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 2014-17
- 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 GP\(^1\). Around 17 people in a population of 100,000 are likely to be newly diagnosed per year with Parkinson’s disease, and two people in a population of 100,000 experience a traumatic spinal injury every year. An 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 condition\(^2\).

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 damage\(^3\).

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 (ie 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 children\(^4\). 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.

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\(^2\) Neuro Numbers, Neurological Alliance [www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf](www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf)

\(^3\) NICE Clinical Guideline CG176 Head Injury, [http://guidance.nice.org.uk/CG176](http://guidance.nice.org.uk/CG176)


* not all neurological conditions covered by this plan are contained within the list
What do we want to achieve?

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

- **Raising awareness of neurological conditions** – Increased awareness of neurological conditions and their symptoms.
- **Timely diagnosis of neurological conditions** – Neurological conditions are detected quickly, allowing timely progress to care and treatment.
- **Fast and effective care** – People with a neurological condition should receive fast, effective care and treatment.
- **Living with a neurological condition** – Whether in the community or in hospital, people, their family and carers are placed at the centre of care. Their individual needs are identified and met so they feel well supported and informed and able to manage the effects of their neurological condition.
- **Children and young people** – Children and young people with neurological conditions receive appropriate care.
- **Improving information** – Information systems to support high-quality care, clinical audit and to drive service improvement. Information available to support travel and accommodation requirements for families travelling to access specialist treatment.
- **Targeting research** – A commitment to research, delivering improved diagnosis, management, treatment options and outcomes.
2. DEVELOPMENT OF HYWEL DDA UNIVERSITY HEALTH BOARD DELIVERY PLAN FOR NEUROLOGICAL CONDITIONS

In response to the “Together for Health – A Neurological Conditions Delivery Plan” (2014), Hywel Dda University Health Board is required, together with their partners, to produce and publish a detailed local service delivery plan to identify, monitor and evaluate action needed within timescales. Hywel Dda University Health Board is required to report progress formally to its Board and publish the annual reports on their websites annually.

Development of the HDUHB plan

The Clinical Strategy of the Health Board set out service changes which have been subject to engagement, consultation and scrutiny during the Your Health: Your Future Consultation process. The Plan also reflects the challenges still ahead for many of our clinical services and which will need to be the subject of further engagement and appraisal over the coming years.

The long term objectives of the Health Board; as an integrated organisation, are:

- To systematically improve population health outcomes and patient experience
- To ensure sustainable services living within our resources and finances
- To be a values driven organisation
- To move care closer to home by moving services from acute and secondary care to community and primary care
- Ensuring that prevention strategies are at the forefront of all that is undertaken

The 3 year Integrated Medium Term Plan describes our vision to deliver these objectives and will align the Delivery Plans to these objectives. We are committed to provide high quality care as close to home as possible, from public health and prevention strategies through primary, community, and social care teams, as well as other partners, such as third and independent sectors, working together.

Population Health Programme

In September 2013 Hywel Dda University Health Board developed Population Health Groups (PHGs) led by Clinicians. The remit of these groups is to systematically improve population health outcomes and patient experience; to ensure sustainable services living within the Board’s resources and finances; and to be a values driven organisation.

The Elderly and Neurological Health Population Health Group (PHG) has a lead role in the development of the Neurological Delivery Plan on behalf of the Health Board.

A Needs Assessment was undertaken by Public Health Wales to inform the Delivery Plan (Appendix 1) on behalf of the Population Health Group.
A Stakeholder workshop including ABMU, HDUHB staff, users and stakeholders took place in September 2014, (List of Attendees Appendix 2) A further workshop with members of the West Wales Neurological Alliance was held in November 2014, (List of Attendees Appendix 3). The key priorities and recommendations discussed at the workshops have been incorporated into our delivery plan for neurological conditions.

The development of the Health Board’s Neurological Conditions Local Delivery Plan is an iterative process. It includes actions against each of the 2017 milestones within the Welsh Government’s Neurological Conditions Delivery Plan (2014).

The Population Health Programme board reports directly to the Strategy and Planning committee of the Board. The monitoring of progress of Delivery Plans sits with this committee.

Working across Health Board boundaries and with other Organisations

As ABMU host Neurological Services for Hywel Dda University Health Board as well as delivering a service for their own population, colleagues from HD attended a stakeholder workshop in the development of the ABMU plan. Key stakeholders and service providers from ABMU Health Board have also been involved in the production of the Hywel Dda University Health Board Delivery Plan. (ABMUHB Delivery Plan Appendix 4)

A joint implementation group between ABMU and HDUHB will oversee the delivery of the plan. Within Hywel Dda the Director of Acute Hospital Services will chair the Hywel Dda Neurological workstreams.

Welsh Health Specialised Services Committee (WHSSC)

WHSSC commission some specialist services on behalf of the Hywel Dda population. The delivery plan for WHSSC is attached as Appendix 5.

The Foundations 4 Change Programme

As a Health Board we are now building on the robust and fundamental pledges made to improve the health of the population by developing the Hywel Dda University Health Board Foundations 4 Change Programme. The aim is to ensure that Hywel Dda delivers a world class healthcare system of the highest quality with improved outcomes for its population. Through the Foundations 4 Change programme, County teams are engaging with their populations in designing and delivering a plan which reflect the needs of the local population, which will interface with the Delivery Plan. The Health Board county teams are focussing on seven outcomes. Two of these are ‘core outcomes’ - Health Inequalities and Life Expectancy. The
remaining five outcomes were selected by the County teams themselves, using all available data sources, both the facts and figures about the population, and also reflecting on local people’s actual experiences. County teams have selected the following outcomes:

<table>
<thead>
<tr>
<th>Carmarthenshire</th>
<th>Ceredigion</th>
<th>Pembrokeshire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Expectancy</td>
<td>Life Expectancy</td>
<td>Life Expectancy</td>
</tr>
<tr>
<td>Health Inequalities</td>
<td>Health Inequalities</td>
<td>Health Inequalities</td>
</tr>
<tr>
<td>Immunisations and vaccinations</td>
<td>Immunisations and vaccinations</td>
<td>Immunisations and vaccinations</td>
</tr>
<tr>
<td>Obesity/overweight</td>
<td>Alcohol misuse</td>
<td>Obesity/overweight</td>
</tr>
<tr>
<td>Dependent Behaviours (Smoking, Alcohol, Drug Abuse)</td>
<td>Improve the outcomes for patients following a stroke</td>
<td>Alcohol</td>
</tr>
<tr>
<td>End of Life Care</td>
<td>Inappropriate admissions</td>
<td>Frailty</td>
</tr>
<tr>
<td>Frailty</td>
<td>People dying in their place of preference</td>
<td>Smoking</td>
</tr>
</tbody>
</table>

The programme also gives Counties a chance to focus on addressing the unique challenges that rurality brings in Hywel Dda and will inform the Locality Development plans with GP Clusters.
3. ORGANISATIONAL PROFILE

Overview of Organisation, Local Health Need and Challenges to neurological services

Hywel Dda University Health Board was established in 2009 as an integrated Health Board and received University Health Board status in 2013. The organisation is responsible for the planning and delivery of a wide range of primary, community, mental health and secondary care health services for the populations of Pembrokeshire, Carmarthenshire and Ceredigion, being coterminous with these Local Authorities.

