

Getting a Referral to the National & Specialist Child & Adolescent OCD Services

What is this Guide for?

This guide will give you the information that you need to know about securing a referral for your child to a national & specialist OCD service. It has some tips and ideas on how you can best present your child's case to their Psychiatrist, who will need to make the referral and who might need to make a request to your local funder¹ to pay for their treatment. This guide can be used for related conditions such as Body Dysmorphic Disorder (BDD).

There are currently two national & specialist OCD services for children & young people in the UK:

- Michael Rutter Centre
Maudsley Hospital
De Crespigny Park
London SE5 8AZ
www.national.slam.nhs.uk/services/camhs/camhs-ocd
020 3228 5222
- The Priory Hospital North London
The Bourne
Southgate
London N14 6RA
020 8920 5611
[The Priory Hospital has a private unit offering in-patient care for a very small number of NHS patients/year](#)

What Can You Expect?

The **NICE² Guidelines** (<http://www.nice.org.uk/CG31>) prescribe a stepped care model³ for OCD treatment. Each step introduces additional interventions. The higher steps normally assume interventions in the previous step have been offered and/or attempted but there are situations where an individual may be referred to more specialist services from the outset.

According to NICE, children & young people should have access to national & specialist services with expertise in OCD when their OCD has made them severely impaired or when they have other significant health problems (co-morbidities). National & specialist OCD services are also recommended when a person with OCD has not responded to combined treatment with Cognitive Behavioural Therapy (CBT) & SSRI medication or when they have only had a partial response or when their OCD has come back strongly.

¹ This might be the local Clinical Commissioning Group (CCG) (England); Health Trust (Northern Ireland); local NHS Board (Scotland)

² National Institute for Health and Care Excellence - Developing national clinical guidelines to secure consistent, high quality, evidence based care for patients using the National Health Service

³ See Appendix 1: The stepped care model

The national & specialist OCD services bring together healthcare professionals with experience in dealing with OCD. They have a wealth of experience in dealing with children & young people who have OCD, often in very severe forms, and will be able to provide the best quality of treatment available to you under the NHS.

How do you get a Referral to a National & Specialist OCD Service?

If you think your child might need treatment by a national & specialist OCD team your child's supervising clinician at your local Child & Adolescent Mental Health Service (CAMHS), who may be a psychologist or psychiatrist, will need to make the referral on your behalf.

In England the local NHS funding body⁴ usually pays for any assessment and treatment at a national specialist OCD service out of their local NHS budget. There is small subgroup of the most severely affected cases of OCD that can be treated at the above hospitals at no cost to local health care services. This is for cases when a person with OCD has not responded to combined treatment with Cognitive Behavioural Therapy (CBT) & SSRI medication.

In most cases across the UK, in order for your child's supervising clinician to make a successful referral, they must also make a funding request⁵ to their local or national funding body⁶.

Many funding requests are refused because the local funding body already pays the local CAMHS to provide treatment for OCD⁷. Unless your child has attempted at least one round of CBT available locally, your clinician or the funding panel will most likely refuse your referral because you have not "exhausted local provision". On some occasions appropriate CBT is simply not available locally & this would also be a reason to consider referral to a specialist service.

In addition to CBT for OCD, some children are prescribed a serotonin reuptake inhibiting drug (SSRI). It is important to note that "exhausting local provision" does not mean your child must have tried a course of SSRI drugs.

There are many reasons why local CBT might not have worked for your child:

- they would not engage or cooperate
- the CBT was not good enough⁸
- your child's OCD is too entrenched
- the CBT worked for a while but the OCD has relapsed

None of these are your fault or your child's fault. It is more likely that your child's OCD is entrenched and "treatment refractory"⁹ and needs intervention from a specialist OCD service. Failing to engage, for example, requires specialist advice and support that may not be available locally.

⁴ Previously the local PCT but now it is a Clinical Commissioning Group (CCG)

⁵ Individual Funding Request (IFR) England; Patient Treatment Request (IPTR) Scotland; Individual Patient Funding Request (IPFR) Wales

⁶ See Appendix 2: for details of the process in the different countries of the UK

⁷ Cognitive Behavioural Therapy (CBT) & Exposure Response Prevention (ERP)

⁸ See OCD Action's guide to good CBT: <https://www.ocdaction.org.uk/files/2011/02/CBT-checklist.pdf>

⁹ Treatment resistant

You can request to see all the documentation to be put before the Funding Panel and you are able to submit a written statement to the panel. You should always be given a written explanation for any refusal to refer or fund.

