Citizen Participation and Public Petitions Committee

2nd Meeting, 2023 (Session 6), Wednesday 8 February 2023

PE1723: Essential tremor treatment in Scotland

Lodged on	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 20 April 2022. At that meeting, the Committee agreed to write to the Scottish Government and the National Services Division.

2. The petition summary is included in **Annexe A** and the Official Report of the Committee's last consideration of this petition is at **Annexe B**.

3. The Committee has received new responses from the Scottish Government, National Services Division and the petitioner which are set out in **Annexe C**.

4. Written submissions received prior to the Committee's last consideration can be found on the petition's webpage. All written submissions received on the petition before May 2021 can be viewed on the petition on the archive webpage.

5. Further background information about this petition can be found in the SPICe briefing for this petition.

6. The Scottish Government’s initial position on this petition can be found on the petition’s webpage.

Action

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

Clerk to the Committee

Annexe A

PE1723: Essential tremor treatment in Scotland

Petitioner

Mary Ramsay

Date lodged

04/07/2019

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.

Previous action

I have raised this issue with Rhoda Grant MSP who held a debate in the Parliament on this matter.

Background information

I have essential tremor and have been to hell and back for the past 62 years. The effects of essential tremor can have a serious impact on a person’s life, with lack of understanding and awareness of the condition leading to ineffective treatment but also bullying. I want to prevent any child or adult going through verbal and physical abuse like i did.

There are over 4000 people in Scotland with essential tremor. The main treatment at the moment is brain surgery or deep brain stimulation (DBS) which some people with the condition do not want to endure. DBS is expensive. The cost to the NHS in Scotland is approximately £30,000. The cost of a focus ultrasound scanner is approximately £10,000. The focus scanner is also a much less invasive procedure.

The introduction of a focus ultrasound scanner together with an awareness raising campaign of essential tremor could help Scotland take the lead in looking at innovative, more effective treatments for the condition.

Annexe B

Extract from Official Report of last consideration of PE1723 on 20th April 2022

The Convener: Welcome back. Item 3 is consideration of continued petitions. PE1723, on essential tremor treatment in Scotland, was lodged by Mary Ramsay. The petition, which was last considered by the committee on 19 January, calls on the Scottish Parliament to urge the Scottish Government to raise awareness of essential tremor and to support the introduction and use of a focused ultrasound scanner for treating people in Scotland who have the condition.

Rhoda Grant will be joining us again.

When we last considered the petition, we agreed to write to the Scottish Government and the National Services Division. We have had a response from the Scottish Government that indicates that the National Services Division is expected to resume applications for the commissioning of new services this month. That was roughly the timetable that was suggested when we last considered the petition.

The National Services Division continues to engage with the clinical team in Tayside to understand what would be required to provide focused ultrasound in Scotland, should it be decided that that is the preferred option.

The Scottish Government submission informs us that “the Scottish Government has not committed funding to the MRgFUS service in 2022/2023. The evidence base ... will inform consideration on any future financial investment.”

The Scottish Government also provided information about its work to raise awareness of essential tremor among patients and healthcare professionals.

The petitioner’s most recent submission highlights that there are 100,000 people in Scotland with essential tremor, and she has suggested that that figure does not include those who are waiting to see specialists or those who have been misdiagnosed.

Rhoda Grant is with us. We are not necessarily taking a lot of additional evidence, because we are waiting to hear what progress can be made, but would you like to contribute anything that would further our understanding?

Rhoda Grant (Highlands and Islands) (Lab): I just have a very quick comment.

I am reasonably disappointed by the Scottish Government’s response, in that it just goes over what it has said before. There is not an awful lot that is different in it.

I note that the National Services Division has not yet responded although, at the time of the previous meeting, it said that it was working with NHS Tayside and was due to meet it at the end of January. It also said that it might be able to consider a formal application in either May or June. It is important to keep the petition open until summer, so that we can see what conclusion the National Services Division reaches.

