



# Halfway through – are we halfway there?

A mid-term review of the  
National Service Framework for  
Long Term Neurological Conditions

**PARKINSON'S<sup>UK</sup>**  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.

**mnda**  
motor neurone disease  
association

**MS**  
Multiple Sclerosis Society

# Putting service users at the heart of neurology commissioning

Neurological Commissioning Support

## Foreword

This snapshot look at the implementation of the National Service Framework for Long Term Neurological Conditions using the Quality Neurology audit tool has not been undertaken to be negative or to highlight deficiencies in the implementation of policy. Many groups of professionals, the voluntary sector and service users and carers have worked tirelessly over the last few years with the sole interest in improving neurology services in the UK. The Government has responded with a National Service Framework and supporters want change to take place. However, achieving change for neurology is not easy; commissioners have competing priorities that inevitably are their foremost thought within primary care.

Quality Neurology audits are not just about discovering what is happening at a grassroots level, but they are also about making service change happen. Many of the audits in this sample were conducted in order to develop baseline information so that change could be effected.

Considerable time and effort has been spent in providing PCTs and Local Authorities with support and facilitation in their neurology commissioning so that services can achieve quality standards and undergo redesign in order to improve efficiency, cost-effectiveness and to meet the needs of service users. New tools, like Neuronavigator, have been developed which provide comprehensive information about care needs, and new services have been developed to address quality, innovation, productivity and prevention (QIPP).

Health and social care has not yet fully implemented the NSF but 2010 is the midpoint for this policy. With 5 years remaining in order to achieve this NSF's Quality Requirements, the aims within the White Paper, 'Liberating the NHS', and newly forming GP consortia could be the mechanism for service change to take place.



PARKINSON'S<sup>UK</sup>  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.

**mnda**  
motor neurone d

**MS**  
Multiple Sclerosis Society

**Simon Gillespie**  
Chief Executive  
MS Society

**Kirstine Knox**  
Chief Executive  
MND Association

**Steve Ford**  
Chief Executive  
Parkinson's UK

**Sue Thomas**  
Head of NCS  
Neurological Commissioning Support



## Key findings

- **Achieving quality standards:** From all sites surveyed not one PCT has fully met a single NSF Quality Requirement (QR) and only 13% of PCTs had met evidence based markers (EBM).
- **Information:** People are not receiving even the basic information they need to manage their condition appropriately. Most services still do not have a single point of contact for people to find information about managing their condition, and access to the services they require. Many people spend significant amounts of time trying to locate information sources or simply give up searching.
- **Workforce:** There are insufficient numbers of health and social care staff with specialist training in neurology who are competent to manage the needs of the 8 million people living with a neurological condition. The lack of understanding of the needs of these people has led to excessive and costly length of stays in hospital or inappropriate emergency admission.
- **Integrated services:** The care needs of people living with a long-term neurological condition span health and social care, but these services are not, on the whole, integrated. Information is also key to integrated working but record sharing (which could facilitate integration between social, primary and secondary care) was not commonplace.
- **Transitions:** People are regularly ‘falling through the care net’. Most services do not have documented transitional arrangements for moving between services such as from younger person’s services to adult services.
- **Inequality:** Whilst services state that all treatments are available, these are often part of a postcode lottery for service users, and frequently given too late to have maximum effect.
- **Perverse financial incentives:** Financial incentives prevent ongoing support and monitoring in long-term neurological conditions. For example, neurologists and elderly care physicians are encouraged to discharge individuals who would really benefit from regular follow up of their condition to minimise complications arising.
- **Maintaining independence:** Access to rehabilitation and timely provision of equipment is a major issue. Rehabilitation can ensure individuals are independent and remain productive in the workforce, providing better quality of life for them, and reaping cost benefits in the long term.
- **Emergency and out of hours care:** Many areas are not providing sufficient out of hours care 24/7, resulting in unnecessary hospital attendances and admissions. This is particularly the case with end of life care.
- **Commissioning:** Neurology service commissioning is vary variable and difficulties arise because of a lack of understanding of neurological conditions and appropriate services to meet need, particularly around rapidly progressive conditions such as motor neurone disease (MND).

## What we want to see:

### Achieving quality standards

1. Service user engagement when redesigning neurology services so that services truly reflect service user need;
2. A National Director for Neurology so that there is leadership to deliver the NSF;
3. NHS quality standards for neurology to avoid patchy fragmented services;
4. A strategy for consistently high-quality neurological care in each health and social care economy;
5. A mid-point review of all neurology services using the Quality Neurology audit tool to enable services to identify areas they need to address in working towards implementation of the strategy. This will also assist in benchmarking between services;
6. Up-to-date clinical guidelines that are implemented.

### Information

7. Improved information exchange between different services, primary and secondary care, social care, ambulance services, care homes, sheltered housing, hospices, etc;
8. A single point of access for service users and carers with keyworker systems in place and information which is both easy to access and to understand.

### Workforce

9. Sufficient numbers of staff in the workforce: consultants, nurses, therapists, social care staff, who understand the needs of service users with neurological conditions. Currently there are only approximately 350 whole-time equivalent neurologists in the United Kingdom, equating to 1 neurologist for every 170,000 people living in the UK. This compares very unfavourably with other European countries, where on average there is one neurologist for every 18,000 to 35,000 members of the population;
10. Transition programmes that enable staff working in none-neurology areas to gain the required skills to work within neurology teams;
11. Workforce neurology champions to provide leadership for NSF implementation, and to establish local clinical networks;
12. Adequate capacity within the workforce;
13. Support to develop new roles to expand capacity, such as through engaging with community pharmacy.

### Integration

14. Integrated working to ensure both co-ordination across health and social care, and that services are joined-up;
15. Development of integrated care pathways with each care pathway reflecting the holistic needs of the individual.

### Transitions

16. Clear guidelines to manage the transitional arrangements of service users, and support for their carers during times of transition.

## Halfway through – are we halfway there?

National Service Framework for Long Term Neurological Conditions

### Inequality

17. Equitable access to all treatment and services and methods in place to monitor equitability across the area and to promptly address this if not evident.

### Perverse financial incentives

18. There needs to be better understanding of the condition's process 'versus' the need to meet targets. There is a reversibility element in Parkinson's that can ensure maximum independence is maintained; likewise, effective management of MS from an early stage can slow the progression of the condition, again, ensuring maximum independence for as long as possible. Building capacity within the workforce could ensure ongoing monitoring of service users by non specialists;
19. There are challenges relating to unbundling neurology spend and difficulties in understanding all of the costs associated with neurology care;
20. Managers and commissioners need to estimate current costs and spend for neurology services and any quality improvements made. Poor quality services are common and costly;
21. Flexibility across the different payment systems and across agencies could release money (from hospital admissions) in order to fund services;
22. How to identify and then merge with, rather than compete with or duplicate, funding for services that already support people as part of current contracts (health and social care), particularly regards specialist condition-specific teams or professionals, and in funded continuing health care.

### Maintaining independence

23. Ensuring rehabilitation, equipment and support is available promptly.

### Out of hours care

24. A coherent 24/7 easily accessed urgent care service that service users understand is required in every health and social care economy so that individuals can make informed choices about their care. This should incorporate GP out-of-hours services and provide urgent medical care for people registered with a GP elsewhere. For end of life care this should include working with ambulance services.

### Commissioning

25. Commission from an 'intelligence' base – such as 'how much?' and 'with what benefits?' (evidenced or closely monitored) for example by providing commissioning support through NCS;
26. Retaining flexibility for commissioners to reflect local service patterns and pathways;
27. Commissioning across agencies;
28. Responding to personalisation;
29. Links to continuing care funding in relation to pathways as well as funding;
30. Increasing public awareness of care pathways and making access points clear and accessible;
31. Sharing of best practice and expertise.

## Putting service users at the heart of neurology commissioning

Neurological Commissioning Support

### Introduction

'A long-term neurological condition results from the disease of, injury or damage to the body's nervous system (i.e. the brain, spinal cord and or their peripheral nerve conditions) which will affect the individual and their family in one way or another for the rest of their life'.<sup>1</sup>

The National Service Framework (NSF) for Long Term Conditions, published in March 2005, is a key tool for delivering the government's strategy to support people with long-term neurological conditions. The NSF's main aim is to transform the way health and social care services support individuals with these conditions.

Key themes within the NSF are: independent living; care planned around the needs and choices of the individual; easier, timely access to services; and joint working across health, social care and the voluntary sector. At the centre of the NSF are eleven Quality Requirements (QRs) [Box2], which are designed to place all individuals with a long-term neurological condition centrally within health and social care so that the services provided are efficient, supportive and appropriate throughout the continuum of the condition, from diagnosis to end of life. Although this NSF focuses particularly on neurology, much of the guidance it contains applies to anyone with a long term condition.

Approximately 8 million people across the United Kingdom (UK) have a long-term neurological condition. These people account for 20% of acute hospital admissions and are the third most common reason for seeing a GP. It is estimated that 350,000 people in the UK need help with the activities of daily living because of a neurological condition, and 850,000 people will be acting as a carer.<sup>2</sup>

The NSF drives the philosophy of supporting people with long term neurological conditions to live as independently as possible. It is recognized that people with long term neurological conditions have improved health outcomes and a better quality of life if they can access prompt advice and support from relevant practitioners with dedicated neurological expertise.



<sup>1</sup>. The National Service Framework (NSF) for Long Term Neurological Conditions (DH 2005), p9

<sup>2</sup>. The National Service Framework (NSF) for Long Term Neurological Conditions (DH 2005)

## Halfway through – are we halfway there?

National Service Framework for Long Term Neurological Conditions

### Box 1

Incidence and prevalence of some neurological conditions in the UK

Condition	Incidence per PCT population (New cases per year)			Prevalence per PCT Population (Cases per 100,000 of population)		
	100,000	200,000	300,000	100,000	200,000	300,000
PCT size	100,000	200,000	300,000	100,000	200,000	300,000
Epilepsy 1	24-58	48-116	72-174	430-1000	860-2000	1290-3000
Huntington's disease		N/k		13.5	27	40.5
Migraine 2 (England)	400	800	1200	15,000	30,000	45,000
Motor neurone disease	2	4	6	7	14	21
Multiple sclerosis 3	3-7	6-14	9-21	140-200	290-350	450-510
Muscular dystrophy		N/k		50	100	150
Parkinson's disease	17	34	51	200	400	600
Spinal cord injury 4,5	2 <sup>27</sup>	4	6	50	100	150
Young onset stroke 6	55 <sup>29</sup>	110	165		N/k	
Traumatic brain injury leading to long term problems <sup>7</sup>	175	350	525	1200	2400	3600
	Leading to hospital admission			With long term problems		

This document aims to set out in detail how the sampled services, incorporating both health and social care, are implementing the Quality Requirements of the National Service Framework for Long-Term (Neurological) Conditions using the Quality Neurology audit and evaluation tool/process.<sup>3</sup>

<sup>3</sup> The Quality Neurology tool was created collaboratively by the Motor Neurone Disease Association, Parkinson's UK, the Multiple Sclerosis Society and Ataxia UK, with support from York University Research and Social Policy Unit, and funding assistance from the Department of Health.

## Putting service users at the heart of neurology commissioning

Neurological Commissioning Support

### Box 2

The Quality Requirements of the National Service Framework

Quality Requirement 1	a person centred service
Quality Requirement 2	early recognition, prompt diagnosis and treatment
Quality Requirement 3	emergency and acute management
Quality Requirement 4	early and specialist rehabilitation
Quality Requirement 5	community rehabilitation and support
Quality Requirement 6	vocational rehabilitation
Quality Requirement 7	providing equipment and accommodation
Quality Requirement 8	providing personal care and support
Quality Requirement 9	palliative care
Quality Requirement 10	supporting family and carers
Quality Requirement 11	caring for people with neurological conditions in hospital or other health and social care settings.

# Halfway through – are we halfway there?

National Service Framework for Long Term Neurological Conditions

## What is Quality Neurology?

The Quality Neurology audit and evaluation tool, and process, was developed collaboratively by the Motor Neurone Disease Association, Parkinson's UK, the Multiple Sclerosis Society and Ataxia UK. The tool was match funded by the Department of Health and had support from the Social Policy Research Unit at York University. Validation of the tool took place between April 2007 and December 2009 following which a report was submitted to the Department of Health Long-Term Research Initiative Programme. The Department of Health subsequently acknowledges:

'The DH contributed to the initial development of the audit tool and is pleased to see it progressing. It is keen that any further development, or adoption, of the tool continues to be led by Quality Neurology and its partners, ensuring that service users and their carers are at the centre of the process.'

The Quality Neurology audit tool breaks down the evidence-based markers (EBMs) for each of the 11 Quality Requirements of the National Service Framework for Long-Term (Neurological) Conditions into auditable statements. Services can evaluate themselves as 'met', 'part met' or 'not met' against each criterion of the evidence-based marker. The tool then gives them a red, amber, green (RAG) score against that criterion.

The sum of the criteria drives the overall score for the evidence base marker which in turn drives the overall score for the Quality Requirement. It must be emphasised that responses are reached by a consensus method through open discussion thus ensuring that the audit is not undertaken from a single individual's point of view.

The evidence-based markers of good practice for the Quality Requirements are shown in the appendices.

