

# Epilepsies in children, young people and adults

Quality standard

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# Contents

Quality statements .....	4
Quality statement 1: Referral and assessment after first seizure .....	5
Quality statement .....	5
Rationale .....	5
Quality measures .....	5
What the quality statement means for different audiences .....	6
Source guidance .....	7
Definitions of terms used in this quality statement .....	7
Equality and diversity considerations .....	7
Quality statement 2: Referral to tertiary specialist services .....	9
Quality statement .....	9
Rationale .....	9
Quality measures .....	9
What the quality statement means for different audiences .....	10
Source guidance .....	11
Definitions of terms used in this quality statement .....	11
Equality and diversity considerations .....	13
Quality statement 3: Epilepsy specialist nurse .....	15
Quality statement .....	15
Rationale .....	15
Quality measures .....	15
What the quality statement means for different audiences .....	16
Source guidance .....	17
Definitions of terms used in this quality statement .....	17
Equality and diversity considerations .....	18
Quality statement 4: Epilepsy care plan .....	19
Quality statement .....	19

Rationale .....	19
Quality measures.....	19
What the quality statement means for different audiences.....	21
Source guidance.....	21
Definitions of terms used in this quality statement .....	22
Equality and diversity considerations .....	23
Quality statement 5: Mental health and wellbeing.....	25
Quality statement.....	25
Rationale .....	25
Quality measures.....	25
What the quality statement means for different audiences.....	26
Source guidance.....	27
Definitions of terms used in this quality statement .....	27
Equality and diversity considerations .....	28
Quality statement 6: Neurodevelopment and learning disabilities.....	30
Quality statement.....	30
Rationale .....	30
Quality measures.....	30
What the quality statement means for different audiences.....	31
Source guidance.....	32
Definitions of terms used in this quality statement .....	33
Equality and diversity considerations .....	34
Update information .....	35
About this quality standard .....	36
Resource impact.....	36
Diversity, equality and language.....	37

This standard replaces QS27 and QS26.

This standard is based on NG217.

## Quality statements

Statement 1 People presenting with a first suspected seizure are seen by a clinician with expertise in epilepsy within 2 weeks of presentation. **[2013, updated 2023]**

Statement 2 People who meet the criteria for referral to a tertiary epilepsy service are seen within 4 weeks of referral, or 2 weeks if they meet the criteria for urgent referral. **[2013, updated 2023]**

Statement 3 People with epilepsy have access to an epilepsy specialist nurse. **[2013, updated 2023]**

Statement 4 People with epilepsy have an up-to-date and agreed comprehensive epilepsy care plan. **[2013, updated 2023]**

Statement 5 People with epilepsy are asked about their memory, mental health, and social and emotional wellbeing at epilepsy appointments. **[new 2023]**

Statement 6 Children and young people with epilepsy are asked at epilepsy appointments about neurodevelopment and learning difficulties or changes in their learning progress, and adults who have learning disabilities are asked at epilepsy appointments about changes in their condition and other comorbidities. **[new 2023]**

In 2023, this quality standard was updated; statements prioritised in 2013 were updated (2013, updated 2023) or replaced (new 2023). For more information, see [update information](#).

The quality standards on [epilepsy in adults](#) and [epilepsy in children and young people](#) replaced by this update are available as pdfs.

# Quality statement 1: Referral and assessment after first seizure

## Quality statement

People presenting with a first suspected seizure are seen by a clinician with expertise in epilepsy within 2 weeks of presentation. **[2013, updated 2023]**

## Rationale

People presenting with a first suspected seizure should be referred urgently to a specialist to ensure prompt, accurate diagnosis. Diagnosing epilepsy can be complex. Involving a specialist early can help avoid misdiagnosis and ensure that the person receives the correct management and support. Timely access is important to avoid delay in delivering care and treatment that may have a positive impact on the person's prognosis and quality of life.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Process

a) Proportion of children and young people presenting with a first suspected seizure referred to a paediatrician with expertise in epilepsy who are seen within 2 weeks.

Numerator – the number in the denominator who are seen within 2 weeks of referral.

Denominator – the number of children and young people presenting with a first suspected seizure who are seen by a paediatrician with expertise in epilepsy.

**Data source:** Royal College of Paediatrics and Child Health's Epilepsy12 audit of seizures

and epilepsies for children and young people includes information on children and young people diagnosed with epilepsy seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral.

b) Proportion of adults presenting with a first suspected seizure referred to a clinician with expertise in epilepsy who are seen within 2 weeks of referral.

Numerator – the number in the denominator who are seen within 2 weeks of referral.