Parent Tip: Don't assume your child's clinician knows how best to prove the case for your child or how the national & specialist OCD service's intervention differs from locally provided CBT. It will really help your case if, when you ask for the referral, you take along the following:

- The NICE guidelines. The NICE guidance carries huge weight, so work out for yourself where you think your child is on the stepped care model. Ask your child's Consultant to do the same and if there is a disparity ask them to put their reasons in writing.
 - Your child's full case history, including a chronology of interventions and outcomes, and why you think treatment has failed.
 - Any supporting documents to show that your child's OCD is entrenched/ treatment refractory.
 - Download and fill out the CY-BOCS rating with your child or have your clinician do this for you.
 - Efficacy of the particular service you're looking for a referral to e.g.; 86% of patients in the 14 week Maudsley programme show a significant improvement. (The Maudsley has high quality outcome data for patients in their service).
 - Parental statement including:
 - the impact it is having at home or at school
 - known crisis points coming up (school transfer, exams, puberty)
 - success in any OCD treatment relies heavily on parental engagement, and you do not want to exhaust your momentum on another round of non-specialist CBT with an uncertain outcome. (Very few CAMHS will be able to provide documented outcomes for children with moderate to severe OCD).
 - If possible include an impact statement from your child
- Make sure you see the referral letter from the local CAMHS before it is sent. These referrals are infrequent and many local consultants do not understand the process and feel that it is a reflection on the performance of their team to have to refer to a specialist centre. They are likely to say that the treatments available at the national & specialist OCD services are all available locally. You may have to negotiate that referral letter with them and emphasise the importance of the wording in that letter. It should clearly state that treatment has been undertaken and recurrence or no response has occurred and that treatment at the national & specialist centre is appropriate and essential.
- CY-BOCS scores are often undertaken at a moment when symptoms have subsided. Try and get that test undertaken when your child is struggling and if possible explain to your child that it is not a good idea to underplay their symptoms. They think that they should be strong and adult and minimise them.
- Make sure that you understand the difference between CBT and ERP.
- Keep your own diary of events and treatments. Local CAMHS records are often inaccurate.

National Funding: In England there is a “pot of money”, which is nationally funded by *NHS England*, for the most serious cases (approximately 20/year at the Maudsley), which does not require approval by your Clinical Commissioning Group (CCG). The criteria for NHS England funding are much stricter than those for CCG funded treatment. Children and adolescents eligible for the NHS England service must fulfil all the following treatment refractory criteria:

- i. a Child Yale Brown Obsessive Compulsive Scale (CY-BOCS) score of 30 or above **and**
- ii. have failed to respond to a previous trial of a serotonin reuptake inhibiting (SSRI) drug at British National Formulary (BNF) recommended doses for a minimum of 3 months (or be unable to take this by virtue of their disorder) **and**
- iii. have failed to respond to a previous adequate trial of CBT including ERP.

<http://psychology.iop.kcl.ac.uk/cadat/general-information/nscag.aspx>

If it is clear from the referral letter (that your child’s clinician writes) that they meet the criteria then NHS England funding will cover the cost of the assessment. If it is not clear or your child does not meet the criteria then local funding would need to be agreed before your child can be assessed at a national specialist OCD service.

Parent tip: In England if your child is very unwell and their clinician believes they meet the criteria they must detail how they do so in the referral letter as the NHS England funding may cover the assessment. If your child might be a borderline case for the NHS England funding ask your local CAMHS to refer your child for just the assessment at a national specialist OCD service in order to confirm eligibility for NHS England funding. They find this easier to agree to, because if your child does qualify for NHS England funding the treatment costs are not borne by the local CCG after the assessment. If not, the case for follow on treatment becomes clearer and more difficult to refuse once you have the assessment. Furthermore, the national & specialist OCD service’s team may be able to be flexible & innovative in their approach.

