

Our Reference North East and North Cumbria ICB\
FOI ICB 26–243

North East and North Cumbria ICB
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Sunderland
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Tel: 0191 535 4288
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By Email

24 August 2026

Dear Applicant

Freedom of Information Act 2000 – Request for Information – NHS North East and North Cumbria Integrated Care Board (NENC ICB)

Thank you for your request received on 13 August 2026 for information held by NHS North East and North Cumbria Integrated Care Board (the ICB) under the provisions of the Freedom of Information Act 2000. The ICB covers the areas of County Durham, Newcastle Gateshead, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley.

Please find the information you requested on behalf of the ICB as follows.

Your Request

We're writing to you as part of a comprehensive review of neuromuscular healthcare provision. We cover more than 60 neuromuscular conditions, including myopathies, peripheral nerve disorders, neuromuscular junction disorders and spinal muscular atrophy (SMA). Please note the remit of this FOI, does not include Motor Neuron Disease (MND). A full list of relevant conditions and ICD-10 codes is attached for your reference.

We are writing to seek access to the following information:

1. Please confirm whether your ICB has any strategies or transformation programmes relevant to neurological services. If so, please provide the relevant strategy documents.
2. Please confirm the total number of children and adults with a known diagnosis of a neuromuscular condition within the population covered by your ICB.
3. Please provide the total annual funding provided for neuromuscular care for the financial year 2025-26. If exact figures are not available, please provide an approximation based on the records you hold.
4. Please provide the total annual funding provided for adults specialised neuroscience neurology (service code NCBPS08O) and specialist neuroscience services for children (service code NCBPS23M) for the past three financial years, or since their delegation from NHS England.

5. Please confirm whether your organisation has held discussions about implementing the [National Neurosciences Advisory Group's \(NNAG\) optimal clinical pathway for neuromuscular conditions](#), since its publication in September 2024.
 - a. If 'yes' to the above, please confirm whether your organisation is delivering the optimal pathway. If you are not delivering the optimal pathway, please outline reasons that prevent you from delivering it.
 - b. If 'no' to the above, please confirm whether your organisation plans to consider the implementation of the optimal clinical pathway for neuromuscular conditions. If not, please outline reasons that prevent you from implementing it.
 - c. Please supply any papers or discussion records about the NNAG optimal pathway for neuromuscular conditions.
 - d. Has your organisation discussed or received communications about the optimal clinical pathway with/from the former NHSE Specialised Commissioning team?
6. Does every place in your ICB have a community neuro team? If not, please provide a list of the places which do not.
7. Can you confirm whether each of the community neuro teams in your ICB treats people with neuromuscular conditions? Please provide the referral criteria used by each team, including a list of conditions which are accepted/covered by the team.
8. Please confirm whether your ICB includes people with lived experience of neurological conditions in decision-making about the commissioning of neurological services. If yes, please provide further details. If not, please outlines the barriers.

Our Response

1. On this occasion it is not possible to provide the requested information. In line with your rights under section 1(1)(a) of the Act to be informed whether information is held, we confirm the ICB does not hold any of the information requested. NENC ICB does not have any strategies or transformation programmes currently which are relevant to neurological services.
2. We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB on this occasion is not able to provide the requested information. In line with your rights under section 1(1)(a) of the Act to be informed whether information is held, we confirm the ICB does not hold any of the information requested. Funding for neuromuscular care is part of a block contract with individual trusts. However, we have determined that the information is held by the acute hospital NHS foundation trusts (FTs) within the North East and North Cumbria region.

In accordance with our duty under s.16 of the FOIA to provide reasonable advice and assistance to an individual requesting information, we have provided the FOI contacts for those foundation trusts.

NENC Acute Hospital FTs	Email/Online portal
County Durham and Darlington NHS FT	cdda-tr.cddftfoi@nhs.net
Gateshead Health NHS FT	ghnt.foi.enquiries@nhs.net
North Cumbria Integrated Care NHS FT	foirequest@cumbria.nhs.uk
North Tees and Hartlepool NHS FT	nth-tr.foi@nhs.net
Northumbria Healthcare NHS FT	foi@northumbria.nhs.uk
South Tees Hospitals NHS FT	stees.foi.admin@nhs.net
South Tyneside and Sunderland NHS FT	stsft@infreemation.co.uk
The Newcastle upon Tyne Hospitals NHS FT	https://www.newcastle-hospitals.nhs.uk/help/foi/

3. We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB on this occasion is not able to provide the requested information. In line with your rights under section 1(1)(a) of the Act to be informed whether information is held, we confirm the ICB does not hold any of the information requested. Funding for neuromuscular care is part of a block contract with individual trusts. Please redirect your request to the individual trusts included in the response to question 2.
4. Please refer to the response to question 3.
5. NENC ICB has not discussed the implementation of the NNAG optimal clinical pathway for neuromuscular conditions as a priority but would expect providers to deliver against that guidance.
6. Please refer to the response to question 1.
7. Please refer to the response to question 1.
8. As a strategic commissioner, NENC ICB would not hold that level of detail requested. The ICB does engage with service users but as this is not currently an ICB priority there are no specific examples relating to this cohort of the population.

In accordance with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log. Therefore, a version of our response which will protect your anonymity will be posted on the NHS ICB website <https://northeastnorthcumbria.nhs.uk/>.

If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me on the above telephone number or at the above address.

If you are unhappy with the service you have received in relation to your request and wish to request a review of our decision, you should write to the Information Governance Manager using the contact details at the top of this letter quoting the appropriate reference number.

If you are not content with the outcome your review, you do have the right of complaint to the Information Commissioner as established by section 50 of the Freedom of Information Act 2000. Generally, the Information Commissioner cannot make a decision unless you have exhausted the ICB's complaints procedure.

The Information Commissioner can be contacted at Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF or www.ico.org.uk.

Any information we provide following your request under the Freedom of Information Act will not confer an automatic right for you to re-use that information, for example to publish it. If you wish to re-use the information that we provide and you do not specify this in your initial application for information then you must make a further request for its re-use as per the Re-Use of Public Sector Information Regulations 2015 www.legislation.gov.uk. This will not affect your initial information request.

Yours faithfully

Information Governance Support Officer

**Information Governance Support Officer
North East and North Cumbria Integrated Care Board**