# ANEURIN BEVAN UNIVERSITY HEALTH BOARD

## TOGETHER FOR HEALTH – A NEUROLOGICAL CONDITIONS DELIVERY PLAN

### LOCAL DELIVERY PLAN

A Delivery Plan up to 2017 for Aneurin Bevan University Health Board and its Partners

### Version Control

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<td>Caroline Bird</td>
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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.

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.

In response to the “Together for Health – A Neurological Conditions Delivery Plan” (2014), Health Boards are required, together with their partners, to produce and publish a detailed local service delivery plan to identify, monitor and evaluate the actions required within specific timescales. Heath Boards are required to report progress formally to their Boards and publish the update reports on their websites annually.

This Local Delivery Plan includes a summary of priorities and key actions against each Delivery Theme of the Neurological Conditions Delivery Plan. It should be noted that this is an iterative process and, therefore, the plan should be regarded as a ‘live’ working document that will be developed and refined as necessary through to 2017.

The Health Board has also developed and published a Local Delivery Plan for Stroke. This plan should be read in conjunction with the Health Board’s ‘Together for Health – Stroke Local Delivery Plan’: http://www.wales.nhs.uk/sitesplus/866/opendoc/218852
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. 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.

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.

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). A 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

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2 Neuro Numbers, Neurological Alliance www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf
all children. 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 (MS), where relapses and remissions lead to marked variation in the care needed.
- **Progressive conditions** for example motor neurone disease (MND), Parkinson’s disease or later stages of multiple sclerosis, where there is progressive deterioration in neurological function. For some conditions (e.g. MND) 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 actions to improve outcomes between now and 2017, in the following key areas:

- **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 conditions should receive fast, effective care and treatment
- **Living with a neurological condition** – Whether in the community or in hospital, people are placed at the centre of care with their individual needs identified and met so they feel

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4 Service Specification Paediatric Neurosciences: Neurology, NHS England
www.england.nhs.uk/wpcontent/.../06/e09-paedi-neurology.pdf
* not all neurological conditions covered by this plan are contained within the list
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

- **Targeting research** – A commitment to research, delivering improved diagnosis, management, treatment options and outcomes

2. **ORGANISATIONAL PROFILE**

2.1 **Overview of Aneurin Bevan University Health Board (ABUHB)**

ABUHB was established in 2009 as an integrated Health Board. The organisation is responsible for the planning and delivery of a wide range of primary, community and secondary care health services for the populations of Caerphilly, Monmouthshire, Newport, Blaenau Gwent and Torfaen. Together with an estimate of people living in South Powys and other areas that use the Health Board for acute services, the patient population served is close to 600,000. 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, urban, and valley areas, and a high proportion of elderly people. ABUHB employs approximately 14,000 staff.

2.2 **ABUHB Neurological Services**

There are a range of services in the Health Board which are integral to providing health care and support to those affected by a neurological condition. These are as follows:

*Primary Care*: Many people’s first point of contact with the NHS is with Primary Care services. The General Practitioners contracted by ABUHB play an important role in providing and coordinating the care of people with neurological conditions, often being the first contact and principal point of contact of continuing care for patients. In addition to GP practices, referrals into the Health Board’s neurological services also come from opticians.
**Neurology Directorate:** The ABUHB Neurology Directorate provides a wide range of therapeutic and diagnostic services for the population of South East Wales. Senior medical staffing for neurology comprises of 5 Consultants and one Associate Specialist. The Neurology Consultants provide responsive speciality review for all inpatients referrals on two acute sites – Nevill Hall Hospital (NHH) and Royal Gwent Hospital (RGH). In addition the RGH Consultant Neurologists and Specialist Registrar provide specialty review for referrals from the Medical Assessment Unit, working closely with the Acute Care Physicians to facilitate discharge and appropriate outpatient management. The Neurology Consultants work closely with the Acute Stroke Service, supporting the delivery of 24/7 Stroke thrombolysis.

The larger aspect of the neurology service in ABUHB is outpatient activity with outpatient clinics undertaken over a number of hospital sites. Demand for outpatient services is high and the Directorate sees in the region of 3000 patients per annum.

Currently, specialist neurology inpatient services in South East Wales are based at the University Hospital of Wales (UHW). In addition, a number of subspecialist neurology clinics are undertaken on a regional basis. Excellent links are maintained with UHW and Consultants have joint job plans supporting the specialist neurology inpatient service and a 24/7 regional South East Wales acute neurology on call rota.

**Neurophysiology**, a sub-speciality within the Neurology Directorate, runs a diagnostic outpatient service at both St Woolos Hospital (SWH) and NHH. This service is currently run, in conjunction with Cardiff and Vale University Health Board (CVUHB), on a hub and spoke model and a number of investigations are, therefore, also undertaken in Cardiff. Investigations include electroencephalography (EEG) - a recording of the electrical activity of the brain from the intact scalp; electromyography (EMG) and nerve conduction studies (NCS) - these assess function of the nerves and muscles within the body.

**Pharmacy:** The interface with both Community Pharmacy and Hospital Pharmacy is key in ensuring people with neurological conditions have timely access to drug interventions and counselling on medicines (e.g. side effects). Pharmacists also provide advice on the use of new agents, aid discharge planning for inpatients from hospital and provide support to homecare services.
**Children and Young People:** Paediatric neurology services are provided to ABUHB residents by CVUHB via a lead centre based in Cardiff. CVUHB provide an outreach service to Gwent with outpatient clinics delivered by CVUHB consultants in RGH and NHH.

ABUHB paediatrics provides secondary care sub speciality services for neurodevelopment/disability including for example epilepsy, cerebral palsy, ASD/ADHD (pre-school children), LD and a range of syndromes. There are three paediatric consultants with an interest in epilepsy who are supported by a specialist nurse team. Paediatrics leads a pan Gwent feeding clinic and many of the patients accessing this will have a neurodisability. The Community Children’s Nursing service provides continuing care (health needs are assessed according to All Wales Continuing Care Guidelines) and enteral feeding services for these children.

There are pathways in place for the following: selective dorsal rhizotomy, intrathecal baclofen, ketogenic diet, telemetry, neuropsychology with referral to the lead centre and onward referral to specialist services in England. There is no tertiary paediatric neurodisability service in Cardiff. Gait analysis and neuropsychology are accessed at Bristol.

ABUHB also provides specialist Dietetics, Physiotherapy, Occupational Therapy, Speech and Language Therapy, Audiology, Orthotics, Arts Therapies, Arts Therapies, Clinical Psychology and Learning Disabilities interventions. CAMHS provide services for school aged children with ASD/ADHD. There are links to ALAC & Bobath.

**Dietetics** – People with neurological disorders may require dietetic assessment and intervention for: weight management, constipation, increased nutritional requirements, specific therapeutic diets, food fortification, texture and fluid modification as well as short and long term artificial tube feeding.

**Physiotherapy** – The physiotherapy service provides assessment and treatment to children and adults with neurological conditions as inpatients, outpatients and in home and school environments. The service supports a wide range of neurological conditions working with individuals, their families and carers with physiotherapists specialised in paediatrics, neurological physiotherapy, respiratory care, musculo-skeletal care as well as general rehabilitation physiotherapists in the in patient, community and frailty teams. Physiotherapists can offer treatment and advice at any stage of a condition; early treatment can continue recovery and prevent
secondary complications. In some cases, although conditions may progress over time, there can still be gains by having physiotherapy to improve quality of life and promote independence.

**Occupational Therapy (Adult)** – A team of 3 Occupational Therapists (OTs) and 2 support workers work in the community from three hospital bases – NHH, St Woolos Hospital (SWH) and Ysbyty Ystrad Fawr (YYF), taking referrals for patients who have long term neurological conditions and providing assessments and individual interventions mainly in patients own homes. The OTs work with individuals and carers to address occupational needs in the areas of self care, productivity / employment and leisure, using a variety of treatment mediums.

