



Llywodraeth Cymru
Welsh Government

Neurological Conditions Delivery Plan

High standard of care for everyone with
a neurological condition

Produced by the Neurological Conditions
Implementation Group

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Introduction by Alison Shakeshaft, Chair of the Neurological Conditions Implementation Group

In this updated Neurological Conditions Delivery Plan, the Welsh Government's commitment to both raising awareness of neurological conditions and ensuring those affected by any kind of neurological condition have timely access to high quality pathways of care, irrespective of where they live and whether these are delivered through hospitals or in the community, is reaffirmed.

Progress has been made against the priorities set out in the 2013-2017 Neurological Conditions Delivery Plan. This is detailed in the latest Annual Statement of Progress - Neurological Conditions¹, published in March 2017. These improvements are a tribute to all those involved in the planning and delivery of services for people with neurological conditions.

The average amount of time an individual spends in hospital has fallen from 6.4 days in 2010-11 to 4.2 days in 2015-16. The length of stay following an elective admission has reduced from 3.9 days to 2.2 days; a similar reduction has been seen for emergency admissions, from 9.2 days to 7 days.

In 2015-16, 511 patients were recruited into a neurological health and care research Wales clinical research portfolio study. This was an increase of 385 patients (300%) compared to 2010-11.

We have seen developments in neuro-rehabilitation services across parts of Wales and neuro-psychological support for children in south, mid and west Wales.

Yet there is still more to do to address the current waiting times for new consultation and follow up assessments and all stakeholders must continue to work together and build on the success to date to continue the improvement seen in recent years. Delivery organisations have already embedded the methodology of the Neurological Conditions Delivery Plan so in this next phase of the plan, I expect to see Health Boards delivering at greater pace to improve outcomes for people with neurological conditions, reduce clinical variation and work across organisational boundaries. I also expect Health Board neurological condition plans to be fully integrated within Health Board strategic planning, for national standards and pathways to be fully delivered.

The development of excellence in care for people with a neurological condition is 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.

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 in a timely manner to all those who need to see them.

We have an enormous challenge ahead of us as our population is growing and ageing. In the context of our socio-economic situation, it is estimated in total there are around 100,000 people with a neurological condition in Wales². In Wales, each year around 2,500 people

¹ <http://gov.wales/topics/health/nhswales/plans/neurological/?lang=en>

² Wales Neurological Alliance

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

It has been estimated between 2% and 3% of children will have some level of disability leading to additional health and educational needs. The vast majority of childhood disabilities are neurological in origin, with paediatric epilepsy the most common neurological disorder affecting about 0.7% of all children.

People with neurological conditions can experience difficulties ranging from living with a condition which may weaken or disable them for periods of time through to needing help for most everyday tasks.

It is an enormous challenge for the health service to absorb anticipated future levels of demand. In terms of productivity the service has responded well. The annual increases in demand have, by and large, not led to reductions in timeliness of care. There were just over 18,500 hospital admissions related to neurological conditions in 2015-16, with an average length of stay of 4.2 days.

It is expected that numbers of people with neurological conditions will increase in the future due to increased longevity, improved survival rates and improved general health care. This increasing level of demand, and the cost and complexity of healthcare must be recognised. This is not an issue confined to neurological conditions and the health service in general is facing enormous challenges and pressures. The latest available figures highlighted between 2010-11 and 2014-15 there was a 65% increase in NHS expenditure on neurological conditions³, making it the tenth biggest spend for the NHS in terms of per head of population. This demand will be set against the finite resources likely to be available for health and care services in Wales, which makes it challenging to simultaneously improve quality and performance.

At the heart of service delivery, a quality improvement focus is tackling variation. As a country with a small number of providers we can do better to tackle differences in pathways of care and reduce inequalities. Our vision is for fully integrated primary, community, secondary and specialist pathways of care, designed around the needs of the patient, to provide the support needed for patients to do what they can to manage their condition. People will spend a small proportion of their lives in direct contact with healthcare professionals and so have personal responsibility to do all they can to manage their condition. This concept is at the heart of the future of healthcare, co-responsibility and co-production of care.

We need to continue our efforts to raise awareness of neurological conditions. I know day in and day out health professionals, management teams, the third sector and the patients themselves are working hard to achieve the best outcomes. The purpose of this Delivery Plan is to support and encourage this effort by providing national leadership, encouraging collaborative working and planning ahead. We are more likely to get to where we need to be by working together.

³ <http://gov.wales/docs/statistics/2016/160511-nhs-expenditure-programme-budgets-2014-15-en.pdf>

We must make the most of our assets in Wales. Not least the skill, dedication and hard work of our clinical staff, service managers and third sector organisations. We should also look to create a more equal relationship between patient and healthcare professional, enabling people to co-produce their treatment based on their values, goals and circumstances.

We have the opportunity in Wales to take a population approach with a shared common vision utilising collaborative and planned approaches. We will continue to bring our providers, stakeholders and commissioners together routinely to deliver this common vision. We will build on our commitment to quality, equity and evidence-based pathways of care to make the most of the resources at our disposal.

This plan builds on the foundations from the previous plan and continues to drive forward the vision for improving neurological services across Wales more effectively and at a greater pace, in conjunction with Health Boards' local vision for their resident population and aligned with Integrated Medium Term Plans. Collaborative working between the Implementation Group, NHS organisations, social services and third sector partners is key to ensure services are effective to meet population need and reduce variability of services.

1. Overview and Context

People with neurological conditions may have complex needs which affect their ability to function not just physical needs, but also psychological and social needs for support, to help the individual achieve their best possible outcome. To improve services for people living with a neurological condition and implement the Delivery Plan in this context is challenging.

