'All documentation around the Welsh Government Department of Health and Social Care's Neurology/Neurological conditions steering group between January 2020 and December 2022'

Neurological Conditions Implementation Group – 2020-22

Neurological Conditions Implementation Group –

8 June 2021

GIG CYMRU NHS WALES | Grŵp Gweithredu Amodau Niwrolegol Neurological Conditions Implementation Group

Neurological Conditions Implementation Group Meeting
Notes of meeting
9th March 2021
14:30-16:30
Via MS Teams

Author: Lyn Kenway	**Version:** 0a

Members present:

Name	**Designation**	**Organisation**
Ana Palazon (AP)	County Director/Chair	Parkinson's/WNA
Annette Morris (AM)	Director Of Neurosciences	BCUHB
Chris Hodcroft (CH)	Consultant, Acute Medicine	CTMUHB
Claire Nelson (CN)	Assistant Director of Planning	CTMUHB
REDACT – WG OFFICER	Policy Lead, Population Health	WG
Hywel Morgan (HM)	Implementation Groups Manager	NHSWHC
Khalid Hamandi (KH)	Consultant Neurologist	CVUHB
Liz Kenward (LiK)	Specialised Planner Neurosciences and Complex Conditions	WHSSC
Michelle Price (MP)	National Clinical Lead for NCIG	NHSWHC
Rebecca Brown (RB)	Project Officer	WNA/MS Society
Rita Stuart (RS)	Service Delivery Manager	HDUHB
Robert Powell (RP)	Consultant Neurologist	SBUHB
Tom Hughes (TH)	Consultant	CVUHB

1. **Welcome and introductions**	
MP & HM welcome all to the meeting and apologised for minutes not being available in a timely manner due to IT issues.	**Action**
2. **Apologies for absence**	
Apologies were received from Alison Shakeshaft, David Heyburn, Jonathan Whelan, Lynne Hughes, Peter Skitt, Sarah Lloyd, Stuart Bourne, Victoria Deakins, and Yolanda Battanaga.	
3. Minutes of previous meeting	

MP shared the notes and actions from the last meeting via Teams. All items from the action log were noted to be on the agenda for further discussion.	**Action**
4. Action Log	
Action card shared and noted.	**Action**
5. WG Response to the CPG Report on Neurological Conditions	
MP recapped that the initial draft of the CPG enquiry report into Neurological Conditions were previously circulated to the group. MP and Chris Jones, Deputy Medical Director attend the CPG on 10th December and gave a verbal response to the CPG recommendations and a written response was also submitted. Of the 10 recommendations, 6 were accepted, 2 accepted in part and 2 rejected. MP discussed further the reasons for the rejection of the recommendations around funding and scrutiny. GH reported that there was a recognition that neurological conditions were not funded as well as other areas and advised that discussions around this would continue once a new government was in place. MP highlighted that it was difficult to ascertain how much money was currently spent on neurological conditions given a patient will access many different services. The second recommendation rejected was around scrutiny and delivery of the Neurological Conditions Delivery Plan and the effectiveness of NCIG as a group at driving change, and delivery improvements. MP recognised that whilst the recommendation for a separate scrutiny board was rejected new plans were underway as part of the new NHS Executive functions, the National Clinical Plan and framework and the development of potential Quality Statements. GH explained that the National Clinical Plan and Quality Statements from Cancer and Cardiac were likely to be published before the election period. The Quality Statements form part of the range of tools to support the delivery of the National Clinical Framework, including new workforce and digital strategies and a Quality & Safety Framework. The QS are not designed to replace the Delivery Plans but instead provide high-level intentions from WG and will be underpinned by a delivery plan that would be NHS owned and delivered with support from the NHS Executive. The group would be involved in the development of the Quality Statements and any delivery plans that come from them. AP highlighted the need to ensure that the neurological conditions community are involved in the drafting of the QS following comments citing two very different experiences of such within the cancer and cardiac communities and that the recommendations that have been accepted by WG from the CPG enquiry are included.	**Action**
6. Epilepsy T&F Group Update	
RP shared a presentation on the work undertaken by the Epilepsy & Seizures task & finish group, which detailed the priorities of the group and the work undertaken. 1. All Wales Epilepsy Pathway - The All Wales Adult First Seizure & Epilepsy Management Pathway was shared with the group. 2. Epilepsy mortality and SUDEP – RP highlighted the letter from the Lead Medical Examiner for Wales and the Deputy CMO and the inclusion of sudden epilepsy death/SUDEP in the Wales bereavement pathway. 3. Epilepsy PROM's and PREM's – R shared the agreed list of PROM's and PREM's which included: PQ9, HADS, quality of life, medication and seizure frequency and noted that there was varying degrees of success with implementation across Health Boards. The task & finish group has now come to an end however will continue to work together as an Epilepsy Clinical Network with meetings 4 monthly and a rotating chair and hope to hold a national event to publicise the Epilepsy Pathway. GH offered to help facilitate wider engagement with primary care. Discussions around including epilepsy on the national dashboard as a way of monitoring services and identifying inequalities are underway and the group recognised the importance of quality data for service improvements and the challenges faced to date in this area.	**Action**
7. Feedback from the Neuro-Rehab T&F Group	
The Neuro-Rehab group was set up in March 2019 with the following priorities: 1. Neuro-rehab evaluation framework for community neuro-rehab which seeks to evaluate services in a standardised way even though they may delivering	**Action**

different interventions, to differing population. The previously developed PROM's and PREM's for neurological conditions were included as was the work around using technology. It was agreed that those services funded through NCIG would utilise the evaluation framework and the PROM & PREM as a basic data set with a view to creating a national data dashboard with the Value Based Health Care team. 2. Directory of Neuro-Rehab Services - The need for clarity around what the different neuro-rehab services are, who they are aimed at and what the referral pathways are was raised. It was agreed that the document would be further populated over time. Work around the Clinical Leadership Programme & spasticity management was also highlighted. **Action 20210309/7.1:** Each HB management & clinical lead to review the Directory of Neuro-Rehab Services for accuracy and content. **Action 20210309/7.2:** The Directory of Neuro-Rehab Services to be published on the WNA website. MP confirmed that the group would cease as a task & finish group and would instead meet as a network/community of best practice.	**7.1** **7.2**
8. Feedback from the Paediatric Neurology T & F Group	
Apologies were sent from Johann Te Water Naude. MP explained that the group had not been particularly successful and recognised that this was due to a lack of consistent HB representation within the group due to smaller numbers of paediatric neurologist in general and no clear deliverables.	**Action**
9. NCIG Finance Update	
HM shared a financial update with the group. Of the £1.3m budget, £22,750 was left unallocated for this financial year. It was suggested that next year the unallocated amount be utilised to support the WNA post and development of the website. **Action 20210309/9.1:** All HB management representatives to ensure that year-end invoices are submitted. The issue of communication around the non-recurrent funding was raised and it was confirmed that WG were aware that the removal of this funding, which provides core services, would be of significant concern. It was also highlighted that clarification around this funding would likely not happen, until the new Welsh Government was in place, and that a decision would be pushed for as soon as possible. **Action 20210309/9.2:** Annette Morris to forward the original funding award letter to Hywel Morgan for the NHSWHC files. **Action 20210309/9.3:** WNA to inform Hywel Morgan of the shortfall in funding figure for the WNA post for the last quarter of the new financial year. The WNA Website update and the potential funding implications were discussed. Developer costs were quoted between £1500 and £2000. The group felt that a standalone NCIG website was not necessary and that signposting to the WNA website was instead the natural pathway from a Health Board perspective. **Action 20210309/9.4:** WNA to put forward a funding proposal for NCIG funding including a breakdown of ongoing costs. A suggestion of funding for data analysis should the VBHC team not be able to support this. HM confirmed that the NHSWHC had just appointed a new Head of Data Analysis who will work with all the groups to look at what their requirements are. It was also highlighted that the FDU were developing a number of dashboards for the chronic disease implementation groups. Suggestions were also put forward around the Epilepsy Pathway launch event and translation services.	**Action** **9.1** **9.2** **9.3** **9.4**

It was agreed that the NCIG budget for 2021-22 would be finalised at the June meeting.	
10. NCIG Effectiveness and the way forward	
MP raised the concerns brought forward by the WNA around the effectiveness of the NCIG in driving forward measurable service improvements. The WNA acknowledged that these issues had been brought up under the CPG enquiry and reiterated that as an organisation they still wanted to contribute and work in partnership with NCIG. However noted there was a disconnect between the reported progress to date and the voice of those with lived experience of the service, the gap between policy and implementation and the impact that then has. It was recommended that regular reporting of progress become an integral part of the work plan moving forward so that improvements could be accurately assessed. Suggestions around governance, the terms of reference, timeliness of minutes, membership, agendas and how the group reflects and learns in a service improvement cycle were all put forward. It was recognised that neurological conditions was a complex area with many different pathways and competing priorities and that as a group it was important to identify the priorities that mattered to all HB's around the table to ensure attendance and buy in on a national level with a patient-level plan and HB-level implementation. From a patient perspective access to information and support for self-management were also highlighted as possible areas for consideration by this group. It was suggested that the group could look at some exemplars and associated guidelines in both common and rare diseases and work from there or group the 250 conditions into broader areas such as movement disorders, epilepsy, neuro inflammation, nerve and muscle etc. that would fit with the 11 main coding groups for neurological conditions. **Action 20210309/10.1:** Representatives to deliver a 10-minute presentation on their HB neurological priorities for the next 12 months at the next NCIG meeting. **Action 20210309/10.2:** Each HB to report on their top five strengths and weaknesses for the NCIG meeting in June. **Action 20210309/10.3:** GH to share the draft Neurological Conditions Quality Statements with the group.	**Action** **10.1** **10.2** **10.3**
11. Date of Next Meeting	
8th June 2021, 14:00 -16:30	**Action**

Agenda Item 2 – Action Log

NCIG Meeting - Action Log						
Agenda Item No & Title	**Action Point**	**Action**	**Assigned to**	**Deadline**	**Status(RAG)**	**Notes/Update**
Mar-21						

7. Feedback from the Neuro-Rehab T&F Group	20210309/7.1	Each HB management & clinical lead to review the Directory of Neuro-Rehab Services for accuracy and content and feedback to Michelle	ALL	#######		
7. Feedback from the Neuro-Rehab T&F Group	20210309/7.2	The Directory of Neuro-Rehab Services to be published on the WNA website.	ALL	TBC		
9. NCIG Finance Update	20210309/9.1	All HB management representatives to ensure that year-end invoices are submitted.	Management Representatives	#######		Completed.
9. NCIG Finance Update	20210309/9.2	Original NCIG funding award letter from 2015 to be forwarded to Hywel Morgan for the NHSWHC files.	Annette Morris	#######		
9. NCIG Finance Update	20210309/9.3	WNA to inform Hywel Morgan of the shortfall in funding figure for the WNA post for the last quarter of the new financial year.	WNA/ Ana Palazon	#######		Completed.
9. NCIG Finance Update	20210309/9.4	WNA to put forward a funding proposal for NCIG funding including a breakdown of ongoing costs.	WNA/ Rebecca Brown	#######		Completed.

