

Agenda – Petitions Committee

Meeting Venue:

Committee Room 3 – Senedd

HYBRID

Meeting date: 17 October 2022

Meeting time: 14.00

For further information contact:

Gareth Price – Committee Clerk

0300 200 6565

Petitions@senedd.wales

1 Introductions, apologies, substitutions and declarations of interest

(Pages 1 – 20)

2 New Petitions

2.1 P-06-1291 Hold an enquiry into the corporate takeover of the veterinary profession in Wales

(Pages 21 – 38)

2.2 P-06-1299 Welsh Government 'Freeze on road building" to include a clause for cases that pose a danger to life

(Pages 39 – 42)

2.3 P-06-1300 Review the decision allowing local authorities to increase council tax premiums on second homes to 300%

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2.4 P-06-1302 Protect Mid-Wales' unique Cambrian Mountains: designate them an Area of Outstanding Natural Beauty

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3 Updates to previous petitions

3.1 P-05-1106 Introduce Personal Health Budgets and Personalised Care in Wales

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- 3.2 P-06-1163 Extend the postgraduate STEMM bursary to all MSc students in Wales
(Pages 74 – 75)
- 3.3 P-06-1240 Improve health services for people with epilepsy living in Wales
(Pages 76 – 122)
- 3.4 P-06-1249 Provide a clinical pathway, medical care, and specialists for people with Tourette’s syndrome in Wales
(Pages 123 – 125)
- 3.5 P-06-1276 Extend section 25B of the Nurse Staffing Levels Act (Wales) 2016
(Pages 126 – 130)
- 4 Motion under Standing Order 17.42(ix) to resolve to exclude the public from the remainder of the meeting**
- 5 Forward work programme**

Document is Restricted

P-06-1291: Hold an enquiry into the corporate takeover of the veterinary profession in Wales

Y Pwyllgor Deisebau | 17 October 2022
Petitions Committee | 17 Hydref 2022

Reference: SR22/3596-4

Petition Number: P-06-1291

Petition title: Hold an enquiry into the corporate takeover of the veterinary profession in Wales

Text of petition: In 1999 legislation was changed by the UK Government which allowed veterinary practices to be owned not just by qualified veterinary surgeons. This paved the way for private equity stakeholder corporates to buy into this market.

These profit driven organisations have changed the profession so that it is barely recognisable. In many parts of Wales, it is virtually impossible to find an independently run veterinary practice.

The corporate buyout now extends to out of hours provision, referral practices as well as general practice. The corporates also own laboratories, drug companies, pet crematorium as well as shares in many pets' food companies. Such a monopoly make the few remaining independently run practices presence virtually untenable. From vet school to recruitment through to practice the corporates have the advantage. Set in this context their influence on bodies such as the RCVS and BVA is predictable.

For those of use with companion animals this monopoly has had devastating consequences. From lack of choice in finding an independent practice, seeing the same Veterinary Surgeon for continuity of care trough to cost. But



most of all clinical decisions being made with the policies of the corporate's taking centre stages.

My experience with My Cat Rosa sadly means I will always mistrust some within the profession. Companion animals are part of people's families. Covid, the isolation and mental health issues have made these relationships even more precious. I dread to think (but have been informed) how the animal rescue sectors in Wales copes. Because they must deal with some of the most abuse and clinically challenged animals who have significant and often complex medical needs.

Despite numerous petitions to the UK Government, Department for Environment Food & Rural Affairs etc have failed to take any action whatsoever. Cymru has led the way before on animals and their welfare, so we ask our Senedd to do so again.

1. Background

A change in law relating to the [Veterinary Surgeons Act 1966](#) was introduced in 1999, allowing persons who are not vets to legally own veterinary practices for the first time in the UK. Prior to this, only qualified and licensed veterinarians were able to own practices.

According to the Royal College of Veterinary Surgeons (RCVS), the change in law was as a result of the [Competition Act 1998](#). This Act was a harmonisation with European competition policy as restricting ownership to vets would have been seen as an anti-competitive or a restrictive action. Section 17.14 of the [RCVS Code of Professional Conduct](#) states that veterinary surgeons provide services through a variety of entities, including limited companies and partnerships and may be managed by non-veterinary surgeons. However, the RCVS expects organisations to appoint a senior veterinary surgeon to provide appropriate professional direction.

The majority of veterinary practices in the UK (over 53%, RCVS) are now owned by seven companies. Of the 343 veterinary practice premises in Wales, 151 are owned by seven companies (44%). The [2019 RCVS Survey of the Veterinary Profession](#) found that 40% of respondents work in practices that are part of a corporate or a joint venture with a corporate group. The same survey also found that some respondents were concerned with the rise in corporate ownership, particularly

about the impact on patient care, younger veterinary surgeons' development and support for smaller businesses.

The British Veterinary Association has a neutral view of corporate ownership and welcomes competition and choice for pet owners. Stakeholders say the positives of corporate ownership include improved employee benefits, professional training and access to new graduate schemes. -However they argue this could be offset by restricted clinical choice, delayed decision making and outsourcing of out of hours services.

On 18 February 2022, the Competition and Markets Authority (CMA) found that the purchase of Quality Pet Care by the CVS Group (which owns 467 vet practices in the UK) raised competition concerns in five local areas, in which the combined businesses would provide over 30% of veterinary services. CVS Group ultimately agreed to divest Quality Pet Care, a decision accepted by the CMA on 27 June 2022.

The RCVS Code of Professional Conduct prohibits veterinary surgeons or groups of veterinary surgeons from entering any agreements that may have the effect of fixing fees.

In the Republic of Ireland, the Veterinary Practice (Amendment) Bill 2021 is currently at the Third Stage in the Houses of Oireachtas. The purpose of the Bill is to amend the Veterinary Practice Act 2005 to prohibit the ownership of veterinary practices by persons other than those persons who are veterinary practitioners and to provide for related matters. The Bill was considered by the Select Committee on Agriculture, Food and the Marine, which recommended it proceed to Third Stage consideration.

2. Welsh Government action

The Minister for Rural Affairs and North Wales, and Trefnydd's ('The Minister') letter on this petition states the provision of veterinary services in Wales remains a non-devolved issue and as such is unable to comment or engage with the matter. The Minister said:

[The petitioners] comments regarding general standards of care and charging are a matter of some concern as I feel strongly that the same professional standards should be expected of all vets who practice and

offer services to the public, regardless of the model of ownership and operation.

3. Senedd action

On 17 March 2022, during Ministerial scrutiny, the Senedd's Economy, Trade and Rural Affairs Committee raised concerns regarding private, large veterinary companies buying up smaller vets practices in rural areas and not being able to offer full provision of vet services.

In response to the question of whether the Minister was aware of this or whether it was an isolated incident, Dr Christianne Glossop, the Chief Veterinary Officer for Wales, replied:

Of course, veterinary practices are commercial businesses and they're going to make their own commercial decisions, but there has been a trend over the last few years of large corporate practices being established, and, indeed buying some of the independent practices. [...] We are watching it carefully. Obviously in itself it doesn't have to be a bad thing. So, as long as the services that we need to be provided are still being provided to the right standard, then it is a matter for the veterinary profession to make its own judgement on that. The Royal College of Veterinary Surgeons sets the standards, so it's not a question of standards being diminished, although certainly, I've been seeing this happening – for example, practices now quite often don't offer the 24-hour cover; there are night services. So, if you're trying to get your dog or cat seen out of hours, you might find yourself having to go to an alternative practice. So, that's an issue. But in terms of provision for the services that we need vets to provide, that's still happening across Wales, but it is something that we are watching very carefully.

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

Lesley Griffiths AS/MS
Y Gweinidog Materion Gwledig a Gogledd Cymru, a'r Trefnydd
Minister for Rural Affairs and North Wales, and Trefnydd



Llywodraeth Cymru
Welsh Government

Eich cyf/Your ref P-06-1291
Ein cyf/Our ref LG/00455/22
Jack Sargeant MS
Chair - Petitions Committee
Senedd Cymru
Cardiff Bay
Cardiff
CF99 1SN

08 Sep.2022

Dear Jack,

Thank you for your letter of 3 August, regarding '**Petition P-06-1291: Hold an enquiry into the corporate takeover of the veterinary profession in Wales**', as originally raised by Dr Linda Evelyn Joyce-Jones.

Dr Joyce-Jones' comments regarding general standards of care and charging are a matter of some concern as I feel strongly that the same professional standards should be expected of all vets who practice and offer services to the public, regardless of the model of ownership and operation.

While, therefore, I may sympathise with the points contained within the petition, I very much regret having to advise that I am prevented from commenting or engaging in this matter as the provision of veterinary services in Wales remains a non-devolved issue, which lies beyond the remit and responsibility of the Welsh Government. In such circumstances, all concerns regarding standards in the corporate sector can only be addressed to the Royal College of Surgeons for further consideration.

I fully appreciate this is unlikely to have been the response Dr Joyce-Jones had hoped to receive. Despite having sent numerous petitions to the UK Government's Department for the Environment and Rural Affairs previously, I am afraid it remains the only avenue open in trying to address this matter.

Yours sincerely,

Lesley Griffiths AS/MS
Y Gweinidog Materion Gwledig a Gogledd Cymru, a'r Trefnydd
Minister for Rural Affairs and North Wales, and Trefnydd

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

P-06-1291 Hold an enquiry into the corporate takeover of the veterinary profession in Wales, Correspondence – CatsMatter to Committee, 23.09.22

Why the corporate take over of veterinary practices is bad for animals and their owners

By CatsMatter

The rule changes in 1999 allowed the non-vet ownership of veterinary practices. It was a move that triggered exponential growth in corporate ownership. This was an opportunity of course, but a financially beneficial opportunity, not an opportunity to maintain or grow animal welfare standards.

While independent veterinary practices accounted for 89% of the UK industry in 2013, this share had fallen to less than half (45%) by 2021, primarily because of independent practices being bought by corporate groups. Less than half of the practices in the UK are now independently owned after practices have sold to corporate giants. Corporates have a variety of business structures and 'reward' the owners for selling up, but ultimately end up controlling the practices pricing, hours worked and targets. Reportedly, some practices had been approached almost monthly with a buyout offer. It's reported that they are made offers that they simply could not refuse and are paid very handsomely. Well beyond what would be affordable or sensible for younger vets within the practice to buy into. The business model is usually a roll-up model, where a medium-sized corporate buys up practices across the country with the aim of eventually selling them on to a bigger company at a higher price after having hit.

Corporates outsize influence on many parts of the veterinary economy, which is impacting the profession in many ways. At least half of the groups owning more than 15 practices have private-equity firm (PE) investment, money from funds and investors that are used to directly invest or buyout companies. These individuals or investors have money they want to grow, but are looking for an alternative to stocks, bonds, real estate, etc. PE firms have a short-term horizon and are often looking to buy businesses, improve them with investments in needed equipment, improve their operations, and increase their net profit margin. The goal is to maximize the return on that initial investment so that they can re-sell the business for a profit within 5 to 7 years. I wish to remind you here that we are not talking about stock markets, we are talking about veterinary practices that deal with the lives and wellbeing of sentient beings. Not to mention their owners, who are often innocently unaware of who owns the practice.

Because private equity exists specifically to maximize return on investment, it is clear how there would be a conflict between patients' best interest and profit margin. To maximise return to investors, this can be achieved either by paying less per person or having fewer employees, among cost saving on pharmaceuticals or equipment, and of course higher prices for the pet owner. A [study](#) presented at the International Veterinary Emergency and Critical Care Symposium (IVECCS) demonstrated a direct link between increasing adverse events and a lower number of veterinary technicians in intensive care units (ICUs). Highlighting how this is now affecting patient care. What we are witnessing now is much higher prices for much lower quality services. This should not be accepted in the veterinary sector when animals' wellbeing and lives are at stake, and people are forced to make heart breaking decisions due to struggling with the untimely extortionate financial burden placed on them. People are not attempting to pay for a new TV or latest iPhone, they are faced with impossible costs to save the lives of their beloved companions who are family to them. In some cases, all that person has. We are an organisation that deals with road traffic accidents involving cats, and we have seen first-hand the severe deterioration of mental wellbeing in people

that have been directly affected by this, either through extortionate out of hours costs, or fees people are just not able to pay. We have known cats to be euthanised with very minor cuts and bruises following a road accident also because no microchip could be located. No microchip means no one locatable to pay for veterinary services. Euthanasia is perhaps an easy and more financially beneficial option for some over pain relief and/or treatment. This now profit driven business is costing animals their lives unnecessarily and causing distress among veterinarians who got into that line of work simply to help the animals they love. Intervention and meaningful action must be taken now before the opportunity is lost and the sector irreparably damaged.

P-06-1291 Hold an enquiry into the corporate takeover of the veterinary profession in Wales, Correspondence – Anonymous Veterinary Surgeon to Committee, 27.08.22

Dear Linda,

Further to your request for [REDACTED] comment on [REDACTED] experiences as, [REDACTED] an independent practice owner competing with the veterinary corporates, [REDACTED] a clinical director within one of the main corporates, and [REDACTED] an independent veterinary surgeon [REDACTED], I have put together these notes. I must point out that, [REDACTED] all clinical directors within corporates are required to sign a Non Disclosure Agreement as part of their employment, I cannot detail any internal policies that have not been made public and I also don't wish to make this a purely personal account of the impact of veterinary corporates but, rather, to highlight the issues that having entities with so much power and wealth is having within our industry. I will, therefore, be avoiding recounting any personal stories.

So what are the major issues that I feel are of a negative impact on our profession from having such large entities now controlling so many practices?

The main impact on the industry is really one of competition, or the restriction thereof. Having so much power and so many sites throughout the UK is creating a monopoly for the corporates over the supply of medications, goods and services. Their buying power is now so great that the peripheral industries that supply our profession are being held to ransom. Pharmaceutical companies are giving massive discounts, though these are rarely passed on to the consumer as most pricing is based on net cost calculations, not net-net. The enticement being that the corporate will add their products to the preferred supplier lists, a list that, nominally, you don't have to follow but, in reality, such a choice is actively discouraged. Indeed, some products are often blacklisted, presumably because their producer refuses to accept the terms of the corporates and put such discounts in place. This is not only true of medications. It's also true of peripheral organisations such as waste disposal, cremation services, laboratories, equipment suppliers, equipment repair services, online pharmacies, IT and software provision, electrical testing, telemedicine providers, health & safety consultants, direct debit suppliers, out of hours hospital services...essentially every service that provides the industry is now under pressure to greatly reduce prices to the corporates for their continued usage. If they get onto the list they have the ability to make greatly increased sales, but failing to do so is likely to result in their exclusion from much of the market and put their viability in jeopardy. But what does this mean for the independent practices that still exist? Well, their costs have sharply risen as a result. Nobody is aware of the real discounts the corporates receive, not even the clinical directors within each practice, because these are kept very much private, but the published net cost of services and goods, that independent practices have to pay, have risen well ahead of even today's inflation rates. It can only be assumed that the independent practices are now subsidising the corporate discounts. Additionally, having bought over the bulk of practices in the UK, the corporates have started to move onto buying up these additional service companies. Many of them now own their own distributors, laboratories, online pharmacies, direct debit providers, cremation companies, pharmaceutical and nutraceutical suppliers etc etc, and those they don't own, that are allowed to remain on the preferred suppliers list, are further pressurised over their pricing by the threat that the corporate will invest into its own purchased entity to push them out of the

market. So the discounts increase, pushing up the net cost to independents and the subsidising continues. In short, while having multiple corporates gives the illusion of competition, the way they pressurise the veterinary submarket providers is creating an unfair monopoly on supplies.

Two markets have changed dramatically, the first being the pharmaceutical industries, who must now compete with each other by offering massive discounts and the promise of uninterrupted supplies for their corporate partners. How this is impacting the profit remaining for research and development of new products, in addition to pushing up independent practice net costs, is for someone within that industry to comment on, but I would very much encourage you to ask them. It also seems to be having a knock on effect of an ever reducing number of drugs being available. Products that don't make it onto at least one corporates list have little financial benefit to the pharmaceutical producer and that seems to be resulting in an increased culling of older and less commonly used products, often with no direct replacement available. Again, something for the pharmaceutical companies to answer as to whether their changing relationship with the corporate buyer is resulting in this loss of choice. The pharmaceutical industry has also punished independent practices in the recent vaccination shortages for both dogs and cats, making sure the corporate sites receive supplies by ring fencing available stock for them, and leaving independent practices with no supplies for months on end.

The second market seeing an effect is the pet food market. It's no secret that the Linnaeus Group is owned by the Mars family, and IVC Evidensia is heavily backed by Nestlé, which is resulting in a great reduction in choice for the consumer when it comes to pet food diets, specifically for prescription diets that can only be bought from their vet, and which the sub-brands of both companies provide. As you would expect, the corporates receive these food at greatly reduced cost, and very much push for their usage in practice over their competitors. Much like the pharmaceuticals, the amount of choice left for the veterinarian and, therefore, the client, is ever decreasing.

