

Commissioning guides

Diagnosis and management of the epilepsies in adults, children and young people

<http://www.nice.org.uk/guidance/cm47>

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1 Commissioning services for the diagnosis and management of the epilepsies

Epilepsy is a common neurological disorder characterised by recurring seizures. There are over 40 different types of epilepsy, with 40 different associated seizure types. The nature of epilepsy can make it difficult to diagnose accurately^[1]. A diagnosis of epilepsy can have a wide-ranging impact on a person's health and lifestyle. This guide for commissioners focuses on improving the diagnosis of epilepsy and ensuring that diagnosis and treatment are both confirmed and reviewed as necessary.

There are currently around 320,000 adults and 34,000 children and young people with a diagnosis of epilepsy and receiving anti-epileptic drugs. The incidence of epilepsy is higher in children aged 0–11 years and adults aged 65 years and over, and the condition is frequently associated with learning disabilities. Studies carried out in various settings have estimated that a proportion of people (between 4.6 and 30%^[2]) are incorrectly diagnosed with epilepsy.

For many people with epilepsy, seizures can be controlled with an anti-epileptic drug (AED) or other interventions. Optimal management improves health outcomes and can help to minimise other, often detrimental, impacts on social, educational and employment activities. However, the recent National audit of seizure management in hospitals found considerable variation between hospitals in the treatment of epilepsy in adults and showed variability in assessment, admission and aftercare^[3]. Therefore, this guide for commissioners also focuses on tailoring treatment to individual circumstances and the needs of people with epilepsy so that they are offered the most suitable treatment.

Epilepsy is associated with a wide range of markers of social and economic disadvantage, including poor academic achievement, unemployment, underemployment and low income^[4].

There are around 1000 epilepsy-related deaths each year in England and Wales^[5]. Just under 300 of these deaths are in children or younger adults (40 years or under). Sudden unexpected death in epilepsy^[6] (SUDEP) accounts for approximately half of all epilepsy-related deaths. The National Sentinel Clinical Audit (2002) estimated that 39% of adults' and 59% of children's SUDEP deaths were potentially, or probably, avoidable.

Commissioners should note the recommendations in [NICE clinical guideline 137](#), which updates and replaces NICE clinical guideline 20 and includes [new recommendations](#) for the pharmacological treatment of people with epilepsy.

^[1] [NICE quality standard 26 for the epilepsies in adults](#) and [NICE quality standard for the epilepsies in children and young people](#) (2013).

^[2] Chowdhury FA, Nashef L, Elwes RD (2008) Misdiagnosis in epilepsy: a review and recognition of diagnostic uncertainty. *European Journal of Neurology* 15(10): 1034–42.

^[3] [National audit of seizure management in hospitals](#), St Elsewhere's clinical report, April 2012, Liverpool.

^[4] Gaitatzis A, Majeed A, Purcell B et al. (2002) Epilepsy prevalence and prescribing patterns in England and Wales. *Health Statistics Quarterly* 15: 23–31.

^[5] Office for National Statistics (2010) Deaths: underlying cause, sex and age-group, England and Wales. London: Office for National Statistics.

^[6] Sudden unexpected death in epilepsy (SUDEP) is defined as the sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in patients with epilepsy, with or without evidence for a seizure, with exclusion of documented status epilepticus, and when post-mortem examination does not reveal a structural or toxicological cause for death.

2 An integrated approach to commissioning high-quality care for the diagnosis and management of the epilepsies

The NICE quality standards describe high-quality and cost-effective care for adults, children and young people with epilepsy. This guide supports the commissioning of integrated care for people with epilepsy, in line with the quality standards. This should improve the effectiveness, safety and experience of care for people with epilepsy.

Commissioning care in line with the quality standards will contribute to achieving the following improvement areas in the [Clinical Commissioning Group outcomes indicator set](#):

Domain 2: Enhancing quality of life for people with long-term conditions.

Improvement area: Reducing time spent in hospital for people with long-term conditions.

Measure: Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults) (from NHS Outcomes Framework indicator 2.3.i)

Measure: Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s (from NHS Outcomes Framework indicator 2.3.ii)

The quality standards, together with the guidance on which they are based, should contribute to the improvements outlined in the following frameworks:

- [NHS Outcomes Framework 2013/14](#)
- [Improving outcomes and supporting transparency: Part 1 – a public health outcomes framework for England, 2013–16](#)
- [Adult Social Care Outcomes Framework, 2013/14.](#)

Table 1 shows the outcomes, overarching indicators and improvement areas from the national outcomes frameworks that commissioning services, in line with the quality standards, could contribute to achieving.

Table 1 Outcomes, overarching indicators and improvement areas from the national outcomes frameworks that commissioning services and quality standards could achieve

The Adult Social Care Outcomes Framework 2013/14	
Domain 1: Enhancing quality of life for people with care and support needs	<p>Overarching measure</p> <p>1A Social care-related quality of life</p> <p>Outcome measures</p> <p><i>People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation</i></p> <p>1E The proportion of adults with a learning disability in paid employment</p>

NHS Outcomes Framework 2013/14	
Domain 1: Preventing people from dying prematurely	<p>Overarching indicator</p> <p>1a Potential years of life lost (PYLL) from causes considered amenable to healthcare</p> <p>1ai Adults</p> <p>1aia Children and young people</p>
Domain 2: Enhancing quality of life for people with long-term conditions	<p>Overarching indicator</p> <p>2 Health-related quality of life for people with long-term conditions</p> <p>Improvement areas</p> <p><i>Ensuring people feel supported to manage their condition</i></p> <p>2.1 Proportion of people feeling supported to manage their condition</p> <p><i>Improving functional ability in people with long-term conditions</i></p> <p>2.2 Employment of people with long-term conditions</p> <p><i>Reducing time spent in hospital by people with long-term conditions</i></p> <p>2.3i Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults)</p> <p>2.3ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s</p>
Domain 3: Helping people to recover from episodes of ill health or following injury	<p>Overarching indicator</p> <p>3a Emergency admissions for acute conditions that should not usually require hospital admission</p>
Domain 4: Ensuring that people have a positive experience of care	<p>Overarching indicator</p> <p>4b Patient experience of hospital care</p> <p>Improvement area</p> <p><i>Improving people's experience of outpatient care</i></p> <p>4.1 Patient experience of outpatient services</p>

Public health outcomes framework 2013–16	
Domain 1: Improving the wider determinants of health	<p>Objective</p> <p>Improvements against wider factors that affect health and wellbeing and health inequalities.</p> <p>Indicators</p> <p>1.8 Employment for those with a long-term health condition including those with a learning difficulty/disability or mental illness</p>

Commissioning for the diagnosis and management of the epilepsies in adults, children and young people is fundamental to commissioning for long term conditions. Commissioners should take into account relevant regional and local plans for Quality, Innovation, Productivity and Prevention (QIPP) for long-term conditions.

An integrated approach to commissioning services for people with epilepsy will ensure that people receive the recommended level of high-quality care and relevant information to reduce misdiagnosis rates, epilepsy-related deaths and avoidable emergency hospital admissions.

Commissioners should work with a range of partners and stakeholders when planning and developing integrated services for people with epilepsy. These include:

- clinical commissioning groups and their support organisations
- health and wellbeing boards
- social care organisations
- public health organisations
- regional epilepsy networks.

Commissioners will also need to engage the following partners when planning services for people with epilepsy:

- people with epilepsy
- carers of people with epilepsy

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- primary, secondary and tertiary care providers
 - ambulance trusts
 - relevant third sector organisations
 - employment agencies
 - [service users and carers](#).