Hywel Dda University Health Board covers a quarter of the landmass of Wales and is one of the most sparsely populated health board areas. The resident population of the Health Board is currently in excess of 375,200.

With 13 per cent of Wales’ population the area’s age profile is similar to that of the Country as a whole. There are, however, notable differences with fewer people aged 25-44 and more people aged 55-79. In rural Pembrokeshire and Ceredigion, there are relatively high numbers of older people.
Current population projections see a rise in the older population [75 years and over] from 35,000 [10% of the total population] in 2006 to 70,000 [16% of the total population] in 2031. These estimates are based on assumptions about births, deaths and migration.

The increase in the number of older people is likely to lead to a rise in neurological conditions such as Parkinson’s disease as well as circulatory and respiratory diseases and cancers. Meeting the needs of these individuals will be a key challenge for the Health Board and its local authority partners.

**Deprivation**

The Health Board serves a diverse range of population groups with different health needs and sizeable inequities in health within and between localities. Service planning and delivery also has to take account of a mix across rural and urban areas.

There are areas of deprivation, including parts of Llanelli, Pembroke Dock and Cardigan. Around 10 per cent of Lower Super Output Areas [LSOAs] are among the most deprived fifth in Wales with 5 per cent in the least deprived fifth. However, within less deprived areas there are often pockets of hidden deprivation.

Understanding the relationship between significant disability, poverty and housing, West Wales is a challenging area to live in for people who experience disability as a result of their neurological condition.
Neurological conditions are the most common cause of serious disability and have a major, but often unrecognised, impact on health, social services and on people’s lives.

1% of the UK population are newly diagnosed with a neurological condition each year approx in Hywel Dda that means 3,839 people

10% of visits to Accident and Emergency Departments are for a neurological problem

7% of GP consultations are for neurological symptoms

19% of hospital admissions are for a neurological problem (Mostly stroke, epilepsy, dementia, headache, Head Injury & MS)

25% of people aged between 16 and 64 with chronic disability have a neurological condition

33% of disabled people living in residential care have a neurological condition
Hywel Dda University Health Board provides a hospital and community based services to its resident population. The vast majority of health and care needs are met in local communities by Primary Care and Community services. This is provided by GP Practices, Dental Practices, Optometry Practices and Community Pharmacies. Primary and Community service delivery has been aligned to seven geographical localities within Hywel Dda to provide a locality partnership network of health, social and 3rd sector services that deliver a bespoke service based on agreed pathways that meet the needs of the local population. Clusters of GP practices and integrated teams of health, social care, independent and 3rd sector professionals will be central to delivery of services for these populations.

Acute medical inpatient care and generic rehabilitation services are provided from four District General Hospitals with support of community hospitals, with a neurological service provided by Abertawe Bro Morgannwg University Health Board. This network approach to care delivery reflects the recommendations of the Steers review (2008) and the Mid and South Wales Implementation programme recommendations (2009).

The table below highlights the location of the four main acute hospitals, Bronglais (BGH) in Ceredigion, Withybush (WBH) in Pembrokeshire, Glangwili General (GGH) and Prince Phillip (PPH) in Carmarthenshire. It also demonstrates the travel times to the secondary and specialist neurology service.
Hywel Dda University Health Board identifies the delivery of effective neurological services as a core feature in improving the health of the population. However, the geography of the Health Board’s catchment area, as shown above, identifies a significant challenge with access to specialist neurological inpatient and day services and neuro-rehabilitation being hosted within ABMU. The diagram demonstrates the drive-time boundaries for the majority of the population and highlights the challenge for people who may access a specialist service from a hospital in ABMU.
Alongside the medical management and neurology beds available, a range of additional services are delivered or commissioned via ABMU for Hywel Dda residents are:

- Neuro psychology
- Neuro Inflammatory Team
- Neuromuscular Coordinator
- MND network
- Palliative care
- Core therapy & District Nursing services & Specialist service in Carmarthenshire
- Tissue Viability / Continuing Care
- HOPE
- Botox

Specialist Neurological services are also commissioned through Welsh Health Specialised Services Committee (WHSSC) for the population of Hywel Dda are:

- Neuro rehab
- Posture and mobility
- Neurosurgery
- neuropsychiatry
- Spinal injuries
- Paediatric neurology
Neurology activity undertaken within HDU Health Board

The PEDW data shows that a large number of patients are admitted to district general hospitals within Hywel Dda with a primary diagnosis of a neurological disease. These patients predominantly remain under the care of a Consultant Physician or Consultant Geriatrician and rarely have access to a Consultant Neurologist opinion. Hywel Dda residents with a neurological condition admitted to ABMU and other Welsh and English Trusts are demonstrated in the table below.

The admissions shown below are codes G00 – G99.

All IP Activity re G Codes

<table>
<thead>
<tr>
<th></th>
<th>10/11</th>
<th>11/12</th>
<th>12/13</th>
<th>13/14</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of discharges</td>
<td>1,162</td>
<td>1,176</td>
<td>1,116</td>
<td>1,042</td>
</tr>
<tr>
<td>Total number of bed days</td>
<td>37,153</td>
<td>11,861</td>
<td>13,866</td>
<td>11,888</td>
</tr>
<tr>
<td>Average LoS (days)</td>
<td>32.0</td>
<td>10.1</td>
<td>12.4</td>
<td>11.4</td>
</tr>
</tbody>
</table>

In order to understand the detail regarding need for service redesign the detail of admission patterns by condition has been reviewed. It should be noted that not all admissions that would generate a need for specialist services and neuro rehabilitation are captured i.e. brain injury and spinal injury codes.

