

# **Clinical Commissioning Policy: Deep Brain Stimulation for Refractory Tourette Syndrome (adults)**

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## Policy statement

NHS England will not routinely commission deep brain stimulation for Tourette syndrome in accordance with the criteria outlined in this document.

In creating this policy NHS England has reviewed this clinical condition and the options for its treatment. It has considered the place of this treatment in current clinical practice, whether scientific research has shown the treatment to be of benefit to patients, (including how any benefit is balanced against possible risks) and whether its use represents the best use of NHS resources.

## Equality statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

## Plain language summary

### About Tourette Syndrome

Tourette Syndrome is a condition that starts in childhood, affecting the brain and nervous system, and characterised by multiple motor tics (sudden, repetitive, non-rhythmic movements) and at least one vocal tic. These tics tend to be preceded by an unwanted urge or sensation in the affected muscles.

About one in a hundred people are affected but most cases are mild and/or spontaneously improve as they pass into adulthood. Severe cases may require medication but a small number of patients do not respond to the drugs prescribed nor appear to improve as they get older.

### **About current treatments**

Behavioural therapy is usually the first approach to treatment. If this is unsuccessful medicine may be given; using drugs developed for the treatment of mental health conditions such as psychosis. In some cases muscle relaxing treatments are used.

### **About the new treatment**

Among the patients with tics that persist into adulthood, a few individuals will experience severe symptoms. Among these, there is a small group of patients who do not respond to the medicines or cannot tolerate them. Deep Brain Stimulation (DBS) is already used in the NHS for movement disorders such as Parkinson's disease and dystonia. DBS represents a potential treatment option for a small group of patients who do not respond to other treatments.

### **What we have decided**

NHS England has carefully reviewed the evidence to treat Tourette Syndrome with deep brain stimulation. We have concluded that there is not enough evidence to make the treatment available at this time.

## 1 Introduction

This policy considers the use of Deep Brain Stimulation for patients with Tourette Syndrome (TS).

Tourette Syndrome is defined as the presence of multiple motor and vocal tics, starting in childhood and persisting for more than one year .

## 2 Definitions

Deep Brain Stimulation: a surgical procedure involving the implantation of a neurostimulator, which sends electrical impulses to specific targets in the brain.

Tourette Syndrome (TS): a neurological condition characterised by multiple motor tics and at least one vocal tic.

Tics: sudden, repetitive, non-rhythmic movements preceded by an unwanted urge or sensation in the affected muscles.

Severe Tourette Syndrome is defined as tics causing functional disability and accompanied by a score on the Yale Global Tic Severity Scale >35/50.

Treatment refractoriness is defined in accordance with published recommendations by Schrock et al. 2015, as; 1. Failed treatment trials from three pharmacological classes: a) alpha-adrenergic agonist, b) two dopamine antagonists (typical & atypical), c) a drug from at least one additional class (e.g., clonazepam, tetrabenazine). 2. A trial of behavioural therapy using Comprehensive Behavioural Intervention for Tics (CBIT) should have been offered or considered.

## 3 Aims and objectives

This policy aims to consider treatment for patients who are not receiving sufficient benefit from existing treatments.

The objectives are to consider the available evidence and inform the policy position.

## 4 Epidemiology and needs assessment

Approximately, 1% of the population under age 18 years has Tourette's Syndrome (Robertson 2008). The majority have mild symptoms and those with a more severe condition generally respond to medication and/or get better spontaneously as they get older, although tics do not usually completely disappear.

Patients with severe, medication refractory Tourette syndrome persisting into adulthood are rare. An estimated 5-10 patients per year would be eligible for DBS in England.

While there are formal epidemiological studies quantifying the age stratified incidence and prevalence of Tourette syndrome, there are no data that include information on disease severity and previous treatment trials.

Estimated numbers of eligible patients for DBS are therefore derived from the only 3 dedicated Tourette syndrome clinics in England. It is assumed that almost all of the severe disabling and treatment refractory Tourette syndrome sufferers in England have been referred at some point to one of these three dedicated specialist clinics.

An estimated 5-10 patients per year would be eligible for DBS in England based on estimates by the clinicians running the 3 dedicated Tourette syndrome clinics, on the basis of disease severity, medication refractoriness, willingness to undergo neurosurgery, and absence of other medical or psychiatric illness that would be a contraindication to DBS surgery.

## 5 Evidence base

NHS England has concluded that there is not sufficient evidence to support the routine commissioning of this treatment for the indication.

The eight studies (see list in reference section 15) included in the evidence review showed an improvement in total Yale Global Tic Severity Scale (YGTSS) scores, although the degree of improvement varied quite widely. Most of the studies were limited by small sample sizes and this, together with differences in how they were

conducted, limits the usefulness of the findings so that we cannot tell with any great degree of certainty, whether DBS would work in the same or similar way in any other patients with severe and difficult to treat TS.

A number of adverse events (AEs) and side effects were reported from the studies. However, these were mostly incidental findings rather than findings from studies designed specifically to look for them. As such, all we can infer is that symptoms such as lethargy and dizziness may be associated with DBS, but it is by no means certain that any of them will occur or that other AEs and side effects that have not yet been identified might be equally likely to occur.

The primary research trials included varied in their quality: the numbers of patients varied between 3 and 17, with the systematic review and meta-analysis including 162 and 150 patients respectively. Hence the power of the studies to identify meaningful results was limited and the results presented may have been an over or under-estimate of reality. The patient characteristics were also either unclear or biased (one study had all male patients), baseline medication and changes to medication were not necessarily reported and neither were co-morbidities. The electrodes were also implanted in different locations in the brain. This means that other factors could have influenced the magnitude of the outcome responses, such as the amount of improvement in YGTSS score, apart from the DBS.

## **6 Documents which have informed this policy**

A comprehensive evidence review was undertaken in order to inform this policy. The outputs of the evidence review have been summarised in section 5.

## **7 Date of review**

This document will be reviewed when information is received which indicates that the policy requires revision.



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