NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards

Briefing paper

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| Quality standard topic: Suspected neurological conditions: recognition and referral  Output: Prioritised quality improvement areas for development.  Date of Quality Standards Advisory Committee meeting: 12 December 2019 |

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1. Introduction

This briefing paper presents a structured overview of potential quality improvement areas for suspected neurological conditions. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

* 1. Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

* 1. Development source

The key development sources referenced in this briefing paper are:

[Suspected neurological conditions: recognition and referral](https://www.nice.org.uk/guidance/ng127/). NICE guideline NG127. Published May 2019.

[Stroke in childhood: Clinical guideline for diagnosis, management and rehabilitation](https://www.rcpch.ac.uk/resources/stroke-childhood-clinical-guideline-diagnosis-management-rehabilitation). Royal College of Paediatrics and Child Health (NICE-accredited). Published May 2017 (2nd edition).

[National clinical guideline for stroke](https://www.strokeaudit.org/Guideline/Full-Guideline.aspx) (NICE-accredited). Royal College of Physicians. Published 2016 (5th edition).

[Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management.](https://www.nice.org.uk/guidance/cg53) NICE guideline CG53. Published 2007. Full update in development. Publication expected October 2020.

1. Overview
   1. Focus of quality standard

This quality standard will cover the initial assessment of symptoms and signs that might indicate a neurological condition. This includes referral for specialist assessment and care for people with existing neurological conditions in the event of a change in symptoms. The quality standard will cover children, young people and adults.

* 1. Definition

A neurological condition is an illness or injury that affects the brain, spine, muscles or nerves. There are many different neurological conditions. Some are lifelong, and some get better over time. They can be inherited, such as muscular dystrophy. They can also develop during childhood, like some types of epilepsy. Some conditions, such as motor neurone disease or Parkinson’s disease, are more common later in life. Neurological problems can also happen suddenly at any age, after a head injury or stroke.

Some people experience neurological symptoms in the absence of any identifiable causative physical or structural abnormality; these are known as a 'functional neurological disorder'. Examples include recurrent dizziness or limb weakness.

* 1. Incidence and prevalence[[1]](#footnote-1)

Onset, progression, prevalence and severity vary across different neurological conditions. Some conditions can be recovered from completely, but others can cause rapid deterioration or have a slower, more sustained disease course.

Neurological conditions result in disability for 1 in 50 of the UK population. Some conditions are quite common, such as migraine (which affects 1 in 5 women or 1 in 15 men). Others are rare, such as Guillain−Barre syndrome, which affects about 1,200 people in the UK per year. Most have an impact on quality of life, and some cause serious disability and have a substantial impact on the person and their family members and carers.

Psychiatric symptoms, including anxiety and depression, are common in patients with neurological symptoms, and patients may benefit from psychological support before, during and after diagnosis.

In 2017/18 there were;

* over 21,000 paediatric neurology first appointments and over 55,000 follow-up appointments.
* over 17,000 new outpatient appointments for paediatric neuro-disability and around 65,000 follow-up appointments.
* over 475,000 adult neurology first appointments and over 860,000 follow-up appointments.

The 2019 Neuro Numbers report highlighted that over 1 million people with a primary diagnosis of a neurological condition in 2016/17 were admitted as emergencies, an increase of 21% over the preceding 5 years.[[2]](#footnote-2)

A 2018 Public Health England data briefing highlighted a 39% increase in neurological deaths compared to a 6% decrease in all-cause deaths 2001-14.[[3]](#footnote-3) It also reported that deaths associated with a neurological condition were 35% more likely to be premature.

* 1. Current service delivery and management

People with suspected neurological conditions often present to their GP with signs and symptoms that are difficult to diagnose. Many people will need referral to a specialist for diagnosis and treatment, but others can have their condition managed in primary care. The decision about whether to refer for a specialist opinion or for investigation is challenging.

There are significantly higher costs of care for people who are diagnosed late, due to increased inpatient hospital care and therapy costs. In 2012-13 the total NHS spend on people with neurological conditions was reported to have been £3.3 billion, 3.5% of the total NHS spend. In 2013-14, 14% of the social care budget was spent on people with neurological conditions.[[4]](#footnote-4) One in 10 visits to GPs and around 10% (excluding stroke) of visits to hospital emergency departments are made by people with symptoms or signs associated with neurological conditions. These range widely, from speech and memory to muscle, movement, balance and coordination problems. Up to one-fifth of new neurology outpatients have functional symptoms. The 2018/19 National Neurology Patient Experience survey[[5]](#footnote-5) reported that nearly 40% of respondents saw their GP 5 or more times about the health problems caused by their condition before being referred to a neurologist. Nearly 30% who needed to see a neurologist waited more than 12 months.

The 2019 methodology document supporting Getting it right first time (GIRFT) highlights that neurology services have developed differently across the country, reflecting local priorities, geography and other factors.[[6]](#footnote-6)

Of 210 hospital sites providing acute neurology sites and specialist neurology services to adults:

* 24 are neurosciences centres (neurology inpatient beds and neurosurgery)
* 27 are neurology centres with inpatient beds
* 67 are district general hospital neurology centres
* 76 have visiting neurologists only
* 16 have no access to visiting neurologists.

The report also highlighted that funding per head for neurology services varies. The cost ranges between £4.80 per head and £17.10 per head, with the highest spend being at the National Hospital for Neurology and Neurosurgery (London). Specialised Commissioning funds specialised and non-specialised inpatient care at neuroscience centres and outpatient referrals. This varies between £55 and £18,000 per 1,000 population each year.

The report also comments on ‘unwarranted’ variation in the numbers of consultant neurologists and trainees (registrars) across regions. The average number of neurologists varies between 1 per 57,000 and 1 per 167,000 for the elective population, and between 1 per 43,000 and 1 per 200,000 for the non-elective population.

* 1. Resource impact

We do not expect this quality standard to have a significant impact on resources. When the suspected neurological conditions: recognition and referral guideline was developed, a resource impact statement was produced which noted that:

* the resource impact of implementing any single guideline recommendation will be less than £1 million per year in England (or £1,800 per 100,000 population) **and**

the resource impact of implementing the whole guideline in England will be less than £5 million per year (or £9,100 per 100,000 population).

Where clinical practice changes as a result of this guideline, there will not be a significant change in resource use. This is because any cost is likely to be offset by savings and benefits. Expert clinical opinion is that the recommendations will help prevent unnecessary referrals and reduce delays for people who need specialist neurological assessment.

These services are commissioned by NHS England and clinical commissioning groups. Providers are NHS hospital trusts and primary care providers.

1. Summary of suggestions
   1. Responses

In total 19 registered stakeholders responded to the 2-week engagement exercise 04/10/2019-18/10/2019. 17 of these registered stakeholders provided areas for quality improvement and 2 advised they had no comment to make. We also received comments from 6 specialist committee members. The responses have been merged and summarised in table 1 for further consideration by the Committee.

Full details of all the suggestions provided are given in appendix 2 for information.

### Table 1 Summary of suggested quality improvement areas

|  |  |
| --- | --- |
| Suggested area for improvement | Stakeholders |
| Improving recognition and referral (over 16s)   * Dizziness and vertigo * Gait ataxia, sensory disturbances and gait apraxia * Limb and facial weakness * Posture distortion * Referral for subarachnoid haemorrhage * Confusion and drowsiness | * SCM1, SCM3 * CUK, SCM1 * NHSE & I and TNA, RCC, SCM 1, SCM3, SCM6, TNA * SCM1, SCM5 * NHSE & I and TNA, TNA * MRF |
| Continuing or new symptoms (over 16s)   * Functional neurological conditions, chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) or fibromyalgia * Peripheral neuropathy | * MEA, SCM3 * PAS |
| Improving recognition and referral (under 16s)   * Headache as a ‘red flag’ symptom * Head shape or size abnormalities * Hypotonia (‘floppiness’) * Duchenne muscular dystrophy * Speech problems in teenagers * Sudden limb weakness | * BAPN, RCPCH, SCM2 * BAPN, RCPCH * BAPN * SCM2 * MRF * BAPN |
| Information and support   * Driving and safety information | * P-CNS |
| Additional areas   * Access to new treatments and improving diagnostics * Conditions covered by other quality standards * Coordination of services and models of care * Equalities Impact Assessment * Information and signposting * Patient experience * Recognition and management of non-epileptic attack * Recognition of rare and early onset neurological conditions * Source recommendations * Training and development | * MEA, PAS * BAPN, PUK, PSPA, SCM3, * BAPN, MEA, NHSE & I – CAHPO, NHSE & I and TNA, P-CNS, RCN, RCOT, RCSLT, SCM4, SCM5, SCM6, TNA * RCSLT * NHSE & I and TNA, PSPA, RCSLT, SCM4, SCM6, TNA * NHSE & I and TNA, P-CNS, PSPA, RCOT, RCSLT, SCM4, SCM6, TNA * SCM3 * MSAT, PSPA, SCM4 * NHSE & I and TNA, RCPCH, SCM6, TNA * P-CNS, RCSLT |
| Abbreviations:  BAPN, British Association of Paediatric Neurologists  CUK, Coeliac UK  MEA, Myalgic Encephalopathy (ME) Association  MRF, Meningitis Research Fund  MSAT, Multiple System Atrophy Trust  NHSE & I – CAHPO, NHS England and Improvement, Office of the Chief Allied Health Professions Officer  NHSE & I and TNA, NHS England and Improvement, Clinical Programmes Team – submission by the Neurological Alliance  PAS, Pernicious Anaemia Society  P-CNS, Primary care and Community Neurology Society  PSPA, Progressive Supranuclear Palsy Association  PUK, Parkinson’s UK  RCC, Royal College of Chiropractors  RCN, Royal College of Nursing  RCOT, Royal College of Occupational Therapists  RCPCH, Royal College of Paediatrics and Child Health  RCSLT, Royal College of Speech & Language Therapists  SCM, Specialist Committee Member (1-6)  TNA, The Neurological Alliance | |

* 1. Identification of current practice evidence

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 2,320 papers were identified for suspected neurological conditions: recognition and referral. In addition, 26 papers were suggested by stakeholders at topic engagement and 120 papers internally at project scoping.

Of these papers, 18 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

1. Suggested improvement areas
   1. Improving recognition and referral (over 16s)
      1. Summary of suggestions

### Dizziness and vertigo

Stakeholders suggested that recognition of sudden-onset dizziness as a sign of posterior circulation stroke needs to be improved to support immediate referral.

Stakeholders felt that adults with vertigo on head movement should be assessed for benign propositional paroxysmal vertigo (BPPV) and treated using a repositioning movement. They commented it would avoid treatment delays, unnecessary specialist referral for tests and unwarranted pharmacological treatment from misdiagnosis.

### Gait ataxia, sensory disturbances and gait apraxia

Stakeholders suggested that testing for vitamin B12 deficiency based on neurological symptoms (gait ataxia and sensory disturbances) supports timely identification and treatment of Coeliac disease.

Stakeholders commented that gait apraxia is not always regarded as a sign of normal pressure hydrocephalus in the elderly, resulting in delayed access to treatment.

### Limb and facial weakness

Stakeholders suggested faster referral from primary care as a quality improvement area for adults with neurological symptoms suggesting brain cancer.

Stakeholders felt that adults referred by chiropractors for suspected cauda equina syndrome to emergency departments are discharged without having all the investigations needed to establish a diagnosis.

Stakeholders felt that uncomplicated cases of Bell’s palsy could be managed in primary care and referral into neurology departments avoided. It was also suggested that more complex cases are not always referred appropriately.

### Posture distortion

Stakeholders suggested that symptoms of dystonia (including those triggered or worsened by medication) are poorly recognised, which delays diagnosis and treatment.

### Referral for subarachnoid haemorrhage

Stakeholders highlighted that immediate referral for specialist investigation of suspected subarachnoid haemorrhage could reduce the risk of mortality.

### Confusion and drowsiness

Stakeholders suggested that improved recognition of signs of meningitis (confusion and drowsiness) in adults would support timely antibiotic treatment.

* + 1. Selected recommendations from development source

Table 2 below highlights recommendations that have been provisionally selected from the development source/sources that may support potential statement development. These are presented in full after table 2 to help inform the committee’s discussion.

### Table 2 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Suggested source guidance recommendations |
| Dizziness and vertigo | **Sudden-onset dizziness with a focal neurological deficit**  NICE NG127 Recommendation 1.2.1  **Vertigo on head movement**  NICE NG127 Recommendation 1.2.6 |
| Gait ataxia, sensory disturbances and gait apraxia | **Gradually progressive unsteady gait (gait ataxia)**  NICE NG127 Recommendation 1.4.3  **Difficulty initiating and coordinating walking (gait apraxia)**  NICE NG127 Recommendation 1.4.4  **Sensory disturbances**  NICE NG127 Recommendation 1.10.6 |
| Limb and facial weakness | **Severe low back pain together with other symptoms**  NICE NG127 Recommendation 1.7.3  **Rapidly progressive weakness of a single limb or hemiparesis**  NICE NG127 Recommendation 1.7.4  **Bell's palsy**  NICE NG127 Recommendations 1.7.11 and 1.7.13 |
| Posture distortion | **Dystonia**  NICE NG127 Recommendations 1.9.1, 1.9.3 and 1.9.4  **Dystonia as a side effect of medications**  NICE NG127 Recommendation 1.9.5 |
| Referral for subarachnoid haemorrhage | **Management of subarachnoid haemorrhage**  RCP National clinical guideline for stroke recommendation 3.7.1.A |
| Confusion and drowsiness | Not directly covered in NICE NG127 |

### Dizziness and vertigo

NICE NG127

Recommendation 1.2.1

For adults with sudden-onset [dizziness](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#dizziness) and a focal neurological deficit such as vertical or rotatory nystagmus, new-onset unsteadiness or new‑onset deafness:

* if the person does not have diabetes, or treating hypoglycaemia

does not resolve the symptoms, and benign paroxysmal positional vertigo or postural hypotension do not account for the presentation, [refer immediately](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#refer-immediately) to exclude posterior circulation stroke, in line with the NICE guideline on [stroke and transient ischaemic attack in over 16s](https://www.nice.org.uk/guidance/ng128).

Recommendation 1.2.6

For adults with transient rotational vertigo on head movement:

* Offer the Hallpike manoeuvre to check for benign paroxysmal positional vertigo (BPPV) if a healthcare professional trained in its use is available. If there is no healthcare professional trained in the Hallpike manoeuvre available, refer in accordance with local pathways.
* If BPPV is diagnosed, offer a canalith repositioning manoeuvre (such as the Epley manoeuvre) if a healthcare professional trained in its use is available and if the person does not have unstable cervical spine disease. If there is no healthcare professional trained in a canalith repositioning manoeuvre available, or the person has unstable cervical spine disease, refer in accordance with local pathways.

Be aware that BPPV is common after a head injury or labyrinthitis.

### Gait ataxia, sensory disturbances and gait apraxia

NICE NG127

Recommendation 1.4.3 (extract)

[Refer](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#refer) adults with gradually progressive unsteady gait (gait ataxia) for neurological assessment and:

* check for vitamin B12 and folate deficiency

consider serological testing for gluten sensitivity as recommended in the NICE [guideline on coeliac disease](https://www.nice.org.uk/guidance/ng20).

Recommendation 1.4.4

Refer adults who have difficulty initiating and coordinating walking (gait apraxia) to neurology or an elderly care clinic to exclude normal pressure hydrocephalus.