The [NICE Pathway on epilepsy](#)^[7] provides a visual summary of NICE guidance and NICE quality standards on epilepsy. The following may be of particular interest to commissioners:

- A [summary of where recommendations differ between children and young people and adults when diagnosing and managing epilepsy](#).
- An overview of NICE recommendations for [special considerations to be taken when managing epilepsy in specific groups of people](#) including people from black and minority ethnic groups, women and girls, older people, people with learning disabilities and young people. (See section 3 for further information).

^[7] The NICE Pathway on epilepsy is an online tool for health and social care professionals that brings together all related NICE guidance and associated products in an interactive diagram to visually represent everything that NICE has published on epilepsy. It provides an easy and intuitive way to find, access and use NICE guidance.

3 Assessing service levels for the diagnosis and management of the epilepsies

When estimating the level of service needed locally for people with epilepsy, commissioners should take into account:

- [epidemiology of epilepsy](#)
- [diagnosis of epilepsy](#)
- [hospital activity data for epilepsy](#)
- [considerations for epilepsy in specific groups of people](#).

Commissioners should use the information included in this section, as well as locally available data, to facilitate discussion on optimum service levels. There is likely to be considerable local variation in the number of adults, children and young people diagnosed with epilepsy who are currently receiving AEDs. This is influenced by social, economic and demographic profiles of the local population. Therefore, commissioners are encouraged to consider local assumptions. They should note that the rates included here do not represent NICE's view of desirable, or maximum or minimum, service levels.

3.1 Epidemiological data on the prevalence and incidence of epilepsy

3.1.1 Prevalence of diagnosed epilepsy

Primary care data^[6] were used to estimate the number of adults and children and young people diagnosed with epilepsy who are currently receiving AEDs in England^[6].

The proportion of adults (18 years or older) with a diagnosis of epilepsy and receiving AEDs is 0.78% (780 people in 100,000), which equates to approximately 320,000 people^[6] in England^[11].

There is an additional 0.66% of the adult population who have a history of epilepsy or are diagnosed with epilepsy but are not receiving AEDs^[12].

The proportion of children and young people aged 17 years or younger with a diagnosis of epilepsy and receiving AEDs is 0.30% (300 people in 100,000), which equates to approximately 34,000^[6] in England.

3.1.2 Incidence of diagnosed epilepsy

Primary care data^[8] have been used to estimate newly identified and diagnosed epilepsy (incidence) in the population^[14]. The data showed that newly diagnosed epilepsy was:

- **0.05%** in children aged 11 years or under
- **0.03%** in young people aged 12–17 years
- **0.03%** in adults aged 18–64 years

- **0.05%** in adults aged 65 years or older.

3.2 Diagnosis of epilepsy

The number of people newly diagnosed with epilepsy in [section 3.1](#) has been used to calculate the number of new referrals of people with a suspected first seizure to a service for the accurate diagnosis of the epilepsies.

The accurate clinical assessment and classification of seizure type or syndrome is imperative for assisting clinical decision-making and providing optimal treatment. Available data suggest that the number of new referrals every year to a [specialist service](#) for the accurate diagnosis of the epilepsies after a suspected first seizure is:

- **0.06%** (60 per 100,000) adults (18 years and older)
- **0.08%** (80 per 100,000) children and young people (17 years and younger).

This equates to approximately 23,000 adults and 9500 children and young people in England being referred to a specialist for the assessment and diagnosis of epilepsy every year.

The [Topic Advisory Group](#) agreed that around 70% of adults who are referred for diagnostic investigation for epilepsy after a suspected first seizure are likely to be subsequently diagnosed with epilepsy^[14]. [Using the current number of newly identified cases of epilepsy each year](#), and inflating this number to take into account the proportion of people who will be assessed by epilepsy specialists but who do not receive a diagnosis of epilepsy (30%), enabled the above estimate to be made on the level of expected activity for adults.

The level of diagnosis in children and young people is lower than the level of diagnosis in adults. The Royal College of Paediatrics and Child Health's national audit [Epilepsy 12](#) found that 45% of children and young people had no epilepsy 12 months after the first paediatric assessment of suspected seizure^[16].

Commissioners can use the [commissioning and budgeting tools](#) within this guide to determine the level of service that might be needed locally and to calculate the cost of commissioning the service using the information contained here and/or local data.

3.3 Hospital activity data for epilepsy

Commissioners can work with healthcare providers and other stakeholders as appropriate to identify the number of unplanned hospital admissions and readmissions for people with epilepsy. This will help them to target specialist support and other therapy, where appropriate, to reduce avoidable emergency admissions and readmissions.

Achieving the quality statements in the [NICE quality standard for the epilepsies in adults](#) and [NICE quality standard for the epilepsies in children and young people](#) (see [section 4](#)) will help commissioners to ensure that people with epilepsy receive appropriate referrals and reviews for their epilepsy.

3.3.1 Emergency hospital activity

[Hospital Episode Statistics](#) (HES)^[1] data showed that in 2010/11 there were around:

- 43,000 emergency hospital episodes for adults with a primary diagnosis of epilepsy^[1] (100 per 100,000 of this population)
- 9800 emergency hospital episodes for children and young people with a primary diagnosis of epilepsy^[1] (90 per 100,000 of this population).

3.3.2 Emergency readmissions

[HES](#) data from 2010/11 show that around 10% of adults admitted to hospital with a primary diagnosis of epilepsy were readmitted within 28 days as an emergency with a primary diagnosis of epilepsy^[1]. This rose to 19% of adults being readmitted as an emergency with a primary diagnosis of epilepsy within 90 days.

3.3.3 Length of stay

Commissioners can refer to the [NHS Atlas of variation in healthcare \(2011\)](#), which looks at the emergency admission rate for children and young people with epilepsy per 100,000 population aged 0–17 years by primary care trusts (PCTs), for the years 2007/08–2009/10. The atlas shows considerable variation between PCTs.

A [best practice tariff](#) is a national tariff that has been structured and priced to incentivise and adequately reimburse care that is high quality and cost effective. The best practice tariff can be

applied when an adult is admitted for an epileptic seizure and is discharged on the same day^[20] (therefore, the length of stay is equal to zero days)^[61]. HES data from 2010/11 revealed that, for the treatment of epilepsy^[18]:

- 31% had a length of stay of zero days
- 41% had a length of stay of 1–2 days
- 28% had a length of stay of 3 or more days.

3.4 Considerations for epilepsy in specific groups of people

The [Topic Advisory Group](#) felt that commissioners of services for the diagnosis and management of the epilepsies in adults, children and young people should consider the following groups when designing services and estimating service capacity requirements.

3.4.1 Women and girls of childbearing potential

Commissioners should ensure that providers can demonstrate that they are adhering to [recommendation 1.15](#) of the NICE clinical guideline on epilepsy. Care and referral pathways need to be in place for women and girls for issues relating to pregnancy. Services should include the provision of accurate information and access to counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause, for women and girls with epilepsy and their partners, as appropriate. Commissioners may also wish to refer to the [NICE pathway on Epilepsy](#), specifically [Special considerations for women and girls with epilepsy](#).

Primary care data^[6] have been used to estimate the number of females aged 12–50 years with a diagnosis of epilepsy who have been prescribed AEDs^[62]. It was found that 0.3% (300 in 100,000 of this population) of girls aged 12–17 years, and 0.60% (600 in 100,000 of this population) of women aged 18–50 years, had a diagnosis of epilepsy and had been prescribed AEDs. This equates to approximately 6500 girls and 75,000 women in England.

