Together For Health –
A Neurological Conditions Delivery Plan

A delivery plan up to 2017 for the NHS and its partners
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Mark Drakeford AM, Minister for Health and Social Services

Ministerial Foreword

The Welsh Government wants to ensure that those affected by a neurological condition have timely access to high-quality care, integrated with social services where appropriate, irrespective of where they live and how these services are delivered.

By 2017, NHS Wales, working with its partners, must deliver the new commitments to the population of Wales.

Health boards must take local ownership and put effective plans in place to deliver well co-ordinated services. Specialised care needs to be well connected to local services, providing better patient experience and outcomes. In particular, it is essential that NHS Wales and its partners focus on meeting our population needs, reducing inequalities in health and variation in access to services across Wales.

This document - one of a suite of national service delivery plans – is designed to develop and improve services for people with neurological conditions. It requires NHS Wales and its partners to:

- Carry out local population needs assessments
- Analyse the gap between current provision and the requirements in this Plan
- Plan and take action to close that gap
- Demonstrate, through regular reporting, improved outcomes for patients, with an emphasis on reducing health inequalities

I believe we can achieve high-quality prudent care for people with a whole range of neurological conditions. This depends on a partnership between the NHS and the user, in which the expertise of both is recognised and put to work, jointly, to bring about improvement individually and collectively. That is what this plan sets out to achieve.
Neurological conditions affect many people in Wales. These conditions can have a very serious and lasting impact on the lives of individuals and their families. It is vital that the response of the NHS and its partners is timely, prudent and effective.

This delivery plan provides the necessary guidance and clarifies required standards. We must provide excellent care, whether that is through timely diagnosis, appropriate treatment or continuing support. The NHS cannot do this alone. It must work with partner organisations in the public and voluntary sector. By focusing on quality and individuals’ experiences we will be able to deliver the improvements we all want to achieve.
1. **Overview**

Neurological conditions affect approximately 500,000¹ people in Wales. The Neurological Conditions Delivery Plan provides a framework for action by health boards and 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:

- Delivery theme one: Raising awareness of neurological conditions
- Delivery theme two: Timely diagnosis of neurological conditions
- Delivery theme three: Fast and effective care
- Delivery theme four: Living with a neurological condition
- Delivery theme five: Children and young people
- Delivery theme six: Improving information
- Delivery theme seven: Targeting research

For each theme it sets out:

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

These complement the quality requirements endorsed in the *Report of the Task and Finish Group on Care Pathways for Long Term Neurological Conditions*, which must be delivered alongside this delivery plan.

Services for people who are at risk of, or who have had, a stroke are covered separately in the Stroke Delivery Plan, although some actions may overlap or benefit from a co-ordinated approach.

2. **Strategic context**

The Welsh Government’s *Programme for Government* and its five-year NHS Plan, *Together for Health*, sets out an ambitious programme for health and well-being in Wales so that:

- Health and well being will be better for everyone
- Access to care and patient experience will be better
- Better service safety and quality will improve health and well being outcomes

*Achieving Excellence: The Quality Delivery Plan* for the NHS in Wales for 2012-16 describes a journey to bring about excellence in our services. It outlines actions for

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¹ Figure estimated based on condition prevalence
quality assurance and improvement. We commit to a quality-driven NHS that provides services that are safe, effective, accessible, affordable, sustainable and that come with an excellent patient experience.

Much of the ongoing care and support for people with long term conditions can be provided by primary and community care at or close to home. Setting the Direction (2010) envisages health boards, local government, third and independent sector partners working together to assess local community and individual need and deliver local integrated health and social care designed to meet that need. The Welsh Government plan Delivering Local Health Care, published in June 2013, brings a renewed focus to the need for rapid change and improvement in primary and community care settings.

This delivery plan should be read alongside the Delivering End of Life Care, Stroke, Heart Disease, Critically Ill and Respiratory Conditions delivery plans, as well as the Welsh Implementation Plan for Rare Diseases, once published.

The Welsh Government is committed to the delivery of services centred on people’s needs as set out in its framework to strengthen Welsh language provision ‘More than just words…’ (2012). This includes satisfying the needs of Welsh speakers and their families or carers, by ensuring they are able to receive services in their own language through the whole care process if they wish. This is especially important for people with some neurological conditions, such as dementia or a brain injury, who may lose their second language. There can be many other communication challenges and barriers people face when accessing health services. Attention to addressing the communication needs all of health service users needs to be an integral element of service planning and delivery.

Supporting people living with a neurological condition is not an issue confined to health services. Local government services such as housing, education, leisure and social services in particular have a vital role to play. This plan should also be considered alongside our Sustainable Social Services: A Framework for Action, Framework for Action on Independent Living and the Social Services and Wellbeing Bill.

