

How to access a specialist service in OCD?

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Specialist service in OCD

Not yet agreed standards which are inspected by peers and users for a specialist service in OCD

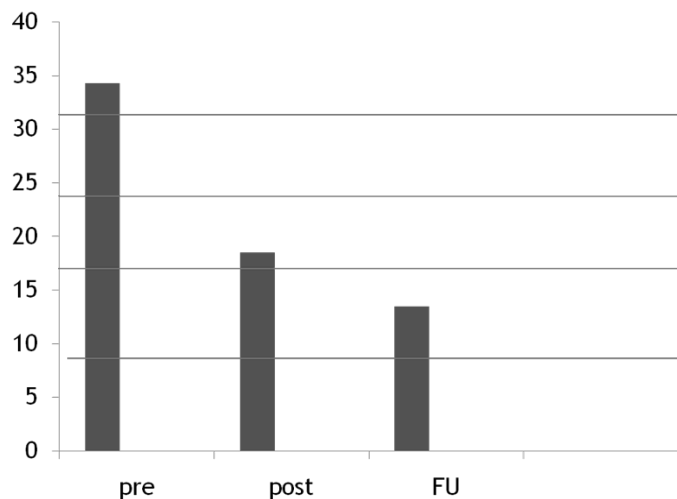
1. How do you deliver good quality CBT for OCD?
(see previous presentation)
2. Do you have a consultant who oversees or reviews medication?
3. Have your therapists chosen to work with OCD?
Do they mainly work in OCD?

Specialist Service in OCD

4. Do the staff have continuing professional development (CPD) that includes OCD (e.g conferences)
5. Does your service train others in CBT for OCD?
6. How does patient feedback influence service?
7. Are there patient representatives in your service (e.g for discussing improvements and staff recruitment)?

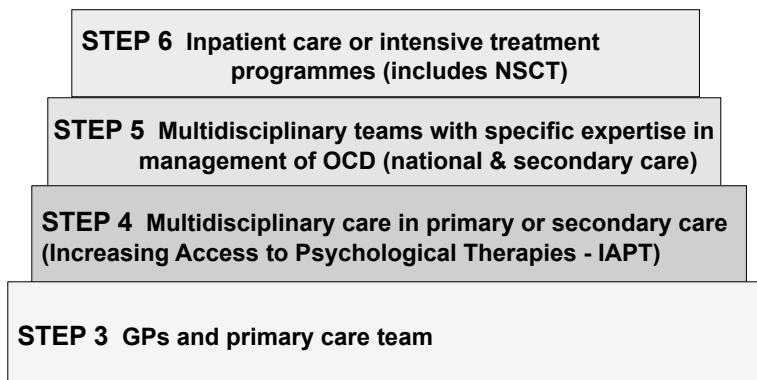
8. [Is there session by session measures of OCD to monitor my progress?](#)
9. Does your service audit its outcome data? Can I see the results? Are you happy with the results achieved?
10. Do any of your staff conduct research into OCD? Where can I find your list of publications?

NSCT OUTCOME ADRU MEAN YBOCS



STEPPED CARE MODEL FOR OCD & BDD

Who is responsible for care?



NHS NICE guidelines on OCD & BDD
<http://www.nice.org.uk/CG031>

Non Specialist Services Tier 3

- GP
 - Is easy to access
 - Can make diagnosis
 - Can start medication if prefer
 - Can signpost & refer to either local Increasing Access to Psychological Therapies (IAPT) (www.iapt.nhs.uk) or community mental health team (depending on complexity & severity)

Non Specialist Services Tier 4

- NHS Increasing Access to Psychological Therapies in most of England www.iapt.nhs.uk (Wales & Scotland more variable)
 - Some services allow self referral
 - May be offered low intensity CBT with Psychological Well-Being Practitioner (PWP) and guided self help or group if less severe
 - Usually individual CBT 12-15 sessions
 - Therapist should be reasonably well trained and receive supervision
 - May be a trainee under supervision

