



# Suspected neurological conditions: recognition and referral

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This standard is based on NG127.

This standard should be read in conjunction with QS15.

# Quality statements

<u>Statement 1</u>Children under 12 years with headache and 'red flag' symptoms are referred immediately for neurological assessment.

<u>Statement 2</u>Children under 4 years with suspected abnormal head size or shape have their head circumference assessed using a standardised growth chart.

Statement 3Adults with suspected dystonia are referred for neurological assessment.

<u>Statement 4</u>Adults with transient rotational vertigo on head movement are assessed using the Hallpike manoeuvre.

<u>Statement 5</u>Adults diagnosed with a functional neurological disorder are supported to manage symptoms that are a part of the disorder in non-specialist care.

<u>Statement 6</u>Adults with suspected neurological conditions using NHS services experience care and treatment that is tailored to their needs and preferences.

NICE has developed guidance and a quality standard on people's experiences using adult NHS services (see the <a href="NICE Pathway on patient experience in adult NHS">NICE Pathway on patient experience in adult NHS</a> <a href="services">services</a>).

Statements 1, 3 and 6 in the <u>NICE quality standard on patient experience in adult NHS services</u> are particularly relevant in the context of supporting adults with suspected neurological conditions.

A full list of NICE quality standards is available from the NICE quality standards topic library.

# Quality statement 1: Headaches and 'red flag' symptoms in children

# Quality statement

Children under 12 years with headache and 'red flag' symptoms are referred immediately for neurological assessment.

#### Rationale

Children aged under 12 years who present with headache may also have one or more 'red flag' symptoms. These children need to be seen by a specialist service within a few hours, or even more quickly if necessary, to diagnose or rule out significant intracranial pathology such as a brain tumour. Immediate referral and assessment will allow the appropriate treatment, including medical or surgical management, to be initiated to minimise morbidity and mortality.

### Quality measures

#### Structure

a) Evidence of written clinical protocols to ensure that 'red flag' symptoms are recognised in children under 12 years presenting with headache.

Data source: Local data collection, for example checklists of symptoms.

b) Evidence of written clinical protocols to ensure that children under 12 years with headache and one or more 'red flag' symptoms are referred for neurological assessment immediately.

Data source: Local data collection, for example referral pathways.

#### **Process**

Proportion of children under 12 years with headache and one or more 'red flag' symptoms who are referred for same-day neurological assessment.

Numerator – The number in the denominator who are referred for same-day neurological assessment.

Denominator – The number of children under 12 years with headache and one or more 'red flag' symptoms.

Data source: Local data collection, for example local audit of patient records.

#### Outcome

Mortality rates from intracranial pathology in children under 12 years.

Data source: Local data collection, for example local audit of patient records.

# What the quality statement means for different audiences

**Service providers** (such as primary care services, secondary care services and neurology departments) work together to ensure that systems are in place for immediate referral to neurological services if a child under 12 years presents with headache and one or more 'red flag' symptoms. They ensure that healthcare professionals are able to recognise the 'red flag' symptoms.

**Healthcare professionals** (such as GPs, neurology specialists and nurses) are aware of local referral pathways for children under 12 years who present with headache and one or more 'red flag' symptoms. They are aware of the 'red flag' symptoms and the requirement for immediate referral to neurological services for assessment.

**Commissioners** (such as clinical commissioning groups and NHS England) ensure that they commission services for children under 12 years who present with headache and one or more 'red flag' symptoms to be referred immediately for neurological assessment. They ensure that local pathways for immediate referral are in place.

Children aged under 12 who develop headache together with certain other symptoms see a specialist within a few hours, or more quickly if necessary, to check for serious illness.

### Source guidance

<u>Suspected neurological conditions: recognition and referral. NICE guideline NG127</u> (2019), recommendation 1.21.1

### Definitions of terms used in this quality statement

#### 'Red flag' symptoms

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 (disorders that affect co-ordination, balance and speech)
- 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').

[NICE's guideline on suspected neurological conditions: recognition and referral, recommendation 1.21.1]

#### Refer immediately

To be seen by the specialist service within a few hours, or even more quickly if necessary. [NICE's guideline on suspected neurological conditions: recognition and referral, terms used in this guideline]

# Quality statement 2: Head size and shape in children

# Quality statement

Children under 4 years with suspected abnormal head size or shape have their head circumference assessed using a standardised growth chart.

#### Rationale

In children aged under 4 years abnormalities of head shape or size are likely to indicate brain growth disorders or raised intracranial pressure. Measurement of head circumference is an important but simple method of identifying children with abnormalities of head shape or size who should be referred for specialist investigation. Using standardised methods of measurement, including plotting measurements on a standardised growth chart, ensures accuracy and consistency when making referral decisions.

