, Lanzenberger R, Kasper S. Antipsychotic augmentation of serotonin reuptake inhibitors in treatment-resistant obsessive-compulsive disorder: a meta-analysis of double-blind, randomized, placebo-controlled trials.	

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

		Int J Neuropsychopharmacol. 2013 Apr;16(3):557-74. doi: 10.1017/S1461145712000740. Epub 2012 Aug 29. Review. PMID: 22932229 Carey PD, Lochner C, Kidd M, Van Ameringen M, Stein DJ, Denys D. Quetiapine augmentation of serotonin reuptake inhibitors in treatment-refractory obsessive-compulsive disorder: is response to treatment predictable? Int Clin Psychopharmacol. 2012 Nov;27(6):321-5. Somatic treatments These are not fully covered in the existing guideline. This is what the guideline says about neurosurgery: 1.6.1.4 Neurosurgery is not recommended in the treatment of OCD. However, if a patient requests neurosurgery because they have severe OCD that is refractory to other forms of treatment, the following should be taken into consideration. There is now consistent emerging evidence supporting the use of either non-invasive e.g. rTMS and or invasive neurostimulation e.g. DBS in OCD. This was not covered in wither the NICE guideline or evidence update and needs to be, as patients are continually asking about it. Curr Med Chem. 2017 May 4. doi: 10.2174/0929867324666170505113631. [Epub ahead of print] New Directions in the Use of Brain Stimulation Interventions in Patients with Obsessive-Compulsive Disorder. Dell'Osso B1, Cremaschi L1, Oldani L1, Altamura AC1 Also see Transcranial Magnetic Stimulation for Obsessive-Compulsive Disorder: An Updated Systematic Review and	

		Meta-analysis. Trevizol AP, Shiozawa P, Cook IA, Sato IA, Kaku CB, Guimarães FB, Sachdev P, Sarkhel S, Cordeiro Q. J ECT. 2016 Dec;32(4):262-266. Clinical and electrophysiological outcomes of deep TMS over the medial prefrontal and anterior cingulate cortices in OCD patients. Carmi L, Alyagon U, Barnea-Ygael N, Zohar J, Dar R, Zangen A. Brain Stimul. 2018 Jan - Feb;11(1):158-165. doi: 10.1016/j.brs.2017.09.004. Epub 2017 Sep 6. And the following Pepper J1, Hariz M, Zrinzo L. Deep brain stimulation versus anterior capsulotomy for obsessive-compulsive disorder: a review of the literature. J Neurosurg. 2015 May;122(5):1028-37. doi: 10.3171/2014.11.JNS132618. Epub 2015 Jan 30. Alonso P1, Cuadras D2, Gabriëls L3, Denys D4, Goodman W5, Greenberg BD6, Jimenez-Ponce F7, Kuhn J8, Lenartz D8, Mallet L9, Nuttin B10, Real E11, Segalas C11, Schuurman R12, du Montcel ST13, Menchon JM1. Deep Brain Stimulation for Obsessive-Compulsive Disorder: A Meta-Analysis of Treatment Outcome and Predictors of Response. PLoS One. 2015 Jul 24;10(7):e0133591. doi: 10.1371/journal.pone.0133591. eCollection 2015. Aum DJ1, Tierney TS2. Front Biosci (Landmark Ed). 2018 Jan 1;23:162-182. Deep brain stimulation: foundations and future trends.	

Royal College of Paediatrics and Child Health	Not answered	No comments provided	Thank you.
Sheffield Health and Social Care NHS Foundation Trust	Yes	There should be advice on further areas of research such as EMDR, and co-morbidity. Consideration of multimodal interventions when patients will not respond to established approaches. This may be as a result of co-morbidity when there is a primary trauma issue or in the case of attachment problems.	Thank you for your comment. No evidence on EMDR or co-morbidity was identified through the surveillance review to indicate these should be considered in an update to the guideline.
OCD Action	Yes	• The current guideline does not take into account patient choice, particularly in terms of medication which becomes particularly important when an individual is attempting to meet the criteria for HSSOCD provision at Step 6. • Individuals with very severe OCD are often not able to access local services and unless they are deemed to have exhausted local treatment options then they risk not being referred to or funded for specialist treatment even though clinically warranted. • Accessibility of treatment at Step 5: In most cases funding for treatment at national and specialist OCD treatment centres comes via CCG Individual Funding Request (IFR) panels. If CBT at the local level is unsuccessful or there is no appropriate treatment available the guideline recommends that people are 'referred to a multidisciplinary team with expertise in OCD/BDD for assessment and further treatment planning'. This referral needs to be made by the CMHT/CAMHS as the	Thank you for your comment. Your concern about the stepped care pathway, access to the treatment and availability of CAMHS consultant psychiatrist are reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update. Patient views and preferences are covered in NICE Guideline CG138.