In addition G codes include those people admitted for a day procedure of carpal tunnel syndrome, admissions to Older Adult Mental Health Wards with Alzheimer’s disease as well as neuropathies and inflammatory diseases that are managed as part of general medicine. Consequently a more detailed analysis has been undertaken which excludes:

G00-G09 Inflammatory diseases of the central nervous system
G30-G32 Other degenerative diseases of the nervous system
G50-G59 Nerve, nerve root and plexus disorders
G60-G64 Polyneuropathies and other disorders of the peripheral nervous system

Inpatient Admissions

<table>
<thead>
<tr>
<th>Provider</th>
<th>Admissions</th>
<th>Bed Days</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10/11</td>
<td>11/12</td>
</tr>
<tr>
<td>HD</td>
<td>917</td>
<td>984</td>
</tr>
<tr>
<td>ABMU</td>
<td>87</td>
<td>62</td>
</tr>
<tr>
<td>Other Welsh HB</td>
<td>48</td>
<td>61</td>
</tr>
<tr>
<td>English Trusts</td>
<td>27</td>
<td>32</td>
</tr>
</tbody>
</table>

Out Patients

Out patient neurology services are commissioned by Hywel Dda UHB and are delivered by ABM UHB through a mix of clinics held in ABMU and satellite
Clinics delivered by 3 visiting neurologists held at Prince Philip and Glangwili General Hospitals. As out patient attendances are not recorded electronically to include diagnostic code, the information regarding people with a neurological condition attending outpatients to see e.g. a physician, are not currently available. Out patient clinics that are designated as Parkinson’s disease and movement disorder have been included, but are served by geriatricians rather than neurologists.

<table>
<thead>
<tr>
<th>Provider</th>
<th>New Patients</th>
<th>Follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10/11</td>
<td>11/12</td>
</tr>
<tr>
<td>HD (incl Medinet)</td>
<td>247</td>
<td>66</td>
</tr>
<tr>
<td>ABMU</td>
<td>308</td>
<td>261</td>
</tr>
<tr>
<td>ABMU Satellite</td>
<td>824</td>
<td>667</td>
</tr>
<tr>
<td>Other Welsh HB</td>
<td>62</td>
<td>71</td>
</tr>
<tr>
<td>English Trusts</td>
<td>5</td>
<td>38</td>
</tr>
</tbody>
</table>

**Day Cases**

<table>
<thead>
<tr>
<th>Provider</th>
<th>10/11</th>
<th>11/12</th>
<th>12/13</th>
<th>13/14</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD</td>
<td>36</td>
<td>54</td>
<td>100</td>
<td>109</td>
</tr>
<tr>
<td>ABMU</td>
<td>100</td>
<td>125</td>
<td>176</td>
<td>224</td>
</tr>
<tr>
<td>(incl 33 re MS)</td>
<td></td>
<td></td>
<td>(incl 59 re MS)</td>
<td></td>
</tr>
<tr>
<td>Other Welsh HB</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>English Trusts</td>
<td>12</td>
<td>16</td>
<td>14</td>
<td>27</td>
</tr>
</tbody>
</table>

**Primary Care Data**

The paucity of available primary care data for the purposes of this report either by GP practice or GP cluster area has meant that it is not possible to provide a robust picture of the localised spread of neurological conditions in the Hywel Dda area. It has not been possible to access data from those practices signed up to the SAIL [Secure Anonymised Information Linkage] system at this time and this is noted as a gap that needs to be addressed as a matter of urgency.

**Condition Specific demand (work in progress)**

**Muscular Sclerosis**

The distribution of MS around the world is uneven. Generally, the prevalence increases as you travel further north or south from the equator. Those parts of Asia, Africa and America that lie on the equator have extremely low levels of MS, whilst Canada and Scotland have particularly high rates.

The UK average prevalence is reported to be 166 per 100,000 total population by the Neurological Alliance [2014]. Based on the known case load of the...
Neuro Inflammatory Service hosted by ABMU, the number of people living in Hywel Dda catchment is 679. This is an incidence of 181 per 100,000 and is higher than the national average. Anecdotally staff describe some people accessing the service for the 1st time with symptoms having been in place for some time. There are approximately 36 new cases per year.

People with MS in Hywel Dda access the South West Wales Regional MS (Neuro Inflammatory) Team. Please see description in attached ABMU Delivery Plan. But may also be admitted to any of the 4 general hospitals in HD under the care of a physician or geriatrician when they have an exacerbation of the disease.

2 of the MS nurses from the Neuro Inflammatory Team serve HDUHB, delivering Nurse Led and joint MS Specialist Nurse / Clinical Specialist Physio outreach clinics in:

- Bronglais
- Aberaeron
- Glangwili
- Withybush
- South Pembs
- Tenby Cottage Hospital

Dr Owen Pearson, Consultant Neurologist holds a weekly Relapse clinic in Morriston Hospital where patients can be seen quickly.

**Parkinson’s disease**

The population estimate within Hywel Dda is 723, however 873 people with Parkinson’s disease are known to our 2.8wte Specialist nurses, (this does include patients from part of Gwynedd and Powys). The incidence of Parkinson’s disease is age related so the increase in line with population projections.

80% of people with Parkinson’s disease will develop dementia or experience cognitive decline. Should specialist support be needed, people are referred to the local memory service.

The majority of people with Parkinson’s disease are referred to one of 4 geriatricians in HD. 2013-14 79 people were newly referred to local Parkinson’s disease clinics. The Annual attendance at specialist clinics within Hywel Dda was 904. People who are admitted for a primary diagnosis of Parkinson’s disease are most likely to be admitted to a medical bed in HD, with 36 admissions last year.

**Epilepsy**

There are 2,934 adults with Epilepsy registered on GP registers within Hywel Dda. The population estimate for Hywel Dda is 3,723 (Neuro Alliance). Hywel
Dda UHB is on the Wales average of 0.7% of patients per practice with epilepsy. This data can be broken down further by GP Cluster area and shows that higher than average percentages are seen in the Amman/Gwendraeth and Llanelli areas.

It is recognised that 70% of people with a diagnosis of Epilepsy can remain symptom free if well managed.

- One of the visiting neurologists holds a “1st fit clinic” on a weekly basis at Glangwili General Hospital.
- A Sapphire Adult Epilepsy nurse – 1 wte was appointed within 2014.
- For the period 2013–14 there were 215 admissions coded as being due to epilepsy.

**Headaches**

Evidence suggests that headaches account for 15 – 20% of out-patient neurology referrals. A review of the top 20 causes of admission for people under 65 in HD includes headaches, with 220 admissions 2013-14.

**Motor Neurone Disease**

There are 39 people known to have a diagnosis of Motor Neurone Diseases, whilst the prevalence data suggests an incidence of 26, so current incidence is high. People with MND access specialist MND multidisciplinary review clinics led by a visiting neurologist. Support services are provided via a mix of generic community and palliative care teams. People with MND have a high incidence of hospital admissions, with an average of 28 admissions per yr to both acute hospitals in HD and neurology beds in Morriston DGH.

