Overview

Neurological conditions can affect people of all ages with onset occurring at any stage of a person’s life. Some conditions particularly affect older people, whilst others are life-long conditions, which can develop through disease or an injury to the nervous system. This group of conditions can have a serious and lasting effect on both the individual and their families.

With the anticipated changes in demographical profiles due to increased longevity, better diagnostics, improved survival rates and improved general health care, the number of people living with a neurological condition is expected to increase over the next two decades. The consequences for both health and social care are significant, as people with a neurological condition can experience a range of difficulties from being weakened or disabled for short periods of time through to needing help for most of their everyday tasks on a daily basis.

In Wales, we want to ensure that people affected by a neurological condition have access to services that are developed and delivered through an approach based on co-production that learns from the individuals affected by the condition, their families and carers. By working with patients we aim to further develop services that are driven by the people who have an understanding of what they need to support them. This includes developing seamless, well-coordinated services across primary, community, social and hospital care, and between statutory and Third Sector organisations.

We have made good progress through 2016-17 in improving services across Wales for people with a neurological condition. This includes new initiatives and the further development of existing neuro-rehabilitation services that have been funded through the Neurological Conditions Implementation Group (NCIG). However, there is still more to do.

The National Delivery Plan was updated in June 2017 and sets out actions to improve outcomes in the following key areas to the end of 2020:
- Raising awareness of neurological conditions
- Timely diagnosis of neurological conditions
- Fast, effective, safe care and rehabilitation
- Living with a neurological condition
- Children and young people
- Targeting research
The plan has been updated to reflect the latest strategic drivers, including prudent healthcare, the primary care plan, and new Welsh legislation including the Social Services and Well-being (Wales) Act 2014 and the Well-being of Future Generations (Wales) Act 2015.

**Progress over the last twelve months**

The priorities for 2016-17 agreed by NCIG were:
1. Developing a co-productive approach to increasing awareness of neurological conditions
2. Delivering clear consistent patient information
3. Delivering access to neurology services, for patients of all ages, consistently throughout Wales
4. Developing consistent and coherent neuro-rehabilitation services, for patients of all ages
5. Developing and responding to patient experience and outcome measures

The NCIG has provided funding to NHS organisations and Third Sector partners across Wales to support these priorities through continued delivery of neuro-rehabilitation services, support for patients with neuro-muscular conditions, development of patient-reported experience measures and raising awareness of neurological conditions.

1. **Developing a co-productive approach to increasing awareness of neurological conditions**

   Our expectations are that all staff involved in delivering care for people with a neurological condition should have an appropriate understanding of the condition and its effects on both the individual and their family. We also recognise that there should be better understanding of neurological conditions amongst the public and other organisations such as educational establishments.

   Abertawe Bro Morgannwg University Health Board (ABMUHB) has been working in partnership with its local authorities and Swansea University to develop personal assistants to work with and support individuals with a neurological condition.

   The majority of people that access the community neuro-rehabilitation service in ABMUHB have ‘higher order needs’ with their higher cognitive functions relatively preserved, but they need support to achieve their potential, in order to achieve all they can within the limitations imposed by their condition. The barriers to this include impaired memory, premature fatigue, physical limitations, problems with social interactions, and difficulty in the regulation of their emotions. They often benefit from someone to help them structure and organise their time, provide feedback to them in the context of a good therapeutic relationship, and help them find different ways to feel valued through enhancing their engagement with activities and voluntary or remunerated employment. The route to this support is often the help of a personal assistant through direct payments (facilitated by a social services assessment). The health board found from feedback from service users that personal assistants tend to want to ‘baby sit’ or ‘fix’ or ‘do things for’ the person rather than ‘enable’, ‘facilitate’ and help the person flourish. Personal assistants often don’t know what to do
because they are used to working with clients who have more severe needs and need caring for.

To address this, ABMUHB is working on a proposal to recruit psychology students who are currently undertaking a Masters' Degree at Swansea University. Due to their background in psychology and desire to gain experience working with people with neurological difficulties, they are ideally placed to meet the requirements of a personal assistant. The University is willing to consider making changes to their Master's program to accommodate this development, in order to support students undertaking personal assistant roles to develop psychological formulations to help the person they are working with achieve their goals and move forwards. In so doing the health board is broadening awareness and developing a model that can be transferred to other areas in order to raise awareness of neurological conditions amongst potential carers and co-produce a training package in collaboration with the relevant educational institutes.

