

Our Reference     North East and North Cumbria  
ICB\FOI ICB839

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By Email

18 April 2024

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 by North of England Commissioning Support (NECS) on 26 March 2024 for information held by NHS North East and North Cumbria Integrated Care Board (NENC ICB) under the provisions of the Freedom of Information Act 2000.

NENC ICB covers the areas of County Durham, Gateshead, Newcastle, North Cumbria, North Tyneside, Northumberland, South Tyneside, Sunderland, and Tees Valley (which covers the 5 councils that make it up – Darlington, Hartlepool, Middlesbrough, Redcar & Cleveland and Stockton-on-Tees).

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

**Your Request**

Under the Freedom of Information Act 2000, I would like to request the following information in regard to the treatment of Duchenne muscular dystrophy (DMD) by your organisation:

- Does your organisation commission any services for people with DMD?
  - If no, does your organisation expect to commission services for DMD in the future?
  - If yes, what services for people with DMD does your organisation commission?
- How many people with DMD does your organisation serve?
- Does your organisation have any DMD-specific (or muscle-wasting disease-specific) policies or guidance?
- 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?
- Is your organisation aware of the work of DMD Care UK (<https://dmdcareuk.org/>)?

## Our Response

We can confirm, as per Section 1(1) of the Freedom of Information Act 2000, the ICB holds some of the information you have requested.

- NENC ICB commissions Neurology services from Newcastle upon Tyne Hospitals Foundation Trust (FT), South Tees Hospitals FT, County Durham and Darlington FT and South Tyneside and Sunderland FT. Treatment for patients with DMD will be provided within these services, though the provider organisations will hold the full details of service delivery.
- On this occasion it is not possible to provide the requested information on those people with DMD served by NENC ICB. 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.

The North East and North Cumbria Integrated Care Board does not hold the records which you have sought. However, we have determined the records are held by the Acute Hospital NHS Foundation Trusts within the North East and North Cumbria region noted above.

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 email addresses for those acute hospitals to make your request.

<b>NENC Acute Hospital FTs</b>	<b>Email</b>
County Durham & Darlington NHS FT	<a href="mailto:cdda-tr.cddftfoi@nhs.net">cdda-tr.cddftfoi@nhs.net</a>
South Tees Hospitals NHS FT	<a href="mailto:foi@stees.nhs.uk">foi@stees.nhs.uk</a>
South Tyneside and Sunderland NHS FT	<a href="mailto:stsft.freedomofinformation@nhs.net">stsft.freedomofinformation@nhs.net</a>
The Newcastle Upon Tyne Hospitals NHS FT	<a href="mailto:nuth.freedom.information@nhs.net">nuth.freedom.information@nhs.net</a>

- NENC ICB does not have any DMD-specific (or muscle-wasting disease-specific) policies or guidance. Our providers are commissioned to deliver all relevant NICE guidance.
- NENC ICB's strategies, objectives, plans, performance indicators, audits, inspections, or similar, do not cite DMD (or any muscle-wasting disease) or use either as a metric.
- NENC ICB as an organisation is not aware of the work of DMD Care UK (<https://dmdcareuk.org/>), however, individual staff may be aware of this company's work.

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 Senior 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 complaints procedure provided by the North of England Commissioning Support Unit.

The Information Commissioner can be contacted at:

Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

[www.ico.org.uk](http://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](http://www.legislation.gov.uk) . This will not affect your initial information request.

Yours sincerely

*S Davies*

**S Davies**  
**Information Governance Officer**