NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Epilepsies in children, young people and adults

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.

The guideline will be developed using the methods and processes outlined in developing NICE guidelines: the manual.

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

1 Why the guideline is needed

Key factors and figures

Epilepsy is one of the most common serious neurological disorders, affecting around 65 million people worldwide and about 533,000 in England and Wales. Of these, around 112,000 are children and young people. The incidence of epilepsy is estimated to be 50 per 100,000 per year and the prevalence of active epilepsy in the UK is estimated to be 5 to 10 people per 1,000. Epilepsy is also a common cause of people attending accident and emergency departments. Epileptic seizures can result in injury, and may also be associated with mortality, for example, because of sudden unexpected death in epilepsy (SUDEP).

Current practice

Most people with active epilepsy (60% to 70%) have their seizures satisfactorily controlled with antiepileptic drugs . Other treatment options may

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

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

The 2004 NICE guideline on epilepsy, the 2004 NICE technology appraisal guidance and the subsequent 2012 pharmacological review on newer drugs for epilepsy, failed to show a difference in effectiveness between newer and older antiepileptic drugs , or between the newer drugs (as monotherapy) for seizure control. The International League Against Epilepsy (ILAE) has proposed new definitions and a framework for classifying epilepsy, and diagnosis and investigation have become more focused on aetiology. The guideline update will reflect this and consider new evidence on treating epilepsy.

2 Who the guideline is for

This guideline is for:

- healthcare professionals in primary, secondary and tertiary care (including accident and emergency departments, inpatient care and transitions between departments and services)
- commissioners of services
- people using services, their families and carers and the public.

It may also be relevant for:

- voluntary organisations.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.

Equality considerations

NICE has carried out equality impact assessments during scoping for epilepsies in children and young people and epilepsies in adults. The assessments:

- list equality issues identified, and how they have been addressed
- explain why any groups are excluded from the scope.

Potential equalities have been identified during scoping relating to:

- managing epilepsy (including treatment with antiepileptic drugs) in women and girls who are able to get pregnant, are pregnant, or breastfeeding
- managing epilepsy (including treatment with antiepileptic drugs) in older people with cognitive impairments
- people who may have difficulties accessing services, including:
  - people from black and Asian and minority ethnic groups
  - people with learning disabilities, and their families or carers
  - people living in socioeconomically deprived areas
  - children and young people who are looked after or in care
  - people with mental health comorbidities.

3 What the guideline will cover

3.1 Who is the focus?

Groups that will be covered

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

Specific consideration will be given to:

- children and young people

- girls and women who are able to get pregnant (including those who are pregnant or breastfeeding)
- older people
- people with learning disabilities

Groups that will not be covered

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

3.2 Settings

Settings that will be covered

- primary, secondary and tertiary healthcare (including accident and emergency departments, inpatient care and transitions between departments and services)
- community settings
- supported care settings

3.3 Activities, services or aspects of care

Key areas that will be covered

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

Children, young people and adults

1 Diagnosis and assessment of epilepsy
2 Information and support needs
3 Pharmacological management of epileptic seizures and epilepsy syndromes
4 Pharmacological management of epileptic seizures and epilepsy syndromes in girls and women who are able to get pregnant (including those who are pregnant or breastfeeding)
5 Non-pharmacological management of epileptic seizures
6 Ongoing monitoring, including referral to specialist services and drug withdrawal

7 Psychological, neurodevelopmental, cognitive and behavioural comorbidities in epilepsy
8 Reducing the risk of epilepsy-related mortality
9 Service design and delivery
10 Transition from children's and young people's services to adults' services

Children and young people only

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

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

Areas that will not be covered

Managing non-epileptic seizures.

Related NICE guidance

Published

- Deep brain stimulation for refractory epilepsy (2012) NICE interventional procedure guidance IPG416
- Transient loss of consciousness ('blackouts') in over 16s (2010) NICE guidance CG109
- Vagus nerve stimulation for refractory epilepsy in children (2004) NICE interventional procedure guidance IPG50
- Partial seizures in children and young people with epilepsy: zonisamide as adjunctive therapy (2014) NICE evidence summary ESNM37
- Partial-onset seizures in epilepsy: zonisamide as monotherapy (2013) NICE evidence summary ESNM17
- Partial-onset seizures in epilepsy: perampanel as adjunctive treatment (2012) NICE evidence summary ESNM7

In development

- Cannabis-based products for medicinal use. NICE guideline. Publication expected October 2019
- Cannabidiol for adjuvant treatment of seizures associated with Dravet syndrome NICE technology appraisal guidance. Publication expected December 2019
- Cannabidiol for adjuvant treatment of seizures associated with Lennox-Gastaut syndrome NICE technology appraisal guidance. Publication expected December 2019

NICE guidance that will be updated by this guideline

- Epilepsies: diagnosis and management (2012) NICE guideline CG137

NICE guidance about the experience of people using NHS services

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

- Decision-making and mental capacity (2018) NICE guideline NG108
- Medicines optimisation (2015) NICE guideline NG5
- Patient experience in adult NHS services (2012) NICE guideline CG138
- Service user experience in adult mental health (2011) NICE guideline CG136
- Medicines adherence (2009) NICE guideline CG76

3.4 Economic aspects

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

3.5 Key issues and draft questions

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

Children, young people and adults

1 Diagnosis and assessment of epilepsy:

1.1 What are the risk factors for a further seizure after a first seizure, and what is the magnitude of risk of those factors?