Recommendation 1.10.6 (extract)

For adults with persistent, distally predominant ('stocking' or 'glove and stocking') altered sensation in the limbs and depressed deep tendon reflexes:

* be alert to the possibility of peripheral neuropathy and consider checking:
  + vitamin B12 deficiency …

if no causes of peripheral neuropathy are found, refer for neurological assessment.

### Limb and facial weakness

NICE NG127

Recommendation 1.7.3

Refer immediately, in line with local pathways, adults who have severe low back pain radiating into the leg and new-onset disturbance of bladder, bowel or sexual function, or new-onset perineal numbness, to have an assessment for cauda equina syndrome.

Recommendation 1.7.4

[Refer urgently](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#refer-urgently) adults with very rapidly (within hours to days) progressive weakness of a single limb or hemiparesis for investigation, including neuroimaging, in line with the recommendation on [brain and central nervous system cancers in adults](https://www.nice.org.uk/guidance/ng12/chapter/1-Recommendations-organised-by-site-of-cancer#brain-and-central-nervous-system-cancers) in the NICE guideline on suspected cancer.

Recommendation 1.7.11

Do not routinely refer adults with an uncomplicated episode of Bell's palsy (unilateral lower motor neurone pattern facial weakness affecting all parts of the face and including weakness of eye closure) and no evidence of another medical condition such as middle ear disease.

Recommendation 1.7.13

[Consider referring](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#consider-referring) adults with Bell's palsy who have developed symptoms of aberrant reinnervation (including gustatory sweating or jaw-winking) 5 months or more after the onset of Bell's palsy for neurological assessment and possible treatment.

### Posture distortion

Recommendation 1.9.1

Suspect cervical dystonia in adults who have persistent abnormalities of head or neck posture, with or without head tremor, especially if the symptom improves when the person touches their chin with their hand.

Recommendation 1.9.3

Be aware that dystonia in adults can affect other parts of the body (for example, it can cause writer's cramp or in‑turned posture of the foot).

Recommendation 1.9.4

[Refer](file:///\\nice.nhs.uk\data\H&SC\QS\Work%20programme\1.%20QS%20in%20development\Suspected%20neurological%20problems\5.%20QSAC%20prioritisation%20meeting\Refer%20adults%20with%20suspected%20dystonia%20to%20have%20an%20assessment%20for%20diagnosis%20and%20possible%20botulinum%20toxin%20treatment) adults with suspected dystonia to have an assessment for diagnosis and possible botulinum toxin treatment.

Recommendation 1.9.5

Be aware that antipsychotic and antiemetic medicines can trigger or exacerbate dystonia in adults.

### Referral for subarachnoid haemorrhage

RCP National Clinical Guideline for Stroke

Recommendation 3.7.1.A

Any person presenting with sudden severe headache and an altered neurological state should have the diagnosis of subarachnoid haemorrhage investigated by:

* immediate CT brain scan (also including CT angiography if a protocol is agreed with the neurosciences centre);
* lumbar puncture 12 hours after ictus (or within 14 days if presentation is delayed) if the CT brain scan is negative and does not show any contraindication

spectrophotometry of the cerebrospinal fluid for xanthochromia.

* + 1. Current UK practice

### Dizziness and vertigo

A 2015 survey of current management of BPPV of 80 UK physiotherapists interested in vestibular rehabilitation reported that:[[7]](#footnote-7)

* less than a third reported the 3 characteristics of nystagmus advocated by Dix and Hallpike; half named only 1; this could result in neurological causes being missed
* cervical instability was under recognised as a precaution relevant to performing testing manoeuvres.

One limitation of this study is that the results are not generalisable to all parts of the UK, as participants were recruited via members of a professional network who were interested in vestibular rehabilitation. Although there was a good response rate overall, it reduced as participants went through the questions.

No current practice regarding assessment and management of BPPV by GPs was identified.

### Gait ataxia, sensory disturbances and gait apraxia

No published studies on current practice were highlighted concerning;

* recognition of testing for vitamin B12 deficiency based on recognition of gait ataxia and sensory disturbances as a quality improvement area.
* referral based on recognition of gait apraxia as a sign of normal pressure hydrocephalus in the elderly.

These areas are based on stakeholders’ knowledge and experience.

### Limb and facial weakness

A secondary analysis of 226 representative brain tumour cases from 2009-10 extracted from the National Audit of Cancer Diagnosis in Primary Care reported that:[[8]](#footnote-8)

* the most common symptom was focal neurology (around a third of cases) including stroke[[9]](#footnote-9)
* around a third of people (cases) had attended at least 3 appointments before referral
* 22 out of 64 people with focal neurology symptoms had attended at least 3 appointments
* overall the median time from symptom presentation to being seen by a specialist was less than 4 weeks. The median interval for focal neurology symptoms was 21 days.

The 2018/19 Cancer Patient Experience Survey reported that 40% of people with brain and central nervous system cancers went straight to hospital. 20% saw their GP once, although 13% saw their GP 3 or 4 times before going to hospital.[[10]](#footnote-10)

No published studies on current practice were highlighted concerning:

* investigation for cauda equine syndrome based on referrals into secondary care from chiropractors.
* management of uncomplicated cases of Bell’s Palsy in primary care, or referral of more complex forms.

These areas are based on stakeholders’ knowledge and experience.

### Posture distortion

The 2018/19 [National Neurology Patient Experience Survey](https://www.neural.org.uk/resource_library/neuro-patience/) reported that less than 40% of people with health problems caused by dystonia saw their GP once or twice before being told they needed to see a neurologist.[[11]](#footnote-11)

### Referral for subarachnoid haemorrhage

No published studies on current practice were highlighted concerning immediate referral for investigation of suspected subarachnoid haemorrhage; this area is based on stakeholders’ knowledge and experience.

### Confusion and drowsiness

No published studies on current practice were highlighted concerning recognition of signs of confusion and drowsiness in adults that may suggest meningitis.

* 1. Continuing or new symptoms (over 16s)
     1. Summary of suggestions

### Functional neurological conditions, chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) or fibromyalgia

Stakeholders suggested that cognitive symptoms support a diagnosis of chronic fatigue syndrome (CFS), myalgic encephalomyelitis (ME) or fibromyalgia and are also very common in functional neurological disorders. It was suggested that post-exertional fatigue is a key symptom of these conditions; if the symptom is not present, the diagnosis should be reviewed. It was also highlighted that GPs need more confidence to recognise and manage neurological symptoms that are unlikely to be symptoms of an underlying neurological condition.

### Peripheral neuropathy

Stakeholders proposed that adults who continue to experience symptoms of peripheral neuropathy despite vitamin B12 serum results being in normal range have a course of vitamin B injections to avoid long-term neurological damage.

* + 1. Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source/sources that may support potential statement development. These are presented in full after table 3 to help inform the committee’s discussion.

### Table 3 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Functional neurological conditions, chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) or fibromyalgia | **Memory problems as part of an anxiety disorder or a functional neurological disorder**  NICE NG127 recommendation 1.8.2  **Concentration difficulties associated with myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome or fibromyalgia**  NICE NG127 recommendation 1.8.3  **Making a diagnosis**  NICE CG53 recommendation 1.3.1.3 |
| Peripheral neuropathy | Not directly covered in NICE NG127 and no recommendations are presented |

### Functional neurological conditions, chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) or fibromyalgia

NICE NG127

Recommendation 1.8.2

Be aware that, for adults who have an anxiety disorder or have been diagnosed with a [functional neurological disorder](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#functional-neurological-disorder) by a specialist, memory problems and concentration difficulties might be part of the disorder and the person might not need re‑referral if there are no new neurological signs. New symptoms or signs in adults who have been diagnosed with a functional neurological disorder by a specialist should be assessed as described in the relevant sections of this guideline.

Recommendation 1.8.3

Do not routinely refer adults for neurological assessment if they have concentration difficulties associated with myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome or fibromyalgia.

NICE CG53

Recommendation 1.3.1.3 (extract)

The diagnosis of CFS/ME should be reconsidered if none of the following key features are present:

* post-exertional fatigue or malaise …
  + 1. Current UK practice

### Functional neurological conditions, chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) or fibromyalgia

No published studies on current practice were highlighted for the recognition and management of cognitive symptoms of people with functional neurological conditions in primary care; this area is based on stakeholders’ knowledge and experience.

A 2013-14 survey of around 2,000 people with ME/CFS by Action for ME highlighted that more than half reported that they hadn’t attended an NHS ME/CFS clinic in the past 5 years. This figure was consistent regardless of the form of ME (mild or moderate and severe).[[12]](#footnote-12)

Another report published by Action for ME (2017) highlighted that provision of specialist services varied across UK NHS trusts.[[13]](#footnote-13) Around 30% (79 trusts) confirmed that they did not commission a specialist ME service. Around 20% did not answer this question.

### Peripheral neuropathy

No published studies on current practice were highlighted for the use of vitamin B injections where symptoms of peripheral neuropathy persist; this area is based on stakeholders’ knowledge and experience.

* 1. Improving recognition and referral (under 16s)
     1. Summary of suggestions

### Headache as a ‘red flag’ symptom

Stakeholders highlighted that children and young people with headache accompanied by ‘red flag’ symptoms that may suggest a brain tumour should be promptly referred to specialist paediatric services. It was suggested that these symptoms are not recognised early enough by non-specialists. Stakeholders also commented that localised headache is likely to indicate a secondary headache.

### Head shape or size abnormalities

Stakeholders suggested that infants with rapidly enlarging head circumference have early referral into specialist paediatric services because this may indicate a serious underlying neurological condition.

Stakeholders also commented that the same person should undertake the 3 measurements of the child’s head circumference to support greater accuracy. It was additionally suggested that parental head measurements should be noted if a child has a smaller or larger head than normal.

### Hypotonia (‘floppiness’)

Stakeholders highlighted the importance of faster referral of infants with signs of hypotonia to specialist services to enable timely access to disease modifying treatments which are available for some neuromuscular conditions.

### Duchenne muscular dystrophy

Stakeholders highlighted the importance of early diagnosis and access to treatment to improve outcomes.

### Speech problems in teenagers

Stakeholders suggested that teenagers with new onset slurred or disrupted speech that is not caused by prescribed medicines, recreational drugs or alcohol are referred for urgent neurological assessment. It was felt that these signs are not always recognised when teenagers present in emergency departments, despite the incidence of meningitis being higher in this group than in younger children.

### Sudden limb weakness

Stakeholders highlighted that sudden onset weakness in children should trigger referral to an emergency department for evaluation for stroke.

* + 1. Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source/sources that may support potential statement development. These are presented in full after table 4 to help inform the committee’s discussion.

### Table 4 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Headache as a ‘red flag’ symptom | **Headaches in children under 12 years**  NICE NG127 Recommendations 1.21.1 |
| Head shape or size abnormalities | **Children aged under 4 years**  NICE NG127 Recommendations 1.22.2, 1.22.3 and 1.22.4 |
| Hypotonia (‘floppiness’) | **Hypotonia ('floppiness')**  NICE NG127 Recommendation 1.23.2 |
| Duchenne muscular dystrophy | **Motor development delay**  NICE NG127 Recommendation 1.25.2  NICE NG127 Recommendation 1.25.3  **Motor development regression**  NICE NG127 Recommendation 1.25.4  NICE NG127 Recommendation 1.25.5 |
| Speech problems in teenagers | **New-onset slurred or disrupted speech**  NICE NG127 Recommendation 1.29.1 |
| Sudden limb weakness | **Sudden-onset or progressive limb or facial weakness**  NICE NG127 Recommendation 1.24.1  **Referral and care pathway for childhood stroke**  RCPCH Stroke in childhood section 4.1, pp. 32-33 (‘Recommendations’: bullets 1-3) |

### Headache as a ‘red flag’ symptom

NICE NG127

Recommendation 1.21.1

[Refer immediately](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline" \l "refer-immediately) children aged under 12 years with headache for same-day assessment, according to local pathways, if they have any one of the following:

* headache that wakes them at night
* headache that is present on awakening in the morning
* headache that progressively worsens
* headache triggered or aggravated by coughing, sneezing or bending down
* headache with fever and features of meningism
* headache associated with vomiting
* headache associated with ataxia
* headache associated with change in conscious level or pervasive lethargy
* headache occurring within 5 days of a head injury

headache associated with squint or failure of upward gaze ('sunsetting').

### Head shape or size abnormalities

NICE NG127

Recommendation 1.22.2

For all children aged under 4 years with suspected abnormal head shape or size:

* take 3 consecutive measurements of the child's head circumference at the same appointment, using a disposable paper tape measure
* plot the longest of the 3 measurements on a standardised growth chart, corrected for gestational age

if the child's head circumference is below the 2nd centile, [refer](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#refer) for paediatric assessment.

Offer follow-up measurements if needed, according to clinical judgement and taking the child's age into account.

Recommendation 1.22.3

For children with a head circumference measurement that differs by 2 or more centile lines from a previous measurement on a standardised growth chart (for example, an increase from the 25th to the 75th centile, or a decrease from the 50th to the 9th centile):

* refer to paediatric services for assessment and cranial imaging to exclude progressive hydrocephalus or microcephaly **or**
* refer immediately to paediatric services if the child also has any of the following signs or symptoms of raised intracranial pressure:
  + tense fontanelle
  + sixth nerve palsy
  + failure of upward gaze ('sunsetting')
  + vomiting
  + unsteadiness (ataxia)
  + headache. **[amended July 2019]**

Recommendation 1.22.4

For children with a head circumference above the 98th centile that has not changed by more than 2 centile lines from the previous measurement on a standardised growth chart, who are developing normally and who have no symptoms of raised intracranial pressure:

* note the head size of the biological parents, if possible, to check for familial macrocephaly

if familial macrocephaly is likely, do not routinely refer the child in the absence of any other problem.

### Hypotonia (‘floppiness’)

NICE NG127

Recommendation 1.23.2 (extract)

For babies aged under 1 year with hypotonia (floppiness) that has been present for weeks or months:

* if the baby is weak (for example, with feeding and breathing difficulties), [refer urgently](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#refer-urgently) to paediatric services …

### Duchenne muscular dystrophy

Recommendation 1.25.2

[Refer](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#refer) children to a child development service, and [consider referring](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#consider-referring) for physiotherapy or occupational therapy, in line with the recommendations in the NICE guideline on [cerebral palsy in under 25s](https://www.nice.org.uk/guidance/ng62), if they:

* are not sitting unsupported by 8 months (corrected for gestational age) **or**
* are not walking independently by 15 months (girls) or 18 months (boys) (corrected for gestational age) **or**

show early asymmetry of hand function (hand preference) before 1 year (corrected for gestational age).

Recommendation 1.25.3

If the child is a boy, consider measuring creatinine kinase level to exclude Duchenne muscular dystrophy before the boy has had a specialist review.

Recommendation 1.25.4

Refer children with motor development regression to a paediatric neurodevelopmental service or paediatric neurology depending on locally agreed pathways.

Recommendation 1.25.5

If the child is a boy, consider measuring creatinine kinase level to exclude Duchenne muscular dystrophy before the boy has had a specialist review.

### Speech problems in children

NICE NG127

Recommendation 1.29.1

[Refer urgently](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#refer-urgently) children with new-onset slurred or disrupted speech that is not attributable to prescribed medicines, recreational drugs or alcohol for neurological assessment.

### Sudden limb weakness

NICE NG127

Recommendation 1.24.1

[Refer immediately](https://www.nice.org.uk/guidance/ng127/chapter/terms-used-in-this-guideline#refer-immediately) children with sudden-onset or rapidly progressive (hours to days) limb or facial weakness for neurological assessment.

