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Health and Care Excellence

Epilepsy in adults

Quality standard
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This standard is replaced by QS211.

This standard is based on CG137.

This standard should be read in conjunction with QS15, QS27, QS71 and QS101.

Quality statements

Statement 1 Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Statement 2 Adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Statement 3 Adults who meet the criteria for neuroimaging for epilepsy have MRI.

Statement 4 Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.

Statement 5 Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Statement 6 Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Statement 7 Adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Statement 8 Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.

Statement 9 Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Quality statement 1: Referral to a specialist

Quality statement

Adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Rationale

Diagnosing epilepsy can be complex, and it has been estimated that misdiagnosis occurs in 5% to 30% of people. It is therefore crucial that specialists are involved early in diagnosing epilepsy and that they take great care to establish the correct diagnosis.

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 arrangements for adults presenting with a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Data source: Local data collection.

Process

a) Proportion of adults presenting with a suspected seizure who are seen by a specialist in the diagnosis and management of the epilepsies.

Numerator – the number of people in the denominator who are seen by a specialist in the diagnosis and management of the epilepsies.

Denominator – the number of adults presenting with a suspected seizure.

Data source: Local data collection.

b) Proportion of adults presenting with a suspected seizure who are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

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

Denominator – the number of adults presenting with a suspected seizure seen by a specialist in the diagnosis and management of the epilepsies.

Data source: Local data collection.

Outcome

a) Diagnosis of epilepsy that is subsequently found to be incorrect.

Data source: Local data collection.

b) Diagnosis of a condition that is subsequently found to be epilepsy.

Data source: Local data collection.

c) Number of adults with a recorded seizure type and/or syndrome.

Data source: Local data collection.

What the quality statement means for different audiences

Serviceproviders ensure systems are in place for adults presenting with a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Healthcare professionals ensure that adults presenting with a suspected seizure are seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Commissioners ensure they commission services for adults presenting with a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

Adults who have a suspected seizure are seen by a doctor with training and expertise in diagnosing and treating epilepsy within 2 weeks.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012, updated 2021), recommendations 1.4.5 (key priority for implementation), 1.4.1 and 1.4.2

Definitions of terms used in this quality statement

Suspected seizure

A suspected epileptic seizure is a reported acute episode of altered functioning, 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.

Specialist in diagnosis and management

A specialist in the diagnosis and management of the epilepsies is a medical practitioner (a consultant neurologist or consultant with epilepsy expertise), who has epilepsy as a significant part of their workload (at least the equivalent of 1 session a week) with training and continuing education in epilepsy, usually working as part of a specialist epilepsy team.

Quality statement 2: Investigations

Quality statement

Adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Rationale

The period between the suspected seizure occurring and diagnosis can be a particularly anxious time for patients and families and it is therefore important that investigations are conducted in a timely manner. The earlier a correct diagnosis of epilepsy is made, the sooner tailored therapy can be initiated. Delays caused by a lack of available diagnostic equipment can lead to distress and impact negatively on the everyday lives of patients.

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 arrangements for adults having initial investigations for epilepsy to undergo the tests within 4 weeks of them being requested.

Data source: Local data collection.

Process

Proportion of adults having initial investigations for epilepsy who undergo the tests within 4 weeks of them being requested.

Numerator – the number of people in the denominator who undergo the tests within

4 weeks of the request.

Denominator – the number of adults having initial investigations for epilepsy.

Data source: Local data collection.

Outcome

Patient satisfaction with the length of time between tests being arranged and the tests being performed.

Data source: Local data collection.

What the quality statement means for different audiences

Serviceproviders ensure systems are in place for adults having initial investigations for epilepsy to undergo the tests within 4 weeks of them being requested.

Healthcareprofessionals ensure that adults having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

Commissioners ensure they commission services for adults having initial investigations for epilepsy to undergo the tests within 4 weeks of them being requested.

Adultshavingtheirfirsttestsforepilepsy have the tests within 4 weeks of them being requested by the doctor.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012, updated 2021), recommendations 1.6.3 and 1.6.22

Definitions of terms used in this quality statement

Initial investigations

Initial investigations for epilepsy include electroencephalogram (EEG) and MRI, as appropriate.

Tests

Tests such as long-term video or ambulatory EEG, which might be used in the assessment of adults in whom there are difficulties with diagnosis after clinical assessment and standard EEG, might not be possible within this timeframe.