The next area of concern is in veterinary manpower, which is a complex issue. Essentially, the corporates have a massive advantage in the recruitment of new graduates but they are contributing, in my opinion, greatly to the lack of ability to retain trained staff within the profession. In terms of recruitment, corporate sponsorship within veterinary schools of lectures, events and student organisations, as well as the provision of under graduate bursaries, creates visibility to the recruitment of new graduates that no independent practice can hope to match. They also offer "graduate academies" which are elongated block release courses where newly qualified graduates receive additional training, and the salaries of these new graduates are not put against the individual corporate practice's balance sheet for much of the initial employment year. Now, this could be seen as a good thing for the graduates, but it also creates a near inability for any independent practice to match them. The contents of these graduate academies teachings also raise some concern. This is purely personal opinion, but the concentration on university/referral level "gold standard" practice is creating the ever increasing bills that clients now face. It will be argued, by its proponents, that "gold standard" is better medicine. However, the reality, again in my personal opinion, is that simple cases end up being excessively worked up, receiving set protocols of laboratory and diagnostic tests that are often not necessary, and just add to the wedge, that is the excessive cost of treatment, that the profession is placing between the clinician and the animal owners. If you teach this to new graduates that know no better, and tell them that any other way is inferior, then you create an entire generation of veterinarians who are comfortable with charging far more than their predecessors. You can take that consequence of the graduate academies as you wish, but it then leads us to the second part of the manpower issue. That of retention of veterinary staff, both vets and nurses, within our profession. We are a profession that is on its knees as a result of losses during

COVID and Brexit (approximately 25% of UK vets were EU nationals pre Brexit), and the dissatisfaction within the profession is ever growing. We are now at a point where surveys have shown that the average veterinary graduate stays in full time employment for just over 4 years. That's one year less than they trained for! And why is their such a move to abandon the profession en masse? As well as the intensity of working hours and the constant emotional turmoil, which have always been part of the vocation, we now have a gargantuan rise in pricing. It's a combination of medicinal supplies increasing (those net-net savings never reaching the consumer), a focus on expensive standard operating protocols, the massive increase in emergency fees (the UK's largest out of hours provider, Vets Now, is wholly owned by IVC Evidensia), and the push from corporate internal "pricing gurus" for ever higher service fees, both consultations and surgical pricing. Independent practices are not free from all of these either. They are paying far more, as outlined above, for their own supplies and the average transaction fee is ever increasing as a result, as they can't afford to absorb the rise without passing it on to the consumer. They are also entirely at the mercy of the Vets Now fee structure if they wish to maintain a separate out of hours supplier rather than covering all of their own on call work. And it is the frontline staff; the vets, nurses and receptionists, that take the brunt of the client's anger and complaints on a daily basis. These massive rises don't just make for increased profits, they are damaging the mental health of the frontline staff who have to defend them, and they are resulting in ever more clients failing to seek help for their pets at an early juncture. Much of the assumption from the pricing "gurus" is that the insurance companies would meet these increasing fees, but the insurance industry's appetite for pet insurance has been on the wane since the banking crisis 12 years ago, and premiums and policy restrictions are increasing at such an exponential rate that most owners simply cannot afford the insurance now.

The last concern I have is the amount of influence that the corporates have within the governing and political bodies of our industry. The main representative body for veterinarians, the British Veterinary Association, and the veterinary nurse equivalent, the British Veterinary Nurse Association, now receive the majority of their membership fees from the veterinary corporates. Most corporates pay their employee's membership fees regardless of whether they wish to be members or not. A nice perk on the surface, but this means a small number of corporate groups finance the majority of both organisations, organisations that are meant to give their members legal advice in regards to disputes with their employers. The BVA also receives corporate sponsorship from the Mars group, nominally for research, which, as mentioned above, also owns the Linnaeus Group. What form that sponsorship takes, I have little information on, but it seems a potentially unwise conflict of interest.

██████████ the Royal College of Veterinary Surgeons, also holds meetings with the Major Employers Group, a group that represents the corporate employers, along with some of the larger charities employing veterinary professionals such as the Blue Cross and PDSA. There have been repeated calls for minutes of these meetings to be made public, as they are for many of the other RCVS committee meetings, but they have never been forthcoming. For commercial groups to hold this much potential political sway over the profession they have bought their way into, without the ability for members of the profession to transparently see what influence they have, or do not have, on policy decisions cannot, surely, be seen as healthy.

I hope this is of some use to you in your continued investigations into the role veterinary corporations play in the profession.

P-06-1291 Hold an enquiry into the corporate takeover of the veterinary profession in Wales, Correspondence – Petitioner to Committee, 09.10.22

Petition P-06-1291

To the Chair and Members of The Petitions Committee of Senedd Cymru.

Thank you for having this petition as an agenda item.

The Minister's correspondence of 8/9/22

I would like to thank Lesley Griffiths MS the Minister for Rural Affairs and North Wales for her response.

It's interesting to note that Lesley is aware of several petitions on this issue that our Welsh Government has had to send to DEFRA and the UK Government.

I am also pleased to hear Lesley putting on the record her view that the same professional standards should be expected irrespective of who owns a veterinary practice.

The Minister is correct in her assertion that the Royal College of Veterinary Surgeons - RCVS is seen as the regulator of such matters. But the RCVS has already made clear to our Petitions Committee previously their stance on this **1**.

It is clear that this matter has been raised numerous times with the UK Government and DEFRA over a considerable amount of time. But they have chosen to take no action.

In a letter to me of 3/3/2022 the former Minister Sir Zac Goldsmith informed me " we have not taken a view on the ownership model of veterinary practices" **2** .

Meanwhile our Senedd and Welsh Government have made great progress in animal welfare. I know you and many other Senedd Cymru Members will not find it acceptable that this issue isn't a devolved matter . Especially when it's clear the UK Government show no appetite in acting.

The Competition Marketing Authority - CMA have in the past year chosen to halt the acquisition of two veterinary groups by different corporate stakeholder companies. But the CMA's remit is very limited and does not encompass animal welfare. The CMA have chosen never to take action against one of the biggest corporate stakeholder companies who also hold the largest interest in out of hours provision, Independent Vetcare Evidensia. In 2011 Independent Vetcare Evidensia owned and operated eleven veterinary practice's in the UK to date they run over 1,500 veterinary practices.

In a recent Senedd Cymru committee meeting chaired by Paul Davies MS. The Chief Veterinary Officer for Wales stated she was "monitoring this situation very closely".

It is very clear in my book and many others too that those that should be acting on these serious issues are failing to do so. Not only that but have failed to do so continually since legislation was changed in 1999.

I would like to commend the submission of a veterinary surgeon that has also been submitted to Members of the Committee. As I think this explains the situation far better than I can from someone who works within the profession. I pay tribute to this veterinary surgeon for doing this .

Next Steps.

I was very grateful to Joel James MS and Carolyn Thomas MS for meeting with me last week . I think it is fair to say they were very surprised to learn the details of how rapidly this corporate takeover has happened. I also shared with them my intention with others to open a Community Interest Group run Mobile Veterinary Practice here on Ynys Môn **3**. To finance this I have taken out an equity release agreement on my home . I simply cannot let matters stay the way they are especially here on the Island. Where we now have no remaining Independently run veterinary practice's.

1: I would like to meet with your Chair Jack Sargeant MS to explain to him further the situation as I know how committed to animal welfare Jack is .

2: I would like a meeting with the Minister Lesley Griffiths MS with my constituency MS Rhun ap Iorworth in attendance too as I know Rhun shares my concerns .

3: I would like this matter referred to the Companion Animal Welfare Group Wales- CAWWG and the Senedd Cymru's Animal Welfare Group chaired by Carolyn Thomas MS.

4: I would like to know from the CMA the reasons they have chosen never to challenge Independent Vetcare Evidensia.

Thank you for your time and attention and as ever if I can assist the Committee further I will try my best to do so .

Cofion Cynnes Dr Linda Joyce-Jones. Ynys Môn 9/10/22.

20.07.20 Correspondence - Ro...



Mrs Janet Finch-Saunders
By email: petitions@senedd.wales

Ref: Exec Office/P-05-895
E-mail: b.myring@rcvs.org.uk
Website: www.rcvs.org.uk

20 July 2020

Dear Mrs Finch-Saunders,

Re: P-05-895 Correspondence from the Chair of the Petitions Committee

Thank you for the opportunity to comment on the Petition P-05-895, proposing a scheme to help people access veterinary care for their companion animals.

The Royal College of Veterinary Surgeons (RCVS) is the regulator of veterinary surgeons and veterinary nurses in the United Kingdom, with responsibility for setting and upholding standards of conduct and education. The RCVS has no specific jurisdiction under the Veterinary Surgeons Act 1966 over the level of fees charged by veterinary practices. There are no statutory charges and fees are essentially a matter for negotiation between veterinary surgeon and client. Nor is the RCVS responsible for regulating the ownership of veterinary businesses, including questions of individual or corporate ownership. These are matters for the Competition and Markets Authority and, where appropriate, the courts. Therefore, questions of whether the UK or devolved governments should provide additional financial support to animal owners fall outside of our purview and it is not appropriate for us comment on the petition.

We note that the petitioner states, in their separate comments, that *"the setting of fees by private veterinary practice's is a business decision. But this is a matter the RCVS (Royal College of Veterinary Surgeons) as the body who claims to regulate the profession in the UK can act on if they choose to do so"*. However, this is not the case; we have no powers under the Veterinary Surgeons Act 1996 or our Royal Charter to set fees.

The petitioner mentions our 'under care' review and expresses concerns that the appropriate authorities will not be consulted. We would like to note that the under care review is not directly related to veterinary fees, and that it will include an open consultation that any stakeholder may respond to.

I hope that this response has been useful; please let me know if there are any areas in which we can provide clarification.

Yours sincerely

Mandisa Greene

President, Royal College of Veterinary Surgeons



Department
for Environment
Food & Rural Affairs



Foreign, Commonwealth
& Development Office

The Rt Hon the Lord Goldsmith of Richmond Park
Minister of State

Dr Linda Joyce-Jones

Our ref: PO2022/04258/DT

lindabach@btinternet.com

3 March 2022

Dear Linda,

Thank you for your email of 7 December 2021 about mergers within the veterinary profession. I apologise for the delay in responding.

I appreciate the concerns that you have raised. Unfortunately, the pressure on my diary is significant and I am sorry it will not be possible for me to meet with you both. However, I understand that you feel strongly about this, and I do hope you both find this response helpful. As a Government, we believe high standards of animal welfare are hallmarks of a civilized society, but we have not taken a view on the ownership model for veterinary practices.

I should like to clarify that veterinary practices are private businesses and neither Defra nor the Royal College of Veterinary Surgeons (RCVS) intervene concerning the level of fees nor the models of ownership. Fees are set by the market through agreement between the vet and their clients.

An exception is if individual vets charged prices that were so disproportionate, they amounted to disgraceful professional conduct, then the RCVS could intervene. For background, may I refer you to the RCVS' Code of Conduct for veterinary surgeons, found here:

<https://www.rcvs.org.uk/setting-standards/advice-and-guidance/code-of-professional-conduct-for-veterinary-surgeons/supporting-guidance/practice-information-and-fees/>.

We are continually in touch with the Competition and Markets Authority (CMA) and other groups such as the RCVS on this matter. As you have correctly identified, it is for the CMA to investigate possible irregularities affecting business competition. As I am sure you would appreciate, the CMA does not divulge the details of any pending or active investigations as this could compromise the success of an investigation.

As you are looking into whether an investigation is being launched into mergers within the veterinary profession in Wales and the United Kingdom more widely and whether the CMA is looking at this matter, please see the link below for details:

<https://www.gov.uk/government/organisations/competition-and-markets-authority>.



Please also find CMA's contact details as below:

Competition and Markets Authority
The Cabot
25 Cabot Square
London
E14 4QZ
United Kingdom

Email: general.enquiries@cma.gov.uk

Telephone: 020 3738 6000

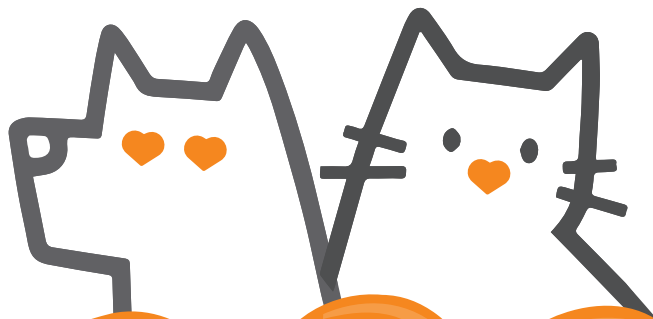
Thank you once again for taking the time to contact me about this important issue. Please let me know if I can be of any further assistance with this or any other matters in the future.

With best wishes,



THE RT HON THE LORD GOLDSMITH OF RICHMOND PARK

Gofalu Am Eich Teulu Yn Eu Cartref

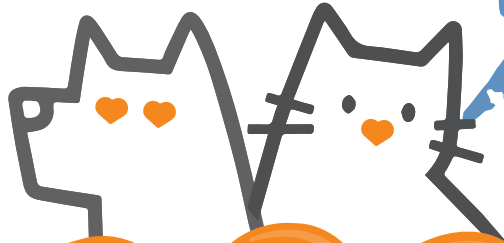


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P-06-1299 Welsh Government 'Freeze on road building" to include a clause for cases that pose a danger to life.

Y Pwyllgor Deisebau | 17 Hydref 2020
Petitions Committee | 17 October 2020

Reference: SR22/3945

Petition Number: P-06-1299

Petition title: Welsh Government 'Freeze on road building" to include a clause for cases that pose a danger to life.

Text of petition: The recent fire at Tylorstown Working Mens' Club proved that the infrastructure in the Rhondda Fach needs urgent updating. With the main road blocked for several days, all traffic was diverted through side streets causing blockages and congestion. Schools had to be shut, public transport halted, school transport cancelled, people were unable to get to work and there was no accessible route for emergency vehicles.

The relief road from Tylorstown to Maerdy has been in the Local Authority's Local Development Plan for years, it's time the people of the Fach see some swift action. This can't happen with the Welsh Government's "freeze" on new roads as stands.



1. Background

In June 2021 the Deputy Minister for Climate Change announced a “roads review” in Plenary. He highlighted that 17% of Welsh greenhouse gas emissions are from transport, and said he was establishing a panel of “some of the UK's leading experts on transport and climate change” which would:

...consider setting tests for when new roads are the right solutions for transport problems, in line with the new Wales transport strategy. And I want the review to consider how we can shift spending towards better maintaining our existing roads, rather than building new ones, as was recommended by the cross-party Economy, Infrastructure and Skills Committee in the last Senedd.

He drew attention to modal shift targets set out in Llwybr Newydd – the Wales Transport Strategy (WTS) – which require 45% of Welsh journeys to be made by sustainable modes by 2045. He said:

To achieve these targets we need a shift away from spending money on projects that encourage more people to drive, and invest in real alternatives that give people a meaningful choice.

Details of the panel were announced in September 2021. In February 2022 a statement by the Deputy Minister confirmed that the panel had submitted an interim report, and that 55 schemes would be looked at in more detail. These would “provide a basis for the panel to provide future looking recommendations on road building in Wales”.

Details, including the panel's terms of reference and the list of schemes reviewed, are published on the Welsh Government website. The panel's terms of reference page identifies five areas which will be “the priority and focus for road investment” in future “in accordance with the WTS”. These include:

investment which maintains the safety and serviceability of the existing road network in compliance with statutory duties.

On 21 September 2022 the Deputy Minister made a statement to say the panel has submitted its final report, with findings on the 55 schemes and “recommendations and tests on the conditions where building new roads is the right thing to do”.

The Deputy Minister said he would consider the report, and publish it with a Welsh Government response “later in the autumn”.

2. Welsh Government response to the petition

The Deputy Minister’s letter to the Chair highlights, as discussed above, that the terms of reference for the panel includes reference to safety as a future focus for road investment.

He reiterates that the response to the report will be announced once the Welsh Government has considered the recommendations.

3. Welsh Parliament action

The roads review has been discussed extensively in the Senedd since it was announced. Discussion has focused on a wide range of areas, including safety. For example in [Plenary in June 2021](#), Paul Davies MS asked the First Minister about safety considerations in relation to diversion of the road at Newgale to mitigate flood risk. The First Minister explained:

The fact we have a roads review does not mean that where there are clear safety considerations, for example, that investment in new road facilities will not go ahead. It’s simply that the bar has to be higher than it was in the past to make a new road the answer to a problem.

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

Lee Waters AS/MS
Y Dirprwy Weinidog Newid Hinsawdd
Deputy Minister for Climate Change



Llywodraeth Cymru
Welsh Government

Eich cyf/Your ref Petition P-06-1299
Ein cyf/Our ref LW/01865/22

Jack Sargeant MS
Chair - Petitions committee

03 October 2022

Dear Jack,

Thank you for your letter of 6 September regarding Petition P-06-1299 Welsh Government 'Freeze on road building" to include a clause for cases that pose a danger to life.

The Terms of Reference (ToR) for the Roads Review Panel can be viewed on our website at [Terms of reference: Roads Review Panel | GOV.WALES](#)

As noted in the ToR, in future and in accordance with the Wales Transport Strategy, one of the priorities and focus for road investment will be on:

- investment which maintains the safety and serviceability of the existing road network in compliance with statutory duties.

Officials have now begun the process of considering the Panel's Final Report. Welsh Government will consider the Panel's advice to inform decision making on the 55 schemes the Panel provide specific advice on, plus the future of road investment, in the following months. We will announce our response to the report once that process is complete.

Yours sincerely,

Lee Waters AS/MS
Y Dirprwy Weinidog Newid Hinsawdd
Deputy Minister for Climate Change

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

Petition: Review the decision allowing local authorities to increase council tax premiums on second homes to 300%

Y Pwyllgor Deisebau | 17 Hydref 2022

Reference: SR22/3945-1

Petition Number: P-06-1300

Petition title: Review the decision allowing local authorities to increase council tax premiums on second homes to 300%

Text of petition: I'm concerned that the significant contribution second homeowners make to the local economy have not been fully considered and explored in relation to this policy. Whilst appreciating that there is a challenge to ensure that there is affordable housing for local people, placing such a financial burden on second homeowners is not the answer.

As second homeowners who spend every weekend in our second home, we feel part of the community and have been warmly welcomed.

More details

We spend our money locally when we visit, including employing local people to build our home. The amount second homeowners contribute cannot be underestimated.

Many second homeowners weren't aware of the Welsh Government consultation ending in November 2021 and therefore feel our voices and concerns have not been heard.



1. Background

The term “second home” is commonly used to refer to a property which isn’t a person’s main residence but is used occasionally by the owner, their family and friends. For council tax purposes, [Section 12B of the Local Government Finance Act 1992](#) (“the 1992 Act”), refers not to second homes but instead to dwellings occupied periodically. To meet this definition there are two conditions that must be met: there must be no permanent resident of the dwelling and the dwelling must be substantially furnished.

There’s not always a clear distinction between second homes retained for personal use and those used occasionally or regularly for short-term lets. Sometimes the term “holiday homes” is used to cover both types of property. Where a property is used to provide self-catering accommodation for short-term lets, it may be registered for business (non-domestic) rates if it meets certain criteria. If it is registered for business rates, it will not be subject to a council tax premium.