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

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

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

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

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

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

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

1.9 In people with epilepsy, who should have genetic testing?

1.10 In people with epilepsy, who should have antibody testing?

2 Information and support needs:

2.1 What is the effectiveness of new technologies (for example, night monitors, wearable devices and apps) in detecting seizures in people with epilepsy?

2.2 What information and support is needed by people, parents or carers in relation to epilepsy, and when should this be provided?

3 Pharmacological management (monotherapy or add-on therapy) of epileptic seizures and epilepsy syndromes

3.1 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of generalised tonic-clonic (GTC) seizures?

3.2 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of focal onset seizures?

3.3 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of absence seizures?

3.4 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of myoclonic seizures?

3.5 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of tonic or atonic seizures?

3.6 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of repeated seizures or clusters of seizures?

3.7 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment for prolonged seizures?

3.8 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of status epilepticus?

3.9 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of seizures in idiopathic generalised epilepsy (IGE), including juvenile myoclonic epilepsy?

3.10 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of seizures in Dravet syndrome?

3.11 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of seizures in Lennox-Gastaut syndrome?

4 Pharmacological management (monotherapy or add-on therapy) of epileptic seizures and epilepsy syndromes in girls and women who are able to get pregnant (including those who are pregnant or breastfeeding):

4.1 What antiepileptic drugs (monotherapy or add-on therapy)are safe in the treatment of generalised tonic-clonic (GTC) seizures?

4.2 What antiepileptic drugs (monotherapy or add-on therapy) are safe in the treatment of focal onset seizures?

4.3 What antiepileptic drugs (monotherapy or add-on therapy) are safe in the treatment of absence seizures?

4.4 What antiepileptic drugs(monotherapy or add-on therapy) are safe in the treatment of myoclonic seizures?

4.5 What antiepileptic drugs (monotherapy or add-on therapy) are safe in the treatment of tonic or atonic seizures?

4.6 What antiepileptic drugs (monotherapy or add-on therapy) are safe in the treatment of repeated seizures or clusters of seizures?

4.7 What antiepileptic drugs (monotherapy or add-on therapy) are safe in the treatment for prolonged seizures?

4.8 What antiepileptic drugs (monotherapy or add-on therapy) are safe in the treatment of status epilepticus?

4.9 What is the appropriate drug monitoring, including timing, in girls or women who are able to get pregnant (including those who are pregnant or breastfeeding)?

5 Non-pharmacological management of epileptic seizures:

5.1 What is the effectiveness of surgical intervention in epilepsy?

5.2 What is the effectiveness of ketogenic diet in epilepsy?

5.3 What is the effectiveness of vagus nerve stimulation in epilepsy?

6 Ongoing monitoring, including referral to specialist services and drug withdrawal:

6.1 When should monitoring be carried out for people with epilepsy?

6.2 How should monitoring be carried out for people with epilepsy, and who should do it?

6.3 What are the criteria for stopping anti-epileptic drugs in people with epilepsy?

6.4 What are the criteria for referral to specialist services?

6.5 What are the criteria for referral to epilepsy surgical services?

7 Psychological, neurodevelopmental, cognitive and behavioural comorbidities in epilepsy:

7.1 What is the prevalence of psychological disorders, neurodevelopmental and cognitive disorders, and behavioural disorders in people with epilepsy?

7.2 What is the effectiveness of psychological interventions in the treatment of epilepsy in children, young people and adults?

8 Reducing the risk of epilepsy-related mortality

8.1 What are the risk factors for epilepsy-related mortality, including SUDEP, and what is the magnitude of risk of the factors?

8.2 What interventions are effective in reducing the risk of seizure-related mortality, including SUDEP?

9 Service design and delivery

9.1 What is the effectiveness of a nurse specialist in managing epilepsy?

10 Transition from children's and young people's services to adults' services

10.1 How should the transition from children's and young people's services to adults' epilepsy services be managed?

Children and young people only

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

1.1 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of infantile spasms or West syndrome?

1.2 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of seizures in childhood epilepsy with centrotemporal spikes?