10. NCIG Effectiveness/ Way Forward	20210309/10.1	HB's to each deliver a 10-minute presentation on their HB neurological priorities for the next 12 months at the next NCIG meeting.	ALL	#######		
10. NCIG Effectiveness/ Way Forward	20210309/10.2	Each HB to report on their top five strengths and weaknesses for the NCIG meeting in June.	ALL	#######		
10. NCIG Effectiveness/ Way Forward	20210309/10.3	Draft Neurological Conditions Quality Statements to be shared with the group	GH	#######		

Agenda item 3 - Community Neurorehabilitation Services in Wales Position Statement February 2021

Community Neurorehabilitation Services in Wales
Position Statement February 2021

Currently most health boards in Wales have a community neurorehabilitation team (CNRT) in place. The table below outlines the services currently offered. The teams have different client groups, differing levels of dependency, different workforce configurations and deliver differing variety and intensity of intervention, for varying lengths of time.

Aneurin Bevan University Health Board

Area covered	Conditions seen	Referral Process	Clinicians involved	Services and Groups Offered
Newport Torfaen Caerphilly Monmouthshire Blaenau Gwent	**Acquired Brain Injury Team: NCIG Funded** TBI, Vascular/Infection Oncology Post-concussion Hypoxic Brain Injury Complex Stroke	Via Consultant, GP or any health care professional	Occupational Therapist Physiotherapist Clinical Nurse Specialist Speech and Language Therapy Clinical Psychologist Health Care Support Worker Band 3 Administrator	Fatigue Group ACT group Brain Education Group- Living Well After Brain Injury Group: Neurofit Community Exercise group

	Huntington's Team	Via Consultant, GP or any health care professional	Physio, Occupational Therapist, Speech and Language Therapy, CPN, Psychologist	
	MND MDT	Via Consultant, GP or any health care professional	In-reach to monthly clinics	
	Supported by :	Via Consultant, GP or any health care professional	Uni-professional specialist skilled clinicians: : Physiotherapy / Occupational Therapy / Speech and Language Therapy / specialist nurses in Epilepsy, MS, Parkinson's Community Rehabilitation Teams	

Betsi Cadwallader University Health Board

Area covered	**Conditions seen**	**Referral Process**	**Clinicians involved**	**Services and Groups Offered**
North Wales	Motor Neurone Disease	GPs and hospital Consultants	specialist nurses	
	Multiple Sclerosis	GPs and hospital Consultants	specialist nurses	
	Movement Disorders	GPs and hospital Consultants	specialist nurses	
	North Wales Brain Injury Service https://bcuhb.nhs.wales/health-services/health-services1/services1/services/brain-injury-service/	GPs and hospital Consultants	specialist nurses, speech and language therapy, neuropsychology physiotherapy	
	Supported by :	Via Consultant, GP or any health care professional	Uni-professional specialist skilled clinicians: Physiotherapy / Occupational Therapy / Speech and Language Therapy / specialist nurses in Epilepsy	

Cardiff and Vale University Health Board

Area covered	**Conditions seen**	**Referral Process**	**Clinicians involved**	**Services and Groups Offered**
	Community Neuro Rehab	Via Consultant, GP or any	Physiotherapist	Living well with neurological condition

Cardiff and the Vale of Glamorgan	**Service: Living Well** Any Neurological condition, including stroke	health care professional	Dietician Occupational Therapist Speech and Language Therapy Rehab Coach Physio Tech	Fatigue management Mindfulness Lower limb balance and strengthening group Upper limb activity group Conversation partner training group Social confidence group Conservation (walking vocational rehab) group Orchard project Walking football Walking netball Introduction to Golf
	Community Brain Injury Team Regional Specialist Community Brain Injury Team (CBIT) - Keeping Me Well Telephone: 029 20 313713 E-mail: Communitybrain.injuryteam@wales.nhs.uk	Via Consultant or GP	Psychology Physiotherapy Occupational Therapy Speech & Language Therapy Rehab Coach	Groups offered: Cognitive Rehab and Strategies Anxiety Management Anger Management Moving Forward (ACT/Positive Psychology) Communication Gardening Vocational Assessment (via Garden) Social Group
	MS Multiple Sclerosis (MS) - Keeping Me Well Telephone answerphone: 02920 745 018	Via Consultant or GP	Physiotherapy, Occupational Therapist, MS Specialist Nurses	
	Neuromuscular service	Via Consultant or GP	Physiotherapist, Care Coordinators	
	Stroke ESD Stroke - Keeping Me Well Early supported discharge: 02921 826 695	Acute Stroke Service	Dietitian, Physiotherapist, Occupational Therapist, Speech and Language Therapy, Rehabilitation Assistants	

	Cardiffandvale.Esd@wales.nhs.uk			
	Supported by :	Via Consultant, GP or any healthcare professional	Uni-professional specialist skilled clinicians: Physiotherapy / Occupational Therapy / Speech and Language Therapy / specialist nurses in Epilepsy, Parkinson's Community Rehabilitation Teams	

Cwm Taf Morgannwg University Health Board

Area covered	Conditions seen	Referral Process	Clinicians involved	Services and Groups Offered
RCT Merthyr https://cwmtafmorgannwg.wales/services/community-neuro-service/	Stroke ABI MS PD Other	Via consultants or allied health professionals	Clinical Psychologist Occupational Therapist Assistant Psychologist	Tai Chi Movement for Wellbeing Woodwork workshop: rolling programme Fatigue management courses: 4 week programmes (provided in person or remotely) Adjustment and living well with condition Assessment to assist return to work Woodland Therapy (in person and remotely) – run in conjunction with Welcome to Our Woods (local organisation)
	Supported by :		Uni-professional specialist skilled clinicians: Physiotherapy / Occupational Therapy / Speech and Language Therapy/ specialist nurses in Epilepsy, Parkinson's FES Service Community Rehabilitation Teams	

Hywel Dda University Health Board

Area covered	Conditions seen	Referral Process	Clinicians involved	Services and Groups Offered
Carmarthenshire, Pembrokeshire, Ceredigion	TBI/ABI/SCI/MS/Ca brain/PD/MD/Ataxia/ Huntingdon's/CP/ Choreoform movement/ Other neurological acquired and	Enquiries or Referral form to be completed by health or social services professional and sent to generic email. BrainInjuryAndNeuroTeam.H	Physiotherapist Speech Therapist Occupational Therapist Neuropsychology (only see TBI patients) Therapy assistant practitioners Admin & Clerical	Fatigue management, horticultural therapy, occupation based neuro rehabilitation groups, walking groups. Down to Earth in project in Murton for Hywel Dda patients Surfability project in Gower accessed by Hywel Dda patients Butterfly Group for Carmarthenshire patients

	degenerative disorders	DD@wales.nhs.uk		Botanical gardens therapeutic gardening project Fatigue management group Clinfew Farm project in Pembrokeshire
	Supported by :		Uni-professional specialist skilled clinicians: Physiotherapy / Occupational Therapy / Speech and Language Therapy / specialist nurses in Parkinson's Community Rehabilitation Teams	

Swansea Bay University Health Board

Area covered	**Conditions seen**	**Referral Process**	**Clinicians involved**	**Services and Groups Offered**
Swansea, Neath Port Talbot, Bridgend	Community Neurorehabilitation Service Acquired Brain Injury https://sbuhb.nhs.wales/hospitals/a-z-hospital-services/community-neurorehabilitation-service-sbuhb-bridgend/	Consultant/GP	Clinical Nurse Specialist Neuropsychologists and clinical psychologists SALT Occupational Therapist Rehabilitation Coach Music Therapist	positive psychology groups, patient support groups over Zoom, Expert Patient Programme Community Neurorehabilitation Programmes: Down to Earth: Social enterprise who aim to teach the community about sustainable building and living. Lee Aspland Mindful Photography: Photography and mindfulness. Mi-Space: Construction Company, specialists in providing property services to affordable housing providers. Swans Community Trust - Swansea City AFC's charity Surf-ability and Bike-ability Learn Thru Music- Nordoff Robbins Various gardening projects
	Vocational Stroke Service https://sbuhb.nhs.wales/hospitals/a-z-hospital-services/vocational-stroke-service/	NHS stroke professionals, GPs and the Stroke Association Community Workers	Neuropsychology Occupational Therapist	

	Stroke ESD	Via acute stroke team	Physiotherapy, Occupational Therapist	
	Supported by :	Consultant, GP/ or Healthcare Professionals	Uni-professional specialist skilled clinicians: Physiotherapy / Occupational Therapy / Speech and Language Therapy/ orthotics/ specialist nurses in Parkinson's, Epilepsy, MS FES Service Community Rehabilitation Teams	