**Occupational Therapy (children and young people)** – Children and young people’s OTs work from the 3 children’s centres in the ABUHB catchment area – NHH; Caerphilly Children’s Centre in Energlyn; and Serennu Children’s Centre in Newport. Referrals are taken for children and young people with cerebral palsy, spina bifida, muscular dystrophy and other neurological conditions. The role of the OT is to work with children and their families in areas of daily occupations such as areas of self care / productivity or school / play and leisure, working on goals that the child or young person wants to or needs to be able to achieve in order to perform at their maximum level of independence. OTs work across homes, schools (mainstream and special), playgroups and nurseries, higher education establishments for those young people transitioning into 3rd level education. 11% of referrals to the children and young people’s OT service are for those with neurological conditions.

**Speech and Language Therapy (SLT):** The SLT service provides assessment and support to patients with neurological conditions where there are speech, language, communication and swallowing disorders.

**Orthotics** – The Orthotic Service provided for individuals with a neurological condition involves providing external bracing (orthoses) to compensate for loss of movement / control; reduce the risk / management of contractures and maintain optimal alignment / energy efficiency during gait. This is a key area of rehabilitation for many patients suffering from neurological conditions and may represent a long term or even lifelong intervention for many patients. There are 4 orthotists employed by ABUHB; this team covers paediatrics, adults, inpatients and outpatients across multiple specialities including neurology. The team works closely with neurophysiotherapy and holds regular joint clinics at County
Hospital and STW although patients with neurological conditions may access orthotic services in children’s centres, general and community hospitals across the health board.

**Arts Therapies** – Arts Therapies work with people with a range of neurological disorders and are particularly indicated for people in psychological distress unable to access verbal forms of psychotherapy / counselling i.e. sufferers of neurological conditions with severe communication or cognitive difficulties and unable to access or make use of other forms of psychological support; and sufferers with entrenched emotional / psychosocial problems who may be resistant to more conventional rehabilitation interventions.

**Clinical Psychology / Neuropsychology:** When an individual sustains an injury to their brain they may experience a corresponding change in their cognition (i.e. their memory, thoughts etc.), emotions (anxiety, low mood etc.) or behaviour. Clinical psychology is concerned with understanding the consequences of neurological conditions and uses this information to help patients to better understand and cope. The Clinical Psychologist is a core member of the neuro-rehabilitation team and plays a central role in screening for mood and cognition problems; the provision of specialist psychological assessment and intervention/therapy; supporting carers/family; and providing training and consultation to staff. Psychology also has a significant role in assessing and treating patients with medically unexplained symptoms.

**Learning Disabilities (LD) Directorate:** ABUHB Learning Disabilities Directorate provides specialist healthcare services for people with learning disabilities. A learning disability is a neurological disorder. However, people with a learning disability experience additional neurological condition in the same way as the general population. Within the LD Directorate, there are five Community Learning Disability Teams with a range of professionals who have specialist skills in supporting people specifically with learning disabilities and also the associated neurological conditions. Each community team has access to community nursing, a range of therapy services and psychiatry. Additionally, these teams are supported by an inpatient assessment and treatment unit and an Intensive Community Intervention Service (ICIS) who work with people with a learning disability who present with complex behaviours that challenge and or mental health difficulties (which may at times be as a result of or in response to a neurological condition). We also provide a Health Liaison Service to support service users with a learning disability admitted to ABUHB general
The Learning Disability service provides comprehensive health care services to people with a learning disability, including where they have additional neurological conditions, responding in an individualised and holistic way to promote the physical, cognitive, emotional and behavioural well-being of service users. The Learning Disability service also works closely with families and paid carers. Specific clinical pathways and specialist services that have been developed to work with service users with additional neurological conditions include: Memory Care Pathway; Development of a Dementia Screening Process for people with Down’s Syndrome; Epilepsy Pathway; ASD Residential Project and Neurodevelopmental Pathway and Delivery Plan.

**Working in Partnership:** The Health Board collaborates and co-operates with organisations at national and local level to enhance the services it provides to those affected by a neurological condition. Our key partners include: Cardiff and Vale University Health Board; Cardiff University School of Medicine; Local Government; Wales Neurological Alliance; Epilepsy Society; Headway; MND Association; MS Society; Parkinson’s UK; Myasthenia Gravis Association; Muscular Dystrophy Campaign; Welsh Association of ME and CFS Support (WAMES); Guillain-Barré Syndrome Support Group; All Wales Neurosciences Specialist Advisory Group (NSAG); Cross Party Group for Neurological Conditions; Cross Party Group for Neuromuscular Conditions; South Wales MND Network; Wales Neuromuscular Network.

### 2.3 Clinical Futures Programme

Following extensive local consultation ABUHB’s Clinical Futures Programme was launched in 2007. Clinical Futures sets out the Health Board’s vision for the development of sustainable services that can provide appropriate access and excellent standards of care for patients. It is a plan that bridges primary, community and hospital services, promoting services in or close to home, along with high quality hospital services available when needed. Hospital provision will be focused on a Specialist and Critical Care Centre (SCCC), enhanced Local General Hospitals (eLGHs), Local General Hospitals (LGHs) and smaller community facilities. Primary and community services will be enhanced to re-balance care between primary, community, secondary and tertiary services to ensure care is provided closer to home where appropriate.

The proposed clinical futures model for neurology is as follows:
3. DEVELOPMENT AND IMPLEMENTATION OF ABUHB’S LOCAL DELIVERY PLAN FOR NEUROLOGICAL CONDITIONS

The development of the Health Board’s Neurological Conditions Local Delivery Plan is an iterative process. This initial document has been developed by engagement and consultation with a range of stakeholders through a variety of mediums – meetings, email communication and a workshop held in August 2014.

The plan has been informed by a review against the expectations set out for 2017 and two Needs Assessments, undertaken by Public Health Wales – the first in October 2011 and the second in July 2012. The needs assessments demonstrated the burden of neurological disease in Mid and South Wales. The first review concluded that epilepsy contributed to a high burden of neurological disease in terms of numbers, whilst other neurological diseases such as motor neurone disease, multiple sclerosis or cerebral palsy may be lower in number but that there can be a high level of health care need associated with these conditions. The two Needs Assessments can be viewed via the Health Board’s Local Delivery Plan website.

The ongoing development, implementation and delivery of the plan will be overseen by the ABUHB Neurological Conditions Planning and Delivery Group. The Group’s overall objectives are to deliver Welsh Government requirements and specifically the actions detailed in this Local Delivery Plan. The Group will also ensure links with the strategic objectives of partner organisations. The terms of reference for the group can be found at Appendix 1.
4. CHALLENGES AND PRIORITIES

4.1 Challenges

Our key challenges are:

**Raising awareness of neurological conditions**
- A significant number of patients with relatively common neurological complaints (pain, sensory symptoms, weakness etc.) may either end up without a clear diagnosis and, therefore, cannot be labelled with a condition or the problem turns out to be functional. As a result, data on these complaints is not always captured and patients can feel lost (with nowhere to go for information/help).
- Coding of patients with a neurological condition is haphazard. Inpatients leave hospital with no clear diagnosis and for outpatient neurology none of the workload is coded. As such, there is poor quality data on our case mix and population level demand for services.
- Lack of train the trainer courses within the epilepsy / Learning Disabilities team means that many individuals caring for people with the most severe types of epilepsy are not adequately (or frequently enough) trained to recognise and deal with seizures and other epilepsy related challenges.
- Educating the large number of healthcare professionals and social care staff involved with patients with a neurological condition takes a lot of time and is, therefore, difficult to deliver.
- Ensuring we have a robust understanding of the number of people with a learning disability with additional neurological conditions.
- Identification of carers of those with a neurological condition in order to raise awareness of ‘condition specific’ support available in undertaking their caring role.

