



Cynghrair Niwrolegol Cymru  
Wales Neurological Alliance

## **WNA Annual Review 2019**

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## Foreword by WNA Chair

Welcome to WNA 2019 Annual Review.

Most of the activity for WNA during 2019 has revolved around the Cross Party Group inquiry into the Neurological Conditions Delivery plan where WNA facilitated the evidence sessions across Wales. These were attended by Assembly Members, people affected by neuro conditions, carers, NHS professionals and representatives from the third sector, including members of WNA.

There is a section within this report outlining the details. The outcome of this inquiry is due to be published in early 2020 and will provide the basis for ongoing influencing and partnership work for the Alliance.

The other main arm of activity for 2019 included feeding into the Neurological Conditions Implementation Group's (NCIG) priorities, taking part in the various subgroups: Community Neuro-rehab and Paediatric Neuro services, and delivering on the Awareness Raising initiative that WNA has developed on behalf of NCIG.

I hope the reader finds this annual review informative and that members of the Alliance are encouraged by its content.

Ana Palazón  
WNA Chair  
December 2019

# Influencing Report

## Cross Party Group (CPG) on Neurological Conditions

During 2019 WNA continued to provide the secretariat for the Cross Party Group on Neurological Conditions. The Cross Party Group on Neurological Conditions decided that its focus for 2019 was to undertake an inquiry into progress made to date on implementing the Welsh Government's Neurological Delivery Plan (NCPD).

The terms of reference for the inquiry were to examine the progress made in implementing the Neurological Conditions Delivery Plan in Wales including:

- To examine the progress made on implementing the plan across each of the local health boards.
- Whether Wales is on course to achieve the outcomes and performance measures, as set out in each of the chapters of the Delivery Plan, by 2020.
- Whether patients across Wales can access the care required (for example timely diagnosis, access to diagnostics and treatments, palliative and end of life care) in an appropriate setting and in a timely manner.
- The level of collaborative working across sectors, especially between the NHS and third sector, to ensure patients receive effective person-centred care from multi-disciplinary teams.
- Whether the current level of funding for neurological services is appropriate, used effectively and provides value for money.

Written evidence was submitted to the inquiry by a wide range of stakeholders, including:

- Individuals living with neurological conditions;
- Charities representing people affected by neurological conditions;
- Royal Colleges;
- Wales Neurological Alliance (WNA); and
- The Neurological Conditions Implementation Group (NCIG)

Three oral evidence sessions were held, their purpose was to capture the views and experiences of a range of stakeholders about the implementation and impact of the Neurological Conditions Delivery Plan. They also provided an opportunity to discuss practical solutions for future action. Attendees were asked to discuss the following:

**Question 1:** Do you feel the Neurological Conditions Delivery Plan has delivered enough change for people with neurological conditions in Wales? Can you give examples to illustrate your answer?

**Question 2:** In what ways do you think the Neurological Conditions Delivery Plan has been most successful? Can you give any examples?

**Question 3:** In what ways do you think the Neurological Conditions Delivery Plan has been least successful? Can you give any examples?

**Question 4:** Do you have any suggestions for future action which could be taken to improve treatments, services, and support for people with neurological conditions in Wales?

**Question 5:** Do you have any comments on the current level of funding for neurological services in Wales? What are your views on whether funding for neurological services is used effectively and provides value for money?

**Question 6:** Do you have any comments on the way in which the NHS works together with other organisations, like charities, in providing person-centred care to people with neurological conditions?

The meetings were held on 4<sup>th</sup> July and 4<sup>th</sup> October, a further session was held on 14<sup>th</sup> November for members of the Neurological Conditions Implementation Group to give evidence.

The following recommendations were made as a result of the inquiry:

Recommendations for the current NCDP

In order to deliver the objectives of the current plan and respond to the concerns raised during this inquiry, we recommend that NCIG and Local Health Boards (LHBs) should be asked to commit to the following:

1. Deliver specific commitments related to the outcome indicators within the NCDP by the end of 2020, and that regular information on progress is publicly available. This should include the delivery of:
  - Comprehensive education frameworks
  - LHB Neurological Conditions Service User Groups
  - The Patient Reported Outcome Measure (PROM)
  - The Patient Reported Experience Measure (PREM)
  - A one stop shop information portal
2. Ensure that the Annual Statement of Progress reports delivery against the actual outcome indicators included within the NCDP, using any management data available.
3. Ensure that information on outputs and activity related to the NCDP is publicly available.

