Healthcare Improvement Scotland

General Standards for Neurological Care and Support

March 2019

NHS SCOTLAND

We are committed to advancing equality, promoting diversity and championing human rights. The general standards for neurological care and support are intended to enhance improvements in health and social care for everyone, regardless of their age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation, socio-economic status or any other status. Suggested aspects to consider and recommended practice throughout the standards should be interpreted as being inclusive of everyone living in Scotland.

We carried out an equality impact assessment to help us consider if everyone will experience the intended benefits of these standards in a fair and equitable way. A copy of the equality impact assessment is published on our website.

Healthcare Improvement Scotland is committed to ensuring that our standards are up-to-date, fit for purpose, and informed by quality evidence and best practice. We consistently assess the validity of our standards documents, working with stakeholders across health and social care, the third sector and those with lived experience. We encourage you to contact the standards and indicators team at hcis.standardsandindicators@nhs.net to notify us of any updates that the general standards for neurological care and support project group may need to consider.

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Contents

Introduction

Background

Neurological conditions are a significant cause of morbidity and mortality in Scotland. The impact of living with a neurological condition differs enormously in individuals. Many conditions can have a significant and life-changing effect on an individual and their family and carers. Care and support services across health, social care and the third sector have a vital role in supporting people to live well.

In 2009, NHS Quality Improvement Scotland (Healthcare Improvement Scotland's predecessor organisation) developed clinical standards for neurological health services. The document publication comprised of four generic standards that applied to services provided for all people living with neurological conditions. The remaining standards were specific to a limited number of neurological conditions.

In May 2016, the Scottish Government supported Healthcare Improvement Scotland's commitment to review the generic standards in the 2009 publication. That year, third sector organisation, Sue Ryder published a report[1] highlighting that the 2009 clinical standards had not been universally implemented across NHSScotland, which had led to a variation in care for people living with neurological conditions.

The 2019 general standards have been developed to ensure consistency in approach to neurological care and support services. They are applicable to anyone living with a neurological condition in Scotland. Organisations across health, social care and the third sector who support people living with neurological conditions will use the standards to demonstrate that they are delivering high quality services. The standards will set out the same high level of care and support for all adults in Scotland regardless of their neurological condition, care setting, geographical location or personal circumstance.

Healthcare Improvement Scotland will support the neurology community to consider the next steps for the condition-specific elements in the 2009 clinical standards following publication of the general standards for neurological care and support.

What are neurological conditions?

Within the standards, the term 'neurological condition' refers to all diseases of the central and peripheral nervous system (the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction, and muscles),[2] from the well-recognised and prevalent to the very rare.

We recognise the challenge in categorising neurological disease as it is an umbrella term to describe an individual's presentation and experience of symptoms which can differ enormously. Differentiation between disorders of the nervous system (for example, multiple sclerosis, stroke and neuropathy) and disorders primarily caused by abnormal function of the nervous system (for example, migraine, movement disorders and functional neurological symptoms) can be complex, with similar symptoms and resultant health problems.

Neurological conditions can be:

- self-limiting – the condition resolves spontaneously with or without treatment (for example, viral meningitis, transient global amnesia)
- recurrent – episodic conditions characterised by the intermittent return of a sign or symptom (for example, migraine, epilepsy)
- persistent – enduring conditions which exist or remain in the same state for an indefinite long time (for example, spina bifida, cerebral palsy)
- progressive – conditions where there is a progressive deterioration in function (for example, Parkinson's disease, multiple sclerosis)
- life-limiting – conditions for which there is no cure that will shorten a person's life (for example, motor neurone disease, Huntington's disease).

National Action Plan on Neurological Conditions

The Scottish Government's National Action Plan on Neurological Conditions[3] articulates a vision for neurological health and care services and aims to drive improvements in the care, treatment and support available to people living with neurological conditions, and their family and carers, in Scotland.

The National Action Plan on Neurological Conditions aims to:

- ensure people with neurological conditions and their carers are partners in their care and support
- improve the provision of co-ordinated health and social care and support for people with neurological conditions
- ensure high standards of effective, person-centred, and safe care and support
- improve equitable and timely access to health and social care and support across Scotland, and
- build a sustainable neurological workforce for the future.

The National Action Plan on Neurological Conditions is committed to promoting and supporting the implementation of the general standards for neurological care and support.

Policy context

In addition to the National Action Plan on Neurological Conditions, the standards should also be read alongside other relevant legislation[4] and guidance[5-12] including:

- National Health and Wellbeing Outcomes[13]
- Realising Realistic Medicine[14]
- Social Care (Self-directed Support) Act 2013[15]
- Health and Social Care Standards[16]
- Carers (Scotland) Act 2016[17]
- Organisational Duty of Candour guidance[18]
- 18 weeks: The Referral to Treatment Standard,[19] and

- other applicable Healthcare Improvement Scotland guidance[20], standards and SIGN guidelines.[21-28]

The general standards for neurological care and support are intended to complement, not duplicate, existing standards and guidelines. References to appropriate and relevant documentation have been included throughout the standards. These references are not an exhaustive list. Organisations, services and staff should continue to refer to appropriate and applicable professional guidance, policy and best practice.

Health and social care integration

In April 2016, following the implementation of the Public Bodies (Joint Working) (Scotland) Act 2014,[29] 31 Health and Social Care Partnerships were established. The aim of health and social care integration is to:

- improve the quality and consistency of care for individuals, carers, and their families
- provide seamless, joined-up care that enables people to stay in their homes or homely setting, where it is safe for them to do so, and
- ensure that resources are used effectively and efficiently to deliver services that meet the needs of the growing population of people with longer term and often complex needs, many of whom are older.

The general standards for neurological care and support aim to support multi-professional and multi-agency delivery of neurological services. The standards have been developed to support organisations within health and social care to deliver high quality care and support for people living with neurological conditions in Scotland.

Health and Social Care Standards

In recognition of the changing landscape of health and social care services in Scotland, the Scottish Government published *Health and Social Care Standards. My support, my life* in 2017.[16] These standards underpin the general standards for neurological care and support which have been developed to complement the guiding principles of the Health and Social Care Standards.

