

Reference: FOI.ICB-2324/488

Subject: Commissioned Services for Duchenne Muscular Dystrophy (DMD)

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

QUESTION	RESPONSE
<p>1. Does your organisation commission any services for people with DMD?</p> <p>i. If no, does your organisation expect to commission services for DMD in the future?</p> <p>ii. If yes, what services for people with DMD does your organisation commission?</p>	<p>Yes – BNSSG ICB (Bristol, North Somerset and South Gloucestershire Integrated Care Board), UHBW (University Hospitals Bristol and Weston NHS Foundation Trust) and NBT (North Bristol NHS Trust) are part of the South West Neuromuscular Operational Delivery Network (SWNODN), further information can be found via the links below;</p> <p>https://www.england.nhs.uk/south/operational-delivery-networks/trauma/neuromuscular-network/</p> <p>https://www.nbt.nhs.uk/south-west-neuromuscular-operational-delivery-network/about-swnodn/swnodn-team</p> <p>https://www.uhbristol.nhs.uk/transition/neuromuscular/support/</p>
<p>2. How many people with DMD does your organisation serve?</p>	<p>The ICB does not hold this data. Please contact the trusts, NBT and UHBW, directly;</p> <ul style="list-style-type: none"> https://www.nbt.nhs.uk/about-us/information-governance/freedom-information/request-information

	<p>FOIArequests@nbt.nhs.uk</p> <ul style="list-style-type: none"> • https://www.uhbw.nhs.uk/p/how-we-use-your-data/freedom-of-information-foi-requests <p>FreedomOfInfo@uhbw.nhs.uk</p>
3. Does your organisation have any DMD-specific (or muscle-wasting disease-specific) policies or guidance?	<p>No, our trusts follow SWNODN policy and guidance.</p> <p>The ICB has the following page on Remedy which links to the SWNODN: https://remedy.bnssq.icb.nhs.uk/adults/neurology/neuromuscular/</p>
4. Do any of your organisation’s strategies, objectives, plans, performance indicators, audits, inspections, or similar, cite DMD (or any muscle-wasting disease) or use either as a metric?	<p>No, our trusts follow SWNODN policy and guidance.</p>
5. Is your organisation aware of the work of DMD Care UK (https://dmdcareuk.org/)?	<p>We advise contacting SWNODN directly: https://www.england.nhs.uk/south/operational-delivery-networks/trauma/neuromuscular-network/</p>

The information provided in this response is accurate as of 2 April 2024 and has been approved for release by Sarah Truelove, Deputy Chief Executive and Chief Finance Officer for NHS Bristol, North Somerset and South Gloucestershire ICB.