

# EPILEPSY SERVICE PROVISION WALES

POSITION STATEMENT

October 2022  
Updated March 2023

**epilepsy** *action*

Cymru

## Executive Summary

- This report draws on available information to provide an overview of the epilepsy services provided by the seven health boards in Wales.
- The report highlights clear discrepancies across health boards in relation to recruitment to Epilepsy Specialist Nurse posts and the availability of neurologists with specialist competency in epilepsy, and in some cases a lack of investment in epilepsy resources.
- It is clear from the available information that there is inequity in the provision of epilepsy services across Wales and shows that urgent action is needed to improve the care for people with epilepsy and reduce pressures on both the specialist epilepsy workforce and neurology waiting lists.
- Through this review it has become apparent that a service model that is supportive of patients with epilepsy requires implementing an 'open access' model with central administration.
  - This approach supports the clinical staff by protecting clinical time. Implementing this has proven to reduce the burden on the appointment system, emergency admissions and A&E attendance and enhances patient experience, mental health and is supportive of other key stakeholders e.g., primary care.
- Given the findings of the report, Epilepsy Action is calling on the Welsh Department of Health to:
  - Support measures to reduce current waiting times for epilepsy services and health professionals in Wales, by ensuring the levels of staffing across the Health Boards of Wales are appropriately resourced to achieve and maintain sustainability, patient safety and quality of service.
  - Implement the widespread adoption of 'epilepsy service coordinators' and adoption of a best practice model, such as 'Open Access'.
  - Review the provision of transition services to ensure these are available across all Health Boards and that there are no inequalities in the transition of children and young people into adult services.

## Contents

1. Introduction .....	3
2. Background.....	3
2.2 Service configuration and Workforce.....	4
2.3 Health Boards.....	6
2.4 NHS Trusts .....	7
2.5 Public Health Wales .....	7
3.0 Health Board Service Provision.....	8
3.1 Aneurin Bevan UHB.....	8
3.2 Swansea Bay University Health Board (SBUHB).....	10
3.3 Hywel Dda UHB.....	12
3.4 Cardiff and Vale UHB .....	13
3.5 Cwm Taf UHB .....	15
3.6 Betsi Cadwaladr UHB North Wales .....	16
3.7 Powys THB.....	18
4.0 Conclusion and Recommendations .....	18

## 1. Introduction

The purpose of this report is to provide an overview of the current healthcare provision and available services across Wales to deliver care for patients and service users with epilepsy.

The report brings together the range of available information to describe what services and associated resources are available against each Health Board and perceived gaps in the inequity of service provision for people with epilepsy across Wales. As part of the review areas of good practice have been highlighted which if adopted nationally, would benefit the health economy and the patients they serve.

The following presents the range of available information drawn upon:

- a) How each Health Board delivers their epilepsy services against the workforce, demographics and available resources.
- b) The findings from the national Neurological Alliance 'My Neuro Survey' published in 2022. The responses were further analysed to be specific to patients and service users in Wales.
- c) Each Health Board's response to the Welsh Parliament's Petitions Committee request for assurance against what services and resources are in place to meet the needs of people with epilepsy across Wales.

It is important to note that the report would have further benefited by including the Welsh national data dashboard for epilepsy. While we did consider submitting FOI requests for information, we felt that this would have been inappropriate given the current constraints on the NHS.

## 2. Background

2.1 Epilepsy is a common, fluctuating, and invisible condition associated with an array of psychosocial complications. Its episodic and varying nature means that conventional models of service delivery are not easily adapted. Comorbidities are common, and epilepsy is especially associated with learning disabilities.

Across Wales, the prevalence of epilepsy is **1%** (approximately **32,000** people with epilepsy (PWE)), with localised variation linked to levels of deprivation. Optimal use of anti-seizure medication (ASM) can control seizures in up to **70%** of patients. Unfortunately, only around **52%** of patients achieve sustained seizure freedom, with **30%** of patients becoming refractory to all treatment. This shortfall in the success of treatment with ASMs may be due to refractory disease, poor tolerability, patient adherence to medication, lifestyle factors (e.g., alcohol, drugs, poor sleep, and stress) or misdiagnosis. This data infers that approximately **5,200** people in Wales have preventable seizures.

Those people with seizures that cannot be controlled with existing treatments continue to face additional risks due to their epilepsy. Each year epilepsy is linked to over **100,000** unplanned hospital admissions and 1000 early deaths in the UK. As many as **40%** of these deaths could be prevented.

In 2021/2022, The Neurological Alliance ran a survey – My Neuro Survey – to give a picture of the experience of care, treatment and support for people affected by neurological conditions. The UK wide survey was run in partnership with the Welsh Neurological Alliance and included a version specifically for children and young people with a neurological condition.

Nationally, over 8,500 people shared their experiences and reported:

- **Delays to treatment and care can change your life forever.** 55% of adults and 60% of children and young people living with a neurological condition experienced *delays to routine appointments with specialists in the last year*.
- **Most people with a neurological condition are unable to access the mental wellbeing support they need.** 40% reported their mental wellbeing needs are not being met at all.
- **Finding out you have a neurological condition is scary and confusing.** Receiving the right information and support can make a real difference. **2 in 10** were not given an explanation of their diagnosis. Almost **4 in 10** adults reported not being given any information at all.

Given the overall findings, the submitted responses specific to epilepsy and localised to Wales highlight a number of specific and concerning issues which fit against the three key findings:

- **62%** of respondents experienced delays with a routine appointment with their neurologist
- **58%** of respondents experienced delays with a mental health appointment
- **44%** of respondents stated that their mental health had become worse over the past 12 months
- **41%** of respondents stated that they felt that their mental wellbeing needs were not being met at all
- **38%** of respondents stated that they waited more than 12 months for a diagnosis after first experiencing symptoms
- **68%** of respondents had not been offered a care and support plan to help manage their neurological condition in the last three years

## 2.2 Service configuration and Workforce

Delivering a coordinated, effective and efficient epilepsy service is dependent on a model that can deliver integrated, timely and patient centred care. Historically, the number of neurologists working in the NHS has been low, and services have developed reflecting this situation. As a result, many disorders that are managed within neurology in other countries, such as stroke and dementia, have predominantly fallen under other specialties in the UK. The time is now right, given the changing population and commissioning of services to manage long term conditions, mental health and an aging population to implement sustainable and efficient service models. Ones which can demonstrate improving outcomes, long term resource use e.g., acute admissions and enhance patient and service user experience.

