'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

		GIG CYMRU NHS WALES	Cydweithrediad Iechyd GIG Cymru NHS Wales Health Collaborative	

**Neurological Conditions Implementation Group
Agenda
Thursday, 30th July
13:00 – 15:00**

Chair: Michelle Price

		Item	Paper	Lead
13.00	1	Welcome and Apologies		Michelle Price
13.05	2	Reflections from the last few months & the recovery plan	Verbal	HB representatives
13.40	3	WNA feedback on peoples experiences during lockdown		Rebecca Brown
13:55	4	CPG Enquiry into the Neurological Conditions Delivery Plan		Ana Palazon
14.05	5	NCIG Priorities 2020/21 and update from the task & finish groups - Neurorehabilitation - Paediatric Neurology - Seizures Pathway - Self-Management - Technology		Michele Price Anurag Saxena Rob Powell Adele Griffiths & Rachel Wallbank Jacqueline Sharp & Karen Bonham
14.20	6	Propose NCIG Priorities and task & finish groups for next 18 months	Verbal	Michele Price
14.50	7	Forward planning - NCIG Annual Report requirements - Successor Planning for the NCIG Delivery Plan	Verbal	REDACT – WG OFFICER Michelle Price

14.55	8	Any Other Business	Verbal	All
15.00	9	Close		

Agenda Item 3 - WNA feedback on people's experiences during lockdown – Rebecca brown

Wales Neurological Alliance Response to the Inquiry into the Covid-19 outbreak on health and social care in Wales.

Introduction

The Wales Neurological Alliance (WNA) is a coalition of more than 20 organisations working together to transform outcomes for people in Wales with neurological conditions – disorders of the brain, spinal cord or nerves. There are more than 250 recognised neurological conditions.

Wales has approximately 100,000 people living with a neurological condition that have a significant impact on their lives. Many neurological conditions are life threatening and the majority significantly affect quality of life. Too often, people with neurological conditions in Wales report substantial barriers to accessing the treatment, services and support that they need from health and care services.

In Wales, each year around 2,500 people are diagnosed with Parkinson's disease, epilepsy, multiple sclerosis or motor neurone disease. The latest prevalence data from Public Health Wales (2014-15) indicates out of the 100,000 over 41,000 people in Wales are estimated to suffer from one of the following neurological conditions; Parkinson's disease, epilepsy, multiple sclerosis, muscular dystrophy, motor neurone disease and cerebral palsy. In addition, a further 10,000 people each year were admitted to hospital for an acquired brain injury.

The WNA has spoken to members and conducted a survey to ensure the views and opinions of people living with neurological conditions are included in this inquiry. The WNA has also sent a letter to the Health Minster to highlighted issues raised by member organisations.

Difficult accessing services before Covid-19

Notwithstanding the COVID-19 pandemic, people with neurological conditions can have difficulty accessing the specialist care they need. The Cross Party Group on Neurological Conditions launched an inquiry in 2019. The Inquiry report highlighted the need for more significant improvements across health and social care. Some of the main recommendations for improvements were:

- Timely referral to specialist services for diagnosis
- Shorter waiting times and more consultants and specialist nurses
- More psychological support for people living with conditions
- Improved access to medications and treatments

Surveying individuals living with neurological conditions

WNA conducted a survey for two weeks at the end of May 2020 to assess the concerns and difficulties for people living with neurological conditions during the pandemic. This was a Wales wide survey which was sent out to individuals and their carers to complete via the alliance member organisations. The survey was completed by 138 people living with neurological conditions in Wales.

Shielding and Vulnerable categories

The main concern was the confusion about whether or not the individual's condition meant they should be in the shielding category or classed as clinically vulnerable. Some 28% of people who responded who did not receive a shielding letter from the Chief Medical Officer believed that they should be placed in this category. A greater proportion of 44% took the precaution to self-isolate because they believed that they were more vulnerable because of their medical condition. The issue was raised that no formal support for people was given who are clinically vulnerable but are not on the shielding list. For example online food delivery slots and when speaking to employers about returning to work.

The WNA are concerned that people with some progressive and life-limiting neurological conditions, such as motor neurone disease and multiple system atrophy, which compromise people's ability to live independently, and which have a significant impact on their health and wellbeing, were not included on the Government's 'extremely vulnerable' list. We understand that some people with neurological conditions have been added to the list, but data on the conditions people have and who have been added to the 'extremely vulnerable' list is not, as we understand it, publicly available. The concern is that decisions about who qualifies to be added to this list may have been applied differently in different areas.

Support from Local Authorities

The survey highlighted that additional support from local councils was not universally offered will only 32% of people shielding or vulnerable being offered additional support with 65% receiving no contact during this lockdown period. Some responses stated that people felt alone and having to rely on local communities and neighbours. It was also mentioned that people were not made aware at an early stage that if they needed help getting the essentials that they should contact their local authorities for assistance.

Access to Care and support

61% of care received by individuals has been received by unpaid carers who are mostly family members. This has put more pressure on family members to complete all care needs. This is of particular concern with conditions such as Parkinson's, where carers have a mean age of 70.7 (Hand et al 2018). From this particular cohort only 9% relied on paid carers regularly. Many people have seen their care support reduced or stopped by local authorities. Some people living with neurological conditions have chosen to cancel care agencies because of the perceived risks of catching Covid 19 as carers attend several households and appropriate levels of personal protective equipment being available.

Individuals also commented that continuing healthcare assessments had stopped and were concerned about what would happen if these assessments were delayed for long periods of time.

Access multidisciplinary care and therapy.

The survey as expected showed that all routine appointments had been cancelled. Some people had received phone or video calls from some specialist services. From the survey results 42% of people had had their appointments cancelled, 8% of people had chosen to cancel their appointments because of concerns attending NHS sites. Around 24% of individuals had reviews by video or telephone calls.

Achieving an appropriate balance between COVID-19 and non-COVID-19 care has not always been possible since NHS services have been reconfigured in the wake of the pandemic. Whilst this is understandable, as significant NHS resources had to be diverted towards meeting the urgent needs of the rising number of COVID-19 patients - and the scale of the need was not known at the outset - there is no doubt that people with neurological conditions have experienced a significant reduction in their levels of routine care and rehabilitation. There is also the point that many neurological conditions have other co-morbidities and have not been able to access these service causing a detrimental effect on health and well-being.

We have heard of situations where some nurses are single-handedly running outpatient clinics which otherwise would have been staffed by multidisciplinary teams. Most commonly, outpatient services are now being provided via video or telephone.

• Reduced services for people with neurological conditions must not become the new norm as this will only result in worse patient outcomes and higher costs to the NHS as patients run the risk of their condition deteriorating in the longer term.

• It is important that an ongoing impact assessment is made of how these skeleton services are affecting the health and outcomes of people with neurological conditions and what measures are being put in place to ensure that scaled back services remain in operation for the minimum length of time possible.

Mental health needs

The survey has highlighted that 18% of people were struggling with their mental health. With 29% finding it difficult because they could not leave their residence. Consideration should urgently be given to prioritising access to mental health services for all people with neurological conditions after the peak of the COVID-19 crisis, as they are likely be at increased risk of having mental health complications following the social distancing and other measures introduced. The other consideration is that 20% of people were finding it difficult to keep physically active at home which can also have a detrimental mental health affect.

Neurological conditions relate to the brain and nervous system. The interaction between physical needs and broader emotional, cognitive and mental health needs is complex. Changes in the brain can directly affect a person's emotions, cognitive abilities and executive functioning. Conversely, depression or anxiety can coexist alongside neurological symptoms. People's mental health difficulties often have an impact on their neurological condition, triggering or exacerbating it. In times of social distancing, loneliness, social isolation, health anxiety and change to established routines all serves to adversely affect people's mental health. Mental health services should be provided holistically as part of a person's overall care, delivered by multi-disciplinary teams.

Meeting the wave of pent-up demand for health and care services that have been delayed due to the coronavirus outbreak

People living with conditions have expressed the understandable view that they expect a significant backlog in delivering some medical treatments which could have a long-term impact on the physical

and mental health of people with neurological conditions. Careful consideration needs to be given to how best to manage a return to a more normal service to be most effective.

The Association of British Neurologists and the Royal College of Physicians have considered how best to address and prioritise the backlog of patients in order that:

• The most urgent neurological cases are prioritised according to agreed and validated tools, procedures and pathways.

• Cancelled procedures such as infusions are reinstated as quickly as is safely possible, bearing in mind the long-term risks to health of not doing so.

• New diagnoses are prioritised, delivered in face-to-face consultations.

Neuro Rehabilitation

Long term impact rehabilitation is critical for the long-term recovery of people who have, for example, had a stroke or brain injury, as well as minimising the long-term impact of progressive neurological conditions. Therefore it is essential that neuro rehabilitation services are seen as a priority.

Patient stories Experiences

The WNA has been producing with the help of Cardiff University Students patient experiences: https://www.youtube.com/watch?v=4LRlgq6pq18 – Gwyneth story highlights the fact that because of the neurological condition affecting every part of an individual's life and living in Lockdown.

Our survey included a free text box; some of the comments are included below:

- *"Waiting for assessments re adaptations etc. but no idea when these will happen now. Specialist nurse now working elsewhere within hospital so having delays in replies to messages. Consultant appointment on hold. Physio assessment/speech and language therapy all on hold.*
- *Feeling isolated. Not being able to get a food shop for online. Being out of routine*
- *Devastated that all trials have been suspended particularly MND Smart. This was some hope which doesn't exist at the moment.*
- *Carers and family have been marvellous in dealing with all my needs. Carers should have been given PPE straight away as they were dealing with the most vulnerable. The knock on effect is more people contacted the virus.*
- *Does seem a lot of people with an Epilepsy condition have been ignored by the government, luckily my local chemist have been really good and I have not had to run out of my medication.*
- *As I have had a lot of time off work due to my condition I work in a frontline vulnerable job I have been off work for 12 weeks now as I'm scared to go to work. My boss has suggested next sickness they are having to let me go. I feel very exposed to covid-19 but still no cover letter from GP or government. I also have high blood pressure anxiety and other issues but still no cover letter."*

Key points for the inquiry to consider:

- It is crucial for people with neurological conditions to continue to access specialist services during the outbreak and beyond to maintain their wellbeing including therapists. The NHS in Wales must apply strong leadership in restarting neurology services, using Association of British Neurologists guidance and in consultation with people living with neurological conditions the NHS must set out their priorities for restarting neurology services.
- Isolation and shielding has meant increased anxiety and impacted many people living with neurological conditions mental health. People's mental health difficulties often have an impact on their neurological condition, triggering or exacerbating it. Mental health services must adapt to meet the needs of people living with neurological conditions.

- Ensuring that social care packages are available to those who require support in line with Social Services and Well-being (Wales) Act 2014. Local authorities should support families to feel re-assured that all precautions are being adhered to prevent the spread of Covid 19 to those who receive care in the community. Unpaid carers should be supported as currently a large burden of care is falling on families to cope with carer fatigue and stress.

Agenda Item 4 - CPG Enquiry into the Neurological Conditions Delivery Plan - Ana Palazon

PowerPoint presentation

Cross Party Group on Neurological Conditions Inquiry Report

Introduction

- ► There are more than 250 recognised neurological conditions. In Wales, approximately 100,000 people are living with a neurological condition that has a significant impact on their lives.
- ► Many neurological conditions are life threatening and the majority significantly affect quality of life.
- ► Too often, people with neurological conditions in Wales report substantial barriers to accessing the treatment, services and support that they need from health and care services.

About the Neurological Conditions Delivery Plan

In 2011, the Welsh Government published a number of Health Delivery Plans . One of these was the Neurological Conditions Delivery Plan (NCDP).

The NCDP provides a focus for improvements in the delivery of services and support for people with neurological conditions across Wales, both at local and national level. Each chapter of the plan looks at a different area. These chapters are:

•   Raising awareness of neurological conditions

•   Timely diagnosis of neurological conditions

•   Fast, effective, safe care and rehabilitation

•   Living with a neurological condition

•   Children and young people

•   Targeting research

•   Implementing the plan

Methodology

► Written and oral evidence was submitted to this inquiry by a wide range of stakeholders, including:
  ► Individuals living with neurological conditions and carers;
  ► Charities representing people affected by neurological conditions;
  ► Specialist clinicians;
  ► Royal Colleges;
  ► The Wales Neurological Alliance; and
  ► The Neurological Conditions Implementation Group.
  ► Three oral evidence sessions were held. Two sessions were located in Cardiff, South Wales, and one in Wrexham, North Wales.