The tool requires 100% compliance with all the criteria of an evidence-based marker for that overall marker to be deemed 'met'. All evidence-based markers of a Quality Requirement are required to be met before the Quality Requirement itself can be deemed 'met'. It is recognised that the tool sets a very high standard for compliance; in the validation report to the Department of Health, it was suggested that further development to provide an 80% compliance rule be undertaken if the tool is transferred to a web-enabled platform.

All of the sample health and social care services had areas of good practice but were not able to replicate this across the whole of their economy. With the need for 100% compliance this therefore meant that they were only able to rate themselves as partially meeting the NSF Quality Requirements.

The full Quality Neurology process, in addition to completion of the audit tool, also takes into account the views of service users and carers. These are gathered via focus groups, questionnaires, and semi structured interviews - both face-to-face and over the telephone – and using existing service user groups to gather the 'lived reality' of those that experience health and social care services.

# Putting service users at the heart of neurology commissioning

Neurological Commissioning Support

Service users who are consulted are predominantly those who are currently or recently discharged from receiving services, and therefore have a view on the services as they are being provided.

The results from the audit and the focus groups are then synthesised into a gap analysis and an action plan for service consolidation, improvement and development. Of the initial QN sample sites, one did not complete the full process, only completing the audit tool. The site chosen to assess the additional functionality of the tool also only completed the audit tool itself. The remaining sites that undertook the QN process, including those who used the tool as part of a more extensive piece of work with Neurological Commissioning Support all completed the full process.



## Sample profiles

This report, looking at the implementation of the NSF Quality Requirements, gathers evidence from a sample of 11 sites across England. These sites – PCT areas and their corresponding Local Authority – were identified in three different ways: through sites engaged in York University's Social Policy Research Unit benchmarking project; through working with Neurological Commissioning Support (NCS) or through identification from the Care Services Improvement Programme (CSIP) (now defunct).

Some sites were integrated across health and social care, whilst others had a close working relationship across the two. Some were considered to be performing well, and some were considered to be struggling. The sample covered large urban areas, rural areas and mixed urban/rural sites, thus ensuring that our sample is representative of the differing types of Primary care Trust / Local Authority organisations today.



**Table 1**

Pilot Site	Profile of PCT
1	High density urban area population 224,000. Large ethnic mix. Budget £496 million
2	Predominantly urban area population 750,000. Budget of over £867million
3	Largely rural population 523,000. Budget of £728 million
4	Mixed urban and rural population 604,000 population. Budget of £681 million
5	Population of 216,000. Budget of £330 million
6	Mixed urban and rural area with integrated health and social care services. Population of 170,000. Budget £250 million
7	Urban PCT population 190,000. Budget £300 million
8	Urban and rural population 300,000. Budget of £426 million
9	Rural health economy population of 515,000. Budget of £675 million
10	Undertaken across a City Primary Care Trust, a County Primary Care Trust and a Secondary Care Trusts, this covered major urban areas and the surrounding communities
11	Urban PCT predominantly younger population of 284,000. Budget of £461 million
12	Mixed urban and rural PCT with a population of 602,000. Budget of £737 million

The in-depth audits took place over an 18 month period to elicit progress towards the Quality Requirements of the NSF and completed in July 2009.

The majority of audits were undertaken via a consensus method whereby the answers to the questions posed by the audit tool were debated and agreed by staff members. Those staff present were representative of all of the teams that supply health and social care services to people affected by long-term neurological conditions.

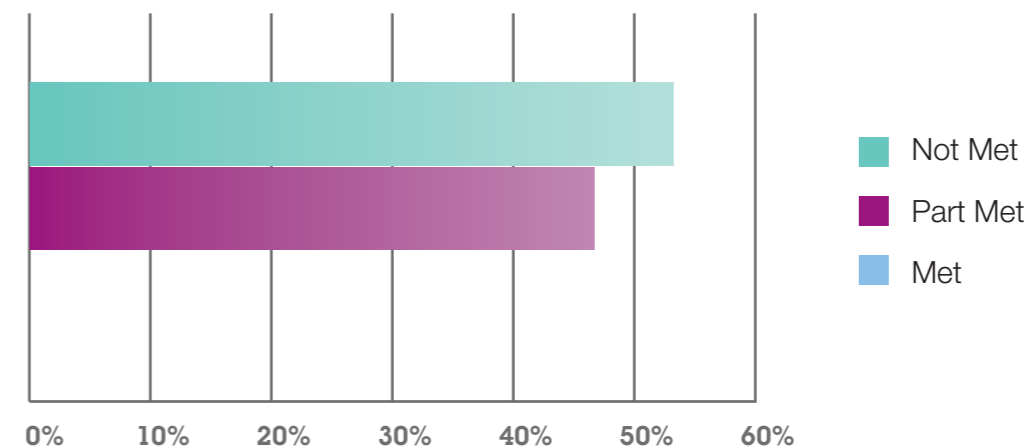
Notes were made regarding exceptions, as well as to provide evidence from the assertion that they had either 'met', 'part met' or 'not met' the criteria within the evidence based marker of the Quality Requirements they were auditing.

This methodology ensured that no single person's view on current service performance could dominate. By using the consensus method, the strengths, weaknesses, gaps, communication problems and overall service performance are made transparent to both those who are commissioning the service, and those who are providing it.

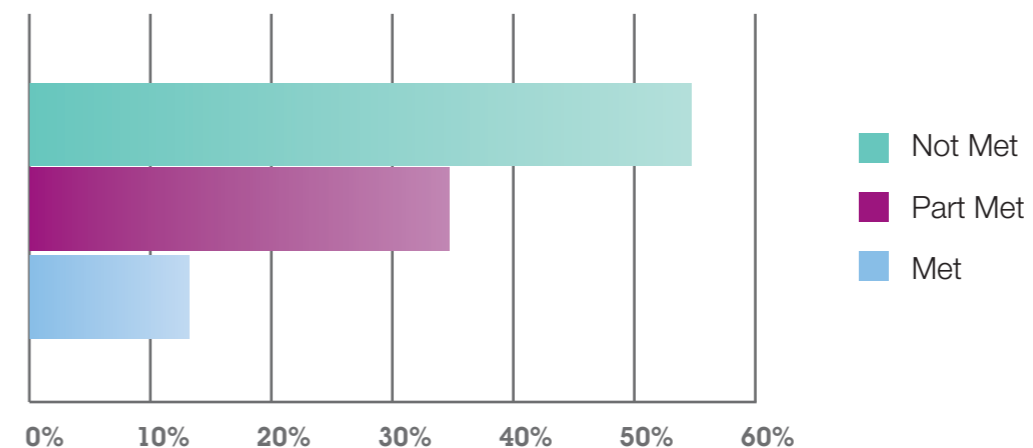
### Overview of the Audit Outcomes

Across all of the sites not a single Quality Requirement was deemed to be 'Met'.

#### Meeting all 11 Quality Requirements



#### Meeting all Evidence Based Markers



In terms of the evidence-based markers and all sites, 13% were 'met', 35% 'part met', and therefore 52% 'not met'.

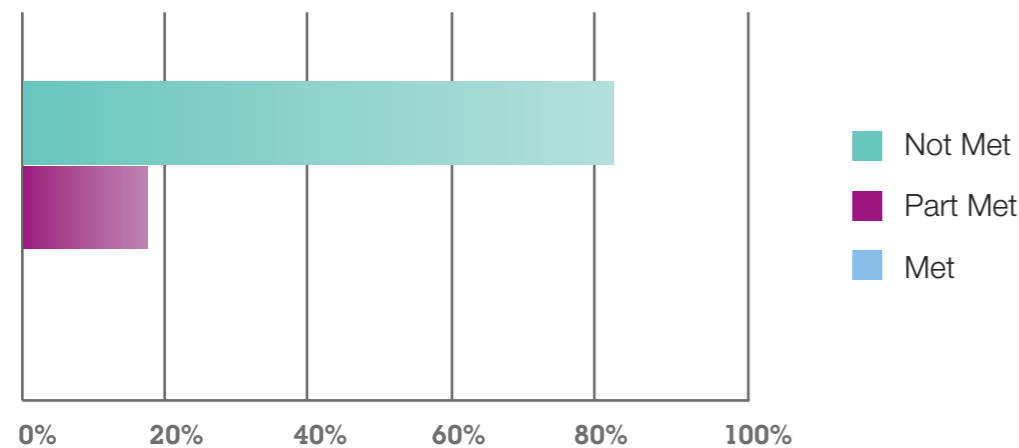
# Halfway through – are we halfway there?

National Service Framework for Long Term Neurological Conditions

## Quality requirement 1: A person centred service

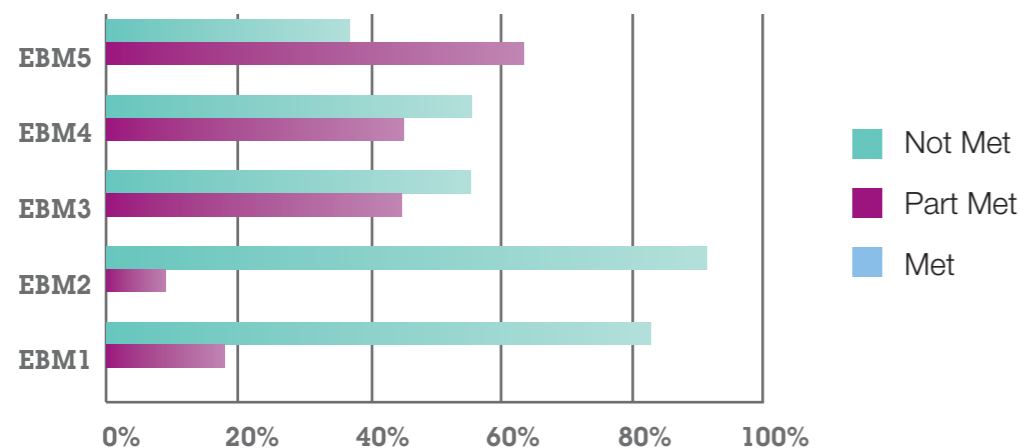
'People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.'

### Meeting Quality Requirement 1



With regards to Quality Requirement 1, 'a person centred service'; only 18% of primary care services 'part met' this requirement. With regard to the evidence based markers for Quality Requirement 1, 18% of services did not meet any of the five evidence-based markers.

### QR 1 Evidence Based Marker Compliance



# Putting service users at the heart of neurology commissioning

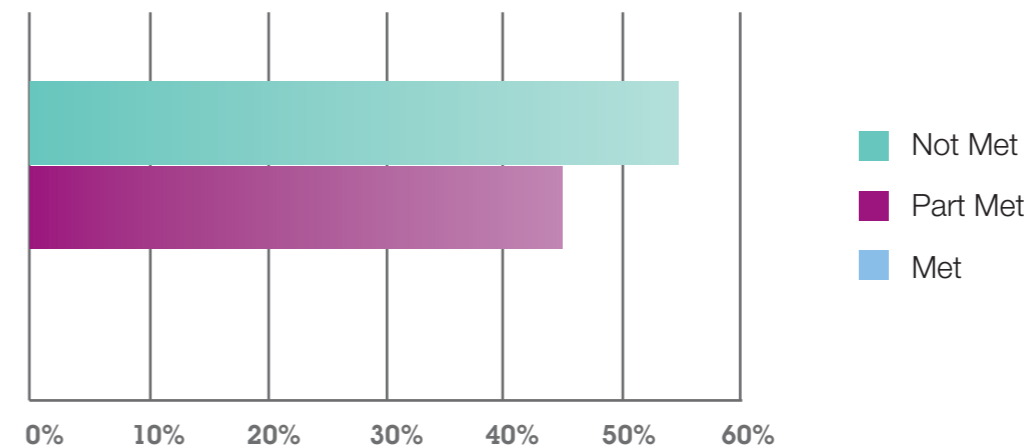
Neurological Commissioning Support

## Quality Requirement 2: Early recognition, prompt diagnosis and treatment

'People suspected of having a neurological condition are to have access to specialist neurological expertise for an accurate diagnosis and treatment is close to home as possible.'

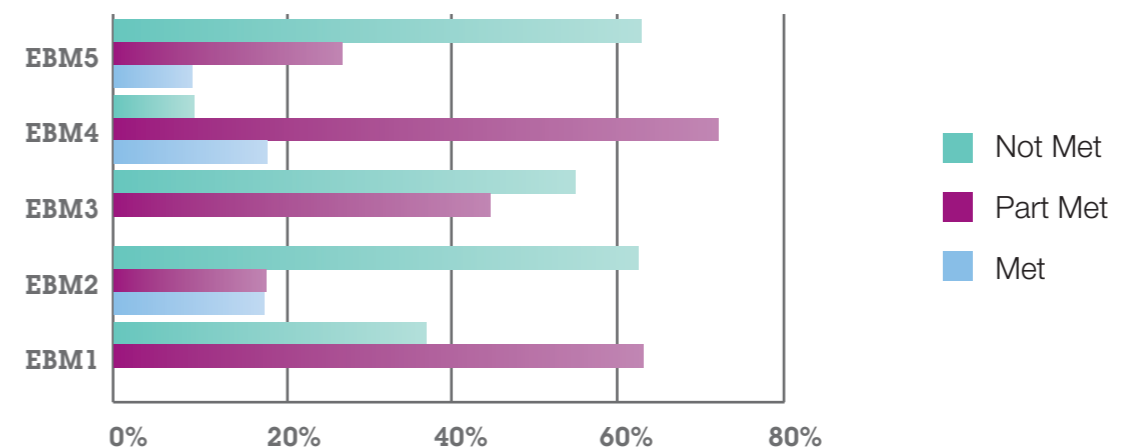
With regard to Quality Requirement 2, no services 'met' the overall Quality Requirement. 45% of services 'part met' the requirement and the remaining services did not meet it.

