

NICE clinical guideline [XX]

Short title of guideline

Audit support

Issue date: [Year]

**Clinical audit tool**

Epilepsy: pharmacological treatment by syndrome

Implementing NICE guidance

2012

NICE clinical guideline 137

This clinical audit tool accompanies the clinical guideline: ‘The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care’ (available online at www.nice.org.uk/CG137).

**Issue date**: 2012

This is a support tool for clinical audit based on the NICE guidance.

It is not NICE guidance.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way which would be inconsistent with compliance with those duties.

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# Using this clinical audit tool

The clinical audit tool can be used to measure current practice in the pharmacological treatment of epilepsy against the recommendations in the NICE guideline. Use it for a local audit project either by using the whole tool or by amending it to suit the project.

The clinical audit tool contains criteria and a data collection tool. The data collection tool can be used or adapted for the data collection part of the clinical audit cycle by the trust, service or practice. This document includes the following sections, each containing audit criteria and a data collection form:

[Infantile spasms](#_Infantile_spasms_1)

[Dravet syndrome](#_Dravet_syndrome)

[Lennox-Gastaut syndrome](#_Lennox-Gastaut_syndrome)

[Benign epilepsy with centrotemporal spikes, Panayiotopoulos syndrome or late-onset childhood occipital epilepsy (Gastaut)](#_Benign_epilepsy_with)

[Idiopathic generalised epilepsy (IGE)](#_Idiopathic_generalised_epilepsy)

[Juvenile myoclonic epilepsy](#_Juvenile_myoclonic_epilepsy)

[Epilepsy with generalised tonic-clonic seizures](#_Epilepsy_with_generalised)

[Childhood absence epilepsy, juvenile absence epilepsy or other absence epilepsy syndromes](#_Childhood_absence_epilepsy,)

[Other epilepsy syndromes](#_Other_epilepsy_syndromes)

A baseline assessment tool is also available http://guidance.nice.org.uk/CG137/BaselineAssessment/xls/English. This can help ascertain your Trust’s baseline against the guideline’s recommendations and enable you to prioritise implementation activity including clinical audit.

The sample for this audit should include people with epilepsy. Select an appropriate sample in line with your project aims or local clinical audit strategy.

Whether or not the audit results meet the standard, re-auditing is a key part of the audit cycle. If your first data collection shows room for improvement, re-run it once changes to the service have had time to make an impact. Continue with this process until the results of the audit meet the standards.

### Links with other clinical audit priorities

The audit based on this guideline should be considered in conjunction with other clinical audit priorities such as:

* Epilepsy12 national audit: <http://www.rcpch.ac.uk/epilepsy12>

# Criteria for Epilepsy: pharmacological treatment by syndrome

|  |  |
| --- | --- |
| Infantile spasms | |
| **Criterion 1** | **When an infant presents with infantile spasms, their treatment should be discussed with, or referred to, a tertiary paediatric epilepsy specialist.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.8.1 |
| **Definitions** | None |
| **Criterion 2** | **Prednisolone, tetracosactide[[1]](#footnote-1) or vigabatrin should be offered as first-line treatment in infantile spasms that are not due to tuberous sclerosis.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.8.2 |
| **Definitions** | The risk–benefit ratio should be considered carefully when using vigabatrin or steroids. |
| **Criterion 3** | **Vigabatrin should be offered as first-line treatment in infantile spasms due to tuberous sclerosis.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.8.3 |
| **Definitions** | The risk–benefit ratio should be considered carefully when using vigabatrin or steroids. |
| **Criterion 4** | **If vigabatrin is ineffective in infantile spasms due to tuberous sclerosis, prednisolone or tetracosactide7 should be offered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.8.3 |
| **Definitions** | The risk–benefit ratio should be considered carefully when using vigabatrin or steroids. |

# Data collection tool for ‘Epilepsy’

Complete one form for each patient.

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient identifier:** | **Sex:** | **Age:** | **Organisation/service:** |

**Ethnicity:**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **White** | | **Mixed** | | **Asian or Asian British** | | **Black or Black British** | | **Other** | |
| British |  | White and  Black Caribbean |  | Indian |  | Caribbean |  | Chinese |  |
| Irish |  | White and  Black African |  | Pakistani |  | African |  | Any other ethnic group |  |
| Any other White background |  | White and  Asian |  | Bangladeshi |  | Any other Black background |  | Not stated | |
|  | | Any other mixed background |  | Any other Asian background |  |  | |  | |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptions** |
| --- | --- | --- | --- | --- | --- |
| Infantile spasms | | | | | |
| 1 |  | Was treatment discussed with, or referred to, a tertiary paediatric epilepsy specialist? |  |  |  |
|  | 1.1 | * discussed |  |  |  |
|  | 1.2 | * referred |  |  |  |
| 2 |  | If the infant had infantile spasms that were not due to tuberous sclerosis were any of the following offered as first-line treatment? |  |  |  |
|  | 2.1 | * prednisolone |  |  |  |
|  | 2.2 | * tetracosactide |  |  |  |
|  | 2.3 | * vigabatrin |  |  |  |
|  | 2.4 | * other |  |  |  |
| 3 | 3.1 | If the infant had infantile spasms that were due to tuberous sclerosis was vigabatrin offered? |  |  |  |
| 4 |  | If vigabatrin was ineffective in infantile spasms due to tuberous sclerosis, were any of the following offered? |  |  |  |
|  | 4.1 | * prednisolone |  |  |  |
|  | 4.2 | * tetracosactide |  |  |  |
|  | 4.3 | * other |  |  |  |
|  | | | | | |

