

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Draft quality standard for the epilepsies in adults

1 Introduction

Epilepsy is a common neurological disorder characterised by recurring seizures. [The joint epilepsy council](#) (2011) estimates that approximately 496,000 adults in England have epilepsy. There are over 40 different types of epilepsy, with 40 different associated seizure types. The nature of epilepsy means that it can be difficult to diagnose accurately. The joint epilepsy council (2011) reported that misdiagnosis rates in the United Kingdom, where diagnosis of epilepsy is incorrectly made, are between 20-31%. A diagnosis of epilepsy can have a wide-ranging impact on a person's health and lifestyle. A key part of this quality standard is therefore focused on improving the diagnosis of epilepsy and ensuring that diagnosis and treatment is confirmed and reviewed as necessary.

For many adults diagnosed with epilepsy the seizures can be controlled through treatment with an anti-epileptic drug or other interventions. Optimal management improves health outcomes and can help to minimise other, often detrimental, impacts on social, educational and employment activity. This quality standard therefore includes a focus on tailoring treatment to the individual circumstances and needs of people with epilepsy so that they are offered the most suitable treatment.

This quality standard covers the diagnosis and management of the epilepsies in adults (aged 18 years and older). For more information see the [scope](#).

This draft quality standard describes markers of high-quality, cost-effective care that, when delivered collectively, should contribute to improving the

effectiveness, safety and experience of care for adults with epilepsy in the following ways:

- Preventing people from dying prematurely.
- Enhancing quality of life for people with long-term conditions.
- Helping people to recover from episodes of ill health or following injury.
- Ensuring that people have a positive experience of care.
- Treating and caring for people in a safe environment and protecting them from avoidable harm.

These overarching outcomes are from [The NHS Outcomes Framework 2012/13](#).

2 Draft quality standard for the epilepsies in adults

Overview

The draft quality standard for the epilepsies in adults specifies that services should be commissioned from and coordinated across all relevant agencies encompassing the whole epilepsy care pathway. An integrated approach to provision of services is fundamental to the delivery of high quality care to adults with epilepsy, and the quality standard should be delivered by multidisciplinary teams through a local epilepsy clinical network.

The quality standard should be read in the context of national and local guidelines on training and competencies. Implementation of this quality standard is based on all healthcare professionals involved in the diagnosis and management of the epilepsies in adults having sufficient and appropriate training, and competence to deliver the actions and interventions described in the quality standard.

No.	Draft quality statements
1	Adults presenting with a first unprovoked seizure are seen by a specialist in the management of the epilepsies within 2 weeks of presentation.
2	Adults having investigations for epilepsy are told the results within 4 weeks of the tests being requested.
3	Adults who need neuro-imaging for epilepsy have magnetic resonance imaging.
4	Adults with uncontrolled seizures, diagnostic uncertainty or treatment failure are referred to a tertiary care specialist and seen within 4 weeks of referral.
5	Adults with a history of prolonged or repeated seizures have a personalised written emergency care plan.
6	Adults with epilepsy have an agreed, comprehensive, personalised written epilepsy care plan.
7	Adults with epilepsy have ongoing access to safety information about their epilepsy syndrome, seizure type(s) and treatment.
8	Adults with well-controlled epilepsy are referred to secondary care if they have specific medical or lifestyle issues that require review by a specialist in

	the management of the epilepsies.
9	Adults with epilepsy are cared for by a clinical team that provides epilepsy specialist nursing.
10	Young people with epilepsy who are due to transfer to adult services have a transition period where their continuing epilepsy care is reviewed jointly by paediatric and adult services.

In addition, quality standards that should also be considered when commissioning and providing a high-quality epilepsy service are listed in section 7.

General questions for consultation:

Question 1	Can you suggest any appropriate healthcare outcomes for each individual quality statement?
Question 2	What important areas of care, if any, are not covered by the quality standard?
Question 3	What, in your opinion, are the most important quality statements and why?
Question 4	Are any of the proposed quality measures inappropriate and, if so, can you identify suitable alternatives?
Please refer to Quality standards in development for additional general points for consideration (available from www.nice.org.uk).	

