

ABERTAWA BRO MORGANNWG UNIVERSITY HEALTH BOARD

NEUROLOGICAL CONDITIONS DELIVERY PLAN

**A Delivery Plan up to 2017 for Abertawe Bro Morgannwg
University Health Board and its Partners**

Index

	Page No
1. BACKGROUND AND CONTEXT	3
The Vision	3
The Drivers	3
What do we want to achieve	4
2. ORGANISATIONAL PROFILE	5
ABMU Health Board Organisational Overview	5
Changing for the Better Programme	5
ABMU Neurological Services	8
3. OVERVIEW OF LOCAL HEALTH NEED AND CHALLENGES FOR NEUROLOGICAL SERVICES	10
4. DEVELOPMENT OF ABMU HEALTH BOARD LOCAL DELIVERY PLAN FOR NEUROLOGICAL CONDITIONS	12
Delivery Plan Development	12
Working across Health Board boundaries	12
IMTP Process	13
Sign off	13
Reporting	13
5. THE PRIORITIES FOR 2014 – 2017	14
6. PERFORMANCE MEASURES/MANAGEMENT	19
7. THE ACTION PLAN 2013-2016	19-41
APPENDICIES	
Appendix 1 Neurological Service – Service Profiles	
Appendix 2 Neurological Conditions Delivery Plan Stakeholder Workshop – List of attendees	
Appendix 3 WHSCC Neurological Conditions Delivery Plan actions	

1. BACKGROUND AND CONTEXT

“Together for Health – a Neurological Conditions Delivery Plan” was published in April 2014 and provides a framework for action by health boards and NHS trusts working together with their partners. It sets out the Welsh Government’s expectations for the planning and delivery of high-quality person-centred care for anyone affected by a neurological condition. It focuses on meeting population need, tackling variation in access to services and reducing inequalities across seven themes:

- Raising awareness of neurological conditions
- Timely diagnosis of neurological conditions
- Fast and effective care
- Living with a neurological condition
- Children and young people
- Improving information
- Targeting research

For each theme it sets out:

- Delivery expectations for the management of neurological conditions
- Specific priorities for 2013-17
- Responsibility to develop and deliver actions to achieve the specific priorities
- Potential assurance measures

These complement the quality requirements endorsed in the report of the task and finish group on care pathways for long term neurological conditions, which must be delivered alongside the delivery plan.

The vision

Our vision is for people with a neurological condition in Wales to have access to high-quality care, wherever they live, whatever their underlying neurological condition and regardless of their personal situation.

The Drivers

Neurological conditions range from relatively common to rare, such as mitochondrial diseases or Wilson’s disease, and taken together, affect many people. For example, eight million people in the UK have migraine and around half a million have epilepsy.

Altogether, approximately 10 million people of all ages across the UK have a neurological condition. These account for up to 20 per cent of acute hospital admissions and are the third most common reason for seeing a GP¹. Around 17 people in a population of 100,000 are likely to be newly diagnosed per year with Parkinson’s disease, 18.5 per 100,000 with MS and two people in a population of 100,000 experiences a traumatic spinal injury every year. An

¹ Long Term (Neurological) Conditions NSF, DH www.gov.uk/government/publications/quality-standards-for-supporting-people-with-long-term-conditions

estimated 350,000 people across the UK need help with daily living because of a neurological condition and 850,000 people care for someone with a neurological condition².

Annually, about 200,000 people in the UK are admitted to hospital with head injury. Of these, one-fifth have features suggesting skull fracture or have evidence of brain damage³.

It is estimated there are more than 500,000 people in Wales affected by a neurological condition and of these, 100,000 will have a long-term neurological condition (LTNC). An LTNC results from disease of, injury or damage to the body's nervous system (i.e. the brain, spinal cord and/or their peripheral nerve connections), which will affect the individual and their family in one way or another for the rest of their life.

It has been estimated that between two and three per cent of the child population will have some level of disability leading to additional health and educational needs. The vast majority of child disabilities are neurological in origin with paediatric epilepsy the most common neurological disorder affecting about 0.7 per cent of all children⁴. Neurological conditions* can be broadly categorised as follows:

- **Sudden onset conditions**, for example acquired brain injury or spinal cord injury, followed by a partial recovery.
- **Intermittent and unpredictable conditions**, for example epilepsy, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed
- **Progressive conditions** for example motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where there is progressive deterioration in neurological function. For some conditions (e.g. motor neurone disease) deterioration can be rapid
- **Stable neurological conditions**, but with changing needs due to ageing, for example post-polio syndrome or cerebral palsy in adults
- **Congenital and developmental neurological conditions**, for example cerebral palsy, spina bifida or Duchenne muscular dystrophy, which may be present at birth or develop during early childhood. Some of these may be associated with varying degrees of learning disability.

What do we want to achieve?

The all-Wales delivery plan sets out action to improve outcomes between now and 2017

² Neuro Numbers, Neurological Alliance

www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

³ NICE Clinical Guideline CG176 Head Injury, <http://guidance.nice.org.uk/CG176>

⁴ Service Specification Paediatric Neurosciences: Neurology, NHS England

www.england.nhs.uk/wpcontent/uploads/2016/06/e09-paedi-neurology.pdf

* not all neurological conditions covered by this plan are contained within the list

2. ORGANISATIONAL PROFILE

ABMU Health Board Organisational Overview

Abertawe Bro Morgannwg University Health Board was launched on 1st October 2009 and combines the former Abertawe Bro Morgannwg University NHS Trust (previously Bro Morgannwg NHS Trust and Swansea NHS Trust) and the three Local Health Boards; Bridgend, Neath Port Talbot and Swansea.

The Abertawe Bro Morgannwg University Local Health Board provides services to approximately 600,000 people, primarily serving the populations of Bridgend, Neath Port Talbot, Swansea and the Western Vale of Glamorgan and their respective communities. In addition, the LHB provides a large range of regional and sub-regional services, including Burns and Plastics, Cardiac Surgery, Forensic Mental Health and Learning Disability Services. A range of community based services are also delivered in patients' homes, via community hospitals, health centres and clinics.

The Health Board has close links with Swansea University, College of Medicine and is fortunate to have state-of-the-art research facilities within close proximity to Singleton Hospital.

The Health Board has a budget of £1.3 billion and employs over 17,000 members of staff, 70% of who are involved in direct patient care.

Changing for the Better Programme

<http://www.wales.nhs.uk/sitesplus/863/page/60278>

In "Together for Health" (November 2011) Welsh Government described unprecedented challenges ahead, it called upon health boards to create services that are safe, sustainable and comparable with the best anywhere. Changing for the Better Programme is ABMU Health Board's response to that challenge.

Since January 2012 the programme has harnessed the experience, energy and commitment of over 300 people: clinicians, patient and carer representatives, partners from local authorities, the third and voluntary sectors, academia, management and emergency services. They have taken a fresh look at what we do well now, what we can learn from others, what the best practice standards tell us we should do and what our patients want and deserve.

In May 2012 the Health Board set out for our staff and citizens the scale of the challenge facing ABMU in "Changing for the better; why your local NHS needs to change."

Through seven clinical work streams the Health Board has looked at nearly every area of care. New thinking has been tested on hundreds of staff and citizens during twelve weeks of intensive engagement between September

and December 2012 and received positive and helpful feedback as well as new ideas.

As a result the *Changing for the Better* programme is moving from ideas to implementation, focusing on how clinical and support services in the ABMU area will be transformed over the next few years to achieve this, whilst coping with the demographic changes which threaten to overwhelm our services if the way they are currently configured does not change.

This transformational work is progressing across the Health Board, focusing initially on 9 key projects:

- Hospital Services
- Community Services
- Women & Children
- Pre-hospital Services
- Staying Healthy
- Rapid Access
- Major Trauma Service
- Primary & Community sites for electives
- Outpatient Modernisation

An outline of each of these projects is detailed below:

Hospital Services

Aims

- To clearly define a role and vision for each of our four main hospital sites
- To agree how they will work together as part of a wider network of hospitals across South Wales
- To support changes to the configuration of services, to identify and manage co-dependencies
- To improve patient experience and outcomes and ensure services are sustainable
- Support the identification of patients entering last year of life

Community Services

- A wide-ranging transformation and strengthening of community services working in partnership with local authority and third/voluntary sector partners. There are three main strands:
 - Wellbeing and keeping healthy
 - Strengthening of community teams
 - Making services sustainable
- Wider use of the Primary Care Quality Outcomes Framework – Palliative Care Register

Outpatient Modernisation

Aims

- To transform the way we deliver “outpatient” care
- To reduce unnecessary outpatient attendances
- To use new approaches and technologies to support outpatients
- To improve the efficiency and experience of the outpatient consultation

Rapid Access

- To create a model for rapid access across the ABMU localities that is specialty specific and provides a range of interventions proactively. This will include specialist advice, rapid assessment, diagnosis and treatment for those at risk of requiring admission to Emergency care:
- Provide specialist assessment of patients within 4, 12, 24, 48 and 72 hours of possible deterioration to prevent admission
- Reduce multiple admissions
- Free up urgent slots in clinics
- Maximise independence for those with long term conditions
- Support colleagues in primary and community teams including using technologies better
- Change the culture regarding admission

Pre-hospital Services

- To develop and strengthen further services and initiatives with the Welsh Ambulance Service NHS Trust (WAST) and other partners to provide alternatives to attendance at Emergency Departments and primary care:
- Improved patient experience of services
- Increased appropriate utilisation of services with reduced Emergency Department, GP Out of Hours and AGPU attendance
- Improved delivery of Emergency Department Targets
- Improved WAST handover delivery against targets
- Advanced care planning

Major Trauma Service

- To ensure that Morriston Hospital is ready to be part of a South Wales trauma network
- To ensure that Morriston Hospital meets the standards for a “trauma centre”
- To support the Princess of Wales Hospital if it is designated a trauma unit

Elective procedures in primary & community care

- To identify procedures & interventions that could be carried out in a community or primary care setting instead of hospitals
- To assess the patient, service and financial benefits

Staying Healthy

Aims

- To harness the commitment and resources of the Health Board and its partners to take actions which deliver the outcomes of the ABMU Public Health Framework
- To help our population make healthier lifestyle choices that assist them to stay healthy
- To use a life course approach to target priority areas such as smoking and obesity to improve our community's health by:
 - Increasing staff knowledge – “making every contact count”
 - Increasing integration across agencies: a healthier community
 - Embedding public health objectives in directorate, locality and wider partnership plans
 - Raising the profile of public health and the needs of our population
 - Narrowing the inequalities gap and delivering healthier outcomes

Women and Children

Aims

- To optimise the service model for women's health
- To develop the case for relocation of maternity and neonatology from Singleton to Morriston
- To strengthen community care for children and reduce further need for admission and provide a single point of access
- To develop clinical pathways for children, young people and their families
- To implement the outcomes of the South Wales Programme

ABMU Neurological Services (See attached document)

Appendix 1 provides a summary of the range of neurological services provided within ABMU Health Board, including:

- Description of the service;
- the population served
- details of the multi disciplinary team;
- access times for services, where appropriate;
- Teaching and research activities.

Neurology and Neuro rehabilitation activity undertaken within ABMU Health Board

Inpatient admissions							
Years	date_of_admission	Rehab		Rehab Total	Neurology		Neurology Total
		ELECTIVE	EMERGENCY		ELECTIVE	EMERGENCY	
2012	full year	38	66	104	61	142	203
2013	full year	67	23	90	54	166	220
2014	jan to august	42	25	67	32	117	149
2014	Full year pro rata	63	38	101	48	176	224
Daycases							
Years	date_of_admission	Rehab	Neurology				
2012	full year	208	510				
2013	full year	237	662				
2014	Jan to August	179	510				
2014	full year pro rata	269	765				
Outpatient attendances							
Years		NEW	Follow ups	Total	New	Follow ups	Total
		Neurology	Neurology		Rehabilitation	Rehabilitation	
2012	full year	3675	5611	9286	338	580	918
2013	full year	3596	5792	9388	302	551	853
2014	jan to august	2332	3862	6194	218	364	582
2014	Full year Pro rata	3498	5793	9291	327	546	873

Of the above approximately 280 new neurology outpatients and 770 follow up patients seen in ABMU are from Hywel Dda Health Board area.