The objectives of the Health and Social Care Standards are to drive improvement, promote flexibility and encourage innovation in how people are cared for and supported. The Health and Social Care Standards cover all health and social care services in Scotland and promote delivery of high quality, compassionate, person-centred, safe and effective care with a focus on outcomes. They describe what we should all expect when using care services in Scotland. They are founded on human rights and seek to provide better outcomes for everyone to ensure that people are treated with dignity and respect. They are designed to ensure that the assessment of quality is not determined by organisations achieving minimum standards, but that people have positive experiences and are supported to achieve their personal outcomes. They will help managers and care staff plan, implement and reflect across strategy, assessment, commissioning as well as delivery of services.

Quality of care approach and framework[30]

The Healthcare Improvement Scotland general standards for neurological care and support are a key component in supporting organisations' approaches to quality assurance. Monitoring and improving performance against these standards, at an organisational and national level, aims to improve the experiences and outcomes of people living with neurological conditions.

Healthcare Improvement Scotland is publishing these standards for services to use to inform their own self-evaluation and improvement of the care they provide. Our approach to quality assurance emphasises the importance of regular open and honest organisational self-evaluation using the quality framework as a basis. We may use these standards along with our Quality Framework, which underpins all our quality assurance activity, when undertaking inspections and reviews of the quality of health services. There is no plan to undertake any specific inspections or routine external quality assurance activity related to these standards.

The Care Inspectorate, Healthcare Improvement Scotland and other scrutiny bodies may take into account these standards in relation to inspections, quality assurance functions and registration of health and social care services.

Scope of the standards

The Healthcare Improvement Scotland general standards for neurological care and support apply to all health and social care services and organisations that support adults in Scotland living with a neurological condition.

The standards cover the following priority areas:

- leadership and governance
- working together
- staff education, training and information
- diagnosis
- assessment of needs
- treatment and management, and
- person-centred care.

More information about the development of the standards is set out in Appendix 1.

Format of the standards

All our standards follow the same format. Each standard includes:

- a statement of the level of performance to be achieved
- a rationale providing reasons why the standard is considered important
- a list of criteria describing the required structures, processes and outcomes
- what to expect if you are a person experiencing care
- what is expected if you are a member of staff, and

- what the standards mean for organisations, including examples of evidence of achievement.

Within the standards, all criteria are considered 'essential' or 'required' in order to demonstrate the standard has been met. In addition, at the end of each standard, a list of examples of evidence of achievement are provided which will enable service providers to demonstrate it has met the standard. While all organisations responsible for the delivery of services to people with neurological conditions are expected to meet all the standards, the detailed implementation of these standards is for local determination.

Terminology

Wherever possible, we have incorporated generic terminology which can be applied across all health and social care settings:

- 'care and support' refers to all health and social care, including treatment and intervention
- 'holistic needs assessment' may include assessment of an individual's physical, psychological, emotional, spiritual and social needs, with an opportunity for the person to discuss and identify other concerns or worries
- 'organisation' refers to all health and social care services and organisations that support people living with a neurological condition, for example, NHS boards, Integration Authorities, social care providers, third sector and independent care providers
- 'person/individual' refers to the person experiencing care and support
- 'self-management' refers to the person-centred approach to include all the actions taken by people living with neurological conditions to recognise, treat, as appropriate, and manage their life and condition or conditions. They may do this independently or in partnership with the health and social care system
- 'social care' refers to all providers of social care, including statutory services, social work services, the third sector and the independent sector who support people living with neurological conditions, and
- 'transition' refers to the process of planning, preparing and moving between services and settings.

Summary of standards

Standard 1: Leadership and governance

To support people living with neurological conditions, each organisation demonstrates effective leadership and governance in the delivery and management of care and support services.

Standard 2: Working together

Organisations work together to support people living with neurological conditions.

Standard 3: Staff education, training and information

Each organisation ensures that staff have the education, training and information to deliver care and support to people living with neurological conditions, appropriate to roles and workplace setting.

Standard 4: Diagnosis

Diagnosis of a neurological condition is accurate, person centred, and followed by appropriate information, support and advice.

Standard 5: Assessment of needs

People living with neurological conditions are offered a holistic needs assessment with opportunities for review as an individual's needs change.

Standard 6: Treatment and management

Treatment and ongoing support for people living with a neurological condition is high quality and person centred.

Standard 7: Person-centred care

People living with neurological conditions experience high quality, well-coordinated and person-centred services.

Standard 1: Leadership and governance

Standard statement

To support people living with neurological conditions, each organisation demonstrates effective leadership and governance in the delivery and management of care and support services.

Rationale

Effective leadership and governance is critical to ensure high standards of safe, person-centred and effective health and social care services. People (and their family and carers, where appropriate) have confidence that every organisation that provides their care and support[13, 16] has high quality leadership and governance.

It is essential that organisations that provide neurological care and support develop and implement a neurological care and support plan to ensure people know what to expect from services.[30] This plan should describe its approach with strategic priorities and actions underpinned by structured review.

Assessing, monitoring and driving improvements in the quality of care and experience of these services[31] can enable positive health and wellbeing outcomes.[13] Continuous organisational self-evaluation through a flexible, responsive approach,[30] and reflective practice ensures people living with neurological conditions experience high quality care and support services.

Criteria

1.1 Each organisation has a nominated lead for neurological care and support.

1.2 Each organisation develops and implements a 3-yearly neurological care and support plan which, at a minimum, includes:

- an annual review
- alignment to the National Action Plan on Neurological Conditions
- development and implementation of a workforce plan
- a quality monitoring, performance management and improvement framework
- a strategy to support collaborative working with agencies, services and people living with neurological conditions, and their family and carers
- an approach to identifying the specific needs of different groups
- holistic health and wellbeing needs assessment procedures with follow-up support, as appropriate
- a strategy to minimise barriers for appropriate referral and access to services, and
- approaches to enable staff to undertake research and innovation.

1.3 To support people living with neurological conditions, there are well-defined pathways of care and protocols to facilitate:

- timely referral to appropriate health, care and wellbeing services
- access to multi-agency input including, but not limited to, primary care, community support, specialist neurological services, mental health, and third sector support
- person-centred and seamless transition between and among services and settings
- structured reviews and personalised care planning which is developed collaboratively with the person (and their family and carer, where appropriate)
- timely and appropriate access to follow-up services
- support for a person's specific communication needs
- shared decision-making with the person, and
- self-management support.