As of January 2022, there were 23,974 second homes in Wales, according to [council tax data](#). Second homes are distributed unevenly across Wales, making up a relatively high concentration of the housing stock in areas popular with holidaymakers, such as Gwynedd, Anglesey and Pembrokeshire.

Campaigners argue that the spread of second homes is [contributing greatly to the housing crisis](#) experienced in rural and coastal areas, as the buying up of secondary properties limits local housing stock. Concerns have also been raised around the effects of second homeownership on community sustainability, as local people may be priced out of their communities and [local businesses and services](#) forced to close due to loss of regular revenue. The popularity of second homes in largely Welsh-speaking areas has also led to fears around the [survival of the Welsh language](#) in its traditional heartlands.

However, the issue of second homes is complex. [Stakeholders in the tourism and hospitality sectors](#) point to the importance of second homes to maintaining the visitor economy in West and North-West Wales. [Others have cautioned](#) against treating the above problems as being caused solely by second homeownership, arguing instead that greater research should be carried out before legislation is passed.

The Welsh Government pledged to tackle the second homes issue in Wales as part of its [2021 Co-operation Agreement](#) with Plaid Cymru.

2. Welsh Government action

In March 2021, Dr Simon Brooks published a report, [Second homes: developing new policies in Wales](#). The Welsh Government had asked Dr Brooks to look at policy issues regarding second homes. One of Dr Brooks' recommendations was that local authorities that consider second homes to be a "serious social problem" should charge the maximum council tax premium.

In July 2021, the Minister for Climate Change announced that the Welsh Government would adopt a ['three-pronged' approach](#) to addressing second homes. This would focus on housing supply, taxation and planning reform.

The *Housing Act (Wales) 2014* ("the 2014 Act") permitted local authorities to [charge a council tax](#) premium of up to 100% on second homes, with the measure taking effect on 1 April 2017. In March 2022, following a [consultation](#), the Welsh Government made the [Council Tax \(Long-term Empty Dwellings and Dwellings Occupied Periodically\) \(Wales\) Regulations 2022](#), which increased the maximum possible premium charged on second homes to 300%. This comes into effect on 1 April 2023. A summary of consultation responses can be viewed [here](#).

Local authorities can determine whether to charge a premium and also set the level of the premium. Of the nine councils currently charging a premium on second homes, only [three are charging the full 100%](#) for the 2022-23 tax year: Gwynedd, Pembrokeshire and Swansea.

The increase in the maximum council tax premium was accompanied by [complementary legislation](#) increasing the number of days that a property must be let out in order to qualify for business rates. The Minister for Finance and Local Government [stated](#) that this accompanying measure is designed to ensure that business rates are applied only to 'genuine businesses which are making a more substantial contribution to the local economy than the existing criteria require' and thus deter second homeowners from simply registering their properties as short-term lets to avoid the new premium.

The Minister for Finance and Local Government has written to the Chair of the Petitions Committee in response to this petition. In her letter, the Minister outlined the opportunities stakeholders had received to contribute to the

consultation process on tax reform. She also stressed that the decision to charge the full 300% premium was entirely down to individual local authorities.

3. Welsh Parliament action

The Local Government and Housing Committee [met with stakeholders](#) on 9 March 2022 as part of their inquiry into the Welsh Government's ongoing action on second homes. The 300% premium was a key issue discussed.

Following their enquiry, the Committee produced a [report](#) assessing the Welsh Government's response to the second homes issue and the body of evidence available to policymakers. This report was published in June 2022 and [debated in plenary](#) on 5 October.

The *Council Tax (Long-term Empty Dwellings and Dwellings Occupied Periodically) (Wales) Regulations 2022* were [debated](#) and agreed by the Senedd on 22 March.

The scrutiny report on the regulations produced by the Legislation, Justice and Constitution Committee can be viewed [here](#).

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.



Eich cyf/Your ref: P-06-1300
Ein cyf/Our ref: RE/00727/22

Jack Sargeant MS
Chair – Petitions Committee
Senedd Cymru
Cardiff Bay
Cardiff
CF99 1SN

21 September 2022

Dear Jack,

Thank you for your letter regarding ‘Petition P-06-1300 Review the decision allowing local authorities to increase council tax premiums on second homes to 300%’.

Ensuring that local people can live affordably in the communities in which they grew up, and the health and vitality of Welsh as a thriving community language, are key priorities for the Welsh Government.

We recognise second home owners can make an important contribution to our local economies, and in Wales we cherish our reputation as a welcoming society. However, we want to ensure that all homeowners and businesses make a fair contribution to the communities in which they own or let property. That is why we consulted on possible changes to local taxes for second homes and self-catering accommodation, as one part of the Welsh Government’s [three-pronged approach](#) to address issues of affordability and the impact large numbers of second homes and holiday lets can have on communities and the Welsh language.

Views on the policy behind these plans were invited as part of a 12-week [consultation](#) which looked at local taxes for second homes and self-catering accommodation. The consultation was open from 25 August to 17 November 2021 and received almost 1,000 responses. A summary of responses was published on 1 March.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

When formulating this policy, a range of evidence was considered including the consultation responses. After careful consideration of the evidence, the Council Tax (Long-term Empty Dwellings and Dwellings Occupied Periodically) (Wales) Regulations 2022 were made. They increase the maximum level at which local authorities can choose to set council tax premiums on second homes and long-term empty properties to 300%. This will be effective from 1 April 2023.

To accompany the Regulations, an [Explanatory Memorandum](#) was required. Part 2 of this document is the Regulatory Impact Assessment (RIA) of the Regulations. RIAs are an integral part of the policy-making and legislative process. RIAs provide Welsh Ministers, the Accounting Officer, Senedd Cymru and stakeholders with information on the likely impact of proposed legislation.

This legislation was subject to scrutiny and debate and approved through the affirmative procedure in the Senedd on 22 March. The scrutiny report of the Legislation, Justice and Constitution Committee on the Regulations is available at: [cr-ld15017-e.pdf \(senedd.wales\)](#).

The ability to charge additional council tax premiums has been welcomed as a mechanism for local authorities to mitigate the negative impacts that second homes and long-term empty properties can have. While many of the opportunities for addressing housing issues through premiums have not yet been fully realised, increasing the maximum level will enable local authorities to decide a level appropriate for their individual local circumstances when the time is right for them. It will be for individual authorities to decide whether to make use of the higher maximum allowed for council tax premiums. It should not be assumed that authorities will move to the new maximum of 300% from 1 April 2023.

Each authority needs to consider all the possible effects in deciding whether to make use of their discretionary powers to introduce a premium and must make a full assessment of possible impacts. This includes taking account of the effect of introducing premiums on communities, the housing market and the local economy. Each local authority can set the premium at any level up to the maximum and can apply different premiums to second homes and long-term empty dwellings. It is a matter for individual authorities as to whether they use their discretionary powers to reduce council tax liability in respect of a premium.

When publishing a consultation the Welsh Government gives consideration on how to reach its target audience. To publicise the consultation on local taxes for second homes and self-catering accommodation, I issued a Written Statement announcing the launch of the consultation. This was published on the Welsh Government website and circulated to Senedd Members who could then bring the consultation to their constituents' attention. In addition the Welsh Government notified a range of stakeholders including local authorities, sector representative bodies and relevant professional bodies/associations. All were requested to pass on the details of the consultation.

The Welsh Government also used its social media channels to publicise the launch of the consultation. The issues of second homes, self-catering accommodation and council tax premiums are often highlighted in the media and the consultation was widely reported in local and national media.

We value the views of our stakeholders. To make sure citizens can contribute to future Welsh Government council tax consultations I would encourage them to sign up for our regular email newsletters about our consultations <https://gov.wales/subscribe/consultations>

Yours sincerely,

A handwritten signature in black ink that reads "Rebecca Evans". The signature is written in a cursive style with a period at the end.

Rebecca Evans AS/MS

Y Gweinidog Cyllid a Llywodraeth Leol

Minister for Finance and Local Government

Protect Mid-Wales' unique Cambrian Mountains: designate them an Area of Outstanding Natural Beauty

Y Pwyllgor Deisebau | 17 Hydref 2022
Petitions Committee | 17 October 2022

Reference: SR22/3945-7

Petition Number: P-06-1302

Petition title: Protect Mid-Wales' unique Cambrian Mountains: designate them an Area of Outstanding Natural Beauty

Text of petition: The Cambrian Mountains: endless open skies, outstanding biodiversity, spectacular hills and valleys, 5000 years' heritage of Welsh language, farming and mining. Their sense of immense space and peace is rare.

Sadly, conservation of these uplands gets little attention. Farms are bought up for conifer planting or for large wind farms despite the lack of infrastructure.

So beautiful a region needs protection AND longer term rural employment. Designate the Cambrians as Mid-Wales' first AONB!

The Cambrian Mountains' peatlands mitigate climate change by absorbing manmade carbon, and reduce river flooding. Biodiverse native woodlands and fens nurture precious plants, animals and birds. Birds of prey cruise the skies; red squirrels, otters and pine martens roam; butterflies, dragonflies, ladybirds and 15 kinds of dung-beetles call it home! Scattered farms, cairns, chapels and ruins record people's lives and work here since the Bronze Age.

AONB designation would bring balance between development, local communities' needs AND people's need for green space. Existing AONBs like



Gower, Anglesey, Clwydian Hills and Dee Valley thrive while promoting and preserving Welsh landscapes for all.

We need to stop and think: Politicians raise concerns over windfarm plans (mynewtown.co.uk). Large scale afforestation will decimate rural communities warns farming union (nation.cymru). Give the Cambrian Mountains prestige AONB branding and coherent management and watch the region flourish!

1. Background

Nationally important landscapes in Wales are designated as Areas of Outstanding Natural Beauty (AONB) or National Parks under the *National Parks and Access to the Countryside Act 1949 (hereafter, the '1949 Act')*. Together these 'Designated Landscapes' cover around 25% of Wales. Although National Parks and AONBs have different statutory purposes, together they seek to:

- conserve and enhance natural beauty, wildlife and cultural heritage; and
- promote opportunities for the understanding and enjoyment of their special qualities.

Natural Resources Wales (NRW) says AONBs are “protected by law because of their special landscape qualities, wildlife, geology and geography”. The designation triggers obligations in relation to development plans, and allows for the making of access orders and the establishment of conservation boards.

AONBs differ from National Parks in that they lack the statutory purpose to promote opportunities for the public to enjoy and understand the area.

Wales is home to 4 AONBs (Anglesey, Clwydian Range & Dee Valley, Llyn Peninsula and Gower – additionally the Wye Valley AONB spans England and Wales), and 3 National Parks (Brecon Beacons, Pembrokeshire Coast and Snowdonia).

Designating AONBs

The power to designate AONBs was originally contained in the 1949 Act but was modified by the Countryside and Rights of Way Act 2000 (hereafter, the '2000 Act'). Under Section 82 of the 2000 Act, NRW can designate any area in Wales (which is not already a National Park) as an AONB if the area is of such outstanding natural beauty that it should be conserved and enhanced. The procedure for designating AONBs is detailed in Section 83 of the 2000 Act.

In response to this petition, the Minister for Climate Change (hereafter, 'the Minister') says NRW is "currently examining the case for designating a new National Park in north-east Wales", adding that this is an "extensive and exhaustive process and will be the priority for the coming years for NRW in terms of new designations".

Planning

NRW says that "AONB have more protection than other areas under the planning process". The Welsh Government's national planning policy – Planning Policy Wales (PPW) – sets out that AONBs must "be afforded the highest status of protection from inappropriate developments" (see section 6.3.8, page 134).

The granting of AONB status may therefore result in the local planning authority (LPA) applying stricter development controls in the area when producing the local development plan, and when deciding planning applications.

PPW states that "major developments should not take place in National Parks or AONBs except in exceptional circumstances". PPW is accompanied by the National Development Framework (the NDF) – Future Wales: the national plan 2040 – which forms the national development plan. The NDF states that "applications for large-scale wind and solar will not be permitted in National Parks and [AONBs]".

The granting of AONB status would also have an impact on smaller household developments with some permitted development rights removed.

Local authority responsibility

Section 89 of the 2000 Act requires the local authority in whose area an AONB lies to prepare and publish an AONB management plan which must be reviewed every 5 years. This will have resource implications for the local authority.

2. Welsh Government action

A review of AONB and National Parks was undertaken in 2015, the resulting '[Marsden Report](#)' provided 69 recommendations.

The Future Landscapes Working Group was later established by the Welsh Government to explore the Marsden Report recommendations, [reporting in 2017](#). The report is explored further in a [Senedd Research article](#).

Welsh Government then published its [Priorities for Areas of Outstanding Natural Beauty and National Parks 2018 \(valued and resilient\)](#), which sets out four goals for AONBs and National Parks in Wales:

- they are Valued Places;
- they contain Resilient Environments;
- they support Resilient Communities; and
- the AONB partnerships and National Park Authorities must adopt Resilient Ways of Working.

The Welsh Government's [Programme for Government](#) includes a commitment to designate a new National Park to cover the Clwydian Range and Dee Valley, which is currently an AONB.

In her response to this petition, the Minister says NRW is "committed to undertaking an all-Wales technical assessment of natural beauty":

It is intended that this will assess areas against the natural beauty criteria which will help to assess their potential need for future protection.

The Minister extends an invitation to the petitioner to meet with Welsh Government officials, together with NRW officers, to "discuss some aspects of the proposal to designate in greater detail".

3. Welsh Parliament action

There has been no Senedd activity regarding the AONB designation of the Cambrian Mountains.

Every effort is made to ensure that the information contained in this briefing is correct at the time of publication. Readers should be aware that these briefings are not necessarily updated or otherwise amended to reflect subsequent changes.

Julie James AS/MS
Y Gweinidog Newid Hinsawdd
Minister for Climate Change



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref JJ/02000/22

Jack Sargeant MS
Chair - Petitions committee
Senedd Cymru
Cardiff Bay
Cardiff CF99 1SN

20 September 2022

Dear Jack Sargeant MS,

Thank you for your letter of 6 September 2022 regarding Lorna Brazell's petition to designate the Cambrian Mountains as an Area of Outstanding Natural Beauty (AONB).

Natural Resources Wales is responsible for undertaking the process of designating AONBs and National Parks in Wales, and they are currently examining the case for designating a new National Park in north-east Wales. This is an extensive and exhaustive process and will be the priority for the coming years for NRW in terms of new designations. We also have much to do to improve and empower current designations to contribute more significantly to combatting the nature and climate crises.

Looking further ahead, however, as part of their designation programme during the next 2-3 years, NRW has also committed to undertaking an all-Wales technical assessment of natural beauty. It is intended that this will assess areas against the natural beauty criteria which will help to assess their potential need for future protection. This work will clearly be of interest to those campaigning for AONB status when taken forward.

For designations to be taken forward it is important to demonstrate a level of local support including local political support for designation. Until recently the Cambrian Mountains Society was campaigning for National Park, rather than AONB, status. I am aware that a proposal was made by the Cambrian Mountains Initiative (CMI), a separate body, that is not seeking a top-down statutory designation but instead maps out an alternative grass-roots approach. A question remains to the extent campaigners have secured local support and aligned different, sometimes conflicting, approaches to protection.

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We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

I am happy for officials, together with NRW officers, to meet Lorna to discuss some aspects of the proposal to designate in greater detail. I will follow these discussions closely.

Yours sincerely,

A handwritten signature in blue ink that reads "Julie James". The signature is written in a cursive, flowing style.

Julie James AS/MS
Y Gweinidog Newid Hinsawdd
Minister for Climate Change



Cambrian Mountains Society/ Petitioner's response to Minister's points

Thank you for the opportunity to respond to Minister James' letters (to the Committee Chair and to us). We address each of her points in turn, below.

1. NRW are busy.

We understand that the Clwyd Hills and Dee Valley project is consuming substantial resources; indeed, it appears that it was necessary for additional staff recruitment and training to take place in order to progress the project. We do not expect AONB designation for the Cambrian Mountains to take place overnight. Rather, we want to see

- agreement in principle that the project *should* be undertaken, and
- a commitment to a practicable timetable,

in the course of this Senedd. The designation of the Cambrian Mountains as a protected landscape has been under discussion, one way or another, since 1968; designation was agreed in 1972 but then not implemented. ***Now, not in another 5, 10 or 50 years, is the time!***

2. Current designations need improving

Drawing on the Marsden Review of 2014 and the subsequent Future Landscapes report in 2017, it is clear that improvement to the system of designations is possible. But it is also clear from the time that has elapsed since those reports that this is not just a multi-year but a multi-decade aspiration.

Time is not on our side in mid-Wales: development and afforestation are taking place now. If a decision on designation is postponed until the ideal solution has been devised and the legislation drafted and implemented, it is quite possible that the natural beauty of these uplands will have been degraded beyond the point where designation under whatever new framework is settled upon is no longer appropriate. Action is needed in the short term; the designation can then, once the new scheme is in place, be migrated across to it along with the migration of the currently designated landscape.



3. An all-Wales technical assessment of natural beauty coming in 2-3 years.

NRW perform regular LandMap assessments, most recently in 2021. Whilst we appreciate that criteria may be modified and an all-Wales exercise will certainly be valuable, we see no reason why designation of a landscape long-acknowledged as meeting the current criteria (since at least the National Park proposal of 1972, itself following recommendations made in 1968) should await yet a further round of assessment. We attach copies of the several NRW assessments relied upon in the Technical Report produced by White Consultants for the Cambrian Mountains Initiative (“CMI”), referred to below, which demonstrate clearly that the Cambrian Mountains meet the statutory criteria for designation.

4. Local support

Our local support speaks for itself in the form of the 12,500 signatures we have collected, the vast majority collected at local events including the Royal Welsh Show, National Eisteddfod and other Ceredigion events and venues over the summer of 2022.