There is further neurology outpatient and follow up work and ward referral activity which is undertaken in Hywel Dda Health Board Hospitals, which is not captured in the above information. Paediatric Neurology activity is also undertaken within ABMU Health Board

3. OVERVIEW OF LOCAL HEALTH NEED AND CHALLENGES FOR NEUROLOGICAL SERVICES

From the Strategic Needs Assessment published in December 2013 ([insert link](#)), the major priorities for Abertawe Bro Morgannwg University Health Board to address through its various change programmes and the Integrated Medium Term Plan are:

Reducing Health Inequalities

- Differences in life expectancy have widened between best and worst areas in ABM University Health Board in the last 10 years
- NHS have a role in reducing health inequalities through ensuring appropriate access to services, and in working with local partners to tackle the broader determinants of health

Cardiovascular Disease, Cancers, Chronic obstructive pulmonary disease

- The three largest causes of death and premature death
- Major causes of chronic illness
- Diseases consuming large amounts of NHS resources
- All three diseases are to a large degree preventable

Smoking

- Risk factor for all three major causes of death
- Major factor in inequalities of health outcomes
- Entirely preventable
- Reductions in smoking are followed by reductions in disease
- Variation in smoking rates across ABM University Health Board

Obesity

- Major risk factor for biggest causes of premature death
- Obesity levels rising generally
- Obesity in children aged 4-5 is higher in ABM University Health Board than Wales, and much higher than England
- Major risk factor for a number of conditions including diabetes and muscular skeletal disorders

Alcohol

- Risk factor for the biggest causes of premature death
- Rising alcohol consumption is reflected in rising hospital admissions for alcohol related problems
- Health issues from excessive alcohol consumption are preventable

Mental Health

- Some evidence of higher self reported mental illness in ABM University Health Board than the Wales average
- Strong association with health inequalities
- Largest single area of spend for NHS

Frail elderly

- Rising life expectancy is reflected in growing numbers of older people, a proportion of whom are frail
- Frail elderly people are major users of NHS and social care services
- Scale of support for integrated services for this group will increase, requiring close working between health and social care

Vaccination and Immunisation

- Consequences of low levels of uptake of childhood vaccination are severe
- Vaccinations coverage are not at Welsh government target levels in ABM University Health Board
- Flu vaccination levels are low
- Effective vaccination levels have the potential to reduce illness levels particularly in frail older people

This high level needs assessment is relevant and important for the wider protection for people with or at risk from developing neurological conditions. Lifestyle factors of smoking, obesity and alcohol have strong links with conditions including stroke, dementias, poor birth outcomes and serious injuries. Vaccination plays an important role in protecting against death and long term disability from, for example, MMR, meningococcal Group C, haemophilus influenza Group B and pneumococcal vaccines protect against encephalitis and meningitis. Flu vaccination for people of all ages with at-risk conditions helps protect them from serious illness, hospitalisation and death. The IMTP will increasingly target interventions to address these needs in the coming years.

The PHW neurology needs assessment* estimated that for ABMU HB area there were:

- Between 4,300 and 5,000 people living with Alzheimer's disease
- Between 3,000 and 4,100 people with epilepsy and 260 new cases being diagnosed each year
- 940 people with cerebral palsy
- 900 people with Parkinson's disease and 90 new cases being diagnosed each year
- 800 people with multiple sclerosis and 50 new cases being diagnosed each year
- 250 people with muscular dystrophy
- 40 people with motor neurone disease and 10 new cases being diagnosed each year.

*Neurology needs assessment: all-Wales prevalence and inpatient tables. PHW Observatory Analytical Team 26 July 2012.

There remains a need to undertake a comprehensive population needs assessment to support the Neurological Conditions Delivery Plan.

4. DEVELOPMENT OF THE ABMU HEALTH BOARD DELIVERY PLAN FOR NEUROLOGICAL CONDITIONS

Delivery Plan Development

The ABMU Neurological Conditions Delivery Plan has been developed in response to the “Together for Health – A Neurological Conditions Disease Delivery Plan” (2014). The plan was developed in collaboration with our partners and provides a detailed local service delivery plan to support progressive implementation of the priorities as outlined in the Neurological Conditions Delivery Plan.

The Executive lead for the Neurological Conditions Delivery plan is Mr Hamish Laing, Medical Director, who has been supported by Leads for each of the delivery plan themes. Table 1 provides details on the theme leads.

Table 1 – Theme leads

Theme No	Theme Description	Clinical Lead
Theme 1	Raising Awareness of Neurological Conditions	Carol Ross. South West Wales Neurological Alliance
Theme 2	Timely diagnosis of a Neurological Condition	Robert Powell. Consultant Neurologist
Theme 3	Fast and effective care	Christopher Rickards, Consultant Neurologist
Theme 4	Living with a Neurological Condition	Tanya Edmonds, Consultant Neuropsychologist Owen Pearson, Consultant Neurologist
Theme 5	Children and Young People	Cathy White, Paediatric Neurology Consultant
Theme 6/7	Improving information and Targeting Research	Inder Sawhney, Consultant Neurologist

The health Board’s delivery plan was developed through the establishment of a stakeholder workshop event held on the 19th September 2014, followed by a short period of consultation in early October 2014. A list of those involved in the stakeholder workshop is included as **Appendix 2**.

Working across Health Board boundaries and with other Organisations

As the provider of Neurological Services for both ABMU Health Board and Hywel Dda Health Board (South West Wales Region) colleagues from Hywel Dda Health Board have been fully engaged in the development of our plan and key stakeholders and service providers from ABMU Health Board have also been involved in the production of the Hywel Dda Health Board delivery plan.

The delivery plans for themes 1, 6 and 7 will be common to ABMU Health Board and Hywel Dda Health Board.

Further work will be required during the implementation phase to align the two Health Boards plans across themes 2, 3,4 and 5 and it has been agreed that a joint implementation group will be established, under the healthcare alliance framework.

Welsh Health Specialised Services Committee (WHSSC) has also produced a summary of the specific actions, which they are leading on in relation to the WG Neurological Conditions Delivery Plan. These are included as **Appendix 3** of this plan.

Third sector organisations and patient representatives have been integral to the production of the plan.

Integrated Medium Term Plan (IMTP)

The priorities identified within the ABMU Health Board Neurological Conditions delivery plan will be embedded into the Health Board's Integrated Medium Term Plan (IMTP) for 2015/2016.

Sign off of the delivery plan

The ABMU Health Board Neurological Conditions Delivery Plan will be signed off as part of the Health Board's Integrated Medium Term Planning process.

Reporting

Our progress in taking forward the actions identified in our Neurological Conditions Delivery Plan will be reported, in line with WG reporting requirements and will be published on our Health Board intranet site.

5. THE PRIORITIES FOR 2014 - 17

Following the multi stakeholder workshop, the key outcomes from that process have been incorporated into our delivery plan for neurological conditions. This delivery plan includes actions against each of the 2017 milestones within the Welsh Government's Neurological Conditions Delivery Plan (2014).

Raising awareness of neurological conditions

What works well	What areas need to be improved
<ul style="list-style-type: none"> • Sign posting and awareness raising good, where specialist MDTs and co-ordinators are in place. • members of these specialist NDTs have awareness raising and teaching/training and education sessions within their roles • National and local media campaigns help to raise awareness and focus. • ABMU Health Board's "in your shoes events" is an important source of positive and negative information on our services • Our patients and their stories are an important resource to support awareness raising. • Newly established networks for MND and neuromuscular have shown what can be achieved, with modest investment. • Enthusiastic and passionate patient groups and organisations. • See Theme 5 for information on paediatric neuro disability conditions and services. 	<ul style="list-style-type: none"> • Awareness raising needs to start early within our education system • There is potentially too much information out there for patients to assimilate. • Information needs to be tailored to reflect local services and needs to be quality assured • Patients and their relatives need to receive the information in the right context and at the right time during their condition pathway. • Patients with rarer neurological conditions are not currently well served. • There is no coordinated programme of awareness raising • improved partnership working required between health professionals and patient groups to raise awareness • Let's not reinvent the wheel, but learn from others. • Use resources which are already available, but localise them. • Health Board staff not aware of condition specific and community services available to patients. • Basic awareness raising across Health Board on needs of people with particular neurological conditions • Strengthen relationships with existing third sector organisations that already undertake significant awareness raising activities both nationally and at local level including the provision of information (as mentioned in theme 4)

Our priorities for 2014 – 17 are:

- To establish a regional neurological conditions awareness raising working group to provide a framework and approach which co-ordinates existing awareness raising activities and links the activities of third sector organisations with health care professionals who provide clinical care.
- To ensure patients and third sector organisations are central to development and implementation of all our plans
- To ensure we learn from others and adopt examples of best practice in all our activities.
- To ensure we use a range of mediums both face to face, group and technological solutions to support and enhance awareness raising.
- To use existing available information resources, but localises those to reflect the health boards services and pathways.

Timely diagnosis of neurological conditions

What works well	What areas need to be improved
<ul style="list-style-type: none"> ● Multi disciplinary access for sub specialty services such as MS/MNS Parkisons and Epilepsy ● Access to Radiology ● 24/7 access to SPR telephone advice across the region ● 1st seizure pathway ● Neuropsychology access in Epilepsy ● Telephone and email advice support for the epilepsy service 	<ul style="list-style-type: none"> ● Sufficient facilities to see patients ● No access to ambulatory/ day case facilities ● Waiting time and capacity to see patients in a timely way ● Equity of access to services across the region (Hywel Dda and Bridgend) ● Inpatient capacity (Beds and access) ● Access to video telemetry ● Access to Neurophysiology in the east of ABMU ● Access to Neuropsychology ● Key clinical/ specialist posts not being filled

Our priorities for 2014 – 17 are:

- Increase access to Neuroradiology and neuropsychology
- Ensure a consistent model for delivery of Neurophysiology across the health board
- Improve access to specialist advice through a range of initiatives including use of technology, non face to face contact and improving access to outpatient consultations.
- Adopt the principles of prudent healthcare to redesign existing resources
- Clear link to developing awareness in primary care to manage patients out of hospital

Fast and effective care

What works well	What areas need to be improved
<ul style="list-style-type: none"> ● Specialist services such as MND, MS and Parkinson's run well. ● Liaison Neurology model in Swansea, to intercept patients before crisis. ● First fit clinic in Swansea ● 24/7 on call service at Morriston Hospital 	<ul style="list-style-type: none"> ● Equity of access for specific elements of service: <ul style="list-style-type: none"> ○ Liaison neurology ○ first fit pathway ○ emergency care ○ Consultant cover ○ access to inpatient beds ● Diagnostic capacity ● Access to PD CNS in Swansea. Due to huge caseload PDCNS is unable to review patients within the timeframe of guidelines set out by NICE. ● Access to Speech and Language therapy, videofluroscopy and FEES for the diagnosis and management of swallowing disorders

Our priorities for 2014 – 17 are:

- Clearly identify the gaps in service provision across the south west region
- Establish appropriate day case and inpatient arrangement to support service requirements and alternative way of working across the south west region.

Living with a neurological condition

What works well	What areas need to be improved
<ul style="list-style-type: none"> Specialist Multi disciplinary clinical services such as Parkinsons, MS,MND Epilepsy and TBIS, supported by close links to third sector organisations. Specialist teams have started to reorganise to meet growing demands on their services Neurology service has a good reputation Self referral service model to Health Board local physiotherapy services. Some models of transition from paediatric to adult services which can be used to develop further transition arrangements. Non Epileptic Attack Disorder service has been developed and could be expanded further for medically unexplained conditions. South West Wales Neurological Alliance is piloting a patient passport. Minor brain injury service developed following prudent healthcare principles 	<ul style="list-style-type: none"> Rehabilitation and support services are fragmented and uncoordinated across the region No MDT provision within Neath Port Talbot for patients with Parkinson's Disease. Due to huge caseload PD CNS in Swansea only able to offer very limited support to patients Lack of neurology sessions, neurology beds or ambulatory service. Neurology is very limited in Hywel Dda and even in ABMU this service is under-resourced. Limited access to neuropsychology in ABMU/HD and long-term cost implications to health boards of leaving psychological problems untreated there are a wide range of neurological conditions that do not have any access to any specialist information, advice. Patients with an unclear diagnosis or medically unexplained symptoms do not have a pathway or service. There is a long wait to access highly specialist wheelchairs. Transition for children to adult services End of life pathways Care planning Lack of shared clinical systems/information portal Need to improve access to commercial assistive technologies Patients not aware of all services available and how to access them.

