Toolkit for Epilepsy 2

Supported by an educational grant from GlaxoSmithKline
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Introduction

This tool kit is intended to help healthcare professionals in primary care begin to review and ultimately improve services for people with epilepsy. It provides a direct response to the Department of Health Action Plan - *Improving services for people with epilepsy*.¹

The action plan seeks to engage the NHS and Primary Care Trusts to suggest reviews of local epilepsy services in light of the National Sentinel Clinical Audit of Epilepsy-Related Death² and address any shortfalls as part of local delivery plans.

The GMS contract encourages the compilation of a register of patients receiving drug treatment for epilepsy and sets three quality indicators with financial rewards.³ These quality indicators aim to encourage the establishment and delivery of a structured management system for patients with epilepsy in primary care. They award points for the production of a register of patients receiving drug treatment for epilepsy and for the percentage of patients age 16 and over on drug treatment for epilepsy who:

- Have a record of seizure frequency in the previous 15 months
- Have a record of medication review in the previous 15 months
- Have been seizure-free for last 12 months recorded in last 15 months

The National Sentinel Clinical Audit of Epilepsy-Related Death highlighted that there is a lack of systems for regular review of people with epilepsy and no standard way of managing or recalling patients who miss appointments.² National guidance now recommends that all people with a diagnosis of epilepsy should receive an annual review.⁴–⁸

Fundamental to the role of primary care in the management of epilepsy is a structured system that provides clear guidance on who should be involved at each stage of a patient's care. Each individual within the primary care team has an essential role to play:

- Practice managers can be involved with developing a register of patients with epilepsy, inviting them for review, ensuring that the required data are entered onto the computer and carrying out quality control.
- Practice nurses can be trained to carry out the routine review of patients with epilepsy. They will then be in an excellent position to identify people with epilepsy who may have unmet needs and then refer them for more appropriate care.
- GPs are often the first to suspect epilepsy and are therefore well placed to obtain an account and make the referral to a specialist. Depending on your practice, they may also carry out annual reviews.

This resource provides tools to aid in:

- The identification of patients with epilepsy within your practice
- Improving communication within the practice and with secondary care
- The development of a structured system which incorporates annual review
- The identification and referral of appropriate patients for specialist review
- The fulfilment of GMS quality indicators for epilepsy.
Overview

This provides a quick reference overview of the information and tools provided in this resource. It outlines how to carry out a practice audit and individual review of your epilepsy patients.

1. Getting started

- Agree and establish all referral and communication pathways within the practice. These include:
  - Practice-patient communication
  - Internal practice communication
  - Practice communication with secondary care
- Collate a resource containing written information for patients

See section: ‘1. Getting started’

2. Identifying patients for review

- Using a combination of computer records and manual review of notes:
  - Identify patients taking anti-epileptic drugs (AEDs)
  - Identify patients with a diagnosis of epilepsy
  - Exclude patients taking AEDs for conditions other than epilepsy
  - Collate a register of people with epilepsy in the practice
  - Run a report of patients over 16 with epilepsy on AEDs
  - Run a separate report for patients under 16 with epilepsy on AEDs.

See section: ‘2. Identifying patients for review’

Tools:
- 2.1 Protocol: Identifying patients
- 2.2 Practice epilepsy contact record
3. Inviting patients for review

- Send first letter of invitation for review
- If a patient fails to attend review, send second letter of invitation for review
- Telephone non-responders to identify their reasons for non-attendance and to arrange a new review time
- Confirm outcome of telephone call with a third letter.

See section: ‘3. Inviting patients for review’

Tools:
- 3.1 Protocol: Inviting a patient for review
- 3.2 First letter of invitation for review
- 3.3 Second letter of invitation for review
- 3.4 Protocol: Phoning a patient
- 3.5 Third letter to confirm phone call - attending review
- 3.6 Third letter to confirm phone call - not attending review

4. Patient review

- Review patients using ‘patient review checklist’ and ‘patient information checklist’
- Encourage the patient to use a seizure diary to help them record seizure patterns
- For the purpose of the GMS Contract, review non-attenders and ‘exceptions’
- Discuss referral to an epilepsy specialist where appropriate
- Obtain patient feedback if possible.

See section: ‘4. Patient review’

Tools:
- 4.1 Patient review checklist
- 4.2 Seizure diary
- 4.3 Checklist: Information for patients and carers
- 4.4 Useful addresses
- 4.5 Patient feedback form
5. Referral

- Compile a list of patients requiring specialist review.
- Send letter of referral to the appropriate specialist.

See section: ‘5. Referral’

Tool: 5.1 Epilepsy specialist referral letter

6. Reporting for the GMS Contract

Although the GMS Contract only requires reporting of patients over the age of 16 years, it is good practice to run annual reports for all patients with epilepsy, including those under the age of 16 years who are not already being reviewed by the paediatric service.

- If the recommendations of this document have been followed it will be simple to fulfil the GMS quality indicators for epilepsy
- This section explains the GMS Contract in more detail. It includes an outline of:
  • The quality indicators for epilepsy
  • Reporting patients as exempt (exception reporting)
  • Using Read Codes to report outcomes

See section: ‘6. Reporting for the GMS Contract’

Tools: 6.1 GMS quality indicators - epilepsy
       6.2 Exception reporting
       6.3 Read Codes
1. Getting started

Before embarking on a review process a practice meeting between the practice manager, lead GP and practice nurse should be held to discuss the following issues:

- Referral criteria to secondary care
- Decide who will carry out annual reviews; this may be an appropriately trained practice nurse or a GP
- Method of communication between practice nurse, if carrying out the reviews, and GP
- Finding out if there is an epilepsy nurse specialist and making contact. They may be able to help
- Referral pathway and criteria with the neurology service
- Level of patient involvement
- Identifying any training needs to improve epilepsy care

Once all these issues have been agreed and before starting the reviews, it would be helpful to gather together written information for patients. This should include information on all the topics outlined in the ‘Checklist: Information for patients and carers’ (Tool 4.3). Any additional sources of information on epilepsy that can be used as reference by the practice team will also be helpful.