This Plan encompasses a range of actions, to meet the needs of people affected by a neurological condition. These will focus on the quality of the pathway of care and the outcomes it delivers by looking at compliance with standards, benchmarking with others and identifying areas for improvement.

This Delivery Plan covers neurological conditions broadly, highlighting the importance of raising awareness and providing high quality diagnosis, treatment and care. Some neurological conditions are life-long with possible onset at any time. Others, such as cerebral palsy, are present from birth. Some conditions, such as muscular dystrophy, commonly appear in early childhood; others, such as Parkinson's disease affect older people. Some neurodegenerative conditions, such as multiple sclerosis, motor neurone disease and Huntington's disease, affect people mainly in adulthood and will cause deterioration over time, affecting a person's quality of life and their ability to live independently.

There are more than 250 recognised neurological conditions. Some are more common than others. They tend to be poorly understood by the general public. Levels of awareness are low, even about relatively common conditions, such as epilepsy.

Some neurological conditions are life threatening; most of them affect a person's quality of life and many cause life-long disability. Caring for someone with a debilitating illness often means carers have to give up their own employment, in addition to the person with the condition being unable to continue to be economically active, with devastating impacts on families.

Patients must have access to timely and expert care often best delivered in the community. We therefore need to encourage health boards to implement the Royal College of Physicians' future hospital workforce model with more specialist care delivered in community settings⁴. This needs to be aligned to the development of general practice clusters in health boards and the advances in technology that allow communication through e-mail or smartphone for advice and telemedicine for consultations.

Stroke and dementia are not covered in this plan as patients with these have their own delivery plans. For some people with neurological conditions it will also be appropriate to refer to the *Respiratory Health Delivery Plan*, *Stroke Delivery Plan*, *Delivering End of Life Care Plan*, *Critically Ill Delivery Plan* and the *Rare Diseases Implementation Plan*.

Despite efforts to work towards making improvements in the care for people with neurological conditions and ensuring NICE guidelines and quality standards are being followed in providing treatment to improve the quality of life, there is a need to raise the profile of these conditions and deliver a quicker pace of change going forward. This will be

⁴ Future Hospital Commission. Future Hospital: caring for medical patients. RCP London, 2013

needed to facilitate the delivery of integrated quality, affordable models of care in the face of growing demand and deliver improved patient care, safety and experiences underpinned by good communication and planning.

Children living with a neurological condition should receive the best possible support and care in Wales in all environments including schools. We also need to consider how we can better engage with patients and gain an insight into their experience, both nationally and locally, to ensure pathways of care are genuinely co-produced with structured and broad input. We must make use of the clinical leaders in this field to drive system change and be responsive to clinical audit and peer review findings, as well as more proactively embedding improvement programmes.

In 2016, the Neurological Conditions Implementation Group started to work with the Stroke Implementation Group to develop/identify appropriate *Patient Reported Experience Measures* (PREMs) and *Patient Reported Outcome Measures* (PROMs) for stroke and neurological conditions in Wales. The Groups have also provided joint funding for the expansion of neurorehabilitation services across Wales to build capacity and expertise across the stroke and neurological rehabilitation workforce. Due to the synergy between both groups, they have appointed a joint co-ordinator to ensure both Groups are working collaboratively to develop local interventions and services based around the common impairments of both stroke and neurological disorders.

This updated Plan builds on the last and gives the NHS and its partners the continuity of approach it needs. This Plan is set out similarly, covering the need to raise awareness, diagnose early, to provide fast, effective and safe care, treatment and research. These chapters are underpinned throughout by the need for quality patient information and digital tools. This plan includes streamlined introduction and performance reporting sections. It has also been written to reflect the latest strategic drivers, including prudent healthcare, the primary care plan and new legislation.

It is vital services pull together and do everything possible to alleviate future demand and deliver the best outcomes for patients. We are at a point where we need to build upon the foundations laid, with focus and determination to deliver not a gradual sustainable improvement but an immediate and fundamental change in pace for Wales to lead the way in providing care for people, of all ages, affected by neurological conditions within Wales.

Since the publication of the first Delivery Plan there have been a number of strategic and legislative changes that have impacted upon policy and need to be reflected in this updated Plan.

2. Raising awareness of neurological conditions

Neurological conditions are common and yet awareness amongst the general public, health and social care staff is poor. Different neurological conditions can present clinically in many ways. Some conditions are treatable, some have no cure, some require long-term chronic management from childhood to old age and some are rapidly progressive and terminal.

As well as the clinical presentation being diverse, the experience of living with a neurological condition can have various psychological, social and emotional impacts on a person's life. At times, this can affect relationships, leisure activities, work and income, often resulting in major lifestyle changes for both the person living with the condition, and their family and carers.

There is evidence of discrimination against people with neurological conditions when accessing services due to ignorance, for example, slurred speech in Parkinson's disease or motor neurone disease has been assumed to be a result of drunkenness. Likewise, people living with ataxia have reported feeling embarrassed about speaking, having difficulty talking on the telephone and having reduced confidence leading to social isolation⁵.

Given the varying clinical and psycho-social complexities across conditions, there is little wonder public and professional understanding of neurological conditions is at best poor and at worst damaging.

Changing awareness to across health, social care, housing and educational services will require the expertise of people living with a neurological condition, their family and carers in the design and delivery of services. Neurological conditions can affect children and adults and so the needs of children living with a neurological condition and those young carers looking after family members require the same partnership in design and delivery of services.

People affected by neurological conditions access clinical support services at different stages of their condition. Entry to the 'system' is varied and may be from GP surgeries, various community and social services, outpatient clinics or emergency units dependent upon the stage or progression of the condition. This poses challenges for clinical coordination and self-management.

