

Reference: FOI.ICB-2526/348

Subject: Commissioning Decisions

I can confirm that the ICB does hold some of the information requested; please see responses below:

QUESTION	RESPONSE
<p>I'd like to obtain any communications, considerations or meetings regarding the following conditions:</p> <ol style="list-style-type: none"> 1. (hypermobile) Ehlers Danlos Syndrome 2. Long COVID 3. Postural Orthostatic Tachycardia Syndrome 4. Dysautonomia 5. Autonomic disorders 6. Small Fiber Neuropathy 7. Mast Cell Activation Syndrome 8. Hereditary Alpha Trypsinemia <p>a) I am particularly looking for information pertaining to decisions to fund/commission or not to fund treatment for these disorders and the reasonings behind those too.</p> <p>b) I would like to know if there are any working groups in any of these areas and if they have been considered, what are the timelines and outcomes associated with those meetings.</p>	<ol style="list-style-type: none"> 1. Hypermobility and EDS <p>Please refer to our Remedy page for more information on Referrals/who to refer: Hypermobility and EDS (Remedy BNSSG ICB)</p> <p>The ICB does not hold the information to answer questions a) to c).</p> 2. Long COVID <ol style="list-style-type: none"> a) There have been no decisions made around changing the commissioning of long COVID services within BNSSG ICB b) No working groups have been established at present. The ICB routinely look to ensure that the services we commission are clinically effective, provide value for money and where relevant look to redesign services to improve outcomes for patients and discussions reflect this. c) No specific outcomes, or timelines have been established for review of, or changes to Long COVID services at this point in

c) I would also like to know if there are plans going forward with any and all of those listed above or anything else that you think may pertain to this request.

time. Information about symptoms, Referral and the Long COVID Clinic can be found on our Remedy page: [Long COVID \(Remedy BNSSG ICB\)](#)

3. Postural Orthostatic Tachycardia Syndrome (PoTS)

Please refer to the ICBs Remedy page regarding referral guidelines: [Postural Orthostatic Tachycardia Syndrome \(PoTS\) \(Remedy BNSSG ICB\)](#)

The ICB does not hold the information to answer questions a) to c).

4. Dysautonomia

See response to question 2.

5. Autonomic Disorders

Please refer to the ICBs Remedy page regarding referral guidelines:
<https://remedy.bnssg.icb.nhs.uk/adults/dementia/dementia-assessment-referral/#:~:text=autonomic%20dysfunction>

The ICB does not hold the information to answer questions a) to c).

6. Small Fiber Neuropathy

	<p>The ICB does not hold the information to answer questions a) to c).</p> <p>Small Fiber Neuropathy (SFN) services are primarily provided through North Bristol Trust (NBT). We advise you to contact NBT for further information: FOIArequests@nbt.nhs.uk</p> <p>7. Mast Cell Activation Syndrome</p> <p>Please refer to the ICBs Long COVID Remedy page: Long COVID (Remedy BNSSG ICB); Sirona care & health's Long COVID Service has produced fact sheets for clinicians on Mast Cell Activation</p> <p>The ICB does not hold the information to answer questions a) to c).</p> <p>8. Hereditary Alpha Trypsinemia</p> <p>The ICB does not hold any information and is therefore not able to answer questions a) to c).</p>
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The information provided in this response is accurate as of 29 January 2026 and has been approved for release by David Jarrett, Chief Delivery Officer for NHS Bristol, North Somerset and South Gloucestershire ICB.