NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Epilepsies in children, young people and adults (update)

NICE quality standard

Draft for consultation

28 February 2013

15 June 2023

|  |
| --- |
| **This quality standard covers** diagnosing and managing epilepsies in children, young people and adults. It describes high-quality care in priority areas for improvement.  This quality standard will update and replace the existing [quality standards on epilepsy in adults](https://www.nice.org.uk/guidance/qs26) (QS26) and [epilepsy in children and young people](https://www.nice.org.uk/guidance/qs27) (QS27) (published February 2013). The topics were identified for update following a review of quality standards. The review identified:   * updated guidance on epilepsies in children, young people and adults * that the quality standards on epilepsy should be combined.   For more information see [update information](http://www.nice.org.uk/guidance/qsXXX/chapter/Update-information).  This is the draft quality standard for consultation (from 15 June 2023 to 13 July 2023). The final quality standard is expected to publish in December 2023.  During development of this draft quality standard, the [Medicines and Healthcare products Regulatory Agency announced that new safety measures for valproate-containing medicines are to be put in place](https://www.gov.uk/drug-safety-update/valproate-reminder-of-current-pregnancy-prevention-programme-requirements-information-on-new-safety-measures-to-be-introduced-in-the-coming-months). [NICE’s guideline on epilepsies in children, young people and adults](https://www.nice.org.uk/guidance/ng217) will be updated when more information on these safety measures is announced. |

# Quality statements

[Statement 1](#_Quality_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](#_Quality_statement_2:) Children referred urgently to a tertiary epilepsy service are seen within 2 weeks of referral and other people are seen within 4 weeks. **[2013, updated 2023]**

[Statement 3](#_Quality_statement_3:) People with epilepsy have access to an epilepsy specialist nurse. **[2013, updated 2023]**

[Statement 4](#_Quality_statement_4:) People with epilepsy have an up-to-date epilepsy care plan. **[2013, updated 2023]**

[Statement 5](#_Quality_statement_5:) People with epilepsy are asked, at epilepsy appointments, about their cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities. **[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](#_Update_information_2).

|  |
| --- |
| Questions for consultationQuestions about the quality standard **Question 1** Does this draft quality standard accurately reflect the key areas for quality improvement?  **Question 2** Can data for the proposed quality measures be collected locally? Please include in your answer any data sources that can be used or reasons why data cannot be collected.  **Question 3** Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment. Questions about the individual quality statements **Question 4** For draft quality statement 1: Is it feasible for epilepsy specialist nurses to be the ‘clinician with expertise in epilepsy’ who identifies the cause of a seizure and ensures a correct diagnosis is made?  **Question 5** For draft quality statement 5: Statement 5 covers planned epilepsy appointments. Are there specific types of epilepsy appointments that should be included or excluded from this statement?  **Question 6** For draft quality statement 5: Is there enough time and capacity at epilepsy appointments to ask about cognitive function, mental health, social and emotional wellbeing and, where relevant, neurodevelopment and learning disabilities?  **Question 7** For draft quality statement 5: Statement 5 covers cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities. It also covers all people with epilepsy. Would it be helpful to focus the statement on a smaller number of areas or a particular population group? If so, what should it focus on?  **Question 8** For draft quality statement 5: What is an appropriate outcome measure for this statement? Please include any known data sources for suggestions. Implementing NICE guidelines **Question 9** What are the challenges to implementing the NICE guidance underpinning this quality standard? Please say why and for whom. Please include any suggestions that could help users overcome these challenges (for example, existing practical resources or national initiatives). |

# 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 suspected first 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 who are seen by a paediatrician with expertise in epilepsy within 2 weeks of referral.

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](https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit) 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 who are seen by a clinician with expertise in epilepsy 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.

### Outcome

Average time to diagnosis of epilepsy from first epileptic seizure.

**Data source:**No routinely collected national data has been identified for this measure. 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 seizure.

