

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE

QUALITY STANDARDS PROGRAMME

Quality standard topic: The epilepsies in adults/children and young people

Output: Briefing paper

Introduction

This briefing paper presents a structured evidence review to help determine the suitability of recommendations from the key development sources listed below, to be developed into a NICE quality standard. The draft quality statements and measures presented in this paper are based on published recommendations from these key development sources:

[The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care](#). NICE clinical guideline 137 (2011; NHS Evidence accredited). Available from www.nice.org.uk/guidance/CG137

Structure of the briefing paper

The body of the paper presents supporting evidence for the draft quality standard reviewed against the three dimensions of quality: clinical effectiveness, patient experience and safety. Information is also provided on available cost-effectiveness evidence and current clinical practice for the proposed standard. Where possible, evidence from the clinical guideline is presented. When this is not available, other evidence sources have been used.

1 Referral – referral to specialist

1.1 NICE CG137 Recommendations 1.4.5 and 1.4.6 (KPIs), 1.4.1 and 1.4.2

1.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

Guideline recommendations	<p>1.4.1 Children, young people and adults presenting to an Accident and Emergency department following a suspected seizure should be screened initially. This should be done by an adult or paediatric physician with onward referral to a specialist¹ when an epileptic seizure is suspected or there is diagnostic doubt. [2004]</p> <p>1.4.2 Protocols should be in place that ensure proper assessment in the emergency setting for children, young people and adults presenting with an epileptic seizure (suspected or confirmed). [2004]</p> <p>1.4.5 It is recommended that all adults having a first seizure should be seen as soon as possible² by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs. [2004]</p> <p>1.4.6 It is recommended that all children and young people who have had a first non-febrile seizure should be seen as soon as possible³ by a specialist in the management of the epilepsies to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs. [2004]</p>
Proposed quality statement	<p>Adults who have had a suspected or confirmed first seizure are seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p> <p>Children and young people who have had a suspected or confirmed first non-febrile seizure are seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p>
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that people who have had a suspected or confirmed first seizure are seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p> <p>Process: The proportion of people who have had a suspected</p>

¹For adults, a specialist is defined throughout as a medical practitioner with training and expertise in epilepsy. For children and young people, a specialist is defined throughout as a paediatrician with training and expertise in epilepsy.

²The Guideline Development Group considered that with a recent onset suspected seizure, referrals should be urgent, meaning that patients should be seen within 2 weeks.

³The Guideline Development Group considered that with a recent onset suspected seizure, referrals should be urgent, meaning that patients should be seen within 2 weeks.

	<p>or confirmed first seizure who are seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p> <p>Numerator – The number of people in the denominator who are seen by a specialist in the management of the epilepsies within 2 weeks of presentation.</p> <p>Denominator – The number of people who have had a suspected or confirmed first seizure.</p>
Questions for the TEG	<p>Is the focus of this statement about people being seen by the right person, or how quickly they are seen? The evidence suggests that being seen by the right person is the issue of quality. Timeliness may be an additional element of quality that is important for us to measure.</p>

1.1.2 Clinical and cost-effectiveness evidence

Misdiagnosis of epilepsy occurs in around 25% of cases. No systematic reviews comparing rates of diagnosis by training, title, or position were found. A paper (1999) assessing the frequency, causes and consequences of an erroneous diagnosis of epilepsy found that erroneous diagnoses were made by all professional groups, but the majority were made by generalists.

There is a lack of health economics evidence on the areas related to diagnosis in epilepsy. The GDG viewed misdiagnosis as a huge problem not only in terms of patient experience but also in terms of waste of resources for the NHS and society as a whole. An economic analysis was carried out to estimate the costs of misdiagnosis, focussing on the direct costs of wrongly diagnosed other conditions as epilepsy. The number of estimated misdiagnosed cases was applied to the average yearly cost per person with epilepsy resulting in an estimated range of direct medical costs of epilepsy misdiagnosis of £24,307,433 to £82,941,252. Adding estimated average nonmedical direct costs results in estimated range for total direct costs of £130,120,729 to £188,754,549.

Misdiagnosis rates referred to in the economic analysis are based on studies focused on adult misdiagnosis, but two studies highlight that the problem could be worse in children. An eight year prospective study of the diagnoses made in children referred to a secondary level “fits, faints, and funny turns” clinic in Bury found that epilepsy was the diagnosis in only 23% of the children referred (although epilepsy may not have been the likely referral diagnosis in all cases, it is probable that it was suspected in many of those subsequently found not to have epilepsy).⁴ Another retrospective study of the final diagnosis compared to the referral diagnosis of 223 children admitted during 1997 to the Danish Epilepsy Centre found that 39% of those referred did not

⁴ Hindley D, Ali A, Robson C (2006) [Diagnoses made in a secondary care “fits, faints, and funny turns clinic”](#)

have epilepsy. For those in whom the diagnosis of epilepsy was not in doubt at the time of referral, 30% were subsequently undiagnosed.⁵

1.1.3 Patient experience

The NICE guideline notes that individuals misdiagnosed with epilepsy may experience social and financial deprivation as a result of having the wrong diagnostic label and from side-effects of antiepileptic medication.

1.1.4 Patient safety

The NICE guideline notes that there may be a risk of unnecessary teratogenicity as a result of anti-epileptic drug (AED) therapy in women incorrectly diagnosed as having epilepsy. In a small number of cases, individuals may die prematurely because the correct diagnosis was not made, and a serious condition was neither diagnosed nor treated. Individuals who have symptoms due to epileptic seizures but who are wrongly diagnosed as having psychiatric or associated disorders are disadvantaged from being labelled with an incorrect diagnosis and by the effects of continuing seizure activity because AEDs are not used.