3.4.2 People with learning disabilities who have epilepsy

A larger proportion of children, young people and adults with learning disabilities have epilepsy than in the general population. The [full guideline on epilepsy](#) reports that epilepsy has a prevalence of 15% in people with mild learning disabilities and 30% in people with severe

learning disabilities. Commissioners may also wish to refer to the [NICE pathway on Epilepsy, specifically Children, young people and adults with learning disabilities](#).

^[8] Primary care data were collected from the IMS disease analyser, which collects data from a sample of around 100 GP practice systems, with about 2.7 million patient records. The sample includes practices from England, Wales, Scotland and Northern Ireland and has a representative UK sample by age and sex. The database holds significant clinical events relating to any period in a patient's life that has been summarised into computer records by the practice. As in any observational database, data entered by panel doctors may be incomplete.

^[9] Patients available in their practice for 12 months from 1/4/2010 to 31/3/2011 with a diagnosis of epilepsy anywhere in their record up to the end of the study year who have received epilepsy medication in the study year linked specifically to epilepsy (as problem).

^[10] Applied to 2011 England, Office for National Statistics population estimates, 2012, London.

^[11] This is in line with the 2011/12 [Quality and outcomes framework](#) (QOF), which reported the prevalence of epilepsy in adults in England who are receiving AEDs as 0.78%.

^[12] This group may include people who are off-treatment and may have been free of seizures for many years.

^[13] Applied to 2011 England, Office for National Statistics population estimates, 2012, London.

^[14] Patients available in their practice for the 12 months from 01/04/2010 to 31/03/2011 with a new diagnosis of epilepsy between 01/04/2010 to 31/03/2011 (incidence). This includes patients who have a record of epilepsy during the study year and who have not previously had a record of epilepsy – that is, first record of epilepsy occurred during the study year.

^[15] In estimating the service levels for the investigation after a suspected first seizure, it is assumed that not all who are referred with suspected epilepsy are subsequently diagnosed with it.

^[16] Table 12a. Diagnosis by 12 months after the first paediatric assessment, non-epileptic episode(s) = 45%. Epilepsy 12, The Royal College of Paediatrics and Child Health's national audit (2012).

^[17] The [HES database](#) contains details of all admissions to NHS hospitals in England. It includes private patients treated in NHS hospitals, patients who were resident outside England and care delivered by treatment centres (including those in the independent sector) funded by the NHS.

^[18] ICD-10 diagnosis codes G40 and G41 have been used here to classify epilepsy. ICD-10 is the 10th revision of the International Statistical Classification of Diseases (ICD) and Related Health Problems, a medical classification list by the World Health Organization.

^[19] Readmissions calculated from 2010/11 HES data, ICD-10 diagnosis codes G40 and G41, emergency admission type; only records with a valid admission and discharge date were included.

^[20] The 2012/13 NHS national tariff now includes a best practice tariff for epilepsy set to encourage the adoption of clinical best practice around the management of emergency admissions. This is applied where the length of stay of emergency admissions is zero days.

^[21] Patient aged 19 years or over and emergency, or transfer admission method (admission method codes 21–25, 28 and 81). Epilepsy coded as HRG4 code AA26Z, or ICD-10 G253, G400, G401, G402, G403, G404, G405, G406, G407, G408, G409 or R568.

^[22] Number of females aged 12–17 years and 18–50 years available in their practice for the 12 months from 01/04/2010 to 31/03/2011 with a diagnosis of epilepsy anywhere in their record up to the end of the study year and who have been prescribed epilepsy medication for any diagnosis in the study year (as medical event) (prevalence).

4 Specifying services for the diagnosis and management of the epilepsies

This section considers the commissioning implications and potential resource impact of implementing the recommendations to achieve the [NICE quality standard for the epilepsies in adults](#) and the [NICE quality standard for the epilepsies in children and young people](#).

4.1 Referral to a specialist

Adults: Quality statement 1

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

Children and young people: Quality statement 1

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

Diagnosing epilepsy can be complex, and studies carried out in various settings estimate that 4.6–30% of people are incorrectly diagnosed. The [Topic Advisory Group](#) agreed that diagnosis by epilepsy specialists will reduce the levels of misdiagnosis towards the lower of these estimates in newly diagnosed cases. It is therefore crucial that specialists are involved early in diagnosing epilepsy and that they take great care to establish the correct diagnosis.

To achieve the NICE quality standard and adhere to [NICE recommendations](#), commissioners need to commission services with [care and referral pathways](#) from both primary and emergency care settings, and with sufficient specialist capacity. This is to enable all people who have had a suspected seizure to be seen by a specialist in the diagnosis and management of the epilepsies within 2 weeks of presentation.

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

The specialist's care of people with epilepsy should be part of an ongoing peer review process related to epilepsy care. Commissioners may wish to ask providers to demonstrate that staff are skilled and competent. For example, they may consider whether paediatric specialists have completed the specialist training module on epilepsy developed by the [Royal College of Paediatrics and Child Health](#), or worked for a minimum of 6 months in a tertiary centre for epilepsy in children and attended appropriate paediatric epilepsy training courses.

In line with [recommendations 1.4.1 and 1.4.2](#) of the NICE clinical guideline on epilepsy, commissioners should also ensure that people presenting to an Accident and Emergency (A&E) department after a suspected seizure are screened initially and receive onward referral to a specialist when an epileptic seizure is suspected or there is diagnostic doubt. This should be done by an adult or paediatric physician as appropriate. Commissioners should check that [protocols](#) are in place to ensure proper assessment in the emergency setting and highlight the need for high-quality communication for onward referral. This information sharing could include details of tests already undertaken and their results, as well as details from the person and eye witnesses to the suspected seizure.

Referral pathways to psychological or psychiatric services for further investigation and treatment in line with [recommendation 1.5.7](#) of NICE clinical guideline 137 should also be in place. This will ensure that people with suspected [non-epileptic attack disorder](#) receive appropriate care, and it will also promote the best use of resources. There may be costs involved when there are shortages of specialist neurologists and a significant number of people with a suspected seizure needing to be seen by a specialist within 2 weeks.

However, increasing the availability of qualified healthcare professionals specialising in epilepsy, improving education and awareness of the condition, and providing access to the recommended diagnostic investigations are likely to reduce the rate of misdiagnosis and the associated direct and indirect costs^[23] (such as those caused by unnecessary and/or ineffective prescribing of AEDs), and provide better value for money (see the [NICE clinical guideline on epilepsy](#)). The use of specialists will also help to improve management of the condition and may lead to a reduction in the number of seizures and seizure-related injuries, thereby reducing avoidable emergency admissions to secondary care. Each hospital emergency or unscheduled admission for epilepsy costs £1045^[24].

Table 2 provides indicative savings per 100,000 population of reducing misdiagnosis^[25].

Table 2 Potential savings per 100,000 of reducing misdiagnosis of epilepsy

Rate of misdiagnosis	5%	30%
Number of people misdiagnosed per 100,000	3	23
Assume 70% could be avoided	2	17
Number of misdiagnoses avoided	1	6

Cost per 100,000	£1100	£9500
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Commissioners should also note that not all people with suspected epilepsy who are referred to specialists are subsequently diagnosed with epilepsy. The [proportion](#) of people who are referred and subsequently diagnosed with epilepsy is likely to be highly variable. The [NICE commissioning and budgeting tools](#) can be used to help estimate the level of service needed and the cost of commissioning decisions.

