Reference:	FOI.16365.25
Subject:	Spinal Muscular Atrophy (SMA)
Date of Request:	21 January 2025

Requested:

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?

2. How many patients have been treated in the last 4 months (September to December 2024) with the following products:
   - Evrysdi (Risdiplam) - total patients
   - Spinraza (Nusinersen) - total patients
   - Zolgensma (Onasemnogene) - total patients
   - Evrysdi (Risdiplam) – new* patients
   - Spinraza (Nusinersen) – new* patients
   - Zolgensma (Onasemnogene) – new* patients

   *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 2024).

3. Of the total patients treated in the last 4 months (September to December 2024) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2024).

4. Of the total patients treated in the last 4 months (September to December 2024) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2024).

5. How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2024)?

Clarified

1. We require “the patients that have a previous inpatient spell with a relevant diagnosis in the calendar year of 2024”.

Response:

1. Hywel Dda University Health Board (UHB) is unable to provide you with the number of patients, due to the low number of cases (less than 5), as there is a potential risk of identifying individuals if this was disclosed. Therefore, the UHB is withholding these details under Section 40(2) of the Freedom of Information Act 2000 (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.

2. - 5. The UHB confirms that it has not prescribed any of the listed medicines during the requested periods covering 1 January to 31 December 2024. These medications are Advanced Therapy Medicinal Products (AMTPs) or gene therapies for rare diseases, and they are prescribed and administered in specialist centres.