Test results should be interpreted by practitioners who have the necessary competencies.

Information should be provided to adults and families and/or carers as appropriate on the reasons for the tests, their results and meaning, the requirements of specific investigations, and the logistics of obtaining them.

Equality and diversity considerations

Adults with learning disabilities or challenging behaviour might need particular care and attention to help them tolerate investigations. The same services and investigations should be offered to adults with learning disabilities as are offered to the general population.

Quality statement 3: Magnetic resonance imaging

Quality statement

Adults who meet the criteria for neuroimaging for epilepsy have MRI.

Rationale

MRI is shown by evidence to be the most sensitive and specific neuroimaging option in terms of identifying structural abnormalities in the brain, but access to MRI scanning and reporting facilities varies across the country.

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

a) Evidence of local arrangements for adults who meet the criteria for neuroimaging for epilepsy to have MRI.

Data source: Local data collection.

b) Evidence of local arrangements for adults with learning disabilities who meet the criteria for neuroimaging for epilepsy to have MRI.

Data source: Local data collection.

Process

Proportion of adults who meet the criteria for neuroimaging for epilepsy who have MRI.

Numerator – the number of people in the denominator who have MRI.

Denominator – the number of adults who meet the criteria for neuroimaging for epilepsy.

Data source: Local data collection.

What the quality statement means for different audiences

Serviceproviders ensure systems are in place for adults who meet the criteria for neuroimaging for epilepsy to have MRI.

Healthcareprofessionals ensure that adults who meet the criteria for neuroimaging for epilepsy have MRI.

Commissioners ensure they commission services for adults who meet the criteria for neuroimaging for epilepsy to have MRI.

Adultswhoarehavingneuroimaging(takingpicturesofthebrain)forepilepsy have magnetic resonance imaging (a type of neuroimaging that uses magnetic fields to produce a picture of the brain, often shortened to MRI).

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012, updated 2021), recommendation 1.6.20

Definitions of terms used in this quality statement

Neuroimaging

Neuroimaging should be used to identify structural abnormalities that cause certain epilepsies. People diagnosed with idiopathic generalised epilepsy are unlikely to have any aetiologically relevant structural abnormalities and should not therefore undergo neuroimaging.

MRI

The criteria for MRI in adults are new-onset epilepsy or failure of first-line medication, unless there is a clear diagnosis of idiopathic generalised epilepsy.

In acute situations, CT may be used to determine whether a seizure has been caused by an acute neurological lesion or illness.

Equality and diversity considerations

The same services, investigations and therapies should be offered to adults with learning disabilities or challenging behaviour as are offered to the general population.

Adults with learning disabilities or challenging behaviour might need particular care and attention to help them tolerate investigations. Reasonable adjustment, such as offering open-bed scanners, sedation or general anaesthesia, should be made if necessary to ensure all people who need MRI have access to it.

Quality statement 4: Epilepsy care plan

Quality statement

Adults with epilepsy have an agreed and comprehensive written epilepsy care plan.

Rationale

There are a number of potential lifestyle, health and wellbeing implications directly related to epilepsy. A care plan is an important tool in ensuring that all aspects of a person's life that could be affected by their epilepsy syndrome and the treatment they are receiving are considered and addressed.

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 arrangements for adults with epilepsy to have an agreed and comprehensive written epilepsy care plan.

Data source: Local data collection.

Process

a) Proportion of adults with epilepsy who have an agreed and comprehensive written epilepsy care plan.

Numerator – the number of people in the denominator who have an agreed and comprehensive written epilepsy care plan.

Denominator – the number of adults with epilepsy.

Data source: Local data collection.

b) Proportion of adults with an epilepsy care plan who feel they have been involved in developing and agreeing their plan.

Numerator – the number of people in the denominator who feel they have been involved in developing and agreeing their plan.

Denominator – the number of adults with an epilepsy care plan.

Data source: Local data collection.

Outcome

Patient satisfaction with involvement in the epilepsy care planning process.

Data source: Local data collection.

What the quality statement means for different audiences

Serviceproviders ensure that systems are in place for adults with epilepsy to have an agreed and comprehensive written epilepsy care plan.

Healthcareprofessionals ensure that adults with epilepsy have an agreed and comprehensive written epilepsy care plan.

Commissioners ensure they commission services for adults with epilepsy to have an agreed and comprehensive written epilepsy care plan.

