Citizen Participation and Public Petitions Committee

4th Meeting, 2024 (Session 6), Wednesday 6 March 2024

PE1952: Specialist services for patients with autonomic dysfunction

Petitioner	Jane Clarke
Petition summary	Calling on the Scottish Parliament to urge the Scottish Government to instruct Scotland's NHS to form specialist services, training resources and a clinical pathway for the diagnosis and treatment of patients exhibiting symptoms of autonomic nervous system dysfunction (dysautonomia).
Webpage	https://petitions.parliament.scot/petitions/PE1952

Introduction

1. The Committee last considered this petition at its meeting on 17 May 2023. At that meeting, the Committee agreed to write to the Scottish Government.
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 Minister for Public Health and Women's Health 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.
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.

7. Every petition collects signatures while it remains under consideration. At the time of writing, 1,842 signatures have been received on this petition.

Action

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

Clerk to the Committee

Annexe A

PE1952: Specialist services for patients with autonomic dysfunction

Petitioner

Jane Clarke

Date lodged

18 August 2022

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to instruct Scotland’s NHS to form specialist services, training resources and a clinical pathway for the diagnosis and treatment of patients exhibiting symptoms of autonomic nervous system dysfunction (dysautonomia).

Previous action

I have spoken with Mr Daniel Johnson MSP on 09/05/22 regarding the current gaps in NHS services for dysautonomia. Mr Johnson offered to submit a motion for a members’ debate and to table written parliamentary questions.

Others have raised questions within Scottish Parliament and Westminster. On 1, 4 and 21 Jun 2016, MSP Ms Aileen Campbell’s responses to parliamentary questions revealed existing national gaps in diagnosing and treating autonomic dysfunction’s many conditions.

Background information

Autonomic nervous system disorders are common. Some cause mild symptoms, but many severely impact upon quality of life or significantly reduce life expectancy. Despite this, Scotland has no clinical pathway for dysautonomia and no specialist hub to diagnose and treat patients. Dysautonomia is a common complication of Long COVID.

With no autonomic clinics in Scotland, most patients do not have access to local or regional healthcare. A fortunate few may be referred to specialists via NHS England, but many are declined referral despite clinical need. Diagnosed patients returning to Scotland can find themselves unable to access necessary medication or follow-up. Treatment may be delayed for years, leaving sufferers unable to work or attend education. It is especially difficult for children to access dysautonomia healthcare.

As many doctors are untrained to recognise and manage symptoms of autonomic dysfunction, dedicated training resources are also needed.

The aims of this petition align with the commitments of the Neurological Care & Support Framework & the UK Rare Disease Strategy.

Further key info: https://dysautonomiapetition.wordpress.com/

Annexe B

Extract from Official Report of last consideration of PE1952: Specialist services for patients with autonomic dysfunction on 17 May 2023

The Convener: PE1952 is on instructing Scotland's NHS to form specialist services for patients with automatic dysfunction—sorry, that should be autonomic dysfunction, which is quite different. The petition, which was lodged by Jane Clarke, calls on the Scottish Parliament to urge the Scottish Government to instruct Scotland's NHS to form specialist services, training resources and a clinical pathway for the diagnosis and treatment of patients exhibiting symptoms of autonomic nervous system dysfunction.

PoTS UK's recent submission disagrees with the Scottish Government, stating that many patients "do not have access to the best possible care and support", and that PoTS, or postural tachycardia syndrome, is "not well recognised within the cardiology profession".

The submission highlights that there are no established pathways to diagnose and treat PoTS in adults across most health boards.

Chest Heart & Stroke Scotland's written submission notes that "Nearly 200,000 people in Scotland" have long Covid and that 76 per cent of long Covid patients had symptoms of dys—gosh, how am I going to say this?—dysautonomia. However, it states that patients with dysautonomia

"struggle to access medical support ... and people ... with PoTS often wait years for a diagnosis".

Chest Heart & Stroke Scotland calls for "quicker and more co-ordinated diagnostic and treatment pathways" for people with long Covid and for "the creation of a clinical pathway that integrates with existing SIGN"—

or Scottish intercollegiate guidelines network— "guidelines."

It also supports training for general practitioners and "further scoping to ascertain the size" of the need for specialist support for people with dysautonomia.

The written response from NHS National Services Scotland states that it "would not anticipate" being "invited to commission a national specialist service," devote "training resources" or develop "a clinical pathway", due to "the broad range of local services and specialities" around "autonomic dysfunctions."?