### Meeting Quality Requirement 2



With regard to the evidence based markers, 27% of services have some elements that were 'met' and one site obtained a 'part met' on all of the elements. The remaining services had elements that were 'part met' or 'not met' to a greater or lesser extent.

### QR 2 Evidence Based Marker Compliance



# Halfway through – are we halfway there?

National Service Framework for Long Term Neurological Conditions

# Putting service users at the heart of neurology commissioning

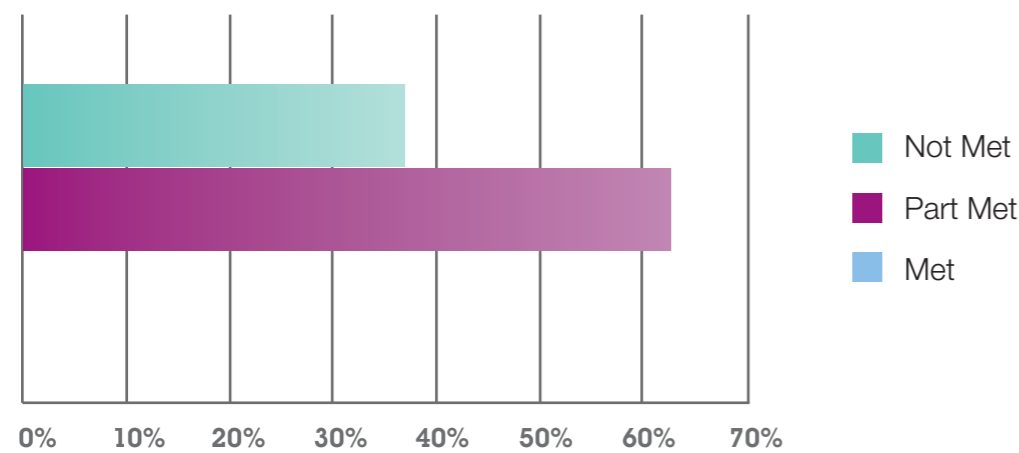
Neurological Commissioning Support

## Quality Requirement 3: Emergency and acute management

'People needing hospital admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.'

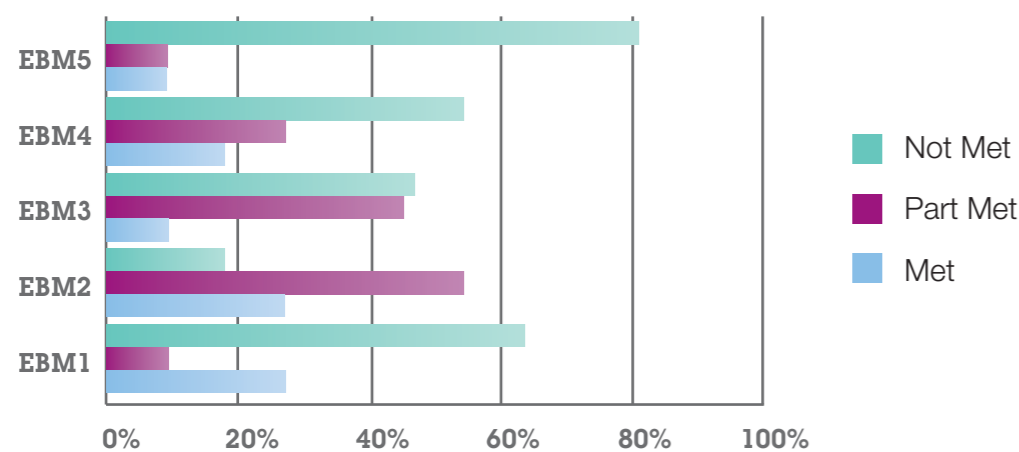
In relation to Quality Requirement 3, no services 'met' the overall requirement; 63% of services 'part met' the requirement.

### Meeting Quality Requirement 3



With regard to evidence-based markers, 36% of services have elements that were 'met', 45% of services had elements that were 'part met' and the remaining 19% of services had no elements that could be deemed to be met in any way.

### QR 3 Evidence Based Marker Compliance

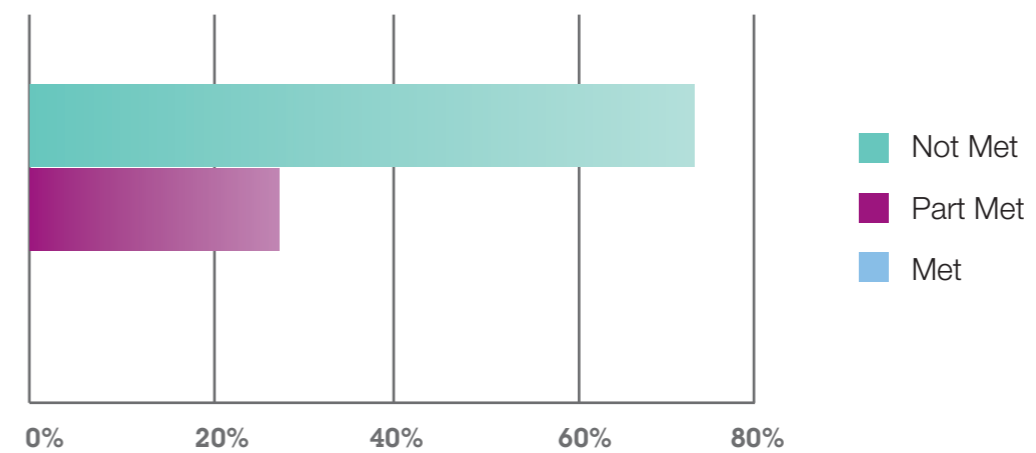


## Quality Requirement 4: Early and specialist rehabilitation

'People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high-quality rehabilitation services in hospital or other specialist setting to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.'

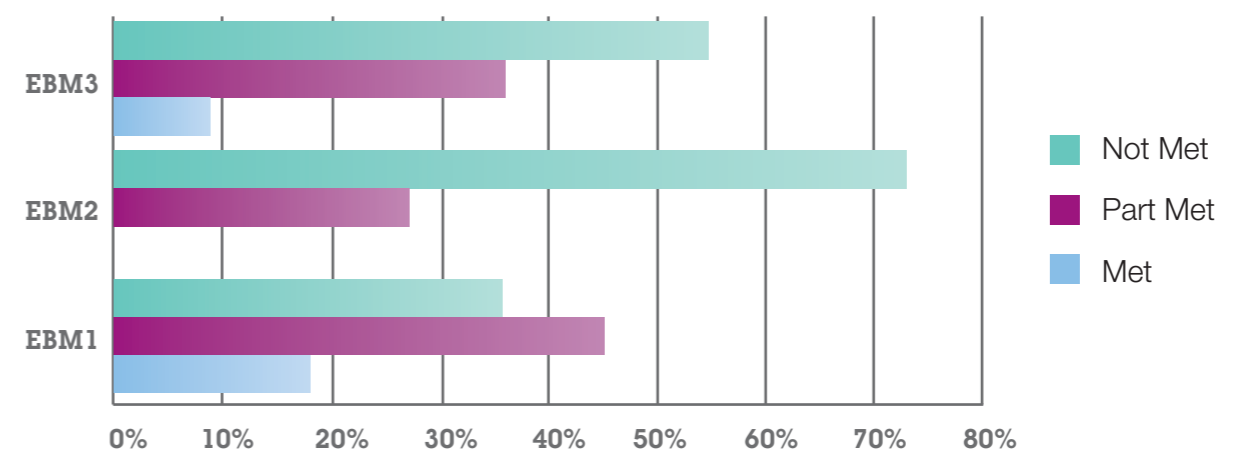
No site 'met' the overall Quality Requirement whilst 45% of services 'part met' the requirement.

### Meeting Quality Requirement 4



With regard to the evidence based markers, only 27% of services had elements that could be deemed to be 'met'. 18% of services did not meet any of the elements.

### QR 4 Evidence Based Marker Compliance



# Halfway through – are we halfway there?

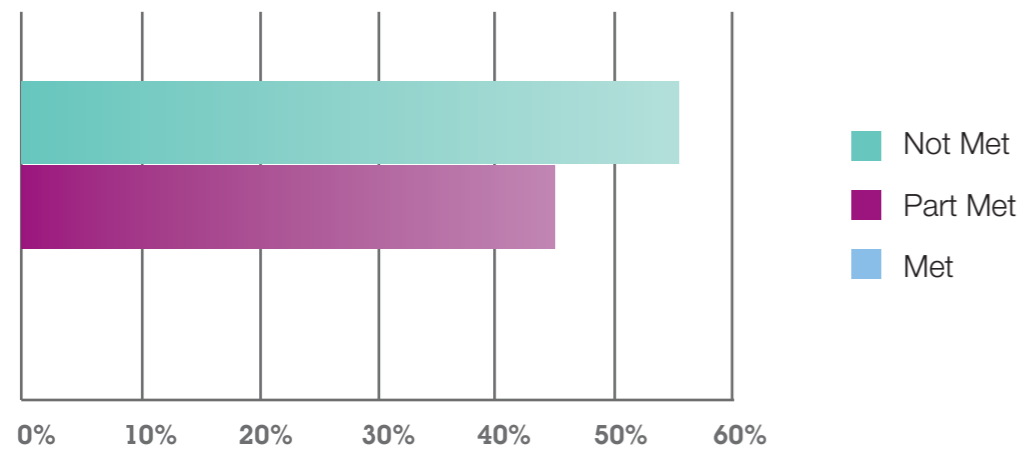
National Service Framework for Long Term Neurological Conditions

## Quality Requirement 5: Community and rehabilitation support

'People with long-term neurological conditions living at home either have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.'

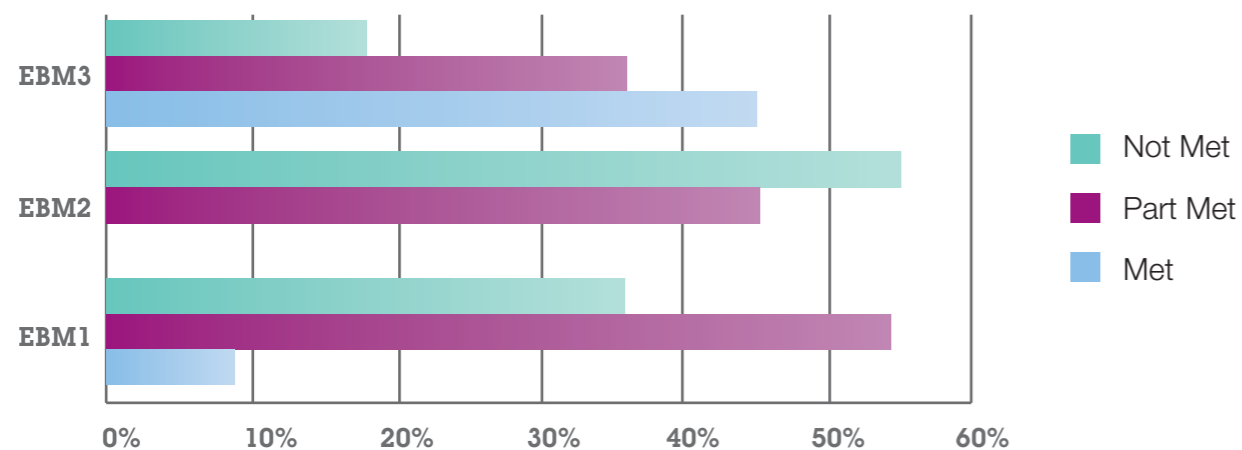
No site 'met' the overall Quality Requirement; 45% of services 'part met' the requirement.

### Meeting Quality Requirement 5



In relation to the evidence based markers, 27% of services had elements that could be deemed to be 'met', and 18% of services failed to meet any of the evidence based markers.

### QR 5 Evidence Based Marker Compliance



# Putting service users at the heart of neurology commissioning

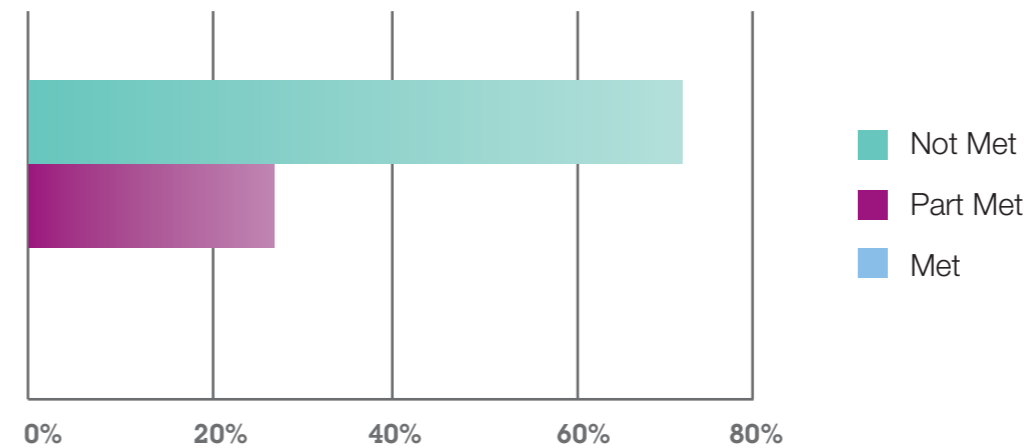
Neurological Commissioning Support

## Quality Requirement 6: Vocational rehabilitation

'People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support to enable them to find, regain or remaining work and access other occupational and educational opportunities.'