Carers are an important consideration when developing services for people with neurological conditions. This plan sets some specific actions and assurance measures linked to the role of carers. In addition, when implementing this delivery plan, the role of the carer needs to be considered in line with the Welsh Government’s Carers Strategy for Wales (2013).

The future development of neurological services needs to be considered in relation to the Welsh Government’s emerging themes of co-production and prudent healthcare. This plan will establish a pilot project that develops a co-produced model of care, centred on the patient and involving input from all relevant organisations.
3. Our vision

The Programme for Government sets out the overall population outcomes that we want to achieve; better health for all and reduced inequalities in health. Reducing the impact of neurological conditions on the lives of people in Wales will contribute significantly to these outcomes.

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
  - devoid of any prejudice in relation to their personal situation

4. Why is this a priority?

There are good reasons for neurological conditions to be a key priority area for NHS Wales.

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% of acute hospital admissions and are the third most common reason for seeing a GP\(^2\). 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\(^3\).

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\(^4\).

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 2%-3% of the child population will have some level of disability leading to additional health and educational needs. The vast majority of

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\(^3\) Neuro Numbers, Neurological Alliance  www.neural.org.uk/store/assets/files/20/original/NeuroNumbers.pdf

child disabilities are neurological in origin with paediatric epilepsy the most common neurological disorder affecting about 0.7% of all children⁵.

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. (Stroke is covered in the Stroke Delivery Plan⁶)
- **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.

The joint report by the Association of British Neurologists and the Royal College of Physicians (2010) outlined the major problems that exist with the current way that neurological services are delivered across the UK. This concern was confirmed and highlighted by detailed independent reports by the National Audit Office (2011) and UK Public Accounts Committee (2012) that outlined the lack of neurological expertise, both in hospitals and in the community, and the wide variability in accessing services.

All three reports agreed that despite the complex needs of those with neurological conditions (health, social care, employment, benefit services, transport, housing and education), co-ordination of care for individuals was poor, and there was often a lack of integration between health and social services.

Not only do people need rapid assessment and the best possible treatment, they also need ongoing support and information about choices when treatment may no longer be effective. The NHS must be able to explain clearly the options and their implications to an individual and their family at the end of life. The NHS in Wales must be committed to taking the lead, working with its partners, to delivering this at every stage of the patient journey.

Individuals who have a neurological condition and a co-existing learning disability should not be disadvantaged in gaining access to high-quality assessment, treatment and support for their health problems. Indeed, they will often require more

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


time, more specialist skills and more resources in order to receive a clear diagnosis and interventions that are appropriate and sensitive to their specific needs.

Across all conditions, the focus needs to be on diagnosis, treatment and the longer term support of people with neurological conditions. For some people with a neurological condition it will also be appropriate to refer to the Delivering End of Life Care Delivery Plan.

5. Our journey so far

Much has already been achieved in Wales, but there is more to do. Following the outcome of the Adult Neurosciences Review in 2008, Local Health Boards developed two implementation plans, one for North Wales and one for Mid and South Wales, and delivery began in the autumn of 2009. As a result of the implementation, services such as neurology and neuro-rehabilitation are being delivered more locally to patients, which will greatly reduce the need for patients to travel and ultimately help improve their health and quality of life.

Within North Wales, a neuroscience network has been established to deliver high-quality services with continuous improvement integrated into everyday working. The expertise, and findings, from the work of this group needs to inform the work of the new neurological conditions implementation group and be shared as best practice as appropriate.

The task and finish group on care pathways for long term neurological conditions published its report and recommendations in 2009 endorsing a set of generic principles for service development, which aims to support people with long-term neurological conditions. Subsequently, a number of care pathways for neurological conditions including epilepsy, motor neurone disease, muscular dystrophy, Parkinson’s disease and acquired brain injury have been published.

The All Wales Neuroscience Standards for Children and Young People’s Specialised Healthcare, published in July 2009, set standards for the care and a number of key actions.

Significant work has been undertaken across Wales implementing the recommendations of the Cross Party Group on Muscular Dystrophy: Access to Specialist Neuromuscular Care in Wales (Thomas Report). Important developments include the establishment of an All Wales Neuromuscular Network, the appointment of family care advisors and improvements to physiotherapy especially for young adults.

6. What do we want to achieve?

This Neurological Conditions Delivery Plan and the new implementation group will spur health boards, trusts, local government and the third and independent sectors to focus collectively on further action to meet the needs of people with a neurological condition.
For many people living with a neurological condition, the main issue is improving the quality of their lives. This delivery plan is designed to put services, care and support in place to promote self care, supporting people to manage their symptoms and live as independently as possible. The plan does not address individual neurological conditions separately as there are so many elements of service provision common to different conditions.