Most patients with epilepsy achieve remission with appropriate medication, and follow-up aims to support those patients (usually the epilepsy specialist nurse) and provide a point of contact for when difficulties arise. Some patients do not achieve remission; the role of follow-up in such cases is to understand:

- Is the diagnosis correct?
- Is the patient on the most appropriate medication?
- Are there other issues or comorbidities?
- Is the patient taking the medication?

These phases of management should be within the competence of a neurologists with an interest in epilepsy outside of a specialist, tertiary hospital.

Patients with refractory or difficult epilepsy need access to clinicians with a particular interest in epilepsy who in turn have access to appropriate neurophysiology – notably, prolonged EEG and video-telemetry - and neuroradiology.

There are neurologists with an interest in epilepsy based at all neuroscience centres and at some neurology centres. At some sites they also assess for surgical management for epilepsy.

The Epilepsy Specialist Nurse (ESN) role has evolved to complement that of the clinician with 94% being involved in the monitoring and adjustment of medication to optimize seizure control. This has also included taking the lead in delivering a range of additional responsibilities, including rescue medication training, and providing or signposting to other support agencies and networks. [The ESPENTE report](#) highlights the cost-effectiveness of employing an adequate number of ESNs, in addition to the time they can save clinicians. But more importantly improve patient and service user experience and wellbeing.

However, the ESN role has over time been downgraded by health boards as a way of reducing staff costs. They have been considered an expensive commodity, with the increasing pressure to demonstrate the value and cost-effectiveness of their role in patient care.

The role of the ESN is regarded as key to providing patient centred care by undertaking work which otherwise would place additional pressure on the consultant neurologist and compromise a patient's access to specialist care and ongoing support in both primary and secondary care.

Prevalence of epilepsy is approximately **1.1%** in Wales with about **32,000** adults with epilepsy in Wales, according to the most recent incidence and prevalence figure.<sup>i</sup> From the total number of available **11.5 WTE ESNs** available in Wales that equates to a ratio of **1 nurse to every 2,823 patients**. This is extremely low and inequitable.

The Steers report (2008) recommended a ratio of **300:1. This being the case then for Wales there should be 107 ENS in post.**<sup>ii</sup>

Recommendations from the Royal College of Physicians and the Association of British Neurologists suggested a minimum of **9 ENS per 500,000 population. Again, given this review Wales should have in place 56 ESN's.**<sup>ii</sup>

The provision of ESNs is nowhere near these numbers and is woefully short. To also note using the 2023 epilepsy population estimates there were 55,314 people in Scotland with approximately **50 ENS, that is 1 ESN per 1,106 of the epilepsy population.**<sup>iv</sup>

<sup>i</sup> Wigglesworth, S. 2023. The incidence and prevalence of epilepsy in the United Kingdom 2013–2018: A retrospective cohort study of UK primary care data. Available at [https://www.seizure-journal.com/article/S1059-1311\(23\)00003-1/fulltext](https://www.seizure-journal.com/article/S1059-1311(23)00003-1/fulltext). Accessed 15 March 2023

<sup>ii</sup> Clwyd, G. 2008. Report of the Welsh Neuroscience External Expert Review Group: Recommendations for Mid and South Wales. Available at <http://www.wales.nhs.uk/documents/NeuroscienceReviewMidSouthWalesRecommendations2018September2008>. Accessed 30th January 2022

<sup>iii</sup> (RCP London 2011 Local adult neurology services for the next decade. Available at <https://mstrust.org.uk> accessed 1st February 2022). This is equivalent to an ENS caseload of approximately 550 patients.

<sup>iv</sup> (Lloyd R. Personal communication 6th February 2022)

## What Does a Good Model Look Like?

From the findings and assessment of each differing Health Board, the recruitment to ESN posts and the availability of neurologists with specialist competency in epilepsy is not widespread or at worst not available or invested in. Considering these findings, what has become apparent is the implementation of:

- a) A resourced 'Open Access' service model, one which is patient centred and service responsive. This model has presented measurable improvement in patient and service outcomes and is well established within three of the seven Health Boards (see 3.0). Although there is also an 'open access' model in place in Hywel Dda, it is not properly resourced. Introducing an 'open access' model, co-ordinated by central administration provides support to clinical staff by protecting essential clinical time. Implementing this has proven to reduce the burden on the appointment system, emergency admissions and A&E attendance and enhances patient experience, mental health and is supportive of other key stakeholders e.g., primary care. Patients and service users have a direct link into secondary and primary care services through a co-ordinated triage system.

Whilst the service runs well within the three Health Boards, this does still require goodwill, tenacity, and enthusiasm from the existing workforce. Additional ESN resource would enhance sustainable quality improvement and further improved patient outcomes.

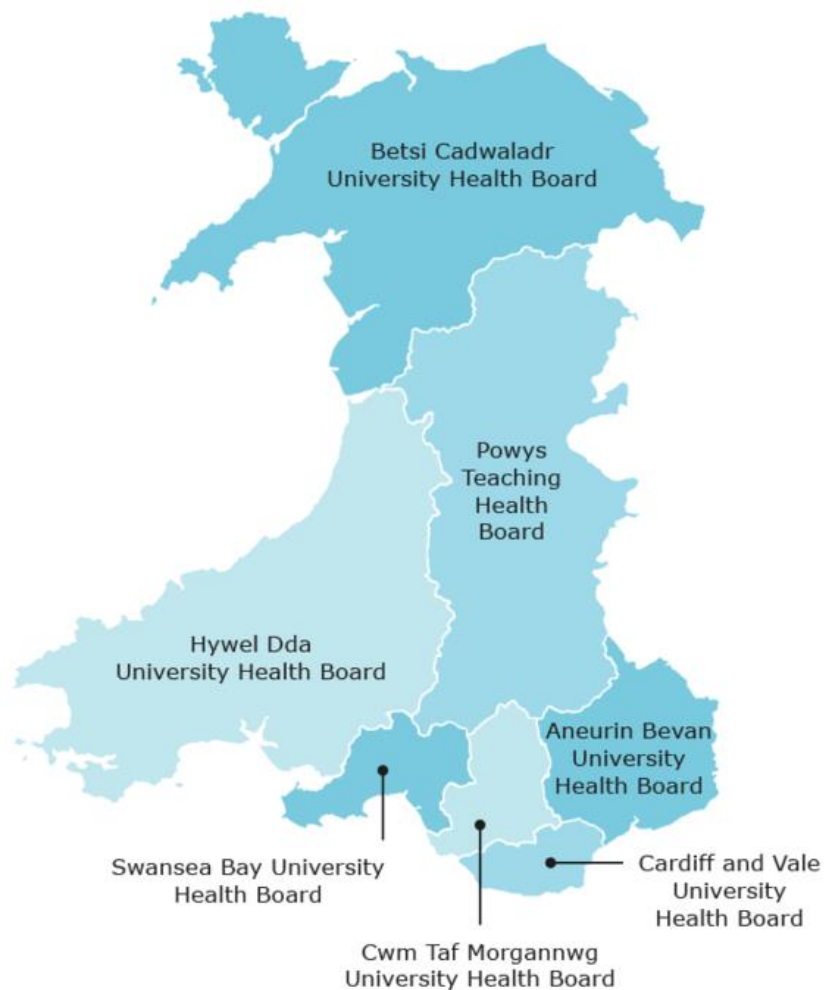
- b) A structured integrated services for the transition of young people into an adult service. The main focus being to ensure that services are available to support and monitor ongoing care and treatment to old age.

