### Stakeholder Comments

Please enter the name of your registered stakeholder organisation below.

<table>
<thead>
<tr>
<th>Stakeholder Organisation:</th>
<th>Epilepsy Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of commentator:</td>
<td>Peter Scott</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Order number</th>
<th>Question number</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Please insert each new comment in a new row.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Please do not paste other tables into this table, as your comments could get lost – type directly into this table.</td>
</tr>
</tbody>
</table>

#### Example 1

<table>
<thead>
<tr>
<th>1</th>
<th>General</th>
<th>This submission has been prepared by Epilepsy Action. The following organisations wish to endorse it.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>• National Society for Young People with Epilepsy (NCYPE).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Epilepsy Connections</td>
</tr>
</tbody>
</table>

#### Example 2

<table>
<thead>
<tr>
<th>2</th>
<th>General</th>
<th>We are pleased that Epilepsy (adults) and Epilepsy (children) are both proposed topics for development of Quality Standards.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>We believe it is imperative that Quality Standards for these two areas are developed as soon as possible. Below we set out below why we believe Quality Standards for epilepsy are required. We also have taken the opportunity to suggest potential Quality Standards for epilepsy.</td>
</tr>
</tbody>
</table>

#### Example 3

<table>
<thead>
<tr>
<th>3</th>
<th>General</th>
<th>Below we have provided information about epilepsy to inform the consultation team.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Approximately 496,000 people in England have a diagnosis of epilepsy and take anti-epileptic drugs. This is equivalent to approximately 1 in 105 people.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Epilepsy is not a single condition. There are over 40 different types of epilepsy consisting of at least 29 syndromes and a further 12 or so clinically distinct groups defined by the specific cause or underlying cause.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>There are at least 40 different seizure types and perhaps as many as 50 and individuals may have one or several different seizure types.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Children and young people aged 18 years and under with epilepsy, the total number</td>
</tr>
</tbody>
</table>

---

1. Epilepsy prevalence, incidence and other statistics, Joint Epilepsy Council of the UK and Ireland, September 2011
Misdiagnosis rates in the United Kingdom, where a diagnosis of epilepsy is incorrectly made, are between 20 – 31 percent.\textsuperscript{4} Using an assumed rate of 23 percent this equates to 138,000 people with a diagnosis of epilepsy and receiving AEDs who do not have the condition.

Every day in the UK, 75 people are diagnosed with epilepsy.

The over 65s is now the largest group in which a first seizure is reported.\textsuperscript{5} As the population ages, the prevalence of the condition is set to increase further.

### General

Below we set out some of the impact of epilepsy.

Epilepsy is one of the most common long-term neurological condition sets effecting both adults and children.

It is a set of conditions requiring a multi-agency and multi-disciplinary approach to be successfully managed.

Epilepsy impacts on:
- health services (primary, acute and tertiary);
- mental health services;
- social services;
- social care and learning disability services;
- educational institutions;
- housing and welfare services;
- and emergency care.

The impact of epilepsy can be substantial and profound. It can affect employment, social life, education and leisure activities. Stigma remains an issue.

These are in addition to medical effects on the individual, such as memory, behaviour and cognitive development.

More than one in five people with epilepsy have learning or intellectual disabilities.\textsuperscript{5}

Epilepsy prevalence is 25 per cent higher in the most socially deprived areas compared to the least socially deprived areas.\textsuperscript{7}

10 per cent of the population in the UK is affected by the social implications of epilepsy (i.e. having epilepsy themselves, or as a family member or carer involved in epilepsy treatments).

### General

Below we set out of the main issues of concern for the health outcomes of people with epilepsy.

It is a matter of agreement that there are longstanding, serious and urgent problems across the country associated with the delivery of NHS services to people with epilepsy and that improving services will lead to substantial budgetary savings, as well as dramatically improving the lives of people with epilepsy.

In 2007 the All Party Parliamentary Group on epilepsy estimated that poor epilepsy services in England cost the NHS £189 million per year through misdiagnosis and

---


\textsuperscript{5} Epilepsy in later life: A guide for clinicians dealing with older people, Epilepsy Action, p3, 2011.