People affected by a neurological condition often do not know how to navigate the complexities of health and social care services systems. People need:

- To have clear information about their condition to support self-management
- To know how to access services for their specific neurological condition when needed
- To have confidence services are proactively coordinated

Many people living with a neurological condition do not need continuous care at a hospital or community service. They need:

- Reassurance they are being cared for within a network of care that supports self-management, shared best practice, good communication and easy access to the service when and where necessary.

The communication and coordination of care between professional disciplines, services and agencies can sometimes appear fragmented and confusing for both the person affected by

⁵ Management of the ataxias towards best clinical practice. 3rd Edition. July 2016. Ataxia UK

the condition and care staff. The level of understanding and experience of neurological conditions amongst clinical and non-clinical care staff is varied. It is therefore understandable generic services do not have condition specific knowledge and expertise, but all staff should have a basic level of knowledge and awareness of neurological conditions. Staff should know how to access condition specific information, expertise, training and development when needed.

These basic principles are necessary to ensure people living with neurological conditions have confidence their condition is understood by whichever health or social care service they access.

Using information from service users on their experience of NHS care is critical to 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.

People with neurological conditions must be at the centre of service development and offered appropriate information in appropriate language and format. Clear information is central to the overall quality of each patient's experience. Quality, accessible health and care information supports people to participate in shared decisions about their care. They must also have clear treatment plans to guide them through what can be very complex care processes. Increasingly people should be able to access their own clinical records and interact digitally with the health service. Information isn't just about leaflets and printed information; it can be hospital signage, appointment notifications, websites, informed consent, personal health records, patient education programmes and social media.

Key information must comply with the Welsh language standards and be produced in a range of formats to enable accessibility. Health and care information for patients, families, carers and the public needs to be of high quality, easy to access and easily understood. It should engage people in their well-being, improve their experience and enable them and their families or carers to make informed choices about their lifestyle, treatment and the services they use. By providing good quality information, we can help to ensure people feel empowered and have greater protection and choice in all key aspects of their healthcare. Information should be planned and coproduced with patients, families and carers to ensure it meets their needs.

The previous Delivery Plan recognised the need for raising awareness of neurological conditions in Wales, resulting in some limited improvements. This updated Plan is, however, far more ambitious and aims to raise awareness of neurological conditions in a more coordinated, evidenced and sustained way for health and social care staff and the general public.

Key actions

1. Wales Neurological Alliance (WNA) to lead on scoping current awareness raising activities across the statutory and third sectors and make recommendations for ongoing awareness raising priorities in partnership between statutory agencies and the third sector.
2. Health Boards and Local Authorities to develop neurological education frameworks to support the training and development needs of staff working with people living with a neurological condition.
3. Health Boards to establish Neurological Service User Forums in partnership with people living with neurological conditions to inform awareness raising needs and service improvements which meet their needs.
4. Health Boards in collaboration with NHS Wales Informatics Services (NWIS) to develop clear and easy access to information and support about neurological conditions through a single NHS portal (once for Wales) linking with statutory and third sector condition specific organisations.
5. Health Boards to involve patients and carers in the design of services; service users' views on services are sought regularly and acted on to ensure continuous improvement.
6. Health Boards and Welsh Government to publish information on NHS performance for neurological conditions that is easily available to the public.

Outcome indicators and assurance measures

- Improvements in awareness evidenced in Patient Experience and Outcome Measures
- Number of Health Boards with comprehensive education frameworks
- Number of Health Boards facilitating active Neurological Service User Forums
- Number of hits on Once for Wales portal

3. Timely diagnosis of neurological conditions

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 Clinical 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 those conditions where they apply, but the wide range of neurological conditions means many will not have a specific guidance.

The first point in the patient pathway for someone presenting with neurological symptoms is varied. It is usually a visit to their GP, but it may be a clinical referral or self-referral to an optician, physiotherapist, podiatrist, dietician, occupational therapist or speech and language therapist. Alternatively it may be via a referral to a hospital speciality such as orthopaedics, ophthalmology, Ear Nose and Throat (ENT) or the acute medical team. Neurological conditions therefore present a challenge, as symptoms can be mistaken for other more common conditions leading to misdiagnosis before finally making a referral to a relevant specialist. Basic education for primary care teams, and hospital healthcare workers, will improve their knowledge and awareness of neurological conditions thus reducing possible delays in referrals.

All GPs should have access to timely specialist advice by telephone or e-mail contact with members of the Multi-Disciplinary Team. GPs are expected to have direct access to a range of diagnostic tests and procedures for those people where neurological condition is suspected. This includes access to Computerised Tomography (CT) scans and where appropriate, nerve conduction studies (NCS).

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.

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

Key actions

1. Health Boards to provide GPs with timely access to specialist advice through structured telephone and email contact, speeding diagnosis for people who may not need referral to a clinic.
2. Health Boards to ensure timely access to multidisciplinary assessment to support diagnosis where necessary.
3. Health Boards to provide GPs with timely and direct access to CT where appropriate and in line with agreed diagnostic protocols.
4. Health Boards and Primary Care Networks to raise awareness of neurological symptoms with GPs and ensure through audit people are referred to secondary and tertiary care in line with national guidance and referral protocols and pathways, where these exist. Referral protocols to be developed where none exist.
5. Health Boards to provide specialist advice within 24 hours (on a 7 day week basis) for those admitted acutely to hospital with a suspected neurological problem.
6. Health Boards to provide appropriate access to outpatient services for new urgent and non-urgent referrals to meet GP and patient need.
7. Health Boards to ensure follow-up arrangements for patients are appropriate and timely.

Outcome indicators and assurance measures

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

4. Fast, effective, safe care and rehabilitation

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 is due to a neurological problem⁶. 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 their condition is “long term” and will be with them for the rest of their lives.