**Criteria for Epilepsy: pharmacological treatment by syndrome**

|  |  |
| --- | --- |
| Dravet syndrome | |
| **Criterion 5** | **When a child presents with suspected Dravet syndrome, their treatment should be discussed with, or referred to, a tertiary paediatric epilepsy specialist.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.9.1 |
| **Definitions** | None |
| **Criterion 6** | **Sodium valproate or topiramate[[2]](#footnote-2) should be considered as first-line treatment.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.9.2 |
| **Definitions** | Sodium valproate and topiramate should be considered but do not necessarily have to be offered, therefore a standard of 100% cannot be set. |
| **Criterion 7** | **If first-line treatments are ineffective or not tolerated, the patient’s treatment should be discussed with a tertiary epilepsy specialist.**  **Clobazam1 or stiripentol should be considered as adjunctive treatment.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.9.3 |
| **Definitions** | Clobazam and stiripentol should be considered but do not necessarily have to be offered, therefore a standard of 100% cannot be set. |
| **Criterion 8** | **Carbamazepine, gabapentin, lamotrigine, oxcarbazepine, phenytoin, pregabalin, tiagabine or vigabatrin should not be offered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.9.4 |
| **Definitions** | None |

# Data collection tool for Epilepsy: pharmacological treatment by syndrome

Complete one form for each patient.

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient identifier:** | **Sex:** | **Age:** | **Organisation/service:** |

**Ethnicity:**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **White** | | **Mixed** | | **Asian or Asian British** | | **Black or Black British** | | **Other** | |
| British |  | White and  Black Caribbean |  | Indian |  | Caribbean |  | Chinese |  |
| Irish |  | White and  Black African |  | Pakistani |  | African |  | Any other ethnic group |  |
| Any other White background |  | White and  Asian |  | Bangladeshi |  | Any other Black background |  | Not stated | |
|  | | Any other mixed background |  | Any other Asian background |  |  | |  | |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptions** |
| --- | --- | --- | --- | --- | --- |
| Dravet syndrome | | | | | |
| 5 |  | Was treatment discussed with, or referred to, a tertiary paediatric epilepsy specialist? |  |  |  |
|  | 5.1 | * discussed |  |  |  |
|  | 5.2 | * referred |  |  |  |
| 6 |  | Were any of the following prescribed as first-line treatment? |  |  |  |
|  | 6.1 | * sodium valproate |  |  |  |
|  | 6.2 | * topiramate |  |  |  |
|  | 6.3 | * other |  |  |  |
| 7 | 7.1 | If first-line treatment was ineffective or not tolerated, was treatment discussed with a tertiary paediatric epilepsy specialist? |  |  |  |
|  |  | Were either of the following prescribed as adjunctive treatment? |  |  |  |
|  | 7.2 | * clobazam |  |  |  |
|  | 7.3 | * stiripentol |  |  |  |
| 8 |  | Were any of the following offered? |  |  |  |
|  | 8.1 | * carbamazepine |  |  |  |
|  | 8.2 | * gabapentin |  |  |  |
|  | 8.3 | * lamotrigine |  |  |  |
|  | 8.4 | * oxcarbazepine |  |  |  |
|  | 8.5 | * phenytoin |  |  |  |
|  | 8.6 | * pregabalin |  |  |  |
|  | 8.7 | * tiagabine |  |  |  |
|  | 8.8 | * vigabatrin. |  |  |  |
|  | | | | | |

# Criteria for Epilepsy: pharmacological treatment by syndrome

|  |  |
| --- | --- |
| Lennox–Gastaut syndrome | |
| **Criterion 9** | **When a child presents with suspected Lennox–Gastaut syndrome, their treatment should be discussed with, or referred to, a tertiary paediatric epilepsy specialist.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.10.1 |
| **Definitions** | None |
| **Criterion 10** | **Sodium valproate should be offered as first-line treatment to children with Lennox–Gastaut syndrome.** |
| **Exceptions** | **B** – sodium valproate is unsuitable |
| **Guideline reference** | 1.9.10.2 |
| **Definitions** | When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |
| **Criterion 11** | **Lamotrigine should be offered as adjunctive treatment if first-line treatment with sodium valproate is ineffective or not tolerated.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.10.3 |
| **Definitions** | None |
| **Criterion 12** | **If adjunctive treatment is ineffective or not tolerated, the patient’s treatment should be discussed with a tertiary epilepsy specialist.**  **Treatment with rufinamide and topiramate can be considered by the tertiary epilepsy specialist.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.10.4 |
| **Definitions** | Rufinamide and topiramate should be considered but do not necessarily have to be offered, therefore a standard of 100% cannot be set. |

|  |  |
| --- | --- |
| **Criterion 13** | **Felbamate[[3]](#footnote-3) should only be offered in centres providing tertiary epilepsy specialist care and when treatment with all of the drugs listed below has proved ineffective or not tolerated:**   * **lamotrigine** * **rufinamide** * **topiramate.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.10.6 |
| **Definitions** | None |
| **Criterion 14** | **Carbamazepine, gabapentin, oxcarbazepine, pregabalin, tiagabine or vigabatrin should not be offered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.10.5 |
| **Definitions** | None |