1.1.5 Current practice

The National Clinical Audit of Epilepsy-related Death (SUDEP audit) in 2002 looked at the overall quality of care received by individuals in general practice and hospitals and found 54% of adults had inadequate care. One of the main deficiencies identified was inadequate access to specialist care (35%). 77% of children had inadequate care, with inadequate access to specialist care being the main deficiency in 36% of these cases. Just under half of individuals diagnosed in the 5 years before death were initially referred to an adult or paediatric neurologist.⁶

Epilepsy in England: time for change (2009) found that only half of acute trusts confirmed they have a consultant neurologist with special interest in epilepsy and 24% did not have a consultant neurologist. From Epilepsy Action's survey less than a third (30%) of patients who were diagnosed with epilepsy within the last two years reported seeing an epilepsy specialist after their first suspected seizure. In addition, more than 90% of trusts have waiting lists of longer than 2 weeks for people with suspected epilepsy to be seen.

The report suggests that the lack of epilepsy specialists contributes to misdiagnosis rates of 21-30% and the wrong treatment for the wrong kind of

⁵ Uldall P, Alving J, Hansen LK, et al (2006) [The misdiagnosis of epilepsy in children admitted to a tertiary epilepsy centre with paroxysmal events](#)

⁶ Department of Health (2003) [Improving services for people with epilepsy: Department of Health action plan in response to the National Clinical Audit of epilepsy-related death](#)

epilepsy, resulting in prolonged difficulties for people with epilepsy and their carers.⁷

The report of a working party of the Royal College of Physicians and the Association of British Neurologists in 2011 noted that although there are regional centres of excellence for neurology services, DGH services have suffered due to a lack of local neurologists. Acute neurology services are of particular concern because they are rarely provided by neurologists, in contrast to those for other acute medical specialties, resulting in potential adverse outcomes. Neurology remains a shortage specialty, with an inequality of more than three to one in numbers of neurologists in different parts of the UK.

Although by 2006 the number of UK neurology consultants had risen from one full-time equivalent (FTE) per 200,000 population in 1996 to one per 115,000 mostly in response to outpatient pressures, this still remains less than a third of the European average. In addition, most neurologists, even newly appointed, are still regional neurosciences centre-based and can only provide a visiting outpatient and ward consultation service to DGHs.⁸ All paediatric neurologists are based in tertiary centres and rely on paediatricians with an expertise in epilepsy in DGHs, and in 2003 the British Paediatric Neurology Association (BPNA) noted that for 50,000 children with epilepsy in the UK there were 63 paediatric neurologists; 12 of whom with a special interest in epilepsy and only 4 practising solely within epilepsy.⁹

The House of Commons Committee of Public Accounts report on services for people with neurological conditions notes that most neurology patients are admitted to a local district general hospital (DGH) where they are rarely seen by or managed by a neurologist. The recent national audit measuring the care of people with epileptic seizures admitted to hospital, the National Audit of Seizure management in Hospitals (NASH), showed that not a single admitted patient was under the care of a neurologist. Evidence given to the RCP working party from Northern Ireland showed that a new or altered diagnosis was made in 43% of admitted patients when seen by the neurologist with a change in management in 80% of epilepsy patients.¹⁰

The National Audit of Seizure management in Hospitals (NASH) 2011 reported that more than half of patients (16 years and over) presenting with a seizure did not receive neurological involvement (for example, a consultation in hospital, referral to an epilepsy clinic, referral to a GP with special interest, referral to a specialist nurse etc). In addition, less than half were reviewed by

⁷ Epilepsy Action (2009) [Epilepsy in England: time for change](#)

⁸ Royal College of Physicians and Association of British Neurologists (2011) [Local adult neurology services for the next decade](#)

⁹ BPNA (2003) [A national approach to epilepsy management in children and adolescents](#)

¹⁰ House of Commons Committee of Public Accounts (2010-12) [Services for people with neurological conditions](#)

a senior physician in the Emergency Department. The audit showed that most patients are managed by general physicians (i.e. non-neurologists). Most admissions are, initially at least, to some form of medical assessment facility but a significant number are managed by the Emergency Department. The audit also reports that of those patients with no history of epilepsy or blackouts/seizures, advice was sought from a neurology/epilepsy team or an assessment taken by a neurologist or epilepsy specialist for 15.8%. It was noted that the use of specialist input varies massively.

The audit also shows that of those patients with no history of blackouts only 25% were referred to an epilepsy/first fit service, 23% to a neurologist and 3% to an epilepsy nurse (total 51%).¹¹

1.1.6 Current indicators

Epilepsy 12 National Audit Performance Indicators - [% with evidence of input by paediatrician with expertise in epilepsy by 1 year.](#)

Epilepsy 12 National Audit Performance Indicators - [% diagnosed epileptic seizures meeting referral criteria with evidence of referral to or discussion with a paediatric neurologist by 1 year.](#)

¹¹[National Audit of Seizure management in Hospitals](#) (2011)

2 Investigation– access to investigations

2.1 NICE CG137 Recommendations 1.6.3 and 1.6.22

2.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

Guideline recommendations	1.6.3 Children, young people and adults requiring an EEG should have the test performed soon after it has been requested. ¹² [2004] 1.6.22 Children, young people and adults requiring MRI should have the test performed soon. ¹³ [2004]
Proposed quality statement	Adults undergoing investigations for epilepsy receive investigative tests within 4 weeks of them being requested. Children and young people undergoing investigations for epilepsy receive investigative tests within 4 weeks of them being requested.
Draft quality measure	Structure: Evidence of local arrangements to ensure that people undergoing investigations for epilepsy receive investigative tests within 4 weeks of them being requested. Process: The proportion of people undergoing investigations for epilepsy who receive investigative tests within 4 weeks of them being requested. Numerator – The number of people in the denominator who receive investigative tests within 4 weeks of them being requested. Denominator – The number of people undergoing investigations for epilepsy.