## Recommendations for the next stage of neurological services improvement

We urge **Welsh Government** to take the following action when the NCDP comes to an end in 2020:

1. End the '*chronic underfunding*' of neurological services by increasing investment in health and social care services to meet the needs of people in Wales.
2. Create a new neurological conditions strategy and action plan with clearer outcomes and a stronger accountability structure.
3. Commit to a workforce development and commissioning strategy to ensure there are adequate numbers of specialist staff within Wales to meet the needs of people with neurological conditions in a timely manner and an appropriate place.
4. Establish a national system for the collection, collation, and publication of outcomes data on neurological services, working with the research community, people with neurological conditions and the third sector.
5. Convene a scrutiny and oversight group to hold LHBs to account for the delivery of the plan, to separate accountability from delivery.
6. Establish a permanent all-Wales forum for neurological conditions which can promote best practice and drive improvement based on the current NCIG model. This should include funded posts for a Clinical Lead and a coordinator.
7. Create a new co-production and participation strategy that mandates and requires NCIG and LHBs to demonstrate the active participation of people with neurological conditions and carers in decisions about improvements to care and support at a national and local level.
8. Ensure all LHBs publish Progress Reports against the outcomes of this plan which are easily accessible on LHB and Welsh Government websites, in the context of this simplified outcomes framework.
9. Mandate that each LHB should have:
  - A Neurological Steering Group with cross sector representation;
  - A Neurological Conditions Service User Forum, or other mechanism to support service user participation;
  - A named neurological lead; and
  - Full attendance by the lead or deputy at each NCIG meeting.
10. Explore ways in which Welsh Government can put into effect measures to ensure social care engagement in the delivery of the plan.

A copy of the full report is available on request.

## **Meeting with the Cabinet Secretary for Health and Social Services**

WNA's annual meeting with the Minister for Health and Social Services did not take place due to ministerial diary clashes. Instead the issues that were due for discussion were addressed via correspondence. A copy of the correspondence is included as appendices at the end of this report.

# **Awareness Raising & Patient Reported Experience Measures - PREMs**

The Project Officer was recruited and took up post in January 2019. Initially the work focused on awareness raising using the guidance from the Pier Head event (reported on last year's review) which included raising awareness in primary care and A and E departments.

A series of five short videos where people living with neurological conditions were asked to tell their stories was commissioned. The stories have since been shared widely and are available on the WNA website as a training resource for the NHS and social care to use.

With the help of a student from Cardiff University the website was updated and refreshed to include the links of all partner organisations to provide information of quality sources of information and support that is available to people supporting individuals. The website was also made accessible to all using current accessibility guidance.

In the latter part of this year (2019), the Project Officer tested an adapted set of PREMs questions based around the generic set of PREMs questions. This was thought to make it simpler and easier to make comparisons with other conditions. There were also four questions directly based on neurological conditions looking at diagnosis. These questions could be changed or adapted for different conditions in order to improve their services. This was tested and feedback received confirmed that this was straightforward and less demanding than the much longer set of questions that was tested originally.

Looking forward the WNA is planning to collaborate with Master's students from the School of Journalism, Media, and Culture at Cardiff University. This will be to develop and run a social media awareness raising campaign with people sharing their personal experience of living with neuro conditions.

# Management & Governance

## Sub-committee Report

This year we introduced the WNA Facebook page and upgraded our website working in partnership with Cardiff University through its student volunteer and work placement scheme. This upgrade facilitated the inclusion of the video stories that were filmed with people with neurological conditions who shared their personal experiences as part of the Awareness Raising project.

As highlighted earlier, our collaboration with Cardiff University also enabled the website to become the single, accessible repository of the many professional learning, information, and training resources that member organisations have for the various conditions. Colleagues from the NHS will be able to access these professional resources in one single location.

The review of membership fees that was implemented last year, in 2018, resulted in a more stable financial position for WNA during 2019. The Executive committee is very grateful to all members for this and to those who have also provided additional voluntary donations. However, we will still need to raise additional funds during 2020 in order to maintain current activity beyond 2022.

Membership: The Executive committee welcomed Kevin Thomas from MND Association who re-joined the committee in 2019.

For various reasons, the following organisations left the alliance: Stroke Association, Different Strokes and Progressive Supra Nuclear Palsy Association. We are grateful for their input over the years.

## **Income Generation Sub-committee Report**

Earlier in the year we contracted an independent funding consultant with whom we crafted an application to the national lottery to secure a grant that would enable an increased capacity for our Coordinator and, therefore, be able to deliver on the additional benefits that were identified in the survey completed by members. Unfortunately, the bid was unsuccessful. The Income Generation sub-committee will be regrouping to resubmit a refreshed application.