Mary Ramsay has pointed out that a number of people are affected by the condition, so it is important that we make some progress. Mary has also stated that she would be happy to give further evidence to the committee, if it wishes, and Ian Sharp, who has benefited from focused ultrasound treatment, has also made that offer.

I encourage the committee to keep the petition open and to keep scrutinising the issue in the hope that we make some progress.

The Convener: Thank you very much for that.

I believe that we will keep the petition open. We are still awaiting some of the key information that we feel would be critical to our coming to a determination. Would colleagues like to make any further recommendations?

David Torrance: I recommend that we keep the petition open and write to the National Services Division’s national specialist services committee to highlight the evidence that we have received on essential tremor treatment and recommend that any application to roll out MRgFUS across Scotland is given early consideration when the application process opens in April 2022. In writing to the National Services Division, the committee could ask for further details of the decision-making process and timescales for next steps, should an application be successful.

We could write to the Scottish Government to highlight our engagement with the national specialist services committee and ask the Scottish Government whether it will commit to a public awareness campaign, should any application prove successful. In writing to the Scottish Government, the committee might also wish to ask for further information about the national patient, public and professional reference group, including its role, remit and membership.

The Convener: Thank you, David. Are colleagues content with that, or do they have any other recommendations?

I reassure Rhoda Grant that we were given to understand that the National Services Division and the Scottish Government co-ordinated the response that we received. I understood that, although we did not receive separate responses, there was input from both into the Government’s response.

Are colleagues content that we keep the petition open and write to see whether we can expedite some of the information that we are looking to receive?

Members *indicated agreement.*

Annexe C

Scottish Government submission of 10 June 2022

PE1723/T: Essential tremor treatment in Scotland

Thank you for your letter of 13 May 2022 on behalf of the Citizen Participation and Public Petitions Committee regarding further questions in relation to Petition PE1723 - 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.

I note that the Committee has recommended that NHS Tayside's application to introduce MRgFUS as a national specialist service is accepted, and wishes to know whether the Scottish Government will commit to a public awareness campaign, should any application prove successful.

There are a number of factors to consider how best to communicate a message to an intended audience. However, should any application for MRgFUS prove successful, policy leads will consider how best to communicate any changes to guidelines/practice with members of the public. There is a process in the Scottish Government whereby policy leads can request social marketing support. With their support, appropriate method/s of communication would be decided. This could consist of website development, release of a statement, a letter to those affected, or a public awareness campaign, should it be deemed appropriate. Nevertheless, until an application is successful, it is too early to commit to any specific details.

I note also that the Committee, in consideration of Rhoda Grant MSP's comments, is interested to know:

- What the function of the National Professional Patient and Public Reference Group (NPPPRG) is and how it relates to the National Services Division (NSD), National Specialist Services Committee (NSSC) and Health Boards;
- details about the NPPPRG's membership; and;

- whether the NPPPRG is still operating and if not, whether a replacement group has been set-up. If there is a replacement group, what its remit is, details of its membership and how it relates to the National Services Division, National Specialist Services Committee and Health Boards.

With regard to the first query, the aim of NHS Scotland’s NSD is to help patients who need access to treatment or investigation of a highly specialised nature, or who have a very rare condition, to obtain the care that they need, while seeking to ensure that the highest possible standards are delivered within available resources. NSD nationally commission very specialist services on behalf of NHS Health Boards. So regardless of where a person stays, they can access the highly specialist treatment they would need.

Applications for designation to become a nationally commissioned service are submitted by NHS Boards, clinicians and Scottish Government and reviewed by the NSSC. NSSC meets quarterly to consider applications. New online submission forms were launched on Friday 1 April 2022, in order to standardise all submissions and provide NSD with the key information required to reduce the decision making time from registration and improve the quality of applications and proposals to designate new services.

The NPPRG is the mechanism to provide expert advice and patient / public views to NSSC on applications for designated services. Working with NSD, who provide secretariat and executive support, NPPPRG work with a broad range of professional, public, and patient groups to source advice on proposals and issues ahead of further consideration by NSSC. NPPPRG meetings occur around 1 month before NSSC meetings. In between NPPPRG meetings, members communicate and seek views on proposals within their respective areas of interest and responsibility, consolidate and submit comments to NSD at least two weeks prior to NPPPRG meetings. NPPPRG are crucial to the approval process of service applications as NSSC decisions are subject to advice from NPPPRG.

