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NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

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Guideline scope

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Epilepsies in children, young people and adults

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The Department of Health in England has asked NICE to update the guideline on the diagnosis and management of epilepsies in children, young people and adults.

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The guideline will be developed using the methods and processes outlined in [developing NICE guidelines: the manual](#).

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This guideline will also be used to update the NICE quality standards for epilepsy in adults and epilepsy in children and young people

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1 Why the guideline is needed

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Key factors and figures

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Epilepsy is one of the most common serious neurological disorders, affecting around 65 million people worldwide and about 533,000 in England and Wales.

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Of these, around 112,000 are children and young people. The incidence of

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epilepsy is estimated to be 50 per 100,000 per year and the prevalence of

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active epilepsy in the UK is estimated to be 5 to 10 people per 1,000. Epilepsy

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is also a common cause of people attending accident and emergency

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departments. Epileptic seizures can result in injury and may also be

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associated with mortality, for example, because of sudden unexpected death

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in epilepsy (SUDEP).

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Current practice

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The majority of people with active epilepsy (60% to 70%) have their seizures

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satisfactorily controlled with anti-epileptic drugs (AEDs). Other treatment

1 options may include surgery, vagus nerve stimulation, and psychological and
2 dietary therapies. Optimal management improves health and wellbeing,
3 including reducing the impact of epilepsy on social activities, education and
4 career choices, and reduces the risk of SUDEP

5 The original NICE guideline on epilepsies (2004) stated that the annual
6 estimated cost of established epilepsy was £2 billion (direct and indirect
7 costs). However, newer and more expensive AEDs are now being prescribed.
8 With an increase in treatment costs likely in coming years, it is essential to
9 ensure that AEDs with proven effectiveness and cost-effectiveness are
10 identified.

11 The NICE guideline and the NICE technology appraisal guidance from 2004,
12 and the subsequent pharmacological review in 2012, on newer drugs for
13 epilepsy in adults and newer drugs for epilepsy in children failed to show a
14 difference in effectiveness between newer and older AEDs, or between the
15 newer drugs (as monotherapy) for seizure control. The International League
16 Against Epilepsy (ILAE) has proposed new definitions and a framework for
17 classifying the epilepsies, and diagnosis and investigation have become more
18 focused on aetiology. The guideline update will reflect this and consider new
19 evidence on treating people with epilepsy.

20 **2 Who the guideline is for**

21 This guideline is for:

- 22 • Healthcare professionals in primary, secondary and tertiary care (including
23 accident and emergency departments, inpatient care and transitions
24 between departments and services)
- 25 • Commissioners of services
- 26 • People using services, their families and carers and the public

27 It may also be relevant for:

- 28 • voluntary organisations.

1 NICE guidelines cover health and care in England. Decisions on how they
2 apply in other UK countries are made by ministers in the [Welsh Government](#),
3 [Scottish Government](#), and [Northern Ireland Executive](#).

4 ***Equality considerations***

5 NICE has carried out [an equality impact assessment](#) during scoping. The
6 assessment:

- 7 • lists equality issues identified, and how they have been addressed
- 8 • explains why any groups are excluded from the scope.

9 Potential equalities have been identified during scoping relating to women and
10 girls who are able to get pregnant, are pregnant, or breastfeeding, as well
11 as older people with cognitive impairments. Important considerations for these
12 groups will relate to the management of epilepsy including the use AEDs.

13 There are also potential inequalities relating to people from black and Asian
14 and minority ethnic groups; people with learning disabilities, and their families
15 or carers; and people living in more deprived areas who may have difficulties
16 accessing services.

17 **3 What the guideline will cover**

18 **3.1 *Who is the focus?***

19 **Groups that will be covered**

20 Children, young people and adults with suspected or confirmed epilepsy.

21 Specific consideration will be given to:

- 22 • children and young people
- 23 • girls and women of who are able to get pregnant (including those who are
24 pregnant and breastfeeding)
- 25 • older people
- 26 • people with learning disabilities

1 **Groups that will not be covered**

2 Newborn babies (under 28 days) with acute symptomatic seizures.

3 **3.2 Settings**

4 **Settings that will be covered**

- 5 • primary, secondary and tertiary healthcare (including accident and
- 6 emergency departments, inpatient care and transitions between
- 7 departments and services)
- 8 • community settings
- 9 • supported care settings

10 **3.3 Activities, services or aspects of care**

11 **Key areas that will be covered**

12 We will look at evidence in the areas below when developing the guideline,
13 but it may not be possible to make recommendations in all the areas.