Theme 1 –Raising Awareness

Issues
  ► Low levels of awareness of neurological conditions within health and social care services.
  ► Experience of poor attitudes and lack of understanding.

Achievements
  ► Coproduction activity particularly around the development of PREM
  ► Discreet educational activity e.g Clinical Leadership programme, BCUHB Neurosciences Conferences and Study days.

Remaining challenges:

► Comprehensive education for health and care staff, Neurological Service User

Forums .

Theme 2 – Timely diagnosis

Issues
  ► Delays and accurate diagnosis
  ► Lack of support whilst people wat for diagnosis
  ► Poor experiences of diagnosis

Achievements
  ► Requirement for LHBs to work with primary care networks to raise awareness with GPs
  ► Cardiff and the Vale – Epilepsy Specialist Nurse on call system supporting Emergency Unit.

Remaining challenges
- Lack of data and measurement

Theme 3 -Fast and Effective Care

Issues
- Lack of consultants, nursing staff and recruitment.
- Lack of publicly expressed patient pathways.
- Timely follow up once diagnosis is made.
- Lack of access to medication and treatment.
- Poor experiences with end of life care.

Achievements
- ABMUHB and partnership with Dr Doctor.
- BCUHB and MNDA – Care Co-ordinators.
- Coproduction Group at CTUHB.

Challenges
- Lack of consistency, roll out of good practice.
- Complexity of aligning neurological services to services provided outside of neurology e.g. care of older teams.
- Lack of sepcilaist support in Mid and North Wales.

Theme 4 – Living with a neurological condition

Issues
- Availability of community services, particularly physiotherapy, SaLT, occupational therapy, services to help people to be physically active.
- Discharged home without adequate support.
- Lack of psychological support.
- Low engagement levels from social care.
- Evaluation of the impact of NCDP funding

Achievements
- Amount of funding given to NHS organisations and third sector partners to support NCDP priorities

Remaining challenges
- Sustained and continued investment

- Complex range of NICE guidance that needs to be adhered to .

Theme 5 – Children and Young People

Issues
- Lack of psychological support.
- Access to specialist treatments.
- Transition to adult services.

Achievements
- Neuro rehab MDT established at Children's Hospital
- Named clinician and co-ordinator for improving stroke services in South wales.
- Named paediatrician with interest in transition of CYP with severe impairment at Children's Hospital

Remaining challenges
- Ensuring that improvements in services for children with neurological conditions have an equal focus.
-

Targeting research

Issues
- Links between NCDP and the neurosciences research community.
- Patient Involvement Network

Achievements
- ► Patient Reported Outcome Measures
- ► Investment by Welsh Government (Health and Care Research Wales) in the BRAIN Unit

Challenges
- ► Ensure that the NCDP is best linked into the research community.

Implementing the plan

Issues
- ► Role of NCIG
  - ► prior to plan there was no existing clinical network so started from a low baseline.
  - ► Consistent representation.
  - ► Capacity and ability to work at a strategic level
  - ► Clinical lead only recently appointed.
  - ► Annual Statement of Progress lacks detail on progress against all outcomes in the refreshed plan.
- ► Chronic underfunding
- ► Limited progress in co-production with people affected by neurological conditions.
- ► Partnership working with third sector – particularly smaller charities.

Achievements
- ► Significance of the plan in giving a Wales wide focus on neurological conditions
- ► Clinical Lead
- ► Prioritisation

Remaining challenges
- ► Maintaining the work of the NCIG post delivery plan.
- ► Accountability for delivery – who is responsible for holding LHBs to account?
- ► Lack of management data
- ► Weakened reporting requirements as a result of LHBs not needing to publish annual reports.

Recommendations

We urge **Welsh Government** to take the following action when the NCDP comes to an end in 2020:
- ► End the '*chronic underfunding*' of neurological services by increasing investment in health and social care services to meet the needs of people in Wales.
- ► Create a new neurological conditions strategy and action plan with clearer outcomes and a stronger accountability structure.
- ► Commit to a workforce development and commissioning strategy to ensure there are adequate numbers of specialist staff within Wales to meet the needs of people with neurological conditions in a timely manner and an appropriate place.
- ► Establish a national system for the collection, collation and publication of outcomes data on neurological services, working with the research community, people with neurological conditions and the third sector.
- ► Convene a scrutiny and oversight group to hold LHBs to account for the delivery of the plan, to separate accountability from delivery.
- ► Establish a permanent all-Wales forum for neurological conditions which can promote best practice and drive improvement based on the current NCIG model. This should include funded posts for a Clinical Lead and a coordinator.

Recommendations continued

- ► Create a new co-production and participation strategy that mandates and requires NCIG and LHBs to demonstrate the active participation of people with neurological conditions and carers in decisions about improvements to care and support at a national and local level.
- ► Ensure all LHBs publish Progress Reports against the outcomes of this plan which are easily accessible on LHB and Welsh Government websites, in the context of this simplified outcomes framework.
- ► Mandate that each LHB should have:
  - ► A Neurological Steering Group with cross sector representation;
  - ► A Neurological Conditions Service User Forum, or other mechanism to support service user participation;
  - ► A named neurological lead; and
  - ► Full attendance by the lead or deputy at each NCIG meeting.

► Explore ways in which Welsh Government can put into effect measures to ensure social care engagement in the delivery of the plan.

Agenda item 5 - Michele Price, Anurag Saxena, Rob Powell, Adele Griffiths & Rachel Wallbank Jacqueline Sharp & Karen Bonham

NCIG Priorities 2020/21 and update from the task & finish groups
- Neurorehabilitation
- Paediatric Neurology
- Seizures Pathway
- Self-Management
- Technology

NHS Wales Neurological Conditions Implementation Group (NCIG) Priorities and Actions for 2020-21 IMTPs

	Description of Priority	
Priority 1	**Implement a co-productive approach to raising awareness of neurological conditions.**	**Year**
DP Section 2 Raising awareness of neurological conditions	Key Action 1. Wales Neurological Alliance (WNA) to lead on scoping current awareness raising activities across the statutory and third sectors and make recommendations for ongoing awareness raising priorities in partnership between statutory agencies and the third sector.	2020-21
	Key Action 2. Health Boards and Local Authorities to develop neurological education frameworks to support the training and development needs of staff working with people living with a neurological condition.	2020-21
	Key Action 3. Health Boards to establish Neurological Service User Forums in partnership with people living with neurological conditions to inform awareness raising needs and service improvements which meet their needs.	2020-21
Priority 2	**Implement a co-productive approach to service development.**	
DP Section 4 Fast, effective, safe care and rehabilitation	Key Action 6. Health Boards to implement PROMs and PREMs for patients with neurological conditions and act on findings to continually improve services.	2020-21
DP Section 5 Living with a neurological condition	Key Action 6. Health Boards will continue to develop their neuro-rehabilitation services, including psychological support and consider opportunities for self-referral for people living with a confirmed neurological condition.	2020-21
Priority 3	**Developing clear pathways and models of care based on best practice and research evidence.**	
DP Section 3 Timely diagnosis of neurological conditions	Key Action 1. Health Boards to provide GPs with timely access to specialist advice through structured telephone and email contact, speeding diagnosis for people who may not need referral to a clinic.	2020-21
	Key Action 2. Health Boards to ensure timely access to multidisciplinary assessment to support diagnosis where necessary.	2020-21

	Key Action 3. Health Boards to provide GPs with timely and direct access to CT where appropriate and in line with agreed diagnostic protocols.		2020-21
	NHS Organisations to work with the NCIG to further improve services for patients with neurological conditions in Wales. National Task and Finish Groups to progress improvements in pathways for: • Adult neuro-rehabilitation • Paediatric neurology • Seizures		2020-21
DP Section 7 Targeting Research	Key Action 1. Health Boards to work with the Health and Care Research Wales specialty lead, researchers and Health and Care Research Wales to increase the number of neurological condition research studies undertaken in Wales.		2020-21

Neurological Conditions Implementation Group
Agenda
Wednesday 7th October
10:00 – 12:00

Chair: Michelle Price

		Item	Paper	Lead
10.00	1	Welcome and Apologies		Michelle Price
10.05	2	Notes and actions from last meeting		Michelle Price
10.15	3	NCIG Priorities and task & finish groups for next 18 months		Michele Price
11:15	4	Funding 2021/22		REDACT – WG OFFICER
11.45	5	Any Other Business	Verbal	All
11.50	6	Close		

Agenda Item 1 – Meeting notes

GIG CYMRU NHS WALES

Grŵp Gweithredu Amodau Niwrolegol
Neurological Conditions Implementation Group

**Neurological Conditions
Implementation Group**
Notes of meeting
30 July 2020
via Skype

Author: Paula Powell		**Version:** 0.1a	

Members present:

Name	Organisation		
Ana Palazon	WNA		
REDACT - WG OFFICER	Welsh Government		
Annette Morris	BCUHB		
Christopher Hodcroft	CTMUHB		
Claire Nelson	WHSSC		
REDACT - WG OFFICER	Welsh Government		
Hywel Morgan	Implementation Groups Manager		
Jackie Sharp	C&VUHB		
Lance Reed	HDdaUHB		
Liz Kenward	WHSSC		
Lyn Kenway	NCIG/SIG Coordinator		
Michelle Price (Chair)	PtHB		
Paula Powell	NCIG/SIG Coordinator Support		
Rebecca Brown	WNA		
Robert Powell	SBUHB		
Stephen Monaghan	PHW		
Tom Hughes	C&VUHB		
Apologies			
Alison Shakeshaft	HDdaUHB	Lynne Hughes	WNA
Anurag Saxena	ABUHB	Marie Evans	CTMUHB
Claire Nelson	WHSSC	REDACT – WG OFFICER	Welsh Government
Gareth Cottrell	SBUHB	Peter Carr	ABUHB
Jonathan Whelan	WAST	Peter Skitt	HDdaUHB
Karen Bonham	SBUHB	Rachel Wallbank	C&VUHB
Louise Cullum	HDdaUHB	Stuart Bourne	PtHB

1. **Welcome and apologies**	
Welcome and introductions.	**Action**

2.   **Reflections from the last few months & the recovery plan**

Health boards reported on the experiences of the last few months: • Telephone clinics have been widely used for outpatient appointments, have worked well and will continue. • Patients have been fearful of visiting the hospital. • Video conferencing has been successfully utilised. • Face to face appointments have taken place for urgent consultations.	

• There was an understanding that more work needs to be carried out to provide administrative support for telephone and virtual consultations and that they can take as long if not longer than face to face ones. • There are still a lot of people on lists waiting to be seen. • Chemotherapy drugs have been administered during this time. • There was enough capacity due to a drop in other patients because of Covid concerns. • The situation generally is now improving, health boards are restarting services but this is subject to limitations and patients' willingness to attend • Community services are being used to reduce footfall in hospital and treat more patients in their own home • For paediatric neurology essential services were delivered across areas where services had been commissioned. The paediatric neurology service currently covers South Wales as North Wales uses Alderhay. The paper concentrates on the south. It will be submitted to the management group in August 2020. **ACTION:** MP to check whether any essential services were stopped	
	MP
3. WNA feedback on people's experiences during lockdown	
Rebecca Brown gave a presentation on this item. WNA responded to a Welsh Government enquiry into the effect on social and health care services during the lockdown. WNA carried out a brief survey in May. The main issues to emerge were: • whether people should shield and who were in a vulnerable category- impacted on support available. • home care concerns about PPE . Impacted on people accepting care and the care on offer from LA. • Many happy to access services via tele medicine. People were generally happy to wait until after the pandemic. • Big impact on anxiety and lack of access to normal sources of informal support • concerns about availability of future services, both acute and rehabilitation Main findings for consideration: - Continue access to specialist services. - Isolation and shielding causing massive anxiety. Need to consider how to manage going forward. - Carers – fatigue caused due to the extra burden with no outside help. Group recognised common issues across many conditions and communities.	**Action**
4. CPG Enquiry into the neurological conditions delivery plan	
Ana Palazon presented on the results of the enquiry, the background of which the group was aware. There were issues and achievements in all areas. Remaining challenges were identified. Positives: • PROMS research • Investment by Welsh Government into the brain unit.	**Action**

• clinical lead was a late, but welcome appointment • Wales wide approach and engagement For further development: • NCDP to link better with the research community • Tracking progress There are 10 main recommendations in the report. The group recognised: common themes from other implementation groups: • local projects work well but are difficult to get rolled out nationally • implementation groups don't have the ability to progress with health boards due to competing priorities. There would be a joint response to the report from NCIG and WG, and the findings from research into the clinical community and patients would inform progress and priorities.	MP, LK, REDACT-WG OFFICER, AL