Moving now to the second query, the NPPPRG has a sufficiently broad membership to ensure that a meaningful debate can take place on all proposals to be considered by the NSSC. NPPPRG membership includes representatives from NHS Board Medical Directors, Nursing, Regional Planning Directors’ Groups, Scottish Health Councils, General Practitioners, Healthcare Improvement Scotland, Managerial and

Financial Staff, Academy of Royal Colleges, a Health Economist and Public and Patient Groups. The Chair of the NPPPRG is a member of NSSC to provide a clear linkage.

NPPPRG is expected to consider detailed information from a range of special interest experts and patient groups when considering applications and advising NSSC. Where advice is required but not represented by membership, expertise would be drawn from existing professional, patient and public groups such as:

- National Planning Board
- Scottish Government Specialty Advisers
- Patient Groups for individual specialist services
- Special NHS Boards such as the Scottish Ambulance Service, NHS 24 and NHS
- Education Scotland
- UK Rare Diseases Advisory Group
- UK Rare Diseases Policy Board and Stakeholder Forum
- NHS England specialist commissioning team

In regard to the final query, the NPPPRG is still operating, and meetings of the NPPPRG are held 4 times per year.

I hope this reply is helpful to the Petitioner and the Citizen Participation and Public Petitions Committee.

National Services Division submission of 24 May 2022

PE1723/U: Essential tremor treatment in Scotland

Thank-you for your recent correspondence in relation to the petition which seeks to raise awareness of Essential Tremor in Scotland and support the introduction and use of MRI guided focused ultrasound for treatment (MRgFUS).

It may be beneficial to your committee to offer some context as to current service provision and some oversight as to the role of the National Specialist Services Committee (NSSC) and National Services Division (NSD).

As the committee will be aware from their written evidence from relevant stakeholders, the University of Dundee and NHS Tayside have been collaborating to develop and establish a service to treat patients using MRgFUS for Essential Tremor.

The academic team have been working towards the goal of being able to offer participation to patients in clinical research into other conditions where this treatment modality may have the potential to benefit patients (for example Parkinson’s Disease) as well as the treatment of tremor.

This locally developed service has now been up and running for over 1 year and has assessed and treated a number of patients with the governance and operational delivery of the service being the responsibility of the University of Dundee and NHS Tayside rather than that of NHS National Services Scotland, National Services Division (NSD).

NSD act as the commissioners on behalf of NHS Scotland for National Specialist Healthcare Services. The governance for their commissioning work sits under the auspices of the National Specialist Services Committee who have delegated decision making responsibilities from the Board Chief Executives.

Designation of National Services

In order for a service to be considered for designation there is a formal application process which allows for the consideration of the needs of the population, specific service needs and delivery model for service, evidence base for the proposed service, financial and human resource considerations and operational implementation.

NSD work closely with applicants to ensure that the information considered by NSSC is proportionate, factually accurate and allows for reasoned decision making. Historically this has been a 3 stage process with consultation with the relevant stakeholders from the various boards as well as patients, the public and professionals via the National Patient, Public and Professional Reference Group (NPPPRG). Over the last year or so the processes of application and designation have been undergoing some redesign with a view to improvement in quality and efficiency however the overall aim of the process remains the same.

In response to your specific queries and points which the committee have raised:

1. At the time of writing there has been no formal application for a national MRgFUS service by NHS Tayside. However members of the Specialist Healthcare Commissioning team within NSD have met regularly with the team in Dundee to support them in their preparation of an application. Their most recent meeting was on 13th May 2022 with further meetings anticipated to take place to discuss this further.

2. Until a formal submission is made to the National Specialist Services Committee, NSD cannot confirm the actual date when the committee will consider the application for this service. The current anticipated dates for the next meetings of the committee are on the 15th September 2022 and the 8th December 2022.