Statement-specific questions for consultation:

Question 5	For draft quality statement 4: Which element of this statement do you consider to be the key area for quality improvement, that is what is not happening now that should be? Is it referral to a tertiary care specialist being made quickly for people with uncontrolled seizures, diagnostic uncertainty or treatment failure? Or is it that those people are seen by a tertiary care specialist quickly once a referral has been made?
Question 6	Two quality standards concerning the epilepsies have been developed concurrently. One covers the care of children and young people; the other covers the care of adults. Would it be more useful if the two standards were merged together to become one product or is it more appropriate for the two standards to remain as 2 standalone products?

Draft quality statement 1: Referral to a specialist

Draft quality statement	Adults presenting with a first unprovoked seizure are seen by a specialist in the management of the epilepsies within 2 weeks of presentation.
Draft quality measure	<p>Structure: Evidence of local arrangements for adults presenting with a first unprovoked seizure to be seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p> <p>Process:</p> <p>a) Proportion of adults presenting with a first unprovoked seizure who are seen by a specialist in the management of the epilepsies.</p> <p>Numerator – the number of people in the denominator who are seen by a specialist in the management of the epilepsies.</p> <p>Denominator – the number of adults presenting with a first unprovoked seizure.</p> <p>b) Proportion of adults presenting with a first unprovoked seizure who are seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p> <p>Numerator – the number of people in the denominator who are seen within 2 weeks of presentation.</p> <p>Denominator – the number of adults presenting with a first unprovoked seizure seen by a specialist in the management of the epilepsies.</p> <p>Outcome:</p> <p>a) Diagnosis of epilepsy that is subsequently found to be incorrect.</p> <p>b) Diagnosis of a condition that is subsequently found to be epilepsy.</p> <p>c) Number of people with a recorded seizure type and/or syndrome.</p>
Description of what the quality statement means for each audience	<p>Service providers ensure systems are in place for adults presenting with a first unprovoked seizure to be seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p> <p>Healthcare professionals ensure that adults presenting with a first unprovoked seizure are seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p> <p>Commissioners ensure they commission services for adults presenting with a first unprovoked seizure to be seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p> <p>Adults who have a first unprovoked seizure are seen by a specialist in the management of epilepsies (a doctor with training</p>

	and expertise in diagnosing and treating epilepsy) within 2 weeks.
Source clinical guideline references	NICE clinical guideline 137 recommendations 1.4.5 (key priority for implementation), 1.4.1 and 1.4.2.
Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome: a), b) and c) Local data collection.</p>
Definitions	<p>Unprovoked seizures are those without any immediate acute identifiable cause (such as acute stroke or a head injury).</p> <p>A specialist in the management of the epilepsies is a medical practitioner, for example a consultant (usually a neurologist), who has epilepsy as a significant part of their workload (at least one session a week) with training and continuing education in epilepsy, usually working as part of a specialist epilepsy team.</p>

Draft quality statement 2: Investigations

Draft quality statement	Adults having investigations for epilepsy are told the results within 4 weeks of the tests being requested.
Draft quality measure	<p>Structure: Evidence of local arrangements for adults having investigations for epilepsy to be told the results within 4 weeks of the tests being requested.</p> <p>Process: Proportion of adults having investigations for epilepsy who are told the results within 4 weeks of the tests being requested.</p> <p>Numerator – the number of people in the denominator who are told the results within 4 weeks of the tests being requested.</p> <p>Denominator – the number of adults having investigations for epilepsy.</p> <p>Outcome: Patient satisfaction with the length of time between tests being arranged and the results being told to them.</p>
Description of what the quality statement means for each audience	<p>Service providers ensure systems are in place for adults having investigations for epilepsy to be told the results within 4 weeks of the tests being requested.</p> <p>Healthcare professionals ensure that adults having investigations for epilepsy are told the results within 4 weeks of the tests being requested.</p> <p>Commissioners ensure they commission services for adults having investigations for epilepsy to be told the results within 4 weeks of the tests being requested.</p> <p>Adults having investigations for epilepsy are told the results within 4 weeks of the tests being requested.</p>
Source clinical guideline references	NICE clinical guideline 137 recommendations 1.6.3 and 1.6.22.
Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	<p>Investigations for epilepsy include electroencephalogram (EEG), magnetic resonance imaging (MRI) and blood tests, as appropriate.</p> <p>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.</p> <p>Tests that need interpretation should be interpreted by</p>

