Department of Health & Social Care

From Ashley Dalton MP
Parliamentary Under-Secretary of State
for Public Health and Prevention

39 Victoria Street
London
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Your Ref: MP02425

PO-1649701

Manuela Perteghella MP
By email to: manuela.perteghella.mp@parliament.uk

11 November 2025

Dear Manuela,

Thank you for your further correspondence of 14 October on behalf of a number of your constituents about postural orthostatic tachycardia syndrome (PoTS).

I was sorry to read that my reply of 7 July (our ref: PO-1615704) did not adequately address your constituents' queries. I appreciate their continuing concerns, and I hope the following information provides further clarification.

As your constituents may be aware, I responded to a Westminster Hall Debate on PoTS on 14 October. In the debate, I acknowledged that patients have faced systemic barriers to care and an unacceptable 'postcode lottery' for support, and that inequality in access to services is often due to the lack of clear national guidance for healthcare professionals. I have, therefore, offered a meeting with patient groups and others to discuss the issues they have raised and to agree a way forward.

NHS England has a structured legal framework under the NHS Act 2006 and related legislation that enables it to intervene when an integrated care board (ICB) is failing, or is at risk of failing, to discharge its statutory functions. These functions include ensuring financial balance, improving service quality, and reducing health inequalities.

When ICBs fail to meet their statutory functions, NHS England has a clear and phased approach to enforcement, as set out in its official guidance. Initial action may involve voluntary engagement but, if concerns persist, NHS England can escalate to formal measures. These include issuing legally binding directions for an ICB to discharge a specific function or undertaking where an ICB formally commits to a remedial action plan.

In the most serious cases, NHS England can give directions that terminate the chief executive's appointment or require an ICB to cease performing certain functions, with NHS England taking over or delegating those duties to another body. This graduated framework ensures that ICB leadership is held accountable for performance, with provisions that can lead to direct intervention and executive replacement if necessary to secure the interests of the health service.

As I mentioned in my previous reply, local health organisations are best placed to make decisions on commissioning services for their communities and any proposed changes to services should be informed by clinical best practice following appropriate engagement with patients and stakeholders.

The Health and Care Act 2022 places a statutory duty on ICBs to involve people in the planning and decision-making processes related to NHS services. This includes situations where significant service changes are proposed, including service closures. This must involve formal consultation processes, where organisations must engage with the public, patients, and relevant committees before making substantial changes to service provision. Organisations must be transparent about how decisions are made and how public input is considered. Proposed changes to services must also pass Government and NHS England tests to ensure good decision-making and that they are demonstrated to be in the interests of service users and the wider public.

Regarding the development of comprehensive National Institute for Health and Care Excellence (NICE) guidelines for PoTS, topics for new or updated guidance are considered through the NICE prioritisation process, where decisions as to whether NICE will create new, or update existing, guidance are overseen by a prioritisation board, chaired by NICE's chief medical officer. The Department and NHS England are then responsible for formally referring topics to NICE for guidance development on the basis of recommendations by the NICE prioritisation board.

The NICE topic selection process is designed to ensure that referred topics are aligned to national priorities to improve outcomes and value for money in the health and care system, and represent the most valuable use of the resources available to NICE. Areas to be prioritised may change depending on major developments or new innovations in health and care and life sciences.

I hope your constituents will appreciate that it is right that decisions on the topics to be prioritised for guidance development should be based on the evidence and in line with NICE's prioritisation process. The Department therefore currently has no plans to instruct NICE to develop guidance on the diagnosis and management of PoTS.

It is important to recognise the challenges that NICE would encounter in developing such guidance. The symptoms and underlying causes of PoTS vary significantly among patients, with several different subtypes, and patients can have features of more than one. This makes a one-size-fits-all treatment guideline challenging to produce. There is also often significant symptom overlap with other complex and related conditions, such as myalgic encephalomyelitis/chronic fatigue syndrome, long COVID and Ehlers-Danlos syndrome, making diagnosis difficult.

A further challenge is that the evidence base to inform treatment is currently limited and consists of mainly small, uncontrolled studies, which may be insufficient to meet NICE's stringent requirement for evidence-based recommendations. A guideline would likely have to rely heavily on expert consensus and extrapolation from related conditions, which is a less-preferred method for formulating strong guidance. This highlights the urgent need for more research and larger, high-quality clinical trials to establish effective interventions.

Guideline development would have to address significant gaps in epidemiological data, diagnostic uncertainty, and the need for a comprehensive, multidisciplinary approach to management. If your constituents wish to suggest a topic for the NICE prioritisation board, they can do so at www.nice.org.uk/forms/topic-suggestion.

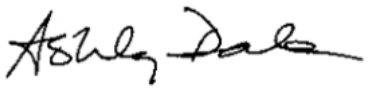
With regard to PoTS UK's involvement in the consultation for NICE's *Transient loss of consciousness ('blackouts') in over 16s* guideline, NICE's records show that PoTS UK was consulted and provided comments during the NICE stakeholder engagement, specifically in response to the surveillance consultation on the *Hypertension in adults* and *Transient*

loss of consciousness ('blackouts') in over 16s guidelines. Its input is documented in the published materials, which can be found at www.nice.org.uk/guidance/cg109/evidence/appendix-a-stakeholder-consultation-comments-table-pdf-11376320366.

There is also a full summary of the surveillance review, including the stakeholder consultation, which can be found at www.nice.org.uk/guidance/cg109/resources/2023-surveillance-of-hypertension-in-adults-diagnosis-and-management-nice-guideline-ng136-and-transient-loss-of-consciousness-blackouts-in-over-16s-nice-guideline-cg109-11376320365/chapter/Surveillance-decision?tab=evidence#stakeholder-consultation. The resulting update was published in November 2023.

I hope this reply is helpful.

Yours sincerely,



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