Powys Teaching Health Board

HB **Area covered**	**Conditions seen**	**Referral Process**	**Clinicians involved**	**Services and Groups Offered**
Powys Webpages link: http://www.powysthb.wales.nhs.uk/community-neuro-services	Community Neurological Rehabilitation Team, any diagnosis, including stroke North Powys TCNRT tel: 01938 558 953	Referrals accepted from all health and social care providers as well as self-referral via Community Neuro Service coordinator 01686 613251 or directly to individual teams or clinicians powyscns@wales.nhs.uk	Physiotherapy Occupational Therapist	Direct Rehabilitation Neuro Cafes
	Therapy Led Spasticity Service, any diagnosis		Physiotherapist	Direct intervention
	Virtual Complex Neuro Meetings- any diagnosis		Continence Specialist Nurse, Dietitian, PT, OT, SALT, District Nurses facilitated by Community Neuro Service Coordinator	Coordination and Communication around support and rehabilitation being delivered
	Virtual Neuro Palliative Meetings (MND, end		Palliative Care Team, SALT, PT, OT, Dietitian facilitated by Community	Coordination and Communication around support and rehabilitation being delivered

	stage PD, PSP, MSA)		Neuro Service Coordinator	
	Stroke Service		Specialist Nurse, Psychologist	Moving on after Stroke
	Supported by :		Uni-professional specialist skilled clinicians: Physiotherapy / Occupational Therapy / Speech and Language Therapy / Orthotics/ Dietetics/ specialist nurses in Parkinson's and continence FES Service Community Rehabilitation Teams	

Regional South West Wales

HB **Area covered**	**Conditions seen**	**Referral Process**	**Clinicians involved**	**Services and Groups Offered**
Swansea, Neath Port Talbot, Pembrokeshire, Carmarthenshire, Ceredigion, South Powys	MS	Via Consultant	Physiotherapy, Specialist Nurses	
	Neuromuscular conditions	Via Consultant	Physiotherapy, Care Coordinators	
	SWMND Network	Via Consultant	Care Coordinators	

Agenda item 4 - Reporting Framework for Projects funded through CNR Fund

Reporting Framework for Projects funded through CNR Fund

Please refer to Rehabilitation Guideline and Evaluation Guidance published by WG:

- https://gov.wales/rehabilitation-needs-people-affected-impact-covid-19-guidance
- https://gov.wales/evaluating-impact-rehabilitation-services-post-covid-19

Value-Based Healthcare is defined as the equitable, sustainable and transparent use of the available resources to achieve better outcomes and experiences for every person (Hurst et al, 2019). In order to deliver value-based rehabilitation across Wales there needs to be:

1. Better data: an understanding of the resource use (including staff, service users and carer time) and outcomes and experiences that matter to patients
2. Better evidence: an understanding of what works to increase value. This requires better evidence about the effectiveness of what happens in the real world of the NHS. This can help inform decision making about resource use and allocation.

3. Multi-disciplinary engagement, involving all stakeholders, especially service users. Multiple skills are needed, and many professional groups must be engaged. But value means different things to different people/stakeholders, and there are multiple perspectives at any one time.

All elements of rehabilitation require multi-professional and multi-agency input, working in an integrated way. A stepped care rehabilitation model is proposed, based on a person-centred approach. This stepped care model can be mapped to the six-component model of the whole system approach described in the National Clinical Framework (NCF):

Enable me to grow well, live well and age well	**Enable me to stay well and support myself**	**Assess and monitor me closely**	**Step up my care and keep me at home**	**Give me good care not in my own home**	**Step-down my care and get me home safely**

Identifying your population:

What client groups does your service provide for- conditions, age

Step One: Recovery

In order to be able to track an individual person's recovery over time on their rehabilitation pathway across health and community settings it is recommended that all services and organisation use the same high-level measure of independence and well-being (PROM):

- 10-item Patient-Reported Outcomes Measurement Information System Global Health version 1.2 (PROMIS Global 10v1.2) asks people to report on last 7 days. There is a Welsh version and a 9-item PROMIS Global Pediatric and Parent Proxy Global 7+2.
- The additional 4 questions that have been validated through research from the ICHOM Stroke Group

This tool has had robust comparative studies undertaken that enable it to be mapped to the EQ5D-5L.

This should be done for all patients at initial assessment and on discharge from service.

Step Two: Demand - please report on a quarterly basis:

- the number of people using the service
- length of stay in service
- number of contacts
- number of different health or social care professionals involved, registered and unregistered
- type of intervention: face to face, telephone or virtual consultation

Step Three: Impact

It is recommended that services funded through CNR Fund support individuals to develop their skills to manage their own conditions. To measure this the All Wales Psychology Group recommend:

- General Self Efficacy Scale

Depending on the interventions provided, Community Neuro Services may choose to use one or more of the following outcome measures and tools, to report to SIG/NCIG:

Measure	Tools	
% with improved impairment	Fatigue	Fatigue Severity Scale [FSS], Fatigue Impact Scale [FIS], Brief Fatigue Inventory [BFI]) Fatigue Symptom Inventory [FSI], Multidimensional Assessment of Fatigue [MAF], and Multidimensional Fatigue Symptom Inventory [MFSI]

	Cognition	Montreal Cognitive Assessment (MoCA), Mini - Addenbrooke's Cognitive Examination (M-ACE-III), Addenbrooke's Cognitive Examination-III (ACE-III)
	Physical Function	Berg Balance Scale, muscle strength, Elderly Mobility Scale, Rivermead Mobility Index, Handgrip, Modified Rankin Scale, Nottingham Extended Activities of Daily Living Scale (NEADL)
	Mood	Patient Health Questionnaire (PHQ) 9, General Anxiety Disorder (GAD) 7, Hospital Anxiety and depression Scale (HADS), Trauma Screening Questionnaire (TSQ)
	Communication	La Trobe Communication Questionnaire
	Swallow/Voice	Voice Handicap Index (VHI), GRBAS, Reflux Symptom Index (RSI), EAT-10, Functional Oral Intake Scale (FOIS), Airway Voice Swallowing (AVS) scale, Newcastle Laryngeal Hypersensitivity Questionnaire
% with improved level of activity	Derbyshire Outcome Measure, Barthel Index, FIM, FIM+FAM, Rockwood Frailty Score, Nottingham Extended Activities of Daily Living Scale (NEADL)	
% with improved wellbeing	Warwick Edinburgh Mental Wellbeing Scale (WEMBS), ReQol, CORE-Outcome Measure (OM), CORE-10, DISC, TSQ	
% that achieved goals that matter to them	Goal Attainment Scale, Adapted Therapy Outcome Measure, Canadian Occupational Performance Measure (COPM), Occupational Self Assessment (OSA) Version 2.2 (MOHO), Goals Achieved Yes/No/Partially	

Step Four: Quality

In order to understand the quality of a rehabilitation intervention organisations and services will need to capture data on:

- The service user experience- using the WNA PREM tool
- The responsiveness of their service- time from referral to first contact
- How close to home rehabilitation delivered- place of intervention

Service Name

1. Population Served
2. Interventions delivered
3. Staffing
4. % funded through CNR Fund
5. Interdependencies (other services involved, health, local authority or third sector)
6. Activity, Impact and Quality- table below

	Measures	**Tools**	**How, when and where collected**	**When reported**

Change over time:	**QOL**	• EuroQOL-5L • PROMIS 10 +4 SNCIG PROM Jan 2020 - VBHC Privacy	National Platform Smart Survey Microsoft Teams Paper Pre and post intervention	Annually
Activity	**the number of people using service**		WPAS/	Quarterly
	length of stay in service		WPAS/	Quarterly
	number of contacts or % of programme completed		WPAS/	Quarterly
	number of different health or social care professionals involved		WPAS/WCCIS	Quarterly
	type of intervention: face to face, telephone or virtual consultation, 1:1, group		WPAS/	Quarterly
Outcome /	Confidence to manage own condition	General Self Efficacy Scale	Pre and post intervention	Annually
	Impairment/ Activity/ Participation/ Well Being/ Goal Attainment	At least one measure	Pre and post intervention	Annually
Quality	**PREM** http://www.wales.nhs.uk/governance-emanual/public-and-patient-involvement	NCIG Meeting WNA March 2020 PREMS.c	National Platform Smart Survey Microsoft Teams Paper Post intervention	Annually
	Responsiveness of their service- time from referral to first contact		WPAS/	Annually
	How close to home rehabilitation delivered- place of intervention		WPAS/	Annually

Grŵp Gweithredu Amodau Niwrolegol
Neurological Conditions Implementation Group

Neurological Conditions Implementation Group Meeting
Notes of meeting
9th March 2021
14:30-16:30
Via MS Teams

Author: Lyn Kenway	**Version:** 0a

Members present:

Name	**Designation**	**Organisation**
Ana Palazon (AP)	County Director/Chair	Parkinson's/WNA
Annette Morris (AM)	Director Of Neurosciences	BCUHB
Chris Hodcroft (CH)	Consultant, Acute Medicine	CTMUHB
Claire Nelson (CN)	Assistant Director of Planning	CTMUHB
REDACT – WG STAFF	Policy Lead, Population Health	WG
Hywel Morgan (HM)	Implementation Groups Manager	NHSWHC
Khalid Hamandi (KH)	Consultant Neurologist	CVUHB
Liz Kenward (LiK)	Specialised Planner Neurosciences and Complex Conditions	WHSSC
Michelle Price (MP)	National Clinical Lead for NCIG	NHSWHC
Rebecca Brown (RB)	Project Officer	WNA/MS Society
Rita Stuart (RS)	Service Delivery Manager	HDUHB
Robert Powell (RP)	Consultant Neurologist	SBUHB
Tom Hughes (TH)	Consultant	CVUHB