3. In their application, the applicant is required to demonstrate the current evidence for the treatment in relation to safety, efficacy and patient outcomes. In addition, where there are key Health Technology Appraisals by organizations such as the Scottish Health Technology Group (SHTG) or National Institute for Health and Care Excellence (NICE) these will be referenced or discussed as will relevant NHS England Service Specifications or Commissioning Policies.

4. Should the committee recommend the designation of the service, prioritization along with other service developments take place towards the end of the year with a view to developing the financial business case for all of the National Services for which NSD act as commissioners and for whom finance is requested from the Board Chief Executives of NHS Scotland. The aim of such consideration is to provide an assurance of resource to deliver the service from the beginning of the next financial year or in line with the phased implementation plan.

5. At the current time the treatment is available in Dundee for those whom the specialist neurology and neurosurgical staff deem it to be clinically appropriate albeit without the designation as a nationally commissioned service. In addition, NHS Boards in Scotland can access the service being commissioned by NHS England via existing relationships and cross-border funding mechanisms in place. At the current time it is most likely that any national commissioning arrangements would not be in place until April 2023 at the very earliest however this could be later due to the systemic pressures as a result of the ongoing issues related to the pandemic.

6. In line with accepted practice, should the treatment centre be commissioned nationally, it would be the service themselves who would promote the service via their clinical stakeholders and patient advocacy groups. On their internet pages, NSD list all national services with short biographical pieces detailing the nature of services and contact details. In addition, the clinical team in Dundee have been exploring working with the National Deep Brain Stimulation Service in Glasgow to support shared decision making and the sharing of clinical experience and knowledge between the teams.

I hope this information meets the requirements and needs of your committee however should you have further queries please do not hesitate to contact us.

Petitioner submission of 5 July 2022

PE1723/V: Essential tremor treatment in Scotland

Thank you for your last communication regarding **PE1723** back in March. Ahead of any future scheduling I would like to put forward a number of questions for the committee to consider in relation to my petition and to consider putting forward to the Scottish Government. Since our last meeting on 20 April 2022 I, and no doubt you, will have not heard or had any updates from the Scottish Government nor the National Services Division regarding commissioning of new services or treatments. We heard back in March that the National Services Division continues to engage with the clinical team in Tayside but no movement has been made and we are no further forward.

My question to the committee is as follows, could you look into why this process of approving new treatment in Scotland takes so long? The National Institute for Health and Care Excellence (NICE) recommended use of the MRI-guided focused ultrasound to treat essential tremor back in **June 2018**. Since then NHS England has considered and found funding for the procedure for suitable patients in England. Since 2018 they have installed and opened two MRgFUS/Focused Ultrasound machines. St Mary’s at Imperial in London and the Walton Centre in Liverpool. A number of countries around the world have been using this treatment for some time and yet Scotland seems to be lagging behind its counterparts.

I hear many times, throughout the weeks and months, that the Scottish Government proclaim that we have a nation that is so full of possibilities, that Scotland outperforms the UK in attracting investment yet, we cannot deliver quickly on a straight forward integration of a new treatment that would help alleviate the pain and debilitating disease that thousands of Scots suffer with every day. That even we have to travel at escalating costs south of the border to seek access to a treatment that should be available here in Scotland. Even more infuriating is that the technology is there, waiting to be rolled out, the willingness from clinicians and NHS trusts and teams is also there. All we seem to be waiting for, is the go ahead from the National Services Division and the Scottish Government. When arguments come down to finance, I have heard and been assured that the budget increase is comparatively miniscule. Therefore, I do not understand why this process is taking so long and what the barriers to decision making are.

I would be grateful if members of the Petitions Committee can look carefully into and scrutinise why the Scottish Government processes appear to hinder access to new treatments for Scots, why roll out of treatments and services that have been approved by NICE take so long in our country in comparison to others and to identify the barriers in improving this system. By doing so, perhaps Parliament can assist in the equitable access to effective treatments and improve patients' wellbeing throughout Scotland.