Denominator – the number of adults presenting with a first suspected seizure who are seen by a clinician with expertise in epilepsy.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

## What the quality statement means for different audiences

**Service providers** (secondary care services such as neurology and paediatric services) have clinics to assess people after a first seizure and clinicians with expertise in epilepsy. They work with GPs and emergency departments to develop processes for urgent referrals to epilepsy services for people who have had a first suspected seizure.

**Healthcare professionals** (GPs, emergency medical doctors and paediatricians who do not specialise in epilepsy or neurological conditions) urgently refer people who present with a first suspected seizure to a clinician with expertise in epilepsy. Clinicians with expertise in epilepsy aim to see people within 2 weeks of presentation to identify the cause of the seizure and ensure a correct diagnosis is made.

**Commissioners** ensure that they commission services in which people presenting with a first suspected seizure are seen by a clinician with expertise in epilepsy within 2 weeks of presentation.

**People who have a first suspected seizure** are seen by a healthcare professional with expertise in epilepsy within 2 weeks.

## Source guidance

Epilepsies in children, young people and adults. NICE guideline NG217 (2022), recommendation 1.1.1

## Definitions of terms used in this quality statement

### First suspected seizure

A reported acute episode of altered functioning, awareness or behaviour, presumed to be the direct result of a change in electrical activity in the brain, the nature of which raises concerns that a seizure has occurred. [Expert opinion]

### Clinician with expertise in epilepsy

For children and young people, this is a paediatrician with expertise in assessing first seizures and diagnosing epilepsy. For adults, this is a clinician with expertise in assessing first seizures and diagnosing epilepsy (usually a consultant neurologist). Expertise may be demonstrated by training and continuing education in epilepsy and/or peer review of practice, and epilepsy must be a significant part of their clinical workload (equivalent to at least 1 session per week). [Expert opinion]

## Equality and diversity considerations

People with epilepsy who are older, have a learning disability, have other complex needs (such as other comorbidities), or who do not read or speak English should have their information and support needs taken into account. This could include:

- giving longer appointments to allow more time for discussion
- providing information in different formats, such as easy read, large print or audio versions
- providing information that is accessible to people who do not speak or read English, and is culturally appropriate
- involving family members, carers, an interpreter, or an advocate if the person wishes (see NICE's guideline on advocacy services)

- sharing information with those involved in the person's care, if appropriate.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](#) or the equivalent standards for the devolved nations.



# Quality statement 2: Referral to tertiary specialist services

## Quality statement

People who meet the criteria for referral to a tertiary epilepsy service are seen within 4 weeks of referral, or 2 weeks if they meet the criteria for urgent referral. **[2013, updated 2023]**

## Rationale

Some people with epilepsy need access to specialist investigations, treatment and management from a tertiary specialist service. Tertiary specialist services include genetic diagnosis, specialist assessment for surgery and treatments such as vagus nerve stimulation and ketogenic diet. Timely access is important to avoid delay in delivering care and treatment that may have a positive impact on the person's prognosis and quality of life. All people who meet the referral criteria for a tertiary epilepsy service should be seen within 4 weeks. Some groups of children are prioritised for urgent referral and should be seen within 2 weeks.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Process

a) Proportion of children referred to a tertiary paediatric epilepsy service who meet the criteria for urgent referral who are seen within 2 weeks of referral.

Numerator – the number in the denominator who are seen within 2 weeks of referral.

Denominator – the number of children referred to a tertiary paediatric epilepsy service

who meet the criteria for urgent referral.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records.

b) Proportion of people referred to a tertiary epilepsy service who meet the criteria for referral to be seen within 4 weeks that are seen within 4 weeks.

Numerator – the number of people in the denominator who are seen within 4 weeks of referral.

Denominator – the number of people referred to a tertiary epilepsy service who meet the criteria for referral to be seen within 4 weeks.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. Information on children and young people who meet the criteria for referral to a paediatric neurologist seen within 4 weeks of referral is included in the [Royal College of Paediatrics and Child Health's Epilepsy12 audit of seizures and epilepsies for children and young people](#).

## Outcome

Number of unplanned hospital attendances and admissions for people with epilepsy.

**Data source:** [Hospital Episode Statistics database](#) contains details of all admissions and A&E attendances at NHS hospitals in England. Data can also be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

## What the quality statement means for different audiences

**Service providers** (tertiary epilepsy services, tertiary paediatric epilepsy services, secondary care epilepsy services) have pathways for referrals from secondary care services to epilepsy specialists who are adult or paediatric neurologists. They have referral criteria with supporting guidance, and systems in place to ensure that people are seen within 2 or 4 weeks of referral as appropriate.