1.4 To support people living with neurological conditions, each organisation has clear systems and processes to demonstrate:

- implementation of relevant policies, procedures, guidance and standards
- compliance with professional and organisational codes of practice
- accountability and responsibility arrangements for reporting any adverse events in line with the national adverse events framework[32]
- ongoing and consistent quality and performance monitoring, assurance and improvement
- referral prioritisation and escalation procedures with processes for crisis prevention and intervention
- an effective multi-agency approach to neurological care and support, where required
- accurate and prompt communications within, and among, services and settings
- effective multi-agency (where appropriate) and appropriate information exchange to ensure continuity of care among teams and settings, and
- continuous engagement with people who experience services to capture feedback and inform service improvements.

What does the standard mean for people living with a neurological condition?
● People can be confident that: - the organisation that provides their care and support has effective leadership and governance, and is committed to quality improvement - professionals will work together and provide clear information to ensure continuity of care

- the organisation implements an organisational plan through a person-centred and multi-agency approach, and
- there are high quality and well-defined care and support pathways and protocols which meet their needs.

- People (including their family and carers, where appropriate) know how to provide feedback and are supported through this process. This includes what to do if they wish to offer positive feedback or make a complaint about the service they have experienced.
- People are supported when they transition between services and settings.
- People with additional communication needs are supported in ways that meet their needs.

What does the standard mean for staff?

- Staff have a clear understanding of:
  - care pathways, systems, protocols, standards and guidance, and
  - their organisation's role in supporting people living with neurological conditions, their family and carers.
- Staff have clear guidance on how to:
  - report and escalate adverse events, which is followed by support for learning and reflection, and
  - share their feedback to inform service improvements.
- Staff are fully informed about who their organisation's nominated lead is for neurological care and support.

What does the standard mean for the organisation?

- Each organisation:
  - provides high quality care and support services to people living with a neurological condition
  - has a nominated lead for neurological care and support
  - provides care and support in a planned and safe way
  - develops and implements a 3-year neurological care and support plan
  - works collaboratively with agencies, including the third sector, in their planning
  - works in partnership with those with lived experience, engaging and involving people in their planning
  - has a workforce plan that ensures that an individual's needs are met by the right people, and
  - has governance arrangements in place demonstrating roles, responsibilities and lines of accountability, including adverse events management.

Practical examples of evidence of achievement *(NOTE: this list is not exhaustive)*

- Multi-professional and multi-agency working, including action plans, care pathways and protocols, and transition planning.
- Evidence of implementation of self-evaluation with reporting of activities and progress.
- Documentation describing roles and responsibilities, lines of accountability and escalation of adverse events.
- Feedback from people who use services, including family, carers and independent advocates, and evidence of learning from complaints or feedback.
- Evidence of support provided to people with additional communication needs, for example, people with learning difficulty or disability or cognitive impairment.
- Risk registers that identify, for example, potential future risks to quality as well as internal risks.
- Evidence of monitoring of performance against national, organisational and local measures, for example, 18 weeks Referral to Treatment Standard, 12 week target for new outpatient appointments and local clinical audit.
- Publication of a 3-yearly organisational neurological care and support plan with annual review reports.
- Documentation understanding the needs of people with specific neurological conditions and evidence of an action plan of how these needs are to be addressed.
- Demonstration of re-entry and re-referral pathways for an individual's changing needs, including access to services due to the nature of their underlying neurological condition.
- A strategy that supports collaboration across agencies with evidence of its impact on people living with a neurological condition.
- Implementation of self-management strategies and frameworks, for example, 'Gaun Yersel' The Self-Management Strategy for Long Term Conditions in Scotland.[33]
- Evidence of improvement work, including action plans, data collection and review of data (for example, person reported outcome and experience measures) and national benchmarking.

Standard 2: Working together

Standard statement
Organisations work together to support people living with neurological conditions.

Rationale

Effective management of a neurological condition is a result of teamwork and a multidisciplinary approach across and between agencies.

People living with neurological conditions (and their family and carers, where appropriate) benefit from health, social care and third sector organisations and services working together to support continuity of care. Organisations have different roles and contributions to make in enabling people living with neurological conditions to be involved in their own health and care in a meaningful way. Partnership working is underpinned by mutual respect and clear understanding of each partner's role and responsibilities to enable people to live well.

Care co-ordination may be managed by a range of professionals and services, including general practitioners, specialist nurses, allied health professionals, neurologists, social workers and care staff. Effective integrated working, communication[34] and building and maintaining strong multi-agency links across health, social care and the third sector addresses fragmentation of care. Co-ordination of multi-agency services ensures that the person's holistic needs and outcomes are met and can lead to improvements in quality of life, physical and mental health and wellbeing.[35, 36]

Criteria

2.1 To enable organisations that support people living with a neurological condition (and their family and carers, where appropriate) to work together effectively, each organisation has protocols and guidance:

- to support a clear understanding of each agency's role and responsibilities
- for transitions, discharge and onward multi-agency referral
- for defined and robust channels of communication within organisations and across settings and services
- to ensure appropriate information is shared promptly, safely and securely, in line with relevant governance arrangements and with consent, where applicable, and
- for accountability and escalation of adverse events.

2.2 To support people living with a neurological condition (and their family and carers, where appropriate) there are locally agreed, well-coordinated pathways and protocols to:

- facilitate holistic needs assessments with timely reviews aligned to relevant condition-specific standards and guidance, where available
- enable access to appropriate physical and mental health, social care and community services for the person, based on their assessed needs
- allow seamless transitions between services and settings, including a timely and efficient approach to documentation sharing
- reduce gaps and unnecessary duplication in service delivery, and
- action anticipatory care plans across health and social care services.

2.3 Each organisation ensures that an individual's assessed needs are met, working collaboratively with third and independent sector agencies, where appropriate.

What does the standard mean for people living with a neurological condition?

- People can be confident that:
  - health and social care professionals will work together to deliver high quality, person-centred support
  - their information will be shared appropriately and promptly, safely and securely following consent and in line with relevant governance arrangements to minimise unnecessary duplication, support continuity and enhance their experience
  - they will be supported to access appropriate health, social care and third sector wellbeing services, appropriate to their assessed needs and wishes
  - the organisation promotes and delivers an approach to care and support centred on an individual's personal outcomes
  - they will experience continuity of care that is consistent and well co-ordinated, and
  - they will experience care and support from staff that have the necessary information to deliver high quality care.

What does the standard mean for staff?

- Staff have clear guidance on:
  - how their role, and the service they deliver, links with other professions and agencies
  - how to report and escalate issues within the multi-agency team
  - pathways and protocols to support seamless transition and discharge among services and across settings, and
  - how to share information sensitively and appropriately in a timely manner between and among health and social care services and settings.