Delivery theme one: Raising awareness of neurological conditions
Increased awareness of neurological conditions and their symptoms.

The diagnosis or onset of a long-term neurological condition generally marks the beginning of profound changes in the life of the person and the lives of their family and friends. It may affect relationships, career prospects, income and expectations for the future.

Everyone’s experience of living with a neurological condition will be different but there are lots of issues and challenges that are shared by many people living with the condition. For people with neurological conditions, stigma and discrimination often result from a lack of public and professional awareness of the condition. This was highlighted in the cross party group for neurosciences report - Inquiry into the Understanding of Neurological Conditions within Emergency Units.

In general, the population do not understand how widespread the conditions are or; their challenges or impact. Therefore, there is a need to increase public awareness of neurological conditions, which would, in turn, reduce their stigma and remove discrimination. Many people with a neurological condition worry about what others will think and consequently attempt to hide their condition. Understanding their illness and taking an active role in managing their condition will increase the possibility of a person maintaining independence. As well as individual education, broader public awareness campaigns and education for health providers will improve understanding of the conditions, removing the stigma associated with them.

The public should also be made aware of any relevant preventative actions they can take such as ways to avoid, or minimise, accidents or taking folic acid while trying to conceive and for the first 12 weeks after conception to reduce the risk of neural tube defects such as spina bifida.

Making a difference can only be achieved through partnership working between Welsh Government, the NHS, local authorities (with particular emphasis on education, social services, housing and leisure departments), the third sector and others.

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

**Specific priorities 2013-17**

1. Work with a broad range of partners (including local service boards, educational institutions and the third sector) to:
   - Raise awareness of neurological conditions
   - Signpost existing sources of information, advice and support

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

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

4. Public Health Wales, in partnership with health boards, to deliver a national awareness campaign through community pharmacies in Wales

**Responsibility to develop and deliver actions**

Health boards, working with partners and with national leadership from Public Health Wales

**Potential assurance measures**

Percentage of population with an awareness of neurological conditions
(Source: to be developed via patient survey or opinion polls)

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**Delivery theme two: Timely diagnosis of neurological conditions**

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

National guidelines set out the Welsh Government’s expectations of effective care for people with a neurological condition. These include the National Institute for Health and Care Excellence (NICE) guidelines, the Quality and Outcomes Framework for GPs, care pathways and other documents such as professional standards or publications such as the service development directives. Services should be developed and delivered in line with the relevant guidance for each condition.
The first point in the patient pathway for someone presenting with neurological symptoms is usually a visit to their GP. Neurological conditions often present a challenge as symptoms can be mistaken for other more common conditions leading to misdiagnosis before finally making a referral to a specialist. Basic education for GPs, and other members of the primary care team, will improve their knowledge and awareness of neurological conditions thus reducing possible delays in referrals.

All GPs are expected to have direct access to a range of diagnostic tests and procedures for those people where a neurological condition is suspected. This includes access to neuroscience investigations such as CT and MRI scans and nerve conduction studies (NCS), where appropriate. It also includes being able to access specialist advice by telephone or e-mail contact within 24 hours and assessment from members of the multi disciplinary team.

Individuals and their families and carers can experience distress and anxiety while waiting for a diagnosis. Early diagnosis can reduce this and lead to earlier treatment and effective management.

People with family members who have inherited neurological conditions should have access to appropriate genetic advice and testing. The person and their family should be offered counselling, access to neuropsychology/psychiatry and information about the implications of their condition so that they can make informed decisions about testing, treatment and other life choices.

**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

**Specific priorities 2013-17**

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
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
3. Ensure timely access to multidisciplinary assessment to support diagnosis where necessary
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
5. Provide specialist advice within 24 hours (on a seven-day-a-week basis) for those admitted to hospital with a primary or suspected neurological condition - reorganising delivery of services to achieve this where necessary

6. Provide rapid access to urgent outpatient services with specialist clinical expertise for referrals to meet GP and patient need

7. Ensure follow-up arrangements for patients are appropriate and timely

8. Time is created within existing job plans to achieve the above initiatives

Responsibility to develop and deliver actions

Health boards and the Welsh Health Specialised Services Committee

Potential assurance measures

Rate of missed or delayed diagnosis (evidenced through serious adverse incidents or patient complaints)

Delivery theme three: Fast and effective care

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

Approximately one in seven consultations in primary care is for a nervous system symptom of some kind and up to one in five emergency admissions to hospital are due to a neurological problem\(^7\). Referrals to neurology outpatients are also increasing and people may not be diagnosed until several months after their first visit to the GP. Once a diagnosis has been given, support in the community is variable and many people are left feeling isolated knowing that their condition is “long term” and will be with them for the rest of their lives.