14 **Adults, children and young people**

- 15 1 Diagnosis and assessment of epilepsy
- 16 2 Information and support needs
- 17 3 Pharmacological management of epileptic seizures and epilepsy
- 18 syndromes
- 19 4 Pharmacological management of epileptic seizures and epilepsy
- 20 syndromes in girls and women who are able to get pregnant (including
- 21 those who are pregnant or breastfeeding)
- 22 5 Non-pharmacological management of epileptic seizures
- 23 6 Ongoing monitoring, including referral to specialist services and drug
- 24 withdrawal
- 25 7 Reducing the risk of sudden unexpected death in epilepsy-related
- 26 mortality
- 27 8 Service design and delivery
- 28 9 Transition from children and young people's services to adults' services

1 **Children and young people only**

2 1 Pharmacological management of childhood-onset epileptic seizures and
3 epilepsy syndromes

4 2 Neurodevelopmental assessment and interventions

5 **Adults only**

6 1 Psychological interventions for epilepsy

7 2 Indications for surgical interventions and type of intervention

8 Note that guideline recommendations for medicines will normally fall within
9 licensed indications; exceptionally, and only if clearly supported by evidence,
10 use outside a licensed indication may be recommended. The guideline will
11 assume that prescribers will use a medicine's summary of product
12 characteristics to inform decisions made with individual patients.

13 **Areas that will not be covered**

14 Management of non-epileptic seizures.

15 **Related NICE guidance**

16 ***Published***

- 17 • [Deep brain stimulation for refractory epilepsy](#) (2012) NICE interventional
18 procedure guidance IPG416
- 19 • [Transient loss of consciousness \('blackouts'\) in over 16s.](#) (2010). NICE
20 guidance. CG109
- 21 • [Vagus nerve stimulation for refractory epilepsy in children.](#) (2004) NICE
22 interventional procedure guidance. IPG50
- 23 • [Partial seizures in children and young people with epilepsy: zonisamide as
24 adjunctive therapy](#) (2014) NICE evidence summary ESNM37
- 25 • [Partial-onset seizures in epilepsy: perampanel as adjunctive treatment](#)
26 (2012) NICE evidence summary ESNM7
- 27 • [Partial-onset seizures in epilepsy: zonisamide as monotherapy](#) (2013)
28 NICE evidence summary ESNM17

1 ***In development***

- 2 • [Cannabidiol for adjuvant treatment of seizures associated with Dravet syndrome or Lennox-Gastaut syndrome](#) NICE technology appraisal
3 guidance. Publication expected November 2019.
- 4 • [Cannabidiol for adjuvant treatment of seizures associated with Lennox-Gastaut syndrome](#) NICE technology appraisal guidance. Publication
5 expected November 2019.
- 6 • [Cannabis-based products for medicinal use. NICE guideline.](#) Publication
7 expected October 2019.

10 ***NICE guidance that will be updated by this guideline***

- 11 • [Epilepsies: diagnosis and management](#) (2012) NICE guideline CG137

12 **NICE guidance about the experience of people using NHS services**

13 NICE has produced the following guidance on the experience of people using
14 the NHS. This guideline will not include additional recommendations on these
15 topics unless there are specific issues related to epilepsy:

- 16 • [Decision-making and mental capacity](#) (2018) NICE guideline NG108
- 17 • [Medicines optimisation](#) (2015) NICE guideline NG5
- 18 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- 19 • [Service user experience in adult mental health](#) (2011) NICE guideline
20 CG136
- 21 • [Medicines adherence](#) (2009) NICE guideline CG76

22 **3.4 Economic aspects**

23 We will take economic aspects into account when making recommendations.
24 We will develop an economic plan that states for each review question (or key
25 area in the scope) whether economic considerations are relevant, and if so
26 whether this is an area that should be prioritised for economic modelling and
27 analysis. We will review the economic evidence and carry out economic
28 analyses, using a NHS and personal social services (PSS) perspective, as
29 appropriate.