# Data collection tool for Epilepsy: pharmacological treatment by syndrome

Complete one form for each patient.

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient identifier:** | **Sex:** | **Age:** | **Organisation/service:** |

**Ethnicity:**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **White** | | **Mixed** | | **Asian or Asian British** | | **Black or Black British** | | **Other** | |
| British |  | White and  Black Caribbean |  | Indian |  | Caribbean |  | Chinese |  |
| Irish |  | White and  Black African |  | Pakistani |  | African |  | Any other ethnic group |  |
| Any other White background |  | White and  Asian |  | Bangladeshi |  | Any other Black background |  | Not stated | |
|  | | Any other mixed background |  | Any other Asian background |  |  | |  | |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptionsa** |
| --- | --- | --- | --- | --- | --- |
| Lennox–Gastaut syndrome | | | | | |
| 9 |  | Was treatment discussed with, or referred to, a tertiary paediatric epilepsy specialist? |  |  |  |
|  | 9.1 | * discussed |  |  |  |
|  | 9.2 | * referred |  |  |  |
| 10 | 10.1 | Was sodium valproate offered? |  |  | **B** |
| 11 | 11.1 | If sodium valproate was ineffective or not tolerated, was lamotrigine offered as adjunctive treatment? |  |  |  |
| 12 | 12.1 | If adjunctive treatment was ineffective or not tolerated, was treatment discussed with a tertiary epilepsy specialist? |  |  |  |
|  |  | Were either of the following prescribed? |  |  |  |
|  | 12.2 | * rufinamide |  |  |  |
|  | 12.3 | * topiramide |  |  |  |
| 13 | 13.1 | If felbamate was offered, was it offered by a centre providing tertiary epilepsy specialist care? |  |  |  |
|  |  | Had the drugs listed below proved ineffective or not tolerated? |  |  |  |
|  | 13.2 | * lamotrigine |  |  |  |
|  | 13.3 | * rufinamide |  |  |  |
|  | 13.4 | * topiramate |  |  |  |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptionsa** |
| --- | --- | --- | --- | --- | --- |
| 14 |  | Were any of the following offered? |  |  |  |
|  | 14.1 | * carbamazepine |  |  |  |
|  | 14.2 | * gabapentin |  |  |  |
|  | 14.3 | * oxcarbazepine |  |  |  |
|  | 14.4 | * pregabalin |  |  |  |
|  | 14.5 | * tiagabine |  |  |  |
|  | 14.6 | * vigabatrin. |  |  |  |
| a Circle exception codes as appropriate. Details of exceptions are listed at the end of the patient data collection tool. | | | | | |

### Exception codes

**B** – sodium valproate is unsuitable

# Criteria for Epilepsy: pharmacological treatment by syndrome

|  |  |
| --- | --- |
| Benign epilepsy with centrotemporal spikes, Panayiotopoulos syndrome or late-onset childhood occipital epilepsy (Gastaut type) | |
| **Criterion 15** | **A discussion should take place with the child or young person and their family and/or carers about whether drug treatment is indicated.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.11.1 |
| **Definitions** | This discussion may not be recorded. Only use this criterion if discussions are routinely recorded by clinicians locally. |
| **Criterion 16** | **Carbamazepine4 or lamotrigine4 should be offered as first-line treatment to children and young people.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.11.2 |
| **Definitions** | None |
| **Criterion 17** | **If carbamazepine and lamotrigine are unsuitable or not tolerated, levetiracetam4, oxcarbazepine4 or sodium valproate should be offered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.11.3 |
| **Definitions** | Carbamazepine and oxcarbazepine may exacerbate or unmask continuous spike and wave during slow sleep, which may occur in some children with benign epilepsy with centrotemporal spikes.  Levetiracetam is not cost effective at June 2011 unit costs[[4]](#footnote-4). Offer levetiracetam provided the acquisition cost of levetiracetam falls to at least 50% of June 2011 value.  When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |

|  |  |
| --- | --- |
| **Criterion 18** | **Carbamazepine4, clobazam[[5]](#footnote-5), gabapentin4, lamotrigine4, levetiracetam4, oxcarbazepine4, sodium valproate or topiramate4** **should be offered as adjunctive treatment if first-line treatments are ineffective or not tolerated.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.11.5 |
| **Definitions** | When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |
| **Criterion 19** | **If adjunctive treatment is ineffective or not tolerated, the patient’s treatment should be discussed with, or referred to, a tertiary epilepsy specialist.**  **Treatment with eslicarbazepine acetate[[6]](#footnote-6), lacosamide5, phenobarbital, phenytoin, pregabalin5, tiagabine5, vigabatrin5 and zonisamide5 can be considered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.11.6 |
| **Definitions** | The risk–benefit ratio should be considered carefully when using vigabatrin because of the risk of an irreversible effect on visual fields. |

# Data collection tool for Epilepsy: pharmacological treatment by syndrome

Complete one form for each patient.