2.1.2 Clinical and cost-effectiveness evidence

The recommendations about the timescale for investigative tests are based on the consensus of the GDG.

2.1.3 Patient experience

The Epilepsy in England: time for change report noted the importance of the timeliness of investigations, as the sooner a correct diagnosis of epilepsy is made, the sooner tailored therapy can be initiated. Delays through insufficient diagnostic equipment cause distress and impact negatively on the everyday lives of patients.

¹² The Guideline Development Group considered that 'soon' meant being seen within 4 weeks

¹³ The Guideline Development Group considered that 'soon' meant being seen within 4 weeks

2.1.4 Patient safety

No patient safety issues have been identified.

2.1.5 Current practice

The 2007 report on the human and economic cost of epilepsy in England by the All Parliamentary Group on Epilepsy recognised the under-provision of MRI and EEG scanners and staff trained to operate such equipment in many NHS trusts. Submissions to the inquiry reported waiting lists for EEG scans of up to several months, and up to 9-12 months for video-telemetry.¹⁴

The 2009 Epilepsy Action survey of acute and primary care trusts in England demonstrated that over a third of patients who require an MRI and/or an EEG have to wait five weeks or more. The Epilepsy Action patient survey found that 51% of patients diagnosed in the last two years who had an MRI scan waited more than four weeks and a further 50% of people reported a waiting-time for an EEG of over four weeks. The survey found that only 41% of acute trusts had access to ambulatory EEGs.

2.1.6 Current indicators

No current indicators identified.

¹⁴ All Parliamentary Group on Epilepsy (2007) [The human and economic cost of epilepsy in England](#)

3 Investigation– MRI as investigation of choice

3.1 *NICE CG137 Recommendation 1.6.20*

3.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

Guideline recommendations	1.6.20 MRI should be the imaging investigation of choice in children, young people and adults with epilepsy. [2004]
Proposed quality statement	Adults undergoing imaging investigations for epilepsy receive magnetic resonance imaging. Children and young people undergoing imaging investigations for epilepsy receive magnetic resonance imaging.
Draft quality measure	Structure: Evidence of local arrangements to ensure that people undergoing imaging investigations for epilepsy receive magnetic resonance imaging. Process: The proportion of people undergoing imaging investigations for epilepsy who receive magnetic resonance imaging. Numerator – The number of people in the denominator who receive magnetic resonance imaging. Denominator – The number of people undergoing imaging investigations for epilepsy.

3.1.2 Clinical and cost-effectiveness evidence

Two systematic reviews of the literature were identified. A 2001 review suggested that the role of MRI in first diagnosis is best established in individuals in whom the CT is non-diagnostic. A 2000 review addressed the use of neuroimaging in children presenting with a first non-febrile seizure, where the evidence consistently demonstrated that MRI was more sensitive than CT scanning.

Numerous sources of primary evidence show magnetic resonance imaging (MRI) to be more sensitive and specific than computed tomography (CT) scanning in identifying structural abnormalities. Examples are detailed below.

A retrospective case note review (2002) of two one year periods (1992-3 and 1996-7) for all children aged 18 or under who had a CT scan or MRI, showed that a definitive diagnosis was made with CT in 12% of children who presented with seizures, and in 27% with MRI. A 1997 study showed that of participants referred for an EEG with a first suspected epileptic seizure, 67% underwent CT scanning, and 19.7% underwent MRI. MRI was abnormal in 16% of those with normal CT scans

A 1991 study of adults with newly diagnosed late-onset epilepsy reported that of 32 with normal CT, MRI was normal in 20, showed irrelevant lesions in 8, and showed the cause of seizures in 4. In the 12 people with non-diagnostic CT, MRI clarified the diagnosis in 5 and was normal in 2. A 2002 study showed that among 199 individuals with a clinical and EEG diagnosis of epilepsy, MRI changed the diagnosis in 12% (although none of these had a diagnosis of generalised epilepsy), and decreased the proportion of individuals in non-specific categories from 37% to 29%.

3.1.3 Patient experience

No relevant patient experience information was presented in the NICE guideline for this recommendation.

3.1.4 Patient safety

No patient safety issues have been identified.

3.1.5 Current practice

A study in 2000 described the use of imaging in 613 children with newly diagnosed epilepsy. 79.6% had imaging: 63.3% had magnetic resonance imaging, 32.1% computed tomography scans, and 15.8% had both.

MRI scanning is now available in most DGHs.¹⁵ However; the National Audit of Seizure management in Hospitals (NASH) 2011 reported that of those patients (16 years and over) presenting to emergency departments with seizure but no history of epilepsy or blackouts/seizures, 5.2% received an MRI scan (in comparison with 44.6% receiving a CT scan). 11.2% received MRI scan following discharge (in comparison with 5.8% receiving CT scan following discharge).¹⁶

3.1.6 Current indicators

No current indicators identified.

¹⁵ Royal College of Physicians and Association of British Neurologists (2011) [Local adult neurology services for the next decade](#)

¹⁶ [National Audit of Seizure management in Hospitals](#) (2011)

4 Investigation and diagnosis – referral to tertiary care

4.1 NICE CG137 Recommendation 1.5.6 (KPI)

4.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

Guideline recommendations	1.5.6 It may not be possible to make a definite diagnosis of epilepsy. If the diagnosis cannot be clearly established, further investigations and/or referral to a tertiary epilepsy specialist ¹⁷ should be considered. Follow-up should always be arranged. [2004]
Proposed quality statement	<p>Adults whose diagnosis of epilepsy cannot be confirmed in secondary care are referred to a tertiary epilepsy specialist.</p> <p>Children and young people whose diagnosis of epilepsy cannot be confirmed in secondary care are referred to a tertiary epilepsy specialist.</p>
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that people whose diagnosis of epilepsy cannot be confirmed in secondary care are referred to a tertiary epilepsy specialist.</p> <p>Process: The proportion of people whose diagnosis of epilepsy cannot be confirmed in secondary care who are referred to a tertiary epilepsy specialist.</p> <p>Numerator – The number of people in the denominator who are referred to a tertiary epilepsy specialist.</p> <p>Denominator – The number of people whose diagnosis of epilepsy cannot be confirmed in secondary care.</p>
Questions for the TEG	Would this statement have unintended consequences of encouraging confirmation of diagnosis in secondary care to avoid referral to tertiary services? Should referral to tertiary services only be considered following further investigation?