Some patients with a neurological condition will need to attend hospital for some part of their treatment, although it is hoped that an increasing proportion may be treated entirely in primary and community care. Hospital services should be co-ordinated with excellent communications and handovers across boundaries, both within the acute setting and primary care. Services should be delivered promptly with a focus on positive patient experience.

A detailed framework for delivering high-quality evidence-based neuroscience services, through well organised multi disciplinary teams, is provided in national guidance, such as National Institute for Health and Care Excellence (NICE) guidance and care pathways. Compliance with such frameworks will be central to the delivery of this plan.

\(^7\) Action on Neurology, NHS Institute for Innovation and Improvement

Overall, the numbers of neurological specialists of all kinds be they clinicians, healthcare scientists, nurses or therapists, remain low. However, neurological services are also often not organised in a way that may be responsive to patients needs or make best use of resources. While increased resources are important, it is clear that these resources need to be used differently to the way they are at present.

Health boards, working with the Welsh Health Specialised Services Committee (WHSSC), should ensure specialised neuroscience services are planned and configured in a way that provides the highest standards of multidisciplinary care and outcomes. The NHS should support patients and families with travel and accommodation arrangements in line with the All-Wales Protocol for Non-Emergency Patient Transport.

There is no single model for neuroscience services since they all serve different communities and different patients, so what works in one organisation or health community might not work in another. What is important are the principles behind change and seeing how a change in one organisation may be translated into another.

For many, managing their neurological condition will not be about recovery, but about delaying and/or diminishing the effects of inevitable deterioration given the progressive nature of the condition. Services need to be provided for this process to be managed with dignity and self-determination as effectively as possible.

People in the later stages of long-term neurological conditions are to receive access to co-ordinated, effective and compassionate palliative and end of life care when they need them to control symptoms, offer pain relief and meet their needs for personal, social, psychological and spiritual support; in line with the Delivering End of Life Care Delivery Plan.

The views of patients on the outcomes of their care should be an important tool in developing appropriate services for the future. Patient reported outcome measures (PROMs) collect information on the effectiveness of care delivered to patients as perceived by the patients themselves. This plan will include the requirement to establish, and implement, a PROMs questionnaire for people with neurological conditions to support this aim.

**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

Specific priorities 2013-17

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

2. Review, plan and deliver evidence-based and timely treatment, in line with latest evidence, standards and guidance

3. Ensure patients with complex needs have appropriate, timely and co-ordinated access to other specialist services as appropriate

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

5. Co-ordinate effective transfer of care and timely repatriation of patients from specialist neurological beds to local hospitals as soon as clinically appropriate, following treatment in line with transfer of care plans and the All-Wales repatriation policy

6. Ensure that services are organised in a manner that will allow a seamless transfer of care from paediatric to adult services

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

8. Develop and implement a PROMs questionnaire for patients with neurological conditions

Responsibility to develop and deliver actions

Health boards and the Welsh Health Specialised Services Committee

Potential assurance measures

Quality of neurological patient care
Number of unscheduled hospital admissions due for a primary neurological condition
Number of delayed discharges due to lack of appropriate community services
(Source: to be developed via patient survey)
People with neurological conditions often need a wide range of services to meet their ongoing physical, psychological and social needs. Services need to be well co-ordinated to avoid duplication or gaps in provision and to ensure that individual organisations and professionals know who else is involved. No matter what type of support is needed, the way it is delivered can have a major impact on the individual's life.

Using medicines effectively is vital to managing many long-term neurological conditions, particularly Parkinson’s disease and epilepsy. It is important to ensure people with a neurological condition admitted to hospital are able to receive their medication on time. People may also need advice and support in managing side effects or if they are considering stopping treatment and should have the opportunity to discuss this with their health professional. Regular reviews of medication are important.

People should have access to services which promote healthy living and prevent complications, such as: the national exercise referral scheme; guidance on accident prevention; healthy lifestyle, nutrition and self-care to minimise ill health. They should also be made aware of third sector organisations that can provide expert advice and support. People with a neurological condition, who would benefit from physiotherapy, should be able to self-refer to local physiotherapy services.

The Welsh Government emphasises the central importance of a primary and community-led NHS and outline this approach in the policy document Setting the Direction (WG, 2010) and Delivering Local Health Care - accelerating the pace of change (2013). Key areas of service redesign need to address ways in which enhanced community care for neurological conditions could reduce the high numbers of emergency admissions to hospitals across Wales. Developing multi-sector locality networks and community resource teams have an important role to play in improving care. Consideration should be given to incorporating innovations in telemedicine for patient consultation and treatment reviews, especially for patients in rural areas.