1 **3.5 Key issues and draft questions**

2 While writing this scope, we have identified the following key issues and draft
3 review questions related to them:

4 **Adults, children and young people**

5 1 Diagnosis and assessment of epilepsy

6 1.1 What are the risk factors for a further seizure following a first seizure
7 and what is the magnitude of risk of those factors?

8 1.2 What clinical features (symptoms and signs) indicate a likely
9 diagnosis of an epileptic seizure?

10 1.3 What is the diagnostic accuracy of electrocardiograph (ECG) in
11 distinguishing between seizures and non-seizure events after a first
12 seizure or seizure-like episode?

13 1.4 What is the diagnostic accuracy of electroencephalogram (EEG)
14 (including specific EEG techniques) in distinguishing between seizures
15 and non-seizure events?

16 1.5 What is the diagnostic accuracy of EEG (including specific EEG
17 techniques) in identifying specific seizure types and epilepsy
18 syndromes?

19 1.6 What is the diagnostic accuracy of EEG (including specific EEG
20 techniques) in assessing the likelihood of seizure recurrence following a
21 first seizure?

22 1.7 What is the diagnostic accuracy of MRI in determining the aetiology
23 of epilepsy?

24 1.8 What is the diagnostic accuracy of CT in determining the aetiology of
25 epilepsy?

26 1.9 What are the risk factors for cognitive dysfunction (particularly in
27 relation to language or memory) in people with epileptic seizures?

28 1.10 What is the effectiveness of genetic testing to guide epilepsy
29 management?

30 1.11 What is the effectiveness of antibody testing in determining the
31 aetiology of epilepsy?

32 2 Information and support needs

- 1 2.1 What is the effectiveness of new technologies (for example night
2 monitors, wearable devices and Apps) in assessing the risk of seizures
3 in people with epilepsy?
4 2.2 What information and support is needed by people, parents or carers
5 in relation to epilepsy and when should this be provided?
- 6 3 Pharmacological management of epileptic seizures and epilepsy
7 syndromes
- 8 3.1 What AEDs (individually or in combination) are effective in the
9 treatment of generalised tonic-clonic (GTC) seizures?
10 3.2 What AEDs (individually or in combination) are effective in the
11 treatment of focal onset seizures?
12 3.3 What AEDs (individually or in combination) are effective in the
13 treatment of absence seizures?
14 3.4 What AEDs (individually or in combination) are effective in the
15 treatment of myoclonic seizures?
16 3.5 What AEDs (individually or in combination) are effective in the
17 treatment of tonic or atonic seizures?
18 3.6 What AEDs (individually or in combination) are effective in the
19 treatment of repeated seizures or clusters of seizures?
20 3.7 What AEDs (individually or in combination) are effective in the
21 treatment for prolonged seizures?
22 3.8 What AEDs (individually or in combination) are effective in the
23 treatment of status epilepticus?
24 3.9 What AEDs (individually or in combination) are effective in the
25 treatment of seizures in idiopathic generalised epilepsy (IGE), including
26 juvenile myoclonic epilepsy?
27 3.10 What AEDs (individually or in combination) are effective in the
28 treatment of seizures in Dravet syndrome?
29 3.11 What AEDs (individually or in combination) are effective in the
30 treatment of seizures in Lennox-Gastaut syndrome?
31