**Timely diagnosis of neurological conditions**
- Although the wait time for a first new outpatient (urgent and routine) appointment for neurology has reduced, challenges remain regarding the length of wait particularly for patients who urgently need to be seen. As at 30th September 2014, there were 113 patients waiting over 26 weeks for a new outpatient appointment.
- Capacity issues for a number of diagnostic investigations e.g. neurophysiology and MRI, resulting in long waits.
- There is currently an inequity of some services between North and South Gwent.
• Although GPs can access timely advice through the e-referral system, email and telephone advice, this is not recorded on patient information systems and activity is, therefore, not visible
• Due to the outpatient focus of neurological services in ABUHB (and across most of the UK) and focus on achieving the Referral to Treatment time target, those patients admitted to hospital with the most severe and acute neurological illnesses do not routinely get rapid access to consultant neurology assessment and generally wait many weeks to be seen in clinic
• People with a learning disability may experience more difficulties in accessing diagnosis, care and support due to such factors as the service user’s communication difficulties, barriers to attending health services and signs and symptoms sometimes being attributed to the person’s learning disability rather than other causes

Fast and effective care
• Although the best available treatments are provided to patients, these are not always available locally and there is considerable confusion about service availability and access
• A significant number of patients are overdue their planned follow up appointment date
• A number of children and young people continue to require health care and support when they reach adulthood. The challenge is to ensure these patients are identified at the earliest opportunity
• Providing rapid review for existing patients of the directorate whose condition deteriorates or destabilises is a challenge.
• Encouraging staff to remember to consider carer involvement at the earliest opportunity is essential
• We currently have an inequity of some services between North and South Gwent

Living with a neurological condition
• Recognising and addressing the needs of carers to enable them to continue in their caring role effectively and sustainably is essential
• Ensuring access to evidence based rehabilitation and treatment for challenging behaviour is essential
• Access to psychology within ABUHB is extremely limited (only 1 WTE Clinical Psychologist who covers a wide number of tasks, large population and wide geographical area)
**Children and young people**
- We need to integrate young carer awareness into all relevant educational establishments
- Meeting both the home (and often respite) and school based needs of children with neurological conditions is a challenge for therapy services, although there are some areas of good practice, e.g. OTs in the Children’s Centre work closely with their counterparts in the local authorities children with disabilities team to avoid duplication of effort and to ensure skills are matched to need and all children receive an appropriate service
- A review against the expectations set out in the All Wales Standards for Children and Young People’s Specialised Healthcare Services has been undertaken and has highlighted a number of issues which need to be addressed, namely: inequalities in access to education and school activities; long waits for a range of services, including diagnostic tests, CAMHS, genetic testing; the transition into adult services for children

**Improving research**
- How we encourage all professional staff to find time to invest in research and teaching of undergraduates and postgraduates
- Accessing appropriate personnel and resources to adequately support clinical research activity without impacting on routine NHS work

**Improving information**
- Improving systems for gathering feedback from service users is essential

In addition to the specific challenges highlighted above, a wider issue for the Health Board is delivery and improving services in the light of considerable demographic and fiscal challenges. In this current period of austerity, this will require different approaches, under the umbrella of ‘Prudent Healthcare’.

### 4.2 Priorities

There are a number of priorities identified against each Delivery Theme. The action plan that follows this section details all of the priorities and key actions but recognising that there are a considerable number of priorities for each Delivery Theme, the stakeholders who attended the workshop held in August 2014 agreed the following were the top priorities for the first five themes:
Raising awareness of neurological conditions
- Priority 1 - Raise awareness of neurological conditions (action plan ref 1.1a)
- Priority 2 - Signpost existing sources of information, advice and support (action plan ref 1.1b)
- Priority 3 - Deliver teaching / training / update sessions to GPs, practice nurses and other staff involved in the management of people with neurological conditions on a regular basis to support better understanding of neurological conditions (action plan ref 1.2)

Timely diagnosis of neurological conditions
- Priority 1 - Provide GPs with timely access to specialist advice through structured telephone and email contact, speeding diagnosis and management for people who may not need referral to a clinic (action plan ref 2.3)
- Priority 2 - Provide rapid access to urgent outpatient services with specialist clinical expertise for referrals to meet GP and patient need (action plan ref 2.7)
- Joint Priority 3 - Ensure timely access to multidisciplinary assessment to support diagnosis where necessary (action plan ref 2.4)
- Joint Priority 3 - Ensure follow-up arrangements for patients are appropriate and timely (action plan ref 2.4)

Fast and effective care
- Priority 1 - Ensure patients with complex needs have appropriate, timely and co-ordinated access to other specialist services as appropriate (action plan ref 3.3)
- Priority 2 - Organise services to ensure people admitted with a neurological condition are assessed by a neurologist (or neurosurgeon as appropriate) within 24 hours of admission to hospital for a primary neurological condition (action plan ref 3.1)
- Priority 3 - 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 (action plan ref 3.4)

Living with a neurological condition
- Priority 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 (action plan ref 4.1)
• **Priority 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 (action plan ref 4.2)

• **Priority 3** - Work proactively with third sector services and provide effective signposting to information and support, enabling patients to easily access support services (action plan ref 4.5)

**Children and young people**

• Ensure children and young people have appropriate, timely assessment of their ongoing care needs and care plan delivery (action plan ref 5.3)
**ACTION PLAN 2014 – 2017**

**Delivery theme one: Raising awareness of neurological conditions**

**Increased awareness of neurological conditions and their symptoms**

**Delivery expectations**

1. All staff involved in managing care for people with a neurological condition should have an appropriate understanding of the condition and its impacts on the individual and their family including an understanding of the roles, interventions and expectations of local and regional services

2. Better understanding of neurological conditions amongst the public and other organisations such as educational establishments

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<th>Actions</th>
<th>Expected outcome</th>
<th>Risks to delivery</th>
<th>Timescales</th>
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<td>1.1 Work with a broad range of partners (including local service boards, educational institutions and the third sector) to:</td>
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<td>• 1.1a Raise awareness of neurological conditions</td>
<td>• Identify who needs to be targeted for awareness raising</td>
<td>• Increased awareness amongst identified target groups</td>
<td>• Education is needed at the point of diagnosis</td>
<td>2014 - 2017</td>
<td>ABUHB Neurological Conditions Planning and Delivery Group</td>
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<td>• Continue to work with a broad range of partners to raise awareness including timely and appropriate education and training for patients and their families</td>
<td>• Earlier presentation to GPs and hospital</td>
<td>• People are not always receptive at the point of diagnosis – support needs to be there when the person needs it</td>
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<td></td>
<td></td>
<td>• There is not always a clear diagnosis</td>
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ABUHB Neurological LDP
V1.6
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<th>Develop a pan ABUHB Expert Patient Awareness campaign e.g. “What have you learnt from your patient today?”</th>
<th>Increased awareness amongst staff groups</th>
<th>Clarity of who is leading and funding neurological conditions awareness campaigns – WG advice may be required</th>
<th>2015 - 16 (linked to action ref 1.4)</th>
<th>ABUHB Neurological Conditions Planning and Delivery Group</th>
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<td>Complete a scoping exercise with regards to people registered with the Community Learning Disabilities Teams</td>
<td>• No. of LD service users known with additional neurological conditions • Understanding of how patients are supported across LD and mainstream services</td>
<td>Resources not available to undertake the scoping exercise</td>
<td>2015-16</td>
<td>Head of Learning Disabilities</td>
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<td>Publish Local Delivery Plan on Health Board’s website</td>
<td>Increased awareness of neurological conditions and actions being taken by the Health Board in conjunction with its partners</td>
<td>Delay in plan being approved</td>
<td>January 2015</td>
<td>Director of Therapies and Health Science</td>
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<td>• 1.1b Signpost existing sources of information, advice and support</td>
<td>Continue to work with a broad range of partners to signpost to existing information, advice and support</td>
<td>Timely access to relevant information and advice</td>
<td>Lack of engagement of key partners</td>
<td>2014 - 2017</td>
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<td>Develop more ‘newly diagnosed induction’ sessions for patients for a wider range of neurological conditions</td>
<td>Timely access to relevant information and advice</td>
<td>Resources may be limited to undertake</td>
<td>2014 - 2017</td>
<td>ABUHB Neurological Conditions Planning and Delivery Group</td>
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<tr>
<td>Provide GPs and relevant professionals with access to point of contact information in order to signpost carers to specialist advice and support in a timely manner. Signpost carers to existing sources of information, advice and support.</td>
<td>• Increased opportunities for carers to access advice and support. • Streamlined access to information to encourage a timely response.</td>
<td>• Increased demand for services required from Local Authorities and Third Sector. • GPs not utilising information available</td>
<td>2014 - 2017</td>
<td>ABUHB Carers Measure Team with support from Local Authorities, Third Sector, Primary Care</td>
</tr>
<tr>
<td>Develop an ABUHB Neurology Directorate Intranet page</td>
<td>Information on the neurology directorate is accessible</td>
<td>Web pages will need to be kept up to date to ensure the information is relevant</td>
<td>January 2015</td>
<td>Directorate Support Manager Neurology</td>
</tr>
</tbody>
</table>
| Develop an ABUHB Carers web page for patients, families, carers and health professionals | Information on carers issues is accessible | • Web pages need to be easily accessible via internet and social media.  
• Web pages will need to be kept up to date | December 2014 | ABUHB Carers Measure Team (via Communication and Education subgroup) |