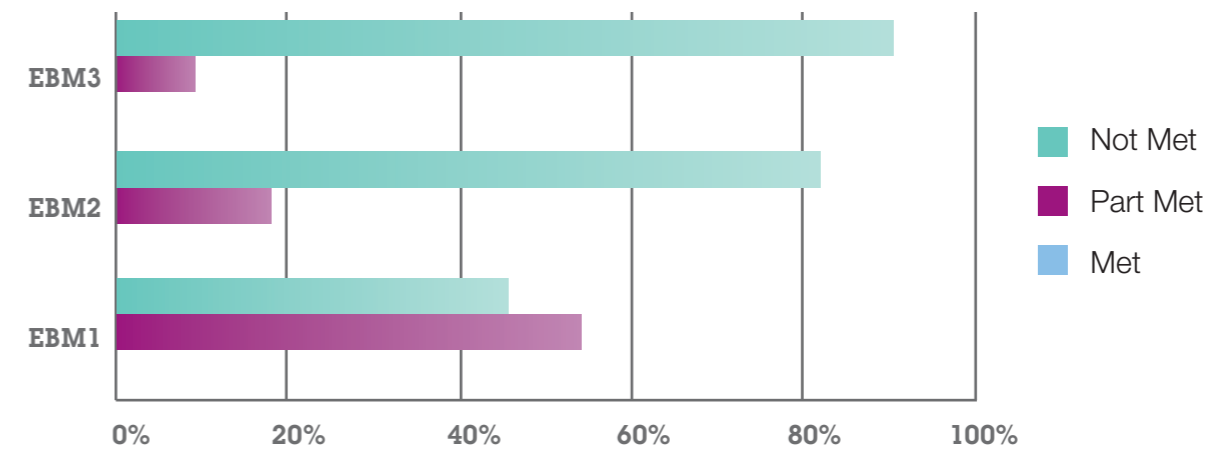
No site met the overall Quality Requirement and only 27% of services 'part met' the requirement.

### Meeting Quality Requirement 6



Of the evidence based markers, 45% of sites' services could not even partially meet any. No elements of the evidence based markers could be deemed as 'met'.

### QR 6 Evidence Based Marker Compliance



# Halfway through – are we halfway there?

National Service Framework for Long Term Neurological Conditions

# Putting service users at the heart of neurology commissioning

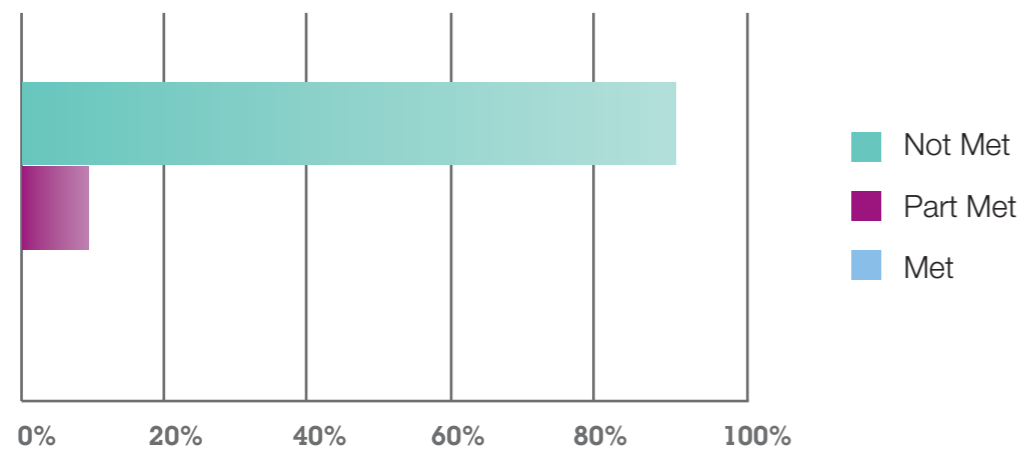
Neurological Commissioning Support

## Quality Requirement 7: Providing equipment and accommodation

‘People with long-term neurological conditions are to receive timely, appropriate assistive technology/equipment and adaptations to accommodation to support them to live independently; help with their care; maintain their health and improve their quality of life.’

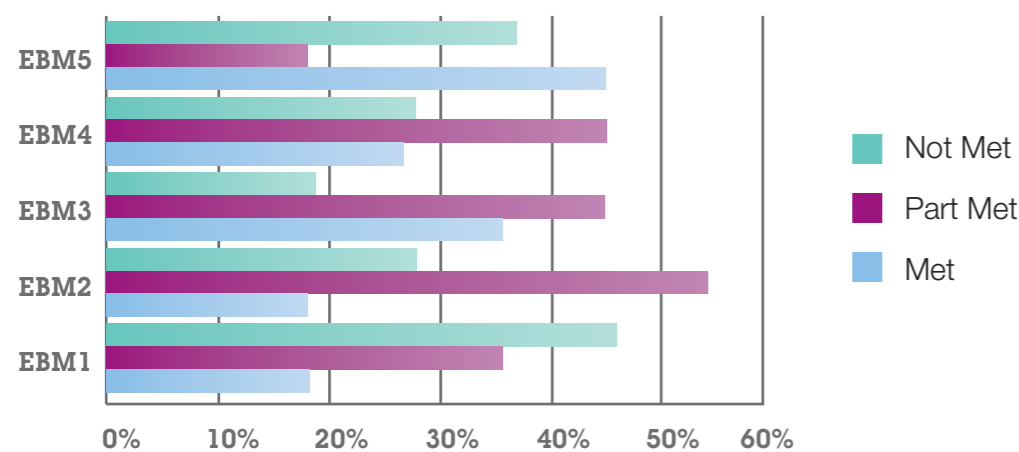
No site met the overall Quality Requirement. One single site ‘part met’ the requirements, whilst the remainder could not.

### Meeting Quality Requirement 7



With regard to evidence based markers, 18% of sites had no elements of the markers that could be deemed as ‘met’. All except one of the ‘part met’ sites had elements of the evidence-based markers that were deemed as ‘met’.

### QR 7 Evidence Based Marker Compliance

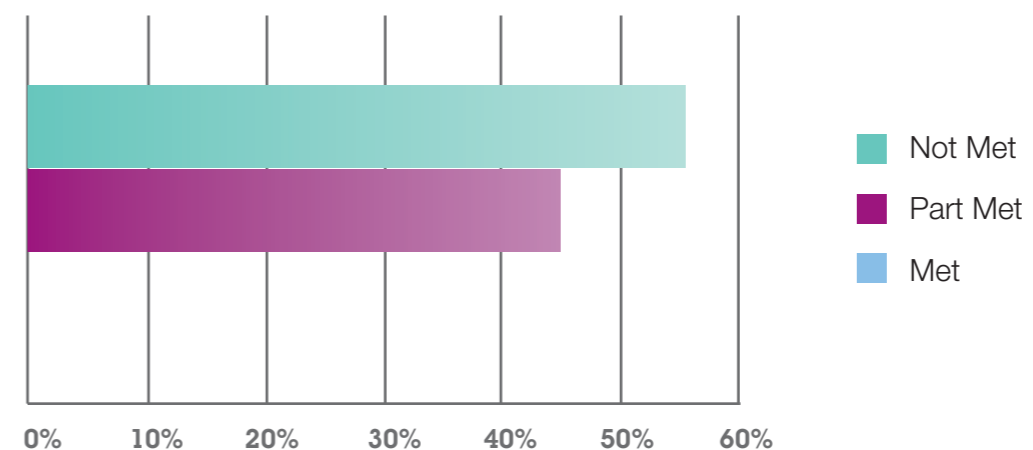


## Quality Requirement 8: Providing personal care and support

‘Health and social care services work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home.’

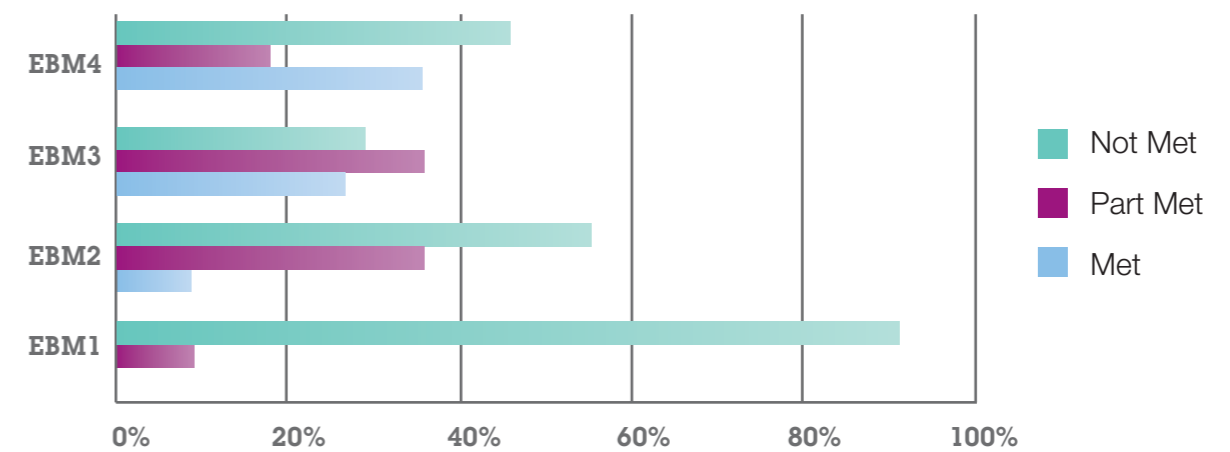
No site ‘met’ the overall Quality Requirement, whilst 45% of services ‘part met’ the overall requirement.

### Meeting Quality Requirement 8



With regard to evidence based markers, 45% of sites had elements that could be deemed as ‘met’ whilst 27% of services had no elements that could be deemed as either ‘part met’ or ‘met’.

### QR 8 Evidence Based Marker Compliance



# Halfway through – are we halfway there?

National Service Framework for Long Term Neurological Conditions

# Putting service users at the heart of neurology commissioning

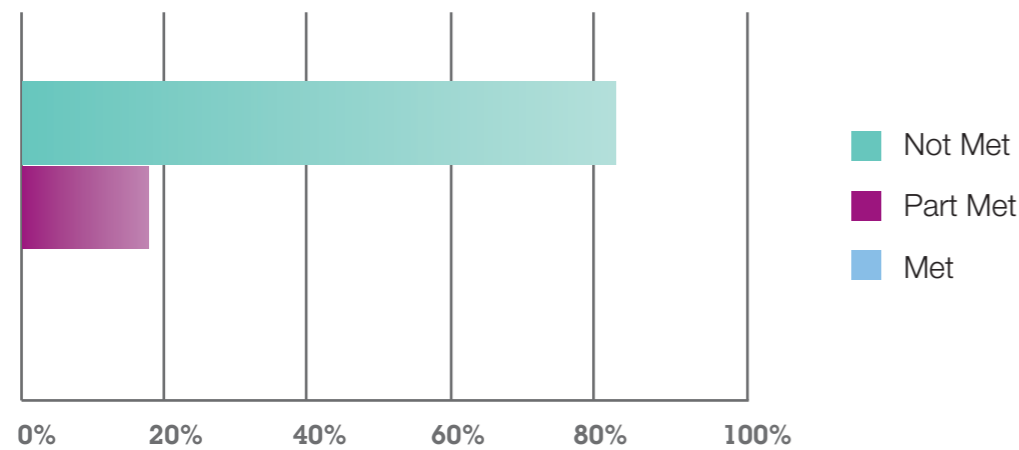
Neurological Commissioning Support

## Quality Requirement 9: Palliative care

‘People in the latter stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms; offer pain relief and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.’