If You’re Not Successful:

- Ask again. Your child’s clinician can apply more than once providing there has been a ‘material change in circumstances’ e.g. new clinical evidence
- If your CAMHS will not agree to a referral then you might consider paying for a private assessment at a national & specialist OCD service and asking your CAMHS to comply with its treatment recommendations.
- If your CAMHS will not agree to a referral, as a last resort, you could go back to your GP with the NICE guidelines, the CY-BOC score, an outline of treatment and outcomes so far and ask your GP to make the referral. The national & specialist OCD service will, however, need to have the CAMHS service involved in order to start treatment. They can not work in isolation from the local CAMHS team.
- You have a right of appeal to the Independent Funding Appeal Panel if funding is refused and you believe that the CCG/Health Trust/NHS Board did not follow their own procedure – see your local CCG/HT/NHS Board’s policy

- If you fail to get a referral or the funding is declined because you think the case was not presented adequately, you can make a complaint either directly or through your local PALS (Patient Advisory and Liaison Service) who will mediate with your health professional.

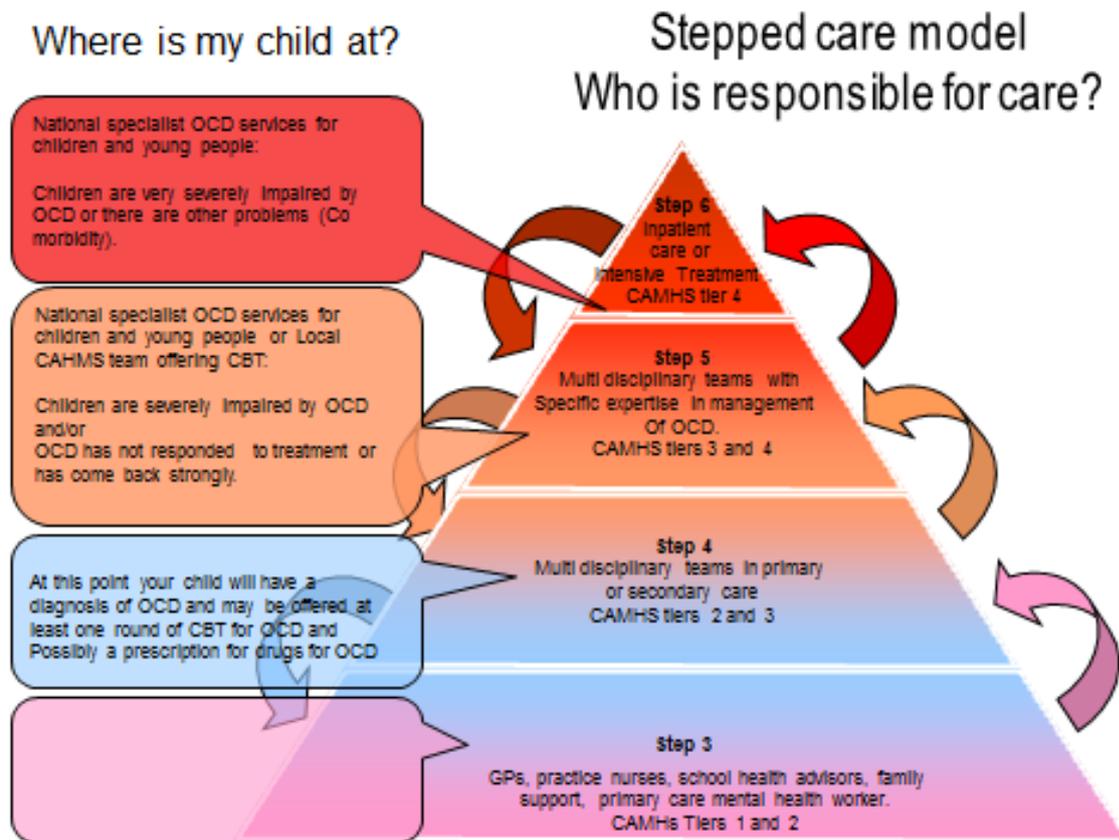
Parent tip:

Most parents have to push hard for this treatment, so expect to be knocked back at first. Sadly, OCD seldom goes away by itself, so it is highly likely to become worse if left untreated. Obviously it is better not to wait for it to reach a crisis point, but if this happens apply again with new clinical information.

In little more than one school term this treatment can make a huge difference to your child's and your family's life. **SO DON'T GIVE UP!**

- Be persistent
- Keep pointing out the NICE guidance & evidence
- Don't be afraid to write to or phone the decision makers directly e.g. the IFR Team Manager or Co-ordinator
- Consider involving your Assembly Member or MP.

Appendix 1: NICE Guidelines – stepped care model for OCD



The national & specialist OCD services are at steps 5&6. Most children & young people will have been offered some assessment and treatment by their local CAMHS at steps 3 to 5.