| 1.2 Deliver teaching / training / update sessions to GPs, practice nurses and other staff involved in the management of people with neurological conditions on a regular basis to support better understanding of neurological conditions | Targeted education sessions planned within Primary Care, based on referral patterns. | • Education and information is provided on how to cope with symptoms and functional difficulties.  
• Educational interventions on neurological conditions that individual practices struggle with. | Risk of preaching to the converted. Need to mitigate by targeting GPs and identifying specific educational needs and relevance | 2014-15 | ABUHB, Third sector providers, support groups |

| Provide carer awareness training to staff, GPs, Local Authorities, Third sector and educational establishments | Increased awareness for carers | Resources limited to provide training to the large number of staff across the partnership | 2014 - 2017 | ABUHB, Local Authorities, Third sector, Primary care |

Also see 2.1 and 2.5.
<table>
<thead>
<tr>
<th>Provide training for Third sector organisations who provide more generic support to patients</th>
<th>Increased awareness in Third sector of types of support needed by patients.</th>
<th>Resources limited to provide training to the large number of staff across the partnership</th>
<th>2014 - 2017</th>
<th>ABUHB Neurological Conditions Planning and Delivery Group</th>
</tr>
</thead>
</table>
| Development of business case for additional Epilepsy CNS to provide Train the Trainer sessions for Buccal Midazolam rescue medication | Approved case demonstrating the need for increased resource for training | Difficulty in obtaining information to support the case  
No identified funding source | 31st March 2015 | Assistant Directorate Manager Neurology |
| 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 | Modify the clinic letter with care plan to include diagnosis, support and patient re-referral | Reduction in number of Accident & Emergency attendances  
Reduction in clinical risk of harm to patient  
Reduction in medico legal risk | 2015-16 | To be led by each Head of Service for their own area of responsibility and also through the Neurology Directorate |
| 1.4 Public Health Wales, in partnership with Health Boards, to deliver a national awareness campaign through community pharmacies in Wales | Consider opportunities to run a public health campaign, identifying suitable topics and partners | Increased awareness | 2015-16 | Public Health Wales (In partnership with Health Boards) and All Wales Chief Pharmacists Committee |

**Modification:**
- Added a third column for负责人 details and dates.
- Changed some entries for dates and titles.
**Delivery theme two: Timely diagnosis of neurological conditions**

**Neurological conditions are detected quickly, allowing timely progress to care and treatment**

**Delivery expectations**

1. Better understanding of neurological symptoms and care among GPs
2. Prompt and appropriate access to specialist advice and diagnostic tests
3. Prompt and appropriate onward referral to clinical specialists