- Staff can:
  - promote and deliver a personal outcomes approach for people
  - support people to access health, social care and third sector support, and
- connect and refer people, where appropriate, to wider community resources.

What does the standard mean for the organisation?

- The organisation ensures that:
  - it has well-coordinated care and support pathways and protocols
  - undertakes continuous development of a knowledgeable and skilled workforce, appropriate to roles and responsibilities
  - there are guidance and processes to enable prompt and appropriate information sharing
  - it works together with agencies to support the continuity of a person's care and support, and
  - it works with agencies, including the third and independent sector where appropriate, to meet a person's assessed needs.

Practical examples of evidence of achievement *(NOTE: this list is not exhaustive)*

- Communications demonstrating multidisciplinary and multi-agency working, for example, discharge summaries, referral letters and clear handover plans between professionals and services in health and social care settings.
- Demonstration of delivery of a personal outcomes approach.
- Evidence of consistent care and support as a result of organisations working together, for example, anticipatory care planning and transition.
- Evidence of appropriate information sharing, for example, Key Information Summary (KIS) and eWard.
- Evidence of collaboration and partnership with other agencies and third sector organisations, for example, joint working agreements between partners, multidisciplinary team meetings and case conferences.
- Feedback on partnership working, which the organisation uses for continual improvement, from people's experiences of services, including family, carers and independent advocates.
- Multidisciplinary or multi-agency care transition planning, for example, team huddles.
- Evidence of provision and uptake of multidisciplinary and multi-agency training.

Standard 3: Staff education, training and information

Standard statement

Each organisation ensures that staff have the education, training and information to deliver care and support to people living with neurological conditions, appropriate to roles and workplace setting.

Rationale

Person-centred care and support for people living with neurological conditions is provided by a number of health and care professionals in a variety of settings. This includes, for example, primary care, community or hospital setting, care at home and residential home accommodation. Given the prevalence, complexity and additional health and wellbeing challenges associated with many neurological conditions, staff are supported to continuously develop their knowledge and skills. They are provided with training appropriate to their role and responsibilities, with personal and peer support available, as required. Promotion of positive working and learning environments supports staff to deliver high quality care to people living with neurological conditions and their families and carers. Staff can support people to realise their personal outcomes and recognise the individual as an expert in their experiences, needs and wishes.[16]

Empowerment of staff to act autonomously, confidently and skilfully[37] within their professional and organisational codes[38-48] with opportunities to feedback on their experiences underpins high quality health and social care services. Staff are provided with current and relevant information and guidance whilst reflecting on their practice to enable them to deliver high quality care.[16]

Criteria

3.1 Each organisation ensures that staff involved in assessing, supporting and caring for people with neurological conditions:

- provide care and support in a sensitive, respectful and person-centred manner, reflective of the guiding principles of the Health and Social Care Standards[16]
- effectively communicate with people ensuring that their individualised needs are met
- develop and maintain high levels of skill, knowledge and competency appropriate to their role and the individuals that they support, and
- implement a multi-professional and multi-agency approach to improve knowledge, communication and partnership working.

3.2 Staff have access to clear guidance on their roles and responsibilities in supporting people living with neurological conditions, including:

- self-management
- transition planning
- escalation of any concerns or issues, and
- signposting people to appropriate support services, including specialist neurological services and third sector support.

3.3 Each organisation empowers staff who support people living with neurological conditions to implement ongoing reflective practice to identify and address, where appropriate, their education and training needs.

3.4 Each organisation ensures the education and training needs of staff who support people living with neurological conditions are aligned to professional development frameworks, where appropriate.

3.5 Each organisation ensures relevant information is available to staff to enable them to care and support people living with neurological conditions. This is aligned to appropriate guidance, standards and best practice, where available.[5-10, 21-28, 49]

3.6 Staff wellbeing is supported through ongoing personal and peer support.

What does the standard mean for people living with a neurological condition?

- People can be confident that staff providing their care and support:
  - are trained, skilled, knowledgeable and competent
  - have a clear understanding of their role and responsibilities and who to report any issues or concerns to
  - have the training to meet their needs and use their learning to ensure care that is safe, effective and person centred
  - implement a multi-professional and multi-agency approach, where appropriate
  - recognise a person as an expert in their own experiences, needs and wishes, and
  - treat them with dignity and compassion, and communications are conveyed in a courteous and respectful way.

What does the standard mean for staff?

- Staff:
  - can demonstrate knowledge, skills and competence relevant to their role, responsibilities, and the people to whom they are delivering care and support
  - attend and participate in relevant training, and achieve and maintain the required competencies and qualifications
  - can access condition-specific training and guidance, where appropriate

- are confident in their role within multidisciplinary and multi-agency teams, and can fulfil their responsibilities
- are clear what their contribution is to ensuring that people have a positive experience of care and support
- receive accurate and current information to enable them to support people, and
- respect people as experts in their own experiences, needs and wishes, and understand the impact that treatment and medications may have.

What does the standard mean for the organisation?

- Organisations provide staff with:
  - the necessary knowledge and skills, appropriate to their roles and responsibilities, to provide high quality care and support
  - ongoing support for continued development, and
  - ongoing personal and peer support opportunities.
- Training and development opportunities are provided, accessible and promoted to all relevant staff.
- Multi-agency and multidisciplinary training is developed and promoted, where appropriate.
- The organisation:
  - ensures that information on services that they deliver is both accurate and current, and
  - supports staff to share their feedback to inform service improvements.

Practical examples of evidence of achievement *(NOTE: this list is not exhaustive)*

- Evidence of provision and uptake of staff training:
  - to continuously improve the information, support, care and treatment they provide
  - to support people (and their family and carers) to self-manage their condition effectively
  - to support effective communication and meaningful conversations, and
  - to support people with additional communication needs, for example, people with sensory impairments or difficulties with speech and language.
- Evidence of:
  - promotion and implementation of the Health and Social Care Standards
  - provision and uptake of multidisciplinary and multi-agency training
  - staff appropriately signposting and referring people to support services, for example, specialist neurological services including neuro rehabilitation, neuropsychology and neurophysiology, and third sector services
  - provision and uptake of staff education and training in quality improvement methodology relevant to their role and responsibilities, and
  - competency and professional conduct frameworks.