\textsuperscript{7} Purcell, Gaitatziz, Sander, Majeed. Epilepsy Prevalence and prescribing patterns in England and Wales, Office of National Statistics, Autumn 2002
unnecessary delays, and treatment.\textsuperscript{8}

The Prime Minister acknowledges that “there are historic weaknesses in the commissioning of services” and that there is an urgency for change “because these failures carry huge costs as well as having a massive impact on the lives of people with epilepsy” with “potentially very significant savings from unplanned emergency admissions to be made by getting this right, which goes hand-in-hand with improvements in outcomes, including life expectancy and a reduction in the number of tragic sudden deaths in epilepsy” (Letter 16/5/11 to The Right Honourable the Lord Howe of Aberavon CH QC). This view is shared by the responsible Health Minister Paul Burstow. At his meeting with the Joint Epilepsy Council (JEC) in January 2011, he acknowledged that we had made the “moral and economic case” for improvements to services and confirmed his views in a subsequent letter to Valerie Vaz MP of March 22.

In 2009 Epilepsy Action published its report Epilepsy in England: time for change. This was based on a survey of all Primary Care and acute trusts in England.

One finding of the survey was that one third (30 per cent) of patients diagnosed with epilepsy in the previous two years reported seeing an epilepsy specialist after their first suspected seizure. This means 70 per cent of diagnoses were likely to have been made by non-specialists.

Quality Standards to guide the treatment and influence the outcomes of care pathway are therefore vital for epilepsy and seizure-related conditions.

A NICE Clinical Guideline for the epilepsies has existed since 2004, and is well regarded among clinicians and patient groups. It is currently under review and a second version is expected to be published in January 2012. Quality Standards covering epilepsy would therefore be a progression of this work.

<table>
<thead>
<tr>
<th>6</th>
<th>General</th>
</tr>
</thead>
<tbody>
<tr>
<td>One important issue regarding epilepsy care is the unnecessary high number of non-elective admissions to hospital.</td>
<td></td>
</tr>
<tr>
<td>We believe epilepsy related non-elective admissions have consistently shown to be among the largest of any neurological condition.</td>
<td></td>
</tr>
<tr>
<td>Epilepsy is the largest single source of one day admissions amongst neurological conditions in the North East of England.\textsuperscript{9}</td>
<td></td>
</tr>
<tr>
<td>The NHS Atlas of Variation establishes the wide variation in both elective and non-elective admission rates (non elective ranging from 38 per 100,000 to 130 per 100,000).\textsuperscript{10} In the Child and Maternal Health Observatory (ChiMat) data for 2009/10,\textsuperscript{11} non-elective admissions for under 19s varied across PCTs from a low of 30 per 100,000 to a high of 176.</td>
<td></td>
</tr>
<tr>
<td>The OPCS codes (G40-41 for Epilepsy and Status Epilepticus) show admission numbers have stayed relatively consistent over the previous five years (2005-2010), with 84% of admissions and bed stays being related emergency admissions. This equates to 148,178 occupied bed days per year.</td>
<td></td>
</tr>
</tbody>
</table>

\textsuperscript{9} Health Needs Assessment for Long Term Neurological Conditions in North East England, North East Public Health Observatory, June 2009.
The NHS Outcomes Framework (2011/12) targets reducing the number of non-elective admissions as an indicator under Domain 2. The framework states that 94% of emergency admissions for children (under 19s) with long-term conditions are for asthma, epilepsy and diabetes, and this lead to the dedicated indicator 'unplanned hospitalisation for asthma, epilepsy and diabetes in under 19s'.

| 7 | General | Achieving seizure freedom is the primary goal of every epilepsy treatment.\(^{12}\) Breakthrough seizures, worsening of their seizure control or worsening of side effects can have a major impact on an individual's life. A breakthrough seizure can mean the loss of an individual's driving licence for a year, which can lead to loss of employment. Seizures carry a risk of injury and can, in some cases, be fatal. Increased seizure frequency is linked to increased risk of epilepsy-related death; people with uncontrolled seizures have a 23-fold increased risk of Sudden Unexpected Death in Epilepsy (SUDEP) compared to people with fully-controlled seizures.\(^{13}\)

At the present time, resective surgery is the only permanent way of preventing seizures. However the capacity for epilepsy surgery is variable. And even where access to surgery is good, too often a person is considered for surgery as a last resort, when they may have benefitted much earlier.

Currently only 52 per cent of the population of people with epilepsy are seizure free\(^{14}\). However, 70 per cent of the population could be seizure free with the appropriate treatment.\(^{15}\) This means, as a conservative estimate, that there are 80,000 people in the UK experiencing seizures who need not be.

Successive GP-based audits over several decades show no improvement in the proportion of patients with epilepsy who are seizure free.\(^{16}\) It is likely that each GP has 1-3 patients whose seizures could be much better controlled, and 1 or 2 who could become seizure free.