# Quality measures

#### Structure

a) Local arrangements and written protocols to ensure that children aged under 4 years with suspected abnormal head shape or size have their head circumference assessed using a standardised growth chart.

Data source: Local data collection, for example local protocols.

b) Local arrangements and written protocols to ensure that healthcare professionals have access to the necessary training needed to assess head shape and size in children aged under 4 years.

Data source: Local data collection, for example staff training records.

#### **Process**

Proportion of children aged under 4 years with suspected abnormal head shape or size who have the longest of 3 head measurements plotted on a standardised growth chart, corrected for gestational age.

Numerator – The number in the denominator who have the longest of 3 head measurements plotted on a standardised growth chart, corrected for gestational age.

Denominator – Children aged under 4 years with suspected abnormal head shape or size.

Data source: Local data collection, for example NHS personal child health records (red books).

#### Outcome

Referrals for specialist neurological assessment in children aged under 4 years with suspected abnormal head shape or size, who have the longest of 3 head measurements plotted on a standardised growth chart, corrected for gestational age.

Data source: Local data collection, for example local audit of patient records.

# What the quality statement means for different audiences

**Service providers** (such as primary care services and community services) ensure that systems are in place for children aged under 4 years with suspected abnormal head shape or size to be assessed at GP appointments and routine health visits using a standardised growth chart corrected for their gestational age. They ensure that systems are in place for referral for specialist assessment when needed.

Healthcare professionals (such as GPs, nurses and health visitors) use a disposable, single-use, paper tape measure to take 3 consecutive measurements of head circumference at the same appointment for children aged under 4 years with suspected abnormal head shape or size. They plot the longest of the measurements on a standardised growth chart, corrected for gestational age, and refer for specialist assessment when needed.

**Commissioners** (such as clinical commissioning groups and NHS England) ensure that they commission services in which children aged under 4 years with suspected abnormal head shape or size are assessed, using a standardised growth chart corrected for their gestational age, at GP appointments and routine health visits.

Children aged under 4 years with an unusual head shape or size have their heads measured by a healthcare professional using a disposable, single-use paper tape measure. The measurement is done 3 times at the same appointment and the largest of the 3 measurements is checked against child growth charts. If the healthcare professional is concerned about the measurement, they refer the child to a specialist.

### Source guidance

<u>Suspected neurological conditions: recognition and referral. NICE guideline NG127</u> (2019), recommendation 1.22.2

### Definitions of terms used in this quality statement

#### Standardised growth chart

A chart allowing healthcare professionals to plot head circumference in children under 4 years, based on WHO child growth standards. [Royal College of Paediatrics and Child Health UK-WHO growth charts - 0-4 years]

#### Standardised methods of measurement

Three consecutive measurements of the child's head circumference at the same appointment, using a disposable, single-use paper tape measure, the longest of which is plotted on a standardised growth chart, corrected for gestational age. [NICE's guideline on suspected neurological conditions: recognition and referral]

# Quality statement 3: Suspected dystonia in adults

# Quality statement

Adults with suspected dystonia are referred for neurological assessment.

#### Rationale

Dystonia can be caused by an underlying neurological condition or by medication. It can present in a variety of ways and can be misinterpreted, for example as an orthopaedic problem or psychological condition. It should be diagnosed on the basis of clinical features. Neurological assessment is needed to confirm the diagnosis and identify the cause so that the correct treatment and management can be offered.

### Quality measures

#### Structure

Evidence of written clinical protocols to ensure that adults presenting with symptoms of dystonia are referred for neurological assessment.

**Data source:** Local data collection, for example clinical pathways.

#### **Process**

Proportion of adults with suspected dystonia who are referred for neurological assessment.

Numerator – The number in the denominator who are referred for neurological assessment.

Denominator – The number of adults with suspected dystonia.

Data source: Local data collection, for example local audit of patient records.

#### Outcome

Diagnosis rates for dystonia in adults.

Data source: Local data collection, for example local audit of patient records.

# What the quality statement means for different audiences

**Service providers** (such as primary care services, secondary care services and neurology departments) ensure that systems are in place for adults presenting with symptoms that suggest dystonia to be referred for neurological assessment. They ensure that staff are aware of the presentation of dystonia and that it can be misinterpreted, for example as an orthopaedic problem or psychological condition.

Healthcare professionals (such as GPs, specialists and nurses) are aware of local referral pathways for neurological assessment to diagnose suspected dystonia in adults. They are also aware of the presentation of dystonia and that it can be misinterpreted, for example as an orthopaedic problem or psychological condition.