**Rare Diseases**

A rare disease is a life-threatening or chronically debilitating disease that affects less than 5 in 10,000 and requires special, combined efforts to enable patients to be treated effectively. There are between 5,000 and 8,000 identified rare diseases.

- 1 in 17 people will be affected by a rare disease at some point in their life. ([European Council](#))
- This amounts to approximately 3.5 million people in the UK.
- 75% of rare diseases affect children and 30% of rare disease patients will die before their 5th birthday. ([EURORDIS](#)).
- There are over 6,000 recognised rare diseases.
- Collectively rare diseases are not rare.

**Brief summary of local issues and challenges**

This plan has demonstrated the burden of neurological disease in the Hywel Dda University Health Board area in terms of prevalence of disease and the volume of inpatient and outpatient utilisation. Epilepsy contributes to a high
burden of neurological disease in terms of numbers, but whilst other neurological diseases such as motor neurone disease, multiple sclerosis or cerebral palsy may be lower in number there can be a high level of health care need associated with these conditions.

Key issues identified during the process of developing the delivery plan:

- Clarity on operational lead for neurological services within Hywel Dda University Health Board
- No dedicated inpatient neurological beds within the HB area and issues relating to accessibility of beds within Abertawe Bro Morgannwg Health Board
- Access to neurology opinion – GP, In-patient, Out-patient, Rapid access
- The increasing demands upon Consultant Neurologists time and workload over the last 3 years and the need to review capacity in order to deliver against need.
- The low numbers of specialist nurse support for a number of key neurological conditions.
- The challenges of accessing timely and high quality data particularly in relation to primary care in order to make commissioning decisions
- The timely access and reporting of diagnostics.
- Access to Neuropsychological support
- Issues of rurality and effect on Transport infrastructure, travel and accommodation information to support patients and families in accessing specialist services.
- Housing adaptations and suitable accommodation to meet long term needs.
4. SUMMARY OF THE PLAN - THE PRIORITIES FOR 2014 - 17

The attached Delivery Plan sets out the detailed actions required to address the requirements of this Neurological delivery plan over the next 3 years. These actions have been compiled following the workshops held in September and November with Stakeholders.

4.1 Raising awareness of neurological conditions

Our key challenges are:

As Specialist Neurological services have always been provided via other health organisations (currently ABMU and other specialist centres) to the population of Hywel Dda UHB, clinical leadership in the specialty has been poorly defined. With this backdrop, there has been no focused approach to developing the knowledge and skill of the workforce regarding neurological conditions and its impact on the individual and their family i.e. an ad-hoc approach only.

The rurality of our Health Board leads to small teams being distributed across the three counties who may have an insular approach to care delivery. This increases the likelihood of variation in the nature and content of services available.

Our priorities for 2014 – 17 are:

- To improve the knowledge and skill of staff involved in the management of people with neurological conditions.
- Ensure relevant health professionals recognise the importance of supporting individuals and families on diagnosis and have knowledge of the impact of neurological conditions.
- Signpost existing sources of information, advice and support to improve quality of life, self management and promote independent living for service users.

4.2 Timely diagnosis of neurological conditions

Our key challenges are:

As Specialist Neurological services have always been provided via other health organisations (currently ABMU and other specialist centres) to the population of Hywel Dda UHB, currently there is not a robust system of accessing specialist advice by telephone or email to support clinical decision making in Primary and Secondary care.

The natural development of local diagnostic services that wrap around neurology has not been developed in a systematic way in the Health Board, nor has information about service development and change.
Our priorities for 2014 – 17 are:

- Review protocols of direct access to CT / MRI for GPs
- Review and clarify the Specification of services currently delivered and hosted by ABMU
- Establish a reliable and sustainable working model that complies with national standards in order to improve access to Neurologists, Neuro radiology and Specialist nurses and therapists required to provide the model of care delivery for HD
- Map pathway and services
- Use GP protected learning time / GP forums to raise awareness of Neuro conditions and Pathway / Resources available / and referral pathways.

### 4.3 Fast and effective care

Our key challenges are:

Ability to 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 in the context of visiting neurologists only to Hywel Dda Health Board sites. Acute hospital beds supported by neurologists are available to residents of Hywel Dda at Morriston Hospital, but the numbers are very limited.

As some of the specialist service provision is commissioned by WHSSC there can be delays in achieving access to the appropriate service.

Our priorities for 2014 – 17 are:

- Reduce Out Patient waiting times to access a Neurologist opinion
- Provision of timely, equitable access to inpatient neurological assessment and neuro radiology within Hywel Dda for people admitted with a neurological condition.
- Review current pathways, against standards and guidelines.
- Streamline transition to other services: palliative care, Paediatrics to Adult care.

### 4.4 Living with a neurological condition

Our key challenges are:

People with neurological conditions living in Hywel Dda access services from a mix of primary care, community and general medical services as well as neurology services hosted by ABMU and tertiary services commissioned by WHSSC. Services are organised by medical condition, function and/or locality, with service development and change frequently being considered autonomously within the service or team. In addition Hywel Dda has different
partnership working arrangements with Local Authority in each of the 3 counties as the organisational structure and working arrangements are not aligned.

Travel times are significant, not just due to distance but also poor roads. There is limited public transport and housing stock in some areas does not readily address the needs of people with disability.

Our priorities for 2014 – 17 are:

- Review and revise clinical/care pathways in order to deliver well co-ordinated care that feels integrated from a user perspective
- Establish structured community Neuro Rehabilitation in Hywel Dda to compliment commissioned neurological as well as local generic services.
- Strengthen partnership working between
  - Regional and local services
  - Statutory and 3rd sector organisations
  - Clinical and user groups

4.5 Children and young people

Our key challenges are:

- Health boards to review progress against the *All Wales Neurosciences Standards for Children and Young People’s Specialised Healthcare Services* 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 *All Wales Neurosciences Standards for Children and Young People’s Specialised Healthcare Services*
- 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.

Our priorities for 2014 – 17 are:

- To be advised by Director of Child and Adolescent Health

4.6 Improving information

Our key challenges are:

As Specialist Neurological services have always been provided via other health organisations (currently ABMU and other specialist centres) to the population of Hywel Dda UHB, an integrated approach to audit and peer review is needed. In addition, Hywel Dda UHB has focused on systems of information sharing between primary care, health board and social care rather
than the less frequent need to share personalised care plans between health boards delivering different aspects of care to a single patient.