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient identifier:** | **Sex:** | **Age:** | **Organisation/service:** |

**Ethnicity:**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **White** | | **Mixed** | | **Asian or Asian British** | | **Black or Black British** | | **Other** | |
| British |  | White and  Black Caribbean |  | Indian |  | Caribbean |  | Chinese |  |
| Irish |  | White and  Black African |  | Pakistani |  | African |  | Any other ethnic group |  |
| Any other White background |  | White and  Asian |  | Bangladeshi |  | Any other Black background |  | Not stated | |
|  | | Any other mixed background |  | Any other Asian background |  |  | |  | |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptions** |
| --- | --- | --- | --- | --- | --- |
| **Benign epilepsy with centrotemporal spikes, Panayiotopoulos syndrome or late-onset childhood occipital epilepsy (Gastaut type)** | | | | | |
| 15 | 15.1 | Is there evidence of a discussion with the child or young person and their family and/or carers about whether drug treatment was indicated? |  |  |  |
| 16 |  | Were any of the following offered as first-line treatment? |  |  |  |
|  | 16.1 | * carbamazepine |  |  |  |
|  | 16.2 | * lamotrigine |  |  |  |
|  | 16.3 | * other |  |  |  |
| 17 |  | If carbamazepine and lamotrigine were unsuitable or not tolerated, were any of the following offered? |  |  |  |
|  | 17.1 | * levetiracetam |  |  |  |
|  | 17.2 | * oxcarbazepine |  |  |  |
|  | 17.3 | * sodium valproate |  |  |  |
|  | 17.4 | * other |  |  |  |
| 18 |  | If first-line treatments were ineffective or not tolerated, were any of the following offered? |  |  |  |
|  | 18.1 | * carbamazepine |  |  |  |
|  | 18.2 | * clobazam |  |  |  |
|  | 18.3 | * gabapentin |  |  |  |
|  | 18.4 | * lamotrigine |  |  |  |
|  | 18.5 | * levetiracetam |  |  |  |
|  | 18.6 | * oxcarbazepine |  |  |  |
|  | 18.7 | * sodium valproate |  |  |  |
|  | 18.8 | * topiramate |  |  |  |
| 19 | 19.1 | If adjunctive treatment was ineffective or not tolerated, was treatment discussed with, or referred to, a tertiary epilepsy specialist? |  |  |  |
|  |  | Were any of the following prescribed as adjunctive treatment? |  |  |  |
|  | 19.2 | * eslicarbazepine acetate |  |  |  |
|  | 19.3 | * lacosamide |  |  |  |
|  | 19.4 | * phenobarbital |  |  |  |
|  | 19.5 | * phenytoin |  |  |  |
|  | 19.6 | * pregabalin |  |  |  |
|  | 19.7 | * tiagabine |  |  |  |
|  | 19.8 | * vigabatrin |  |  |  |
|  | 19.9 | * zonisamide |  |  |  |
|  | | | | | |

# Criteria for Epilepsy: pharmacological treatment by syndrome

|  |  |
| --- | --- |
| Idiopathic generalised epilepsy (IGE) | |
| **Criterion 20** | **Sodium valproate should be offered as first-line treatment.** |
| **Exceptions** | **B** – sodium valproate is unsuitable |
| **Guideline reference** | 1.9.12.1 |
| **Definitions** | Sodium valproate is the preferred option if there is a photoparoxysmal response on EEG.  When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |
| **Criterion 21** | **Lamotrigine[[7]](#footnote-7) should be offered if sodium valproate is unsuitable or not tolerated.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.12.2 |
| **Definitions** | Lamotrigine can exacerbate myoclonic seizures. If JME is suspected see the recommendations in section 1.9.13 of the guideline. |
| **Criterion 22** | **Topiramate6 should be considered as a treatment option.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.12.3 |
| **Definitions** | Topiramate has a less favourable side-effect profile than lamotrigine and sodium valproate.  Topiramate can be considered but does not necessarily have to be offered, therefore a standard of 100% cannot be set. |
| **Criterion 23** | **Lamotrigine6, levetiracetam6, sodium valproate or topiramate6 should be offered as adjunctive treatment if first-line treatment is ineffective or not tolerated.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.12.4 |
| **Definitions** | When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |

|  |  |
| --- | --- |
| **Criterion 24** | **If adjunctive treatment is ineffective or not tolerated, the patient’s treatment should be discussed with, or referred to, a tertiary epilepsy specialist.**  **Treatment with clobazam6, clonazepam or zonisamide6 should be considered by the tertiary epilepsy specialist.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.12.5 |
| **Definitions** | Clobazam, clonazepam and zonisamide should be considered but do not necessarily have to be offered, therefore a standard of 100% cannot be set. |
| **Criterion 25** | **Carbamazepine, gabapentin, oxcarbazepine, phenytoin, pregabalin, tiagabine or vigabatrin should not be offered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.12.6 |
| **Definitions** | None |

# Data collection tool for Epilepsy: pharmacological treatment by syndrome

Complete one form for each patient.