Our priorities for 2014 – 17 are:

- Delivery equity of access across the south west wales region
- Improve access to neurology and rehabilitation services for people with Neurological conditions
- Address gaps in Neuropsychology access

Children and Young People

What works well	What areas need to be improved
<p><u>Neuromuscular</u></p> <ul style="list-style-type: none"> avoidance of hospital admission through ambulatory care model good links with social services and education person centred planning transition muscle clinic neuro-orthopaedic clinics. joint neurosurgery clinics Access to specialist support Single point of access for community services Twice yearly paediatric muscle clinic in Worthybush Hospital. Patients from the east of Hywel Dda Health Board come to the monthly clinics in Singleton Hospital. <p><u>Paediatric Epilepsy</u></p> <ul style="list-style-type: none"> avoidance of hospital admission through ambulatory care good links with social services and education first seizure clinic transition epilepsy clinics 	<p><u>Neuromuscular</u></p> <ul style="list-style-type: none"> No out of hours service Equalise ambulatory care model across the Health Board Transition clinics required in Hywel Dda Health Board Speech and Language Therapy support particularly towards end of life. Speech and Language Therapy support particularly towards end of life for assessment & management of communication needs & dysphagia. Communication aid funding <p><u>Paediatric Epilepsy</u></p> <ul style="list-style-type: none"> No out of hours service Equalise ambulatory care model across the Health Board Transition clinic in East required <p><u>Neuro-disability</u></p> <ul style="list-style-type: none"> Service only available to our patients time required to support the service – Job Planning

<p><u>Neuro-disability</u></p> <ul style="list-style-type: none"> • Botox • Continuing care MDT working, training and finance • Good service delivered • Linked up MDT service (across acute, community and therapy) • Skilled workforce • ambulatory care/access to specialist advice • Good end of life care • Website with information on conditions, services • Timely access to dysphagia assessment and on-going management. <p><u>General Neurology</u> Skilled workforce Multidisciplinary working</p>	<ul style="list-style-type: none"> • No out of hours service • Equalise ambulatory care model across the Health Board • Funding for Continuing Health Care should follow the patient • All Wales Neurology on call rota so that complex unstable patients can be managed • Joint meetings with geneticists • Psychology support • Non stated transition to adult services needs to improve • Joint working in Bridgend • Spasticity service with joint assessment clinic and adequate therapy support • Access to funding for communication aids • Access to SLT assessment & management to address speech, language & communication needs & support use of communication aids <p><u>General Neurology</u> No out of hours service</p>
---	---

Our priorities for 2014 – 17 are:

- Establish a model of care for complex neuro-disability
- Address gaps psychology and therapy support
- Ensure that there is equity of service and access across the south west wales region

Improving information

<p>What works well</p> <ul style="list-style-type: none"> • Participation in regular audits at local and regional level. • Participation in some national audits. • Regular local peer review and modification of clinical practice. • Communication within the ABM Health Board is good 	<p>What areas need to be improved</p> <ul style="list-style-type: none"> • Communication with GPs • Sharing of information to patients and carers is variable • Participation in Parkinson's UK national audit across MDT (neuro, elderly care, physiotherapy, Speech and Language, occupational therapy) and ABMU participation would be welcomed to establish clear local picture of Parkinson's services comparable across Wales and rest of UK.
---	---

Our priorities for 2014 – 17 are

- To build on the work already being undertaken to develop a strong, consistent foundation to measuring the impact of and outcomes of neurological services.

Targeting research

<p>What works well</p> <ul style="list-style-type: none"> • Well established programme of R&D and excellent Health Board Research Unit • 40% of MS patients are in research. 	<p>What areas need to be improved</p> <ul style="list-style-type: none"> • Need to increase research profile amongst the Multi disciplinary team • Need to increase the research portfolio • Increase involvement of wider MDT in research • Improve links with third sector organisations, such as Parkinson's UK, who have a strong research portfolio in order to support increased access to clinical trials
---	---

Our priorities for 2014 – 17 are

- To establish the building blocks (awareness, time, skills partnerships) to develop research capacity within neurological conditions.

6. PERFORMANCE MEASURES/MANAGEMENT

The Welsh Government's Neurological Conditions Delivery Plan (2014) contained an outline description of the national metrics that health boards will need to consider

Progress against these NHS outcomes and assurance measures will form the basis of each health board's annual report on neurological services. They will be calculated on behalf of the NHS annually at both a national and local population level.

Health board's delivery plans and their milestones will be reviewed and updated annually.

ACTION PLAN 2014 – 2015

Theme 1 - Raising awareness of neurological conditions

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead	
<p>Work with a broad range of partners (including local service boards, educational institutions and the third sector) to:</p> <ul style="list-style-type: none"> • Raise awareness of neurological conditions • Signpost existing sources of information, advice and support 						
1.1	A need for a co-ordinated approach to evaluation and roll out of theme 1 actions.	Establish a raising awareness project group with key partners including communications team, primary care, patient representatives third sector organisations and Information Technology specialist.	To provide a focus and momentum on developing and implementing a programme of actions for raising awareness.	Time Input from key people Primary care, IT, Communications.	Group established in November 2014 Outline programme of work confirmed Year 1 (Qtr 1)	Theme 1 Lead DGM Regional Services This forum will also cover Hywel Dda Health Board
1.2	Lack of Care Plans/signposting	Develop information portal. Pilot Patient Passport Engage with other neurological services across Wales (e.g. University Hospital of Wales/ Rookwood) to develop transfer of care and discharge documentation.	Co-ordinated signposting Self Management Co-ordinated pathways		Year 3 Year 1 Year 1 Raising Awareness Project Group Managers, clinicians work with SWWNA to pilot this Passport. Relevant Clinicians	

Theme 1 - Raising awareness of neurological conditions

Priority		Actions	Expected outcome	Risks to delivery	Timescales	Lead
1.3	Co-ordinated Information on services across south west wales region.	<p>Expand website currently being developed by neurology for patients, carers and clinicians to access. This would provide information/links to ABMU/HD services (clear information on referral criteria) and links to LA (CRT), 3rd Sector, other community services and activities etc (including information on community services for sensory impairments).</p> <p>Links to services that will develop their own webpages.</p> <p>Establish a shared information portal</p>	<p>Clinicians can also be kept up-to-date and will have a central place to access information for patients/families.</p> <p>Clinicians can direct patients and carers to one central place for 'up-to-date' information.</p>	Requires a key person responsible for ensuring website is kept up-to-date.	<p>Year 1 (qtr3/4)</p> <p>Year 3</p>	<p>Raising Awareness Project Group</p> <p>Raising Awareness Project Group</p>
1.4	Develop a culture to promote self-management	<p>All patients and carers should have access to education and training to develop the skills to promote self-management and living well with a neurological condition and to understand the progression of their condition to facilitate advanced care planning/ceilings of care/coping with changing function.</p> <p>Develop a business case for providing the Expert Patient Programme (EPP) with some additional MDT sessions to cover neuro-specific problems such as cognition (remediation) and introduce positive psychology.</p> <p>Build on the Self Help management course currently in place, which focuses on cocreation with patients and careres.</p>	<p>Promote self-management and living well with a neurological condition for all patients and carers (wherever possible immediately post diagnosis) and ensure that (as part of this education) they receive information about the ABMU/HD Website to signpost them to further</p>	<p>Education on self-management provided by specialist services</p> <p>Work with EPP service and allocate some clinical sessions to cover the neuro-specific information (e.g. specialist nursing role and/or neuropsychology)</p>	Year 1	

Theme 1 - Raising awareness of neurological conditions

Priority		Actions	Expected outcome	Risks to delivery	Timescales	Lead
			specialist information and support (e.g. 3rd Sector).			
1.5	Provide targeted high quality information to patients at the time they need it.	Undertake a benchmarking exercise with other organisations re what patient information is available and provided and the format and access arrangements for that information.	Learn from others		Year 1 (qtr 2)	Raising Awareness Project Team
1.6	Signpost basic, updated information to primary care on the local services available	Make basic information on our services available to our GPs and ensure that is accessible and updated.			Year 1 (qtr2)	Raising Awareness Project Team
1.7	Information on services should be co-ordinated across the south west wales region.	<p>Expand website currently being developed by neurology for patients, carers and clinicians to access. This would provide information/links to ABMU/Hywel Dda services (clear information on referral criteria) and links to Local Authority (Community Resource Team), 3rd Sector, other community services and activities etc (including information on community services for sensory impairments).</p> <p>Links to services that will develop their own webpages.</p> <p>Establish a shared information portal</p>	<p>Clinicians can also be kept up-to-date and will have a central place to access information for patients/families.</p> <p>Clinicians can direct patients and carers</p>	Requires a key person responsible for ensuring website is kept up-to-date.	<p>Year 1 (qtr3/4)</p> <p>Year 3</p>	<p>Raising Awareness Project Group</p> <p>Raising Awareness Project Group</p>

Theme 1 - Raising awareness of neurological conditions

Theme 1 - Raising awareness of neurological conditions						
Priority		Actions	Expected outcome	Risks to delivery	Timescales	Lead
			to one central place for 'up-to-date' information.			
1.8	Develop a increased focus on rarer neurological conditions	<p>With the appointment of a new Generic Neurology Nurse Specialist role in early 2015 need to:</p> <ul style="list-style-type: none"> confirm that raising awareness of rarer conditions is part of their role; agree pathways for how the Generic Clinical Nurse Specialist links in to patients with those rarer conditions. <p>Targeted information exchange with relevant primary care teams supporting patients at home/care home during condition progression.</p>	Provide a much needed focus for rarer conditions	Minimal role is funded and appointed to. Capacity of role	Year 1 (early 2015)	Senior Clinical Nurse (Neurosciences)
Deliver teaching/training/update sessions to GPs, practice nurses and staff involved in the management of people with neurological conditions on a regular basis to support better understanding of neurological conditions						
1.9	Develop a co-ordinated programme of raising awareness with Primary Care	<p>Map current attendance at the Protective Time for Learning session.</p> <p>Develop a planned programme over the next three years for attendance at ABMU Health Board Protective Time for</p>	<p>Baseline understanding of current programmes</p> <p>co-ordinated programme</p>		<p>Year 1 (qtr 1)</p> <p>Year 1 (qtr 2) on-going</p>	<p>Raising Awareness Project Team</p> <p>Neurology Team</p> <p>Third sector organisations</p>

Theme 1 - Raising awareness of neurological conditions

Priority		Actions	Expected outcome	Risks to delivery	Timescales	Lead
		<p>Learning sessions. Delivery is a partnership approach between secondary care neurological teams and patient organisations and 3rd sector at those sessions. Utilise this approach across South West Wales including Hywel Dda Health Board.</p> <p>Develop a supplementary programme for attendance at GP surgeries</p>	<p>health care professionals and patient representatives and third sector organisations involved</p>		<p>across 3 years</p> <p>Year 1 (qtr 3)</p>	
Ensure all health professionals recognise the importance of supporting individuals and families on diagnosis in a clear and objective manner and are appropriately trained to do so						
1.10	Develop a co-ordinated programme of raising awareness with secondary care health care professionals	Map current awareness and training programmes, prioritise secondary care health professionals and teams			Year 1	
		Develop a co-ordinated programme of training and teaching targeted at priority areas/staff. Utilise this approach within Hywel Dda Health Board.				
		Pilot and evaluation of a Emergency Medic Alert Wristband for patients with neurological conditions accessing emergency services	Improved treatment pathway for patients during an emergency admission		Year 1	South West Wales Neurological Alliance and Emergency Departments
		Development and evaluation of a health passport for patients with neurological conditions going into hospital	Improved experience for a patient during hospital stay Improved understanding on patients needs, incontinence,		Year 1	South West Wales Neurological Alliance and Emergency Departments