The epilepsy teams across three health boards (Cardiff and Vale, Swansea Bay and Aneurin Bevan) continue to work through a clinical network with quarterly meetings. This collective approach has resulted in publication of a First Seizure Pathway (2021). The group also continue to work on refinement of an epilepsy data dashboard which will be critical to informing future understanding of epilepsy epidemiology and need.

## 2.3 Health Boards

There are seven Local Health Boards (LHBs) within Wales. Each is responsible for the planning, securing and delivery of healthcare services in their area. They now replace the 22 LHBs and the 7 NHS Trusts which together performed these functions in the past.

- Aneurin Bevan Health Board;
- Swansea Bay University Health Board;
- Hywel Dda Health Board;
- Cardiff & Vale University Health Board;
- Cwm Taf Morgannwg Health Board;
- Betsi Cadwaladr University Health Board; and
- Powys Teaching Health Board.



## 2.4 NHS Trusts

There are two NHS Trusts in Wales, these are the Welsh Ambulance Services Trust (emergency services) and Velindre NHS Trust offering specialist services in cancer care and a range of national support services.

- [Welsh Ambulance Services NHS Trust](#);
- [Velindre NHS Trust](#)

## 2.5 Public Health Wales

Public Health Wales is the unified Public Health organisation in Wales.

The organisation became fully operational on 1 October 2009 and now exercises the functions of the National Public Health Service, Wales Centre for Health, Welsh Cancer Intelligence & Surveillance Unit, Congenital Anomaly Register & Information Service for Wales, and Screening Services Wales all with a nation-wide remit.



### 3.0 Health Board Service Provision

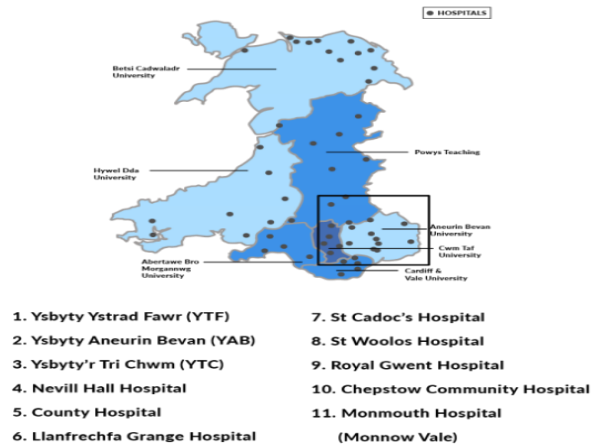
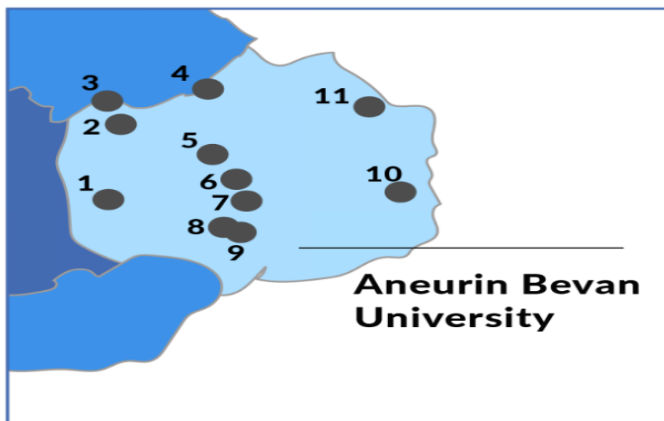
To inform the assessment of each individual Health Board’s current epilepsy service provision, key lines of inquiry have been applied. This also includes the responses made to the Welsh Petitions Committee’s request for information and assurance (appendix 1). It must be noted that responses were received from all, with the exception of Hywel Dda.

For the purpose of this report each Health Board has been addressed in turn, presenting the service configuration, areas of good practice, gaps in service, threats and opportunities.

### 3.1 Aneurin Bevan UHB

Aneurin Bevan University Health Board covers the former Gwent region, including Blaenau Gwent, Caerphilly, Monmouthshire, Newport, Torfaen, and south Powys.

The total number of people registered with epilepsy is approximately **6,000** patients. The number of patients registered on the adult epilepsy team database who have and continue to receive care in the last 5 years is **2664**.



### Workforce and Service Configuration

The current workforce is described below. The Health Board is currently advertising for an additional 1 x WTE Epilepsy Clinical Nurse Specialist and 1 x WTE Consultant with a Specialist Interest in Epilepsy to address gaps in current provision.

<b>ESN</b>	X2.5 PT Adult X1 WTE Epilepsy Coordinator at a Band 2 X4 PT Paediatric
<b>Coordinator</b>	X1 FT HCA (Fixed Term)
<b>Consultant</b>	X1 Neurologist (1 day/week) X1 Epileptologist

An 'open access' epilepsy service is in place. The co-ordinator role is a (fixed term) full time health care support worker acting as an epilepsy coordinator. This has been transformational and well evaluated to support the team and access for patients to the services including e-referrals from GPs and hospital teams.

The local hub for patients and service user access is through the Royal Gwent Hospital. A transitional service is in place which is consultant led.

Transition Clinics are jointly run with paediatrics, both at Consultant, and Nurse Led level. The Adult Epilepsy Team also offer a Nurse Led Welcome to Adults Clinic to complete the transition process, as suggested by Ready Steady Go Transition Tool.