			specialist OCD services will not consider treatment without a CMHT/CAMHS remaining involved. The referral also requires the Consultant Psychiatrist (most usually) putting in a funding request which, in all the cases we have supported over the last 5 years, is made to the IFR panel at the CCG. Very often such funding is refused by the IFR panel because the case is not deemed 'exceptional' and the reason frequently offered for this is that there is a cohort of such patients. The reality is that OCD is very common and it is likely that there will always be a cohort of patients in any given area whose OCD is similarly severe and so they will not be deemed 'exceptional'. Similarly, the treatment for OCD is not an exceptional treatment. Our view is that this is an error in policy on the part of CCGs and that the IFR route is not appropriate for people with severe OCD needing to access specialist OCD services. Instead, we feel that this should be treated by the CCG as a routine funding decision for an out of area service. We feel that the guideline should recommend an ECR funding route to all CCGs to correct this error and to provide the missing link in funding routes so that people can make the transition from local services to national and specialist OCD services. To give you some idea of the numbers of people that this might affect: our Advocacy Service has worked with more than 650 people over the past 5 years and roughly 60% of the cases we take on are those where people are struggling to access	

		specialist treatment for their OCD & BDD. The vast majority of these cases are where people are struggling to move from local services to national & specialist ones. We understand that this funding situation is having an impact on the number of referrals received by national and specialist OCD services. • The guideline needs to include more detail on the need for and type of aftercare from CAMHS/CMHTs after discharge from national & specialist/HSSOCD services. • DBS is not currently available within the UK	
Royal College of Psychiatrists	Yes	Cynthia Turner, Beth O'Gorman, Archana Nair and Richard O'Kearney, Moderators and predictors of response to cognitive behaviour therapy for pediatric obsessive-compulsive disorder: A systematic review, Psychiatry Research, 261, (50), (2018 Sophie D. Bennett, Anna E. Coughtrey, Roz Shafran and Isobel Heyman, Measurement Issues: The measurement of obsessive compulsive disorder in children and young people in clinical practice, Child and Adolescent Mental Health, 22, 2, (100-112), (2017). H. M. Brown, K. J. Lester, A. Jassi, I. Heyman and G. Krebs, Paediatric Obsessive-Compulsive Disorder and Depressive Symptoms: Clinical Correlates and CBT Treatment Outcomes, Journal of Abnormal Child Psychology, 43, 5, (933), (2015). **THIRD LINE TREATMENTS:**	Thank you for your comment. Thank you for the references. We will add the highlighted studies (Turner et al. 2018; Bennett et al, 2017; Brown et al. 2015) to this surveillance review. During the update of the guideline, developers may consider the highlighted studies for inclusion in the evidence reviews. <u>Third line treatment</u> Thank you for the references. All highlighted studies were identified and assessed in current surveillance review and informed the proposal to update. During the update of the guideline, developers may consider the highlighted studies for inclusion. Studies before 2013 (date of Evidence Update) were not qualified for inclusion in this surveillance. <u>Somatic treatments</u>

		Third line treatments are not covered in the original guideline. This is what the guideline currently says for patients who fail to respond to first or second line treatments; 1.5.4.7 Following multidisciplinary review, for adults with OCD if there has been no response to a full trial of at least one SSRI alone, a full trial of combined treatment with CBT (including ERP) and an SSRI, and a full trial of clomipramine alone, the following treatment options should also be considered (note, there is no evidence of the optimal sequence of the options listed below): • additional CBT (including ERP) or cognitive therapy • adding an antipsychotic to an SSRI or clomipramine • combining clomipramine and citalopram. Since the 2006 guideline (and the 2013 evidence update) there has been publication of very many RCTS of different pharmacological treatments that have a role as third line treatments for OCD that were not covered at all in the original guidelines. These pharmacological compounds are now being used in clinical practice but were not considered in the existing guideline or evidence update and therefore changes to the recommendations in this section are now needed. EG Riluzole Pittenger, C.; Bloch, M.H.; Wasylink, S.; Billingslea, E.; Simpson, R.; Jakubovski, E.; Kelmendi, B.; Sanacora, G.; Coric, V. Riluzole augmentation in treatment-refractory obsessive-compulsive disorder: a pilot randomized placebo-controlled trial. J. Clin. Psychiatry, 2015, 6, 1075-1084.	Thank you for the references. All highlighted studies that met our inclusion criteria were identified and assessed in current surveillance review and informed the proposal to update. During the update of the guideline, developers may consider the highlighted studies for inclusion.

		Emamzadehfard, S.; Kamaloo, A.; Paydary, K.; Ahmadipour, A.; Zeinoddini, A.; Ghaleiha, A.; Mohammadinejad, P.; Zeinoddini, A.; Akhondzadeh, S. Riluzole in Augmentation of Fluvoxamine for Moderate to Severe Obsessive Compulsive Disorder: Randomized, Doubleblind, Placebo-Controlled Study. Psychiatry Clin. Neurosci., 2016 Apr 23,. doi: 10.1111/pcn.12394. <u>Memantine</u> Kavirajan, H. Memantine: a comprehensive review of safety and efficacy. Expert Opin. Drug Saf., 2009, 8, 89-109. Pasquini, M.; Biondi, M. Memantine augmentation for refractory obsessive-compulsive disorder. Prog. Neuropsychopharmacol. Biol. Psychiatry, 2006, 30, 1173-1175. Hezel, D.M.; Beattie, K.; Stewart, S.E. Memantine as an augmenting agent for severe pediatric OCD. Am. J. Psychiatry, 2009, 166, 237. Aboujaoude, E.; Barry, J.J.; Gamel, N. Memantine augmentation in treatment-resistant obsessive-compulsive disorder: an open-label trial. J. Clin. Psychopharmacol., 2009, 29, 51- Ghaleiha, A.; Entezari, N.; Modabbernia, A.; Najand, B.; Askari, N.; Tabrizi, M.; Ashrafi, M.; Hajiaghaee, R.; Akhondzadeh, S. Memantine add-on in moderate to severe obsessivecompulsive disorder: randomized double-blind placebo-controlled study. J. Psychiatr. Res., 2013, 47, 175-180.	

