

Better Value, Better Care –

**Your Guide to Commissioning
in Epilepsy**

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About this booklet

Epilepsy is one of the most common serious neurological disorders seen in primary care.¹ Around 600,000 people in the UK have a diagnosis of epilepsy and are prescribed anti-epileptic drugs (AEDs) – the equivalent of 10 per 1,000 people – and an estimated 32,000 new cases are diagnosed each year.² The incidence of epilepsy is high in the very young (<5 years old), decreases in the adult population, and peaks in the population of older people (>70 years old),² which has important implications for commissioning.

Urgent actions commissioners should do to improve epilepsy care

- **Review** existing services using the [Service specification checklist](#) provided on page 12.
- **Undertake** a baseline audit of existing services using the [Audit checklist for commissioners](#) provided on page 36.

Epilepsy is not a single condition. There are several types of epilepsy, and accurate diagnosis and classification of these can be a complicated process.² An epilepsy diagnosis can have important health, social, educational and employment implications and these are associated with substantial non-medical costs that far outweigh the costs of treatment.² Epilepsy is also an under-recognised killer, accounting for the deaths of 1,150 people in the UK in 2009 alone – more than the number of deaths due to HIV/AIDS and cot death combined³ – yet the Medical Research Council allocated just 0.6% of its funding budget to epilepsy research that same year.²

This booklet aims to encourage health commissioners to take epilepsy seriously and to consider the needs of epilepsy patients by commissioning epilepsy care in their Trust. Commissioning a new service, or developing existing epilepsy care, is seldom easy, and there is no single best way to achieve it. A commissioning manager must have a passion for local change, and be able to develop arguments for that change to convince others to get involved. Commissioning managers and clinicians need to enter into a process of engagement, to begin to understand the difficulties and frustrations that the other faces.

Ten key facts about epilepsy

- The number of people in the UK diagnosed with epilepsy and taking AEDs has risen sharply in recent years to around 600,000 people. However, the exact number of people living with epilepsy in the UK is currently unknown.
- Misdiagnosis of epilepsy is common (20–31% of patients are wrongly diagnosed and treated) and can have important consequences in terms of patient outcomes and cost to the NHS.
- The mortality rate among people with epilepsy is high, despite 42% of epilepsy-related deaths being potentially avoidable.
- Epilepsy is responsible for a high number of emergency department visits. Reducing non-elective epilepsy admissions may offer significant cost savings.
- An estimated 18% of patients are not receiving optimal treatment with AEDs, and are having unnecessary seizures as a result.
- Side-effects of AEDs can include degenerative diseases such as osteoporosis and osteomalacia, which, if left untreated, can result in high additional treatment costs and impaired quality of life.
- Many people who could potentially benefit from neurosurgery face spending years on waiting lists, and are therefore placed at unnecessary risk for seizures and death.
- Patient education can dramatically reduce the number of emergency admissions, driving down costs and promoting self-care.
- Pre-conception counselling and precautions during pregnancy can reduce the impact on the foetus of mothers who have epilepsy.
- The non-medical costs of epilepsy far outweigh the cost of treatment. For example, an epilepsy diagnosis can result in unemployment, loss of mobility (ie revoked driving licence) and mental health problems.

What does this mean for me?

Based on current statistics from the Joint Epilepsy Council,² a typical Clinical Commissioning Group with a catchment area of 300,000 population will have an estimated:

- 2,910 people living with a diagnosis of epilepsy and being treated with AEDs
 - of these, six will die from epilepsy-related causes this year
- 582–902 patients wrongly diagnosed with epilepsy and receiving inappropriate treatment
- 153 new cases of epilepsy diagnosed this year
- 524 patients having seizures that would be avoidable with optimal AED treatment
- 25 adults and 11 children who could benefit from surgery but are not receiving it
- 57–544 young people (aged 17 years or under) with an epilepsy-related emergency admission this year.

What could this mean for my patients?

Mr Smith, 28, attended an emergency department following a seizure-type attack and was referred to a nearby epilepsy clinic directly. He was advised to inform the DVLA and to stop driving his car, which he duly did. His clinic appointment was not until five weeks later, and in the meantime he had two further attacks. The second occurred while he was at work as a forklift driver, and both led to further emergency department attendances. His employer subsequently asked him to see his GP and to ask for a sick note, which the GP supplied. The result of this clinic attendance was that his attacks were thought to be generalised tonic-clonic seizures and he was started on carbamazepine therapy. An electroencephalogram (EEG) and magnetic resonance imaging (MRI) scan were both normal. The carbamazepine caused a significant allergic rash so it was stopped, and the attacks continued.

Mr Smith's attacks tended to be in public places, so a number of them led to emergency department visits. A second anti-epileptic drug was started, with little impact on the seizures. The loss of his driving licence impacted on Mr Smith's ability to support his elderly mother who lived 15 miles away, and additional social care had to be accessed. The new anti-epileptic drug caused his mood to lower considerably, but the cause went unrecognised and he was referred to the community mental health team and started on anti-depressants.

Mr Smith returned to the epilepsy clinic six months after the initial appointment. He continued to be unable to work and concern was raised because, despite the treatment, the frequency of his attacks had increased to two to three per week. After his clinical history was revised suspicion arose that the attacks might not be epileptic. Video telemetry was arranged, which recorded an attack and confirmed that they were in fact non-epileptic. Mr Smith was advised to stop his current medication and his depression lifted. He received psychotherapy, which identified bullying in the workplace as the trigger for the attacks, which keyed into his school day experiences of bullying. His attacks resolved, he was able to drive again and found alternative employment. However, the financial impact of his temporary inability to work had strained his relationship with his partner, which subsequently broke up.

Please note that Mr Smith's story is a cautionary tale, which could be avoided by following guidance in this booklet. Please see the summary on page 40 for key markers of good practice.

Why commission epilepsy care services?

Despite some similarities with other chronic neurological conditions, epilepsy has its own unique complexities.

- Life expectancy is reduced by up to 10 years in people with symptomatic epilepsy and by up to two years in people with idiopathic epilepsy.⁴
- The mortality rate among epilepsy patients is high, with around half of epilepsy-related deaths attributable to sudden unexpected death in epilepsy (SUDEP).²
- An estimated 42% of epilepsy-related deaths are potentially avoidable through improved management plans, better record keeping, increased referral and better access to higher quality care.³ Epilepsy has been ranked as the fifth highest amenable cause of life-years lost in men, and eighth highest in women.³
- Prenatal factors can lead to epilepsy in childhood. Some of these cases could be prevented by pre-conception counselling, good antenatal care and maternity education.⁵
- Epilepsy is responsible for a high number of emergency department visits.
 - In north-east England, epilepsy accounted for the highest percentage of patients with two or more emergency hospitalisations for the same condition in the year 2006/07.⁶
 - Across England in 2007–2010, the emergency admission rate for children with epilepsy per 100,000 population aged 0–17 years showed an unexplainable nine-fold variation between PCTs.^{7,8}
- A 2007 study found that for every 1% increase in the proportion of treated, seizure-free epilepsy patients in England there was a 0.43% reduction in the number of patients with at least one epilepsy-related emergency hospitalisation.⁹
- Although anyone can have epilepsy, more than one in five people with epilepsy also have a learning disability; these people have additional needs.¹⁰