Discussions are underway between Hywel Dda UHB and West Wales Neurological Alliance to redefine the working partnership in order to enable the health board to proactively seek insight into service user experience and views. It is acknowledged that variation in user experience and insight may be a consequence of where they live, the team(s) they access, their neurological condition, needs and expectations.

Our priorities for 2014 – 17 are:
- Interface between information systems (access to timely information regarding plan of care)
- Strengthen partnership working with the West Wales Neurological Alliance/service users
- Establish robust communication with neurological/specialist services regarding clinical practice and outcomes

4.7 Improving Research

Our key challenges are: Aligned with ABMU Delivery Plan

Our priorities for 2014 – 17 are:
- To work with ABMU as lead organisation for this section.
5.0 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.

The Hywel Dda University Health Board’s delivery plans and their milestones will be reviewed and updated annually.
### Theme 1 - Raising awareness of neurological conditions

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<thead>
<tr>
<th>Priority</th>
<th>Actions</th>
<th>Expected outcome</th>
<th>Risks to delivery</th>
<th>Timescales</th>
<th>Lead</th>
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<tbody>
<tr>
<td>1.1 Work with a broad range of partners (including local service boards, educational institutions and the third sector) to:</td>
<td>Improve range of information available and access to a multimedia approach - Working in tandem with ABMU including participation in ‘Raising Awareness project Group’ regarding raising awareness. - Establish a HDUHB workstream to support local implementation. - Work in partnership with Neurological alliance and user groups. - Align communication with Public Information Delivery Plan within Health Board</td>
<td>To improve timeliness of referral to specialist neurological services. To raise public awareness of the impact of neurological conditions and network support services.</td>
<td>Rurality Dependency on ABMU implementation of relevant actions.</td>
<td>Group established in November 2014 Outline programme of work confirmed Year 1 (Qtr 1)</td>
<td>Service Manager / Medicine Service Manager Community</td>
</tr>
<tr>
<td>1.1.1 Raise Awareness of neurological conditions</td>
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<tr>
<td>1.1.2 Signpost existing sources of information, advice and support</td>
<td>Continue to develop the intranet website currently being developed by neurology for patients, carers and clinicians to access To provide: - information/links to ABMU/HDUHB services - clear information on referral criteria - links to LA (CRT), 3rd Sector, other community services and activities - information on community services for</td>
<td>Clinicians can also be kept up-to-date and will have a central place to access information for patients/families.</td>
<td>Maintaining accuracy of information Dependency on ABMU implementation of relevant actions. Effective</td>
<td>Year 2</td>
<td>Service Manager / Medicine</td>
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<tr>
<td></td>
<td>sensory impairments.</td>
<td>Clinicians can direct patients and carers to one central place for ‘up-to-date’ information.</td>
<td>communication</td>
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<tr>
<td>1.2 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</td>
<td>Deliver a partnership approach between secondary care neurological teams (predominantly hosted by ABMU) and patient organisations and 3\textsuperscript{rd} sector to deliver training and education. Specialist nurses to develop a programme of education on an annual basis.</td>
<td>To improve clinical management</td>
<td>Rurality, Capacity of staff, Availability of neurologists to deliver training, Host organisations releasing staff to attend</td>
<td>Year 1</td>
<td>Raising Awareness workstream lead / Service Manager, Ass Director of Nursing.</td>
</tr>
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</table>
### Theme 1 - Raising awareness of neurological conditions

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<tr>
<td><strong>1.3 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</strong></td>
<td>• Map current knowledge &amp; skills of local staff regarding supporting people to understand initial diagnosis and the impact of neurological conditions.&lt;br&gt;• Work with service user and carers to identify good practice and priorities for service improvement, utilising a range of patient experience strategies.&lt;br&gt;• Incorporate training re best practice into education, training and service delivery as described above.</td>
<td>Improve patient &amp; family experience</td>
<td>Rurality&lt;br&gt;Capacity of staff&lt;br&gt;Availability of relevant trainers to deliver training.&lt;br&gt;Host organisations releasing staff to attend</td>
<td>To be confirmed</td>
<td>Raising Awareness workstream lead / Service Manager&lt;br&gt;Patient Experience Psychology</td>
</tr>
<tr>
<td><strong>1.4 Public Health Wales, in partnership with health boards, to deliver a national awareness campaign through community pharmacies in Wales</strong></td>
<td>HDUHB Health Board will participate fully in the national awareness campaign being developed through community Pharmacies.&lt;br&gt;Local action plan will be developed in line with national campaign requirements.</td>
<td>Raise public awareness</td>
<td>To be confirmed</td>
<td>To be confirmed</td>
<td>Public Health&lt;br&gt;Primary care Pharmacy Lead</td>
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## Theme 2 - Timely diagnosis of neurological conditions

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<tr>
<td>2.1. 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</td>
<td>Review protocols of direct access to CT/MRI for GPs.</td>
<td>Reduce risk through improved diagnosis</td>
<td>Waiting Times, Access out of hours, Capacity</td>
<td>Year 1</td>
<td>Service Manager / Radiology</td>
</tr>
<tr>
<td>2.2. 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</td>
<td>Develop a clear system of working with GPs and Consultant Neurologists to outline parameters of guidance protocols for Telephone, email advice.</td>
<td>Improved access to advice, Released capacity in clinics to see urgent patients, Improved referrer knowledge, reduction in attendances to hospital</td>
<td>Measuring impact and success</td>
<td>Year 1</td>
<td>Primary Care Lead / Service Lead ABMU</td>
</tr>
<tr>
<td>2.3. Ensure timely access to multidisciplinary assessment to support diagnosis where necessary</td>
<td>Review access, scope, effectiveness, capacity and waiting times for diagnostic clinical services. This will include:  - Neurophysiology  - Neuropsychology  - Neuroradiology working in partnership with ABMU. Restructure to reflect the</td>
<td>Improve appropriate access to diagnostic support services and will impact on the effectiveness and speed of diagnosis as well as appropriate care planning.</td>
<td>Wide geographic patch, Different medical teams supporting the service, Waiting times, Capacity</td>
<td>Year 2</td>
<td>Service Manager / relevant Clinical Leads HD &amp; ABMU</td>
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### Theme 2 - Timely diagnosis of neurological conditions