Should further evidence be required, we also rely upon the Technical Report drawn up for CMI by White Consultant in 2019 following an extensive programme of local consultation with Town and Community Councils around the Cambrian Mountains. For ease of reference (the report being a very long document) two of the tables summarising the results of that consultation are set out below (with numerical scoring added). In summary, AONB designation was strongly favoured by CMI’s consultees compared to all other models other than a ‘customised’ solution: introduction of a French model, which exists nowhere in the UK and is funded under a French model of local taxation (unlikely to be possible in Wales). The French model’s combined score was 27, compared to 26 for AONB; the differential is meaningless compared to the legislative and political difficulty of bringing it into existence. Indeed, if the score of ‘uncertain’ which the consultation gave to AONB designation under the theme of ‘flexibility’ were instead the more appropriate ‘positive’ (since flexibility is one of the very highlights of the AONB Partnership model) then AONB designation would be the highest scoring, preferred option. It is further noteworthy that the French model scores a negative rating on the theme of bureaucracy, while the AONB model is not rated negative for any theme or topic.

5. Past campaigning in favour of a National Park

CMS, founded in 2005, has since 2006 consistently campaigned for AONB designation. We have sound justifications for our proposal as it stands. We are not currently campaigning for a National Park designation, and have no plans to do so in the future.





6. Is the CMI approach (“bottom up”) to be preferred and have CMS aligned our different, sometimes conflicting, approach to protection?

It was in fact the outcome of the ‘bottom up’ consultation process undertaken by CMI, carrying out local meetings and discussions as part of their survey, set out in White Consultants’ resulting Technical Report, which inspired us to re-launch our campaign seeking AONB designation. The AONB campaign is accordingly equally as ‘bottom up’ as CMI’s proposal for discussion.

In any event, we do not consider that there is any conflict in practice between the approaches to protection. The AONB model itself is very similar to the Regional Natural Park model, in that the latter is managed by a *syndicat mixte*, a local authority grouping which is a public corporation in charge of the implementation of the Park charter, a territorial project approved by all members. An AONB is managed by an AONB Partnership which comprises the relevant local authorities and other stakeholders or representatives of stakeholder groups. The AONB Partnership implements the AONB Management plan which is drawn up in consultation with stakeholders. The area covered by the Regional Natural Park is agreed between the participating communities; we assume that the discussion of area to be included within an AONB would, likewise, include an opportunity for the relevant communities to input.

7. Has CMI progressed their proposal at all?

In order to respond to this question we have spoken to CMI, who tell us that they were contracted only to commission and supervise the preparation of the report by White Consultants. We understand that they had not planned to do any further work, and have had no further engagement with the issue of designation.



WHITE CONSULTANTS TECHNICAL REPORT CHARTS 2 AND 4 WITH NUMERICAL SUMMARIES





Consistency matrix: themes

Pack Page 61

	Bureaucrati	o ni tion	Coordination	Definition	Designation	density	Representation	Flexibility
National Park	negative response	positive response	strong positive response	strong positive response	negative response	strong positive response	positive response	negative response
AONB	positive response	positive response	positive response	strong positive response	positive response	strong positive response	positive response	uncertain
Biosphere Reserve	positive response	positive response	uncertain	positive response	uncertain	positive response	positive response	positive response
Geopark	positive response	positive response	uncertain	uncertain	uncertain	positive response	positive response	positive response
National Scenic Area (Scotland)	strong positive response	uncertain	negative response	strong positive response	positive response	positive response	negative response	negative response
French Regional Natural Park	negative response	positive response	strong positive response	strong positive response	positive response	strong positive response	strong positive response	uncertain
Scottish Regional Park	positive response	positive response	uncertain	strong positive response	positive response	uncertain	uncertain	negative response
English Regional Park	positive response	positive response	uncertain	strong positive response	strong positive response	positive response	positive response	positive response
Welsh Valleys Regional Park	negative response	positive response	strong positive response	strong positive response	uncertain	strong positive response	strong positive response	positive response

Colour code: strong positive response positive response uncertain negative response





Consistency with combined themes

Scoring: **Strong positive** = 3 **Positive** = 2 **Uncertain** = 0 **Negative** = -1

- National Park 10
- AONB 16
- Biosphere Reserve 12
- Geopark 10
- National Scenic Area (Scotland) 7
- French Regional Natural Park 13
- Scottish Regional Park 6
- English Regional Park 12
- Welsh Valleys Regional Park 13





Consistency matrix: topics

Pack Page 63

	Access	Community	Planning	Land	Economy
National Park	Strong positive response	Positive response	Strong positive response	Positive response	Positive response
AONB	Positive response	Positive response	Positive response	Positive response	Positive response
Biosphere Reserve	Uncertain	Positive response	Uncertain	Uncertain	Positive response
Geopark	Uncertain	Uncertain	Uncertain	Uncertain	Uncertain
National Scenic Area (Scotland)	Positive response	Uncertain	Uncertain	Uncertain	Uncertain
French Regional Natural Park	Positive response	Strong positive response	Strong positive response	Strong positive response	Strong positive response
Scottish Regional Park	Strong positive response	Uncertain	Uncertain	Uncertain	Uncertain
English Regional Park	Positive response	Uncertain	Positive response	Uncertain	Positive response
Welsh Valleys Regional Park	Uncertain	Strong positive response	Positive response	Positive response	Positive response

Colour code: strong positive response positive response uncertain negative response

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www.cambrian-mountains.co.uk





Consistency with combined topics

Scoring: **Strong positive = 3** **Positive = 2** **Uncertain = 0** **Negative = -1**

- National Park 12
- AONB 10
- Biosphere Reserve 4
- Geopark 0
- National Scenic Area (Scotland) 2
- French Regional Natural Park 14
- Scottish Regional Park 3
- English Regional Park 6
- Welsh Valleys Regional Park 9

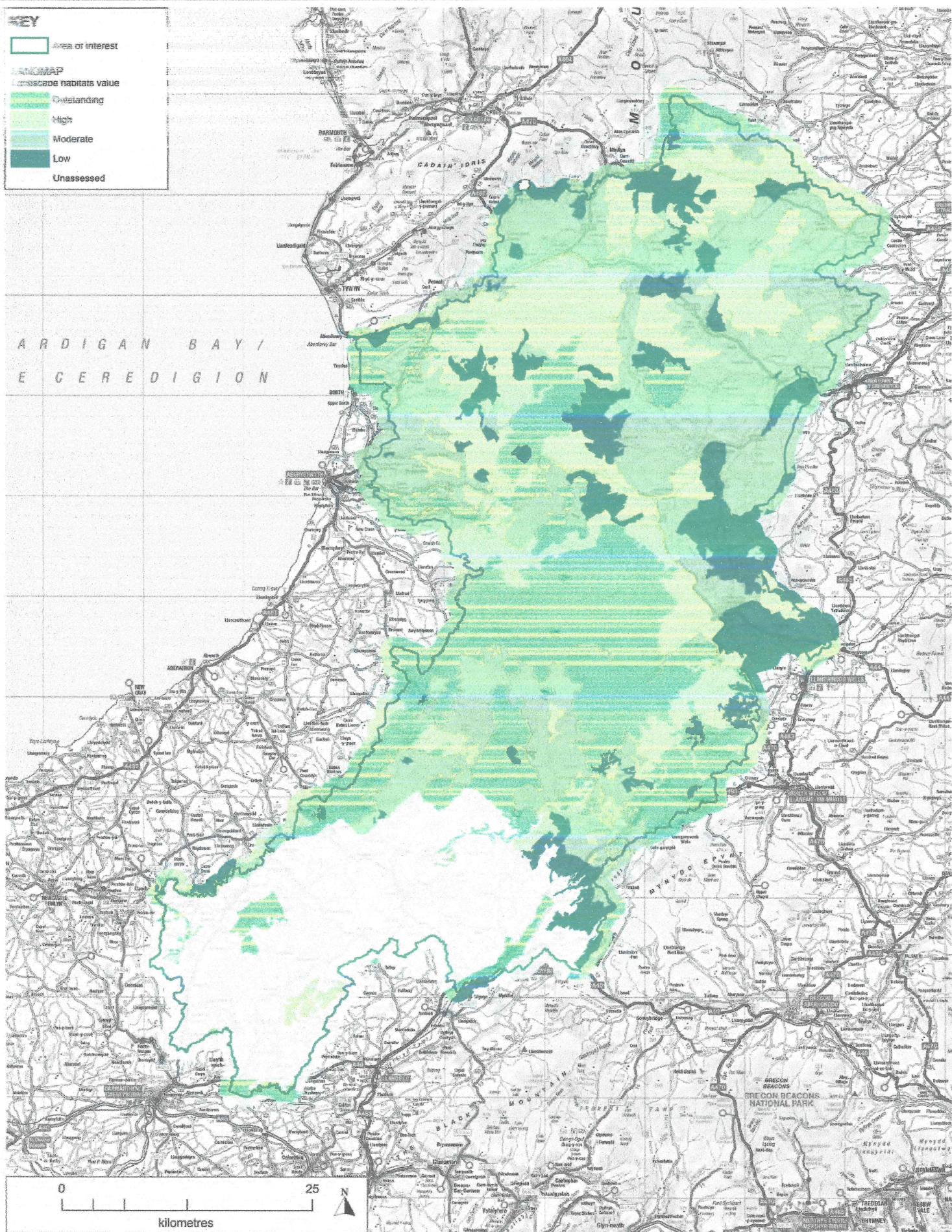




Overall ranking

- National Park
- AONB
- Biosphere Reserve
- Geopark
- National Scenic Area (Scotland)
- French Regional Natural Park
- Scottish Regional Park
- English Regional Park
- Welsh Valleys Regional Park





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**Figure A7 - LANDMAP
Landscape habitats value**



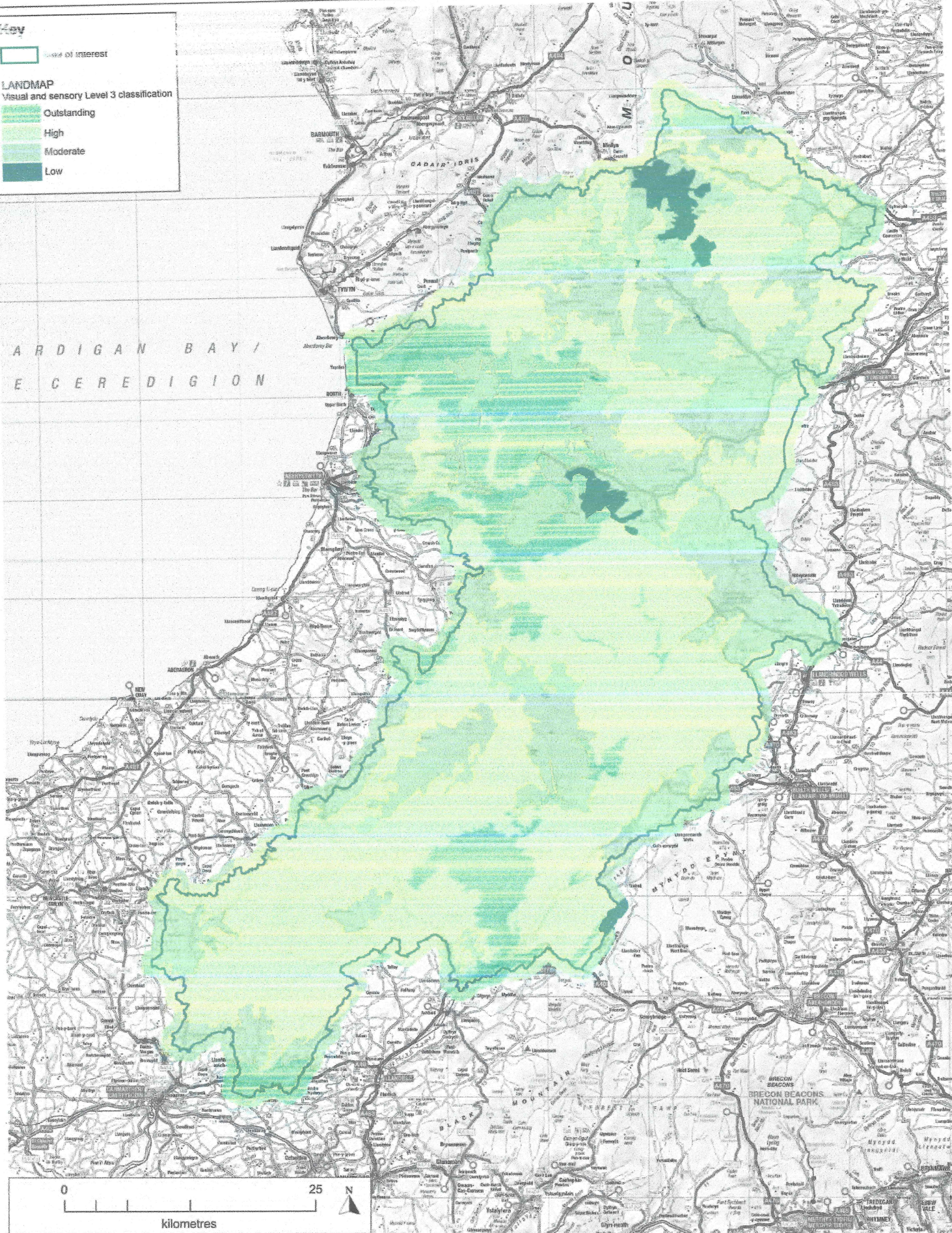
www.whiteconsultants.co.uk

Key

Area of Interest

LANDMAP
Visual and sensory Level 3 classification

- Outstanding
- High
- Moderate
- Low



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Figure A9 - LANDMAP
Visual and sensory value



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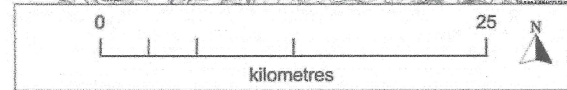
KEY

— Area of Interest

LANDMAP
historic landscape value

- Outstanding
- High
- Moderate
- Low

ARDIGAN BAY /
E C E R E D I G I O N

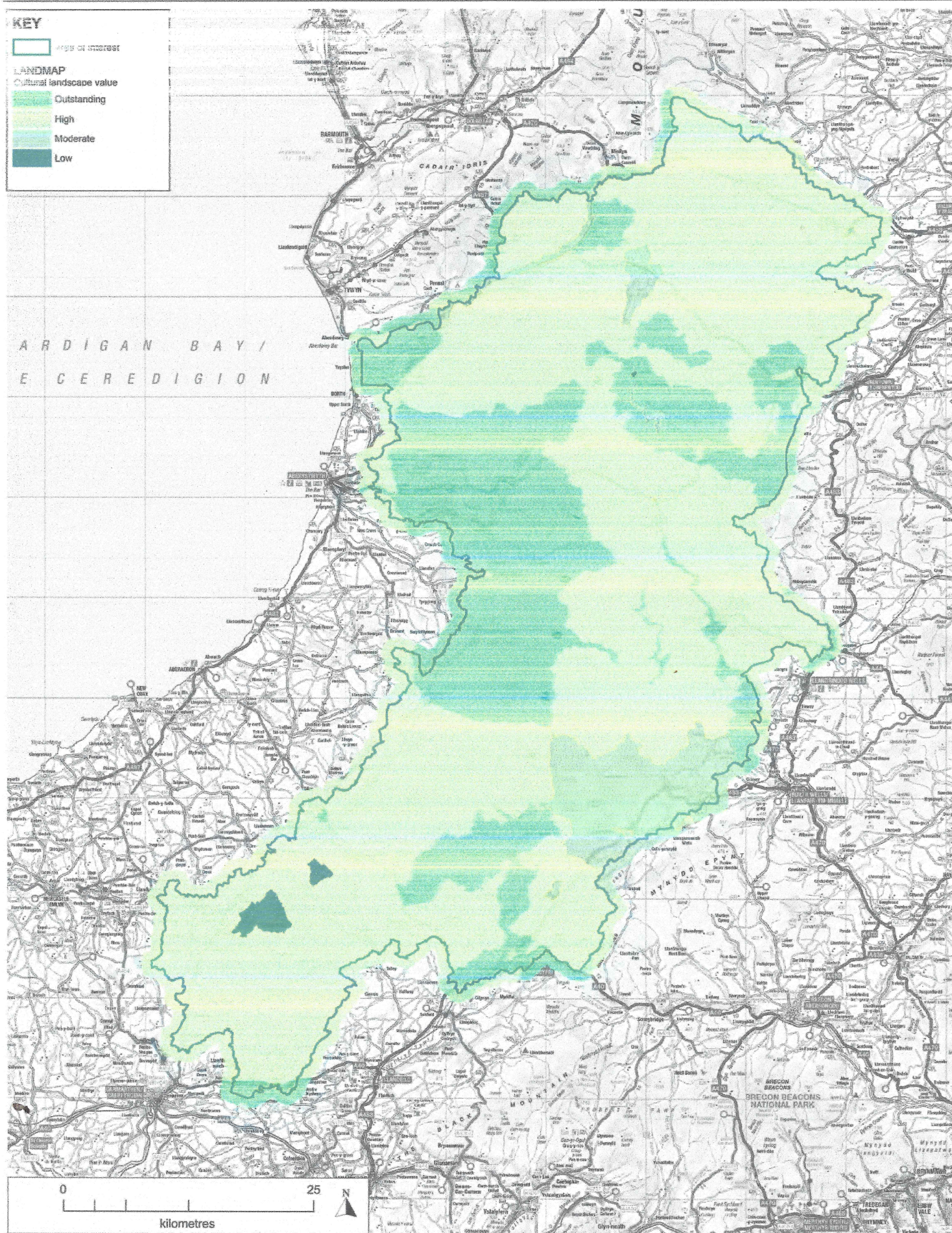


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Figure A10 - LANDMAP
Historic landscape value



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Figure A11 - LANDMAP
Cultural landscape value

Agenda Item 3.1

P-05-1106 Introduce Personal Health Budgets and Personalised Care in Wales

This petition was submitted by Rhys Bowler having collected a total of 779 signatures.

Text of Petition:

Rhys has Duchenne Muscular Dystrophy and lives in daily fear for his life, left alone for hours hoping the ventilator he needs to breathe doesn't break. He must choose between poorly funded social care and an NHS Continuing Healthcare package that takes away his choice over who cares for him.