<table>
<thead>
<tr>
<th>Priority</th>
<th>Actions</th>
<th>Expected outcome</th>
<th>Risks to delivery</th>
<th>Timescales</th>
<th>Lead</th>
</tr>
</thead>
</table>
| 2.1 Provide GPs with timely and enhanced direct access to CT / MRI, without the need for secondary referral, where appropriate and in line with agreed diagnostic protocols | Although there is a direct access service in place for GPs for CT and MRI without the need for secondary referral, improved outcomes by improving GP referral practice for CT / MRI using diagnostic protocols – to be actioned through CPD sessions and audit. Work with neurology advice service to provide feedback to GPs. | • Streamlined diagnosis processes.  
• Improved outcomes  
• Avoidance of unnecessary clinic appointments  
• Understand demand and plan to accommodate. | Availability of staff and GPs to attend CPD sessions | CPD sessions to commence Nov 2014 | NCN Lead in conjunction with Clinical Director of Radiology / Directorate Manager of Radiology |
| 2.2 Ensure timely access to diagnostic tests where necessary | Review current service provision for neurophysiology and develop proposal to improve access times and physical access to facilities | • Patients undergo investigations in a timely manner and according to clinical priority  
• Improved patient outcomes through more | Successful recruitment of staff  
Financial constraints | Commence October 2014 through to September 2015 | Clinical Director Neurology / USC Service Group Manager |
<table>
<thead>
<tr>
<th>Review current service provision for lumbar puncture and, working with Cardiff, develop a proposal to improve access times. This may include repatriation of activity</th>
<th>timely and better diagnostic information • Improved efficiency in use of investigations • Physical space is limited in the Neurology Day Unit in Cardiff meaning capacity for lumbar puncture has a limit • Commissioning issues</th>
<th>Commence October 2014 through to September 2015</th>
<th>Neurology Directorate Support Manager</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review Speech and Language Therapy access to video-fluoroscopy.</td>
<td>Determine appropriate skill mix and resource needs to deliver service and link back to SLT.</td>
<td>2015-16</td>
<td>Head of SLT in conjunction with Radiology Manager</td>
</tr>
<tr>
<td>Review current service provision and timeliness for genetic testing</td>
<td>Patients undergo genetic tests in a timely manner Difficulty in obtaining information to support review</td>
<td>By June 2015</td>
<td>Service Group Manager, Neurology</td>
</tr>
<tr>
<td>Continue to work with Radiology Directorate to ensure patients receive timely access for MRI scans</td>
<td>Patients undergo diagnostic investigation in a timely manner • Lack of resources / capacity • Demand on the service from other specialties</td>
<td>2014-15</td>
<td>Neurology Directorate Management Team</td>
</tr>
<tr>
<td>2.3 Provide GPs with timely access to specialist advice through structured telephone and email contact, speeding diagnosis and management for people who may not need referral to a clinic</td>
<td>• Continued expansion of advice letters and emails and further develop open access service model for follow up patients • Increasing GP awareness of willingness to receive telephone/email contact to avoid clinic referrals. • Reduction in clinical governance risks associated with patients not being seen within prescribed time frames • Reduction in RTT wait times • Admission avoidance • Reduced anxiety and better health outcome for patient • Provides learning / education for better management of • Inadequate IT / telephony systems • Insufficient CNS resource / time • Insufficient consultant resource / time</td>
<td>Already in place but plan to continually improve and expand</td>
<td>Clinical Director Neurology (through Neurology Directorate)</td>
</tr>
</tbody>
</table>
| **2.4 Ensure timely access to multidisciplinary assessment to support diagnosis where necessary** | Neurology Directorate to work with relevant Directorate and C&V to develop a plan to improve access to neuropsychology | Improve access to neuropsychological assessment for early diagnosis | Resource limitations | By June 2015 | Service Group Manager Neurology  
Clinical Director Therapies  
Therapies Leads |
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<tr>
<td><strong>Raise priority of need to move clinical letters electronically from secondary to primary care via WCCG with NWIS</strong></td>
<td>Rapid safe transfer of clinical care documentation improves patient safety</td>
<td>Funding in NWIS to complete WCCG PID 2 work</td>
<td>To be determined following discussions with NWIS</td>
<td>Assistant Director of Performance</td>
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<tr>
<td><strong>Develop structured PD / MS / Epilepsy / MND / adults with LTC clinics with consistent MDT support pan Gwent, including OT, SLT, PT and dietetics</strong></td>
<td>Timely access to multidisciplinary services</td>
<td>Resource limitations</td>
<td>2014-16</td>
<td>Neurology Directorate in conjunction with Therapies Leads</td>
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</tr>
<tr>
<td><strong>Maintain current access to therapy support and build business case as required to meet demand/capacity deficit.</strong></td>
<td>Timely access to multidisciplinary services</td>
<td>Resource limitations</td>
<td>In line with timescales outlined in Integrated Medium Term Plan</td>
<td>Clinical Director Therapies</td>
<td></td>
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</table>
| 2.5 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 | Continued use of National Audit of Seizure Management in Hospitals (NASH) audit | • Consistent delivery of service on an all Wales basis  
• Enables benchmarking of sub-speciality / general services | 2015-16 | Clinical Director Neurology (through Neurology directorate) |
|---|---|---|---|---|
| Neurology NCN Lead & Directorate working with Primary Care colleagues to establish uniformity of referral patterns across Gwent GP surgeries: Audit of neurological referrals to be conducted in one NCN area with high level of referrals | Influence and alter referral behaviour within Primary Care reducing demand for Neurology service | • Inaccessibility of data from ABUHB systems  
• Inability to maintain influence on GP behaviour in the longer term resulting in continued unsustainable referral rates  
• Third sector as information gathering is sporadic and patients access services at many points e.g. GPs, A&E, orthopaedics | December 2014 | NCN Lead for Neurology in conjunction with Neurology Directorate |
| Ensure the guidelines for headache management are known and in use across all GP practices | • Patients managed appropriately in line with guidelines  
• Reduction in delays to correct treatment and morbidity resulting from inadequate/inappropriate treatment | • Consultant time for dealing with queries and reiteration of guidelines  
• Patient expectations/demand for secondary care referral. | December 2014 | NCN Lead for Neurology |
<table>
<thead>
<tr>
<th>Action</th>
<th>Description</th>
<th>Outcomes</th>
<th>Timeframe</th>
<th>Responsible Party</th>
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</thead>
<tbody>
<tr>
<td>Improve the uptake of the Carers Local Enhanced Service (LES) by GPs across Gwent and ensure continued update and development of the LES, including extending the GP LES service to focus on young carers</td>
<td>Carers of all ages are engaged at the earliest point of identification</td>
<td>• Lack of engagement from GPs that have not signed up to LES • Communication difficulties. • Behavioural difficulties. • Lack of insight. All mean self reporting is problematic and patients are often labelled as problem patients.</td>
<td>2014 – 2016</td>
<td>Clinical Director Primary Care</td>
</tr>
<tr>
<td>Ensure Carer awareness training is accessible to GPs</td>
<td>Training provided through RCGP toolkit and/or e-learning</td>
<td>Lack of engagement from GPs that have not signed up to LES</td>
<td>2014 – 2016</td>
<td>Clinical Director Primary Care</td>
</tr>
<tr>
<td>2.6 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</td>
<td>• Continue to participate in South East Wales Neurology and ABUHB Thrombolysis rotas • Implementation of Neurologist of the Week (NOW) rota</td>
<td>• Facilitate provision of 24/7 consultant Neurologist review • Ensure clinically urgent patients are treated on timely basis • Reduction in overall length of stay / bed days • Reduce urgent demand for OPD consultations freeing capacity for routine priority patients</td>
<td>NOW 6 month pilot to commence 5th January 2015</td>
<td>Clinical Director Neurology</td>
</tr>
<tr>
<td><strong>delivery of services to achieve this where necessary (Links to 2.7 below)</strong></td>
<td><strong>2.7 Provide rapid access to urgent outpatient services with specialist clinical expertise for referrals to meet GP and patient need</strong></td>
<td><strong>2.8 Ensure follow up arrangements for patients are appropriate and timely</strong></td>
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<tr>
<td>Ongoing work to be maintained for :-</td>
<td>- Transient Loss of Consciousness (TLOC) - Epilepsy - Multiple Sclerosis - Motor Neurone Disease - Parkinson’s Disease - General</td>
<td>Clinical validation of follow up waiting lists through virtual clinics inc GP, Social Services and Third sector input. Continue with Follow Up outpatient project to ensure solutions are identified and implemented to ensure patients receive appropriate and timely follow up time. This</td>
<td></td>
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</tr>
</tbody>
</table>
| **- Improved compliance with RTT target**  
**- Reduced clinical risk for patients and staff**  
**- More rapid diagnosis of the most serious disorders**  
**- Improved health outcome**  
**- Reduction in number of informal / formal complaints**  | **- Ongoing capacity issues**  
**- Hidden levels of demand may exist for some sub-specialities (e.g. TLOC)**  
**- Need to reduce overall wait time to 26 weeks for routine priority patients which can pull resources from urgent care**  
**- Patients need local and accessible facilities** | **- Effective utilisation of OPD capacity**  
**- Patients are offered timely follow up appointment**  
**- Patients are seen when they need to be seen i.e. See on symptoms service model (Open access)**  | **- Resources – financial and staff** |
| **2014-15** | **Clinical Director Neurology (though Neurology Directorate)** | **Clinical validation commenced Sept 2014** | **Clinical Director Neurology** |
| **2014-16** | **Directorate Support Manager** |
includes, validation and considering further opportunities to expand open access service model and self re-referral

<table>
<thead>
<tr>
<th>2.9 Time is created within existing job plans to achieve the above initiatives</th>
<th>Ensure initiatives are discussed and included in annual job planning</th>
<th>Time is created in job plans, where appropriate</th>
<th>Delay in job planning</th>
<th>Annually – in accordance with job planning timetable</th>
<th>USC Divisional Director &amp; Clinical Director Neurology</th>
</tr>
</thead>
</table>

| 2.10 Review services for people with unclear diagnosis but who need support until / if diagnosis made. | • Consider development of generic care pathway for patients with unexplained or functional neurological symptoms.  
• Review referral criteria and develop guidelines for accessing specialist services such as CNS, third sector before diagnosis. | • Patients without diagnosis can get early help and support to meet their needs.  
• Access to psychological therapy for those patients who have a functional component to presentation. | 2017 | Establish working group to scope. |
Delivery theme three: Fast and effective care

People with a neurological condition should receive fast, effective care and treatment

Delivery expectations

1. Prompt and appropriate access for all patients to clinically and cost-effective treatment and care in line with latest evidence and national standards and guidelines
2. Assessment by a specialist as appropriate, within 24 hours of admission to hospital for all patients who are admitted due to a primary or suspected neurological condition
3. Admission to specialist neurological beds for inpatient assessment
4. Seamless transfer of care from paediatric to adult neurological services through coordinated and individualised transition programmes
5. For patients who need it, timely transfer to palliative and end of life services
6. Patients' views on the effectiveness of the care they receive is recorded, and acted upon, in the development of neurological service models

