

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Interventional procedures

Patient Organisation Submission

Transcranial magnetic stimulation for obsessive- compulsive disorder IP1768

Thank you for agreeing to give us your views on this procedure or operation and how it could be used in the NHS.

When we are developing interventional procedures guidance we are looking at how well a procedure or operation works and how safe it is for patients to have.

Patient and carer organisations can provide a unique perspective on conditions and their treatment that is not typically available from other sources. We are interested in hearing about:

- the experience of having the condition or caring for someone with the condition
- the experience of having the procedure or operation
- the outcomes of the procedure or operation that are important to patients or carers (which might differ from those measured in clinical studies, and including health-related quality of life)
- the impact of the procedure or operation on patients and carers. (What are the benefits to patients and their families, how does it affect quality of life, and what are the side effects after the procedure or operation.)
- the expectations about the risks and benefits of the procedure or operation.

To help you give your views, we have provided this template. You do not have to answer every question — they are there as prompts. The text boxes will expand as you type, the length of your response should not normally exceed 10 pages.

Please note, all submissions will be published on the NICE website alongside all evidence the committee reviewed. Identifiable information will be redacted.

About you	
1. Your name	██████████
2. Name of organisation	OCD-UK
3. Job title or position	██████████
4. Brief description of the organisation (e.g. who funds the organisation? How many members does the organisation have?)	<p>OCD-UK is a service user charity in that our organisation is led by people affected by Obsessive-Compulsive Disorder. So in your terms is 100% patient led.</p> <p>The charity is funded primarily through donations and fundraising and membership subscription of about 700 people with OCD across the UK.</p> <p>OCD-UK do not have any conflicts of interest to declare.</p>
<p>5. How did you gather the information about the experiences of patients and carers to help your submission?</p> <p>(For example, information may have been gathered from one to one discussions with colleagues, patients or carers, telephone helplines, focus groups, online forums, published or unpublished research or user-perspective literature.)</p> <p>We gathered the information through postings on our discussion forums and through conversation at support groups.</p>	

Living with the condition

6. What is it like to live with the condition or what do carers experience when caring for someone with the condition?

Rather strange question to ask... But... it's like a nightmare, except it's an awake nightmare. The condition impacts on every aspect of a persons life and often loves ones too. It impacts on education (young people), relationships, careers and sometimes with sad and tragic consequences.

Advantages of the procedure or operation

7. What do patients (or carers) think the advantages of the procedure or operation are?

One patient made the point without evidence that it works, no advantage.

Another suggested giving the brain a jump start may change the pattern of electrical signalling, in doing so changing the thought patterns the impulses translate to.

Generally there is little evidence that users are increasingly looking for treatments like TMS to treat OCD. In the last 3 years we have only had two enquiries (and those following a newspaper article).

Disadvantages of the procedure or operation

8. What do patients (or carers) think the disadvantages of the procedure or operation are?

Some patients believe it would be no more effective than a placebo.

Others are questioning why NICE are reviewing TMS for OCD when earlier in the year acknowledged said current evidence about the effectiveness of TMS to treat OCD was inconclusive, due to mixed findings.

Another user suggested the procedure implies that OCD is a problem of the brain, which hasn't been shown by conclusive evidence and that it will offer a lot of false hope to vulnerable people.

If the claim is TMS reduces OCD thoughts (which would be debatable), what evidence is there that normal everyday thoughts would not be reduced?

As there been a global review of all TMS use and how frequently TMS resulted in the patient having series side effects, such as Epileptic seizures? What are the odds of TMS resulting in serious side effects? Important patients know this and important this evidence is reviewed before NICE consider recommending.

What evidence is TMS remains effective in any capacity (without medication or CBT) after 3, 6, 12, 18+ months?

At this time OCD-UK consider the evidence insufficient for procedures like TMS (and DBS) to be recommended for the use of treatment of Obsessive Compulsive Disorder. Although TMS for OCD has been looked at in a number of studies, the stimulation parameters used, the brain areas targeted, and the length of treatment has varied from study to study, making it difficult to compare results.

Significant more research is needed before it should be considered a NHS recommendation for OCD.

Patient population
9. Are there any groups of patients who might benefit either more or less from the procedure or operation than others? If so, please describe them and explain why.
Equality
10. Are there any potential equality issues that should be taken into account when considering this topic?
Other issues
11. Are there any other issues that you would like the Committee to consider?
Key messages
12. In no more than 5 bullet points, please summarise the key messages of your submission. <ol style="list-style-type: none">1. Why NICE are reviewing TMS for OCD when earlier in the year acknowledged said current evidence about the effectiveness of TMS to treat OCD was inconclusive2. If the claim is TMS reduces OCD thoughts (which would be debatable), what evidence is there that normal everyday thoughts would not be reduced?3. As there been a global review of all TMS use and how frequently TMS resulted in the patient having series side effects, such as Epileptic seizures?4. What evidence is TMS remains effective in any capacity (without medication or CBT) after 3, 6, 12, 18+ months?5. At this time OCD-UK consider the evidence insufficient for procedures like TMS to be recommended for the use of treatment of Obsessive Compulsive Disorder.

Thank you for your time.

Please return your completed submission to jp@nice.org.uk

