Grŵp Iechyd a Gwasanaethau Cymdeithasol
Health and Social Services Group

'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
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		

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

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.	**Action**

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.	
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 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.	**Action**

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. 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**
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	**Action**

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.	**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	ALL	TBC		

		the WNA website.				
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	#####		Completed.
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	#####		On agenda for further discussion
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	#####		On agenda for further discussion
10. NCIG Effectiveness/Way Forward	20210309/10.3	Draft Neurological Conditions Quality Statements to be shared with the group	GH	#####		Completed.

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.

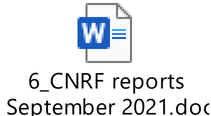
Appendix One- Group membership to date

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

Agenda Item 5 – Data Dashboard

Data Dashboard.docx

Agenda Item 6 - Community Neuro-Rehab Reports – Feedback



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	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.

	people out of county for specialist intervention. More effective local services should reduce demand on health and social care 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 within Swansea Bay for all medical attendances and admissions to be	Increasing need to cross cover inpatient programmed activities, for succession planning, training, capacity planning prioritisation and future workforce availability.

	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-ordinated assessment or treatment services is non-existent. In the South West Wales Region the neurology and ED data indicate that	• 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 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

	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.	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

Neurological Conditions Implementation Group
Agenda
Tuesday, 14th December 2021
10:00-12:00hrs

		Item	Paper	Lead
10:00		Welcome and Apologies		Michelle Price
10:05	1	Minutes & Outstanding actions from previous meetings	1 2	Michelle Price
10:10	2	Quality Statements Update	3	REDACT – WG STAFF
10:15	3	Organisational Priority Proposals 2021-22	To follow/ verbal	Michelle Price
10:35	4	Update from WHSCC	Verbal	Liz Kenward
10:55	5	Data Dashboards • Epilepsy • Acquired Brain Injury	To follow/ presentation	Michelle Price Sally Cox & Keith Howkins
11:20	6	Community Neuro-Rehab Workshop – Feedback	Verbal	Michelle Price
11:30	7	Neuro-physiology Workshop - Feedback	Verbal	Michelle Price

11:40	8	Finance Update	Verbal	Lyn Kenway
11:45	9	AOB	Verbal	All
12:00	10	Dates of next meeting Close		

Neurological Conditions Implementation Group
Minutes of Meeting
23rd September 2021
Via Teams

Author: Lauren Edmunds-Smith	**Version:** 1

Members present:

Name	Organisation
Adele Griffiths	ABUHB
REDACT – WG STAFF	Welsh Gov
Alison Shakeshaft	HDUHB
Annette Morris	BCUHB
Claire Nelson	CTMUHB
David Heyburn	PHW
REDACT – WG STAFF	Welsh Gov
Jonathan Bevan	DHCW
Joseph Anderson	ABUHB
Kevin Duff	CTMUHB
Lance Reed	HDUHB
Lisa Simm	C&VUHB
Lucie Cornish	PTHB
Lynda Kenway	PHW
Michelle Price	PTHB
Peter Carr	ABUHB
Rebecca Brown	MS Society
REDACT – WG STAFF	Welsh Gov
Sally Cox	DHCW
Shakeel Ahmad	C&VUHB
Stephan Monaghan	PHW
Steve Evans	ARCH
Tanya O’Sullivan	HDUHB
Tom Hughes	

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• Further expansion and development of PROMs and PREMs into sub-speciality areas where it has yet to be applied.
• Increased community working, developing care closer to home. Work around long COVID falls as part of this wider piece of work.

BCUHB: Annette Morris unable to connect during this section of the meeting.

CVHB:
• Recovery and improvement of services post COVID, including ensuring any future model is flexible.
• Alternative OPD facility required.
• New day-unit facility required.
• Restoration of telemetry and restarting Epilepsy surgery.
• New posts linked to priorities, new consultants and trainees.
• Business case for paediatric telemetry
• Business case for Huntingtons Disease.
• New treatments for Neuro-inflammatory disease & second consultant.
• Development in tandem of secondary and tertiary services, including neurology and stroke.

CTMUHB:

• Additional Neurology consultant capacity.
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- Epilepsy Nursing: Develop local nursing provision.
- Neurodiology: Stabilisation of service and capacity.
- Neurophysiology: Develop further capacity.