	practitioners who have the necessary competencies.
Equality and diversity considerations	Adults with learning disabilities 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.

Draft quality statement 3: Magnetic Resonance Imaging

Draft quality statement	Adults who need neuro-imaging for epilepsy have magnetic resonance imaging.
Draft quality measure	<p>Structure:</p> <p>a) Evidence of local arrangements for adults who need neuro-imaging to have magnetic resonance imaging.</p> <p>b) Evidence of local arrangements for adults with learning disabilities who need neuro-imaging for epilepsy to have magnetic resonance imaging.</p> <p>Process: Proportion of adults who need neuro-imaging for epilepsy who have magnetic resonance imaging.</p> <p>Numerator – the number of people in the denominator who have magnetic resonance imaging.</p> <p>Denominator – the number of adults needing neuro-imaging for epilepsy.</p>
Description of what the quality statement means for each audience	<p>Service providers ensure systems are in place for adults who need neuro-imaging for epilepsy to have magnetic resonance imaging.</p> <p>Healthcare professionals ensure that adults who need neuro-imaging for epilepsy have magnetic resonance imaging.</p> <p>Commissioners ensure they commission services for adults who need neuro-imaging investigations for epilepsy to have magnetic resonance imaging.</p> <p>Adults needing neuro-imaging (taking pictures of the brain) for epilepsy have magnetic resonance imaging (a type of neuro-imaging that uses magnetic fields to produce a picture of the brain; often shortened to MRI).</p>
Source clinical guideline references	NICE clinical guideline 137 recommendation 1.6.20.
Data source	<p>Structure:</p> <p>a) and b) Local data collection.</p> <p>Process: Local data collection.</p>
Equality and diversity considerations	<p>The same services, investigations and therapies should be offered to adults with learning disabilities or challenging behaviour as for the general population.</p> <p>Adults with learning disabilities or challenging behaviour might need particular care and attention to help them tolerate</p>

	investigations. Reasonable adjustment, such as offering open-bed scanners, sedation or general anaesthesia should be made if necessary to ensure all people who need magnetic resonance imaging have access to it.
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Draft quality statement 4: Referral to tertiary care

Draft quality statement	Adults with uncontrolled seizures, diagnostic uncertainty or treatment failure are referred to a tertiary care specialist and seen within 4 weeks of referral.
Draft quality measure	<p>Structure: Evidence of local arrangements for adults with uncontrolled seizures, diagnostic uncertainty or treatment failure to be referred to a tertiary care specialist and seen within 4 weeks of referral.</p> <p>Process:</p> <p>a) Proportion of adults with uncontrolled seizures, diagnostic uncertainty or treatment failure who are referred to a tertiary care specialist.</p> <p>Numerator – the number of people in the denominator who are referred to a tertiary care specialist.</p> <p>Denominator – the number of adults with uncontrolled seizures, diagnostic uncertainty or treatment failure.</p> <p>b) Proportion of adults referred to a tertiary care specialist who are seen within 4 weeks of referral.</p> <p>Numerator – the number of people in the denominator who are seen within 4 weeks of referral.</p> <p>Denominator – the number of adults referred to a tertiary care specialist.</p> <p>Outcome: Patient satisfaction with referral to a tertiary care specialist.</p>
Description of what the quality statement means for each audience	<p>Service providers ensure systems are in place for adults with uncontrolled seizures, diagnostic uncertainty or treatment failure to be referred to a tertiary care specialist and seen within 4 weeks of referral.</p> <p>Healthcare professionals ensure that adults with uncontrolled seizures, diagnostic uncertainty or treatment failure are referred to a tertiary care specialist and seen within 4 weeks of referral.</p> <p>Commissioners ensure they commission services for adults with uncontrolled seizures, diagnostic uncertainty or treatment failure to be referred to a tertiary care specialist and seen within 4 weeks of referral.</p> <p>Adults with uncontrolled epilepsy that is hard to treat or complicated for other reasons are referred to a tertiary care specialist (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) and seen within 4 weeks of referral.</p>
Source clinical guideline references	NICE clinical guideline 137 recommendation 1.10.2.

