

FOI 2872

27th January 2025

FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST

Question 1. How many patients have a current diagnosis for Spinal Muscular Atrophy (ICD-10 Code G12.0, G12.1, G12.8 and G12.9) at your trust?

Response:

We can only provide the number of patients who were admitted to hospital as an inpatient or daycase with a diagnosis = Spinal Muscular Atrophy.

	NUMBER OF PATIENTS (based on count of Casenote Number)
Based on diagnosis coded in <u>12 month</u> period 01/10/2023 - 30/09/2024	<5
Based on diagnosis coded in <u>6 month</u> period 01/04/2024 - 30/09/2024	0

The Trust has a legal duty to protect patient confidentiality and, 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 and the sensitivity of the information requested. 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

Question 2. How many patients have been treated in the last 4 months (September to December 2024) with the following products:

Evrysdi (Risdiplam)

Response:

0

Spinraza (Nusinersen)

Response:

0

Zolgensma (Onasemnogene)

Response:

0

Evrysdi (Risdiplam)*

Response:

0

Spinraza (Nusinersen)*

Response:

0

Zolgensma (Onasemnogene)*

Response:

0

*new patients are defined as patients who were not treated with any of Spinraza (Nusinersen), Evrysdi (Risdiplam) or Zolgensma (Onasemnogene) in the previous 4-month period (May to August 2024).

Question 3. Of the total patients treated in the last 4 months (September to December 2024) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2024).

Response:

N/A- No patients treated.

Question 4. Of the total patients treated in the last 4 months (September to December 2024) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2024).

Response:

N/A- No Patients treated.

Question 5. How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2024)?

Response:

0

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