		Haghighi, M.; Jahangard, L.; Mohammad-Beigi, H.; Bajoghli, H.; Hafezian, H.; Rahimi, A.; Afshar, H.; Holsboer-Trachsler, E.; Brand, S. In a double-blind, randomized and placebocontrolled trial, adjuvant memantine improved symptoms in inpatients suffering from refractory obsessive-compulsive disorders (OCD). Psychopharmacology (Berl.), 2013, 228, 633-640. <u>Ketamine</u> Rodriguez, C.I.; Kegeles, L.S.; Levinson, A.; Feng, T.; Marcus, S.M.; Vermes, D.; Flood, P.; Simpson, H.B. Randomized controlled crossover trial of ketamine in obsessive-compulsive disorder: proof-of-concept. Neuropsychopharmacology, 2013, 38, 2475-2483. Bloch, M.H.; Wasylink, S.; Landeros-Weisenberger, A.; Panza, K.E.; Billingslea, E.; Leckman, J.F.; Krystal, J.H.; Bhagwagar, Z.; Sanacora, G.; Pittenger, C. Effects of ketamine in treatment-refractory obsessive-compulsive disorder. Biol. Psychiatry, 2012, 72, 964-970. <u>Topiramate</u> Mowla, A.; Khajeian, A.M.; Sahraian, A.; Chohedri, A.H.; Kashkoli, F. Topiramate Augmentation in Resistant OCD: A Double-Blind Placebo-Controlled Clinical Trial. CNS Spectr., 2010, 15, 613-617. Berlin, H.A.; Koran, L.M.; Jenike, M.A.; Shapira, N.A.; Chaplin, W.; Pallanti, S.; Hollander, E. Double-blind, placebo-controlled trial of topiramate augmentation in treatment-resistant	

		obsessive-compulsive disorder. J. Clin. Psychiatry, 2011, 72, 716-721. Afshar, H.; Akuchekian, S.; Mahaky, B.; Zarean, E. Topiramate augmentation in refractory obsessive-compulsive disorder: A randomized, double-blind, placebo-controlled trial. J. Res. Med. Sci., 2014, 19, 976-981. <u>Lamotrigine</u> Arrojo-Romero, M.; Tajes Alonso, M.; de Leon, J. Lamotrigine augmentation of serotonin reuptake inhibitors in severe and long-term treatment-resistant obsessive-compulsive disorder. Case Rep. Psychiatry, 2013, 2013:612459. Uzun, O. Lamotrigine as an augmentation agent in treatment-resistant obsessive-compulsive disorder: a case report. J. Psychopharmacol., 2010, 24, 425-427. Bruno, A.; Mico, U.; Pandolfo, G.; Mallamace, D.; Abenavoli, E.; Di Nardo, F.; D'Arrigo, C.; Spina, E.; Zoccali, R.A.; Muscatello, M.R. Lamotrigine augmentation of serotonin reuptake inhibitors in treatment-resistant obsessive-compulsive disorder: a double-blind, placebocontrolled study. J. Psychopharmacol., 2012, 26, 1456-1462. Poyurovsky, M.; Glick, I.; Koran, L.M. Lamotrigine augmentation in schizophrenia and schizoaffective patients with obsessive-compulsive symptoms. J. Psychopharmacol., 2010, 24, 861-866. <u>N Acetyl cysteine</u>	

		Lafleur, D.L.; Pittenger, C.; Kelmendi, B.; Gardner, T.; Wasylink, S.; Malison, R.T.; Sanacora, G.; Krystal, J.H.; Coric, V. N-acetylcysteine augmentation in serotonin reuptake inhibitor refractory obsessive-compulsive disorder. Psychopharmacology (Berl.), 2006, 184, 254-256. Afshar, H.; Roohafza, H.; Mohammad-Beigi, H.; Haghighi, M.; Jahangard, L.; Shokouh, P; Sadeghi, M.; Hafezian, H. N-acetylcysteine add-on treatment in refractory obsessivecompulsive disorder: a randomized, double-blind, placebo-controlled trial. J. Clin. Psychopharmacol., 2012, 32, 797-803. Sarris, J.; Oliver, G.; Camfield, D.A.; Dean, O.M.; Dowling, N.; Smith, D.J.; Murphy, J.; Menon, R.; Berk, M.; Blair-West, S.; Ng, C.H. N-Acetyl Cysteine (NAC) in the Treatment of Obsessive-Compulsive Disorder: A 16-Week, Double-Blind, Randomised, Placebo-Controlled Study. CNS Drugs, 2015, 29, 801-809. Paydary, K.; Akamaloo, A.; Ahmadipour, A.; Pishgar, F.; Emamzadehfard, S.; Akhondzadeh, S. N-acetylcysteine augmentation therapy for moderate-to-severe obsessive-compulsive disorder: randomized, double-blind, placebo-controlled trial. J. Clin. Pharm. Ther., 2016, 41, 214-219. There also have been additional RCTS as well as scholarly metaanalyses and analyses of moderators of effect relating to the use of antipsychotic augmentation in OCD that need to be added to update and refine this part of the guideline, as they will provide greater clarity for the clinician on	