Research from The National Hospital for Neurology and Neurosurgery suggests that 16 per cent of people with uncontrolled epilepsy will become seizure free with changes in medication. And those who are suitable for surgery have an even higher chance, about 60-70 per cent.\(^{17}\)

| 8 | General | Epilepsy related death is a major area of health inequality, with Early mortality in people with epilepsy is two to three times higher than the general population.\(^{18}\)

New research published recently in the British Journal of General Practice has shown that epilepsy mortality is rising. Deaths in epilepsy rose by 31 per cent in males and 39 per cent in females between 1995 and 2005 at a time when mortality from all causes in the general population declined.

Deaths that are amenable to medical intervention through risk factors have been targeted in the UK’s health policies, but not for epilepsy\(^{19}\).
1016 people in England and Wales died in 2009 from epilepsy.

In England and Wales between 2007 and 2009, 68,422 years of life were lost due to epilepsy\(^1\) in people aged between one and 74, more than double the number of years of a condition such as asthma.\(^2\) These are just the reported deaths as a result of epilepsy, where epilepsy is stated as a cause of death. We believe there are many other cases where epilepsy is a cause but where death is recorded as accident.

People who had not been seizure-free in the previous year were reported to have had a 23-fold increased risk of Sudden Unexpected Death in Epilepsy (SUDEP) compared to people with fully-controlled seizures.\(^3\) This is on top of a 24 times higher risk of death that a person with epilepsy has compared to the general population.\(^4\)

The National Sentinel Clinical Audit of Epilepsy-Related Death (2002)\(^5\) found that there are around 500 cases of Sudden Unexpected Death in Epilepsy (SUDEP) in the UK every year, and another 500 deaths due to epilepsy related causes. Of the 1,000 epilepsy related deaths in 2001, 54 per cent of the adults had experienced inadequate care. This led to the conclusion that 39 per cent of adult and 59 per cent of childhood, deaths were considered potentially or probably avoidable.

The main deficiencies identified included:

- Inadequate drug management (20%);
- Lack of appropriate investigations (13%);
- No evidence of a package of care (5%);
- Inadequate recording of patients’ histories (5%);
- Adults with learning disabilities ‘lost’ in transfer from child to adult services (6%);
- One or more major clinical management errors (5%).

In primary care management (general practice) the main problems identified included sparse evidence of structured management plans, missed triggers for referral and professional communication failures. The report also found that just over half (19/37) of individuals diagnosed in the 5 years before death were not initially referred to an adult or paediatric neurologist.

In England and Wales 11 per cent of the deaths are young adults or children under the age of 25.\(^6\)

The EUROSTAT figures for epilepsy mortality show no decline in the epilepsy mortality rate over the years since the audit\(^7\), maintaining a Standardised Death Rate (SDR) per 100,000 inhabitants of between 1.5-1.7 of the EU-15 average in each year since.

However the incidence of mortality is increasing as the population rises. One recent study, published earlier this year, found patients who have alcohol problems, do not collect repeat prescriptions for anticonvulsant drugs, have recent injuries, or have


\(^{21}\)Years of life lost due to mortality from epilepsy (ICD10 G40-G41), The NHS Information Centre for health and social care, 2007-2009.


\(^{27}\)Ridsdale, Leone; Charlton, Judith; Ashworth, Mark; Richardson, Mark; Gulliford, Martin C. ‘Epilepsy mortality and risk factors for death in epilepsy: a population-based study’. British Journal of General Practice 61 (586), May 2011. pp. e271-e278(8).
been treated for depression are at increased risk of death; with patients who remain seizure free over 12 months at a lower risk.\(^7\)

Therefore receiving better appropriate treatment, including regular assessment by an epilepsy specialist, appears to help reduce epilepsy mortality rates.

<table>
<thead>
<tr>
<th>9</th>
<th>2</th>
</tr>
</thead>
</table>

In line with the invitation from Dr Judith Richardson, Associate Director – Clinical at NICE we are including some suggestions of areas that Quality Standards for Epilepsy might cover. These suggestions are made to indicate that there are key areas where Quality Standards could be developed that could improve the current patchy state of services for people with epilepsy.

We would welcome the opportunity to develop these into formal quality standards and are able to supply evidence and rationale for each of these proposals.

**These are not in order of priority.**

1. All individuals with a recent onset suspected seizure should be seen urgently (within two weeks) by an epilepsy specialist to ensure precise and early diagnosis and initiation of therapy as appropriate to their needs.

   For children with epilepsy, a specialist is defined as a paediatrician with expertise and training in the epilepsies.

2. The seizure type(s) and epilepsy syndrome, aetiology and co-morbidity should be determined and the person with epilepsy should be provided with appropriate, clear and accessible information.