RCPCH Stroke in childhood

Section 4.1, pp. 32-33 (‘Recommendations’: bullets 1-3)

Community medical services and ambulance services (including call handlers, telephone triage and advice services such as National Health Service (NHS) 111 and primary care reception staff) should be trained to recognise children and young people with symptoms suggesting an acute stroke as an emergency requiring urgent transfer to hospital.

Children and young people seen by ambulance clinicians, or primary care providers outside hospital with the sudden onset of acute focal neurological symptoms should be screened for hypoglycaemia with a capillary blood glucose, and for stroke using a simple screening tool such as FAST (‘Face, Arms, Speech Time’). Where these are normal or negative, but stroke is still suspected, the acute stroke pathway should be used.

Children and young people with persisting neurological symptoms who screen positive using a validated tool (or who screen negative, but in whom stroke is suspected) should be transferred to an emergency department with paediatric services urgently.

* + 1. Current UK practice

### Headache as a ‘red flag’ symptom

A large-scale record linkage study of data from Clinical Research Datalink and Hospital Episode Statistics (HES) for babies, children, young people and adults aged between 18 and 24 years diagnosed with an intracranial brain tumour between 1989 and 2006 reported that:[[14]](#footnote-14)

* headache was the most common presenting symptom, except in babies and children aged between 0 and 5 years
* the primary care presentation rate for headache in children age 5 to 11 years was 0.64 per 100 person-months
* the frequency of primary care consultations for headache began to increase 24 months before diagnosis of an intracranial tumour

the frequency of hospital admissions for headache increased about 6 months before diagnosis.

A limitation of the study is that it uses data which is over 10 years old and includes young people and adults aged between 17 and 24 years.

A review of the impact of the HeadSmart: Be Brain Tumour Aware Campaign (launched in 2011), which highlighted headache as a ‘red flag’ symptom, reported that the median interval between initial presentation to a healthcare professional and diagnosis had fallen to 1.4 weeks (2012 to 2013) from 3.3 weeks in 2011. The study also highlighted that the overall median time to diagnosis had fallen to 6.7 weeks (2012 to 2013) from 9.1 weeks in 2011.[[15]](#footnote-15)

### Head shape or size abnormalities

No published studies on current practice were highlighted regarding the identification and referral of children with head shape or size abnormalities; this area is based on stakeholders’ knowledge and experience.

### Hypotonia (‘floppiness’)

No published studies on current practice were highlighted regarding the recognition and referral of floppiness; this area is based on stakeholders’ knowledge and experience.

### Duchenne muscular dystrophy

No published studies on current practice were highlighted regarding testing for Duchenne muscular dystrophy; this area is based on stakeholders’ knowledge and experience.

### Speech problems in teenagers

No published studies on current practice were highlighted regarding the recognition of speech problems as a sign of meningitis among teenagers; this area is based on stakeholders’ knowledge and experience.

### Sudden limb weakness

No published studies on current practice were highlighted regarding the recognition limb weakness as a symptom of stroke in children; this area is based on stakeholders’ knowledge and experience.

* 1. Information and support
     1. Summary of suggestions

### Driving and safety information

Stakeholders suggested that information about driving and safety in relation to specific neurological conditions should be given at the time of referral.[[16]](#footnote-16)

* + 1. Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source/sources that may support potential statement development. These are presented in full after table 5 to help inform the committee’s discussion.

### Table 5 Specific areas for quality improvement

|  |  |
| --- | --- |
| Suggested quality improvement area | Selected source guidance recommendations |
| Driving and safety information | **Information and support**  NICE NG127 Recommendation 1.16.2 |

### Driving and safety information

NICE NG127

Recommendation NG127 1.16.2 (extract)

Advise adults with suspected neurological conditions to:

* check the government's information on [driving with medical conditions](https://www.gov.uk/browse/driving/disability-health-condition) to find out whether they might have a condition that needs to be notified to the DVLA (Driver and Vehicle Licensing Agency) ….
  + 1. Current UK practice

### Driving and safety information

A study reported on responses to a 25-point questionnaire based on DVLA guidelines available in 2013[[17]](#footnote-17) of 140 doctors including foundation year doctors and senior house officers across 5 study centres in England.[[18]](#footnote-18) The study tested their knowledge of medical restrictions on driving. Neurology was among the 5 speciality areas, and there were 5 questions for each.

* knowledge among the cohort was low (the overall mean score was 31%)
* the mean scores for neurology was 33%.

The study highlighted that improving awareness among hospital doctors on driving restrictions for common neurological conditions is important. Otherwise some patients may be discharged and wrongly assume that they are fit to drive, which increases the risk of road traffic accidents.[[19]](#footnote-19)

The focus on junior doctors is important in the acute setting because they are often responsible for planning and coordinating the patients being discharged. A key limitation of this study is that it does not cover primary care.

* 1. Additional areas

### Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However, they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or need further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 12 December 2019.

### Access to new treatments and improving diagnostics

Improving protocols to introduce new treatment options into the NHS was proposed as an improvement area.

Improving diagnostic testing for vitamin B12 deficiency to diagnose pernicious anaemia was also suggested as an improvement area.

These suggestions have not been progressed because they are beyond the scope of a quality standard.

### Conditions covered by other quality standards

Improved recognition of infantile epileptic seizures was suggested as a quality improvement area. Referral for suspected epilepsy in all age groups is covered in NICE’s quality standards on [epilepsy in adults](https://www.nice.org.uk/guidance/qs26) and [epilepsy in children and young people](https://www.nice.org.uk/guidance/qs27).

Diagnosis and treatment of migraine was proposed as an improvement area to reduce unnecessary referrals by improving diagnosis and management in primary care. The classification and treatment of headache and migraine are covered by NICE’s quality standard [headache in the over 12s](https://www.nice.org.uk/guidance/qs42).

Specialist review of people with Parkinson’s disease to monitor their condition was suggested as a quality improvement area. This falls outside of the scope of this quality standard. It was also considered during the development of NICE’s quality standard on [Parkinson’s disease](https://www.nice.org.uk/guidance/qs164/). However, QSAC did not prioritise it for progression as a quality statement.

Screening for signs of depression and anxiety based on these symptoms to support earlier diagnosis of Parkinson’s disease was suggested as an improvement area. There are no supporting recommendations in NICE’s guidance on [suspected neurological conditions](https://www.nice.org.uk/guidance/NG127/).

### Coordination of services and models of care

It was suggested that capacity and knowledge in paediatric neurology services differ to that in adult neurology services, and that they are barriers to providing high quality care. Transfer between paediatric and adult neurology services to support better treatment outcomes was highlighted as a specific area. Transfer between paediatric and adult health services is covered by NICE’s quality standard [transition from children’s to adults’ services](https://www.nice.org.uk/guidance/qs140).

It was suggested that greater integration and coordination between neurology departments and other specialities could improve care for people with neurological conditions. Referral into mental health services was also identified as an important area. It was proposed that commissioners review and where appropriate develop new service models to help reduce waiting times for first and follow-up appointments with neurologists. Access to timely diagnostic tests such as MRI and for people unable to travel due to their condition were identified as other important areas. Reducing variation in access to diagnostic tests for people with suspected dystonia was highlighted as a specific improvement area.

Potential barriers to accessing services are considered as part of discussion of equality and diversity. The other suggestions have not been progressed because they are beyond the scope of this quality standard.

### Equality Impact Assessment

A stakeholder suggested amendments to the equality impact assessment document.

The suggestions will be discussed at the prioritisation meeting on 12 December 2019.

### Information and signposting

It was suggested that giving people with suspected neurological conditions information about specific conditions and signposting them to further sources of information before they are diagnosed is an improvement area.

This suggestion has not been progressed because the primary development source does not contain specific recommendations relating to this area.

### Patient experience

It was suggested that better communication between healthcare professionals would help ensure that test results ordered before referral are available to neurologists. Providing information in different formats to support shared decision making was suggested as an improvement area.

This suggestion has not been progressed because it is covered by NICE’s quality standard on [patient experience in adult NHS services](https://www.nice.org.uk/guidance/qs15/) (statements 3 and 6).

There were various suggestions concerning the need to provide individualised care. Opportunities to discuss end of life care planning (motor neurone disease was highlighted as a specific example) and identifying psychological needs were felt to be particularly important.

These suggestions have not been progressed because providing individualised care is covered by NICE’s quality standard on [patient experience in adult NHS services](https://www.nice.org.uk/guidance/qs15/) (statement 4) and an update of the quality standard on [end of life care](https://www.nice.org.uk/guidance/qs13) is in development. Additionally, NICE’s quality standard on [motor neurone disease](https://www.nice.org.uk/guidance/qs126/) contains a statement on planning end of life care.

### Recognition and management of non-epileptic attack

Improving recognition and management of non-epileptic attack in non-specialist settings supported by specialist input was proposed as an improvement area. This suggestion was identified as an area of developmental practice and is not supported by recommendations in NICE guidance.

### Recognition of rare and early-onset neurological conditions

Improving recognition of the symptoms of rarer neurological conditions such as supranuclear palsy and corticobasal degeneration was suggested as an improvement area. It was also suggested that using correct ICD codes in patient records would support monitoring the quality of care for these conditions.

It was suggested that early-onset presentation of conditions such as dementia and Parkinson’s disease should be covered. The suggestions do not suggest a specific neurological symptom or group of symptoms that are currently poorly recognised outside specialist settings. Diagnosis of dementia and Parkinson’s disease are beyond the scope of this quality standard. Improving practices for ICD coding is beyond the remit of a quality standard.

### Source recommendations

Stakeholders queried the evidence base and some of the recommendations in NICE’s guidance on [suspected neurological conditions](https://www.nice.org.uk/guidance/ng127/). Stakeholders queried the rationale and evidence used to determine which neurological conditions were covered by the guideline. They also queried the lack of recommendations on signposting to sources of support, including support for mental health.

Regarding recommendations for the under 16s specifically, it was suggested that it should be clarified whether certain symptoms indicating epilepsy are reported by the child or have been observed by others in order to support the diagnosis.

It was also suggested that the content of other recommendations for the under 16s should be changed.

These comments will be passed to the centre for guidelines.

### Training and development

The training of staff in primary care to support community-based neurology care was suggested as an area of quality improvement.

This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place. The committee should consider which parts of care and support would be improved by increased training. Training may be referred to in the audience descriptors.

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# Appendix 1: Review flowchart

Records identified through topic engagement  
[n =26]

Records identified through IS scoping search  
[n = 120]

Records identified through ViP searching  
[n = 2,320]

Records excluded  
[n = 2,283]

Records screened  
[n = 2,466]

Citation searching or snowballing

[n=17]

Full-text papers excluded  
[n =182]

Full-text papers assessed   
[n = 217]

Current practice examples included in the briefing paper  
[n = 18]

# Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

| ID | Stakeholder | Suggested key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- | --- |
| 1. Improving recognition and referral (over 16s) | | | | | |
| **Dizziness and vertigo** | | | | | |
| 01 | SCM1 | Sudden onset dizziness | Stroke is usually identified by FAST test which does not identify posterior circulation stroke | Patients with posterior circulation stroke are sometimes not referred urgently with resulting avoidable morbidity and mortality | [Acad Emerg Med.](https://www.ncbi.nlm.nih.gov/pubmed/31295763) 2019 **Avoiding Misdiagnosis in Patients With Posterior Circulation Ischemia: A Narrative Review.**  [Gurley KL](https://www.ncbi.nlm.nih.gov/pubmed/?term=Gurley%20KL%255BAuthor%255D&cauthor=true&cauthor_uid=31295763)1,2,3, [Edlow JA](https://www.ncbi.nlm.nih.gov/pubmed/?term=Edlow%20JA%255BAuthor%255D&cauthor=true&cauthor_uid=31295763)1,2. |
| 02 | SCM3 | Key area for quality improvement 1  Diagnosis and treatment of Benign paroxysmal postural vertigo (BPPV) | BPPV is a common benign cause of dizziness that can be diagnosed without investigations with a high degree of certainty in the consulting room; and treated on the spot with a repositioning manoeuvre. It is commonly misdiagnosed, leading to multiple trials of pointless prescription treatments. | BPPV is frequently misdiagnosed as labirynthitis, leading to inappropriate treatment with anti-emetics, vestibular sedatives, steroid inhalers and even antibiotics. None of these treatments work for this condition so instead the failed interventions increase anxiety among patients and primary health professionals alike.  Alternatively they are referred to ENT, where they can undergo extensive testing before treatment, and/or neurology outpatients for an assessment and intervention that could be confidently undertaken in primary care. | NG127 1.2.6 |
| **Gait ataxia, sensory disturbances and gait apraxia** | | | | | |
| 03 | Coeliac UK | Key area for quality improvement 1:  Consideration of testing for coeliac disease in patients with suspected neurological conditions | We are reassured that the NICE guideline on suspected neurological conditions recommends considering testing for coeliac disease in patients presenting with gait ataxia and persistent, distally pred ominant altered sensation in the limbs and depressed deep tendon reflexes.  There is a need to increase awareness of neurological symptoms as a presentation of coeliac disease as non-specialists may not consider coeliac disease to be a cause of neurological symptoms. As serological testing for coeliac disease can be carried out in primary care it has the potential to reduce delays to diagnosis. This is important as an early diagnosis allows treatment with the gluten free diet to be initiated early on. | This is a key area for improvement as the majority of people with coeliac disease are undiagnosed. Research shows that 1 in 100 people have coeliac disease [1] but only 30% have a diagnosis.[2]  Furthermore, there is also evidence of a need for earlier recognition of people with a neurological presentation of coeliac disease. People with coeliac disease presenting with neurological symptoms are diagnosed on average 10 years later than those with a classical gastrointestinal presentation.[3] | [1] Bingley PJ, Williams AJ, Norcross AJ, Unsworth DJ, et al Undiagnosed coeliac disease at age seven: population based prospective birth cohort study. BMJ [internet] 2004 Feb 7 328(7435):322-3. Available from: https://doi.org/10.1136/bmj.328.7435.322  [2] West J, Otete H, Sultan AA, Crooks CJ. Changes in Testing for and Incidence of Celiac Disease in the United Kingdom. Epidemiology [Internet]. 2019 Jul;30(4):e23–4. Available from: <http://dx.doi.org/10.1097/EDE.0000000000001006>  [3] Hadjivassiliou M, Dasappaiah RG, Grinewald RA, Aeschlimann DP, et al. Neurological Dysfunction in Coeliac Disease and Non-Coeliac Gluten Sensitivity. Am J Gastroenterol. 2016 Apr; 111(4): 561–567. Available from: 10.1038/ajg.2015.434 |
| 04 | SCM1 | Gait apraxia | Diagnosis of normal pressure hydrocephalus is sometimes not considered in the elderly | Normal pressure hydrocephalus is potentially treatable | Prevalence of idiopathic normal pressure hydrocephalus: A prospective, population-based study.  [Andersson J](https://www.ncbi.nlm.nih.gov/pubmed/?term=Andersson%20J%255BAuthor%255D&cauthor=true&cauthor_uid=31141553)1, [Rosell M](https://www.ncbi.nlm.nih.gov/pubmed/?term=Rosell%20M%255BAuthor%255D&cauthor=true&cauthor_uid=31141553)1, [Kockum K](https://www.ncbi.nlm.nih.gov/pubmed/?term=Kockum%20K%255BAuthor%255D&cauthor=true&cauthor_uid=31141553)1, [Lilja-Lund O](https://www.ncbi.nlm.nih.gov/pubmed/?term=Lilja-Lund%20O%255BAuthor%255D&cauthor=true&cauthor_uid=31141553)1, [Söderström L](https://www.ncbi.nlm.nih.gov/pubmed/?term=S%25C3%25B6derstr%25C3%25B6m%20L%255BAuthor%255D&cauthor=true&cauthor_uid=31141553)2, [Laurell K](https://www.ncbi.nlm.nih.gov/pubmed/?term=Laurell%20K%255BAuthor%255D&cauthor=true&cauthor_uid=31141553)1.  [Neurology](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4001197/). 2014  Prevalence of idiopathic normal-pressurehydrocephalus [Daniel Jaraj](https://www.ncbi.nlm.nih.gov/pubmed/?term=Jaraj%20D%255BAuthor%255D&cauthor=true&cauthor_uid=24682964), MD, [Katrin Rabiei](https://www.ncbi.nlm.nih.gov/pubmed/?term=Rabiei%20K%255BAuthor%255D&cauthor=true&cauthor_uid=24682964), MD, [Thomas Marlow](https://www.ncbi.nlm.nih.gov/pubmed/?term=Marlow%20T%255BAuthor%255D&cauthor=true&cauthor_uid=24682964), BSc, [Christer Jensen](https://www.ncbi.nlm.nih.gov/pubmed/?term=Jensen%20C%255BAuthor%255D&cauthor=true&cauthor_uid=24682964), MD, [Ingmar Skoog](https://www.ncbi.nlm.nih.gov/pubmed/?term=Skoog%20I%255BAuthor%255D&cauthor=true&cauthor_uid=24682964), MD, PhD, and [Carsten Wikkelsø](https://www.ncbi.nlm.nih.gov/pubmed/?term=Wikkels%2526%2523x000f8%253B%20C%255BAuthor%255D&cauthor=true&cauthor_uid=24682964), MD, PhD |
| **Limb and facial weakness** | | | | | |
| 05 | NHS England &  Improvement - Clinical Programmes Team (submission by The Neurological Alliance) | Key area for quality improvement 1  Faster referral of people with suspected neurological conditions requiring urgent specialist care (including suspected brain tumour, suspected sub-arachnoid haemorrhage, suspected epilepsy). | Being seen by specialists as soon as possible is key to ensuring better outcomes for people with SAH, brain tumour and epilepsy – conditions which can (epilepsy, brain tumour)/will (SAH) lead to mortality where not treated as soon as possible. Moreover, NHS resource required to optimise outcomes may increase the longer the  delay starting treatment (brain tumour).  The NICE guidance on the epilepsies recommends that both children and adults with a suspected first seizure should be seen as soon as possible by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs.  The NICE guideline on suspected cancer: recognition and referral, recommends urgent direct access to MRI scan of the brain to assess for brain or central nervous system cancer in adults with progressive, sub-acute  loss of central neurological function. | 22% of brain tumour respondents to the national cancer patient experience survey saw their GP three or more times before told they needed to go to hospital  44% epilepsy respondents to our national neurology patient experience survey saw their GP three or more times  before being referred to see a neurologist  Waiting list times being high also contributes to a situation where people are not seen as fast as would be desired, making the onus on quick referral by a GP all the higher.  Our national neurology patient experience survey found that of respondents with epilepsy, 22% waited 3-6 months to see a specialist after first being referred, 10% waited 7-12 months, and 20% waited more than 12 months. Of respondents with brain tumour, 30% waited 3-6 months to see a specialist after first being referred, 16% waited 7-12 months, and 24% waited more than 12 months. | Please see our national neurology patient experience survey which collects data relating to referral times as reported by patients. |
| 06 | Royal College of Chiropractors | Appropriate referral for suspected Cauda Equina Syndrome (CES). | CES is a neurological condition with the potential for severe, life changing outcomes which are time-dependent. | There is evidence that emergency referrals for CES made by chiropractors to Accident & Emergency departments are not always taken seriously and patients are inappropriately discharged. This appears to be due to an uninformed mistrust of the chiropractor’s clinical ability to refer CES appropriately. |  |
| 07 | SCM1 | Bell’s Palsy | Patients with uncomplicated Bell’s palsy referred inappropriately to Neurology. Those with long term complications not referred appropriately | Management of simple Bell’s palsy should be in primary care but refer those with aberrant re-innervation may benefit from treatment with botulinum toxin | [J Plast Reconstr Aesthet Surg.](https://www.ncbi.nlm.nih.gov/pubmed/28389084) 2017  **Botulinum toxin treatment for facial palsy: A systematic review.**  [Cooper L](https://www.ncbi.nlm.nih.gov/pubmed/?term=Cooper%20L%255BAuthor%255D&cauthor=true&cauthor_uid=28389084)1, [Lui M](https://www.ncbi.nlm.nih.gov/pubmed/?term=Lui%20M%255BAuthor%255D&cauthor=true&cauthor_uid=28389084)2, [Nduka C](https://www.ncbi.nlm.nih.gov/pubmed/?term=Nduka%20C%255BAuthor%255D&cauthor=true&cauthor_uid=28389084)3 |
| 08 | SCM3 | Key area for quality improvement 2  **Diagnosis and treatment of Bell’s palsy** | Patients with Bell’s palsy are being increasingly recognised in primary care and appropriately treated with steroids but:  1 the steroid regimes vary widely  2. they are still being offered aciclovir treatment, when neurologists believe the evidence is strong that this is ineffective  3. many are also being referred unnecessarily to ED/stroke services | Front-line professionals who are not confident about making a diagnosis of Bell’s palsy worry about missing a stroke; or about the possibility that brain imaging may additionally be required for whatever reason. A diagnosis of uncomplicated Bell’s palsy can be made confidently in primary care and does not require brain imaging.  The issue of antivirals may need further thought. Neurologists stopped using them 15 years ago because of clear negative trials but I note that the a recent Cochrane review sits on the fence. | NG127 1.7.11 |
| 09 | SCM6 | Key area for quality improvement 1  **Faster referral of people with suspected neurological conditions requiring urgent specialist care (including suspected brain tumour, suspected sub-arachnoid haemorrhage, suspected epilepsy).** | Being seen by specialists as soon as possible is key to ensuring better outcomes for people with SAH, brain tumour and epilepsy – conditions which can (epilepsy, brain tumour)/will (SAH) lead to mortality where not treated as soon as possible. Moreover, NHS resource required to optimise outcomes may increase the longer the delay starting treatment (brain tumour).  The NICE guidance on the epilepsies recommends that both children and adults with a suspected first seizure should be seen as soon as possible by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs.  The NICE guideline on suspected cancer: recognition and referral, recommends urgent direct access to MRI scan of the brain to assess for brain or central nervous system cancer in adults with progressive, sub acute loss of central neurological function. | 22% of brain tumour respondents to the national cancer patient experience survey saw their GP three or more times before told they needed to go to hospital  44% epilepsy respondents to The Neurological Alliance’s national neurology patient experience survey saw their GP three or more times before being referred to see a neurologist  Waiting list times being high also contributes to a situation where people are not seen as fast as would be desired, making the onus on quick referral by a GP all the higher.  Our national neurology patient experience survey found that of respondents with epilepsy, 22% waited 3-6 months to see a specialist after first being referred, 10% waited 7-12 months, and 20% waited more than 12 months. Of respondents with brain tumour, 30% waited 3-6 months to see a specialist after first being referred, 16% waited 7-12 months, and 24% waited more than 12 months. | Please see The Neurological Alliance’s [national neurology patient experience survey](https://www.neural.org.uk/categories_rl/our-reports/) which collects data relating to referral times as reported by patients. |
| 10 | The Neurological Alliance | Key area for quality improvement 1  Faster referral of people with suspected neurological conditions requiring urgent specialist care (including suspected brain tumour, suspected sub-arachnoid haemorrhage, suspected epilepsy). | Being seen by specialists as soon as possible is key to ensuring better outcomes for people with SAH, brain tumour and epilepsy – conditions which can (epilepsy, brain tumour)/will (SAH) lead to mortality where not treated as soon as possible. Moreover, NHS resource required to optimise outcomes may increase the longer the  delay starting treatment (brain tumour).  The NICE guidance on the epilepsies recommends that both children and adults with a suspected first seizure should be seen as soon as possible by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs.  The NICE guideline on suspected cancer: recognition and referral, recommends urgent direct access to MRI scan of the brain to assess for brain or central nervous system cancer in adults with progressive, sub-acute  loss of central neurological function. | 22% of brain tumour respondents to the national cancer patient experience survey saw their GP three or more times before told they needed to go to hospital  44% epilepsy respondents to our national neurology patient experience survey saw their GP three or more times  before being referred to see a neurologist  Waiting list times being high also contributes to a situation where people are not seen as fast as would be desired, making the onus on quick referral by a GP all the higher.  Our national neurology patient experience survey found that of respondents with epilepsy, 22% waited 3-6 months to see a specialist after first being referred, 10% waited 7-12 months, and 20% waited more than 12 months. Of respondents with brain tumour, 30% waited 3-6 months to see a specialist after first being referred, 16% waited 7-12 months, and  24% waited more than 12 months. | Please see our [national neurology patient experience survey](https://www.neural.org.uk/categories_rl/our-reports/) which collects data relating to referral times as reported by patients. |
| **Posture distortion** | | | | | |
| 11 | SCM1 | Dystonia | Diagnosis often delayed as condition is poorly recognised | Dystonia is often easily treated with botulinum toxin | [J Clin Neurosci.](https://www.ncbi.nlm.nih.gov/pubmed/26601813) 2016 **Delays to the diagnosis of cervical dystonia.**  [Bertram KL](https://www.ncbi.nlm.nih.gov/pubmed/?term=Bertram%20KL%255BAuthor%255D&cauthor=true&cauthor_uid=26601813)1, [Williams DR](https://www.ncbi.nlm.nih.gov/pubmed/?term=Williams%20DR%255BAuthor%255D&cauthor=true&cauthor_uid=26601813)2. |
| 12 | SCM5 | Timely referral by Primary Care (GP) to Specialist (Neurological Consultant/Movement disorder specialist) for assessment. | NICE guidance for Dystonia  makes a specific recommendation for neurological referral to ensure that dystonia caused by an underlying neurodegenerative condition, or by medication, is identified and managed. If the dystonia is idiopathic, treatment can be offered. | Of the 10,339 respondents to the Neuro Patience report, 39 per cent reported seeing a GP five or more times before being referred to a neurologist. Following referral, one in three patients waited more than 12 months for their appointment. The survey also found wide regional variation in waiting times.  Members of The Dystonia Society (currently 1,800) have reported their frustrations at accessing treatments and support, including pressure on the NHS services resulting in delays and cancellations. | Dystonia: A Guide to Best Practice For health and social care professionals, 2014  https://www.dystonia.org.uk/Handlers/Download.ashx?IDMF=2b634984-6d69-4612-9c53-b0d9c81b20ea  Neuro-Patience presents the findings of the 2018/19 National Neurology Patient Experience Survey.  /www.neural.org.uk/patient-experience-survey/  Out of a total of 10,339 responses  524 were from patients with dystonia representing 24.5% of the responses given.  TDS Annual report 2019: Delivering best practice –p.5.  http://apps.charitycommission.gov.uk/Accounts/Ends95/0001062595\_AC\_20190331\_E\_C.PDF  https://bestpractice.bmj.com/topics/en-gb/1096 |
| **Referral for subarachnoid haemorrhage** | | | | | |
| See comments 05, 09 and 10 | | | | | |
| **Confusion and drowsiness** | | | | | |
| 13 | Meningitis Research Foundation | In all patients with sudden onset neurological signs such as confusion, drowsiness, signs of meningism and of raised intracranial pressure, recognition of and investigation for neurological infection needs to be improved - not just in children. | Frontline doctors in the adult setting see patients with meningitis infrequently, but it can be rapidly fatal. It is important that signs of neurological infection, which are normally of sudden and rapid onset, are not missed. | Frontline doctors in the adult setting see patients with meningitis infrequently, but it can be rapidly fatal. It is important that signs of neurological infection, which are normally of sudden and rapid onset, are not missed. | Not yet published but due to be presented at the 2019 Federation of Infection Societies national conference and at Meningitis and Septicaemia 2019 (authors Fiona McGill, Jayne Ellis, David Harvey, Sylviane Defres, Tom Solomon, Arjun Chandna, Eloisa Maclachlan, Robert Heyderman on behalf of the NAMM investigators). |
| **2. Continuing or new symptoms (over 16s)** | | | | | |
| **Functional neurological conditions, chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy) or fibromyalgia** | | | | | |
| 14 | ME Association | Recognition of ME and CFS and the key symptom of post-exertional malaise. | This is a sizable patient group presenting with symptoms which are recognisably neurological in nature, but multi-system in effect. They have been ill-served by poorly argued assumptions of causality, limiting or distorting diagnosis and treatment, so greatly increasing the burden and duration of illness and consequent costs. | The degrees of illness presented place a continuing demand on service provision, so improvement in quality and effectiveness of initial service provision in particular are bound to have long-term benefits for patients and society. In addition to patient numbers, the undue levels of missed and mis-diagnosis are unsupportably high. Patients presenting with symptoms of or similar to ME & CFS include significant numbers of patients presenting with forms of (usually early onset) multiple sclerosis, parkinson's, and epilepsy, as well as other types of chronic illness which present with symptoms considered to be neurological. Time taken to arrive at consideration of this diagnosis and then progress to confirmation and treatment is unduly prolonged. Some patients could have been effectively treated in the time taken for many diagnoses. Currently available standards of diagnosis and treatment are relatively limited and demand unusual levels of evaluation by practitioners, but the potential benefits from practicing to this available standard clearly outweigh any issues over demand on services. | Current NICE, and subsequent international guidance, recognises the established nature of myalgic encephalomyelitis and chronic fatigue ayndrome, and particulary the major signature symptom of post exertional malaise. The ongoing revision process of NICE guideline CG53 includes a wealth of evidence supporting the basis for improving current practice to meet the 2007 standard and imminent updates. |
| 15 | SCM3 | Key area for quality improvement 4  **Recognition and reassurance of patients with cognitive symptoms in the context of a functional neurological disorder (FND) / chronic fatigue syndrome (CFS) / fibromyalgia** | Cognitive symptoms are very common in FND and form part of the diagnostic criteria for both CFS and fibromyalgia. They are a cause of significant concern for patients and GPs alike but are not a marker of organic neurological disease. | FND/CFS/fibromyalgia are extremely common; cognitive symptoms are particularly common in this population, who are often disproportionately young compared to other people with superficially similar symptoms.  Our GPs are increasingly expert at managing functional symptoms but FND is a cause of worry. Giving them the confidence to recognise cognitive symptoms that are highly unlikely to be markers of organic neurological disease will help them better manage this patient population. | NG127 1.8.2, 1.8.3 |
| **Peripheral neuropathy** | | | | | |
| 16 | Pernicious Anaemia Society | Key area for quality improvement 3 | Patients whose serum B12 is within the ‘normal’ range but who have pins and needles or numbness should be given a therapeutic trial of B12 injections | As the assays available for B12 status and Pernicious Anaemia are so unreliable only a trial of B12 injection can rule out any deficiency. | It should be noted that only some patients will notice an improvement in any neurological issues after B12 injections have been given though usually there is an improvement in any peripheral neuropathy.  There is some evidence that using one particular form of B12 (Methylcobalamin) does lead damage to the myelin sheath being repaired. See Hooper: Pernicious Anaemia; the forgotten disease. Hammersmith Health Books, London 2012 |
| **3. Improving recognition and referral (under 16s)** | | | | | |
| **Headache as a ‘red flag’ symptom** | | | | | |
| 17 | British Association of Paediatric Neurologists | 1. Children and young people with headache who have red flag symptoms/signs should be promptly referred to paediatric services | There is evidence that children and young people with brain tumours often have symptoms and signs indicative of brain tumours that are not recognised early by non-specialists | Children with brain tumours have delayed diagnosis which leads to excess death and morbidity | HeadSmart |
| 18 | Royal College of Paediatrics and Child Health | Key area for quality improvement 3 | 1.21.1 Localisation is important and significant as well. | It is more likely to be secondary rather than primary headache. |  |
| 19 | SCM2 | Early diagnosis of brain tumours in children | Headache is a common problem in childhood and adolescence. Brain tumours are an important but unusual causes of headaches in this population. Delay in diagnosis affects response to treatment, reduces chances of cure, and adds to long-term disability | Red flag symptoms and signs are well recognised, yet delay in referral and diagnosis is common | Headsmart campaign  <https://www.headsmart.org.uk/clinical/clinical-guideline/> |
| **Head shape or size abnormalities** | | | | | |
| 20 | British Association of Paediatric Neurologists | 4. Infants with rapidly enlarging head circumference should be referred early to specialist services | Rapidly enlarging head circumference in infants can be caused by serious underlying neurological conditions e.g. hydrocephalus, brain tumour | Prompt diagnosis and management by specialist services is necessary to institute correct management and reduce mortality and morbidity |  |