		which specific antipsychotic agents are effective and which patients are more likely to respond to this strategy e.g. Dold M, Aigner M, Lanzenberger R, Kasper S. Int J Neuropsychopharmacol. 2015 May 4;18(9). pii: pyv047. doi: 10.1093/ijnp/pyv047. PMID: 25939614 Antipsychotic Augmentation of Serotonin Reuptake Inhibitors in Treatment-ResistantObsessive-Compulsive Disorder: An Update Meta-Analysis of Double-Blind, Randomized, Placebo-Controlled Trials. Veale D, Miles S, Smallcombe N, Ghezai H, Goldacre B, Hodsoll J. Atypical antipsychotic augmentation in SSRI treatment refractory obsessive-compulsive disorder: a systematic review and meta-analysis. BMC Psychiatry. 2014 Nov 29;14:317. doi: 10.1186/s12888-014-0317-5. Review. PMID: 25432131 Dold M, Aigner M, Lanzenberger R, Kasper S. Antipsychotic augmentation of serotonin reuptake inhibitors in treatment-resistant obsessive-compulsive disorder: a meta-analysis of double-blind, randomized, placebo-controlled trials. Int J Neuropsychopharmacol. 2013 Apr;16(3):557-74. doi: 10.1017/S1461145712000740. Epub 2012 Aug 29. Review. PMID: 22932229 Carey PD, Lochner C, Kidd M, Van Ameringen M, Stein DJ, Denys D. Quetiapine augmentation of serotonin reuptake inhibitors in treatment-refractory obsessive-compulsive disorder: is response to treatment predictable? Int Clin Psychopharmacol. 2012 Nov;27(6):321-5. Somatic treatments These are not fully covered in the existing guideline.	

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

		This is what the guideline says about neurosurgery: 1.6.1.4 Neurosurgery is not recommended in the treatment of OCD. However, if a patient requests neurosurgery because they have severe OCD that is refractory to other forms of treatment, the following should be taken into consideration. There is now consistent emerging evidence supporting the use of either non-invasive e.g. rTMS and or invasive neurostimulation e.g. DBS in OCD. This was not covered in wither the NICE guideline or evidence update and needs to be, as patients are continually asking about it. Curr Med Chem. 2017 May 4. doi: 10.2174/0929867324666170505113631. [Epub ahead of print] New Directions in the Use of Brain Stimulation Interventions in Patients with Obsessive-Compulsive Disorder. Dell'Osso B1, Cremaschi L1, Oldani L1, Altamura AC1 Also see Transcranial Magnetic Stimulation for Obsessive-Compulsive Disorder: An Updated Systematic Review and Meta-analysis. Trevizol AP, Shiozawa P, Cook IA, Sato IA, Kaku CB, Guimarães FB, Sachdev P, Sarkhel S, Cordeiro Q. J ECT. 2016 Dec;32(4):262-266. Clinical and electrophysiological outcomes of deep TMS over the medial prefrontal and anterior cingulate cortices in OCD patients. Carmi L, Alyagon U, Barnea-Ygael N, Zohar J, Dar R, Zangen A. Brain Stimul. 2018 Jan - Feb;11(1):158-165. doi: 10.1016/j.brs.2017.09.004. Epub 2017 Sep 6. And the following	

		Pepper J1, Hariz M, Zrinzo L. Deep brain stimulation versus anterior capsulotomy for obsessive-compulsive disorder: a review of the literature. J Neurosurg. 2015 May;122(5):1028-37. doi: 10.3171/2014.11.JNS132618. Epub 2015 Jan 30. Alonso P1, Cuadras D2, Gabriëls L3, Denys D4, Goodman W5, Greenberg BD6, Jimenez-Ponce F7, Kuhn J8, Lenartz D8, Mallet L9, Nuttin B10, Real E11, Segalas C11, Schuurman R12, du Montcel ST13, Menchon JM1. Deep Brain Stimulation for Obsessive-Compulsive Disorder: A Meta-Analysis of Treatment Outcome and Predictors of Response. PLoS One. 2015 Jul 24;10(7):e0133591. doi: 10.1371/journal.pone.0133591. eCollection 2015. Aum DJ1, Tierney TS2. Front Biosci (Landmark Ed). 2018 Jan 1;23:162-182. Deep brain stimulation: foundations and future trends.	
Medtronic	None	No additional comments	Thank you.
Royal College of Nursing	Not answered	No comments provided	Thank you.
Department of Health and Social Care	Not answered	No comments provided	Thank you.
NHS England	**SC:** Yes.	Third line treatments are not covered in the original guideline. This is what the guideline currently says for patients who fail to respond to first or second line treatments;	Thank you for your comment. In relation to recommendation 1.5.4.7, we recognise the advance of pharmacological treatments since guideline publication and the gap in the third line treatments in our proposal to update the guideline.

	Third line treatments for OCD. Somatic treatments for OCD (including rtms- covered above, other forms of non invasive neurostimulation, deep brain stimulation).	1.5.4.7 Following multidisciplinary review, for adults with OCD if there has been no response to a full trial of at least one SSRI alone, a full trial of combined treatment with CBT (including ERP) and an SSRI, and a full trial of clomipramine alone, the following treatment options should also be considered (note, there is no evidence of the optimal sequence of the options listed below): • additional CBT (including ERP) or cognitive therapy • adding an antipsychotic to an SSRI or clomipramine • combining clomipramine and citalopram. Since the 2006 guideline (and the 2013 evidence update) there has been publication of very many RCTS of different pharmacological treatments that have a role as third line treatments for OCd that were not covered at all in the original guidelines. These pharmacological compounds are now being used in clinical practice but were not considered in the existing guideline or evidence update and therefore changes to the recommendations in this section are now needed. EG Riluzole Pittenger, C.; Bloch, M.H.; Wasylink, S.; Billingslea, E.; Simpson, R.; Jakubovski, E.; Kelmendi, B.; Sanacora, G.; Coric, V. Riluzole augmentation in treatment-refractory obsessive-compulsive disorder: a pilot randomized placebo-controlled trial. J. Clin. Psychiatry, 2015, 6, 1075-1084. Emamzadehfard, S.; Kamaloo, A.; Paydary, K.; Ahmadipour, A.; Zeinoddini, A.; Ghaleiha, A.; Mohammadinejad, P.; Zeinoddini, A.; Akhondzadeh, S. Riluzole in Augmentation of	These concerns will be passed onto the developer for consideration during the update. Thank you for the highlighted references. All highlighted studies that met our inclusion criteria were identified and assessed in current surveillance review and informed the proposal to update. During the update of the guideline, developers may consider the highlighted studies for inclusion. Somatic treatments Thank you for the highlighted references. All studies that met our inclusion criteria were identified and assessed in current surveillance review and informed the proposal to update. Studies before 2013 (date of Evidence Update) were not qualified for inclusion in this surveillance. During the update of the guideline, developers may consider the highlighted studies for inclusion. Your concerns about third line and somatic treatment are reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update