**Healthcare professionals** (such as neurologists and paediatricians with expertise in epilepsy) use referral criteria to ensure that people who will benefit most from specialist services are referred to tertiary epilepsy service providers, and to prioritise particular groups who should be referred urgently. Epilepsy specialists providing tertiary services (adult or paediatric neurologists) see children who meet urgent referral criteria within 2 weeks, and all other people who meet referral criteria within 4 weeks.

**Commissioners** commission tertiary epilepsy services with capacity to see people who meet urgent referral criteria within 2 weeks and all other people who meet referral criteria within 4 weeks. Integrated care boards develop improvement plans in line with [NHS England's National bundle of care for children and young people with epilepsy](#). They ensure there are agreed pathways of referral into tertiary neurology services within each secondary care epilepsy service. They identify and map the provision and waiting times for paediatric neurology input and work with their tertiary paediatric neurology centres to determine paediatric neurologist provision within their system (bundle of care 'Tertiary care 1' recommendations).

**People with epilepsy** are seen promptly by a tertiary epilepsy service if they need further investigations or additional expertise to manage their epilepsy. People who need an urgent appointment are seen within 2 weeks, and all other people are seen within 4 weeks.

## Source guidance

[Epilepsies in children, young people and adults. NICE guideline NG217 \(2022\)](#), recommendations 3.1.3 and 3.1.4

## Definitions of terms used in this quality statement

### Tertiary epilepsy service

A service provided by epilepsy specialists who are adult or paediatric neurologists who undertake continuing professional development in the investigation, diagnosis and management of complex epilepsy. It offers:

- access to additional specialist assessments, including:
  - neuropsychology

- neuropsychiatry
- specialised neuroimaging, including 3T MRI
- specialised neurophysiology, including video electroencephalogram (EEG) telemetry
- specialised assessment and management of particular patient groups, including:
  - people with learning disability
  - pregnant women and pregnant people
  - people transitioning between services
  - older people with epilepsy
- access to:
  - specialised non-surgical treatments; for example, cannabidiol, ketogenic diet
  - genetic diagnosis and counselling
  - specialised assessment for surgery
  - vagus nerve stimulation
  - participation in relevant clinical trials and research studies.

[[NICE's guideline on epilepsies in children young people and adults](#), terms used in this guideline]

## Criteria for urgent referral to a tertiary epilepsy centre

Particular groups of children with suspected or confirmed epilepsy are referred to a tertiary paediatric epilepsy service to be seen within 2 weeks, if they:

- are younger than 3 years
- are younger than 4 years and have myoclonic seizures
- have a unilateral structural lesion (if there are accompanying symptoms, signs or radiological features suggestive of raised intracranial pressure they will be referred

immediately to neurosurgery)

- are showing deterioration in their behaviour, speech or learning.

[[NICE's guideline on epilepsies in children young people and adults](#), recommendation 3.1.4 and expert opinion]

## Criteria for referral to a tertiary epilepsy service to be seen within 4 weeks

People with epilepsy are referred to a tertiary epilepsy service to be seen within 4 weeks, if any of the following apply:

- uncertainty about the diagnosis or cause of epilepsy, the seizure type or epilepsy syndrome
- the person has an epilepsy syndrome likely to be drug resistant, their seizures are drug resistant or their treatment is associated with intolerable side effects
- further assessment and treatment approaches are indicated, such as: video electroencephalogram (EEG) telemetry, neuropsychology or neuropsychiatry, specialised neuroimaging, specialised treatments (for example medication that can only be prescribed by a tertiary epilepsy service, or a ketogenic diet), epilepsy surgery or vagus nerve stimulation
- the person is eligible for and wishes to participate in a clinical trial or research study.

[[NICE's guideline on epilepsies in children young people and adults](#), recommendation 3.1.3]

## Equality and diversity considerations

People with a learning disability, a mental health condition, who are neurodiverse or have physical health conditions may find it difficult to access tertiary services if their comorbidities overshadow their epilepsy needs. People with these comorbidities, or who do not read or speak English, should have their information and support needs taken into account. This could include:

- giving longer appointments to allow more time for discussion
- providing information in different formats, such as easy read, large print or audio

versions

- providing information that is accessible to people who do not speak or read English, and is culturally appropriate
- involving family members, carers, an interpreter, or an advocate if the person wishes (see [NICE's guideline on advocacy services](#))
- sharing information with those involved in their care, if appropriate.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](#) or the equivalent standards for the devolved nations.

# Quality statement 3: Epilepsy specialist nurse

## Quality statement

People with epilepsy have access to an epilepsy specialist nurse. [2013, updated 2023]

## Rationale

Epilepsy specialist nurses support people with all aspects of living with epilepsy and play a key role in ensuring continuity of care. They act as a point of contact for people with epilepsy, their families or carers; support other healthcare professionals in primary and secondary care, educational, respite and social care settings; provide training and advice; and have a central role in care planning and transition to adult services.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of availability of epilepsy specialist nurses.

