

20 January 2026

Spinal Muscular Atrophy (SMA)

I have a **Freedom of Information** request related to the diagnosis and treatment of **Spinal Muscular Atrophy**.

Adult Services

Neuromuscular Service sits within the South Eastern Health and Social Care Trust (SET). The request concerning Adults should therefore be redirected to SET.

Paediatric Services

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?

In the Royal Belfast Hospital for Sick Children (RBHSC), we currently have 11 patients with a diagnosis of SMA.

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

• Evrysdi (Risdiplam) - total patients	<5
• Spinraza (Nusinersen) - total patients	<5
• Zolgensma (Onasemnogene) - total patients	<5
• Evrysdi (Risdiplam) – new* patients	<5
• 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 (May to August 2025).*

Use of <5 (less than five): We are unable to provide an exact figure as the small numbers involved could make patients personally identifiable – the information is exempt from release under Section 40(2) of the Freedom of Information Act - Personal Information relating to a third party.

Disclosure would constitute a breach of the principles of the General Data Protection Regulation 2018.

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

Zero

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

Zero

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

Zero