Also, in relation to income generation, we had confirmation from the Neurological Conditions Implementation Group (NCIG) that the funding for the Awareness Raising programme would be extended to end March 2021. This work includes providing basic information resources to the LHBs to develop their co-productive patients' forums.

However, WNA Executive committee members agreed that the participation of patients in service design and having a strong voice should be a priority. Therefore, we will be working over 2020 to secure funding from other funders to be able to deliver a holistic approach to this work in the longer term.

## Treasurer's Report

<b>WNA accounts from 1 January 2019 to 31 December 2019</b>		
<b>Opening bank balances</b>		
<b>01 January 2019</b>		
	BMM account	<b>£0.25</b>
	Community account	<b>£16,710.37</b>
	<b>Total</b>	<b>£16,710.62</b>
<b>Income for the year</b>		
	Membership fees	£5,355.00
	Cardiff University	£612.50
	<b>Total</b>	<b>£5,967.50</b>
<b>Expenditure for the year</b>		
	Diane Gleeson Co-ordinator fees	6885.80
	Catering Welsh Assembly CPG meeting	£179.94
	AGM room hire and buffet	£173.43
	Postage	£37.14
	Web hosting	
	<b>Total</b>	<b>£7,276.31</b>
	<b>Bank balance</b>	
	BMM account	<b>£0.25</b>
	Community account	<b>£15,401.56</b>
	<b>Total</b>	<b>£15,401.81</b>

## WNA Executive Committee Members & Staff 2019

Name	Organisation	Position
Ana Palazon	Parkinson's UK	Chair
Lynne Hughes	MS Society	Co-Vice Chair
Carol McCudden	Ataxia UK	Co-Vice Chair
Ann Sivapatham	Epilepsy Action	Treasurer
Dave Maggs	Headway	Member
David Murray	The Cure Parkinson's Trust	Member
Kevin Thomas	MDNA	Member
John Meredith	Dystonia Association	Member
Kate Steele	Shine	Member
Rebecca Brown	WNA Awareness Raising Project Officer	<a href="mailto:Rebecca.brown@mssociety.org.uk">Rebecca.brown@mssociety.org.uk</a>
Diane Gleeson	WNA Coordinator	<a href="mailto:wnacoordinator@gmail.com">wnacoordinator@gmail.com</a>

## WNA Membership 2019

Member name	Type
Ataxia UK	Full
Brain Injury Rehabilitation Trust	Full
British Polio	Full
Chartered Society of Physiotherapy	Associate
Child Brain Injury Trust	Full
College of Occupational Therapists	Associate
Dystonia Society	Full
Epilepsy Action Cymru	Full
Epilepsy Wales	Full
Headway Wales	Full
Huntington's Disease Association	Full
Motor Neurone Disease Association	Full
Multiple Sclerosis Society Cymru	Full
Muscular Dystrophy UK	Full
Neuro Therapy Centre	Full
Parkinson's UK Cymru	Full
Shine Cymru	Full
SWWNA	Reciprocal
The Brain Tumour Charity	Full
The Cure Parkinson's Trust	Full
The Neurological Alliance	Reciprocal
Welsh Association of ME & CFS Support (WAMES)	Full

Further information regarding membership of the WNA is available from the WNA Coordinator [wnacoordinator@gmail.com](mailto:wnacoordinator@gmail.com)

# Appendix 1

## Letter to Health Minister (sent as an email)

**From:** Lynne Hughes  
**Sent:** 30 September 2019 17:51  
**To:** 'Correspondence.Vaughan.Gething@gov.wales'  
<Correspondence.Vaughan.Gething@gov.wales>  
**Subject:** Wales Neurological Alliance

Dear Minister

We were disappointed to have another meeting cancelled with you, and given that it has been some time since we met with you thought it would be helpful to outline some of the issues that we would have raised with you at the cancelled meeting:

### **Neurological Delivery Plan**

We welcome the appointment of a clinical lead and are interested in the Minister's views on the impact to date of this appointment.

The WNA has been involved in the development of the PREMS to date, though this work has stalled for the last six to twelve months, though we are hopeful that this will now pick up pace again. How does Welsh Government intend condition specific PREMs to sit alongside the validated national set of PREMs to be used across all specialities and settings that have been developed by the NHS Wales PROMs, PREMs and Effectiveness Programme.