Adult Epilepsy Nurses also run antenatal clinics, VNS clinics, and Epilepsy (open access clinics). These are a mixture of face-to-face and telephone consultations.

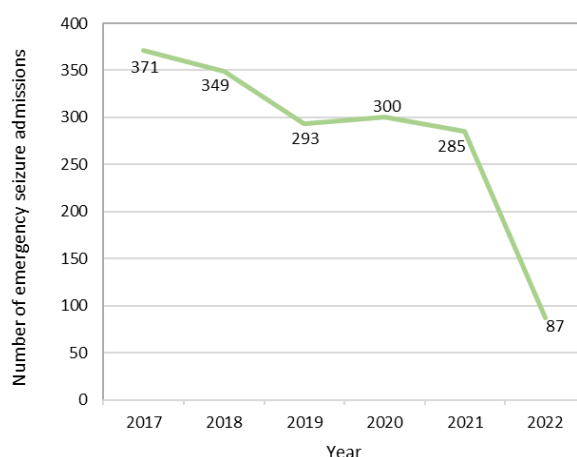
Consultants Prof Lawthom and Dr Anderson also run VNS clinics. LD colleagues are also supported with regular MDT's and joint clinics.

The current waiting time to be seen for a first seizure clinic is **2-3 months**. However, a number of patients may also have direct access whilst waiting for their 'formal' clinic assessment using the acute neurology service, which supports patients at admission or in emergency department.

Routine epilepsy appointment ranges from **6-10 months**.

The number of emergency seizure admissions has demonstrated a reduction from 2017 to 2022. This is predominantly in response to the 'open access' co-ordinator role (Graph1) This is also complimented with the new single point of access service located within ABUHB. The reduction since 2021 (**285**) to **87** in 2022.

**Graph 1**



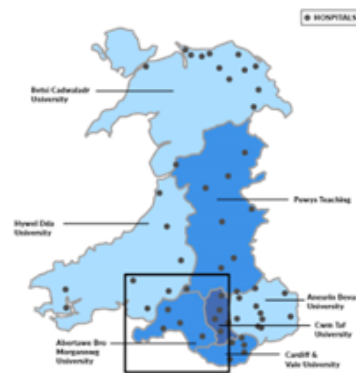
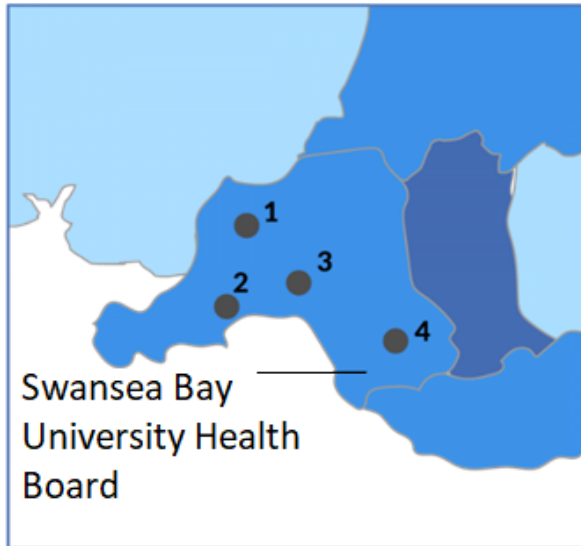
### Identified Risks

- Inadequate workforce to run the service, particularly insufficient ESN resources to cover for leave, run additional specialist services e.g., transition, community services.
- The co-ordinator is not a substantive role.

### 3.2 Swansea Bay University Health Board (SBUHB)

Swansea Bay UHB covers Swansea, Neath Port Talbot, and Bridgend. It serves a population of approximately half a million people and manages an annual budget of £1.3bn.

SBUHB has approximately **6,000** patients with epilepsy and has in place well organised paediatrics and adult transitional care.



- 1. Morriston Hospital
- 2. Singleton Hospital
- 3. Neath Port Talbot General Hospital
- 4. Princess of Wales Hospital

#### Workforce and Service Configuration

The Swansea Bay Regional Epilepsy Service (SBRES) evolved from a need to provide the best quality support for patients, and the need for change was made more pressing by the combination of the pandemic and austerity.

<b>ESN</b>	X2 FT adult X2 FT paediatric X2 LD Nurse
<b>Co-ordinator</b>	X1 Co-ordinator (80% FTE for epilepsy)
<b>Consultant</b>	3 Neurologists Professor Rob Powell Dr Owen Pickrell (60% FTE NHS) Professor Inder Sawhney

In times of prudent health care, pandemics and long waiting lists, it's clear that traditional systems no longer serve the people as they should. SBRES have clear, shared values and as a team have transformed a clunky, inflexible service into one that works for all.

Two epilepsy specialist nurses and the epilepsy coordinator joined the team in 2020, which is when the current patient-centred service took shape. Patients call or email the open access (OA) service at any time. Clinical responses to raised concerns or change in condition are made within 48 hours. Patients are triaged over the phone. Most issues including

prescriptions, medication changes, patient counselling, fact finding, reassurance, and education around mental health and epilepsy is managed.

The longest waiting patients are offered a choice between open access (OA) or a routine appointment. Most people choose the OA route and are placed on the '*Patient Initiated Follow Up*' (PIFU) supported by the OA service. Patients' evaluation indicates a positive experience to the "call us whenever you need us", particularly as they are given back control and the ability to self-manage.

The epilepsy coordinator coordinates a triaging system, collecting and screening all epilepsy referrals, identifying patients known to the service and those who may be suitable for phone or e-mail advice. The coordinator actively monitors waiting times for appointments, mapping capacity to demand.

A weekly multidisciplinary team meeting is in place where all new referrals are reviewed to identify those suitable for telephone or email advice. Bookings are managed at the time by the coordinator, resolving waiting times. The flexibility in the approach means instead of booking an appointment a simple call can be arranged between the ESN or consultant with the patient.

Answerphone and email messages are monitored Monday to Friday, and patients are contacted within 48 hours. All telephone and email consultations form monitored clinical activity. Evaluating the OA service indicates a positive decline in a range of measurable outcomes (Table 1) and referral time to treatment.

**Table 1**

	Before Open Access Service	After Open Access Service
Total number of patients on ' <i>Follow Up Not Booked</i> ' (FUNB) lists	1394	213
Total number breaching targets	784	39
Average waiting times for first seizure clinic (weeks)	21	3

The improvements in experience for patients has meant that:

- They can access virtual telephone clinics and general access to the clinical staff
- Reduced travel to clinic, particularly important as most are unable to drive
- Seen at times of need - more efficient consultations
- There has been fewer did not attends

Other service developments include.

