

# NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

## QUALITY AND OUTCOMES FRAMEWORK (QOF) INDICATOR DEVELOPMENT PROGRAMME

### Briefing paper

**QOF indicator area:** Epilepsy

**Potential output:** Recommendations for indicator development

**Date of Primary Care QOF Indicator Advisory Committee meeting:** 16 June  
2009

**Note:** The content of this document is derived from the previous QOF process and the work of the NICE external contractor. It has been put into a NICE template to allow for consistency in reviewing proposed QOF indicators.

### Introduction

This briefing paper presents an assessment of the suitability of an indicator developed through the previous QOF processes for inclusion in the NICE menu of QOF indicators. It is based on the QOF evidence summarised in the QOF expert panel report (Smithson 2007)

The briefing paper is split into two sections.

- An overview of the topic, including epidemiology and current management.
- A review of the proposed indicator and a summary of the evidence that informs the indicator.

### Related existing QOF indicators

Epilepsy relates to an existing QOF clinical domain as defined in the 2009/10 GMS Contract guidance. The existing QOF indicators are outlined below.

**EPILEPSY 5.** The practice can produce a register of patients aged 18 and over receiving drug treatment for epilepsy.

EPILEPSY 6. The percentage of patients age 18 and over on drug treatment for epilepsy who have a record of seizure frequency in the previous 15 months.

EPILEPSY 7. The percentage of patients age 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.

EPILEPSY 8. The percentage of patients age 18 and over on drug treatment for epilepsy who have been seizure free for the last 12 months recorded in the previous 15 months.

## **Overview of epilepsy**

### ***Epidemiological summary***

#### **Definition**

Epilepsy is the most common serious neurological condition, affecting 382,000 people in England, or 1 in every 131 people. It can affect anyone at any age. Epilepsy is not a single condition. There are about 30 different epileptic syndromes and more than 38 different types of seizure – a person may have more than one type.

#### **Incidence, prevalence and evidence of variation by age, sex and ethnicity**

Approximately 456,000 people in the UK have epilepsy. The prevalence data for epilepsy in the UK does not differentiate between people with epilepsy who are being treated and people with epilepsy who have seizures who have chosen not to be treated. Measuring the prevalence of epilepsy has always been problematic. The unadjusted national prevalence for the condition reported by strategic health authorities in 2005 varies by a factor of almost two, from 0.4% to 0.7%. The discrepancies in reported prevalence may be explained by the nature of the condition. The stigma of epilepsy, low expectations of care and unenthusiastic clinical engagement with epilepsy in general practice can put people with epilepsy off regularly visiting their GP for a review of their condition. There is an even greater lack of incentive for people with epilepsy to report seizures to their GP if they hold a driving licence.

The national raw prevalence for 2006/7 was 0.6% in England according to data from the NHS Information Centre, adjusted to 0.8% for people over 18 years.

There are 131,000 women of childbearing age (12–50 years) in the UK, which is about 29% of the total population of people with epilepsy. This is specifically relevant to the proposed indicator.

Epilepsy prevalence is 25% higher in the most socially deprived areas than the least socially deprived areas (Purcell et al. 2002).

### **Morbidity and mortality**

People with epilepsy are at increased risk of depression, suicide and accidents. Every year 990 people in England die of epilepsy-related causes. The 2002 deaths audit suggested that about 365 of these deaths are in young adults and children. Of the total number of deaths, about 400 per year are avoidable (NICE 2002).

### ***Impact on health services***

#### **Primary care**

General practice is taking an increasing role in epilepsy care and high QOF achievement may result in fewer epilepsy-related emergency hospital admissions. Shohet et al. claim that there is 'a significant and relatively strong relationship between the quality of epilepsy management in primary care (proportion of seizure-free patients) and an important care outcome (epilepsy-related emergency hospitalisation)'. They add that their findings 'support the current and future use of Quality Outcomes Framework indicators to measure the quality of epilepsy care' (Shohet, et al. 2007).

#### **Secondary care**

'The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care' (NICE clinical guideline 20) states:

#### ***Referral for complex or refractory epilepsy***

- All individuals with epilepsy should have access via their specialist to a tertiary service when circumstances require.