If Rhys lived in England he would have a personal health budget, allowing him to use NHS Continuing Healthcare while still being able to choose who cares for him. This is not available in Wales

Additional Information:

I'm Rhys, 33 and living with Duchenne Muscular Dystrophy in Pontypridd, Wales. I have extremely limited mobility and need a ventilator to breathe.

I've employed my own care assistants for decades and have a lot of experience of training and employing them. I've had bad experiences using agencies and not having a say in who cares for me. I want to choose the care assistants I want. I want to know who is coming in my home to help me with my intimate personal care, and I want them to be people I trust and have trained in how best to provide my care. Don't let my experience go to waste!

I want a Personal Health Budget so I can have both 24 hour care and a choice over who my care assistants are. This has been available in England since 2014, it's time Wales took this seriously and started giving people real choice and control about the care they receive.

Senedd Constituency and Region

- Pontypridd
- South Wales Central



Eich cyf/Your ref P-05-1106
Ein cyf/Our ref JMSS/00664/22

Jack Sargeant MS
Chair - Petitions committee
Senedd Cymru
Cardiff Bay
Cardiff
CF99 1SN

6 July 2022

Dear Jack,

Thank you for your letter, dated 7 June 2022, regarding Petition P-05-1106 – ‘Introduce Personal Health Budgets and Personalised Care in Wales’.

We note the concern regarding the lack of independence and control some individuals have over their care provision. To this end we have set out a specific commitment to ‘Improve the interface between Continuing Health Care (CHC) and direct payments’ within our Programme for Government (PfG). To deliver on this commitment we have already put in motion a number of actions with the aim to introduce further flexibility for people using CHCs which I would like to share with you and the Committee.

The Welsh Government published ‘*Continuing NHS Healthcare – the National Framework for Implementation in Wales*’ in 2014 that sets out the policy for eligibility for CHC and the responsibilities of NHS organisations and local authorities under the Framework and related matters. Since the initial publication we have consulted closely with stakeholders to review and revise the framework.

The revised version of the Framework was published in 2021 and it has been operational as of 1 April 2022.

The revised framework includes a range of options and measures to ensure voice and control for individuals, including:

- health boards employing personnel (either directly or via an agency) who were previously employed by the individual via direct payments
- health boards commissioning an Independent User Trust (IUTs), potentially set up by a family member of the person receiving care, to manage that person’s care.

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Gohebiaeth.Julie.Morgan@llyw.cymru
Correspondence.Julie.Morgan@gov.wales

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

The framework also states that further guidance on these measures will be published on the Welsh Government website.

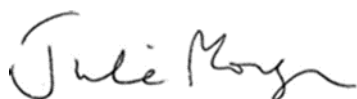
To support the broader delivery of our PfG commitments, we have formed a CHC/direct payments Working Group to ensure empowerment and inclusion of disabled people in development of policy in this area. The group includes representatives from the Welsh Government (Health, Social Care, Equality), health boards, local authorities, third sector groups, disability organisations, disabled people and people with lived experience, the Disability Equality Forum and the Disability Rights Taskforce. This group is now co-producing the guidance to support voice and control.

The group has agreed that the additional guidance should include a range of measures, such as general guidance on voice and control and person-centred care, IUTs, health boards employing staff previously employed via direct payments, notional budgets as well as proposing some new solutions being trialled by some health boards in the form of a personal care budget.

We would like to thank the Committee for raising these issues and providing the suggested actions with regards to strengthening the promotion, guidance and support around IUTs. We will include these considerations as part of our ongoing work to develop the guidance. and will take this forward through a co-productive approach utilising the expertise of our Working Group.

This work will continue over the coming months, and we would welcome the opportunity to return to the Committee with an update on the progress in due course.

Yours sincerely,



Julie Morgan AS/MS

Y Dirprwy Weinidog Gwasanaethau Cymdeithasol
Deputy Minister for Social Services

Agenda Item 3.2

P-06-1163 Extend the postgraduate STEMM bursary to all MSc students in Wales

This petition was submitted by Rachel Wrathall, having collected a total of 88 signatures.

Text of Petition:

In June 2019 Welsh Government announced a bursary scheme to increase the number of Welsh graduates who remained or returned to Wales to undertake a master's degree in Science, Technology, Engineering, Mathematics or Medicine (also known as 'STEMM' subjects). This funding currently only extends to traditional Universities, excluding students who choose a STEMM Masters through alternative providers. This excludes some students, who need more flexibility in STEMM subject matter or course delivery.

Additional Information:

The Diamond review recommended that efforts are made "to enable students to study in the mode that best supports their circumstances". (The Review of Higher Education Funding and Student Finance Arrangements in Wales, 2016).

Currently students studying for STEMM Masters at the Centre for Alternative Technology (CAT) School of the Environment in Machynlleth are excluded from Welsh Government's STEMM bursary funding. The courses provided at CAT have a specific sustainability focus, which aligns with Welsh Government efforts to change the course of Wales onto a more sustainable path (e.g. through principles outlined in the Well-being of Future Generations (Wales) Act 2015).

Teaching at CAT is flexible, and unlike traditional universities, enables students to study a taught Masters whilst continuing work/caring responsibilities.

We believe that the exclusion of STEMM students at organisations like CAT from STEMM bursary funding is counter to the STEMM bursary policy aims.

Senedd Constituency and Region

- Vale of Glamorgan
- South Wales Central

Agenda Item 3.3

P-06-1240 Improve health services for people with epilepsy living in Wales

This petition was submitted by Janet Paterson, having collected a total of 1,334 signatures.

Text of Petition:

We are concerned that the current services for people with epilepsy living in Wales are not providing people with the help and support they need.

Epilepsy Action recommends a caseload of no more than 250 people per Epilepsy Specialist Nurse (ESN), in order to minimise the effects of their condition and provide the best possible care. Currently no area in Wales is meeting this recommendation.

There is a lack of ESNs and waiting times to see neurologists are over 12 months in many areas.

Additional Information:

Increasing the number of ESNs in all health boards across Wales would help significantly improve access to services and the support that people with epilepsy receive.

ESNs are vital team members providing care to people with epilepsy. They work alongside consultant neurologists and other healthcare professionals to provide essential advice and support during and, as importantly, in-between appointments.

ESNs are often the first point of contact for people with epilepsy who require advice or support related to their condition and their contribution is invaluable. The crucial role of epilepsy specialist nurses in caring for and supporting people with epilepsy is set out in Epilepsy Action's recent ESPENTE report <https://www.epilepsy.org.uk/research/espente>

In addition to increasing the number of ESNs, all epilepsy services in Wales need more funding to ensure that people with epilepsy receive the support and care they need.

Senedd Constituency and Region

- Arfon
- North Wales



Eich cyf/Your ref P-06-1240
Ein cyf/Our ref EM/02219/22

Jack Sargeant MS
Chair - Petitions Committee
Senedd Cymru
Cardiff Bay
Cardiff
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Government.Committee.Business@gov.wales

21 July 2022

Dear Jack,

Thank you for your letter of 7 June as Chair of the Petitions Committee about *Petition P-06-1240 Improve health services for people with epilepsy living in Wales*, and the question from the committee about how the Welsh Government are monitoring that each health board has the appropriate level of support that is needed for people with epilepsy.

Welsh Government set the strategy, vision, and expectations for neurological services, including epilepsy, through the Neurological Conditions Implementation Plan. The implementation of this plan has and continues to be supported by the Neurological Conditions Implementation Group (NCIG) and the national Clinical Lead for Neurological Conditions.

The NCIG and clinical lead have highlighted several challenges in relation to monitoring services for those people with neurological conditions, including the availability, quality and timeliness of data related to neurological conditions, including epilepsy. This is an area ripe for improvement, and one that has been prioritised by the clinical lead and NCIG, who are currently working with the Value Based Health Care team and Digital Health and Care Wales to develop a data dashboard for epilepsy. This will provide valuable information from a monitoring and assurance perspective, but also help to support health boards to develop business cases for developing services for people with epilepsy going forward. An early version of the dashboard has been published, but development is continuing to include patient reported experience and outcome measures.

Discussions around the addition of neurological conditions, including epilepsy, on the national dashboard as a way of monitoring services and identifying inequalities (such as number of Epilepsy Specialist Nurses and caseloads) are also underway. The NCIG has

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

secured clinical representation at the modernising outpatients dataset programme as part of the planned care programme, which will help improve quality and availability of data.

Moving forward, the Neurological Conditions Implementation Plan will be replaced by the Neurological Conditions Quality Statement. This has been developed by the NCIG and will be published later this year. Quality Statements are a key feature introduced by the National Clinical Framework (published in March 2021) which describes how the strategic development of healthcare services can make the NHS in Wales fit for the 21st century. 'Quality Statements' set out what good looks like for high quality, patient focused services.

We expect health boards, trusts and Special Health Authorities to respond to Quality Statements through their planning processes, and the monitoring of all services, including those for people with epilepsy, will be significantly improved as the work initiated by NCIG to improve the availability, quality and timeliness of data continues to develop.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'M. E. Morgan'.

Eluned Morgan AS/MS

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Aneurin Bevan
University Health Board

Our Ref: GJ/rm

Direct Line: [REDACTED]

Date: 15th June 2022

Letter sent by email only: petitions@senedd.wales

Clerking Team
Welsh Parliament
Cardiff Bay
Cardiff
CF99 1SN

Dear Sir, Madam

Re: Petition P-06-1240 Improve health services for people with epilepsy living in Wales

Reference Mr Jack Sargeant's letter dated 7th June 2022.

Thank you for the opportunity to provide information on what services and resources are in place within the Aneurin Bevan University Health Board to meet the needs of people living with Epilepsy, and any gaps in the service.

Within the Health Board the service consists of 2 x Consultant Neurologists with a Special Interest in Epilepsy (1 of which is part time, totalling 1.2 WTE), 1 x Band 7 full time Epilepsy Specialist Nurse, and 1 x Band 6 Epilepsy Nurse (0.5 WTE). The service is also supported by a Health Care Support Worker who provides daily telephone triage for our open access service.

The services provided are:

- Weekly consultant led clinics, including a suspected first seizure service
- Weekly MDT to discuss complex patients
- Specialist Nurse led clinics i.e. antenatal clinics and a vagal nerve stimulator (VNS) clinics
- Learning disabilities clinic (joint with LD psychiatrists)

Cont/d

Bwrdd Iechyd Prifysgol Aneurin Bevan

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Ysbyty Sant Cadog
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Aneurin Bevan University Health Board

Headquarters
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Tel No: 01633 436700
Email: abhb.enquiries@wales.nhs.uk



Bwrdd Iechyd Prifysgol Aneurin Bevan yw enw gweithredol Bwrdd Iechyd Lleol Prifysgol Aneurin Bevan
Aneurin Bevan University Health Board is the operational name of Aneurin Bevan University Local Health Board

- Adolescent transition clinics (joint with paediatricians)
- Open Access telephone line (for returned call within 5 days) – the majority of our workload is through this route

With regards to current gaps in service, Epilepsy Action recommends that there is 1 x WTE Epilepsy Clinical Nurse Specialist to manage a cohort of 250 patients. The current situation demonstrates that the Health Board's staffing levels are below these recommendations. The Health Board is therefore advertising for an additional 1 x WTE Epilepsy Clinical Nurse Specialist and 1 x WTE Consultant with a Specialist Interest in Epilepsy.

We hope that the above information is helpful and would welcome any feedback.

Yours faithfully

A handwritten signature in black ink, appearing to read 'Glyn Jones', with a large, stylized flourish above the name.

Glyn Jones
Prif Weithredwr Dros Dro / Interim Chief Executive



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Bloc 5, Llys Carlton, Parc Busnes Llanelwy,
Llanelwy, LL17 0JG

Block 5, Carlton Court, St Asaph Business
Park, St Asaph, LL17 0JG

Mr Jack Sargeant MS
Chair
Petitions Committee
Welsh Parliament
Cardiff Bay
CF99 1SN

Ein cyf / Our ref: JW/AM/DL/CE22-1039/31176

Eich cyf / Your ref:

☎: [REDACTED]

Gofynnwch am / Ask for: [REDACTED]

E-bost / Email: [REDACTED]

Dyddiad / Date: 16th June 2022

Dear Jack

Re: Petition P-06-1240 Improve health services for people with epilepsy living in Wales

Adult Epilepsy services

The adult Epilepsy service in North Wales is provided by the Walton Centre NHS Foundation Trust. There are two Consultant Neurologists working in North Wales with a specialist interest in Epilepsy. The Walton Centre also employs one highly experienced Epilepsy Nurse Specialist to support our North Wales patient population who are under the care of the Walton Centre Neurological service. The post holder covers the service extremely well.

We have access to MRI and also to EEG investigations through our Neurophysiology service within the Health Board, with more specialised investigations available through the Walton Centre.

We work closely with the Walton Centre team regarding the best models of care for our patients to deliver agreed pathways of care within the resources available to us, and these discussions are ongoing. The average waiting time for first appointment with a Consultant Neurologist is currently 26 weeks unless the patient is marked to be seen sooner.

Epilepsy service provision for children and young people

With respect to services for children and young people with Epilepsy living in North Wales, we have Consultant Paediatricians with an interest in childhood Epilepsy in each of our 3 areas (Centre, East and West) and they provide Epilepsy clinics in each of the areas. Each of the 3 areas has a specialist Children's Epilepsy Nurse who works seamlessly with our acute and community paediatricians with an interest in childhood Epilepsy, supporting families and the delivery of best quality clinical care. We have tertiary specialist children's Consultant Neurologists who deliver outreach clinics in all three of our hospitals in North Wales and these are joint clinics, held in partnership with our local consultants with an interest in children's Epilepsy, in a hub and spoke model, which is well established.



Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Children's and young people's Epilepsy services are part of the EPIC (Epilepsy in Children) regional network, with Alder Hey Children's Hospital being our Tertiary hub and centre. In addition to the visiting children's neurology clinics, we have access to specialist services for children and young people with Epilepsy, including the NorCESS (The Northern Children's Epilepsy Surgery) service and Ketogenic Diet Service. We have access to MRIs and also to EEG investigations through our Neurophysiology services within the Health Board, with more specialised investigations, for example high resolution MRI (3T) and video-telemetry available through Alder Hey children's hospital.

The next available appointment with a Consultant Paediatric Neurologist at Alder Hey is 7 weeks.

Transition services

Joint transition clinics are held between our local paediatric consultants with an interest in Epilepsy and adult Neurologists in each area, however, over the last 2-3 years, due to staff changes and retirements in adult neurology, these have been variable in 2 of our 3 areas. We are working with our local adult tertiary centre to address this and are making progress towards these being re-established. In the meantime we continue to have good communication and pathways with our adult Consultant Neurologists and adult Specialist Epilepsy Nurse from the Walton Centre to ensure that young people entering adult services receive appropriate support and follow up.

Partnership working with the Third Sector

We have extremely strong partnership arrangements with the Third Sector and work very closely with both Epilepsy Wales and Epilepsy Action Cymru to meet the needs of people with Epilepsy living in our Health Board area.

- **Epilepsy Wales**

We have an agreed contract with Epilepsy Wales to deliver services to our patients with Epilepsy.

Epilepsy Wales help people with Epilepsy in North Wales to live as full, independent and active lives as is possible in the community. Helping them gain a better understanding and control of their condition limits the impact of the condition, with the aim of improving job opportunities, improving health and wellbeing, supporting people to stay in their own homes, maintaining independence and avoiding hospital admissions. Epilepsy Wales provide 1:1 support to people with Epilepsy who have complex needs supporting their families and carers. They also provide support to children with Epilepsy and their carers.

- **Support for Epilepsy Clinics**

Epilepsy Wales provide support and take referrals from Consultant led, GP and Specialist Nurse clinics in North Wales. Clinics are held at Ysbyty Gwynedd Bangor, Ysbyty Glan Clwyd, Colwyn Bay Community Hospital and Wrexham, and where necessary Epilepsy Wales visit people in their own home. They also attend Multidisciplinary meetings when required to support people with Epilepsy and liaise

with various agencies to address needs identified within the clinic- this includes first aid advice and training for families, safety issues, benefits advice, emotional support and advocacy. They undertake home visits, visit schools and care homes visits, and maintain contact both online and over the phone. They offer training for families and carers with Midazolam care plans, and work alongside practitioners to deliver a person centred service, either in an individuals home or within Epilepsy Wales' own training facility for those unable to access online training.

- Stakeholder Involvement

Epilepsy Wales hold family events for our individual patients with Epilepsy and for the children and parents of children with Epilepsy. In addition, they hold regular "walk and talk" meetings in local parks and support group meetings in Wrexham, Conwy and Bangor, including evening events.

They also offer an online support service via a closed Facebook page. During lockdown they arranged both educational and social opportunities at a local level online. They shared activities that promoted wellbeing, capturing people's lockdown experiences, volunteering activities, crafting, garden and environmental projects. They produced a permanent record book, "Lockdown Creations," which highlights the achievements, volunteering endeavours and promotion of the mental and physical health and wellbeing of the support group members.

- Education and Training

BCU work in close partnership with Epilepsy Wales on education and training, and as an organisation Epilepsy Wales support education initiatives across BCUHB. Epilepsy Wales also support us to raise awareness of Epilepsy, its causes, treatment and ways to control the condition to the public and to Health and Social Care Organisations and Care Agencies, providing training and promoting cooperation and contact with, and between, Statutory agencies (Health and Social Care), voluntary and private sector groups. They offer free online training to adults supporting them with their well-being, and they also have a course that parents who have children with epilepsy can access too, which is free. They offer a free service called 'Epilepsy Space' which is aimed at young people aged 16-24. This was created by young people themselves to help manage their epilepsy.

- Befriending service

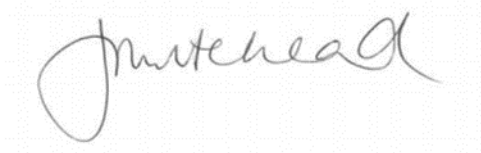
Epilepsy Wales have also started the process of setting up a befriending service for our patients.