5. NCIG Priorities 2020/21 and update from the task & finish groups	
The Chair advised that an update was needed on priorities and progress, and progress of the task and finish groups. • Neuro Rehab- working on mapping where the services are and producing an evaluation framework so that its effectiveness and efficiency can be measured. Discussions have taken place with the Value Based Healthcare team to agree a way forward. This work was used to inform the Post Covid Rehabilitation Framework, Evalaution and Modelling work led by REDACT – WG OFFICER. • Paediatric Neurology The Chair met the lead Johann Te Water Naude in March 2020 when he was planning to look at the report that had been published. He was to speak to Rob Powell about coordinating the work. • Seizures Pathway Rob Powell, are working on an all Wales pathway for seizures and epilepsy for emergency departments and GPs. Sheila Shepley has been leading as part of her Clinical Leadership Programme project. Ann Sivapatham has proposed launching an event. Following a letter on behalf of NCIG to Medical Examiner on SUDEP, RP met the leading medical examiner and he has passed on comments to the coroner about it being a recognised cause of death to facilitate learning. PROMS, being led by Charlotte Lawthom. Also ongoing discussions about information for a national dashboard The Chair had conversations with members of VBHC and NWSS staff and they would be picking up dashboard work again.	Action

RP concluded that it had been productive getting different professionals together. When the work is finished in 2020 they intend to stay together as a network. The Chair commented that the group had been cited as an example of what worked well in the annual NCIG report. - Supporting Self-Management The Chair had received feedback from Adele Griffiths and Rachel Wallbank who had been unable to attend the meeting. The group had struggled to move forward. With the new post covid world it was important to save the behaviour change element. The group will put something together by the end of the year. - Technology in Rehabilitation Jackie Sharp reported back that Covid had helped to remove many of the barriers to implementation of virtual consultation. Kerrie Phipps, Lead AHP for PC has been leading on this nationally. Rehab technology- group has identified applications and kit, but think that relates to the neuro rehab workstream. Funding available is an issue. Lyn Kenway advised that in terms of storing the documentation. A Sharepoint site will be available for use by NHS Wales staff shortly.	

6. Propose NCIG Priorities and task & finish groups for next 18 months

	Action
The Chair suggested that the group needs to consider, in light of previous discussions and the current situation, what its priorities are. This needs to be done for discussion in the December meeting. Initial proposals included: - a SSNAP type audit to drive improvement in inpatient care - raising awareness of functional neuro condition - a patient forum that all the workstreams can stream work through. - A community of best practice. The Chair asked the group to canvas their health boards. The target would be a first draft by the beginning of September 2020 for use at the October meeting. The drafts would be circulated before the meeting. **ACTION:** Group members to complete proposal form for future priorities	
	All

7. Forward Planning

	Action
- NCIG Annual Report requirements – REDACT – WG OFFICER confirmed a review of requirements by WG is now taking place, but no annual report is required as this stage. - Successor Planning for the NCIG Delivery Plan –National Clinical Framework still not published. Need to have plans and priorities for 12-18 months, and shape the plan for what works for neurological conditions.	

• National Executive currently on pause, may have implications for condition specific plans. The Chair agreed and reiterated the proposal to have a draft in place for October 2020. The Chair said that she and Lyn Kenway would collate the proposal forms and again asked the group to put forward their ideas.	
8. Any other business	
There was no AOB.	**Action**

Agenda Item 3 - NCIG Priorities and task & finish groups for next 18 months

GIG CYMRU NHS WALES — Grŵp Gweithredu Amodau Niwrolegol / Neurological Conditions Implementation Group	
Priorities Proposal	
Proposal Title: Neurorehabilitation Clinical Network	
Author: Michelle Price	
Proposed Chair:	
Date: 05/10/2020	**Executive Support:**

1. **Background**

There has been a Neurorehabilitation Task and Finish Group of the NCIG for the past 18 months. This has had specific projects which it will deliver on by December 2020:

- An evaluation framework that can be used by all services delivering neurorehabilitation, either in the hospital or in the community

- Mapping exercise of current community neurorehabilitation services

Many of the members of the group members of the group have valued the opportunity to meet to:

- get a better understanding of service developments around neuro rehabilitation nationally, in their own and in other health boards

- share good practice

- develop communication networks across Wales to enhance patient care and cross organisational working

- provide peer support

- maximise effectiveness by reducing duplication of effort in service developments

The recent role out of Teams across health boards in Wales and the shift to virtual meetings has made it easier to meet, and lack of need to travel has minimised the impact on patient contact and job plans.

2. **Purpose**

The group would:

- annually update the service mapping of neurorehabilitation services across Wales and provide NCIG with an update on implementation of the evaluation framework.
- act to drive and disseminate learning and good practice around developments in:
  - Promoting and supporting self care
  - Utilising technology in neurorehabilitation
  - MDT symptom management- e.g. spasticity, postural management, functional neurological disorders

3. **Key Functions**

The group would:

- Meet at least twice a year via Teams and provide a "newsletter" that can be circulated more widely.
- Act as a community of practice to share knowledge and expertise support service and workforce development
- Improve communication around developments in neurorehabilitation to disseminate learning and facilitate roll out of successful local initiatives

4. **Benefits**

The group would:

- annually update to NCIG on the service map of neurorehabilitation services across Wales and provide with an update on implementation of the evaluation framework.
- act as a reference group for the VBHC Data Dashboard Task and Finish Group
- reduce duplication of effort by adopting a once for Wales" approach

5. **Membership**
AHPs, Specialist Nurses and Neurorehabilitation Consultants from community teams and inpatient services from across Wales
WHSSC

GIG CYMRU NHS WALES | Grŵp Gweithredu Amodau Niwrolegol **Neurological Conditions Implementation Group**	
Priorities Proposal	
Proposal Title: Development of a VBHC Dashboard for Neurological Conditions	
Author: Michelle Price	
Proposed Chair:	
Date: 05/10/2020	**Executive Support:**

1. **Background**

As highlighted in the GPG Report on NCDP, the lack of robust data has been a limiting factor for understanding the demand for and improving the quality and effectiveness of services for people with neurological conditions for many years.

With the publication of "A Healthier Wales" and the focus on Value Based Healthcare there is an opportunity to develop a data dashboard for neurological conditions that would facilitate the development of a common dataset to inform and evaluate service developments.

The NCIG has supported the development of a nationally agreed PROM and PREM for use across stroke and neurological conditions over the past 3 years. To date there has been little uptake of these tools, as there is not an efficient way to collect, collate and report the tools. These tools would form the basis of a value-based data dashboard.

A nationally agreed dataset and a national dashboard would enable NCIG focus on reducing inequality and driving up quality and effectiveness in healthcare provision for people with neurological conditions on a national basis.

2. Purpose

- Promote and support use of nationally agreed PROM and PREM at service and organisational level March 2021

- Review existing datasets and outcomes used across Wales- March 2021

- Identify limitations of data repositories and data sharing agreements June 2021

- Agree a core dataset and present to NCIG September 2021

- Utilise the Post Covid rehabilitation modelling tool, using core data set to support service and workforce planning and development March 2022

- Work with VBHC to put in place data sharing agreements and build a data dashboard March 2022

3. Key Functions

- Identify and engage key stakeholders and experts

- Agree a common dataset, which includes PROMs and PREMs that can be collected, collated and reported at a service level, organisational level or Wales wide level.

- Provide recommendations, advice and support for local clinical and information teams on what information to collect and efficient ways to do so

- Share examples of existing good practice and use of data to support service development

4. Benefits

The dashboard will help to identify:

- Examples of effective and efficient service provision

- Variation in demand for services across Wales

- Inequalities in service provision

- Changes in the quality of life of people living with a neurological condition over time

- Changes in the effectiveness of services over time

5. Membership

Representation from:

- Value Based Healthcare Team

- Clinicians, data leads and service planners/managers from each health board and or specialist service

- WNA and service users.

GIG CYMRU NHS WALES	**Grŵp Gweithredu Amodau Niwrolegol** / **Neurological Conditions Implementation Group**
Priorities Proposal	

Proposal Title: MS Services Audit	
Author: Lynne Hughes	
Proposed Chair:	
Date:	**Executive Support:**

1. **Background**

5,600 people in Wales live with multiple sclerosis (MS).

MS can be relentless, painful and exhausting. It's a condition which damages nerves in your body, making it harder to do everyday things like walk, talk, eat and think. Symptoms can fluctuate, making life unpredictable. They can include loss of balance, stiffness, spasms, speech problems, fatigue, pain, bladder and bowel, and vision problems.

MS affects three times as many women than men, and typically starts affecting people at pivotal times in their professional and personal lives. Some people with MS will need social care and welfare support to continue to live well independently.

We've seen huge advances in the treatment options for people living with relapsing remitting MS (RRMS) over the last 20 years. Crucially, they've helped people to manage their condition, identify early signs of complications and put in place prevention and treatment strategies to avoid unscheduled hospital admissions.

There are now over a dozen Disease Modifying Therapies (DMTs) available for RRMS,– but each new DMT leads to additional assessment and monitoring requirements which places further demand on a service which is already working at full capacity. 2019 saw the first treatment being licensed for some people living with early primary progressive MS (PPMS) – and with others in development, clinicians in Wales have voiced concerns over the lack of infrastructure to administer and monitor them.

Far too many people living with MS in Wales still face barriers accessing vital treatments and support – and they are less likely to access specialist help when they need to;

MS Specialist clinician in Wales are they are of the view that they are offering DMTs to all those eligible under NICE guidelines but are concerned of the impact on their ability to offer care and support to the wider cohort of people with MS, especially those with more progressed diseases because of the increasing demands of offering and monitoring DMTS.

2. Purpose

The group would aim to complete a Wales wide audit of a three-month period in 2019 (pre COVID) to ascertain whether there is variability in service across Wales

3. Key Functions
- An in-debth data trawl would be undertaken to include:
- Number of people with MS per Specialist MS Service, where they reside type of MS.
- Workforce i.e number of consultant, number of specialist nurses, number of specialist OY, PT
- Outpatient Capacity – i.e clinic times
- Number of people reporting relaps, number of people attending a relapse clinic, number of people scanned, number of people eligible for DTM, number of people on which DTM.
- % Of people living with MS offered an annual review compared to type of MS, DNA rate.
- Wating times to see general neurology clinics
- Waiting times for MS clinics
- Number of home visits completed.

4. Benefits

An analyst of the data would identify and regional differences in the care and support for people living with MS and enable Health Boards to develop improvements if needed.

5. Membership

Emma Tallyntyre Consultant Neurologirst, Cardiff and the Vale UHB

Jackie Smee – Lead Nurse Cardiff and Vale UHB

Gillian Ingram Consultant Neurologist, Swansea Bay

Helen Owen – LeadNurse – Swansea Bay

Katherine Hardifn Consultant Neurologist, Aneurin Bevan

Emma Horton, lead Nurse, Aneyrin Bevan

Agenda Item 4 – Welsh Government/NCIG Response to the CPG Inquiry into the Neurological Conditions Delivery Plan – Initial Considerations

Welsh Government/NCIG Response to the CPG Inquiry into the Neurological Conditions Delivery Plan – Initial Considerations

Context

It is important to recognise that the challenges this winter will be even greater, given the need to respond to the coronavirus outbreak and the resurgence of the virus over recent weeks. As such the recommendations within the CPG report must be considered alongside the significant pressure that health and social services are continuing to face. However, the Welsh Government and NCIG remains committed to ensuring that anyone with a neurological condition should have access to the best possible care.

Recommendations

1. **End the 'chronic underfunding' of neurological services by increasing investment in health and social care services to meet the needs of people in Wales.**

£1m has been invested per annum throughout the duration of the Neurological Conditions Delivery Plan (NCDP) along with an additional £300k per annum from the Stroke Implementation Group. This funding will continue until at least March 2022. This is in addition to core service provision provided by health boards and funding to support delivery of the Allied Health ProfessionalFframework. Further investment will depend on any new Government's priorities post May 2021 when the Welsh election is held.

2. Create a new neurological conditions strategy and action plan with clearer outcomes and a stronger accountability structure.

The existing NCDP has been extended to March 2022 along with the £1m funding. We are currently reviewing our current approach to delivery plans in order to continue to drive improvements in quality and outcomes for major condition areas. Welsh Government will be considering over the winter what any successor approach should be. Options being considered include the new NHS Executive leading on the approach and could mean a new neuro plan based around rehab. However, we would need to consider what this would mean for acute services. Consideration is also being given to possible high level policy statement from Welsh Government within the National Clinical Framework with the NHS Executive producing its own plan. Networks for more major health conditions are also being considered.