		Fluvoxamine for Moderate to Severe Obsessive Compulsive Disorder: Randomized, Doubleblind, Placebo-Controlled Study. Psychiatry Clin. Neurosci., 2016 Apr 23,. doi: 10.1111/pcn.12394. <u>Memantine</u> Kavirajan, H. Memantine: a comprehensive review of safety and efficacy. Expert Opin. Drug Saf., 2009, 8, 89-109. Pasquini, M.; Biondi, M. Memantine augmentation for refractory obsessive-compulsive disorder. Prog. Neuropsychopharmacol. Biol. Psychiatry, 2006, 30, 1173-1175. Hezel, D.M.; Beattie, K.; Stewart, S.E. Memantine as an augmenting agent for severe pediatric OCD. Am. J. Psychiatry, 2009, 166, 237. Aboujaoude, E.; Barry, J.J.; Gamel, N. Memantine augmentation in treatment-resistant obsessive-compulsive disorder: an open-label trial. J. Clin. Psychopharmacol., 2009, 29, 51- Ghaleiha, A.; Entezari, N.; Modabbernia, A.; Najand, B.; Askari, N.; Tabrizi, M.; Ashrafi, M.; Hajiaghaee, R.; Akhondzadeh, S. Memantine add-on in moderate to severe obsessivecompulsive disorder: randomized double-blind placebo-controlled study. J. Psychiatr. Res., 2013, 47, 175-180. Haghighi, M.; Jahangard, L.; Mohammad-Beigi, H.; Bajoghli, H.; Hafezian, H.; Rahimi, A.; Afshar, H.; Holsboer-Trachsler, E.; Brand, S. In a double-blind, randomized and placebocontrolled	

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

		trial, adjuvant memantine improved symptoms in inpatients suffering from refractory obsessive-compulsive disorders (OCD). Psychopharmacology (Berl.), 2013, 228, 633-640. <u>Ketamine</u> Rodriguez, C.I.; Kegeles, L.S.; Levinson, A.; Feng, T.; Marcus, S.M.; Vermes, D.; Flood, P.; Simpson, H.B. Randomized controlled crossover trial of ketamine in obsessive-compulsive disorder: proof-of-concept. Neuropsychopharmacology, 2013, 38, 2475-2483. Bloch, M.H.; Wasylink, S.; Landeros-Weisenberger, A.; Panza, K.E.; Billingslea, E.; Leckman, J.F.; Krystal, J.H.; Bhagwagar, Z.; Sanacora, G.; Pittenger, C. Effects of ketamine in treatment-refractory obsessive-compulsive disorder. Biol. Psychiatry, 2012, 72, 964-970. <u>Topiramate</u> Mowla, A.; Khajeian, A.M.; Sahraian, A.; Chohedri, A.H.; Kashkoli, F. Topiramate Augmentation in Resistant OCD: A Double-Blind Placebo-Controlled Clinical Trial. CNS Spectr., 2010, 15, 613-617. Berlin, H.A.; Koran, L.M.; Jenike, M.A.; Shapira, N.A.; Chaplin, W.; Pallanti, S.; Hollander, E. Double-blind, placebo-controlled trial of topiramate augmentation in treatment-resistant obsessive-compulsive disorder. J. Clin. Psychiatry, 2011, 72, 716-721. Afshar, H.; Akuchekian, S.; Mahaky, B.; Zarean, E. Topiramate augmentation in refractory	

		obsessive-compulsive disorder: A randomized, double-blind, placebo-controlled trial. J. Res. Med. Sci., 2014, 19, 976-981. <u>Lamotrigine</u> Arrojo-Romero, M.; Tajes Alonso, M.; de Leon, J. Lamotrigine augmentation of serotonin reuptake inhibitors in severe and long-term treatment-resistant obsessive-compulsive disorder. Case Rep. Psychiatry, 2013, 2013:612459. Uzun, O. Lamotrigine as an augmentation agent in treatment-resistant obsessive-compulsive disorder: a case report. J. Psychopharmacol., 2010, 24, 425-427. Bruno, A.; Mico, U.; Pandolfo, G.; Mallamace, D.; Abenavoli, E.; Di Nardo, F.; D'Arrigo, C.; Spina, E.; Zoccali, R.A.; Muscatello, M.R. Lamotrigine augmentation of serotonin reuptake inhibitors in treatment-resistant obsessive-compulsive disorder: a double-blind, placebocontrolled study. J. Psychopharmacol., 2012, 26, 1456-1462. Poyurovsky, M.; Glick, I.; Koran, L.M. Lamotrigine augmentation in schizophrenia and schizoaffective patients with obsessive-compulsive symptoms. J. Psychopharmacol., 2010, 24, 861-866. <u>N Acetyl cysteine</u> Lafleur, D.L.; Pittenger, C.; Kelmendi, B.; Gardner, T.; Wasylink, S.; Malison, R.T.; Sanacora, G.; Krystal, J.H.; Coric, V. N-acetylcysteine augmentation in serotonin reuptake inhibitor	