That was all quite technical, but important nonetheless. Do members have any comments or suggestions?

David Torrance: We should write to the Scottish Government, highlighting the issues raised in the written submissions from PoTS UK and Chest Heart & Stroke

Scotland and asking whether it has received feedback on or evaluated its implementation support note. In particular, we should ask whether the implementation support note has increased knowledge of long Covid and PoTS.

We should also ask how diagnostic and treatment pathways for people with long Covid are monitored and tracked to ensure appropriate care is provided in a quick and co-ordinated way, including to people with dys—we have both got problems pronouncing this word, convener—dysautonomia. Further, we should ask whether it will request that training is provided to GPs on dysdyonomia—

The Convener: Dysautonomia.

David Torrance: Yes. Thank you.

The Convener: Are members content to proceed with that request for further information?

Members *indicated agreement.*

Annexe C

Minister for Public Health and Women's Health submission of 21 December 2023

PE1952/F: Specialist services for patients with autonomic dysfunction

Thank you for the Committee's correspondence to the Scottish Government of 2 June 2023 regarding petition PE1952: '*Specialist services for patients with autonomic dysfunction,* and the opportunity to respond to the questions posed by the Committee following its meeting of 17 May 2023.

Firstly, I would like to sincerely apologise for the delay in the Committee receiving a response to its letter. This was caused by an administrative error in the process that the Scottish Government uses to triage and issue responses to correspondence of this type.

Please find below a response to the questions raised by the Committee, which asked:

1. **Whether the Scottish Government has received feedback on or evaluated its Implementation Support Note. In particular, whether the implementation Support Note has increased knowledge of Long Covid and PoTS;**

On 26 July 2021, NHS National Services Scotland issued a questionnaire to 928 General Practices which contained questions relating to the SIGN/NICE/RCGP clinical guideline 'managing the long-term effects of COVID-19'. 21.7% of General Practices (201/928) responded to the questionnaire, however not every practice provided an answer to all questions contained within it.

The results highlighted that 60% (117/196) of practices were aware of the SIGN/NICE/RCGP clinical guideline. In addition, 25% (49/196) were aware of the accompanying Implementation Support Note produced by the Scottish Government. Of these 46.9% (23/49) found it moderately to very helpful. The results also highlighted that 77% (148/193) of practices indicated that some or all of practice clinicians were confident giving verbal advice on the new and ongoing symptoms of COVID-19 after acute recovery and management.

The long COVID National Strategic Network operated by NHS National Services Scotland is currently reviewing and updating the content of the Implementation Support Note. This process is being supported by consultation with a range of relevant clinical and subject matter experts.

In addition, in June 2023 the National Strategic Network developed a recommended pathway for the assessment and management of Postural Orthostatic Tachycardia Syndrome in people living with long COVID, for use by NHS Boards. This was supplemented by an educational webinar on PoTS held on 24 August 2023 for healthcare staff across Scotland supporting people living with long COVID.

2. How diagnostic and treatment pathways for people with Long Covid are monitored and tracked to ensure appropriate care is provided in a quick and coordinated way, including to people with dysautonomia;

Under the leadership of Public Health Scotland (PHS), the long COVID Strategic Network has developed a theory of change and logframe which form the basis of a comprehensive framework to evaluate long COVID services. Both the theory of change and logframe were developed in close consultation with representatives across the Network, including people with lived experience of long COVID, clinicians, researchers, service planners, local boards, PHS and Scottish Government officials.

In addition, the National long COVID Strategic Network has contracted the University of Leeds to support the initial evaluation of long COVID services in Scotland. This will provide an analysis of demand and capacity within services; analysis of longer-term outcomes for long COVID patients assessed within services; and where possible, compare differences in service models.

The previous response sent by the Scottish Government to the Committee on 17th August 2022 outlines access to clinical support for people with autonomic disorders not related to long COVID.

3. **Whether the Scottish Government will request that training is provided to GPs on dysautonomia.**

NHS Education for Scotland’s learning platform ‘Turas’ contains the training resources on dysautonomia listed below. These resources are accessible to a multidisciplinary audience, including GPs.

14 June 2022 – PoTs UK webinar *‘Long Covid and the autonomic nervous system - a top - down and bottom - up approach’*.

17 July 2023 – NHS Education for Scotland slide pack learning bite *‘The autonomic nervous system and long COVID’*.

I hope the Committee finds the information outlined in this letter to be helpful.