**Healthcare professionals** - GPs and emergency medical doctors urgently refer people who present with a first 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](https://www.nice.org.uk/guidance/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 adults, this is a doctor, physician associate or epilepsy specialist nurse with training and expertise in assessing first seizures and diagnosing epilepsy. For children and young people, this is a paediatrician with expertise in assessing first seizures and diagnosing epilepsy. Expertise may be demonstrated by training and continuing education in epilepsy and 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 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 or an advocate if the person wishes
* 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](https://www.england.nhs.uk/ourwork/accessibleinfo/) or the equivalent standards for the devolved nations.

## Question for consultation

Is it feasible for epilepsy specialist nurses to be the ‘clinician with expertise in epilepsy’ who identifies the cause of a seizure and ensures a correct diagnosis is made?

# Quality statement 2: Referral to tertiary specialist services

## Quality statement

Children referred urgently to a tertiary epilepsy service are seen within 2 weeks of referral and other people are seen within 4 weeks. **[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.

## 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 urgently to a tertiary paediatric epilepsy service 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 urgently to a tertiary paediatric epilepsy service.

**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 are seen within 4 weeks of referral.

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.

**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](https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit).

### Outcome

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

**Data source:** [Hospital Episode Statistics database](https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics) 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) refer children urgently to tertiary epilepsy service providers to be seen within 2 weeks of referral if they meet the appropriate referral criteria, and refer all other people to be seen within 4 weeks. 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 children who meet urgent referral criteria within 2 weeks and all other people who meet referral criteria within 4 weeks.

**People with epilepsy** are seen promptly by a specialist in a tertiary epilepsy service if they need further investigations or additional expertise to manage their epilepsy. Children 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](https://www.nice.org.uk/guidance/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
  + 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](https://www.nice.org.uk/guidance/ng217), terms used in this guideline]

### Children referred urgently

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

* are aged under 3 years
* are aged under 4 years and have myoclonic seizures
* have a unilateral structural lesion
* are showing deterioration in their behaviour, speech or learning.

[[NICE’s guideline on epilepsies in children young people and adults](https://www.nice.org.uk/guidance/ng217), recommendation 3.1.4]

### All other people referred

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](https://www.nice.org.uk/guidance/ng217), recommendation 3.1.3]

## Equality and diversity considerations

People with a learning disability or a mental health problem may find it difficult to access tertiary services if their comorbidities overshadow their epilepsy needs. People with these 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 or an advocate if the person wishes
* 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](https://www.england.nhs.uk/ourwork/accessibleinfo/) 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 play a key role in ensuring continuity of care for people with epilepsy. 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 by helping them understand care plans
* provide training and advice on epilepsy and acute seizure management
* have a central role in care planning, transition to adult services and supporting people to manage epilepsy by providing help, advice and support.

## 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 Epilepsy12 audit of seizures and epilepsies for children and young people](https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit) 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?](https://www.hqip.org.uk/resource/ncepod-disordered-activity-2022/) 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 with epilepsy who have the contact details of a named epilepsy specialist nurse.

Numerator – the number of people in the denominator who have the contact details of a named epilepsy specialist nurse.

Denominator – the number of people with a diagnosis of epilepsy.

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected locally using patient surveys or surveys of people with epilepsy.

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.

### Outcome

Health-related quality of life for people diagnosed with epilepsy.

**Data source:** Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, a survey of people with epilepsy using a quality of life questionnaire. The [Neurological Alliance’s National Neuro Patient Experience Survey](https://www.neural.org.uk/togetherforthe1in6/) includes a national level quality of life score for people with epilepsy.

## 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.

**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](https://www.nice.org.uk/guidance/ng217) (2022), recommendation 11.1.1

## Definitions of terms used in this quality statement

### Epilepsy specialist nurse

A clinical nurse specialist in supporting children, young people and adults with all aspects of living with epilepsy. This includes 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](https://www.nice.org.uk/guidance/ng217), box 1 for recommendation 2.1.11, rationale for recommendations 11.1.1 to 11.1.4]

## Equality and diversity considerations

People with epilepsy who are older, have a learning disability, have other complex needs 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 advocate or interpreter if the person wishes
* 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](https://www.england.nhs.uk/ourwork/accessibleinfo/) or the equivalent standards for the devolved nations.