Theme 1 - Raising awareness of neurological conditions

Theme 1 - Raising awareness of neurological conditions						
Priority		Actions	Expected outcome	Risks to delivery	Timescales	Lead
			medications, mobility needs communication difficulties and sensory needs.			
Public Health Wales, in partnership with health boards, to deliver a national awareness campaign through community pharmacies in Wales						
1.11	To deliver a national awareness campaign through community pharmacies in Wales	<p>ABMU Health Board will participate fully in the national awareness campaign being developed through community Pharmacies.</p> <p>Local action plan will be developed in line with national campaign requirements.</p>	To be confirmed	To be confirmed	To be confirmed	To be confirmed

Theme 2 - Timely diagnosis of neurological conditions

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead	
Provide GPs with timely and enhanced direct access to CT/MRI, without need for secondary referral, where appropriate and in line with agreed diagnostic protocols						
2.1	Neuro-radiology	Review options to improve access to Neuro-radiology in Hywel Dda Health Board.	Reduce risk through improved diagnosis	Skilled workforce	Year 1/2	Hywel Dda Health Board Delivery Plan
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						
2.2	Alternative options for accessing specialist advice	To evaluate the impact of the Epilepsy email advice. Consider roll out of concept to other appropriate neurological referrals and treatment pathways.	improved access to advice Released capacity in clinics to see urgent patients. Improved referrer knowledge reduction in attendances for to hospital	measuring impact and success	Year 1 qtr1/2/3 Year 1 qtr4	Epilepsy MDT team Wider Neurological Conditions team
Ensure timely access to multidisciplinary assessment to support diagnosis where necessary						
2.3	Neurophysiology	Establish a consistent and sustainable Neurophysiology service model across South West Wales Region.	Improve access for all patients to Neurophysiology	Wide geographic patch Different medical teams supporting the service	Year 2	Senior Specialty Manager Neurosciences/ ABMU Neurophysiology Consultants Involve Cardiff and Vale HB clinical and management team
2.4	Improve Neuropsychology access	Improve Neuropsychology access across south west wales region. Develop a business case to be submitted to each Health Board	Avoidance of admission/re-referrals		Year 1 (Qtr 4)	Neuropsychology Consultant in conjunction with Neurology clinical team

Theme 2 - Timely diagnosis of neurological conditions

Theme 2 - Timely diagnosis of neurological conditions						
Priority		Actions	Expected outcome	Risks to delivery	Timescales	Lead
		outlining the cost/benefits of enhancing neuropsychology capacity				
2.5	Improve access to advanced practice in Speech and language therapy for the diagnosis and treatment of swallowing disorders using radiological imaging i.e.	Videofluoroscopy and developing use of Fiberoptic Endoscopic Evaluation of the Swallow (FEES) – develop business case,	reduce harm, improve quality of life, increases capacity for medical workforce as S< manage patient and reviews.		Year 2	Head of Speech and Language Therapy
Raise awareness of neurological symptoms with GPs and ensure through audit that 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						
2.6	Improve Primary Care awareness (See Theme 1)	Attend Protected time to Learn (PT4L) sessions/Study Days	increase awareness of pathways and services	Minimal	Year 1-3	Raising Awareness Project Group
2.7	Develop referral pathways for other neurological conditions	Agree prioritised list of referral pathways to be developed.			Year 1 Qtr 4	Generic Clinical Nurse Specialist in conjunction with identified consultant lead
Provide specialist advice within 24 hours (on a seven-day-a-week basis) for those admitted to hospital with a primary or suspected neurological condition -reorganising delivery of services to achieve this where necessary						
2.8	Enhance access to specialist advice using technology	Develop telemedicine capacity at the Hub site (Morrison) to enhance specialist advice across the region	Improved communication and advice to support clinical care	Capital	Year 1	DGM Regional Services
Provide rapid access to urgent outpatient services with specialist clinical expertise for referrals to meet GP and patient need						

Theme 2 - Timely diagnosis of neurological conditions

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead
Ensure follow-up arrangements for patients are appropriate and timely					
2.9	Increase Capacity to see patients within existing resources	New outpatients – Pilot a range of initiatives to review referrals and provide rapid access for urgent referrals	See patients in a more timely manner Reduce risks		Year 1 Neurology Clinical Team
2.10	(Prudent Healthcare Principles)	Follow up not booked – Pilot and evaluate a range of alternative initiatives to review follow up patients including: <ul style="list-style-type: none"> • virtual clinics; • see on symptom appointment arrangements • advice lines • non face to face contact with other health professionals <p>Evaluation outcome will inform on-going roll out.</p>	Increase capacity in clinics for patients		Year 1 Neurology Clinical Team Senior Specialty Manager Neurosciences

Theme 3 - Fast and effective care

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead	
<ul style="list-style-type: none"> • Organise services to ensure people admitted with a neurological condition are assessed by a consultant neurologist or neurosurgeon as appropriate, within 24 hours of admission to hospital for a primary neurological condition • Review, plan and deliver evidence-based and timely treatment, in line with latest evidence, standards and guidance • Ensure patients with complex needs have appropriate, timely and co-ordinated access to other specialist services as appropriate • Deliver prompt and equitable access to appropriate interventions, including new diagnostic procedures, technologies, treatment and techniques, in line with the latest evidence and guidance and with evidence based policies and priorities agreed by NHS Wales 						
3.1	<p>Infrastructure</p>	<p>Establish a neurology ambulatory Unit for regional neurology requirements.</p> <p>Review the therapy support requirements for the ambulatory Unit.</p> <p>Establish the local ambulatory requirements are across South West Wales. (See theme 2)</p>	<p>Improve timely access to diagnostic and specialist opinion</p>	<p>Access to identified space</p>	<p>Year 1</p>	<p>DGM Regional Services</p> <p>Senior Specialty Manager Neurosciences and Heads of Therapy</p> <p>Neurology team/Hywel Dda Health Board</p>
3.2		<p>Establish a flexible inpatient bed model in Morriston Hospital to enhance the regional neurology beds, including the therapy support requirements for this model. (See theme 2)</p>	<p>More efficient working, better patient experience, improve access Reduction in Length of Stay</p>	<p>Other ward moves and Hospital services Programme plans</p>	<p>Year 1/2</p>	<p>DGM Regional Services</p>
3.3		<p>Consider different model for Video telemetry provision (See theme 3)</p>	<p>improve access for patients</p>	<p>Reorganise resource/ increase tech time for ambulatory unit</p>	<p>Year 1/2</p>	<p>Neurophysiology Head of service</p> <p>Senior Specialty</p>

						Manager Neurosciences
3.4	Improve Neurology access across south West Wales region	<p>Undertake a comprehensive baseline review of access to neurology services across ABMU/Hywel Dda Health Boards with a view to developing a business case for each Health Board identifying priority gaps in service.</p> <p>Review should focus:</p> <ul style="list-style-type: none"> on out of hours and inpatient liaison requirements for Hywel Dda and Bridgend Localities. on urgent consultation requirements and sub specialty requirements on routine consultation and diagnostic requirements Therapy support requirements 	<p>Understand baseline review.</p> <p>Inform priorities and improvement plan</p> <p>See priority patients in a more timely</p> <p>reduce risk</p> <p>reduction in LOS from early intervention by neurology specialist team</p>	<p>Time to undertake review</p> <p>Financial Workforce</p>	Year 1 (qtr2)	<p>Neurology Clinical team Management and finance teams from Hywel Dda and ABMU Health Boards</p> <p>(South West Wales Healthcare Alliance)</p>
3.5	Telemedicine links	To improve range of telemedicine links between Hywel Dda and Morriston for outpatients and to determine feasibility and appropriateness for acute in patients	Improve patient access to neurology advice	Equipment	Year 1	Clinical Lead/Hywel Dda HB team
3.6	HB Wide Review of Parkinsons services	<p>Undertake a HB wide service review for Parkinsons Disease using the Parkinsons UK national audit template.</p> <p>Develop a business case identifying the gaps in current provision for inclusion in 2016 IMTP.</p>	equitable access to service		Year 1 qtr 4	Parkinsons consultants East and West Parkinsons UK
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						
3.7	Timely repatriation	Ensure compliance with All Wales repatriation policy requirements.	Assure access to specialist beds and advice	Access to beds Communication arrangements	Year 1 on-going	Clinical Team/Hywel Dda Health Board

Ensure that services are organised in a manner that will allow a seamless transfer of care from paediatric to adult services						
3.8	Seamless transfer of care from Paediatrics to adult services	<p>Patient and carers understand their condition and what to expect as the condition progresses.</p> <p>Ensure that Primary Care teams are informed about the information given to patient and carers about their condition progression.</p>			Year 1 on-going	Paediatric Neurology Clinical team
For patients who need it, ensure effective transition to appropriate palliative and end of life care, in line with the <i>Delivering End of Life Care Plan</i>						
3.9	Ensure effective transition to appropriate palliative care and end of life care	<p>Patient and carers understand their condition and what to expect as the condition progresses.</p> <p>Ensure that Primary Care teams are informed about the information given to patient and carers about their condition progression.</p> <p>Include patient on the primary care palliative care register as they transition into the last year of life.</p>			On-going	Neurological MDT
Develop and implement a Patient Reported Outcome Measures (PROMS) questionnaire for patients with neurological conditions						
3.10	Implement PROMS for patients with neurological conditions	<p>To evaluate validated proms questionnaires and agree approach for Neurology</p> <p>To implement the agreed proms questionnaire within neurology</p> <p>To use the outcome of the PROMS to improve the quality of care delivered</p>	Improve quality of care	technology central support	<p>2015</p> <p>2016</p> <p>2017</p>	Neurology MDT

Theme 4 - Living with a neurological condition

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead	
<ul style="list-style-type: none"> • Plan and deliver services to meet the ongoing needs of people with neurological conditions as locally as possible to their home and in a manner designed to support self management and independent living. This should include as appropriate: <ul style="list-style-type: none"> ○ Evidence based follow-up in the community where possible ○ Drug and device management, including a policy on self administration of medication ○ Neuro rehabilitation (including neuropsychological management and exercise) ○ Posture and mobility services ○ Guidance on healthy lifestyle, nutritional advice, accident prevention and self-care to minimise ill health • Assess the clinical and relevant non-clinical needs of people with a diagnosis of a neurological condition and – in liaison with patients (and where appropriate family/carers) - record relevant clinical and non-clinical needs and preferences in a care plan. The care plan should include information on what the diagnosis means for the patient, what to look out for and which service to access should problems occur; it should be reviewed at appropriate points along the pathway • Make arrangements to ensure that information in the care plan or GP letter is available both to the patient and recorded on clinical information systems and is accessible to others who have clinical responsibility for the patient, including out-of-hours GP services, on a 24/7 basis • Provide access to expert patient and carer programmes when required • Work proactively with third sector services and provide effective signposting to information and support, enabling patients to easily access support services • Develop a project to explore the development of co-produced neuroscience services • Review the evidence base and current provision of hydrotherapy across Wales and develop all Wales evidence based guidelines for access to this therapy for both in-patients and out-patients 						
4.1	Improve Neurology access across south West Wales region	Undertake a comprehensive baseline review of commissioning and access to neurology services across ABMU/Hywel Dda Health Boards	Understand baseline review. Inform priorities and improvement plan	Financial Workforce	Year 1 (qtr2)	Neurology Clinical team Management and finance teams from Hywel Dda and ABMU Health Boards (South West Wales Healthcare Alliance)
4.2	Improve Neuropsychology access (See Theme 2)	Improve Neuropsychology access across south west wales region. Develop a business case to be submitted to each Health	Avoidance of admission/re-referrals	Financial	Year 1 (Qtr 4)	Neuropsychology Consultant in conjunction with Neurology clinical