4.1.2 Clinical and cost-effectiveness evidence

This recommendation is based on the consensus of the GDG.

4.1.3 Patient experience

No relevant patient experience information was presented in the NICE guideline for this recommendation.

¹⁷ In this recommendation, 'centre' has been replaced with 'specialist' for consistency across recommendations.

4.1.4 Patient safety

No patient safety issues have been identified.

4.1.5 Current practice

The All Parliamentary Group on Epilepsy reported in 2007 that tertiary referrals can be vital for a number of reasons such as diagnostic uncertainty, specialised advice on drugs, surgery, epilepsy combined with other complicated medical conditions or psychological problems. Many of those seen in tertiary care indicated that they had to battle with local Primary Care Trusts over a protracted period to get the referral approved. Expert submissions to the inquiry suggested that there are many who are dissuaded from onward referral to tertiary services and are then denied the opportunity for optimal advice and care.¹⁸

4.1.6 Current indicators

No current indicators identified.

¹⁸ All Parliamentary Group on Epilepsy (2007) [The human and economic cost of epilepsy in England](#)

5 Treatment – convulsive status epilepticus

5.1 NICE CG137 Recommendation 1.14.1.4

5.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<p>Guideline recommendations</p>	<p>1.14.1.4 Treatment should be administered by trained clinical personnel or, if specified by an individually agreed protocol drawn up with the specialist, by family members or carers with appropriate training. [2004]</p> <p>1.14.2.1 For children, young people and adults with ongoing generalised tonic-clonic seizures (convulsive status epilepticus) who are in hospital, immediately: [2012]</p> <ul style="list-style-type: none"> • Secure airway • Give high-concentration oxygen • Assess cardiac and respiratory function • Check blood glucose levels and • Secure intravenous access in a large vein • See also the suggested protocols in appendix K. <p>1.14.2.4 Follow the suggested protocols in appendix K for treating refractory convulsive status epilepticus in secondary care. [2012]</p>
<p>Proposed quality statement</p>	<p>Adults with convulsive status epilepticus are treated in emergency care settings by clinicians or family members/carers with appropriate training using agreed protocols.</p> <p>Children and young people with convulsive status epilepticus are treated in emergency care settings by clinicians or family members/carers with appropriate training using agreed protocols.</p>
<p>Draft quality measure</p>	<p>Structure: Evidence of local arrangements to ensure that people with convulsive status epilepticus are treated in emergency care settings by clinicians or family members/carers with appropriate training using agreed protocols.</p> <p>Process: The proportion of people with convulsive status epilepticus who are treated in emergency care settings by clinicians or family members/carers with appropriate training using agreed protocols.</p> <p>Numerator – The number of people in the denominator who are treated by clinicians or family members/carers with appropriate training using agreed protocols.</p> <p>Denominator – The number of people with convulsive status</p>

	epilepticus.
Questions for the TEG	Is this statement about treatment in the emergency care setting (i.e. the emergency department), or in emergency situations in general, where we need to ensure family member/carers have received appropriate training?

5.1.2 Clinical and cost-effectiveness evidence

These recommendations were based on the consensus opinion of the GDG. No economic data was available to inform on the relative cost effectiveness of emergency measures. However basic resuscitative procedures are recommended to reduce intensive care admission and longer term morbidity.

The GDG considered the need for emergency protocols to be in place to ensure patients receive the correct medication to stop the seizures as quickly as possible.

5.1.3 Patient experience

No relevant patient experience information was presented in the NICE guideline for this recommendation.

5.1.4 Patient safety

No relevant patient safety issues have been identified.

5.1.5 Current practice

No current practice data identified.

5.1.6 Current indicators

No current indicators identified.

6 Management – Provision of information

6.1 NICE CG 137 Recommendation 1.3.1, 1.17.1

6.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

<p>Guideline recommendations</p>	<p>1.3.1 Children, young people and adults with epilepsy and their families and/or carers should be given, and have access to sources of, information about (where appropriate): epilepsy in general; diagnosis and treatment options; medication and side effects; seizure type(s), triggers and seizure control; management and self-care, risk management, first aid, safety and injury prevention at home and at school or work, psychological issues, social security benefits and social services, insurance issues, education and healthcare at school, employment and independent living for adults, importance of disclosing epilepsy at work, if relevant (if further information or clarification is needed, voluntary organisations should be contacted), road safety and driving, prognosis sudden death in epilepsy (SUDEP), status epilepticus, lifestyle, leisure and social issues (including recreational drugs, alcohol, sexual activity and sleep deprivation), family planning and pregnancy, voluntary organisations, such as support groups and charitable organisations, and how to contact them. [2004]</p> <p>1.17.1 The information given to young people should cover epilepsy in general and its diagnosis and treatment, the impact of seizures and adequate seizure control, treatment options including side effects and risks, and the risks of injury. Other important issues to be covered are the possible consequences of epilepsy on lifestyle and future career opportunities and decisions, driving and insurance issues, social security and welfare benefit issues, sudden death and the importance of adherence to medication regimes. Information on lifestyle issues should cover recreational drugs, alcohol, sexual activity and sleep deprivation (see section 1.3). [2004]</p>
<p>Proposed quality statement</p>	<p>Adults with epilepsy and their family and carers are given and have access to [information] about their condition, its treatment and the [implications] it has on their health and lifestyle choices.</p> <p>Children and young people with epilepsy and their family and carers are given and have access to [information] about their condition, its treatment and the [implications] it has on their health and lifestyle choices.</p>
<p>Draft quality measure</p>	<p>Structure: Evidence of local arrangements to provide people and their family and carers information that they understand about their condition, its treatment and the implications it has on their health and lifestyle choices</p> <p>Process: The proportion of people with epilepsy who have</p>