As you know the Cross Party Group on Neurological Conditions is undertaking an Inquiry into the implementation of the Government's neurological Delivery Plan, written evidence has been submitted from charities, people living with neurological conditions and Royal Colleges. Two oral evidence sessions will also have been completed by the end of October. We hope the Minister will be willing to discuss the findings of the Inquiry when they are published early in 2020.

Does the Minister have any further information regarding NCDP post 2020. We have obvious concerns that neurological services are often a Cinderella service and worry that without a specific plan and focus that the needs of people living with neurological services will get an even poorer service than they do now.

There continues to be no Local Authority representation on the Neurological Conditions Implementation Group, despite the WNA raising this at several meetings with yourself and officials.

### **Workforce planning**

There continue to be recruitment issues in various Health Boards, for example Specialist Nurses (Parkinson's/ Epilepsy/ Paediatric Epilepsy) in Hywel Dda despite previous assurances these continue to be vacant.

Cwm Taf have still not recruited to the Neurorehabilitation Co-ordinator and there are no longer clinics for people with migraines at UHW (these used to be held by a GP with a specialist interest who has now retired). We hear anecdotally that clinicians are at breaking point.

### **Access to medicines/ treatments**

The Dystonia Society continue to be very concerned that there isn't a plan for sustainable neurotoxin injections for South East Wales, they welcome your involvement to date and would ask that you continue to monitor the situation.

The MS Society are pleased to see that Ocrelizumab is now available for a small number of people with primary progressive MS in Wales, and given that clinicians have raised concerns that they will not have access to the infrastructure to support its prescription e.g. MRI scans, clinic times, follow up etc. would ask that the Minister seek assurance from LHBs that the infrastructure is in place.

We are also disappointed about the decision this week by the NICE's decision to refuse to make the treatment erenumab (Aimovig) available for use for chronic or episodic migraine on the NHS. We would ask that, as Health Minister you take steps to improve the treatment options available to the many thousands of people living with chronic migraine in Wales by making erenumab available on the NHS in Wales, in the same way you intervened to improve access to PrEP in Wales. Please will you work with the All Wales Medicines Strategy Group and with the pharmaceutical company manufacturing erenumab to ensure people in Wales have the same access to this new treatment as people in Scotland. The decision by NICE not to recommend erenumab's use on the NHS in England and Wales is a devastating blow for everyone living with chronic migraine.

We have attached the recent *No time to waste – Continuing NHS Healthcare for people with MND in Wales report* which describes the experiences that people with MND and their family/carers can have in relation to Continuing NHS Healthcare (CHC), and would appreciate your views on the recommendations outlined within.

With best wishes  
Lynne  
(on behalf on WNA)



Llywodraeth Cymru  
Welsh Government

## Appendix 2

### Letter from Health Minister

Vaughan Gething AC/AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Ein cyf/Our ref VG/07977/19  
Lynne Hughes lynne.hughes@mssociety.org.uk

28 October 2019

Dear Lynne,

Thank you for your letter of 30 September on behalf of the Wales Neurological Alliance. Please accept my apologies for not being able to meet with you on 2 October, this was due to unforeseen changes to my diary concerning matters relating to Brexit. I look forward to meeting you on 25 March 2020, in the meantime I have responded to the various points raised in your letter below.

#### **Future of Delivery Plans**

A Healthier Wales committed to a review of national delivery groups and their funding as well as the creation of an NHS executive function and a national clinical plan.

I have announced that the new NHS Executive will take the form of a Special Health Authority, using powers under the NHS Wales Act 2008; this was also the preferred governance model proposed by the NHS Chairs group. The aim is to create an organisation that provides the strong leadership and strategic direction which any complex system requires if it is to be capable of change. It will ensure a consistent approach to planning, priority setting based on outcomes, performance management and accountability. It will both support and challenge health organisations in Wales and facilitate the development of capacity and capability across the systems.

Work on a National Clinical Plan is ongoing and will embed prudent healthcare philosophy into how clinical services are designed, planned and developed across Wales over the next decade. The Clinical Plan will aim to provide the mandate for a national approach to configuration of some of our most vulnerable and fragile specialist services, providing validation and empowerment in the system for anticipated change and transformation. It will empower shifts in settings, emphasising prevention and care in the community and will provide clear examples. It will also adopt broad principles of national leadership, describing patient outcome-based design and planning of services.

Quality improvement and integrated health pathways will guide planning at a national level and localised pathways at the Health Board level.

The future of delivery plans beyond 2020 will therefore need to align with both the NHS Executive and the national clinical plan and I intend to make an announcement on our intended way forward later in the autumn.

In the meantime, my expectation is for Health Boards to continue to implement the plans and to align them with the IMTP process.

