

FOI 3797

25th June 2026

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

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

Response:

<5

The Trust has a legal duty to protect patient confidentiality, in line with this duty the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

S 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the redacted information from disclosure. The Trust does not consider the disclosure of the redacted information to be fair to the individuals concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018.

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

Response:

None

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

Response:

Please see attachment 1 for response.

Please note that patients are not booked into clinics based on diagnosis; even dedicated clinics do not guarantee accuracy, as some patients may also be seen within general clinics rather than dedicated specialist services.

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

Response:

Please see attachment 1 for response.

5. Of the newly diagnosed wild type ATTR-CM patients, how many were initiated with the following treatments:

Response:

9 on tafamidis

Vutrisiran - <5

The Trust has a legal duty to protect patient confidentiality, in line with this duty the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

S 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the redacted information from disclosure. The Trust does not consider the disclosure of the redacted information to be fair to the individuals concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018.

Tafamidis 61mg - 9 prescriptions issued – cannot confirm when initiated

Acoramidis – Not stocked

Enrolled in a clinical study – 0

6. Of the newly diagnosed ATTR-PN patients, how many were initiated with the following treatments –

Response:

Vutrisiran - <5

The Trust has a legal duty to protect patient confidentiality, in line with this duty the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

S 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the redacted information from disclosure. The Trust does not consider the disclosure of the redacted information to be fair to the individuals concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018.

Eplontersen - Not stocked

Enrolled in a clinical study – 0

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)?

Response:

Diagnosis is confirmed by NAC.

8.Of the diagnosed patients, how many had their diagnosis made/confirmed

Response:

In your Trust:

9 (initial diagnosis made and then confirmed by NAC)

9.By the National Amyloidosis Centre (NAC) London

Response: 9

10.How many patients have been confirmed for treatment initiation either

Virtually

In person

Response:

All confirmed in person.

Email: Foi.Team@Southerntrust.hscni.net