	<p>received information that is relevant to them in a form they understand about their condition, its treatment and the implications it has on their health and lifestyle.</p> <p>Numerator – The number of people in the denominator who have received information that is relevant to them in a form they understand about their condition, its treatment and the implications it has on their health and lifestyle.</p> <p>Denominator – The number of people diagnosed with epilepsy</p> <p>Outcome: Evidence that people with epilepsy feel more informed about their condition and the implication its and the treatment they are receiving has on their health and lifestyle choices.</p>
Definitions	<p>Information and implications related to health and lifestyle choices - epilepsy in general; diagnosis and treatment options; medication and side effects; seizure type(s), triggers and seizure control; management and self-care, risk management, first aid, safety and injury prevention at home and at school or work, psychological issues, social security benefits and social services, insurance issues, education and healthcare at school, employment and independent living for adults, importance of disclosing epilepsy at work, if relevant (if further information or clarification is needed, voluntary organisations should be contacted), road safety and driving, prognosis sudden death in epilepsy (SUDEP), status epilepticus, lifestyle, leisure and social issues (including recreational drugs, alcohol, sexual activity and sleep deprivation), family planning and pregnancy, voluntary organisations, such as support groups and charitable organisations, and how to contact them.</p>
Questions for the TEG	<p>We need this statement to be epilepsy specific! Are the specific issues concerning the impact of the condition on people's wider lifestyle, particularly concerning safety issues, medication etc? Do we need to focus this statement on an epilepsy specific issues?</p>

6.1.2 Clinical and cost-effectiveness evidence

Recommendation 1.3.1 of the full NICE clinical guideline 137 was primarily based on the findings of a systematic review of evidence concerning information and counselling needs of people with epilepsy conducted by Couldridge in 2001. The review identified 15 papers where specific information needs of people with epilepsy were identified. The main topics identified were;

- epilepsy in general
- diagnosis and treatment options
- medication and side effects
- seizures and seizure control
- injury prevention

- psychological issues
- social security
- driving and insurance
- employment
- prognosis
- life style and social issues

The review identified only 1 published paper that specifically focused on the experiences of young people with epilepsy (Wilde 1996). This study focused on young people's experiences of being diagnosed and living with epilepsy rather than focusing specifically on what information they may require. The qualitative study identified issues such as bullying / teasing at secondary school and apprehension about telling people about their epilepsy including potential employers.

6.1.3 Patient experience

None identified.

6.1.4 Patient safety

A patient safety incident is any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care (see Appendix A). The patient safety function of the NHS Commissioning Board identified a number of cases of congenital damage to in newborn babies as a side effect of the mother taking certain AED's during pregnancy.

6.1.5 Current practice

None identified.

6.1.6 Current indicators

[NHS Outcomes Framework](#) – Health Related quality of life indicator

7 Treatment – Care planning

7.1 NICE CG137 Recommendation 1.8.2 [KPI]

7.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

Guideline recommendations	1.8.2 All children, young people and adults with epilepsy should have a comprehensive care plan that is agreed between the person, family and/or carers where appropriate, and primary care and secondary care providers. This should include lifestyle issues as well as medical issues. [2004]
Proposed quality statement	<p>Adults with epilepsy have a [comprehensive] [individualised written care plan] that includes both medical and lifestyle issues, that has been agreed between the person, family / and or carers where appropriate and the primary and secondary care providers.</p> <p>Children and young people with epilepsy should have a [comprehensive] [individualised written care plan] that includes both medical and lifestyle issues, that has been agreed between the person, family / and or carers where appropriate and the primary and secondary care providers.</p>
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that people with epilepsy have a comprehensive, individualised written care plan.</p> <p>Process: The proportion of people with epilepsy who have an individualised written care plan.</p> <p>Numerator – The number of people in the denominator who have an individualised written care plan.</p> <p>Denominator – The number of people with epilepsy.</p> <p>Outcome: The number of people with epilepsy who feel they have been involved in developing and agreeing their care plan.</p> <p>The number of people with epilepsy, who feel that they have a comprehensive, individualised written care plan.</p>
Definitions	<p>Comprehensive</p> <p>Lifestyle issues as well as medical issues – to include any issues related to the topics described in CG137 Recommendation 1.3.1</p> <p>Individualised written care plan</p> <p>This should be a written record of the decisions made concerning care following a consultation and what the next and future steps are concerning treatment and review of care.</p>
Questions for the TEG	This needs to be more epilepsy specific. What do we want this statement to achieve in terms of improving care for people with

epilepsy?

7.1.2 Clinical and cost-effectiveness evidence

No published high quality reviews were identified by the guideline development group (GDG) when developing the full NICE Epilepsies clinical guideline. Therefore this recommendation was based on the consensus expert opinion of the GDG members. The GDG discussed the need for a comprehensive individualised written care plan for all people with epilepsy as part of a wider discussion concerning the most effective ways of delivering a co-ordinated and effective package of care for people with epilepsy. The need a comprehensive written plan was identified as particularly important in managing care with primary and shared care settings.

7.1.3 Patient experience

None identified.

7.1.4 Patient safety

A patient safety incident is any unintended or unexpected incident which could have or did lead to harm for one or more patients receiving NHS care (see Appendix A). A comprehensive analysis of recent reported incidents (please see full accompanying report from the NPSA) identifies the following priority areas relating to patient safety in managing the care of people with epilepsy:

Medication – Missed or delayed medication can lead to seizures, impacting patient well-being and safety. Ensuring patients receive the correct medication, at the correct dose, at the correct time, was identified to be the most important issue when looking at the incident data.

