

FOI REF: 24/044

24th January 2025

Tel: 0300 131 4500
Website: www.esht.nhs.uk

FREEDOM OF INFORMATION ACT

I am responding to your request for information under the Freedom of Information Act. The answers to your specific questions are as follows:

We have a freedom of information request related to the diagnosis and treatment of Spinal Muscular Atrophy. Your answers to the following questions would be greatly appreciated.

Q1. 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?

Please see the table below for the number of patients with a diagnosis of Spinal Muscular Atrophy, during the period 1st January to 31st December 2024:

Number of Patients	Number of Admissions	Primary Diagnosis
22	22	1

Q2. How many patients have been treated in the last 4 months (September to December 2024) with the following products:

- Evrysdi (Risdiplam) - total patients 0
- Spinraza (Nusinersen) - total patients 0
- Zolgensma (Onasemnogene) - total patients 0
- Evrysdi (Risdiplam) – new* patients 0
- Spinraza (Nusinersen) – new* patients 0
- Zolgensma (Onasemnogene) – new* patients 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).

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Q3. 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).

0.

Q4. 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).

0.

Q5. How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2024)?

0.

If I can be of any further assistance, please do not hesitate to contact me.

Should you be dissatisfied with the Trust's response to your request, you have the right to request an internal review. Please write to the Freedom of Information Department (esh-tr.foi@nhs.net), quoting the above reference, within 40 working days. The Trust is not obliged to accept an internal review after this date.

Should you still be dissatisfied with your FOI request, you have the right of complaint to the Information Commissioner at the following address:

The Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire SK9 5AF

Telephone: 0303 123 1113

Yours sincerely

Freedom of Information Department
esh-tr.foi@nhs.net