HDUHB & SBUHB:
- Focus on headaches, epilepsy, FND and standardising the approach across the region.
- Aim for a single neurology service across the region.
- Deliver FND business case.
- Develop case for Epilepsy for submission.
- Ensure plans are included in IMTP/Annual plan for 2022/23

PTHB:
- Stakeholder engagement- setting up service for user forums to support with shaping the service going forward.
- Speciality Community frameworks – make sure our clinicians have the right knowledge and skills to meet the needs of the local population.
- Data – to understand the local demand and evaluate changes in service.

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- Identify gaps
- Evaluate impact and outcomes
- Demonstrate value

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Epilepsy pathways were presented and discussed. The ViH team have started to develop a dashboard for Epilepsy with the following data sets at present:
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- Emergency department
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Further plans are to look at:
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- WAST
- Primary care
- Welsh Clinical Portal
- Patient Care Database

There will be a presentation by the ViH team at the next meeting.
A model of what the data presentation will look like was provided within the presentation.

ABI Data:
Team are currently scoping the data for the data dashboard with DCHW..

Recommendations provided:
- HBs to ensure that they have appropriate representation in each of the clinical reference groups.

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9. AOB	
Ensuring that the group is aware of the neurophysiology work going forward. The Chair closed the meeting.	

10. Date and Time of Next Meeting	
14th December 10:00 – 12:00	

Neurological Conditions Implementation Group
Agenda
Tuesday, 15th March 2022
10:00-12:00hrs

		Item	Paper	Lead
10:00		Welcome and Apologies		Alison Shakeshaft
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11:05	5	CEG Paper (Neuromuscular Network)	4	Michelle Price
11:35	6	Planned Care Programme, Bevan Commission Submission	5	Khalid Hamandi
11:45	7	Finance updates & future plan • Future funding letter	6 7	Lyn Kenway
11:55	8	AOB • Migraine Trust	Verbal 8	All
12:00	9	Dates of next meeting Close		

Grŵp Iechyd a Gwasanaethau Cymdeithasol
Health and Social Services Group

Neurological Conditions Implementation Group
Minutes of Meeting
23rd September 2021
Via Teams

Author: Lauren Edmunds-Smith	**Version:** 1

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14th December 10:00 – 12:00	

Agenda Item 2 – Action Log

NCIG Meeting - Action Log						
Agenda Item No & Title	**Action Point**	**Action**	**Assigned to**	**Deadline**	**Status(RAG)**	**Notes/Update**
Sep-21						
3. Quality Statements	20210923/3.1	Further Quality Statements T&F Group meeting to be arranged to discuss comments from the patient reference group and develop the next draft of the document.	LK	########	Completed	On agenda for further discussion
3. Quality Statements	20210923/3.2	Comments to be given on the latest draft of the Quality Statements by 14th October.	LK/ALL	TBC	Completed	On agenda for further discussion
5. HB Priority areas	20210923/5.1	Meeting to be arranged to decide on the areas to take forward as high-level priorities and reported back at the next NCIG in December.	LK	########	Completed	On agenda for further discussion
5. HB Priority areas	20210923/5.2	LK to pull together the organisational priorities for discussion at the priorities meeting.	LK	########	Completed	On agenda for further discussion
6. Data Dashboard	20210923/6.1	Nominations for clinical reference groups from each Health Board (if not already represented) should be sent to Lyn and Michelle.	ALL/MP/LK	########	Completed	On agenda for further discussion
7. CNRF Reports Feedback	20210923/7.1	Report to be refined and returned to HB's to return quarterly updates. Conversations will be undertaken with the teams to	MP/LK	########	Completed	

		refine the templates.				
7. CNRF Reports Feedback	20210923/7.2	Suggestion of a weekly meeting to influence performance to be taken forward	AS	########		Update pending.

Agenda Item 3 – *NCIG priorities 2022 and beyond*

GIG CYMRU NHS WALES Grŵp Gweithredu Amodau Niwrolegol Neurological Conditions Implementation Group	
NCIG priorities 2022 and beyond	
Lead: Michelle Price	
Date: 8th March 2022	**Version:**
Purpose and Summary of Document: To update NCIG on the priorities that were agreed in a subgroup meeting on 30th November 2021.	

The NCIG are asked to:							
Approve	X	**Endorse**		**Discuss**		**Note**	
Consider							

Situation

NCIG last set priorities for work in April 2019. These were:

- Seizure pathway
- Neurorehabilitation
- Paediatric neurology

The NCIG now needs to plan its work from April 2022 for the next 12 months and beyond.