**Commissioners** (such as clinical commissioning groups and NHS England) ensure that they commission services in which adults presenting with symptoms that suggest dystonia are referred for neurological assessment.

Adults with symptoms of dystonia (such as uncontrolled and sometimes painful muscle movements or spasms) are seen by a specialist. The specialist can confirm whether they have dystonia, and if so, what is causing it and how best to treat it.

# Source guidance

<u>Suspected neurological conditions: recognition and referral. NICE guideline NG127</u> (2019), recommendation 1.9.4

### Definitions of terms used in this quality statement

#### Suspected dystonia

Involuntary muscle contractions possibly resulting in a change in posture or distortion of a limb. It may be task-specific and only become apparent when a specific activity is undertaken, for example writer's cramp. It may be characterised by involuntary contractions of the eyes, tongue, face, neck, trunk, limbs, or larynx, which can be sustained or fluctuating (spasmodic). Other examples include tongue twisting or protrusion and in-turning of the ankle.

Cervical dystonia is the most common type of dystonia and is characterised by a tendency of the neck to twist, flex, extend or be pulled laterally. Head tremor is a common feature of cervical dystonia; however, cervical dystonia can present without tremor. [NICE's full guideline on suspected neurological conditions: recognition and referral]

# Quality statement 4: Hallpike manoeuvre for adults

# Quality statement

Adults with transient rotational vertigo on head movement are assessed using the Hallpike manoeuvre.

#### Rationale

The Hallpike manoeuvre can be used to check for benign paroxysmal positional vertigo (BPPV) in adults with vertigo on head movement. If BPPV is confirmed, treatment to relieve it using a canalith repositioning manoeuvre can be given. Use of the Hallpike manoeuvre can reduce unnecessary referrals for specialist assessment.

### Quality measures

#### Structure

Evidence of written clinical protocols to ensure that adults presenting with symptoms of transient rotational vertigo on head movement are assessed for BPPV using the Hallpike manoeuvre.

Data source: Local data collection, for example clinical pathways.

#### **Process**

Proportion of adults presenting with transient rotational vertigo on head movement who are assessed using the Hallpike manoeuvre.

Numerator – The number in the denominator who are assessed using the Hallpike manoeuvre.

Denominator – The number of adults presenting with transient rotational vertigo on head movement.

Data source: Local data collection, for example local audit of patient records.

#### Outcome

a) Proportion of adults presenting with transient rotational vertigo on head movement referred to ear, nose and throat services who were assessed using the Hallpike manoeuvre.

Numerator – The number in the denominator who were assessed using the Hallpike manoeuvre.

Denominator – The number of adults presenting with transient rotational vertigo on head movement who are referred to ear, nose and throat services.

**Data source:** Local data collection, for example local audit of patient records.

b) Patient satisfaction with investigation of transient rotational vertigo on head movement.

**Data source:** Local data collection, for example patient satisfaction surveys.

# What the quality statement means for different audiences

**Service providers** (such as primary care services, secondary care services, physiotherapy services and neurology departments) ensure that systems are in place for adults with transient rotational vertigo on head movement to have the Hallpike manoeuvre performed by a healthcare professional trained in its use, to assess for BPPV. If there is not a trained healthcare professional available locally within primary care, then systems should be in place to refer adults for the Hallpike manoeuvre in accordance with local pathways.

Healthcare professionals (such as GPs, neurology specialists, nurses and physiotherapists) know when to use the Hallpike manoeuvre to assess for BPPV in adults with transient rotational vertigo on head movement. They are aware of staff in their healthcare setting who are trained in use of the Hallpike manoeuvre and local pathways for

referral if there are no trained staff available.

Commissioners (such as clinical commissioning groups and NHS England) ensure that they commission services in which adults with transient rotational vertigo on head movement have the Hallpike manoeuvre performed to assess for BPPV. They agree local pathways for referral between service providers where services do not have access to a healthcare professional trained in performing the manoeuvre.

Adults who experience vertigo (the feeling that they or everything around them is spinning) when they move their head have a test done to check whether this is being caused by a condition called benign paroxysmal positional vertigo (BPPV). In the test they are asked to move their head in certain ways. If BPPV is diagnosed it can be treated to relieve the vertigo.

# Source guidance

<u>Suspected neurological conditions: recognition and referral. NICE guideline NG127</u> (2019), recommendation 1.2.6

# Quality statement 5: Functional neurological disorders in adults

# Quality statement

Adults diagnosed with a functional neurological disorder are supported to manage symptoms that are a part of the disorder in non-specialist care.