Adultswithepilepsy have a written epilepsy care plan that includes details about treatment and any preferences and lifestyle issues and is agreed between them and their healthcare team.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012, updated 2021), recommendations 1.3.1 and 1.8.2

Definitions of terms used in this quality statement

Comprehensive written epilepsy care plan

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

It should be discussed and agreed between the adult with epilepsy, their family and/or carers if appropriate and 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 based on NICE's guideline on epilepsies, recommendation 1.3.1. The plan should be reviewed at least annually.

The care plan should include any issues relating to the following topics:

- epilepsy in general
- the person's specific epilepsy syndrome
- diagnosis and treatment options
- medication and side effects
- seizure type(s), triggers and seizure control
- management and self-care
- risk management
- first aid, safety and injury prevention at home and at college or work
- psychological issues
- social security benefits and social services

- insurance issues
- education and healthcare at college
- employment and independent living for adults
- importance of disclosing epilepsy in college or at work, if relevant (if further information or clarification is needed, voluntary organisations should be contacted)
- road safety and driving
- prognosis
- sudden unexpected death in epilepsy (SUDEP)
- status epilepticus
- lifestyle, leisure and social issues (including recreational drugs, alcohol, sexual activity and sleep deprivation)
- family planning and pregnancy
- voluntary organisations, such as support groups and charitable organisations, and how to contact them.

[Adapted from NICE's guideline on epilepsies, recommendation 1.3.1]

Equality and diversity considerations

Consideration should be given to the capacity of someone with epilepsy to be involved in agreeing their epilepsy care plan. Best interest decision making, in accordance with the Mental Capacity Act, should be adhered to.

Quality statement 5: Epilepsy specialist nurse

Quality statement

Adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Rationale

Epilepsy specialist nurses play a key role in supporting continuity of care between settings for people with epilepsy. There is some evidence that epilepsy specialist nurses improve clinically important outcomes such as knowledge, anxiety and depression for people with epilepsy in secondary and tertiary care.

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 arrangements for adults with epilepsy to be seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Data source: Local data collection.

Process

a) Proportion of adults with epilepsy who have seen a named epilepsy specialist nurse at diagnosis.

Numerator – the number of adults in the denominator who have seen an epilepsy specialist nurse at diagnosis.

Denominator – the number of adults with epilepsy.

Data source: Local data collection.

b) Proportion of adults with epilepsy who have seen an epilepsy specialist nurse at their review.

Numerator – the number of people in the denominator who have seen an epilepsy specialist nurse at their review.

Denominator – the number of adults with epilepsy.

Data source: Local data collection.

c) Proportion of adults with epilepsy who have the contact details of a named epilepsy specialist nurse.

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

Denominator – the number of adults with epilepsy.

Data source: Local data collection.

Outcome

Patient satisfaction with access to epilepsy specialist nursing.

Data source: Local data collection.

What the quality statement means for different audiences

Serviceproviders ensure that systems are in place for adults with epilepsy to be seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Healthcareprofessionals ensure that adults with epilepsy are seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Commissioners ensure they commission services for adults with epilepsy to be seen by an epilepsy specialist nurse who they can contact between scheduled reviews.

Adultswithepilepsy see an epilepsy specialist nurse (a nurse who has training and experience in caring for people with epilepsy) who they can contact between scheduled reviews.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012, updated 2021), recommendation 1.8.3

Definitions of terms used in this quality statement

Epilepsy specialist nurse

The role of the epilepsy specialist nurse is to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the adult, and their families or carers where appropriate.

Epilepsy specialist nursing may be provided in a number of different teams, for example the learning disabilities team.

At diagnosis in this context means within 3 months of the epilepsy diagnosis being confirmed.

[Adapted from NICE's guideline on epilepsies, recommendation 1.8.3, and expert opinion]

Quality statement 6: Prolonged or repeated seizures

Quality statement

Adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Rationale

An emergency care plan is an important tool in improving the quality of emergency care in the community. It ensures that previous incidents and the agreed treatment strategies are taken into account by healthcare professionals. It also provides guidance for family members or carers who may need to administer emergency treatment. The timely and appropriate management of a prolonged or repeated seizure may significantly reduce the risk of mortality and morbidity (long-term complications) known to be associated with prolonged or repeated seizures.

