

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.