



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Cwm Taf Morgannwg
University Health Board



Freedom of Information Request: Our Reference CTMUHB_525_25

the ICD-10 codes are as follows:

G12.0: Infantile spinal muscular atrophy, type I (Werdnig-Hoffmann)

G12.1: Other inherited spinal muscular atrophy

G12.8: Other spinal muscular atrophies and related syndromes

G12.9: Spinal muscular atrophy, unspecified

You asked:

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?**

Cwm Taf Morgannwg University Health Board commission Neurological Services from Cardiff & Vale (C&V) and Swansea Bay (SB) University Health Boards (UHB). Support is also provided within C&V and SB UHB's for patients with more complex needs/those who require specialist inpatient care.

Therefore, you may wish to redirect your request directly to:

Cardiff and Vale University Health Board (Children's Hospital for Wales / University Hospital of Wales) - CAV_FOI.Requests@wales.nhs.uk

Swansea Bay University Health Board - FOIA.Requests@wales.nhs.uk

- 2. How many patients with Spinal Muscular Atrophy have been referred in:**

- The last 12 months? (or the latest 12 months of data you have available)**
- The last 5 years?**

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

Please note we do not code or centrally record outpatient diagnosis or reason for referral. Therefore, we are unable to provide any additional information.

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

N/A.

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

We can confirm that the Health Board does not centrally record this information. To provide you with this data, would require a manual trawl through individual records. The Health Board estimates that the cost of locating, retrieving and extracting this data would significantly exceed the 18 hours time and £450 cost limit set out within Section 12 of the Freedom of Information Act.

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?

N/A.