



Ref: FOIA Reference 2024/25-227

Date: 24<sup>th</sup> July 2024

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

Dear Sir/Madam

I am writing in response to your email dated 4<sup>th</sup> July 2024 requesting information under the Freedom of Information Act (2000) regarding pathways for genetic/ genomic testing in motor neuron disease.

As of 1<sup>st</sup> November 2014 University Hospitals of North Midlands NHS Trust (UHM) 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 We are requesting details on pathways for genetic/ genomic testing in motor neuron disease in your Trust, including non-physician led pathways. The information we request is listed below this email. We appreciate your response to all questions, even where the answer is 'no' or 'not relevant'.**

**On behalf of which organisation and department are you answering this request?**

A1 North midlands MND care and Research Network

**Q2 Is there a pathway for genetic/ genomic testing for MND in your organisation?**

A2 Yes

**Q3 Is there a pathway for non-physician led genetic testing for MND in your organisation (e.g., led by a nurse or allied health professional such as a physiotherapist)? (Please give details)**

A3 No

**Q4 If you have a pathway, which non-physician undertakes the pathway?**

A4 Not applicable

**Q5 If you have a pathway, does the non-physician led pathway occur on the same day as a neurology appointment or is it separate?**

A5 Not applicable

**Q6 Are non-physician led appointments conducted in person or virtually or both?**

A6 Not applicable

**Q7 What paperwork is completed during this pathway: Record of discussion form Y/N, Test order form Y/N (please delete as appropriate)**

A7 Yes to both

**Q8 How and by whom are results of genetic testing fed back?**

A8 By letter to patient from Consultant Neurologist. Also there is an opportunity to discuss this in subsequent face to face follow up appointments.

\*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,



University Hospitals  
of North Midlands  
NHS Trust

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