Theme 4 - Living with a neurological condition

Priority		Actions	Expected outcome	Risks to delivery	Timescales	Lead
		Board outlining the cost/benefits of enhancing neuropsychology capacity				team
	Improve access to rehabilitation services for people with Neurological conditions	Engage in discussion with Hywel Dda Health Board re scope of specialist community rehabilitation provided locally, This will involve reviewing and implementing pathways that build on phase 2 of the Neurosciences review for community rehabilitation and will include joint working with Traumatic Brain Injury Service to provide a service for people with Acquired Brain Injury Service. Identify resource gaps. Develop business case to quantify resource needed	Equitable access to specialist community rehabilitation across region (according to need not diagnosis). Provision of training, consultation and support to CRTs across ABMU/HD. Implement Hub and spoke model (as outlined by the Neurosciences Review Phase 2.	Financial Organisational Boundaries	Year 2	Lead Therapist ABMU/Hywel Dda Hywel Dda Community Managers Finance
4.4	Align Liaison Neurology to planned changes in ABMU stroke service changes	Ensure that Neurological services are aligned to planned changes to ABMU Health Board stroke service.			To be confirmed	Liaison Neurology/ ABMU Stroke Service
4.5	Improved access to specialist equipment - adults	Undertake baseline review on specialist equipment needs and provision for adult services (e.g. mobility aids, standing frames or other	Establish a uniform model for adult equipment across		Year 2/3	Physiotherapy/OT joint Lead

Theme 4 - Living with a neurological condition

Priority		Actions	Expected outcome	Risks to delivery	Timescales	Lead
		devices/technologies). Develop a Uniform Model to meet need	the Health Board			
4.6	Improved access to specialist equipment – Paediatrics (See Theme 5)	Undertake baseline review on specialist equipment needs and provision for children Develop a uniform model to meet need.	Establish a uniform model for Paediatric equipment across the Health Board		Year2/ 3	Physiotherapy/OT joint Lead
4.7	Ensure timely access to NICE approved medication	To ensure the Health Board meets the implementation timescales for NICE approved therapies		Delays in implementing infrastructure solutions	On-going	Clinical Teams
4.8	Review the evidence base and current provision of hydrotherapy across Wales and develop all Wales evidence based guidelines for access to this therapy for both in-patients and out-patients	Undertake a review of current evidence base in relation to Hydrotherapy. Participate in all Wales work to develop evidence based guidelines for access. Undertake an assessment of the ABMU provision against the access guidelines. Develop a plan to address gaps.	Improved provision	Ability to meet the agreed guidelines.	Year 1 Year 1 Year 2 Year 2/3	All Wales arrangements to be confirmed ABMU Health Board representation to be agreed

Theme 5 - Children and Young People

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead
<ul style="list-style-type: none"> • Health boards to review progress against the <i>All Wales Neurosciences Standards for Children and Young People's Specialised Healthcare Services</i> and ensure participation in Welsh Government mandated audit and outcome programmes. • Update local plans to address any shortfalls in the full implementation of the standards set out <i>All Wales Neurosciences Standards for Children and Young People's Specialised Healthcare Services</i> • Ensure patients with complex needs have appropriate, timely assessment of their continuing care needs • The paediatric national specialist advisory group to advise the Welsh Government on possible, further actions that should be adopted for treatment of neurological conditions not covered within specialised services and their agreed recommendations to be incorporated in health boards' local delivery plans. 					
Establish a model of care for complex neuro-disability	Care co-ordination for Neuro-disability supported by a Nurse Specialist or paediatric therapist	Free up capacity Compliance with NICE		Year 1	Theme Lead 5/ Paediatric Therapy Lead
Develop an equitable spasticity service across the South West Region.	Consider repatriation of services to bring in new investment Work with Hywel Dda Health Board to confirm requirements and service model			Year1/ 2	Theme Lead 5/ Paediatric Therapy Lead Hywel Dda Health Board
Establish Psychology service for children and families (CAMHS-Neurology input)	Develop a business case which outlined the costs and benefits of establishing a psychology service.	Free up capacity Compliance with NICE	financial workforce	Year 1	WCH Directorate
Development of equitable Transitional services across the Health Board and South West Wales Region	Undertake a baseline review of transitional services across the Health Board. Identify what transitional services are required and develop business case to address gaps in service.	Establish an equitable service	Financial	Year 2/3	Theme 5 Lead Hywel Dda Health Board
Improved access to specialist equipment	Undertake baseline review on	Establish a uniform		Year2/ 3	Physiotherapy/OT

Theme 5 - Children and Young People

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead
– Paediatrics (See Theme 5)	specialist equipment needs and provision for children (including communications aids) Develop a uniform model to meet need.	model for Paediatric equipment across the Health Board (to include the provision include communication aids)			joint Lead
Develop additional therapy support by utilising existing workforce (OT, Physiotherapy, Speech and Language Therapy and Dietetics)	Redesign existing services and workforce identify gaps and develop business case for new investment	Improve outcomes for patients	Workforce Funding	Year 3	WCH Directorate team
OOH Service – Paediatric Neurology on call for South Wales (timely with reconfiguration of children’s services – SWC)	Establish an out of hours service	Improved outcomes for patients		Year 1	Cardiff and Vale ABMU Health Board Medical directors
Integrated models of care between Health, SS, Education and 3 rd sector. (C4B women, children and families looking at this)	Establish an Integrated model of care	Improved outcomes for patients		confirm timescale	C4B women Children and families group

Theme 6 - Improving information

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead
<p>Ensure IT infrastructure supports effective sharing of clinical records/personalised care plans</p> <p>Put effective mechanisms in place for seeking and using patients' views about their experience of neuroscience and related services</p> <p>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:</p> <ul style="list-style-type: none"> • neuro rehabilitation services caring for Welsh patients, in the UK rehabilitation outcomes collaborative (UK Roc) • spinal injury units caring for Welsh patients, in the national spinal cord injury database • neurosurgery units caring for Welsh patients, in the consultant outcomes publications programme <p>Participate in and act on the outcome of peer review</p> <p>Publish regular and easy to understand information about the effectiveness of neuroscience services</p> <p>Establish an annual national audit day for neurological services provided to Welsh Patients</p>					
Improving patient information <i>(for healthcare professionals)</i>	Establish a neurology website on the Trust intranet. It should have details of Neurology services, waiting times and disease specific information		IT department representative did not attend the meeting	Year 1	Raising awareness project group (Theme 1)
	More written information should be made available to give to patients	Improved awareness at different stages of disease progression.	minimal resource for printed leaflets	Year 1	Raising awareness project group (Theme 1)
	Increase opportunities for more face to face information giving				
Improve information provision to Primary Care	Establish email advice line for Epilepsy Service.	Evaluate success of epilepsy email service.	Ensure continuity of data collected	Year 1	Epilepsy MDT team
	Identify key measures for evaluating the impact of the email advice line.	Use the information to assess impact of expanding the service to Neurology	Analysis of information		

Theme 6 - Improving information

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead
	Based on evaluation outcomes develop wider roll out programme within neurology			Year 2/3	Neurology MDT
Patient feedback/experience	Establish group specific meetings utilising existing mechanisms in place via third sector organisations e.g. Parkinson's UK local support groups and Information and Support Workers				Third sector groups/MDT team
	Invite patients to specific service development meetings	Approach to be discussed at the Neurosciences specialty Board.		On-going	Neurology MDT
	Routinely run patient experience initiatives.			On-going	Neurology MDT
Health Board Digital Vision	ABMU Health Board developing technologies to support and underpin recording of alternative ways of interfacing with patients	Improved documentation of alternative patient contacts Continuity of care	Access to technology	Year 2/3	Medical Director
Quality Dashboard	Work with WHSCC to establish quality dashboards for specialised services in ABMU Health Board.	Populated quality dashboard	Resources to support data collection	Year 1	Neuro rehabilitation MDT team
	Develop case for participation in UKRoc national audit.			Year 1 (qtr 1)	
National audit programmes	Fully participate in the WHSSC multi centre national audit	Populated quality and access dashboard	time data	Already established	Neuro rehab MDT team

Theme 6 - Improving information

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead
	programme for specialised rehabilitation services	Benchmarking information to inform local service development and change		On-going	
	Fully participate in the WHSSC national audit programme for posture and mobility and prosthetic services.	Populated quality and access dashboard Benchmarking information to inform local service development and change		Already established On-going	ALAC team
	Participate fully in an annual national audit day for neurological services provided to Welsh Patients	Populated quality and access dashboard Benchmarking information to inform local service development and change		To be confirmed	Neurology MDT team

Theme 7 - Targeting research

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead
<ul style="list-style-type: none"> • Support and encourage protected teaching time for clinically-active staff (in primary as well as secondary and tertiary care) • Support and encourage protected research time for clinically-active staff (in primary as well as secondary and tertiary care) • Build on and extend academic training schemes to develop a highly skilled workforce • Promote collaboration with key research initiatives, including the NISCHR funding infrastructure • Increase the number of non-commercial clinical research portfolio and commercial studies • Increase the number of people with a neurological condition entered into clinical trials and number retained on longitudinal trials • Ensure that key clinical data is in a format that can be incorporated into the SAIL (Secure Anonymised Information Linkage) database for population-level health and social care research to support epidemiological research, clinical trials, the impact of interventions and service delivery modelling and assessment • Collaborate effectively with universities and businesses within and outside Wales to enable a speedier introduction of new evidence-based and cost effective technology into the NHS 					
Create more awareness amongst health professionals	Invite R&D as well Clinical Research Unit staff to Neuroscience Meetings and discuss the facilities available for research.			Year 1	Theme 7 Lead
Seek opportunities for collaborative research with a range of organisations	Increase interaction with a range of organisations in respective condition fields.			Year 1 – on-going	Lead consultant in each sub specialty/Medicines Management
Secure research time within MDT staff's job plans	Improve links with third sector organisations, such as Parkinson's UK, who have a strong research portfolio in order to support increased access to clinical trials		Workforce Capacity Funding	Year 3	Neurological MDT team/R&D/CRU/Third sector organisations
Create a database for neurological disorders and patient awareness	Develop a clear specification and requirements for the database for neurological disorders and patient awareness	Outcome data Support research, audit and evaluation of service changes.	Resources Time Technology to support data collection	Year 2	lead consultant in each sub specialty

Theme 7 - Targeting research

Priority	Actions	Expected outcome	Risks to delivery	Timescales	Lead
	<p>Identify priority areas</p> <p>Develop a business case outlining the resources required and the benefits from establishing neurological disorder data base</p>				Senior Specialty Manager. Theme 7 Lead
Interact with other research networks	<p>Epilepsy – Welsh Epilepsy Research Network (Already involved).</p> <p>Undertake a mapping exercise of other research networks in the various specialist fields.</p> <p>Appoint a research coordinator from within the neurology consultant team</p>		Capacity	Year 3	Theme 7 Lead

Neurological Services – Service Profiles

Neurology Service

Workforce

- 10 consultants and 1 locum consultant currently
- Specialist nurses in sub specialties such as MS and Epilepsy but first generic nurse to commence in post in January 2015
- Secretarial and administrative support

Population Served

ABM and Hywel Dda Health Boards serving a population of approx 1 million.

Activity Undertaken

- Average of 400 referrals received per month into Neurology and an average of 500 patients seen per month across OPD Clinics in East and West of ABM.
- Average of 22 inpatients per month staying 9.4 days average length of stay.
- 84 day cases undertaken per month on average, around 30 of which MS infusion and 19 lumbar punctures. This activity will move to new Ambulatory Unit funded through recent Strategic Transformation Team projects

Access Times

- First Neurology OPD appointment - 28 weeks
- Lumbar Puncture – 5 months (will reduce once Ambulatory Unit in place)
- Liaison Service – patients seen within 24 hours in general in Swansea
- On call SPR and consultant available 24/7

Clinic Service Location:

- Morriston Hospital
- Singleton Hospital
- Neath and Port Talbot Hospital
- Princess of Wales Hospital
- Maesteg Hospital
- Gorseinon Hospital
- West Wales General Hospital
- Prince Philip Hospital
- Telemedicine links within HD

- 6 inpatient beds in Morriston Hospital
- Ambulatory Unit from early 2015

Teaching

Support teaching of medical students and SHO/SPR education.

Research

3 of the consultants currently undertaking research. Links with Clinical Research Unit, Trials for MS New Drugs and UHW, Cardiff.

