Citizen Participation and Public Petitions Committee

15th Meeting, 2022 (Session 6), Wednesday 9 November 2022

PE1952: Specialist services for patients with autonomic dysfunction

Note by the Clerk

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. This is a new petition that was lodged on 18 August 2022.

2. A full summary of this petition and its aims can be found at **Annexe A**.

3. A SPICe briefing has been prepared to inform the Committee's consideration of the petition and can be found at **Annexe B**.

4. While not a formal requirement, petitioners have the option to collect signatures on their petition. On this occasion, the petitioner elected to collect this information. 1,660 signatures have been received.

5. The Committee seeks views from the Scottish Government on all new petitions before they are formally considered. A response has been received from the Scottish Government and is included at **Annexe C** of this paper.

6. A submission has been provided by the petitioner. This is included at **Annexe D**.

Action

7. 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

SPICe The Information Centre
An t-Ionad Fiosrachaidh

Briefing for the Citizen Participation and Public Petitions Committee on petition PE1952: Specialist services for patients with autonomic dysfunction, lodged by Jane Clarke

Brief overview of issues raised by the petition

PE1952 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 (dysautonomia).

Background

- The autonomic nervous system controls involuntary actions like a person's heart rate, body temperature, digestion, perspiration and the widening or narrowing of their blood vessels.

- The term dysautonomia is used to describe any medical condition that causes the autonomic nervous system to stop working properly.

- It can be caused by a range of conditions such as diabetes and Parkinson's disease. It is also associated with postural tachycardia syndrome (PoTS), which is an abnormal increase in heart rate that occurs after sitting up or standing. Some typical symptoms include dizziness and fainting.

- In response to a written question in Session 5, S5W-00309, then Minister for Public Health and Sport Aileen Campbell MSP responded: "As the majority of cases of dysautonomia are diagnosed in an outpatient or GP setting, the number of people diagnosed with this condition is not held centrally".

- NHS Education for Scotland (NES) is an education and training body and a national health board within NHS Scotland. It is responsible for developing and delivering healthcare education and training for the NHS, health and social care sector and other public bodies.

- National Services Scotland operates a number of national networks including clinical and diagnostic networks. These are intended to "ensure patients across Scotland have the best possible access to high-quality specialist care." They bring together a range of health and other professionals involved in providing care for patients with rare and/or complex conditions when the full range of skills required isn't available within an NHS board or region.

- The Scottish Government's submission notes that "in circumstances where the local or regional specialist teams feel they require additional expertise, which is not available within Scotland, pathways are in place to allow access to services commissioned by NHS England. Examples of such services are those provided by the NHS National Amyloidosis Centre, Royal Free Hospital, London or Autonomic Unit within The National Hospital for Neurology and Neurosurgery, Queen Square, London."

Recent developments

- The Scottish Government published its Neurological care and support: framework for action 2020-2025 in April 2022. This refers to the World Health Organization's definition of neurological disorders as diseases of the central and peripheral nervous system. In other words, the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction, and muscles. It makes 17 commitments around shared decision making, improving the provision of health and social care, standards of care, access to care and support and workforce.

- In 2019 Healthcare Improvement Scotland published general standards for neurological care and support.

- The Scottish Intercollegiate Guidelines Network has not published a guideline on autonomic nervous system dysfunction (dysautonomia) although it has published one on Managing the long-term effects of COVID-19.

- The Scottish Government's submission notes that application of COVID-19 guideline in Scotland is supported by an Implementation Support Note, published in May 2021. This is intended to provide information for clinicians on the assessment and management of symptoms associated with long COVID, including dysautonomia, and PoTS.

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18/08/2022

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Annexe C

Scottish Government submission of 29 August 2022

PE1952/A: Specialist services for patients with autonomic dysfunction

The Scottish Government position is clear; it is important that that all people living in Scotland with a neurological condition can access the best possible care and support, and benefit from healthcare services that are safe, effective, and put the person at the centre of their care.

Within the body the autonomic nervous system controls involuntary actions like heart rate, body temperature, digestion, perspiration, and the widening or narrowing of blood vessels. People with autonomic disorders may have a variety of symptoms. Autonomic disorders can occur alone but are more commonly experienced in association with another underlying condition, such as Parkinson’s disease or diabetes.

Within local and regional clinical services across Scotland there is expertise in a number of clinical specialties to investigate and manage these conditions. Where required the secondary care services also work with GPs and community nursing teams to help people manage their condition and symptoms outside of hospital.

In circumstances where the local or regional specialist teams feel they require additional expertise, which is not available within Scotland, pathways are in place to allow access to services commissioned by NHS England. Examples of such services are those provided by the NHS National Amyloidosis Centre, Royal Free Hospital, London or Autonomic Unit within The National Hospital for Neurology and Neurosurgery, Queen Square, London.

The identification, assessment, and management of people with long-term effects of COVID-19 in Scotland is guided by the recommendations of an evidence-based UK-wide clinical guideline developed by the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of GPs (RCGP).

The application of this guideline in Scotland is supported by an ‘Implementation Support Note’ developed by the Scottish Government in collaboration with specialist clinicians in various disciplines. This has been circulated to all NHS Health Boards and provides information for clinicians on the assessment and management of symptoms associated with long COVID, including dysautonomia, and PoTS.

The clinical guideline on managing the long-term effects of COVID-19 recommends testing for PoTS in patients with long COVID with symptoms of orthostatic intolerance. Following a detailed history and appropriate examination, if PoTS is suspected, GPs can make the diagnosis with an active stand test (also known as a NASA Lean Test).