**Data source:** Data can be collected from electronic staff records. The [Royal College of Paediatrics and Child Health's Epilepsy<sup>12</sup> audit of seizures and epilepsies for children and young people](#) contains information on whole time equivalent epilepsy specialist nurses by health board and trust. The [National Confidential Enquiry into Patient Outcome and Death's Disordered activity review](#) of the quality of epilepsy care provided to adult patients includes national level information on availability of epilepsy specialist nurses.

## Process

a) Proportion of people receiving epilepsy care who are given the contact details of a named epilepsy specialist nurse or an epilepsy nurse team.

Numerator – the number of people in the denominator who are given the contact details of a named epilepsy specialist nurse or an epilepsy nurse team.

Denominator – the number of people receiving care from an epilepsy service.

**Data source:** Data can be collected locally using patient records or audits of clinic letters.

b) Proportion of people with epilepsy who continue to have seizures who have had an information and care-planning session with an epilepsy specialist nurse at least twice within the past year.

Numerator – the number in the denominator who have had an information and care-planning session with an epilepsy specialist nurse at least twice within the past year.

Denominator – the number of people with epilepsy who continue to have seizures.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

c) Proportion of children and young people diagnosed with epilepsy who received input from an epilepsy specialist nurse within the first year of care.

Numerator – the number in the denominator who received input from an epilepsy specialist nurse.

Denominator – the number of children and young people diagnosed with epilepsy in their first year of care.

**Data source:** The [Royal College of Paediatrics and Child Health's Epilepsy12 audit of seizures and epilepsies for children and young people](#) Performance Indicator 2.

## What the quality statement means for different



## audiences

**Service providers** (adult and paediatric epilepsy services) ensure they have enough epilepsy specialist nurses to meet local need. They ensure the specialist nurses perform a central role in care planning, support people to manage their epilepsy and act as a point of contact for people with epilepsy and other services.

**Healthcare professionals** (epilepsy specialist nurses) are a point of contact and a source of information, education and support for people with epilepsy and their families and carers. They provide information and care-planning sessions for people with epilepsy, and liaise with and support others working with people with epilepsy such as epilepsy specialists, other health, education and social care professionals, and respite carers.

**Commissioners** ensure that they commission services in which people with epilepsy have access to epilepsy specialist nurses. Integrated care boards develop improvement plans in line with [NHS England's National bundle of care for children and young people with epilepsy](#). They identify gaps in epilepsy specialist nurse provision and work with relevant providers to ensure plans are in place to address any variation in access (bundle of care 'Variation 1' recommendation).

**People with epilepsy** have an epilepsy specialist nurse (a nurse who has training and experience in caring for people with epilepsy) who coordinates their care, helps them manage their epilepsy and is their point of contact within the epilepsy service.

## Source guidance

[Epilepsies in children, young people and adults. NICE guideline NG217 \(2022\), recommendation 11.1.1](#)

## Definitions of terms used in this quality statement

### Access

Being able to contact and use the services provided by an epilepsy specialist nurse. These include providing information, education and support on administering medications, care planning, self-management, problems with cognition, the impact of epilepsy on daily activities, management of side effects, mental health, reproductive health and pregnancy,

and sudden unexpected death in epilepsy. [Adapted from [NICE's guideline on epilepsies in children young people and adults](#), box 1 for recommendation 2.1.11, rationale for recommendations 11.1.1 to 11.1.4]

## Epilepsy specialist nurse

A clinical nurse with specialist knowledge and experience of supporting children, young people and adults with all aspects of living with epilepsy. They have responsibility for providing care for people with epilepsy as part of their clinical role. [[NICE's guideline on epilepsies in children young people and adults](#), recommendation 11.1.1 and expert opinion]

## Equality and diversity considerations

People with epilepsy who are older, have a learning disability, have other complex needs (such as other comorbidities) or whose first language is not English should have their information and support needs taken into account. This could include

- giving longer appointments to allow more time for discussion
- providing information in different formats, such as easy read, large print or audio versions
- providing information that is accessible to people who do not speak or read English, and is culturally appropriate
- involving family members, carers, an interpreter or an advocate if the person wishes (see [NICE's guideline on advocacy services](#))
- sharing information with those involved in their care, if appropriate.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](#) or the equivalent standards for the devolved nations.

