National Procurement NHSScotland Assure Specialist Healthcare Commissioning NHS National Services Scotland Gyle Square, 1 South Gyle Crescent EDINBURGH, EH12 9EB Telephone 0131 275 6000





Date: Our ref: Email: 02 September 2024 K: FOI/Ref: 2024-000289 <u>nss.pcf-foi@nhs.scot</u>

Dear

Freedom of Information Reference: FOI-2024-000289 – POTS Pathway.

I refer to your freedom of information request that we received on 05 August 2024. We have now completed the search of our records and can provide you with the following information:

1. Scottish Government involvement: Your letter states: "I understand that colleagues in Scottish Government will respond to you on behalf of Caroline Lamb, Chief Executive of NHS Scotland and Jenni Minto, Minister for Public Health and Women's Health". However, the Scottish Government's reply (from Christopher Doyle) said: "I can confirm that the

development of the pathway was facilitated by NHS National Services Scotland's long COVID Strategic Network. I understand that the Network's programme team – which is best placed to provide the information you have requested – has also received a copy of your letter, and will respond to you shortly". I do not feel Scottish Government have adequately addressed their involvement in this:

i. I would like to know whether the Scottish Government instructed the Long COVID Strategic Network to create the POTS pathway, and what checks were in place that the appropriate team had been assembled to take on such a task. I have CC'd the relevant representatives for ease.

ii. In addition, I would like to know whether the Scottish Government are providing funding for POTS services recommended by the Network, and if so, relevant details of this funding (e.g. how much money will be provided)?

Under section 17 of the Freedom of Information Scotland Act, 2002 (FOISA), an organisation does not have to provide that information if it does not hold it. National Services Scotland (NSS) do not hold the information you have requested.

2. In response to my questions: "Who was involved in (a) creating, (b) finalising, and (c) approving this "pathway"?" and "What expertise they have in POTS that qualified them to create this "pathway"?":

i. You have stated that a draft POTS pathway was created by allied health professionals (AHPs), but gave no details as to who these are. Ideally, for the sake of accountability, names should be given. If there are issues with providing names, I am at a minimum requesting a list of job titles of those involved, considering "openness, honesty, and responsibility" are inscribed into NHS Scotland Principles and Values (Available from: <u>https://workforce.nhs.scot/about/principles-and-values/</u>).



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Please refer to the attached Appendix 1 – TOR_redacted, detailing the terms of reference for the Clinical Subject Matter Expert Group (CSME), which was formed to support the network in sharing best practice and developing pathways of diagnosis and treatment for Long COVID symptoms.

Some of the documentation being released includes personal data of third parties, specifically, names of individuals which have not been released into the public domain on any previous FOIs or literature regarding this topic. Where this is the case, these names and contact details have been redacted in line with exception Section 38 ((1)(b)) of the Freedom of Information Scotland Act – Personal information.

ii. In addition to point 2(i), I would like a list of each AHPs experience in supporting POTS, e.g. what training they have had, research they have been involved in, how long they have supported "the non-pharmacological treatment of the condition", which specialist doctors they work under in order to effectively perform this role, and other relevant information regarding their experience and expertise.

Under section 17 of the Freedom of Information Scotland Act, 2002 (FOISA), an organisation does not have to provide that information if it does not hold it. NSS does not hold the information you have requested. NSS do not employ nor manage any of the Allied Health Professionals (AHPs) and are therefore unable to comment on their training, experience, research and clinical supervision. This is a responsibility of the various Health Boards who are responsible for ensuring that the staff that they employ are adequately trained and supported to deliver services. NSS cannot comment on the roles and responsibilities of individual professions as this is a responsibility of their professional regulators. I would advise you contact the individual Health Boards who may be able to provide you with the requested information, addresses are as follows:

Ayrshire and Arran - foi@aapct.scot.nhs.uk

Borders - foi.enquiries@borders.scot.nhs.uk

Dumfries and Galloway - foi@dumgal.gov.uk

Fife - fife.foirequestfife@nhs.scot

Forth Valley – fv.freedomofinformation@nhs.scot

Grampian - gram.foi@nhs.scot

Greater Glasgow & Clyde - foi@ggc.scot.nhs.uk

Highland - nhsh.foirequestshighland@nhs.scot

Lanarkshire - foi@lanarkshire.scot.nhs.uk



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Lothian – <u>foi@nhslothian.scot.nhs.uk</u>

Orkney - ORK.FOIrequests@nhs.scot

Shetland - shet.foi@nhs.scot

Tayside - tay.informationgovernance@nhs.scot

Western Isles - wi.foi-requests@nhs.scot

NHS24 – foi@nhs24.scot.nhs.uk

NHS National Waiting Times Centre - FOI@gjnh.scot.nhs.uk

Scottish Ambulance Service - sas.foi@nhs.scot

Healthcare improvement Scotland - his.foi@nhs.scot

Mental Welfare Commission for Scotland - mwc.enquiries@nhs.scot

NHS Education for Scotland - foidp@nes.scot.nhs.uk

Public Health Scotland - PHS.FOI@phs.scot

State Hospital Board for Scotland - tsh.info@nhs.scot

iii. I am very concerned that AHPs were assigned with this task as POTS is not in their remit to treat directly; why were these people chosen to perform such a task? Who decided these AHPs should do this task? Why did the AHPs feel this was an acceptable task for them to undertake?