Taking a similar approach Cardiff and Vale University Health Board (C&VUHB) has made significant progress with developing its partnership working with Cardiff University Brain Research Imaging Centre (CUBRIC). Key members of staff from the Neurosciences Department and CUBRIC have met and developed joint working and governance arrangements to enable improved research and clinical models of care for patients with neurological conditions. Clinical meetings and teaching sessions have continued with engagement from both organisations, with positive feedback being received by the multiple sclerosis and epilepsy services.

Over the past year Betsi Cadwaladr University Health Board (BCUHB) has delivered a number of highly successful multi-disciplinary training and education days for staff from statutory and non-statutory organisations, including GPs, Practice Nurses, Local Authority and Third Sector organisations who are involved with the management of people with specific neurological conditions such as multiple sclerosis, motor neurone disease, movement disorders and neuro-muscular disorders to support better understanding of these conditions. Key themes of the study days have focussed on management and support, living with a neurological condition, the perspectives of experts, transitional care services (paediatric to adult services), rehabilitation and goal setting, postural mobility, neuro-psychology and making the most of psychological input, pain and neurological conditions and highlighting the role of our key care advisors, such as the neuro-muscular care advisor in BCUHB.

The study days have demonstrated the benefits of multi-disciplinary working in the care of people affected by neurological conditions by helping everyone to understand each other's roles and the range of services accessed by people living with neurological conditions. For example, in the motor neurone disease sessions, bringing together all agencies and disciplines involved in the care of people has enabled sharing how practice is delivered and supported through the coordination of care between the multi-disciplinary team's across North Wales and the Walton Centre NHS Foundation Trust, Liverpool. The days have explored new developments and promoted an understanding of the services available for both the people living with motor neurone disease and the professionals helping to manage their conditions, bringing together a range of disciplines with an interest in the field.
2. Delivering clear consistent patient information
The NCIG, working in collaboration with health boards and the Third Sector, has actively encouraged engagement events and improved patient information. Although patient information is often available, the supporting structures to ensure that it is accessible and kept up to date can falter.

Powys Teaching Health Board (PTHB) delivers a number of multi-disciplinary community neuro-rehabilitation clinics, virtual multi-disciplinary team meetings and specialist team support for patients with motor neurone disease and those at end of life. However, historically there was no dedicated administrative support for these, so clinical time was being taken up with organising and documenting them and attendance rates were variable. Through funding from the national delivery plan, a number of roles have been developed including a neurological service coordinator role that has facilitated a number of improvements including:

- Updating the health board’s internet pages www.powysthb.wales.nhs.uk/community-neuro-services
- Producing information leaflets on:
  - Community Neuro Clinic (CNC)
  - Spasticity Service
  - Moving on after Stroke
  - Neuro Emotional Intervention Service
- Developing documentation to support the new Functional Electrical Stimulation Service (FES)
- Introducing a register to support the organisation of the CNC

3. Delivering access to neurology services, for patients of all ages, consistently throughout Wales
With an increasing demand from primary care some health boards have implemented an e-advice system to support primary care in order to reduce inappropriate referrals and improve the effectiveness of referrals and subsequent interventions. The Neurosciences department in ABUHB and C&VUHB have fully implemented HERS-2, an electronic GP referral system, through which it is monitoring the effect of referrals and requests for advice from GPs. There is early evidence to suggest that offering specialist support, information and advice to the referrer improves the referral process for patients requiring an outpatient appointment. A full audit will be undertaken next year to determine the overall effect of the system. Similar processes are being explored by other health boards.

The NCIG provided investment for the child psychology service in the Children’s Hospital for Wales to provide a neuro-psychological support service for secondary and tertiary services for children from South, Mid and West Wales. Following the establishment of the Paediatric Acute Neuro-Rehabilitation service in the Children’s Hospital of Wales, children no longer need to travel to England for treatment. The first outpatient clinic was held in September 2017 and neuro-psychology assessment and advice is now available on site.
4. Developing consistent and coherent neuro-rehabilitation services, for patients of all ages.

The NCIG identified the establishment of responsive and efficient neuro-rehabilitation services across Wales as its top priority. Jointly with the Stroke Implementation Group £1.2m annually was invested in the development of such services. Health boards were asked to work proactively with the Third Sector and service users in their local service developments.

At the end of 2017, the Community Neuro-Rehabilitation Service in Cwm Taf University Health Board (CTUHB) had received 105 referrals. Psychology (mood/adjustment) and functional activities groups and projects are now available in a number of locations across the Health Board. The service has partnered with the health board’s stroke Early Supported Discharge service and offered a carer’s group. Plans are in place to offer this group in several locations across the health board, to increase the uptake of the service for carers. The group has been evaluated, with positive feedback received and modifications to the content/structure have been made based on the feedback received.