- a GP email advice service providing specialist epilepsy management advice (satisfaction rate of 98% amongst users)
- a rapid access "First Seizure Clinic" for the prompt assessment and investigation of patients who have suffered a first epileptic seizure, allowing patients to be discharged quickly from the emergency department

- biweekly antenatal epilepsy clinic for women with epilepsy to have the best possible care and support during pregnancy
- bimonthly adolescent Transition to Adult Services Clinics, run jointly with Paediatric services

Swansea are constantly studying and evaluating the service to understand the impact of the changes and take the learning to improve services. is involves consistently

Working to develop a national epilepsy dashboard to measure the number of ED attendances and hospital admissions. Using this data alongside patient related outcome measures (PROMs) continues.

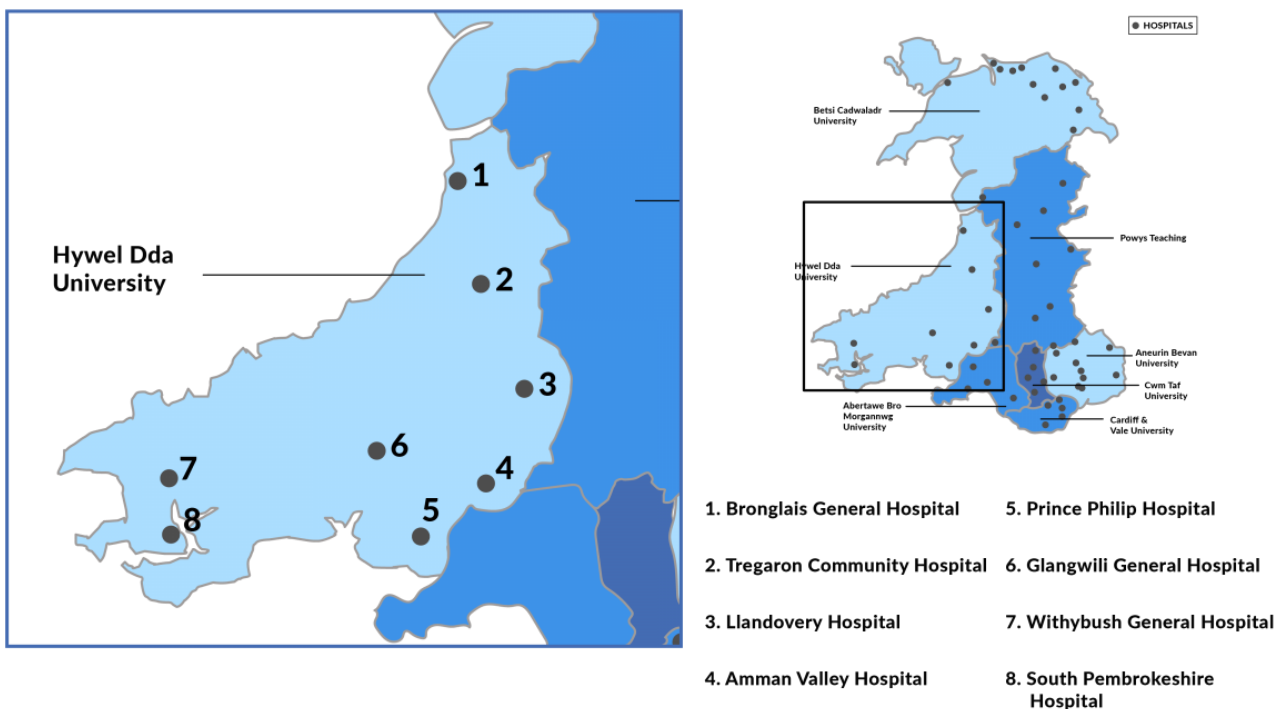
**Identified Risk**

- Inadequate workforce to perform a full regional service for Swansea and Hywel Dda
- Insufficient ESN resources to cover for leave, run additional specialist services e.g., transition, community services
- Heavy load of ESN doing open access work – risks of burnout
- One consultant approaching retirement
- Inequity across the region, limited access for patients from Hywel Dda
- Delays for epilepsy surgery and VNS treatment.

**3.3 Hywel Dda UHB**

Covering the west Wales region including Carmarthenshire, Ceredigion, and Pembrokeshire, Hywel Dda University Health Board provides healthcare to around 384,000 people.

Approximately **4,500** patients with epilepsy. This figure has been extrapolated from GP register available extracts as there was no access to any other data.



## Workforce and Service Configuration

There is little information or response from the Health Board and Swansea Bay UHB support the service with little recognition.

The two consultant neurologists have no specific epilepsy competencies. They are invited to the Swansea Bay UHB multidisciplinary team meetings. As they have no specialist knowledge the patients receive and inadequate specific epilepsy service. This is where possible picked up by Swansea Bay UHB, who are now feeling the constraints and impact on providing their own open access service.

The 'open access' available at Hywel Dda is poorly resourced and is led by the adult fulltime ESN. Which means that the burden is great on the nurse. At this time, we have no outcome data, or a response made to the Welsh Parliamentary Petitions Committee.

There is an ESN for learning disabilities in post.

There is no dedicated transitional service for paediatrics to adults

<b>ESN</b>	X2 FT Adult X1 PT Paediatric (Covering 8 hospitals)
	X1 LD Nurse
<b>Co-ordinator</b>	0
<b>Consultants</b>	X2 Neurologists – No epilepsy specialist – general neurology