Data source	<p>Structure: Local data collection.</p> <p>Process: a) and b) Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	<p>NICE clinical guideline 137 recommends that referral to tertiary services should be considered when one or more of the following criteria are present:</p> <ul style="list-style-type: none"> • The epilepsy is not controlled with medication within 2 years. • Management is unsuccessful after two drugs. • The adult experiences, or is at risk of, unacceptable side effects from medication. • There is a unilateral structural lesion. • There is psychological and/or psychiatric co-morbidity. • There is diagnostic doubt as to the nature of the seizures and/or seizure syndrome.
Question for consultation	<p>Which element of this statement do you consider to be the key area for quality improvement, that is, what is not happening now that should be? Is it referral to a tertiary care specialist being made quickly for people with uncontrolled seizures, diagnostic uncertainty or treatment failure? Or is it that those people are seen by a tertiary care specialist quickly once a referral has been made?</p>

Draft quality statement 5: Prolonged or repeated seizures

Draft quality statement	Adults with a history of prolonged or repeated seizures have a personalised written emergency care plan.
Draft quality measure	<p>Structure: Evidence of local arrangements for adults with a history of prolonged or repeated seizures to have a personalised written emergency care plan.</p> <p>Process: Proportion of adults with a history of prolonged or repeated seizures who have a personalised written emergency care plan.</p> <p>Numerator – the number of people in the denominator who have a personalised written emergency care plan.</p> <p>Denominator – the number of adults with a history of prolonged or repeated seizures.</p> <p>Outcome:</p> <ul style="list-style-type: none"> a) Accident and emergency attendances for prolonged or repeated seizures. b) Hospital admissions for prolonged or repeated seizures. c) Patient satisfaction with emergency care for prolonged or repeated seizures.
Description of what the quality statement means for each audience	<p>Service providers ensure systems are in place for adults with a history of prolonged or repeated seizures to have a personalised written emergency care plan.</p> <p>Healthcare professionals ensure that adults with a history of prolonged or repeated seizures have a personalised written emergency care plan.</p> <p>Commissioners ensure they commission services for adults with a history of prolonged or repeated seizures to have a personalised written emergency care plan.</p> <p>Adults with a history of prolonged or repeated seizures have a personalised written emergency care plan.</p>
Source clinical guideline references	NICE clinical guideline 137 recommendation 1.14.1.4.
Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome:</p> <ul style="list-style-type: none"> a) Hospital episode statistics contain the data necessary for the monitoring of accident and emergency attendances.

	b) and c) Local data collection.
Definitions	<p>A personalised emergency care plan should describe what happens in the event of a prolonged seizure, including pharmacological treatment should be given and actions to take, who to contact and when. 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.</p> <p>Prolonged seizures are seizures that last 5 minutes or more.</p> <p>Repeated seizures are seizures that occur 3 times or more within 1 hour.</p>