Neuropsychology

Workforce

3.4 wte neuropsychologists , a Assistant psychologist and Admin support

Scope of the Service

The **Neuropsychology regional service** accepts referrals from Consultants in Neurosurgery, Neurology, Rehabilitation Medicine and Consultants caring for Morriston Hospital inpatients with neurological conditions (excluding stroke). Main focus is working with people who have an acquired brain injury or a neurodegenerative condition living in the ABMU and Hywel Dda Health Board catchment areas. Only consultation to Stroke Services in ABMU is possible with current resources.

The remaining Neuropsychology team work within:

- the **Traumatic Brain Injury Service**. This service provides community MDT neurorehabilitation to people with a severe traumatic brain injury living in the ABM ULHB catchment area.
- the inpatient **Neurorehabilitation Service** located in Neath and Port Talbot Hospital for South West Wales patients (ABMU and Hywel Dda Health Boards).
- the new **Non-Epileptic Attack Disorder Service**, which provides assessment and intervention - one-to-one and/or group interventions (NEADS Education Group) ABMU and Hywel Dda Health Boards. **new**

An assistant psychologist (Band 4) works across TBIS, Neuropsychology, the Epilepsy/NEAD Service, and spends one day per week working with the voluntary organisation Headway via a service contract.

Prior to April 2013 - an annual 150 patients were referred by A&E to the **Mild Brain Injury Service** at Singleton Hospital. In April 2013 following Professor Woods's retirement a prudent healthcare model was adopted whereby patients referred from A&E were screened and a package of information sent to patients to enable them to self-manage symptoms. This included a self-referral form and patients were given the option of referring themselves to the service if their symptoms persisted beyond 6 months post injury (consistent with scientific evidence). **new**

All the neuropsychologists contribute to the **community neurorehabilitation projects** led by the neuropsychologist /OTs in TBIS. This has enabled patients with other neurological conditions and/or patients in the Hywel Dda Health Board area to access some neurorehabilitation (e.g. Down-To-Earth and Camera projects). The team delivers positive psychology and support groups for patients and carers. This is done in partnership with Headway. This work is supported by a team of volunteers. **new**

Access times

General Neuropsychology ABMU - 9 months Hywel Dda - 12 months

NEADS - 2-4 weeks

MTBI - 3-4 weeks

Teaching

Wide ranging - medical students, postgraduate clinical psychology students, multidisciplinary AHPs, local authority/CRT, nursing, presentations to neurology.....

Research

All staff have doctorate level research skills. Regular audits and service evaluations undertaken. Research project with neurology colleagues to screen affective well-being and offer positive psychology group interventions for epilepsy patients. Close links in place with Swansea and Cardiff Universities.

South West Wales Regional MS (Neuro Inflammatory) Team

Workforce

1 Consultant Neurologist, 4 clinical nurse specialists, clinical specialist physiotherapist and Administration team

Population served

Established in 2004, team are based at Morriston Hospital and provide a regional service covering both ABMU LHB and Hywel Dda Health Boards and parts of Powys. The population served is approx 1 million, with 1553 active patients.

Service Provided

Consultant led clinics at Morriston (DMT and rapid access)

Nurse led outreach clinics in:

- ABMU (Princess of Wales, Neath/Port Talbot and Morriston)
- Hywel Dda (Glangwili, South Pembrokeshire, Tenby Cottage, Withybush, Aberaeron and Bronglais)

Day case activity – IV natalizumab infusions weekly/ Fingolimod initiation weekly/Mitoxantrone infusions 6 weekly at Morriston Hospital

Email Helpline and telephone consultations

Telemedicine – via hospital to hospital polycom and Hospital to pts home via facetime/Skype

Newly diagnosed information days (joint with MS society)

FACETS – Fatigue Management courses for MS patients

Access times

Consultant

- DMT clinic – 10-16 weeks, rapid access clinic- 1 week

Nurse Led

- Newly diagnosed – 4-6weeks
- Symptom management – 6-8 weeks
- FUNB – 2-4 months behind

Teaching

Medical students in DMT clinic weekly and apprenticeships with Dr Pearson

DPP projects supervised by Dr Pearson

Nursing/medical students in Nurse-led clinics

Patient Teaching days – newly diagnosed information days

Teaching to AHP on MS / Professional nurse forums

Teaching delivered at National Conferences

Research

UK MS register – NISCHR Clinical Research Portfolio – UK lead recruitment, member of Clinical Advisory Group (CAG)

Clinical Trial Program – Completed – MOBILE (2ND worldwide in recruitment), MS pathways

Ongoing- OPERA (UK lead in recruitment), ASCEND, ASSURE, PASSAGE trials

Awarded – ENHANCE, ARRPEGIO, MS108

UK DoH Risk sharing scheme

Neurophysiology ABMU West

Workforce

1.2WTE Consultant Neurophysiologist , 3 .6 WTE Registered Practitioners , 1 Trainee Assistant Practitioner
1WTE Clerk/receptionist and 1 Medical Secretary

Population

The team is based at Morriston Hospital and provide both secondary as well as tertiary services covering both ABM and Hywel Dda University Health Boards as well as parts of Powys. There are close link with the Department of Clinical Neurophysiology at West Wales General Hospital in Carmarthen, which is attended one day per week by the Consultant in Clinical Neurophysiology.

Service provided (adult and Paediatrics)

Routine video Electroencephalography (EEG) Inpatient and outpatients . Every day

Prolonged Electroencephalography (EEG). As requested

Sleep deprived . Every day

Sedation recordings. As requested

5 Day Ambulatory recording .1 per week for 5 days monitoring

5 Day Inpatient Video Telemetry 1 per week for 5 day monitoring .(subject to bed availability)

Sleep Studies, Mean Sleep Latency Test MSLT (as of November 3rd) 1 per week

Visual Evoked Potentials. 2 per week

Somato Sensory Evoked Potentials. As requested

Brain stem Evoked. As requested

Portable service in other hospitals for critically ill patients e.g. SCBU Singleton Hospital.

Nerve conduction studies

Electromyography (qualitative)

Repetitive nerve stimulation

Electromyography (quantitative)

Single fibre electromyography (SFEMG)

Portable ICU studies

Access times ABMU Health Board

EEG

Test	Waiting time
Routine	6-8 weeks
MSLT	Proposal to share Video telemetry bed start 3/11/2014
Sleep Deprived	6-8weeks
Prolonged	6-8weeks
Ambulatory	12 weeks
Video telemetry	32 weeks months
Paediatric Video telemetry	Within next 2 months

Immediate response provided for urgent inpatient e.g. ITU, Status Epileptics, Encephalography etc.

NCS/EMG

Routine

TEST	NCS	EMG	CTS
Waiting time	16 weeks	12 weeks	16 weeks

Urgent - There is one weekly session for urgent inpatient cases at Morriston Hospital. Access requires a prior discussion with the Consultant in Clinical Neurophysiology.

Access times Hywel Dda University HB

Routine

TEST	NCS	EMG	CTS
Waiting time	5 weeks	4 weeks	5 weeks

Urgent - There are no formal slots for urgent inpatient cases at Hywel Dda University HB. Every effort is made to accommodate urgent cases as a priority in the weekly routine outpatient clinics at West Wales General Hospital.

Teaching

Medical students
Lecturing at Swansea University on Msc course.
Mentoring/teaching WED's funded students in department.
Alliances with other hospitals in Wales to rotate student cohort
Placement of STP practitioners
Piloting Associate practitioner post.
Formal signing off competencies for students .
Presentations at Scientific meetings.
Participate as part of Skills Cymru Wales/NHS Wales Careers network

ABMU East

Workforce (POW and Cwm Taf Combined)

Band 7 1 wte, Band 6 2.4 wte and Admin 0.54 wte

Population Served Bridgend 250,000 and Cwm Taf 289,000

Service Provided

The service provides a full range of Neurophysiology tests including:

- Electroencephalography (EEG)
- Prolonged Electroencephalography (EEG)
- Sleep Deprived
- Sedated Sleep Electroencephalography (EEG)
- Ambulatory Electroencephalography (EEG)
- Nerve Conduction studies
- Electromyography

Access Time(weeks)

Area	NCS	EMG	EEG
POW	13 weeks	11 weeks	6 weeks

The above waiting times are being supported by additional capacity funded by Welsh Government. new

Clinic/Service Location

Service location	Use	Weekly Capacity
POW	EEG/NCS/EMG	4 Days EEG 1 day EMG/NCS(3 out of 4 weeks)

Teaching

We are one of the South East Wales Neurophysiology Services student rotation sites. Currently there is 1 student now in his second year with a further 2 students starting in January of next year.

Adult and Paediatric Neuromuscular Service

Workforce

Dr R Jon Walters	Adult Muscle Disease
Dr Nigel Hinds	Adult neuropathy
Dr Cathy White	Paediatric neuromuscular disease
Dr Marguerite Hill	Myasthenia gravis (acquired)
Dr Soren Raasch	Neurophysiology
Dr David Abankwa	Consultant in Rehabilitation Medicine
Richard Pawsey	Specialist adult physiotherapist
Kate Greenfield	Specialist Paediatric Physiotherapist

Sarah Harris Neuromuscular Care Advisor

Care coordination across ABMU and Hywel Dda for patients with muscle disease including support for patients the families and carers. Signposting to other specialities for patients with muscle disease. Implementation of Emergency Care Plans for patients with NM conditions.

Population served

South West Wales; AMBU and Hywel Dda

Activity undertaken / access times / service location

	Activity	Access times	Service Location	Teaching
Dr Jon Walters	Specialised adult muscle clinic every 6 weeks in Morriston that provides for ABMU and all further West. Gorseinon clinic every 2 weeks for some other neuromuscular diseases	Can review patients within days. Very long wait for considerable number of muscle patients awaiting follow-up	Morriston and Gorseinon hospital	Ad hoc teaching to Swansea GEM students, not specifically related to neuromuscular disease
Dr Nigel Hinds				Ad hoc teaching to Swansea GEM students, not specifically related to neuromuscular disease
Dr Cathy White	Specialist paediatric multidisciplinary muscle clinic every month for ABMU patients and eastern part of HD UHB. Twice yearly multidisciplinary muscle clinic in Withybush for western HD UHB patients. Three monthly multidisciplinary transition clinics for non ambulant young adults with Dr Abankwa in Morriston Hospital. Dedicated peripheral nerve clinics (mostly CMT) in Neath Port Talbot and Swansea - x4/year in total.	Can review patients within days, but new patient wait up to 8 weeks. Increased clinic capacity means most patients followed up as requested.	Singleton Hospital Morriston Hospital Withybush Hospital Neath Port Talbot Hospital Childrens Orthopaedic Clinic	Medical students attend paediatric neurology clinics; lecture to Swansea GEM students on inherited neurological diseases which includes muscular dystrophy
Dr Marguerite Hill	Diagnosis and long term management of patients with Myasthenia Gravis. Patients seen in general neurology clinic; no specialised clinic provision.	Patients with brittle MG seen within days. New diagnosis / stable disease (new patients) 8-12 weeks FU dependent on clinical need	Morriston Hospital	Considerable teaching commitment to Swansea GEM students but this is not specifically related to neuromuscular disease
Dr Soren Raasch	Nerve conduction studies Needle electromyography (qualitative and quantitative) Repetitive nerve stimulation	New diagnosis around 12 weeks Acute cases within days after discussion with consultant colleague	Morriston Hospital	Regular teaching commitment for Swansea GEM students every Tuesday am

Adult Epilepsy Service

Workforce

Dr Sawhney, Consultant Neurologist
Dr Powell, Consultant Neurologist
Alison Mead, Clinical Nurse Specialist Epilepsy
Band 6 *newly funded under ABMU Service Transformation Programme*
Epilepsy field workers (from voluntary services)

Population served

ABMU and Hywel Dda Health Board (complex cases are referred to specialist epilepsy clinics in Morriston Hospital otherwise patients treated by general neurologists visiting Hywel Dda Health Board.)