Appendix 2

FUNDING PROCESSES ACROSS THE UK

IFR Process - England

Screening of an IFR

All requests made are screened by a designated officer of the funder who decides whether the request is appropriate for consideration by the Individual Funding Request Panel. There can be many reasons why a request is screened out including:

- Insufficient clinical & other information
- The request represents a service development i.e. there is a 'cohort of similar patients.'

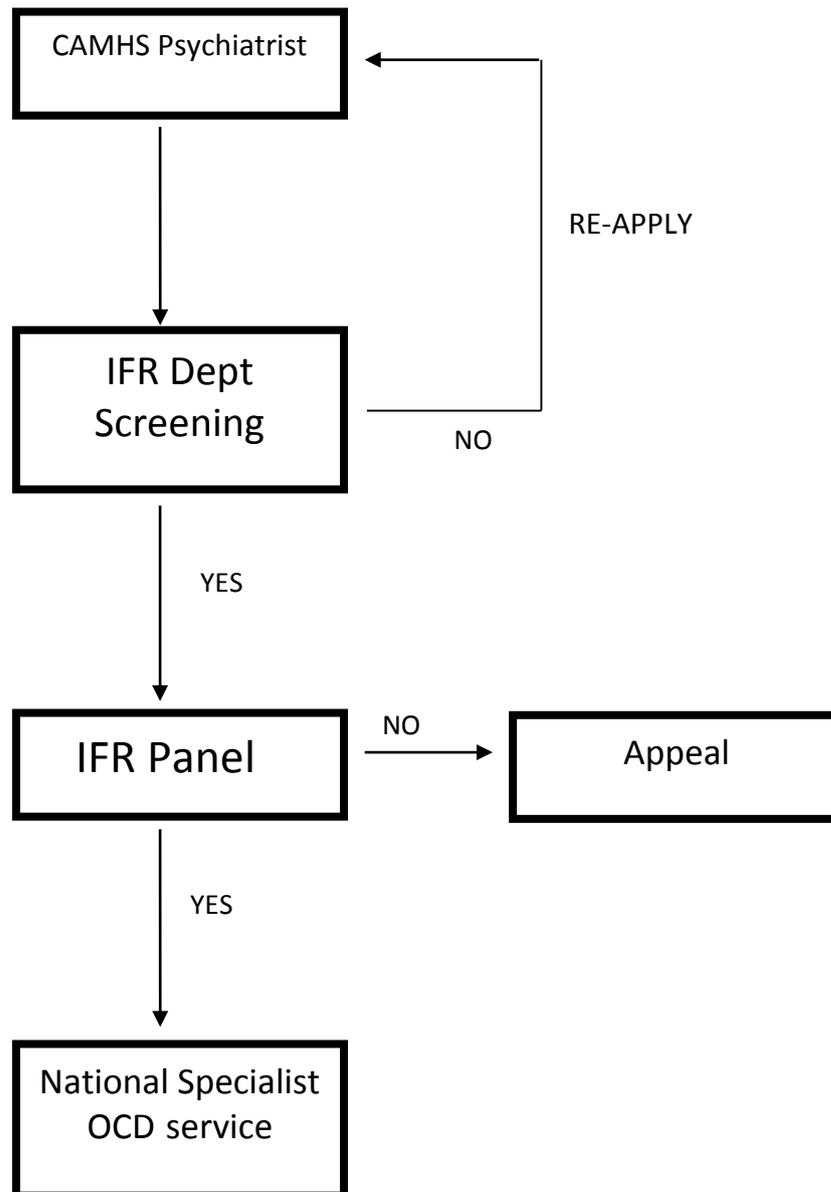
It may be possible to request a review of the screening decision - you should check your funder's policy.

Individual Funding Request Panel

If the application is not screened out then it is passed to the Individual Funding Request Panel. The Panel will consider such issues as:

- The nature of the proposed treatment or investigation and its clinical effectiveness
- An analysis of alternative treatment and its cost effectiveness
- The long term benefits
- Clinical Exceptionality i.e. that the patient is significantly different to the general population of patients with the condition in question & that the patient is likely to gain significantly more benefit from the intervention than the average patient with the condition, at the same stage of progression.
- The number of other people in the area that may be affected by the decision
- Whether the decision will set a precedent.