| 21 | Royal College of Paediatrics and Child Health | Key area for quality improvement 5 | 1.22.2 It is advisable that the same person does the measurement.  Please measure parents’ OFC, and this applies for large or small heads. | It is well established that there are interpersonal differences in these measurements. |  |
| **Hypotonia (‘floppiness’)** | | | | | |
| 22 | British Association of Paediatric Neurologists | 3. Floppy infants should be referred early to specialist services | There are treatments available now for some neuromuscular conditions e.g. spinal muscular atrophy which can alter the disease course if given early. It is important therefore that specialist services see floppy infants early for diagnostic and management purposes | Patients should access disease modifying treatments early |  |
| **Duchenne muscular dystrophy** | | | | | |
| 23 | SCM2 | Diagnosis of Duchenne Muscular Dystrophy | The early diagnosis of DMD allows genetic counselling and early access to emerging therapies that alter natural history of disorder, improving outcome and life expectancy | There is still a significant delay in diagnosis of boys with DMD despite presence of signs and symptoms that would warrant referral and/or investigation |  |
| **Speech problems in teenagers** | | | | | |
| 24 | Meningitis Research Foundation | Urgent referral for children with new-onset slurred or disrupted speech that is not attributable to prescribed medicines, recreational drugs or alcohol for neurological assessment extent of disease in a standardised format with image storage and transfer facility | Use of recreational drugs and alcohol in teenagers is a more common reason for presentation to emergency services, than meningitis. However incidence of meningitis due to meningococcal infection is higher in this age group than in younger school children. There have been regular case reports of meningitis being mistaken for signs of intoxication in teenagers and young adults. | A recent letter in Journal of Infection draws attention to the importance of considering the diagnosis of meningitis or neurological infection in such cases, and ensuring samples are taken for culture as well as toxicology. | Invasive meningococcal disease as a cause of sudden and unexpected death in a teenager: The public health importance of confirming the diagnosis  Campbell, Helen et al.  Journal of Infection, Volume 78, Issue 4, 323 - 337 |
| **Sudden limb weakness** | | | | | |
| 25 | British Association of Paediatric Neurologists | 5. Children/young people presenting with sudden onset of limb weakness should be promptly referred to emergency department | These clinical features may be associated with stroke which requires prompt diagnosis (with neuroimaging) and early treatment to reduce morbidity and mortality | Children/young people are not always getting access to acute treatments due to delaying diagnosis | RCPCH stroke guidelines |
| **4. Information and support – driving and safety information** | | | | | |
| 26 | Primary Care and Community Neurology Society | Key area for quality improvement 2  **The patient is** **offered (condition specific) advice/support from the time of referral to a neurologist or as soon as possible at the first consultation.** | This is an important area - an example would be advice in relation to driving and safety. Even if the referrer has diagnostic uncertainty (hence the basis of the referral), and the duration of any period of ineligibility may not be clear, the patient should be given initial advice. | Provision of information to patients (in relation to referral) - it is important to manage expectations appropriately - all too often patients come to clinic saying 'I thought I was coming from a brain scan today': where the patient is being referred for a clinical opinion, this needs to be made clear, otherwise 'misunderstandings' can further drive over-investigation. | In one service in Preston, referral of suspected CNS cancer, they have implemented 'direct access imaging' (as per NICE 2015 guidance) but have included a weekly 'mini-MDT' service (review of GP referral info and scan jointly by neurologist and neuroradiologist) so that some interpretation of incidental and other findings can be fed back to GPs to give some guidance, where possible, with a view to minimising unnecessary neurology clinic referral |
| **Additional areas** | | | | | |
| **Access to new treatments and improving diagnostics** | | | | | |
| 27 | ME Association | Develop better protocols for introduction of new treatment options into the NHS | With increasing demand on medical research competing with limited resources, there is a need for more effective dissemination of research implementation into stages of practice development. | To make more effective use of limited resources, it is necessary to ensure that while testing of applicability of proposed new treatments remains at least as robust as current standards, methodology for recognising potential new treatments has to be more efficient |  |
| 28 | Pernicious Anaemia Society | Key area for quality improvement 1  Vitamin B12 Deficiency is a widespread heath problem that affects between 10-12% of the UK’s Population | Left undiagnosed and untreated, vitamin B12 Deficiency leads to irreversible damage to the peripheral and central nervous systems. Symptoms of B12 deficiency are vague and often associated with other diseases. | Unfortunately, there is no reliable assay available to determine the B12 Status of patients. As a consequence, many patients suffering from B12 Deficiency are unaware of being deficient and doctors routinely misdiagnose or simply don’t diagnose any deficiency | See the Guideline on B12 and Folate Disorders by the British Committee for Standards in Haematology:  <https://onlinelibrary.wiley.com/doi/full/10.1111/bjh.12959> |
| 29 | Pernicious Anaemia Society | Key area for quality improvement 2 | The most common cause of Vitamin B12 Deficiency is Pernicious Anaemia. A survey of patients showed that:  34% waited up to a year  22% waited up to two years  20% waited up to five years  14% waited over ten years.  10% waited between five years and ten years for a diagnosis | Getting a diagnosis is difficult as the Schilling Test which was used for several decades to verify that the patient has Pernicious Anaemia is no longer available and the current assay, the Competitive Binding Luminescence Assay is unreliable. | <https://www.nhs.uk/conditions/vitamin-b12-or-folate-deficiency-anaemia/>  The BCSH Guideline states that if the test for Intrinsic Factor Antibody is positive then the patient has Pernicious Anaemia; if negative he or she may have Negative Antibody Pernicious Anaemia (see guideline above).  <https://www.magonlinelibrary.com/doi/abs/10.12968/bjon.2014.23.7.376> |
| **Conditions covered by other quality standards** | | | | | |
| 30 | British Association of Paediatric Neurologists | 2. Recognition of infantile epileptic seizures | Prompt diagnosis and treatment may improve neurodevelopmental outcomes | There is evidence that delayed treatment of certain infantile epilepsies results in worse developmental and epilepsy outcomes (evidence from both United Kingdom Infantile Spasm Study (UKISS) and International Collaborative Infantile Spasm Study (ICISS). | **O'Callaghan, F. J. K**., Lux, A. L., Darke, K., Edwards, S. W., Hancock, E., Johnson, A. L., Kennedy, C. R., Newton, R. W., Verity, C. M., Osborne, J. P. (2011). The effect of lead time to treatment and of age of onset on developmental outcome at 4 years in infantile spasms: Evidence from the United Kingdom Infantile Spasms Study. Epilepsia, 52(7), 1359-1364. doi:10.1111/j.1528-1167.2011.0312 |
| 31 | Parkinson’s UK | Screening for anxiety and depression as potential pre-diagnostic features of Parkinson’s disease | There is strong evidence to suggest that both depression and anxiety as pre-diagnostic features or Parkinson’s can occur both at 2 and 5 years prior to diagnosis (Schrag A, Horsfall L, Walters K, Noyce A, Petersen I, (2015) ‘Prediagnostic presentations of Parkinson's disease in primary care: a case-control study.’ Lancet Neurol. 2015 Jan; 14(1):57-64.). | Psychological symptoms of Parkinson’s are often a lower priority than physical symptoms when professionals provide care and treatment for the condition (All-Party Parliamentary Group on Parkinson’s (2018) ‘Mental health matters too - improving mental health services for people with Parkinson’s’).  However there is a higher prevalence of anxiety and depression in people with Parkinson’s compared with the general population. (Broen MPG et al (2016) ‘Prevalence of anxiety in Parkinson’s disease: a systematic review and metaanalysis’ Movement Disorders; 31: 1125–1133 and Aarsland D et al (2012) ‘Depression in Parkinson’s disease – epidemiology, mechanisms and management’ Nature Reviews Neurology; 8: 35–47)  We therefore recommend that there should be a greater emphasis on the psychological symptoms of anxiety and depression as pre-diagnostic features of Parkinson’s in order to provide people with a timely diagnosis of the condition. | None at present. |
| 32 | Progressive Supranuclear Palsy Association | **Key area for quality improvement 3** | People not responding to treatment for a neurological diagnosis may re-present to the GP.  These quality standards are being written for non-specialist healthcare professionals in primary and secondary care – if patients re-present to them, these professionals should think of rarer conditions such as PSP|CBD if the illness and treatment response is not typical or there is more rapid progression of symptoms  This will include patients already with a Parkinson’s or vertigo diagnosis re-presenting exhibiting symptoms not seen in the disease | We know that misdiagnosis is very common in the rarer diseases such as PSP|CBD.  Even between individuals with the same disease the symptoms are experienced with varying degrees of severity  Early diagnosis is vital to allow people access to the right help and support. | [Nice guideline NG71](https://www.nice.org.uk/guidance/ng71) ‘People diagnosed with Parkinson's disease should be seen at regular intervals of 6–12 months to review their diagnosis’ |
| 33 | SCM3 | Key area for quality improvement 3  **Diagnosis and treatment of migraine; especially severe migraine** | A lot of neurology referrals are still being made of individuals with migraine in whom (1) the diagnosis has not been made and (2) prophylaxis has not been tried.  The problem also arises in ED and MAU departments, where patients are given increasing doses of opiates (which makes them more nauseous) When the investigations are negative, the patient is “reassured” but no diagnosis is given and migraine prophylaxis is not offered, or recommended to the GP. | There are clear guidelines on the appropriate diagnosis and management of migraine which is an extremely common pain disorder.  In practice, ED and MAU departments inappropriately treat severe headaches with increasing doses of opiates (which makes them more nauseous) even while investigations, which may be appropriate, are ongoing. And fail to initiate prophylactic measures.  GPs are probably better at making the diagnosis but still miss some; they can initiate prophylactic medication but do not pursue treatment for long enough or at high enough doses. | While technically not part of NG127, the NICE headache guideline is referenced in it. And this is a really major cause of unnecessary neurology referrals. |
| **Coordination of services and models of care** | | | | | |
| 34 | British Association of Paediatric Neurologists | Children/young people with neurological conditions and comorbid mental health disorders should have access to appropriate mental health support | Mental health disorders are very common in children/young people with neurological disorders and may present to primary care. It is crucial that these children are referred on to appropriate mental health support | Mental health disorders are under recognised in children/young people with neurological disorders and a they cause major impact in life and child/young person and family |  |
| 35 | ME Association | Correcting misuse of terminology - "functional" and "medically unexplained" | The current, selective usage is reductive and a basis of inadequate and inappropriate clinical practice | If neurology is to play a constructive part in delivering effective integrated medical practice within a constricted NHS budget, it needs to jettison false dichotomies based on abuse of terminology and assumed, generalised diagnoses and treatments based on false syllogisms. | Standard English usage.  "Medical" means all of medicine and cannot be used to refer to any false divisions between partly substantiated and ill-substantiated diagnoses, and between physical, psychiatric, psychological or sociological characterisation. "Medically unexplained" cannot be partially applied in any medical specialism with the meaning that absence of evidence for any substantiable diagnosis for that speciality can then be assumed to indicate substantiability of another type of diagnosis. While there may be probable indication for other diagnoses in many cases, these remain within the normal range of medical practice for safe clinical and diagnostic assessment.  "Functional" refers to all functions as affected by and affecting any and all aspects of medicine. Partial interpretations of medical terminology, whether aimed at redressing residual bias against recognition of the range of mental health and social issues integral across illness presentations, or aimed at limiting informed consideration of possible illness functions outwith the formally established evidence base, simply cause confusion and promote poor, bad or mal-practice. |
| 36 | ME Association | Integrate neurology with other medical specialisms. Actively develop practice improvement through workshopping, and using existing sociological resources to support, monitor and disseminate specifics and common practice standards. | Neurology practice continues to exhibit poor coordination of case assessments with other specialist consultations, and poor, partial reporting of assessment to general practice. | Many cases amongst the larger neurological patient bodies can receive more effective support from other specialities, but require monitoring in neurology. It would normally be of benefit to patients, practitioners and the NHS budget for consultants to recognise the interaction of their inputs, the lead role in coordinating each patient's care, and the need to properly inform general practice, allowing them to target the delivery of ongoing treatment. | Patients who experience ineffective treatment and access their notes, continue to regularly report the limited and uncoordinated nature of consultants' reports. |
| 37 | ME Association | Recognise the current limits on paediatric services, their scope and efficacy, plus the continuing poor standard of transference to adult services. | Paediatric cases of enduring illness are currently ill-served in many areas, particularly if they have unusual presentations. Transfer to adult services for young adult patients can exacerbate problems with effectiveness of care. | Children and young people with enduring illness can have a better prognosis for recovery and improvement than adults, and better paediatric practice offers benefits for patients and society. Current limitations on knowledge for paediatric compared to adult services limits potential outcomes, so potentially loading costs of chronic illness. The understanding of life-long health awareness emphasises the need for best practice in the youngest patients. Adjustment to adult status can generate a number of issues for young patients, and poor transference to adult services can seriously exacerbate problems. | Parents and older children continue to report lack of effective practice across diagnosis and treatment for unclear presentations of illness. This is compounded by resulting lack of recognition of need for support in education and social participation, which can aggravate illness and chronicity. |
| 38 | ME Association | Recognise the lack of service provision for some of the most severely ill patients, and develop practice to overcome this shortcoming | Patients with the most need for effective treatment can be receiving the least service. | Severely ill patients who are unable to easily access outpatient services, or even manage to sustain engagement with telehealth home consultations, and who are unlikely to benefit from or justify in-patient care, can be regularly isolated from any effective treatment or monitoring. Although the socio-economic benefit of treatment may be unclear, the quality of life outcomes are normally clear, and the potential for future improvement or recovery is increased. Again, workshopping, development and dissemination of practice improvement should be pursued. | Severely ill patients who have been required to access outpatient services for an adequate level of assessment and treatment can suffer a relapse or worsening of symptoms as a result of the burden of travel involved, and are subsequently likely to be distanced from any further consideration of treatment adjustment or change which is deemed to require consultant input. With NHS resources effectively precluding allowance for patient recovery from the trauma of transporting, or allowance for required sensory isolation, remote and home delivery of effective practice can be both effective and efficient. |
| 39 | NHS England and Improvement – Office of the Chief Allied Health Professions Officer | NHSE/I Office of the Chief Allied Health Professions Officer have no specific comments but would expect to see the quality standard include measures around timeliness of referrals and possibly associated diagnostics, specifically cross sectional imaging to enable appropriate prioritisation an area that has increasing demands for such interventions for diagnosis. | | | |
| 40 | NHS England and Improvement - Clinical Programmes Team (submission by The Neurological Alliance) | Key area for quality improvement 2  **Fewer inappropriate referrals to secondary care** | Inappropriate referrals to secondary care drive up waiting times, and can result in those who do need to be seen having to wait longer to see a neurologist.  For patients, inappropriate referrals can result in disappointment.  Better management of patients in the community e.g. the provision of community migraine education clinics, can help meet the needs of some people with neurological conditions in a primary care setting, thereby reducing the number  who subsequently feel they still need to see a neurologist. | There is significant room for improvement in GP referrals to neurologists. Neurologists too often receive referrals with little or no information. Moreover, neurologists often have people referred to them who they deem inappropriate as they are not best placed to help them.  Advice and guidance can help improve referrals, and drive down inappropriate referrals. For example, The Walton Centre’s consultant advice line – for GPs to speak directly to neurologists to ask their advice – has resulted in a reduction in neurology outpatient appointments, as well as improved management of conditions; the top three reasons for calls were for headache (24%), sensory/ motor problems 20% and seizures (19%) | Please see our national neurology patient experience survey which collects data relating to how long respondents wait to see a neurologist, and those who did not need to see a neurologist, and can be broken down by primary condition. It can also be broken down to show regional variation. |
| 41 | NHS England and Improvement - Clinical Programmes Team (submission by The Neurological Alliance) | Key area for quality improvement 5  Establish best practice local pathways, including referral pathways into mental health services | The Guideline provides plenty of guidance on when patients should be referred on. In order for smooth referrals, local pathways into appropriate services should be established. There is a need for commissioners to review system capacity for accepting new referrals into local neurology services, and where appropriate, identify opportunities for new service models in primary care to speed up referrals to specialists e.g. utilising specialist nurses to triage referrals that may be able to reduce waiting times for first and follow up appointments, electronic referral systems, or an  advice line for GPs to get advice from a specialist.  There is a proliferation of guidance on best practice regarding neurology care pathways emerging, including the RightCare’s Progressive Neurological Conditions Toolkit (as well as epilepsy toolkit - about to be published, and forthcoming headache and migraine toolkit), as well as the work being undertaken in relation to NHSE’s spec comm neurosciences transformation project and accompany work by the National Neuro Advisory Group to establish best practice pathways across a number of conditions. As such there is a strong opportunity for improvements to be made. | As outlined above, too many people with neurological conditions have to wait too long to be seen by a neurologist. Moreover, too few people are having their mental wellbeing needs met. As the NHS RightCare Progressive Neurological Toolkit outlines, there are a number of national challenges relating to delays in primary and secondary care leading to delayed diagnosis and treatment, and fragmented or uncoordinated multidisciplinary working, as well as a significant opportunity for improvement. |  |
| 42 | Primary care and Community Neurology Society | Key area for quality improvement 1  **Existing services are developed to speed up the time to diagnosis to ensure that any suspected neurological condition is managed within a timely manner** | In order to limit the damage to the nervous system associated with any neurological condition, a diagnosis needs to be made in a timely manner. | By focusing on this, it will ensure appropriate management is commenced asap with the objective of minimising/repairing the damage and therefore the person with the neurological condition, has the potential to enjoy a much better quality of life. | Data from the [Neurological Alliance Patient Experience Survey](https://www.neural.org.uk/categories_rl/our-reports/) highlights the unsatisfactory situation concerning a timely diagnosis and the need to address this issue.  Although there is not current cure for many progressive neurological conditions, there are many published studies in for conditions such as Multiple Sclerosis and Parkinson’s Disease, providing evidence that early access to appropriate management will slow the progression of the condition. |
| 43 | Royal College of Nursing | Key area for quality improvement 1  **Timely Access to neurologists** | Access to neurologists in a timely manner for all those with suspected neurological conditions | Waits across the country are variable and do not support timely diagnosis | See National data on which supports this |
| 44 | Royal College of Nursing | Key area for quality improvement 2  **Timely Access to MRI and other diagnostics tests** | Access to MRI and other diagnostics again in a timely manner | Waits across the country are variable and do not support timely diagnosis | See National data which supports this |