- An estimated 20% to 31% of people receiving treatment for epilepsy have been wrongly diagnosed. In some cases, misdiagnosis may be linked to confusing symptoms of a learning disability, but this is unlikely to account for all cases.¹¹
- While epilepsy itself is neither progressive nor degenerative, unlike other chronic neurological conditions, the side-effects of AEDs include degenerative bone diseases (osteoporosis and osteomalacia).¹²
- The prevalence of epilepsy in the UK is 25% higher in the most socially deprived areas compared with the least socially deprived areas.¹³

The number of patients diagnosed with epilepsy has risen sharply since the introduction and implementation of clinical guidelines from the National Institute for Health and Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN), as well as the Department of Health's GP Quality and Outcomes Framework (QoF).² This rise is partly due to the general population increase, particularly the ageing population who have a higher incidence of epilepsy, and partly due to better recording and monitoring of patients.² However, obtaining an exact figure for the number of people in the UK with epilepsy is complicated by the high rate of misdiagnosis and by inconsistent reporting.²

The epilepsy treatment gap

- In 2004 it was estimated that up to 70% of the UK population with epilepsy could be seizure-free with optimal treatment with AEDs,⁷ but only 52% were achieving this.¹⁴
- In present day terms, this equates to around 108,000 people with epilepsy having avoidable seizures.²
- In 2008, only 108 operations were carried out in children with epilepsy, despite an estimated backlog of 2,300 children who could benefit from surgery.²
- In adults, the backlog is estimated to be at least 5,000 yet no more than 200–300 adults per year receive surgical treatment for epilepsy.²

Since the introduction of NICE guidance in 2004, and 2012 guidance update, there has been significant progress in epilepsy management, better access to care and better quality of care.³ However, in 2009, most PCTs in England fell short of some of the Institute's key recommendations.³ Updated costs published by the Joint Epilepsy Council in 2011 estimated that the cost to the NHS of epilepsy misdiagnosis (assuming a rate of 23%) was around £270 million per year, driven largely by non-medical costs (82% of total).² In 2009, 69,700 people with epilepsy in England, Wales and Scotland were claiming disability benefits at an annual cost of £244 million.²

Despite the progress made in recent years, there remains a clear need for effective commissioning of epilepsy services to further improve management of epilepsy, access to care, quality of care and overall outcome for patients with epilepsy in the UK.

What does effective commissioning involve?

Commissioning enables the priorities for a local area to be translated into services delivered by the most effective and efficient organisations and companies. It is not just a set of technical activities. A more detailed explanation of how commissioning is changing in light of new government legislation covering the NHS, including the newly formed Clinical Commissioning Groups (CCGs), can be found in the Appendix ('Commissioning in the NHS').

Commissioning epilepsy care can be approached in different ways. Whatever the approach, the care service should be patient-centred and well integrated with other aspects of ongoing epilepsy care. Service users, communities and voluntary and community organisations often have knowledge, ideas and skills that can be vital to the design and implementation of the best services possible.

If local data are unreliable or not available, PCTs may use the commissioning benchmark calculated by NICE to reflect the national average detection rate of new cases of epilepsy per year in people aged 15 years and older (0.03%).¹⁵ The benchmark can be adjusted to reflect specific aspects of the local population. For instance, if the child or elderly population in the local area is higher than the national average, or if the area is among the most socially deprived, you might expect the incidence to be higher than 0.03%. Public health specialists may be able to help derive a more appropriate benchmark.¹⁵ The Child and Maternal (ChiMat) Health Observatory data atlas available at www.chimat.org.uk may also be useful for obtaining local paediatric data.

Ten questions to consider when commissioning epilepsy care services

- Will the service be visible and accessible to people with epilepsy within my CCG?
- How many people would use the service? (see Epidemiological data on page 14)
- Where would the service fit within the referral pathway for people with epilepsy?
- What will the impact be on primary care, and what changes will need to be considered at practice level?
- What are the skill levels of my staff?
- What training could my staff be given to improve their skill levels?
- What information technology and infrastructure would be required to support the service?
- How will patient outcomes be monitored and assessed?
- How might the service develop in response to these assessments?
- How will patients be discharged from the service?

Service specification checklist

While epilepsy services may be commissioned separately, it is likely that, unless a General Practice has a particular interest in the condition, services will be commissioned as part of a comprehensive Community Support package. Either way, a well-designed approach should aim to:

- establish a clear picture of the epilepsy population in the community, especially in children and young adults
- give special consideration to people who have problems in managing their epilepsy (eg people with drug-refractory epilepsy)
- give special consideration to children and older people (particularly those transitioning between care models), to people presenting with their first seizure, and people with learning disabilities
- provide patients with recent-onset suspected seizure access to a specialist within two weeks¹⁵
- provide patients with access to appropriate investigations (including neuroimaging) within four weeks¹⁵
- provide patients with an accurate diagnosis, with classification of seizure type and epilepsy¹⁵
- offer a quality-assured service by adhering to commissioning procedures¹⁵
- provide the community with at least one full-time epilepsy specialist nurse
- provide a point of contact, education and support for all people with epilepsy in the local area

- provide all patients with a comprehensive care plan if they want one, and ensure that it includes an annual review of their epilepsy
- provide all patients with a witness checklist (see Witness checklist on page 18) and emphasise the importance of the involvement of the witness at the first referral appointment
- include provisions for ambulatory emergency care, thereby reducing hospital admissions resulting in an overnight stay (see Reducing non-elective hospital admissions on page 23)
- record reasons for hospital admissions and, where appropriate, subsequent referral to an epilepsy specialist as part of planned care
- record any unplanned care that people using the service receive
- establish a procedure to manage the discharge of service users from the service. This is necessary to avoid unmanageable caseloads
- include provisions for audit (See Audit checklist for commissioners on page 36).

Epidemiological data

Commissioners should use epidemiological data to guide the necessary level of cover for epilepsy services in the local population. Some key figures are listed below:

- the age-standardised prevalence of epilepsy in the UK is 9.7 per 1,000 people²
- there are an estimated 51 newly treated cases of epilepsy per 100,000 people every year²
- the prevalence of diagnosed epilepsy in people aged 18 years and under is one in 220²
- the prevalence of diagnosed epilepsy in people aged 65 and over is one in 67.²

The average rate of adults (aged 15 years or older) who require a new referral for epilepsy was estimated by NICE to be 0.03% of the population.¹⁵ This is equivalent to:

- 70 cases per year for an average PCT with a population of 300,000
- two cases per year for an average General Practice with a list size of 10,000.

Similar calculations can be performed for the list size of newly formed Clinical Commissioning Groups (see the Appendix).