Under section 17 of the Freedom of Information Scotland Act, 2002 (FOISA), an organisation does not have to provide that information if it does not hold it. NSS does not hold the information you have requested. NSS do not employ nor manage AHPs to deliver clinical services to patients. This is a responsibility of the various Health Boards who are responsible for ensuring that the staff that they employ are adequately trained and supported to deliver services. NSS cannot comment on the roles and responsibilities of individual professions as this is a responsibility of their professional regulators. I would advise you contact the individual Health Boards at the above addresses who may be able to provide you with the requested information.

iv. Your letter states that GPs, cardiologists, and neuropsychiatrists were asked to provide input towards the draft:

a. Similar to requests in points 2(i) and 2(ii), please provide details of who these are and what expertise they have.



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I refer you to our answer to point 2(i). The pathway was shared with the Scottish Government's Heart Disease Task Force for their awareness and feedback was received from the chairs of the Task Force. NSS do not employ nor manage any of the specialists directly and are therefore unable to comment on their training, experience, research and clinical supervision.

b. Could you provide information on the level of input these clinicians had in the POTS pathway that has now been retracted, for example, did they provide evidence that fed into the pathway on pharmaceutical recommendations, or did they review the pathway draft and give comments, or something else? At what point of drafting where they involved, and how heavy was their involvement? Did they all approve the final version (if no, please provide details, e.g. of any objections)?

Clinicians provided different levels of input to the pathway, depending on their experience and expertise in managing the condition.

c. I am very concerned that neuropsychiatrists were involved. POTS is not within their remit (similar to AHPs). Please could you explain why outright non-experts were involved, and who made the decision to involve them?

The Network aims to be inclusive and allow for the experience of professionals from different professions to contribute to the work in improving patient care. A very broad approach to the choice of clinical experts that we have in our clinical subject matter expert group allows for differing needs to be met.

3. Pathway review: You state that "A review of the pathway is already being undertaken by the Network with further specialists which will consider the evolving evidence base as well as the professional and lived experience of Network members. The revised pathway will be approved through the appropriate Network and National Services Directorate governance". This raises concerns that the same Network that produced a pathway that quite obviously (to anyone with knowledge of POTS) had high potential for harm is now reviewing and approving a revised pathway: i. Is it the norm for a Network like this to be creating and reviewing pathways, and if so, can you provide examples of other pathways created by equivalent Networks?

Within NHS Scotland, pathways are often developed by networks of individuals working together to aid local, regional or national decision making and patient care. There are several national networks (Managed Clinical Networks, Managed Diagnostic Networks and Strategic Networks) who have developed guidelines and pathways to share best practice and support consistency of care across NHS Scotland.



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ii. I am reassured that "further specialists" will be consulted. I would appreciate elaboration on who these experts are (names and/or qualification and expertise, similar to requests above).

A review group is being established with members nominated from across NHS Scotland and third sector partners to ensure appropriate representation while developing the pathway.

iii. Can you please outline how the Network will avoid the mistakes that have already happened from re-occurring? For example, who will be selecting who is involved in the redrafting and approval of the POTS pathway, and how will they be deciding who is expert enough to contribute, along with any other relevant information.

Membership of the pathway review group is agreed by the CSME Group, which includes representatives from across NHS Scotland. The pathway review group will include interested parties from within the CSME Group and nominated representatives from relevant teams across NHS Scotland.

As noted already, we are establishing a group to review the pathway, which will be made up of experts from across NHS Scotland and third sector partners. This will ensure that a new pathway shares best practice across NHS Scotland to support the diagnosis and management of POTS.

I trust you will find the information of assistance and if you require any further information, please do not hesitate to contact me.

If you are unhappy with any aspect of how we have dealt with your request, you can make representations to us asking us to review the handling of your request. Please write to the Associate Director Governance and Board Services (Board Secretary) at the email address <u>nss.foi@nhs.scot</u> within 40 working days of the date of this correspondence.

If after a review you are still unhappy, you also have the right to apply to the Scottish Information Commissioner, who can be contacted at Kinburn Castle, St Andrews, Fife, KY16 9DS, or via their <u>online application form</u>.

If you have any queries about this letter, please contact me at the above address.

Yours sincerely,





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