- **Epilepsy Action Cymru**

Epilepsy Action Cymru also support our patients with Epilepsy in North Wales:

- A new course has been established which is aimed at parents called 'Your Child and Epilepsy' which is free to access.
- A new tool kit for employers has been produced which includes specified information that employers need when they recruit or anyone who has a newly diagnosis of Epilepsy.
- They also offer 'Epilepsy Space' to our young people aged 16-24
- Local and general support groups are running virtually
- New Parents and Carers support groups are running weekly. These enable parents to share their experiences worries and concerns in a safe environment.
- A new bespoke Epilepsy awareness training for Schools and employers is being delivered virtually.
- Counselling service for people with Epilepsy - Epilepsy Action Cymru are looking to create a counselling service for anyone over 18. This could be adults caring for someone with Epilepsy, or a parent of someone affected by Epilepsy. This will provide emotional support for our patients at various stages of their condition. This could be at point of diagnosis, a change in condition, or coping with living with a long-term condition.

Yours sincerely

A handwritten signature in cursive script that reads 'Jo Whitehead'.

Jo Whitehead, PSM
Prif Weithredwr/Chief Executive



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Executive Headquarters / Pencadlys Gweithredol

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Ffordd Maes-y-Coed
Caerdydd
CF14 4HH

Eich cyf/Your ref:
Ein cyf/Our ref: SR-jb-0622-9618
Welsh Health Telephone Network:
Direct Line/Llinell uniongychol: 029 2183 6010

Suzanne Rankin
Chief Executive

23 June 2022

Jack Sargeant MS
Chair
Petitions Committee
Welsh Parliament
Cardiff Bay
Cardiff
CF99 1SN

Dear Mr Sargeant

Petition P-06-1240 Improve Health Services for People with Epilepsy Living in Wales

Thank you for seeking our views on Petition P-06-1240 on the Improvement of Health Services for People with Epilepsy living in Wales.

You will recall that you posed the question "what services and resources are in place to meet the needs of people with epilepsy living in your Health Board area, and if there are any gaps in services and resources at present."

Following discussion with colleagues from our Specialist Services Clinical Board I provide the following response to your question – for convenience broken down into the sub-components of the overall question.

Services and resources in place to meet the needs of people living with epilepsy in Cardiff and the Vale

The Welsh Epilepsy Centre is based within Cardiff and Vale University Health Board ('the UHB'). It was established in the mid-1990s at University Hospital of Wales, and at that time provided services across South Wales. However, under current commissioning arrangements the UHB provides secondary care epilepsy for patients in our own and Cwm Taf Morgannwg UHB areas; this catchment population covers a population of approximately 700,000. Furthermore, current commissioning also requires the UHB to provide tertiary services (through a WHSSC funded programme), mainly for epilepsy surgery to a South Wales catchment population of 2.4M.

Outpatient activity in the epilepsy centre consists of on average 1300 new referrals each year, over 1400 under long term follow up review, along with an open access system to all patients reviewed previously. This allows patients to contact the department directly if they have concerns about their epilepsy without at times the need for outpatient appointment. Access through the telephone and email advice lines averages 5000 patient encounters per year, with most receiving instant access to care and changes in treatment where required. The suspected first seizures is an area of clinical priority for the department; NICE recommend that this patient type be reviewed within 14 days, and the current wait within the UHB is on average 22 days.

The centre delivers a multidisciplinary approach to epilepsy care and offers comprehensive services, across many platforms to include face to face and virtual. Current staffing of the centre is two Consultant Neurologists, and 4 WTE Adult Epilepsy Clinical Nurse Specialists. The Clinical Nurse Specialists are supported by the Consultant Neurologists and lead on follow-up outpatients, 1st seizure clinic, ante-natal clinics, outreach clinics at Cardiff prison, vagal nerve stimulator clinic and specialist prescribing for new treatments such as Epidiolex (cannabis oil) and Stirovento. The centre also has a unique Wales only service offering specialist assessment in the emergency unit by the epilepsy specialist nursing team, Monday to Friday, 08.30–1630 hours. The epilepsy surgery programme, pre-surgical evaluation to surgery and follow up is based in Cardiff alongside the Neurosurgery Department.

Patients with epilepsy are also seen and managed by local neurologists and learning disability specialists and teams.

The centre's close links with other departments within the UHB (paediatric neurology, psychiatry, learning disabilities, antenatal, clinical pharmacology, ophthalmology, clinical psychology, neuroradiology, neurophysiology and neurosurgery) enables patients to receive treatments most appropriate to their circumstances. It is also research active, undertaking and recruiting to various local, national and international trials to ensure patients have access to cutting edge care.

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 continue to work on refinement of an epilepsy data dashboard which will be critical to informing future understanding of epilepsy epidemiology and need.

Current Gaps in Services and Resources

Whilst the service is comprehensive and safe there are nonetheless gaps in provision.

At the onset of the COVID-19 pandemic the dedicated epilepsy outpatient facilities was stepped down, and relocated to meet national social distancing guidelines.

Presently the epilepsy centre has limited footfall available at the University Hospital of Wales, with the all outpatient activity taking place at another site (Rookwood Hospital). The essential inpatient telemetry service was suspended during the pandemic, it has now reopened but is not yet operating at pre-COVID levels. This is due to the telemetry service currently utilising a footprint within a non-neurology inpatient area. This has impacted on the epilepsy surgery programme which remains fragile. We have insufficient outpatient capacity to ensure timely new and follow up appointments.

It is notable that there is an increasing patient demand within these new and follow up appointments. This increase occurs because of an increase in the provision of medicines requiring specialist prescription or monitoring, and a change in practice to repatriate to the epilepsy centre prescriptions in all women of child bearing age taking sodium valproate.

Patients within the Cwm Taf Morgannwg UHB population access clinical nurse specialist support from the service within Cardiff. Whilst this service is comprehensive and safe there would be some merit in Cwm Taf Morgannwg UHB commissioning the service locally to enable patient access in their own locality. Cardiff and Vale UHB have recommended this option to Cwm Taf Morgannwg, and if requested we are able to provide the commissioning process with supporting data and evidence.

There is currently no psychology provision for patients within Cardiff and Vale and Cwm Taf Morgannwg Health Boards, despite there being a recommendation in NICE guidelines for the management of epilepsy in children, young people and adults. Access to psychology services would be of real benefit to the epilepsy population, particularly at the point of diagnosis. The service does mitigate the risk via regular clinical review and access to the CNS team. However, additional investment would be required to establish a service that provides comprehensive health psychology support to this patient group and work has commenced on the development of a business case for psychology support.

The service is currently experiencing increased patient demand to see a consultant neurologist which has increased the overall weeks wait for patients to be seen in a clinic setting. There are plans in place to resolve some of these issues. The clinical team have put in place several systems to address this such as:

- Open Access: Where patients with urgent clinical questions / needs can contact the clinical team and receive clinical input within 24hrs.
- Epilepsy Telephone Helpline: This service allows allow to the CNS and Medical Team to provide clinical information to other healthcare professional and patient (Monday-Friday 9am-5pm).
- Weekly Multi-Disciplinary Team Meetings at which all referrals into the department are reviewed and appointed on clinical need.

With the increase demands on the service the waiting time for patients triaged as 'routine' have increased, although for those triaged as urgent the waiting times are similar compared to periods before the pandemic and before the altered clinical pathway requiring specialist prescribing or pharmaceutical monitoring. The consultant neurologist clinical team are reassured that all patients have access to expert clinical advice via the nursing and medical teams when needed via the services listed above.

Discussions regarding the epilepsy centre footprint and outpatient recovery plans are ongoing as the UHB restore services following the pandemic response. Outpatient services will continue to be delivered from Rookwood Hospital until outpatient facilities are provided on the University Hospital Wales site. We recognise that even when the epilepsy outpatient services return to their original footprint on this site there will still be a requirement for an optimised location to encompass the whole of the epilepsy service and gain maximal benefit from the telemetry capability. The UHB are in the initial stages of developing a case for capital funding to establish a future outpatient and day case facility at University Hospital Wales.

Clear challenges have arisen from the pandemic and the essential improvements in the epilepsy care pathway necessitating increased specialist activity. Nonetheless, the Welsh Epilepsy Centre, in partnership with other Health Boards, has adapted to fit the needs of the ever changing post pandemic health service and it continues to provide the best care that it can to patients with epilepsy, their families and carers. Furthermore, the Welsh Epilepsy Centre recognises its future development needs and can, subject to capital investment, design an optimised and future proofed service.

Yours sincerely



Suzanne Rankin
Chief Executive

Mr Jack Sargeant MS
Chair
Petitions Committee
Senedd Cymru
Cardiff Bay
Cardiff
CF99 1SN

Dear Mr Sargeant

Petition P-06-1240 Improve health services for people with epilepsy living in Wales

Thank you for your letter of the 7 June 2022.

Epilepsy Services for CTM UHB are provided via the Neurology team. However, Neurology services are not provided directly by CTM UHB, but via a Service Level Agreement (SLA) from Cardiff and Vale UHB to 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.

The visiting Consultants provide a range of services including outpatient clinics, review of ward referrals, prioritising new referrals into the service and reviewing results of existing patients under the care of the service, many of whom have life-long neurological conditions and answering queries from other medical staff.

A Neurology Services review was undertaken by the Health Board's Commissioning team in March 2018 which showed significant shortfalls across the range of Neurological services. The Association of British Neurologists (ABN) suggests that there is 1 whole time equivalent (wte) Consultant Neurologist per 100,000 population. There is great disparity amongst Health

Croeso i chi gyfathrebu â'r bwrdd iechyd yn y Gymraeg neu'r Saesneg. Byddwn yn ymateb yn yr un iaith a ni fydd hyn yn arwain at oedi.

You are welcome to correspond with the health board in Welsh or English. We will respond accordingly and this will not delay the response.

Cyfeiriad Dychwelyd/Return Address:
Bwrdd Iechyd Prifysgol Cwm Taf Morgannwg, Pencadlys, Parc Navigation, Abercynon, CF45 4SN
Cwm Taf Morgannwg University Health Board, Headquarters, Navigation Park, Abercynon, CF45 4SN

Cadeirydd/Chair: Emrys Elias Prif Weithredwr/Chief Executive: Paul Mears

against the ABN standard for the number of Consultant Neurologists, outlined below:

- Aneurin Bevan has a population of 594,164 with 8 working time equivalent (wte), equating to 1 per 74,000.
- Cardiff and Vale has a population of 500,490 with 7.5wte, equating to 1 per 66,000.
- Swansea has a population of 390,308 with 11wte, equating to 1 per 35,000.
- Cwm Taf Morgannwg has a population of 448,639 with 2wte, equating to 1 per 224,000.

Regarding Epilepsy services, it is good practice to have Epilepsy Clinical Nurse Specialists providing clinical input and care to people living with epilepsy. There are currently no Epilepsy CNS dedicated to the CTMUHB population and this service is provided by Cardiff and Vale CNS's 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.

Shortfalls in Neurological provision have been highlighted in the Health Board's Integrated Medium Term Plan over the last few years but due to competing priorities have not received additional funding.

Yours sincerely



Paul Mears
Prif Weithredwr/Chief Executive



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Bwrdd Iechyd Prifysgol
Bae Abertawe
Swansea Bay University
Health Board

Cadeirydd/Chair: **Emma Woollett**
Prif Weithredwr/Chief Executive: **Mark Hackett**

gofalu am ein gilydd, cydweithio, gwella bob amser
caring for each other, working together, always improving

Rydym yn croesawu gohebiaeth yn y Gymraeg ac yn y Saesneg.
We welcome correspondence in Welsh or English.

Date: 24th June, 2022

Swansea Bay University Health Board
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Port Talbot SA12 7BR

01639 683302
WHTN: 1787 3302

Jack Sargeant MS
Chair
Petitions Committee
Welsh Parliament
Cardiff Bay, Cardiff CF99 1SN
Petitions@senedd.wales

Dear Jack,

Re: Petition P-06-1240 Improve health services for people with epilepsy living in Wales

Thank you for your letter of 7th June 2022 requesting information about the services and resources that are in place to meet the needs of people with epilepsy living in our Health Board area, and asking if there are any gaps in services and resources at present. I'm happy to respond as follows:

In Swansea Bay in 2019, we faced a serious challenge to provide an epilepsy service (for patients with a common, long-term condition characterised by sudden and unpredictable fluctuations in seizure control), with limited resources. Issues included:

- long waiting times for first appointments;
- large numbers of patients on 'follow up not booked' (FUNB) waiting lists, and
- a lack of flexibility and responsiveness in the epilepsy service.

Prior to our service changes, waiting times to be seen in epilepsy clinics were 18 weeks for urgent cases and 23 weeks for routine cases. Waiting times to see the epilepsy specialist nurses (ESN) were 20 weeks. Moreover, there was a lack of flexibility to see patients, or to offer advice, at short notice, resulting in patients presenting to A&E and unnecessary hospital admissions. A 'first seizure' clinic was established in Swansea but waiting times for this could be as long as 16 weeks. A total of 1,394 patients were on epilepsy FUNB lists.



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Bwrdd Iechyd Prifysgol Bae Abertawe yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Bae Abertawe
Swansea Bay University Health Board is the operational name of Swansea Bay University Local Health Board

We redesigned the SBUHB epilepsy service to try and overcome this challenge. In 2020, we introduced an 'Open Access' service model. This encourages patients to take ownership of their epilepsy care and reduces the number of appointments that they have to attend. Open access epilepsy clinics are designed for patients to be seen in a flexible and timely manner when their need is greatest. Instead of routine booked follow up appointments, patients are advised and encouraged to contact us via a telephone or email helpline with any issues. This helps prevent unnecessary hospital admissions and outpatient burden, and increases capacity for telephone advice and necessary follow up appointments, ensuring outpatient waiting times remain low.

Other service developments introduced during 2019-2020 included:

- providing rapid access to the first seizure clinic, for the prompt assessment and investigation of patients who have suffered a first epileptic seizure, which enabled patients to be discharged quickly from the emergency department;
- an email advice service to GPs, providing specialist epilepsy advice regarding their patient's epilepsy management (surveys have demonstrated a satisfaction rate of 98% amongst users);
- a weekly epilepsy multi-disciplinary team meeting to grade all epilepsy referrals, identifying those suitable for telephone or email advice;
- a triaging system run by an epilepsy co-ordinator who collects and screens all epilepsy referrals, monitors waiting times for appointments and maps capacity to demand, and
- development of a dissociative seizures service run jointly by a neuropsychologist and ESN.

Waiting times significantly improved:

Impact of Open Access Model		
Measure	Before	After
Total number of patients on FUNB lists	1,394	410
Total number breaching targets	784	116
Average waiting times for consultant epilepsy clinic (weeks)	21	3

Patients can now contact us immediately (via email or phone) to inform of us of changes in epilepsy control and will receive a response within 48 hours with clinical advice, including medication changes. From a patient perspective, the improvements mean:

- more virtual/telephone clinics;
- patients don't need to travel to clinic, particularly important as most are unable to drive;
- patients seen at times of need so more efficient consultations, and
- fewer non-attendances at appointments.

Regarding gaps in services and resources, the significant improvements described above have been made possible only by the appointment of a 2nd ESN and an epilepsy service coordinator. While service development is ongoing, waiting times and numbers are falling much more slowly as nurse caseload capacity has reached its limit. Even with the changes we have made, we are just about meeting demand for the most sick patients. We are failing



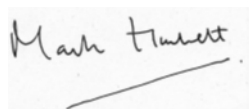
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 Bwrdd Iechyd Prifysgol Bae Abertawe yw enw gweithredu Bwrdd Iechyd Lleol Prifysgol Bae Abertawe
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to offer specialist services such as antenatal and transition epilepsy clinics across the West Wales region.

The low numbers of ESNs in Wales (1 nurse per 2,195 patients) and in our region compare poorly to the Epilepsy Action recommendation (1:250), the Steers Report recommendation (1:300) and even the RCP recommendation (1:500). This is important because, having demonstrated in Swansea Bay how a small team can adapt to meet the challenge of providing a high quality and safe service for a common, long term condition, there is an opportunity to extend the open access model with Hywel Dda UHB (HDUHB).

We would offer one service to patients with epilepsy across the West Wales region, in keeping with the principles of our unique collaboration between Swansea Bay University Health Board, HDUHB and Swansea University, A Regional Collaboration for Health. We will look at the totality of demand and capacity in the region and work with HDUHB through our partnership arrangements in developing our future service plan.

Yours sincerely,



Mark Hackett
CEO



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Vivienne Harpwood, Cadeirydd / Chair

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Addysgu Powys
Powys Teaching
Health Board

CS/PW

4 July 2022

Jack Sargent MS
Chair of the Senedd Petitions Committee
Welsh Parliament
Cardiff Bay
Cardiff
CF99 1SN

Dear Mr Sargent

Petition P-06-1240 Improve health services for people with epilepsy living in Wales

Thank you for your letter dated 7th June 2022 enquiring about the services and resources that are in place to meet the needs of people with epilepsy living in Powys, and if there are any gaps in services and resources at present.

Within Powys, our primary care services for example, general practice, are well placed to undertake routine monitoring of patients with epilepsy. For patients whose condition deteriorates to such an extent that emergency treatment is necessary, patients can access emergency care services via their local District General Hospital (DGH) in either Wales or England, depending on where they live. In terms of speciality secondary care services, including diagnostics and neurological services, if patients require specialist intervention, again these are typically provided at a local DGH. However, these services maybe further afield if services have been centralised as part of a recognised clinical network of specialist centre.

With regards to Children and Young people, the health board does not directly deliver specialist epilepsy services. Children and Young people are referred to a DGH for commissioned specialist services as required. Our health and care strategy 'A Healthy, Caring Powys' sets out our ambition to provide care closer to home, and where this is not possible due to the pathway of care, we do our utmost to support this principle in partnership

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with other health boards and Trusts. Our community paediatricians within the health board will liaise with their secondary care colleagues to support care for those children and young people who are known to the community paediatric service. Initial investigation and commencement of treatment will be undertaken by general paediatric, or neurology services commissioned from the DGHs bordering Powys.

