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.

<u>"Within local and regional clinical services across Scotland there is expertise in a number of clinical specialties to investigate and manage [underlying] conditions."</u>

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.

<u>"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."</u>

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.

“We are not currently aware of any reliable data on the prevalence of autonomic dysfunction disorders in Scotland.”

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.