Service provided

Both consultants run 1.5 Epilepsy clinics per week (New, Follow-up's, 1st seizure/rapid access/ Open access (to be set soon). In addition there is one Adolescent Epilepsy Clinic once in 3 months.
X3 Nurse-led clinics per week which will increase in the future when the band 6 is ready i.e. management of Epilepsy, advice and information, medication titrations, setting up rescue medication, risk and safety, ante-natal care.
Nurse led Telephone advice line. *new*
Nurse led GP e-mail service *new*
Non Epileptic Attack Disorder (NEADS) service- joint service with Epilepsy and Neuro-psychology *new*

Access times

Consultants- 24/7- Neurology on- call service
Nurse - 8-4 Monday – Friday. (expanded cover with new post)

Clinic/service locations

Consultant and nurse led clinics at Princes of Wales and Morriston Hospitals

Teaching

Presentations from nurse:- Epilepsy Awareness and rescue medication training, pre-conceptual counselling and ante-natal care, Driving, 'Train the trainer'
Epilepsy MDT's
Neurologists and nurse- Trainee's in clinics and undergraduates students
Epilepsy Master class – supported by pharmaceuticals
Lectures for GPs – part of GP CME programme

Research

Empire Trial – AED levels in pregnancy
Sanad 2 – AED efficacy
Protocol N01358: A Randomized, Double-Blind, Placebo-Controlled, Multicenter, Parallel-Group Study to Evaluate the Efficacy and Safety of Brivaracetam in Subjects (≥16 to 80 Years Old) with Partial Onset Seizures supported by Union Chiriquí Bilge (UCB)
Protocol No. 1379 An open label multicentre, follow-up study to evaluate the long safety and efficacy of Brivaracetam used as adjunctive treatment in subjects aged 16 years or older with partial onset seizures Supported by Union Chiriquí Bilge (UCB)
Pregabalin in participants with primary generalised tonic-clonic seizures (supported by Pfizer)
Protocol VIKEL CT001 Investigations into efficacy and application of non-invasive sensor technology to produce a community based seizure alarm/monitor for epilepsy and episodic motor disorders Welsh Epilepsy Research Network (WERN) Project.
Review of Hospitalized Patients of Epilepsy to Avoid Future Admissions supported by Union Chiriquí Bilge.

Neuroradiology

Workforce

4 full time neuroradiologists based on the Morriston site but with sessions in Neath Port Talbot Hospital and Princess of Wales. 1 of the 4 has a split contract with in Prince Phillip Hospital, Hywel Dda.

Population Served

Patients seen within the ABMU Health Board. A substantial portion of time is also used in reviewing imaging for patients from Hywel Dda Health Board.

Service Provided

The types of patients scanned include adults and children that are assessed clinically either in primary, secondary or specialist tertiary neurology clinics. ABMU and some Hywel Dda patients who are under the care of the neurosurgical team in UHW are also imaged in ABMU and the scans reported by the neuroradiology service. Other scans reported by the neuroradiology service include patients who have been seen by ophthalmology, ENT, maxillofacial surgery, spinal and orthopaedic surgeons as well as oncology patients with cord compression. Patients from SCBU and paediatric wards are also scanned.

- **In Patient Cover** - Duty neuroradiologist in Morriston Monday to Friday 9am to 5 pm for any urgent neuroimaging and specialist opinion for any patients around the region.
- **On Call Work** - The Morriston Hospital MRI scanner is the only scanner open out of hours in the South West region. 1:4 on call in place to support this service.
- **Subspecialty Interests** - Two consultants have subspecialty interest in **head and neck cancer imaging** and
Two consultants have a subspecialty interest in **paediatric neuroradiology**.
- **Specialist neuroradiology meetings** - One consultant attends the **neuro-oncology meeting in UHW** every Monday to discuss regional brain tumour cases. The others attend via VC link.

Regional weekly MS meeting

Fortnightly **paediatric regional neuroradiology meeting**.

Attendance at the **All Wales Stroke Conference** (meeting is led from UHW and attended by VC link).

Weekly meetings with the neurology consultants. This is a clinical meeting to help in the management of acutely ill neurology patients in the South West region as well as viewing OP scans- there is a substantial number of these from Hywel Dda Health Board.

Access times

CT – approximately 6 weeks

MRI- approximately 8 weeks

Most USC work is imaged and reported within 10 days.

Teaching

Three of the four consultants who work full time within ABMU are committed to teaching on the anatomy course for the graduate entry programme as well as clinical lectures in later years.

Teaching of pre FRCR radiology registrars on the All Wales radiology training scheme and juniors from within departments within ABMU such as emergency medicine and neurology is also undertaken.

Research

Several multi centre trials involve ABMU patients who have MRI studies locally as part of their trial protocol. The safety reporting for the MS and stroke trials is undertaken by neuroradiologists. However, there is little involvement with any of the new studies undertaken at ILS 2.

Parkinson Service (ABMU East)

Workforce

- 2 consultant sessions - Dr Sandip Raha
- 1 WTE PDNS – Bridgend and Western Vale of Glamorgan – Louise Ebenezer
- 1 WTE PDNS - Neath & Port Talbot - Greta Jones

There is an additional general neurology OPD session provided by Dr Jon Walters and Dr Inder Sawhney. Many older patients in NPT locality are referred to Dr S Raha in Princess of Wales for diagnosis, assessment and advice on managing complex patients.

Population Served

Population of Bridgend County Borough Council Area and Western Vale of Glamorgan, Neath Port Talbot County Borough Council Area. Part of this population is also served by Neurology clinic in POWH and NPT run by Neurology services.

Service provided

Princess of Wales Hospital - **Two dedicated Movement Disorder Clinics** per week based in Pendre Day Hospital

Community clinics – 3 clinics within Bridgend locality and Neath and Port Talbot localities.

Home visits undertaken by both PDNS

Inpatient consultation service also provided for POWH and Neath Port Talbot Hospital.

Access times

Princess of Wales – within 6 weeks of referral

As per NICE guidelines and all PD patients are seen at 3-4 months interval either in Hospital or Community Clinics,

Emergency slots available in each clinic.

Teaching

Attendance at movement disorder clinic by SpR's Physiotherapy students, Nurse Practitioners and junior doctors

PDNS have student Nurses, Physiotherapists both qualified and students and nurse practitioners shadowing their clinics and community visits.

Louise Ebenezer is an honorary lecturer in Swansea University and facilitates and runs one of only 3 Parkinson's disease specific nurse degree and masters level courses in the UK which is also available for therapists and is also involved in International nurse education and raising awareness.

Research

Team involved in PD research and particularly Parkinson's disease dementia.

Dr Raha Chair of Welsh Movement disorder E Network Database developed between Bridgend, Cardiff, Caerphilly, Abergavenny. This database has supported production of over 15 posters in National and International movement disorder and Parkinson's congress over past 10 years. Active research group developing areas of further research.

Qualitative research on Use of Rasagiline in real life; a retrospective study supported by Teva pharmaceuticals in last two years through the data base.

Parkinson Treatment Centre (ABMU West)

Location: Parkinson's treatment Centre, Gorseinon

Population served

PD for Swansea Complex PD and Movement Disorders ABMU and HD ~850 patients under active follow up

Clinical Workforce

F Thomas Consultant Neurologist 1 clinic /wk

R Weiser Consultant Neurologist 1 clinic/wk

O Powell GP with special interest 1 clinic /wk

Maralyn Thomas PD specialist nurse

Activity

3-4 doctor lead clinic/wk

Open access Nurse lead consultations

Telephone consultations and advice

Multidisciplinary 12 week Parkinson's disease treatment programme meeting weekly at centre

Access times

New patients seen ~6 wks

Teaching and research

Multidisciplinary teaching

Weekly Medical student teaching

Involved in National PD audit

Traumatic Brain Injury service (TBIS)

Service Aim

- To provide a co-ordinated community rehabilitation service for adults who have suffered a Traumatic Brain Injury(TBI).
- To minimise disability, promote independence and maximise quality of life through a comprehensive inter -disciplinary rehabilitation programme.
- Support the client/family and carers through relevant information, advice and appropriate intervention.
- Provide educational programmes to other health professional and outside agencies.

Workforce

Clinical Nurse Specialist – 0.8 WTE

Speech and Language Therapist – 0.6 WTE

Occupational Therapists – 1.2 WTE

Physiotherapist – 0.5 WTE

Generic Assistant – 0.6 WTE

Clinical Psychologist – 1.0 WTE

Assistant Psychologist - 0.4 WTE (vacant)

Secretary – 0.9 WTE

Population served - ABMU HB approximately 600,000

Referral Criteria

Inclusion: All patients must have suffered a TBI identifying at least one of the following:-

- Glasgow Coma Scale of 8 or below
- Post Traumatic Amnesia of 24 hrs or more
- Evidence of brain lesion on computerized tomography
- Be a resident of Swansea, Neath, Port Talbot or Bridgend. Be 16 years and above
- Require comprehensive rehabilitation and/or support
- Have the ability to participate in and benefit from the rehabilitation process

Exclusions: Patients with a diagnosis of any other acquired brain injury in the absence of a TBI. Patients with Mild TBI are seen in the neuropsychology Mild Brain Injury Service.

Brief outline of activity undertaken

Community-based, multi-disciplinary team, providing outpatient assessment and rehabilitation for persons with traumatic brain injury. In recent years developments in the team include the development of co-produced, task based neurorehabilitation project:

- Neurorehabilitation Projects/Positive Psychology Groups/ Co-production initiatives/ Hydrotherapy and Balance groups

Access times for service

Initial Neurological Rehabilitation Assessment within two weeks of receiving all of the relevant medical information. Within the team waiting times varies between 4 weeks for Physiotherapy and Speech and Language to several months for Occupational Therapy and Neuropsychology

Teaching and training

Provision of teaching and training to medical students, postgraduate clinical psychology students, multidisciplinary AHPs, local authority/CRT, nursing, neurology etc. Clinical placement opportunities to physiotherapy and psychology students. Final year elective placements for the South Wales Doctoral Programme in Clinical Psychology.

Research

Evaluations of the 'Neurorehabilitation Projects', 'Co-production Initiatives' and 'Positive Psychology Groups' being undertaken using both qualitative and quantitative research methods.

Neurorehabilitation Inpatient Unit

Service aim

The Neurorehabilitation unit is a 13 bedded unit in Neath Port Talbot Hospital providing specialist input for patients with a variety of neurological conditions.

Workforce

The multidisciplinary team consists of two Consultants in Rehabilitation Medicine, one Associate Specialist, nurses, Physiotherapists, Occupational therapists, Speech & Language Therapists and Clinical Psychologist.

Population served

The unit takes patients from across South West Wales.

Typically patients would have a disabling neurological condition such as traumatic brain injury or ruptured cerebral aneurysm. Many of our patients would have received their initial treatment at the Neurosurgical unit in Cardiff.

Following admission to the unit, patients will be assessed by the multidisciplinary team and an individualised rehabilitation programme will be devised in conjunction with the patient and their family. The medical team also provide weekly outpatient clinics in Neath Port Talbot Hospital where patients are reviewed following discharge. The unit provides placements for students including Clinical Apprenticeships for medical students.

Motor Neurone Disease

Aims of network

- Development of multidisciplinary teams (MDT's) and clinics within each local health board to include regular 3 monthly assessment at clinic from consultant neurologist, consultant in palliative medicine, respiratory services, care co-ordinator, occupational therapist, physiotherapist, dietetics speech and language therapist, social worker and support from MND association visitor. MDT outreach to community for patients with Motor Neurone Disease unable to attend clinic.
- Promotion of effective integrated working between health, social service and voluntary sectors.
- Improved support and co-ordination of services including training and education.

Workforce

Ruth Glew network lead 0.4 WTE (for all 5 LHB's) 0.6 WTE are coordination SW Wales (ABMU and Hywel Dda)

Katie Hancock 0.6 WTE SE Wales 0.2 WTE Cwm Taf development

Cynthia Butcher 0.65 WTE funded by Cardiff and Vale University LHB

Population served

Number of patients with MND in South Wales ranges between 180-200 . No of Patients in ABMU ranges from 44-55

Referrals (no of diagnoses) to the network since 2013 = 146

No referral ABMU =55

Achievements to date

8 multi-disciplinary MND clinics established in South Wales, and the original Cardiff clinic with associated MDT meetings. Early indications from both patients with MND and health and social service staff involved in caring for this patient group that the network approach is an efficient and effective way of addressing the needs of people with MND and their families.