Many patients with a neurological condition will need to attend hospital for some part of their management, although it is hoped an increasing proportion will thereafter be managed predominantly in primary and community care.

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.

The vital role of carers in supporting patients with a neurological condition and providing therapeutic interventions should not be forgotten. As a familiar face, with a depth of understanding of the individual’s condition, this can provide many benefits, including psychological support and stability, especially during periods of hospitalisation.

Some people with learning disabilities can deteriorate rapidly and this may be difficult to identify especially if they are unable to communicate verbally, carers often accompany patients in hospital and listening to their concerns may help in identifying where a person is in danger of deterioration in their condition. Learning disability liaison nurses, can support staff to ensure reasonable adjustments are made.

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. Where a patient with a neurological condition is admitted to hospital, whether or not the reason for admission is neurological in nature, the neurological team should be notified as soon as practically possible. Systems and protocols should be developed to respect and enable patients to self-manage their medication whilst in hospital where deemed appropriate. For some conditions e.g. Parkinson’s disease the timing of medication is key to controlling symptoms and managing their condition and disruption to well-established patterns can lead to significant set-backs.

A detailed framework for delivering high quality evidence based neuroscience services, through well organised Multi-Disciplinary Teams, is provided in national guidance, such as NICE guidance and care pathways. Compliance with such frameworks will be central to the delivery of this Plan. Health Boards and Trusts must ensure effective governance and reporting arrangements are in place to monitor the provision of safe and effective care.

The Health and Care Standards 2015 published by Welsh Government are designed so they can be implemented in all health care services, settings and locations. They establish

⁶ Action on Neurology, NHS Institute for Innovation and Improvement
www.institute.nhs.uk/index.php?option=com_joomcart&main_page=document_product_info&products_id=222&cPath=67

a basis for improving the quality and safety of healthcare services by providing a framework which can be used in identifying strengths and achieving excellence.

Achieving Excellence: The Quality Delivery Plan for the NHS in Wales 2012-16 describes a journey to consistent excellence in service. It outlines actions for quality assurance and improvement and provides a commitment to a quality-driven NHS that provides services which are safe, effective, accessible and affordable, and come with an excellent user experience. This Plan is being updated.

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.

Overall, the numbers of all kinds of neurological clinical specialists, be they doctors, healthcare scientists, nurses or therapists, remain low and this needs to be addressed. However, it is important neurological services are organised in a way that is responsive to patients needs and make best use of existing resources. While increased resources are important, it is clear 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.

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 should be supported in having early discussions about escalation and their end of life care, if appropriate. Individuals, and those important to them, need the opportunity to have open and transparent discussions about personalised plans that enable a holistic approach to promoting their choices of treatment, care and support; in line with the *Delivering End of Life Care Plan*.

Understanding the experience of living with the effects of neurological conditions and of being an NHS patient or service user, is fundamental for patient-centred, co-operative services. This understanding is also key to developing appropriate services and for measuring the effectiveness of services. Patient Reported Outcome Measures (PROMs) and Patient Experience Outcome Measures (PREMS) capture a person's perception of their experience with health care service as well as capturing a person's perception of their health. This plan requires the establishment and implementation of appropriate PROMs and PREMs for people with neurological conditions, with findings acted upon to improve services.

Key actions

1. Health Boards to organise services to ensure people admitted with a neurological condition are assessed by a member of the neurology/neurosurgery team, within 24 hours of admission to hospital.
2. Health Boards to review, plan and deliver evidence-based and timely treatment, in line with latest evidence, standards and NICE guidance, including access to new diagnostics, technologies, treatments and techniques.
3. Health Boards to ensure patients with complex needs have appropriate, timely and co-ordinated access to other specialist services as appropriate.
4. Health Boards in collaboration with the Wales Ambulance Service Trust (WAST) to co-ordinate effective transfer of care and timely repatriation of patients from specialist neurological beds to local hospitals as soon as clinically appropriate, following treatment in line with transfer of care plans and the All Wales Repatriation Policy.
5. Health Boards to ensure effective and appropriate palliative and end of life care, in line with the *Delivering End of Life Care Plan* for patients who need it.
6. Health Boards to develop and implement PROMs and PREMs for patients with neurological conditions and act on findings to continually improve services.
7. Health Boards to ensure effective governance arrangements are in place to monitor and review the provision of safe and effective care. This includes taking into account all relevant evidence and guidance including NICE guidelines and quality standards.
8. Health Boards to ensure full (100%) participation in national clinical audits - to support service improvement and support medical revalidation of clinicians – and ensure that findings are acted on. In addition, participation of all:
 - neurorehabilitation services caring for Welsh patients, in the United Kingdom Rehabilitation Outcomes Collaborative
 - spinal injury units caring for Welsh patients, in the National Spinal Cord Injury Database
 - neurosurgery units caring for Welsh patients, in the Neurosurgical National Audit Programme
9. Health Boards to participate in and act on the outcome of peer review and implement any actions.

Outcome indicators and assurance measures

- Referral to treatment times
- Emergency admission rates
- Access to interventional neuroradiology
- Average length of hospital stay
- Number of unscheduled hospital admissions due for a primary neurological condition
- Organisational compliance audits against NICE guidelines

5. Living with a neurological condition

People living with a neurological condition may experience a wide range of physical, psychological and emotional symptoms that impact on their day to day level of ability. These symptoms may fluctuate on a daily, weekly or monthly basis, or may get progressively worse over time. Alternatively some individuals may experience rapid deterioration in their condition, which can prove challenging for services to keep up with rapidly changing needs.

Symptoms can impact on the individual's ability to look after themselves or their families, get around their house, their local environment or travel further afield. It can affect their employment and their role in their community, which must not be underestimated.

