

15 February 2023

Diagnosis and Treatment of Spinal Muscular Atrophy

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?**

Adult Service:

In adult services, there are 10 patients with a diagnosis of SMA.

Paediatric Service:

There are 10 patients with a diagnosis of SMA in paediatrics.

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

Adult Service:

Evrysdi (Risdiplam) - total patients	8
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

Paediatric Service:

Less than 5 patients within the last 4 months have had ongoing treatment:

<5 on Risdiplam
<5 receiving Nusinersen.

Use of < 5 (less than five): We are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act - as this could make patients personally identifiable. Disclosure would constitute a breach of the principles of the General Data Protection Regulation 2018.

Zero new patients during May to August 2022.

15 February 2023

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).**

Adult Service:

Zero

Paediatric Service:

Zero new* patients treated with Evrysdi (Risdiplam) in the last 4 months (January to December 2022).

Zero new* patients treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).

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).**

Adult Service:

Zero

Paediatric Service:

Zero new* patients treated with Zolgensma (Onasemnogene) in the last 4 months (September to December 2022).

Zero new* patients treated in with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).

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

Adult Service:

Zero

Paediatric Service:

In the last 12 months (January to December 2022) we have treated less than 5 new* patients with Zolgensma (Onasemnogene).

We are unable to provide an exact figure - exempt from release under Section 40(2) of the Freedom of Information Act