Draft quality statement 6: Epilepsy care plan

Draft quality statement	Adults with epilepsy have an agreed, comprehensive, personalised written epilepsy care plan.
Draft quality measure	<p>Structure: Evidence of local arrangements for adults with epilepsy to have an agreed, comprehensive, personalised written epilepsy care plan.</p> <p>Process:</p> <p>a) Proportion of adults with epilepsy who have an agreed, comprehensive, personalised written epilepsy care plan</p> <p>Numerator – the number of people in the denominator who have an agreed, comprehensive, personalised written epilepsy care plan</p> <p>Denominator – the number of adults with epilepsy.</p> <p>b) Proportion of adults with an epilepsy care plan who feel they have been involved in developing and agreeing their plan.</p> <p>Numerator – the number of people in the denominator who feel they have been involved in developing and agreeing their plan.</p> <p>Denominator – the number of adults with an epilepsy care plan.</p> <p>Outcome: Patient satisfaction with involvement in the epilepsy care planning process.</p>
Description of what the quality statement means for each audience	<p>Service providers ensure that systems are in place for adults with epilepsy to have a comprehensive, personalised, written epilepsy care plan.</p> <p>Healthcare professionals ensure that adults with epilepsy have a comprehensive, personalised written epilepsy care plan.</p> <p>Commissioners ensure they commission services for adults with epilepsy to have a comprehensive, personalised written epilepsy care plan.</p> <p>Adults with epilepsy have a personal, written epilepsy care plan (a written record that includes details about treatment and any preferences and lifestyle issues, and is agreed between them and their healthcare team).</p>
Source clinical guideline references	NICE clinical guideline 137 recommendation 1.8.2.
Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	The comprehensive and personalised epilepsy care plan should

	<p>be a written record of the decisions made about the person's past, present and future care.</p> <p>It should be discussed and agreed between the adult with epilepsy, their family and/or carers where appropriate and their primary and secondary health and social care professionals. A local template should be developed to ensure consistency in the content of each epilepsy care plan based on NICE clinical guideline 137, recommendation 1.3.1. The care plan should include any issues related to the topics described in NICE clinical guideline 137 recommendation 1.3.1.</p>
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Draft quality statement 7: Provision of information - safety

Draft quality statement	Adults with epilepsy have ongoing access to safety information about their epilepsy syndrome, seizure type(s) and treatment.
Draft quality measure	<p>Structure: Evidence of local arrangements for adults with epilepsy to have ongoing access to safety information about their epilepsy syndrome, seizure type(s) and treatment.</p> <p>Process: Proportion of adults with epilepsy who have ongoing access to safety information about their epilepsy syndrome, seizure type(s) and treatment.</p> <p>Numerator – the number of people in the denominator who have ongoing access to safety information about their epilepsy syndrome, seizure type(s) and treatment.</p> <p>Denominator – the number of adults with epilepsy.</p> <p>Outcome: Patient satisfaction with access to safety information.</p>
Description of what the quality statement means for each audience	<p>Service providers ensure systems are in place for adults with epilepsy to have ongoing access to safety information about their epilepsy syndrome, seizure type(s) and treatment.</p> <p>Healthcare professionals ensure they provide adults with epilepsy ongoing access to safety information about their epilepsy syndrome, seizure type(s) and treatment.</p> <p>Commissioners ensure they commission services for adults with epilepsy to have ongoing access to safety information about their epilepsy syndrome, seizure type(s) and treatment.</p> <p>Adults with epilepsy are given ongoing access to safety information about their epilepsy syndrome, seizure type(s) and its treatment.</p>
Source clinical guideline references	NICE clinical guideline 137 recommendation 1.3.1.
Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	<p>Safety information should include that contained in recommendation 1.3.1 of NICE clinical guideline 137.</p> <p>In addition this information should include contact details of any national or local voluntary and community support groups.</p>
Equality and diversity	Information provided for adults with epilepsy should be made available in easily understandable formats/languages that enable them to be fully informed about the issues and risks associated

considerations	<p>with a diagnosis of epilepsy and its treatment.</p> <p>A number of charities supporting people diagnosed with epilepsy provide easy to read information about epilepsy in general and the risks associated with the condition and the different treatment options that are available.</p>
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Draft quality statement 8: Review