3. **Welcome and introductions**	
MP & HM welcome all to the meeting and apologised for minutes not being available in a timely manner due to IT issues.	**Action**
4. Apologies for absence	
Apologies were received from Alison Shakeshaft, David Heyburn, Jonathan Whelan, Lynne Hughes, Peter Skitt, Sarah Lloyd, Stuart Bourne, Victoria Deakins, and Yolanda Battanaga.	
12. Minutes of previous meeting	
MP shared the notes and actions from the last meeting via Teams. All items from the action log were noted to be on the agenda for further discussion.	**Action**
13. Action Log	
Action card shared and noted.	**Action**
14. WG Response to the CPG Report on Neurological Conditions	
MP recapped that the initial draft of the CPG enquiry report into Neurological Conditions were previously circulated to the group. MP and Chris Jones, Deputy Medical Director attend the CPG on 10th December and gave a verbal response to the CPG recommendations and a written response was also submitted. Of the 10 recommendations, 6 were accepted, 2 accepted in part and 2 rejected. MP discussed further the reasons for the rejection of the recommendations around funding and scrutiny. GH reported that there was a recognition that neurological conditions were not funded as well as other areas and advised that discussions around this would continue once a new government was in place. MP highlighted that it was difficult to ascertain how much	**Action**

money was currently spent on neurological conditions given a patient will access many different services.
The second recommendation rejected was around scrutiny and delivery of the Neurological Conditions Delivery Plan and the effectiveness of NCIG as a group at driving change, and delivery improvements. MP recognised that whilst the recommendation for a separate scrutiny board was rejected new plans were underway as part of the new NHS Executive functions, the National Clinical Plan and framework and the development of potential Quality Statements.
GH explained that the National Clinical Plan and Quality Statements from Cancer and Cardiac were likely to be published before the election period. The Quality Statements form part of the range of tools to support the delivery of the National Clinical Framework, including new workforce and digital strategies and a Quality & Safety Framework. The QS are not designed to replace the Delivery Plans but instead provide high-level intentions from WG and will be underpinned by a delivery plan that would be NHS owned and delivered with support from the NHS Executive. The group would be involved in the development of the Quality Statements and any delivery plans that come from them.
AP highlighted the need to ensure that the neurological conditions community are involved in the drafting of the QS following comments citing two very different experiences of such within the cancer and cardiac communities and that the recommendations that have been accepted by WG from the CPG enquiry are included.

15. Epilepsy T&F Group Update

Action

RP shared a presentation on the work undertaken by the Epilepsy & Seizures task & finish group, which detailed the priorities of the group and the work undertaken.

4. All Wales Epilepsy Pathway - The All Wales Adult First Seizure & Epilepsy Management Pathway was shared with the group.
5. Epilepsy mortality and SUDEP – RP highlighted the letter from the Lead Medical Examiner for Wales and the Deputy CMO and the inclusion of sudden epilepsy death/SUDEP in the Wales bereavement pathway.
6. Epilepsy PROM's and PREM's – R shared the agreed list of PROM's and PREM's which included: PQ9, HADS, quality of life, medication and seizure frequency and noted that there was varying degrees of success with implementation across Health Boards.

The task & finish group has now come to an end however will continue to work together as an Epilepsy Clinical Network with meetings 4 monthly and a rotating chair and hope to hold a national event to publicise the Epilepsy Pathway.
GH offered to help facilitate wider engagement with primary care.
Discussions around including epilepsy on the national dashboard as a way of monitoring services and identifying inequalities are underway and the group recognised the importance of quality data for service improvements and the challenges faced to date in this area.

16. Feedback from the Neuro-Rehab T&F Group

Action

The Neuro-Rehab group was set up in March 2019 with the following priorities:

3. Neuro-rehab evaluation framework for community neuro-rehab which seeks to evaluate services in a standardised way even though they may delivering different interventions, to differing population. The previously developed PROM's and PREM's for neurological conditions were included as was the work around using technology. It was agreed that those services funded through NCIG would utilise the evaluation framework and the PROM & PREM as a basic data set with a view to creating a national data dashboard with the Value Based Health Care team.
4. Directory of Neuro-Rehab Services - The need for clarity around what the different neuro-rehab services are, who they are aimed at and what the referral pathways are was raised. It was agreed that the document would be further populated over time.

Work around the Clinical Leadership Programme & spasticity management was also highlighted.
Action 20210309/7.1: Each HB management & clinical lead to review the Directory of Neuro-Rehab Services for accuracy and content.
Action 20210309/7.2: The Directory of Neuro-Rehab Services to be published on the WNA website.

MP confirmed that the group would cease as a task & finish group and would instead meet as a network/community of best practice.	**7.1** **7.2**
17. Feedback from the Paediatric Neurology T & F Group	
Apologies were sent from Johann Te Water Naude. MP explained that the group had not been particularly successful and recognised that this was due to a lack of consistent HB representation within the group due to smaller numbers of paediatric neurologist in general and no clear deliverables.	**Action**
18. NCIG Finance Update	
HM shared a financial update with the group. Of the £1.3m budget, £22,750 was left unallocated for this financial year. It was suggested that next year the unallocated amount be utilised to support the WNA post and development of the website. **Action 20210309/9.1:** All HB management representatives to ensure that year-end invoices are submitted. The issue of communication around the non-recurrent funding was raised and it was confirmed that WG were aware that the removal of this funding, which provides core services, would be of significant concern. It was also highlighted that clarification around this funding would likely not happen, until the new Welsh Government was in place, and that a decision would be pushed for as soon as possible. **Action 20210309/9.2:** Annette Morris to forward the original funding award letter to Hywel Morgan for the NHSWHC files. **Action 20210309/9.3:** WNA to inform Hywel Morgan of the shortfall in funding figure for the WNA post for the last quarter of the new financial year. The WNA Website update and the potential funding implications were discussed. Developer costs were quoted between £1500 and £2000. The group felt that a standalone NCIG website was not necessary and that signposting to the WNA website was instead the natural pathway from a Health Board perspective. **Action 20210309/9.4:** WNA to put forward a funding proposal for NCIG funding including a breakdown of ongoing costs. A suggestion of funding for data analysis should the VBHC team not be able to support this. HM confirmed that the NHSWHC had just appointed a new Head of Data Analysis who will work with all the groups to look at what their requirements are. It was also highlighted that the FDU were developing a number of dashboards for the chronic disease implementation groups. Suggestions were also put forward around the Epilepsy Pathway launch event and translation services. It was agreed that the NCIG budget for 2021-22 would be finalised at the June meeting.	**Action** **9.1** **9.2** **9.3** **9.4**
19. NCIG Effectiveness and the way forward	
MP raised the concerns brought forward by the WNA around the effectiveness of the NCIG in driving forward measurable service improvements. The WNA acknowledged that these issues had been brought up under the CPG enquiry and reiterated that as an organisation they still wanted to contribute and work in partnership with NCIG. However noted there was a disconnect between the reported progress to date and the voice of those with lived experience of the service, the gap between policy and implementation and the impact that then has. It was recommended that regular reporting of progress become an integral part of the work plan moving forward so that improvements could be accurately assessed. Suggestions around governance, the terms of reference, timeliness of minutes, membership, agendas and how the group reflects and learns in a service improvement cycle were all put forward. It was recognised that neurological conditions was a complex area with many different pathways and competing priorities and that as a group it was important to identify the priorities that mattered to all HB's around the table to ensure attendance and buy in on a national level with a patient-level plan and HB-level implementation. From a patient	**Action**

perspective access to information and support for self-management were also highlighted as possible areas for consideration by this group. It was suggested that the group could look at some exemplars and associated guidelines in both common and rare diseases and work from there or group the 250 conditions into broader areas such as movement disorders, epilepsy, neuro inflammation, nerve and muscle etc. that would fit with the 11 main coding groups for neurological conditions. **Action 20210309/10.1:** Representatives to deliver a 10-minute presentation on their HB neurological priorities for the next 12 months at the next NCIG meeting. **Action 20210309/10.2:** Each HB to report on their top five strengths and weaknesses for the NCIG meeting in June. **Action 20210309/10.3:** GH to share the draft Neurological Conditions Quality Statements with the group.	**10.1** **10.2** **10.3**
20. Date of Next Meeting	
8th June 2021, 14:00 -16:30	**Action**

Agenda item 2 – Action log

NCIG Meeting - Action Log						
Agenda Item No & Title	**Action Point**	**Action**	**Assigned to**	**Deadline**	**Status(RAG)**	**Notes/Update**
Mar-21						
7. Feedback from the Neuro-Rehab T&F Group	20210309/7.1	Each HB management & clinical lead to review the Directory of Neuro-Rehab Services for accuracy and content and feedback to Michelle	ALL	#######		
7. Feedback from the Neuro-Rehab T&F Group	20210309/7.2	The Directory of Neuro-Rehab Services to be published on the WNA website.	ALL	TBC		
9. NCIG Finance Update	20210309/9.1	All HB management representatives to ensure that year-end	Management Representatives	#######		Completed.

		invoices are submitted.				
9. NCIG Finance Update	20210309/9.2	Original NCIG funding award letter from 2015 to be forwarded to Hywel Morgan for the NHSWHC files.	Annette Morris	#######		
9. NCIG Finance Update	20210309/9.3	WNA to inform Hywel Morgan of the shortfall in funding figure for the WNA post for the last quarter of the new financial year.	WNA/ Ana Palazon	#######		Completed.
9. NCIG Finance Update	20210309/9.4	WNA to put forward a funding proposal for NCIG funding including a breakdown of ongoing costs.	WNA/ Rebecca Brown	#######		Completed.
10. NCIG Effectiveness/Way Forward	20210309/10.1	HB's to each deliver a 10-minute presentation on their HB neurological priorities for the next 12 months at the next NCIG meeting.	ALL	#######		
10. NCIG Effectiveness/Way Forward	20210309/10.2	Each HB to report on their top five strengths and weaknesses for the NCIG meeting in June.	ALL	#######		
10. NCIG Effectiveness/Way Forward	20210309/10.3	Draft Neurological Conditions Quality Statements to be shared with the group	GH	#######		

Agenda item 3 - NCIG Community Neuro Rehabilitation Data Dashboard

NCIG Community Neuro Rehabilitation Data Dashboard

The aim of this evaluation framework is to enable organisations to demonstrate the quality and effectiveness of their Community Neurorehabilitation Services and identify areas where the demand for services exceeds capacity.