Commissioners need to check that providers are adhering to recommendations in the [NICE clinical guideline on epilepsy](#) and providing relevant information to people with epilepsy. People who have experienced a possible first seizure should be given and have access to sources of information as detailed in [recommendation 1.3.1](#). Essential information should include how to recognise a seizure, first aid and the importance of reporting further attacks. This information should be provided to the person while they are waiting for a diagnosis and to their family and/or carers ([recommendation 1.4.9](#)). Providers should be aware that high-quality information is available from voluntary organisations and other sources. Information should be provided in formats, languages and methods that are suited to people's needs and should consider a person's developmental age, sex, culture and stage of life. Commissioners may wish to work with providers to ensure that communication aids and interpreters are available when necessary.

Commissioners may refer to [section 3.1](#), which examines the number of people with a suspected first seizure who will need to be referred to a specialist.

Commissioners may also wish to use the commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) to help them identify local service requirements and calculate the cost of commissioning the service.

Commissioners may consider the use of local data collection activities, as well as NICE's [clinical audit tools](#) and [baseline assessment tool](#), to measure current practice against the [NICE recommendations](#) and to monitor providers and the steps taken to achieve the statements in the quality standards.

4.2 Investigations

Adults: Quality statement 2

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

Children and young people: Quality statement 2

Children and young people having initial investigations for epilepsy undergo the tests within 4 weeks of them being requested.

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

Recommendations 1.6.3 and 1.6.22 of NICE clinical guideline 137 state that electroencephalogram (EEG) and magnetic resonance imaging (MRI) should be carried out within 4 weeks of them being requested. This is to ensure precise and early diagnosis, and initiation of therapy as appropriate to the needs of the person. Commissioners should note that additional 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 in this timeframe.

Commissioners will need to specify that people with suspected epilepsy should have access to initial investigations within 4 weeks of them being requested by the specialists. The Topic Advisory Group considered access to videotelemetry and MRI investigations to be a priority for commissioners. Commissioners should therefore review services, ensure there are adequately trained healthcare professionals with the necessary interpretation competencies to meet the needs of the local population, and increase local service provision where necessary.

Commissioners should note that, because it may not be possible to make a definite diagnosis of epilepsy, service provision should be in place to allow for further investigations if necessary and/or referral to a tertiary care epilepsy specialist^[a].

Commissioners should also check that providers are adhering to NICE recommendation 1.6.1, and that people are provided with relevant information 'on the reasons for tests, their results and meaning, the requirements of specific investigations, and the logistics of obtaining them'.

Commissioners are reminded to consider the needs of people with [learning disabilities](#) (recommendation 1.16.2.2) and [children](#) (recommendation 1.6.2). Commissioners will need to ensure that providers have facilities available for imaging under anaesthesia if necessary (including MRI, see also [section 4.3](#)), and that all investigations for children are performed in a child-centred environment.

Therefore, there may be costs associated with increasing capacity to enable diagnostic investigations to be undertaken within 4 weeks of them being requested.

Commissioners may refer to [section 3.1](#), which examines the number of people with a suspected first seizure who will need to be referred to a specialist for accurate diagnosis.

Commissioners can use the commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) to help them to identify local service requirements and to calculate the cost of commissioning the service.

Commissioners can also refer to the [NICE 'do not do' recommendations database](#) for specific advice on NHS clinical practices relating to diagnosis and investigations that should be discontinued completely or should not be used routinely in accordance with [NICE clinical guideline 137](#).

Commissioners may consider local data collection activities, as well as NICE's [clinical audit tools](#) and [baseline assessment tool](#) to measure current practice against the [NICE recommendations](#) and to monitor providers and steps taken to achieve these statements in the quality standards.

Commissioners and providers can also refer to the [NICE shared learning database^{\[a\]}](#), which provides an example of implementation of [NICE clinical guideline 137](#) on the epilepsies. [Improving services by incorporating NICE guidelines for EEG referral](#) describes an initiative that resulted in a reduction in waiting times (despite staffing levels remaining constant) and routine outpatient EEG recordings being performed within 4 weeks and urgent outpatient cases performed within 1 week.

^[a] The [NICE shared learning database](#) offers examples of how commissioners and service providers have used NICE guidance to create innovative and effective local implementation programmes for service improvements.

4.3 Magnetic resonance imaging

Adults: Quality statement 3

Adults who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

Children and young people: Quality statement 3

Children and young people who meet the criteria for neuroimaging for epilepsy have magnetic resonance imaging.

MRI is shown by evidence to be the most sensitive and specific neuroimaging option in terms of identifying structural abnormalities in the brain, but access to MRI scanning and reporting facilities is variable across the country. [Recommendation 1.6.20](#) of NICE clinical guideline 137 recommends that MRI should be the imaging investigation of choice for people with epilepsy. To achieve these quality statements, commissioners will need to ensure that people who meet the criteria for neuroimaging for epilepsy have an MRI scan^[27].

The National Audit Office reported that the percentage of people waiting less than 2 weeks from referral for an MRI scan in 2009/10 varied between trusts from below 20% to 93%.

Commissioners should review services to check that there is adequate provision of MRI equipment and adequate numbers of trained healthcare professionals with the necessary interpretation competencies to meet the needs of the local population. If there is limited or no local access to the recommended investigations, robust referral pathways to other providers and timely, high-quality communication with the requesting team are important for good patient care.

Ensuring that people who meet the criteria for neuroimaging for epilepsy have an MRI scan might increase costs if current arrangements are not adhering to NICE guidance. Commissioners can refer to [section 3.2](#) for information on the number of new referrals every year to a specialist service for the accurate diagnosis of epilepsies after a suspected seizure. It is assumed that only a small number of these may meet the criteria for having MRI; therefore, costs are not anticipated to be significant. Commissioners should assess the level of service needed for their local population and estimate costs at a local level. Unit costs for an MRI scan range from £153 to £279 depending on the nature of the scan^[28].

Local data collection exercises can be used to look at evidence of local arrangements to ensure that all people (including those with learning disabilities) who meet the criteria have an MRI scan.

Commissioners can use the commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) to help them to identify local service requirements and to calculate the cost of commissioning the service.

Commissioners can also refer to the [NICE 'do not do' recommendations database](#) for specific advice on NHS clinical practices relating to diagnosis and investigations that should be discontinued completely or should not be used routinely in accordance with [NICE clinical guideline 137](#).

Commissioners may consider local data collection activities as well as NICE's [clinical audit tools](#) and [baseline assessment tool](#) to measure current practice against the [NICE recommendations](#) and to monitor providers and steps taken to achieve these statements in the quality standards.

Commissioners can collect data on the percentage of children with defined indications for MRI, and who had MRI within 1 year, using the [Epilepsy 12 national audit](#).

4.4 Epilepsy care plan

Adults: Quality statement 4

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

Children and young people: Quality statement 4

Children and young people with epilepsy have an agreed and comprehensive written epilepsy care plan.

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

In line with [recommendation 1.8.2](#) of NICE clinical guideline 137 and to achieve these quality statements, commissioners should specify that providers facilitate a process that ensures all people with epilepsy have a comprehensive written epilepsy care plan that is agreed between the person, their family and/or carers where appropriate, and primary and secondary care providers. Commissioners should ensure that equality and diversity considerations are taken into

account and that providers are adhering to best interest decision-making, in accordance with the Mental Capacity Act.

The written epilepsy care plan should ideally begin at the point of diagnosis, include lifestyle as well as medical issues and should be reviewed at least annually. Commissioners may wish to specify the use of a local template that should be based on the recommended sources of information listed in [recommendation 1.3.1](#) of NICE clinical guideline 137, for consistency of content in each epilepsy care plan.

