

25 March 2025

Dear

## ATISN 24538 – Arachnoiditis

Thank you for your request to Welsh Government for information under the Freedom of Information Act (2000) received on 14 March 2025 relating to Arachnoiditis. You have requested the following information:

1. **Official NHS Wales Policy on Arachnoiditis**
  - Copies of any **guidelines, policies, or protocols** related to **the diagnosis, management, and treatment** of Arachnoiditis.
  - Any **internal documents or clinical pathway policies** used by NHS Wales in relation to suspected or confirmed cases of Arachnoiditis.
2. **Statistical Data on Arachnoiditis Diagnoses**
  - The **total number of patients** diagnosed with Arachnoiditis in Wales in each year from **2015 to 2024**.
  - Breakdown by **Health Board** of **new cases diagnosed annually**.
  - Number of **patients referred to specialists** (neurology, pain clinics, etc.) after a suspected diagnosis.
3. **Reporting & Recognition of Arachnoiditis Cases**
  - How does NHS Wales **track** or **record** cases of Arachnoiditis?
  - Is there any **centralised database** or specific **coding system** (such as ICD-10) used to classify Arachnoiditis cases?
  - Are there **reporting obligations** for physicians who suspect or diagnose a patient with Arachnoiditis?
4. **Causes & Medical Interventions**
  - How many cases of **Arachnoiditis** recorded in NHS Wales have been **linked to medical procedures**, including:
    - Epidural steroid injections
    - Spinal surgeries
    - Lumbar punctures
    - Myelograms
    - Spinal anaesthesia
  - How many cases have resulted in **legal claims** against NHS Wales?
5. **Access to Treatment & Specialist Referral Times**
  - What **treatment options** are available for patients diagnosed with Arachnoiditis within NHS Wales?
  - Average **waiting time** for specialist referrals (neurology, pain management) following an Arachnoiditis diagnosis.
  - Number of **specialist pain clinics** in Wales that explicitly treat Arachnoiditis patients.
6. **Arachnoiditis and NHS Wales Acknowledgment**
  - Does NHS Wales **officially recognise Arachnoiditis as a chronic disabling condition**?
  - Are there **disability support pathways** available for Arachnoiditis patients within NHS Wales?
7. **Complaints & Legal Actions**

- Number of **formal complaints** made by patients with Arachnoiditis against NHS Wales in each year from **2015 to 2024**.
- Number of **legal claims** brought against NHS Wales related to Arachnoiditis (whether due to medical negligence, lack of diagnosis, or improper treatment).

## Our Response

The Welsh Government does not hold the information you have requested.

Your request refers several times to 'NHS Wales', so you may be interested to know that NHS Wales does not exist as an autonomous authority. The Welsh Government sets the healthcare strategy for Wales, and that strategy (and associated health care services) are delivered via seven health boards, three NHS trusts and two special health authorities. There is also a newly established organisation called the NHS Wales Executive which provides a national support function designed to transform clinical services in line with national priorities and standards.

The information you have requested may be held on a region-by-region basis by each individual health board, so you may wish to contact them separately on this matter. Or you may wish to contact Public Health Wales, as the designated body with responsibility under the Freedom of Information Act for the NHS Wales Executive. You can do so via the following link: [Freedom of information - NHS Wales Executive](#)

It is important to note that the Freedom of Information Act 2000 gives individuals a right of access to recorded information held by a public authority at the time the request was received. It does not require an authority such as the Welsh Government to provide views or opinions where those views are not already recorded. This is confirmed by the Information Commissioner's guidance 'The Guide to Freedom of Information', page 7:

*"The Act does not cover information that is in someone's head. If a member of the public asks for information, you only have to provide information you already have in recorded form. You do not have to create new information or find the answer to a question from staff who may happen to know it."*

## Next Steps

If you are dissatisfied with the Welsh Government's handling of your request, you can ask for an internal review within 40 working days of the date of this response. Requests for an internal review should be addressed to the Welsh Government's Freedom of Information Officer at:

Information Rights Unit  
Welsh Government  
Cathays Park  
Cardiff  
CF10 3NQ  
or Email: [Freedom.ofinformation@gov.wales](mailto:Freedom.ofinformation@gov.wales)

Please remember to quote the ATISN reference number above.

You also have the right to complain to the Information Commissioner. The Information Commissioner can be contacted at:

Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

However, please note that the Commissioner will not normally investigate a complaint until it has been through our own internal review process.

Yours sincerely,