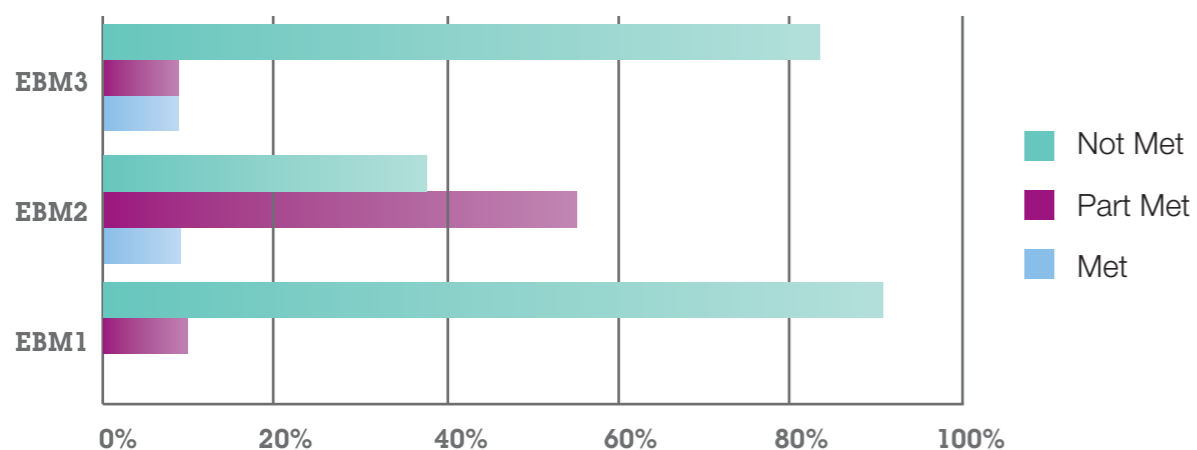
No site ‘met’ the overall Quality Requirement, and only 18% of services could claim a ‘part met’ for the overall requirement,

### Meeting Quality Requirement 9



Only one service had evidence based markers that could be deemed as ‘met’ and 36% of services had no elements of the evidence based markers that could be deemed either ‘part met’ or ‘met’.

### QR 9 Evidence Based Marker Compliance

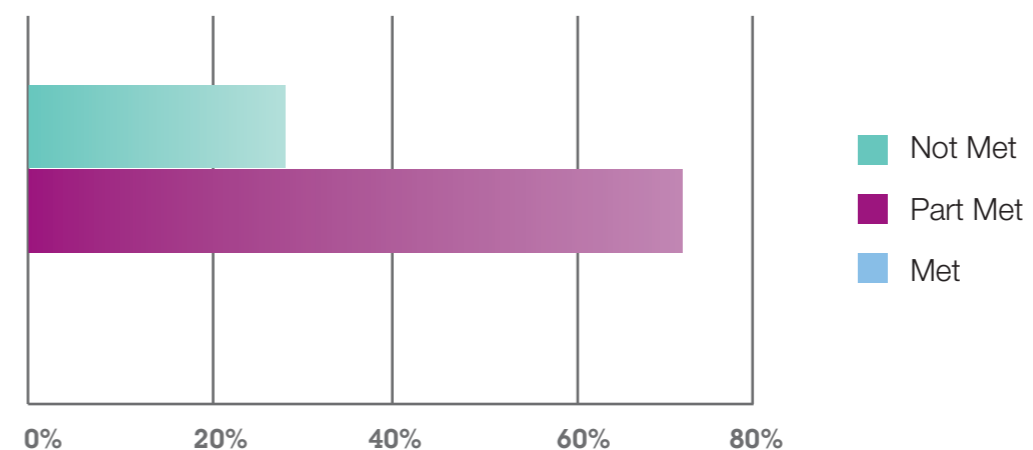


## Quality Requirement 10: Supporting families and carers

‘Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.’

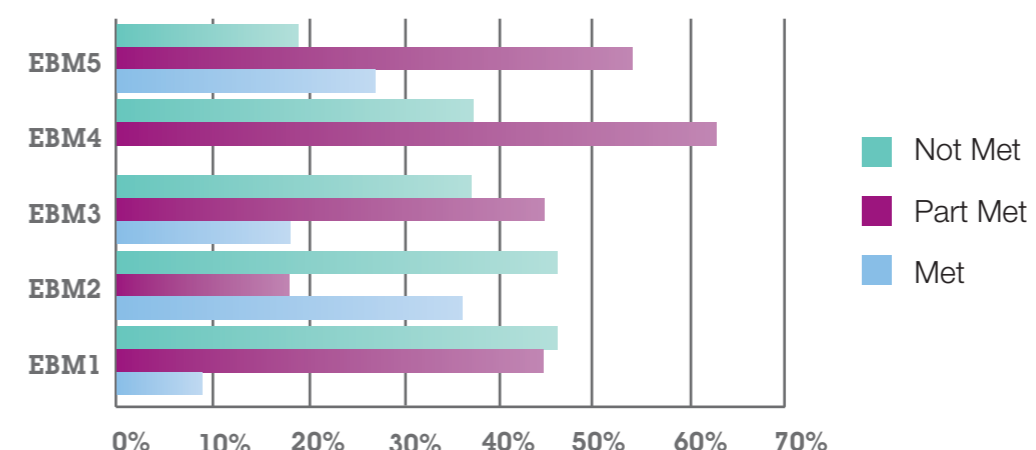
No site ‘met’ the overall Quality Requirement, whilst 73% of sites ‘part met’ the requirement.

### Meeting Quality Requirement 10



45% of the sample sites had elements of the evidence based markers that could be deemed as ‘met’, with only one site having no evidence based markers that could be deemed as either ‘part met’ or ‘met’.

### QR 10 Evidence Based Marker Compliance

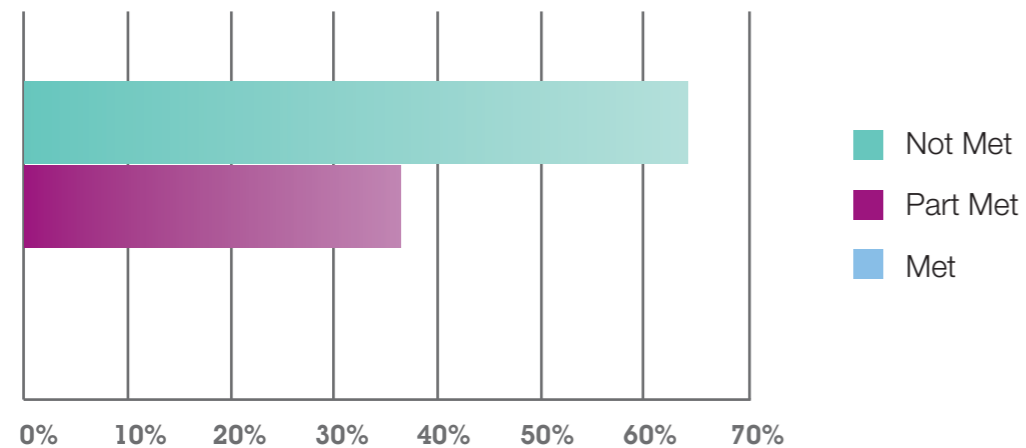


## Quality Requirement 11: Caring for people with a neurological condition in hospital or other health and social care settings

‘People with long-term neurological conditions are to have their specific and neurological needs met while receiving care for other reasons in any health or social care setting.’

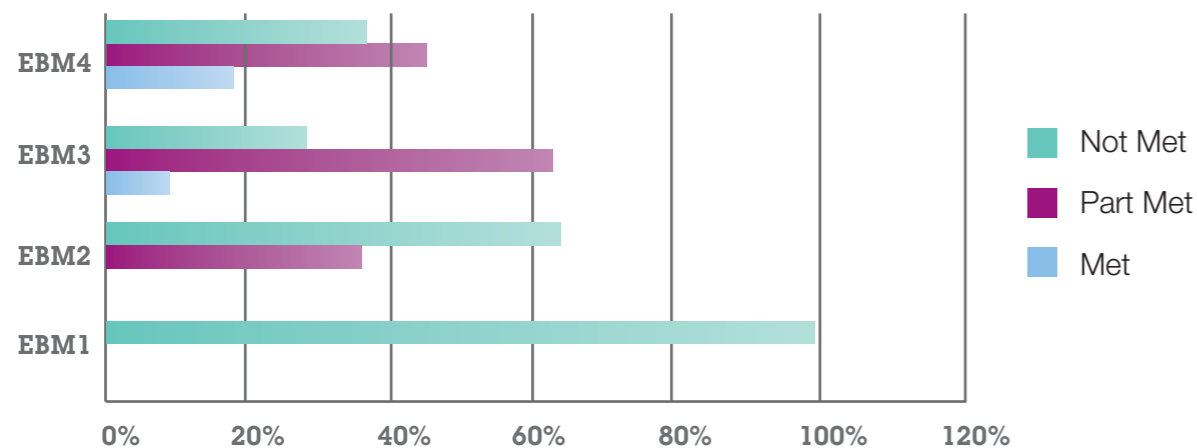
No sites ‘met’ the overall Quality Requirement and only 36% of sites obtained a ‘part met’ score.

### Meeting Quality Requirement 11



Only 27% of sites had a single evidence based marker that could be deemed as ‘met’ and one site failed to score on a single evidence-based marker.

### QR 11 Evidence Based Marker Compliance



## Summary

In brief summary, it can be seen from the overview above that implementation of the Quality Requirements, and the elements for the evidence of implementation through the evidence based markers, is very irregular across all of the sites, and therefore the services. Whilst it is accepted that the above appears quite negative, it must be reasserted that the tool requires a 100% compliance rate. In translating this observation to the results: a high percentage of ‘part met’ criteria of the evidence based markers alludes to the fact that health and social care services had areas of good practice. However, that these were not replicated across the whole service, or the whole site, meant that they could only score themselves as ‘part met’. This might be a site where existing services were serving 80% of the population well, whilst the remaining 20% were accessing no, or a limited, service by comparison.

## Specifics in relation to the Quality Requirements

### Quality Requirement 1: Person centred care

**1.1** The major difficulty in meeting this Quality Requirement was due to a lack of integrated assessment. This related to a lack of integration at multiple levels; with social care from both primary and secondary care, between primary and secondary care and between departments within social care, primary care and secondary care. Often the Single Assessment Process was cited as the solution to the problem. However, this did not address disparities between what was considered an integrated assessment and of those that have input into an integrated assessment. A frequently cited problem was an inability for health professionals to gain access to care records whether in social, primary or secondary care.

Information-sharing is a key area to progress if a site is to deliver person-centred care. Some sites allowed patients to hold summary records of their care, which could be helpful in addressing this difficulty, but service users often cited problems with health and social care professionals completing or updating the records that they held.

**1.2** Emotional and cultural needs were often cited as being difficult to address; the emotional needs more so due to the lack of psychological and counselling services for people at all stages of their journey with a long-term neurological condition. This applied, not only to those living with the conditions, but to their family carers as well.

## Halfway through – are we halfway there?

National Service Framework for Long Term Neurological Conditions

**1.3** Many services did not have a single point of contact for advice and information, and there were multiple routes into health and social care systems. Where a specialist nurse existed, they were often cited as the single point of contact for all issues of health and social care for people with long-term neurological conditions. Service users supported the use of specialist nurses / practitioners as their single point of contact / gatekeeper into associated health and social care services. They also found specialist nurses / practitioners are of great assistance in terms of healthcare advice, but that their understanding of social care is often insufficient to provide robust advice.

### Case History

Service users living in Gloucestershire identified a need for a better information source for neurology services, after discovering from the Quality Neurology audit that an array of services were available that had been previously unknown to them. They themselves, with support from NCS, have developed a 'Frequently Asked Questions in Neurology' guide specific to Gloucestershire so that service users and carers can access information more easily, and can understand what is available to support them.

**1.4** Most services did not have documented transitional arrangements for people with long-term neurological conditions from child to adult services, and adult to elderly care services. Service users cited 'falling through gaps' or coming up against barriers when these transitions took place.

### Cost Breakdown:

It is estimated that PCTs will have more than 10 patients requiring IV steroid treatment for relapse per annum. If an MS nurse is available to treat the patient at home rather than in hospital, a cost saving of £17,970 per annum will be made.

Porter, B; Matheson, F and Chataway, J (2007), p40, 'Key steps to delivery of a person centred relapse service', The National Hospital for Neurology and Neurosurgery and the Multiple Sclerosis Trust

**1.5** People with long-term neurological conditions and their carers appeared to have ad hoc arrangements in terms of education around self-management programmes. Many services directed people towards the Expert Patient Programme and events such as 'Newly Diagnosed Days' and 'Living with... Days', which are organised by third sector organisations. However, service users' experience of the Expert Patient Programme was largely that it was not specific enough to their condition, or non-relevant to them at that point in their journey living with their condition.



## Putting service users at the heart of neurology commissioning

Neurological Commissioning Support

### Service users and carers share their views:

"Health and social services don't seem to know what each other are doing, and sometimes seem to be working in ways that certainly don't complement each other".

"Before I had my specialist nurse I never knew who to contact for any advice and information".

"When you turn 65 and become an older person things just seem to stop happening. Nobody tells you why things change and what you can and can't have".

"Somebody said there were courses to help me manage my condition, but didn't tell me how I could get on them"!

"The most frustrating thing with my condition was that, as \*\*\*\*\* said, they say, 'It is a degenerative condition, there is nothing you can take to stop it' and that is it and you are left in limbo about what to do".

### Case History

One key way in which a person centred service can be delivered, is through the availability of specialist nurses. Often the first point of contact for people regards information, a 24 hour resource for reassurance, and – for many - a means of coordinating the maze that is the health and social care system, the specialist nurse is a vital role, which can be overlooked.

