

**Reference Number:** FOIAH2425/563  
**From:** Commercial  
**Date:** 14 January 2025  
**Subject:** Diagnosis and treatment of Spinal Muscular Atrophy

**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?

**A1** 15

**Q2** How many patients have been treated in the last 4 months (September to December 2024) 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 2024).

- A2**
- Evrysdi (Risdiplam) - 0
  - Spinraza (Nusinersen) – 9
  - Zolgensma (Onasemnogene) - 0

Zero new patients were treated with Evrysdi (Risdiplam), Spinraza (Nusinersen) and Zolgensma (Onasemnogene)

**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).

**A3** Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to ascertain the data the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.

**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).

**A4** Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to ascertain the data

the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.

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

A5 Information not held - Zolgensma (Onasemnogene) is not used within the Trust.