### **National Clinical Lead**

The Neurological Conditions Implementation Group (NCIG) is responsible for overseeing the implementation of the delivery plan and I am delighted it is now supported by the national clinical lead for neurological conditions; Michelle Price, a Consultant Therapist for Stroke and Neuro-rehabilitation in Powys Teaching Health Board. Michelle's appointment coincided with a 6 month sabbatical that she had planned a number of years earlier. I am confident that now Michelle is back in work full time, we will be to see the benefits that having a dedicated clinical lead brings.

### **Social Services Representation on NCIG**

I am pleased to be able to advise that Chris Humphrey, Head of Adult Social Services for Newport will be attending future meetings of the Neurological Conditions Implementation Group.

### **Cross Party Group (CPG) on Neurological Conditions**

Unfortunately, I am unable to attend the CPG meeting on 14 November, but I have confirmed that I will be providing written evidence in advance of the meeting. The CPG final report is due to be published early next year and I will be responding accordingly. I am also happy for this to be an agenda item when we meet next year.

### **PROMS/PREMS**

I understand NCIG's intention is focused on the development and testing of a patient reported outcome measure (PROM) and a patient reported experience measure (PREM), to ensure a co-productive, outcome focused approach, in all of our Delivery Plan priorities. The PREM is being developed further in response to evaluation by the Welsh Neurological Alliance. The PROM is being developed with the Stroke Implementation Group with a view that this will apply across all patients. The national platform developed by the NHS PROMs, PREMs and Effectiveness Programme can provide an electronic platform upon which PROMs can be collected. The national platform is in the process of developing a standard PREM that could be used across a number of different health conditions. We will need to work with them to understand the requirements of the neurological PREM and how this is to be administered before deciding how the two can sit together.

## **Workforce**

Health Education and Improvement Wales (HEIW) and Social Care Wales are developing a long term high level national workforce strategy for health and social care. The strategy is being developed in partnership with the NHS and local government, the voluntary and independent sectors as well as regulators, professional bodies and education providers. This will provide a more strategic framework for planning and developing the workforce including recruitment and retention.

## **Access to Medicines/treatments**

In Wales, we take an evidence-based approach to decide which treatments should be routinely available. To do this, we rely on the expert advice of NICE and our own appraisal body, the All-Wales Medicines Strategy Group (AWMSG). These two bodies analyse the clinical benefits and the cost charged by the manufacturer to assess if the benefits are in balance with the price the NHS has to pay. In doing this, they take advice from expert clinicians and take account of patient views.

As you are aware, NICE draft guidance does not recommend Erenumab as an effective use of NHS resources. This is because NICE's Appraisal Committee has concerns regarding both the clinical and cost effectiveness of this treatment.

In terms of cost effectiveness estimates for Erenumab are higher than that which NICE usually considers to be acceptable. In regards to its clinical effectiveness, the Committee had concerns regarding its long-term effectiveness. The Committee's conclusion is based on the best available evidence. As noted, we are guided by this independent and evidence based approach.

In respect of Ocrelizumab and your comment that concerns have been raised by about the necessary infrastructure to support provision, the Director General for Health and Social Services, Dr Andrew Goodall CBE recently wrote to all Health Board Chief Executives about their compliance with the New Treatment Fund. It was specifically noted that the availability of the medicines made available via the Fund is dependent on additional capacity being available before they can be prescribed.

All Health Boards gave assurances about their processes, with some acknowledging improvements had been made since a previous request had been made by the Welsh Government. We do recognise the importance of ensuring these processes are sufficiently flexible and robust to respond to increasingly complex requirements and of planning investments to support continued delivery against the 60-day deadline. Officials will therefore continue to monitor this compliance.

## **'No Time to Waste' report**

Finally, thank you for sharing the 'No time to waste' report. I very much value the support and cooperation of the Motor Neurone Disease Association in helping the Welsh Government deliver on its commitments in A Healthier Wales. The third sector has a key role to play in the effective delivery of complex care and support services and I am keen to ensure that the Welsh Government supports you in this task. The publication of their report was both informative and timely. I recognise that CHC arrangements need to be looked at and the public consultation on proposed policy revisions to our National Framework for the Implementation of Continuing NHS Healthcare in Wales ("the Framework") closed on 19 August. I will be considering the outcome of the public consultation in due course and a summary report on the consultation of the revised Framework will be published in November 2019.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive style with a large initial 'V' and a long, sweeping tail on the 'g'.

Vaughan Gething AC/AM  
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services