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 arrangements for adults with a history of prolonged or repeated seizures to have an agreed written emergency care plan.

Data source: Local data collection.

Process

Proportion of adults with a history of prolonged or repeated seizures who have an agreed written emergency care plan.

Numerator – the number of people in the denominator who have an agreed written emergency care plan.

Denominator – the number of adults with a history of prolonged or repeated seizures.

Data source: Local data collection.

Outcome

a) Accident and emergency attendances for prolonged or repeated seizures.

Data source: The NHS hospital episode statistics contain the data necessary for the monitoring of accident and emergency attendances.

b) Hospital admissions for prolonged or repeated seizures.

Data source: Local data collection.

c) Patient satisfaction with emergency care for prolonged or repeated seizures.

Data source: Local data collection.

What the quality statement means for different audiences

Serviceproviders ensure systems are in place for adults with a history of prolonged or repeated seizures to have an agreed written emergency care plan.

Healthcareprofessionals ensure that adults with a history of prolonged or repeated seizures have an agreed written emergency care plan.

Commissioners ensure they commission services for adults with a history of prolonged or repeated seizures to have an agreed written emergency care plan.

Adults who have had a prolonged seizure (a seizure that lasted 5 minutes or longer) or

repeated seizures (3 or more seizures within 1 hour) have a written emergency care plan agreed with their healthcare team that sets out how they should be cared for if they have prolonged or repeated seizures again.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012, updated 2021), recommendation 1.14.1.4

Definitions of terms used in this quality statement

Prolonged or repeated seizures

Prolonged seizures are seizures that last 5 minutes or more. Repeated seizures are seizures that occur 3 times or more within 1 hour.

Any adult with epilepsy who has experienced a prolonged or repeated seizure is considered to have a history of prolonged or repeated seizures.

Agreed written emergency care plan

An agreed written emergency care plan should describe what happens in the event of a prolonged or repeated seizure, including pharmacological treatment that should be given and actions to take, who to contact and when. It should be agreed between the adult with epilepsy, their family and/or carers if appropriate and their primary and secondary healthcare professionals. Family members and/or carers of adults with epilepsy will need training in order to initiate treatment at home or in the community when necessary. The plan should be reviewed at least annually.

Quality statement 7: Referral to tertiary care

Quality statement

Adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Rationale

Tertiary referrals can be vital for a number of reasons such as diagnostic uncertainty, specialised advice on drugs, surgery, epilepsy combined with other complicated medical conditions or psychological problems. Timely and appropriate access to tertiary services remains variable across the country.

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 arrangements for adults who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks of referral.

Data source: Local data collection.

Process

Proportion of adults who meet the criteria for referral to a tertiary care specialist 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 adults who meet the criteria for referral to a tertiary care specialist.

Data source: Local data collection.

Outcome

Patient satisfaction with referral to a tertiary care specialist.

Data source: Local data collection.

What the quality statement means for different audiences

Serviceproviders ensure systems are in place for adults who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks of referral.

Healthcareprofessionals ensure that adults who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

Commissioners ensure they commission services for adults who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks of referral.

Adultswhomeetthecriteriaforreferraltoatertiarycarespecialist (someone who works as part of a specialist centre with a team of healthcare professionals experienced in assessing epilepsy that is hard to treat or complicated) are seen within 4 weeks of referral.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012, updated 2021), recommendation 1.10.2

Definitions of terms used in this quality statement

Referral to a tertiary care specialist

Referral to tertiary services should be considered when one or more of the following criteria are present:

- the epilepsy is not controlled with medication within 2 years of onset
- management is unsuccessful after 2 drugs
- the adult experiences, or is at risk of, unacceptable side effects from medication
- there is a unilateral structural lesion
- there is psychological or psychiatric comorbidity
- there is diagnostic doubt as to the nature of the seizures or the seizure syndrome.

A tertiary care specialist in epilepsy is an adult or paediatric neurologist who devotes the majority of their working time to epilepsy, is working in a multidisciplinary tertiary referral centre with appropriate diagnostic and therapeutic resources, and is subject to regular peer review.

[Adapted from NICE's guideline on epilepsies, recommendation 1.10.2, and expert opinion]

Quality statement 8: Re-access to specialist care

Quality statement

Adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.

Rationale

People living with epilepsy may need to seek expert opinion if there are changes in their medical situation or they have lifestyle issues that are affected by their epilepsy or its treatment. It is important that they are able to have timely reviews by specialists to address any issues and receive accurate information to help them make informed choices.