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<td></td>
<td>Timely diagnosis of neurological conditions</td>
<td>Improve timeliness of referral to neurologist as well as primary care management of simple presentation e.g. headache pathway</td>
<td>Capacity: Frequency of primary care exposure to e.g. individual rare diseases.</td>
<td>Year 1-3</td>
<td>Raising Awareness Project Group (Primary Care Lead with Consultant lead)</td>
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<tr>
<td>2.4. 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</td>
<td>In partnership with ABMU: • Incorporate update neurology training into Protected time to Learn (PT4L) sessions/Study Days in primary care • Review and update current referral protocols/pathways • Agree a sustainable approach to audit of pathways</td>
<td>Improve timeliness of referral to neurologist as well as primary care management of simple presentation e.g. headache pathway</td>
<td>Capacity: Frequency of primary care exposure to e.g. individual rare diseases.</td>
<td>Year 1-3</td>
<td>Raising Awareness Project Group (Primary Care Lead with Consultant lead)</td>
</tr>
<tr>
<td>2.5. Provide specialist advice within 24 hours (on a seven-day-a-week basis) for those admitted to hospital with a primary or suspected</td>
<td>All neurologists serving Hywel Dda are employed by ABMU as host HB. Consequently: • Review, clarify and established agreement regarding HB neurology admissions to ABMU • Explore potential for telemedicine</td>
<td>Improve diagnosis and clinical management</td>
<td>Environmental capacity to cluster beds</td>
<td>Year 2/3</td>
<td>Service Manager Medicine / HD Lead Consultant Neurologist / Telemedicine Manager</td>
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Hywel Dda University Health Board  
Neurological Delivery Plan – January 2015 Version 2
### Theme 2 - Timely diagnosis of neurological conditions

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| neurological condition - reorganising delivery of services to achieve this where necessary | links to neurologist  
- May require acute hospital beds in HD to be grouped on 1 site for people with neurological conditions. Beds to be supported by 7 day access to a visiting neurologist  
Clarify the scope of the recommendation regarding neurological condition i.e. a number of conditions that are coded as neurological are appropriately managed within other specialties e.g. Alzheimer’s Disease, carpel tunnel syndrome | | | | |
| 2.6. Provide rapid access to urgent outpatient services with specialist clinical expertise for referrals to meet GP and patient need | Build on the established model regarding 1<sup>st</sup> fit clinic based on a review of need | Timely access  
Potential admission prevention | Accessibility to Clinic as held in GGH only within HD | Year 1 | Service Manager Medicine HD / ABMU |
| 2.7. Ensure follow-up arrangements for patients are appropriate and timely | Follow-up arrangements to be considered in the context of the review of neurological services | Improved management for people with long term neurological conditions | Capacity  
Skill mix / poorly defined pathway  
Effectiveness of pathway | Year 2 | Service Manager Medicine HD / ABMU |
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</table>
| 2.8. | **Time is created within existing job plans to achieve the above initiatives** | Increase Capacity to see patients within existing resources (Prudent Healthcare Principles) by:  
- Reviewing all Out patient clinics held on HD hospital sites by visiting consultants and use of Medinet.  
- Validate lists, clinical priorities and Follow Up Not Booked appointments.  
- Review job plan of Visiting Consultants. | See patients in a more timely manner  
Reduce risks | Capacity to review data  
Determine resources following review. | Year 1 | Neurology Clinical Team / Service Manager Medicine HD |
### Theme 3 - Fast and effective care

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<tr>
<td>3.1. 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</td>
<td>Work with ABMU to undertake a comprehensive baseline review of access to <strong>neurology</strong> identifying priority gaps in service. Review should include: • Routine consultant access for people admitted to HD acute hospitals with a primary diagnosis of neurological condition. • Effective diagnostic support • Potential scope of use of telemedicine for assessment of acute inpatients. • Therapy support requirements • Access to specialist neurological beds and ambulatory care unit. • The role of inpatient liaison • Urgent consultation and sub specialty demands. • Out of hours To improve reliable access to <strong>neurosurgery</strong>, work with: • Neurosciences Network • WHSSC • WG Neurological Delivery Plan Implementation Group to address Review arrangements regarding repatriation to ensure that patients are transferred to an appropriate and suitable ward.</td>
<td>Understand baseline review. Inform priorities and improvement plan See priority patients in a more timely reduce risk reduction in LoS from early intervention by neurology specialist team</td>
<td>Time to undertake review Financial Workforce</td>
<td>Year 1</td>
<td>HD Service management Medicine Team ABMU Neurosciences Network WHSSC WG NDPIG</td>
</tr>
<tr>
<td>3.2. Review, plan and deliver evidence-based and timely</td>
<td>• Review the local adoption of regional neurological pathways • Complete a training needs analysis based on the</td>
<td>Improve timeliness of accessing fast and effective care</td>
<td>Capacity Financial</td>
<td>Year 1/2</td>
<td>Service Manager Medicine / ABMU</td>
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### Theme 3 - Fast and effective care

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</table>
| **treatment, in line with latest evidence, standards and guidance** | review  
• Identify outstanding pathway development needs, working in partnership with ABMU to develop and implement. |  |  |  |  |
| **3.3. Ensure patients with complex needs have appropriate, timely and co-ordinated access to other specialist services as appropriate** | For people with complex needs:-  
• Develop a virtual team approach to delivering care  
• Adopt a reliable system of care co-ordination  
• Strengthen interface with tertiary specialist neurological services including outcome focused reporting | Specialist services are available as required | Capacity  
Financial implications | Year 2 | Service manager  
medicine / Community / ABMU / WHSSC |
| **3.4. 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** | Network approach with ABMU in to maintain best practice approach to neurological care | Effective outcomes | Financial | Ongoing | Service manager  
medicine / Community / ABMU / WHSSC |
| **3.5. Co-ordinate effective transfer of care and timely repatriation of** | • Review arrangements regarding repatriation to ensure that patients are transferred to an appropriate and suitable ward. | Assure access to specialist beds and advice  
Access to beds Communication arrangements |  | Year 1 on-going | Clinical Team / ABMU / Cardiff & Vale UHB |
### Theme 3 - Fast and effective care

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<tbody>
<tr>
<td><strong>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</strong></td>
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| **3.6. Ensure that services are organised in a manner that will allow a seamless transfer of care from paediatric to adult services** | A structured and reliable approach to transition including:  
- Incorporating self-management skills into the plan of care for adolescents who have on-going needs whenever possible.  
- Patient and carers to understand the nature of their neurological condition.  
- Information summary to be available to primary care and appropriate adult services should care be transferred. | Improved transition | Engagement | Year 1 on-going | Child and Adolescent Clinical Team HD / ABMU |
| **3.7. For patients who need it, ensure effective transition to appropriate palliative and end of life care, in line with the Delivering End of Life Care Plan.** | Review current practice regarding those people who are at end of life being supported to establish an advanced care directive.  
- Adopt a structured shared care approach for people that require skilled neurological end of life intervention.  
- Relevant neurological pathways to include transfer to palliative care and end of life pathway. | Improved end of life care and support to patient and family  
Increase use of Advanced Care Directive as part of care plan for | Training needs | Year 1 and On-going | Service manager medicine / Community / ABMU / WHSSC |
### Theme 3 - Fast and effective care

