

FOI 3335

10th October 2025

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

Please provide the number of MND patients referred by your Trust to the Clinical Genetics Service for genetic testing in 2023/24 and 2024/25.

Please provide details of any counselling services available locally to MND patients and their families in relation to genetic testing, including:

- a. Whether counselling is provided before and after testing**
- b. Which professionals deliver the service**
- c. How patients are referred**

What is the average waiting time to access such counselling services for MND patients and their families within your Trust area?

Response:

This information is not recorded centrally and therefore retrieving it would involve a manual search of patient records. As such we cannot provide this information as the cost of locating and retrieving it exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. In order to obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

Under section 12 of the Freedom of Information Act 2000, Public Authorities are not obliged to comply with an information request where to do so would exceed the cost limit.

In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

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