Reference:	FOI.18874.25
Subject:	Spinal Muscular Atrophy (SMA) treatment
Date of Request:	19 November 2025

Requested:

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?

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?
   c. 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?

Additional Email

- Following on from my previous email, 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

Response:

1. Hywel Dda University Health Board (UHB) confirms that patients with a diagnosis of SMA are referred and managed via the NHS Wales Joint Commissioning Committee (NWJCC) and tertiary agreement with Swansea Bay University Health Board (SBUHB). However, the UHB does provide an element of care for patients with a diagnosis of acute SMA if required.

2. The UHB is unable to provide you with this information due to the low number of cases (less than 5), as there is a potential risk of identifying individuals if this was disclosed. The UHB is therefore withholding this detail under Section 40(2) of the FoIA. This information is protected by the Data Protection Act 2018 (DPA)/UK General Data Protection Regulations, as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles of the UK GDPR. This exemption is absolute and therefore, there is no requirement to apply the public interest test.

In reaching this decision, the DPA and UK GDPR define personal data as data that relates to a living individual who can be identified solely from that data or from that data and other information, which is in the possession of the data controller.

3. The UHB confirms that any referrals for SMA are made from the Fetal Medicine Department and Maternity Services, this is predominantly the antenatal clinic.

4. Section 40 exemption applied.

5. The UHB confirms there is no local treatment centre for acute SMA referrals. See response to question 1.