Commissioning epilepsy care services

Improved diagnosis

As the clinical and cost data show,² there is a clear need to keep misdiagnosis of epilepsy to a minimum. This is supported by the NICE clinical guideline on the epilepsies (CG137).¹⁶ In the accompanying commissioning guide to support clinical service designs, NICE describes a number of approaches to improving diagnosis of epilepsy in adults.¹⁵

Effective commissioning should provide fast access to specialist neurological services, leading to more patients receiving the right care faster. Efforts should be made to reduce emergency admissions to secondary care, and to provide a good service to all people with epilepsy regardless of their social or financial status. The service should encourage people with epilepsy to progress to a point where they feel comfortable in managing their condition independently.¹⁵

Benefits of improved diagnosis

Prompt access to epilepsy specialists will help to avoid delayed or incorrect diagnosis, improving access to optimal treatment and reducing the risk of premature death. This is because accurate clinical diagnosis is often based on being able to understand descriptions of the attacks given by witnesses, and to differentiate between epileptic and other features. Better diagnosis and treatment will lead to a reduction in the number of seizures and seizure-related injuries, thereby reducing emergency admissions to secondary care. Fewer incidences of misdiagnosis and incorrect prescriptions of medicines will reduce costs (both medical and legal) to the NHS, and provide better value for money through knock-on effects on other epilepsy services.¹⁵

Limiting the rate of misdiagnosis will help to reduce the risk of teratogenicity in wrongly diagnosed patients and will prevent patients wrongly diagnosed with epilepsy from facing, for example, unnecessary restrictions in employment and in other areas of life. Better diagnostic services are also likely to reduce any treatment gaps or inequalities, and, through encouraging independent living, improve the rate of employability for people with epilepsy. Finally, patients will have a greater choice of treatment options and a greater sense of empowerment.¹⁵

Managing non-epileptic attacks

Misdiagnosis of epilepsy is common, but the major alternative diagnosis of non-epileptic attack disorder (NEAD) still falls – or should still fall – within the responsibilities of epilepsy care services. The prognosis for patients with NEAD is unfavourable and there are currently no guidelines for treatment of the condition. However, studies have shown that patients with NEAD may benefit from psychotherapy (based on cognitive behavioural principles and psychodynamic methodologies),^{17,18} with one reporting that eight of 16 patients were seizure-free after six months of treatment. In addition to control of the attacks, patients showed improvements in general psychopathology, anxiety, depression, coping, dissociation and health-related quality of life.¹⁷

Clinical targets for improved diagnosis

The NICE commissioning guide for epilepsy services recommends four clinical targets for achieving improved diagnosis.¹⁵

- **Patients with recent-onset suspected seizure should be seen within two weeks by a specialist.** This will ensure a timely and precise diagnosis. Protocols for specialist assessment in emergency care settings are also required for patients presenting with seizures; this should include specialist screening in accidents where a seizure is suspected.
- **Access to appropriate investigations within four weeks of request.** During the initial assessment, the specialist should have access to one or more of the following neuroimaging technologies: electroencephalogram (EEG), magnetic resonance imaging (MRI) or computed tomography (CT). The NICE guidance recommends MRI as the preferred neuroimaging technology.

- **Patients to receive an accurate diagnosis with classification of seizure type and epilepsy.** This measure will lead to an increased likelihood of effective treatment.
- **Offering a quality assured service.** Adhering to commissioning procedures will ensure that the diagnostic service will meet the clinical targets described and improve patient care.

Provision of a service for improved diagnosis

The diagnosis of epilepsy is based on a clinical assessment rather than any established diagnostic test, meaning that information about what happened during the suspected seizure(s) is very important in determining the aetiology of the attack. For example, it is important to know whether consciousness was lost during the suspected seizures as this could indicate an underlying cardiac problem. This information cannot be reliably obtained from the person who had the attack, and therefore must come from an eyewitness. A person presenting to primary care after one or more suspected seizures can be given a witness checklist (see box overleaf) to aid this, as well as the necessary referral to a specialist. The checklist may be able to be retrospectively completed by a friend or family member, or given to them in the advent of a further suspected seizure before the referral appointment. This can then be given to the specialist to improve the clinical assessment.

Witness checklist

The information provided by eyewitnesses is crucial for differentiating between the epilepsies and non-epileptic attack disorders, and may help the specialist/consultant neurologist to determine the correct classification for an individual's epileptic seizure or seizures. Patients should bring a copy of the witness checklist to their first hospital appointment, even if it is not fully completed or if they have not had any further attacks. If possible, a witness should attend the first hospital appointment with them.

Below are some questions you may wish to use in developing your own witness checklist. Another example is provided in the primary care resource pack.

- When did the suspected seizure happen? (date and time)
 - Where were they at the time of the suspected seizure?
 - What were they doing immediately before the suspected seizure?
- Can you describe the nature of the suspected seizure?
 - Did you notice any mood changes, such as excitement, anxiety or anger?
 - Did they mention any unusual sensations, such as an odd taste or smell?
 - Did the suspected seizure occur without warning?
 - What drew your attention to the 'seizure'? A cry? A fall? Body movements (eyes rolling or head turning)?
 - Did they lose consciousness or appear confused?
 - Did they do anything unusual, such as mumble, wander around, fumble with their clothes or any objects?
 - Did they change colour, becoming pale, flushed or 'blue'? If so, where on the body (for example, face, lips or hands)?
 - Did their breathing alter (for example, become noisy or difficult)?
 - Did any part of their body stiffen, jerk or twitch? If so, which?
 - Did they lose control of their bladder?
 - Did they bite their cheek or tongue?

- How long did the seizure last?
- What happened after the seizure?
 - Did they feel tired or need to sleep? If so, for how long?
 - How long was it before they were able to resume normal activities?
- Did you notice anything else?

Comprehensive patient information and support

Providing accessible and trusted information for people living with epilepsy is crucial. Establishing comprehensive information and support is an essential part of any commissioning initiative for people living with epilepsy. Support should be tailored to each individual person, taking into account any special needs or circumstances that person may have, for example, people with depression, women who wish to become pregnant, or people wishing to travel abroad.

Benefits of comprehensive patient information and support

Being well informed about their condition, and especially how to manage it on a daily basis, is of enormous benefit to any person living with epilepsy. People with comprehensive knowledge of their condition are likely to feel more independent and confident about managing their epilepsy at home, school or work. They will have better compliance with medication and be more aware of triggers for seizures, and how to avoid them. They will be less likely to visit the emergency department or require unplanned care, saving the NHS money. Having the opportunity to talk with other people living with epilepsy, in the context of a support group or other patient organisation, can also be of benefit.

Clinical targets for comprehensive patient information and support

All people living with epilepsy, and, where appropriate, their families or carers.