| 45 | Royal College of Nursing | Key area for quality improvement 3  **Access to follow up appointments with neurologists** | Access to follow up appointments with neurologists vary significantly across the country | Waits across the country are variable and do not support timely diagnosis | See National data which supports this |
| 46 | Royal College of Occupational Therapists | Key area for quality improvement 1  Referral to a specialist neurologist | People with suspected neurological conditions should be referred by their GP/A & E to a general neurologist for assessment, who should then triage to a specialist neurologist at tertiary centres for further assessment and management as needed. | There are many neurological conditions which require specialist knowledge to manage. Pathways should be established between primary, secondary and tertiary care to support quick referral of people so they can access the correct management in a timely manner |  |
| 47 | Royal College of Occupational Therapists | Key area for quality improvement 3  Maintaining independence | People with suspected neurological conditions should be asked whether they are having difficulties managing their daily tasks including school/college and work and be referred to appropriate professionals to assess and support them in these activities. This might include occupational therapy, physiotherapy, speech and language therapy, psychology etc. This support should be provided in an integrated way through a multidisciplinary assessment. | Maintaining independence or engagement with daily tasks is important as people are learning to live with a neurological condition. Not doing this can have a negative impact on mood and quality of life. |  |
| 48 | Royal College of Occupational Therapists | Key area for quality improvement 4  Support across the lifespan | People with suspected neurological  conditions should have the ability to  access specialist support across the lifespan. | As conditions develop and change people require regular review by professionals with expertise in managing neurological conditions to ensure their care is optimised. |  |
| 49 | Royal College of Occupational Therapists | Key area for quality improvement 5  Management of FND | The assessment and treatment of functional neurological disorder (FND) should be covered in this quality standard. Many people with suspected neurological conditions will be diagnosed with this condition, but the current assessment and treatment pathway is very poor. | Many patients with FND are not diagnosed for many months and have experience of not being believed by health professionals which has a negative effect. Swifter assessment by people skilled in this area and referral onto appropriate integrated rehabilitation programmes is needed. |  |
| 50 | Royal College of Speech and Language Therapists | Key area for quality improvement 2  **Timely referral to speech and language therapy** | Many neurological disorders, including Huntington’s disease (Yoon et al., 2006), dementia (Szaloczki et al., 2015), Parkinson’s disease (Hlavnicka et al. 2017) and progressive supranuclear palsy (Boxer et al., 2017) have been linked to early presentations of speech, language, communication or swallowing disorders. Assessment of speech, language, communication or swallowing is therefore beneficial where neurological conditions are suspected.  Given this, people should have timely referral to specialist services including speech and language therapy to assess for and support people with swallowing challenges or changes to their speech, language and voice. | The RCSLT and research has found that access to specialist speech and language therapy can be restricted, despite the evidence that shows the improvement it makes to people’s speech, language and communication and swallowing function (e.g. Miller et al., 2011). Engagement with SLT services at the point of assessment and diagnosis would likely support continued access and thereby more positive outcomes. | [RCSLT Online Outcome Tool](https://www.rcslt.org/speech-and-language-therapy/guidance-for-delivering-slt-services/outcome-measurement/outcome-tool-overview) collates data relating to medical condition and Therapy Outcome Measures (TOMs) (Enderby and John, 2015) from speech and language therapy services UK wide. |
| 51 | SCM4 | Key area for quality improvement 1 | Variation in referral can be associated with variation in prevalence, under diagnosis, and potentially under treatment. | The new guideline in particularly aims to ensure appropriate use of neurology hospital resource; it may be useful to explore variation in referral rates by GPs for specific conditions e.g. epilepsy, MS, to focus awareness and learning. It may be that available resources e.g. neuro toolkit, are not necessarily being employed to encourage this | <https://fingertips.phe.org.uk/profile/atlas-of-variation>  <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf> |
| 52 | SCM4 | Key area for quality improvement 2 | Variation in demand and capacity at hospital level may affect referrals from the community. | Ensure appropriate referral could also help address variation in OPD wait times and demands upon neurological hospital resource.  Wait times are increasing, as such a quality measure to assure the system that resources are being employed optimally to maximise efficient e.g. using telephone triage or a telephone advice service | <https://fingertips.phe.org.uk/profile/atlas-of-variation> |
| 53 | SCM5 | Universal access to multi-disciplinary team | Provision of a range of tests and therapies, including genetic testing for inherited dystonias (DYT1, DYT6, DYT11) | Complex conditions requiring multi-disciplinary approach to diagnosis and treatment should involve staff experienced in movement disorders, including physio, OT, SLT, specialist nurse, psychologists, pain management team etc, and where appropriate genetic counselling. The provision of a personalised care plan should also be agreed. | As above **[NICE analyst comment: see comment 12]**  Neuro-Numbers report  Annex: Summary of recommended neurological outcome measures, p.13  <https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-numbers-2019.pdf> |
| 54 | SCM5 | Universal access to diagnostics. | Regional variations in provision of service | Limited availability of clinicians with expert knowledge of dystonia. Reducing the diagnosis time can make a huge, tangible difference for people affected, giving them access to the support that they need much sooner | As above  TDS Annual Report 2016: Delivering best practice – p.2  <http://apps.charitycommission.gov.uk/Accounts/Ends95/0001062595_AC_20160331_E_C.PDF> |
| 55 | SCM6 | Key area for quality improvement 2  **Fewer inappropriate referrals to secondary care** | Inappropriate referrals to secondary care drive up waiting times, and can result in those who do need to be seen having to wait longer to see a neurologist.  For patients, inappropriate referrals can result in disappointment.  Better management of patients in the community e.g. the provision of community migraine education clinics, can help meet the needs of some people with neurological conditions in a primary care setting, thereby reducing the number who subsequently feel they still need to see a neurologist. | There is significant room for improvement in GP referrals to neurologists. Neurologists too often receive referrals with little or no information. Moreover, neurologists often have people referred to them who they deem inappropriate as they are not best placed to help them.  Advice and guidance can help improve referrals, and drive down inappropriate referrals. For example, The Walton Centre’s consultant advice line – for GPs to speak directly to neurologists to ask their advice – has resulted in a reduction in neurology outpatient appointments, as well as improved management of conditions; the top three reasons for calls were for headache (24%), sensory/ motor problems 20% and seizures (19%) | Please see The Neurological Alliance’s national neurology patient experience survey which collects data relating to how long respondents wait to see a neurologist, and those who did not need to see a neurologist, and can be broken down by primary condition. It can also be broken down to show regional variation. |
| 56 | SCM6 | Key area for quality improvement 5  **Establish best practice local pathways, including referral pathways into mental health services** | The Guideline provides plenty of guidance on when patients should be referred on. In order for smooth referrals, local pathways into appropriate services should be established. There is a need for commissioners to review system capacity for accepting new referrals into local neurology services, and where appropriate, identify opportunities for new service models in primary care to speed up referrals to specialists e.g. utilising specialist nurses to triage referrals that may be able to reduce waiting times for first and follow up appointments, electronic referral systems, or an advice line for GPs to get advice from a specialist.  There is a proliferation of guidance on best practice regarding neurology care pathways emerging, including the RightCare’s [Progressive Neurological Conditions Toolkit](https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf) (as well as epilepsy toolkit - about to be published, and forthcoming headache and migraine toolkit), as well as the work being undertaken in relation to NHSE’s spec comm neurosciences transformation project and accompany work by the National Neuro Advisory Group to establish best practice pathways across a number of conditions. As such there is a strong opportunity for improvements to be made. | As outlined above, too many people with neurological conditions have to wait too long to be seen by a neurologist. Moreover, too few people are having their mental wellbeing needs met. As the NHS RightCare Progressive Neurological Toolkit outlines, there are a number of national challenges relating to delays in primary and secondary care leading to delayed diagnosis and treatment, and fragmented or uncoordinated multidisciplinary working, as well as a significant opportunity for improvement. |  |
| 57 | The Neurological Alliance | Key area for quality improvement 2  Fewer inappropriate referrals to secondary care | Inappropriate referrals to secondary care drive up waiting times, and can result in those who do need to be seen having to wait longer to see a neurologist.  For patients, inappropriate referrals can result in disappointment.  Better management of patients in the community e.g. the provision of community migraine education clinics, can help meet the needs of some people with neurological conditions in a primary care setting, thereby reducing the number who subsequently feel they still need to see a neurologist. | There is significant room for improvement in GP referrals to neurologists. Neurologists too often receive referrals with little or no information. Moreover, neurologists often have people referred to them who they deem inappropriate as they are not best placed to help them.  Advice and guidance can help improve referrals, and drive down inappropriate referrals. For example, The Walton Centre’s consultant advice line – for GPs to speak directly to neurologists to ask their advice – has resulted in a reduction in neurology  outpatient appointments, as well as improved management of conditions; the top three reasons for calls were for headache (24%), sensory/ motor problems 20% and seizures (19%) | Please see our national neurology patient experience survey which collects data relating to how long respondents wait to see a neurologist, and those who did not need to see a neurologist, and can be broken down by primary condition. It can also be broken down to show regional variation. |
| 58 | The Neurological Alliance | Key area for quality improvement 5  Establish best practice local pathways, including referral pathways into mental health services | The Guideline provides plenty of guidance on when patients should be referred on. In order for smooth referrals, local pathways into appropriate services should be established. There is a need for commissioners to review system capacity for accepting new referrals into local neurology services, and where appropriate, identify opportunities for new service models in primary care to speed up referrals to specialists e.g. utilising specialist nurses to triage referrals that may be able to reduce waiting times for first and follow up appointments, electronic referral systems, or an advice line for GPs to get advice from a specialist.  There is a proliferation of guidance on best practice regarding neurology care pathways emerging, including the RightCare’s [Progressive Neurological Conditions Toolkit](https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf) (as well as epilepsy toolkit - about to be published, and forthcoming headache and migraine toolkit), as well as the work being undertaken in relation to NHSE’s spec comm neurosciences transformation project and accompany work by the National Neuro Advisory Group to establish best practice pathways across a number of conditions. As such there is a strong opportunity for improvements to be made. | As outlined above, too many people with neurological conditions have to wait too long to be seen by a neurologist. Moreover, too few people are having their mental wellbeing needs met. As the NHS RightCare Progressive Neurological Toolkit outlines, there are a number of national challenges relating to delays in primary and secondary care leading to delayed diagnosis and treatment, and fragmented or uncoordinated multidisciplinary working, as well as a significant opportunity for improvement. |  |
| **Equalities Impact Assessment** | | | | | |
| 59 | Royal College of Speech and Language Therapists | The phrase in the Equality Impact Assessment “people with speech impediments” is outdated and offensive. We strongly recommend that this is changed to people with speech, language and communication needs. | | | |
| 60 | Royal College of Speech and Language Therapists | People with pre-existing speech, language and communication problems or presenting symptoms of communication problems may have difficulty describing the symptoms they are experiencing or responding to clinicians’ questions as part of the assessment process. Due to speech and language difficulties, people are at higher risk of not using or losing contact with services, misdiagnosis and mismanagement.  We recommended this this is made more explicit in the Equality Impact Assessment. | | | |
| **Information and signposting** | | | | | |
| 61 | NHS England and  Improvement - Clinical Programmes Team (submission by The Neurological Alliance) | Key area for quality improvement 3  **Better signposting to information and support for people with neurological symptoms at the pre-diagnosis/early diagnosis stage** | The Guideline states at 1.16.1 ‘Follow the principles in the NICE guideline on patient experience in adult NHS services relating to communication, information and shared decision making.’  This guideline is clear that clinicians should, where appropriate, discuss with patients their need for support, and that they should “Offer support and information to the patient and/or direct them to  sources of support and information. Review their circumstances and need for support regularly.” (1.1.7)  We hear from patients that they often stumble across sources of support later in their ‘patient journey’ and how much of a difference this would have made if they had discovered this information earlier, around the time of diagnosis. Often this is a time where people feel isolated and anxious, experiencing symptoms with knock-on impacts on their daily lives, and having to try and cope with this without any advice and support. Improved signposting would help alleviate this need for support, and improve their overall experience. | Our national neuro patient experience survey showed that after receiving a neurological diagnosis, there appears to be an issue with patients being told where they should look for further information about their condition by the professional who gave them their diagnosis, with over half of respondents (56%) not being told anything about finding further information. | Please see our national neurology patient experience survey which collects data relating to  • Whether people get written info at time of diagnosis  • Whether people understand their diagnosis  • Whether people feel fully involved in making choices about their health care (which can be segmented by when the respondent was first told they had a neurological condition to show those recently diagnosed/not yet diagnosed) |
| 62 | Progressive Supranuclear Palsy Association | **Key area for quality improvement 2** | Patients given information prior to being seen by onward referral – we hear that people who have PSP|CBD are left with no information about their suspected condition in the gap between referral and being seen. Individuals will seek their own details from Google etc., so instead we support the practice of directing patients to support information and helplines etc., at this stage, with the clear message that their diagnosis has not been confirmed and may change in the future. | We acknowledge the [guideline](https://www.nice.org.uk/guidance/ng127) comment that; ‘there would be difficulty developing a focused protocol due to a very broad population of this guideline population that covers a large number of neurological conditions.’  However there could be an inclusion that some direction is given for patients to improve their journey at this stage. | Condition specific charities such as PSPA are competent and capable of speaking to people suspected of having a diagnosis via their dedicated helpline and the introduction of this valuable means of support should not be delayed – even if the support needs to be redirected at a later stage. |
| 63 | Royal College of Speech and Language Therapists | Key area for quality improvement 4  **All information is clear, accessible and user-friendly** | Information needs to be clear, accessible and patient centred. Written information needs to be accompanied with pictures, be user-friendly, compassionate and simple.  Accessible information supports good care planning.  Shared decision making underpins this, where understanding is critical to processing information and making decisions about care and support. | This supports the national drive towards shared decision making.  Clear information will support people to make the best decisions about their care and treatment (NICE, 2019, Rightcare, 2019). | Please see the Communication Access UK (partnership) [www.rcslt.org](http://www.rcslt.org) |
| 64 | SCM4 | Key area for quality improvement 3 | Support for those whilst those awaiting a diagnosis. | Waiting for a potentially life changing diagnosis is incredibly stressful; as highlighted in the reports by neural.  In a similar cross cutting Quality standard addressing a broad clinical area e.g. cancer – a patient – centred quality standard was introduced; similarly, could be done for suspected neurological conditions. | <https://www.neural.org.uk/assets/pdfs/2017-07-parity-of-esteem.pdf>  NB point 4.2  <https://www.nice.org.uk/guidance/qs124/>  <https://www.nice.org.uk/guidance/ng12> |
| 65 | SCM6 | Key area for quality improvement 3  **Better signposting to information and support for people with neurological symptoms at the pre-diagnosis/early diagnosis stage** | The Guideline states at 1.16.1 ‘Follow the principles in the NICE guideline on [patient experience in adult NHS services](https://www.nice.org.uk/guidance/cg138) relating to communication, information and shared decision making.’  This guideline is clear that clinicians should, where appropriate, discuss with patients their need for support, and that they should “Offer support and information to the patient and/or direct them to sources of support and information. Review their circumstances and need for support regularly.” (1.1.7)  We hear from patients that they often stumble across sources of support later in their ‘patient journey’ and how much of a difference this would have made if they had discovered this information earlier, around the time of diagnosis. Often this is a time where people feel isolated and anxious, experiencing symptoms with knock-on impacts on their daily lives, and having to try and cope with this without any advice and support. Improved signposting would help alleviate this need for support, and improve their overall experience. | Our national neuro patient experience survey showed that after receiving a neurological diagnosis, there appears to be an issue with patients being told where they should look for further information about their condition by the professional who gave them their diagnosis, with over half of respondents (56%) not being told anything about finding further information. | Please see The Neurological Alliance’s national neurology patient experience survey which collects data relating to  • Whether people get written info at time of diagnosis  • Whether people understand their diagnosis  Whether people feel fully involved in making choices about their health care (which can be segmented by when the respondent was first told they had a neurological condition to show those recently diagnosed/not yet diagnosed) |
| 66 | The Neurological Alliance | Key area for quality improvement 3  Better signposting to information and support for people with neurological symptoms at the pre-diagnosis/early diagnosis stage | The Guideline states at 1.16.1 ‘Follow the principles in the NICE guideline on [patient experience in adult NHS services](https://www.nice.org.uk/guidance/cg138) relating to communication, information and shared decision making.’  This guideline is clear that clinicians should, where appropriate, discuss with patients their need for support, and that they should “Offer support and information to the patient and/or direct them to  sources of support and information. Review their circumstances and need for support regularly.” (1.1.7)  We hear from patients that they often stumble across sources of support later in their ‘patient journey’ and how much of a difference this would have made if they had discovered this information earlier, around the time of diagnosis. Often this is a time where people feel isolated and anxious, experiencing symptoms with knock-on impacts on their daily lives, and having to try and cope with this without any advice and support. Improved signposting would help alleviate this need for support, and improve their overall experience. | Our national neuro patient experience survey showed that after receiving a neurological diagnosis, there appears to be an issue with patients being told where they should look for further information about their condition by the professional who gave them their diagnosis, with over half of respondents (56%) not being told anything about finding further information. | Please see our national neurology patient experience survey which collects data relating to  • Whether people get written info at time of diagnosis  • Whether people understand their diagnosis  • Whether people feel fully involved in making choices about their health care (which can be segmented by when the respondent was first told they had a neurological condition to show those recently diagnosed/not yet diagnosed) |
| **Patient experience** | | | | | |
