

Ref: FOI-044-202425- Clinical Data and Processes- Muscular Dystrophy

Newcastle Road  
Stoke-on-Trent  
Staffordshire  
ST4 6QG

Date: 22<sup>nd</sup> April 2024

Email [foi@uhnm.nhs.uk](mailto:foi@uhnm.nhs.uk)

Dear

I am writing to acknowledge receipt of your email dated 15th April 2024 requesting information under the Freedom of Information Act (2000) regarding Duchenne muscular dystrophy

On 16<sup>th</sup> April 2024 we contacted you via email with the following:

To continue with your request we require clarification on what time frame you are referring to

On the same day you replied via email with:

*'We mean how many patients with Duchenne muscular dystrophy does your organisation have.'*

We responded with:

Thank you, but what year are you referring to? This year, last year?

You replied:

*'In the last twelve months'*

As of 1<sup>st</sup> November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

**Q1 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?**

- o If no, does your organisation expect to commission services for DMD in the future?**
- o If yes, what services for people with DMD does your organisation commission?**

**A1** University Hospitals of North Midlands NHS Trust is not a commissioning authority, it is a provider of services.

Since July 2022, commissioners of services are Integrated Care Boards.

**Q2 How many people with DMD does your organisation serve?**

- A2 Information not held – see answer 4, however, University Hospitals of North Midlands NHS Trust provides services for patients with Duchenne Muscular Dystrophy (DMD), as referred to us by the regional neuromuscular services based at Robert Jones & Agnes Hunt Hospital in Oswestry and Birmingham Children’s Hospital. The numbers seen within varied sub-specialities, e.g. respiratory, gastroenterology, spinal surgery, is different depending on the needs of the patients. However, there is excellent liaison with the regional neurologists and the sub-specialities provided for children by Staffordshire Children’s Hospital and adults within the larger organisation, University Hospitals of North Midlands NHS Trust.
- Q3 Does your organisation have any DMD-specific (or muscle-wasting disease-specific) policies or guidance?**
- A3 The University Hospital of North Midlands NHS Trust uses the following guidelines for the management of DMD:  
Regional Partners in Paediatrics Paediatric Guidelines (edited 2-yearly by relevant specialists from all over the West Midlands)  
Clinical Care Guidelines for Children with DMD, MD-UK 2018  
Respiratory Care Guidelines published in British Medical Journal 2021 (endorsed by British Thoracic Society)  
Multi-disciplinary team meetings and liaison with neurologists in the regional service are also important guidance for clinicians at University Hospitals of North Midlands NHS Trust.
- Q4 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?**
- A4 Information not held by UHNM - the numbers managed by Oswestry and Some of their patients may go to Birmingham or Liverpool for certain specialities.
- Q5 Is your organisation aware of the work of DMD Care UK (<https://dmdcareuk.org/>)?**
- A5 Yes, alongside other charities that serve patients with DMD, such as MD-UK, DMDCareUK, TreatNMD, and DuchenneUK, and in addition to charities that serve patients with other neuromuscular disorders.

\*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via [www.ico.org.uk](http://www.ico.org.uk).

Yours,



**Rachel Montinaro**  
Data Security and Protection Manager - Records