All health boards were asked to submit their individual priorities. These are attached in appendix one. These were reviewed on 30th November 2021 by a subgroup. There were several common themes- including clearer levels of care, care closer to home and recovery from Covid to better than pre-pandemic levels

2 Background

The Neurological Conditions Delivery Plan, initially published in 2014, was due to come to an end in 2020. It has been rolled over for the past 2 years while the new NHS Clinical Framework has been finalised and Quality Statements developed.

Due to the pandemic, there have been no new priorities or workplan agreed by NCIG for the past 2 years. Work has been continuing developing the data dashboards for acquired brain injury and epilepsy. As we emerge from the pandemic there is a focus on recovery and renewal and it is important the NCIG focus on making measurable improvements to the quality and equity of services for people living with neurological conditions across Wales.

1 Assessment

Three pieces of work have been identified that can be addressed at a national level, are not condition specific and support the delivery of the Quality Statements:

1. Review of Neurology Services- reviewing model for neurology across Wales- in line with English Neurology Service Specification and Get it Right First-Time (GIRFT) work- what is highly specialist and what should be delivered in DGH or closer to home. Opportunities to link with the planned care programme, particularly for optimisation of neurology outpatients. Can utilise resources developed by NHS England:

    - NHS commissioning » D04. Neurosciences (england.nhs.uk)
    - https://www.england.nhs.uk/wp-content/uploads/2013/06/d04-neurosci-spec-neuro.pdf

    Outputs:

    i. What is highly specialist and should be centralised- possibly commissioned through WHSSC
    ii. What should be core business in DGH
    iii. What specialist practitioner provision is needed to support that: Associate specialists, clinical specialists, advanced practitioners

2. Develop equitable pathways for people who require neurorehabilitation; reviewing local, regional and national provision, linking with the Major Trauma Networks building on the work that has been done by the Neurorehabilitation Task and Finish Group, the development of patient reported outcome measures and experience measures and the data dashboard for acquired brain injury.

    Outputs

    i. Map out and agree tiers of rehabilitation based on NHS England specification:
        1. Tier one commissioned by WHSSC
        2. Tier one commissioned regionally
        3. Tier three and community neurorehabilitation
    ii. Build on data dashboard to include community services
    iii. Utilise the delivery unit rehabilitation modelling matrix

3. Support the development and implementation of a stepped care psychology services for people with physical health problems similar to that recommended for people following stroke: Stroke_Psychological_support_2017 (england.nhs.uk), looking at local, regional and national options for people living with neurological conditions- Facilitated by WHSSC and Director of Therapies and Healthcare Sciences.

    Outputs

i. Identify a sustainable model for physical health psychological support; across neurological conditions and potentially more broadly across chronic conditions
ii. Develop pathways and support decision tools- who to refer where- what should be available

Recommendation

- These priorities need to be agreed by the wider NGIC.
- A work plan needs to be agreed with specific task and finish groups with appropriate representation form health boards and stakeholders

Going forward NCIG should

- Build links with Neurophysiology Workstream and receive regular updates
- Receive feedback from 2 HB each NCIG on their current programmes of work

  Receive feedback on one priority each meeting

Appendix One: Organisational Priorities

ABUHB:
- Business case being developed around neurology repatriation from CVUHB to ABUHB
- Review of MS infusion services & the ongoing sustainability of the service
- Development of workforce, particularly around Physicians Assistants and the development of a model and flexible workforce for the future including better integration with Primary Care.
- Further expansion and development of PROMs and PREMs into sub-speciality areas where it has yet to be applied.
- Increased community working, developing care closer to home. Work around long COVID falls as part of this wider piece of work.

BCUHB:
- Post Covid recovery
- Address current capacity and demand challenges
- Continue to deliver care closer to home and repatriate services where clinically appropriate to do so
- Neurology service provision, including Therapies
- Therapy services / establishment of baseline therapy workforce across North Wales
- Development of a Level 2 Neurorehabilitation service
- Neuropsychology
- Neuropsychiatry
- FES

CVHB:
- Recovery and improvement of services post COVID, including ensuring any future model is flexible.
- Alternative OPD facility required.
- New day-unit facility required.
- Restoration of telemetry and restarting Epilepsy surgery.
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- Speciality Community frameworks – make sure our clinicians have the right knowledge and skills to meet the needs of the local population.
- Data – to understand the local demand and evaluate changes in service.
- Dystonia
- FND

WG:

- Cerebral palsy,
- Acquired brain injury,
- Essential tremor,
- MS,
- Neuromuscular,
- Migraine/headaches
- MND
- Parkinsons disease
- Sleep disorder (non-respiratory)

WHSCC: Update to follow

WNA: None provided

Commonalities/key areas:

- Workforce provision and development
- Data: particularly around FND, PROMs/PREMs, service development, capacity/demand modelling
- Epilepsy: workforce and service provision
- Community neuro-rehab
- MS

Agenda Item 5 - Planned Care Neurology Project

Planned Care Neurology Project

Situation

There are an estimated 14.7 million cases of neurological disorder in the UK, which equates to one in six people having a neurological condition.