Communication – Effective communication of a patient's history, status, care plan and medication is essential to ensure they receive appropriate and timely treatment.

7.1.5 Current practice

In 2002, the National Sentinel Clinical Audit of Epilepsy was published. The audit reviewed the GP case notes of 285 individuals who died; 45 who received their care entirely within general practice and 241 who also received secondary care.

After a first seizure most individuals (84%) were referred to secondary care. There was a low level of clinical information recording in relation to all those who died. Documented evidence of individual, written care plans was lacking. In the year prior to death, there had been no recorded review of 67% of

people receiving all their care in general practice. 78% of those who were receiving combined care had been reviewed by either the specialist or the GP.

In 2009 Epilepsy Action published findings from a national survey of PCT's and patients with epilepsy. The patient survey found that only 13 per cent of the respondents had a care plan. Of the 105 responses from Primary Care Trusts only 20 (19%) of PCTs provided an answer to the question of whether care plans were in place for people with epilepsy and of the 92 Acute Trusts that responded only 54 (59%) were able to provide some information whether care plans were used for people with epilepsy, with some trusts only providing a figure for adults and some only for children.

7.1.6 Current indicators

None identified.

DRAFT

8 Treatment – Access to epilepsy specialist nurses

8.1 NICE CG137 Recommendation 1.8.3

8.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

Guideline recommendations	1.8.3 Epilepsy specialist nurses (ESNs) should be an integral part of the network of care of children, young people and adults with epilepsy. The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the child, young person or adult, families, carers and, in the case of children, others involved in the child's education, welfare and well-being. [2004]
Proposed quality statement	<p>Adults with epilepsy are offered a care package that is supported by an epilepsy specialist nurse.</p> <p>Children and young people with epilepsy are offered a care package that is supported by an epilepsy specialist nurse.</p>
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that epilepsy specialist nurses are part of the care network for all people accessing epilepsy services.</p> <p>Process: The proportion of patients whose package of care is supported by an epilepsy specialist nurse.</p> <p>Numerator – The number of people in the denominator whose package of care is supported by an epilepsy specialist nurse.</p> <p>Denominator – The number of people with epilepsy.</p>
Questions for the TEG	How do we define “supported by” ? Is there something more specific we can focus on – e.g. having contact details of an ESN?

8.1.2 Clinical and cost-effectiveness evidence

Recommendation 1.8.3 from the full NICE clinical guideline is based on the findings of a Cochrane review that assessed the effectiveness of specialist epilepsy nurses compared to routine care. Three trials were included in the review, one in general practice and two in a neurology centre. The three trials only included individuals aged 15 years or older.

The reviewers found that for specialist nurses, the evidence was of a higher quality service but showed no differences regarding seizure frequency or seizure severity between those receiving care from specialist nurses or usual care. There was some evidence that incidence of depression was decreased

(one study of three) and there was good evidence to show that the process of care was improved and that user satisfaction was improved.

The full clinical guideline references a systematic review conducted by Meads 2002 that looked at cost effectiveness of epilepsy specialist nurses. The review identified one RCT that assessed the cost effectiveness of nurse specialists. The trial found that the total mean NHS cost per patient per year was calculated to be £674 for the epilepsy nurse group and £858 for usual care; however, this was not a statistically significant reduction and was largely accounted for by the lower cost for an epilepsy nurses' time compared to that for a doctor.

8.1.3 Patient experience

None identified.

8.1.4 Patient safety

None identified.

8.1.5 Current practice

The National Audit of Seizure Management in Hospitals (2012) reported that of 2492 patients included in the audit who had a diagnosis of epilepsy only 5.5% had seen an epilepsy specialist nurse (ESN) in the past 12 months.

An enquiry by the All Party Parliamentary Group on Epilepsy (2007)¹⁹ reported that there are approximately 152 epilepsy specialist nurses in England and the epilepsy organisations have been campaigning for this number to increase to 920 in England. A number of witnesses to the enquiry gave evidence which suggests that many ESNs across the UK are currently threatened with redundancy, reduced hours or assignment to non-specialist duties. Evidence presented to the enquiry suggested that access to ESNs is still patchy. A witness from Epilepsy Bereaved suggested that ESNs play an essential role in raising awareness of SUDEP.

A report by Epilepsy Action²⁰ (2008) stated that 60% of Acute Trusts and 64% of Primary Care Trusts did not have an ESN. A patient survey showed that only 40% of patients involved had been referred to a specialist nurse for support.

¹⁹ [Wasted Money, Wasted Lives APPG on Epilepsy \(2007\)](#)

²⁰ [Epilepsy Action; Epilepsy in England: Time for change \(2009\)](#)

8.1.6 Current indicators

Royal College of Paediatrics and Child Health, [Epilepsy 12 National Audit](#)–
Performance indicator 2 - the % with evidence of input by, or referral to, an ESN by 1
year.