3. Commit to a workforce development and commission strategy to ensure there are adequate numbers of specialist staff within Wales to meet the needs of people with a neurological condition in a timely manner in a timely place

Helpful to consider this alongside 4 and 6.

We need to have a better understanding of the demand for and impact of services for people with neurological conditions. This can then help inform workforce planning. We also need to have a better understanding of what specialist knowledge and skills currently exist in Wales on which to develop a robust education and training programme.

Discussions took place between key members *of NCIG and SIG and Health Education and Improvement Wales (HEIW) in January about their role in the development of education and training for physicians, AHPs and nurses with a special interest in stroke and neurological conditions. A new post has been appointed to in HEIW, Head of Allied Health Professional Transformation, which will support the development of a specialist skilled workforce for Wales.*

4. Establish a national system for the collection, collation and publication of outcomes data on neurological services, working with the research community, people with neurological conditions and the third sector.

The lack of robust information and data on services for people with neurological conditions has been a limiting factor for understanding the demand for and improving the quality of services for people with neurological conditions for many years. In line with the recommendations in "A Healthier Wales" and the Value based healthcare approach being adopted across NHS Wales, the NCIG is committed to developing a national system for the collection, collation and publication of outcomes data on neurological services.

5. Convene a scrutiny and oversight group to hold LHBs to account for the delivery of the plan, to separate accountability from delivery.

Welsh Government already has a performance and accountability framework in place for health boards and has a number of levers at its disposal when health boards are not performing. These include quality and delivery boards, medical director meetings, primary care director meetings, board exec to exec meetings. Much will depend on successor arrangements and progress of recommendation 4.

6. Establish a permanent all-Wales forum for neurological conditions which can promote best practice and drive improvement based on the current NCIG model. This should include funded posts for a Clinical lead and a coordinator.

Over the past 18 months the NCIG has tried to strengthen clinical engagement with the NCIG and support the development of special interest groups. It will continue to encourage specialist networks and groups to engage with NCIG to build an All-Wales forum.

Funding for a clinical lead and co-ordinator is available until March 2022. This will also be a key part of any successor approach.

7.   Create a new co-production and participation strategy that mandates and requires NCIG and LHBs to demonstrate the active participation of people with neurological conditions and carers in decisions about improvements to care and support at a national and local level.

The Neurological Conditions Implementation Group has had "implement a co-productive approach to raising awareness of neurological conditions" and implement a co-productive approach to service development" as two of their 3 main priorities for the past 3 years.

It has funded a project worker, through WNA to support the first priority and has required task and finish groups to engage with relevant 3rd sector to include the service user voice. This has worked particularly well in the Seizures and Epilepsy Task and Finish Group. It is important to maintain this as the workstreams are agreed for 2021/22.

Last year it was agreed that the project worker employed to help deliver priority one would also support the development of service user networks to support local and national strategic groups. This has been disrupted by the Covid pandemic.

8. Ensure all LHBs publish progress reports against outcomes of this plan, which are easily accessible and on LHB and Welsh Government websites, in the context of this simplified outcomes framework.

The development of a value based dashboard should be a priority for NCIG for the next 18 months to build a robust foundation and inform all service improvements and development going forward.

9. Mandate that each LHB should have:

- **A Neurological Steering Group with cross sector representation;**
- **A Neurological Conditions Service User Forum, or other mechanism to support service user participation;**
- **A named neurological lead; and**
- **Full attendance by the lead or deputy at each NCIG meeting.**

Yes fully support. Representation at NCIG meetings has been disappointing over recent years.

10. Explore ways in which Welsh Government can put into effect measures to ensure social care engagement in the delivery of the plan.

We will work with our social care colleagues to secure representation on the NCIG and consider how neuro conditions can increase its profile in social services groups and forums.

<table>
<tr><td colspan="5" align="center">GIG CYMRU NHS WALES | Grŵp Gweithredu Amodau Niwrolegol
Neurological Conditions Implementation Group</td></tr>
<tr><td colspan="5" align="center">**Neurological Conditions Implementation Group
Agenda
Tuesday 9th March 2021
14:30 – 16:30**</td></tr>
<tr><td></td><td></td><td>**Item**</td><td>**Paper**</td><td>**Lead**</td></tr>
<tr><td>14.30</td><td></td><td>Welcome and Apologies</td><td></td><td>Michelle Price</td></tr>
<tr><td>14:30</td><td>1</td><td>Outstanding actions from previous meetings</td><td></td><td>Michelle Price</td></tr>
<tr><td>14:40</td><td>2</td><td>Cross Party Group Report</td><td>1</td><td>Michelle Price</td></tr>
<tr><td>14:50</td><td>3</td><td>Final Reports on T&F Groups
• Seizures
• Neurorehabilitation</td><td>
2
3</td><td>
Dr Rob Powell
Michelle Price</td></tr>
<tr><td>15:20</td><td>4</td><td>Funding
• projected underspend
• website development
• proposed continuation of WNA post</td><td>
4</td><td>All</td></tr>
<tr><td>15:35</td><td>5</td><td>Discussions on effectiveness of NCIG</td><td></td><td>All</td></tr>
<tr><td>15:50</td><td>6</td><td>Review of available data from 2017-19</td><td>5</td><td>Michelle Price</td></tr>
<tr><td>16:05</td><td>7</td><td>Proposals for 2021-22</td><td>verbal</td><td>All</td></tr>
<tr><td>16:20</td><td></td><td>Proposed Welsh Government Quality Statement</td><td></td><td>Michelle Price /REDACT – WG OFFICER</td></tr>
<tr><td>16:30</td><td>8</td><td>Any Other Business</td><td>Verbal</td><td>All</td></tr>
<tr><td></td><td>9</td><td>Dates of future meetings</td><td></td><td></td></tr>
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Agenda Item 2 - Welsh Government and Neurological Conditions National Clinical Lead joint response to recommendations to the Cross Party Group Report on Neurological Conditions

Context

It is important to recognise that the challenges this winter have been even greater, given the significant increase in the number of Covid-19 cases over the past few months and the speed at which the new variant of the virus spread. As such the recommendations within the Cross Party Group (CPG) report must be considered alongside the significant pressure that health and social services are continuing to face. However, the Welsh Government and Neurological Conditions

Implementation Group (NCIG) remains committed to ensuring that anyone with a neurological condition should have access to the best possible care.

Recommendation 1 (Funding) *End the 'chronic underfunding' of neurological services by increasing investment in health and social care services to meet the needs of people in Wales.*

<u>**Reject**</u>

£1m has been invested per annum throughout the duration of the Neurological Conditions Delivery Plan (NCDP) along with an additional £300k per annum from the Stroke Implementation Group. This funding will continue until at least March 2022. This is in addition to core service provision provided by health boards and funding to support the delivery of the Allied Health Professional Framework. We are committed to improving support for those people with a neurological condition and helping them rebuild their lives and last year announced an additional £1.4m for rehabilitation services for all people at risk of losing their independence. Further investment will depend on any new Government's priorities post May 2021 when the Welsh election is held.

Recommendation 2 (Delivery Plan Strategy) *Create a new neurological conditions strategy and action plan with clearer outcomes and a stronger accountability structure.*

<u>**Accept in part**</u>

The existing NCDP has been extended to March 2022 along with the £1m annual funding. This extension will allow for reflection on the lessons learned and new models of care utilised during the pandemic. Any new approach to neurological conditions delivery would also need to fit in with and take advantage of the opportunities set out in A Healthier Wales. These include the development of the National Clinical Framework and an NHS Executive function.
Over the last year, my officials have also been developing the concept of Quality Statements that will be underpinned by NHS implementation plans as part of the intended NHS Executive function. We have undertaken some preliminary engagement with stakeholders but I look forward to setting out more detail in the coming months. In parallel, I expect my officials to set out in the NHS planning framework what individual NHS bodies need to focus on in order to deliver the quality statement. This provides the best means of ensuring effective direction is set and rapid progress is made for the NHS and patients in Wales.

Recommendation 3 (Workforce) *Commit to workforce development and commission a strategy to ensure there are adequate numbers of specialist staff within Wales to meet the needs of people with a neurological condition in a timely manner in a timely place.*

Helpful to consider this alongside recommendations 4 and 6.

<u>**Accept in part**</u>

We need to have a better understanding of the demand for and impact of services for people with neurological conditions. This can then help inform workforce planning. We also need to have a better understanding of what specialist knowledge and skills currently exist in Wales on which to develop a robust education and training programme.

Discussions took place between key members of NCIG and SIG and Health Education and Improvement Wales (HEIW) last year about their role in the development of education and training for physicians, AHPs and nurses with a special interest in stroke and neurological conditions. A new post has been appointed to in HEIW, Head of Allied Health Professional Transformation, which will support the development of a specialist skilled workforce for Wales.

Recommendation 4 (Data Collections) *Establish a national system for the collection, collation and publication of outcomes data on neurological services, working with the research community, people with neurological conditions and the third sector.*

<u>**Accept**</u>

The lack of robust information and data on services for people with neurological conditions has been a limiting factor for understanding the demand for and improving the quality of services for people with neurological conditions for many years. In line with the recommendations in "A Healthier Wales" and the Value Based Healthcare Approach being adopted across NHS Wales, the NCIG is committed to developing a national system for the collection, collation and publication of outcomes data on neurological services.

Recommendation 5 (Scrutiny and Delivery Plan) *Convene a scrutiny and oversight group to hold LHBs to account for the delivery of the plan, to separate accountability from delivery.*

<u>**Reject**</u>

Welsh Government already has a performance and accountability framework in place for health boards and has a number of levers at its disposal when health boards are not performing. These include quality and delivery boards, medical director meetings, primary care director meetings, board exec to exec meetings. Much will depend on successor arrangements and progress of recommendation 4.

Recommendation 6 (All-Wales forum) *Establish a permanent all-Wales forum for neurological conditions which can promote best practice and drive improvement based on the current NCIG model. This should include funded posts for a Clinical lead and a coordinator.*

<u>**Accept**</u>

Over the past 2 years the NCIG has tried to strengthen clinical engagement within the NCIG and support the development of special interest groups. It will continue to encourage specialist networks and groups to engage with NCIG to build an All-Wales forum.
Funding for a clinical lead and co-ordinator is available until March 2022. This will also be a key part of any successor approach.

Recommendation 7 (Co-production and participation strategy) *Create a new co-production and participation strategy that mandates and requires NCIG and LHBs to demonstrate the active participation of people with neurological conditions and carers in decisions about improvements to care and support at a national and local level.*

<u>**Accept**</u>

The Neurological Conditions Implementation Group has had "implement a co-productive approach to raising awareness of neurological conditions" and implement a co-productive approach to service development" as two of their 3 main priorities for the past 3 years.
It has funded a project worker, through WNA to support the first priority and has required task and finish groups to engage with relevant 3rd sector to include the service user voice. This has worked particularly well in the Seizures and Epilepsy Task and Finish Group. It is important to maintain this as the work streams are agreed for 2021/22.
Last year it was agreed that the project worker employed to help deliver priority one would also support the development of service user networks to support local and national strategic groups. This has been disrupted by the Covid-19 pandemic.

Recommendation 8 (Progress Reports) *Ensure all LHBs publish progress reports against outcomes of this plan, which are easily accessible and on LHB and Welsh Government websites, in the context of this simplified outcomes framework.*

<u>Accept</u>

The development of a value based dashboard should be a priority for NCIG for the next 18 months to build a robust foundation and inform all service improvements and development going forward.

Recommendation 9 *Mandate that each LHB should have***:**

- *A Neurological Steering Group with cross sector representation;*
- *A Neurological Conditions Service User Forum, or other mechanism to support service user participation;*
- *A named neurological lead; and*
- *Full attendance by the lead or deputy at each NCIG meeting.*

<u>Accept</u>

Fully support. Representation at NCIG meetings has been disappointing over recent years and we will work with LHBs to improve attendance. We will also seek to establish a Neurological Conditions Service User Forum.

Recommendation 10 (Social Care Engagement) *Explore ways in which Welsh Government can put into effect measures to ensure social care engagement in the delivery of the plan.*

<u>Accept</u>

We will work with our social care colleagues to secure representation on the NCIG and consider how neurological conditions can increase its profile in social services groups and forums.

Agenda Item 3 Feedback on Neuro Rehab Task and Finish Group March 2021

Feedback on Neuro Rehab Task and Finish Group March 2021

Situation

Neurorehabilitation was agreed as a priority for a task and finish group by NCIG in March 2019. The existing Community Neuro Rehab working group was developed to include inpatient neurorehabilitation, to become a Neurorehab Task and Finish Group. It was co-chaired by Michelle Price, the clinical lead for NCIG and Clare Nelson, Specialised Planner - Neurosciences and Complex Conditions, WHSSC.