		refractory obsessive-compulsive disorder. Psychopharmacology (Berl.), 2006, 184, 254-256. Afshar, H.; Roohafza, H.; Mohammad-Beigi, H.; Haghighi, M.; Jahangard, L.; Shokouh, P; Sadeghi, M.; Hafezian, H. N-acetylcysteine add-on treatment in refractory obsessivecompulsive disorder: a randomized, double-blind, placebo-controlled trial. J. Clin. Psychopharmacol., 2012, 32, 797-803. Sarris, J.; Oliver, G.; Camfield, D.A.; Dean, O.M.; Dowling, N.; Smith, D.J.; Murphy, J.; Menon, R.; Berk, M.; Blair-West, S.; Ng, C.H. N-Acetyl Cysteine (NAC) in the Treatment of Obsessive-Compulsive Disorder: A 16-Week, Double-Blind, Randomised, Placebo-Controlled Study. CNS Drugs, 2015, 29, 801-809. Paydary, K.; Akamaloo, A.; Ahmadipour, A.; Pishgar, F.; Emamzadehfard, S.; Akhondzadeh, S. N-acetylcysteine augmentation therapy for moderate-to-severe obsessive-compulsive disorder: randomized, double-blind, placebo-controlled trial. J. Clin. Pharm. Ther., 2016, 41, 214-219. There also have been additional RCTS as well as scholarly metaanalyses and analyses of moderators of effect relating to the use of antipsychotic augmentation in OCD that need to be added to update and refine this part of the guideline, as they will provide greater clarity for the clinician on which specific antipsychotic agents are effective and which patients are more likely to respond to this strategy e.g. Dold M, Aigner M, Lanzenberger R, Kasper S. Int J Neuropsychopharmacol. 2015 May 4;18(9). pii: pyv047.	

		doi: 10.1093/ijnp/pyv047. PMID: 25939614 Antipsychotic Augmentation of Serotonin Reuptake Inhibitors in Treatment-ResistantObsessive-Compulsive Disorder: An Update Meta-Analysis of Double-Blind, Randomized, Placebo-Controlled Trials. Veale D, Miles S, Smallcombe N, Ghezai H, Goldacre B, Hodsoll J. Atypical antipsychotic augmentation in SSRI treatment refractory obsessive-compulsive disorder: a systematic review and meta-analysis. BMC Psychiatry. 2014 Nov 29;14:curr317. doi: 10.1186/s12888-014-0317-5. Review. PMID: 25432131 Dold M, Aigner M, Lanzenberger R, Kasper S. Antipsychotic augmentation of serotonin reuptake inhibitors in treatment-resistant obsessive-compulsive disorder: a meta-analysis of double-blind, randomized, placebo-controlled trials. Int J Neuropsychopharmacol. 2013 Apr;16(3):557-74. doi: 10.1017/S1461145712000740. Epub 2012 Aug 29. Review. PMID: 22932229 Carey PD, Lochner C, Kidd M, Van Ameringen M, Stein DJ, Denys D. Quetiapine augmentation of serotonin reuptake inhibitors in treatment-refractory obsessive-compulsive disorder: is response to treatment predictable? Int Clin Psychopharmacol. 2012 Nov;27(6):321-5. Somatic treatments These are not fully covered in the existing guideline. This is what the guideline says about neurosurgery: 1.6.1.4 Neurosurgery is not recommended in the treatment of OCD. However, if a patient requests neurosurgery because they have severe OCD that is refractory to other	

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

		forms of treatment, the following should be taken into consideration. There is now consistent emerging evidence supporting the use of either non-invasive e.g. rTMS and or invasive neurostimulation e.g. DBS in OCD. This was not covered in wither the NICE guideline or evidence update and needs to be, as patients are continually asking about it. Curr Med Chem. 2017 May 4. doi: 10.2174/0929867324666170505113631. [Epub ahead of print] New Directions in the Use of Brain Stimulation Interventions in Patients with Obsessive-Compulsive Disorder. Dell'Osso B1, Cremaschi L1, Oldani L1, Altamura AC1 Also see Transcranial Magnetic Stimulation for Obsessive-Compulsive Disorder: An Updated Systematic Review and Meta-analysis. Trevizol AP, Shiozawa P, Cook IA, Sato IA, Kaku CB, Guimarães FB, Sachdev P, Sarkhel S, Cordeiro Q. J ECT. 2016 Dec;32(4):262-266. Clinical and electrophysiological outcomes of deep TMS over the medial prefrontal and anterior cingulate cortices in OCD patients. Carmi L, Alyagon U, Barnea-Ygael N, Zohar J, Dar R, Zangen A. Brain Stimul. 2018 Jan - Feb;11(1):158-165. doi: 10.1016/j.brs.2017.09.004. Epub 2017 Sep 6. And the following Pepper J1, Hariz M, Zrinzo L. Deep brain stimulation versus anterior capsulotomy for obsessive-compulsive disorder: a review of the literature. J Neurosurg. 2015 May;122(5):1028-37. doi: 10.3171/2014.11.JNS132618. Epub 2015 Jan 30.	

