

# Citizen Participation and Public Petitions Committee

1<sup>st</sup> Meeting, 2022 (Session 6), Wednesday 19  
January 2022

## PE1723: Essential tremor treatment in Scotland

### Note by the Clerk

**Lodged:** 4 July 2019

**Petitioner:** Mary Ramsay

**Petition  
summary:** Calling on the Scottish Parliament to urge the Scottish Government to raise awareness of essential tremor and to support the introduction and use of a focus ultrasound scanner for treating people in Scotland who have this condition.

**Webpage:** <https://petitions.parliament.scot/petitions/PE1723>

### Introduction

1. The Committee last considered this petition at its meeting on [8 September 2021](#). At that meeting, the Committee agreed to write to the Cabinet Secretary for Health and Sport. It also agreed to write to the University of Dundee to seek an update on the MRgFUS system which was due to be ready for use in 2021.
2. A summary of past consideration of the petition and responses to information requests are provided for the Committee's consideration.
3. The petitioner submission is awaiting approval for publication and will be circulated to the Committee ahead of its meeting.

### Background

4. During its consideration of this petition, the Committee received 17 written submissions and to date has written to:
  - Scottish Government (x3)

- University of Dundee (x2)
- Cabinet Secretary for Health and Sport (x2)
- NHS Tayside
- National Institute for Health and Care Excellence

5. According to the [National Institute for Health and Care Excellence \(NICE\)](#)—
- ‘Essential tremor is the most common cause of disabling tremor and is distinct from Parkinson's disease. It typically affects the arms and hands, although it may also involve the head, jaw, tongue and legs. The cause is not known but many patients have a family history of the condition. At first, the tremor may not be present all the time. However, it gradually worsens. Purposeful movement, stress, tiredness, hunger, heightened emotions or extremes in temperature make it worse.’
6. Treatment for Essential Tremor (ET) includes drug treatment and, if the condition is not responsive to this, a surgical procedure called Deep Brain Stimulation (DBS) can be undertaken. It is noted that while DBS is effective at improving symptoms, the benefits tend to diminish over time and the procedure is invasive with associated risks.
7. The alternative proposed by the petitioner is Magnetic Resonance-guided focused ultrasound (MRgFUS) which is a relatively new and non-invasive procedure.
8. MRgFUS uses an MRI to guide powerful focused ultrasound to a very small point in the body. At that point, the ultrasound causes molecules to vibrate extremely quickly, creating an intense local heat. That heat can destroy tissue. MR-guided focused ultrasound allows a very specific focal point to be targeted, ensuring that only this targeted tissue is affected.
9. During its last consideration of the petition, the Committee considered written submissions from the Scottish Government, University of Dundee, NICE and the petitioner.
10. The Committee also heard from Rhoda Grant MSP on behalf of the petitioner, who stated that: ‘When the petition started, NHS Tayside and the University of Dundee were working together to fund and purchase a machine. They have now done that—the machine is available and is giving treatment in Scotland. However, that treatment is termed experimental treatment—I say “termed” because it is not experimental; it has been approved elsewhere. It is called experimental because it is under that locus that it can be used to treat people. A general practitioner or consultant in Scotland cannot always refer someone to the facility in Dundee unless they are talking about experimental treatment; if they do not do that, they have to refer the person to Professor Nandi and his colleagues in London. There is a huge waiting list for treatment in London, as you can imagine, and it seems wasteful that we have this treatment available in Scotland, but Scottish people cannot access it.’

11. The Committee heard that while there are no major safety concerns associated with the use of MRgFUS for essential tremor treatment, current evidence of its efficacy is limited in quantity.
12. The petitioner highlighted that MRgFUS is currently available in the USA, in Japan and in other countries around Europe.

## University of Dundee

13. The University of Dundee confirmed that their MRgFUS system has been used to treat five patients with Essential Tremor and state that 'the evidence base for MRgFUS effectiveness in ET is now beyond doubt'.
14. The submissions notes that NHS England have approved the treatment for 150 ET treatments per year as part of its standard service. Initially, funding was not available in Scotland and the first treatments were made possible by charitable funds. However, funding approval has been obtained from individual NHS health boards for patients to be treated in Dundee over the forthcoming months.
15. The University of Dundee states that its long-term goal to undertake clinical trial research into emerging indications for MRgFUS in conditions such as Parkinson's Disease. To achieve this, it indicates that establishing MRgFUS as a standard care for ET patients in Scotland will be critical in delivering on this goal.
16. The submission requests clarification from the Scottish Government as to the timeframe within which a re-application to [NHS National Services Scotland's National Service's Division \(NSD\)](#) would be accepted [to establish MRgFUS as standard care]. It notes that this would allow future service planning to 'ensure continued access for patients and a sustainable model of service delivery for this life changing treatment.'

## Cabinet Secretary for Health and Social Care submission

17. At its meeting of 8 September 2021, the Committee agreed to write to the Cabinet Secretary for Health and Social Care requesting an update on plans to submit a proposal to [the National Specialist Services Committee \(NSSC\)](#) [which considers and advises NHS boards and the Scottish Government on the provision of nationally designated specialist services for Scotland] for an MRgFUS service. The Committee also asked the Cabinet Secretary why NHS Scotland does not as yet appear to make use of the facility in Dundee and whether it has plans to do so in the future.
18. The Cabinet Secretary stated in his response that, due to the pandemic, the NSSC has agreed not to progress new applications (with some limited

exceptions). He states that this position is being regularly reviewed 'with a view to resume services when system pressures have eased'. In the meantime, eligible patients in Scotland can be referred for MRgFUS treatment in London.

19. It is noted that a partnership between NHS Tayside and the University of Dundee has also enabled a small number of eligible patients to receive MRgFUS treatment in Dundee. Of 80 patients referred for assessment in Dundee last year, around 25% of those patients have been considered appropriate for treatment.
20. The submission states that the National Services Division 'continues to engage with the clinical team in Tayside with a view to the development of an application for national designation in Scotland'. The Cabinet Secretary concludes by stating that the National Services Division are engaging with clinicians in Dundee and colleagues in NHS England 'on how the treatment might be made available more widely to eligible Scottish patients.'

## **Petitioner submission**

21. The petitioner reiterates their own experience of Essential Tremor and highlights ongoing research in the use of MRgFUS to treat other conditions such as Parkinson's disease and brain tumours. The petitioner explains that previous information from the Scottish Government indicated that NICE would not approve MRgFUS treatment, however the treatment was later approved.
22. In response to the Cabinet Secretary's submission, the petitioner expresses confusion as to why treatment in London is suggested, given that the skills, equipment and finances are available in Scotland.
23. She also highlights concerns around the affordability of patients in Scotland seeking treatment in England, suggesting that schemes designed to support this do not meet the actual costs involved.

## **Action**

The Committee is invited to consider what action it wishes to take.

## **Clerk to the Committee**

## Annexe

The following submissions are circulated in connection with consideration of the petition at this meeting –

- [PE1723/O: University of Dundee submission of 18 November 2021](#)
- [PE1723/P - Cabinet Secretary for Health and Social Care submission of 9 December 2021](#)

The Scottish Parliament launched a new website at the end of Session 5.

All written submissions received on the petition before May 2021 can be viewed on the petition on the [archive webpage](#). Written submissions received on the petition after May 2021 can be viewed on its [new webpage](#).