In Aneurin Bevan University Health Board (ABUHB) additional funding has enabled the Community Neuro-rehabilitation Service, initially established to deliver early supported discharge for stroke patients, to expand to include support for patients with other types of Acquired Brain Injury (ABI). Before this development there was no service to support ABI within the health board. The service model was developed with service user and Third Sector input and includes funding for a member of staff from Headway to work as part of the multi-disciplinary team. The service was launched in September 2016 with 140 referrals accepted within the first 12 months of operation. Links have been established with C&VUHB to facilitate smooth discharge planning from Rookwood Hospital and further developments will include links with Velindre NHS Trust to support patients with brain tumours.

Funding has enabled Hywel Dda University Health Board to implement a Brain Injury and Complex Neurological Therapy Service. The team, now fully established consists of two neuropsychologists, neuro-specialist occupational therapists, physiotherapists, a speech and language therapist and administrative support. The service covers the whole Hywel Dda area with the aim of providing assessment and longer term, low intensity rehabilitation and review within the community. More general aims of rehabilitation within the service include increasing understanding of the nature of brain injury, improving independence in self-care and activities around the home, better communication and mobility, and enhancing specific physical skills with the goal of a return to work, study or leisure activities. The team also assesses emotional and cognitive function which might be impaired, and provides cognitive rehabilitation and support to patients and their families.

Funding support has also been provided to facilitate training in the Bridges approach to self-management support across Wales. Bridges is an innovative and evidenced-based programme where self-management support is integrated within every interaction and consultation. It has the potential to improve patient’s experiences and satisfaction and lead to better utilisation of health and social care resources.
5. **Developing and responding to patient experience and outcome measures**

In collaboration with the Stroke Implementation Group, the NCIG has made progress in the development and implementation of patient reported experience measures (PREMs) and patient reported outcome measures (PROMs) to evaluate services and inform improvements to continue to drive up the quality of neurological and stroke services in Wales.

The Welsh Neurological Alliance is leading a work-stream to finalise the development of a PREM to capture the experience of patients with a neurological condition, including stroke, which can be used across Wales.

ABUHB is hosting two Portfolio Studies, the first of which aims to deliver a validated stroke PROMs tool available for use in Wales; improved information on patient outcomes; improved services for stroke patients based on measurable patient outcomes; and to maximise the benefits of stroke research.

This study will provide an assessment of a delivery strategy for the PROMIS-10 Global Health questionnaire and a number of extra questions that are recommended for use in people who have had a stroke by the International Consortium for Health Outcomes Measurement (ICHOM). The best way of delivering these questions for stroke survivors is unknown. To ascertain the best form of delivery an all Wales approach will test 808 stroke survivors via four methods of questionnaire delivery – face to face, telephone, paper and electronic. The project has been registered as a portfolio study and four English NHS Trusts have also signed up to the project, which will complete in March 2018. At the end of the study there will be a tested tool and a preferred method of delivery identified for use across NHS Wales.

The second study is piloting the use and validity of the PROMIS-10 Global Health questionnaire with the additional questions developed for the stroke study against the generic EQ5d and a condition specific PROM in three distinct neurological conditions - Parkinson’s Disease, Multiple Sclerosis and Acquired Brain Injury. This project is also due to complete at the end of March 2018.

**Focus for 2017-18 and beyond**

In refreshing the Neurological Conditions Delivery Plan we recognised that there are still significant differences in care pathways and service provision across Wales. It was also clear that a greater focus on research and evidence based practice was required.

The Delivery Plan contains 50 actions for the health community across Wales to address in order to continue to improve services for the population in relation to neurological conditions. The Implementation Group considered that health boards required some strategic direction on which of these actions should be prioritised within the development of their Integrated Medium Term Plans. As a result a Task and Finish Group was established to review the actions contained within the Delivery Plan for 2017-20 and map them over the three years to identify short, medium and long-term objectives for the period of the plan. This work informed the development of the following high level priorities for 2018-19:
• Implement a co-productive approach to raising awareness of neurological conditions
• Implement a co-productive approach to service development
• Develop clear pathways and models of care based on best practice and research evidence

Summary and conclusion

The services across Wales have continued to show improvements despite being at different starting points in their service delivery. Projects that were in their development stage last year are now delivering consistently and continue to develop. The Neurological Conditions Implementation Group is moving in a positive manner towards a co-productive approach, which is now a priority for the next year. Our updated delivery plan and agreed priorities for the next 12 months will ensure that we keep this momentum going in order to deliver sustainable improvements. The nature of some long term conditions can affect the health and social care needs of an individual for the rest of their life and therefore the continued partnership with social services and the Third Sector will continue to explore innovative and effective ways of improving care.