

Date 3 August 2026
Your Ref
Our Ref 11503

Enquiries to Richard Mutch
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Dear

FREEDOM OF INFORMATION – ATTR-CM

I write in response to your request for information in relation to ATTR-CM.

Question:

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

Answer:

We do not collect this data*

Question:

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

Answer:

No patients in the last 4 months

Question:

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

Answer:

We do not collect this data*

Question:

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

Answer:

We do not collect this data*

Question:

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

Answer:

a.	None
b.	None
c.	None
d.	None

Question:

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

Answer:

a.	No new patients in the last for months
b.	
c.	No active research studies recruiting amyloid patients locally. There was an imaging study called iCare which Craig recruited into past 2 years but not in the last 4 months.

Question:

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)?

Answer:

Diagnosis is now confirmed within the health board using the standard NAC-approved diagnostic algorithm relying upon DPD (currently external) or CMR

Either presentations and test results discussed at National MDT with Scottish colleagues, staff from NNAC attend that meeting to give advice. Most patients with confirmed disease will have attended at least once as well.

Question:

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

Answer:

None diagnosed in the past 4 months. There were five or fewer requests for referrals to National Amyloidosis Centre in 2024, and 7 requests in 2023.

Question:

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

Answer:

None confirmed for treatment in the last 4 months

*This information is not held in a centrally extractable format. Under the Freedom of Information Act NHS Lothian is not required to create new records to enable it to respond to your enquiry. This information is not collated or held in aggregate form and it would be necessary to review all case files relating to patients over the period you have requested to assemble the information you seek. Even if NHS Lothian did this – and there would be significant cost implications in doing so – it would be unable to respond in full to your request. The information requested is therefore exempt under section 12.1 – Cost.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing
Cc: Chief Executive