- 1 4 Pharmacological management of epileptic seizures and epilepsy
2 syndromes in girls and women who are able to get pregnant (including
3 those who are pregnant or breastfeeding)
- 4 4.1 What AEDs (individually or in combination) are effective in the
5 treatment of GTC seizures?
- 6 4.2 What AEDs (individually or in combination) are effective in the
7 treatment of focal onset seizures?
- 8 4.3 What AEDs (individually or in combination) are effective in the
9 treatment of absence seizures?
- 10 4.4 What AEDs (individually or in combination) are effective in the
11 treatment of myoclonic seizures?
- 12 4.5 What AEDs (individually or in combination) are effective in the
13 treatment of tonic or atonic seizures?
- 14 4.6 What AEDs (individually or in combination) are effective in the
15 treatment of repeated seizures or clusters of seizures?
- 16 4.7 What AEDs (individually or in combination) are effective in the
17 treatment for prolonged seizures?
- 18 4.8 What AEDs (individually or in combination) are effective in the
19 treatment of status epilepticus?
- 20 4.9 What is the appropriate drug monitoring, including timing, in girls or
21 women who are pregnant?
- 22 5 Non-pharmacological management of epileptic seizures
- 23 5.1 What is the effectiveness of surgical intervention in epilepsy?
- 24 5.2 What is the effectiveness of ketogenic diet in epilepsy?
- 25 5.3 What is the effectiveness of vagus nerve stimulation in epilepsy?
- 26 6 Ongoing monitoring, including referral to specialist services and drug
27 withdrawal
- 28 6.1 When should monitoring be carried out for people with epilepsy?
- 29 6.2 How should monitoring be carried out for people with epilepsy?
- 30 6.3 What are the criteria for anti-epileptic drug withdrawal in people with
31 epilepsy?
- 32 6.4 What are the criteria for referral to specialist services?

- 1 7 Reducing the risk of sudden unexpected death in epilepsy-related
2 mortality
- 3 7.1 What are the risk factors for epilepsy-related mortality, including
4 SUDEP, in people with epilepsy and what is the magnitude of risk of the
5 factors?
- 6 7.2 What interventions are effective in reducing the risk of seizure-
7 related mortality, including SUDEP, in people with epilepsy?
- 8 8 Service design and delivery
- 9 8.1 What is the effectiveness of a nurse specialist in the management of
10 epilepsy?
- 11 9 Transition from children and young people's services to adults' services
- 12 9.1 How should transition from children and young people's services to
13 adults' epilepsy services be managed?

14 **Children and young people only**

- 15 1 Pharmacological management of childhood-onset epileptic seizures and
16 epilepsy syndromes
- 17 1.1 What AEDs (individually or in combination) are effective in the
18 treatment of infantile spasms or West syndrome?
- 19 1.2 What AEDs (individually or in combination) are effective in the
20 treatment of seizures in childhood epilepsy with centrotemporal spikes?
- 21 1.3 What AEDs (individually or in combination) are effective in the
22 treatment of seizures in myoclonic astatic epilepsy (Doose syndrome)?
- 23 2 Neurodevelopmental assessment and interventions
- 24 2.1 What is the effectiveness of neurodevelopmental psychological
25 assessment in children and young people with epilepsy?
- 26 2.2 What is the effectiveness of neurodevelopmental psychological
27 interventions in children and young people with epilepsy?

28 **Adults only**

- 29 1 Psychological interventions for epilepsy

- 1 1.1 What is the effectiveness of psychological interventions in the
2 treatment of seizures in adults with epilepsy?
- 3 2 Indications for surgical interventions and type of intervention
- 4 2.1 What are the indications for surgery in adults with epilepsy?
- 5 2.2 In which adults with epilepsy should positron emission tomography
6 (PET) imaging be considered?
- 7 2.3 In which adults with epilepsy should single-photon emission
8 computed tomography (SPECT) imaging be considered?
- 9 2.4 What is the effectiveness of different surgical techniques (for
10 example, temporal lobectomy vs selective amygdalohippocampectomy)
11 in adults with epilepsy?

12 **3.6 Main outcomes**

13 The main outcomes that may be considered when searching for and
14 assessing the evidence are:

- 15 • mortality
- 16 • seizure freedom
- 17 • seizure frequency
- 18 • time to first seizure
- 19 • time to withdrawal of treatment
- 20 • quality of life
- 21 • social functioning
- 22 • cognitive outcomes
- 23 • neurodevelopment (children and young people)
- 24 • adverse events

25 **4 NICE quality standards and NICE Pathways**

26 **4.1 NICE quality standards**

27 **NICE quality standards that may need to be revised or updated when**
28 **this guideline is published**

- 29 • [Epilepsy in children and young people](#) (2013) NICE quality standard 27

