

21 November 2025

## **Spinal Muscular Atrophy**

- 1. Within your Trust/ Health Board, where are patients (aged 2yrs +) with a diagnosis of Spinal Muscular Atrophy referred to for treatment?**
- 2. How many patients with Spinal Muscular Atrophy have been referred in:**
  - A. The last 12 months? (or the latest 12 months of data you have available)**
  - B. The last 5 years?**

**Could you please split this out into SMA type if possible ( Type 0, 1, 2, 3, 4) – (see attached ICD-10 codes)**

- 3. If your Trust/ Health Board receives referrals, where are these referrals made from?**
- 4. How many patients return to local care for continued treatment once referred to a specialist centre?**
- 5. If you have a treating centre for Spinal Muscular Atrophy in your trust, what is the average length of stay (or annual bed days) of patients being treated?**

**If you are unable to answer all of these questions, please provide answers to those that are possible to answer. Thank you for taking the time to look into this request.**

The Neuromuscular service no longer sits with Belfast Health and Social Care Trust.

Please redirect your enquiry to South Eastern Health and Social Care Trust @ [informationgovernance@setrust.hscni.net](mailto:informationgovernance@setrust.hscni.net)