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<tr>
<th>Priority</th>
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<th>Timescales</th>
<th>Lead</th>
</tr>
</thead>
</table>
| 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 | • Implement Neurologist of the Week rota  
• Look at co-location of patients with neuro conditions e.g. a stroke ward in SCCC. One bed needed for hyper acute with step down to neuro- rehabilitation unit. This should include Acute Traumatic Brain Injury. | • Facilitate provision of 24/7 Neurologist review  
• Ensure clinically urgent patients are treated on timely basis  
• Reduction in overall length of stay / bed days  
• Reduction in inpatient investigation usage, e.g. MRI  
• Reduce urgent demand for OPD consultations freeing capacity for routine and follow up priority | • No provision of Neurology beds  
• Data collection / analysis is needed to understand demand and overall success  
• Stroke ward may not have capacity.  
• Specialist nurses essential for fast effective care – can reduce unnecessary referrals / interventions and give better support to patients. | 2014-15 | Clinical Director Neurology |
<table>
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<tr>
<th>Plan</th>
<th>Action</th>
<th>Expected Outcome</th>
<th>Timeframe</th>
<th>Responsible Party</th>
</tr>
</thead>
</table>
| **3.2 Review, plan and deliver evidence-based and timely treatment, in line with latest evidence, standards and guidance** | Explore the feasibility of local bed provision, prior to commissioning of SCCC | • Repatriation of funding  
• Bed capacity and pressures in ABUHB | 2014-16 | Service Group Manager Neurology |
| | Re-audit MS service following implementation of rapid access service | • Evidence based and timely service  
• Lack of workforce resource to undertake audit | 2015 | MS Team and Neurology Directorate Management |
| | Continue to monitor suspected first seizure services with ILAE-UK first seizure audit | • Evidence based and timely service | 2015 | Neurology Directorate |
| **3.3 Ensure patients with complex needs have appropriate, timely and co-ordinated access to other specialist services as appropriate** | Consider and develop work programme, identifying appropriate leads and timescale to meet some service gaps, including:  
• Deep Brain stimulation service (National service – UHW)  
• Neuro toxin service  
• Acquired Brain injury service  
• Neurological Sleep disorder service (working with Dr Thomas in NHH)  
• Screening for mood and | • Agreed and prioritised work programme  
• Resource limitations in taking forward the work programme | Work programme to be developed by June 2015 | ABUHB Neurological Conditions Planning and Delivery Group |
<table>
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<tr>
<th>cognition issues</th>
<th>Swallowing screen training</th>
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<tbody>
<tr>
<td>Provide equitable access of Dietetic and SLT services through development of appropriate business cases, including implement rapid access nutrition support clinic in YYF and NHH and Joint SLT / Dietetic dysphagia clinics / community service across all ABUHB.</td>
<td></td>
<td>Equitable service provision across the HB</td>
<td></td>
<td>2015-16</td>
</tr>
<tr>
<td>Reorganise resource for neuro conditions for orthotics to provide more equitable service.</td>
<td></td>
<td>Equitable service provision across the HB</td>
<td></td>
<td>2015-16</td>
</tr>
<tr>
<td>Develop joint business case with Parkinsons UK for an additional Clinical Nurse Specialist with a dementia special interest</td>
<td></td>
<td>Improved access and care for PD patients with dementia</td>
<td></td>
<td>Financial resources</td>
</tr>
<tr>
<td>Finalise funding streams and service model (e.g. pharmacy support) for MS service, working in conjunction with Commissioning Team regarding repatriation issues</td>
<td>• Funded MS service meeting needs of patients</td>
<td>• Repatriation of required level of funding</td>
<td>By September 2015</td>
<td>Service Group Manager, Neurology (in conjunction with MS Team, Commissioning &amp; Pharmacy)</td>
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<tr>
<td>Consolidate Third Sector model of service delivery in OT.</td>
<td>• Improved geographical cover and responsiveness to referrals</td>
<td>• Lack of OT resource</td>
<td>• Growth in referrals to OT.</td>
<td>Ongoing</td>
</tr>
</tbody>
</table>

| 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 | See 2.2 and 2.4 |

| 3.5 Co-ordinate effective transfer | The Health Board has already agreed and implemented a local repatriation process to co-ordinate the timely transfer of patients back to ABUHB when they are declared fit for transfer. This is managed through Bed Management at the |
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.

| 3.6 Ensure that services are organised in a manner that will allow a seamless transfer of care from paediatric to adult services | relevant hospital sites. |
| 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 service provision and where improvements need to be made. Note: MND & PD links are good for accessing palliative care |
| 3.8 Develop and implement | • Reduction in number |

| Stronger / structured epilepsy transition clinics | Smoother transition for adolescent epilepsy patients with improved onward care and identification of needs. |
| Need demand / forecast data from paediatric services to determine numbers accessing the service | • Paucity of epilepsy CNS support (particularly in adult service) |
| • No specialist paediatric neuro-psychologist within ABUHB | Commencing across all UHB sites Oct 2014 |
| • Accessibility of data | December 2014 |
| Patients with Palliative Care needs are identified in a timely manner and referred on appropriately. | Neurology Directorate |
| • Lack of awareness of benefits of palliative care and how and when to refer. | 2014-15 |
| implement a PROMs questionnaire for patients with neurological conditions | condition specific PROM / PREM questionnaire | of informal/formal complaints
- Enhanced patient experience
- Engaged patient focussed services | be identified to manage this | Support Manager Neurology |
Delivery theme four: Living with a neurological condition

Whether in the community or in hospital, people are placed at the centre of care with their individual needs identified and met so they feel well supported and informed and able to manage the effects of their neurological condition

Delivery expectations

1. People have timely access to information – tailored to their needs – to ensure they understand their condition, what to look out for and what to do and which service to access should problems occur
2. People’s clinical and relevant non-clinical needs and wishes are discussed with them (and if appropriate family/carers) and recorded in a holistic care plan that is used to inform delivery of all care and reviewed on an ongoing basis
3. Care is given in the most appropriate place for the patient, as close as is possible to the patient’s home
4. People have access to timely drug and non-drug interventions, neuropsychological management, neurorehabilitation and nutritional assessment/advice according to clinical need
5. People receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help them with their care; maintain their health and improve their quality of life
6. Fewer people with neurological conditions are admitted or readmitted to hospital unnecessarily or as an emergency
7. People’s experience of NHS and third sector care and support services is integrated and seamless
8. People are supported to manage their own condition and where appropriate are able to self-refer to local physiotherapy services based on clear access criteria
9. Carers of people with long term neurological conditions have access to appropriate support and services that recognise their needs, both in their role as carer and in their own right
10. People receive fair and equitable access to hydrotherapy across Wales

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<tr>
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<th>Risks to delivery</th>
<th>Timescales</th>
<th>Lead</th>
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<tbody>
<tr>
<td>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</td>
<td>Develop Neuro-rehabilitation service using temporary funding with focus on stroke &amp; ABI in the community to demonstrate outcomes &amp; build case for long term investment to provide sustainable, equitable</td>
<td>• Aim to deliver integrated and coordinated MDT approach  • Patients feel valued members of community  • Reduced levels</td>
<td>• Insufficient resource in the community.  • Big gaps in services, e.g. no neuropsychology or access to cognitive rehabilitation  • Lack of awareness of Third sector</td>
<td>April 2015</td>
<td>CD Therapy Services</td>
</tr>
<tr>
<td>Service to include services for other neurological conditions requiring rehabilitation.</td>
<td>Education, training and information tailored for patients and carers, delivered appropriately and on individual basis.</td>
<td>Resources to support delivery of this priority</td>
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<td><strong>4.1a</strong> Evidence based follow-up in the community where possible</td>
<td><strong>4.1b</strong> Drug and device management, including a policy on self administration of medication</td>
<td><strong>4.1c</strong> Neurorehabilitation (including neuropsychological management and exercise)</td>
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</table>
| **4.1d** Posture and mobility services | **4.1e** Guidance on healthy lifestyle, nutritional advice, accident prevention and self-care to minimise ill health | **Provision of clinical psychology services to provide:**
- Specialist assessment
- Specialist intervention / therapy
- Support to carers / family
- Training and consultation to staff
- Assessing and treating patients with medically unexplained symptoms | **To offer evidence based neuro rehabilitation in line with current guidelines and models of best practice** |
| | | **Resource limitations** |
| | | **Timescale to be confirmed** |
| | | **Head of Psychology in conjunction with Neurology Directorate** |
| **Community physiotherapy rehabilitation services to be reviewed and consideration given to provision of a pan Gwent service** | | **Timescale to be confirmed** |
| | | **Head of Physiotherapy** |
| Improve timeliness of access to MDT interventions, through: | • Three sector model of delivery in OT. | • Improved geographical cover and responsiveness to referrals | • Lack of resource
• Growth in referrals
• Needs national support from NWIS. | Ongoing | Head of ABUHB OT Services |
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<tbody>
<tr>
<td>Model demand and capacity for dietetic pre-assessment for Percutaneous Endoscopic Gastrostomy (PEG) insertion to ensure service meets need, building on existing pan Gwent service.</td>
<td>Maintain current spread of local OP units for clinical neurology at Chepstow, YYF, NHH, County, SWH, YAB, RGH</td>
<td></td>
<td>In accordance with timescales set out in Integrated Medium Term Plan</td>
<td></td>
<td>Head of Dietetics</td>
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<tr>
<td>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</td>
<td>Undertake a Care plan review, involving patient, carer, social services, care providers. Third sector, doctors, therapists and GP.</td>
<td>• Patients more likely to receive relevant, up to date and reliable information at the right time and to act on it. • Reduced need for consultant / GP visits. • Maintenance of independence • Crisis avoidance</td>
<td>• Limited resource to undertake review and implement any resultant actions</td>
<td>2015 / 2016</td>
<td>ABUHB Neurological Conditions Planning and Delivery Group.</td>
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</table>
and which service to access should problems occur; it should be reviewed at appropriate points along the pathway

| 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 systems and is accessible to others who have clinical responsibility for the patient, including out-of-hours GP services, on a 24/7 basis | • Early identification of issues. | | |