## Identified Risks

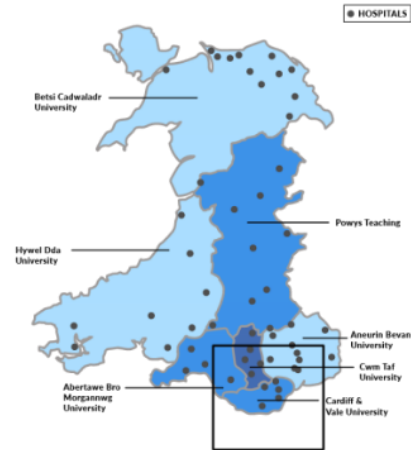
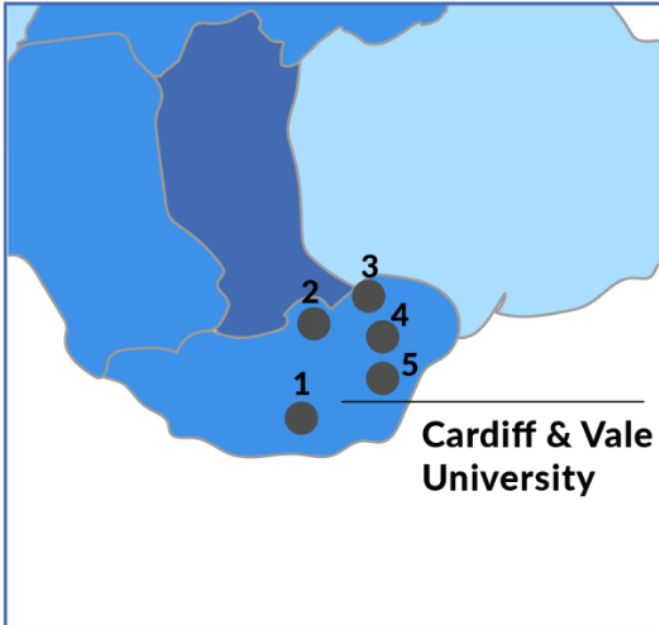
- It has the highest budget overspend of all the Wales health boards, partly due to problems attracting and retaining staff in its rural locations.
- Only one nurse allocated to deliver the adult epilepsy service
- Open clinic with only one nurse and no co-ordinator
- No response received to the Petitions Committee.

### 3.4 Cardiff and Vale UHB

There are currently 5000 active patients requiring on going management, with a further 1300 new referrals a year and around 15000 as having been through the department living with Epilepsy.

Under current commissioning arrangements the UHB provides secondary care for epilepsy for patients in their own, and Cwm Taf Morgannwg UHB areas. This catchment area covers a population of approximately 700,000.

Furthermore, current commissioning also requires the UHB to provide tertiary services, mainly for epilepsy surgery to a South Wales catchment population of 2.4m.



- 1. Barry Community Hospital
- 2. Rookwood Hospital
- 3. University Hospital of Wales (UHW)
- 4. St David's Hospital
- 5. University Hospital Llandough

**Workforce and Service Configuration**

Current waiting times for patients with a suspected first seizure is on average 22 days, which does not meet NICE guidelines, which recommend a waiting time of no longer than 2 weeks.

In addition, the current wait for new cases (routine) is just under a year with some reduction noted.

The increase in demand in general for a patient to be seen in a clinical setting by a neurologist has also increased. With increased demands on the service the waiting time for patients triaged as 'routine' has also increased.

<b>ESN</b>	X4WTE Adult X1.5WTE Paediatric (covers all 5 hospitals)
<b>Coordinator</b>	0
<b>Consultant</b>	X2 Neurologist (Adult) X1 Neurologist (paediatric) X4 Neurosurgeons – based at Cardiff & Vales

The 'Open Access' system allows patients to contact the department directly if they have concerns about their epilepsy, without the need for outpatient appointments. Access through this system averages 5000 patient encounters per year, with most receiving instant access to care, clinical input within 24 hours, and changes in treatment where required.

Cardiff and Vale, also use the single point access for patients. Through this service, patients are referred into a team of professionals who meet to decide which service and team is best placed to provide the correct treatment plan.

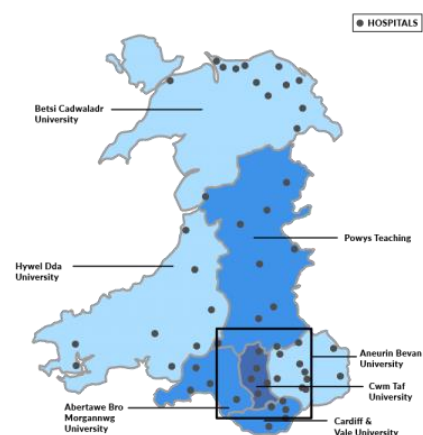
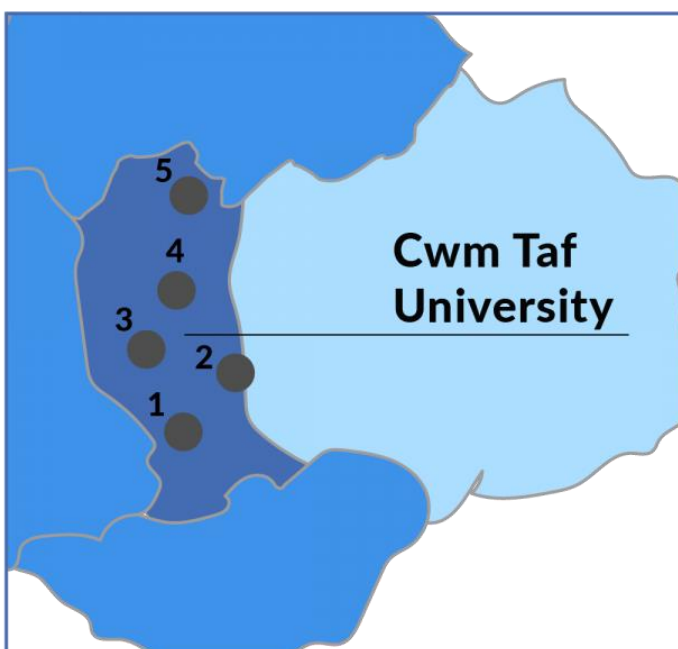
Patients are referred to see a consultant neurologist via their GP. However acute cases are directed through the emergency department.

The ESNs provide a range of specialty clinics, including antenatal and low-grade glioma within the University Hospital of Wales (Cardiff).

### Identified Risks

- There is currently no psychology provision for patients within Cardiff and Vale in line with current NICE guidance which recommends access to this service.
- Cardiff and Vale does not have any other epilepsy hub provision except outpatient treatment and review within Rookwood hospital.
- Providing a widespread open access service without a central coordinator.

### 3.5 Cwm Taf UHB



1. Royal Glamorgan Hospital
2. Pontypridd Cottage Hospital
3. Ysbyty Cwm Rhondda
4. Ysbyty Cwm Cynon
5. Prince Charles Hospital

Cwm Taf University Health Board(CTMUHB) provides services to **300,000** people in Merthyr Tydfil and Rhondda Cynon Taf, using prevalence statistics we can estimate that this equates to 3,000 people with epilepsy.