The CNR Steering Group met 3 times before March 2019 and the NR group has met 4 times since.

The recent Covid-19 pandemic has disrupted many healthcare services and groups, however it has also provided opportunities to accelerate certain projects and plans, such as the development of the use of technology in rehabilitation.

Background

A Community Neuro Rehabilitation workshop was set up by Michelle Price (PTHB) and Steve Davies (NCIG Coordinator) in June 2018. 24 AHPs attended, with representation across therapies from every health board in Wales and the WNA. This was an opportunity to share examples of good practice and identify areas of work where an all Wales approach might be useful. These are outlined in appendix one. It was felt that there was value in setting up a steering group to agree priorities for Wales-wide working groups and to oversee and facilitate progress of these groups. It would meet every 4 to 6 months. The meeting will be split across 2 sites joined by videoconferencing, one north, one south; to facilitate attendance, minimise travel time but maximise opportunity for Wales-wide working. At the

follow up meeting in November 2018 three priority areas were agreed with working groups with specific deliverables (see appendix two):

• Community Neuro Teams

• Self Management and Peer Support Groups

• Using Technology to Support Rehabilitation

Once the group evolved into the Neurorehab Task and Finish Groups, the main deliverables became:

1. Evaluation framework for Community Neurorehabilitation Teams

2. Directory of Neurorehabilitation services across Wales

Assessment

The CNR Steering Group and the Neurorehabilitation Task and Finish group which it evolved into have:

1. Piloted and developed the Patient Reported Outcome Measure and Patient Reported Experience Measure to make them as accessible as possible to people who may have cognitive or communication problems. These measures are available for use in all services in Wales and are embedded in the recommended evaluation framework for Community Neuro Services.

2. Developed a repository and resources and information for supporting the use of technology in rehabilitation, but a digital platform could not be found. Since the pandemic, there has been a huge increase in the use of technology to engage service users and deliver rehabilitation. An All Wales Clinical Advisory Group on Technology Enabled Care was set up which has neuro therapy representation on it. There has also been significant support made available for clinicians and services who want to embrace technology through TEC Cymru who provide a national platform to enable the sustainable use, scale up and spread of value added technology and Digital Health Ecosystem Wales (DHEW) which brings together industry, clinicians, policy makers, academics, innovators and funders to create an environment of digital innovation in Welsh healthcare.

3. Agreed an evaluation framework for community neuro services. The work to develop this framework informed the development of a the guidance on Evaluating the impact of rehabilitation services post COVID-19 published by Welsh Government in response the pandemic Evaluating the impact of rehabilitation services post COVID-19 | GOV.WALES.

4. Developed a high-level directory of available community neuro services across Wales, for ratification by HB executive and clinical leads, which will then be published on WNA webpages

In addition, the initial workshop in June 2018 highlighted the lack of support for development of leadership skills amongst AHPs and nurses, which led to the development and funding of the Stroke and Neurological Conditions Leadership Programme, that started in September 2019. It was disrupted by the pandemic, but the programme has continued to be developed on line. A formal evaluation of the programme will be presented back to the NCIG when complete.

A spasticity clinical professional development group has been set up for physiotherapists prescribing and or injecting for spasticity. This is chaired by Garry Morris, HDHB and Cardiff University and is meeting via teams on a regular basis. As this group evolves it is interested in supporting spasticity service development across Wales.

Recommendations

The members of NCIG are asked to approve:

1. The directory of community neurorehabilitation services in Wales for publication on WNA webpages

**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
Cardiff and the Vale of Glamorgan	**Community Neuro Rehab Service: Living Well** Any Neurological condition, including stroke	Via Consultant, GP or any health care professional	Physiotherapist Dietician Occupational Therapist Speech and Language Therapy Rehab Coach Physio Tech	Living well with neurological condition 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: 02920 313713	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

	E-mail: Communitybrain.injuryteam@wales.nhs.uk			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 Cardiffandvale.Esd@wales.nhs.uk	Acute Stroke Service	Dietitian, Physiotherapist, Occupational Therapist, Speech and Language Therapy, Rehabilitation Assistants	
	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 degenerative disorders	Enquiries or Referral form to be completed by health or social services professional and sent to generic email. BrainInjuryAndNeuroTeam.HDD@wales.nhs.uk	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 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-	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.
z-hospital-services/community-neurorehabilitation-service-sbuhb-bridgend/			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 stage PD, PSP, MSA)		Palliative Care Team, SALT, PT, OT, Dietitian facilitated by Community Neuro Service Coordinator	Coordination and Communication around support and rehabilitation being delivered
	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	
	Neuro muscular conditions	Via Consultant	Physiotherapy, Care Coordinators	
	SWMND Network	Via Consultant	Care Coordinators	

2. The evaluation framework for community neurorehabilitation services and make this compulsory for services funded through the Community Neurorehabilitation Fund to collect 5 activity measures, a PROM and a PREM as a basic data set.

NCIG Neuro Rehabilitation Evaluation Guidance

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.

Neuro Rehabilitation Services should be based on VBHC principles. All services should have an evaluation framework that:

1. **Clearly identifies the population they provide a service for:**
   - Age range
   - Referral and exclusion criteria

2. **Clearly identify the desired outcome they want for this population**

3. **Have measures that, in line with Value Based Healthcare principles capture data from a person-centred perspective on:**
   - Quality of care
   - Cost effectiveness
   - Outcomes

See table one below and table two in appendix two to see what types of measures you might want to capture, depending on how you define 1 and 2 above. Consider what you want to capture before you

	Quantity (Cost Effectiveness)	Quality
Effort	**How much?** **Number of people provided with rehabilitation** **length of stay in service** **number of contacts or % of programme completed** number of different health or social care professionals involved **type of intervention: face to face, telephone or virtual consultation, group**	**How well** **Patient reported experience measure** Intensity of rehabilitation provide **Responsiveness of rehabilitation services** Where rehabilitation provided, home, school, community setting, hospital setting Type of rehab interventions- face to face/ virtual, group or one to one
Effect	**Is anyone** # 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	**better off? 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

think about which tools.

Consider how you can automate any data capture, collation and reporting on existing systems such as WPAS, PARIS, CIS, WCCIS, Dr Doctor or using Forms in Microsoft Teams or Smart Survey.

Consider how you would use the data to provide reports and feedback for different groups of people, e.g. service users, your team, your managers, in a business case.

For more info see post-Covid rehabilitation resources at: https://gov.wales/rehabilitation-coronavirus

Table One below uses a Results Based Accountability© framework that looks at quantity, quality, effort and effect of rehabilitation to give examples of performance measures that demonstrate:

1. How much rehabilitation has been delivered
2. How well it was delivered
3. What impact it had on service users

Table One: RBA© Framework for Rehabilitation

The following measures (in bold in the table one above and two below) are the minimum dataset recommended for reporting to NCIG for Community Neuro Rehab Fund Projects.

Quantity:

- Number of people provided with rehabilitation
- Length of stay in service
- Number of contacts or % of programme completed
- Types of intervention: face to face, telephone, virtual, group or one to one

Quality:

- Patient reported experience measure (PREM)
- Time from referral to first contact

Impact and change over time:

- Patient reported outcome measure

REFERENCES

Hurst L, Mahtani K, Pluddemann A, Lewis S, Harvey K, Briggs A, Boylan A-M, Bajwa R, Haire K, Entwistle A, Handa A and Heneghan C. Defining Value-based Healthcare in the NHS: CEBM report May 2019. https://www.cebm.net/2019/04/defining-value-based-healthcare-in-the-nhs/

Service Evaluation Template

Service: Neurorehabilitation Services

Population served: people with a neurological condition who require an episode of multidisciplinary neurorehabilitation, either in bedded facility, as an outpatient, in their own home or in the community.

Aim/objective of interventions: support individuals to:

- achieve their optimal level of function and quality of life
- maximise their emotional, cognitive and physical well being
- have confidence to understand, monitor and manage their condition

	Measures	Tools	How, when and where collected
Change over time:	**QOL**	- EuroQOL-5L - PROMIS 10 +4 SNCIG PROM Jan 2020 - VBHC Privacy	National Platform Smart Survey, Dr Doctor Microsoft Teams, Paper, Excel Spreadsheet
Activity	**the number of people using their service**		WPAS/ WCCIS/ CIS/ PARIS
	length of stay in service		WPAS/ WCCIS/ CIS/ PARIS
	number of contacts or % of programme completed		WPAS/ WCCIS/ CIS/ PARIS
	number of different health or social care professionals involved		WPAS/ WCCIS/ CIS/ PARIS
	type of intervention: face to face, telephone or virtual consultation		WPAS/ WCCIS/ CIS/ PARIS
Outcome / Impact	Confidence to manage own condition		
	Impairment		
	Activity	**PROMIS 10 + 4**	Dr Doctor, Microsoft Teams, Paper, Excel Spreadsheet
	Participation		
	Well Being	**PROMIS 10 + 4**	Dr Doctor, Microsoft Teams, Paper, Excel Spreadsheet
	Goal Attainment		
Quality	**PREM** http://www.wales.nhs.uk/governance-emanual/public-and-patient-involvement	NCIG Meeting WNA March 2020 PREMS.c	
	Responsiveness of their service-time from referral to first contact		WPAS/ WCCIS/ CIS/ PARIS
	How close to home rehabilitation delivered- place of intervention		WPAS/ WCCIS/ CIS/ PARIS

Possible Outcome Measures and Tools

Measure	Non-Condition Specific Tools	
% who are confident to manage their health in the long term	Patient Activation Measure, General Self Efficacy Scale, Therapy Outcome Measure, Occupational Self-Assessment (OSA) Version 2.2, Morriston Occupational Therapy Outcome Measure (MOTOM)	
% who have returned to previous level of independence and well being	EuroQol 5d (EQ5D-5L), World Health Organisation Disability Assessment Schedule 2.0 (WHO-DAS 2.0), Patient-Reported Outcomes Measurement Information System Global Health version 1.2 (PROMIS Global10 v1.2), Medical Outcomes Study (MOS) 36-Item Short Form Health Survey (SF-36), SF-12,	
% 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	

* MOCA now requires a licence and specific training for use which has a cost implication

There is an online resource which details which tools have been translated to Welsh and validated
http://micym.org/llais/static/index.html#

APPENDIX ONE: The International Classification of Functioning, Disability and Health
https://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1

Body Functions are physiological and psychological functions of body systems

Body Structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in body function or structure such as a significant deviation or loss.

Activity is the execution of a task or action by an individual. **Activity Limitations** are difficulties an individual may have in executing activities.

Participation is involvement in a life situation. **Participation Restrictions** are problems an individual may experience in involvement in life situations.

Environmental Factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

APPENDIX TWO: Factors to consider when choosing an outcome tool

Outcome measures help to assess the quality and effect of a rehabilitation intervention or service. Different tools will measure the outcome in different populations and situations.

First you need to consider who is the **population** you are delivering your intervention or service to, for example:

- Age range- adults, older people, children,
- People with cognitive impairment or learning disabilities, people with communication difficulties
- Availability of a Welsh language version (check Mesurau Iechyd Cymraeg or Welsh Language Health Measures website http://micym.org/llais/static/index.html#)
- Medical condition- is it a condition specific group, such as stroke survivors or people living with a respiratory condition, or is it a more general group- D2RA

Then you need to decide what **impact** you think your intervention or service might have- what **outcome** would you expect a person to have. Are you trying to have an impact on someone's:

- overall health and well-being
- confidence
- mental health
- their ability to manage their own condition, or
- a specific impairment (swallow, balance, weight, mood) or
- an activity (walking, self-care, social interaction, well-being) or
- their participation (environmental interaction, vocational activities, family roles, social networks).

You need to consider who will be administering the tool

- is it the participant who self-administers (patient reported outcome measure PROM)?
- is it a profession specific tool (see training below)?
- can it be used by a wide number of professions or service providers (health and social care/third sector)?

Lastly you need to think about:

- Interoperabilty- can it be used across multiple existing systems?
- Training requirements- is specific training require to establish inter-rater reliability?
- Cost implications- do you need a license and/or there is a cost associated with using the tool, such as MoCA and PAM?