1.3 What antiepileptic drugs (monotherapy or add-on therapy) are effective in the treatment of seizures in myoclonic astatic epilepsy (Doose syndrome)?

3.6 Main outcomes

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

- mortality
- seizure freedom
- seizure frequency
- time to first seizure
- time to withdrawal of treatment
- quality of life
- social functioning
- cognitive outcomes
- neurodevelopment (children and young people)
- adverse events

4 NICE quality standards and NICE Pathways

4.1 NICE quality standards

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

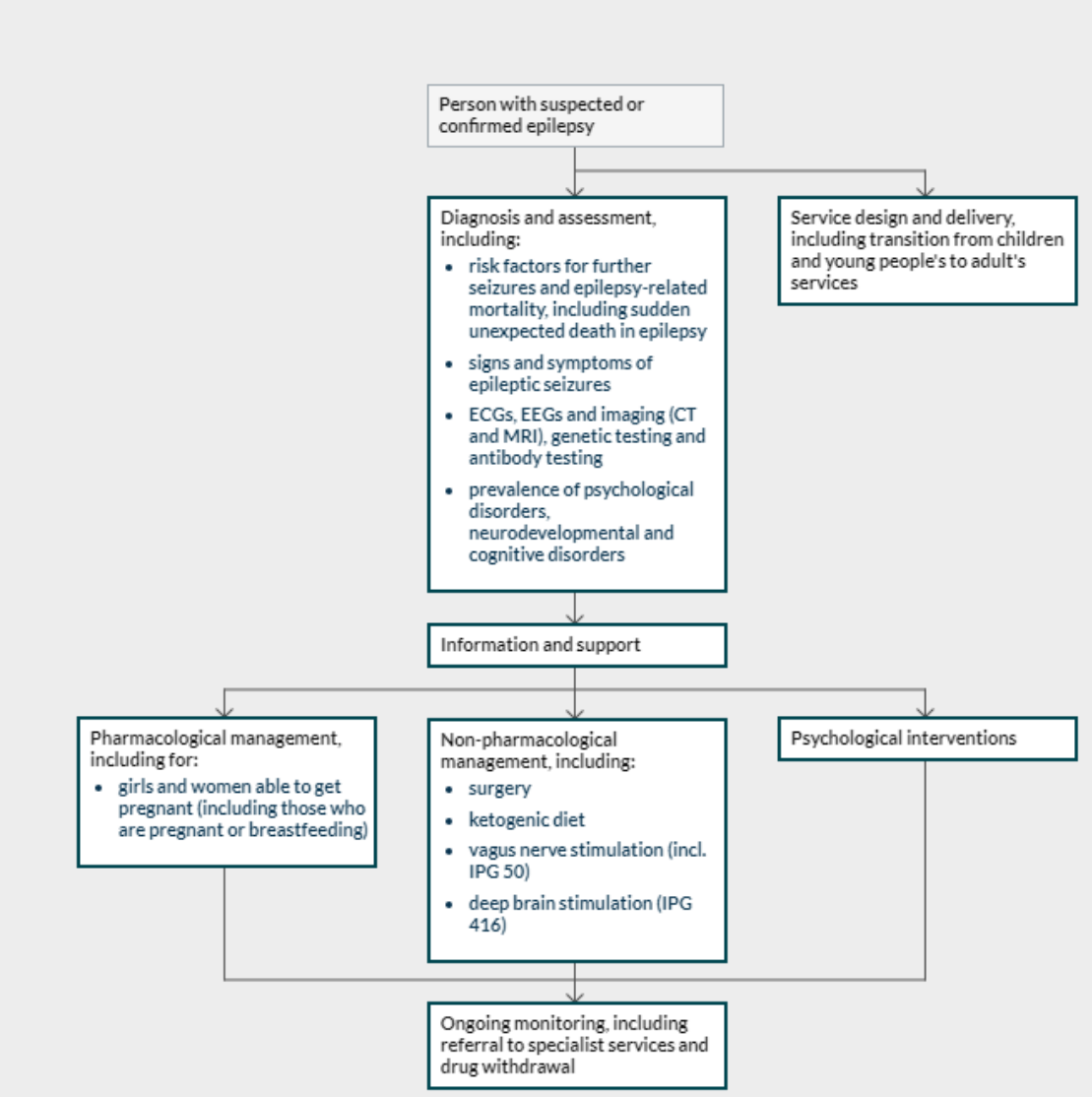
- Epilepsy in children and young people (2013) NICE quality standard 27
- Epilepsy in adults (2013) NICE quality standard QS26

4.2 NICE Pathways

When this guideline is published, we will update the NICE Pathway on epilepsy, which brings together everything we have said on epilepsy in an interactive flowchart.

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

Epilepsy overview



5 Further information

This is the final scope, which takes into account comments from registered stakeholders during consultation.

Our website has information about how NICE guidelines are developed.