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient identifier:** | **Sex:** | **Age:** | **Organisation/service:** |

**Ethnicity:**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **White** | | **Mixed** | | **Asian or Asian British** | | **Black or Black British** | | **Other** | |
| British |  | White and  Black Caribbean |  | Indian |  | Caribbean |  | Chinese |  |
| Irish |  | White and  Black African |  | Pakistani |  | African |  | Any other ethnic group |  |
| Any other White background |  | White and  Asian |  | Bangladeshi |  | Any other Black background |  | Not stated | |
|  | | Any other mixed background |  | Any other Asian background |  |  | |  | |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptionsa** |
| --- | --- | --- | --- | --- | --- |
| **Idiopathic generalised epilepsy** | | | | | |
| 20 | 20.1 | Was sodium valproate offered as first-line treatment? |  |  | **B** |
| 21 | 21.1 | If sodium valproate was unsuitable or not tolerated, was lamotrigine offered? |  |  |  |
| 22 |  | Was topiramate prescribed or is there evidence that it was considered? |  |  |  |
|  | 22.1 | * prescribed |  |  |  |
|  | 22.2 | * considered |  |  |  |
| 23 |  | If first-line treatment was ineffective or not tolerated, were any of the following offered as adjunctive treatment? |  |  |  |
|  | 23.1 | * lamotrigine |  |  |  |
|  | 23.2 | * levetiracetam |  |  |  |
|  | 23.3 | * sodium valproate |  |  |  |
|  | 23.4 | * topiramate |  |  |  |
|  | 23.5 | * other |  |  |  |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptionsa** |
| --- | --- | --- | --- | --- | --- |
| 24 |  | If adjunctive treatment was ineffective or not tolerated, did the following happen? |  |  |  |
|  | 24.1 | * patient’s treatment was discussed with a tertiary epilepsy specialist |  |  |  |
|  | 24.2 | * patient’s treatment was referred to a tertiary epilepsy specialist |  |  |  |
|  |  | If yes, did the tertiary epilepsy specialist prescribe any of the following? |  |  |  |
|  | 24.3 | * clobazam |  |  |  |
|  | 24.4 | * clonazepam |  |  |  |
|  | 24.6 | * zonisamide |  |  |  |
|  | 24.7 | * other |  |  |  |
| 25 |  | Were any of the following offered? |  |  |  |
|  | 25.1 | * carbamazepine |  |  |  |
|  | 25.2 | * gabapentin |  |  |  |
|  | 25.3 | * oxcarbazepine |  |  |  |
|  | 25.4 | * phenytoin |  |  |  |
|  | 25.5 | * pregabalin |  |  |  |
|  | 25.6 | * tiagabine |  |  |  |
|  | 25.7 | * vigabatrin. |  |  |  |
| a Circle exception codes as appropriate. Details of exceptions are listed at the end of the patient data collection tool. | | | | | |

### Exception codes

**B** – sodium valproate is unsuitable

# Criteria for Epilepsy: pharmacological treatment by syndrome

|  |  |
| --- | --- |
| Juvenile myoclonic epilepsy | |
| **Criterion 26** | **Sodium valproate should be offered as first-line treatment.** |
| **Exceptions** | **B** – sodium valproate is unsuitable |
| **Guideline reference** | 1.9.13.1 |
| **Definitions** | When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |
| **Criterion 27** | **Lamotrigine[[8]](#footnote-8), levetiracetam7 or topiramate7 should be considered if sodium valproate is unsuitable or not tolerated.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.13.2 |
| **Definitions** | Topiramate has a less favourable side-effect profile than lamotrigine, levetiracetam and sodium valproate. Lamotrigine may exacerbate myoclonic seizures. |
| **Criterion 28** | **Lamotrigine7, levetiracetam7, sodium valproate7 or topiramate7 should be offered as adjunctive treatment if first-line treatments are ineffective or not tolerated.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.13.3 |
| **Definitions** | When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |
| **Criterion 29** | **If adjunctive treatment is ineffective or not tolerated, the patient’s treatment should be discussed with, or referred to, a tertiary epilepsy specialist.**  **Treatment with clobazam7, clonazepam and zonisamide7 should be considered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.13.4 |
| **Definitions** | None |

|  |  |
| --- | --- |
| **Criterion 30** | **Carbamazepine, gabapentin, oxcarbazepine, phenytoin, pregabalin, tiagabine or vigabatrin should not be offered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.13.5 |
| **Definitions** | None |

# Data collection tool for Epilepsy: pharmacological treatment by syndrome

Complete one form for each patient.