In terms of nursing provision, the Epilepsy specialist nurse service is commissioned from the DGHs and as a health board, we identified that a link nurse would improve service provision for Children and Young People in Powys. There is currently a review to scope the requirement for establishing a role. The link nurse role enhances the current epilepsy service provided by the district general hospitals but does not replace the skill and expertise of the epilepsy clinical nurse specialist who remains responsible for prescribing care and supporting training.

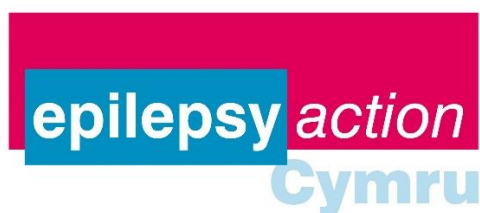
I hope this information is helpful to the Committee.

Yours sincerely

A handwritten signature in cursive script that reads "Carol Shillabeer".

Carol Shillabeer
Chief Executive

**P-06-1240 Improve health services for people with epilepsy living in Wales,
Correspondence – Petitioner to Committee, 07.10.22**



Dear Jack

Thank you for your email on behalf of the Petitions Committee. Please accept our apologies for the delay in responding to you.

We have reviewed the letters received from the Health Boards and the Minister for Health and Social Services, though we note that no response has been received from the Hywel Dda University Health Board. As this is an area for which we have significant concerns about the provision of epilepsy services it is especially disappointing that they have not provided a response.

We have used these responses, as well as information gleaned from other sources, to produce the attached report on the state of Epilepsy Services in Wales, which we will be presenting to officials in the Department for Health and Social Services. This report breaks down the epilepsy services and workforce in each health board area, as well as identifying the risks to epilepsy services in each area. We have also sought to identify instances of best practice in epilepsy services.

I appreciate that this document is too long to be fully considered by the committee members, so I have summarised the key findings in the second attached document.

In short, while we welcome the information provided by the health boards, we still have concerns about the regional discrepancies in epilepsy services, as well as the existing workforce issues. We do not believe that these will be resolved by the Neurological Conditions Quality Statement as outlined by the Minister.

It is clear that both the Department of Health and Social Services and the individual Health Boards need to do more to ensure that people with epilepsy in Wales are able to access appropriate services in a timely fashion, regardless of where they live.

The attached summary of the report includes our recommendations for how these issues can be addressed, and we would be grateful if the Committee could support us in raising these with the Health Minister and Health Boards.

We would welcome any further support the Committee can offer in addressing the issues raised with epilepsy services in Wales. We would also be more than happy to discuss these issues directly with the Committee.

Kind regards

Jan Paterson

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

EPILEPSY SERVICE PROVISION WALES

POSITION STATEMENT

5th October 2022

epilepsy *action*

Cymru

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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 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 must be noted that responses were received from all, with exception of Hywel Dda.

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

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

2.1 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 why:

- 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 as 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.

Set in context the Office for National Statistics estimates that the adult population of Wales (aged 16 and over) mid 2020 to be **2,606,856**.

Prevalence of epilepsy is approximately **0.8%** in Wales which is about **20, 850** adults with epilepsy in Wales. From the total number of available **9.5 WTE ESNs** available in Wales that equates to a ratio of **1 nurse to every 2,195 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 70 ENS in post.**ⁱ

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 47 ESN's.**ⁱⁱ

The provision of ESNs is nowhere near these numbers and is woefully short. To also note using the 2012 epilepsy population estimates in there were 39,650 cases in Scotlandⁱⁱⁱ with approximately **50 ENS, that is 1 ESN per 793 of the epilepsy population.**^{iv}

ⁱ 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

ⁱⁱ (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.

ⁱⁱⁱ Thomas, R. et al 2012. 056 Variability in adult epilepsy prevalence in the UK. Available at [056 Variability in adult epilepsy prevalence in the UK | Journal of Neurology, Neurosurgery & Psychiatry \(bmj.com\)](https://doi.org/10.1136/bmj-2012-025605)

^{iv} (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 two of the five Health Boards (see 3.0). 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 two 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.

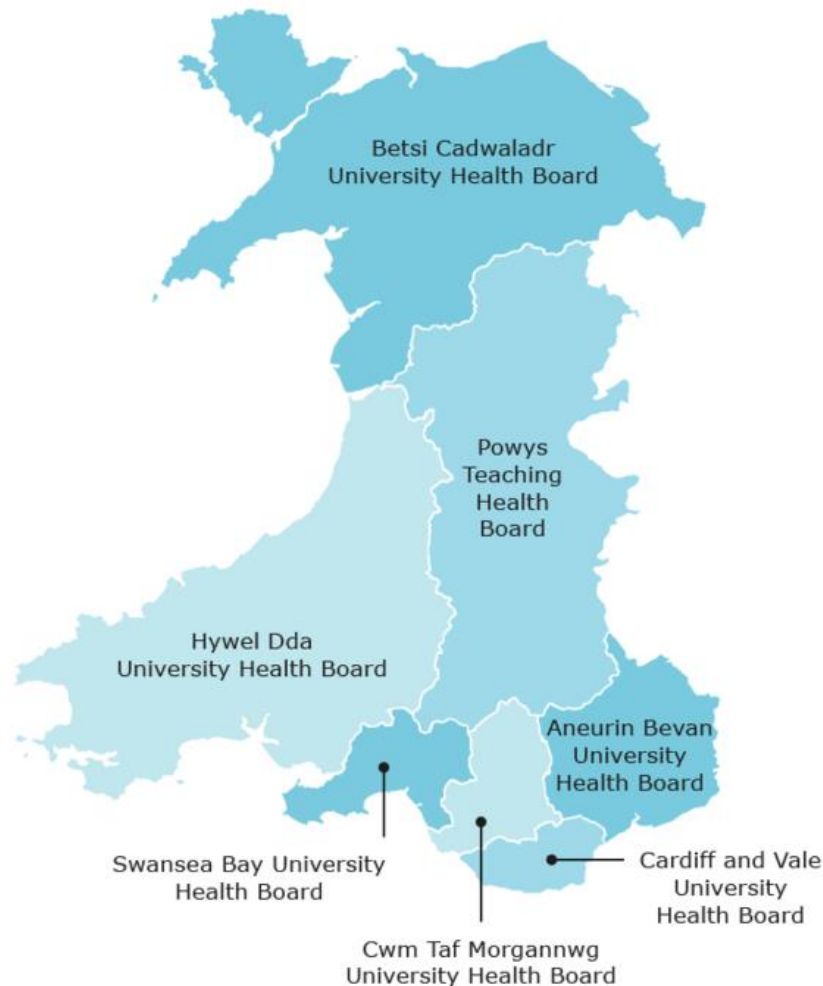
- b) A structured integrated services for the transition of young people into an adult service. The main focus being to ensure that services are available to support and monitor ongoing care and treatment to old age.

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.

2.2 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.



2.3 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](#)

2.4 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

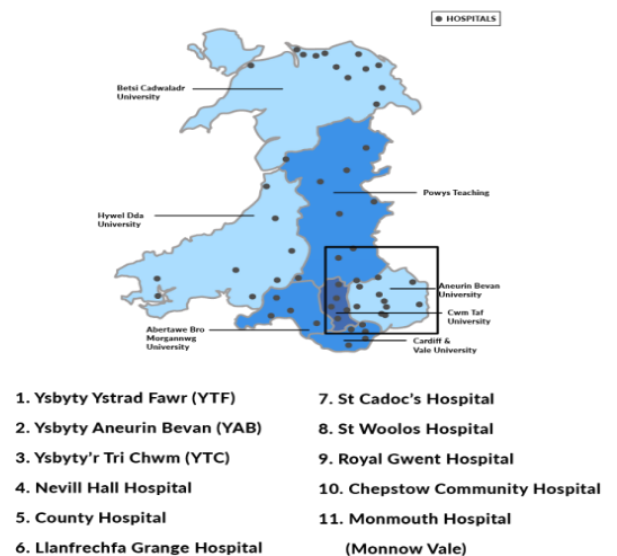
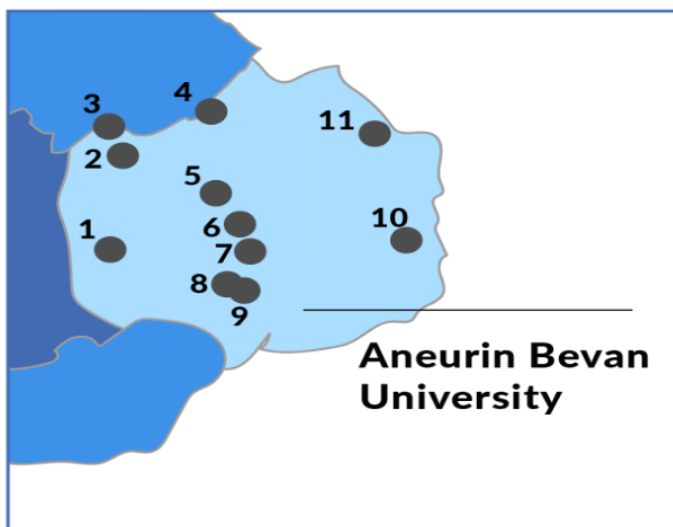
Petitions Committee’s request for information and assurance (appendix 1). It must be noted that responses were received from all, with the exception of Hywel Dda.

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.

ESN	X1 FT Adult X2 PT Adult (1 about to leave) X4 PT Paediatric
Coordinator	X1 FT HCA (Fixed Term)
Consultant	X1 Neurologist (1 day/week) X1 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. 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.

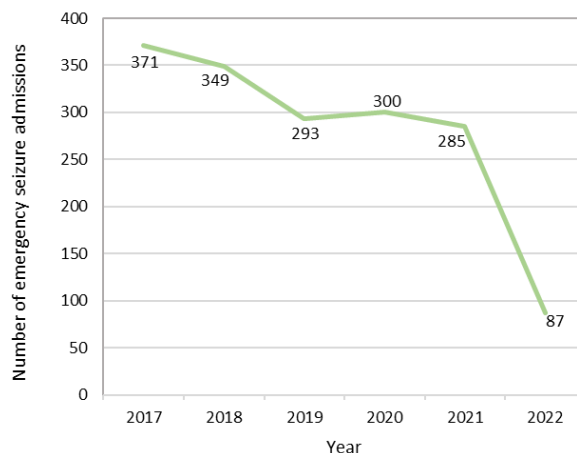
The local hub for patients and service user access is through the Royal Gwent Hospital. A transitional service is in place which is consultant led.

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



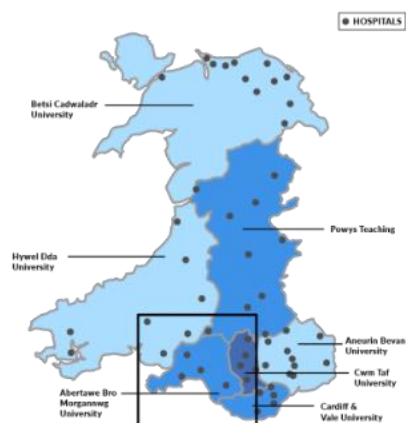
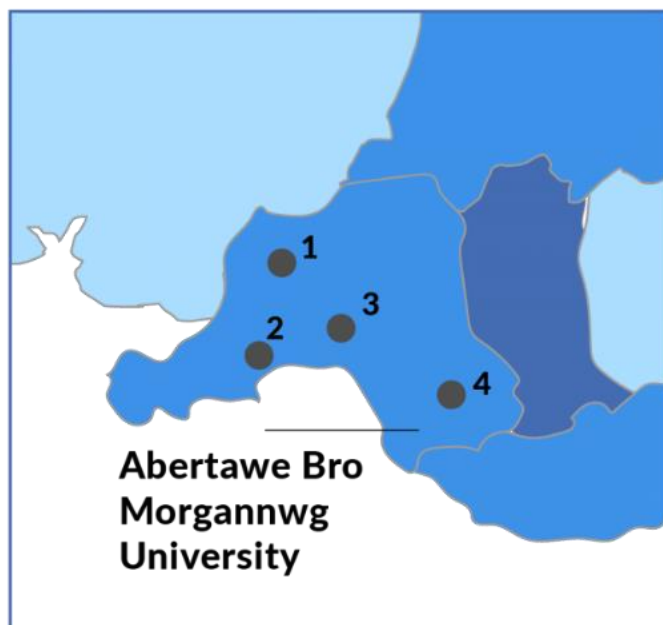
Identified Risks

- 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. Murryston 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.

ESN	X 2 FT adult X 2 FT paediatric
Co-ordinator	X1 Co-ordinator (80% FTE for epilepsy)
Consultant	3 Neurologists Dr Rob Powell Dr Owen Pickrell (60% FTE NHS) Dr 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 'Follow Up Not Booked' (FUNB) lists	1394	213
Total number breaching targets	784	39
Average waiting times for consultant epilepsy 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. This 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.

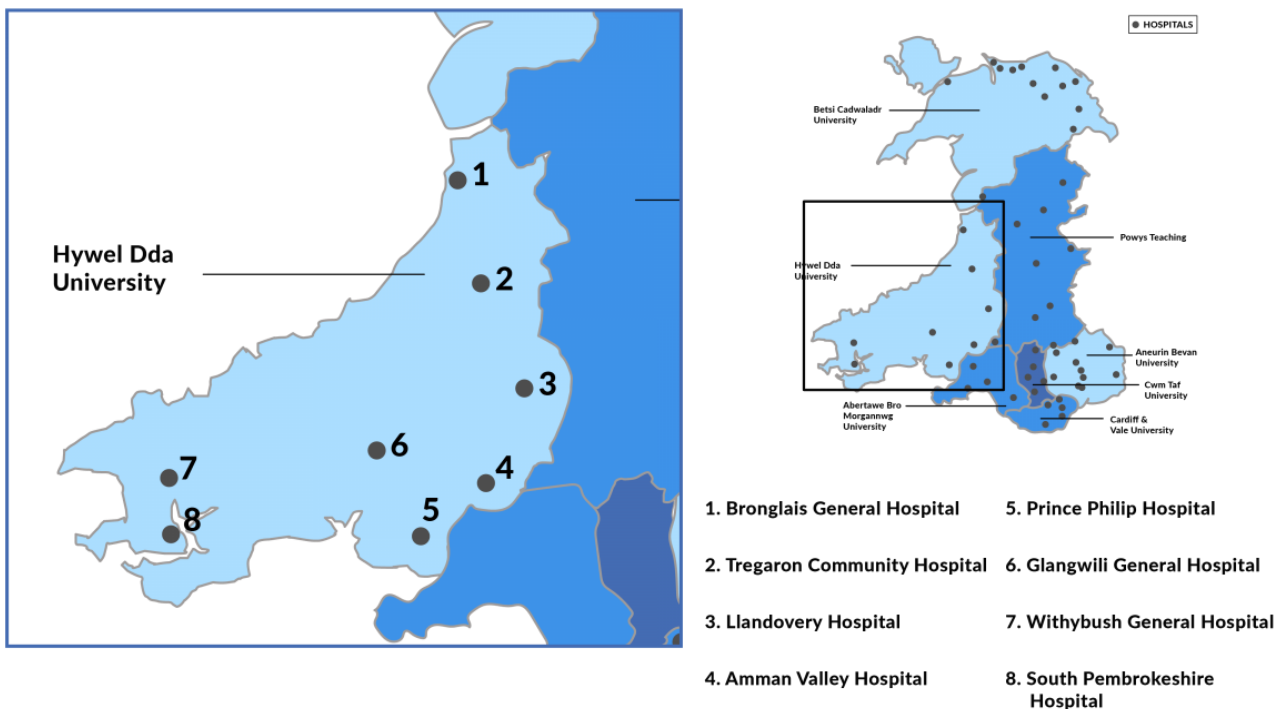
Identified Risk

- 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

ESN	x1 FT Adult x1 PT Adult x1 Paediatric (Covering 8 hospitals)
	x 1 LD Nurse
Co-ordinator	0
Consultants	X2 Neurologists – No epilepsy specialist – general neurology

Identified Risks

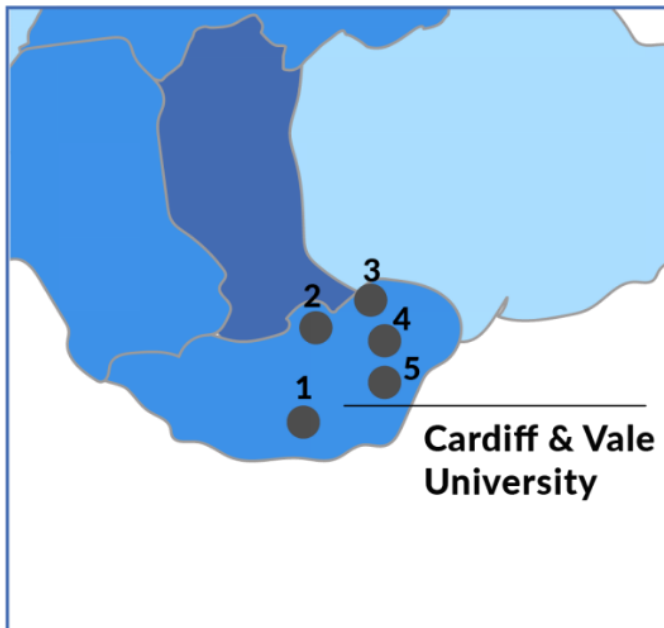
- It has the highest budget overspend of all the Wales health boards, partly due to problems attracting and retaining staff in its rural locations.
- Only one nurse allocated to deliver the adult epilepsy service
- Open clinic with only one nurse and no co-ordinator
- No response received to the Petitions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

ESN	X4WTE Adult X1.5WTE Paediatric (covers all 5 hospitals)
Coordinator	0
Consultant	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 in to a team of professionals who meet to decide which service and team is best placed to provide the correct treatment plan.