Non Specialist Services Tier 5

- If treatment failed at IAPT or more complex, stepped up to Community Mental Health Team (CMHT)
- Do risk assessments and crisis work mainly for people with bipolar disorder, schizophrenia etc
- Usually have a psychology service but long wait list - often referred to IAPT
- Expertise in OCD variable - may be a trainee under supervision
- Likely to be offered individual CBT 12-15 sessions
- If treatment fails then advocacy may help to get referral to a specialist service

Non-NSCT Specialist Services Tier 5/6

- [Access by referral from Community Mental Health Team and funding](#) agreed by Primary Care Trust (some uncertainty in the future whether funded by GP commissioning)
- Occasionally block funding for region
- Specialist services for NHS patients
 - Maudsley & Bethlem Hospitals, London
 - QE2, Welwyn
 - Springfield, South London
 - Sheffield
 - Guilford
 - Private sector for some NHS - Priory North London

Recommendations identified as key priorities in NHS NICE guidelines on OCD & BDD

<http://www.nice.org.uk/CG031>

- All people with OCD should have access to evidence-based treatments: CBT including exposure and response prevention and/or pharmacology (SSRI)
 - PCTs, mental healthcare trusts and children's trusts that provide mental health services should have access to a specialised OCD multidisciplinary healthcare team
- (Note NICE guidance is only recommended good practice for NHS and best evidence treatments)

Severity of OCD

- **Complexity - OCD/ BDD is complex or additional** problems like depression or Aspergers
- Degree of interference in your ability to work or study; relationships & family life; social life
- Severity - Use total for Yale Brown Obsessive Compulsive Scale www.psymed.info
 - 0-7 is sub-clinical
 - 8-15 is mild
 - 16-23 is moderate
 - 24-31 is severe
 - 32-40 is extreme

Treatment so far

- Success with nature or quality of CBT so far (see previous presentation)
- Stepped care in NICE guidelines recognizes that if fail treatment at a local service, your care should be stepped up as specialists may have greater expertise and success as they treat OCD all the time; often more intense
- Patient choice (for example whether you choose to have further medication or not) is also important
- Ask for second opinion/ assessment first
- Need support of your local consultant or senior psychologist to obtain funding from the primary care trust

NSCT Tier 6

- [Nationally Specialist Commissioning Team](#)
- [National funding from Dept of Health \(all Primary Care Trusts are top-sliced\)](#)
- Consortium
 - [Maudsley \(o-p\) and Bethlem Royal Hospitals \(residential unit\)](#)
 - [Springfield \(o-p, home, i-p\)](#)
 - [QE2 \(o-p, i-p\)](#)
 - [Priory \(i-p\)](#)

Criteria for NSCT funding

- Referred for an assessment at one of the centres by your Community Mental Health Team (CMHT)
- OCD or BDD severe (greater than 30 on rating scale)
- Failed two sets of CBT locally (of adequate quality & duration)
- Failed three trials of medication in adequate dose & duration (two sets of SSRIs and “augmentation” i.e. high dose SSRI or adding anti-psychotic drug)
- CMHT will continue to take responsibility for you after treatment and discharge
- After assessment, your case is discussed and funding agreed with other centres on teleconference

Securing your referral- Non NSCT

NHS organisations and any organisations that provide care under the NHS must act according to The NHS Constitution. The constitution states that:

- **“You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you.”**
- **“You have the right to expect local decisions on funding of other drugs and treatments to be made rationally following a proper consideration of the evidence. If the local NHS decides not to fund a drug or treatment you and your doctor feel would be right for you, they will explain that decision to you.”**

Who can refer me?

- Your Psychiatrist or another senior member of your team such as your Psychologist has to make the referral to the specialist centre.
- They will also need to get funding approved for the initial assessment, and ideally, for the whole treatment. In most cases they will need to make sure that funding is in place before speaking to the specialist centre.
- If funding is not in place, then the specialist centre can apply to the PCT on your behalf.

The Individual Funding Panel

The Individual funding panel of the Primary Care Trust (PCT) or Local Health Board (LHB) will meet to consider your clinician's application. In cases of urgent treatment, a decision can be made by one of the Executive Directors (Authorised Officer). The panel will consider such issues as:

- Do you meet the PCT's referral criteria?
- 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
- Any exceptional circumstances
- The number of other people in the area that may be affected by the decision
- Whether their decision will set a precedent.