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient identifier:** | **Sex:** | **Age:** | **Organisation/service:** |

**Ethnicity:**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **White** | | **Mixed** | | **Asian or Asian British** | | **Black or Black British** | | **Other** | |
| British |  | White and  Black Caribbean |  | Indian |  | Caribbean |  | Chinese |  |
| Irish |  | White and  Black African |  | Pakistani |  | African |  | Any other ethnic group |  |
| Any other White background |  | White and  Asian |  | Bangladeshi |  | Any other Black background |  | Not stated | |
|  | | Any other mixed background |  | Any other Asian background |  |  | |  | |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptionsa** |
| --- | --- | --- | --- | --- | --- |
| **Juvenile myoclonic epilepsy** | | | | | |
| 26 | 26.1 | Was sodium valproate offered as first-line treatment? |  |  | **B** |
| 27 |  | If sodium valproate was unsuitable or not tolerated, were any of the following prescribed? |  |  |  |
|  | 27.1 | * lamotrigine |  |  |  |
|  | 27.2 | * levetiracetam |  |  |  |
|  | 27.3 | * topiramate |  |  |  |
| 28 |  | If first-line treatment was ineffective or not tolerated, were any of the following offered as adjunctive treatment? |  |  |  |
|  | 28.1 | * lamotrigine |  |  |  |
|  | 28.2 | * levetiracetam |  |  |  |
|  | 28.3 | * sodium valproate |  |  |  |
|  | 28.4 | * topiramate |  |  |  |
|  | 28.5 | * other |  |  |  |
| 29 |  | If adjunctive treatment was ineffective or not tolerated, did the following happen? |  |  |  |
|  | 29.1 | * patient’s treatment was discussed with a tertiary epilepsy specialist |  |  |  |
|  | 29.2 | * patient’s treatment was referred to a tertiary epilepsy specialist |  |  |  |
|  |  | If yes, did the tertiary epilepsy specialist prescribe any of the following? |  |  |  |
|  | 29.3 | * clobazam |  |  |  |
|  | 29.4 | * clonazepam |  |  |  |
|  | 29.6 | * zonisamide |  |  |  |
|  | 29.7 | * other |  |  |  |
| 30 |  | Were any of the following offered? |  |  |  |
|  | 30.1 | * carbamazepine |  |  |  |
|  | 30.2 | * gabapentin |  |  |  |
|  | 30.3 | * oxcarbazepine |  |  |  |
|  | 30.4 | * phenytoin |  |  |  |
|  | 30.5 | * pregabalin |  |  |  |
|  | 30.6 | * tiagabine |  |  |  |
|  | 30.7 | * vigabatrin. |  |  |  |
| a Circle exception codes as appropriate. Details of exceptions are listed at the end of the patient data collection tool. | | | | | |

### Exception codes

**B** – sodium valproate is unsuitable

# Criteria for Epilepsy: pharmacological treatment by syndrome

|  |  |
| --- | --- |
| Epilepsy with generalised tonic–clonic seizures | |
| **Criterion 31** | **Lamotrigine or sodium valproate should be offered as first-line treatment.**  **Carbamazepine and oxcarbazepine8 should be considered as first-line treatment.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.14.1 and 1.9.14.2 |
| **Definitions** | If the person has suspected myoclonic seizures, or are suspected of having juvenile myoclonic epilepsy, offer sodium valproate first, unless it is unsuitable.  When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |
| **Criterion 32** | **Clobazam[[9]](#footnote-9), lamotrigine, levetiracetam, sodium valproate or topiramate** **should be offered as adjunctive treatment if first-line treatments are ineffective or not tolerated.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.14.3 |
| **Definitions** | When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |

# Data collection tool for Epilepsy: pharmacological treatment by syndrome

Complete one form for each patient.

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient identifier:** | **Sex:** | **Age:** | **Organisation/service:** |

**Ethnicity:**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **White** | | **Mixed** | | **Asian or Asian British** | | **Black or Black British** | | **Other** | |
| British |  | White and  Black Caribbean |  | Indian |  | Caribbean |  | Chinese |  |
| Irish |  | White and  Black African |  | Pakistani |  | African |  | Any other ethnic group |  |
| Any other White background |  | White and  Asian |  | Bangladeshi |  | Any other Black background |  | Not stated | |
|  | | Any other mixed background |  | Any other Asian background |  |  | |  | |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptions** |
| --- | --- | --- | --- | --- | --- |
| **Epilepsy with generalised tonic–clonic seizures** | | | | | |
| 31 |  | Were any of the following offered as first-line treatment? |  |  |  |
|  | 31.1 | * lamotrigine |  |  |  |
|  | 31.2 | * sodium valproate |  |  |  |
|  | 31.3 | * carbamazepine |  |  |  |
|  | 31.4 | * oxcarbazepine |  |  |  |
|  | 31.5 | * other |  |  |  |
| 32 |  | If first-line treatment was ineffective or not tolerated, were any of the following offered? |  |  |  |
|  | 32.1 | * clobazam |  |  |  |
|  | 32.2 | * lamotrigine |  |  |  |
|  | 32.3 | * levetiracetam |  |  |  |
|  | 32.4 | * sodium valproate |  |  |  |
|  | 32.5 | * topiramate |  |  |  |
|  | 32.6 | * other |  |  |  |
|  | | | | | |