# Quality statement 4: Epilepsy care plan

## Quality statement

People with epilepsy have an up-to-date and agreed comprehensive epilepsy care plan.  
[2013, updated 2023]

## Rationale

An individualised care plan provides details of diagnosis, treatment, care and support. It is discussed and agreed with the person and, if appropriate, their family or carers. The plan allows people to make informed choices about their epilepsy and helps to coordinate care between healthcare and other professionals in different settings.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Process

a) Proportion of people with epilepsy who have an up-to-date and agreed comprehensive epilepsy care plan.

Numerator – the number in the denominator who have an up-to-date and agreed comprehensive epilepsy care plan.

Denominator – the number of people with epilepsy.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from local audits of patient records. Information on the proportion of children and young people diagnosed with epilepsy with evidence of a care plan that has been updated and agreed is included in the [Royal College of Paediatrics and Child Health's Epilepsy12 audit of seizures and epilepsies for children](#)

and young people.

b) Proportion of young people with epilepsy who have an epilepsy care plan that covers transition to adult services.

Numerator – the number in the denominator who have an epilepsy care plan that covers transition to adult services.

Denominator – the number of young people with epilepsy.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from local audits of patient records. NHS England's National bundle of care for children and young people with epilepsy includes an example local audit proforma for collecting information on young people undergoing transition or who completed transition within the last year.

c) Proportion of women of childbearing potential who have an epilepsy care plan that covers pre-conception care and pregnancy.

Numerator – the number in the denominator who have an epilepsy care plan that covers pre-conception care and pregnancy.

Denominator – the number of women of childbearing potential with epilepsy.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from local audits of patient records. For measurement purposes, girls and women aged 13 to 54 can be used to represent women of childbearing potential. Sourced from the NHS Business Services Authority Valproate safety dashboard.

d) Proportion of people with epilepsy who have experienced status epilepticus, repeated or cluster seizures, or prolonged seizures, who have an epilepsy care plan that covers emergency management.

Numerator – the number in the denominator who have an epilepsy care plan that covers emergency management.

Denominator – the number of people with epilepsy who have experienced status

epilepticus, repeated or cluster seizures, or prolonged seizures.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from local audits of patient records. Information on the proportion of children and young people diagnosed with epilepsy who have evidence of planning of care that encompasses a parental or carer prolonged seizure care plan is collected for the [Royal College of Paediatrics and Child Health's Epilepsy12 audit of seizures and epilepsies for children and young people](#).

## What the quality statement means for different audiences

**Service providers** (adult and paediatric epilepsy service providers) ensure systems are in place for people with epilepsy to take part in shared decision making and be involved in developing and reviewing individualised plans for their care. They ensure staff are trained in how to involve people in developing care plans and shared decision making.

**Healthcare professionals** (such as neurologists, paediatric neurologists, paediatricians and epilepsy specialist nurses) develop an epilepsy care plan with people diagnosed with epilepsy. They discuss with the person their priorities and preferences for management, and whether to share the plan with family members or carers. They identify interventions and support to address the particular needs of the person, jointly agree the plan and set a review date.

**Commissioners** ensure that they commission services in which people with epilepsy are involved in developing and reviewing an epilepsy care plan. Integrated care boards develop improvement plans in line with [NHS England's National bundle of care for children and young people with epilepsy](#). They identify care-planning completion rates and work with service providers to increase them (bundle of care 'Variation 3' recommendation).

**People with epilepsy** have an epilepsy care plan that includes details about their care, treatment and preferences, which they develop and agree with their healthcare team.

## Source guidance

[Epilepsies in children, young people and adults. NICE guideline NG217 \(2022\)](#), recommendations 2.1.7, 4.4.1, 4.4.2, 4.6.3, 4.6.4, 7.1.12, 7.2.4, 7.3.3, 7.3.4, and 11.2.5.

## Definitions of terms used in this quality statement

### Up-to-date and agreed comprehensive epilepsy care plan

The epilepsy care plan should be an individualised, patient-centred comprehensive document that covers decisions made about the person's past, present and future care. The level of detail in a plan, and the areas it covers, will vary depending upon the person's needs. A plan can be a clinic letter if it includes the care-planning information shown below.

It should be discussed and agreed between the person with epilepsy and (if appropriate) their family and carers, and with their primary and secondary health and social care professionals. The plan should include an agreed date for review, which will depend on the complexity of a person's needs.

The care plan should include information relating to the following topics:

- seizure types and epilepsy syndrome if classified
- aetiology if known
- triggers that may provoke seizures
- regular medication, including adherence to antiseizure medication, experiences of side effects from medication and coping strategies
- reducing epilepsy-related risks, including how to reduce the risk of sudden unexpected death in epilepsy
- name and contact details of the epilepsy team (including epilepsy specialist nurse, consultant responsible for their care and primary care doctor).