DRAFT

9 Management - Review

9.1 NICE CG137 Recommendation 1.20.2(KPI), 1.20.3[KPI], 1.20.4(KPI), 1.20.5 (KPI)

9.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

Guideline recommendations	<p>1.20.2 (KPI) Adults should have a regular structured review with their GP, but depending on the person's wishes, circumstances and epilepsy, the review may be carried out by the specialist. [2004]</p> <p>1.20.3 (KPI) Children and young people should have a regular structured review with a specialist. [2004]</p> <p>1.20.4 (KPI) For adults, the maximum interval between reviews should be 1 year but the frequency of review will be determined by the person's epilepsy and their wishes. [2004]</p> <p>1.20.5 (KPI) For children and young people, the maximum interval between reviews should be 1 year, but the frequency of reviews should be determined by the child or young person's epilepsy and their wishes and those of the family and/or carers. The interval between reviews should be agreed between the child or young person, their family and/or carers as appropriate, and the specialist, but is likely to be between 3 and 12 months. [2004]</p>
Proposed quality statement	<p>Adults with epilepsy have a [regular] [structured] review with their GP or with a specialist covering all aspects of their individualised care plan.</p> <p>Children and young people with epilepsy have a [regular] [structured] review with a specialist covering all aspects of their individualised care plan.</p>
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that adults with epilepsy have a regular structured review with an [appropriate] healthcare professional.</p> <p>Evidence of local arrangements to ensure that children and young people with epilepsy have a regular structured review with a [specialist].</p> <p>Process:</p> <p>a) The proportion of adults with epilepsy who have a regular structured review with an [appropriate] healthcare professional.</p> <p>Numerator – The number of people in the denominator who have a regular structured review with an appropriate healthcare professional.</p> <p>Denominator – The number of people with epilepsy.</p> <p>b) The proportion of children and young people with epilepsy</p>

	<p>who have a regular structured review with a specialist.</p> <p>Numerator – The number of people in the denominator who have a regular structured review with a specialist.</p> <p>Denominator – The number of children and young people with epilepsy.</p>
Definitions	<p>The decision as to whether a review should be carried out by a person's GP or a specialist depends on individual requirements including the persons' wishes, their circumstances and their epilepsy.</p> <p>Structured</p> <p>1.17.1 The physical, psychological and social needs of young people with epilepsy should always be considered by healthcare professionals. Attention should be paid to their relationships with family and friends, and at school.</p> <p>Regular</p> <p>1.20.5 For children and young people, the maximum interval between reviews should be 1 year, but the frequency of reviews should be determined by the child or young person's epilepsy and their wishes and those of the family and/or carers. The interval between reviews should be agreed between the child or young person, their family and/or carers as appropriate, and the specialist, but is likely to be between 3 and 12 months. [2004]</p> <p>1.20.4 For adults, the maximum interval between reviews should be 1 year but the frequency of review will be determined by the person's epilepsy and their wishes. [2004]</p>
Questions for the TEG	<p>Are there specific aspects of the care plan that need to be referred to?</p>

9.1.2 Clinical and cost-effectiveness evidence

The GDG for the full NICE Epilepsies clinical guideline suggested that there was a lack of good quality evidence of effectiveness for structured annual review in primary care. They did reference findings from the National Sentinel Clinical Audit of Epilepsy Related Death that a high proportion of adults who died of epilepsy had not had a structured review.

The guideline reports findings from a review of the evidence on the quality of care provided in primary care for people with epilepsy that showed care is often reactive and of variable quality. The GDG argued that this provided evidence of the need for GPs to provide a structured management system for epilepsy, along the lines of that provided for diabetes and asthma, stating that this could be achieved by a structured annual review.

With regard to children and young people, the full guideline references expert opinion that stated the adolescent period was an important time to review the diagnosis of both epilepsy and the epilepsy syndrome, and to consider any

underlying cause. The reasons for this included previous misdiagnosis, and particularly the potentially serious implications of misdiagnosis for employment, driving, and psychosocial health.

9.1.3 Patient experience

None identified.

9.1.4 Patient safety

None identified.

9.1.5 Current practice

None identified.

9.1.6 Current indicators

[National QOF Indicator](#) Epilepsy 7 - The percentage of patients aged 18 and over on drug treatment for epilepsy who have a record of medication review involving the patient and/or carer in the previous 15 months.

10 Women and young women of childbearing potential – Contraception and pregnancy

10.1 NICE CG 137 Recommendation 1.15.1.1 (KPI)

10.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

Guideline recommendations	<p>1.15.1.1 (KPI) In order to enable informed decisions and choice, and to reduce misunderstandings, women and girls with epilepsy and their partners, as appropriate, must be given accurate information and counselling about contraception, conception, pregnancy, caring for children and breastfeeding, and menopause. [2004]</p>
Proposed quality statement	<p>Women with epilepsy and their partners, as appropriate, are offered (information / a review) and counselling concerning potential risks associated with epilepsy/ the treatment of epilepsy and; contraception, conception, pregnancy, caring for children and breastfeeding and menopause.</p> <p>Young women or girls of child bearing age with epilepsy and their parents/carers as appropriate are offered (information / a review) and counselling concerning potential risks associated with epilepsy/ the treatment of epilepsy and; contraception, conception, pregnancy, caring for children and breastfeeding.</p>
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that women and their partners, as appropriate, are offered (information/ a review) and counselling concerning the potential risks associated with epilepsy / the treatment of epilepsy and: contraception, conception, pregnancy, caring for children and breastfeeding and menopause</p> <p>Evidence of local arrangements to ensure that young women and their parents / carers, as appropriate, are offered (information/a review) and counselling concerning the potential risks associated with epilepsy / the treatment of epilepsy and; contraception, conception, pregnancy, caring for children and breastfeeding.</p> <p>Process:</p> <p>a) The proportion of women with epilepsy who are offered (information/ a review) and counselling concerning the potential risks associated with epilepsy / the treatment of epilepsy and; contraception, conception, pregnancy, caring for children and breastfeeding.</p> <p>Numerator – The number of people in the denominator who receive (information/ a review) and counselling concerning the potential risks associated with epilepsy / the treatment of epilepsy and: contraception, conception, pregnancy, caring for children and breastfeeding and menopause.</p>