Patients report feeling more supported and reassured by the presence of a team. They are able to develop a relationship with Palliative medicine professionals supporting end of life decision making. There are fewer hospital appointments and less disruption to other activities. Team members report better communication between them and report feeling more supported in providing care. Each patient referred to the network is offered an initial assessment at home. The care –coordinators offer on-going support and co-ordination of care to both patients and families and also support health and social care professionals in providing input to these patients

Access times

Each patient referred to the Patients is seen for an initial assessment within 4 weeks of referral. Within ABMU there are monthly MDT clinics in Swansea, Neath Port Talbot and Bridgend localities with patients seen on average every 3 months as per current national standards.

Teaching

Network education days

Training sessions for social services and other allied health professionals and teaching within the MDT clinics.

Research

Network in the early stages of development.

The new database will enable collection of patient data to enable participation in research projects in the future. This will provide a strong foundation for engaging with other UK centres for multicentre research

Neurophysiotherapy

Physiotherapy is “a healthcare profession that works with people to identify and maximise their ability to move and function” and it “plays an important role in enabling people to improve their health, wellbeing & quality of life”. Within the Cross Party Group for Neurological Conditions (2013) it is suggested that “For the majority of neurological conditions physiotherapy can offer the prospect of maintaining and improving mobility and independence, slowing the speed of a progressive condition or offer the prospect of rehabilitation and a return of function”. Neurophysiotherapy is available on an outpatient basis at Murrison, Neath & Port Talbot & Princess of Wales Hospital sites and is not included in the information below.

Workforce

Within the Adult Neurosciences Services provided by the Regional Services Directorate there are 3 Band 7 physiotherapists who are highly experienced in the assessment and delivery of Neurophysiotherapy. These individuals are based within:

- **Neurorehabilitation Unit (NRU)**
Band 7 physiotherapist (0.8wte)
This physiotherapist co-ordinates a small team of a rotational Band 6 physiotherapist and a Band 3 Physiotherapy Assistant, who deliver ward-based neurophysiotherapy.
- **Neuro-inflammatory Team (MS Team)**
Band 7 physiotherapist (1 wte)
This team is regional and as such covers both ABMU & Hywel Dda Health Boards. This physiotherapist provides specialist assessment and advice to help optimise and maintain physical function and also to help manage other symptoms.
- **Traumatic Brain Injury Service (TBIS)**
Band 7 physiotherapist (0.5wte)
This team is within ABMU, the physiotherapist assesses for and treats the physical difficulties encountered after traumatic brain injury: including vestibular rehabilitation & aquatic therapy

There are also physiotherapists present in the following services:

Parkinsons Treatment Centre

Band 6 physiotherapist (0.2 wte)

The Parkinsons Treatment Centre based in Gorseinon Hospital provides an educational course which runs for one day a week (Tuesday) over 11 weeks. The course is targeted for individuals who have recently been diagnosed with Parkinsons Disease (PD)

Functional Electrical Stimulation (FES) Service

Band 7 physiotherapist (0.2wte)

Within this regional service, provided by the Rehabilitation Engineering service, a physiotherapist contributes to a clinic which runs on one day per week. At present this service provides functional electrical stimulation to support gait.

Spasticity Service

Band 7 physiotherapist (approx 0.3 wte)

This therapist provides some input to Spasticity Clinics, contributing to clinical decision making regarding intervention and facilitating communication with local treating therapists and supporting patients to develop the skills and confidence to self-manage their spasticity. Community visits and reviews are offered following botulinum toxin injection.

2-3 physiotherapy injectors also attend clinics (employed on Honorary Contracts)

Adult Neuro-Muscular Service

A Band 7 physiotherapist (approx 0.2wte)

Therapist attends a clinic co-ordinated by Dr Walters & the Neuro-Muscular care Co-ordinator every 6 weeks, providing physiotherapy assessment and advice for patients from both AMBU & HD Health Boards. These patients may be encouraged to manage their condition, referred to the National Exercise Referral Scheme (NERS) or referred to their local physiotherapy service. Community assessment of specialist equipment is also offered.

Currently being piloted is a Co-ordinator led Charcot-Marie-Tooth (CMT) clinic, involving the care Co-ordinator, physiotherapist, orthotist and a representative from the CMT Association.

Motor Neurone Disease Clinic

Band 7 (Respiratory Specialist) therapist contributes to the MND service.

This Respiratory Physiotherapist attends a multidisciplinary MND clinic and contributes to the “general” physical assessment of these patients as well as their respiratory & ventilator needs.

Occupational Therapy

Occupational therapists assist those with long-term conditions by using their knowledge and skills in prevention and early intervention; reablement and rehabilitation; reducing the effects of a disabling environment, and enabling people's safety and independence. Occupational Therapists take a functional approach when working with individuals, helping to treat the person "as a whole" by recognising all their needs together. This promotes increased integration across health, social care and employment, resulting in cost-savings and more effective care

Workforce

Within the Neurology Services provided by the Regional Services Directorate there are 2.3 WTE Band 7 and 1 WTE Band 6 Occupational Therapists who are highly experienced in the assessment and delivery of neurological practice. These individuals are based within:

- Neurorehabilitation Unit (NRU)
- Traumatic Brain Injury Service (TBIS)

In addition there is occupational therapy input into the following:

Parkinsons Treatment Centre (Swansea)

Band 6 Occupational Therapist (0.2 wte)

The Parkinsons Treatment Centre based in Gorseinon Hospital provides an educational course which runs for one day a week (Tuesday) over 11 weeks. The course is targeted for individuals who have recently been diagnosed with Parkinsons Disease (PD)

Motor Neurone Disease Clinic

Band 6 Occupational Therapist (0.2 wte) funded by the MNDA.

Attends MDT clinic providing OT advice, liaison with community services and local teams. Expert resource for other professionals

Neuro Speech and Language Therapy-Adult Service

Speech and language therapists work with people with neurological conditions using their knowledge and skills of communication and swallowing within the context of the core multidisciplinary team, social services, palliative care and Third Sector to ensure;

Promotion and maintenance of independence, providing intervention at the appropriate time

Promotion and maintenance of an acceptable quality of life

Self management of condition working with carers, family and friends as appropriate

Facilitation of individuals choice and decision making around lifestyle and end of life issues

Provision of equipment to meet the communication needs of the patient

Speech and language therapists with specialist skills in the management of neurological conditions work in the following services in ABMU HB:

Neuro-Rehabilitation

Neurorehabilitation Unit (NRU) at Neath Port Talbot Hospital

Band 7 speech and language therapist (0.8wte)

Band 6 speech and language therapist (0.4wte)

The speech and language therapists form part of the multidisciplinary team providing intensive rehabilitation for patients who have acquired or progressive neurological conditions

Traumatic Brain Injury Service (TBIS)

Band 6 speech and language therapist (0.6wte)

The speech and language therapist assesses and provides intervention for patients following traumatic brain injury.

Parkinsons Treatment Centre

Band 6 Speech and Language Therapist (0.2 wte)

The Parkinsons Treatment Centre based in Gorseinon Hospital provides an educational course which runs for one day a week (Tuesday) over 11 weeks. The course is targeted for individuals who have recently been diagnosed with Parkinsons Disease (PD). The Speech and language Therapist is part of this multidisciplinary team managing the communication and swallowing difficulties that arise for people living with PD.

Motor Neurone Disease Clinic

Band 7 Speech and Language Therapists contribute to the MND clinics across ABMU HB.

The Speech and language Therapist is part of the multidisciplinary MND clinic and contributes to the communication, swallowing and secretion management needs of these patients.

Stroke Services

In-Patient Services:

Swansea - Band 7 (0.6wte), band 6 (1.0wte), band 5 (0.6wte)

Neath Port Talbot - Band 7 (0.3)

Bridgend - Band 6 (0.6wte) and band 5 (0.4wte)

Speech and Language Therapists assess, diagnose and provide interventions to manage difficulties with swallowing and communication at all stages of the patients pathway.

Out-patient Services for Patients with Neurological Conditions

Band 7, 6 and 5 Speech and language therapists undertake out-patient clinics across ABMU HB, receiving referrals for patients with neurological conditions such as Multiple Sclerosis, Huntington's Disease, Parkinson's Disease, Guillian Barre, MND, MSA and Stroke.

The therapists accept referrals from Consultant's, GP's and clinical nurse specialists requesting our opinion and advice in the management of swallowing and communication difficulties.

Appendix 2

Neurological Conditions Delivery Plan Stakeholder Workshop – List of attendees					
1	Hamish Laing	Medical Director	31	Julie Thomas	Senior Clinical Nurse Neurology
2	Jane Harrison	Associate Medical Director	32	Kerry Thompson	Directorate Support Officer
3	Dr Tom Lawson	Consultant Rheumatologist	33	Malcolm Turner	Finance Resource Manager
4	Carol Ross	South West Wales Neurological Alliance	34	Manisha Rickards	GP
5	Lisa Chess	S<	35	Marguerite Hill	Consultant Neurologist
6	Savvas Hadjikoutis	Consultant Neurologist	36	Sarah Harris	Neuromuscular Care Advisor
7	Alan Thomas	Patient Representative for Ataxia South Wales	37	Sharon Brown	Clinical Nurse Specialist Paediatric Epilepsy
8	Zoe Wallace	Primary Care Planning	38	Nia Wyn Davies	Clinical Psychologist in Neuropsychology
9	Suzanne Marchmant	Parkinsons Society	39	Owen Pearson	Consultant Neurologist
10	Carol Smith	MND Association	40	Paul Harry	Finance Manager
11	Tersa Humphreys	General Manager Regional Services	41	Rachael Powell	Changing for the Better Improvement Manager
12	Alison Mead	Epilepsy Nurse Specialist	42	Rebecca Pearce	MS Society
13	Amanda Aldridge	Community Independence & Wellbeing Team Manager, Bridgend	43	Richard Pawsey	Neuro Physiotherapist
14	Andrea John	Associate Directorate Manager	44	Sandra Morgan	Co Chair Population Health Group Elderly & Neurology – Hywel Dda
15	Audrey Rodgers	Assistant Director Therapies and Health Science Hywel Dda	45	Sandy Mather	Patient Representative South Wales MG Organisation
16	Bunny Pinkington	Epilepsy Wales	46	Sarah Ingham Jones	Specialty Manager Neurosciences
17	Carol Smith	MND	47	Shaheena Sadiq	Consultant Neuro radiology

18	Dr Christopher Rickards	Consultant Neurologist	48	Sharon Saunders	Epilepsy Wales
19	Dr Claire Hirst	Consultant Neurologist	49	Soren Raasch	Consultant Neurophysiologist
20	Dr David Abankwa	Consultant Neuro rehabilitation	50	Sue Learmonth	Lead Occupational Therapist
21	Dr Gareth Thomas	Consultant Paediatric Neurologist	51	Dr Sue Morgan	Consultant Palliative Care
22	Dr Ffion Thomas	Consultant Neurologist	52	Susan Sear	Stroke Patient Carer
23	Helen Bankhead	Occupational Therapist, Traumatic Brain Injury Service	53	Dr Tanya Edmonds	Consultant Neuropsychologist
24	Helen Owen	Lead Multiple Sclerosis Specialist Nurse	54	Trudi Cook	Speech & Language Therapist
25	Susan England	Senior Clinical Physiologist	55	Lydia Bowser	
26	Dr Inder Sawhney	Consultant Neurologist	56	Zoe Fisher	Clinical Psychologist in Neuropsychology
27	Hannah Davies	Specialist Speech and Language Therapist			
28	Jemma Hughes	Research & Development Manager			
29	Jenny Sanders	Associate Directorate General Manager – Women & Child Health			
30	Julie Harvey/ Kate Greenfield	Head of Paediatric Physiotherapy/Senior Physiotherapist Paediatrics			

WHSSC Neurological Conditions Delivery Plan



Agenda Item 14 -
WHSSC Neuro Deliver