Special considerations for adolescent patients with epilepsy transitioning to adult care services

Adolescence is an important time for young people with epilepsy in terms of providing them with the knowledge and tools for an ongoing self-care approach to their condition. However, in the process of transitioning to adult care services, the delivery of this information is sometimes not as effective as it should be.¹⁹

Factors negatively influencing this exchange include learning disabilities, behavioural problems and epilepsy-related emotional distress (eg fear of seizures, dysphoria), and, commonly, from the adolescent feeling excluded from discussions of their epilepsy. There is some evidence that age-appropriate, structured psycho-educational interventions at this crucial stage can help to improve young people's knowledge of epilepsy and that this can lead to better quality of life. However, more research is required.¹⁹

NICE recommends that, during adolescence, a named clinician should take responsibility for the ongoing management of the young person's condition and ensure the smooth transition of care to adult services. This individual should be able to work alongside other agencies. Multidisciplinary services provided jointly by adult and paediatric specialists have a key role in the care of the young person with epilepsy.¹⁶

Provision of comprehensive patient information and support

A well-planned epilepsy service should be able to offer advice on any matter likely to concern a person living with epilepsy, including, but not limited to, the areas listed below. If further information or clarification is needed, patients should be provided with details of support groups and charitable organisations, including how to contact them.¹⁵

- Epilepsy in general, including seizure types and syndromes.
- Diagnosis and treatment options, including surgery and side-effects of medication.
- Triggers and seizure control.
- SUDEP and status epilepticus.
- Management and self-care, including risk management.
- Safety and injury prevention; first aid.
- Psychological issues, including depression.
- Lifestyle, leisure and social issues, including relationships, recreational drug and alcohol use, sexual activity, sport and sleep deprivation.
- Road safety and driving.
- Education and healthcare at school; employment and independent living for adults.
- The importance of disclosing epilepsy at work, if relevant.
- Social services and social security benefits; insurance issues.
- Family planning and pregnancy, including information on inherited epilepsy.
- Travel, including travel abroad.

The NICE 2012 guidance recommends that healthcare professionals should highlight the Expert Patients Programme (www.expertpatients.co.uk) to children, young people and adults with epilepsy who wish to manage their condition more effectively.¹⁶

Patient care planning

Epilepsy Action has been working closely with NHS Yorkshire and the Humber to develop a patient care planning template within SystmOne. Screenshots from the template can be found in the primary care resource pack on pages 118-123. The template guides clinicians through the annual review with an aim to improving the health and healthcare of a patient with epilepsy. Based on guidance from Epilepsy Action, it can be completed by anyone who makes a contribution to the patient's epilepsy care.

The patient care planning template is divided into two parts: essential information about the patient's epilepsy and details about keeping a healthy lifestyle. In addition, there are links to other sources of help and information, together with embedded leaflets. The care planning element of the template also aims to provide proactive rather than reactive care. By challenging the current thinking with regards to doctor-patient relationships and allowing clinicians and patients to work together in goal setting and problem solving, it is hoped that using the templates will improve quality of care.

Reducing non-elective hospital admissions

Using hospital episodes data, commissioners may find that the emergency admission rate for epilepsies is surprisingly high compared with other long-term conditions. For example, in 2008 Wakefield district commissioners found that in the previous three financial years, epilepsy had the highest non-elective admission rate for long-term conditions.²⁰ Nearly two-thirds of the admissions could be attributed to individuals being admitted on a single occasion and for a length of stay that was less than two days.²⁰ Non-elective admissions can be reduced by treating people with epilepsy who present in the emergency setting as day cases, where possible, and supporting them with the management of their condition in a community setting.²¹

Although the reduction of non-elective admissions should be considered an important driver of effective commissioning, such admissions account for only a small proportion of the total number that a PCT will pay for in a year.²² However, a much larger scheme developed by the NHS Institute for Innovation and Improvement provides added value to this target.²³ 'Ambulatory emergency care' (often referred to as emergency day care) is intended to increase the number of appropriate discharges that occur within 24 hours of individuals arriving in an emergency department.²³ These may be discharges straight from an emergency department, or admissions with a length of stay less than one day.²³

Ambulatory emergency care in epilepsy

Epilepsy is one of over 50 clinical conditions/scenarios identified by the NHS Institute for Innovation and Improvement that could be managed via ambulatory emergency care. The Institute believes that up to 30% of all epilepsy admissions can be dealt with in this way.²³

To aid this, the Payment by Results scheme for 2012/13 will see the introduction of a best-practice tariff for epilepsy. The intention of this is to incentivise hospital trusts to increase the number of patients treated with a zero length of stay, and reduce the number admitted for a length of stay greater than zero.²⁴

Benefits of reducing non-elective hospital admissions

Epilepsy is also an ambulatory-sensitive condition, meaning that better management in the community or primary care setting can effectively avoid visits to the emergency department and hospital admissions. This, combined with the development of a local ambulatory emergency care model, will reduce the pressure on the emergency care system as a whole, improve management of emergency care workload, and lead to better quality patient outcome and experience.

The service may also save the NHS money by reducing hospital bed occupation. However, it should be noted that social factors may mean that dealing with non-elective hospital admissions on an outpatient basis may not be possible (for example, if the patient is frail and presents after dark).

Clinical targets for reducing non-elective hospital admissions

Commissioners may wish to use local hospital episodes data to identify any groups of people who tend to access emergency care more frequently than other people with epilepsy, for example:²⁰

- people who wish to receive advice, education and support for their (diagnosed) epilepsy
- people who have been referred by a GP to secondary care following a suspected epileptic seizure
- people who, following a diagnosis of epilepsy in secondary care, require post-diagnosis support
- people who have been misdiagnosed
- people who have problems with managing their epilepsy
- people whose epilepsy is unresponsive to medication
- children and young people with a diagnosis of epilepsy who are approaching the age of transition to adult services
- people needing local care services or living in care homes.

Commissioners may wish to record indicative figures for the size of the target population in a table, for example:

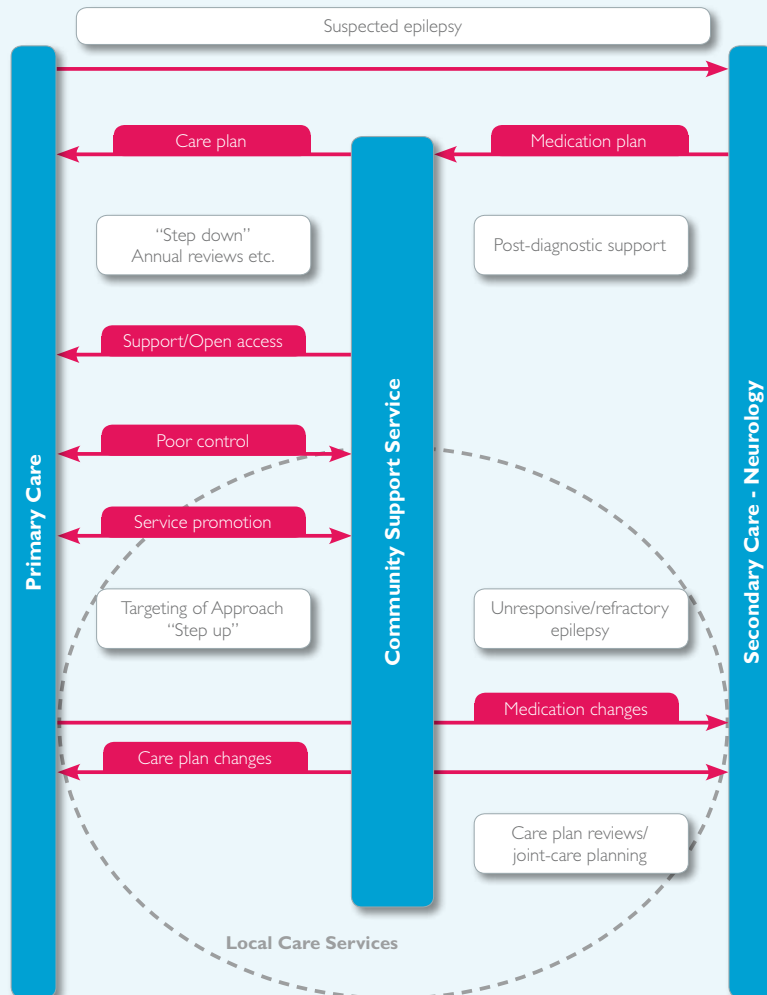
	Number of patients
To be supported to be seizure-free	
To be supported with unresponsive/refractory epilepsy	
Those who have been misdiagnosed	

Provision of a service for reducing non-elective hospital admissions

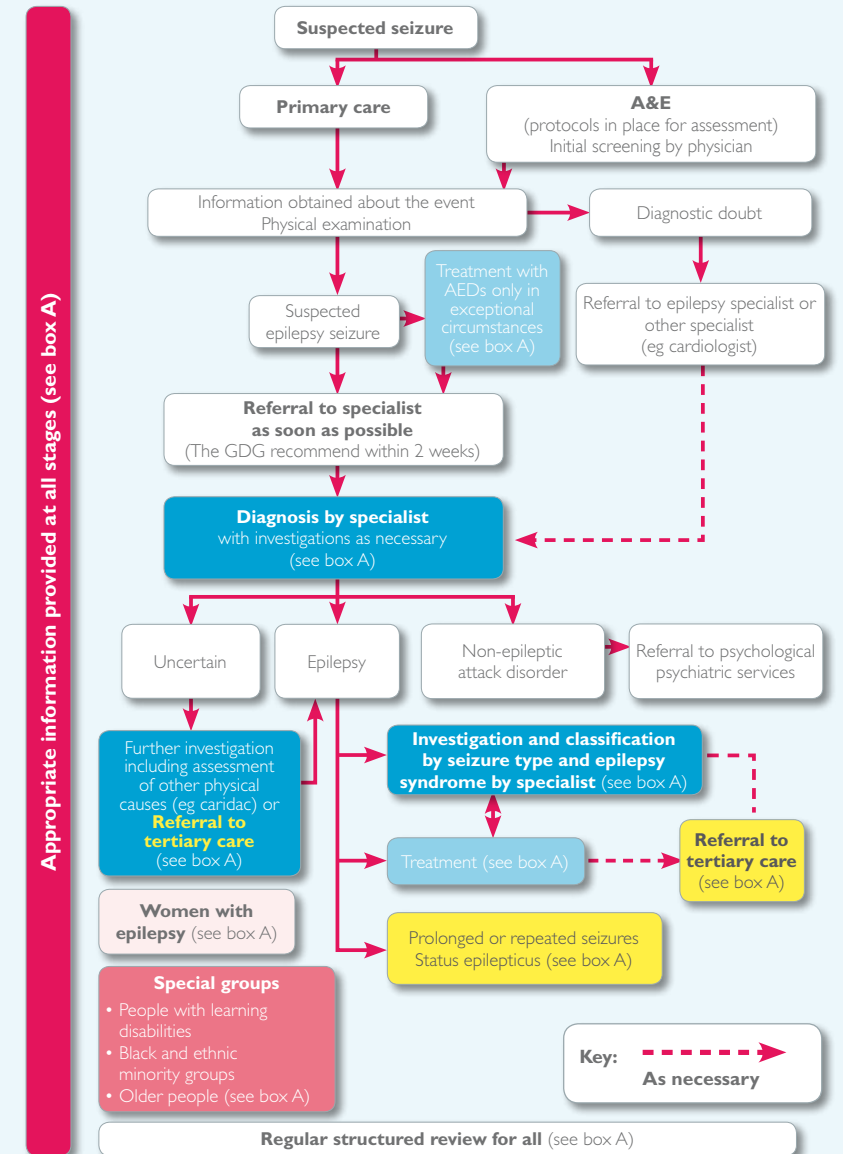
Key components of the service could include, but are not limited to: care pathways, information management and technology, accessibility, geographical coverage, referral criteria, avoiding inappropriate referrals, response times and prioritisation, assessment tools, relationship building, goal setting, support interventions, discharge planning and community support.²⁰ You may also find information on commissioning in the primary care resource pack useful.

Service overview: Wakefield District PCT

In early 2010, Wakefield District PCT introduced a community support service that provides an enhanced and specialist level of care for people with epilepsy designed to complement the existing approaches and resources of primary and secondary care, and for the subset of patients with a learning disability.



Adult care algorithm, adapted from NICE CG137, 2012¹⁶



An ESN in the A&E

When a baseline audit of the direct referral process from the emergency department at University Hospital of Wales in Cardiff to The Alan Richens Unit/Welsh Epilepsy Centre identified that some people were waiting as long as 10 weeks for an initial appointment, a new and unique service was devised by two ESNs to bring first contact with these individuals to the point of presentation. A new clinical protocol and pathway between the epilepsy unit, emergency department and cardiology was developed, and the ESNs undertook extensive training in the recording and interpretation of electrocardiograms (ECGs).

The new service was designed to provide people who had a suspected first seizure access to one of the ESNs within four hours of presenting to the emergency department. During this first contact, the ESNs take a detailed history from the patient and, where possible, an eyewitness account (see Witness checklist on page 18) to determine whether or not the patient had experienced an epileptic seizure or a non-epileptic attack. Based on this assessment, the ESN is able to refer patients for further assessments and to provide specialist advice ahead of an outpatient referral to a consultant neurologist where appropriate. The patient is also asked to undergo an ECG, which is then reviewed during a weekly meeting with a consultant cardiologist.

Since the service began in January 2010, the percentage of patients presenting to the epilepsy unit being reviewed within two weeks of referral has increased from 35% to 61%, and the average time to make a diagnosis has fallen from 111 days to 30 days. As of July 2010, the mean number of hospitalisations for suspected seizures has been cut by more than 50% from 2008/2009 levels. The service has now become an integrated part of the emergency department, earning positive feedback from staff and patients alike.