This will form the first step of developing a data dashboard for neurorehabilitation for Wales that will enable us to better understand the demand for neurorehabilitation services, where they are being delivered and the impact they are having on people living with a neurological condition. This will facilitate ongoing service developments to address the gaps identified.

The framework, based on Results-Based Accountability™ aims to capture from the service users' perspective in line with value- based healthcare principles:

1. How much neurorehabilitation is being delivered
2. How well it is being delivered and

What impact is it having?

See Evaluating the impact of rehabilitation services post COVID-19 | GOV.WALES for details.

	Quantity (Cost Effectiveness)	Quality
Effort	**How much?** # people provided with rehabilitation length of stay in service	**How well** Patient reported experience measure Intensity of rehabilitation provided Responsiveness of rehabilitation services Where rehabilitation provided, home, school, community setting, hospital setting Type of rehab interventions- face to face, group, virtual
Effect	**Is anyone better off?** # who have returned to previous level of independence and well-being (PROM) # who are confident to manage their health in the long term (PROM) # with improved impairment (COM) # with improved level of activity (PROM/COM) # with improved well-being (PROM) # that achieved goals identified by them that matter to them # of people who return to meaningful occupation /work-based activity/ participation	**Outcomes** **% who have returned to previous level of independence and well-being (PROM)** % who are confident to manage their health in the long term (PROM) % with improved impairment (COM) % with improved level of activity (PROM/COM) % with improved well-being (PROM) % that achieved goals identified by them that matter to them % of people who return to meaningful occupation /work-based activity/ participation

CNRF Reporting Framework

Project title:
Organisation:
Project lead: Contact details:

Project start date		**Project end date**		**Reporting period**		**Progress status**	(RAG)

Allocation:		**Spend to date:**		**Forecast end year spend:**		**% of service funded by CNRF**	

Population served: (area, conditions, age etc)

Aim/objective of interventions: (restorative, palliative, vocational etc):

Healthcare professionals involved: (summary of professions, banding and WTE)

	AFC Banding	**WTE**
Occupational Therapy		
Physiotherapy		
Psychology		
Speech and Language Therapy		
Rehab Assistants		

Interdependencies: other services or organisations worked with, profession specific, health, local authority or 3rd sectors

Measures Used

Patient reported outcome measure (PROM)	
Patient reported experience measure (PREM)	
Validated Clinical Outcome Measures (COM)	

Data Dashboard

Number of referrals per month	***Time from referral to first contact*** ***% seen within 72 hours*** ***% seen within 2 weeks*** ***% seen within 12 weeks***	***Length of stay in service***
Active cases per month	***Number of HCP involved*** ***%***	***Number or % of contacts per referral***
Place of intervention ***% in own home*** ***% in community setting*** ***% in hospital/clinic setting***	***Type of Intervention;*** ***% face to face*** ***% one to one*** ***% group*** ***% virtual*** ***% telephone***	
PROM on referral and discharge	***% patients with positive change in Clinical Outcome Measure***	***PREM at discharge***

If you are not able to report this data. Please complete the table in appendix one to enable NWIS to see where you capture relevant data so that it can be pulled into a data dashboard.

Service Evaluation Template

Aim/objective of interventions:

	Measures	**Tools**	**How, when and where collected**
Change over	QOL  SNCIG PROM Jan 2020 - VBHC Privacy	• EuroQOL-5L • PROMIS-10 + 4 stroke questions	
Activity	The number of people using their service	New referrals per month Active cases per month	
	Length of stay in service	Time from referral to discharge	
	Number of contacts or % of programme completed	Number of contacts for individual care % of whole programme competed if set number of contacts	
	Number of different health or social care professionals involved	% of caseload seen by different HCP	
	Type of intervention: face to face, telephone or virtual consultation	% of total interventions	
Outcome / Impact	Confidence to manage own condition	General Self Efficacy Scale	
	Impairment	To be agreed locally	
	Activity	To be agreed locally	
	Participation	To be agreed locally	
	Well Being	To be agreed locally	
	Goal Attainment	To be agreed locally	
Quality	PREM	 NCIG Meeting WNA March 2020 PREMS.c	
	Responsiveness of their service	Time from referral to first contact	
	How close to home rehabilitation delivered	Place of intervention	

GIG CYMRU NHS WALES
Grŵp Gweithredu Amodau Niwrolegol
Neurological Conditions Implementation Group

Neurological Conditions Implementation Group
Agenda
Thursday, 23rd September 2021
13:00 – 15:00

Click here to join the meeting

		Item	**Paper**	**Lead**
13.00		Welcome and Apologies		Alison Shakeshaft
13:05	1	Minutes & Outstanding actions from previous meetings	1 2	Alison Shakeshaft
13:10	2	Quality Statements Update	3	Lyn Kenway
13:15	3	BCUHB Development of Level Two Rehab Unit Progress	Verbal	Annette Morris
13:25	4	Organisational Priority Proposals 2021-22	Verbal	All
14:20	5	Data Dashboards • Epilepsy • Acquired Brain Injury	4 5	Michelle Price Sally Cox & Keith Howkins
14:40	6	Community Neuro-Rehab Reports – Feedback	6	Michelle Price
15:00	7	Any Other Business • Neuro-physiology Review	Verbal	All
Close	8	Dates of future meetings		

Grŵp Gweithredu Amodau Niwrolegol
Neurological Conditions Implementation Group

Neurological Conditions Implementation Group Meeting
Notes of meeting
9th March 2021
14:30-16:30
Via MS Teams

Author: Lyn Kenway	**Version:** 0a

Members present:

Name	**Designation**	**Organisation**
Ana Palazon (AP)	County Director/Chair	Parkinson's/WNA
Annette Morris (AM)	Director Of Neurosciences	BCUHB
Chris Hodcroft (CH)	Consultant, Acute Medicine	CTMUHB
Claire Nelson (CN)	Assistant Director of Planning	CTMUHB
REDACT – WG STAFF	Policy Lead, Population Health	WG
Hywel Morgan (HM)	Implementation Groups Manager	NHSWHC
Khalid Hamandi (KH)	Consultant Neurologist	CVUHB
Liz Kenward (LiK)	Specialised Planner Neurosciences and Complex Conditions	WHSSC
Michelle Price (MP)	National Clinical Lead for NCIG	NHSWHC
Rebecca Brown (RB)	Project Officer	WNA/MS Society
Rita Stuart (RS)	Service Delivery Manager	HDUHB
Robert Powell (RP)	Consultant Neurologist	SBUHB
Tom Hughes (TH)	Consultant	CVUHB

5. **Welcome and introductions**	
MP & HM welcome all to the meeting and apologised for minutes not being available in a timely manner due to IT issues.	**Action**
6. Apologies for absence	
Apologies were received from Alison Shakeshaft, David Heyburn, Jonathan Whelan, Lynne Hughes, Peter Skitt, Sarah Lloyd, Stuart Bourne, Victoria Deakins, and Yolanda Battanaga.	
21. Minutes of previous meeting	
MP shared the notes and actions from the last meeting via Teams. All items from the action log were noted to be on the agenda for further discussion.	**Action**
22. Action Log	
Action card shared and noted.	**Action**
23. WG Response to the CPG Report on Neurological Conditions	
MP recapped that the initial draft of the CPG enquiry report into Neurological Conditions were previously circulated to the group. MP and Chris Jones, Deputy Medical Director attend the CPG on 10th December and gave a verbal response to the CPG recommendations and a written response was also submitted. Of the 10 recommendations, 6 were accepted, 2 accepted in part and 2 rejected. MP discussed further the reasons for the rejection of the recommendations around funding and scrutiny. GH reported that there was a recognition that neurological conditions were not funded as well as other areas and advised that discussions around this would continue once a	**Action**

new government was in place. MP highlighted that it was difficult to ascertain how much money was currently spent on neurological conditions given a patient will access many different services. The second recommendation rejected was around scrutiny and delivery of the Neurological Conditions Delivery Plan and the effectiveness of NCIG as a group at driving change, and delivery improvements. MP recognised that whilst the recommendation for a separate scrutiny board was rejected new plans were underway as part of the new NHS Executive functions, the National Clinical Plan and framework and the development of potential Quality Statements. GH explained that the National Clinical Plan and Quality Statements from Cancer and Cardiac were likely to be published before the election period. The Quality Statements form part of the range of tools to support the delivery of the National Clinical Framework, including new workforce and digital strategies and a Quality & Safety Framework. The QS are not designed to replace the Delivery Plans but instead provide high-level intentions from WG and will be underpinned by a delivery plan that would be NHS owned and delivered with support from the NHS Executive. The group would be involved in the development of the Quality Statements and any delivery plans that come from them. AP highlighted the need to ensure that the neurological conditions community are involved in the drafting of the QS following comments citing two very different experiences of such within the cancer and cardiac communities and that the recommendations that have been accepted by WG from the CPG enquiry are included.	
24. Epilepsy T&F Group Update	
RP shared a presentation on the work undertaken by the Epilepsy & Seizures task & finish group, which detailed the priorities of the group and the work undertaken. 7. All Wales Epilepsy Pathway - The All Wales Adult First Seizure & Epilepsy Management Pathway was shared with the group. 8. Epilepsy mortality and SUDEP – RP highlighted the letter from the Lead Medical Examiner for Wales and the Deputy CMO and the inclusion of sudden epilepsy death/SUDEP in the Wales bereavement pathway. 9. Epilepsy PROM's and PREM's – R shared the agreed list of PROM's and PREM's which included: PQ9, HADS, quality of life, medication and seizure frequency and noted that there was varying degrees of success with implementation across Health Boards. The task & finish group has now come to an end however will continue to work together as an Epilepsy Clinical Network with meetings 4 monthly and a rotating chair and hope to hold a national event to publicise the Epilepsy Pathway. GH offered to help facilitate wider engagement with primary care. Discussions around including epilepsy on the national dashboard as a way of monitoring services and identifying inequalities are underway and the group recognised the importance of quality data for service improvements and the challenges faced to date in this area.	**Action**
25. Feedback from the Neuro-Rehab T&F Group	
The Neuro-Rehab group was set up in March 2019 with the following priorities: 5. Neuro-rehab evaluation framework for community neuro-rehab which seeks to evaluate services in a standardised way even though they may delivering different interventions, to differing population. The previously developed PROM's and PREM's for neurological conditions were included as was the work around using technology. It was agreed that those services funded through NCIG would utilise the evaluation framework and the PROM & PREM as a basic data set with a view to creating a national data dashboard with the Value Based Health Care team. 6. Directory of Neuro-Rehab Services - The need for clarity around what the different neuro-rehab services are, who they are aimed at and what the referral pathways are was raised. It was agreed that the document would be further populated over time. Work around the Clinical Leadership Programme & spasticity management was also highlighted. **Action 20210309/7.1:** Each HB management & clinical lead to review the Directory of Neuro-Rehab Services for accuracy and content.	**Action**

