

## PE1723/C

Scottish Government submission of 3 December 2019

The Scottish Government is committed to making sure all people living with neurological conditions in Scotland are able to access the best possible care and support, and benefit from healthcare services that are safe, effective and put people at the centre of their care.

That is why we have worked with the neurological community to develop Scotland's first ever National Action Plan on Neurological Conditions. We have included the Plan in our Programme for Government, a sign of our commitment to this agenda.

The vision is that everyone with a neurological condition will be able to access the care and support they need to live well, on their own terms. These aims include improving the co-ordination of services and ensuring high standards of person-centred care.

We are currently refining the National Action Plan based on consultation responses, and in extensive discussion with policy colleagues spanning multiple Directorates in the Scottish Government that have relevant commitments included in the Plan.

We expect to publish the final National Action Plan later this year, along with a high level outline of priorities for the first year of implementation. We look forward to working closely with all stakeholders on the implementation of the national action plan over the next five years.

The role of the Scottish Government is to provide policies, frameworks and resources to NHS Boards to allow them to deliver services that meet the needs of their local populations. Within this context the actual provision of healthcare services is the responsibility of local NHS Boards taking into account national guidance, local service needs and priorities for investment. We expect all NHS Boards to regularly review services and facilities to ensure they continue to reflect local needs and provide the best quality healthcare services.

We recognise that essential tremor is a progressive disease and involves uncontrolled shaking movements in parts of the body. It is more common with increasing age. It tends to occur in families. It is mild in some people but can become severe and disruptive to daily activities in others. It tends to become worse over time but does not shorten expected lifespan and does not lead on to any other neurological disorders.

**Treatment - medicine:** There is good treatment available in the form of medication but essential tremor cannot be cured. Treatment reduces the severity of the tremor, sometimes greatly. There are various treatments that are used

- Propranolol hydrochloride or another beta-adrenoceptor blocking drug may be useful in treating essential tremor or tremors associated with anxiety or thyrotoxicosis.
- Primidone in some cases provides relief from benign essential tremor; the dose is increased slowly to reduce side-effects.

A wide range of other medicines (for example, topiramate or gabapentin) have also been shown to have some effect on reducing the severity of the tremor.

**Treatment – surgery:** If medicine-based treatment is not effective and the tremor is severe, a surgical procedure may be an option. There are two main surgical procedures that may be considered - thalamic deep brain stimulation and thalamotomy.

- Thalamic deep brain stimulation (DBS) - this procedure involves placing a fine wire (an electrode) into the thalamus on one or both sides of the brain. It seems to interrupt or block the nerve signals coming through the thalamus that cause the tremor
- Thalamotomy - in this procedure, the thalamus on one side of the brain is destroyed. The brain tissue is usually destroyed by using a special ultrasound or by using beams of radiation.

Both of these surgical approaches carry risk of side effects, including muscle weakness, loss of sensation, speech problems and memory loss.

In June 2018 the National Institute for Health and Care Excellence (NICE) published guidelines on the use of unilateral MRI-guided focussed ultrasound thalamotomy for treatment-resistant essential tremor ([www.nice.org.uk/guidance/ipg617](http://www.nice.org.uk/guidance/ipg617))

This concludes that while clinical evidence does not raise safety concerns, current evidence of efficacy is limited. Therefore evidence of patient benefit is too limited for the NHS to currently adopt MRI guided ultrasound technology for treatment of essential tremor.

The key recommendations contained within these guidelines are given below:

- The evidence on the safety of unilateral MRI-guided focused ultrasound thalamotomy for treatment-resistant essential tremor raises no major safety concerns. However, current evidence on its efficacy is limited in quantity. Therefore, this procedure should not be used unless there are special arrangements for clinical governance, consent, and audit or research.
- Clinicians wishing to do unilateral MRI-guided focused ultrasound thalamotomy for treatment-resistant essential tremor should:

Inform the clinical governance leads in their NHS trusts.

Ensure that patients and their carers understand that this procedure is only done to treat tremor on one side of the body, and that the effect of this on the functional ability and quality of life of patients with bilateral disease is uncertain. Patients should be informed about alternative treatments, including those that can be done bilaterally. Provide patients with clear written information to support shared decision-making. In addition, the use of NICE's information for the public is recommended.

Audit and review clinical outcomes of all patients having unilateral MRI-guided focused ultrasound thalamotomy for treatment-resistant essential tremor. NICE has identified relevant audit criteria and has developed an audit tool <https://www.nice.org.uk/guidance/ipg617/resources> (which is for use at local discretion).

- Patient selection should be done by a multidisciplinary team experienced in managing essential tremor, including clinicians with specific training in the procedure.
- Further research, which could include randomised controlled trials, should address patient selection, report on functional improvement and quality of life, and provide long-term follow-up data.

The National Specialist Services Committee (NSSC) met on 4 December 2018 to consider a stage one application for specialist treatment of patients with Essential Tremor using MRI-guided focused ultrasound (MRgFUS).

The committee was unable to endorse the application for funding as a nationally designated service. It was highlighted that NICE guidance is 'permissive' and whilst there is some evidence for use of MRgFUS in essential tremor there is a clear statement that research is needed into its application for Parkinson's Disease and MS tremor.

NSSC was clear that should the evidence base be further developed and MRgFUS be recognised as a safe and effective intervention for treatment of tremor the committee would be willing to consider a re-application in future.

The Scottish Government funds research through the Chief Scientist Office (CSO).

Researchers can apply directly to CSO for funding. The CSO's Translational Clinical Studies Committee and the Health Improvement, Protection and Services Research Committees each meet twice per year to consider funding applications. Funding of up to £300,000 per project is available. Details of the application process are published on the CSO website. <http://www.cso.scot.nhs.uk/funding-2/>

Applications looking at the effectiveness of focussed ultrasound thalamotomy for treatment-resistant essential tremor are welcomed. In common with all other applications, these would go through the CSO's standard independent peer review process.

Through a Scottish Government contribution to the National Institute for Health Research, Scottish-based researchers are able to apply for large UK-wide funding awards. Both the NIHR Health Technology Assessment (HTA) and Efficacy and Mechanism Evaluation (EME) programmes have remits appropriate to the evaluation of surgical procedures. <https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-technology-assessment.htm>  
<https://www.nihr.ac.uk/explore-nihr/funding-programmes/efficacy-and-mechanism-evaluation.htm>