### Workforce and Service Configuration



A Neurology Services review was undertaken by the Health Board’s Commissioning team in March 2018 which demonstrated significant shortfalls across the range of neurological services.

The neurology service is not provided directly by CTMUHB, a service level agreement (SLA) exists between Cardiff and Vale UHB for patients in the Rhondda Taf Ely and Merthyr Cynon areas. The Bridgend and Maesteg areas receive their neurology services via an SLA with Swansea Bay UHB.

<b>ESN</b>	0 –integrated service with Cardiff
<b>Coordinator</b>	X2 WTE Paediatric - Base Cwm Taf
<b>Consultant</b>	X2 Neurologist (general)

Patients within the CTMUHB population access clinical nurse specialist support from the service within Cardiff. Whilst this service is comprehensive and addresses patient safety, a positive step would be for CTMUHB to commissioning the service locally and support patients to locally access a service in their own locality.

**Identified Risks**

- There are currently no ESNs dedicated to the CTMUHB population, this service is provided by Cardiff and Vale ESNs on a goodwill basis which is unsustainable and serviced by clinics in Cardiff and Swansea Bay ESNs and Neurologists. Some clinics are also provided in Morriston and Neath Port Talbot by SBUHB. This results in a high DNA rate within the clinics as they are not close to the population they serve.
- For the past two years, shortfalls in neurological provision have been highlighted as a risk within the Health Board’s Integrated Medium-Term Plan, but due to competing priorities has not received additional funding.

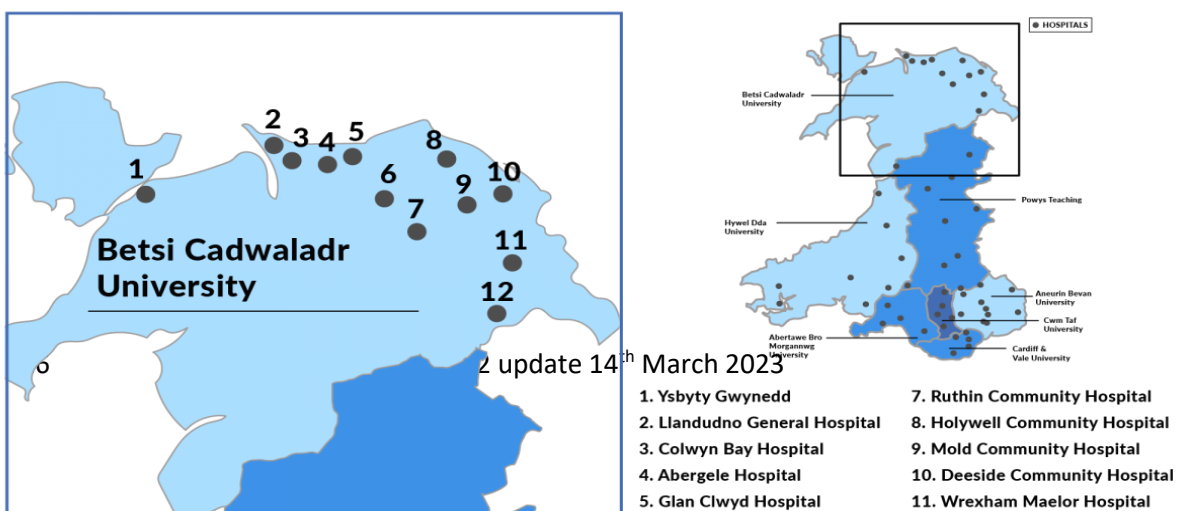
**3.6 Betsi Cadwaladr UHB North Wales**

Betsi Cadwaladr University Health Board is the largest health organisation in Wales, covering Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire, and Wrexham.

With an annual budget of £1.3bn, it serves a population of around **678,000** people and has three main hospitals and several community hospitals.

The number of people within the population with epilepsy is **approximately 5,020**

The health board is made up of 12 hospitals and co-ordinates more than 100 GP practices including dental, optical and pharmacy services.



### Workforce and Service Configuration

The Health Board was put into special measures in 2015. In 2022 extra funding was secured with an improvement team to facilitate and support quality improvement. In February 2023 it was announced that Betsi Cadwaladr University Health Board will be put back into special measures because of serious concerns about performance, leadership, and culture.

The average waiting time for first appointment with a Consultant Neurologist is **currently 26 weeks**.

<b>ESN</b>	X1 WTE Adult X3 Paediatric
<b>Co-ordinator</b>	0
<b>Consultant</b>	X4 Neurologist (x1 Walton Centre / North Wales) X2 Alder Hey

Currently the ESNs do not operate an open access service but share workloads with the neurologist.

A satellite service, including midwifery support is provided by one ESN covering 3 hospitals and a large geographical area.

### Transitional service:

Alder Hey is committed to improving Transition as it is one of the Trust's strategic objectives. There is a Transition Steering Group, a 10 step Transition Plan, a lead transition nurse and lead transition consultant.

To support epilepsy management and treatment there is a monthly transition clinic based at the Walton Centre. This is supported by both an adult neurologist and a paediatric neurologist from Alder Hey. Approximately 60 young people with complex epilepsy are seen as new patients in this clinic per year.

There is currently no nursing provision at this clinic due to paucity of resources within both children and adult epilepsy nursing teams. However not every young person with epilepsy is referred to the Walton clinic as some are referred back to their local adult services and /or GP.

