

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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<p>The purpose of this briefing is to provide a brief overview of issues raised by the petition. SPICe research specialists are not able to discuss the content of petition briefings with petitioners or other members of the public.</p>

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