The care planning process needs to be well co-ordinated to ensure the individual is receiving the right care at the right time in the most appropriate setting to enable them to live as independently as possible. This involves a multi-disciplinary and integrated approach, ensuring a person’s individual treatment and support needs, such as access to information, are assessed, recorded and met. Personalised care plans should be produced in collaboration with individuals and should take account of co-morbidities. This approach, completed by the appropriate lead professional (in primary or secondary care), should ease transition between services and also improve communication between the NHS and social services. Crucially, they must be easily available to all those involved in an individual's care.
A responsive and efficient neurorehabilitation service, provided as locally as possible, is vital and should be considered and offered to all who would benefit from it. Anxiety and depression are common in chronic conditions and neurological conditions in particular, and can reduce quality of life. Appropriate neuropsychological and neuropsychiatric support and treatment should be provided to those who have functional neurological symptoms and to those with anxiety, depression and other mental health disorders that may be frequently part of the neurological condition or a secondary effect.

Posture and mobility services also have a key role in maintaining independent living for significant numbers of people with a neurological condition.

The third sector has an important role to play both in the provision of rehabilitation services, supporting independent living skills and have developed a wide range of services in partnership with health and social care organisations to improve access to rehabilitation and other forms of support. Health boards should work proactively with the third sector, involving them in service planning, to deliver an integrated neuroscience care service.

Family members and friends who care for and support people with long-term neurological conditions are often vital to the progress, wellbeing and quality of life of the person. Most choose to take on this role willingly, but it is important that health and social care services enable them to exercise choice, support them effectively and protect their health and independence.

The Framework for Self Care, currently under development, will include an action to raise public and professional awareness of the information, support and advice available nationally and in the local community for individuals, their families and friends. It will build on the education programmes currently available such as the Public Health Wales education programme for patients, designed to give people confidence in managing their long term health conditions.

Co-production can be a strong and effective tool to develop services that reflect the needs of service users and the wider group of service developers and deliverers. Under this plan, the Welsh Government, in conjunction with the implementation group, local government and the third sector should consider options for the development and establishment of a co-production project for neurological conditions services, based on the principles of prudent healthcare.

**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

Specific priorities 2013-17

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
   - Neurorehabilitation (including neuropsychological management and exercise)
   - Posture and mobility services
   - Guidance on healthy lifestyle, nutritional advice, accident prevention and self-care to minimise ill health

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

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. Provide access to expert patient and carer programmes when required

5. Work proactively with third sector services and provide effective signposting to information and support, enabling patients to easily access support services

6. Develop a project to explore the development of co-produced neuroscience services

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

Responsibility to develop and deliver actions

Health boards, Welsh Health Services Specialised Services Committee, local government, Welsh Government and the third sector

Potential assurance measures

Percentage of people with a diagnosis of neurological condition who have a care plan

Percentage of patients and carers satisfied with care
(Source: to be developed via patient survey)

Delivery theme five: Children and young people

Children and young people with neurological conditions receive appropriate care.

Children and young people with serious neurological conditions achieve the best quality of life, through the provision of excellent diagnosis, investigation, intervention, management and information. The NICE clinical guidelines note that optimal management improves health outcomes and can also help to minimise other, often detrimental, impacts on social, educational and employment activity.

In July 2009, the Welsh Government issued the All Wales Neurosciences Standards for Children and Young People’s Specialised Healthcare Services. The document identifies and defines specialised neurosciences standards of care for children and young people in Wales, and how these services must be delivered. The All Wales Neurosciences Standards should also be read and used in conjunction with the National Service Framework for Children, Young People and Maternity Services in Wales (Children’s NSF), in particular chapter two, “Key actions universal to all children”, which is relevant to all services and all children and young people.

The standards and key actions apply to all children and young people up to 18. However, key actions that relate to transition apply to all young people who may require ongoing services beyond this age range. The age for transition to adult
services must be flexible to ensure that all young people are treated by the most appropriate professional and in the most appropriate setting. This will depend on the young person’s mental, emotional and physical development. Poorly planned transition from young people’s to adult-oriented health services can be associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences.

The *Children and Young People’s Continuing Care Guidance* is designed for use by all those planning and providing children’s continuing care services in health boards and local authorities and their partners. It describes the interagency process, led by health boards, that all organisations should implement in assessing needs and putting in place bespoke packages of continuing care for those children and young people who require it because their needs cannot be met by existing universal or specialist services alone.