Draft quality statement	Adults with well-controlled epilepsy are referred to secondary care if they have specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies.
Draft quality measure	<p>Structure: Evidence of local arrangements for adults with well-controlled epilepsy to be referred to secondary care if they have specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies.</p> <p>Process: Proportion of adults with well-controlled epilepsy who are referred to secondary care if they have specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies.</p> <p>Numerator – the number of people in the denominator who are referred to secondary care.</p> <p>Denominator – the number of adults with well-controlled epilepsy and specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies.</p>
Description of what the quality statement means for each audience	<p>Service providers ensure systems are in place for adults with well-controlled epilepsy to be referred to secondary care if they have specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies.</p> <p>Healthcare professionals ensure that adults with well-controlled epilepsy are referred to secondary care if they have specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies.</p> <p>Commissioners ensure they commission services for adults with well-controlled epilepsy to be referred to secondary care if they have specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies.</p> <p>Adults with well-controlled epilepsy are referred to secondary care if they have specific medical or lifestyle issues that require review by a specialist in the management of the epilepsies (a doctor with training and expertise in diagnosing and treating epilepsy).</p>
Source clinical guideline references	NICE clinical guideline 137 recommendation 1.20.7 (key priority for implementation).
Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p>
Definitions	<p>Epilepsy that is well-controlled in adults can usually be managed within primary care. The epilepsy care plan should define what the person considers to be ‘well-controlled’ in terms of their condition.</p> <p>Specific medical or lifestyle issues that require review by a</p>

	<p>specialist include, for example, pregnancy, consideration/risks of drug withdrawal, recurrence of seizures and side effects of medication.</p> <p>A specialist in the management of the epilepsies is a medical practitioner, for example a consultant (usually a neurologist), who has epilepsy as a significant part of their workload (at least one session a week) with training and continuing education in epilepsy, usually working as part of a specialist epilepsy team.</p>
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Draft quality statement 9: Access to epilepsy specialist nursing

Draft quality statement	Adults with epilepsy are cared for by a clinical team that provides epilepsy specialist nursing.
Draft quality measure	<p>Structure: Evidence of local arrangements for adults with epilepsy to be cared for by a clinical team that provides epilepsy specialist nursing.</p> <p>Process: Proportion of adults with epilepsy who are cared for by a clinical team that provides epilepsy specialist nursing.</p> <p>Numerator – the number of people in the denominator who are cared for by a clinical team that provides epilepsy specialist nursing.</p> <p>Denominator – the number of adults with epilepsy.</p> <p>Outcome: Patient satisfaction with access to epilepsy specialist nursing.</p>
Description of what the quality statement means for each audience	<p>Service providers ensure that systems are in place for adults with epilepsy to be cared for by a clinical team that provides epilepsy specialist nursing.</p> <p>Healthcare professionals ensure that their clinical team provides epilepsy specialist nursing.</p> <p>Commissioners ensure they commission services for adults with epilepsy to be cared for by a clinical team that provides epilepsy specialist nursing.</p> <p>Adults with epilepsy receive care from a clinical team of people that includes provision of epilepsy specialist nursing.</p>
Source clinical guideline references	NICE clinical guideline 137 recommendation 1.8.3.
Data source	<p>Structure: Local data collection.</p> <p>Process: Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	The role of the epilepsy specialist nurse is described in NICE clinical guideline 137 recommendation 1.8.3 as: 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 child, young person or adult, families, carers.

