

FOI 3468

17<sup>th</sup> December 2025

## **FREEDOM OF INFORMATION ACT 2000 – INFORMATION REQUEST**

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**I would be grateful if you could please answer the following questions with regards to treatment of 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?**

**Response:**

Paediatric patients with Muscular Atrophy are referred to a joint team - RBHSC Neurology, SHSCT Child Development Clinic and will remain under the care of SHSCT General Paediatricians.

**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?**

**Response:**

5 or less children in the last three years. These are the numbers that we have been able to clarify within this time period.

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

S 40 (2) (third party information) of the Freedom of Information Act 2000 has been applied to exempt the redacted information from disclosure. The Trust does not consider the disclosure of the redacted information to be fair to the individuals concerned as there is the potential risk of identification of an individual(s) which they would not expect, and which would therefore breach the fairness element of the first principle of the Data Protection Act 2018.

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

**Response:**

5 or less children in the last three years. We are unable to split this into SMA type.

The Trust has a legal duty to protect patient confidentiality and, in line with this duty, the figure <5 has been provided where figures are very low. This is because of the potential risk of identification of an individual. In reaching this decision the Trust has taken into account the small geographical area which the Trust serves and the sensitivity of the information requested. In addition the Trust has taken into account the fact that all information disclosed in response to an FOI is disclosed to the 'world at large' and is published on the Trust website.

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**3. If your Trust/ Health Board receives referrals, where are these referrals made from?****Response:**

These children are generally identified at birth and referrals tend to originate from the Neonatal Unit. Children who present later are referred by the General practitioner or Health Visitor. A referral in these cases would be made to the SHSCT General Paediatrician who will then refer to RBHSC Neurology and SHSCT Child Development Clinic

**4. How many patients return to local care for continued treatment once referred to a specialist centre?****Response:**

All these children will continue to receive care locally.

**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?****Response:**

N/A

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