- Where appropriate to role, demonstration of staff having access to regular supervision, appraisal and support to identify training needs.
- Use of incident reports or significant event analysis for learning, reflecting and supporting training action plans, for example, audit to measure medication errors and improve medicines management in inpatient care.
- Evaluation of training needs and training programmes.
- Information and support mechanisms for staff.
- Evidence of competency frameworks, appropriate to role and workplace setting.
- Implementation of self-management strategies and frameworks, for example, 'Gaun Yersel' The Self-Management Strategy for Long Term Conditions in Scotland.[33]

Standard 4: Diagnosis

Standard statement

Diagnosis of a neurological condition is accurate, person centred, and followed by appropriate information, support and advice.

Rationale

Neurological symptoms are common and do not always reflect neurological disease. Diagnosis of a neurological condition can be complex. The cause of an individual's neurological symptoms can be more promptly identified in some people than in others, and some individuals may not be able to receive a formal or specific diagnosis.

People living with a neurological condition can benefit from a person-centred assessment with access to clinical investigations, as appropriate, to determine the cause of their neurological symptoms. This is followed by an accurate diagnosis, where possible, with information, support and advice in a format, style and time that is right for the person.[8, 9, 16]

Some diagnoses can be made by a clinician within a primary or acute care[50] setting. Where further advice on the diagnosis and management of a person's symptoms is required, the individual is appropriately referred, in line with relevant guidance and standards,[5-10, 19, 21-28, 49] to a clinician with expertise in neurological conditions.

Effective collaboration, whether between primary and secondary care or acute and specialist care, can support both an accurate and timely diagnosis. This can be improved through enhanced training for staff who manage people who first present with symptoms indicative of a neurological condition, as well as an agreed referral pathway to a clinician with neurological expertise.[51]

Where no formal or specific diagnosis can be identified or confirmed and the cause of the individual's symptoms remains unclear, the person (and their family and carers, where appropriate), are supported to manage their symptoms through access to services based on their assessed needs and through shared decision-making.

Criteria

4.1 Where a person requires input from a clinician with expertise in neurological conditions, they:

- receive timely and appropriate referral to the relevant neurology service in line with relevant guidance and standards, where available,[5-10, 19, 21-28, 49] and
- are offered appropriate information, support and advice to manage their symptoms before their first appointment with the relevant neurology service.

4.2 Where there is an urgent clinical request for a neurological opinion from a care team, timely advice and clinical review is provided by a clinician with neurological expertise. This is aligned to relevant guidance, standards and best practice, where available.[5-10, 19, 21-28, 49]

4.3 Access to appropriate clinical assessments and investigations is planned and people are:

- promptly provided with appropriate and person-centred information and support
- offered opportunities to ask further questions, and
- asked how they would like to be informed of any outcomes and diagnosis.

4.4 All results, including further actions where appropriate, are provided promptly to the person (including person-centred feedback) and the referring clinician.

4.5 Where a diagnosis can be confirmed to the person (and their family and carers, where appropriate):

- it is conveyed by a clinician with neurological expertise
- information to understand the diagnosed condition and its potential change over time is provided in a format that is right for them, and
- condition-specific advice, including treatment, symptom and medicines management is provided, where appropriate.

4.6 Where a person's neurological symptoms cannot be formally diagnosed, the individual (and their family and carers, where appropriate) receive person-centred information and advice to manage their symptoms, and referred to relevant support services, where required.

4.7 People have access to appropriate re-evaluations and re-investigations where a diagnosis is clinically uncertain.

What does the standard mean for people living with a neurological condition?

- People:
  - will know why they have been referred
  - will be informed of how long their appointment should take, what assessments they may need and a plan for further review, where required
  - can have confidence that the organisations that provide clinical care will have agreed referral protocols and prioritisation processes
  - will have access to appropriate investigations and support services for their suspected condition
  - will have a clear understanding of any outcomes from appointments which are communicated in a way that is appropriate to their needs
  - receive information to understand their condition in a format and style that is appropriate to their needs

- are involved in decisions following their diagnosis, and
- will have access to re-assessment and re-investigation if clinically appropriate.

What does the standard mean for staff?

- Staff:
  - have clear guidance on referral protocols and prioritisation processes, including how practitioners and services link with one another
  - can appropriately refer people to the relevant neurology service
  - can support people to understand why they are having assessments or investigations
  - can communicate the diagnosis to the person in the way that they have requested, providing relevant information and condition-specific advice, where appropriate
  - can support people who do not receive a formal diagnosis with relevant information, advice and options for referral to relevant symptom management support services, and
  - can support, signpost and refer people to appropriate services where a diagnosis is clinically uncertain.

What does the standard mean for the organisation?

- The organisation:
  - ensures clear and robust referral and service re-entry protocols are developed (with multidisciplinary input) and implemented
  - supports people to receive prompt access to investigations, and
  - demonstrates a commitment to supporting post-diagnostic referral, investigation, information sharing and signposting.

Practical examples of evidence of achievement *(NOTE: this list is not exhaustive)*

- Agreed referral pathways and protocols to care and support services, for example, rehabilitation services, adaptations and equipment services.
- Implementation of referral pathways or protocols, for example, from acute unscheduled care.
- Evidence of audit or action plans for referrals to acute neurology.
- Agreed referral pathways and protocols for assessment and investigation with evidence of and timely access to neuro-imaging, neurophysiology, neuropsychological testing and ancillary investigations, with inpatient assessment, where indicated.
- Implementation of plans for assessment and investigation.
- Development and implementation of a referral prioritisation process within services, for example, acute unscheduled care presentations or where there is rapid clinical change of an individual.
- Evidence of review following diagnosis by a clinician with neurological expertise, for example, consultant neurologist or specialist neurological nurse.

- Information and support available in a format, style and at a time that is right for the person living with a neurological condition (and their family and carers), for example, confirmation of a diagnosis, advice about their condition and medicines management.
- Implementation of action plans to address barriers to service re-entry in recurrent episodic conditions, for example, epilepsy or long term chronic progressive conditions, for example, cerebellar ataxia.
- A person-centred approach to clinical consultations, where appropriate, for example, Attend Anywhere.[52]
- Adaptive patient booking systems, for example, Rapid Access Neurology Clinics (RANC).
- Evidence of using feedback from the individual's experience to inform service improvements with action plans.

Standard 5: Assessment of needs

Standard statement

People living with neurological conditions are offered a holistic needs assessment with opportunities for review as an individual's needs change.

