



Llywodraeth Cymru
Welsh Government

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PUBLICATION

The quality statement for neurological conditions

The quality statement describes what good quality services for neurological conditions should look like.

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Quality statement

Our aim is to ensure that people of all ages living with or affected by a neurological condition have timely and equitable access to high quality services to enable them to live their best lives.

The Quality Statement for Neurological Conditions replaces the Neurological Conditions Delivery Plan for Wales.

Introduction

There are more than 577 recognised neurological conditions, disorders and syndromes which affect the brain, spinal cord, nerves and muscles. These systems therefore control all aspects of the mind and body. Neurological conditions can affect the way people think, feel and interact with the world around them. They often have a huge impact on a person's quality of life and their ability to live independently and participate in family life and their community.

Neurological conditions can be caused by a variety of factors:

- traumatic injury
- inflammation
- infection
- degeneration
- genetic
- environmental

All neurological conditions follow a different disease course, with onset from before birth, through to older age. There are, however, some commonalities and

neurological conditions can manifest by:

- sudden onset, may improve over time or stay the same
- progressive, will deteriorate over time
- relapse and remit, may come and go
- stable with changing needs

This requires a biopsychosocial approach and be influenced by medical intervention, pharmacological and symptom management and rehabilitation as part of a multi-professional, multi-agency response.

It is estimated that one in six people in the UK have a neurological condition. The number of people living with a neurological condition is set to increase over the coming years as more children survive beyond birth into adulthood and as the UK's population ages, so do the number of people living with age-related neurological conditions. The number of years lost due to ill health, disability or early death as a result of a neurological condition is higher than that of diabetes. The impact of neurological conditions on quality of life is greater than that of cardiovascular conditions or diabetes.

Neurological conditions can have a devastating impact on people's lives and those around them. People living with a neurological condition require the knowledge and skills to be able to manage their symptoms and enable them to live well within any limitations imposed by their condition. They need rapid access to diagnosis and ongoing support from a wide range of health, social care and third sector services to live their best lives. The complexity of needs for those living with a neurological condition require services to be consistent in their approach to communication, collaboration and coordination of care across all relevant services, including older people, paediatric and transitional care. We will work with children, young people and adults and their carers to help them understand the meaning and significance of their condition. We will co-develop intervention plans that support them to manage their symptoms, minimise risks to wellbeing and live well.

Building on the work of the 2013 and 2017 Neurological Conditions Delivery Plans, the Neurological Conditions Implementation Group (NCIG) will provide national leadership and drive forward change to deliver better quality, higher value, more consistent and accessible services for people affected by neurological conditions. This should take into account workforce challenges and the impact and opportunities of different ways of working during the Covid-19 pandemic.

The Welsh Government's '**More than just words plan** (<https://gov.wales/more-just-words-welsh-language-plan-health-and-social-care>)' to strengthen Welsh language in health and care services through the 'active offer' principle should become an integral part of the way we provide to people with a neurological condition. Service providers should build on current best practice and plan, commission and provide care based on this principle.

Health boards and trusts will remain responsible for planning and delivering services for those with neurological conditions. They will work closely with voluntary organisations and people with a lived experience of a neurological condition to continually improve patient-centred services. Health boards and trusts will be supported to deliver improved neurological condition services by the NHS Executive function. This will be discharged through NCIG who will set out a rolling, three-year implementation plan to identify and prioritise service developments based on the quality attributes described below.

Quality attributes of Neurological Condition Services in Wales

Equitable

- The NHS Executive supports the national approach to service improvement through NCIG. Those living or affected by a neurological condition will be

fully involved in the design of services from the outset.

- Deliver evidence based and timely treatment, in line with latest evidence, standards, best practice and NICE guidance. This will include access to diagnostics, technologies, treatments, techniques and innovations regardless of geography or condition.
- Neurological services collaborate through NCIG in a networked approach to ensure transparency, support equity of access and ensure consistency in standards of care whilst addressing unwarranted variation. This will be developed through regional and national approaches.
- Neurological services will be measured and held accountable using metrics; Patient Reported Experience Measures (PREMs), Patient Reported Outcome Measures (PROMs), national dashboards, audits and peer challenge via NCIG, that reflect the quality of patient care and its outcomes.
- Neurological rehabilitation services including physical, communication, cognitive and psychological support are consistently accessible for those affected by a neurological condition and built around the needs of the individual including consideration of Welsh and other language needs.