	<p>Denominator – The number of women with epilepsy.</p> <p>b) The proportion of young women with epilepsy who are offered information and counselling concerning the potential risks associated with epilepsy / the treatment of epilepsy and; contraception, conception, pregnancy, caring for children and breastfeeding.</p> <p>Numerator – The number of people in the denominator who receive information and counselling concerning the potential risks associated with epilepsy / the treatment of epilepsy and; contraception, conception, pregnancy, caring for children and breastfeeding and menopause.</p> <p>Denominator – The number of young women with epilepsy.</p> <p>Outcome: Reduction in the number of foetus' affected by anti-epileptic medication.</p> <p>Reduction in the number of unplanned pregnancies in women with epilepsy who were taking the contraceptive pill.</p>
<p>Questions for the TEG</p>	<p>Is there a specific issue that we would like the statement to focus on? We already have a statement concerning information about the potential issue associated with treatment for epilepsy. Is there a specific aspect of care for women and girls of child bearing potential that we want to focus on?</p>

10.1.2 Clinical and cost-effectiveness evidence

A systematic review of the literature relating to this issue did not find any relevant RCT's. Recommendation 1.15.1.1 was therefore primarily based on evidence from a systematic review of non RCT studies concerning the information needs of women about how epilepsy and AED's in particular can impact on contraception, pregnancy and other related matters.

A review by Crawford (2003) referenced a study conducted by Epilepsy Action. The most important issues for women aged 19 to 44 years who were considering having children were:

1. risk of epilepsy/medication affecting the unborn child (87%)
2. effect of pregnancy on seizure control (49%)
3. risk of a child developing epilepsy (42%)

For women aged 45 years or more, the most important issues were:

1. epilepsy medication and osteoporosis (63%)
2. epilepsy medication as you get older (57%)
3. changes in seizures during the menopause (44%).

10.1.3 Patient experience

The full NICE clinical guideline reports the results of a questionnaire survey of female members of the British Epilepsy Association.

- 47% of women taking oral contraception felt they had not been given enough information about the oral contraception pill and their AED(s).

- 43% reported receiving no information about pregnancy,
- 25% had discussed pregnancy with no-one.
- Many women intending to have children in the subsequent two years felt they still had unanswered questions (see Figure 11-1).

10.1.4 Patient safety

The NPSA identified a large number of cases where congenital damage was identified in new born babies as a result of side effects from the use of anti-epileptic drugs during pregnancy.

10.1.5 Current practice

None identified.

10.1.6 Current indicators

Royal College of Paediatrics and Child Health, [Epilepsy 12 National Audit](#) – Performance indicator 11. % females >12 years old commenced on epilepsy medication with evidence of discussion regarding pregnancy or contraception related issues.

11 Transition – Preparation for transition

11.1 NICE CG 137 Recommendation 1.17.4

11.1.1 Relevant NICE clinical guideline recommendations and proposed quality statement

Guideline recommendations	1.17.4 During adolescence a named clinician should assume responsibility for the on-going management of the young person with epilepsy and ensure smooth transition of care to adult services, and be aware of the need for continuing multi-agency support. [2004]
Proposed quality statement	Young people with epilepsy have their transfer to adult services managed by a named clinician.
Draft quality measure	<p>Structure: Evidence of local arrangements to ensure that young people with epilepsy have their transfer to adult services managed by a named clinician.</p> <p>Process: The proportion of young people who have their transfer to adult services managed by a named clinician.</p> <p>Numerator – The number of people in the denominator have the transfer managed by a named clinician.</p> <p>Denominator – The number of young people with epilepsy being transferred to adult services.</p> <p>Outcome: Continuity in care for young people with epilepsy transferring to adult services.</p>
Questions for the TEG	Is the issue here about management and co-ordination of care between settings or is it more about the transition from adolescents to adulthood for people with a long term condition such as epilepsy and the additional emotional / practical needs that they might have?

11.1.2 Clinical and cost-effectiveness evidence

The full NICE Epilepsies clinical guideline recognised how living with epilepsy brings additional challenges to young people who are managing the physical and mental transition from adolescents to adulthood. Particular challenges were recognised with the transition from dependence to independence. These issues along with the need for smooth continuity of care from paediatric services to adult services were identified as key reasons for effective transition management. The guideline states that 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.

11.1.3 Patient experience

The full NICE epilepsies clinical guideline states how the transition from paediatric to adult care is a difficult time for many adolescents suffering from epilepsy. There is often a break in the intensity of care, and some adolescents are lost to follow-up.

11.1.4 Patient safety

None identified.

11.1.5 Current practice

Epilepsy Action (2009) reported findings from a survey that found transition services are not properly mapped out, leading to poor services for young adults as they move out of paediatric care into adult care. Only 36 per cent of Acute Trusts and 33 per cent of Primary Care Trusts had transition services for children already in place. The report went on to conclude that the lack of transition services, together with the lack of paediatric specialist nurses and lack of data regarding children's epilepsy services paint a poor picture of care for children with epilepsy.

11.1.6 Current indicators

None identified.

Appendix A: Definition of patient safety

The National Patient Safety Agency (NPSA) defines patient safety in the following terms:

Every day more than a million people are treated safely and successfully in the NHS, but the evidence tells us that in complex healthcare systems things will and do go wrong, no matter how dedicated and professional the staff. When things go wrong, patients are at risk of harm, and the effects are widespread and often devastating for patients, their families and the staff involved. Safety incidents also incur costs through litigation and extra treatment, and in 2009/10 the NHSLA paid out approximately £827, 000,000 in litigation costs and damages. These incidents are often caused by poor system design rather than the error of individuals i.e. 'they are an accident waiting to happen'.

In short patient safety could be summarised as 'The identification and reduction of risk and harm associated with the care provided to patients 'or 'Preventing patients from being harmed by their treatment'. Examples of this might be 'operating on or removing the wrong organ, ten times the dose of an opioid, giving a colonoscopy to the wrong patient with the same name as someone else in the waiting room etc.' These risks are unlikely to be identified through clinical trials or traditional evidence bases and so other evidence sources, such as the National Reporting and Learning System, need to be analysed to highlight the risks and improve system development. This does not however give an accurate picture of prevalence in that way that methods such as casenote review may do.