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<tbody>
<tr>
<td>3.8. Develop and implement a Patient Reported Outcome Measures (PROMS) questionnaire for patients with neurological conditions</td>
<td>Work in partnership with ABMU to evaluate validated PROMS questionnaires and agree approach for Neurology. To implement the agreed proms questionnaire within neurology. To use the outcome of the PROMS to improve the quality of care delivered.</td>
<td>Improve quality of care</td>
<td>technology central support</td>
<td>2015, 2016, 2017</td>
<td>Service manager medicine / Community / ABMU / WHSSC</td>
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### Theme 4 - Living with a neurological condition

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</table>
| 4.1.     | 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:  
- 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  
  - Review care pathways in order to ensure that appropriate community follow up is provided as a feature of on going care and support. This will involve joint working between ABMU hosted services, community and primary care in Hywel Dda.  
  - Systematically review of prescription compliance in the context of evidence based guidance, including opportunities to improve self management  
  - Develop a comprehensive structured and reliable community neuro rehabilitation service, aligned with specialist services hosted by ABMU as well as Cardiff and Vale.  
  - Continue to work in partnership with posture and mobility services.  
  - Operating within the WHSSC/neurology implementation network, establish a system of service reporting to ensure equity of prescription and access to services hosted by Betsi and Cardiff and Vale. | Improve quality of life, self management and independent living                                    | Rurality          | Year 1.2 and 3   | Hywel Dda / ABMU          |
|          |                                                                                                                                                                                                          |                                                                                                   | Capacity          |                  | Medical and Pharmacy leads |
|          |                                                                                                                                                                                                          |                                                                                                   |                   |                  | County Directors HD/ ABMU  |
### Theme 4 - Living with a neurological condition

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<td><strong>minimise ill health</strong></td>
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<td><strong>4.2. 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</strong></td>
<td>To adopt a partnership approach between ABMU hosted services, HDUHB acute hospital, community and primary care to embed needs and preferences into an integrated assessment and care planning process. Continue working in partnership with local Social Care and Housing teams, Third Sector and transport services to achieve an integrated and cohesive approach to support and service delivery for people with neurological conditions and their carers</td>
<td>Improve quality of life, self management and independent living</td>
<td>Partnership priorities</td>
<td>Year 2</td>
<td>HD Neurology workstream</td>
</tr>
<tr>
<td><strong>4.3. Make arrangements to ensure that information in the care plan or GP letter is available both to the patient and recorded on clinical information</strong></td>
<td>Incorporate into local information sharing strategy</td>
<td>Improvement in communication and care coordination</td>
<td>IT Strategy and timescales</td>
<td>Year 2 / 3</td>
<td>HD Neurology workstream</td>
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### Theme 4 - Living with a neurological condition

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<tbody>
<tr>
<td>4.4. Provide access to expert patient and carer programmes when required</td>
<td>Work in partnership with Third Sector organisations to strengthen and expand on current programmes available.</td>
<td>Improve quality of life, self management and independent living</td>
<td>Capacity</td>
<td>Year 2</td>
<td>Ass Director of Partnerships / Chronic Condition lead HD</td>
</tr>
<tr>
<td>4.5. Work proactively with third sector services and provide effective signposting to information and support, enabling patients to easily access support services</td>
<td>Develop reliable working partnership with Neurological Alliance and other 3rd Sector services.</td>
<td>Improve quality of life, self management and independent living</td>
<td>IT support / Financial</td>
<td>Ongoing</td>
<td>Director of Partnerships / PHG</td>
</tr>
<tr>
<td>4.6. Develop a project to explore the development of co-produced neuroscience services</td>
<td>Negotiate a partnership working relationship with Neurological Alliance, Voluntary organisations and service users to develop a shared approach</td>
<td>Service that meets the need of people with neurological condition</td>
<td>Ability and resources to sustain engagement / Rurality</td>
<td>Year 1</td>
<td>Director of Acute Hospital Services HD / PHG</td>
</tr>
<tr>
<td>4.7. Review the evidence base and current provision of hydrotherapy across Wales and develop all Wales evidence based</td>
<td>Support an All Wales approach to developing guidance and subsequent local implementation</td>
<td>Evidence based access to hydrotherapy</td>
<td>Adequate facilities / Travel distances / Rurality</td>
<td>Year 1</td>
<td>All Wales Physiotherapy Network / HD rep.</td>
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### Theme 4 - Living with a neurological condition

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<td></td>
<td>guidelines for access to this therapy for both in-patients and out-patients</td>
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## Theme 5 - Children and Young People

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</table>
| **5.1.** Health boards to review progress against the *All Wales Neurosciences Standards for Children and Young People’s Specialised Healthcare Services* and ensure participation in Welsh Government mandated audit and outcome programmes. | • Complete a baseline assessment regarding *All Wales Neurosciences Standards for Children and Young People’s Specialised Healthcare Services*.  
• Maintaining engagement in Welsh Government mandated audit e.g. National Paediatric Diabetes Audit. | Gap analysis with recommendations to address Improve quality of life, self management and independent living | Rurality  
Capacity | Year 1 & 2 | Hywel Dda / ABMU  
Clinical Director, Child and Adolescent Health |
| **5.2.** Update local plans to address any shortfalls in the full implementation of the standards set out *All Wales Neurosciences Standards for Children and Young People’s Specialised Healthcare Services* | Local plans as a result of gap analysis to include:  
• Development of Epilepsy Pathway/s including:  
  − 1<sup>st</sup> Fit Pathway (incorporating role of Children’s Epilepsy Nurse as a new post)  
  − Transition arrangements to adult services.  
• Neuromuscular Disorders  
  − Maintain map of patient spread.  
  − Establishment of peripatetic neuromuscular clinic based | Improve condition management, quality of life and reduce risk of complications from the primary condition. | Capacity  
Travel distances / rurality | To be agreed | To be agreed |
## Theme 5 - Children and Young People