The Neurological Conditions Implementation Group (NCIG) have recognised that there are significant delays in timely access to diagnosis is an ongoing issue for the population of Wales, which has been

further exacerbated by disruption to services caused by the Covid-19 pandemic and difficulty recruiting to consultant neurology posts. This can result in significant distress to those who are awaiting a diagnosis, increases in unplanned admissions and emergency department attendances, delays in treatment and potentially worse outcomes for patients.

There are hundreds of different neurological conditions with varying incidence and prevalence rates, complexity and severity which can broadly categorised into:

- sudden-onset conditions
- intermittent and unpredictable conditions
- progressive conditions
- stable conditions with changing need

In Wales, neurology services are provided or commissioned by health boards with huge variation in service design and delivery. The Welsh Health Specialist Services Committee (WHSSC) have recognised that there are different level of specialisms and levels of care for different neurological conditions and have agreed to work with NCIG to undertake a review of neurology services. This has been agreed as a priority workstream for NCIG for 2022/23.

In November 2021, the Welsh Health Minister announced an additional £170m of funding at the inaugural Planned Care Summit to “build a planned care system that is bigger and better and more effective than we have seen before”.
The five goals for planned care, in line with the objectives of “A Heathier Wales”, are:

- **Effective referral:** Ensure that referral guidance and thresholds are in place to ensure those most in clinical need are referred to the appropriate setting.
- **Advice and guidance:** Develop access to high quality advice and guidance to enable informed decision making for individuals as well as primary and secondary care clinicians.
- **Treat accordingly:** Access to appropriate care at the right time at the right place.
- **Follow up prudently:** Giving individuals more choice and control over their care.
- **Measure what’s important:** Transforming care to better meet the clinical need of the patient.

In September 2021 NHS England produced a report and recommendations on improving effectiveness and efficiency of neurology services as part of the Get it Right First Time (GIRFT) Programme.

NCIG are currently working with the Value in Health Team to develop dashboards for Epilepsy and Acquired Brain Injury, which the first two categories outlined above and are an excellent staring point to evaluate any changes in efficiency and effectiveness as a result of improvements to the clinical pathways.

Service users across Wales have highlighted their frustration at the time it takes to get a diagnosis of a neurological condition. Focussing on improving this element of the pathway has potential to improve outcomes for people with neurological conditions and release capacity in the system for further service improvements.

A programme managed approach to implementing the recommendations of the GIRFT Neurology Programme in Wales would result in measurable improvements in effectiveness and efficiency of neurology services and improved patient outcomes.

Background

NHS England have recommended a tiered, network approach to delivering neurology planned care as part of the Get it Right First-Time (GIRFT) programme that could be implemented in Wales.

The GIRFT Programme has recommended a model for active management of outpatient referrals that would allow more patients to receive advice on management, have investigations booked and thus access earlier diagnosis and management where appropriate and could be implemented on a regional basis across Wales.

This would require the:

1. development of regional bespoke screening and advice service where a consultant neurologist can:
   - request further information from the GP before considering a referral;
   - provide advice;
   - arrange an investigation and give advice;
   - arrange an appointment in the hot clinic – on an urgent or routine basis;
   - arrange an appointment in a sub speciality clinic
   - arrange an appointment with a specialist nurse.
2. Establish mechanisms to better understand outpatient activity to support service planning and enable benchmarking
3. Improve access to outpatient investigations, by introducing nurse or allied health professional or health scientist led clinics
4. Improve GP direct access to investigations
5. Improve Maximise infrastructure and capacity for remote consultation
6. Development of standard guidance and training for GPs and patients on a common range of neurological issues, as has already been done for first seizure and epilepsy in adults
7. Identification of a suitable on line platform for GP and service user educational resources such as the Welsh Neurological Alliance (WNA), Health Improvement and Education Wales (WNA), or GP One