How do you get your clinician to agree to a referral?

- You need the full support of your Psychiatrist or Psychologist who will undertake the referral and funding request process.
- Before any consultation with the clinician, it is helpful to write out the main points of your argument. In particular make sure you note down your views on why you think that previous treatment has not helped, how you have actively tried to engage with it and why you feel that you have not got any better.
- Try and be as specific as you can about the treatment you have received and how OCD affects your life. Tell them about how long you spend on certain rituals or activities such as leaving the house or taking a shower or how often you experience intrusive thoughts. If you feel that you would rather write to your consultant, OCD Action has a letter template that you can use and adapt.

Personal Statements

You are able to submit a statement to the panel outlining your case for funding and the exceptionality of your case. **The referring clinician is expected to advise you that you can submit comments to the panel for consideration in the decision making process.** Your statement should be forwarded with their completed application. You may need to find out the name of the Commissioner who is responsible for mental health in your trust.

What if I cannot get a referral?

- You could ask for a second opinion, for example you could try asking for an opinion from the Medical Director or Head of Psychology of the Mental Health Trust, or get a private opinion from a Consultant at a Centre of Excellence.
- Ask your clinician why they think a referral is not appropriate and always ask for the clinician's opinion in writing or alternatively write down what they tell you in front of them. Make sure that they give a clear explanation as to why they will not support an application to the PCT or LHB. It may be that they do not have the information that they need, that they are not aware that your case would meet referral under the NICE guidelines and do not know the routes to the Centres of Excellence.
- *Some other things to think about... (verbal list)*

What if the PCT refuses to fund my treatment?

- PCTs are unlikely to fund your treatment at a centre of excellence if they feel you have not tried all the treatments that they are able to provide locally, the term often used for this is “**not exhausted local services**”.
- You can always argue that because of the severity of your condition, you need to jump a few steps in the NICE Guideline stepped care process, so you don't have to have done everything on offer.
- There is now an emphasis on patient choice, so that if you do not now wish to take recommended medication, then you do not have to. Although the guidelines are not legally enforceable, teams would have to give a pretty good reason not to follow them.
- Don't accept the argument “You've tried CBT” and “they are not going to do anything different at the specialist centre”. Always refer to the best practice NICE guidelines for OCD.

Appeals

- You have the right to appeal the decision of the Individual Funding Panel within a time period set out by them. Any appeal will be heard by the Appeals Panel. The role of the Appeals Panel is to see if the Individual Funding Panel has followed its own procedures correctly, considered all the evidence and come to a reasonable decision based on the evidence. **The Appeal Panel has a different membership from the standard Individual Funding panel.**
- The Appeals Panel can uphold your appeal and refer the case for reconsideration to the IFR panel. The Appeals Panel will do this if they believe that the Individual Funding Panel has:
 - Failed in a material way to follow its own procedures
 - Failed in material way to consider the evidence presented to it
 - Come to a decision that no reasonable IFR panel could have reached on the evidence before it

The appeals panel do not have authority to grant funding; they can only make recommendations to the IFR panel.

What you will need (see handout)

Getting your clinician on your side..

Your clinician should be part of the appeals process. Where the request for funding is declined, your health professional can ask for the decision to be reconsidered if supported by additional and new information. If your clinician feels that the process had not been handled appropriately, he or she may appeal against the decision by writing to the Individual Funding Request Appeal Panel, asking for the case to be reconsidered.

If all else fails..

- The appeals process is the first step but you also have the right to make a complaint under the NHS and Social Care Complaints Regulations. You should be aware however that any investigation under these regulations will **examine whether the correct policies and procedures have been followed** when considering a funding request and will not make a comment on the decision made.
- **Sources of Help & Information**
- OCD Action's Advocacy Service: 0845 390 6234
- OCD Action's website: www.ocdaction.org.uk (for advocacy documents)
- NICE Guidelines on OCD & BDD www.nice.org.uk/CG31
- OCD Action's Helpline: 0845 390 6232 (for OCD information and emotional support).