| 67 | NHS England and Improvement - Clinical Programmes Team (submission by The Neurological Alliance) | Key area for quality improvement 4  Patients with suspected neurological conditions are screened for mental health needs and referred/signposted on as appropriate | The Guideline states at 1.16.1 ‘Follow the principles in the NICE guideline on patient experience in adult NHS services relating to communication, information and shared decision making.’  That Guideline states “Patients have needs other than the treatment of their specific health conditions. There should be recognition of the potential need for psychological and emotional support”  There is a complex relationship between  mental health and neurological conditions such that some people with a neurological condition will experience corresponding mental health problems.  Often the point at which a person starts experiencing symptoms is a time where people feel isolated and anxious, experiencing symptoms with knock-on impacts on their daily lives, and having to try and cope with this without any advice and support. Improved screening would help pick up where additional mental health support is needed, and improve a person’s overall experience. | There is increasing recognition on a national level that the mental health needs of people with long term conditions are underserved. We found there is a significant level of unmet need through our Parity of Esteem report (which is quoted within the guidance associated within the Guideline), which was compounded by our recent national neuro patient experience survey which showed that overall well over half of respondents had not been asked about their mental health or emotional wellbeing, and  that almost a third of respondents were not referred for support with their mental health and wellbeing but would have liked to have been. For respondents not yet diagnosed, 66% had not been asked about their mental health and wellbeing by a health or social care professional, and 26% had not been referred or signposted to support for their mental wellbeing by a health professional, but would have liked this. | Please see our national neurology patient experience survey which collects data relating to whether people feel their mental health needs are being met. This can be segmented by time of diagnosis, to show those recently diagnosed, and those not yet diagnosed. |
| 68 | Primary care and Community Neurology Society | Key area for quality improvement 4  **Managing expectations where imaging and/or other investigations are requested prior to referral.** | Support and guidance need to be provided to encourage better practice concerning advising patients over the likelihood of incidental findings on brain imaging - patient referrals often stem from this type of situation;  Communication of any such investigations to the patient should really be handled by the referrer; on a related note, perhaps the quality standards should highlight that any such investigations (eg scan images from imaging done elsewhere, reports, etc) are made available to the neurologist when the patient is seen | If the neurologist does not have access to the results from the scan data etc organised by the referrer this is a frequent cause of frustration for all, as well as making the encounter less effective/productive for both patient and doctor. |  |
| 69 | Primary care and Community Neurology Society | Key area for quality improvement 5  **Patients with suspected neurological conditions are screened for mental health needs and referred/signposted on as appropriate** | There is good evidence that co-morbidity, and especially mental illness and a neurological condition, is a common occurrence.  People with neurological conditions are at a very significant risk of mental illness partly due complex relationship between mental health and neurological conditions and the underlying pathology of neurological condition.  Receiving the news of the diagnosis of a neurological condition or going through brain surgery before the diagnosis is given is traumatic. | Recognising this association would significantly improve the likelihood of patients receiving intervention and the support to prevent mental illness.  Addressing mental health concerns at this stage would also help to prevent mental illness in the person’s spouse/carer.  Mental health care at this stage would also accelerate the process of enabling the patient or the spouse/care to return to work. | The Neurological Alliance report, [Parity of Esteem report](https://www.neural.org.uk/resource_library/parity-of-esteem/), provide clear evidence that that the mental health needs of people with long term neurological conditions are underserved.  As stated previously in this document, the NHS Improvement website states:  “Lord Carter’s 2018 review of community and **mental health** services highlighted that despite the importance of these services in keeping people safe and well at home, services do not always support staff to care for patients in the best way.” Therefore, training will be an important priority. |
| 70 | Progressive Supranuclear Palsy Association | **Key area for quality improvement 4** | We would like to see a focus of quality on the psychological condition of the person at time they present to the GP.  We note that the Guideline Committee agrees that psychological support may be needed especially before there is certainty about the potential diagnosis; referral to Neuro/clinical psychology may be part of the protocol but also exploring other means of support (local groups etc.) will address the psychological support of both patient and care-giver. | Psychiatric symptoms, including anxiety and depression, are common in patients with neurological symptoms, and patients may benefit from psychological support before, during and after diagnosis. | Evidence for this is challenging - PSPA and the Scottish Chief Scientist Office are currently funding a three year research fellowship in Scotland, to drive forward earlier diagnosis and better care for people with PSP|CBD. Publication is expected in 2020 |
| 71 | Royal College of Occupational Therapists | Key area for quality improvement 2  Management of mental health | People with suspected neurological conditions should be asked about their mental health/any cognitive changes in this context and referred for psychological assessment/support as needed. The neuropsychological consequences of neurological conditions are identified and intervention provided as an equal focus with physical consequences | There are many ‘hidden symptoms’ of neurological conditions and poor management of this can have a negative impact on wider health/wellbeing and engagement in employment. |  |
| 72 | Royal College of Speech and Language Therapists | Key area for quality improvement 3  **End of life planning and mental capacity considerations for rapidly progressive conditions** | Whilst most neurological disorders deteriorate over time, some conditions such as MND progress very rapidly. In this case people with rapidly progressive conditions need the opportunity to discuss end of life decisions at key stages as their disease progresses.  Healthcare professionals need to take into account the person’s communication ability and mental capacity in decision making. |  | Please see the RCSLT mental capacity (amendment) bill briefings [www.rcslt.org](http://www.rcslt.org) |
| 73 | SCM4 | Key area for quality improvement 4 | Ensuring that people have a positive Experience of care | Patients and their carers often describe poor communication and sub-optimal coordination of care; not only is this unpleasant for patients, but also impedes efficient use of resources.  23% of respondents to neural’s survey were not explained their diagnosis, that  they understood, when they were first  told they had a neurological condition.  28% felt that information about  their treatment and condition are not effectively passed  between the different people who care for them. | <https://www.neural.org.uk/wp-content/uploads/2019/07/Download-key-findings.pdf>  <https://www.nice.org.uk/guidance/qs15/chapter/Quality-statement-3-Information-exchange> |
| 74 | SCM6 | Key area for quality improvement 4  **Patients with suspected neurological conditions are screened for mental health needs and referred/signposted on as appropriate** | The Guideline states at 1.16.1 ‘Follow the principles in the NICE guideline on [patient experience in adult NHS services](https://www.nice.org.uk/guidance/cg138) relating to communication, information and shared decision making.’  That Guideline states “Patients have needs other than the treatment of their specific health conditions. There should be recognition of the potential need for psychological and emotional support”  There is a complex relationship between mental health and neurological conditions such that some people with a neurological condition will experience corresponding mental health problems.  Often the point at which a person starts experiencing symptoms is a time where people feel isolated and anxious, experiencing symptoms with knock-on impacts on their daily lives, and having to try and cope with this without any advice and support. Improved screening would help pick up where additional mental health support is needed, and improve a person’s overall experience. | There is increasing recognition on a national level that the mental health needs of people with long term conditions are underserved. We found there is a significant level of unmet need through The Neurological Alliance’s [Parity of Esteem report](https://www.neural.org.uk/resource_library/parity-of-esteem/) (which is quoted within the guidance associated within the Guideline), which was compounded by recent national neuro patient experience survey which showed that overall well over half of respondents had not been asked about their mental health or emotional wellbeing, and that almost a third of respondents were not referred for support with their mental health and wellbeing but would have liked to have been. For respondents not yet diagnosed, 66% had not been asked about their mental health and wellbeing by a health or social care professional, and 26% had not been referred or signposted to support for their mental wellbeing by a health professional, but would have liked this. | Please see The Neurological Alliance’s national neurology patient experience survey which collects data relating to whether people feel their mental health needs are being met. This can be segmented by time of diagnosis, to show those recently diagnosed, and those not yet diagnosed. |
| 75 | The Neurological Alliance | Key area for quality improvement 4  Patients with suspected neurological conditions are screened for mental health needs and referred/signposted on as appropriate | The Guideline states at 1.16.1 ‘Follow the principles in the NICE guideline on [patient experience in adult NHS services](https://www.nice.org.uk/guidance/cg138) relating to communication, information and shared decision making.’  That Guideline states “Patients have needs other than the treatment of their specific health conditions. There should be recognition of the potential need for psychological and emotional support”  There is a complex relationship between  mental health and neurological conditions such that some people with a neurological condition will experience corresponding mental health problems.  Often the point at which a person starts experiencing symptoms is a time where people feel isolated and anxious, experiencing symptoms with knock-on impacts on their daily lives, and having to try and cope with this without any advice and support. Improved screening would help pick up where additional mental health support is needed, and improve a person’s overall experience. | There is increasing recognition on a national level that the mental health needs of people with long term conditions are underserved. We found there is a significant level of unmet need through our [Parity of Esteem report](https://www.neural.org.uk/resource_library/parity-of-esteem/) (which is quoted within the guidance associated within the Guideline), which was compounded by our recent national neuro patient experience survey which showed that overall well over half of respondents had not been asked about their mental health or emotional wellbeing, and  that almost a third of respondents were not referred for support with their mental health and wellbeing but would have liked to have been. For respondents not yet diagnosed, 66% had not been asked about their mental health and wellbeing by a health or social care professional, and 26% had not been referred or signposted to support for their mental wellbeing by a health professional, but would have liked this. | Please see our national neurology patient experience survey which collects data relating to whether people feel their mental health needs are being met. This can be segmented by time of diagnosis, to show those recently diagnosed, and those not yet diagnosed. |
| **Recognition and management of non-epileptic attack** | | | | | |
| 76 | SCM3 | Additional developmental areas of emergent practice | Non-epileptic attack disorder is another FND which, with appropriate support and education, could be better managed by primary care, ED and MAU. | Many GPs already have a sixth sense when a seizure presentation is non-organic. Giving GPs the right information would help triage referrals that may not need an out of hours ED referral but instead a neurology OPD, discussion with epilepsy nurse specialist, or possibly no referral at all. | Link to NG127 is more tenuous than headache; and yet it is almost as important. |
| **Recognition of rare and early-onset neurological conditions** | | | | | |
| 77 | Multiple System Atrophy Trust | Key area for quality improvement 1  Earlier accurate diagnosis of Multiple System Atrophy (MSA) and other rare neurological conditions. This includes ensuring accurate ICD coding is made on records. | People are living with a condition that has been labelled something that it actually isn’t. This can mean inappropriate treatment and for rapidly progressing conditions like MSA can mean that they are unprepared and unaware of the ways to effectively prepare for, and manage, the deterioration. | The quicker the more accurate diagnosis the better prepared people are and the more effective the management of the condition will be. See NHS England Rightcare Progressive Neurological Toolkit. | The majority of people with MSA are initially diagnosed with something else such as Parkinson’s, Ataxia or through identification of problems with their autonomic bodily functions, such as urinary problems. (MSA Trust Needs Survey 2019 currently unpublished and all other evidence from this unless stated).In our survey of 284 people living with MSA 64% of respondents said that they had lived with problems with their autonomic system for at least a year before diagnosis with 70% experiencing difficulties with moving for at least a year before diagnosis. In the Neuro Patience research nearly half of respondents with MSA reported that they that they had seen their GP at least 3 times before referral to a Neurologist.  We have a very simple resource for GP’s and other Health and Care Professionals called “Red Flags for Multiple System Atrophy” which identifies things that would lead to effective referral to Neurologists. We are not sure how the IT knowledge system for GP’s works but if this resource and others like it could be integrated in to aid GP diagnosis this would help.  Similarly, if GP’s were unsure as to what they were dealing with, an ability to have an initial exploratory phone call with a Neurologist would help to ensure quicker, more accurate and targeted referrals.  Depression, anxiety and urinary problems are all associated with MSA so it is also important that these issues are not treated in isolation but seen as interconnected.  Without effective data input with ICD codes it is difficult to monitor delays in diagnosis and to track usage of services throughout the NHS and thus difficult to ensure constant improvement. |
| 78 | Progressive Supranuclear Palsy Association | **Quality improvement area 1** | PSPA would like to see emphasis in the Quality Standard on consideration of rarer neurological conditions not just those for which guidelines are already in production.  For example - PSP and Corticobasal degeneration (CBD) have a series of red flags which act as warning signs that should raise clinical suspicion of PSP or CBD  If rarer conditions are suspected, the GP should include the wording of ‘possible PSP|CBD (other rare disease)’ in the referral letter. | A report from the Neurological Alliance in 2014 found that over 40% of people with a neurological condition had to see their primary care physician 5 or more times before being referred to a specialist. By 2016 this has worsened to 42%,  We acknowledge the guideline comment that ‘It is impractical for a generalist to keep abreast of the range of neurological treatments available and sometimes to appreciate the significance of neurological symptoms.’ However, the UK Strategy for Rare Diseases (Department of Health) highlights issues with delays to diagnosis and aims to improve the overall patient journey from first contact with the NHS. Department of Health. | The Neurological Alliance. The invisible patients: revealing the state of neurology services. London. The Neurological Alliance, 2015. Available from: <http://www.neural.org.uk/store/assets/files/495/original/Invisible_patients_-_revealing_the_state_of_neurology_services_final_14_January_2015_.pdf>  The UK strategy for rare diseases. London. Department of Health, 2013. Available from: <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/260562/UK_Strategy_for_Rare_Diseases.pdf> |
| 79 | SCM4 | Key area for quality improvement 5 | Need to be mindful that the guideline does not lose those who are rare by focusing on the majority; e.g. early onset conditions within subset of dementia, Parkinson’s**.** |  | Rare disease strategy 2019  <https://www.neural.org.uk/wp-content/uploads/2019/07/neuro-numbers-2019.pdf> |
| **Source recommendations** | | | | | |
| 80 | NHS England and Improvement - Clinical Programmes Team (submission by The Neurological Alliance) | In submitting these proposals, we are aware that the Guideline, (which will be the primary source of information for developing the Quality Standard), does not have consensus across the neurological community. Concerns of the community range from the Guideline being too complex for a primary care audience, majoring in on some conditions and excluding others (with little evidence to back up why), and a lack of reference to signposting to other sources of support including mental health.  We are concerned that maintaining broadly the same committee to develop the Quality Standard will not help resolve the lack of consensus in the neurological community. We would urge NICE to consider broadening the membership of the committee to attempt to build greater consensus on what constitutes quality in relation to this area of care. | | | |
| 81 | Royal College of Paediatrics and Child Health | Key area for quality improvement 1 | 1.17.1 & 2 It is worth clarifying if these symptoms are personally complained of or were observed by others. The latter could be subjective while the former are more reliable. | The importance of this is related to establishing a firm diagnosis. |  |
| 82 | Royal College of Paediatrics and Child Health | Key area for quality improvement 2 | 1.17.3 & 4 In this area, please mention the ‘social impact’ as well. | This is relevant to establishing a functional impact. |  |
| 83 | Royal College of Paediatrics and Child Health | Key area for quality improvement 4 | 1.21.4 four limb blood pressure compare femoral with brachial pulses.  3rd bullet point: it should be the reverse of what is in the guidelines, please check this point. | To confirm coarctation of the aorta. |  |
| 84 | SCM6 | In submitting these proposals, we are aware that the Guideline, (which will be the primary source of information for developing the Quality Standard), does not have consensus across the neurological community. Concerns of the community range from the Guideline being too complex for a primary care audience, majoring in on some conditions and excluding others (with little evidence to back up why), and a lack of reference to signposting to other sources of support including mental health.  We are concerned that maintaining broadly the same committee to develop the Quality Standard will not help resolve the lack of consensus in the neurological community. We would urge NICE to consider broadening the membership of the committee to attempt to build greater consensus on what constitutes quality in relation to this area of care. | | | |
| 85 | The Neurological Alliance | In submitting these proposals, we are aware that the Guideline, (which will be the primary source of information for developing the Quality Standard), does not have consensus across the neurological community. Concerns of the community range from the Guideline being too complex for a primary care audience, majoring in on some conditions and excluding others (with little evidence to back up why), and a lack of reference to signposting to other sources of support including mental health.  We are concerned that maintaining broadly the same committee to develop the Quality Standard will not help resolve the lack of consensus in the neurological community. We would urge NICE to consider broadening the membership of the committee to attempt to build greater consensus on what constitutes quality in relation to this area of care. | | | |
| **Training and development** | | | | | |
| 86 | Primary care and Community Neurology Society | Key area for quality improvement 3  **Education is improved amongst non-neuro specialists, both medical and nursing** | Access to community services so patients can be managed closer to home, requires the health professionals in the community to be appropriately trained in managing and caring for people with neurological conditions. | The NHS Elective Care Transformation Programme is focussed on keeping people out of hospitals or returning people to the community as soon as possible after a hospital stay. NHS Improvement states on their website:  “Improving how we deliver community-based services is essential to achieve the ambitions of the NHS Long Term Plan, in particular for improving response times, quality of care and the productivity of the workforce.” | The NHS Improvement website states:  “Lord Carter’s 2018 review of community and mental health services highlighted that despite the importance of these services in keeping people safe and well at home, services do not always support staff to care for patients in the best way.” Therefore, training will be an important priority. |
| 87 | Royal College of Speech and Language Therapists | Key area for quality improvement 1  **Timely identification and support at diagnosis** | People require information about their diagnosis and management of their condition from an expert with up-to-date training, skills and knowledge in that condition.  The professional must possess competent communication skills and the ability to engage with the person who may have the start of communication challenges themselves. | Evidence shows that people with neurological conditions are experiencing delays in diagnosis (NHS England data, 2019).  People want to be seen by competent trained experts with the knowledge to have these sensitive conversations. |  |
| **No comment** | | | | | |
| 88 | Royal College of General Practitioners | No comments at this time | | | |
| 89 | Royal College of Physicians | No comments at this time | | | |