# Quality statement 4: Epilepsy care plan

## Quality statement

People with epilepsy have an up-to-date 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 epilepsy care plan.

Numerator – the number in the denominator who have an up-to-date 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 who, at the time of auditing, had evidence of a care plan that had been both updated within the last year 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](https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit).

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:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records.

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

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

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

**Data source:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records.

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:** No routinely collected national data for this measure has been identified. Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records.

### Outcome

Proportion of people with epilepsy who feel fully involved in making choices about their health care.

Numerator – the number in the denominator who feel fully involved in making choices about their health care.

Denominator – the number of people with epilepsy.

**Data source:**Data can be collected from information collected locally by healthcare professionals and provider organisations, for example, from patient surveys. The [Neurological Alliance’s National Neuro Patient Experience Survey](https://www.neural.org.uk/togetherforthe1in6/) presents information on the proportion of adults with epilepsy who feel fully involved in making choices about their health care.

## 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, 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.

**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](https://www.nice.org.uk/guidance/ng217) (2022), recommendation 2.1.7

## Definitions of terms used in this quality statement

### Up-to-date epilepsy care plan

The epilepsy care plan should be a comprehensive written record of the decisions made about the person's past, present and future care.

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. A local template or checklist should be developed to ensure consistency in the content of each epilepsy care plan. The plan should include an agreed date for review.

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
* an emergency care plan for prolonged seizures (if there have been previous prolonged seizures), including instructions regarding the timing and administration of rescue medication
* regular medication, including adherence to antiseizure medication, experiences of side effects from medication and coping strategies
* name and contact details of the epilepsy team (including epilepsy specialist nurse, consultant responsible for their care, primary care doctor)
* comorbidities, including learning disability and mental health problems
* activities that should be adapted or avoided to reduce risk
* goals of the person with epilepsy
* care and supervision requirements along with contact details
* reproductive health and pregnancy, if appropriate, including contraception, changes in medications, teratogenicity of antiseizure medications, pre-conception planning, planning the birth, postnatal care and breastfeeding
* reducing epilepsy-related risks, including sudden unexpected death in epilepsy.

[Adapted from [NICE’s guideline on epilepsies in children young people and adults](https://www.nice.org.uk/guidance/ng217) recommendations 2.1.6 and 2.1.11 and expert opinion]

## Equality and diversity considerations

People with epilepsy who are older, have a learning disability, have other complex needs 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 advocate or interpreter if the person wishes
* 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](https://www.england.nhs.uk/ourwork/accessibleinfo/) or the equivalent standards for the devolved nations.

In this statement we use the term 'women of childbearing potential' based on the source guidance used in its development. The term also applies to people of childbearing potential who do not identify as women.

# Quality statement 5: Psychological, neurobehavioural, cognitive and developmental comorbidities

## Quality statement

People with epilepsy are asked, at epilepsy appointments, about their cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities. **[new 2023]**

## Rationale

There is a higher prevalence of mental health problems, learning disabilities, neurodevelopmental comorbidities (for example, attention deficit hyperactivity disorder and autism spectrum disorder), dementia, and a higher risk of suicide in people with epilepsy compared with the general population. Some of the treatments aimed at controlling seizures can also have an adverse effect on some people, for example affecting cognitive function, behaviour and alertness. 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, educational psychology and learning disability 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](https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/epilepsy12-audit) contains information on trusts which have referral pathways for children and young people with epilepsy who have mental health concerns.

### Process

Proportion of epilepsy clinic appointments where people are asked about cognitive function, mental health, social and emotional wellbeing and, where relevant, neurodevelopment and learning disabilities.

Numerator – the number in the denominator in which people are asked about cognitive function, mental health, social and emotional wellbeing and, where relevant, neurodevelopment and learning disabilities.

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

**Data source:** No routinely collected national data for this measure has been identified. 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) 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 and learning disability services to ensure access to more specific assessments and treatment. They ensure that epilepsy appointments include discussions about cognitive function, mental health, and social and emotional wellbeing and, if appropriate, neurodevelopment and learning disabilities.

