

Reference:	FOI.10706.23
Subject:	Diagnosis and treatment of Spinal Muscular Atrophy
Date of Request:	17 January 2023

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 2022) 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 2022).

3. Of the total patients treated in the last 4 months (September to December 2022) with Evrysdi (Risdiplam), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).
4. Of the total patients treated in the last 4 months (September to December 2022) with Zolgensma (Onasemnogene), please provide the number of patients that were treated with Spinraza (Nusinersen) in the previous 4 months (May to August 2022).
5. How many patients have been treated with Zolgensma (Onasemnogene) in the last 12 months (January to December 2022)?

Response:

1. Hywel Dda University Health Board (UHB) is unable to provide you with the information requested, due to the low number of cases (5 and under), 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 and the UK General Data Protection Regulations (UK GDPR), as its disclosure would constitute unfair and unlawful processing and would be contrary to the principles and articles 6 and 9 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 Data Protection Act 2018/UK GDPR define personal data as data which 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. to 5. The UHB confirms that none of the medications referred to have been prescribed from the UHB's Pharmacy Department.