Rationale

People who live with a neurological condition (and their family and carers, where appropriate), are at the centre of decisions that affect them.[53] They are recognised as experts in their experience of their neurological condition.[16]

A growing evidence base suggests that a holistic approach to assessing an individual's needs and their involvement in shared decision-making can lead to positive outcomes for people living with a long term condition.[15, 33, 34, 53-55] People are supported to identify their goals, discuss their care and support, and agree and co-ordinate a plan for how their goals and personal outcomes will be met.[56] A holistic needs assessment considers a person's neurological condition and also their physical, psychological, emotional, spiritual and social needs to support them to live in good health.[57]

Effective care and support planning with the individual (and their family and carers, where appropriate) can ensure that a person's holistic needs are met in a timely and appropriate way.[58] Shared decision-making supports people to understand their options and express their values and preferences to make decisions about how to manage their neurological condition and wider healthcare.[59]

A coordinated and effective multidisciplinary and multi-agency approach to care and support planning enables people to develop the knowledge, skills and confidence to manage their neurological condition, general health, care and wellbeing.

Appropriate to the individual and their neurological condition, development of an anticipatory care plan can support people to consider their personal wishes and preferences and enable them to make informed and positive choices about their future.[60, 61]

Criteria

5.1 People living with a neurological condition are offered a holistic needs assessment. This is in line with relevant condition-specific guidance and standards, where available.[5-10, 21-28, 62]

5.2 People living with a neurological condition (and their family and carers, where appropriate) are involved in identifying their needs through:

- discussing what matters to them
- identifying goals and personal outcomes
- clear identification, recording and action (where appropriate) of their assessed needs, and

- support to achieve their personal outcomes with an opportunity for review as their needs change. This is in line with relevant condition-specific guidance and standards, where available.[5-10, 21-28, 62]

5.3 A person-centred neurological care and support plan is:

- developed through shared decision-making with the individual (and their family and carer, where appropriate) with care planning support from the organisation
- informed by an individual's assessed needs with opportunities for regular review as these needs change
- shared with the individual, their family and carers (if applicable), professionals and organisations, and
- used to inform handovers, care and setting transitions, discharge planning and emergency health or crisis support.

5.4 A review of an individual's assessed needs, with a professional with neurological expertise, can be accessed:

- by the individual as their needs change,
- through appropriate and flexible service delivery models in organisational pathways, and
- in line with relevant condition-specific guidance and standards, where available.[5-10, 21-28, 62]

5.5 People are supported to have an anticipatory care plan, where appropriate. This plan is:

- developed, agreed and shared with the person, their family and carer (if applicable)
- acted on appropriately
- shared in an appropriate manner with professionals and organisations, and
- reviewed and discussed at agreed intervals.

5.6 People are fully informed of who to contact for further advice, support and access to services throughout the course of their neurological condition.

What does the standard mean for people living with a neurological condition?
● People: - are offered a comprehensive needs assessment - are supported to identify and achieve their goals and personal outcomes - will have a person-centred care and support plan - will be fully supported to discuss significant changes to their needs - can access a person-centred review as their assessed needs change - can plan their care and support to meet their assessed needs, and

- can be confident that their wishes are taken into account to ensure their future care needs are anticipated.

What does the standard mean for staff?

- Staff can:
  - confidently complete a holistic needs assessments and anticipatory care plan or know how to engage with others to do this
  - appropriately engage with people living with a neurological condition to identify their goals and personal outcomes
  - support people to discuss what matters to them
  - develop, review and appropriately share care and support plans,
  - understand their role in reviewing assessed needs, and
  - provide information of who to contact if an individual requires further advice, support and intervention.

What does the standard mean for the organisation?

- The organisation has systems and processes in place to ensure an appropriate response to people's needs, goals and personal outcomes, including:
  - holistic needs assessments
  - regular review of an individual's needs
  - development of person-centred care and support plans
  - appropriate and timely sharing of information
  - shared decision-making with the person living with a neurological condition
  - an innovative and flexible approach to conducting reviews, and
  - clear guidance on supporting staff to develop an anticipatory care plan with the individual which is outcomes focused, reviewed and discussed at regular intervals and confidentially shared, as appropriate.

Practical examples of evidence of achievement ***(NOTE: this list is not exhaustive)***

- Evidence of local arrangements and written guidance to ensure that people living with a neurological condition are offered a holistic needs assessment with further opportunities to have one, even if previously declined.
- Evidence of organisations implementing condition-specific guidance, where available, for example, SIGN Guideline 143 - diagnosis and management of epilepsy in adults.
- Evidence of supporting people to achieve their personal outcomes with regular review, for example, an annual review with the multidisciplinary team followed by information and support for the person, including a summary of the review and next steps.
- Evidence of how an individual's personal outcomes are being met, for example, using a personal outcomes data collection tool.
- Review to determine the impact the service is having on an individual's experience, including follow-up actions with timescales.

- Person-centred care and support plans demonstrating involvement of the individual incorporating their needs and wishes, for example, support to manage risk to meet personal outcomes.
- Availability of information for people, their family and carers, including leaflets and appropriate websites, for example NHS Inform[63] and ALISS.[64]
- Evidence of care and support plans being used to inform the transition of an individual from for example, secondary to community care.
- Evidence of anticipatory care plans, including how these are monitored, reviewed and updated.
- Implementation of the Anticipatory Care Planning Toolkit.[60]
- Demonstration of using anticipatory care plans and key information summary (KIS).
- Evidence of an individual being supported to update their anticipatory care plan through the Let's Think Ahead – My ACP app.
- A flexible approach in how reviews are undertaken, where appropriate, for example Attend Anywhere[52], person-led review appointments, planned review within a social care setting or in an individual's home.
- Evidence of information provided to an individual of who to contact for further advice, support and intervention following transition or discharge, for example, re-referral from GP, direct contact with service for follow-up appointment and annual review appointment.

Standard 6: Treatment and management

Standard statement

Treatment and ongoing support for people living with a neurological condition is high quality and person centred.

Rationale

Neurological disease affects people in different ways. People have their own unique experience of living with a neurological condition. Individuals may need access to a range of high quality health, care and support services in a number of settings to effectively treat, as appropriate, and manage their condition. Timely support to access high quality and person-centred services with clear, safe and effective access routes across health, social care and the third sector, ensures the assessed needs of people (and their family and carers, where appropriate) can be met.

The impact of living with a neurological condition differs enormously in individuals. There are a range of self-limiting neurological diseases which spontaneously resolve with or without treatment. Many people living with a neurological condition may benefit from new and effective treatments that can be provided as part of an effort to manage symptoms, restore lost function, and as a proactive measure to prevent worsening of their condition.