# Criteria for Epilepsy: pharmacological treatment by syndrome

|  |  |
| --- | --- |
| Childhood absence epilepsy, juvenile absence epilepsy or other absence epilepsy syndromes | |
| **Criterion 33** | **Ethosuximide or sodium valproate should be offered as first-line treatment.**  **If there is a high risk of GTC seizures, sodium valproate should be offered first.** |
| **Exceptions** | **B** – sodium valproate is unsuitable |
| **Guideline reference** | 1.9.15.1 |
| **Definitions** | When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |
| **Criterion 34** | **If ethosuximide and sodium valproate are unsuitable, ineffective or not tolerated, lamotrigine[[10]](#footnote-10) should be offered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.15.2 |
| **Definitions** | None |
| **Criterion 35** | **If two first-line drugs are ineffective, a combination of two of the following should be considered as adjunctive treatment:**   * **ethosuximide** * **lamotrigine9** * **sodium valproate.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.15.3 |
| **Definitions** | A combination of the drugs listed above should be considered but do not necessarily have to be offered, therefore a standard of 100% cannot be set.  When prescribing sodium valproate to women and girls of present and future childbearing potential, discuss the possible risk of malformation and neurodevelopmental impairments in an unborn child, particularly with high doses of this drug or when using as part of polytherapy. |

|  |  |
| --- | --- |
| **Criterion 36** | **If adjunctive treatment is ineffective or not tolerated, the patient’s treatment should be discussed with, or referred to, a tertiary epilepsy specialist and the following drugs considered:**   * **clobazam9** * **clonazepam** * **levetiracetam9** * **topiramate9** * **zonisamide9.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.15.4 |
| **Definitions** | The drugs listed above should be considered but do not necessarily have to be offered, therefore a standard of 100% cannot be set. |
| **Criterion 37** | **Carbamazepine, gabapentin, oxcarbazepine, phenytoin, pregabalin, tiagabine or vigabatrin should not be offered.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.15.5 |
| **Definitions** | None |

# Data collection tool for Epilepsy: pharmacological treatment by syndrome

Complete one form for each patient.

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient identifier:** | **Sex:** | **Age:** | **Organisation/service:** |

**Ethnicity:**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **White** | | **Mixed** | | **Asian or Asian British** | | **Black or Black British** | | **Other** | |
| British |  | White and  Black Caribbean |  | Indian |  | Caribbean |  | Chinese |  |
| Irish |  | White and  Black African |  | Pakistani |  | African |  | Any other ethnic group |  |
| Any other White background |  | White and  Asian |  | Bangladeshi |  | Any other Black background |  | Not stated | |
|  | | Any other mixed background |  | Any other Asian background |  |  | |  | |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptionsa** |
| --- | --- | --- | --- | --- | --- |
| Childhood absence epilepsy, juvenile absence epilepsy or other absence epilepsy syndromes | | | | | |
| 33 |  | Were any of the following offered as first-line treatment? |  |  |  |
|  | 33.1 | * ethosuximide |  |  |  |
|  | 33.2 | * sodium valproate |  |  |  |
|  | 33.3 | * other (specify) |  |  |  |
|  | 33.4 | Was there a high risk of GTC seizures? |  |  |  |
|  | 33.5 | If yes, was sodium valproate offered first? |  |  | **B** |
| 34 |  | If ethosuximide and sodium valproate were unsuitable, ineffective or not tolerated, were any of the following offered? |  |  |  |
|  | 34.1 | * lamotrigine |  |  |  |
|  | 34.2 | * other (specify) |  |  |  |
| 35 |  | If two first-line drugs are ineffective, was a combination of two of the following prescribed as adjunctive treatment? |  |  |  |
|  | 35.1 | * ethosuximide |  |  |  |
|  | 35.2 | * lamotrigine |  |  |  |
|  | 35.3 | * sodium valproate |  |  |  |
|  | 35.4 | * other (specify) |  |  |  |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptionsa** |
| --- | --- | --- | --- | --- | --- |
| 36 |  | If adjunctive treatment was ineffective or not tolerated, did the following happen? |  |  |  |
|  | 36.1 | * patient’s treatment was discussed with a tertiary epilepsy specialist |  |  |  |
|  | 36.2 | * patient’s treatment was referred to a tertiary epilepsy specialist |  |  |  |
|  |  | If yes, did the tertiary epilepsy specialist prescribe any of the following? |  |  |  |
|  | 36.3 | * clobazam |  |  |  |
|  | 36.4 | * clonazepam |  |  |  |
|  | 36.5 | * levetiracetam |  |  |  |
|  | 36.6 | * topiramate |  |  |  |
|  | 36.7 | * zonisamide |  |  |  |
|  | 36.8 | * other |  |  |  |
| 37 |  | Were any of the following offered? |  |  |  |
|  | 37.1 | * carbamazepine |  |  |  |
|  | 37.2 | * gabapentin |  |  |  |
|  | 37.3 | * oxcarbazepine |  |  |  |
|  | 37.4 | * phenytoin |  |  |  |
|  | 37.5 | * pregabalin |  |  |  |
|  | 37.5 | * tiagabine |  |  |  |
|  | 37.6 | * vigabatrin. |  |  |  |
| a Circle exception codes as appropriate. Details of exceptions are listed at the end of the patient data collection tool. | | | | | |