Individuals need timely access to help, support and care in order to keep as healthy and active as possible and be able to fulfil their roles within their families, communities and working lives. This may include:

- information to improve understanding of their condition or symptoms and how best to manage these
- medication to limit the progress of the disease or manage symptoms
- rehabilitation to regain a previous level of function after an acute exacerbation of symptoms or to slow ongoing progression
- advice on strategies to compensate for a loss of function
- equipment and assistive technologies to increase independence
- emotional and psychological support to help cope with the impact of the condition.

Carers play a vital role in supporting individuals with a neurological condition. They often have a detailed understanding of the condition, the individual's experience, and their physical, social and emotional needs. Their role in supporting and delivering direct care and therapeutic interventions must be recognised and supported by multi-disciplinary, multi-agency health and social care teams and third sector organisations. The Social Services and Well-being (Wales) Act 2014 sets out clear expectations for joint working practice to support the needs of individuals and carers. We must not forget there will be times where carers themselves may need respite, professional advice and support. Special consideration must be given to the needs of young carers.

The bulk of the £1 million made available by Welsh Government for neurological conditions was allocated to Health Boards to improve provision of neurorehabilitation across Wales. The funding has allowed a baseline platform to be built for ongoing service development. However, there is still more to do, for example we still have significant gaps in psychological and neuro-psychiatric support available to individuals with neurological conditions.

The NHS in Wales continues to be committed to work with its partners towards developing a coherent and responsive service for people living with a neurological condition across Wales.

Key actions:

1. Health Boards will place the service user and their family/carers at the centre of care planning and delivery based on co-productive principles.
2. Health Boards and Third Sector providers will use holistic approaches to meet the physical, psychological and emotional needs of the individual, including vocational rehabilitation.
3. Health Boards, other statutory and third sector providers will support the individual to self-manage their own condition where possible, through the provision of information, support and timely access to expert help and interventions from health, social care or third sector organisations when required.
4. Health Boards to adopt the principle that care and support will be provided as close to home as possible by a flexible workforce with the appropriate level of evidence-based knowledge, skill and expertise.
5. Health Boards and Local Authorities will promote integration across all health; care and support providers with the service user and their family and carers will ensure timeliness, improve coordination and reduce duplication and unnecessary interventions, in line with prudent healthcare principles.
6. Health Boards will continue to develop their neuro-rehabilitation services, including psychological support and consider opportunities for self-referral for people living with a confirmed neurological condition.
7. Health Boards should have a system to offer reviews with a skilled health care professional in line with NICE guidelines.

Outcome indicators and assurance measures

- Waiting times to services
- Organisational compliance audits against NICE guidelines
- Availability of annual reviews

6. Children and Young People

Children and young people (CYP) 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 optimal management improves health outcomes and can also help to minimise other, often detrimental, impacts on social, educational and employment activity. Services should be developed and delivered in line with the relevant guidance for each condition^{78 9}.

Sources estimate up to 1 in 6 children has a neurological disorder but this would also include developmental problems such as dyslexia and attention deficit hyperactivity disorder (ADHD), which are not covered within this Plan.

There are fundamental differences between adults and children and young people (CYP) with neurological disorders:

- CYP with disorders such as cerebral palsy grow up to become disabled adults who may or may not come under the remit of the neurological service as an adult
- There is a great deal of overlap with psychiatric & psychological disorders as the mind/brain divide is an artificial construct. The Isle of Wight study of 1970 recognised 30% of children with epilepsy have psychiatric disorders yet these children to date have no dedicated psychology support in many parts of the UK
- There are also huge overlaps with education and with social care.
- The stigma of neurological disorders and disability in children can contribute to educational underachievement.

Most CYP with neurological disorders are treated in secondary and tertiary care. This can lead to a primary care gap, which becomes a big issue after transition to adult services. Many of these CYP would benefit from a system where a named GP or other primary health care professional who has known them throughout childhood would continue into their adult life. Similarly specialist nurses play a significant role in the care of children with neurological disorders such as epilepsy and there is a role for them in other disorders such as neuromuscular disease. Currently the psychological/psychiatric needs of this population are underprovided. Access to respite and community nursing care can be challenging for this group and sometimes can only be provided by the hospice system (many individuals with neurodisability survive to adulthood).

Links with primary care need to be clearly identified and strengthened. The reduced level of school nursing services has impacted on CYP with neurological disorders. There is therefore a potential for the primary/nursing/community care service in schools to improve care, reduce stigma, increase school attendance and educational potential and provide primary mental healthcare. Investment at this stage reduces the eventual financial burden to the population of those who have never achieved in education and employment.

Access to Therapy Services for assessment, diagnosis and management can reduce the impact of neurological conditions on a child's functioning and these services should be integral to individual Health Board delivery plans.

The *Children and Young People's Continuing Care Guidance* is designed for use by all

⁷ NICE QS27 (2013) Epilepsy in children and young people

⁸ NICE CG 62: cerebral palsy in under 25s; assessment and management

⁹ NICE IPG 50: Vagus nerve stimulation for refractory epilepsy in children (2004)

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.

Services must be flexible to ensure 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.

Children with health needs have the same rights of admission to schools as other children. Schools are legally obliged to ensure all children with health needs are properly supported in school and have full access to education, including school trips and physical education. Schools, Local Authorities, health professionals and other support services are advised to work together to ensure children with medical conditions receive a full education. Future service provision will need to be informed by the Additional Learning Needs Bill.

Investment in CYP with neurological disorders (eg epilepsy, the most common of these disorders in children) can improve their health and employability when they reach adulthood. Improvements in secondary care services for infants and young children with severe brain injury or disease has led to survivors with extreme neurodisability.

There is currently no single specialist to look after these individuals when they leave paediatric services. When they are admitted to hospital as an adult they may not fit within the current condition specific organisational configuration.