IFR Process



In Wales, since December 2012, funding for all referrals to national & specialist services in England is controlled by the Welsh Health Specialist Services Committee (WHSSC) See documents CP16 & CP19: <http://www.wales.nhs.uk/sites3/page.cfm?orgid=898&pid=46592>.

To get funding from WHSSC you have to have the approval of the Clinical Gatekeeper (CG). There is a CG in South and North Wales; they will be a tier 4 CAMHS psychiatrist. Your local psychologist/psychiatrist will probably need to check that your child has exhausted all local options (either because they haven't worked or are unsuitable) before writing to the CG formally. All alternatives to an out-of-area placement would need to be considered before an application for a placement is made.

Local services may be unsuitable for a number of reasons, for instance if there is no one with the necessary experience to do CBT with ERP for OCD, or a previous attempt at CBT has been unsuccessful.

If the CG gives approval, then your child's Consultant will need to make an All Wales Individual Patient Funding Request (IPFR) and send it to WHSSC along with the CG's report to get an authorisation code which confirms the funding. If The CG does not give their approval, check they had all the relevant information, it may sometimes be necessary for the case notes to be sent to them, or to ask for a face-to-face consultation. You can also appeal if you think the process hasn't been applied fairly or there is new clinical information.

It is likely that approval will only be given for assessment initially and then you will have to reapply for funding for treatment once the national & specialist service have made their recommendations.

Parent tips- your child's care and treatment plan is a legally binding document in Wales, which you should have had input into drawing up, so try to ensure it contains phrases such as 'treat according to NICE guidance' and also some contingency planning in the event of things getting worse e.g. 'refer to the Maudsley if clinically indicated'. It also specifies who your Care Coordinator is; usually it is your child's psychologist or psychiatrist.

The letter from your child's Consultant asking for the opinion of the CG is crucial, so if possible work with your child's Consultant to ensure it contains as much information as possible and demonstrates clearly how local options have been exhausted. It should also state where your child is on the NICE stepped care model. Ask for personal statements to be attached from yourself and your child. Ask to be copied in to all correspondence.

For procedures in Northern Ireland please see: HSCB Arrangements for the Consideration of Requests for Care and/or Treatment on Behalf of Individual Patients (see link below) and your Health Trust's policy on Individual Funding Requests/Extra Contractual Referral (Non Acute ECR). Your child's consultant needs to make an Extra Contractual Referral through your Health Trust's process and if it is agreed that your child's assessed service need cannot be met in the Trust or accessed in Northern Ireland then it will be endorsed by your Health Trust's Director of Mental Health or Learning Disability or the Clinical Director. The policy below covers the regional funding application (Non-Acute ECR) that your child's Consultant would then need to make to the Health & Social Care Board (HSCB) for consideration.

http://www.hscbusiness.hscni.net/pdf/Protocol_ECR_and_IFR_arrangements.pdf

In Scotland: Your child's clinician would need to make an Individual Patient Treatment Request (IPTR) through the local NHS Board's process. Once approved by the NHS Board the request is passed to the National Services Division (NSD) which is a division within NHS National Services Scotland. NSD funds services provided in England by managing a pool of funds (risk share scheme) on behalf of NHS Boards for specialised services in England which are not nationally designated.

The NSD would assess the request by ensuring that the requested treatment is not available locally and that your child meets the NHS England criteria.

Acknowledgements

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GLOSSARY

CBT: Cognitive Behavioural Therapy

ERP: Exposure Response Prevention

SSRI: Selective Serotonin Reuptake Inhibitor – often referred to as an anti-depressant

CAMHS: Child & Adolescent Mental Health Services

NICE: National Institute of Health & Clinical Excellence

CY-BOCS: Children’s Yale-Brown Obsessive Compulsive Scale

HSOCD: Highly Specialist OCD service – where the provision is funded through NHS England funding i.e. Michael Rutter Centre at the Maudsley & the Priory Hospital North London

CCG/HT/NHS Board: Local funding bodies - Clinical Commissioning Group (England); Health Trust (Northern Ireland); NHS Board (Scotland)

CG: Clinical Gatekeeper (Wales)

IFR/IPFR/IPTR: Individual Funding Request (England & Northern Ireland), Individual Patient Funding Request (Wales), Individual Patient Treatment Request (Scotland)

WHSSC: Welsh Health Specialist Services Committee

NSD: National Services Division (Scotland)

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