

Our Ref: 77/2023
JANUARY 2023

Re: Your request made under the Freedom of Information Act 2000

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?

No patients currently in hospital with the above diagnosis codes

Question 2. How many patients have been treated in the last 4 months (September to December 2022) with the following products:

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

*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 2022).

Question 3. Of the total patients treated in the last 4 months (September to December 2022) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).

Question 4. Of the total patients treated in the last 4 months (September to December 2022) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).

Question 5. How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2022)?

- **Our pharmacy system doesn't store diagnosis data, so we're unable to determine this against the prescribed treatment. To ascertain this data, the Trust would need to perform an audit of each individual patient record, which wouldn't be achievable within the s.12 timescale of the Freedom of Information Act 2000.**

Please get back in touch if you would like the number based on patients in general regardless of diagnosis /condition