For some people with epilepsy, the care plan may also include:

- an emergency care plan for prolonged seizures (if there have been previous prolonged seizures), including instructions about the timing and administration of rescue medication
- comorbidities, including learning disability and mental health conditions

- activities that should be adapted or avoided to reduce risk, including clear advice on driving if appropriate
- goals of the person with epilepsy
- care and supervision requirements, along with contact details
- arrangements to coordinate and support transition of young people moving from children's to adults' services
- reproductive health and pregnancy, including contraception, changes in medications, teratogenicity of antiseizure medications, pre-conception planning, planning the birth, postnatal care and breastfeeding.

[Adapted from [NICE's guideline on epilepsies in children young people and adults](#), recommendations 2.1.6 and 2.1.11 and expert opinion]

## Women of childbearing potential

We use the term 'women of childbearing potential' based on the source guidance used in developing this statement, and so the terminology is in line with the [NHS Business Services Authority valproate safety dashboard](#). The measures also apply to people of childbearing potential who do not identify as women.

## Equality and diversity considerations

People with epilepsy who are older, have a learning disability, have other complex needs (such as other comorbidities), or who do not read or speak English, should have their information and support needs taken into account. This could include:

- giving longer appointments to allow more time for discussion
- providing information in different formats, such as easy read, large print or audio versions
- providing information that is accessible to people who do not speak or read English, and is culturally appropriate
- involving family members, carers, an interpreter, or an advocate if the person wishes (see [NICE's guideline on advocacy services](#))

- sharing information with those involved in their care, if appropriate.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](#) or the equivalent standards for the devolved nations.



# Quality statement 5: Mental health and wellbeing

## Quality statement

People with epilepsy are asked about their memory, mental health, and social and emotional wellbeing at epilepsy appointments. **[new 2023]**

## Rationale

Good epilepsy care is more than just control of seizures and should address the whole person, including their mental health and wellbeing. There is a higher prevalence of mental health conditions, and a higher risk of suicide, in people with epilepsy than in the general population. Some treatments aimed at controlling seizures can have adverse effects on mood, memory (cognitive function), behaviour and alertness. Also, receiving a diagnosis of epilepsy can have a negative impact on a person and their quality of life. Asking relevant questions as part of epilepsy care can help identify comorbidities and adverse effects of antiseizure medications to enable appropriate interventions and treatment adjustments.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of local referral pathways between epilepsy services and mental health, neuropsychology and educational psychology services.

**Data source:** Data can be collected from information recorded locally by provider organisations, for example from service specifications. The [Royal College of Paediatrics and Child Health's Epilepsy12 audit of seizures and epilepsies for children and young people](#) contains information on trusts that have referral pathways for children and young

people with epilepsy who have mental health concerns.

## Process

Proportion of epilepsy clinic appointments in which people are asked about memory, mental health, and social and emotional wellbeing.

Numerator – the number in the denominator in which people are asked about memory, mental health, and social and emotional wellbeing.

Denominator – the number of clinic appointments for people with epilepsy.

**Data source:** For adults, data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records. For children and young people, use the [Royal College of Paediatrics and Child Health's Epilepsy12 audit of seizures and epilepsies for children and young people](#) Performance Indicator 6 (percentage of children with epilepsy for whom there is documented evidence that they have been asked about mental health either through clinical screening, or a questionnaire or measure).

## What the quality statement means for different audiences

**Service providers** (adult and paediatric epilepsy service providers) ensure that epilepsy professionals are offered training to identify signs of mental health conditions or decline in mental health. They develop referral pathways with mental health services to ensure access to more specific assessments and treatment. They ensure that epilepsy appointments include discussions about memory, mental health, and social and emotional wellbeing.

**Healthcare professionals** (neurologists, paediatric neurologists, paediatricians, epilepsy specialist nurses) ask people at epilepsy appointments brief questions about their memory, mental health, and social and emotional wellbeing. They liaise with GPs, advise on how any problems can be addressed and, if necessary, make onward referrals for specialist assessment (for example to neuropsychologists, mental health teams and educational psychology services).

**Commissioners** commission epilepsy services that discuss memory, mental health, and social and emotional wellbeing. They work with service providers to develop referral pathways between epilepsy and mental health services. Integrated care boards develop improvement plans in line with [NHS England's National bundle of care for children and young people with epilepsy](#). These include ensuring that processes are in place for all children and young people with epilepsy to be routinely screened for mental health difficulties at the point of diagnosis and in subsequent annual reviews (bundle of care 'Mental Health 1' recommendation). They map provision of, and referral pathways to, relevant mental health providers and services within their system, identify gaps and develop plans to address any gaps (bundle of care 'Mental Health 2' recommendation). They identify providers that do not have mental health care integrated within the epilepsy service and develop plans to mitigate this risk by developing appropriate pathways into mental health services (bundle of care 'Mental Health 3' recommendation).