### Identified Risks

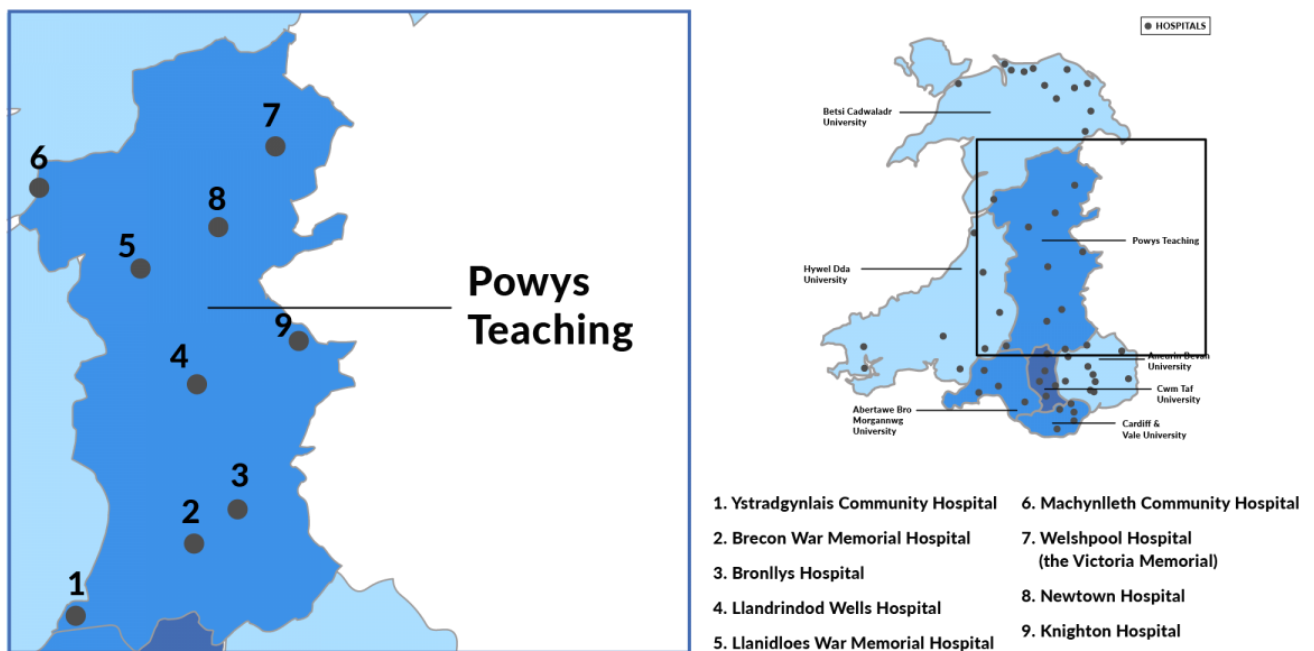
- As the largest health board in Wales, and one covering a rural area, it is of very real concern that there is currently only one adult ESN. This puts an incredible amount of pressure of this individual.

- Patients in this area are facing incredibly long waiting times for Consultant Neurologists.
- Betsi Cadwaladr also relies on the Walton Centre and Alder Hey for a number of services.
- 3 Paediatric ESN’s cover 6 counties in North Wales, this includes support in schools and means they are stretched to provide acute and primary care.

### 3.7 Powys THB

It has been recognised that Powys does not have a dedicated neurology service – these are provided by the neighbouring health boards and includes Aneurin Bevan, Betsi, Swansea Bay and possibly some provided by England.

The health board is responsible for providing services to a population of 133,000 people. From current prevalence statistics, we can estimate that there are around 1,330 people with epilepsy in this area.



### Identified Risks

- With no neurology services people with epilepsy in Powys are reliant on services in neighbouring health boards, including services in England.
- As a rural area, this puts increased pressure on people with epilepsy living within Powys travelling out of the area to access services.

### 4.0 Conclusion and Recommendations

In response to the available information, it is clear that there is inequity in service provision across Wales. It is acknowledged that one model does not always fit all demographics, inequalities, or available resource. However, what the collective intelligence tells us is that action at pace is required to improve the care for people with epilepsy and reduce pressures on both the specialist epilepsy workforce and neurology waiting lists.

We acknowledge that the availability of ESN's and Neurologists is more complex than purely identifying investment, they need to be there to be recruited, particularly within this current climate. This is why we want the focus on having in place widespread adoption of an epilepsy service with a dedicated coordinator role, recognising the positive impact this brings. Adoption of the best practice model 'Open Access' has shown demonstrable.

Access to treatments, services and support helps people living with neurological conditions manage their condition; to identify early signs of complications; and put in place prevention and treatment strategies to avoid unscheduled hospital admissions. However, neurology has historically been an underfunded, low priority service in Wales and all too often, our community has reported substantial barriers to accessing the treatment, services and support that this group of patients need from health and care services.

Epilepsy Action is calling on the Welsh Department of Health to support and influence those Health Boards where there are inequalities in service provision for people with epilepsy, and to learn from existing good practice and to fully implement national guidance (NICE CG 217 (2022)) by:

- Supporting measures to reduce current waiting times for epilepsy services and health professionals in Wales. This can be achieved by ensuring the levels of staffing across the Health Boards of Wales are appropriately resourced to achieve and maintain sustainability, patient safety and quality of service. Based on the recommendations from the Royal College of Physicians and the Association of British Neurologists, which suggested a minimum of 9 ENS per 500,000 population - equivalent to an ENS caseload of approximately 550 patients, this table presents the number of ESNs each health board should have in place.

Health Board	Population with epilepsy	Total number required ESNs	Total number of current ESNs (adults and paediatrics)
<b>Aneurin Bevan</b>	<ul style="list-style-type: none"> <li>• 6000 adults with epilepsy</li> </ul>	11	4.5 (WTE)
<b>Swansea Bay</b>	<ul style="list-style-type: none"> <li>• 6000 adults with epilepsy</li> </ul>	11	4
<b>Hywel Dda</b>	<ul style="list-style-type: none"> <li>• 4500 adults with epilepsy</li> </ul>	8	3
<b>Cardiff</b>	<ul style="list-style-type: none"> <li>• 5000 active patients requiring on going management</li> </ul>	9	4
<b>Cwm Taf</b>	<ul style="list-style-type: none"> <li>• provides services to a total population of 300,000 (no available</li> </ul>	5	0 integrated service with Cardiff

	information about epilepsy population)		
<b>Betsi Cadwaladr</b>	<ul style="list-style-type: none"> <li>approximately 5,020 adults with epilepsy</li> </ul>	9	4
<b>Powys</b>	<ul style="list-style-type: none"> <li>provides services to a total population of 133,000 (no available information about epilepsy population)</li> </ul>	2	No dedicated neurology service

- Implementing the widespread adoption of ‘epilepsy service coordinators’ and the positive impact this role has on epilepsy services to support a best practice model, such as ‘Open Access’; has shown demonstrable improvements in clinical outcomes (reduced emergency admissions), reduction in outpatient attendances and improved patient experience. This approach preserves clinical resources and expedites timely access to services.
- Reviewing the provision of transition services to ensure these are available across all Health Boards and that there are no inequalities in the transition of children and young people into adult services. This reduces patient safety issues and improves clinical outcomes as a long-term condition.

### **Epilepsy Action**

Alison Fuller - Director of Health Improvement & Influencing

Jan Paterson - Wales Services & Project Manager

Daniel Jennings - Senior Policy & Campaigns Officer

### **Consultant Neurologists**

Professor Robert Powell

Dr Owen Pickrell

---