

## Epilepsy Service Provision Wales – Summary

### What Does a Good Model Look Like?

From the findings and assessment of the differing health boards, it has become clear that recruitment to ESN posts and the availability of neurologists with specialist competency in epilepsy is not widespread or invested in.

What has also become apparent from our review is that a service model that is supportive of the patient 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. Patients and service users have a direct link into secondary and primary care services through a co-ordinated triage system.

This model is well established within two of the five health boards which is discussed in detail in 3.0. Whilst the service runs, this is predominantly based on the goodwill, tenacity and enthusiasm of the existing workforce. Additional ESN resource would enhance sustainable quality improvement and patient outcomes.

- Integrated services for the transition of young people into an adult service. The main focus being to ensure that service is 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 continues to work on refinement of an epilepsy data dashboard which will be critical to informing future understanding of epilepsy epidemiology and need.

### Epilepsy services and workforce by Health Board

Health Board	Current Workforce	Good practice	Risks
<b>Aneurin Bevan Health Board</b>	1 Full time adult ESN 2 Part time adult ESNs 4 Part time paediatric ESNs 1 Full Time Co-ordinator 1 Neurologist (1 day/week) 1 Epileptologist	An ‘open access’ epilepsy service is in place. The co-ordinator role is a (fix term) full time health care support worker acting as an epilepsy coordinator.	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.
<b>Swansea Bay University Health Board</b>	2 Full time adult ESNs 2 Full time paediatric ESNs 1 Co-ordinator (80% FTE for epilepsy) 3 Neurologists	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.	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.,

		The epilepsy coordinator runs 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.	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.
<b>Hywel Dda Health Board</b>	1 Full time Adult ESN 2 Part time Adult ESNs 1 Paediatric ESN (Covering 8 hospitals) 2 Neurologists – No epilepsy specialist – general neurology		It has the highest budget overspend of all the Wales health boards Only one nurse allocated to deliver the adult epilepsy service Open clinic with only one nurse and no co-ordinator
<b>Cardiff &amp; Vale University Health Board</b>	3 WTE Adult ESNs 1 WTE Paediatric ESN (covers all 5 hospitals) 2 Neurologists (Adult) 1 Neurologist (paediatric) 4 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.	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.
<b>Cwm Taf Morgannwg Health Board</b>	No ESNs – integrated service with Cardiff 2 WTE Paediatric coordinators - Base Cwm Taf 2 Neurologists (general)		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. 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.
<b>Betsi Cadwaladr University Health Board</b>	1 WTE Adult ESN 3 Paediatric ESNs 4 Neurologist (x1 Walton Centre / North Wales) 2 Consultant Neurologists (Alder Hey)		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.
<b>Powys Teaching Health Board</b>			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.

### 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.

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 ENSs each health board should have in place.

Health Board	Population with epilepsy	Total number required ENSs	Total number of current ENSs
Aneurin Bevan	6000 adults with epilepsy	11	7
Swansea Bay	6000 adults with epilepsy	11	4
Hywel Dda	4500 adults with epilepsy	8	2
Cardiff	5000 active patients requiring on going management	9	4
Cwm Taf	provides services to 300,000	5	0 integrated service with Cardiff
Betsi Cadwaladr	approximately 5,020 adults with epilepsy	9	4
Powys	provides services to 133,000	2	No dedicated neurology service

- Implementing the widespread adoption of ‘epilepsy service coordinators’ and the positive impact this role has on epilepsy services. Adoption of 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 by implementing a co-ordinator role and expediting 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.