		Alonso P1, Cuadras D2, Gabriëls L3, Denys D4, Goodman W5, Greenberg BD6, Jimenez-Ponce F7, Kuhn J8, Lenartz D8, Mallet L9, Nuttin B10, Real E11, Segalas C11, Schuurman R12, du Montcel ST13, Menchon JM1. Deep Brain Stimulation for Obsessive-Compulsive Disorder: A Meta-Analysis of Treatment Outcome and Predictors of Response. PLoS One. 2015 Jul 24;10(7):e0133591. doi: 10.1371/journal.pone.0133591. eCollection 2015. Aum DJ1, Tierney TS2. Front Biosci (Landmark Ed). 2018 Jan 1;23:162-182. Deep brain stimulation: foundations and future trends.	
OCD-UK		The NICE Surveillance proposal consultation suggested that topic experts indicated a need to update the guideline for Deep Brain Stimulation (DBS) and that consistent emerging evidence supporting the use of neurostimulation and rising demand from the patients for the intervention. We have seen no increased demand from our service-users, and are unable to find any supporting evidence to back this claim up. **Antipsychotic Medications** The existing NICE Guidelines state Antipsychotics have not been found to be effective on their own, but may have a role as agents of augmentation in cases where the response to an SRI is poor or incomplete and go on to suggest adding antipsychotic to an SSRI or Clomipramine for patients not responding. Recently published research	Thank you for your comment. We found evidence that indicates some benefits of BDS and neurostimulation for OCD treatment. As this is not currently recommended we are proposing as a trigger for update. During the guideline update, the committee will consider the evidence base and other factors when making recommendations. Thank you for the reference. Veale et al (2014) was identified and assessed through our surveillance; we will add the other study (Simpson et al. 2013) to this surveillance. During the update of the guideline, developers may consider the highlighted studies for inclusion. Your concerns about 'recognition and assessment', 'OCD during pregnancy and postnatal period' and 'home based treatment' are

		patients receiving risperidone did not significantly differ from those receiving placebo. Cognitive-Behavioral Therapy vs Risperidone for Augmenting Serotonin Reuptake Inhibitors in Obsessive-Compulsive Disorder A Randomized Clinical Trial JAMA Psychiatry. 2013 Nov;70(11):1190-9. doi: 10.1001/jamapsychiatry.2013.1932. Helen Blair Simpson, MD, PhD1,2; Edna B. Foa, PhD3; Michael R. Liebowitz, MD1; et al Another stated the clinical implications are that if aripiprazole or risperidone is used in severe treatment resistant OCD, then to determine effectiveness it should be a trialled for no longer than 4 weeks and without any other interventions such as CBT to determine effectiveness. However it may not be particularly helpful to conduct further trials of other anti-psychotics in OCD until bio-psychosocial markers can identify the minority who may respond. Atypical antipsychotic augmentation in SSRI treatment refractory obsessive-compulsive disorder: a systematic review and meta-analysis David Veale et al. BMC Psychiatry201414:317	reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update.

		Recognition and assessment (any age group) The assessment questions about possible symptoms fail to take into account people whose compulsions are not typical, i.e. seek reassurance, google online, avoid object, people or places. It also fails to take into account people whose OCD is primarily obsessional thoughts who themselves may not always be aware they're carrying out compulsions. **OCD during Pregnancy and Postnatal period** OCD during pregnant can provide different challenges for women with existing OCD. Health professionals should be made aware of how OCD can manifest during this period, including specific ways in which OCD obsessions can focus on the baby and rituals or obsessive thoughts the mother may be experiencing. With significant focus on the sensitively women need in order to discuss their condition without fear of judgement or worry that they are an unfit parent. This may require adjustment to the stepped care model for women with OCD during a prenatal or postnatal period. **Home based Treatment** Little consideration is given in the NICE guidelines to consider the restrictions the condition can frequently play on a persons ability to leave the house or attend hospitals	

		or clinics. All mental health services should give consideration to this and offer home based treatment for a short period to enable a patient to attend the clinic to continue their therapy.	

Do you have any comments on equalities issues?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
Association for Family Therapy and Systemic Practice - UK	Not answered	No comments provided	Thank you.
British Association for Psychopharmacology	Yes	Children and young adults, especially those aged 16-18y, are being required to see a child psychiatrist to obtain SSRI that is disadvantaging them relative to other groups. Women with postnatal ocd are not receiving the care for OCD they need and are often unfairly discriminated and stigmatised as being of 'high risk' of harming their children because of having OCD thoughts that do not actually increase this risk.	Thank you for your comment. We recognise the concern about reserving SSRI in young people with OCD to a second line treatment and also limited availability of CAMHS consultants and its impact on patients. These are reflected in our proposal to update the guideline. Thank you for noting that comorbidities, in particular adequate OCD care during pregnancy and the postnatal period, have been identified as gaps in the guidance. Although no evidence was identified in this area during the surveillance review, we have noted this concern and will pass over to developers for further consideration during the scoping of the update. Note that the NICE guideline on antenatal and postnatal mental health recommends the following in relation to anxiety disorders: 1.5.3 Recognise that the range and prevalence of anxiety disorders (including generalised anxiety disorder, obsessive-compulsive disorder, panic disorder, phobias, post-traumatic stress disorder and