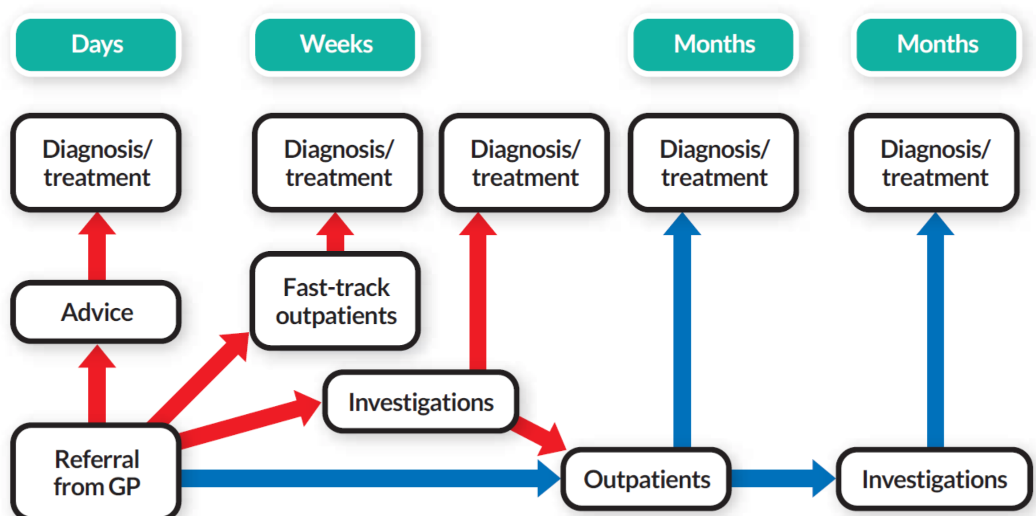


Fig One: Active management in comparison to the conventional process (in blue), an active assessment (in red) taken from GIRFT Neurology report

Evidence from elsewhere in the UK suggests that 10 to 25% of patients referred are provided with advice and few of these subsequently require appointments. There is also potential to reduce current "did not attend rates" to further release capacity.

Assessment

There are already examples of where excellent service provision in Wales, that could be built on to implement a regional neurology service, but this would require a programme approach with additional funding to support a project manager, clinical time and data analyst involvement, with resources available to develop education and training resources for GPs.

The development of a regional neurology triage service could:

- Improve equity of access
- significantly reduce referral to diagnosis time,
- improving service user experience and outcome
- reduce demand on already overstretched neurology services
- reduced unplanned admissions and attendances at A&E
- reduce did not attend rates
- offer opportunity to develop workforce of specialist nurses and AHPs to support to support the neurologists to provide investigations, assessment and improve management of conditions

NCIG could provide the programme board function

Recommendations

NCIG has limited capacity to manage an improvement programme that can deliver measurable improvements in equity, quality and timeliness of diagnosis. There are 2 sessions a week of a clinical lead and 4 sessions a week of a programme manager to support the group. There is no identified resource for data analysis or project support.

All health boards in Wales are engaged in the Neurological Conditions Implementation group, which would form the programme board for this project and the NHS Collaborative could host the project manager.

Additional resource and support from the Planned Care programme is required to deliver these improvements, as set out below.

Role	Resource	Costs
Project manager	**1 WTE B6**	**£46,831**
Data analyst	**0.4 WTE B6**	**£18,732**
Clinical Time	**GP 0.2WTE** **Neurologist 0.2WTE**	**£20,000**
Travel, engagement events		**£4,000**
Educational resource development	**B5 0.3WTE**	**£7,839**

Total		**£97,402**

Appendix

Agenda item 6 - NCIG Finance Update – 15th March 2021 – Financial Year 2021-22

1. Final Position – 2021-22

Below is the final financial statement for NCIG for the financial year 2021-22. The statement reflects the previously agreed spends under TC35.

From the original budget of £1m, and £300k from the Stroke Implementation Group **£1,294,550** had been allocated, leaving around **£5450k unallocated**.