Local data collection exercises can be used to look at evidence of local arrangements for people with epilepsy to have an agreed and comprehensive written epilepsy care plan, as well as patient satisfaction with involvement in the epilepsy care planning process.

It is not anticipated that there will be costs associated with having an agreed and comprehensive written epilepsy care plan. However, this care plan will improve quality of care for people with epilepsy and could reduce the incidence of emergency hospital admissions, thereby saving the NHS resources that could be deployed elsewhere for epilepsy care. Each emergency hospital admission costs £1045^[24].

Commissioners may refer to [section 3.1](#), which examines the number of people with epilepsy and receiving AEDs in England who are likely to need an agreed and comprehensive written epilepsy care plan.

Commissioners may also consider local data collection activities as well as NICE's [clinical audit tools](#) and [baseline assessment tool](#) to measure current practice against the [NICE recommendations](#) and to monitor providers and steps taken to achieve these statements in the quality standards.

4.5 Epilepsy specialist nurse

Adults: Quality statement 5

Adults with epilepsy are seen by an epilepsy specialist nurse and have access to a named epilepsy specialist nurse who they can contact between scheduled reviews.

Children and young people: Quality statement 5

Children and young people with epilepsy have access to a named epilepsy specialist nurse who they can contact between scheduled reviews.

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

To achieve these quality statements, commissioners need to ensure that they commission services that include ESNs as an integral part of the network of care for people with epilepsy. Epilepsy specialist nursing may be provided in a number of different teams – for example, in the learning disabilities team. Commissioners should specify that providers adhere to [recommendation 1.8.3](#) of NICE clinical guideline 137 and that ESNs support both epilepsy specialists and generalists to ensure access to community and multi-agency services, and to provide information, training and support to people with epilepsy.

Local data collection exercises can be used to look at evidence of local arrangements for people with epilepsy to have access to a named ESN whom they can contact between scheduled reviews, as well as patient satisfaction with access to epilepsy specialist nursing.

In 2010, [Epilepsy Action](#) stated that 'currently there are only around 250 ESNs across the UK despite a need for 1100 and a number of these posts are under threat with reduced hours or posts being cut altogether'. Therefore, there may be costs associated with ESN provision where it is currently lacking. The cost of an ESN post is £43,000 per annum based on the NHS Agenda for Change (AfC) band 7 midpoint of scale. Any necessary investment in additional ESN posts has the potential to improve care and reduce follow-up needs by consultant neurologists. This might also lead to a potential reduction in emergency hospital admissions.

Based on the [Epilepsy Action report on best care: the value of epilepsy specialist nurses](#), it is likely that additional investment in ESNs may be needed. The cost would be approximately £70,000 for a population of 100,000 people.

Table 3 provides indicative costs per 100,000 population for investing in additional ESNs if needed.

Table 3 Cost of additional epilepsy specialist nurses per 100,000 population

Details	Whole time equivalent	Cost (per 1 whole time equivalent) (£000)	Total cost (£000)
Recommended posts	2.11	43	91
Filled posts	0.48	43	21
Posts to be filled	1.63	43	70

Commissioners may wish to refer to [section 3.1](#), which examines the number of people with epilepsy and receiving AEDs in England, who should have access to a named ESN.

Commissioners can use the commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) to help them to identify local service requirements and to calculate the cost of commissioning the service.

Commissioners may consider local data collection activities as well as NICE's [clinical audit tools](#) and [baseline assessment tool](#) to measure current practice against the [NICE recommendations](#) and to monitor providers and steps taken to achieve these statements in the quality standard.

Commissioners can collect data on the percentage of children with evidence of input by, or referral to, an ESN within 1 year, using the [Epilepsy 12 national audit](#) section 2.

4.6 Prolonged or repeated seizures

Adults: Quality statement 6

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

Children and young people: Quality statement 6

Children and young people with a history of prolonged or repeated seizures have an agreed written emergency care plan.

An emergency care plan is important for improving the quality of emergency care in the community. It ensures that previous incidents and the agreed treatment strategies are taken into account by healthcare professionals. It also provides guidance for family members or carers who

may need to administer emergency treatment. The timely and appropriate management of a prolonged or repeated seizure may significantly reduce the risk of mortality and morbidity (long-term complications) known to be associated with prolonged or repeated seizures.

To achieve these quality statements, commissioners should specify that providers facilitate a process that ensures all people with a history of prolonged or repeated seizures have an agreed emergency care plan. The emergency care plan should describe what happens in the event of a prolonged seizure, including pharmacological treatment that should be given and actions to take, whom to contact and when. Treatment should be administered by trained clinical personnel or, if specified by an agreed protocol drawn up with the specialist, by family members and/or carers with appropriate training. Commissioners should therefore ensure that family members and/or carers of people with epilepsy receive training to initiate treatment at home or in the community when necessary in line with [recommendation 1.14.1.4](#) of NICE clinical guideline 137, and should specify that emergency plans are reviewed at least annually^[23].

Local data collection exercises can be used to look at evidence of local arrangements for people with a history of prolonged or repeated seizures to have an agreed written emergency care plan, as well as patient satisfaction with emergency care for prolonged or repeated seizures. The [HES](#) data source can be used to look at A&E attendances and hospital admissions for prolonged or repeated seizures.

It is not anticipated that there will be costs associated with having an agreed written emergency care plan. However, having emergency care plans may improve quality of care and could help to reduce the incidence of avoidable emergency hospital admissions, thereby saving the NHS resources that could be deployed elsewhere to improve care of people with epilepsy. Each emergency hospital admission costs £1045^[24].

Commissioners can refer to [section 3.3](#) to consider the number of unplanned hospital admissions and readmissions for people with epilepsy to enable specialist support and other therapy to be targeted where appropriate to reduce avoidable emergency admissions and readmissions.

Commissioners can use the commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) to help them to identify possible cost savings.

Commissioners may consider local data collection activities as well NICE's [clinical audit tools](#) and [baseline assessment tool](#) to measure current practice against the [NICE recommendations](#) and to monitor providers and steps taken to achieve these statements in the quality standard.

Commissioners can use the [HES](#) data source, which contains the data necessary for monitoring A&E attendances.

4.7 Referral to tertiary care

Adults: Quality statement 7

Adults who meet the criteria for referral to a tertiary care specialist^[30] are seen within 4 weeks of referral.

Children and young people: Quality statement 7

Children and young people who meet the criteria for referral to a tertiary care specialist are seen within 4 weeks of referral.

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

In line with [recommendation 1.10.2](#) of the NICE clinical guideline 137, people should be referred to tertiary services for further assessment if seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, and in circumstances defined in the recommendation.

To achieve these quality statements, commissioners need to commission services with referral pathways and enough capacity in tertiary care services to ensure that all people who meet the [criteria](#) for referral to a tertiary care specialist are referred and seen within 4 weeks of referral. Tertiary services should include a multidisciplinary team, experienced in the assessment of people with complex epilepsy, and have adequate access to investigations and treatment by both medical and surgical means in line with [recommendation 1.10.7](#) of the NICE guideline.

As access to tertiary services is variable across the country, costs may be incurred when there is a change in practice that needs increased capacity in the service to be commissioned. The costs will depend on local needs and the current level of tertiary care provision. Commissioners should therefore assess their local service need and costs. Local data collection exercises can be used to look at evidence of local arrangements for people who meet the criteria for referral to a tertiary care specialist to be seen within 4 weeks, as well as patient satisfaction with referrals to tertiary care specialists.