Many people effectively self-manage their condition day-to-day. Supported self-management encourages people to make decisions and positive choices about their health and wellbeing. People who recognise that they have an important role in managing their own condition experience better health and wellbeing outcomes.[65]

Specialist input from, for example, neuropsychiatry and neuropsychology services, may be required to meet the assessed needs of individuals. Some people living with a neurological condition may benefit from interventions and support, including drug therapies and neurological rehabilitation.

A number of complex neurological conditions are appropriately managed through a palliative approach that focuses on improving or maintaining the quality of life for individuals and their family and carers.[66, 67] Evidence indicates that for many life-limiting conditions, beginning palliative treatment as early as possible through a multidisciplinary approach can not only improve symptoms but also address some of the associated psychological challenges.[66, 67]

There is a recognition that access to treatment and ongoing management services can be challenging. This often increases the pressures on other parts of the health and social care system,[36] precipitating unscheduled episodes of care. A consistent approach to supporting people living with neurological conditions can improve their outcomes and experiences.

Criteria

6.1 People living with neurological conditions can access treatment in line with relevant condition-specific guidance and standards, where available.[5-10, 19, 21-28, 49, 62]

6.2 People living with a neurological condition can access ongoing support to manage their condition at the right time for them, in a format appropriate for their needs. This is directed by their neurological care and support plan, and in line with relevant condition-specific guidance and standards, where available.[5-10, 19, 21-28, 49, 62]

6.3 Organisations ensure individuals living with a neurological condition, (and their family and carers), where appropriate, can access:

- further support and review from a multidisciplinary team, appropriate to their condition and symptoms with multi-agency support (if required)
- alternative support or signposting should there be a delay in their care and support, and
- physical, emotional, cognitive, mental health and wellbeing support, including self-management support.

6.4 People living with a neurological condition (and their families and carers, where appropriate) can access specialist clinical intervention and support from services throughout the course of their condition, as appropriate, including:

- neuropsychology
- neuropsychiatry, and
- neuro-rehabilitation.

6.5 People are signposted and supported to access third sector organisations, support groups and local services.

6.6 Palliative care is discussed sensitively with individuals and their family and carers, when required throughout the course of their condition, and with actions recorded within their care and support plan. This includes:

- respiratory support
- nutritional support
- medicines management
- postural care, and
- end of life care.[68]

What does the standard mean for people living with a neurological condition?

- People:
  - can have confidence that staff and organisations will work together to ensure that they can access the right care and support at the right time for them
  - experience consistency and continuity throughout their care and support
  - are informed of any delay to their care and support with an interim measure put in place to address the delay
  - can choose from a range of services, where appropriate, which is informed by their neurological care and support plan, and
  - can access information about relevant third sector organisations, support groups and local services.

What does the standard mean for staff?

- Staff:
  - work in partnership with the individual (and their family and carers, where appropriate), professionals and organisations to plan their care and support
  - support people to access the right care and support at the right time
  - can deliver care and support in a format appropriate to the individual's needs, and
  - can confidently refer and signpost people to appropriate health, social care and third sector support services.

What does the standard mean for the organisation?

- The organisation:
  - ensures that there are clear, safe and effective routes for people to access treatment and support services that met their assessed needs
  - supports people to access appropriate care and support services, and
  - ensures that people living with a neurological condition experience consistency and continuity of care.

Practical examples of evidence of achievement ***(NOTE: this list is not exhaustive)***

- Evidence that the organisation demonstrates and supports continuity of care.
- Self-management options, for example, emergent use of Buccal Midazolam for seizure control and intermittent self-catheterisation.
- Evidence of onward referral for people's health and wellbeing needs, for example, referral to neuropsychology and clinical psychology.
- Evidence of signposting and support to access appropriate third sector and specialist organisations.
- Evidence of pathways with appropriate access to specialist services, for example, neurological rehabilitation, including physiotherapy, occupational therapy, speech and language therapy and dietetics, neurophysiology, neuropsychiatry and neuropsychology/mental health teams.
- Agreed treatment protocols, for example, treatment pathways to neurosurgery and orthopaedic spinal surgery.

- Multidisciplinary team clinic access to neuropsychological assessment and psychological intervention.
- Evidence of individuals being supported to access psychological interventions, for example, cognitive rehabilitation and behaviour therapy and motivational interviewing.
- Information and support available to people about support services, including, referral services and information leaflets.
- Implementation of the Strategic Framework for Action on Palliative and End of Life Care.[69]
- Provision and uptake of palliative and end of life care: enriching and improving experience[70] framework and learning resource.

Standard 7: Person-centred care

Standard statement

People living with neurological conditions experience high quality, well-coordinated and person-centred services.

Rationale

A person-centred approach is fundamental to achieving the quality ambition for people who experience care and support services in Scotland.[71] Personalised and well-coordinated neurological care and support enables people and their family and carers to live an independent and fulfilling life. Care provision that focuses on positive experiences of care and support, personal outcomes and an individual's needs and wishes can result in more effective care and a better experience for people who use health and social services.

Individuals who live with neurological conditions and their family and carers will experience compassionate care which is provided by people and organisations who understand their support needs.[16, 72]

Criteria

7.1 Organisations ensure that people living with a neurological condition are fully informed and supported at all stages of their care with:

- accurate information provided at a suitable time and in a format and language that is appropriate to their communication needs, and
- signposting and access to health, social care and third sector services, choices and care options that meet their needs.

7.2 People living with a neurological condition are empowered and supported:

- by compassionate staff who respect their wishes and personal outcomes
- by organisations that promote and implement the guiding principles of the Health and Social Care Standards[16]
- to develop the knowledge, skills and confidence to manage their own condition and medication, as appropriate, and
- to be as independent and as in control of their health and wellbeing as they can be.

7.3 A person's additional needs or health conditions are recognised and supported by staff with signposting and referral, to appropriate multi-agency services, if required.

7.4 People have the opportunity to involve their carers, families and/or other representatives in their care, if they wish.

What does the standard mean for people living with a neurological condition?

- People:
  - are recognised as individuals and treated with compassion and respect
  - are involved in discussions and decisions about their neurological care and support
  - have the opportunity to plan their care with staff who work together to achieve outcomes which are important to them and their quality of life
  - can be confident that there is an emphasis on understanding their perspective and how their condition impacts on their lives
  - have a positive experience of care and support services
  - are supported to have an understanding, skills and confidence to use health information, to be active partners in their own care and to navigate health and social care systems
  - can be confident that the multidisciplinary and multi-agency teams providing care and support are holistic and designed to effectively meet their needs, and
  - are given the opportunity to involve their families, carers and/or other representatives in their care, as appropriate.