3. All individuals with epilepsy should have a regular annual structured review, carried out by a healthcare professional that has attended an epilepsy training course within the past 5 years or can demonstrate equivalent experience from CPD. At the review, individuals should have access to: written and visual information; counselling services; information about voluntary organisations; epilepsy specialist nurses; timely and appropriate investigations; referral to tertiary services, including surgery if appropriate.

   More frequent reviews may well be required for children.

4. All individuals with epilepsy should be provided with the information specified in the NICE guidelines.

5. Where the individual with epilepsy is not seizure free for two years; and or experiences unacceptable side effects; and or there is diagnostic doubt; they should be referred to a tertiary epilepsy specialist.

   Children with suspected epilepsy should be considered for immediate referral to tertiary services because of the profound developmental, behavioural and psychological effects that may be associated with continuing seizures.

6. All girls and young women with epilepsy of child bearing potential and their partners, as appropriate, must be given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause.

7. All women with epilepsy who are pregnant should have their pregnancy managed jointly by both an obstetrician and an epilepsy specialist.

8. The individual should be advised of and have access to a wide range of treatment, where appropriate, including VNS, the ketogenic diet and brain surgery.

9. The AED (anti-epileptic drug) treatment strategy should be individualised according to the seizure type, epilepsy syndrome, co-medication and co-morbidity, the individual’s lifestyle, and the preferences of the individual, their family and/or carers as appropriate.
10. All individuals with epilepsy should have a comprehensive care plan that is agreed between the individuals, their family and/or carers as appropriate, and primary and secondary care providers. Individuals should have a copy of their care plan that they can share appropriately with people who need to know what to do to support them in an emergency etc.

11. Individuals with epilepsy should receive care from staff who are appropriately trained in epilepsy.

12. All individuals with epilepsy should have access to an epilepsy specialist nurse.

13. Individuals with epilepsy should have access to neuropsychological services to evaluate learning disabilities and cognitive dysfunction, particularly in regard to language and memory.

14. Individuals with a suspected first seizure or unexplained blackout should be reviewed both by an epilepsy specialist and cardiologist to see if there is a neurological or cardiological explanation for their episode.

15. When admitted to accident and emergency or to hospital non-electively all individuals with a suspected first seizure or blackout should be referred to the epilepsy service urgently.

16. When admitted to hospital individuals with epilepsy should receive the correct version of their drugs, at the right dosage, at the right time.

17. The withdrawal of treatment should be considered where appropriate and a full discussion had with the individual, their family or carers and the epilepsy specialist.

18. Where an individual was not diagnosed by an epilepsy specialist or was diagnosed before 2000 or reports problems with side effects or has not achieved an acceptable outcome from medication prescribed referral to an epilepsy specialist for review should be considered to rule out misdiagnosis. Annual reviews in primary care should identify such cases.

19. There should be a shared protocol between and accessible to primary and secondary care, with a clear pathway of care that enables information to be shared on unplanned hospitalisation.

20. Initial care plans and annual reviews should include a basic psychological assessment tool to identify possible anxiety and depression/ risk of self harm suicide.

21. All individuals and carers where appropriate, should, unless there are sound clinical reasons not to, receive information about the risk of SUDEP and methods to reduce that risk.

22. During adolescence a named clinician should assume responsibility for the ongoing 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.

23. Patients with poorly-controlled seizure freedom should have access to specialist assessments for surgery, non-epileptic attack disorder, and neuropsychological and neuropsychiatric conditions.

24. Healthcare consultations should enable the individual with epilepsy, and their family and/or carers, to participate as partners in all decisions about their healthcare.

25. Information and data should be retained by commissioners and clinicians on key output and outcome indicators. This should include number of unplanned admissions, number of people with a diagnosis of epilepsy, waiting times for access to specialists and tests, perceptions of the epilepsy health service, and any other relevant information that aids service development and evaluation.
We would also like to support the proposed development of Quality Standards for:

- **Acute medical admissions in the first 48 hours.**
  We believe seizure related non-elective admissions are a leading cause of preventable admissions and are among the biggest causes from any single medical condition. We believe these admissions can be reduced if the underlying cause of the seizure is investigated before discharge.

- **Managing the transition from children’s to adult services.**
  The transition services for those moving from paediatric to adult service are not always adequate to meet the needs of the young people. Our Time for change report (2009) found that only 36 per cent of acute trusts and 33 per cent of primary care trusts in England have transition services in place for young people with epilepsy.28

- **Consultant review within 12 hours of admission.**
  We believe consultant review within 12 hours of admission has the potential to lower admission rates, and is a suitable topic for selection as a Quality Standard.

