Reference:	FOI.21576.26
Subject:	Spinal Muscular Atrophy (SMA)
Date of Request:	11 September 2026

Requested:

1. Within your trust, how many patients currently have a diagnosis for:
   a. SMA Type 1, aged less than 6 months (ICD-10 Code G12.0)
   b. SMA Type 2, aged 6–17 months (ICD-10 Code G12.1)
   c. SMA Type 3, aged 18 months–17 years (ICD-10 Code G12.1)
   d. SMA Type 4, aged 18 years and over (ICD-10 Code G12.1)
   e. SMA Unspecified (ICD-10 Code G12.9)

2. Please provide the number of total patients, who have been treated in the last 4 months (May to August 2026) with the following products:

Drug Type		**Total Patients**
Evrysdi (Risdiplam)	Total	
	Tablets	
	Oral Solution	
Spinraza (Nusinersen)	Total	
	12 mg/5 mL Intrathecal Injection	
	28 mg/5 mL Intrathecal Injection	
Zolgensma (Onasemnogene)	Total	

Response:

Hywel Dda University Health Board (UHB) is unable to provide you with all the information requested for question 1, as it is estimated that the cost of answering your request would exceed the “appropriate limit” as stated in the Freedom of Information Act 2000 (Appropriate Limit and Fees) Regulations 2004. The “appropriate limit” represents the estimated cost of one person spending 18 hours (or 2 ½ working days) in determining whether the UHB holds the information, and locating, retrieving and extracting the information.

The UHB’s coded data, held on Welsh Patient Administration System (WPAS) only records diagnoses for inpatients. Any patients that may have been diagnosed as an outpatient or that were diagnosed outside of the 10-year data retention window on the WPAS, would not be recorded within the centrally held data. In order to provide you with the information requested, the UHB would need to manually search the records of all Neurology patients for both adults and children and young people (CYP), to identify any information that would fulfil your request, as it is not recorded centrally.

The UHB can confirm that it currently has two thousand, three hundred and twenty-five (2,325) adult Neurology patients on the follow-up waiting list. It is estimated that a manual search of these records alone would exceed the 18 hours stipulated within the Freedom of Information Act 2000 (FoIA). Based on the number of records identified, conducting a search, taking a minimum of five (5) minutes per record, would exceed the ‘appropriate limit’, costing the UHB the following:

2,325 @ 5 minutes per record = 193 hours and 45 minutes

193 hours and 45 minutes @ £25 per hour = £ 4,843.75

The UHB is therefore applying an exemption under Section 12 of the FoIA, which provides an exemption from a public authority's obligation to comply with a request for information where the cost of compliance is estimated to exceed the appropriate limit.

However, under Section 16 of the FoIA, we are required as a public authority, to provide advice and assistance so far as it is reasonable to individuals who have made a request under the FoIA, this can include assisting a requestor to further refine their request.

Unfortunately, the UHB is unable to provide advice on how you can refine your request further. This is due to the UHB still requiring a manual trawl of all Neurology patient records to be undertaken, to identify any information that would fulfil your request.

Additionally, the UHB is unable to provide you with the information broken down as requested, due to the low number (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 (UK GDPR) 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.

1. An exemption under Sections 12 and 40 of the FoIA has been applied. Under Section 16, the UHB can confirm that thirteen (13) inpatients have been diagnosed with SMA, as recorded on the Welsh Patient Administration System (WPAS), during the period 1 September 2016 to 31 August 2026.
   The WPAS only holds data for the most recent ten (10) year period.

2. The UHB does not hold the requested information as it does not issue the listed medications. The medications are commissioned by the NHS Wales Joint Commissioning Committee (NWJCC) and patients requiring them are treated in Cardiff and Vale University Health Board (CAVUHB) or Swansea Bay University Health Board (SBUHB).

   If required, further information can be sought directly from the relevant Freedom of Information Teams. The contact details are as follows:

   NWJCC.Governance@wales.nhs.uk or alternatively in writing to:
   NHS Wales Joint Commissioning Committee, Freedom of Information Request, Corporate Governance, Unit G1, The Willowford, Main Avenue, Treforest Industrial Estate, Pontypridd, CF37 5YL

   FOI.Requests@wales.nhs.uk or alternatively in writing to:
   Freedom of Information Team, Cardiff and Vale University Health Board, Headquarters, University Hospital for Wales, Health Park, Cardiff, CF14 4XW.

   FOIA.Requests@wales.nhs.uk or alternatively in writing to:

FOIA Team, Swansea Bay University Health Board, Health Board Headquarters, 1 Talbot Gateway, Port Talbot, SA12 7BR.