- Information should be provided to individuals and families and/or carers as appropriate about the reasons for considering surgery. The benefits and risks of the surgical procedure under consideration should be fully explained before the individual's informed consent is obtained.
- If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, individuals should be referred to tertiary services soon for further assessment. Referral should be considered when one or more of the following criteria are present:
  - the epilepsy is not controlled with medication within 2 years
  - management is unsuccessful after two drugs
  - the individual is aged under 2 years
  - an individual experiences, or is at risk of, unacceptable side effects from medication
  - there is a unilateral structural lesion
  - there is psychological and/or psychiatric co-morbidity
  - there is diagnostic doubt as to the nature of the seizures and/or seizure syndrome.

### ***Current management in primary care***

The guideline on epilepsy (NICE clinical guideline 20) made the following recommendations:

#### **Management**

- Healthcare professionals should adopt a consulting style that enables the individual with epilepsy, and their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare, and take fully into account their race, culture and any specific needs.
- 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.
- 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.

## **Review and referral**

- All individuals with epilepsy should have a regular structured review. In children, this review should be carried out at least yearly (but may be between 3 and 12 months by arrangement) by a specialist. In adults, this review should be carried out at least yearly by either a generalist or specialist, depending on how well the epilepsy is controlled and/or the presence of specific lifestyle issues.
- 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.
- If seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, individuals should be referred to tertiary services soon<sup>1</sup> for further assessment.

## **Special considerations for women of childbearing potential**

- Women with epilepsy and their partners, as appropriate, must be given accurate information and counselling about contraception, conception, pregnancy, caring for children, breastfeeding and menopause.

## ***NHS priorities and timeliness for guidance***

Epilepsy was the subject of an All-Party Parliamentary Group (APPG) report 'Wasted money – wasted lives' in June 2007. This report criticised epilepsy care, saying: 'During the course of our Inquiry, it has become clear that ... the case for improving epilepsy services is overwhelming. A vicious circle of social stigma, secrecy and widespread medical ignorance has led to a poor service, from which patients cannot confidently expect good treatment at primary or secondary level. The waste of money in delivering this inadequate service is almost as appalling as the unnecessary deaths and damage to quality of life experienced by people with epilepsy.'

The APPG took evidence from a number of specialists, generalists and patient organisations and it made the following recommendations relating to the QOF: 'The APPG recommends that the maximum number of points which GP surgeries can

---

<sup>1</sup> The Guideline Development Group considered that 'soon' meant being seen within 4 weeks.

earn under QOF for Epilepsy be increased from the current 15 out of a possible 1000 and that the quality criteria under QOF be revised so that they reflect optimal care as opposed to basic care. The APPG recommends that a new QOF indicator be introduced which states the percentage of women with epilepsy of child-bearing potential who have been given information and counselling about contraception, conception and pregnancy. The APPG recommends that a new QOF indicator is introduced which states the percentage of adult patients who are not seizure-free in the last 12 months who have been referred to tertiary services when circumstances allow.'

Following the NICE guideline on epilepsy (NICE clinical guideline 20) the Royal Society of Medicine developed a consensus guideline on issues of women and epilepsy (Royal Society of Medicine Press 2004). This report states that 'information and guidance on effective contraception has importance for women with epilepsy because an unplanned pregnancy may place the woman and her developing foetus at risk'. It also advises that 'women with epilepsy should be offered comprehensive preconceptual counselling to allow them to make informed decisions about minimising the risk factors for themselves and their baby'.

## **Review of proposed indicator**

### ***Proposed indicator:***

**The percentage of women with epilepsy under the age of 55 who are taking antiepileptic drugs who have been given information and counselling about contraception, conception and pregnancy.**

### ***Evidence summary for proposed new indicator***

#### **Clinical effectiveness**

It is estimated that in the UK 131,000 women with epilepsy are of child-bearing age (12–50 years). Approximately 25% of all people with epilepsy are women of reproductive age, and 1 in 200 women attending antenatal clinics are receiving antiepileptic drugs (AEDs) (Royal Society of Medicine Epilepsy Guidelines Group 2004). Around 2500 women with epilepsy will have a baby each year in the UK. Antiepileptic drugs taken during pregnancy are associated with an increased risk of

major congenital malformations (MCMs). Women in the general population have a 1–2% chance of having a baby with an MCM. Women with epilepsy taking one AED have a chance of having a baby with an MCM of slightly over 3.5%, while for women taking two or more AEDs the average chance increases to 6% (Morrow et al. 2006). The risk of MCMs occurring can relate to having epilepsy and to taking AEDs while pregnant. Crawford and Hudson (2003) said: ‘The impact of some commonly prescribed anti-epileptic drugs (AEDs) on female health is well documented. Yet many women continue to experience side effects such as menstrual irregularities, interactions with hormonal contraception/HRT and teratogenicity through lack of awareness or opportunity to discuss problems with a health professional on a regular basis.’