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. When children and young people who use paediatric services are moving to access adult services these should be organised so all those involved in the care, treatment and support cooperate with the planning and provision to ensure the services provided continue to be appropriate to the age and needs of the person using those services.

As one third of a general paediatrician's workload will involve children who have a neurological problem, there is also the need to consider whether pathways can be improved for those children and young people not accessing specialised neuroscience services.

Key actions

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

Outcome indicators and assurance measures

- Number of unscheduled hospital admissions due to an acute neurological condition
- Waiting times for urgent appointments
- Waiting times for non-urgent appointments
- Waiting times for follow-up appointments
- Waiting times for outpatient diagnostics (imaging, neurophysiology)

7. Targeting Research

Investment in research taking place across both the university sector and the NHS is important to help ensure discoveries made in the laboratory are turned into new treatments and better care for people living with neurological conditions.

Research is critical to effective care for people with a neurological condition, can be a driver for clinical excellence, and NHS Wales 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. A balance is required to ensure both biomedical and quality of life/social research is achieved. Third sector organisations are key partners in the development of research, both as funders of research and supporting patient involvement in clinical trials and social research.

Within the university sector, Welsh researchers are producing high quality research. In the most recent UK-wide assessment of research quality, over three quarters of the research in Welsh universities was seen as world-leading or internationally excellent. However, it has been identified in a number of reports that Wales attracts a lower percentage of competitive research funding than it should, given its population size. According to a recent report by the Leadership Foundation for Higher Education, this may be down to the fact that Wales has a shortfall of around 600 academics, largely across Science, Technology, Engineering, Mathematics and Medicine (STEMM) disciplines.

Welsh Government has recognised the need to increase research capacity in Wales and outlines a number of initiatives in its [Science for Wales](#) strategy to enable this, including the Seer Cymru programme, which aims to bring 'research stars' to Wales.

Within the NHS, research is supported by Health & Care Research Wales, with each of Wales' seven Health Boards and three Trusts supported by a research and development team. The need to build research capacity has also been identified as a priority for health and social care research, with health and care research Wales highlighting capacity building as a strategic aim in its [2015-2020 Strategic Plan](#). There needs to be support across the whole research pipeline with strong interactions between academia and the NHS to ensure an enhanced translation of research discoveries into better patient care.

The Welsh Government through Health & Care Research Wales provides an infrastructure to support and increase high quality research with a number of funding schemes and management of NHS R&D allocation. Relevant to neurological disorders this includes the Brain Repair and Intracranial Neurotherapeutics (BRAIN) Unit, Centre for Ageing and Dementia Research, Clinical Trials Units in North, South East and South West Wales, the Wales Gene Park and Secure Anonymised Information Linkage (SAIL) Databank.

Health and Care Research Wales also provides responsive-mode competitive research funding, for example RfPPB (Research for Patient and Public Benefit) and works with other UK funders to maximise opportunities for researchers in the field of neuroscience to apply for research funds.

Over the next four years, we will sharpen our focus on the quality and impact of our research. We need to ensure we enable all researchers to pursue and produce their best work possible, publishing in the highest quality places, working with the best partners both inside and outside the health sector and addressing the major challenges our communities

face. Clear expectations about research performance will be set and, at the same time, the mechanisms will be created to support and develop a culture of research excellence.

Attention needs to be given to the wide dissemination of research opportunities and findings including raising public awareness. Public events and research newsletters could be used to identify and celebrate achievements.

Key actions

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

Outcome indicators and assurance measures

- Increased number of neurological conditions research studies and clinical trials in Wales, including nurse/therapies and health science led research
- Percentage of people with neurological conditions entered into clinical trials
- Increased external grant funding for neurological research
- Increased academic and industry collaboration with health and social care services

8. Implementing the Neurological Conditions Delivery Plan

This Delivery Plan has set out our vision and ambitions for people, of all ages, affected by a neurological condition within Wales. Doing this will involve joint working between all those responsible for the care of people with neurological conditions in Wales.

We have set out the health outcomes we expect for the people of Wales and the Neurological Conditions Implementation Group and the Welsh Government will hold NHS Wales to account to ensure that the actions in this Plan and the health outcomes we desire are achieved.

The lines of accountability will be through the Chairs of the Health Boards and Trusts to the Cabinet Secretary for Health, Well-Being and Sport and, with the Chief Executives of the Health Boards and Trusts reporting to the Chief Executive of the NHS Wales, who is also the Director General of the Welsh Government's Health and Social Services Group.

We are in a strong position to move ahead with pace. The role of the Neurological Conditions Implementation Group is to oversee the National Delivery Plan and support Health Boards and partners to deliver their local plans. The Implementation Group brings together the key stakeholders, including all the Health Boards, the Welsh Ambulance Trust, the third sector, primary care, secondary care, government and managers to work collaboratively.

The Neurological Conditions Implementation Group will review progress against this Delivery Plan at least once a year. The group will support delivery of the plan and ensure a focus on working across traditional boundaries to deliver improvements in the care for people with neurological conditions.

Health Boards are responsible for planning, securing and delivering local services to ensure that those people who require care can access the right care at the right time and place.

Each Health Board will have a local Neurological Conditions Delivery Group, which will need to plan services effectively for their population and build and lead coalitions with all key stakeholders including the Welsh Ambulance Service Trust, other Health Boards in Wales and neighbouring NHS England organisations, GPs, local government, third sector organisations and most importantly, patients and carers. Health Boards will need to integrate their plans for neurological conditions into the overall Health Board Integrated Medium Term Plan (IMTP) and ensure that all aspects of the Delivery Plan are included in their planning process.