What does the standard mean for staff?

- Staff:
  - are familiar with and demonstrate a person-centred approach, ensuring that people feel well supported and listened to
  - are competent in providing and supporting effective communication, and demonstrate a dignified person-centred approach
  - can actively engage with people (and where appropriate their families and carers) to understand their needs and preferences, and
  - understand that people are affected by neurological conditions in different ways and offer appropriate support that reflects needs and preferences.

What does the standard mean for the organisation?

- Organisations:
  - have systems and processes to ensure that they deliver responsive care and support
  - provide information in formats that are accessible
  - ensure that staff have time to support and care for individuals, and
  - have an enabling attitude towards individuals.
- Care plans will set out how an individual's needs will be met and respect their wants and wishes.

Practical examples of evidence of achievement *(NOTE: this list is not exhaustive)*

- Evidence of supporting people who manage their own medications to do so at times which are right for them when there is a change in their environment, for example, hospital admission.

- Evidence of support for people in communicating their needs, for example, interpretation and translation services and independent advocacy services.
- Evidence of support for people with additional communication needs, for example, people with sensory impairments or difficulties with speech and language.
- Initiatives to enhance person-centred approaches, for example “What Matters to You”.[73]
- Evidence of people being supported to manage risk to meet personal outcomes which enhance their quality of life.
- Innovative approaches to accessing care and support, where appropriate, for example, Attend Anywhere.[52]
- Information and support available to people around self-management, for example, referral services and information leaflets.
- Initiatives to maximise support provided to family and carers, for example, information about services and how to engage with relevant support groups.
- Evidence of signposting and supporting people to access, for example, advocacy, legal advice, employment, housing and financial support.
- Implementation of person-led appointments systems, for example, patient focused booking (PFB).
- Provision and uptake of relevant training for family and carers, where appropriate, for example, in the use of hoist and peg feed training.

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Appendix 1: Development of the general standards for neurological care and support

A short life working group (SLWG), convened in January 2017, was assigned to review and assess the currency of the clinical standards for neurological health services published in 2009. The group's recommendations were based on defined criteria, including best practice, personal outcomes, evidence base and other related standards and indicators. Following recommendations from the SLWG, Healthcare Improvement Scotland agreed to review the 2009 standards.

The general standards for neurological care and support have been informed by current evidence, best practice recommendations, and developed by group consensus.

Development activities

To ensure each standard is underpinned with the views and expectations of health and social care staff, third sector representatives, individuals and the public in relation to neurology, information has been gathered from a number of sources and activities, including:

- a literature review
- an equality impact assessment
- three standards development meetings between March 2018 and August 2018
- a 12-week consultation exercise on the draft standards between September and December 2018, and
- two finalisation meetings with the development group between January and February 2019.

The standards development group, chaired by Dr Tracey Baird, Consultant Neurologist, NHS Greater Glasgow and Clyde, was convened in March 2018 to consider the evidence and to help identify key themes for standards development.

Membership of the standards development group is set out in Appendix 2.

Consultation feedback and finalisation of standards

Following the consultation exercise, the development group reconvened to review all comments received and to make final decisions and changes relating to the content of the standards. More information can be found in the consultation feedback report which is available on the Healthcare Improvement Scotland website: http://www.healthcareimprovementscotland.org/

Quality assurance

All standards development group members were responsible for advising on the professional aspects of the standards. Clinical members of the group were also responsible for advising on clinical aspects of the work. The chair was assigned lead responsibility for providing formal clinical assurance and sign-off on the technical and professional validity and acceptability of any reports or recommendations from the group.

All group members made a declaration of interest at the beginning stages of the project. They also reviewed and agreed to the group's Terms of Reference. More details are available on request from hcis.standardsandindicators@nhs.net. Healthcare Improvement Scotland also reviewed the standards document as a final quality assurance check. This ensures that:

- the standards are developed according to agreed Healthcare Improvement Scotland methodologies
- the standards document addresses the areas to be covered within the agreed scope, and
- any risk of bias in the standards development process as a whole is minimised.

For more information about Healthcare Improvement Scotland's role, direction and priorities, please visit:
www.healthcareimprovementscotland.org/drivingimprovement.aspx.

Appendix 2: Membership of the general standards for neurological care and support development group

Name	Position	Organisation
Tracey Baird	Chair, Consultant Neurologist	NHS Greater Glasgow and Clyde
Lee Emslie	Dietitian	NHS Grampian
Rachel Gaddi	Speech and Language Therapist	NHS Ayrshire & Arran
Gregory Hill-O'Connor	Our Voice Co-ordinator	Health and Social Care Alliance Scotland
Charlie Hood	Patient representative	Health and Social Care Alliance Scotland
Wendy Jack	Interim Head of Strategy, Planning and Health Improvement	West Dunbartonshire Health and Social Care Partnership
Elinor Jayne	Policy and Public Affairs Manager - Scotland	Sue Ryder
Annie Macleod	Scotland Director	Parkinson's UK
Jim McNally	Inspector	Care Inspectorate
Patrick Mark	Patient representative	Health and Social Care Alliance Scotland
Jenny Preston	Consultant Occupational Therapist and Clinical Lead Neuro Rehabilitation	NHS Ayrshire & Arran
Ann Silver	Specialist Neurological Nurse	NHS Greater Glasgow and Clyde
Angela Sprott	Registered Manager	Lomond & West Dunbartonshire Brain Injury Service
Anita Stewart	Senior Policy Manager - Neurological Conditions, Chronic Pain and Long-term Conditions	Scottish Government
Anissa Tonberg	Policy Officer	Epilepsy Scotland
Susan Walker	General Manager - Regional Services	NHS Greater Glasgow and Clyde
Rachael Wallace	Patient representative	
Geraldine Ward	Patient representative	Health and Social Care Alliance Scotland
Andy Wynd	Chief Executive	Spina Bifida Hydrocephalus Scotland

The standards development group was supported by the following members of Healthcare Improvement Scotland's standards and indicators team:

- **Wendy McDougall** – Project Officer
- **Paula O'Brien** (*to September 2018*) – Administrative Officer
- **Donna O'Rourke** – Programme Manager
- **Fiona Wardell** – Team Lead
- **Stuart Waugh** (*from October 2018*) – Administrative Officer

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