Project Reference	Project Title	Delivery Organisation	Planned Spend
Staffing (NCIG-21-22)	National Clinical Lead for Stroke	NCIG	£17,250
NCIG-21-01	Early Supported Neurology Discharge Team (ESD) / Developing a Stratified Community Neurorehabilitation Team for SBUHB (with in-reach)	SBUHB	£152,000
NCIG-21-02	Community neuro-rehab service (CNRS)	ABUHB	£206,000
NCIG-21-03	Establishment of a level 2 neuro-rehab unit in N Wales	BCUHB	£100,000
NCIG-21-04	Community neuro-rehab service	CVUHB	£174,000
NCIG-21-05	Multidisciplinary Community Neuro-rehab Team	CTUHB	£117,000
NCIG-21-06	Stratified, integrated community neuro-stroke rehab	HBUHB	£145,000
NCIG-21-07	Community neuro-rehab service	PTHB	£96,000
NCIG-21-08	Development of specialist physiotherapy service for adult patients with neuromuscular	WNMN	£120,000

	conditions and Family Care Advisor		
NCIG-21-09	Paediatric Neuro-Rehabilitation	WHSCC	£150,000
NCIG-21-09	WNA - Website & Admin Support	WNA	£17,000
NCIG-21-10	Epilepsy Pathway Launch	SBUHB	£300.00
			£1,294,550

Future Funding 2022 onwards.

On the 7th January 2022, Deputy CMO, REDACT – WG STAFF wrote to the Director of the NHS Wales Health Collaborative to advise him of the funding arrangements from 2022 onwards, for the Major Condition Implementation Groups currently funding by a £1m allocation. This letter was then forwarded to NCIG on 2nd February 2022. The letter details the following:

- Funding arrangements for the financial year 2022/23 will remain the same however from 2023 onwards any funding that is currently used to pay directly for the delivery of health board or trust patient facing services should cease by the end of March 2023 (and if possible earlier).
- Funding post 2023 will cease in its current format; the funding allocations and their uses should be fully aligned to the vision for clinical networks and national programmes described in the National Clinical Framework by April 2023.
- There is not yet clarity around the future of the Implementation Groups, however these groups should continue to support NHS Wales.

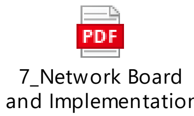
Health Boards and other organisations in receipt of funding from the Neurological Conditions Implementation Group are therefore urged to ensure that they have made alternative arrangements to support services currently funded by the £1m. It is imperative that Finance Directors in your organisation are made aware of these changes and that IMTP's reflect this.

Proposed Neurological Conditions Implementation Group Commitments 2022-23

Changes to the balance sheet above are, on the whole, are expected to remain the same for 2022-23

Action: The NCIG is asked to agree the continuation of support currently given to the WNA post, £17,000k.

Agenda Item 7 – NATIONAL CLINICAL NETWORK PROGRAMME FUNDING



Grŵp Iechyd a Gwasanaethau Cymdeithasol
Health and Social Services Group

Neurological Conditions Implementation Group
Agenda
Tuesday 13th December 2022
10:00-12:00hrs

		Item	Paper	Lead
10:00		Welcome and Apologies Any declarations of interest to be noted.		Chair
10:05	1	Minutes & Outstanding actions from previous meetings	1	Chair
10:15	3	Welsh Government Update • Quality Statement	Verbal	REDACT WG STAFF
10.30	4	Update regarding NHS Executive	Verbal	Rhys Blake
11.00	5	Epilepsy and ABI Dashboard update	Verbal	Sally Cox
11.10	5	Updates from workstreams • Model for delivering neurology services • Neurorehabilitation • Bevan Commission • Psychological support	Verbal	Rhiannon – GIRFT Adele – CNR Michelle – BC Daryl – Psychological support
11:30	7	Finance and HB reporting including exit strategy	Slide	Rhiannon Edwards
11:35	9	Discussion on prioritising work for the new clinical network 2023-24	Discussion	All
11:55	10	AOB Arrangements for NCIG support in absence of clinical lead		All

12:00	11	Dates of next meeting: 14th March 10-12.00 Close		

Neurological Conditions Implementation Group
Minutes of Meeting
6th September 2022
Via Teams

Author: Emma Parry/Rhiannon Edwards | **Version:** 2

Members present:

Name	**Organisation**
Annette Morris	BCUHB
Adele Griffiths	ABUHB
REDACT – WG STAFF	WG
Emma Parry	NHS Collab
Kevin Duff	CTMUHB
Rhian Meredith-Spurr	WHSSC
Michelle Price	PTUHB
Rhiannon Edwards	NHS Collab
Stephen Monaghan	PHW
Tanya O' Sullivan	HDUHB
Alison Shakeshaft	HDUHB
REDACT – WG STAFF	WG
Ana Palazon	WNA
Caroline Bidder	Network lead MND Wales
Christopher Hodcroft	CTUHB
Elizabeth Beadle	CTUHB
Huw Davies	CAVUHB
Lucie Cornish	PTHB
Rebecca Brown	WNA
Sarah Bant	HIEW
Shelley Elgin	WNA
REDACT – WG STAFF	WG
APOLOGIES:	**Organisation:**
Jonathan Whelan	WAST
Khalid Hamandi	CAVUHB
Peter Carr	ABUHB
Joanne Oliver	NHS Collab

Carly Hill	HDUHB
Jason Killens	WAST
Liz Kenway	WHSSC
Joanne Janes	BCUHB
Lance Reed	SBUHB
Kate steele	WNA

Abbreviations

ABUHB	Aneurin Bevan University Health Board
SBUHB	Swansea Bay University Health Board
CTMUHB	Cwm Taf Morgannwg University Health Board
CAVUHB	Cardiff and Vale University Health Board
PTHB	Powys Teaching Health Board
BCUHB	Betsi Cadwalladr University Health Board
HDUHB	Hywell Dda University Health Board
WHSSC	Welsh Health Specialist Services Committee
WG	Welsh Government
WNA	Wales Neurological Alliance
PHW	Public Health Wales
WAST	Welsh Ambulance Service Trust
HIEW	Health improvement and Education Wales
MND	Motor Neurone Disease
GIRFT	Getting It Right First Time
WNMN	Wales NeuroMuscular Network
HB	Health Boards

Welcome, introductions and apologies

The Chair welcomed everyone to the meeting, and everyone was asked to do a quick introduction.

1. Minutes of last meeting & outstanding actions from previous meeting

The minutes were reviewed and the outstanding actions either completed or part of the agenda to be discussed during the meeting.

2. Results from My Survey

A presentation was shown during this part of the agenda which outlined the results of the 'My Neuro Survey'

Please see appendix 1 for a full description of the presentation.

Discussion following the presentation, detailed the lack of surprise at the concerns and responses the survey results. It was noted that although Wales did slightly better in some categories than the other UK countries, the results were still poor and the survey gave a good foundation to understand the experiences individuals went through in their contact with healthcare services.

MP and RE stated that these findings were informing the work ongoing in the Bevan Commission project, and that patient views and experiences were an important part of co-production activities within the project.

3. Welsh Gov Update

<u>Report of government enquiries</u>

One piece of work is currently happening at a UK level around Acquired Brain Injury (ABI) and developing an ABI strategy in England. This involved a call for evidence from the 4

Nations, which has now been completed. The call of evidence will determine the next steps in developing the Strategy. The second piece of work is around Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome(CFS). There have been a few meetings that have taken place for ME/CFS and some structures have been built. There was a request to ensure that we are participating and engaging widely to ensure that we are feeding information into the two pieces of work. There was a discussion around whether ME/CFS should be part of NCIG following the circulation of the delivery plan the previous day. It was agreed that it should be kept a separate group due to the previous lengthy discussions. It was reiterated that there is no intention to commit NCIG to be part of it, just to share information regarding this widely within their networks. NHS Executives There has been some high-level functions that have been determined for the NHS executive. These are around reinforcing and refocusing National Leadership for Quality Improvement and Transformation, planning and enabling stronger performance management and quality improvements. At the moment, the NHS delivery Unit, the NHS collaborative, finance, the Delivery Unit and Improvement Cymru are the current organisations and there is work ongoing with the on where they will all sit within the NHS executive. Quality Statements During the meeting, there was a need to finalise the Quality Statements as it is due to go through the Policy Forum and signed off by the minister the following day. The final version was signed off by the NCIG Attendees for the meeting. **ACTION: Circulate Quality Statement when approved by policy group**	
4. Updates from workstreams	
A slideshow was presented with an update on all the workstreams. **Review National Commissioning Framework for delivering neurology services** Currently, the England Neurological conditions GIRFT report audit questions are being collated into a Microsoft Forms which will be circulated shortly to the directorate Neurological Leads. This will enable NCIG to understand the current services provision across Wales. The next steps will be to arrange meeting in with each Health board Neurology teams to support understanding the current pressures in the system. **Support Neuromuscular Business Case development** WNMN meeting to be held in September to discuss Service Specification, this was following support on workforce mapping. It was reiterated during the meeting that this isn't a specific high priority for NCIG, but MP and RE will support as part of their role within the NHS Wales Collaborative if they have capacity. Following discussions this will be taken off the priority list for NCIG. **Bevan Commission Planned Care Project**	

A working group has been set up which meets monthly to drive forward the aims and objectives of the project. To date: Datasets have been produced with waiting times for neurological referral across Wales. Two primary care workshops (Nov, edited since NCIG and January) are being planned to gain insight into the challenges with referring patients with neurological symptoms. 15 members of a patient co-production group have been recruited and are feeding into the working group.