I hope to meet with you all again in the near future, hopefully with some positive movement in regards to the petition.

Petitioner submission of 12 January 2023

PE1723/W: Essential tremor treatment in Scotland

Waiting list and costs

MRgFUS provides not only an opportunity for more effective and less invasive treatment but also has an untapped potential for research into other neurological conditions such as Parkinsons. By providing MRgFUS for patients on the NHS it would not only save money, provide better care, but also allow Scotland to utilise and enhance its research in the field. It would allow opportunities for patients out-with Scotland to be referred to and treated here too.

There are several aspects to consider when considering costs and savings by rolling out MRgFUS on the NHS. I have it on good authority that the minimum cost of DBS is £30,000 per treatment, per patient. **The cost of MRgFUS is £10,000**. **A saving of £20,000 per patient**.
Now, the folk in Dundee treated 25 eligible patients in 18 months. Out of these 25, 14 were eligible for DBS. The waiting list for DBS is some 2 and a half years. If they had not received MRgFUS, they would still be waiting for DBS.

Let’s focus on savings though. 4 of these patients would have cost the NHS £420,000. Instead by received MRgFUS they saved £280,000 of NHS funding.

Those that are referred for MRgFUS treatment in England face years of waiting lists, and additional costs burdens to both themselves and the taxpayer for patient travel reimbursement. The English NHS have realised the cost savings and potential in MRgFUS. They have invested in and now have two centres in England that offer MRgFUS and we current refer and send our patients to be treated south of the border when we have the potential and capacity to do so in Scotland.

There is an opportunity sitting right in front of the Scottish Government and there is no time like the present to realise this.

Statement from Ian, an Essential Tremor patient

A bit of my History prior to MIR focused ultrasound procedure (MRgfus).

Where do I start? To begin a brief history of my Essential Tremor.
I am 68 years old and was first aware of a problem in my early 30s when I noticed an issue with my writing in my left hand which was my primary hand. This slowly progressed over the years until my late 40s when I started to find it difficult to carry a cup or glass of liquid without spilling it. I also had difficulty in eating and using cutlery. I was also an avid DIY enthusiast and also tied flies for my hobby of flyfishing, as you can imagine not being able to carry out these activities was extremely frustrating and had a profound impact in my work life as a senior manager in the electronics industry. Furthermore, by my early 50s I started to have tremors in my right hand and this was when I was diagnosed with essential tremor.

I embarked on a course of medication however, this had very little effect on the tremor and had some unpleasant side effects. The tremors continued to get worse until eventually I had to give up my job when I was 55 years old as I was incapable of doing it properly. As you can imagine this had severe impact on my mental health as well my physical health.

This brings me to the benefits of MRgfus

If you believe in miracles, then the benefit of this procedure is up there with the best of them.

The procedure is carried out on only one side of the brain at present. The effect is immediate. Within 5 minutes of the procedure being completed I had no tremor anymore. I could lift a glass of water to drink from it, hold my hand steady and sign my own name for the first time in over 20 years.

The effect of this procedure is life changing for me and everyone else who has had it since.

I am able to socialise again eat and drink properly. Although my right hand still causes issues, I can tie flies go fishing do DIY etc.
The added benefits are that this procedure is extremely cost effective compared to the alternative procedure DBS (Deep Brain Stimulation). Added to this, it is **non-invasive**, requires no surgery, or follow up drugs - just informal check-ups for first year.
I cannot thank the fabulous team at Ninewells in Dundee enough for giving me my life back.

Conclusion

The Committee may wish to note that this treatment follows on from initial development carried out at Glasgow University, Western General Hospital, and Kelvin & Hughes Ltd. This was recognised by the Scottish Parliament on 11 December 2018 in a Members Business Debate, marking the 60th anniversary of the publication in 1958 by Donald, McVicar and Brown, in the Lancet. We would hope that the committee would urge the Scottish Government, the SNHS, and other research bodies to continue Scotland's proud history in the field to be continued to be developed. Part of this development is to make available this treatment to all potential patients on the NHS.