

FOI 3120

2nd June 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:**

Please see attachment 1 for number of inpatient episodes.

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 exact figures from disclosure. The Trust does not consider the disclosure of the 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 (January to April 2025) with the following products:****Response:**

- 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 (September to December 2024).**

Question 3.

Of the total patients treated in the last 4 months (January to April 2025) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (September to December 2024).

Response:

N/A

Question 4.

Of the total patients treated in the last 4 months (January to April 2025) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (September to December 2024).

Response:

N/A

Question 5.

Of the total patients treated in the last 4 months (January to April 2025) with Spinraza (Nusinersen) please provide the number of patients that were treated with Evrysdi (Risdiplam) in the previous 4 months (September to December 2024).

Response:

N/A

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