They added: ‘Unfortunately current epilepsy services in the UK are such that many women remain unaware of the issues or risks. Important conversations about contraception and unplanned pregnancy and pre-conception counselling may not take place until it is too late.’

Crawford and Hudson’s survey results show that women are not receiving important information about their condition and the possible effects of AEDs. Only 28% of women aged 19–34 years have received information about oral contraception and epilepsy medication. Of women aged 19–34 years, 71% said that the risk of epilepsy and/or an AED affecting the unborn child is an important issue. Only 46% of women with epilepsy who have had children had been told that their medication might affect their unborn child, which implies that 54% of women who had been through a pregnancy had not been given such information. The vast majority of women surveyed who were considering having children (87%) said that they would like to have more information about epilepsy treatment (Crawford and Hudson 2003).

The Scottish Intercollegiate Guidelines Network (SIGN) guideline states: ‘Advice on contraception should be given before young women are sexually active. Women with epilepsy should be advised to plan their pregnancies’ (SIGN 2003).

### **Cost effectiveness**

Relevant cost-effectiveness data was not identified.

## ***Assessment of indicators against current practice***

### **Reduction of health inequalities**

There was no evidence identified to directly show that the recommendations outlined in this briefing paper can reduce health inequalities. However, people from black and minority ethnic groups may have different cultural and communication needs and these should be considered during diagnosis and management. The need for interpretation should be considered alongside other means of ensuring that each person's needs are appropriately met.

### **Will implementation of these recommendations lead to cost-effective improvements in the delivery of primary care?**

No evidence was identified to directly show that the recommendations may lead to cost-effective improvements in the delivery of primary healthcare.

### ***Feasibility assessment***

Two key questions are asked to make the initial feasibility assessment.

Question 1: Would the proposed primary care recommendations allow the development of indicator that can be used in primary care information systems?

Question 2: Are the proposed primary care recommendations likely to lead to indicators that can be measured in a clear, reproducible and precise manner?

The proposed indicator received a high consensus score through the previous QOF process and is viewed by NPCRDC as feasible.

## **References**

Crawford P, Hudson S (2003). Understanding the information needs of women with epilepsy at different lifestages: results of the 'Ideal World' survey. *Seizure* 12: 502–7

Morrow J, Russell A, Guthrie E et al. (2006) Malformation risks of antiepileptic drugs in pregnancy: a prospective study from the UK Epilepsy and Pregnancy Register. *Journal of Neurology, Neurosurgery and Psychiatry* 77: 193–8

National Institute for Health and Clinical Excellence (2004). The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. NICE clinical guideline 20. London: National Institute for Health and Clinical Excellence. Available from [www.nice.org.uk/CG20](http://www.nice.org.uk/CG20)

National Institute for Clinical Excellence (2002). National clinical audit of epilepsy-related deaths. London: National Institute for Clinical Excellence. Available from [www.nice.org.uk/media/94E/3C/epilepsyreport.pdf](http://www.nice.org.uk/media/94E/3C/epilepsyreport.pdf)

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

Royal Society of Medicine Epilepsy Guidelines Group (2004) Primary Care Guidelines for the Management of Females with Epilepsy. London: Royal Society of Medicine Press

Shohet C, Yelloly J, Bingham P et al. (2007) The association between the quality of epilepsy management in primary care, general practice population deprivation status and epilepsy-related emergency hospitalisations. *Seizure* 16: 351–5

Smithson WH (2007) Epilepsy QOF panel report. Available from [http://www.pcpoh.bham.ac.uk/primarycare/qof/reports\\_list\\_2008.shtml](http://www.pcpoh.bham.ac.uk/primarycare/qof/reports_list_2008.shtml) [accessed 15 July 2009]

Scottish Intercollegiate Guidelines Network (2003) Diagnosis and management of epilepsy in adults. Clinical guideline 70. Edinburgh: Scottish Intercollegiate Guidelines Network. Available from [www.sign.ac.uk/guidelines/fulltext/70/index.html](http://www.sign.ac.uk/guidelines/fulltext/70/index.html)