Commissioners can use the commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) to help them to identify local service requirements and to calculate the cost of commissioning the service.

Commissioners may consider local data collection activities as well as NICE's [clinical audit tools](#) and [baseline assessment tool](#) to measure current practice against the [NICE recommendations](#) and to monitor providers and steps taken to achieve these statements in the quality standard.

4.8 Re-access to specialist care for adults

Adults: Quality statement 8

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

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

In line with [recommendation 1.20.7](#) of the NICE clinical guideline 137, adults with well-controlled epilepsy may have specific medical or lifestyle issues (for example, pregnancy or drug cessation) that may need the advice of a specialist. Specialist epilepsy services include secondary care services, tertiary services and [specialist epilepsy nursing](#) that may be based in the community.

To achieve this quality statement, commissioners need to commission services with referral pathways and enough capacity to ensure that all adults with a medical or lifestyle issue needing review can be referred and seen by a specialist epilepsy service.

Commissioners are reminded of the need to consider women and girls of childbearing potential when planning services, and may wish to refer to [section 3.4.1](#) for further information.

Local data collection exercises can be used to look at local arrangements for adults with medical or lifestyle issues needing review and referrals to specialist epilepsy services.

There are costs associated with referrals to specialist epilepsy services for reviews. These are shown in table 4. However, reviews will help improve the quality of care of patients and save the NHS resources.

Table 4 Neurology and neurosurgery outpatient attendance tariff ¹

Treatment function code	Treatment function name	WF01B First attendance - single professional (£)	WF02B First attendance - multi professional (£)	WF01A Follow-up attendance - single professional (£)	WF02A Follow-up attendance - multi professional (£)
150	Neurosurgery	323	323	132	165
400	Neurology	225	225	130	136
421	Paediatric neurology	401	401	228	249

¹ NHS 2012/13 tariff – non-mandatory tariffs

Commissioners can use the commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) to help them to identify local service requirements and to calculate the cost of commissioning the service.

Commissioners may consider local data collection activities as well as NICE's [clinical audit tools](#) and [baseline assessment tool](#) to measure current practice against the [NICE recommendations](#) and to monitor providers and steps taken to achieve these statements in the quality standard.

Commissioners can also refer to the [NICE 'do not do' recommendations database](#) for specific advice on NHS clinical practices relating to contraception and AEDs, and monitoring of AEDs in pregnancy that should be discontinued completely or should not be used routinely in accordance with the [NICE clinical guideline on epilepsy](#).

4.9 Review for children and young people

Children and young people: Quality statement 8

Children and young people with epilepsy have a structured review with a paediatric epilepsy specialist at least annually.

Reviews are important in ensuring that ongoing interventions are effectively meeting the needs of children and young people, and to identify any changes in how their epilepsy is being controlled. They also ensure that epilepsy care plans remain relevant and up to date.

In line with [recommendations 1.20.3 and 1.20.5](#) of the NICE clinical guideline 137, children and young people should have a regular structured review with a paediatric epilepsy specialist. The maximum interval between reviews for children and young people should be 1 year, but is likely to be between 3 and 12 months.

To achieve this quality statement, commissioners need to commission services with referral pathways and enough capacity in tertiary care services for all children and young people to receive a structured review with a paediatric epilepsy specialist at least annually. Commissioners may also wish to refer to the [NICE pathway on Epilepsy](#), specifically [Special considerations for young people with epilepsy](#).

Local data collection exercises can be used to look at evidence of local arrangements for children and young people having a structured review. Commissioners may also wish to assess patient or parent/carer satisfaction with review content and the frequency of reviews.

There are costs associated with referrals to specialist epilepsy services for reviews. These are shown in table 4. However, reviews will help improve the quality of care of patients and save the NHS resources.

Commissioners may refer to [section 3.1](#) to help them estimate the number of children and young people with epilepsy who should have a structured review with a paediatric epilepsy specialist at least annually.

Commissioners can use the commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) to help them to identify local service requirements and to calculate the cost of commissioning the service.

Commissioners may consider local data collection activities as well as NICE's [clinical audit tools](#) and [baseline assessment tool](#) to measure current practice against the [NICE recommendations](#) and to monitor providers and steps taken to achieve this statement in the [NICE quality standard for the epilepsies in children and young people](#).

4.10 Transition from children's services to adult services

Children and young people: Quality statement 9

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

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

Commissioners should specify that young people have an agreed transition period during which their continuing epilepsy care is reviewed jointly by multidisciplinary services with adult and

paediatric specialists in line with [recommendation 1.17.5](#) of the NICE clinical guideline 137. 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. Commissioners should specify that the period of transition is a joint clinical action between paediatric and adult services, with at least 1 meeting at a joint consultation and a clear action plan for conducting a review after the young person has transferred into adult services, and that there needs to be clarity about who the lead clinician is to ensure continuity of care.

Commissioners should ensure that care pathways are managed according to the best practice guidance in line with the [NICE clinical guideline on epilepsy](#) and the Department of Health's [Transition: getting it right for young people](#). There might be costs involved for the provision of joint clinics, for example; however, the cost is not expected to be significant.

Commissioners are reminded to consider the needs of young people with learning disabilities and should ensure that a longer period of transition is possible to accommodate the additional complexity of their clinical and psychological needs.

Local data collection exercises can be used to look at local arrangements for young people to have an agreed transition period, as well as young people's experience of transition to adult services.

Primary care data were used to establish the number of young people aged 15–19 years with a diagnosis of epilepsy who have been prescribed AEDs^[31]. It was found that 0.42% (420 in 100,000 of this population) of young people (15–19 years) may need transition services between paediatric and adult services. This is equivalent to around 14,000 people in England.

Commissioners can use the commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) to help them to identify local service requirements and to calculate the cost of commissioning the service.

Commissioners may consider local data collection activities as well as NICE's [clinical audit tools](#) and [baseline assessment tool](#) to measure current practice against the [NICE recommendations](#) and to monitor providers and steps taken to achieve these statements in the quality standard.

^[23] [The human and economic cost of epilepsy in England – Wasted money, wasted lives](#) (2007) All Parliamentary Group on Epilepsy Report. London.

^[24] National Tariff 2012/13. Currency code AA26Z – muscular, balance, cranial or peripheral nerve disorders; epilepsy, head injuries.

^[25] The commissioning and budgeting tools for the [epilepsies in adults](#) and the [epilepsies in children and young people](#) have been used to estimate potential savings associated with a 70% reduction in misdiagnosis rates.

^[26] The NICE recommendation 1.5.6 has replaced 'centre' with 'specialist' for consistency across the recommendations.

^[27] NICE clinical guideline 137 (recommendation 1.6.24): Computerised Tomography (CT) Scan should be used to identify underlying gross pathology if MRI is not available or is contraindicated, and for children or young people in whom a general anaesthetic or sedation would be required for MRI but not CT. NICE clinical guideline 137 (recommendation 1.6.25): In an acute situation, CT may be used to determine whether a seizure has been caused by an acute neurological lesion or illness.

^[28] 2012/13 NHS tariff – other mandatory prices – Direct access services (MRI scan).

^[29] Prolonged seizures are seizures that last 5 minutes or more. Repeated seizures are seizures that occur 3 times or more within 1 hour.

^[30] NICE clinical guideline 137 (appendix G: abbreviations and glossary). A tertiary epilepsy specialist is an adult or paediatric neurologist who devotes the majority of their working time to epilepsy, is working in a multidisciplinary tertiary referral centre with appropriate diagnostic and therapeutic resources, and is subject to regular peer review.