Epilepsy specialist nurses

A key role of ESNs is to take on mainly patient-related activities that would otherwise fall to epilepsy specialists and consultants or be overlooked.²⁵ ESNs also play a pivotal role in providing access to information, training and support for patients and their families/carers.²⁵ They facilitate access to specialist and community services, and are also involved in the education and general welfare of children with epilepsy.²⁵ The support provided by ESNs may be home-based; this may include helping families and carers to encourage treatment adherence and provide guidance on lifestyle management, and helping patients to achieve their maximum level of independence and choice in lifestyle.

Benefits of epilepsy specialist nursing

If adequately resourced, ESNs can optimise and standardise care for people with epilepsy, and reduce the burden on their GP colleagues.²⁶ Commissioning an ESN can also reduce the workload of consultants, which can save the NHS money since nurse-led care is less expensive than consultant-led care.²⁶ People with epilepsy may also benefit from building personal relationships with ESNs, making them feel more comfortable and confident about their ability to manage their epilepsy practically without needing to access primary care.²⁷

Community epilepsy nursing in East Kent

In East Kent, a community Epilepsy Nursing Service was commissioned to provide epilepsy assessments, advice, support and monitoring of medication changes to improve the quality of life of patients. Local volunteers from Epilepsy Action felt they had little support and worked closely with consultants to create a new nurse post in 1999. The service originally covered a population of 609,000 but this has since expanded to 742,000. Currently, three ESNs and a head of epilepsy nursing service who maintains a small case load, cover 38 clinics per month in 13 venues including acute hospital outpatients, health centres, GP surgeries and community hospitals. The nurses also visit residential homes for people with learning disabilities, and make at least eight home visits per week.

ESNs refer into the community matron service and undertake joint visits as required. They also work alongside the community service medicines management team, who will support patients in their own home with medication adherence, and sometimes do joint visits with them. They also offer rescue medication training and individual drug guidelines to prevent frequent hospitalisation. Some nurses are non-medical prescribers, which reduces the need for patients to see a GP or consultant.

After seeing a patient, nurses send written correspondence to the patient's GP or consultant. Patients are sent a copy of the correspondence and are advised to take this with them to their next consultation. All patients receive a written care plan, which they sign to indicate that they have been actively involved in devising it, at the time of their appointment. Patients are encouraged to share their care plans with other relevant professionals.

This is important to ensure a safe, integrated service, and regular audits are used to check that correspondence is being received promptly. A further two audits per year are carried out to assess the quality of the service as a whole. Commissioners monitor the waiting times with an agreed action plan to focus on improving in specific areas. The 'did not attend' rate in East Kent has fallen from 24% to 1.6% as a result.

In addition, the service provides patients with ongoing feedback opportunities, either in written format or electronically, and responds to the feedback in a timely manner. Recent patient feedback indicated that patients are satisfied with the service, giving positive feedback about the availability of home visits and the opportunity to have a person-centred discussion with plenty of time with the nurse.

Clinical targets for epilepsy specialist nursing

Clinicians should consider whether some appointments with neurologist consultants could be appropriately provided instead by an ESN-led service. Reducing the number of unnecessary new referrals, and the number of follow-up appointments with consultants should be considered an important driver in an effective commissioning service for people living with epilepsy.

Clinicians should also consider who is likely to require home support (for example, older people or those with learning disabilities), and what this will involve (for instance, specialist and paediatric care).

Provision of epilepsy specialist nursing

Provision of epilepsy specialist nursing should be based on estimates of how many individuals an ESN service can support within a CCG, and for how long. Without this planning stage, the service caseload risks becoming unmanageably large and inadequately resourced, which benefits neither the CCG nor the patient.²⁵ NICE recommends that for a population of 500,000 people, nine ESNs should be available.²⁶

Although it is undoubtedly clear that ESNs play a key role in managing patients with epilepsy within the community, no national standards exist to clearly define what tasks ESNs should and should not be expected to do.¹⁹ Epilepsy Action is calling for the Department of Health to develop guidelines on the appropriate caseload and responsibilities of ESNs.²⁵

Making the most of epilepsy specialist nurses

- The NICE¹⁶ and SIGN²⁸ guidelines both recommend that all patients with epilepsy should have access to an ESN. However, as of 2010, only 250 ESN posts had been commissioned.²⁵
- The £20 billion budget saving imposed by the Treasury on the NHS has made some ESN posts vulnerable to being cut.
- To help strengthen their position in the community, ESNs should aim to work closely with people involved in other aspects of local epilepsy care.²⁹
- Funding a single ESN post should not be considered to be equivalent to creating an epilepsy care service.²⁹

General practitioners with a special interest in epilepsy

GPs with a special interest (GPwSI) in epilepsy^{30,31} can also add value to a comprehensive, multidisciplinary specialist epilepsy service. Like an ESN, a GPwSI fulfils a community role and is well placed to liaise between primary and secondary care, focusing on local delivery of epilepsy services. GPwSIs typically do not have the same skill set as epilepsy consultants, but they can help to cut down waiting lists to see consultants. National guidance and competences for the provision of services using GPwSIs have been published by the Department of Health. The exact role of a GPwSI varies according to locality but typically includes aspects of clinical work, education and leadership.

In the Bradford area, a group of four GPs (with other surgeries of their own) have formed a part of the community epilepsy service for over 10 years, since the government first piloted the GPwSI schemes. Other GPwSI teams in the area include musculoskeletal, ophthalmology and general neurology groups. Patients are referred to the epilepsy team from their own GPs (or other healthcare professionals), or are transferred from community or

hospital-based neurologist services. All four members of the team are involved in conducting one epilepsy clinic per week in around eight or nine sites that include community hospitals, larger GP practices and other community settings. During these appointments, patients are assessed for seizure frequency, risk factors, medication and dosage, side-effects and other problems. Some of these appointments may be managed by an ESN alone.

Any changes to medication are discussed together with the patient and/or carer, where possible, and letters to the patient's GP are generated. To save time, these may be dictated by the GPwSI/ESN and typed up by administrative staff. Care plans are made, with one copy placed into the notes and another given to the patient. If the patient requires urgent care or change to medication, a template letter stating the prescription they need is given to the patient to present to their GP. Agreed follow-up appointments are entered into the database and a reminder sent to the patient usually two to three weeks in advance. GPwSIs are unable to issue the prescriptions themselves at the clinics. However, they can request imaging (EEG, MRI) and refer the patient to other relevant services. They also act as a point of contact for ESNs to answer questions and provide advice.

The ESNs and GPwSIs sometimes collaborate on joint epilepsy training sessions for GP practices and other interested parties. The whole team meets once every three months with the community epilepsy service neurologist to discuss clinical governance, audit, updates, service issues, current research (journal club) and complex patients.

Epilepsy care audits

In its most basic form, an audit involves asking a series of questions about a service, collecting answers to these questions from service users, and analysing those answers to assess whether the approach to epilepsy care is meeting its goals. A well-designed audit process should be as short as possible while still collecting all the relevant information. Each additional step in the process means that fewer and fewer people will complete the audit.