These case histories display the value of the specialist nurse through three specific examples:

**1.** Expert opinion estimates that PDNS care can reduce admission for PD by 50%. Hospital inpatient and outpatient figures obtained from Hospital Episodic Statistics data (HES). This showed 6,313 admissions for PD in 2004/5. Cost data of £1,220 per admission (2006/7 PbR tariff) would indicate that a specialist nurse could reduce care costs for 3,157 patients.

**2.** An MS nurse, working alongside the local multidisciplinary team, was able to streamline clinical practice between teams dealing with the management of urinary tract infections and the number of infusions offered per year. This resulted in a significant reduction in waiting times for treatment - from 6.2 weeks to just 6.1 days.

Matheson, F. and Porter, B (2006) 'The evolution of a relapse for multiple sclerosis: challenges and recommendations', British Journal of Neuroscience Nursing, vol 2 (4), pp.180-186

**3.** Outpatient care can be reduced by up to 40% where a PD specialist nurse takes the lead for clinical monitoring and medication adjustment. Outpatient attendance for PD is estimated at 62,569 which is 14% neurology follow up OP attendance (Reference costs 2005). Based on HES data 2004/5 Parkinson's represents 14% of all finished consultant episodes (FCE) which has been used as the basis for estimating the proportion of OP attendance. Cost data of £103 per attendance obtained from the 2006/7 PbR tariff. The above assumptions lead to an estimate saving of £6 million when providing this service by a PDNS.

NICE clinical guideline 35: Parkinson's disease: diagnosis and management in primary and secondary care, (National Institute for Health and Clinical Excellence: 2006)

## Quality Requirement 2: Early recognition, prompt diagnosis and treatment

**2.1** Here, greater clarity was required surrounding some very key issues: which staff are trained to improve the recognition of neurological symptoms; what is the definition of a multidisciplinary neurological clinic; and what professionals should be involved in this?

**2.2** Whilst most services claimed that patients had access to appropriate treatments and that treatments were available (including all those approved by NICE), service users would refute this fact, either from an inability to access the service, as was common, or a lack of knowledge that it was there. They cited, as an example, that access to drugs and technologies approved by NICE were part of a postcode lottery. Frequently these had lead times that meant the effectiveness of the drug or technology was reduced due to the delay in obtaining it.

**2.3** There were issues in several services surrounding access to specialist practitioners when a person's diagnosis was not yet confirmed. It was also clear that there were perverse incentives in place to discharge people with long-term neurological conditions thus denying them access to ongoing specialist advice and treatment – something which has been recommended by the NICE Guidelines<sup>4</sup> and can ensure that independence is maintained.

### QIPP: Quality, Innovation, Productivity and Prevention

Patients often know a great deal about their condition. Allowing them to manage their health on line, by telephone or in partnership with their community pharmacy can boost self sufficiency and restrain demand.

**2.4** There were variable levels of review and monitoring of people with long-term neurological conditions, and these often did not take into account the patient's needs and individual preferences. For example currently NICE guidelines advise that both MS and Parkinson's patients are followed up for diagnosis and diagnostic review every 6 to 12 months. However, in some areas, average outpatient attendances are paid for by commissioners on the basis that there will be one new patient attendance and 1.7 follow ups. Primary Care Trusts would not pay for further work with regards to monitoring unless that patient is discharged back to their GP and then re-referred as a new patient. Therefore clinicians are being urged by their Acute Trust to discharge patients back to the community with consequent loss of continuity and care by the available specialist teams unless the individual with MS or Parkinson's is re-referred by the GP.

This could be very disconcerting and worrying to those living with these conditions who require more guaranteed regular specialist follow-up by team members that they can develop a relationship with, and who they both know and trust. One has to be sympathetic to an Acute Trust's dilemma because, if patients are not discharged back to their GPs under the current proposal commissioning arrangements, they could risk a fine for failing to achieve the 1 to 1.7 follow-up ratio.

This “one size fits all” could be wholly detrimental to patients who need a chronic disease management programme. Flexibility in the system is required here, whereby Trusts can be suitably recompensed for the work which they do in following up patients appropriately, with jointly agreed protocols between providers and commissioners.

### Good Practice:

Cornwall and Isles of Scilly PCT has expanded capability in managing Parkinson's through community pharmacy and Parkinson's prescribing pharmacists. Improvements such as: medication reconciliation; better communication about medication concordance through the Medicines Usage Reviews; and ensuring medication is given correctly can assist individuals in self-sufficiency and in maintaining independence. Regular Medicines Usage Reviews ensure that problems are identified earlier and individuals signposted to support when needed, preventing unnecessary hospital admissions, and premature degeneration of the individual's condition.



**2.5** Those individuals who were on disease modifying therapies, or drugs trials received high levels of input and monitoring which ceased when these therapies or trials were stopped, leaving patients feeling at a loss as to how to now access relevant services or ensure they receive the treatment or alternative drugs, which they need in order to effectively manage their condition.

### Service users and carers share their views:

“From what I've just heard - I can tell you things haven't got any better. I'm only recently diagnosed and the doctor just said to me “Oh well, yes its MS and you've probably had it for quite some time and there's not a lot we can do for it. Come back and see me in six months” and that was that”!

“Once I was diagnosed it took weeks and weeks and weeks before anyone actually explained what it was I had, and what I can expect in the future. All that time I was worried sick and making myself worse”.

“Within two weeks of being diagnosed I was contacted by a specialist nurse who explained everything, and boy did that make me feel a lot more confident about my future”.

4. NICE clinical guideline 35: Parkinson's disease: diagnosis and management in primary and secondary care, (National Institute for Health and Clinical Excellence: 2006)National Institute for Health and Clinical Excellence, June 2006)

## Quality Requirement 3: Emergency and acute management

**3.1** There were issues concerning capacity and timeliness for transfer of patients with neurological emergencies presenting in A&E departments to specialist spinal cord injury, neuroscience and neurological rehabilitation centres. These issues were also apparent when dealing with people with Acquired Brain Injury.

**3.2** People with long-term neurological conditions admitted to hospital via emergency departments or transferred from specialist neuroscience centres were not always transferred to suitable wards or facilities where their ongoing neurological care, supervision or rehabilitation was provided appropriately by staff with neurological expertise.

**3.3** Removal of Parkinson's drugs on admission was a key issue in several areas. By not getting their medication on time many patients lost their ability to self-care, reducing function which necessitated lengthy stays for rehabilitation and an excessive number of days needlessly spent in hospital.

### Good Practice:

The Get it On Time campaign developed by Parkinson's UK helps hospital staff to understand the importance of appropriately timed medication. A DVD to highlight the problems to staff and a range of service users support materials are available from Parkinson's UK. Ensuring drug regimes are given on time has reduced length of admission time, resulting in patients remaining independent for longer, as well as creating significant financial savings.

**3.4** Individuals with motor neurone disease who were denied respiratory support at home were sent to Accident & Emergency departments and ventilated, something which was preventable and which caused distress to the individuals concerned and unnecessary expenditure to the site.

### Service users and carers share their views:

"When I transferred hospitals, I was stuffed on a ward where nobody seemed to understand my condition. All the things I used to have stopped and nobody seemed to know what to do with me".

## Quality Requirement 4: Early and specialist rehabilitation

**4.1** Whilst the majority of services claim to provide rehabilitation in compliance with NICE Guidelines, and other nationally accepted guidance, there were issues around interpretation of this Quality Requirement. More specifically, interpretation of evidence-based marker 2, which states 'at high intensity appropriate to need', and all issues related to this, caused difficulty.

Both social care and primary care thought that secondary care interpreted this marker where 'high intensity' meant 'to get the patient out of a bed and into the community' in relation to secondary care needs, whereas social and primary care saw the phrase as meaning that the patient needed to reach optimal stability for discharge. Representatives across both social and primary in a number of areas cited patients being discharged into the community without having reached agreed goals set against discharge protocols. This also meant that often, community services struggled to provide ongoing care that was needed at an unexpectedly high intensity, due to the individual not attaining goals.

### Service users and carers share their views:

"The physio and OT were great in trying to get me going, but the nurses kept wanting to do everything for me, to save them time. It seemed daft really, one lot trying to get me to help myself and the other is making me stay sat down or stay in bed"!

"It was quite a gap between leaving hospital and getting more rehabilitation, I think that in that time I went backwards quite a bit".

**4.2** There was generally considered to be a lack of appropriate rehabilitation facilities as well as a lack of ability to consistently support people in the community at a level that optimised their recovery and ability to live independently. Services were not always seamless with inreach / outreach arrangements being the exception rather than the rule, and an irregularity of specialists in neuro-rehabilitation services.

### Case History:

Representatives from SWANO (the South West Alliance of Neurological Organisations) had a series of meetings with the Clinical Lead from Great Western Ambulance Trust to look at how the needs of people with neurological conditions could be better met by the Ambulance Service in acute situations.

1. The 'Message in a Bottle' scheme was revitalised, with support from local Lions Clubs who provided the bottles. 500 bottles were distributed through third sector branches, groups and support meetings to people with complex neurological conditions. This was to ensure that any Ambulance Staff called to someone in an acute situation within their home had access to core information about their needs and wishes, and also whether the person had written an Advance Decision to Refuse Treatment.
2. The 'Allow a Natural Death' form was promoted and clinicians were encouraged to discuss and record the wishes of individuals appropriately so that Ambulance Staff were aware.
3. The standard letter which can be completed by neurologists to allow a person with a complex conditions being taken to a designated hospital was promoted.

## Quality Requirement 5: Community rehabilitation and support

**5.1** There were issues of irregular access, capacity and timeliness in terms of access to community rehabilitation. Community teams were often stretched, had little access to specialist community rehabilitation and struggled to provide flexible, individualised programmes which focused on individual goals. Most care failed to go beyond basic daily care and was failing in promoting participation across a full range of life roles.

### Service users and carers share their views:

“Specialist nurse, physio and OT were great but couldn’t come as often as they wanted and I wanted as there weren’t enough of them to go around”.

“The carers that came in were so rushed that they just did everything and didn’t have the time to help me do things for myself”.

“My wife thought I was going mental and put a lot of strain on her but after a long time we did manage to see I think it was a psychologist who helped, but I wish it would have been quicker”.

“I think I need to be seen regularly but keep having to go back to my GP to get back on the books again as I keep getting discharged”.

**5.2** There was a general lack of holistic outpatient or daily rehabilitation programmes. While some areas had excellent multidisciplinary rehabilitation services, these were not replicated across the whole of the service area, or were condition specific and not replicated across all neurological conditions.

### Case History:

In Cumbria, following consultation with service users and carers, it became apparent that the rurality of the area was causing difficulties for a large number of people in accessing the multidisciplinary team. The extent of travel needed for some was also hindering them from accessing a specialist nurse on a reasonably regular basis.

The Primary Care Trust and Adult Social Care together agreed to re-distribute their resources, and now provide a roving, community-based multidisciplinary team comprising both health and social care staff, to enable as many people as possible to access the team with minimal travel.

**5.3** Nearly all the services audited highlighted the fact that there were limited psychological services for people with long-term conditions, and that where they did exist, there were major capacity issues.

### Good Practice:

Treatment closer to, or within, the home, was consistently a top priority amongst those consulted with in focus groups, across all of the sites. This is beneficial for the person living with a long-term neurological condition, as well as the site, making financial savings at the same time as delivering a better level of care.

Treating people living with MS for a relapse by administering intravenous steroids in the home, as opposed to within a day care hospital setting saw an average cost saving of £1,797 per patient. It also proved home delivery to be superior to the outpatient experience, and safer to administer, as well as cheaper. Coordination of care was better, treatment was more convenient and timely, and patients found the calmness of their home environment comforting and reassuring.

### Case History:

In Hammersmith & Fulham, an MS clinic was set up where people could see an MS nurse, consultant neurologist, community physiotherapist, occupational therapist and local MS Society chairman in one visit to develop a person-centred plan.

The clinic meets psychological needs, at the same time as providing easy access to specialist nursing, medical, therapy and social care, as well as a wealth of information.

The area saw a 45% decrease in A&E attendances, 22% decrease in non-elective admissions, and 67% increase in planned day case admissions.



### Quality Requirement 6: Vocational rehabilitation

**6.1** Of all the services audited across all of the sites, healthcare professionals almost consistently cited a lack of vocational rehabilitation within social care. Coordinated multi-agency vocational rehabilitation did not appear to exist. Service users cited a lack of rotational assessment, support and guidance on returning to work, remaining in work or getting any support and advice on withdrawing from work. Very few service users received any assessment or counselling.

**6.2** Job Centre Plus was often cited as being the route through which the more able-bodied persons with long-term neurological conditions were directed. However, no-one seemed to know whether people with long-term neurological conditions had their needs routinely evaluated in terms of their ability to remain in, or return to, employment.

#### Service users and carers share their views:

“I have had to do voluntary work, because I found that nobody would take me on, because of the problems: lack of eyesight, the brain haemorrhage, and the fact that I have never worked in an office.”

“I would love to do physical labour, but nobody will take me on because of health and safety regulations.”

“What I am more concerned about is I cannot get back into employment, and there is no help with that. I am in contact with the Disability Employment Advisor, but there is nothing. It is on their terms, but there is no feedback for me.”

“Being an electrician there was no way I could do my trade and all I could have done was office work. But I could not stick at that because I cannot sit all day; I have got to get up and move. Genuinely disabled persons are trying to get back to work, and I do my charity work.”