# Appendix 3: Suggestions from stakeholder engagement exercise – non-registered stakeholders and individual respondents

| ID | Non-registered stakeholder / individual | Suggested key area for quality improvement | Why is this important? | Why is this a key area for quality improvement? | Supporting information |
| --- | --- | --- | --- | --- | --- |
| 001 | Individual 1 | Communicating associated risks (including SUDEP) of epilepsy during diagnostic period | Current NICE guidelines mean that significant epilepsy risks such as SUDEP are communicated only after a formal diagnosis of epilepsy is made. This limits patient safety and awareness favouring ‘not distressing’ families when the bereaved epilepsy community campaign and raise awareness for professionals to share risks as easy as epilepsy is suspected rather than holding back until after formal diagnosis is made. Our son died whilst awaiting genetic testing for SNC1A gene mutation and his posthumous diagnosis of Dravet Syndrome meant his very substantial risk of SUDEP was not communicated to us. | The risk of SUDEP is present without a formal diagnosis and better informing patients/ parents and carers that this significant risk to life for people with epilepsy can help prevent future deaths. With lived experience of child bereavement due to SUDEP better communication of risk is necessary for families to be aware of modifiable risks that can make all the difference. Please see SUDEP Action (listed as a stakeholder) for research and resources and recommendations. |  |
| 002 | Individual 1 | That differential diagnoses that include forms of epilepsy be included in care plans before formal diagnosis has been made. | Without the inclusion of differential diagnosis in patients care plans during diagnostic periods patient care can stagnate and key associated risks be disregarded. Our son’s care had multiple missed opportunities to reach a clinical diagnosis of Dravet Syndrome because this potential diagnosis was not included in his notes or care plan. | Missed opportunities to ensure patients are offered appropriate treatment to control and manage seizures (and potentially prevent SUDEP) in epilepsy patients may be avoided if full communication of potential diagnosis is open and inclusive. The ‘formal diagnosis’ for epilepsy guideline can cripple real-time patient care and for our family can feed back in more detail how this impacted our son’s healthcare in the weeks prior to his SUDEP related death. |  |
| 003 | Individual 1 | Dravet Syndrome be flagged as possible to clinically diagnose based on presentation of symptoms not just a proved genetic mutation | Reliance on genetic testing for SCN1A gene mutation as preferred diagnosis method may delay appropriate treatment and communicating associated risks to families. | Dravet Syndrome UK should be consulted for best practise in diagnosis, treatment and management of Dravet Syndrome which includes research and evidence of why early, accurate diagnosis is so important for Dravet Syndrome patients. This includes clinically diagnoseable symptoms and treatment pathways. The Dravet Syndrome bi-annual conference takes place in London on 15/16 November and the work that their experts offer should have the opportunity to be flagged as part of this consultation. |  |

1. Unless stated otherwise, information in sections 2.3 and 2.4 is taken from the NICE guideline on [suspected neurological conditions](https://www.nice.org.uk/guidance/ng127), full guideline. [↑](#footnote-ref-1)
2. The Neurological Alliance (2019) [Neuro Numbers 2019](https://www.neural.org.uk/resource_library/neuro-numbers-2019/) [↑](#footnote-ref-2)
3. Public Health England (2018) [Deaths Associated with Neurological Conditions in England 2001-2014: data briefing](https://www.gov.uk/government/publications/deaths-associated-with-neurological-conditions). Public Health England. [↑](#footnote-ref-3)
4. NHS England [Neurological conditions](https://www.england.nhs.uk/ourwork/clinical-policy/ltc/our-work-on-long-term-conditions/neurological/) [↑](#footnote-ref-4)
5. The Neurological Alliance (2019) [Neuro Patience: The National Neurology Patient Experience Survey 2018/19: Policy report](https://www.neural.org.uk/resource_library/neuro-patience/) [↑](#footnote-ref-5)
6. Fuller, G et al (2019) [Neurology Methodology and Initial Summary of Regional Data report](https://gettingitrightfirsttime.co.uk/medical-specialties/neurology/) [↑](#footnote-ref-6)
7. Male AJ et al (2019) A survey of current management of Benign Paroxysmal Positional Vertigo (BPPV) by physiotherapists’ interested in vestibular rehabilitation in the UK Physiotherapy 105: 307-14 [↑](#footnote-ref-7)
8. Ozawa, M et al (2018) [Symptoms in primary care with time to diagnosis of brain tumours](https://doi.org/10.1093/fampra/cmx139) Family Practice 35 (5): 551–558 [↑](#footnote-ref-8)
9. A complete list of focal neurology symptoms, which also include hemiparesis, weakness and numbness is available in the supplementary table that accompanies the article. This is [available via the journal website - supplementary table 1](https://academic.oup.com/fampra/article/35/5/551/4840710). [↑](#footnote-ref-9)
10. NHS England and Picker (2018) [National Cancer Patient Experience Survey – national results](https://www.ncpes.co.uk/reports) [↑](#footnote-ref-10)
11. The Neurological Alliance (2019) [Neuro Patience: The National Neurology Patient Experience Survey 2018/19: Policy report](https://www.neural.org.uk/resource_library/neuro-patience/) and [Neuro Patience: The National Neurology Patient Experience Survey 2018/19: Technical report (Annexe A)](https://www.neural.org.uk/resource_library/neuro-patience/) [↑](#footnote-ref-11)
12. Action for ME (2014) [Time to deliver: Initial findings of Action for M.E.’s 2014 survey](https://www.actionforme.org.uk/make-a-difference/resources/our-publications/) [↑](#footnote-ref-12)
13. Action for ME (2017) [Spotlight on specialist services: UK healthcare for people with M.E](https://www.actionforme.org.uk/make-a-difference/resources/our-publications/). [↑](#footnote-ref-13)
14. Chu TPC et al (2015[) Pattern of symptoms and signs of primary intracranial tumours in children and young adults: a record linkage study](http://dx.doi.org/10.1136/archdischild-2014-307578) Archives of Disease in Childhood 100: 1115-1122 [↑](#footnote-ref-14)
15. Shanmugavadivel D et al (2016) HeadSmart: are you brain tumour aware? Paediatrics and Child Health 26 (2): 81-86 [↑](#footnote-ref-15)
16. DVLA (2016, last updated September 2019) [Assessing fitness to drive: a guide for medical professionals](https://www.gov.uk/government/publications/assessing-fitness-to-drive-a-guide-for-medical-professionals) provides information regarding the responsibilities of healthcare practitioners – see ‘General information’ section for details. [↑](#footnote-ref-16)
17. In 2013, information for medical professionals was: <http://www.gov.uk/government/publications/at-a-glance>. [↑](#footnote-ref-17)
18. Bonnie Ng Ka Y et al (2016) [Knowledge of Driving Vehicle Licensing Agency guidelines](https://journals.sagepub.com/doi/full/10.1177/2054270415601586)

    [among NHS doctors: a multicentre observational study](https://journals.sagepub.com/doi/full/10.1177/2054270415601586) Journal of the Royal Society of Medicine Open 6 (10): 1-8 [↑](#footnote-ref-18)
19. [↑](#footnote-ref-19)