

Our ref: IG/FOI/FOI.591.25

05 January 2026

Sent via email to: [REDACTED]

Dear [REDACTED]

## Request under the Freedom of Information Act 2000

I write further to your request for information which was received on 19 November 2025 and subsequent clarification received on 10 December 2025, to confirm, in accordance with S.1(1)(a) of the Freedom of Information Act 2000, that Powys Teaching Health Board (PTHB) does not hold the information that you require. For ease of reference your request is set out below and the Health Board's response follows.

### Your Freedom of Information (FOI) Request:

I am writing to you under the Freedom of Information Act to request the following information: I would be grateful if you could please answer the following questions with regards to treatment of spinal muscular atrophy:

Q1. Within your Trust/ Health Board, where are patients (aged 2yrs +) with a diagnosis of Spinal Muscular Atrophy referred to for treatment?

Q2. 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?

Could you please split this out into SMA type if possible ( Type 0, 1, 2, 3, 4) – (see attached ICD-10 codes)

Q3. If your Trust/ Health Board receives referrals, where are these referrals made from?

Q4. How many patients return to local care for continued treatment once referred to a specialist centre?

Q5. 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?

### Clarification Requested

Q2. (see attached ICD-10 codes)- Please can you provide us with this attachment

### Clarification Received

Thank you for your response, 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

### Powys Response:

Q1 – Q3 & Q5. I can confirm that Powys Teaching Health Board (PTHB) does not have a service that would diagnose and treat Spinal Muscular Atrophy (SMA) patients within Powys. Adult and Paediatric Neurology referrals are made to neighbouring health boards in Wales and NHS Trusts in England. We therefore recommend that you approach our provider organisations directly for this information. The table below lists the main health boards and NHS Trusts from which we commission health services for Powys residents. Please note that all providers may not necessarily offer services that fall within the definition of your request.

<b>Health Trust/Organisation</b>	<b>FOI Contact Details</b>
Gloucestershire Hospitals NHS Foundation Trust	ghn-tr.foi@nhs.net
Midlands Partnership University NHS Foundation Trust	FOI@mpft.nhs.uk
The Robert Jones Agnes Hunt Orthopaedic Hospital NHS Foundation Trust	rjah.foi@nhs.net
Sandwell and West Birmingham NHS Trust	swb-tr.SWBH-GM-FOIRequests@nhs.net
The Shrewsbury and Telford Hospital NHS Trust	sath.foi@nhs.net
The Royal Wolverhampton NHS Trust	rwh-tr.foi@nhs.net
Worcestershire Acute Hospitals NHS Trust	wah-tr.FOI@nhs.net
Wye Valley NHS Trust	Freedom.Information@wvt.nhs.uk

<b>Health Board/Organisation</b>	<b>FOI Contact Details</b>
Aneurin Bevan University Health Board	FOI.ABB@wales.nhs.uk
Betsi Cadwaladr University Health Board	bcu.foi@wales.nhs.uk
Cardiff & Vale University Health Board	FOI.Requests@wales.nhs.uk
Cwm Taf Morgannwg University Health Board	CTM.FreedomOfInformation@wales.nhs.uk
Hywel Dda University Health Board	FOI.hyweldda@wales.nhs.uk
Swansea Bay University Health Board	FOIA.Requests@wales.nhs.uk
Velindre University NHS Trust	Foi.vunhst@wales.nhs.uk

Q4. Adults with this condition who meet the therapy community neurological rehab team (CNRT) criteria are accepted into CNRT, but we do not hold data on the number of patients with this specific condition or condition type. 0 children with SMA have returned to local care for continued treatment over the past 5 years.

If you have queries or any concerns, contact details are given at the top of the letter. Please remember to quote the reference number above in any future communications. If you are dissatisfied with the handling or response to your request and wish to ask for a review of this, please contact us and we will arrange for this to be done.

Further information is available from the Information Commissioner's Office who can be contacted at:

Address: Information Commissioner's Office (Wales), 2nd Floor, Churchill House, Churchill Way, Cardiff, CF10 2HH.

Telephone: 0330 414 6421

Complaints Portal: [www.ico.org.uk/foicomplaints](http://www.ico.org.uk/foicomplaints)

Web site: <https://ico.org.uk/>

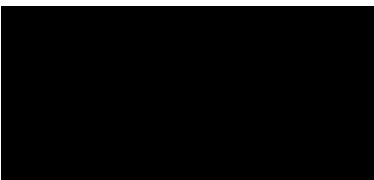
### **Re-use of Public Sector Information**

All information supplied by the Health Board in answering a request for information (RFI) under the Freedom of Information Act 2000 will be subject to the terms of the Re-use of Public Sector Information Regulations 2015.

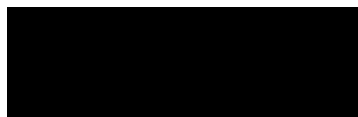
Under the terms of the Regulations, the Health Board will licence the re-use of any or all information supplied if being used in a form and for the purpose other than which it was originally supplied. This license for re-use will be in line with the requirements of the Regulations and the licensing terms and fees as laid down by the Office of Public Sector Information (OPSI). Most licenses will be free; however, the Health Board reserves the right, in certain circumstances to charge a fee for the re-use of some information which it deems to be of commercial value.

Further information including a sample license terms and fees can be found at Open Government Licence.

Yours sincerely



**Amie Symes**  
**Director of Midwifery, Women and Family**



**David Farnsworth**  
**Assistant Director, Community Services Group**

Rydym yn croesawu derbyn gohebiaeth yng Nghymraeg. Byddwn yn ateb y fath ohebiaeth yng Nghymraeg ac ni fydd hyn yn arwain at oedi.

We welcome receiving correspondence in Welsh. We will reply to such correspondence in Welsh and this will not lead to a delay.