Draft quality statement 10: Transition from children's to adults services

Draft quality statement	Young people with epilepsy who are due to transfer to adult services have a transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.
Draft quality measure	<p>Structure: Evidence of local arrangements for young people with epilepsy who are due to transfer to adult services to have a transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.</p> <p>Process:</p> <p>a) Proportion of young people with epilepsy who are transferred to adult services.</p> <p>Numerator – the number of people in the denominator who are transferred to adult services.</p> <p>Denominator – the number of young people with epilepsy due to transfer to adult services.</p> <p>b) Proportion of young people with epilepsy who are due to transfer to adult services who have a transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.</p> <p>Numerator – the number of people in the denominator who have a transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.</p> <p>Denominator – the number of young people with epilepsy who are due to transfer to adults services.</p> <p>Outcome: Young people's experience of transition to adult services.</p>
Description of what the quality statement means for each audience	<p>Service providers ensure systems are in place for young people with epilepsy who are due to transfer to adult services to have a transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.</p> <p>Healthcare professionals ensure young people with epilepsy have a transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.</p> <p>Commissioners ensure they commission services for young people with epilepsy to have a transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services.</p> <p>Young people with epilepsy who are due to transfer to adult services have a period of time where their continuing epilepsy care is reviewed jointly by paediatric and adult services.</p>
Source clinical	NICE clinical guideline 137 1.17.5, 1.20.2, 1.20.3, 1.20.4 and

guideline references	1.20.5.
Data source	<p>Structure: Local data collection.</p> <p>Process: a) and b) Local data collection.</p> <p>Outcome: Local data collection.</p>
Definitions	<p>The purpose of the joint review is to optimise the care and treatment for young people with epilepsy and facilitate their move into adult services.</p> <p>The period of transition should be a joint clinical action between paediatric and adults services, with at least 2 meetings at a joint consultation and a clear action plan for conducting a review after the young person has transferred into adult services.</p>
Equality and diversity considerations	<p>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 and clinical needs.</p>

3 Status of this quality standard

This is the draft quality standard released for consultation from 14 September 2012 until 12 October 2012. This document is not NICE's final quality standard on the epilepsies in adults. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 12 October 2012. All eligible comments received during consultation will be reviewed by the Topic Expert Group and the quality statements and measures will be refined in line with the Topic Expert Group considerations. The final quality standard will then be available on the [NICE website](#) in February 2013.

4 Using the quality standard

It is important that the quality standard is considered alongside current policy and guidance documents listed in the evidence sources section.

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of healthcare. They are not a new set of targets or mandatory indicators for performance management.

Expected levels of achievement for quality measures are not specified. As quality standards are intended to drive up the quality of care, achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, we recognise that this may not always be appropriate in practice when taking account of patient safety, patient choice and clinical judgement, and therefore desired levels of achievement should be defined locally.

We have indicated where national indicators currently exist and measure the quality statement. National indicators include those developed by the Health and Social Care Information Centre through its [Indicators for Quality Improvement Programme](#). For statements where national quality indicators do not exist, the quality measures should form the basis for audit criteria developed and used locally to improve the quality of healthcare.

For further information, including guidance on using quality measures, please see [‘What makes up a NICE quality standard’](#).

5 Diversity, equality and language

During the development of this quality standard, equality issues have been considered and equality assessments will be published on the NICE website with the final version of the quality standard.

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.

6 How this quality standard was developed

The evidence sources used to develop this quality standard are listed in appendix 1, along with relevant policy context, definitions and data sources. Further explanation of the methodology used can be found in the [‘Quality Standards Programme: interim process guide’](#).

7 Related NICE quality standards

Published

- [Patient experience in adult NHS services](#). NICE quality standard (2012).

Under development

- The epilepsies in children and young people (publication expected February 2013).

Referred for development

- Medicines adherence.
- Managing the transition from children’s to adult services.

Appendix 1: Development sources

Evidence sources

The document below contains clinical guideline recommendations or other recommendations that were used by the TEG to develop the quality standard statements and measures.

[The epilepsies](#). NICE clinical guideline 137 (2012; NICE accredited).

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

Royal College of Physicians and Association of British Neurologists (2011)

[Local adult neurology services for the next decade](#).

Department of Health (2005) [The National Service Framework for long term conditions](#).

Department of Health (2003) [Improving services for people with epilepsy: Department of Health action plan in response to the National Clinical Audit of epilepsy-related death](#).

Definitions, and data sources for the quality measures

References included in the definitions and data sources sections:

[Hospital Episode Statistics](#)