Clinical audit is an established part of the NHS landscape.³² All healthcare professionals are now expected to participate in clinical audit work, and since 2008 a number of mandated National Clinical Audits have been developed and introduced.³² The Department of Health requires National Clinical Audit activity to be published via Quality Accounts.³² These are clinical audit reports that are made available to the Care Quality Commission, which was formed in 2009 to regulate, inspect and review all adult social care services throughout England.³² NICE Quality Standards are currently being developed for epilepsy in children and epilepsy in adults.³³

Benefits of commissioning epilepsy care audits

Commissioning managers should not expect to design the perfect service from the ground up first time around. There will always be service components that can be improved, and thorough yearly audits can help to identify these so that the service can be changed for the better; for example, becoming more cost-effective, or becoming more visible to potential service users.

Clinical targets for epilepsy care audits

National Clinical Audits are mandated for all patients but a local audit may wish to place additional emphasis, where relevant, on service users with specific needs or concerns. These may include children and older people, women of childbearing age, and teenagers who are approaching the age for transition from paediatric to adult services.

Provision of epilepsy care audits

A number of national epilepsy audits are ongoing, most notably:

- EPILEPSY 12, a three-year programme funded by the Health Quality Improvement Partnership (HQIP) and included in mandated Quality Accounts www.rcpch.ac.uk/epilepsy12
- National Audit of Seizure Management in Hospitals (NASH) www.nashstudy.org.uk

Fulfilling the criteria of national audits can be labour intensive and costly, and may not provide commissioning managers with all the local information that they might need. An alternative is to design one specific to the local context. This could include, for example, to drive better use of existing services, assess the ratio of planned to unplanned care, and to encourage better communication between service components.

An example of one existing service that could be addressed is ambulance services. Commissioners engaging with people with epilepsy and their families or carers are likely to find that most have experienced at least one unwanted ambulance journey to an emergency department. There is a lack of individual choice, and one that has a high chance of leading to unnecessary hospital admissions. An audit could help to address this important health inequality for epilepsy patients.

Audit checklist for commissioners

Audit criteria will vary according to the requirements of individual CCGs. Here are some examples that you might wish to include in your own audit.

- What percentage of patients received an accurate diagnosis with classification of seizure type and epilepsy? (Target: 100%)

The working assumption is that a patient will be misdiagnosed as having epilepsy in 25% of cases. However, it is almost impossible to know which patients this involves as many of them will be on medication and seizure-free. They will believe that they are seizure-free, but actually they are epilepsy-free. Ideally, the auditing process should be based on good-quality care reviews.

- In what percentage of patients who lost consciousness during a suspected seizure were cardiac features and syncope considered prior to diagnosis? (Target: 100%)

This can be measured through case note reviews or asked as part of a questionnaire to GPs.

- What percentage of these patients were referred to cardiology pathways in the absence of seizure features? (Target: 100%)

These data can be difficult to collect, due largely to the quality of outpatients data. Spot audits may be helpful in this case.

- In what percentage of patients who did not lose consciousness during a suspected seizure were diabetes and transient ischaemic attack considered prior to diagnosis? (Target: 100%)

These data can be difficult to collect, due largely to the quality of outpatients data. Spot audits may be helpful in this case.

- What percentage of patients were offered comprehensive patient information, including what to do in the event of a further suspected seizure, at the point of referral? (Target: 100%)

Patients should be asked if they received comprehensive information, with the view that even one patient who was not offered such information is unacceptable.

- What percentage of patients were instructed not to drive until after their first referral appointment? (Target: 100%)

Patients should be asked if they were instructed not to drive, with the view that even one patient who was not warned about the potential danger of driving is unacceptable.

- What percentage of patients were seen by a specialist within two weeks of a suspected seizure? (Target: 100%)

This audit point will only work if the service includes a specific epilepsy outpatient clinic or a specific first-seizure clinic (see 'An ESN in the A&E' on page 28). If one of these exists, the local hospital trust can set something up locally to look at this.

- What percentage of patients received appropriate investigations (including neuroimaging) within four weeks of request? (Target: 100%)

This audit point will only work if the service includes a specific epilepsy outpatient clinic or a specific first-seizure clinic (see 'An ESN in the A&E' on page 28). If one of these exists, the local hospital trust can set something up locally to look at this.

- What percentage of patients were accompanied by a witness at the first referral appointment? (No target set)

A questionnaire to neurologists may be helpful here. This does not have to be 100% as in some cases there will not have been a witness.

- What percentage of patients presented at least one completed witness checklist at the first referral appointment? (Target: 100% if witness present)

A questionnaire to neurologists may be helpful here. This does not have to be 100% as in some cases there will not have been a witness.

- What percentage of patients received a first definitive treatment within 18 weeks of the original referral date? (Target: 100%)

These data can be difficult to collect, due largely to the quality of outpatients data. Spot audits may be helpful in this case.

- What percentage of patients were receiving optimal AED treatment? (Target: 100%)

This audit point is equivalent to the seizure-free QOF indicator:

- What percentage of patients who would potentially benefit from surgery are still on the waiting list for an operation? (Target: 0%)

No patient should wait longer than 18 weeks for necessary treatment. The 18-week data returns can be used here.

- What percentage of non-elective hospital admissions for epilepsy had a length of stay greater than zero? (No target set)

Use the NHS Institute standard as part of ambulatory emergency care.

- What percentage of ambulance journeys were unwanted by the patient or unnecessary? (Target: 0%)

This audit point cannot be answered from either Health Examination Surveys (HES) or A&E data. The only way is to ask the patients themselves. HES and ambulance data, however, can help to determine how many patients should be asked.

Other sources of information

NHS Information Centre: Users are able to search deaths where epilepsy is the original underlying cause. GP practice data for QOF Epilep08 (patients aged 18 and over on drug treatment for epilepsy who have been seizure-free for the last 12 months recorded in the previous 15 months) can also be obtained.

NHS atlas of variation: This illustrates variation in the directly standardised rate of emergency admissions in persons with epilepsy per 100,000 population by PCT. Available at www.rightcare.nhs.uk/atlas

ChiMat disease management tool for epilepsy: The Disease Management Information Toolkit (DMIT) uses HES data to enable PCTs to extract local reports which highlight variations at PCT level and allow benchmarking to inform the commissioning decision-making process for children with long-term conditions. Available at www.chimat.org.uk

Summary

Those involved in commissioning services for the epilepsies should aim to deliver the markers of good practice for a comprehensive service:

- to provide an accessible and trustworthy source of advice, information, and interventions of support across the local population
- to work with local care services to target support to both those who display a poor management of their epilepsy, and those whose epilepsy is unresponsive to medication
- to support service users and their families/carers to develop, consolidate and reinforce their methods of treatment adherence and lifestyle management
- to support service users and their families/carers to exercise the maximum levels of independence and lifestyle choice possible
- to liaise with local care services to provide specialist advice, education and guidance on treatment adherence and lifestyle management
- to work with local care services to ensure that service users and their families/carers receive appropriate and tailored packages of care.