			social anxiety disorder) and depression are under-recognised throughout pregnancy and the postnatal period. [new 2014]
Royal College of Paediatrics and Child Health	Not answered	No comments provided	Thank you.
Sheffield Health and Social Care NHS Foundation Trust	Yes	Access for people from BME backgrounds across mental health is poor. In OCD this is no different. Consideration as to how we can improve the access and cultural sensitivity of services need to be addressed.	Thank you for your comment. Thank you for highlighting the access issue for people from BAMER backgrounds to the OCD services. This will be passed onto developers for detailed consideration when developing the updated guideline.
OCD Action	No	None with the guideline itself but we are aware that individuals from BAMER communities are under-represented in figures of those accessing specialist OCD services.	Thank you for your comment. Thank you for highlighting the access issue for people from BAMER backgrounds to the OCD services. This will be passed onto developers for detailed consideration when developing the updated guideline.
Royal College of Psychiatrists		**Access and health economics:** Turner C.M., Mataix-Cols D., Lovell K., Krebs G., Lang K., Byford S., Heyman I. Telephone cognitive-behavioral therapy for adolescents with obsessive-compulsive disorder: A randomized controlled non-inferiority trial (2014) Journal of the American Academy of Child and Adolescent Psychiatry, 53 (12) , pp. 1298-1307.e2. Nair A, Turner C, Heyman I, Mataix-Cols D, Lovell K, Krebs G, Lang K, Byford S, O'Kearney R. Moderators and predictors of outcomes in telephone delivered compared to face-to-face cognitive behaviour therapy for paediatric obsessive-compulsive disorder:	Thank you for your comment. We recognise development of the tele-mental health and technology interventions since the guideline publication in our proposal to update the guideline. <u>Access and health economics</u> Thank you for references. Two out of 3 highlighted studies (Turner et al. 2014; Nair et al. 2018) were identified and assessed through current surveillance; we will add the third study (Tie et al, 2019) to this surveillance review. During the update of the guideline, developers may consider the highlighted studies for inclusion.

		preliminary evidence from a non-inferiority RCT. Cogn Behav Ther. 2018 Sep 17:1-16. doi: 10.1080/16506073.2018.1513555. [Epub ahead of print] Tie, H., Krebs, G., Lang, K., Shearer, J., Turner, C., Mataix-Cols, D., . . . Byford, S. (2019). Cost-effectiveness analysis of telephone cognitive–behaviour therapy for adolescents with obsessive–compulsive disorder. BJPsych Open, 5(1), E7. doi:10.1192/bjo.2018.73 **Ethnicity:** Fernández de la Cruz L, Llorens M, Jassi A, Krebs G, Vidal-Ribas P, Radua J, Hatch SL, Bhugra D, Heyman I, Clark B, Mataix-Cols D. Ethnic inequalities in the use of secondary and tertiary mental health services among patients with obsessive-compulsive disorder. Br J Psychiatry. 2015 Dec;207(6):530-5. doi: 10.1192/bjp.bp.114.154062. Epub 2015 Jul 23. **Individuals with autism should have access to CBT for OCD:** Russell AJ, Jassi A, Fullana MA, Mack H, Johnston K, Heyman I, Murphy DG, Mataix-Cols D. Cognitive behavior therapy for comorbid obsessive-compulsive disorder in high-functioning autism spectrum disorders: a randomized controlled trial. Depress Anxiety. 2013 Aug;30(8):697-708. doi: 10.1002/da.22053. Epub 2013 Feb 6. Children and young adults, are being required to see a child psychiatrist to obtain SSRI. This may be disadvantaging them in terms of access to evidence based treatment and merits further consideration. Women with postnatal OCD are not receiving the care for OCD they need and are often unfairly discriminated and	<u>Ethnicity</u> Thank you for references. We will add the highlighted study (Fernández et al, 2015) to this surveillance review. During the update of the guideline, developers may consider the highlighted study for inclusion. <u>Individuals with autism</u> Thank you for references. We will add the highlighted study (Russell et al, 2013) to this surveillance review. During the update of the guideline, developers may consider the highlighted study for inclusion.

Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees

		stigmatised as being of 'high risk' of harming their children because of having OCD thoughts that do not actually increase this risk.	
Medtronic	None	No additional comments	Thank you.
Royal College of Nursing	Not answered	No comments provided	Thank you.
Department of Health and Social Care	Not answered	No comments provided	Thank you.
NHS England	Yes	Children and young adults, especially those aged 16-18y, are being required to see a child psychiatrist to obtain SSRI that is disadvantaging them relative to other groups. Women with postnatal ocd are not receiving the care for OCD they need and are often unfairly discriminated and stigmatised as being of 'high risk' of harming their children because of having OCD thoughts that do not actually increase this risk. I think there is a need to update this, if only to remove all reference to tiers 5 and 6 as these have no evidence base and have been used to support the provision of specialist national services.	Thank you for your comment. Your concerns about difficulty in SSRI access for children and OCD during pregnancy and postnatal period are reflected in our proposal to update the guideline and will be passed onto the developer for consideration during the update. Thank you for noting that comorbidities, in particular adequate OCD care during pregnancy and the postnatal period, have been identified as gaps in the guidance. Although no evidence was identified in this area during the surveillance review, we have noted this concern and will pass over to developers for further consideration during the scoping of the update. Note that the NICE guideline on antenatal and postnatal mental health recommends the following in relation to anxiety disorders:

			1.5.3 Recognise that the range and prevalence of anxiety disorders (including generalised anxiety disorder, obsessive-compulsive disorder, panic disorder, phobias, post-traumatic stress disorder and social anxiety disorder) and depression are under-recognised throughout pregnancy and the postnatal period. [new 2014]
OCD-UK		The existing NICE Guidelines already recommend consider seeking, with the patient's consent, the advice of an appropriate religious or community leader to support the therapeutic process if the boundary between religious or cultural practice and obsessive-compulsive symptoms is unclear. However some users have expressed a preference for a therapist from the same sex, religion or ethnic background. The NICE guidelines could be reviewed to ensure health professionals are sensitive to culture differences and where appropriate assign a therapist according to the patients preference. The NICE guidelines should also advise health professionals how to work sensitively with service-users with other disabilities, physical or mental, for example for patients on the autistic spectrum, treatment approaches may sometimes need to take into consideration co-morbidity.	Thank you for your comment. Tailoring healthcare services for each patient and patient views and preferences are covered in NICE Guideline CG138