**People with epilepsy** are asked about their memory, mental health and wellbeing at epilepsy appointments to assess their general health. They are advised on how any problems can be addressed and are referred to other services if more specific assessment, treatment or care is needed.

## Source guidance

[Epilepsies in children, young people and adults. NICE guideline NG217 \(2022\), recommendation 9.2.2](#)

## Definitions of terms used in this quality statement

### Asked about their memory, mental health, and social and emotional wellbeing

Asking people about memory, mental health, social and emotional wellbeing involves asking brief questions to explore these areas such as:

- Have you noticed any difficulties with your memory since the previous appointment? If so, do you think that things are getting worse?
- Have you felt down, depressed or hopeless in the past month?

- Have you been bothered by little interest or pleasure in doing things in the past month?
- Have there been any specific psychosocial stresses that have affected your health since the previous review?

Formal or specialist assessments, such as an assessment of cognitive function, are not included. [Expert opinion]

## Epilepsy appointment

This includes planned appointments with an epilepsy professional, such as regular monitoring reviews, patient-initiated monitoring reviews and specialist nurse appointments.

Some appointments may need a specific focus, such as appointments focused on medicine changes, medicine dose changes or alterations to the emergency care plan, and it may not be appropriate to ask these questions at such appointments. [Adapted from [NICE's guideline on epilepsies in children young people and adults](#), recommendations 4.5.1, 4.5.2, 4.5.4, 11.1.3 and expert opinion]

## Equality and diversity considerations

People with epilepsy who are older, have other complex needs (such as other comorbidities), or who do not read or speak English should have their information and support needs taken into account. This could include:

- giving longer appointments to allow more time for discussion
- providing information in different formats, such as easy read, large print or audio versions
- providing information that is accessible to people who do not speak or read English, and is culturally appropriate
- involving family members, carers, an interpreter or an advocate if the person wishes (see [NICE's guideline on advocacy services](#))
- sharing information with those involved in their care, if appropriate.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](#) or the equivalent standards for the devolved nations.

# Quality statement 6: Neurodevelopment and learning disabilities

## Quality statement

Children and young people with epilepsy are asked at epilepsy appointments about neurodevelopment and learning difficulties or changes in their learning progress, and adults who have learning disabilities are asked at epilepsy appointments about changes in their condition and other comorbidities. **[new 2023]**

## Rationale

There is a higher prevalence of learning disabilities and neurodevelopmental conditions (for example, attention deficit hyperactivity disorder and autism spectrum disorder) in people with epilepsy than in the general population. Some treatments aimed at controlling seizures can also have adverse effects, for example on behaviour and alertness. Asking relevant questions as part of epilepsy care can help identify problems, comorbidities and adverse effects of antiseizure medications to enable appropriate interventions and treatment adjustments.

## Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

## Structure

Evidence of agreed referral criteria for children and young people with epilepsy who have neurodevelopmental conditions and adults with epilepsy who have learning disabilities.

**Data source:** The [Royal College of Paediatrics and Child Health's Epilepsy12 audit of seizures and epilepsies for children and young people](#) contains information on trusts that have agreed referral criteria for children and young people with neurodevelopmental

conditions. This can be found in the organisational audit.

## Process

a) Proportion of epilepsy clinic appointments in which children and young people with epilepsy are asked about neurodevelopment and learning difficulties or changes in their learning progress.

Numerator – the number in the denominator in which children and young people are asked about neurodevelopment and learning difficulties or change in their learning progress.

Denominator – the number of clinic appointments for children and young people with epilepsy.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

b) Proportion of epilepsy clinic appointments in which adults with epilepsy who have learning disabilities are asked about changes in their condition and other comorbidities.

Numerator – the number in the denominator in which adults are asked about changes in their condition and other comorbidities.

Denominator – the number of clinic appointments for adults with epilepsy who have learning disabilities.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

## What the quality statement means for different audiences

**Service providers** (adult and paediatric epilepsy service providers) agree referral pathways with services for children and young people with neurodevelopmental conditions and learning difficulties, and adults with learning disabilities to ensure access to more specific assessments and treatment when necessary. They ensure that epilepsy appointments for children and young people include discussions about neurodevelopment

and difficulties with learning or changes in their learning progress, and appointments for adults with learning disabilities include discussions about changes in their condition and any other comorbidities.