As one third of a paediatrician’s workload will involve children who have a neurological condition, there is also the need to consider whether additional actions should be developed to address those children not accessing specialised neuroscience services.

**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

**Specific priorities 2013-17**

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.

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*

3. Ensure patients with complex needs have appropriate, timely assessment of their continuing care needs

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.
Responsibility to develop and deliver actions

Health boards, Welsh Health Services Specialised Services Committee, local government, working with partners and with national leadership from Public Health Wales

Potential assurance measures

Number of unscheduled paediatric hospital admissions due to an acute neurological condition
Number of delayed discharges due to lack of appropriate community services

Delivery theme six: Improving information

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

The development of excellence in care for people with a neurological condition is heavily dependent on the quality of information available, both up-to-date patient information and the data which evidences treatment outcomes and informs the development of best practice. Information on NHS performance is essential to inform policy, drive continuous improvement in service delivery and to provide transparent information to the public on the services which matter to them.

Realising the benefits of this delivery plan will require continuous improvement in all these areas and especially in developing patient records and personalised care plans accessible to all those who need to see them.

Using information from service users on their experience of NHS care is a critical tool for improving future patient experience. Health boards in collaboration with the third sector must use effective ways of finding out patients' views and using these to plan and deliver better care.

Participation in national clinical audits is a requirement which health boards must ensure is achieved. Full (100%) participation is required to effectively monitor progress in the delivery of care for people with a neurological condition, to provide comparative outcome data and allow effective benchmarking. It is essential that this data is used for direct service improvement, to look at clinical performance, and for research. Advice is provided for NHS Wales by the National Clinical Audit and Outcome Review Advisory Committee.

The Welsh Government expects health boards to make information publically available on the services that they provide and their effectiveness. This delivery plan requires regular public reporting on the quality and delivery of services for people with a neurological condition. These requirements are set out in the final section of this plan, what needs to happen when.
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. Transparently published information on NHS performance for neurological conditions is easily available to the public

Specific priorities 2013-17

1. Ensure IT infrastructure supports effective sharing of clinical records/personalised care plans

2. Put effective mechanisms in place for seeking and using patients’ views about their experience of neuroscience and related services

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 services caring for Welsh patients, in the UK rehabilitation outcomes collaborative
   - spinal injury units caring for Welsh patients, in the national spinal cord injury database
   - neurosurgery units caring for Welsh patients, in the consultant outcomes publications programme

4. Participate in and act on the outcome of peer review

5. Publish regular and easy to understand information about the effectiveness of neuroscience services

6. Establish an annual national audit day for neurological services provided to Welsh Patients

Responsibility to develop and deliver actions

Health boards, NHS Wales Informatics Service, Healthcare Inspectorate Wales

Potential assurance measures

Percentage compliance with national audit
(Source: National Clinical Audit and Outcome Review Advisory Committee)
Delivery theme seven: Targeting research
A commitment to research, delivering improved diagnosis, management, treatment options and outcomes

Research is critical to effective care for people with a neurological condition and the NHS must respond to the latest research evidence in the planning and delivery of its services. Neuroscience research in Wales is also vital in attracting investment and first class NHS staff. Wales already has an excellent reputation in this area.

Neuroscience research results in ongoing improvements in patient outcomes. The NHS must promote research and ensure appropriate access to clinical trials. Patients benefit through the ongoing implementation of evidence based best practice. In the longer term, patients also benefit from better understanding of the causes of neurological conditions. Promoting a research culture in hospitals attracts highly-skilled personnel to Wales, providing opportunities to develop skills and gain experience of delivering innovative treatments.

The Welsh Government, through the National Institute for Social Care and Health Research (NISCHR), funds a number of initiatives relevant to neurological conditions. This includes support for the Neurodegenerative Diseases and Dementia Research Network (NEURODEM), the Wales Epilepsy Research Network (WERN), the Wales Gene Park and the Cardiff Fetal Tissue Bank. NISCHR also provides responsive-mode competitive research funding and works with other UK funders to maximise opportunities for researchers in the field of neuroscience to apply for research funds.

Health Research Wales, another NISCHR-funded initiative, works with the NHS to deliver fast-track, high-quality, industry-sponsored research including research into neurological conditions.

It also needs to be recognised that the third sector are key partners in the development of research, both as a funder of research and supporting patient involvement in clinical trials and social research.