Safe

- Use the evidence base, clinical guidelines and shared learning to improve services.
- Develop and embed evidence based, comprehensive and integrated neuro-rehabilitation services for all conditions, including psychological support and opportunities for self-referral for those living or affected by a neurological condition.
- Further develop Value Based Health Care dashboards for Neurological Conditions to inform and evaluate service improvements and outcomes.
- Promote the importance of research into neurological conditions, supporting patients to develop and participate in clinical trials to inform the work of the clinical community, improve quality of life, influence patient care, and optimise resources.

Effective

- Implement a co-productive approach to raising awareness and of neurological conditions and developing and delivering effective services.
- Support all those living with a neurological condition to live their best lives, recognising the impact of their wider lived environment and need to participate in daily occupations.
- Embed evaluation and outcome measurement consistently in all services in line with the evaluation frameworks for rehabilitation.

Efficient

- Utilise technology throughout the pathway for improved coordination and integration of care across care settings and disciplines.
- Provide clinical consultations and interventions in person and with the use of technology where appropriate. This should not disadvantage those who are not able to access technology.
- Further develop research, innovation and education to enable delivery of high quality, evidenced based, clinical care by a well-trained, integrated workforce, supported by modelling tools and data to inform understanding of demand and capacity.
- Deliver services in the most appropriate setting, close to home wherever possible.

Person centred

- Person-centred care with shared decision making will ensure people affected by neurological conditions are able to access services in a way that suits them and achieve the outcomes that matter to them
- Co-produced evaluation of services and pathways, ensuring service users

are integral in the processes.

- Ensure integration and coordination of care across services, professions and agencies recognising the wider health and care needs of people living with a neurological condition.
- Ensure equitable access to services for those with protected characteristics (as described in the Equality Act 2010) and provision of information and services when needed in a format that is accessible, including consideration of both Welsh and other language needs.

Timely

Patients have timely and co-ordinated access to all services.

Annex A: Glossary of terms

Biopsychosocial

An inter-disciplinary approach to the connections between biology, psychology and social-economic factors.

Co-productive

A way of working where service providers and service users, work together to reach a collective outcome. Works on the principle that those who are affected by a service are best placed to help design it.

Evidence based

Practices informed by robust, peer reviewed clinical research, scientific evidence or expert opinion. **Facilitators and barriers to implementing clinical care pathways (BMC Health Services Research)**

(<https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-10-182>)

Implementation plan

Detailed action plan, with clear timescales and achievable targets.

Lived environment

All aspects that impact on the health and well-being of the individual and their dependents to include financial and economic situations.

NICE guidance

The National Institute for Health and Care Excellence providing guidance, advice and information services for health, public health and social care professionals.

Pathways

the common journey/route a person with a particular condition takes through health care services. An NHS Pathway is a clinical tool used for assessing, triaging and directing people through healthcare services. Care pathways can provide patients with clear expectations of their care, provide a means of measuring patient's progress, promote teamwork on a multi-professional team, facilitate the use of guidelines.

Pharmacological

Related to the branch of medicine concerned with the uses, effects, and modes of action of drugs.

Progression

The rate or way in which a condition progresses over time. This may be rapid or slow.

Quality Statement

High-level statement of intent for what “best” looks like for services for people with neurological conditions.

Rehabilitation

A holistic person-centred process which includes approaches that focus on early intervention for prevention, prehabilitation, supported self-management and interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment. **World Health Organisation factsheet on rehabilitation** (<https://www.who.int/news-room/factsheets/detail/rehabilitation>).

Self-management

the ways that health and care services encourage, support and empower people to manage their ongoing physical and mental health conditions themselves.

Service specifications

Written guideline that sets out details on how specific services will be delivered and measured.

Shared decisions

A joint process in which a healthcare professional works together with a person to reach a decision about care. **NICE guidelines on shared decision making** (<https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>).

Third sector

Charities and non-governmental organisations.

Unwarranted variation

Refers to variation that cannot be explained by illness, medical need, or the dictates of evidence-based medicine, often referred to as the 'postcode lottery'.

Value Based Health Care

Delivering the best possible healthcare outcomes for our population with the resources that we have. **What is Value-Based Health Care (nhs.wales)** (<https://vbhc.nhs.wales/>)

Annex B: service specifications and references

The NHS Executive will support the local implementation of nationally agreed, optimised clinical pathways. These will be added as they become available as set out in the implementation plan

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