^[31] The IMS disease analyser collects data from a sample of around 100 GP practice systems. The number of young people aged 15–19 years available in their practice for the 12 months from 01/04/2010 to 31/03/2011 with a diagnosis of epilepsy anywhere in their record up to the end of the study year and have been prescribed epilepsy medication in the study year (as medical event). (Prevalence). (This is patients who have a record of epilepsy at any point to the end of

the study year and who have been prescribed epilepsy medication for any diagnosis during the study year.)

5 Service models

Commissioners may wish to consider commissioning services for the diagnosis and management of the epilepsies in adults, children and young people in several different ways, and mixed models of provision may be appropriate across a local health economy. A managed network model of delivering epilepsy care could help to improve seizure control in people with epilepsy and rationalise clinical decision-making about the need for admission.

As well as a focus on secondary and tertiary care and the provision of specialists and recommended diagnostic investigations, commissioners may wish to focus on investment in relation to community-based epilepsy services, such as community support services for epilepsy and epilepsy specialist nursing services to support the review of people with epilepsy, coordination of the care pathway, family support, population education and liaison with primary care and other agencies including social care, as appropriate.

Commissioners may also wish to work with their local [QIPP](#) lead to develop service models for people with epilepsy. Example models are included in table 5.

Table 5 Delivering QIPP through service models

QIPP model	Example output
Self-care support for long-term conditions	Service redesign: embedding self-care as an integral part of patient pathways and within the choice agenda. Public awareness: raising awareness of self-care support available to people with long-term conditions.
Personalised care plans for long-term conditions	Quality may be improved by better communication, understanding, improved clinical outcomes and reduced error. Productivity may be improved by increasing compliance with treatment and reduced need for unplanned admissions.

(The [NHS Evidence's QIPP](#) collection examples have all been assessed against a set of criteria and subject to an external peer review process. The best of these are highlighted on the NHS evidence website as 'highly recommended' examples).

Case studies

Commissioners may wish to refer to examples of service models and developments for epilepsy services. Examples are included in table 6.

Table 6 Examples of service models for people with epilepsy

Setting	Examples of service models	Service model
Secondary care	Wessex neurological centre – specialist epilepsy service University Hospital Southampton NHS Foundation Trust	A dedicated, integrated 24-hour acute neurosurgical and neurological assessment, investigation and treatment service. Includes a rapid access clinic for suspected seizures with direct referrals from A&E or GPs through a direct booking system. Also includes a transition service with clinics run by a paediatric neurologist, adult neurologist and epilepsy nurse specialist.
Secondary care	Services for the care of adults with epilepsy Cambridge University Hospitals NHS Foundation Trust	Diagnosis, treatment and relevant long-term follow-up services are run by specialists with expertise in managing epilepsy which includes consultant neurologists and an epilepsy specialist nurse. Clinics include first seizure, epilepsy, epilepsy in pregnancy and vagal nerve stimulation clinics.

<p>Secondary care – Accident and Emergency Department</p>	<p><u>First-fitter clinic</u> Alder Hey Children's Hospital</p>	<p>Children who present to the A&E department after a first tonic–clonic epileptic seizure are offered an appointment for the first-fitter clinic. The clinic is supervised by an advanced nurse practitioner. Children who need investigations (such as EEG) are referred to a consultant in paediatric neurology or a general paediatric consultant with an interest in epilepsy.</p>
<p>Primary care</p>	<p><u>Community support service for the epilepsies</u> Wakefield District Primary Care Trust</p>	<p>A community support service that provides an enhanced and specialist level of care for people with epilepsy including those with learning disabilities, designed to complement services in primary and secondary care.</p>
<p>Primary care</p>	<p><u>GPwSI epilepsy service</u> East Kent</p>	<p>A network of GPs with Special Interest (GPwSI) in epilepsy. Referrals are received from both GPs and neurologists for patients who have a current diagnosis of epilepsy and need advice (for example, epilepsy and pregnancy) or who have experienced a recent seizure.</p>
<p>Primary care</p>	<p><u>Epilepsy specialist nursing service</u> Solent NHS Trust</p>	<p>Working closely with neurologists, paediatricians, GPs and allied health professionals and supported by the tertiary epileptologist, the epilepsy specialist nurse service is community based to support adults with newly diagnosed epilepsy. The service includes assessment, review and follow-up, and specific services for women of child-bearing potential, transition services, services for complex epilepsy in people with learning disabilities and comorbidities, and for people who are frequent non-attendees of hospital appointments.</p>

<p>Primary and secondary care</p>	<p><u>Management of seizure disorders in adults – Pathway</u> <u>Management of seizures disorders in adults – Service Model</u> Greater Manchester Neurosciences Network</p>	<p>The Pathway and Service model were developed in collaboration with clinicians and voluntary sector organisations from across Greater Manchester for the managing seizure disorders, covering first seizure, referral to specialist services, long-term management, referral to tertiary services and people with complex epilepsy and comorbidities.</p>
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(Please note – these examples are offered to share good practice and NICE makes no judgement on the compliance of this service with its guidance).

Table 7 Examples of development work or improvements

Development	Purpose
<p>Greater Manchester Strategy for the management of seizure disorders in adults (2011) <u>Greater Manchester Neurosciences Network</u></p>	<p>Supporting a consistent approach to epilepsy service provision across Greater Manchester. The strategy aims to improve services for adults based on an integrated care pathway which ensures the delivery of coordinated and timely services. Improved access to epilepsy specialist nurses is also a focus of the strategy which offers a basis for commissioning local services.</p>

<p><u>East Kent Health economy. Strategy for epilepsy services</u> Developing a service model and recommendations for modernising epilepsy services in East Kent</p>	<p>A comprehensive joint approach to care for people with epilepsy living in East Kent. The strategic vision includes close integration between health services, social services, education authorities, employment agencies and voluntary organisations. The strategy focuses on the development of integrated care pathways across primary, secondary and tertiary care and social services including GPwSI, epilepsy specialist nurses and specialist neurologists and paediatricians, to ensure access to appropriate primary and specialist care.</p>
<p><u>Specialist epilepsy and learning disability service</u> Nottinghamshire NHS Trust</p>	<p>Improvement in the standard of service provision for people with epilepsy and learning disability in Nottinghamshire. The service includes a specialist epilepsy service for adults with learning disability in partnership with the neurology departments of the local acute hospital trusts, joint transition clinics within local special schools and epilepsy-related information for adults with learning disability and their carers. A standardised epilepsy awareness teaching package has been produced for health trainers.</p>
<p><u>Children's Epilepsy Workstream in Trent</u></p>	<p>A 'network' of people in the East Midlands region with interest and responsibilities for children and young people with epilepsies. The group contains 'link professionals' from health services across the region. The aim of the workstream is to work together to further develop and resource services for children and young people with epilepsies.</p>
<p><u>Emergency admissions for epilepsy in children</u> Luton PCT</p>	<p><u>RightCare's Case-study 2:</u> In 2008, Luton PCT had the highest rate of emergency admissions for epilepsy per 100,000 children in England. The number of children presenting with epilepsy as an emergency attendance was almost twice the national average, and was one of the highest of any NHS trust in the East of England region. Opportunities for intervention were identified at different points along the patient pathway including education of families, pre-hospital care, education of ambulance service for pre-hospital management and network care pathways.</p>

<p>Ambulatory emergency care for epilepsy</p>	<p>Epilepsy is identified by the NHS Institute for Innovation and Improvement as a clinical condition that could be managed through ambulatory emergency care. The Institute believes that up to 30% of all epilepsy admissions could be dealt with in this way^[a].</p>
<p>^[a] NHS Institute for Innovation and Improvement (2007) The directory of ambulatory emergency care in adults. Coventry: NHS Institute for Innovation and Improvement.</p>	

(Please note – these examples are offered to share good practice and NICE makes no judgement on the compliance of this service with its guidance).