Delivery expectations
1. Flourishing research into 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

Specific priorities 2013-17
1. Support and encourage protected teaching time for clinically-active staff (in primary as well as secondary and tertiary care)
2. Support and encourage protected research time for clinically-active staff (in primary as well as secondary and tertiary care)
3. Build on and extend academic training schemes to develop a highly skilled workforce
4. Promote collaboration with key research initiatives, including the NISCHR-funding infrastructure
5. Increase the number of non-commercial clinical research portfolio and commercial studies
6. Increase the number of people with a neurological condition entered into clinical trials and number retained on longitudinal trials
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
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

Responsibility to develop and deliver actions
Health boards, Welsh Health Services Specialised Services Committee, Local Government, working with other partners including Public Health Wales, universities and pharmaceutical companies and NISCHR-funded infrastructure groups

Potential assurance measures
Number of people with a neurological condition entered into clinical trials and number retained on longitudinal trials (Source: NISCHR)

7. Working together

People with neurological conditions may have complex needs that affect their ability to function not only physically but also emotionally and mentally. The condition may impact on different aspects of their lives including family and carers, education, housing, finance and employment. A person-centred service therefore requires that all aspects of an individual’s life are taken into account when assessing needs, often involving a number of different professionals and organisations across health and social care.

Therefore, all of us have a part to play in our efforts to ensure effective diagnosis, treatment and ongoing support for people with a neurological condition.

The Welsh Government is responsible for strategic leadership through setting the health outcomes it expects for the people of Wales. It holds the NHS to account on how well it delivers the outcomes we want. The lines of accountability are via the chairs of the health boards and trusts to the Minister for Health and Social Services.
The chief executives of the health boards and trusts report to the chief executive of NHS Wales who is also the director general of the Welsh Government’s department for health and social services. There are regular performance reviews and progress against this Delivery Plan will be monitored as set out in sections eight and ten.

**NHS Wales** is made up of seven health boards and three NHS trusts. Health boards are responsible for planning and delivering local services to diagnose, treat and care for people affected by a neurological condition. All seven health boards plan and fund a defined range of specialist services through the Welsh Health Specialised Services Committee (WHSSC).

To plan services effectively to meet population need and reduce variability of services, health boards must work together and also build and lead coalitions with: NHS England, NHS trusts, pharmacists, local government and the third sector including local neurological alliances. Patients’ and carers’ views also need to be sought on current service provision and they should be involved in future service development. NHS organisations must ensure actions are delivered seamlessly across primary and secondary care and local communities. Charities/third sector organisations supporting people with neurological conditions play an important role in meeting the needs of people affected by a neurological condition and their contribution needs to be part of this integrated suite of services. In some cases, independent hospices also play an important role in meeting the needs of people at the end of life.

Public Health Wales provides health boards with information and advice to inform service planning. The Welsh Ambulance Service NHS Trust plays a vital role in transporting patients who need to access services in an emergency. The NHS Wales Informatics Service (NWIS) supports health boards in the collecting and reporting of information.

**Local government** has a vital role in supporting people to live with a neurological condition. To promote a coordinated approach, they need to work with health boards through local service boards. This work includes development of single integrated plans, informed by evidence, showing what they will do to improve health outcomes, in areas such as smoking, obesity, nutrition and exercise.

The newly established national specialist advisory group (NSAG) for neurosciences provides expert professional advice to the Welsh Government and the NHS.

An **All Wales Neurological Condition Implementation Group** will be established to provide strong and joined-up strategic leadership and oversight of delivery by 2017 against this plan. The group will:

- Ensure a relentless focus on delivering the priorities and outcomes of the delivery plan
- Identify constraints and solutions to delivery
- Operate at an all-Wales level to focus and support health boards to deliver in a consistent way across Wales
• Agree how best to measure success, advising on outcome and quality indicators and assurance measures
• Scrutinise local delivery plans and assess progress – providing peer challenge of performance
• Facilitate the sharing and implementation of best practice

The group will include leads from each health board, Public Health Wales, the Welsh Ambulance Service, the Welsh Health Specialised Services Committee, chair of the Neuroscience NSAG, representatives from local government and the Wales Neurological Alliance. Expertise may also be accessed from the various professions involved in providing care for people with a neurological condition and the third sector. The group’s relationship with the NSAG will also be set out in the terms of reference. The chair will be accountable to the Welsh Government; the group will report annually on progress.

The third sector has an important role to play, in delivering services and providing service user perspectives to inform the development of improved services and better patient experience.

The people of Wales also have a role to play. People do not choose to develop a neurological incurable condition. We all need to take more responsibility to ensure people living with a neurological condition do not encounter discrimination and prejudice.

8. Measuring success

The Welsh Government’s Quality Delivery Plan (2012-2016) sets out how we will monitor performance and progress in improving health and healthcare in Wales.

The quality delivery plan places requirements on NHS organisations to monitor a set of nationally specified performance measures and report them to the public and hence to Welsh Government and their boards at regular intervals. This delivery plan now places a requirement on each organisation to publish an annual report on services for people with a neurological condition in Wales to demonstrate progress. The first year will therefore be one of transition as we move to this new approach.