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 arrangements for adults with epilepsy who have medical or lifestyle issues that need review to be referred to specialist epilepsy services.

Data source: Local data collection.

Process

Proportion of adults with epilepsy who have medical or lifestyle issues that need review who are referred to specialist epilepsy services.

Numerator – the number of people in the denominator who are referred to specialist epilepsy services.

Denominator – the number of adults with epilepsy who have medical or lifestyle issues that need review.

Data source: Local data collection.

What the quality statement means for different audiences

Serviceproviders ensure systems are in place for adults with epilepsy who have medical or lifestyle issues that need review to be referred to specialist epilepsy services.

Healthcareprofessionals ensure that adults with epilepsy who have medical or lifestyle issues that need review are referred to specialist epilepsy services.

Commissioners ensure they commission services for adults with epilepsy who have medical or lifestyle issues that need review to be referred to specialist epilepsy services.

Adultswithepilepsywhocontinuetohaveseizures,havesideeffectsfrommedicationorneedspecialis are referred to specialist epilepsy services for a review.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012, updated 2021), recommendation 1.20.7 (key priority for implementation)

Definitions of terms used in this quality statement

Medical or lifestyle issues

Medical or lifestyle issues that need review by a specialist include:

- diagnostic uncertainty
- pregnancy

- consideration of drug withdrawal
- recurrence of seizures
- side effects of medication.

Any healthcare professional the person with epilepsy sees may determine that they need a specialist review, for example a GP, nurse or hospital doctor.

Specialist epilepsy services

Specialist epilepsy services include secondary care services, tertiary services and specialist epilepsy nursing, which may be based in the community. The service that is most appropriate to provide the review will depend on the particular medical or lifestyle issue.

Quality statement 9: Transition from children's to adult services

Quality statement

Young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Rationale

The need for continuity of care during transition from paediatric to adult services is particularly important for young people managing the physical and mental transition from adolescence to adulthood. Good management of this transition period by healthcare professionals is vital to develop and maintain the self-esteem and confidence of the adolescent with epilepsy. It also provides an important opportunity to review the diagnosis, classification, cause and management of a young person's epilepsy before they enter adulthood.

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 arrangements for young people with epilepsy to have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Data source: Contained within the Royal College of Paediatrics and Child Health (RCPCH) Epilepsy12 national audit.

Process

Proportion of young people with epilepsy who are being discharged from paediatric epilepsy services who had an agreed transition period between paediatric and adult services.

Numerator – the number of people in the denominator who had an agreed transition period between paediatric and adult services.

Denominator – the number of young people with epilepsy who are no longer being cared for by paediatric services.

Data source: Local data collection.

Outcome

Young people's experience of transition to adult services.

Data source: Local data collection.

What the quality statement means for different audiences

Serviceproviders ensure systems are in place for young people with epilepsy to have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Healthcareprofessionals ensure young people with epilepsy have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Commissioners ensure they commission services for young people with epilepsy to have an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.

Youngpeoplewithepilepsywhoarechangingoverfromchildren'stoadulthealthcareservices have a period of time when they are supported by both children's and adult services so that the changeover is handled smoothly.

Source guidance

Epilepsies: diagnosis and management. NICE guideline CG137 (2012, updated 2021), recommendation 1.17.5.

Definitions of terms used in this quality statement

Joint review

The purpose of the joint review is to optimise care and treatment for young people with epilepsy and help their move into adult services.

The period of transition should be a joint clinical action between paediatric and adults services, with at least 1 meeting at a joint consultation and a clear action plan for conducting a review after the young person has transferred into adult services.

Equality and diversity considerations

People with learning disabilities might need a longer transition period to accommodate the additional complexity of their clinical and psychological needs. In addition, people with learning disabilities might remain in paediatric services for longer than those without learning disabilities, depending on their personal preferences, ability to manage their own condition and clinical needs.

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.

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.

Good communication between health and social care professionals and adults with epilepsy is essential. Treatment and care, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. Adults with epilepsy should have access to an interpreter or advocate if needed.

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Supporting organisations

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

- Association of British Neurologists (ABN)
- Epilepsy Action
- Epilepsy Society
- Royal College of General Practitioners (RCGP)
- Royal College of Physicians (RCP)