**Grŵp Iechyd a Gwasanaethau Cymdeithasol
Health and Social Services Group**

Llywodraeth Cymru
Welsh Government

APPENDIX THREE: Measures recommended by specialist services and professional groups

UK Specialist Rehabilitation Outcomes Collaborative (UKROC)

http://www.ukroc.org/

The full UKROC dataset represents the inpatient rehabilitation subset of the Long Term Neurological Conditions dataset. It comprises 30 items of demographic and process data for each admitted case episode together with:

- The Rehabilitation Complexity Scale (RCS-E) (as a measure of rehabilitation needs)
- At least one of an agreed set of outcome measures which include:
  - Full dataset - The UK FIM ± FAM
  - Minimum dataset - Barthel index (Wade and Collin Manual 1988)
- The Northwick Park Dependency Scale and Care Needs Assessment – to derive cost-efficiency

The Trauma Audit & Research Network (TARN)

https://www.tarn.ac.uk/

Glasgow Coma Scale (GCS) should be recorded for all patients

Patient reported outcomes:

- Patient Experience in hospital
- EQ5D-5L
- VAS (Visual Analogue Scale) where patients rank how they're feeling on a scale of 0 (worse health imaginable) to 100 (best health imaginable)
- Employment/education status prior to injury.

All Wales Psychology Group

% who are confident to manage their health in the long term	General Self Efficacy Scale
% who have returned to previous level of independence and well being	EQ-5D-5L, WHO - DAS
% with improved wellbeing / mood	**PHQ 9, GAD 7, TSQ** CORE-10, 34 and LD, DISC, HADS,
% that achieved goals that matter to them	GAS, Recovery Star

RCSALT

% who have returned to previous level of independence and well being	TOMS- SALT
% with improved impairment	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	La Trobe Communication Questionnaire

We are still awaiting confirmation of whether the National Value Based Healthcare team are going to support the development of a data dashboard for Neuro Rehab, which would enable ongoing development and evaluation of neurorehabilitation services in Wales.

3. To support the group to continue to meet as a community of practice to share good practice and identify projects that are best taken forward on an all-Wales basis.

4. Appendix One- areas for development in Wales from initial Community Neurorehabilitation Workshop, June 2018

1. Clinical Leadership- develop the next generation of clinical leads across therapies
2. Vocational training
3. PD MDT working- groups aimed at early intervention (e.g. PD Warrior)
4. Spasticity Management; therapy led services, education/ peer support
5. Community Neuro Teams; evaluation and share best practice
6. Assistive technologies; apps, video consultation, virtual therapy, FLORENCE (Cardiff and Vale UHB)
7. Peer support/self-management groups: training for Bridges/ACT, accessibility, critical mass, barriers to using community venues, third sector initiatives, pop up groups, evaluation
8. Education and Training
   a. FES- ongoing training and support-
   b. Bridges develop in house short training programme
   c. Acceptance and Commitment Therapy
9. Research- opportunities for doing research in this area on an all Wales basis

Appendix Two- workplan for initial working groups November 2018

Community Neuro Teams- Chaired by Rhiannon Rees and Tanya O'Sullivan from Hywel Dda Health Board. The group met predominantly by video conference. Clinicians from any health board from any condition specific or multi condition neurorehabilitation team or service were encouraged to engage.
The workplan for the group was:
• compile accurate database of current Wales neuro teams- mapping capacity, demand and outcomes
• review referral forms to see if value in creating single form that can be used for inpatient and community referrals to simplify patient pathway
• pilot PREM/PROMs in community

Self-Management and Peer Support Groups Chaired by Rachel Wallbank from Cardiff and Vale HB and Malin Falck from Cwm Taf Health Board. Anyone involved with developing or delivering self-management or peer support interventions were encouraged to get involved.
The work plan for the group was:
• Define what is meant by self-care management
• Identify existing self-management or peer support groups across Wales
• Review skills, training and resources needed by clinicians to deliver self-management

Using Technology to Support Rehabilitation Chaired by Jackie Sharp and Karen Bonham from Cardiff and Vale Health Board. Anyone involved with developing or delivering neurorehabilitation using technology was encouraged to attend.
The work plan for the group was to develop a web-based resource that included:
• Information on what technology is currently or can be used to support rehabilitation- what, when, how, by whom
• Resources that can be shared- policies, guidelines, instructions, governance structures, training
• Exemplars- stories from people who have actually used/implemented technologies in Wales

Agenda Item 3 – All Wales Adult First Seizure and Epilepsy Management Pathway

PDF

3. GR_06_Adult
Seizure and Epilepsy

Agenda Item 4 – Funding

- **projected underspend**
- **website development**
- **proposed continuation of WNA post**

Agenda Item 5 - Neurological Conditions Delivery Plan 2017

Neurological Conditions Delivery Plan 2017

Raising awareness of neurological conditions

Key actions	Progress
1. Wales Neurological Alliance (WNA) to lead on scoping current awareness raising activities across the statutory and third sectors and make recommendations for ongoing awareness raising priorities in partnership between statutory agencies and the third sector.	
2. Health Boards and Local Authorities to develop neurological education frameworks to support the training and development needs of staff working with people living with a neurological condition.	Several condition or profession specific frameworks in place in most health boards, but no integrated ones.
3. Health Boards to establish Neurological Service User Forums in partnership with people living with neurological conditions to inform awareness raising needs and service improvements which meet their needs.	BCU have several condition specific groups in place and a neurosciences board with service user engagement National Forum to be set up by WNA
4. Health Boards in collaboration with NHS Wales Informatics Services (NWIS) to develop clear and easy access to information and support about neurological conditions through a single NHS portal (once for Wales) linking with statutory and third sector condition specific organisations.	VBHC Data Dashboard planned for 2021/22
5. Health Boards to involve patients and carers in the design of services; service users' views on services are sought regularly and acted on to ensure continuous improvement.	PREMs undertaken in individual services,
6. Health Boards and Welsh Government to publish information on NHS performance for neurological conditions that is easily available to the public	Meaningful data not available

Outcome indicators and assurance measures

- Improvements in awareness evidenced in Patient Experience and Outcome Measures

- Number of Health Boards with comprehensive education frameworks
- Number of Health Boards facilitating active Neurological Service User Forums
- Number of hits on Once for Wales portal

Timely diagnosis of neurological conditions

Key actions	
1. Health Boards to provide GPs with timely access to specialist advice through structured telephone and email contact, speeding diagnosis for people who may not need referral to a clinic.	Consultant Connect Wales wide Part of wider Outpatient Review
2. Health Boards to ensure timely access to multidisciplinary assessment to support diagnosis where necessary.	Increase in availability of specialist nurses and AHPs across organisations across Wales, but varies, depending on service design, recruitment and funding
3. Health Boards to provide GPs with timely and direct access to CT where appropriate and in line with agreed diagnostic protocols.	Probably able to access this info
4. Health Boards and Primary Care Networks to raise awareness of neurological symptoms with GPs and ensure through audit people are referred to secondary and tertiary care in line with national guidance and referral protocols and pathways, where these exist. Referral protocols to be developed where none exist.	Pathways developed for Seizures and epilepsy
5. Health Boards to provide specialist advice within 24 hours (on a 7 day week basis) for those admitted acutely to hospital with a suspected neurological problem.	SB, C&V, ABUHB have on call system in place
6. Health Boards to provide appropriate access to outpatient services for new urgent and non-urgent referrals to meet GP and patient need.	Know the number of referrals and number of new and follow up appointments, unable to get info on waiting times
7. Health Boards to ensure follow-up arrangements for patients are appropriate and timely.	How measured?

Outcome indicators and assurance measures

- Waiting times for urgent appointments
- Waiting times for non-urgent appointments
- Waiting times for follow-up appointments- how measured
- Waiting times for outpatient diagnostics (imaging, neurophysiology)
- Referral protocols to be developed and audited

Fast, effective, safe care and rehabilitation

	Key actions	
1.	Health Boards to organise services to ensure people admitted with a neurological condition are assessed by a member of the neurology/neurosurgery team, within 24 hours of admission to hospital.	How measured SB, C&V, ABUHB have on call system in place
2.	Health Boards to review, plan and deliver evidence-based and timely treatment, in line with latest evidence, standards and NICE guidance, including access to new diagnostics, technologies, treatments and techniques.	
3.	Health Boards to ensure patients with complex needs have appropriate, timely and co-ordinated access to other specialist services as appropriate.	Hoe defined, how measured
4.	Health Boards in collaboration with the Wales Ambulance Service Trust (WAST) to co-ordinate effective transfer of care and timely repatriation of patients from specialist neurological beds to local hospitals as soon as clinically appropriate, following treatment in line with transfer of care plans and the All Wales Repatriation Policy.	How measured?
5.	Health Boards to ensure effective and appropriate palliative and end of life care, in line with the Delivering End of Life Care Plan for patients who need it.	How measured?
6.	Health Boards to develop and implement PROMs and PREMs for patients with neurological conditions and act on findings to continually improve services.	PROM and PREM agreed, not all services using them. Will become a requirement for services funding by CNRF from March 2021
7.	Health Boards to ensure effective governance arrangements are in place to monitor and review the provision of safe and effective care. This includes taking into account all relevant evidence and guidance including NICE guidelines and quality standards.	NICE Searches: limited to NICE guidance and Policy, secondary summaries and medicines current awareness. Results for • neurology 124 • neurological conditions 297 • neurosurgery 41 • neurophysiology 9 • neuroradiology 200
8.	Health Boards to ensure full (100%) participation in national clinical audits - to support service improvement and support medical revalidation of clinicians – and ensure that findings are acted on. In addition, participation of all: • neurorehabilitation services caring for Welsh patients, in the United Kingdom Rehabilitation Outcomes Collaborative • spinal injury units caring for Welsh patients, in the National Spinal Cord Injury Database • neurosurgery units caring for Welsh patients, in the Neurosurgical National Audit Programme	Overseen by WHSSC
9.	Health Boards to participate in and act on the outcome of peer review and implement any actions.	None undertaken

Outcome indicators and assurance measures

- Referral to treatment times

- Emergency admission rates

- Access to interventional neuroradiology

- Average length of hospital stay

- Number of unscheduled hospital admissions due for a primary neurological condition

- Organisational compliance audits against NICE guidelines

Living with a neurological condition

Key actions	
1. Health Boards will place the service user and their family/carers at the centre of care planning and delivery based on co-productive principles.	Not measurable
2. Health Boards and Third Sector providers will use holistic approaches to meet the physical, psychological and emotional needs of the individual, including vocational rehabilitation.	Not measurable
3. Health Boards, other statutory and third sector providers will support the individual to self-manage their own condition where possible, through the provision of information, support and timely access to expert help and interventions from health, social care or third sector organisations when required.	Not measurable
4. Health Boards to adopt the principle that care and support will be provided as close to home as possible by a flexible workforce with the appropriate level of evidence-based knowledge, skill and expertise.	Not measurable
5. Health Boards and Local Authorities will promote integration across all health; care and support providers with the service user and their family and carers will ensure timeliness, improve coordination and reduce duplication and unnecessary interventions, in line with prudent healthcare principles.	Not measurable
6. Health Boards will continue to develop their neuro-rehabilitation services, including psychological support and consider opportunities for self-referral for people living with a confirmed neurological condition.	NCIG and SIG CNR funding used to help set up Community Neurorehabilitation Services in 6 health boards and scope out a Tier 2 neurorehab centre in one.
7. Health Boards should have a system to offer reviews with a skilled health care professional in line with NICE guidelines	

Outcome indicators and assurance measures

- Waiting times to services

- Organisational compliance audits against NICE guidelines

- Availability of annual reviews

Children and Young People

Key actions	
1. Health Boards and other service providers in Wales need to work together with specialist centres to deliver care, including:	
• Ensuring there are agreed referral and treatment pathways	
• Communicate effectively with other specialised services as required to ensure high quality care for children with co-morbidities	
• Provide age-appropriate, safe and effective services as locally as possible	
• Agree treatment plans with patients and their families	
• Ensure that parents and children have co-ordinated care throughout the entire pathway, and feel supported and informed	
• Provide appropriate counselling and psychological support to patients and their families	
• Provide an individualised palliative care and bereavement service, where appropriate	
• Provide good patient experience, including information to patients and their families and consideration of access and support to families when they have to be away from home	
2. Health Boards in collaboration with Local Authorities will ensure patients with complex needs have appropriate, timely assessment of their continuing care needs.	
3. Health Boards will develop and implement integrated and co-ordinated plans for the transfer of care from paediatric to adult services.	
4. Health Boards in conjunction with primary care networks should develop named key health care professionals to ensure continuity of care for CYP with a neurological condition.	
5. Health Boards should consider the role of a care coordinator for CYP with complex needs to support navigation across multi-disciplinary and multi-agency boundaries.	
6. Health Boards to develop and implement PROMs and PREMs for patients with neurological conditions and act on findings to continually improve services.	