**Healthcare professionals** (neurologists, paediatric neurologists, paediatricians, epilepsy specialist nurses) ask people, at epilepsy appointments, about their cognitive function, mental health, social and emotional wellbeing and, where relevant, neurodevelopment and learning disabilities. They advise on how any problems can be addressed and, if necessary, refer people for specialist assessments (such as neurodevelopmental assessment, cognitive assessment), treatment and care to mental health, neuropsychology, educational psychology or learning disability services.

**Commissioners** commission epilepsy services that discuss cognitive function, mental health, social and emotional wellbeing and, where relevant, neurodevelopment and learning disabilities, at epilepsy appointments. They work with service providers to develop referral pathways between epilepsy, mental health and learning disability services.

**People with epilepsy** are asked about their 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 assessments, treatment or care is needed. The epilepsy care team of people with a disability (such as a learning disability, autism or dementia) 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](https://www.nice.org.uk/guidance/ng217) (2022), recommendation 9.2.2

## Definitions of terms used in this quality statement

### Epilepsy appointment

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

[Adapted from [NICE’s guideline on epilepsies in children young people and adults](https://www.nice.org.uk/guidance/ng217), recommendations 4.5.1, 4.5.2, 4.5.4, 11.1.3 and expert opinion]

### Cognitive function, mental health, social and emotional wellbeing

Asking people about cognitive function, mental health, social and emotional wellbeing includes asking people with epilepsy or their parents or carers about the person with epilepsy’s:

* daily functioning, wellbeing and quality of life
* language, learning, memory, concentration and attention
* social skills
* behaviour
* play (in the case of children)
* mental health
* mood
* symptoms of anxiety and depression
* possible difficulties and how they have changed over time.

Initial enquiries and changes since the last appointment are included. Formal or specialist assessments such as an assessment of cognitive function, a neurodevelopmental assessment, assessment for attention deficit hyperactivity disorder are not included.

[Expert opinion]

### Neurodevelopment and learning disabilities

Asking people, where relevant, about neurodevelopmental conditions and learning disabilities, means asking people with these conditions or disabilities, and their parents, carers or advocates if appropriate, about changes in their condition or disability that may affect their epilepsy treatment.

[Expert opinion]

## Equality and diversity considerations

People with epilepsy who are older, have a learning disability, have other complex needs 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 advocate or interpreter if the person wishes
* 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](https://www.england.nhs.uk/ourwork/accessibleinfo/) or the equivalent standards for the devolved nations.

## Questions for consultation

Are there specific types of epilepsy appointments that should be included or excluded from this statement?

Is there enough time and capacity at epilepsy appointments to ask about cognitive function, mental health, social and emotional wellbeing and, where relevant, neurodevelopment and learning disabilities?

Statement 5 covers cognitive function, mental health, social and emotional wellbeing, and, where relevant, neurodevelopment and learning disabilities. It also covers all people with epilepsy. Would it be helpful to focus the statement on a smaller number of areas or a particular population group? If so, what should it focus on?

What is an appropriate outcome measure for this statement? Please include any known data sources for suggestions.

# Update information

**June 2023:** This quality standard was updated and statements prioritised in 2013 were replaced. The topic was identified for update following 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.

# 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](https://www.nice.org.uk/standards-and-indicators/timeline-developing-quality-standards) is available from the NICE website.

See our [webpage on quality standards advisory committees](http://www.nice.org.uk/Get-Involved/Meetings-in-public/Quality-Standards-Advisory-Committee) 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](https://www.nice.org.uk/guidance/indevelopment/gid-qs10162).

NICE has produced a [quality standard service improvement template](https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-uptake-of-nice-guidance) 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.](https://www.nice.org.uk/guidance/ng217/resources)

## Diversity, equality and language

Equality issues were considered during development and [equality assessments for this quality standard](https://www.nice.org.uk/guidance/indevelopment/gid-qs10162/documents) 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.

ISBN:

© NICE 2023. All rights reserved. Subject to [Notice of rights](https://www.nice.org.uk/terms-and-conditions#notice-of-rights).