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 systems and is accessible to others who have clinical responsibility for the patient, including out-of-hours GP services, on a 24/7 basis

| 4.4 Provide access to specialist expert patient and carer programmes when required and specialist support groups/social media networks | See 4.2 | |

| 4.4 Provide access to specialist expert patient and carer programmes when required and specialist support groups/social media networks | As and when required, provide access to programmes, including:
  • Self referral programmes
  • Expert patient and programme | Timely awareness and access to programmes | As and when required | Neurology Directorate working with Third Sector |

| 4.5 Work proactively with third sector services and provide effective signposting to information and support, enabling patients to easily access support services | See Theme 1 | |

| 4.5 Work proactively with third sector services and provide effective signposting to information and support, enabling patients to easily access support services | Project to be considered to explore the development of co-produced neuroscience services | • Defined terms of reference | 2015-16 | ABUHB Neurological Conditions Planning and Delivery Group. |
4.7 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

<table>
<thead>
<tr>
<th>Provision of hydrotherapy services pan Gwent. ABUHB provides equitable access based on established triage to 2 hydrotherapy pools. Any change to this service model would require significant capital investment. Provide support for Care agencies to assist with swimming sessions in public pools. Open up access to existing hydrotherapy pools outside of core hours to service user groups using principles of co-production.</th>
<th>Equitable and accessible hydrotherapy provided.</th>
<th>No capital funding for expansion. Links with public and private sector pools needed. Physiotherapists need sufficient time to facilitate people to make effective use of community exercise / activity schemes. Shortfall in workforce capacity. Governance and safety.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timescale to be confirmed</td>
<td>Head of Physiotherapy</td>
<td></td>
</tr>
</tbody>
</table>
Delivery theme five: Children and young people

Children and young people with neurological conditions receive appropriate care

Delivery expectations

1. Services are delivered in line with the standards set out in the All Wales Neurosciences Standards for Children and Young People’s Specialised Healthcare Services.
2. A continuing care pathway is put in place for any child or young person who requires bespoke packages of care
3. Properly integrated and co-ordinated transfer of care from paediatric to adult neurological services through individualised transition plans

<table>
<thead>
<tr>
<th>Children and young people</th>
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<tbody>
<tr>
<td>Priority</td>
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</tbody>
</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. | A review has been undertaken against the All Wales Neurosciences Standards for Children and Young People’s Specialised Healthcare Service and the following actions identified:  
- To continue to work with partners in education to ensure that all children with neurological conditions have equal access to education and school activities – Paediatrics/CCN & All Children’s Services & Education  
- To improve access to EEG – current waiting times for non-urgent EEG 5-6 months – Requires equipment & staff resources - Neurophysiology  
- Video telemetry not available at lead centre in Cardiff – CVUHB  
- To improve MRI access. MRI scans are carried out locally. GA MRI list waiting time is currently 8 mths – Radiology  
- To improve access to CAMHS – current wait 12 mths+ - CAMHS  
- To improve access to genetics – current wait 9 mths – CVUHB  
- Development of specialist services at lead centre to include provision of neuropsychology and telemetry – CVUHB  
- To improve transition into to Adult Services – Children’s Services/Adult Services  
- Further develop a single service for the assessment of adhd and autism – CAMHS/Children’s Services, Children’s Therapies | Not all actions identified | Timescales will be set out against specific actions in the plans | Leads will be identified against the specific actions |

5.2 Update local plans to address any shortfalls in the full implementation of the standards set out All Neurological Conditions Local Delivery Plan or Local implementation plans to be updated to Updated local delivery plans | Not all actions identified | Timescales will be set out against specific actions in the plans | Leads will be identified against the specific actions |
| 5.3 Ensure children and young people have appropriate, timely assessment of their ongoing care needs and care plan delivery | Improve timeliness of access to MDT assessment, through: Effective triage of referrals Improved education of referrers Agree a standard referral pathway and MDT assessment process Provide more information e.g. published pathway to signpost services Create a MDT for Young People transitioning to Adult services. Create a single point of access. | • Waiting times within operational standards • Transition time is vital time to maximise MDT support re. work, social, accommodation, education. • Maximise recovery potential • Maximise independence will mean less dependence on LA and PC. | • Growth in referrals • Poor quality referrals despite education • Children transitioning to adult services do not always want to engage, but may do so later on. At that point they should be able to access the same level of input as before. | December 2014 | Clinical Director Paediatrics |

| Improve timeliness of access to MDT interventions (individual and group) through: Group work to treat greater numbers of children Consultation and advice Team around the child | • Timely and effective interventions with good outcomes • Improved parental satisfaction | • Growth in demand for the service • Changing needs of client group requiring more long term intention e.g. complex CP and ASD | March 2015 | Clinical Director Paediatrics |
| / family model with MDT |  |  |  |  |
|-------------------------|------------------|------------------|------------------|
| Develop a business case for local service for ketogenic diet intervention and decommission service at Bristol. | • Less travel for patients | • Small number of patients | March 2015 (BC) | Head of Dietetics |
|  | • More appropriate and timely access to care. | • Lack of capacity in dietetics to deliver |  |  |
|  | • Reduced costs. |  |  |  |

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.

This will be taken forward by the paediatric national specialist advisory group in discussion with the Neurosciences National Specialist Advisory Group.
**Delivery theme six: Improving information**

Information systems to support high-quality care, clinical audit and to drive service improvement

**Delivery expectations**

1. IT and communication links which give clinical staff fast, safe and secure access anywhere in Wales to the information needed to care for patients
2. Patients and carers are regularly involved in the design of services; service users views on services are sought regularly and acted on to ensure continuous improvement
3. Services are audited and reviewed systematically and findings are used to improve care
4. Transparantly published information on NHS performance for neurological conditions is easily available to the public

<table>
<thead>
<tr>
<th>Improving information</th>
<th>Priority</th>
<th>Actions</th>
<th>Expected outcome</th>
<th>Risks to delivery</th>
<th>Timescales</th>
<th>Lead</th>
</tr>
</thead>
</table>
| 6.1 Ensure IT infrastructure supports effective sharing of clinical records/personalised care plans | Work with Informatics to ensure the IT infrastructure supports sharing of clinical records / personalised care plans | Fit for purpose IT infrastructure | • Poor IT infrastructure  
• Resources – staff & financial – to support delivery | 2014-17 | ABUHB Neurological Conditions Planning and Delivery Group. |
<p>| | NWIS to deliver Welsh Clinical Communications Gateway enabling clinical letter (care plan) to transfer to GP | Safe timely movement of clinical information from secondary to primary care with opportunity to make available in future via My Health online | • Poor IT infrastructure in clinical areas – e.g. slow machines | To be determined following discussions with NWIS | Assistant Director of Performance (through NWIS) |</p>
<table>
<thead>
<tr>
<th>6.2</th>
<th>Put effective mechanisms in place for seeking and using patients’ views about their experience of neuroscience and related services</th>
<th>Review current mechanism in neurology for capturing patients’ feedback and develop a programme to ensure that all services are surveyed.</th>
<th>• Learn from patient experience and modify services to better meet patient expectation</th>
<th>• Lack of staffing resource to facilitate</th>
<th>2014-15</th>
<th>Neurology Directorate</th>
</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td>Develop PROMS and PREMS (patient reported outcome / experience measures), ensuring patients, professionals and third sector are involved in the process</td>
<td>• Learn from patient experience and modify services to better meet patient expectation</td>
<td>• Lack of staffing resource to facilitate</td>
<td>Dec 2015</td>
<td>Directorate Support Manager</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Involve carers in the design of services through ABUHB Carers Measure implementation structure</td>
<td>• Carers are fully involved and services modified to better meet carer expectation</td>
<td>• Identifying and engaging new carers</td>
<td>2014-2016</td>
<td>ABUHB Carers Measure</td>
</tr>
<tr>
<td>6.3 Ensure full (100%) participation in national clinical audits - to support service improvement and support medical revalidation of clinicians – and</td>
<td>Participate in national clinical audits, as and when required, and act upon findings</td>
<td>Health Board fully participates in National Audits</td>
<td>Lack of staffing resource to allow participation and data collection</td>
<td>As and when required</td>
<td>Lead will depend on the audit</td>
<td></td>
</tr>
</tbody>
</table>
ensure that findings are acted on. In addition, participation of all:

- **6.3a** neurorehabilitation services caring for Welsh patients, in the UK rehabilitation outcomes collaborative
- **6.3b** spinal injury units caring for Welsh patients, in the national spinal cord injury database
- **6.3c** neurosurgery units caring for Welsh patients, in the consultant outcomes publications programme

| 6.4 Participate in and act on the outcome of peer review | Quality and safety meetings are held in Neurology | A strong foundation of monitoring practice, group discussion, sharing learning and mistakes and continuous improvement. | Implemented | - |
| 6.5 Publish regular and easy to understand information about the effectiveness of neuroscience services | Health Board representative to play an active role in agreeing the outcome measures and format of reporting to be developed through the All Wales Neurological Conditions Delivery Plan Implementation group. Pursue the outcome of PROMS work to describe the value of the service to Gwent residents. | • Information available to the public about effectiveness of services provided to those affected by a neurological condition | • Outcome data may be difficult to extract | • As a minimum annually, in line with Welsh Government timescale |

| 6.6 Establish an annual national audit day for neurological services provided to Welsh Patients | This will be taken forward on an All Wales basis and the Health Board will participate as appropriate | Health Board’s representative on the All Wales Neurological Conditions Delivery Plan Implementation group Neurology Directorate |
Delivery theme seven: Targeting research
A commitment to research, delivering improved diagnosis, management, treatment options and outcomes

Delivery expectations
1. Flourishing research into and teaching and training related to neurological conditions to improve care and treatment, making NHS Wales an attractive place to live and work for high calibre clinicians
2. Rapid uptake of research findings

<table>
<thead>
<tr>
<th>Priority</th>
<th>Actions</th>
<th>Expected outcome</th>
<th>Risks to delivery</th>
<th>Timescales</th>
<th>Lead</th>
</tr>
</thead>
</table>
| 7.1      | Continue to support and encourage protected teaching time to clinically active staff (in primary as well as secondary and tertiary care) | Greater awareness of how to manage patients with neurological conditions | • Lack of resource  
• Time constraints due to small number of staff | In accordance with timescales for annual job planning or Performance & Development Review | Clinical Director, Neurology  
Service Group Manager, Neurology |
|          | Neurology NCS to participate in training for ward staff | | | | |
|          | Undertake a baseline assessment in conjunction with Research & Development to identify current clinical trial Epilepsy consultants involved in recruiting for multi-centre SANAD II study. | Greater awareness of how to manage patients with neurological conditions | • Lack of resource  
• Time constraints due to small number of staff | 2015  
Recruitment to commence shortly. | Neurology Directorate |
<table>
<thead>
<tr>
<th>7.3 Build on and extend academic training schemes to develop a highly skilled workforce</th>
<th>Continue to support Welsh Clinical Academic Trainees (WCAT)</th>
<th>Development of highly skilled workforce</th>
<th>2014-2017</th>
<th>Neurology Directorate</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Incorporate Carer awareness into protected teaching time at University</td>
<td>Pre-registration nursing students are Carer aware prior to embarking on their ABUHB careers</td>
<td>Lack of resource to deliver rolling programme</td>
<td>2014-2016</td>
</tr>
<tr>
<td>7.4 Promote collaboration with key research initiatives, including the NISCHR-funding infrastructure</td>
<td>Identify and promote collaboration with key research initiatives</td>
<td>Neurology Directorate collaboration with key research initiatives</td>
<td>2014-2017</td>
<td>Neurology Directorate</td>
</tr>
<tr>
<td>7.5 Increase the number of non-commercial clinical research portfolio and commercial studies</td>
<td>See 7.2</td>
<td></td>
<td></td>
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<tr>
<td>7.6 Increase the number of people with a neurological condition entered into clinical trials and number retained on longitudinal trials</td>
<td>Develop awareness and communication strategy for clinical trials</td>
<td>Agreed awareness and plan that can be considered at Neurology Directorate</td>
<td>2015-16</td>
<td>Directorate Support Manager (with support from Neurology Directorate)</td>
</tr>
<tr>
<td>7.7 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>
<td>This is already in place</td>
<td></td>
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</table>

| 7.8 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 | Develop a case, in conjunction with Powys LHB, for a joint senior lecturer / honorary consultant post with Cardiff University as a focus for research and application of new treatments. |

- Limited resource
- Lack of engagement

By March 2015
Service Group Manager, Neurology
5. WHSSC ACTION PLAN

WHSCC has developed its own action plan. This can be viewed via the Health Board’s Local Delivery Plan website.

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 the 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.
Appendix 1

ABUHB Neurological Conditions Planning & Delivery Group
Terms of Reference

PURPOSE

The ABUHB Neurological Conditions Planning & Delivery Group will bring together health professionals working across primary and secondary care with Public Health Wales, WHSCC, patient representatives and third sector to improve services for patients with a neurological condition in line with ‘Together for Health – a Neurological Conditions Delivery Plan’

AIMS

The principle aims of the Group are to lead service change in order to:

- Raise awareness of neurological conditions
- Provide high quality detection and treatment of all neurological conditions
- Plan high quality, effective, person centred care for anyone affected by a neurological condition

OBJECTIVE

The Group will plan and oversee delivery of the ABUHB Neurological Conditions Delivery Plan.

The work programme and timescales to deliver the objectives will be agreed by the Group in accordance with the agreed Local Delivery Plan. It will take into account further direction from Welsh Government and the All Wales Neurological Conditions Implementation Group.

ACCOUNTABILITY

The reporting arrangements for the Planning & Delivery Group are to be determined.

FREQUENCY

The Group will meet on a quarterly basis.

COMMUNICATION AND STAKEHOLDER ENGAGEMENT

The Group will agree a communication and stakeholder engagement process in order to ensure that all stakeholders are informed and involved as appropriate in the work of the Group.
## MEMBERSHIP

<table>
<thead>
<tr>
<th>Category</th>
<th>Joint Chairs</th>
<th>Executive Director of Therapies &amp; Sciences Clinical Director Neurology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secondary Care Management</td>
<td>Alison Shakeshaft</td>
<td>Executive Director of Therapies &amp; Sciences Clinical Director Neurology</td>
</tr>
<tr>
<td></td>
<td>Dr Gareth Llewelyn</td>
<td>Executive Director of Therapies &amp; Sciences Clinical Director Neurology</td>
</tr>
<tr>
<td></td>
<td>Caroline Bird</td>
<td>Service Group Manager, Unscheduled Care Division</td>
</tr>
<tr>
<td></td>
<td>Janet Kelly</td>
<td>Head of OT (representing all Therapies)</td>
</tr>
<tr>
<td>Primary Care</td>
<td>Dr David Minton</td>
<td>NCN Lead, Neurology</td>
</tr>
<tr>
<td>Public Health</td>
<td>Jane Layzell</td>
<td>Consultant in Public Health</td>
</tr>
<tr>
<td>Public / Patient representative</td>
<td>David Murray</td>
<td>Wales Neurological Alliance</td>
</tr>
<tr>
<td>Third sector representative</td>
<td>To be confirmed</td>
<td></td>
</tr>
<tr>
<td>WHSCC or Commissioning</td>
<td>To be confirmed</td>
<td></td>
</tr>
<tr>
<td>representative</td>
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