6 The commissioning and budgeting tools

Download the [services for the diagnosis and management of the epilepsies for adults commissioning and budgeting tool](#).

Download the [services for the diagnosis and management of the epilepsies in children and young people commissioning and budgeting tool](#).

Use the commissioning and budgeting tools for diagnosis and management of the epilepsies to determine the level of service that might be needed locally and to calculate the cost of commissioning the services. Further information and data is provided in [section 3](#).

6.1 Identify indicative local service requirements

The commissioning and budgeting tools help you to assess local service requirements using the indicative service levels as a starting point. With knowledge of your local population and its demographics, it is recommended that the information and data provided are amended to better reflect local circumstances.

Available data suggest in England that the number of new referrals every year to a specialist service for the accurate diagnosis of the epilepsies after a suspected first seizure is^[a]:

- **0.06%** (60 per 100,000) adults aged 18 years and older
- **0.08%** (80 per 100,000) children and young people aged 17 years and younger.

This equates to approximately 23,000 adults and 9500 children and young people in England being referred to a specialist for the assessment and diagnosis of epilepsy every year.

6.2 Model future commissioning intentions and associated costs

The commissioning and budgeting tools can be used to calculate the capacity and resources needed to implement the NICE quality standards and [NICE clinical guideline 137](#) and to model the changes needed over a specified period of time. The tools can also be used to calculate the level and cost of activity needed and to consider the settings in which services for the diagnosis and management of the epilepsies in adults, children and young people may be provided (comparing the costs of commissioning the service across the various settings).

The tools are pre-populated with data on the potential recurrent cost elements that may need to be considered in future service planning, which can be reviewed and amended to accurately reflect your local circumstances.

Commissioning decisions should consider both the clinical and economic viability of the service, and take into account the views of local people. Commissioning plans should also take into account the costs of monitoring the quality of the services commissioned.

6.3 Potential savings

You can use the commissioning and budgeting tools to calculate potential savings from reduced inappropriate emergency hospital admissions.

Reducing inappropriate emergency hospital admissions can lead to a direct saving for commissioners through reduced charges via the national tariff. However, for a hospital provider, only the costs of consumables will be saved in the short term and overheads will be unchanged. A step-change needs to be brought about so capacity can be released if savings are to be reflected in hospital expenditure.

A non-elective spell tariff and example reductions of 10%, 20% or 30% are modelled in the commissioning and budgeting tool. Users should amend these figures to reflect local expectations.

For the adult population, the tool also looks at the potential cost impact associated with the introduction of the [best practice tariff](#). Best practice tariff is discussed in [section 3](#).

^[32] It is assumed that approximately 70% of adults and 55% of children and young people newly referred for the diagnosis of epilepsy after a suspected first seizure may be expected to have the diagnosis of epilepsy confirmed (see [section 3](#)).

7 Further Information

Commissioners may find the following resources useful when developing service specifications:

Department of Health resources

- [The standard NHS contracts for acute hospital, mental health, community and ambulance services](#)
- [NHS Specialised Services](#) – the national organisation responsible for the commissioning of specialised services to help improve the lives of children and adults with rare diseases or disorders. See also the Specialised Service's national definitions set (third edition): [Specialised neurosciences services \(adult\) – Definition No. 08](#) and [Specialised services for children – Definition No. 23](#)
- Safe and Sustainable's review of [Children's neurosurgical services](#) (2009). NHS Specialised services
- [The National Service Framework for long-term conditions](#) (2005) Department of Health
- [Improving services for people with epilepsy: Action plan in response to the National Clinical Audit of epilepsy-related death](#) (2003). Department of Health

NICE resources

- NICE implementation support for [NICE clinical guideline 137](#) include a [baseline assessment tool](#), [clinical audit tools](#), [clinical case scenarios](#), [costing statement](#), [electronic audit tools](#), [slide set](#) and [pharmacological treatment tables](#)

- Other NICE implementation support tools include [an online educational tool](#) and [NPC online educational tools](#)
- [Retigabine for the adjunctive treatment of partial onset seizures in epilepsy](#). NICE technology appraisal guidance 232 (2011)
- [Transient loss of consciousness \('blackouts'\) management in adults and young people](#). NICE clinical guideline 109 (2010)
- [Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence](#). NICE clinical guideline 76 (2009)
- [Vagus nerve stimulation for refractory epilepsy in children](#). NICE interventional procedure guidance 50 (2004)
- [NHS Evidence](#): provides free access to clinical and non-clinical information (local, regional, national and international) and includes a QIPP library with case studies
- [QIPP service models](#) ^[33] include [ambulatory care for adults](#), [toolkit for improving urgent and emergency care pathways by understanding increases in 999 demand](#), [optimisation of communication channels used in patient pathways](#), [physiological assessment and treatment for medically unexplained symptoms and long-term conditions](#), [self-care support for long-term conditions](#), [personalised care plans for long-term conditions](#)

Other resources

- [Local adult neurology services for the next decade](#) (2011). Royal College of Physicians and Association of British Neurologists
- The King's Fund's [Transforming our healthcare system: 10 priorities for commissioners](#) which includes sections on [active support for self-management](#), [managing ambulatory care sensitive conditions](#) such as epilepsy, [improving the management of patients with both mental and physical health needs](#), [care coordination through integrated health and social care teams](#) and [effective medicines management](#)
- The [Expert Patients Programme Community Interest Company](#) provides and delivers free courses aimed at helping people who are living with a long-term health condition to manage their condition better on a daily basis

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- [Royal College of Paediatrics and Child Health – Epilepsy 12](#), a national 3-year audit to help improve patient outcomes and the quality of care and service provided
 - [National Sentinel Clinical Audit of epilepsy-related death report \(2002\)](#)
 - [Diagnosis and management of epilepsy in adults](#). Scottish Intercollegiate Guidelines Network (SIGN) Guideline No. 70 (2003; updated 2005)
 - [Diagnosis and management of the epilepsies in children and young people](#). SIGN Guideline No. 81 (2003; updated 2005)

^[33] The NHS evidence QIPP collection examples have all been assessed against a set of criteria and then subject to an external peer review process. The best of these are highlighted on the NHS evidence website as 'highly recommended' examples.

8 Topic Advisory Group: diagnosis and management of the epilepsies in adults, children and young people

A topic advisory group was established to review and advise on the content of the guide for commissioners. This group met once, with additional interaction taking place via email.

Dr Richard Appleton

Consultant Paediatric Neurologist, Alder Hey Children's NHS Foundation Trust

Hannah Ahle

Quality improvement manager, Greater Manchester Neurosciences Network

Rebecca Case

Epilepsy nurse specialist, Wessex Neurological Centre, Southampton

Erica Chisanga

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Professor J Helen Cross

The Prince of Wales's Chair of Childhood Epilepsy and Honorary Consultant in Paediatric Neurology, UCL-Institute of Child Health, Great Ormond Street Hospital for Children, London and Young Epilepsy, Lingfield, UK

Sally Gomersall

Lay member

Michael Harnor

Lay member

Dr Margaret Jackson

Consultant Neurologist, Royal Victoria Infirmary

Martin O'Keeffe

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Dr Gregory Rogers

GPwSI (epilepsy) East Kent

Claire Wrigglesworth

Lay member