Outcome indicators and assurance measures

- Number of unscheduled hospital admissions due to an acute neurological condition

- Waiting times for urgent appointments

- Waiting times for non-urgent appointments

- Waiting times for follow-up appointments

- Waiting times for outpatient diagnostics (imaging, neurophysiology)

Targeting Research
Key actions

Key actions	
1. Health Boards work with the Health and Care Research Wales specialty lead, researchers and Health and Care Research Wales to increase the number of neurological condition research studies undertaken in Wales.	
2. Health Boards and Third Sector service providers across Wales to encourage more people with neurological conditions to participate in research activity, especially children and other underrepresented sectors of the population.	
3. Health Boards and Third Sector service providers to ensure research findings result in service change to improve clinical practice and patient outcomes so patients get quicker access to innovative new diagnostic tools, treatments and medical technologies.	
4. Health Boards to monitor the key relevant performance indicators set out in the Delivery Framework for the Performance Management of NHS R&D.	

Outcome indicators and assurance measures

• Increased number of neurological conditions research studies and clinical trials in Wales, including nurse/therapies and health science led research

• Percentage of people with neurological conditions entered into clinical trials

• Increased external grant funding for neurological research

• Increased academic and industry collaboration with health and social care services

Implementing the Neurological Conditions Delivery Plan

| Key actions	
1. The Neurological Conditions Implementation Group will work in a co-ordinated way, at an all Wales level, to support Health Boards and partners to deliver the actions within this plan and achieve the desired outcomes.	Yes
2. The Neurological Conditions Implementation Group will agree a focus for delivery and priorities each year to provide clear guidance to Health Boards to support the production of their IMTPs; ensuring neurological conditions are fully embedded within their plans.	Since 2019
3. The Neurological Conditions Implementation Group will facilitate the sharing and implementation of best practice.	Yes. Through reports from T&F groups, CNRTs and special interest groups
4. The Neurological Conditions Implementation Group will identify constraints and develop national solutions to common issues where a strategic approach is needed.	Limited by lack of data
5. The Neurological Conditions Implementation Group will review and critically assess Health Board delivery plan actions in light of progress and new developments.	No
6. The Neurological Conditions Implementation Group will review appropriate outcome and performance measures annually.	No
7. The Neurological Conditions Implementation Group will allocate, monitor and report on the use of £1m annual funding from Welsh Government in line with the delivery against clearly stated priorities.	Yes
8. The Neurological Conditions Implementation Group will produce an annual statement highlighting progress made throughout the year.	Yes
9. Health Boards are required to monitor their performance against the Neurological Conditions Delivery Plan against a set of nationally specified performance measures and report them to implementation group and the Welsh Government annually.	No
10. Health Boards to incorporate feedback from local Neurological Service User Forums into the work of their Neurological Delivery Group.	In some HBs
11. The Welsh Government will continue to maintain oversight of delivery and assurance framework and produce a national statement of achievement annually. It will also support and enable liaison between the Implementation Group and Welsh Ministers	Yes

Outcomes

- Improvements in awareness evidenced in Patient Experience and Outcome Measures
- Number of Health Boards with comprehensive education frameworks
- Number of Health Boards facilitating active Neurological Service User Forums
- Number of hits on Once for Wales portal
- Waiting times for urgent appointments
- Waiting times for non-urgent appointments
- Waiting times for follow-up appointments
- Waiting times for outpatient diagnostics (imaging, neurophysiology)
- Referral protocols to be developed and audited
- Referral to treatment times

Inpatients

- Emergency admission rates
- Number of unscheduled hospital admissions due for a primary neurological condition
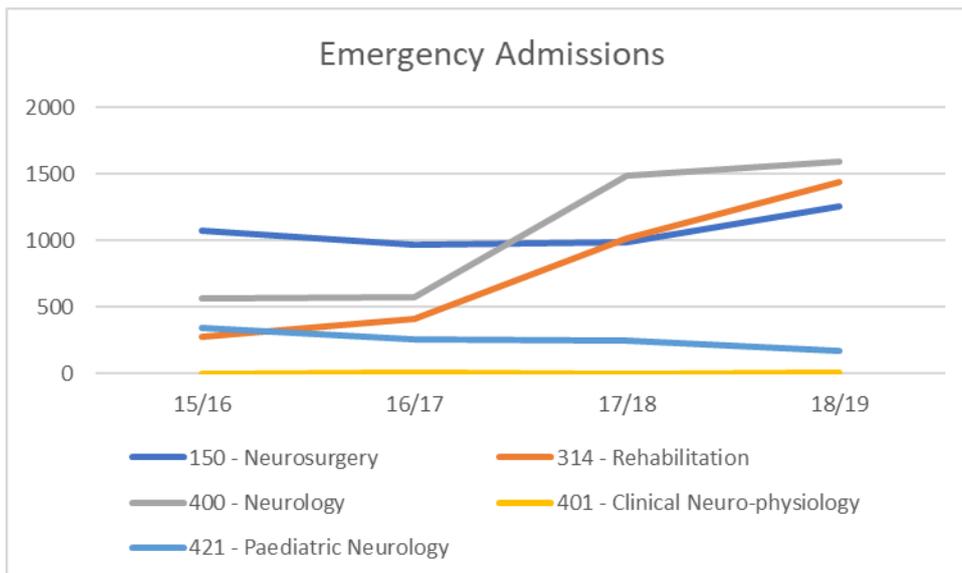
- Access to interventional neuroradiology
- Average length of hospital stay

Grŵp Iechyd a Gwasanaethau Cymdeithasol
Health and Social Services Group

Llywodraeth Cymru
Welsh Government

Mean Length of Stay

- Total Episodes
- 150 - Neurosurgery
- 314 - Rehabilitation
- 400 - Neurology
- 401 - Clinical Neuro-physiology
- 421 - Paediatric Neurology

Outpatients

Neurology Referrals

Neurology Outpatients
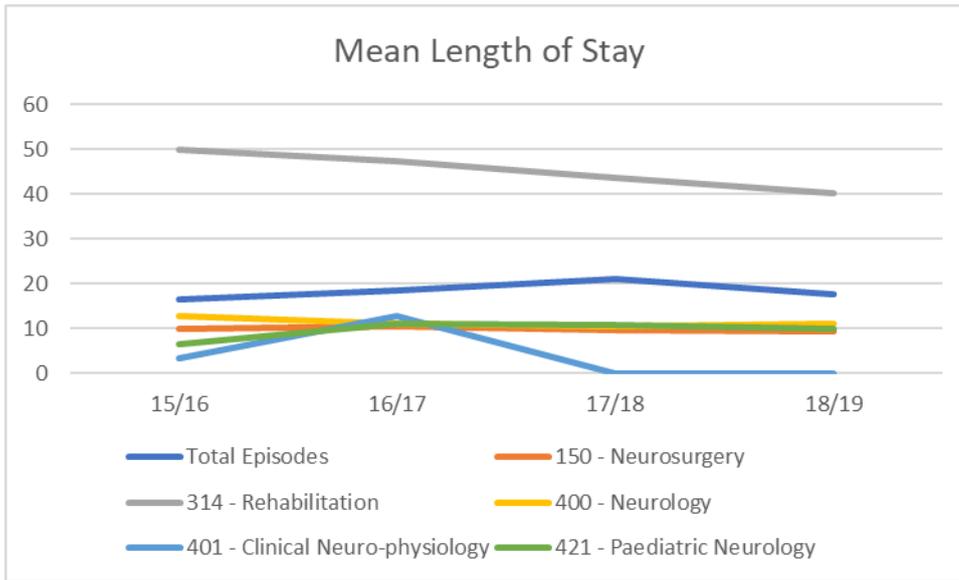
Did Not Attend Rates
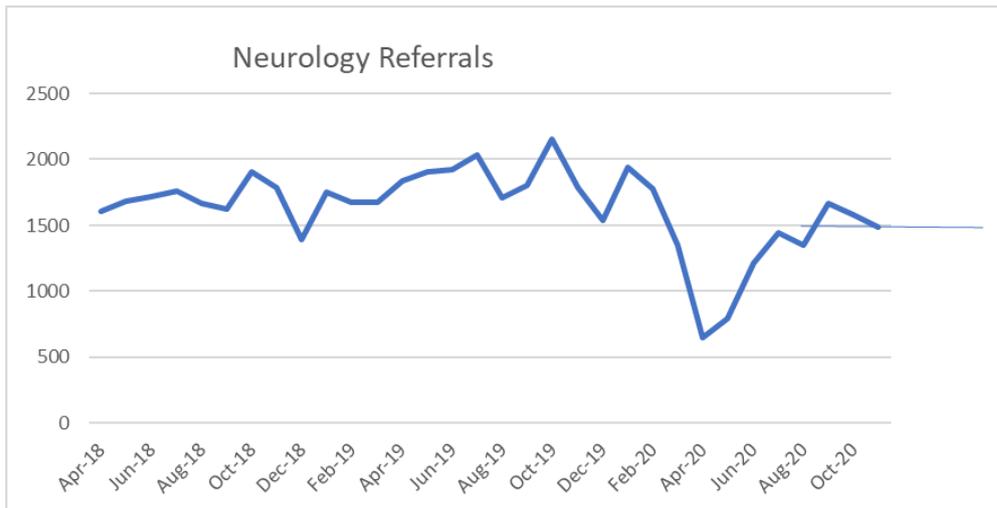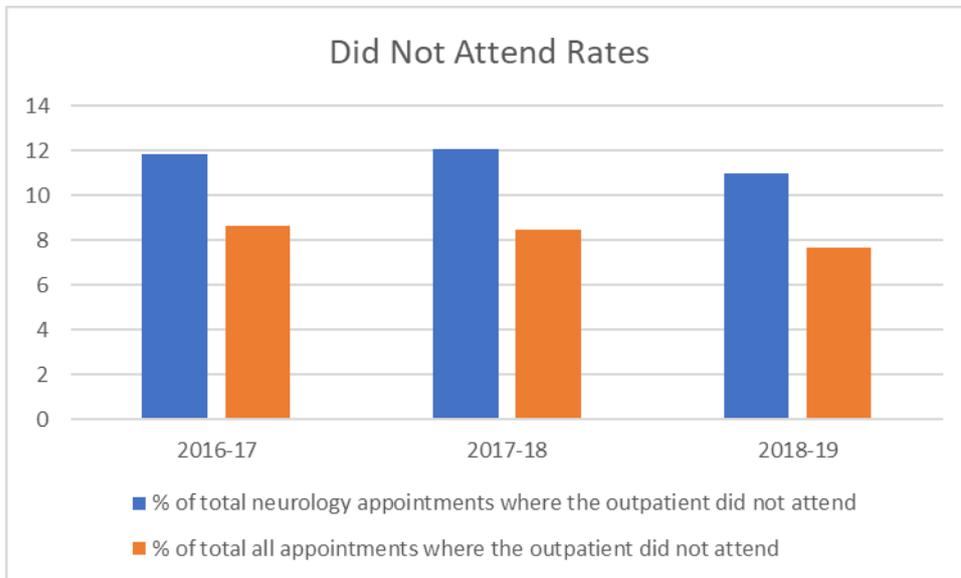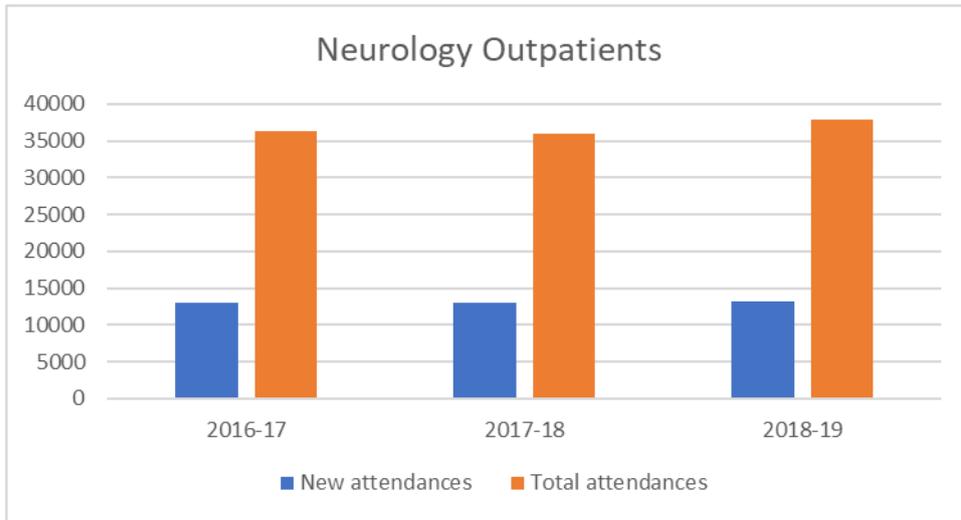
Other data available- Inpatients
FCE for admitted to hospital

