

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.