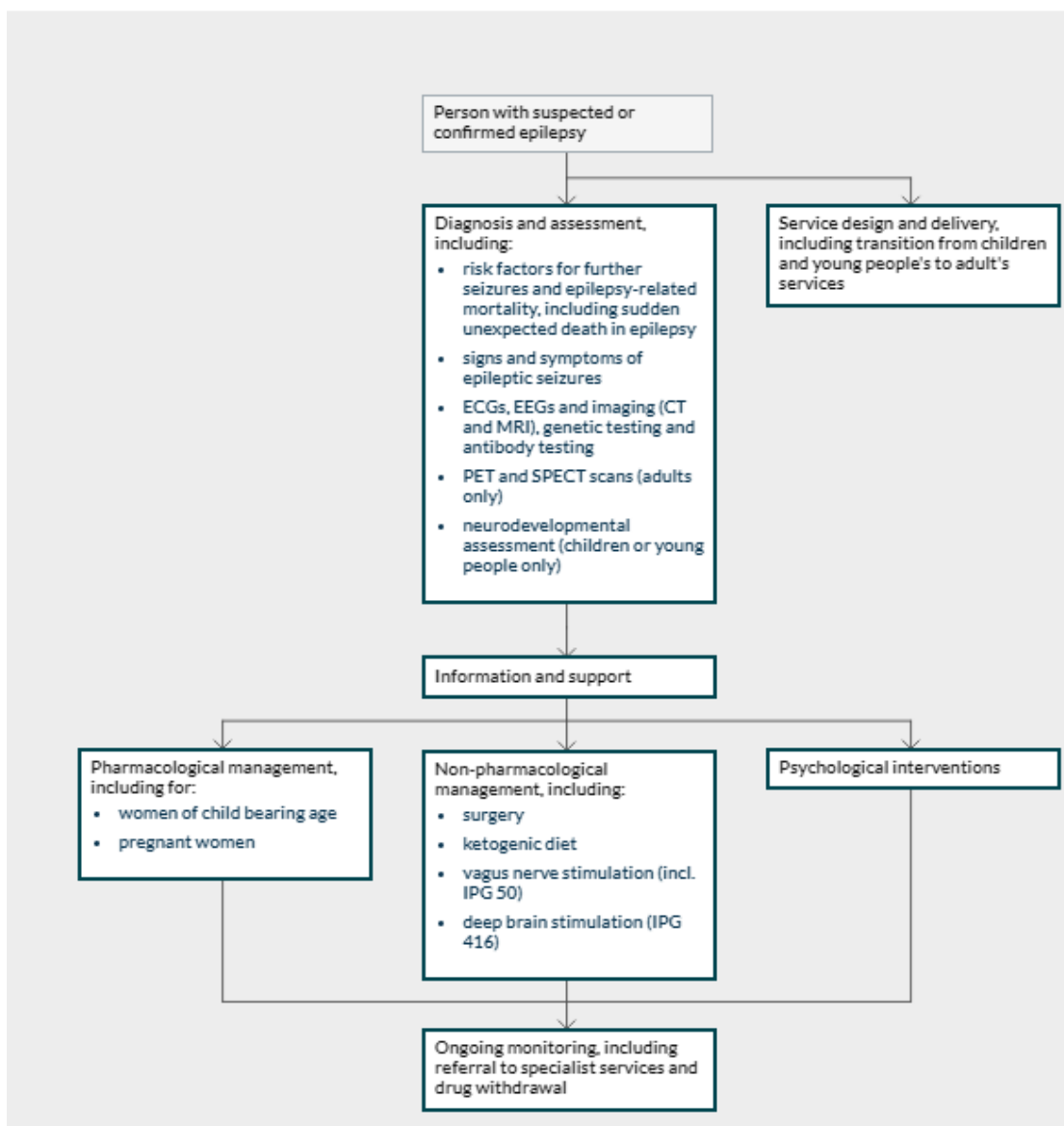
- 1 • [Epilepsy in adults](#) (2013) NICE quality standard QS26

2 **4.2 NICE Pathways**

3 When this guideline is published, we will update the NICE Pathway on
 4 [epilepsy](#), which brings together everything we have said on epilepsy in an
 5 interactive flowchart.

6 An outline based on this scope is included below. It will be adapted and more
 7 detail added as the recommendations are written during guideline
 8 development.

Epilepsy overview



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2 **5 Further information**

This is the draft scope for consultation with registered stakeholders. The consultation dates are 7 January to 4 February 2019.

The guideline is expected to be published in April 2021.

Our website has information about how [NICE guidelines](#) are developed.

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