Project Manager is still yet to be recruited.

Action – Circulate Dates for the Primary Care Workshops

Oversee the development of equitable pathways for people who require neurorehabilitation

CNR learning event will be held in October to share best practice. The intention is to host two learning events, one which will be looking at the feedback from all of the local neuro rehab services on lessons learned and developments but also looking at the support needed going forward for putting business cases to health boards regarding ongoing funding.

Develop appropriate local, Regional and National options for psychological support with people living with neurological conditions

Initial conversations surrounding the creation of a psychological support network with Welsh Government and SameYou Round table discussion. ToR have been developed and EOI has been requested for Chair and Vice Chair. The next steps are to look what can be achieved within the group which will start with mapping of current services. The next meeting is planned for 30th September 2022.

Action- Ensure ToR and current membership details are circulated via the NCIG.

5. Reporting

A summary of the reporting templates completed was presented. Common themes were the improvement of face-to-face services and partnership/collaboration, especially with community groups and the development of PROMS to accompany evaluation reporting. Consequences of the cessation of NCIG funding was a common theme across all health boards.

NCIG Funded services are required to complete a report, including funding details on a quarterly basis to the NCIG Coordinator. Robust governance processes have been developed due to the increased scrutiny of the financial environment. There has been a delay in receiving these reports in Q1, therefore please ensure that the key dates are planned for subsequent Quarter reports.

Dates are as follows:

Q2 report due 31st October, invoiced following approval 30th November

Q3 report due 31st January, invoice following approval 28th February

Q4 report due 10th March, invoiced following approval 24th March

Action- Ensure all members of NCIG feedback the importance of timely reporting and invoice submission.

6. Finance

A slide was presented during this agenda item of the NCIG financial position which has been broken down into quarterly projected costs against invoiced spend. Some of the reporting from some Health Boards were sent within a few days of the deadline set. AM expressed concern about the perceived underspend for BCUHB in Q1. RE explained that this was a representation of current spend and that current planned spend Q2-Q4 had been agreed and mapped to the allocated budget.

The chair reiterated the importance of providing finance information in a timely manner and to suggestion to add on the organisation name onto the finance charts. It was agreed that a reminder letter is sent from the NCIG chair to key directors in the HB's to re-enforce the cessation of NCIG funding.
It was re-enforced that in 2022-23, that all implementation groups had had the funding reduced to support administration resources needed.

Action – Reminder Letter to be drafted to HB's regarding the cessation of NCIG funding

7. Exit Strategy for the Community Neuro Rehab fund

Due to time constraints, this agenda item was not able to be discussed.

8. Comms Update. Twitter/Website.

Due to time constraints, this agenda item will be discussed during the next meeting.

8. AOB

Michelle Price, NCIG Clinical Lead is planning on stepping down but will be continuing to support the Bevan Commission Planned Care Project. EOI will be requested shortly, with the intention of appointing a new clinical lead by December in time for the next NCIG meeting.

. Date and Time of Next Meeting

13th December 2022 10:00 – 12:00

Agenda Item 2 – Action Log

NCIG Meeting - Action Log						
Agenda Item No & Title	**Action Point**	**Action**	**Assigned to**	**Deadline**	**Status(RAG)**	**Notes/ Update**
Sep-21						
15. Welsh Gov	20220906 3.1	Circulate Quality Statement when approved by policy group	TW/BD	01/11/2022		

16. BC primary care workshops	20220906 4.1	Circulate Dates for the Primary Care Workshops	RE/EP	01/10/2022	
17. Terms of reference	20220906 4.2	Ensure ToR and current membership details are circulated via the NCIG.	RE/EP	01/10/2022	
18. Reporting	20220906 6.1	Ensure all members of NCIG feedback the importance of timely reporting and invoice submission.	All	31/10/2022	
19. Exit planning	20220906 6.2	Action – Reminder Letter to be drafted to HB's regarding the cessation of NCIG funding	RE/AS	01/12/2022	