Our Ref:84

May 2026

Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust

Freedom of Information Act Request

I am writing to request information under the Freedom of Information Act 2000.

FOI Request: Transthyretin Amyloidosis (ATTR) Information, May-26

1. How many new patients have been diagnosed with wild type Transthyretin Amyloid Cardiomyopathy (ATTR-CM) in your Trust in the last 4 months?

2. How many new patients have been diagnosed with hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN) in your Trust in the last 4 months?

3. What is the total number of patients with wild type Transthyretin Amyloid Cardiomyopathy (ATTR-CM) being treated in your Trust?

4. What is the total number of patients with hereditary Transthyretin Amyloid Polyneuropathy (ATTR-PN) being treated in your Trust?

For the above questions, we have had less than 5 patients who have been inpatients and received one on the above procedures.
Where figures are fewer than five, they have been replaced with "#".
This is because the disclosure of very small numbers, particularly when combined with other information provided (such as year, service area or site), may risk the identification of individuals. The Trust has therefore applied small number suppression in accordance with **Section 40(2) of the Freedom of Information Act 2000 (Personal Data)**.
Section 40(2) exempts information from disclosure where it constitutes personal data and where disclosure would be unfair or unlawful under the UK General Data Protection Regulation and the Data Protection Act 2018.
Replacing small numbers with "#" helps ensure that individuals cannot be identified from the information provided.

5. Of the newly diagnosed wild type ATTR-CM patients, how many were initiated with the following treatments
    a. Vutrisiran
    b. Tafamidis 61mg
    c. Acoramidis
    d. Enrolled in a clinical study

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6. Of the newly diagnosed ATTR-PN patients, how many were initiated with the following treatments
    a. Vutrisiran
    b. Eplontersen
    c. Enrolled in a clinical study

DBTH holds the information on the subject you have requested. However, I advise you that we will not be able to answer your request without exceeding the appropriate limit. This is because our pharmacy system doesn't store diagnosis data, so we're unable to determine this against the prescribed treatment. To ascertain this data, the Trust would need to perform an audit of each individual patient record, which wouldn't be achievable within the s.12 timescale of the Freedom of Information Act 2000.

Section 12 of the Act makes provision for public authorities to refuse requests for information where the cost of dealing with them would exceed the appropriate limit, We have estimated that it would take more than 18 hours to carry out a manual search to locate, retrieve, and extract all the information you have requested. In this situation the associated cost would therefore exceed the appropriate fee limit of £450 set out under Freedom of Information & Data Protection (Appropriate Limit and Fees) Regulations 2007.

The fee limit specified in regulations for NHS trusts represents the cost of one person spending 2½ working days at a rate of £25 per hour determining whether the Trust holds the information sought and then locating, retrieving and extracting that information.

7. What is your Trust's protocol for confirming diagnosis of ATTR patients? Is diagnosis confirmed by your Trust or the National Amyloidosis Centre (NAC)?

Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust may undertake initial investigations where ATTR is suspected. However, definitive diagnosis and confirmation of ATTR is undertaken by specialist centres with expertise in amyloidosis and associated specialist cardiac and nuclear medicine diagnostics. The Trust does not act as the specialist diagnostic centre for ATTR.

Accordingly, diagnosis is typically confirmed by the relevant specialist centre rather than by DBTH.

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8. Of the diagnosed patients, how many had their diagnosis made/confirmed
    a. In your Trust
    b. By the National Amyloidosis Centre (NAC) London or Midlands

The Trust does not hold this information.

As ATTR diagnoses are confirmed through specialist centres rather than within DBTH, the Trust does not maintain a local dataset recording the number of patients whose diagnosis was confirmed by a particular specialist organisation, including the National Amyloidosis Centre.

9. How many patients have been confirmed for treatment initiation either
    a. Virtually
    b. In person

The Trust does not hold this information.
Patients with confirmed ATTR are managed through specialist services and centres. The Trust does not maintain records categorising treatment initiation as having been confirmed virtually or in person and therefore does not hold the requested information.

If you are not satisfied with the handling of your request, you have the right to request an internal review. Requests for an internal review should be submitted within 40 working days from the date of this response, and should be addressed to d.wraith@nhs.net.

If you remain dissatisfied after the internal review, you have the right to appeal to the Information Commissioner's Office (ICO). The ICO can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 0303 123 1113
Website: https://ico.org.uk/make-a-complaint/

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