The Neurological Conditions Implementation Group will support Health Boards and their local delivery groups through the provision of strong and joined-up leadership and oversight. They will co-ordinate national priorities and actions in a strategic way.

The revised Implementation Group reporting arrangements will maintain governance and transparency while streamlining processes. The Implementation Group will provide annual assurance to Welsh Government on the delivery of the Plan, which links to quality and performance processes established with Health Boards.

Key actions

1. The Neurological Conditions Implementation Group will work in a co-ordinated way, at an all Wales level, to support Health Boards and partners to deliver the actions within this plan and achieve the desired outcomes.
2. The Neurological Conditions Implementation Group will agree a focus for delivery and priorities each year to provide clear guidance to Health Boards to support the production of their IMTPs; ensuring neurological conditions are fully embedded within their plans.
3. The Neurological Conditions Implementation Group will facilitate the sharing and implementation of best practice.
4. The Neurological Conditions Implementation Group will identify constraints and develop national solutions to common issues where a strategic approach is needed.
5. The Neurological Conditions Implementation Group will review and critically assess Health Board delivery plan actions in light of progress and new developments.
6. The Neurological Conditions Implementation Group will review appropriate outcome and performance measures annually.
7. The Neurological Conditions Implementation Group will allocate, monitor and report on the use of £1m annual funding from Welsh Government in line with the delivery against clearly stated priorities.
8. The Neurological Conditions Implementation Group will produce an annual statement highlighting progress made throughout the year.
9. Health Boards are required to monitor their performance against the Neurological Conditions Delivery Plan against a set of nationally specified performance measures and report them to implementation group and the Welsh Government annually.
10. Health Boards to incorporate feedback from local Neurological Service User Forums into the work of their Neurological Delivery Group.
11. The Welsh Government will continue to maintain oversight of delivery and assurance framework and produce a national statement of achievement annually. It will also support and enable liaison between the Implementation Group and Welsh Ministers.

Health boards are required to monitor their performance against the Neurological Conditions Delivery Plan against a set of nationally specified performance measures and report them to implementation group and the Welsh Government annually.

The Welsh Government will continue to maintain oversight of delivery and assurance framework and produce a national statement of achievement annually. It will also support and enable liaison between the Implementation Group and Welsh Ministers.

Annex 1 - Supporting Strategic and Legislative Documents

Since the publication of the first delivery plan there have been a number of strategic and legislative changes that have impacted upon policy and need to be reflected in this updated delivery plan.

New Programme for Government and the NHS Plan

The Welsh Government's *Programme for Government* and NHS Plan set out an ambitious programme for health and well-being in Wales focussing on improving our healthcare services; our healthcare staff; being healthy and active; our mental health and well-being; the best possible start for children and care for older people.

Achieving Excellence: The Quality Delivery Plan for the NHS in Wales for 2012-16 outlined actions for quality assurance and improvement. A commitment to a quality-driven NHS that provides services which are safe, effective, accessible, and sustainable. This plan is currently being updated.

Well-being of Future Generations (Wales) Act 2015

The Welsh Government published the Well-being of Future Generations (Wales) Act in April 2015 to improve the social, economic, environmental and cultural well-being of Wales. It aims to make public bodies think more about the long-term, work better with people and communities and each other and look to prevent problems and take a more joined-up approach. The Act sets out seven well-being goals, and five ways of working in order to support the implementation of these goals:

- a prosperous Wales
- a resilient Wales
- a healthier Wales
- a more equal Wales
- a Wales of cohesive communities
- a Wales of vibrant culture and thriving Welsh Language
- a globally responsible Wales

The Act also establishes Public Services Boards (PSBs) for each local authority area in Wales who must prepare and publish a local well-being plan setting out its objectives and the steps it will take to meet them. It is expected that these plans inform local priority setting.

Social Services and Well-being (Wales) Act 2014

A number of actions in this delivery plan have been developed to further embed the requirements of the Social Services and Well-being (Wales) Act 2014 which came into force on the 6 April 2016. The Act places a duty on health boards and local authorities to jointly undertake an assessment of the local population's care and support needs, including the support needs of carers. The population assessment is intended to ensure that health boards and local authorities produce a clear and specific evidence base to inform various planning and operational decisions, including Integrated Medium Term Plans.

Population Needs Assessment

Population needs assessments are critical to the development of good long-term strategies. The Well-being of Future Generations Act makes it clear that this needs to be done in conjunction with other public service bodies, such as local authorities, education and housing. Population needs assessment should underpin the local well-being plan, developed by public service boards.

The 64 primary care clusters are the mechanism for this collaborative approach to integrated service planning and delivery. Making best use of available financial, workforce and other resources, not just those of the NHS but of local authorities, the third and independent sectors and the assets of local communities.

Prudent Healthcare

In addition, the plan has also been underpinned by the principles of Prudent Health and Care. The way in which services have been shaped and delivered in recent years provide good evidence of prudent health and care in practice and this delivery plan aims to strengthen that approach through a greater emphasis on prevention, integration and long term sustainability. Placing the needs of service users at the heart of service design, co-production in care and treatment planning and delivering services by professionals in both the statutory and third sector are good examples of how the prudent health and care principles underpin service delivery.

Health and Social Care Inequalities

Delivering the actions set out in the plan will make a positive contribution to the Welsh Government's equality agenda objectives through a commitment to identify and meet the needs of all groups in relation to stroke, including those from disadvantaged backgrounds who are statistically more likely to be living in poverty and be at greater risk of heart disease. This has also included consideration to the articles contained within the United Nations Convention on the Rights of the Child (UNCRC).

Welsh Language

The objectives of 'More than just words' the Welsh Government's strategic framework for Welsh language services in health, social services and social care have also been embedded into the plan through actions that make it clear all organisations associated with service delivery must ensure that such services are available to those who wish to communicate in Welsh.