“One of the questions on the back to work form was ‘can you lift anything’. That refers to picking up a desk there and moving it to there. Yes, I can do that, but I cannot bend down and pick anything off the floor. They are getting the wrong people to go back to work. You need something to do; you do not want to be sat at home doing nothing.”

“We all need to work because we get reward from it financially and intellectually. I do not want to feel that I am not part of society anymore. I do not want to be an outsider and I do not like the word ‘invalid’; it is almost like saying I am invalid. I am not invalid, I can still do something but I need help finding my niche.”

“There were days when I was a teenager when I would just sit at home and do nothing. Since I have been talking with my social worker, I have been coming up with ideas about things that I can manage to do.”

### Quality Requirement 7: Providing equipment and accommodation

**7.1** Where joint equipment stores existed, services were generally felt to be reasonably reactive and service users felt these to be of good quality. However, there were issues around wheelchair services in nearly all of the sample sites, as well as confusion around eligibility for types of wheelchair, and a lack of understanding of the wheelchair voucher scheme. These were coupled with timeliness issues, point of contact for repairs and servicing, and re-evaluation of complex seating needs.

#### Good Practice:

A number of Wheelchair Partnerships have been developed across the country between the MND Association and various Wheelchair Services. The responsibility for all these partnerships and the development of new partnerships has now been passed to Jenny Rolfe, an OT for the Oxford Centre for Enablement, who has been employed to oversee this work.

The aim of the partnerships is to allow people who are rapidly deteriorating to have access to high-spec powered chairs as soon as is feasibly possible, without having to wait the lengthy periods of time that most eligibility criteria dictate. Unfortunately, the waits caused by eligibility criteria often leave people with deteriorating conditions in receipt of a chair which they can no longer use, or in the case of those with MND, it is not unusual for the person to have passed away without ever reaching the end of that waiting period.

**7.2** Nearly all services cited issues around timeliness and lead times for obtaining specialist equipment, especially communication aids. There were also issues around funding and information to service users regarding alternatives as against a statutory provision and their costs.



**7.3** Access to appropriate housing was a major issue for all services. There were several incidents of service users being in unsuitable accommodation with no prospect of obtaining suitable accommodation that would allow them to increase their independence.

### Service users and carers share their views:

“My house is really bad at the moment. I had to sell my flat because it was on the first floor. I bought it and did it up really nice, but I had to sell it. They also made me give my mum half the money. They gave me temporary accommodation and told me that it would be for a year to 18 months, but I will have been there for four years in November. I cannot get out to the front, because there is a step. I cannot get out to the back, because it has a slope.”

“They make it the easiest thing that they can put up and they are the ugliest things but then people should have a choice of how they want it, not this unsightly thing that becomes a target for people to see that you are vulnerable.”

“They made me a ramp to get outside, but someone has to be there with me to get me out and back in. I cannot get up and down by myself. That is why I no longer use it. It was pointless them making it, because the ramp sits in the hallway.”

“I told my OT, who applied for an adaptation last year, but I am still waiting. They told me they would turn it into a shower room, but they have not even phoned me to say that I am in a queue or that they can do it on a certain date. They told me that they would do it, but when? I have been waiting since last year.”



### Quality Requirement 8: Providing personal care and support

**8.1** Service users felt that health and social care did not work together to provide a full range of accommodation care and support options, or facilities to maximise their choice. Nearly all sites indicated that they struggled to provide residential care or supported living in suitable environments for people with long-term neurological conditions that were both age and culturally appropriate.

### Service users and carers share their views:

“The staff are really lovely, but they just don’t understand my mum’s condition.”

“I found that, when we had overnight care to give me a break, I couldn’t sleep anyway because I was worried how they’d manage him. They didn’t seem to understand his needs, or what the condition meant for his care.”

**8.2** For those service users in residential / nursing care, there were concerns regarding their care ‘by appropriately trained nursing therapy and care staff with experience in managing long-term conditions’. It was generally felt by health and social care professionals that those people with long-term neurological conditions who needed to access residential / nursing care did not always have their neurological condition taken into full consideration, nor were they as fully supported and encouraged in remaining as independent as they could possibly be.

Community health care professionals often found it difficult to access private residential / nursing care accommodation and to instruct support staff in these establishments in the best methods of dealing with the individual living with a long-term neurological condition.

### Case History:

Anna\* was the primary carer for her mother, who was living with Alzheimer’s in addition to another neuro-degenerative condition which affected her mobility. Her mother was in a small, one-bedroom flat, and Anna wanted to move her mother into her two-bedroom flat to care for her there. However, there were a set of two steps between the road and the lift for Anna’s flat. Anna requested that a ramp be constructed here so that her mother could move it. The Local Authority said that they were unable to do this as it was not her mother’s place of residence, and despite a number of letters, they were unable to agree with this. Anna’s mother, if unable to move in with her, was very soon going to have to go into government-funded care - costing the Local Authority a great deal more than a ramp.

**8.3** There was general confusion amongst healthcare professionals and service users concerning direct payments and individual budgets, and no apparent means for increasing this understanding, whether through professional’s training or information, or through social workers explaining to service users their options regarding personalisation.

## Quality Requirement 9: Palliative care

**9.1** It was generally felt by most sites that this was an area that was showing some improvement although it is likely that this has been influenced by the publication of the End of Life Care Strategy.

### Service users and carers share their views:

“It took so long to get what we wanted to enable him to die at home. I had to do all the fact finding - no-one told me where to get help. I had no idea, for example, I could get continuing care funding. Respect us and treat us with dignity – it took us a long time to get all the services in place but it can be done. My husband said “I want to be at home not in a hospital” - it was a major challenge to ensure this happened.”

“Don’t ignore us.”

**9.2** The absence of 24/7, urgent and out of hours care at the end of life was an area causing major problems for families. Many individuals were unnecessarily transferred to Accident and Emergency departments and admitted into hospital due to problems that could have been addressed in the home such as prompt response to concerns and worries, provision of adequate pain relief or simple reassurance that such problems were normal at end of life.

### Case History:

One of the sample sites had, on retrospective case note analysis, admitted two people with MND into hospital at the end of life, and ventilated them, causing unnecessary distress to the patient, and unnecessary cost to the Trust. If a respiratory care pathway had been used and the patients given NIPPV this would not have happened and the Trust would have only had to pay the £12,000 costs for ventilation.

**9.3** Staff, particularly in care home settings, were anxious that they were not doing ‘all they could’ for someone and that the person would be better cared for if they were in hospital. This regularly meant admitting patients in the last hours of life.

### Good Practice:

NCS has run roadshows in End of life Care Management in neurology in conjunction with the National Council for Palliative Care, the Royal College of Nursing, and the British Geriatrics Society: Movement Disorders Section, to enable both specialist palliative care teams, and condition-specific neurology teams, to understand how their patients may die and how best to support them in their choices.

**9.4** Hospices and other palliative care services are now beginning to look at end of life care for patients with conditions other than cancer but there is still a long way to go in terms of their understanding of the needs of people living with a long-term neurological condition. Some sites showed confusion concerning people with long-term neurological conditions requiring palliative care before they had reached the ‘end of life’ stage, and there were examples where service users were being managed for their complex needs by a community matron without reference to the specialist practitioners in that neurological condition.

### Case History:

In Bath and Northeast Somerset, NCS worked alongside health and social care to consult with people affected by a long-term neurological condition on their views and preferences at the end of life. This consultation resulted in the realisation that staff were ill-equipped to deal with the frank discussions and open questions both needed, and wanted, by people living with a neurological condition. A bespoke training programme was rolled out to all staff in the area, highlighting the need for Advance Care Planning, and respecting the wish of the patient, at times over the professional’s opinion.

**9.5** Neuro-rehabilitation teams generally considered themselves to have adequate knowledge of basic palliative care skills but did not consider themselves specialist in any way. None of the sites audited had specialised neurological and community rehabilitation services specifically for palliative care within the community.

### Cost breakdown:

1. If someone with MND has a respiratory crisis and is admitted to hospital, often resulting in
2. unplanned intensive care results, the cost of this one night in an acute hospital Intensive
3. Care Unit (ICU) is around £1,500.
4. Once admitted as an emergency to an ICU most people with MND in a respiratory crisis will stay there until they die. This type of unplanned emergency care costs the NHS thousands of pounds for a single case – typically £45,000 per month for the ICU admission alone.
5. The cost of providing non-invasive ventilation equipment (NIPPV) at home for a person with MND and a visiting respiratory therapist for a twelve month period is £12,000 - £44,000 per month less than the ICU admission.
6. This equates to a saving of £528,000 per annum – for one person.

In addition, the NIPPV equipment needed can be reused by other patients for up to 8 years – an further saving.

### Quality Requirement 10: Supporting family and carers

**10.1** Those caring for loved ones who were living with a long-term neurological condition were generally unaware that they were entitled to an integrated health and social care assessment in their own right. They were often not aware that they had a choice as to the extent of their caring role regarding the kinds of care they were providing. They were also uninformed of the fact that they should be offered a written care plan that would be both agreed with them, and reviewed regularly. Many did not have an allocated person serving as their first point of contact.

**10.2** Most professionals within the sample sites purported to treat carers as partners in care and, where possible, to help them acquire appropriate skills that would support them in their caring role. Many services like to give carers the opportunity to work in partnership with them but cited capacity and timeliness issues as a major hurdle.

**10.3** Most sites were unable to articulate how their services responded appropriately, and which both provided care which dealt effectively with emergency situations, and supported highly dependent people at short notice. Most carers said they found it difficult to obtain information about care breaks across a range of settings that were age and culturally appropriate. Most carers had no support or training to deal with the person that they cared for in the case of those who had cognitive behavioural difficulties.

**10.4** Most health and social care staff were aware that care awareness education and training was occasionally made available, but few had availed themselves of that training.

**10.5** In general, the majority of health and social care professionals signposted carers towards the voluntary sector in order to receive the necessary support.

#### Service users and carers share their views:

“I have never had family counselling. My husband and my family are brilliant. They look after me when I am poorly.”

“During my rough years, nobody asked whether my family was dealing with it. My MS nurse is brilliant.”

“We lose sight of the fact that each individual has their own family. People assume that you can cope because you have had experience of it.”

“When I told my friend who has just been diagnosed about the nurse, she was there within 10 days and has started helping the family already.”

“If a family member is willing to do something, ‘fair enough, on you go’. If you have nothing, no family, nobody to help you, they will hand out support. Anybody who tries their best to keep their head above water gets no help whatsoever.”

“I have had a care assessment; I work for Mr \*\*\*\*\*, but I also have a daughter who is not well, so I have had a care assessment in my own right.”

### Quality Requirement 11: Caring for people with neurological conditions in hospital or other health and social care setting

**11.1** Most healthcare professionals stated that an integrated neurological care plan was not available to them when a person with a long-term neurological condition was admitted to a general hospital ward or care facility that was a non-neurological setting.

**11.2** Many professionals stated that there was no liaison with the patient’s usual neurological care team. This was in turn supported by service users who stated that often their neurological condition was ignored when they were admitted to hospital with co morbidities, and as such their independence, mobility and dignity decreased.

#### Case History:

Jack\* cares for his wife April\* (63), who was diagnosed with Parkinson's 8 years ago. April went into hospital for 5 days for a hysterectomy. April's Parkinson's medication was not given on time. As a result, her symptoms became unmanageable. April had to stay in hospital for 25 days rather than the planned 5 days and needed rehabilitation. Since discharge, her sleeping patterns are completely random and she has been experiencing hallucinations. Both Jack's and April's quality of life has deteriorated. She has had to have her medication changed to try and re-gain control of her symptoms once more. This has caused great stress for both of them. They are still going through a complaints process with the hospital.

Even in instances where there was a planned admission, often specific needs such as equipment provision, communication aids, and the like were ignored. In many instances, across a range of conditions, the patient's condition deteriorated whilst in hospital due to the fact that they were not allowed to self manage their own medication. Staff largely seem to be ignorant of the need for certain medications to be given at specific times or on demand, demonstrating a lack of evidence of consultation between neurological teams and general hospital wards or care facilities.





## Appendices

### Quality Requirement 1: A person centred service

**EBM1:** There is timely integrated assessment involving all relevant agencies leading to individual care plans which:

- Cover current and anticipated it needs (including health, social, emotional and cultural needs);
- Are held by the person and regularly evaluated and reviewed with them by the clinical team. Review is based on clinical need, including self assessment (see QR2): and
- Ensure that staff has access to all relevant records and background information about the person's condition, test results and previous consultations.

**EBM2:** arrangements are in place to ensure that:

- All people with long-term neurological conditions have a main point of contact for advice and information.
- People with complex needs who require skilled input from a number of professionals have a named individual (e.g. a care coordinator, Case manager or community matron) who is responsible for coordinating the input from all relevant agencies and producing a care plan.

**EBM3:** The care assessment and planning process ensures that appropriate services are available to provide support for life transitions and to enable people with long-term neurological conditions to receive continuity of care (e.g. when they transfer to adult health or social care services or across geographical boundaries, or following a change in circumstances such as the death of a carer).