Action 20210309/7.2: The Directory of Neuro-Rehab Services to be published on the WNA website. MP confirmed that the group would cease as a task & finish group and would instead meet as a network/community of best practice.	**7.1** **7.2**
26. Feedback from the Paediatric Neurology T & F Group	
Apologies were sent from Johann Te Water Naude. MP explained that the group had not been particularly successful and recognised that this was due to a lack of consistent HB representation within the group due to smaller numbers of paediatric neurologist in general and no clear deliverables.	**Action**
27. NCIG Finance Update	
HM shared a financial update with the group. Of the £1.3m budget, £22,750 was left unallocated for this financial year. It was suggested that next year the unallocated amount be utilised to support the WNA post and development of the website. **Action 20210309/9.1:** All HB management representatives to ensure that year-end invoices are submitted. The issue of communication around the non-recurrent funding was raised and it was confirmed that WG were aware that the removal of this funding, which provides core services, would be of significant concern. It was also highlighted that clarification around this funding would likely not happen, until the new Welsh Government was in place, and that a decision would be pushed for as soon as possible. **Action 20210309/9.2:** Annette Morris to forward the original funding award letter to Hywel Morgan for the NHSWHC files. **Action 20210309/9.3:** WNA to inform Hywel Morgan of the shortfall in funding figure for the WNA post for the last quarter of the new financial year. The WNA Website update and the potential funding implications were discussed. Developer costs were quoted between £1500 and £2000. The group felt that a standalone NCIG website was not necessary and that signposting to the WNA website was instead the natural pathway from a Health Board perspective. **Action 20210309/9.4:** WNA to put forward a funding proposal for NCIG funding including a breakdown of ongoing costs. A suggestion of funding for data analysis should the VBHC team not be able to support this. HM confirmed that the NHSWHC had just appointed a new Head of Data Analysis who will work with all the groups to look at what their requirements are. It was also highlighted that the FDU were developing a number of dashboards for the chronic disease implementation groups. Suggestions were also put forward around the Epilepsy Pathway launch event and translation services. It was agreed that the NCIG budget for 2021-22 would be finalised at the June meeting.	**Action** **9.1** **9.2** **9.3** **9.4**
28. NCIG Effectiveness and the way forward	
MP raised the concerns brought forward by the WNA around the effectiveness of the NCIG in driving forward measurable service improvements. The WNA acknowledged that these issues had been brought up under the CPG enquiry and reiterated that as an organisation they still wanted to contribute and work in partnership with NCIG. However noted there was a disconnect between the reported progress to date and the voice of those with lived experience of the service, the gap between policy and implementation and the impact that then has. It was recommended that regular reporting of progress become an integral part of the work plan moving forward so that improvements could be accurately assessed. Suggestions around governance, the terms of reference, timeliness of minutes, membership, agendas and how the group reflects and learns in a service improvement cycle were all put forward. It was recognised that neurological conditions was a complex area with many different pathways and competing priorities and that as a group it was important to identify the priorities that mattered to all HB's around the table to ensure attendance and buy in on	**Action**

a national level with a patient-level plan and HB-level implementation. From a patient perspective access to information and support for self-management were also highlighted as possible areas for consideration by this group. It was suggested that the group could look at some exemplars and associated guidelines in both common and rare diseases and work from there or group the 250 conditions into broader areas such as movement disorders, epilepsy, neuro inflammation, nerve and muscle etc. that would fit with the 11 main coding groups for neurological conditions. **Action 20210309/10.1:** Representatives to deliver a 10-minute presentation on their HB neurological priorities for the next 12 months at the next NCIG meeting. **Action 20210309/10.2:** Each HB to report on their top five strengths and weaknesses for the NCIG meeting in June. **Action 20210309/10.3:** GH to share the draft Neurological Conditions Quality Statements with the group.	**10.1** **10.2** **10.3**
29. Date of Next Meeting	
8th June 2021, 14:00 -16:30	**Action**

Action 3 - The quality statement for neurological conditions

The quality statement for neurological conditions

Our aim is to continue to raise awareness of neurological conditions, and to ensure those affected by any kind of neurological condition have timely access to high quality pathways of care from symptom onset to end of life.

First published: XX October 2021
Last updated: XX October 2021

The Quality Statement for Neurological Conditions replaces the Neurological Conditions Delivery Plan for Wales.

Introduction

There are more than 250 recognised neurological conditions, disorders and syndromes which affect the brain, spinal cord, nerves and muscles. These systems therefore control all aspects of the mind and body, neurological conditions can affect the way people think, feel and interact with the world around them. They often have a huge impact on a person's quality of life and their ability to live independently and participate in family life and their community.

Neurological conditions can be caused by a variety of factors; traumatic injury, inflammation; infection; degeneration, genetic or environmental.

All neurological conditions follow a different disease course, with onset from birth, through to older age. There are, however, some commonalities and neurological conditions can manifest by:

- sudden onset - may improve over time or stay the same;
- slowly progressive - will deteriorate over time;
- relapse and remit – may come and go

These can be influenced by medical intervention, pharmacological and symptom management and rehabilitation.

It is estimated that one in six people in the UK have a neurological condition. The number of people living with a neurological condition is set to increase over the coming years as more children survive beyond birth into adulthood and as the UK's population ages, so do the number of people living with age-related neurological conditions. The number of years lost due to ill health, disability or early death as a result of a neurological condition is higher than that of diabetes. The impact of neurological conditions on quality of life is greater than that of cardiovascular conditions or diabetes.

Neurological conditions can have a devastating impact on people's lives and those around them. People living with a neurological condition require the knowledge and skills to be able to manage their symptoms. They need rapid access to diagnosis and ongoing support from a wide range of health, social care and third sector services in order optimise their quality of life and wellbeing. The complexity of needs for those living with a neurological condition require services to be consistent in their approach to communication, collaboration and coordination of care. Patients and their carers should be supported to make shared decisions on care including the self-management of their symptoms where appropriate.

Building on the work of the Neurological Conditions Delivery Plan, the Neurological Conditions Implementation Group (NCIG) will provide national leadership and drive forward change to deliver better quality, higher value, more consistent and accessible services for people affected by neurological conditions.

Health boards and trusts will remain responsible for planning and delivering services for those with neurological conditions. They will work closely with voluntary organisations and people with a lived experience of a neurological condition to continually improve services. Health boards and trusts will be supported to deliver improved neurological condition services by the NHS Executive function. This will be discharged through NCIG who will set out a rolling, three-year implementation plan. This will identify and prioritise service developments based on the quality attributes described below. Detailed service specifications will also be developed to support the planning and accountability arrangements for the NHS in Wales; these will be set out in Annex A as they become available.

Quality attributes of Neurological Condition Services in Wales

Equitable

1. The NHS Executive supports the national approach to service improvement through NCIG.

2. Deliver evidence based and timely treatment, in line with latest evidence, standards, best practice and NICE guidance. This will include access to diagnostics, technologies, treatments, techniques and innovations regardless of geography or condition.

3. Neurological services collaborate through NCIG in a networked approach to ensure transparency, support equity of access and ensure consistency in standards of care whilst addressing unwarranted variation. This will be developed through regional and national approaches.
4. Neurological services will be measured and held accountable using robust metrics; Patient Reported Experience Measures (PREMs), Patient Reported Outcome Measures (PROMs), national audits.

5. Rehabilitation services including physical, communication, cognitive and psychological support are consistently accessible for those affected by a neurological condition.

Safe

6. Use the evidence base and clinical guidelines to improve services.

7. Develop and embed comprehensive and integrated neuro-rehabilitation services for all conditions, including psychological support and opportunities for self-referral for those living or affected by a neurological condition.

8. Development of a Value Based Health Care dashboard for Neurological Conditions to inform and evaluate service improvements and outcomes.

9. Promote the importance of research into neurological conditions, supporting patients to develop and participate in clinical trials to inform the work of the clinical community, improve quality of life, influence patient care, and optimise resources.

Effective

10. Implement a co-productive approach to raising awareness of neurological conditions.

11. Support all those living with a neurological condition to maximise their well-being and quality of life.

Efficient

12. Utilise technology throughout the pathway for improved coordination and integration of care across care settings and disciplines.
13. Provide clinical consultations in person and with the use of technology where appropriate. This should not disadvantage those who are not able to access technology.

14. Further develop research, innovation and education to enable delivery of high quality, evidenced based, clinical care by a well-trained, specialist workforce.

15. Deliver services in the most appropriate setting, close to home wherever possible.

Person centred

16. Person-centred care with shared decision making will ensure people affected by neurological conditions are able to access services in a way that suits them and achieve the outcomes that matter to them.