Informed health and care – A digital health and social care strategy for Wales: The Welsh Government has outlined its commitment to providing access to the best possible services to the public by enabling health professionals to access the most up-to-date technology in its digital health strategy published in 2015. This provides the driver for development and innovation in the use of information technology in critical care for the benefit of patients.

Building a Brighter Future

A coordinated programme to ensure that children have the best possible start in life through early intervention, family support and integrated services, focused on achieving better outcomes and reduced inequality for children.

Healthy Child Wales programme

Commenced in October 2016 to offer a coordinated, Wales wide universal core programme of interventions in the first 1000 days from conception, continuing up to the child's 7th birthday.

Developing a Skilled Workforce

The workforce is the most critical element of both the NHS and the third sector and is the key determinant to the success of any organisation. An engaged, sustainable and skilled workforce is essential to delivering high standards of care and transforming the way services are delivered in order to meet the many challenges faced by NHS Wales today. Workforce must be planned and developed around the prudent healthcare principles (i.e. how is the profile of your workforce going to change to allow professionals to concentrate on where they can add the greatest value).

ANNEX 2 – UPDATED LINKS TO REFERENCE DOCUMENTS

Rare Diseases Implementation Plan

<http://gov.wales/topics/health/nhswales/plans/rare/?lang=en>

Delivering End of Life Care Plan

<http://gov.wales/topics/health/nhswales/plans/end-of-life-care/?lang=en>

Delivery plan for the critically ill

<http://gov.wales/topics/health/nhswales/plans/delivery-plan/?lang=en>

Respiratory Health Delivery Plan (to be updated during 2017)

<http://gov.wales/topics/health/nhswales/plans/respiratory/?lang=en>

Stroke Delivery Plan

<http://gov.wales/topics/health/nhswales/plans/plan/?lang=en>

Health and care standards (April 2015)

<http://gov.wales/topics/health/publications/health/guidance/care-standards/?lang=en>

Achieving excellence - The quality delivery plan for the NHS in Wales

<http://gov.wales/topics/health/nhswales/plans/excellence/?lang=en>

NHS Wales Planning Framework

<http://gov.wales/topics/health/nhswales/organisations/planning/>

Primary Care Services Plan

<http://gov.wales/topics/health/nhswales/plans/care/?lang=en>

Well-being of Future Generations (Wales) Act 2015

<http://gov.wales/topics/people-and-communities/people/future-generations-act/?lang=en>

Social Services and Well-being (Wales) Act 2014

<http://gov.wales/topics/health/socialcare/act/act-nhs/?lang=en>

Informed health and care – A digital health and social care strategy for Wales

<http://gov.wales/topics/health/nhswales/about/e-health/?lang=en>

Health and Care Research Wales Strategic Plan 2015

https://www.healthandcareresearch.gov.wales/uploads/Policy%20&%20Strategy/Health_and_Care_Research_Wales_Strategic_Plan_2015_2020.pdf

More than just words.... Follow-on strategic framework for Welsh language services in health, social services and social care

<http://gov.wales/topics/health/publications/health/guidance/words/?lang=en>

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

<http://wales.gov.uk/topics/health/publications/health/guidance/standards/?lang=en>

Framework for Assuring Service User Improvement and Core Questions

<http://www.wales.nhs.uk/governance-emanual/public-and-patient-involvement>

***Safe Care, Compassionate Care*: National Governance Framework to enable high quality care in NHS Wales**

<http://www.wales.nhs.uk/sitesplus/documents/888/Appendix%20Item%206%20Safe%20Care%20Compassionate%20Care.pdf>

Improving general hospital care of patients who have a learning disability

<http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/How%20to%20%2822%29%20Learning%20Disabilites%20Care%20Bundle%20web.pdf>

A framework for delivering integrated health and social care for older people with complex needs

<http://gov.wales/topics/health/publications/socialcare/strategies/integration/?lang=en>

Children and young people's continuing care guidance

<http://gov.wales/topics/health/publications/socialcare/guidance1/care/?lang=en>

Supporting Learners with healthcare needs

<http://gov.wales/about/cabinet/cabinetstatements/2017/59000855/?lang=en>

Self care and care plans

<http://gov.wales/docs/dhss/publications/100102frameworkselfcareen.pdf>

<http://gov.wales/topics/health/nhswales/healthservice/chronic-conditions/?lang=en>

Patient Consent

<http://www.wales.nhs.uk/sites3/page.cfm?orgid=465&pid=11930>

All-Wales Policy on Do Not Attempt Cardiopulmonary Resuscitation

<http://www.wales.nhs.uk/news/35793>

Lasting Power of Attorney

http://www.olderpeoplewales.com/en/Publications/pub-story/16-01-04/An_easy_guide_to_lasting_powers_of_attorney.aspx#.VoprFWcqXcs

Health and Care Research Wales Performance Management Framework

<http://www.healthandcareresearch.gov.wales/performance-management/>

Industry Engagement in Wales

<http://www.healthandcareresearch.gov.wales/industry-engagement/>

Delivery Framework for the Performance Management of NHS R&D

<http://www.healthandcareresearch.gov.wales/nhs-randd-funding-policy/>

Epilepsy 12 national clinical audit of children and young people with epilepsy

<http://www.rcpch.ac.uk/system/files/protected/page/Epilepsy12%20report%202014%20for%20web.pdf>

HeadSmart: national guidelines for early identification of brain tumours in children and young people

<https://www.headsmart.org.uk/https://www.headsmart.org.uk/>

<https://www.disabilitymatters.org.uk/>

Royal College of Paediatrics and Child Health (RCPCH)

<https://www.disabilitymatters.org.uk/https://www.disabilitymatters.org.uk/>