**EBM4:** local arrangements for providing information in sure that:

- People receive timely, quality assured, culturally appropriate information in a range of formats on:
- All relevant aspects of service provision;
- The condition and how best to manage it;
- Wider social inclusion issues (e.g. employment and transport).
- Health and social care professionals, people with long-term neurological conditions and carers receive appropriate training on effective ways to provide and use information. Assessment of information needs is part of the review and any interaction with health and social services.

**EBM5:** people with long-term neurological conditions and their carers can access education and self-management programs, tailored to their individual needs and these are available at different stages of the condition.

### Quality Requirement 2: Early recognition, prompt diagnosis and treatment

**EBM1:** there is improved access to specialist neurological expertise through:

- Training for frontline staff to improve recognition of neurological symptoms
- Shared protocols for referral for further specialist assessment so that people receive appropriate priority within locally agreed target times.
- The guidelines on the management of genetic disorders include referral to genetic services.
- Multidisciplinary neurology clinics run in hospital and community settings where possible:
- Communication routes for GPs to obtain a rapid specialist neurological advice about urgent clinical problems.

**EBM2:** Diagnostic services are effectively designed and have sufficient capacity to enable prompt diagnosis. Services should be delivered according to NICE guidelines and take account of agreed national guidance and protocols for delivering diagnoses, using staff trained in delivering 'bad news'.

**EBM3:** there is improved access to appropriate treatments and:

- Treatment available to people includes all those approved by NICE.
- Early integrated assessment and care planning ensure timely access to treatment and to multidisciplinary support, if necessary before diagnosis is confirmed.
- Individuals receive the appropriate information before starting medication to enable informed choice and are supported to manage side-effects or any other problems they may be having.

**EBM4:** Or people with long-term neurological conditions have prompt access to ongoing specialist neurological advice and treatment. Specialist nurses and practitioners with specific knowledge of long-term neurological conditions are available to support people in the community.

**EBM5:** There is improved access to treatment review that ensures:

- Processes are in place to provide review and monitoring of treatment appropriate to individual need;
- People taking medicines on a long-term basis have access to regular medication reviews to enable them to get the most out of treatment. To some people, especially those taking three or more medicines, it may be appropriate to have a face to face the review.

### Quality Requirement 3: Emergency and acute management

**EBM1:** acute and emergency management of sudden onset of neurological conditions complies with NICE guidelines and takes into account the nationally agreed standards and guidelines.

**EBM2:** local hospitals except in people with a neurosurgical or neurological emergency have appropriate resources to treat, manage and review individuals presenting with a sudden onset of neurological condition, including

- Trained staff/teams (A&E, medical assessment, acute medical, neurological) to ensure that people with acute neurological symptoms receive prompt neurological assessment;
- Appropriate facilities and links to a specialist in neuroscience centre and spinal cord injuries Centre for prompt expert opinion if necessary;
- Protocols of care agreed with specialist spinal cord injury, neuroscience and neuro rehabilitation centres.

**EBM3:** There are protocols in place which comply with NICE guidelines on head injury and take account of nationally agreed standards and guidelines, the people with acquired brain injury not admitted to hospital.

**EBM4:** transfer to specialist centres is available when needed, and:

- Specialist neuroscience centres and spinal cord injury centres have the capacity, staff and facilities to accept prompt transfer of people who need more specialist management and to conform to national standards,
- Protocols are in place to support prompt transfer of people to district all local services when specialist intervention is no longer needed.

**EBM5:** Local hospitals admit people transferred from specialist neuroscience centres to suitable wards or facilities where any necessary ongoing neurological care, supervision or rehabilitation can be appropriately provided, involving senior specialist medical staff and other staff with neurological expertise.

### Quality Requirement 4: Early and specialist rehabilitation

**EBM1:** rehabilitation is provided which complies with NICE guidelines and takes account of other nationally accepted guidance

**EBM2:** there is improved access to rehabilitation and:

- Rehabilitation is provided:
  - Early,
  - At high intensity appropriate to need,
  - By a co-ordinated interdisciplinary team,
  - In an appropriate specialist setting, and
  - On an on going all the accessible basis to people with changing needs,
  - With specialist equipment (including wheelchairs and seating support systems) where required,
- Trained rehabilitation, nursing or allied health professional staff support people to apply the skills acquired during therapy sessions in routine daily living activities,
- The person, their family and the rehabilitation team all work towards the same agreed goals,
- Inpatient rehabilitation programs are followed by ongoing rehabilitation and support in the community for those who need them.

**EBM3:** Seamless transition of care is provided through:

- Integrated working with other healthcare professionals/teams,
- In reaching/outreach arrangements between:
  - Specialist neuro-rehabilitation and acute care services; and
  - In patient and community-based specialist neuro-rehabilitation services.

**EBM4:** Specialist rehabilitation services are provided to meet the needs of people with very severe and complex disabilities, including:

- Profound and complex disabilities (e.g. vegetative or low awareness states, high or complete spinal cord injury or severe brain injuries);
- Severe cognitive and behavioural problems needing a structured environment;
- Other long-term medical problems needing intervention.

### Quality Requirement 5: Community rehabilitation and support

**EBM1:** there is improved access to community rehabilitation through:

- Flexible, individualised programs and community rehabilitation and support which are focused on individual goals beyond a basic daily care and to promote participation in a full range of life roles;
- Interventions provided according to individual need may include:
  - Rehabilitation and support centred on the person's home and environment,
  - Holistic outpatient or day rehabilitation programs.

**EBM2:** local multidisciplinary rehabilitation and support are provided in the community by professionals with the right skills and experience, and:

- Involve health and social services working together;
- Include access to specialist neurological expertise (e.g. neuro rehabilitation, neuro-psychology) to address the full range of practical and emotional challenges;
- Are available in the longer term based on clinical need.

**EBM3:** providers of community rehabilitation and support services support people and their family members and carers to:

- Live with a long-term neurological condition;
- Develop knowledge and skills to manage their condition;
- Achieve a sense of well-being and make long-term psychological adjustments to altered personal, family and social circumstances;
- Provide proactive intervention, where relevant, to maintain function and prevent deterioration as the condition progresses.



### Quality Requirement 6: Vocational rehabilitation

**EBM1:** coordinated a multi agency vocational rehabilitation is provided which takes account of agreed national guidance and best practice

**EBM2:** local rehabilitation services are provided at which:

- Address the occasional needs during review of a person's integrated care plan and as part of any rehabilitation programme;
- Work with other agencies to provide:
  - Vocational assessment;
  - Support and guidance on returning to all remaining in work;
  - Support and advice on withdrawing from work;
- Refer people with neurological conditions who have more complex occupational needs to specialist the occasional services

**EBM3:** specialist the occasional services are provided for people with neurological conditions to address more complex problems in remaining in the all returning to work or alternative occupation including:

- Specialist vocational assessment and counselling;
- Interventions that job retention, including workplace support;
- Specific vocational rehabilitation or work preparation programs;
- Alternative occupational and educational opportunities;
- Specialist resources for advice for local services.

**EBM4:** specialist vocational rehabilitation services routinely evaluate and monitor long-term occasional outcomes, including the reasons for failure to remain in employment.

### Quality Requirement 7: Providing equipment and accommodation

**EBM1:** Assistive technology/equipment is provided and maintained in accordance with nationally agreed standards and guidelines.

**EBM2:** people with long-term neurological conditions have access to integrated community and specialist assistive technology/equipment services which work closely with neurology and rehabilitation services to provide,

- Specialist assessment and advice to help them select the most appropriate assistive technology/equipment for their needs and lifestyles;
- Support in using direct payments the equipment and vouchers for wheelchairs;
- Assistive technology/equipment to maintain their health, help with their care, and support independence;
- More specialist equipment on temporary loan or trial;
- Systems for tracking and recycling equipment to increase cost efficiency or temporary provision;
- Regular and ongoing review of their assistive technology needs, especially in response to changing need, including the needs of their carers, where appropriate.

**EBM3:** Assistive technology/equipment needs are documented in a person's integrated care plan.

**EBM4:** there are specific arrangements the joint funding of specialist assistive technology provision (e.g. communication aids electric standing frames and special seating aids).

**EBM5:** social services work closely with housing/accommodation and Supporting People services to provide timely, suitably adapted or purpose-built accommodation.

### Quality Requirement 8: Providing personal care and support

**EBM1:** health and social services work together to provide the full range of accommodation, care and support options and facilities to maximise choice, and  
Where day or residential care or supported living is provided it, they are in suitable settings or people with neurological conditions.

**EBM2:** care in all settings is provided by appropriately trained nursing, therapy and care staff with experience in managing long-term neurological conditions; and  
Care staff receives support and advice from community rehabilitation and support providers and other specialist neurological, palliative care and rehabilitation services as appropriate.

**EBM3:** health and social care services work together to provide programmes of care that help the person to remain as independent as possible as their condition progresses.

**EBM4:** people with long-term neurological conditions have equitable access to services and assessments based on many health and social care support (with prompt reassessment when needs change), and are supported in the applying for:

- Direct Payments, to increase their control and choice over their care;
- Fully funded NHS continuing care that takes account of the particular needs of long-term neurological conditions, including physical, communication, cognitive, the failure will and emotional problems,
- Adult social care delivered under the Fair Access to Care Services scheme based on need;
- Help from the Supporting People Program which provides housing related support for vulnerable people; and
- Staff administering these assessments and schemes are aware of the particular needs of people with neurological conditions (e.g. for social inclusion, independent living, preventative care).

### Quality Requirement 9: Palliative care

**EBM1:** specialised numerology, rehabilitation and palliative care multidisciplinary teams and providers work together to provide care for people with advanced long-term neurological conditions.

**EBM2:** people with advanced long-term neurological conditions have access to specialised and generalised palliative care services which support them in their home or in a specialised setting according to their choice and needs and in line with national best practice guidelines, and Specialised neurological and community rehabilitation services provide support, advice and training for all staff delivering palliative care in the community.

**EBM3:** staff providing care and support in the later stages of a long-term neurological condition have appropriate training so that:

- Neurologists and neurological rehabilitation teams are trained in palliative care skills.
- All staff providing care for people in the advanced stages of neurological illness is trained in both the management of long-term neurological conditions and palliative care.



### Quality Requirement 10: Supporting the family and carers

**EBM1:** carers of people with long-term neurological conditions:

- Can choose the extent of their caring role and the kinds of care they provide,
- Are offered an integrated health and social care assessment at diagnosis and all future interactions, together with information that addresses their needs;
- Are offered a written care plan agreed with them and reviewed regularly;
- Have an allocated contact person.

**EBM2:** Involving carers is part of the planning process so that:

- All carers are treated as partners in care and helped to acquire appropriate skills to support them in their caring role, including how to move and handle the cared for person and how to use equipment to help in daily living.
- Carers are given the opportunity to work in partnership with specialist teams.

**EBM3:** A range of flexible, responsive and appropriate services is provided for all carers which:

- Deals effectively with emergency situations,
- Can support highly dependent people at short notice;
- Provide appropriate support of the children in the family;
- Provides carers with breaks across a range of settings;
- Is culturally appropriate (e.g. to the needs of black and ethnic communities).

**EBM4:** Carers who need help to adjust to changes especially of the cognitive or behavioural kind have access to support based (where appropriate) on a whole family approach and delivered (where necessary) on a condition specific basis and in partnership with the voluntary sector; and Current service models are evaluated to inform future good practice.

**EBM5:** staff working with people with long-term neurological conditions receive care that awareness education and training which involves carers in planning and delivery.

### Quality Requirement 11: Caring for people with neurological conditions in hospital or other health and social care settings

**EBM1:** whenever the person is managed in a non-neurological setting (e.g. a general hospital wards or care facility).

- The integrated neurological care plan is available for all staff;
- There is a close liaison with their usual neurological care team

**EBM2:** Arrangements are in place to ensure that neurological needs can be met in all settings:

- Planned admission:
- There are preadmission interviews to establish any special needs, including equipment provision, communication aids and transport.
- Emergency admission:
- Protocols are in place for liaison with:
  - A person's community care team; and
  - Any relevant specialist team (e.g. neurosciences centre or SCIC).
- There is evidence of appropriate consultation between teams.

**EBM3:** There is effective consultation with the person about their management and, where appropriate, involvement of the family/carers who are familiar with the person's care needs; and interpreters are available for people who need them.

**EBM4:** specialist neurosciences, rehabilitation and spinal cord injury services are involved in providing advice and training for staff in general hospitals and other care settings.

### References

1. The National Service Framework (NSF) for Long Term Neurological Conditions (DH 2005), p9
2. The National Service Framework (NSF) for Long Term Neurological Conditions (DH 2005)
3. The Quality Neurology tool was created collaboratively by the Motor Neurone Disease Association, Parkinson's UK, the Multiple Sclerosis Society and Ataxia UK, with support from York University Research and Social Policy Unit, and funding assistance from the Department of Health.
4. NICE clinical guideline 35: Parkinson's disease: diagnosis and management in primary and secondary care, (National Institute for Health and Clinical Excellence: 2006) National Institute for Health and Clinical Excellence, June 2006)







**PARKINSON'S<sup>UK</sup>**  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.

**mnda**  
motor neurone disease  
association

**MS**  
Multiple Sclerosis Society

Halfway through  
– are we halfway there?

Neurological Commissioning Support  
372 Edgware Road  
London NW2 6ND

[www.csupport.org.uk](http://www.csupport.org.uk)