This delivery plan sets out some potential assurance measures which will indicate whether progress is being made. Assurance measures will need to be developed by the implementation group to drive progress in delivery against this plan. They should work with the newly established Neuroscience NSAG to develop service, quality of life, health and wellbeing measures.

The strong focus of this plan is on reducing health inequalities and inequitable access to services. Scrutiny will focus on the differences across Wales and on whether there is a reduction in the gap between the most and least deprived parts of the country.

In line with our intention to deliver high-quality neuroscience services, we will make international comparisons where possible.
9. Local plans – local action

Health boards are required to carry out local population needs assessments and to develop and publish local delivery plans highlighting how they will progressively implement the priorities within this plan and tackle inequalities. They will report annually on progress.
## What needs to happen and when

### Actions to support delivery of themes one-seven

| Action |
|------------------|------------------|
| **1:** Establish the All Wales Neurological Conditions Implementation Group to provide strategic leadership and work at an all Wales level to support delivery of this delivery plan |
| **2:** Review the need for an all Wales neuroscience network, to support delivery against this delivery plan |
| **3:** Carry out local population needs assessments to diagnose and treat neurological conditions and other co-morbidities; review services in the light of the assessments, identifying gaps between need and current provision; and identify where service provision needs to change to meet demand |
| **4:** Write local delivery plans, demonstrating a systematic approach to progressive implementation of this Delivery Plan including how the plan will reduce inequalities by 2017 |

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<td>Each health board, with support from Public Health Wales and local neurological alliances</td>
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<td>Each health board, in liaison with NHS trusts, WHSSC, local government and the third sector including local neurological alliances to ensure integrated care provision</td>
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ANNEX 1 – LINKS TO REFERENCE DOCUMENTS

Adult Neurosciences Expert Review
http://wales.gov.uk/about/cabinet/cabinetstatements/2008/indexprev/?lang=en

Implementation of the Welsh Neuroscience Review
http://wales.gov.uk/topics/health/publications/health/reports/neuroscience/?lang=en

Task and Finish Group Report on Care Pathways for Neurological Conditions

All Wales Neuroscience Standards for Children and Young People’s Specialised Healthcare Services

National Service Framework for Children, Young People and Maternity Services in Wales
http://www.wales.nhs.uk/sites3/home.cfm?OrgID=441

Continuing Care Guidance for Children
http://wales.gov.uk/topics/childrenyoungpeople/publications/care/?lang=en

National Framework for Continuing NHS Healthcare in Wales
http://wales.gov.uk/consultations/healthsocialcare/continuing/?status=closed&lang=en

Delivering Local Health Care – Accelerating the pace of change
http://wales.gov.uk/topics/health/publications/health/strategies/healthcare/?lang=en

Integration Framework for Older People with Complex Needs

Framework for Action on Independent Living

Social Services and Well-being Bill

The Carers Strategy for Wales 2013

Stroke Delivery Plan
http://wales.gov.uk/topics/health/publications/health/reports/plan/?lang=en
Delivery Plan for the Critically Ill

Heart Disease Delivery Plan
http://wales.gov.uk/topics/health/publications/health/reports/heart_plan/?lang=en

Delivering End of Life Care Plan

Respiratory Delivery Plan

Draft Welsh Implementation Plan for Rare Diseases
http://wales.gov.uk/consultations/healthsocialcare/disease/?lang=en

Achieving Excellence – Quality Delivery Plan for the NHS in Wales

More than Words - Strategic Framework for Welsh Language Services in Health, Social Services and Social Care
http://wales.gov.uk/topics/health/publications/health/guidance/words/?lang=en

The All Wales Standards for communication and information for people with sensory loss

Fairer Health Outcomes for all
http://wales.gov.uk/topics/health/publications/health/reports/fairer/?lang=en

Our Healthy Future

Programme for Government
http://wales.gov.uk/about/programmeforgov/?lang=en

Setting the Direction

The People’s NHS
http://wales.gov.uk/consultations/healthsocialcare/people/?status=closed&lang=en

Rural Health Plan – Improving Integrated Service Delivery Across Wales

Service Development Directive for Epilepsy

Service Development Directive for Chronic Non-Malignant Pain

Cross Party Group for Neurosciences - Inquiry into the understanding of neurological conditions within Emergency Units (March 2011)

Cross Party Group for Neurological Conditions - Inquiry into physiotherapy services for people living with neurological Conditions (February 2013)

http://www.walesneurologicalalliance.org.uk/documents/e_thomasreportaccesstospecialistneuromuscularcareinwales.php