#### Rationale

Adults with symptoms that occur as part of a functional neurological disorder can benefit from support and management in non-specialist care. These symptoms may include fatigue, difficulties with concentration, difficulties with movement, recurrent dizziness, recurrent limb or facial weakness, memory problems, and numbness and tingling. Non-specialist care can provide accessible reassurance and information on the nature of the symptoms and their fluctuation over time, advice on how to manage them, offers of psychological support when appropriate, and signposting to other sources of support. If new symptoms are identified, the person should be referred promptly for neurological assessment.

# Quality measures

#### Structure

Evidence of written clinical protocols to ensure that adults with a functional neurological disorder have symptoms that are a part of their condition recognised and are supported to manage them in non-specialist care.

Data source: Local data collection, for example local audit of patient records.

#### Outcome

The proportion of adults diagnosed with a functional neurological disorder satisfied with

symptom management support from non-specialist care.

Numerator – The number in the denominator who are satisfied with symptom management support from non-specialist care.

Denominator – The number of adults diagnosed with a functional neurological disorder.

Data source: Local data collection, for example patient surveys.

# What the quality statement means for different audiences

**Service providers** (such as primary care services, secondary care services and neurology departments) ensure that adults with a functional neurological disorder are supported to manage their symptoms in non-specialist care, or are referred for neurological assessment if they present with new signs or symptoms.

Healthcare professionals (such as GPs, neurology specialists and nurses) are aware that adults with a functional neurological disorder can be supported to manage their symptoms in non-specialist care, with referral for neurological assessment if they present with new signs or symptoms. They are aware that people who experience dizziness, recurrent limb or facial weakness, memory problems, and numbness and tingling as part of their functional neurological disorder can be managed outside of specialist services.

**Commissioners** (such as clinical commissioning groups and NHS England) ensure that they commission services that support adults with functional neurological disorders to manage the symptoms associated with their disorder, and refer them for neurological assessment if they present with new signs or symptoms.

Adults with a functional neurological disorder are given support to manage the symptoms that are a part of their disorder by healthcare professionals in non-specialist care settings. They are referred for assessment by a specialist if they develop new symptoms that are not a part of their diagnosed disorder.

### Source guidance

Suspected neurological conditions: recognition and referral. NICE guideline NG127 (2019),

recommendations 1.2.8, 1.7.7, 1.8.2 and 1.10.7

# Definitions of terms used in this quality statement

#### Functional neurological disorder

A condition in which people experience neurological symptoms in the absence of any identifiable causative physical or structural abnormality. [NICE's guideline on suspected neurological conditions: recognition and referral]

#### Non-specialist care

Care delivered by a professional other than a neurology specialist. This may include GPs, occupational therapists, physiotherapists, social care and mental health professionals, and third-sector workers. [NICE's guideline on suspected neurological conditions: recognition and referral and expert opinion]

# Quality statement 6: Individualised care for adults

# Quality statement

Adults with suspected neurological conditions using NHS services experience care and treatment that is tailored to their needs and preferences.

#### Rationale

The <u>NHS Constitution for England</u> states that services must reflect, be coordinated around and tailored to the needs and preferences of patients. Recognising people as individuals improves the safety, efficiency and effectiveness of healthcare. Understanding which aspects of individuality and service responsiveness are important and valued by patients ensures that the human nature of healthcare is not lost. This involves giving people opportunities to discuss their needs and preferences. Engaging people in their own care helps them to actively manage their health and wellbeing. People with suspected neurological conditions may have particular needs and preferences, including those relating to psychological support.

# **Quality measures**

#### Structure

a) Evidence of local arrangements to ensure that adults with suspected neurological conditions have opportunities to discuss their health beliefs, concerns and preferences.

Data source: Local data collection.

b) Evidence of local arrangements and written protocols to ensure that the needs and preferences of adults with suspected neurological conditions are assessed, addressed and regularly reviewed.

Data source: Local data collection.

c) Evidence of local arrangements to ensure that care and treatment are tailored to the needs and preferences of adults with suspected neurological conditions.

Data source: Local data collection.

#### **Process**

a) Proportion of adults with suspected neurological conditions given the opportunity to discuss their health beliefs, concerns and preferences.

Numerator – The number in the denominator who were given the opportunity to discuss their health beliefs, concerns and preferences.

Denominator – The number of adults with suspected neurological conditions accessing NHS services.

Data source: Local data collection, for example patient records.

b) Proportion of adults with suspected neurological conditions with care tailored to their needs and preferences, taking into account their circumstances, ability to access services and coexisting conditions.