### Exception codes

**B** – sodium valproate is unsuitable

# Criteria for Epilepsy: pharmacological treatment by syndrome

|  |  |
| --- | --- |
| Other epilepsy syndromes | |
| **Criterion 38** | **When a child or young person presents with continuous spike and wave during slow sleep, Landau–Kleffner syndrome or myoclonic-astatic epilepsy, their treatment should be referred to a tertiary paediatric epilepsy specialist.** |
| **Exceptions** | None |
| **Guideline reference** | 1.9.16.1 |
| **Definitions** | None |

# Data collection tool for Epilepsy: pharmacological treatment by syndrome

Complete one form for each patient.

|  |  |  |  |
| --- | --- | --- | --- |
| **Patient identifier:** | **Sex:** | **Age:** | **Organisation/service:** |

**Ethnicity:**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **White** | | **Mixed** | | **Asian or Asian British** | | **Black or Black British** | | **Other** | |
| British |  | White and  Black Caribbean |  | Indian |  | Caribbean |  | Chinese |  |
| Irish |  | White and  Black African |  | Pakistani |  | African |  | Any other ethnic group |  |
| Any other White background |  | White and  Asian |  | Bangladeshi |  | Any other Black background |  | Not stated | |
|  | | Any other mixed background |  | Any other Asian background |  |  | |  | |

| **No.** | **Data item no.** | **Criteria** | **Yes** | **No** | **NA/**  **Exceptions** |
| --- | --- | --- | --- | --- | --- |
| **Other epilepsy syndromes in children and young people** | | | | | |
| 38 |  | Did the child or young person present with any of the following? |  |  |  |
|  | 38.1 | * continuous spike and wave during slow sleep |  |  |  |
|  | 38.2 | * Landau–Kleffner syndrome |  |  |  |
|  | 38.3 | * myclonic-astatic epilepsy |  |  |  |
|  | 38.4 | If yes, were they referred to a tertiary paediatric epilepsy specialist? |  |  |  |
|  | | | | | |

# Further information

For further information about clinical audit refer to a local clinical audit professional within your own organisation or the Healthcare Quality Improvement Partnership (HQIP) website [www.hqip.org.uk](http://www.hqip.org.uk). HQIP was established in April 2008 to promote quality in healthcare, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales.

# Supporting implementation

NICE has developed tools to help organisations implement the clinical guideline on Epilepsy (listed below). These are available on our website (www.nice.org.uk/CG137).

* Costing statement.
* Slides highlighting key messages for local discussion.
* Clinical case scenarios: an educational resource that can be used in individual or group learning situations.
* Pharmacological treatment tables: tables from appendix E of the NICE guideline separated for ease of use and printing.
* Baseline assessment tool for identifying current practice and prioritising implementation of the guideline.
* Clinical audit tools for local clinical audit (including this document)
* Electronic audit tool.

A series of practical guides to implementation are also available on our website ([www.nice.org.uk/usingguidance/implementationtools](http://www.nice.org.uk/usingguidance/implementationtools)).

# The guidance

You can download the guidance documents from www.nice.org.uk/CG137. For printed copies of ‘Understanding NICE guidance’, phone NICE publications on 0845 003 7783 or email [publications@nice.org.uk](mailto:publications@nice.org.uk) and N2697 (‘Understanding NICE guidance’).

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1. At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population. Informed consent should be obtained and documented. [↑](#footnote-ref-1)
2. At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population. Informed consent should be obtained and documented. [↑](#footnote-ref-2)
3. At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population. Informed consent should be obtained and documented. [↑](#footnote-ref-3)
4. Estimated cost of a 1500 mg daily dose was £2.74 at June 2011. Cost taken from the National Health Service Drug Tariff for England and Wales, available at [www.ppa.org.uk/ppa/edt\_intro.htm](http://www.ppa.org.uk/ppa/edt_intro.htm) [↑](#footnote-ref-4)
5. At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population. Informed consent should be obtained and documented. [↑](#footnote-ref-5)
6. At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population. Informed consent should be obtained and documented. [↑](#footnote-ref-6)
7. At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population. Informed consent should be obtained and documented. [↑](#footnote-ref-7)
8. At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population. Informed consent should be obtained and documented. [↑](#footnote-ref-8)
9. At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population. Informed consent should be obtained and documented. [↑](#footnote-ref-9)
10. At the time of publication (January 2012), this drug did not have UK marketing authorisation for this indication and/or population. Informed consent should be obtained and documented. [↑](#footnote-ref-10)