17. Services and pathways are evaluated from the service users perspective.

18. Ensure integration and coordination of care across services and disciplines recognising the wider health needs of people living with a neurological condition.

Timely

19. Patients have timely and co-ordinated access to all services.

Annex A - service specifications

The NHS Executive will support the local implementation of **nationally agreed, optimised clinical pathways**. These will be added as they become available as set out in the implementation plan.

Action 4 - Data Dashboards for Neurological Conditions

Value in Health
Data Dashboards for Neurological Conditions

Situation

The Neurological Conditions Implementation Group (NCIG) has recognised the need to improve the use of information and data in Wales in order to be able to;

- Understand the demand for services for people with neurological conditions across Wales
- Identify gaps and inequalities in access to services
- Evaluate the impact and outcomes of existing and developing services from a service user and organisation perspective
- Demonstrate value in health care
- Support business cases
- Promote cross organisational working

The Value in Health (ViH) team are currently supporting Neurological Conditions Implementation Group NCIG to develop 2 national data dashboards:

- Epilepsy
- Acquired brain injury

Background

The first Neurological Conditions Implementation Plan was published in 2014, with the NCIG set up to oversee delivery. It covers over 250 different neurological conditions with different disease profiles and trajectories. The plan requires the development of national evidence based clinical pathways. From the outset NCIG recognised that the paucity of data available made it extremely difficult to understand the demand for, gaps in and impact of services across Wales to reduce inequity drive and evaluate improvements. This has been highlighted again more recently in the Cross-Party Group Report on NCIG, published in 2020.

Between 2016 and 2019 the NCIG worked with the Stroke Implementation Group (SIG) to agree and validate a patient reported outcome measure (PROM), and with the Welsh Neurological Alliance (WNA) to develop and agree a patient reported experience measure (PREM) to evaluate the services for people with neurological conditions.

A Healthier Wales, published in 2018, stated that Welsh Government (WG) would embed the Value Based Health Care (VBHC) approach as part of making Prudent Healthcare philosophy a reality. A three-year action plan for putting value at the centre of health and care in Wales was published in 2019. This was presented to NCIG in 2019.

In 2019 NCIG agreed 3 specific task and finish groups to drive improvements in particular pathways:

- Seizures
- Neurorehabilitation
- Paediatrics

The seizure group delivered some national pathways and agreed a dataset including a patient reported outcome measure.

The neurorehabilitation group mapped out community neurorehabilitation services across Wales and developed an evaluation framework to enable the services funded through the Community Neurorehabilitation Fund to be able to report against and to be incorporated into a data dashboard.

The recent development of the new Quality Statements for Neurological Conditions has identified 3 main disease trajectories that incorporate most neurological conditions:

- sudden onset - may improve over time or stay the same:
- relapse and remit – may come and go
- slowly progressive - will deteriorate over time;

Epilepsy and acquired brain injury have been prioritised for development of supporting data dashboards. These two areas represent conditions follow the first 2 trajectories and the learning from this will inform the development of other dashboards for other conditions or groups of conditions going forward. This builds on the work undertaken over the past 2 years by the task and finish groups and the development of the PROM and PREM.

Other work that has impacted on the development of data dashboards for neurological conditions is the Development and Implementation of the South Wales Major Trauma Network, which went live in September 2020 and the work of the Health and Rehabilitation Task and Finish Group 2020 as part of WG COVID-19 Planning and Response and for the Adferiad programme. The work of the Neurorehabilitation Task and Finish group informed the guidance, evaluation framework and modelling resource developed by the Covid-19 Health and Rehabilitation Group.

Assessment

Significant progress has been made with both the epilepsy and ABI dashboards.

A clear structure and timeline is now needed to drive this forward, with good engagement from all stakeholders to ensure the dashboards fulfil the purpose set out above.

Some datasets are readily available and can be incorporated into the dashboard easily. Others will require specific data sharing agreements to be put in place and will need support from individual organisations.

The dashboards will evolve over time as the National Data Repository develops.

Recommendations

Each health board needs to ensure there is appropriate representation from their organisation on each of the clinical reference groups.

Each clinical reference group will need to ensure that they have identified interdependencies with other national developments and made links with relevant stakeholders.

Health boards will need to support requests from the ViH team for access to some datasets.

The ViH team will demonstrate the dashboards to the NCIG at the next meeting in December.

Appendix One- Group membership to date

Epilepsy	**Acquired Brain Injury**
Sally Cox ViH Jonathan Bevan ViH	Sally Cox ViH Jonathan Bevan ViH

Keith Howkins ViH Navjot Kalra ViH Joseph Anderson (Aneurin Bevan UHB - Neurology) Robert Powell (Swansea Bay UHB - Neurology) Hamandi (Cardiff and Vale UHB - Neurosciences) William Pickrell (Swansea Bay UHB - Neurology)	Keith Howkins ViH Navjot Kalra ViH Michelle Price (PTHB) Dr Jenny Thomas (C&V) Renee Groesvelt (HDU HB) Joanne Janes (BCU HB) Adele Griffiths (ABUHB)

Agenda Item 6 - Community Neuro-Rehab Reports – Feedback

Community Neurorehabilitation Fund Reports September 2021

Background

The Neurological Conditions Implementation Group (NCIG) and Stroke Implementation Group (SIG) allocated a total of £1.3million to a Community Neurorehabilitation Fund in 2015. This was from the £1M allocated to each of the implementation groups by Welsh Government. Initially this funding was thought ot be recurrent, however more recently it has become apparent that this funding is likely to end within the next financial year.

Community Neurorehabilitation Funding was allocated to health boards via a bidding process in the following way:

Organisation	Allocation
Aneurin Bevan UHB	£206,000
Betsi Cadwaladr UHB	£100,000
Cardiff &Vale UHB	£174,000
Cwm Taf UHB	£117,000
Hywel Dda UHB	£145,000
Powys THB	£96,000
Swansea Bay UHB	£152,000
WHSSC	£150,000

Services funded by the Community Neurorehabilitation Fund (CNRF) were asked to submit reports using the evaluation framework developed as part of the Neurorehabilitation Task and Finish group in June 2021 for the period April 2020 to March 2021.

The purpose was to identify what activity data was being captured and how services were being evaluated from a service users' perspective. This information is needed to be able to inform the development of a value-based data dashboard for neurorehabilitation and also to support the securing

of ongoing funding for the services from health boards as part of the IMTP process should/when the central funding from Welsh Government cease.

Assessment

Four reports were received:

- Aneurin Bevan
- Cwm Taf
- Powys
- Swansea Bay

BCU's allocation was used to scope out and develop a business case for a tier two neurorehabilitation service, which is reported on separately.

The full reports are embedded in appendix one. Many have detailed information on the services that have been provided and developed over the past 2 years.

There has been significant work undertaken within the services to continue to improve the quality and effectiveness of their interventions despite the impact of the Covid pandemic on their staffing levels and the confidence of people accessing services.

The basic data included in the reports were collated into an excel spreadsheet to identify what data is being collected and what the gaps currently are. This is included in appendix two.

Recommendations

Health boards are asked to review their submissions against the CNRF framework for completeness. Any missing reports or data points should be submitted by end of October.

Representatives from each of the services funded by the CNRF should be nominated to work with the clinical reference group for the acquired brain injury data dashboard to ensure the dashboard enables the services to identify inequalities, gaps, patient outcomes and value of their service to support ongoing service development.

The rehabilitation modelling group should be asked to present at the next NCIG to demonstrate how this data can be used in the modelling tool to identify future demand for services to support business cases.

Appendix One

- Aneurin Bevan

ABUHB CNRS ABI Review 2021 DHAG.D

- Powys

PTHB CNRF Rehabilitation Evaluat

- Cwm Taf

CTM CNS Service Report April 2021.doc

- Swansea Bay

SBUHB CNRF Rehabilitation Evaluat

Appendix Two

	ABUHB	CTM	SBUHB	PTHB
Name	Acquired Brain Injury Service	Community Neurorehab Service (CNS):	Vocational Stroke Rehabilitation & Community Neurorehabilitation	Powys Community Neuro Service
Service definition	provides multi-disciplinary rehabilitation for people who have suffered a mild to moderate acquired brain injury.	for adults with a diagnosed long-term neurological condition (not including functional neurological disorders)		Support adults living in Powys with neurological conditions (including stroke) optimise their health and well being
	£206K	£117K	£152K	£96K
% funded by CNRF		100%	100%	34%
Population served	Gwent and Caerphilly	Merthyr and Rhondda Cynon Taf region of Cwm Taf Morgannwg UHB	Swansea Bay Health Board	Powys THB
Average age		56.8 years, with a range of 17 – 88 years		
Nurse				0
Occupational Therapy		1 x 0.85 WTE Band 7 Occupational Therapist	0.45 WTE B7 OT	1.8WTE B7
Physiotherapy		0	0	2.15WTE B7 and 8b
Psychology		1 x 0.5 WTE Band 8B Clinical Psychologist / Service Lead	0.6WTE 8c, 0.5WTE 8a, 1WTE B7,	0.25WTE 8b
Speech and Language Therapy		0	0.6WTE B7	0

Rehab Assistants		1 x 1.0 WTE Band 5 Assistant Psychologist	0.6WTE B4	0
Administrative support		1 x 0.27 Band 3 Administrator (Temporary Contract)		1WTE B3
Patient Reported Experience Measures	locally agreed			SIG/NCIG PREM
Patient Reported Outcome Measures	PROMIS 10 + 4			EQ5D
Clinical Outcome Measures	TOMS, FIM+FAM		St. Andrews-Swansea Neurobehavioural Outcome Scale (SASNOS) (proxy and self-rated versions), SWEMWBS 7 Item, MOCA, RBANS, HADS, Goal planning	Variety of COM across professions
Annual Activity	92	66 referrals received, 53 were accepted	159 people provided with community rehabilitation from January 2020- April 2021: 73 ABI (including Vocational Stroke) and 86 TBI	505 new patients, 1916 contacts
Length of stay in service	variable- no average given		Length of stay ranges from 6 months to 4 years	currently looking at how this can be pulled from WPAS
Average number of hours face to face intervention	5			majority of people seen 1 to 6 times, up to 46 contacts
number of different health or social care	1 to 5			1 to 4

professionals involved				
Responsiveness of their service-time from referral to first contact	3 days			currently looking at how this can be pulled from WPAS

Agenda Item 7 - NCIG Priorities Form June 2021

NCIG Priorities Form June 2021

Please list your organisations top 5 priorities for development for the next 1-2 years.