Numerator – The number in the denominator whose care was tailored to their needs and preferences, taking into account their circumstances, ability to access services and coexisting conditions.

Denominator – The number of adults with suspected neurological conditions accessing NHS services.

Data source: Local data collection, for example patient records and surveys.

c) Proportion of adults with suspected neurological conditions accessing NHS services who have their needs and preferences assessed, addressed and regularly reviewed.

Numerator – The number in the denominator who have their physical and psychological needs regularly assessed, addressed and regularly reviewed.

Denominator – The number of adults with suspected neurological conditions accessing

NHS services.

Data source: Local data collection, for example patient records and surveys.

#### Outcome

a) Evidence from patient experience surveys and feedback that adults with suspected neurological conditions believe their care has been informed by their health beliefs, concerns and preferences.

Data source: Local data collection, for example patient surveys.

b) Evidence from patient experience surveys and feedback that the care of adults with neurological conditions was tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions.

**Data source:** Local data collection, for example, local surveys and records of feedback from adults with suspected neurological conditions using services.

c) Evidence from patient experience surveys and feedback that adults with suspected neurological conditions believe their physical and psychological needs were assessed, addressed and regularly reviewed.

**Data source:**Local data collection, for example, local surveys and records of feedback from adults with suspected neurological conditions using services.

# What the quality statement means for different audiences

Service providers (such as GPs, hospitals, community services and local authorities) ensure that systems are in place to provide opportunities to establish the health beliefs, concerns and preferences of adults with suspected neurological conditions and to use them to offer individualised care. Service providers tailor care and treatment to the needs and preferences of adults with suspected neurological conditions, taking into account their ability to access services and their coexisting conditions. They also have systems in place to regularly assess, address and review the physical and psychological needs of adults

with suspected neurological conditions.

Health and social care practitioners (such as GPs, doctors, nurses and social workers) discuss health beliefs, concerns and preferences with adults who have suspected neurological conditions. They tailor care and treatment to each person's needs and preferences, taking into account the person's circumstances, ability to access services and coexisting conditions. They also assess, address and regularly review the person's physical and psychological needs.

**Commissioners** (such as clinical commissioning groups and NHS England) commission services in which the individual health beliefs, concerns and preferences of adults with suspected neurological conditions are established, and care is tailored to each person's needs and preferences. Services take into account the person's ability to access services and coexisting conditions. Services also assess, address and regularly review each person's physical and psychological needs.

Adults with suspected neurological conditions using NHS services have opportunities to discuss their health beliefs, concerns and preferences with the people providing their care. Their care and treatment take these into account, along with their needs, personal circumstances, how easy it is for them to use the services and any other health problems they have.

# Source guidance

- Suspected neurological conditions: recognition and referral. NICE guideline NG127 (2019), recommendation 1.16.1
- Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. NICE guideline CG138 (2012), recommendations 1.1.4, 1.2.4 to 1.2.9 and 1.3.1 to 1.3.3

# Definitions of terms used in this quality statement

#### Needs and preferences

These relate to an individual and include:

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- health beliefs
- concerns
- preferences
- personal circumstances including ability to access services
- physical needs including nutrition, hydration, pain relief, personal hygiene and anxiety
- psychological needs including anxiety and depression
- coexisting conditions.

[NICE's guideline on patient experience in adult NHS services]

# About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about <u>how NICE quality standards are developed</u> is available from the NICE website.

See the <u>NICE webpage on quality standard advisory committees</u> for details of standing committee 1 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available from the <u>webpage for this quality standard</u>.

This quality standard has been included in the <u>NICE Pathway on neurological conditions</u>, which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a <u>quality standard service improvement template</u> to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards, and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

### Improving outcomes

This quality standard is expected to contribute to improvements in the following outcomes:

- time to diagnosis
- unnecessary attendance at accident and emergency departments
- health-related quality of life for people with existing neurological conditions
- patient experience of adult NHS services.

It is also expected to support delivery of the NHS outcomes framework.

### Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the <u>resource impact statement for the NICE guideline on suspected neurological conditions</u> to help estimate local costs.

# Diversity, equality and language

Equality issues were considered during development and <u>equality assessments for this</u> <u>quality standard</u> are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

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# **Endorsing organisation**

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

# Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- Association of Paediatric Chartered Physiotherapists
- Royal College of Nursing (RCN)
- Primary care and Community Neurology Society (P-CNS)
- Royal College of Emergency Medicine
- Society and College of Radiographers (SOR)
- Meningitis Research Foundation
- Royal College of Paediatrics and Child Health