

FOI 3330

3rd October 2025**FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST**

I 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.

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:

This information is not recorded centrally and therefore retrieving it would involve a manual search of individual patient records. As such we cannot provide this information as the cost of locating and retrieving the information exceeds the “appropriate limit” as stated in the Freedom of Information (Fees and Appropriate Limit) Regulations 2004. To obtain this information from a number of individual patient records would exceed the £450 limit and is therefore cost prohibitive.

Under section 12 of the Freedom of Information Act 2000, Public Authorities are not obliged to comply with an information request where to do so would exceed the cost limit.

In addition, it would not be appropriate to search through individual patient records for the purposes for responding to a FOI request, there would be no patient expectation that medical records would be used in this way.

Question 2. How many patients have been treated in the last 4 months (May to August 2025) with the following products:

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

*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 (January to April 2025).

Question 3. Of the total patients treated in the last 4 months (May to August 2025) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (January to April 2025).

Response:

N/A

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

Response:

N/A

Question 5. Of the total patients treated in the last 4 months (May to August 2025) with Spinraza (Nusinersen) please provide the number of patients that were treated with Evrysdi (Risdiplam) in the previous 4 months (January to April 2025).

Response:

N/A

Email: Foi.Team@Southerntrust.hscni.net