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|          | on geographic need.  
  - Confirm pathway for respiratory support (from adult respiratory team).  
  - Review of generic core community paediatric services to clarify shortfall based on need in e.g.  
  - physiotherapy  
  - occupational therapy  
  - specialist nurse support  
  - dietetics  
  - speech and language therapy  
  - Neurodisability Services  
  - Develop and implement robust pathway for spasticity, including specific support from physiotherapy and occupational therapy.  
  - Define the model for complex needs clinics and apply reliably across 3 counties.  
  - Review commissioning arrangements for paediatric services | Improve condition management, quality of life and reduce risk of complications from the primary condition. Additionally enable the development of self management and independent living skills | Travel distances / rurality  
  Facilities  
  Funding to address service gaps | Travel distances / rurality  
  Capacity | |
### Theme 5 - Children and Young People

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<td></td>
<td>orthopaedics in ABMU.</td>
<td>Improve condition management, quality of life and reduce risk of complications from the primary condition. Additionally enable the development of self management and independent living skills</td>
<td>Capacity</td>
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|          | Development of continence pathway/s including:  
- Individual toileting program development & implementation for children to provide the best opportunity to acquire long term continence.  
- Self management skills to promote healthy bladder and bowel function  
- Transition arrangements to adult services. | Improve diagnostic process i.e. timely and effective | Rurality |          |      |
|          | Review access, scope, effectiveness, capacity and waiting times for diagnostic clinical services. This will include:  
- Paediatric Neuroradiology  
- Videofluoroscopy  
- Neuropsychology working in partnership with ABMU. | | Funding |          |      |
|          | Restructure to reflect the recommendations generated through review, acknowledging the | | Recruitment |          |      |
|          | | | Capacity |          |      |
|          | | | Capacity |          |      |
|          | | | Funding |          |      |
## Theme 5 - Children and Young People

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<td>possibility that a business case may be required to deliver the appropriate level of service. • Mapping of <strong>dental service</strong> for children with special needs • Establish a consistent approach to the access of <strong>specialist equipment</strong> for children</td>
<td>Improve dental health of children with neurological conditions Improve timely condition management, quality of life and reduce risk of complications from the primary condition. Additionally enable the development of self management and independent living skills</td>
<td>Capacity Facilities Funding Joint agency agreement regarding priorities</td>
<td>Year 1, 2 &amp; 3</td>
<td>To be agreed</td>
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<tr>
<td>5.3. Ensure patients with complex needs have appropriate, timely assessment of their continuing care needs.</td>
<td>Build on current working structure to establish a sustainable service model by:- • Review current working structure, arrangements and staffing to confirm gaps and work pressures. • Adopt a stratified approach to services available to ensure that</td>
<td>Deliver effective, appropriate and timely care, improving quality of life, opportunities to develop personal management and basic independent living skills as well as reduce</td>
<td>Capacity in view of increasing demand Gaps in lower level services (leading to deterioration that meet continuing care criteria)</td>
<td>Year 1, 2 &amp; 3</td>
<td>To be agreed</td>
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## Theme 5 - Children and Young People

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|          | lower level services can reduce risk of needing access to continuing care e.g.  
− Emotional & psychological needs of children  
− Emotional & psychological needs of children with learning disability  
− Sensory integration  
− ASD services  
Implementation of Continuing Care Service Policy and Transition Policy | risk of complications from the primary condition | rurality | Year 1 | Clinical Director, Child and Adolescent Health |
|          | Confirm relationship with the national specialist advisory groups.  
Improved communication  
Advice that reflects the challenges faced by rural services | Capacity  
Dominant representation from urban services | |

5.4. 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.
## Theme 6 - Improving information

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<tr>
<td>6.1. Ensure IT infrastructure supports effective sharing of clinical records/personalised care plans</td>
<td>Alignment of IT Strategic development as outlined in IMTP ie Adastra, Myrddin, PACS and Community Information System connectivity. Agreement of Information Sharing via email</td>
<td>Improved care delivery</td>
<td>Timescales of IT strategy</td>
<td>Year 2</td>
<td>Ass Director of IT</td>
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<td>6.2. Put effective mechanisms in place for seeking and using patients’ views about their experience of neuroscience and related services</td>
<td>Negotiate a partnership working relationship with Neurological Alliance, Voluntary organisations, CHC and service users to develop a shared approach to understanding the impact of current service provision from a user perspective</td>
<td>Service that meets the need of people with neurological condition</td>
<td>Ability and resources to sustain engagement Rurality</td>
<td>Year 1</td>
<td>ABMU / HD Integrated Deliver Plan Implementation Group</td>
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<td>6.3. Ensure full (100%) participation in national clinical audits - to support service improvement and support medical revalidation of clinicians – and ensure that findings are acted on. In addition, participation of all: • neurorehabilitation</td>
<td>Working in partnership with regional services to support audit compliance requirements. E.g Community / Primary care</td>
<td>Improved compliance with evidence based standards</td>
<td>Capacity Communication and knowledge of timescales of audit</td>
<td>As required</td>
<td>ABMU / HD</td>
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<td>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</td>
<td>Support the peer review of ABMU Neurology Medical Staffing</td>
<td>Improve patient experience</td>
<td>Engagement</td>
<td>Annual</td>
<td>ABMU</td>
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<td>6.5 Publish regular and easy to understand information about the effectiveness of neuroscience services</td>
<td>Establishing an agreed framework for reporting effectiveness of neuroscience services via the WG Neurological Delivery Plan Implementation Group. Integrated Implementation Group to establish evaluation process to populate the agreed framework</td>
<td>Provide the opportunity to improve services utilising an informed outcome focused approach.</td>
<td>Capacity and sustainability</td>
<td>Annual</td>
<td>WG Neurological Delivery Plan Implementation Group ABMU / HDUHB Joint Implementation DP Group</td>
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### Theme 6 - Improving information

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<td>6.6</td>
<td>Establish an annual national audit day for neurological services provided to Welsh Patients</td>
<td>Support All Wales Approach</td>
<td>To be advised</td>
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### Theme 7 - Targeting research

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<td>• Support and encourage protected teaching time for clinically-active staff (in primary as well as secondary and tertiary care)</td>
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<td></td>
<td>• Support and encourage protected research time for clinically-active staff (in primary as well as secondary and tertiary care)</td>
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<td>• Build on and extend academic training schemes to develop a highly skilled workforce</td>
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<td>• Promote collaboration with key research initiatives, including the NISCHR funding infrastructure</td>
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<td>• Increase the number of non-commercial clinical research portfolio and commercial studies</td>
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<td>• Increase the number of people with a neurological condition entered into clinical trials and number retained on longitudinal trials</td>
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<td>• 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</td>
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<td>• 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</td>
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Actions within ABMU plan are applicable for Hywel Dda UHB.
Appendices

- ABMU Neurological Conditions delivery plan
- WHSSC - Neurological Condition
- Neuro Needs Assessment2014_FINAL
- Workshop Attendance updated