

Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 51

Ymateb gan: | Response from: Epilepsy Action

Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor Initial priorities identified by the Committee

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrysgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?

Q1. Which of the issues listed above do you think should be a priority, and why?

We agree that the health and social care workforce should be a priority, and for us this means increasing the numbers of both specialist nurses and neurologists.

We know from our own work that in many areas there are far too few Epilepsy Specialist Nurses. For example currently there are only two part time adult ESN in Hywel Dda UHB with a caseload of over 4000 patients between them. Providing additional ESNs would make a huge difference to the level of care for people with epilepsy, as well as reducing pressure on services in the medium to long term.

We recommend 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.



Waiting times to see neurologists are over 12 months in many areas. 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 ESPENTE report <https://www.epilepsy.org.uk/research/espente>

These nurses are an important part of the epilepsy specialist team and they often leave a huge impression on the people they care for. They are often a friendly face and a more accessible point of contact to answer questions and offer specialist advice. They also build a relationship with their patients and offer an incredible support to people. An Epilepsy Specialist Nurse's work also involves raising awareness and spreading information about epilepsy in the health service and the community.

We also know from speaking to ESNs across Wales that their current workloads can be a significant contributing factor to stress and further mental health problems. Therefore, ensuring that there are sufficient numbers of ESNs would help address concerns around the wellbeing of the workforce.

The Committee could look to carry out a survey of the workforce and services in the health service with a view to highlight gaps in provision that need to be addressed.

We also agree that access to services for long-term chronic conditions should be a priority.

This should include access to pre-conception counselling for pregnant women with epilepsy. There has long been evidence that using the epilepsy medication sodium valproate during pregnancy can increase the risk of babies born with birth defects and problems with learning and development, and recently there is increasing evidence that other epilepsy medications can also cause harm to unborn children. It is therefore vitally important that women are able to access preconception counselling so that they can make an informed decision about their medication and starting a family.

By highlighting the available research on the harm that valproate and other epilepsy medications (<https://www.gov.uk/government/publications/public-assesment-report-of-antiepileptic-drugs-review-of-safety-of-use-during-pregnancy>), and the findings and recommendations of the IMMDS "First Do No Harm" report (https://www.immidsreview.org.uk/downloads/IMMDSReview_Web.pdf), the committee can push for these to be implemented.

Blaenoriaethau allweddol ar gyfer y Chweched Senedd

Key priorities for the Sixth Senedd

C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:

- a) gwasanaethau iechyd;**
- b) gofal cymdeithasol a gofalwyr;**
- c) adfer yn dilyn COVID?**

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

- a) health services;**
 - b) social care and carers;**
 - c) COVID recovery?**
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Gwasanaethau iechyd

Health services

The Committee should prioritise the post-COVID recovery of health services. This should focus on ensuring that services get back to pre-COVID levels, and indeed the Committee should look to use learnings from the pandemic to push for services to go beyond pre-COVID levels of service. For example many services have adopted Open Access services, which when properly utilised and resourced can help to free up the time of frontline staff and services. The Committee should look to identify best practices across health services and where possible encourage these to be adopted in other areas.

In certain circumstances video or telephone consultations have proved to be very useful, both for patients and health professionals, and where possible and appropriate these should be adopted and continued. However, it is important to note that in some cases it is beneficial or necessary to hold face-to-face consultations.

Unrhyw faterion eraill

Any other issues

C3. A oes unrhyw faterion eraill yr hoffech dynnu sylw'r Pwyllgor atynt?

Q3. Are there any other issues you wish to draw to the Committee's attention?

Health inequalities, both in terms of outcomes for patients and the provision of service, is another area the Committee should prioritise. We know from a variety of research that the provision of services and outcomes for patients are worse in more deprived areas.

Inequalities reduction should be a central focus for all health services and the Committee should encourage the development of a cross-government strategy on health inequalities. This should include binding, ambitious targets to improve the nation's health and reduce inequalities accompanied by clear accountability for meeting these targets. The strategy should make faster progress across the full range of important social and economic determinants of health.

In addition, the Committee should look to analyse progress towards meeting the targets of the Neurological Conditions Delivery Plan. Many of the key points have not been delivered and the plan ends in March 2022. The Committee should look to carry out an audit of the progress and outcomes once the delivery plan has finished, in order to determine how successfully it has been implemented. This work could then influence the priorities for the next iteration of the delivery plan.