Appendix: Commissioning in the NHS in England

The way that services are commissioned for the NHS is currently undergoing an overhaul, and 2012/13 is a critical year for this process.³⁴ The proposed changes are outlined in the Health and Social Care Bill,³⁴ which has undergone several amendments since it was first heard at Parliament.^{35,36}

At its heart, the bill espouses a philosophy of putting patients first. This encompasses an emphasis on shared decision making, greater choice and more patient control over their care.³⁵ Key to this strategy is a change in the responsibility for commissioning, from Primary Care Trusts to Clinical Commissioning Groups. In doing this the government hopes to drive a patient-centric, outcomes-focused and clinically-led approach to care in the NHS.³⁵

What bodies are involved in the new commissioning structure?

Clinical Commissioning Groups lie at the heart of the Health and Social Care Bill.³⁷ Responsible for commissioning local services, CCGs are statutory bodies made up of General Practices, as well as a range of other professional groups.³⁷ This ensures that decisions are based on a truly multi-disciplinary perspective, maximising the impact of clinical leadership and stakeholder engagement on the health of the local population.³⁷

General Practices play a pivotal role within CCGs.³⁷ They act as the intermediary for all the care patients receive, connecting patients with specialists, connecting specialists who care for the same patient, and linking patients, carers and families with the full range of support offered by the NHS and social care services.³⁵

To be formally established as a statutory body, CCGs need to go through an authorisation process conducted by the NHS Commissioning Board.³⁷ The Commissioning Board will assess CCGs on an ongoing annual basis to ensure they are delivering their statutory responsibilities. By April 2013, the whole of England will be covered by CCGs.³⁷

Health and Wellbeing Boards will also be created to help guide local commissioning in health, social care and public health issues.³⁴ These bodies will assist in developing joint strategic needs assessments and joint health and wellbeing strategies in upper-tier local authorities.³⁸ Part of this role will include joint commissioning. They will also play a role in the authorisation of CCGs and support The NHS Commissioning in holding CCGs to account.³⁸

Provider landscape

Just as the commissioning structure of the NHS is undergoing substantial changes, so is the provider landscape. As part of the strategy of improving health services, healthcare providers will be paid according to outcomes. However, the Health and Social Care Bill has also been amended to ensure that price competition is illegal. Policies that could affect the market share of specific sectors or providers are also disallowed under amendments.

Providers will encompass both Foundation Trusts and Any Qualified Providers (AQPs).

Foundation trusts

Eventually, all NHS trusts will be required to evolve into Foundation Trusts.³⁴ Most are expected to achieve this by April 2014, though some will be given more time under exceptional circumstance.³⁴

Achieving Foundation Trust status is part of the 'Liberating the NHS' ambition to create the 'largest social enterprise sector in the world'.³⁵ The aim is for NHS staff to have a say in the future of their organisations, including employee-led social enterprises.³⁵ Foundation trusts will be required to hold public board meetings, and file separate accounts for their NHS and private funded activities.³⁸

Any Qualified Providers

Under the proposals, Any Qualified Providers (AQPs) will be permitted to provide NHS-funded services. When they are referred, patients will be able to choose to receive their care from a list of qualified providers who have met NHS service quality requirements, prices and contractual needs.³⁹ This gives patients a choice about where they are referred to, with the guarantee that all providers will offer care that meets the appropriate professional standards.³⁹

It will be the responsibility of CCGs to commission AQPs according to outcome-based criteria. This will focus providers on delivering high-quality services.³⁴ Because providers are paid on a fixed national tariff, competition will be based on quality, not pricing.³⁹

Commissioners are expected to use the national qualification process and questionnaire to qualify the providers they use.³⁴ Currently commissioners can use www.Supply2health.nhs.uk to advertise service opportunities in health and social care. It will be the commissioners' role to set local care pathways and referral protocols.³⁴

Specialised services

The Department of Health has stated that paediatric neurology, paediatric neuroscience and adult neurosurgery will not be the responsibility of individual Clinical Commissioning Groups. These services will instead be commissioned by the NHS Commissioning Board. You may find the following documents useful:

- NHS Specialised Services (2011). Children's Neurosurgical Services in England: A Framework for the future. www.specialisedservices.nhs.uk/library/31/Childrens_Neurosurgical_Services_in_England_A_Framework_for_the_future.pdf
- NHS Specialised Services (2011). Children's Neurosurgical Specification Standards. www.specialisedservices.nhs.uk/library/31/Children_Neurosurgical_Specification_Standards_May_2011.pdf

English priorities and policy context

Several pre-existing national policies have an impact on what services and care should be made available to patients with epilepsy. While the new commissioning environment means these are dated, they still offer some insight into commissioning epilepsy services. You may find the following documents useful:

- National Institute for Health and Clinical Excellence (2008). Service for the accurate diagnosis of the epilepsies in adults. Commissioning guide. www.nice.org.uk/usingguidance/commissioningguides/epilepsiesinadults/epilepsydiagnosis.jsp
- Department of Health (2005). The National Service Framework for long term conditions. www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPublicationsPolicyAndGuidance/DH_4105361
- National Primary and Care Trust Development Programme (2005). Practitioners with a special interest. www.natpact.info/cms/165.php

Scotland, Wales and Northern Ireland

The four countries that make up the UK have different administrative structures for health policy. The parliaments and assemblies in Scotland, Wales, Northern Ireland and England each have responsibility for health within their own country.⁴⁰

In Scotland, local priorities are ascertained by 14 health boards based on a mix of needs assessment, local and national strategic priorities, Scottish government direction and guidelines (such as SIGN) as well as priorities highlighted by community health partnerships (CHPs), managed clinical networks (MCNs), Health Improvement Scotland and national plans. Health board activity is also directed by HEAT (Health, Efficiency, Access and Treatment) targets. GP priorities are dictated by national contract and by a variety of enhanced services, which allows some freedom for GPs to focus on local priority areas. The Scottish Government Health Directorate influences spending where action across all GPs in Scotland is desirable. National and tertiary services are developed through National Services Scotland, ensuring provision of services to patients with less common conditions and setting up national MCNs where needed. Plans are underway to develop parts of the GP contract in Scotland to better reflect Scottish patient and health system needs.

In Wales, since October 2009, healthcare services (but not social services) are delivered through the seven health boards and three trusts of NHS Wales. The intention of the reorganisation was to replace the commissioning process – previously the responsibility of 16 NHS trusts (primary care) and 22 local health boards (secondary care) – with service planning and delivery by the health boards designed to promote seamless working between primary and secondary care. Specialist and tertiary care services are planned collaboratively by the health boards and trust through the Welsh Health Specialised Services Committee.

In Northern Ireland, since April 2009, commissioning of healthcare and social services has been the responsibility of a single Health and Social Care (HSC) Board. Five HSC trusts manage hospitals, health centres, residential homes, day care centres and other health and social care facilities.

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