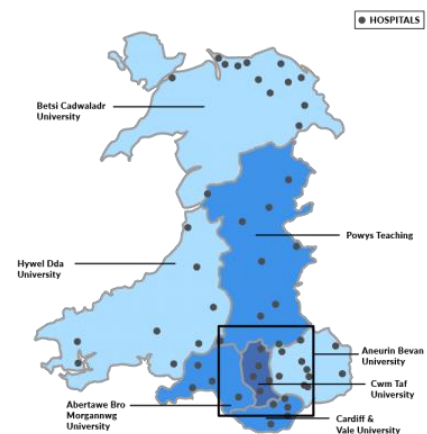
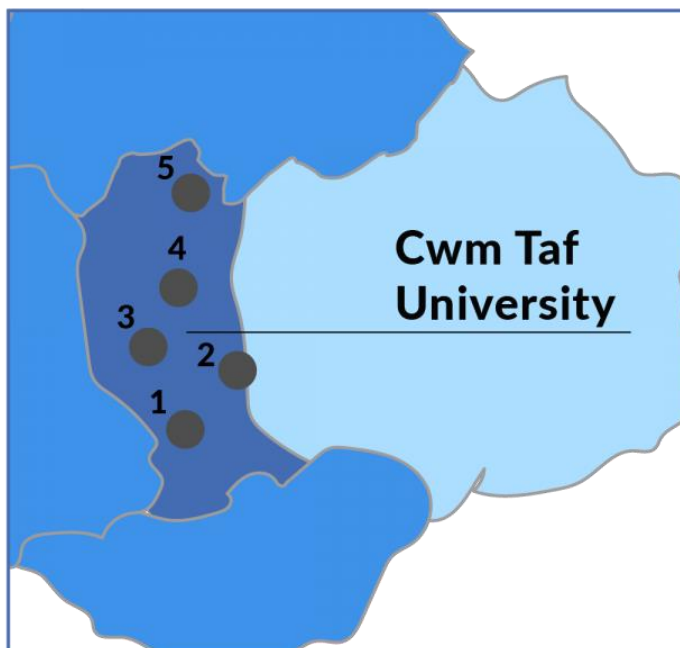
Patients are referred to see a consultant neurologist via their GP. However acute cases are directed through the emergency department.

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.

ESN	0 –integrated service with Cardiff
Coordinator	X2 WTE Paediatric - Base Cwm Taf
Consultant	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. 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.

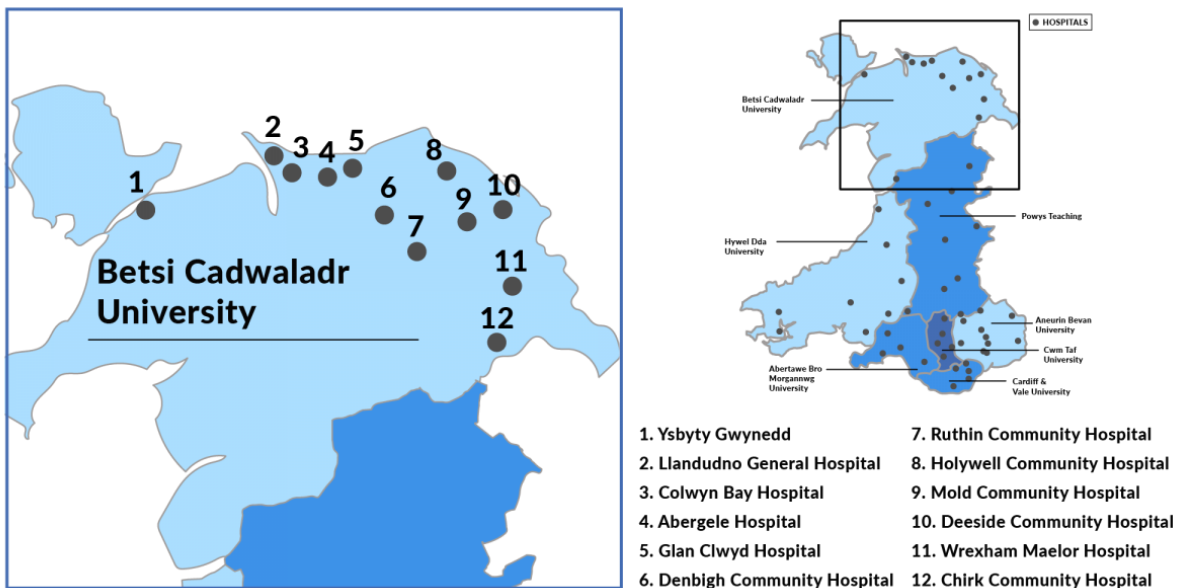
3.6 Betsi Cadwaladr UHB North Wales

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.

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

ESN	X1 WTE Adult X3 Paediatric
Co-ordinator	0
Consultant	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.

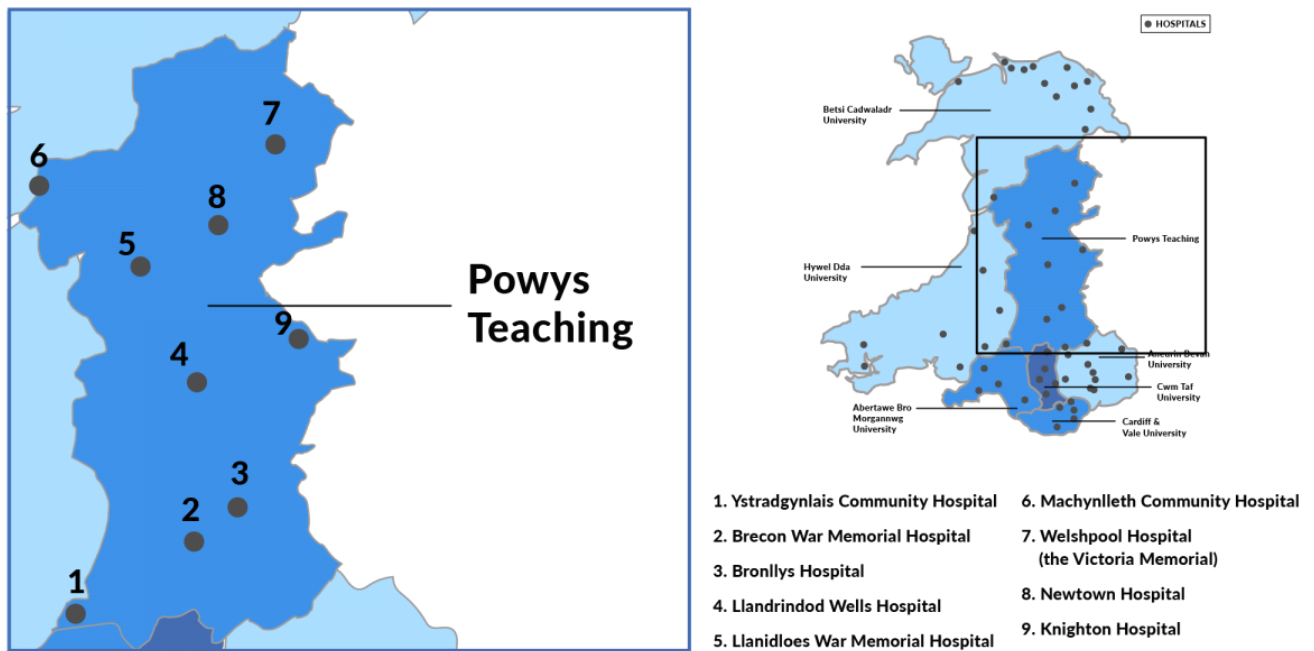
Identified Risks

- 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 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
Aneurin Bevan	<ul style="list-style-type: none"> • 6000 adults with epilepsy 	11	7
Swansea Bay	<ul style="list-style-type: none"> • 6000 adults with epilepsy 	11	4
Hywel Dda	<ul style="list-style-type: none"> • 4500 adults with epilepsy 	8	3
Cardiff	<ul style="list-style-type: none"> • 5000 active patients requiring on going management 	9	4

Cwm Taf	<ul style="list-style-type: none"> provides services to 300,000 	5	0 integrated service with Cardiff
Betsi Cadwaladr	<ul style="list-style-type: none"> approximately 5,020 adults with epilepsy 	9	4
Powys	<ul style="list-style-type: none"> 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 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

Dr Robert Powell
Dr Owen Pickrell

Agenda Item 3.4

P-06-1249 Provide a clinical pathway, medical care, and specialists for people with Tourette's syndrome in Wales

This petition was submitted by Helen Reeves Graham, having collected a total of 10,393 signatures.

Text of Petition:

Tourette's affects 1 in 100 children. It is not a rare condition. In Wales there is 1 specialist who doesn't see children.

Tourette's syndrome is a neurological disorder that affects the nervous system and causes tics. Tics are involuntary, sudden, and repetitive movements and sounds. Tourette's syndrome can be painful and debilitating.

Lots of people are unable to get a diagnosis due to no pathway or get discharged the same day with no ongoing medical care and support.

Tourette's isn't just swearing.

Additional Information:

Not getting medical care and support can lead to long term mental health problems. People with Tourette's can have difficulties with anxiety, sleep, rage and social isolation.

We NEED a proper, clear, clinical pathway and access to specialist provision and medical care for people with Tourette's syndrome in Wales.

Senedd Constituency and Region

- Preseli Pembrokeshire
- Mid and West Wales

Written Statement by the Deputy Minister for Social Services: Improvements in Neurodevelopmental Conditions Services, 6 July 2022

I am pleased to inform Members that, in addition to more than £11.5m already invested to improve autism services over the next three years, we will be making an additional £12m available to support a new national improvement programme for neurodevelopmental conditions to 2025.

This programme will support the development of timely and consistent all-age neurodevelopmental services and will include much-needed additional advice and support services for parents and carers.

This new investment follows our strong track record in investing in and supporting autistic people. Wales was the first part of the UK to publish an autism strategy in 2008 and, more recently, our statutory Code of Practice on the Delivery of Autism Services, came into effect in September 2021.

Our aim is to build on these foundations to ensure equity of services and support for people with other neurodevelopmental conditions, such as ADHD and Tourette's syndrome.

Neurodevelopmental services are under pressure, which has only intensified as a result of the pandemic. Increased awareness of autism and other neurodevelopmental conditions has led to rising demand for assessment and support, which has unfortunately led to longer waiting times and gaps in provision, which need to be addressed urgently.

To help us understand where action should be targeted, we commissioned an independent demand and capacity review. [A summary report](#) is published today. It highlights where our existing reforms have worked well, where there are gaps, and where urgent attention is needed. The full report will be published shortly.

The review confirms long-standing concerns that swifter access to support and assessment is needed. Services should be based on need rather than led by diagnosis – this echoes the Children's Commissioner for Wales' 2020 [No Wrong Door](#) report about children's mental health and wellbeing.

The collaborative working evident in the Integrated Autism Service is working well across traditional health and local authority service boundaries, providing support based on need and reflecting the social model of disability. We will build on this success, taking a whole systems approach, placing the individual and their families and carers at the centre of the care they receive.

But we have a significant task ahead of us to take forward the conclusions from the review as we develop a sustainable approach to future service delivery.

To make progress we will advance the legacy of the Together for Children and Young People's programme which worked with stakeholders to create a solid base for service improvement across assessment services. We will also build on the work of the National Autism Team; the autism leads network and the Integrated Autism Service. The views of people with lived experience will be at the centre of everything we want to achieve.

The reform programme will have three main work streams – the first taking immediate action to provide additional support to reduce some of the here-and-now pressures on assessment services, and to quickly put in place much needed support for parents and families.

The second workstream will co-produce and test models to reform neurodevelopmental condition services so they meet identified needs and are sustainable in the long term. The third workstream will develop important cross-cutting priorities, including developing a workforce strategy, improved data collection and monitoring and making the best use of digital opportunities to support services in the future.

Since taking responsibility for this area last year, I have had the opportunity to meet families and carers of children and young people with neurodevelopmental conditions. I have been struck by their resilience and determination to navigate their way through complex systems often with very little support.

I want this situation to change; to become easier. We must protect and support families so they can continue in their vital caring roles and enable their loved ones to lead fulfilling lives.

I will be monitoring delivery of our programme closely, there will be a new Ministerial Advisory Group on neurodevelopmental conditions which will provide me with advice on progress.

Over the next three years we will also be evaluating the implementation of the Autism Code of Practice to find out if we are making the positive difference to people's lives we want to achieve.

I will keep Members updated about progress.

Agenda Item 3.5

P-06-1276 Extend section 25B of the Nurse Staffing Levels Act (Wales) 2016

This petition was submitted by Richard Jones, having collected a total of 10,572 signatures.

Text of Petition:

Nurses across Wales are short of 1,719 highly-skilled, life-saving staff members. This means nursing staff give NHS Wales 34,284 extra hours every single week – and it still isn't enough. Research shows that where there are fewer nurses, patients are 26% more likely to die overall rising to 29% following complicated hospital stays. The Welsh Government should extend Section 25B of the Nurse Staffing Levels (Wales) Act 2016 to give the Welsh public the full team of nurses they desperately need.

Additional Information:

Section 25B of the Nurse Staffing Levels (Wales) Act 2016 requires health boards and NHS trusts in Wales to take all reasonable steps to maintain a specified nurse staffing level. The nurse staffing level is the number and skill mix of nurses required to provide sensitive patient care. In addition, health boards and trusts are required to inform the public of the levels of nursing staff on any ward covered by Section 25B.

When the law was first passed, Section 25B only applied to acute adult medical and surgical wards. On 1 October 2021, it was extended to children's wards. We want it to apply in all settings where nursing care is provided, starting with community nursing and mental health inpatient wards.

Follow our campaign on social media and get involved

#ForTheFullTeam.

Website: <https://forthefullteam.com>

Twitter: <https://twitter.com/RCNWales>

Facebook: <https://www.facebook.com/RCNWales>.

Senedd Constituency and Region

- Cynon Valley
- South Wales Central

Royal College of Nursing

Ty Maeth
King George V Drive East
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CF14 4XZ

Richard Jones MBE

RCN Wales Board Chair, RCN
Council Member

Telephone 02920 680703

Email Richard.Jones@rcn.org.uk

12 October 2022

Jack Sargeant MS,
Chair of the Petitions Committee
Welsh Parliament
Cardiff Bay
Cardiff
CF99 1SN

Dear Jack

I am writing to you in response to the plenary debate on petition P-06-1276, 'Extend Section 25B of the Nurse Staffing Levels (Wales) Act 2016'.

As the Chair of the Royal College of Nursing (RCN) Wales, and as the petitioner, I would first like to thank the Petition Committee for recommending our petition for debate. It is of great value to the Senedd that topics such as nurse staffing levels can be debated in plenary due to the democratic processes of the Senedd.

I'd specifically like to thank members of the Committee that spoke in favour of the petition during the debate, including Joel James MS and Buffy Williams MS.

I was pleased to hear from Joel James MS that the Welsh Conservative's wholeheartedly support the petition as in his words it is clear the 'situation nurses find themselves in is both unacceptable, and in the long term, completely unsustainable for the profession'.

Continued....

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Llywydd/President
Dr Denise Chaffer
Ysgrifennydd Cyffredinol a Phrif Weithredwr/General Secretary & Chief Executive
Pat Cullen

Cyfarwyddwr, RCN Cymru/Director, RCN Wales
Helen Whyley

Mae'r RCN yn cynrychioli nrysys a nyrsio, gan hyrwyddo rhagoriaeth mewn arfer a llunio polisiau iechyd
The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

INVESTORS IN PEOPLE®
Rydym yn buddsoddi mewn llesiant Arian

Mae'r Coleg Nyrsio Brenhinol yn Goleg Brenhinol a sefydlwyd drwy Siarter Frenhinol ac Undeb Llafur Cofestr Arbennig a sefydlwyd a dan Ddeddf Undebau Llafur (Cydgrynhai) 1992.

The RCN is a Royal College set up by Royal Charter and a Special Register Trade Union established under the Trade Union and Labour Relations (Consolidation) Act 1992.

I wholeheartedly agree with Buffy Williams MS when she voiced that nurses are the 'heart and soul of our national health services'. Buffy's statement summarising the debate, perfectly outlines the strength of feeling for the Nurse Staffing Levels (Wales) Act 2016, detailing that 'whatever party we belong to and whatever community we represent, we all want to ensure that we have the appropriate number of nurses to ensure the safety and wellbeing of patient'.

Rhun Ap Iorwerth MS also outlined Plaid Cymru's support for the petition and explaining that 'yes, requiring the Act to reach all parts of the NHS back in 2016 was asking a lot in practical terms. Well, given that we are in 2022, it's time to extend it further'.

I'd also like to thank Jenny Rathbone MS for asking vital questions regarding nurse staffing levels in community and mental health settings and the use of agency nursing. Questions such as these are important to understanding the wider debate surrounding nursing as a profession in Wales.

However, I was disappointed by the response from the Welsh Government.

Eluned Morgan MS, Minister for Health and Social Services, detailed that the Act is grounded in evidence, which I completely agree with. However, the Minister expressed that the evidence-based tools for the extension of Section 25B 'do not currently exist'. The Minister failed to recognise the tremendous work of the All Wales Nurse Staffing Programme and did not say whether this work would continue.

The All Wales Nurse Staffing Programme has been gathering the evidence needed to extend Section 25B for a number of years. Principles for district nursing were published in 2017 and have received several audits to test their validity. Principles have also been developed for health visiting and mental health inpatient wards. Unfortunately, and with deep concern to RCN Wales, the Chief Nursing Officer has expressed that she does not plan on publishing these principles. This will effectively pause the gathering of evidence and extension of Section 25B. This was not reflected in the Ministers response to the petition, nor addressed when directly asked by Rhun Ap Iorwerth MS.

Despite the response by the Welsh Government, I believe the petition has been a great successful for members of the public that support safe nurse staffing levels. The debate has shown the strength of feeling among the public, the nursing profession, and politicians for the extension of Section 25B of the Nurse Staffing Levels (Wales) Act 2016.

Continued

12 October 2022

3

RCN Wales will continue to call for safe nurse staffing levels through the extension of Section 25B of the Nurse Staffing Level (Wales) Act 2016 to community nursing and mental health inpatient wards as I know this is a top priority for the nursing profession and patients in Wales.

I'd like to thank you for your support.

Kind regards

A handwritten signature in black ink that reads "R Jones". The signature is written in a cursive style with a large, looped 'R' and a long, sweeping tail.

Richard Jones
Chair
RCN Wales Board