This may be a particular care pathway, service, workforce development, or resource to support the development of neurological conditions within your organisation.

Organisation: _____Powys_____

Priority	**Rational and supporting evidence**	**Benefit of taking forward nationally**
Stakeholder engagement- develop systems to support service user and other stakeholders to be involved in service design, delivery and evaluation	NCDP has co-production as underpinning principle. If we are not involving service users in the development and design of our services we are unlikely to meet their needs.	Share resources for supporting service users and stakeholders Local groups can feed in and support NCIG
Competency Framework across specialist nurse/AHP across conditions/impairments	We are reviewing how we develop and deliver a neuro skilled workforce in Powys, to support recruitment and retention and provide skilled care closer to home. We have developed an integrated Community Neuro Advanced Practitioner post/JD and want to have clear job plans and competency frameworks underpinning each post- eg MS Specialist Practitioner for north Powys.	Opportunity to develop education and training on an all Wales basis, with links to HEI. Reduce duplication and effort

Data Dashboard	Have a better understanding of the pathways the population of Powys currently access- understand the activity, quality and outcome in order to support development and delivery of services and care closer to home	Common language and data set about effectiveness, quality and impact of services to inform and evaluate service development across wales, and enable establishment of cross organisational pathways and services
Pathway for people with Functional Neurological Disorder	There are increasing numbers of people presenting with FND in Powys. These people are supported by our Community Neuro Rehab Teams, who are working to develop their knowledge and skills and a network of health and social care practitioners with an interest. If we can build better expertise locally there will be a reduced need to refer people out of county for specialist intervention. More effective local services should reduce demand on health and social care services.	Small numbers of people with FND. A wales wide stepped care approach, underpinned by robust education, training and communication is the most clinically and cost effective way to deliver services.
Dystonia Pathway	Already have a therapy led spasticity pathway in Powys. With move of neurology services from SATH to Wolverhampton, developing a local therapy led dystonia service would reduce the need for people to have to travel long distances for repeat botulinum toxin injections and reduce demand on neurologists	Several HBs already have nurses and AHPs supporting dystonia services. Already a spasticity peer support group. Developing a national dystonia pthway would assure that there are clear standards, training and competencies, guidelines and

		governance for which people can have symptoms managed locally and which people need to access neurologist led services.

NCIG Priorities Form June 2021

Please list your organisations top 5 priorities for development for the next 1-2 years.

This may be a particular care pathway, service, workforce development, or resource to support the development of neurological conditions within your organisation.

Organisation: Swansea Bay UHB and Hywell Dda HB

Priority	**Rational and supporting evidence**	**Benefit of taking forward nationally**
Regional Review of Neurosciences	1. Deficient workforce in several sub-specialisms within overarching Neurology umbrella 2. Access to specialist teams is limited at best, worsening n some cases 3. Access to acute neurology inpatient care is severely restricted 4. Access to outreach liaison specialist neuro team extremely limited 5. Outdated LTA and SLA arrangements in place restricting ability to improve and reinvest in the service	Improve access to specialist clinical teams irrelevant of the locality / operating platform Improve patient experience and outcomes Reduce burden on emergency department and inpatient capacity

Establishing the workforce to deliver a regional epilepsy service	Epilepsy is the most common neurological condition with 30,000 cases in Wales with active disease (1), equating to 6,000 patients in Swansea Bay University Health Board (SBUHB) territory, and a further 4000 in Hywel Dda University Health Board (HDUHB). The prevalence of epilepsy is highest in areas of greatest deprivation and epilepsy is more common in people with a learning disability than in the general population - about 1 in 3 people (32%) who have a mild to moderate learning disability also have epilepsy. Epilepsy is associated with significant medical and social morbidity and is the second commonest cause of neurological sudden death after stroke, with patients at much younger ages. People with epilepsy have an overall 2-3 times higher risk of premature death than the general population, with a 20-fold increase in sudden death in young people with epilepsy. As well as causing seizures epilepsy is associated with higher rates of mental health problems and significantly increased mortality. The local population covered by SBUHB is approximately 600,000 and therefore we might expect to see a minimum of 300 new cases of epilepsy per year, and based on the maxim of seeing 3-4 new patients with symptoms that mimic epilepsy for each with epilepsy, this equates to 1200 new appointments for "possible epilepsy" per year, or 100 per month. For HDUHB we estimate 800 new appointments for "possible epilepsy" per year, or 66 per month.	• Extend the innovative open access service introduced by the Swansea Bay epilepsy team. This service allows increased management of patients in the community, reduces the number of outpatient appointments needed and hence relieves pressure on the 26 week Referral to Treatment Time (RTT) target time • Increase Consultant Neurologist outpatient capacity to assess more urgent neurology referrals, both epilepsy and general • Reduce the numbers of emergency department attendances and hospital admissions due to improved preventative management of epilepsy • Reduce the increased mortality rate demonstrated in people with epilepsy where there is poor access to timely specialist services • Improve the quality of care and management of patients with epilepsy and reduce the effects of this long term health condition
Strengthening Acute Neurology Provision	Currently, clinically urgent patients across the SBUHB and HDHB region often experience prolonged delays awaiting admission for specialist acute treatment due to their identified high acuity, and there is a risk that this will worsen following the planned changes	Increasing need to cross cover inpatient programmed activities, for succession planning, training, capacity planning prioritisation and future workforce availability.

	within Swansea Bay for all medical attendances and admissions to be managed on one site (Morriston Hospital).	
Muscular Dystrophy	Re-ignite previous work which was halted due to pandemic.	All wales SBAR produced for Chief Executives sets out the national context.
Functional Neurological Disorder	FND is a common and disabling cause of neurological symptoms (examples include dissociative seizures/blackouts, dissociative memory problems, functional paralysis and abnormal movements etc). At the extreme end, patients develop chronic, and extremely debilitating multiple somatic, cognitive, behavioural and emotional unexplained complaints (Brown, 2007). These problems are a common cause of attendance in ED, primary care and general medical inpatient facilities (and have included some cases of inappropriate admissions to ICU in SBUHB). These conditions are on the rise and most experts believe that, with the advent of COVID, the situation is likely to get worse over time. Even prior to COVID, an estimated third of the neurology clinical workload involves providing consultations to patients presenting with FND. They have been described as a “crisis for neurology” owing to their frequency, consequences, prognosis, and burden (Hallett, 2006). Despite being one of the commonest reasons for neurology consultation and with rates of long-term disability similar to those seen in people with MS, patient experiences of healthcare are routinely poor, there are no pathways and provision of co-	• To provide a neurology-led team which will develop an evidence-based integrated and coherent care pathway, with colleagues in liaison psychiatry. • Promote self-management and psychoeducation from the time of initial diagnosis. • Work closely with colleagues in primary care to support appropriate patients outside of ED, secondary care/neurology clinics. • Provide liaison, psychoeducation, training and support for a professionals in ED, primary care, community and secondary care etc • Develop a local network involving patient support groups and organisations such as FND Hope UK. • Access to a telephone/email helpline for patients and professionals (including GPs). • Use of digital technology tools, apps and webinars for information and self-management advice. • Use of assistive technology for individual, family and group therapy. • Develop a website for patients in the South West Region and work with FND

	ordinated assessment or treatment services is non-existent. In the South West Wales Region the neurology and ED data indicate that people experience multiple episodes of re-assessment and re-investigation, and patient outcomes remain poor. The mortality rates for FND are higher than in the general population.	Hope UK to provide appropriate digital resources. • Specialist advice and support with discharging complex FND cases. • Offer training in FND and formulation skills, as well as a network of supervision and consultation to staff across the region. • Collaborative working with community rehabilitation teams, services and agencies. The aim is to stratify primary, secondary care and community services. • Work with community providers, vocational services, education and the third sector (e.g. FND Hope) to promote self-help, community integration and well-being. • Establish a network of MDT professionals with expertise in FND in Wales. • Provide support to enable employers to understand the condition and keep people in work, thereby reducing the need for welfare benefits. • Engage in neuroscience research, collect data, evaluate therapeutic interventions (e.g. based on latest poly-vagal evidence).

NCIG Priorities Form June 2021

Please list your organisations top 5 priorities for development for the next 1-2 years.

This may be a particular care pathway, service, workforce development, or resource to support the development of neurological conditions within your organisation.

Organisation: Aneurin Bevan UHB

Priority	Rational and supporting evidence	Benefit of taking forward nationally
Neurology Repatriation Business Case	Scheme is compatible with care closer to home and equity of service.	N/A
Review of MS infusion service	Expansion in available disease modifying treatments in MS – requiring a review of current service to ensure sustainability.	Link in with national priorities for MS service
Development of workforce – PA's	Modernisation of new flexible agile ways of working Improved integration with acute medicine and primary care	NA
PROMS and PREMs further expansion into other sub specialities	Increasing value based health care evidence. Importance of clinical outcomes Managing outpatient demand	Already agreed all wales epilepsy proms via seizure task and finish group for NCIG
Increased community working	Relates organisations priority of delivering care closer to home. Post covid secondary care is contracting; driving forward acceleration with integrated care models.	Links in with National priorities.

Agenda Item 7 - Neuro-physiology Review

Neuro Physiology review.docx