

Please contact: Access to Information
Team
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County Hall
Fishergate Hill
Preston
PR1 8XB

25 April 2024

t: 0300 373 3550
www.lancashireandsouthcumbria.icb.nhs.uk

Re: Your request for information under the Freedom of Information Act 2000
Ref no: FOI-3952-LSC

Thank you for your request dated 26 March 2024.

We can confirm that the ICB does hold part of the information you requested.

Please find our response to your questions below:

1. 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?

We do not commission specific services for treatment of DMD as this is commissioned by the NHS England North West specialised commissioning team. At the time of the request it was autonomously within NHSE. Children and Young People would be seen by the paediatric neurology service and community paediatrics.

We now host the team in the ICB from 1st April, but have no operational input to their work.

2. How many people with DMD does your organisation serve?

Unknown, this data would sit with the service providers.

Please redirect to <https://www.england.nhs.uk/contact-us/foi/>

3. Does your organisation have any DMD-specific (or muscle-wasting disease-specific) policies or guidance?

No, this would sit with the service providers as listed above.

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?

No.

5. Is your organisation aware of the work of DMD Care UK (<https://dmdcareuk.org/>)?

We are not aware of this work.

Right of Appeal

Should you require any further information or clarification regarding this response please do not hesitate to contact us. If you are dissatisfied with the response, you are entitled to request an internal review which should be formally requested in writing and must be within 40 working days from the date this response was issued.

To request an internal review

You can request this by contacting the FOI team by email at MLCSU.FOITeam@nhs.net or by post to Leyland House, Lancashire Business Park, Leyland, PR26 6TR, specifying why you require a review.

If you are not content with the outcome of your internal review, you may apply directly to the Information Commissioner's Office (ICO) for a decision. Generally, the ICO cannot make a decision unless you have exhausted the CCGs FOI complaints procedure. The ICO can be contacted at:

Information Commissioner's Office, Wycliff House, Water Lane, Wilmslow, Cheshire, SK9 5AF
www.ico.gov.uk

Yours sincerely

Dr David Levy – Chief Medical Officer

**On behalf of Kevin Lavery
ICB Chief Executive**