PoTS is a well-recognised condition within the cardiology profession and can be managed effectively within Scottish cardiology services. People displaying symptoms of PoTS may be referred on from primary care to cardiology or syncope clinics to have tests to rule out other causes – including possible heart conditions – to confirm a diagnosis and support with decisions about treatment.

We are not currently aware of any reliable data on the prevalence of autonomic dysfunction disorders in Scotland. The Scottish Primary Care Information Resource (SPIRE) is a tool managed by Public Health Scotland which facilitates the extraction of data from GP Practice systems. Recently, it became possible for authorised organisations to request, via Public Health Scotland, SPIRE aggregate-level anonymised data extracts which do not include any patient-identifiable information. This offers the potential for future requests to explore the recorded prevalence of specific conditions by GP practices across Scotland.

Within the Scottish Government funding and support for health and care research comes under the remit of the Chief Scientist Office (CSO). The main mechanism through which CSO directly funds research is through its two funding committees that cover Health Services Research and Translational Clinical Research. The role of these committees is well-known across the health and care research community in Scotland. Applications to the committees on the underlying causes, diagnosis, treatment, and management of dysautonomia are welcomed. Any such application would go through a standard process of independent expert evaluation to enable a funding decision to be made.

Annexe D
Petitioner submission of 26 September 2022
PE1952/B: Specialist services for patients with autonomic dysfunction

Please find below new or additional information in response to the Scottish Government's written submission.
“Within local and regional clinical services across Scotland there is expertise in a number of clinical specialties to investigate and manage [underlying] conditions.”

Those experiencing dysautonomia with no known primary cause — if the cause is not immediately evident, or the form of dysautonomia is rare — may wait long for treatment or receive none. Specialist Long Covid clinics are generally unavailable.

“Where required the secondary care services also work with GPs and community nursing teams to help people manage their condition and symptoms outside of hospital.”

This statement does not fit with the experience of Scottish patients and contradicts what Scottish GPs report when referring patients on for further advice. Many GPs have no dysautonomia experience and find community nursing teams lacking knowledge. Not all specialists have experience with dysautonomia; some disbelieve it to be a true condition.

Regarding referrals to England, there are significant problems: —

- The majority of patients report to PoTS UK that they cannot obtain such referrals;
- The option for referral to England was established when dysautonomia was far rarer. 173,000 Scots now have Long Covid, putting acute pressure on the service. An April study estimated around 67% of those with Long Covid have dysautonomia (https://doi.org/10.1101/2022.04.25.22274300);
- Many GPs cannot/will not prescribe treatments without specialist authorisation;

- The most ill, complex patients — bedbound or housebound — cannot access referrals as they are unable to travel such distances;

- Listed services are oversubscribed with English patients;

- Re-referrals to London hospitals for new symptoms leave patients suffering a downturn in life quality and can exacerbate other health issues.

"The identification, assessment, and management of people with long-term effects of COVID-19 in Scotland is guided by the recommendations of an evidence-based UK-wide clinical guideline developed by…NICE…SIGN…and RCGP."

Dr Lesley Kavi, member of the NICE expert panel on long-term effects of COVID-19, is quoted in italics below.

"The identification, assessment, and management of people with long-term effects of COVID-19 in Scotland does ***not*** *follow NICE /SIGN/RCGP guidance. The guideline recommends the following:*

- *referral to an integrated multidisciplinary assessment service*

- *multidisciplinary services should be led by a doctor with relevant skills and experience and appropriate specialist support*

- *referral to specialist care for specific complications.*

NHS Scotland says that there is no need for multidisciplinary long covid clinics as there are few referrals, but it is inevitable that there will be few referrals if there is nowhere to refer into. Our experience is that patients are unable to access multidisciplinary doctor led services. We ask you to provide evidence of these services and their availability to patients within each health board in Scotland."

"[A]n Implementation Support Note'…has been circulated to all NHS Health Boards" —
Unfortunately, this does not mean that Boards are delivering these recommendations. See below.

"PoTS is a well-recognised condition within the cardiology profession and can be managed effectively within Scottish cardiology services."

Parties contributing to this petition understand this statement to be incorrect; patients are poorly managed within Scottish cardiology services. Scottish cardiologists have reported to PoTS UK that they are not equipped to investigate and manage patients with PoTS. I understand that there are cardiologists' signatures on this petition.

<u>"We are not currently aware of any reliable data on the prevalence of autonomic dysfunction disorders in Scotland."</u>

Given there is no reliable data on the prevalence of autonomic dysfunction disorders within Scotland, there is also no data on whether services are adequate.
FOI requests relating to PoTS and Long Covid services were submitted to 14 territorial health boards in February 2022. This is a summary of the boards' responses: —
PoTS

- 7 boards miscode PoTS as a cardiac arrhythmia. Only 3 follow PHS guidance to code it as a disorder of the ANS. Other codes may be used.

- 9 boards have no established pathway to diagnose and treat PoTS, 1 has a generic cardiology pathway, 1 provides a single appointment, signposting patients to self-management websites. 3 have established pathways.

- 11 have no PoTS specialist, 2 refer to general cardiology, 1 mentioned a possible locum.

- 12 have no specialist management clinics/services for adults or children. 1 sees patients in general cardiology. 1 may have a locum service. None has services specific to children.

Long Covid (LC)

- For patients experiencing breathlessness, palpitations, fatigue, chest pain and syncope, 9 boards screen for orthostatic intolerance (OI) following SIGN guidelines. 2 do so if clinically indicated. 3 do not offer OI screening, simply referring to GP.

- 2 signpost LC patients to self-management/GP. 4 responded that they have no specialist clinics or services for LC patients. The remainder channel patients through multiple existing pathways depending on symptoms.