Finished Consultant Episodes
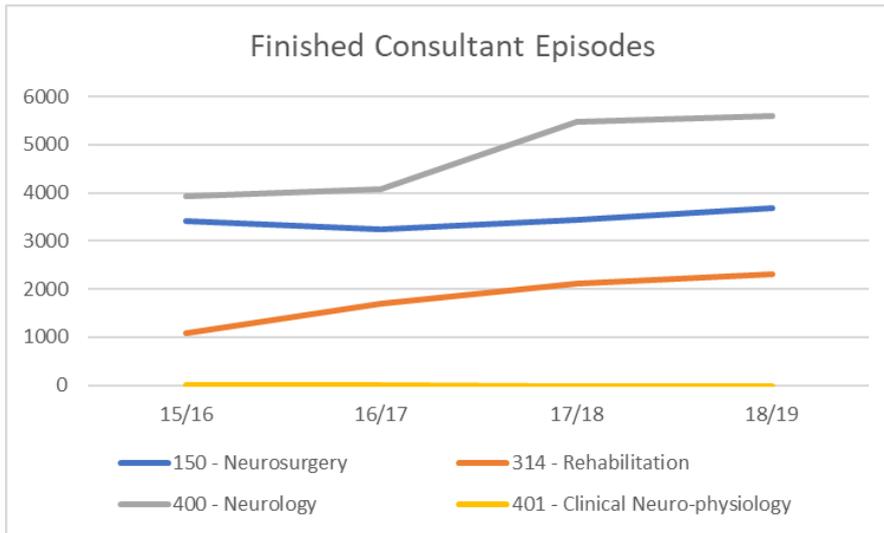
Mean waiting Time for admission to hospital

Mean Waiting Time
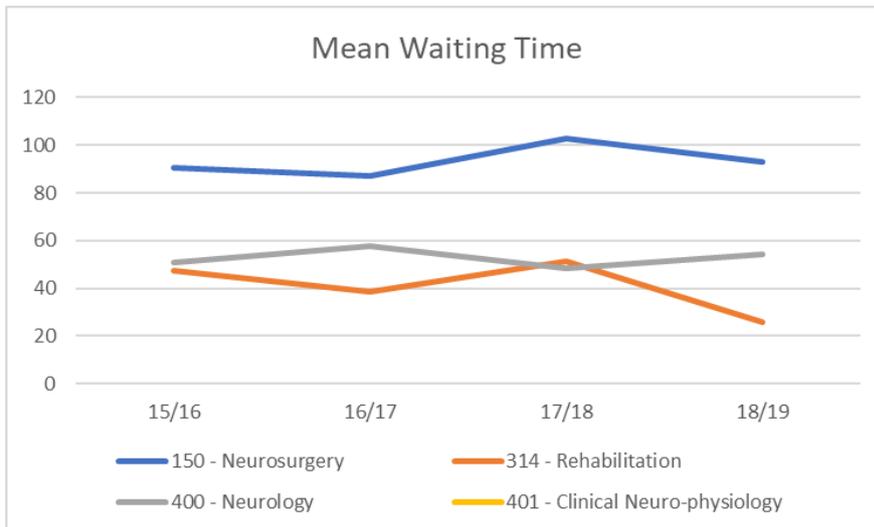
Condition Specific Hospital Data
Most Common Conditions being admitted to hospital 2018/19

Finished Consultant Episodes

Horizontal bar chart titled "Finished Consultant Episodes" with categories (top to bottom):
- G70-G73 Diseases of myoneural junction and muscle
- G10-G14 Systemic atrophies primarily affecting the CNS
- G00-G09 Inflammatory diseases of the CNS
- G80-G83 Cerebral palsy and other paralytic syndromes
- G60-G64 Polyneuropathies and other disorders of PNS
- G30-G32 Other degenerative diseases of the nervous system
- G20-G26 Extrapyramidal and movement disorders
- G35-G37 Demyelinating diseases of the CNS
- G90-G99 Other disorders of the nervous system
- G50-G59 Nerve, nerve root and plexus disorders
- G40-G47 Episodic and paroxysmal disorders

X-axis: 0, 2,000, 4,000, 6,000, 8,000

Highest numbers:

2. G40-G47 Episodic and paroxysmal disorders

3. G50-G59 Nerve, nerve root and plexus disorders

4. G90-G99 Other disorders of the nervous system

Emergency Admissions

Horizontal bar chart titled "Emergency Admissions" with categories (top to bottom):
- G70-G73 Diseases of myoneural junction and muscle
- G10-G14 Systemic atrophies primarily affecting the CNS
- G60-G64 Polyneuropathies and other disorders of PNS
- G35-G37 Demyelinating diseases of the CNS
- G00-G09 Inflammatory diseases of the CNS
- G80-G83 Cerebral palsy and other paralytic syndromes
- G20-G26 Extrapyramidal and movement disorders
- G30-G32 Other degenerative diseases of the nervous system
- G50-G59 Nerve, nerve root and plexus disorders
- G90-G99 Other disorders of the nervous system
- G40-G47 Episodic and paroxysmal disorders

X-axis: 0, 1,000, 2,000, 3,000, 4,000, 5,000

1. G40-G47 Episodic and paroxysmal disorders

2. G90-G99 Other disorders of the nervous system

3. G50-G59 Nerve, nerve root and plexus disorders

Number of bed days
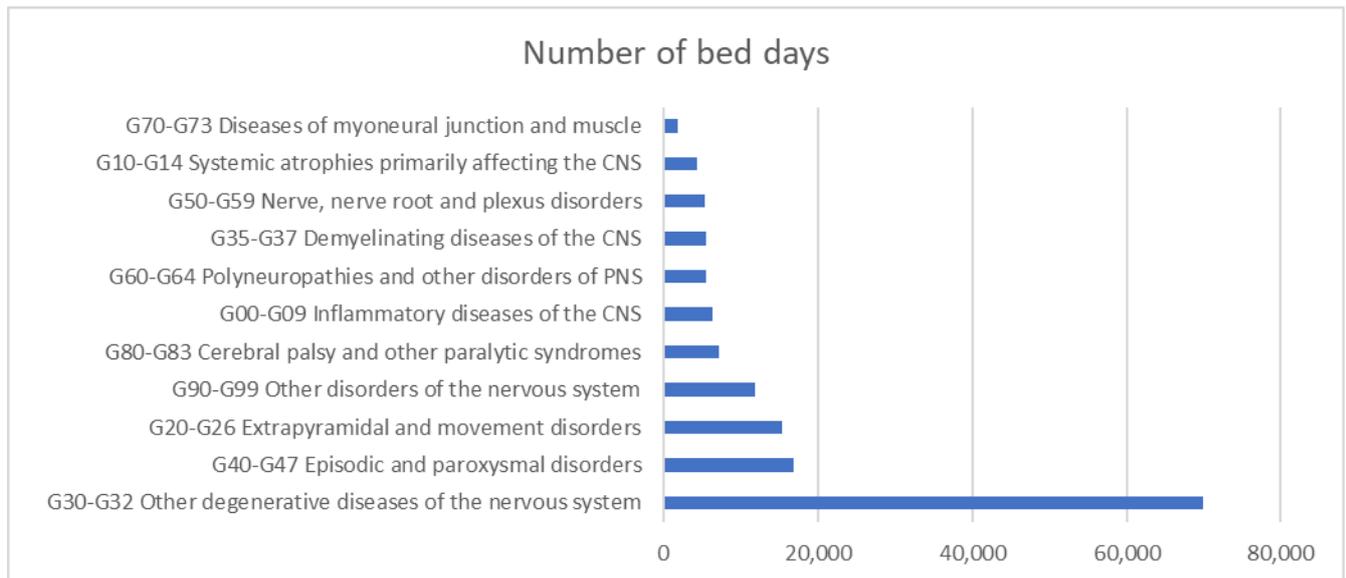
1. G30-G32 Other degenerative diseases of the nervous system

2. G40-G47 Episodic and paroxysmal disorders

3. G20-G26 Extrapyramidal and movement disorders

Top 30 conditions hospitalised in 2018/19 by FCE

NHS Wales Informatics Service, PEDW Statistics - 2018/19	Finished Consultant Episodes
Total Episodes	**20,642**
G56 - Mononeuropathies of upper limb	4,314
G40 - Epilepsy	2,428
G43 - Migraine	1,543
G35 - Multiple sclerosis	1,522
G93 - Other disorders of brain	1,044
G30 - Alzheimer's disease	911
G20 - Parkinson's disease	728
G47 - Sleep disorders	510
G55 - Nerve root and plexus compressions in diseases classified elsewhere	477
G51 - Facial nerve disorders	422
G61 - Inflammatory polyneuropathy	416
G44 - Other headache syndromes	408
G81 - Hemiplegia	297
G62 - Other polyneuropathies	282
G12 - Spinal muscular atrophy and related syndromes	244
G31 - Other degenerative diseases of nervous system, not elsewhere classified	236

G41 - Status epilepticus	232
G80 - Cerebral palsy	218
G50 - Disorders of trigeminal nerve	208
G70 - Myasthenia gravis and other myoneural disorders	189
G57 - Mononeuropathies of lower limb	168
G91 - Hydrocephalus	153
G25 - Other extrapyramidal and movement disorders	148
G95 - Other diseases of spinal cord	138
G83 - Other paralytic syndromes	132
G24 - Dystonia	124
G04 - Encephalitis, myelitis and encephalomyelitis	121
G97 - Postprocedural disorders of nervous system, not elsewhere classified	119
G99 - Other disorders of nervous system in diseases classified elsewhere	105

Top 30 Conditions by Mean Wait 2018/19

NHS Wales Informatics Service, PEDW Statistics - 2018/19	Mean Waiting Time
G61 - Inflammatory polyneuropathy	531
G24 - Dystonia	369
G51 - Facial nerve disorders	278
G57 - Mononeuropathies of lower limb	188
G50 - Disorders of trigeminal nerve	186
G47 - Sleep disorders	184
G56 - Mononeuropathies of upper limb	168
G55 - Nerve root and plexus compressions in diseases classified elsewhere	161
G99 - Other disorders of nervous system in diseases classified elsewhere	158
G54 - Nerve root and plexus disorders	145
G25 - Other extrapyramidal and movement disorders	125
G58 - Other mononeuropathies	118
G71 - Primary disorders of muscles	97
G80 - Cerebral palsy	91
G40 - Epilepsy	84
G62 - Other polyneuropathies	82
G82 - Paraplegia and tetraplegia	79
G95 - Other diseases of spinal cord	75

G30 - Alzheimer's disease	68
G43 - Migraine	68
G91 - Hydrocephalus	67
G70 - Myasthenia gravis and other myoneural disorders	59
G44 - Other headache syndromes	56
G81 - Hemiplegia	40
G35 - Multiple sclerosis	39
G93 - Other disorders of brain	30
G37 - Other demyelinating diseases of central nervous system	29
G12 - Spinal muscular atrophy and related syndromes	27
G20 - Parkinson's disease	23

NHS Wales Informatics Service, PEDW Statistics - 2018/19	Mean Length of Stay
G30 - Alzheimer's disease	90
G31 - Other degenerative diseases of nervous system, not elsewhere classified	88
G82 - Paraplegia and tetraplegia	72
G10 - Huntington's disease	72
G37 - Other demyelinating diseases of central nervous system	37
G23 - Other degenerative diseases of basal ganglia	33
G06 - Intracranial and intraspinal abscess and granuloma	33
G21 - Secondary parkinsonism	29
G20 - Parkinson's disease	29
G60 - Hereditary and idiopathic neuropathy	29
G36 - Other acute disseminated demyelination	23
G46 - Vascular syndromes of brain in cerebrovascular diseases	20
G11 - Hereditary ataxia	20
G95 - Other diseases of spinal cord	19
G04 - Encephalitis, myelitis and encephalomyelitis	19
G35 - Multiple sclerosis	19
G72 - Other myopathies	18
G81 - Hemiplegia	18
G61 - Inflammatory polyneuropathy	17
G71 - Primary disorders of muscles	16

G56 - Mononeuropathies of upper limb	15
G08 - Intracranial and intraspinal phlebitis and thrombophlebitis	15
G63 - Polyneuropathy in diseases classified elsewhere	15
G96 - Other disorders of central nervous system	15
G91 - Hydrocephalus	15
G12 - Spinal muscular atrophy and related syndromes	15
G62 - Other polyneuropathies	13
G00 - Bacterial meningitis, not elsewhere classified	12
G70 - Myasthenia gravis and other myoneural disorders	11