Minister for Public Health and Women’s Health, Jenni Minto MSP

Petitioner submission of 25 January 2024

PE1952/G: Specialist services for patients with autonomic dysfunction

(Written by Jane Clarke, Petitioner and Patient and Dr Lesley Kavi, Chair of the national charity, PoTS UK)

Petition PE1952 raised concerns around the lack of specialist autonomic support in Scotland for **all** patients with dysautonomia. We are disappointed that the Committee’s questions and Scottish Government comments mostly do not address the original petition question and focus mainly on Long Covid.

It is important to note that autonomic neurologists diagnose and treat various forms of dysautonomia in their specialist clinics, including the management of PoTS. Autonomic (or neurovascular) neurologists and cardiologists are the experts in autonomic dysfunction at the forefront of research, learning and treatment.

There are no specialist autonomic clinics in Scotland to the detriment of patients, their employers, and their families.

PoTS is a complex multi-system condition. Due to the way in which it presents, patients are sometimes referred to cardiology clinics. The

Government has previously said that *“PoTS is a well-recognised condition within the cardiology professions. And can be managed effectively within Scottish cardiology services.”*

However, the experience of the national charity and patients is the opposite. Consultants in cardiology tell us that they do not have the expertise to manage such patients. Patients are unable to access appropriate tests and therapies or obtain referral to clinics in England (which are currently overwhelmed).

We would like to respond to the Scottish Governments response to the committee’s questions as follows:

1. **Whether the Scottish Government’s evaluation of the Implementation Support Note and if this has increased knowledge of Long Covid and PoTS**

The Minister highlighted that only 60% of Scottish GP practices are aware of the Long Covid SIGN guidelines. This does not mean that every practitioner within that practice has read or implemented it and provides no evidence of proper assessment or management of patients with autonomic dysfunction.

Only 21.5% of practices were aware of the Implementation support note and only 11.7% found this to be helpful.

We are pleased that the National Strategic network developed a pathway for PoTS in long COVID, but we are aware that there is still no pathway for the majority of PoTS patients whose illness was not triggered by COVID-19.

2. **How diagnostic and treatment pathways for people with Long Covid are monitored and tracked to ensure appropriate care is provided in a quick and coordinated way, including to people with dysautonomia.**

Again, the focus of the Minister’s response is on Long COVID services. Regarding PoTS, the Minster refers to the Government’s previous response of August 2022, stating that the services for non-COVID PoTS patients have already been covered in the document. In the August response, the Government agreed that, 'Specialist medical assessment may be required for those who don’t respond to first-line measures' and claimed that *‘Within local and regional clinical services across Scotland* *there is expertise in a number of clinical specialties to investigate and manage these conditions ’and there are ‘pathways are in place to allow access to services commissioned by NHS England’.*

The national charity, PoTS UK is not aware of these services and this expertise. In a recent survey by PoTS UK, 70% of Scottish PoTS patients were informed by their healthcare professional that there are no specialist services in Scotland that they can access, and many had to resort to private healthcare. A recent freedom of information request to Scottish Health Boards revealed that 11 boards do not have a specialist. Of the 2 that do, one reported that their service has an uncertain future. If such specialist services exist, we challenged NHS Scotland to provide locations of the expert services and names of specialist healthcare professionals. We were unable to obtain a response.

Dysautonomia is a complex neurological issue, and as the nervous system affects all body systems, a multi-disciplinary approach is usually recommended. We are not aware of any PoTS specialists with access to a trained multidisciplinary team in Scotland.

3. **Whether the Scottish Government will request that training is provided to GPs on dysautonomia.**

The Minister refers to the ‘Turas’ training platform which gives healthcare professionals access to a video and PowerPoint. Whilst we welcome these additions, we would like to make it clear that these are not a substitute for specialist services. For example, they do not contain detail about prescribing medication, which can be complex. There is also no information about the autonomic battery of tests including tilt table testing and their interpretation.

In summary, despite the Government’s claims, our experience and evidence from Health Boards and patients’ surveys is that people with PoTS throughout Scotland do not have access to knowledgeable autonomic or cardiology specialists.

We ask the Committee and Scottish Government to provide evidence of specialists and specialist clinics so that patients and GPs may be directed to them appropriately. If there are indeed only 2 specialists in Scotland (as Scottish Health Boards report), then we request that further services are commissioned to ensure patients have local or regional access to the care that the Scottish Government agrees that they require.