**Healthcare professionals** (neurologists, paediatric neurologists, paediatricians, epilepsy specialist nurses) ask children and young people, and their parents or carers as appropriate, at epilepsy appointments about their neurodevelopment, and any difficulties at school or with wider learning. They ask adults with learning disabilities, and their carers or advocates as appropriate, at epilepsy appointments about any changes in these conditions and other comorbidities. They advise on how any problems can be addressed and, if necessary, refer people for specialist assessments (such as a neurodevelopmental assessment), learning disability psychiatry input and social work support. For children this may involve referral to a neurodevelopmental paediatrician or a multidisciplinary team including speech and language therapists, educational psychologists and learning disability nurses.

**Commissioners** commission epilepsy services that discuss neurodevelopment and learning disabilities at epilepsy appointments. They work with service providers to develop referral pathways between epilepsy services, services for children and young people with neurodevelopmental conditions and learning difficulties, and services for adults with learning disabilities. Integrated care boards develop improvement plans in line with [NHS England's National bundle of care for children and young people with epilepsy](#). These include mapping provision of, and referral pathways to, relevant neurodevelopmental services (bundle of care 'Mental Health 2' recommendation).

**Children and young people with epilepsy and adults with epilepsy who have learning disabilities** are asked questions at epilepsy appointments about difficulties they are having and changes they are experiencing. They are advised on how any problems can be addressed and are referred to other services if more specific assessments, treatment or care are needed. The epilepsy care team for disabled people (including people with a learning disability) and autistic people ensures they are receiving the support they need and that it fits with their epilepsy treatment.

## Source guidance

[Epilepsies in children, young people and adults. NICE guideline NG217 \(2022\), recommendation 9.2.2](#)



## Definitions of terms used in this quality statement

### Asked about neurodevelopment and learning disabilities

Asking people (and their parents, carers or advocates if appropriate) about neurodevelopment and learning disabilities involves asking brief questions to explore these areas, such as:

- Have there been any concerns about thinking or development since the previous review?
- Have teachers or other educators raised any concerns?
- Have you noticed any change in thinking or behaviour since the previous review?

[Expert opinion]

### Other comorbidities

Psychological, neurobehavioural, cognitive and developmental comorbidities. These include changes in memory and overall cognitive abilities, mood and behaviour. [Expert opinion]

### Epilepsy appointment

This includes all planned appointments with an epilepsy professional for children with epilepsy and adults with epilepsy and a learning disability (either suspected or diagnosed). These appointments include regular monitoring reviews, patient-initiated monitoring reviews and specialist nurse appointments.

Some appointments may need a specific focus, such as appointments focused on medicine changes, medicine dose changes or alterations to the emergency care plan, and it may not be appropriate to ask these questions at such appointments. [Adapted from [NICE's guideline on epilepsies in children young people and adults](#), recommendations 4.5.1, 4.5.2, 4.5.4, 11.1.3 and expert opinion]

## Equality and diversity considerations

People with epilepsy who are older, have a learning disability, have other complex needs (such as other comorbidities), or who do not read or speak English should have their information and support needs taken into account. This could include:

- giving longer appointments to allow more time for discussion
- providing information in different formats, such as easy read, large print or audio versions
- providing information that is accessible to people who do not speak or read English, and is culturally appropriate
- involving family members, carers, an interpreter or an advocate if the person wishes (see [NICE's guideline on advocacy services](#))
- sharing information with those involved in their care, if appropriate.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](#) or the equivalent standards for the devolved nations.

## Update information

**December 2023:** This quality standard was updated and statements prioritised in 2013 were replaced. The topic was identified for update after a review of quality standards. The review identified that NICE guidance on epilepsies in children, young people and adults had been updated and the quality standards on epilepsy in adults and epilepsy in children and young people should be combined.

Statements are marked as:

- **[new 2023]** if the statement covers a new area for quality improvement
- **[2013, updated 2023]** if the statement covers an area for quality improvement included in the 2013 quality standard, and has been updated.

The quality standards on [epilepsy in adults](#) and [epilepsy in children and young people](#) replaced by this update are available as pdfs.

## 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 [how NICE quality standards are developed](#) is available from the NICE website.

See our [webpage on quality standards advisory committees](#) for details about our standing committees. Information about the topic experts invited to join the standing members is available from the [webpage for this quality standard](#).

NICE has produced a [quality standard service improvement template](#) 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 guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

## 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 [resource impact report for NICE's guideline on epilepsies in children, young people and adults](#).

## Diversity, equality and language

Equality issues were considered during development and [equality assessments for this quality standard](#) 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.

- [Epilepsy Action](#)
- [Society for Acute Medicine \(SAM\)](#)
- [Jon Shaw Foundation](#)
- [Association of Clinical Psychologists UK](#)
- [Peter Doody Foundation](#)
- [Royal College of Paediatrics and Child Health](#)
- [Young Epilepsy](#)