- **Readmissions.**
  We are aware of people with epilepsy who have been consistently admitted to hospital, and discharged without thorough investigation of the cause of their admission or review of their treatment. This is an unaddressed need that leads to further utilisation of healthcare in the future.

- **Long-term conditions, people with co-morbidities, complex needs.**
  Many people with epilepsy have more than one medical condition, and the interaction between these conditions can lead to complications which are as a result of their multiple needs. We believe a Quality Standard for this area is necessary to provide the best care for this group of higher needs, often vulnerable, people.

- **Safe prescribing.**
  The vast majority of people with epilepsy are treated by anti-epileptic drugs. Successful treatment by anti-epileptic drugs (the prevention of seizures) can be reliant on consistent serum concentration of the medication’s active ingredients. However there is significant and compelling anecdotal, survey-based and case study evidence from clinicians and patients to indicate that a number of people with epilepsy experience difficulties in the management of their condition when switching between different versions of an anti-epileptic drug.

  Consistency of supply (including switching between brands and formulas) is a significant issue to many people with epilepsy, and can be a cause of loss of seizure control. A 2009 survey by Epilepsy Action found that substituting AEDs could negatively affect as many as 50,000 people with epilepsy in the UK. Of those given alternative versions of their usual anti-epileptic drugs in the last year, almost a quarter (23 per cent) said their epilepsy got worse. Most of these people reported an increase in the number of seizures they had.

  Therefore we believe people with epilepsy should receive the same version of their drug each and every time they pick up a prescription, and we believe this message is not satisfactorily communicated. We would expect a safe prescribing Quality Standard to include information on consistency of supply for anti-epileptic drugs, and as such would welcome a Quality Standard on this area.

- **Falls.**
  Seizures can be the undetected, underlying cause of a fall. We believe that there are many, particularly older people, who have epilepsy but are

---

undiagnosed because their symptoms are unidentified or mistaken for other incorrect causes. A Quality Standard to cover this could improve diagnostics and may lead to better identification of underlying causes of falls.

- **Medicines adherence.**
  Medicine adherence is vital for seizure control. This is because successful treatment by anti-epileptic drugs (the prevention of seizures) can be reliant on consistent serum concentration of the medication’s active ingredients. We try to educate our members to understand the importance of medicines adherence. But often we hear that medical adherence is not well understood by medical staff, who are unaware of the importance of correct and timely dosages of anti-epileptic drugs.

| 11 | 4 | Epilepsy is a highly prevalent condition among users of social care, and is a condition that impacts across the health and social care sectors. Epilepsy can affect anyone, at any age, from any walk of life. There are over 40 different types of epilepsy (at least 29 different syndromes and a further 12 clinically distinct groups defined by a specific or underlying cause). There are at least 40 different seizure types and individuals may have one or more different types of seizure. Nursing and care homes will both have residents with the condition. These people with epilepsy will have additional needs and may be reliant on staff to support medication adherence and to know what to do when they experience seizures. This area of the workforce has not been sufficiently trained in epilepsy. Social care staff are also involved in helping people with epilepsy, living in their own homes, to find appropriate support workers and to apply for adaptations. Therefore a basic knowledge of the health requirements related to epilepsy is a necessity in the social care sector. Information about the number of younger people in the social care system who have epilepsy is not collected. However more than one in five people with epilepsy have learning or intellectual disabilities. There are 74,000 people with epilepsy who claim Disability Living Allowance. In addition, approximately 10 per cent of patients with ischaemic stroke develop post-stroke seizures. For older people, there approximately 154,000 (or 1 in 67) people aged 65 and over with epilepsy in the UK. From information provided by The Alzheimer’s Society, over 750,000 people in UK have dementia, of which at least 20 per cent have vascular or mixed dementia (vascular dementia combined with Alzheimer’s). In the UK, 417,000 people have Alzheimer’s disease. Epileptic seizures are a main symptom of vascular dementia and there are 150,000 people in the UK with vascular dementia. In addition, between seven and 21 per cent of patients with Alzheimer’s disease can experience epileptic seizures. Another research paper puts this at 10-22 per cent, a further potential 90,000 people with epilepsy. |

---

Epilepsy Action believes there is a considerable shortfall in the numbers of people over-65 identified as having, and treated for their epilepsy.

Quality Standards for epilepsy (adult) and epilepsy (children) would therefore be effectual in social care settings, as well as health.

Please email this form to: NQBQEngagement@nice.org.uk

Closing date: 14th October 2011

34 Seizures in elderly patients with dementia: epidemiology and management, Drugs Aging (2003), 20 (11) 791-803.