It is important to ensure that the information is available in an appropriate format for all your patients with epilepsy. Consider appropriate:

- Language
- Use of audio tapes
- Text size
- Levels of comprehension

Written information will help patients develop a greater understanding of epilepsy and gives them additional support to take away with them. Epilepsy Action produces a comprehensive range of patient information leaflets, available from their Helpline (0808 800 5050, e-mail: helpline@epilepsy.org.uk), or as PDF files that can be downloaded at www.epilepsy.org.uk. Tool 4.3 includes a list of Epilepsy Action publications.

It would be useful to find out about local support services for people with epilepsy, i.e. groups, meeting venues and contact names. These details are also available from Epilepsy Action.

Finally, customise the standard letters in Sections 4 and 5 of this toolkit.

For those practices that decide to use their nurses to carry out reviews, additional training may be required. Nurses interested in additional training (professional diploma in epilepsy care) should contact Dr Steve Mera or the Centre Administrator at Leeds Metropolitan University (Tel: 0113 283 5918; Fax: 0113 283 3416; E-mail: ccnsenquiries@leedsmet.ac.uk).
2. Identifying patients for review

Having agreed upon and discussed the review process, it is now necessary to search the practice records to identify all patients with a diagnosis of epilepsy.

The GMS contract requires only those who have a diagnosis of epilepsy, who are currently receiving treatment, to be identified. This excludes those who have had epilepsy in the past and may have been off treatment and seizure-free for many years. The contract also notes that exception reporting (see Tool 6.2) will be more common in epilepsy than in other chronic conditions. The targets should therefore be achievable, but it is important to attempt to review ALL patients with a diagnosis of epilepsy as some will have chosen not to take AEDs and would otherwise not be reviewed if only those receiving treatment were identified.

This section aims to aid in the compilation of a register of patients with a diagnosis of epilepsy and to flag any special considerations, such as:

- Women with epilepsy
- Patients with learning difficulties
- Adolescent patients
- Elderly patients.

Although fulfilling the quality indicators for epilepsy in the GMS contract only requires including those patients over the age of 16, it is still important that patients under 16 are identified. Not only will you need to know when they are old enough to be included in the future as the handover to adult care is a critical period, but these patients still require structured management as much as other patient groups. It is therefore important to ensure they are being regularly reviewed by the paediatric service and ask if they want a regular review in primary care.

A protocol to facilitate the identification of patients with a diagnosis of epilepsy is included in this section. Having identified these patients, you are then ready to send invitations to patients to attend for a review of their epilepsy.

Disease registers in primary care will increasingly be used to form the basis of performance assessment; for example, to monitor the fulfilment of quality indicators in the GMS contract. The tool used to do this is a software system that searches for Read codes in the electronic patient notes. It is therefore important to use these Read codes when entering on to the practice database any information relating to a patient’s condition. Further information on using Read codes can be found in Section 6.

The practice computer is central to the review process. External links search the computer and tell the Department of Health exactly what Read codes have been entered in your patients’ notes. Your practice payments for epilepsy care depend on how many of the correct Read codes have been entered, so it is very important to get them right. Further information on how to use the correct Read codes can be found in Section 6.

Tools

- 2.1 Protocol: Identifying patients
- 2.2 Practice epilepsy audit record.
2.1 Protocol: Identifying patients

This protocol outlines the steps that need to be taken to maintain a practice register, including the relevant Read codes.

Procedure
1. Identify patients with a diagnosis of epilepsy

Identify all patients with a diagnosis of epilepsy who have taken AEDs. Your computer software will help you do this. All major suppliers have on screen prompts to let the user know when a patient is in a disease category that qualifies for quality and outcomes framework (QOF) points. All major suppliers also have pre-set report libraries to quickly identify patients in any QOF category. You may well have done much work in the last year or two to find all, or nearly all, of your patients with epilepsy. However, you may have missed some, which may be identified in step two.

2. Identify epilepsy patients without a Read code diagnosis

Some patients may actually have epilepsy, but the diagnosis has not yet been registered on your computer with a recognisable Read code. Some of these may be new diagnoses which have escaped being entered on the practice computer. Others may have been diagnosed many years ago but the diagnosis is only in old paper notes and has never been entered on the computer. You can find most of these by searching for patients taking AEDs. Once a year, preferably early in the annual QOF cycle, ask your computer for a report on all patients who have received AEDs in the last year who do not have a diagnosis of epilepsy. Your computer supplier’s software probably has a pre-set report so you can do this easily. The software may even have a report to pick out patients that the software thinks may have epilepsy but who do not have a valid Read code in the notes. If you do not have the skills in your practice to run these reports, ask your PCT IT department for help. For those very few practices that cannot use a computer, a manual search can be done by reviewing all repeat prescriptions for AEDs over a three month period, then checking the notes to see if these patients have epilepsy. Conditions other than epilepsy for which AEDs are prescribed may include neuropathic pain, bipolar disorder, essential tremor, infantile spasms, migraine, cardiac arrhythmia, trigeminal neuralgia and mood stabilisation. Ensure that all those identified as patients with epilepsy on AEDs are marked in their computer records with the Read code F25%. Make sure that the correct start date is used when you enter a code – it should be the date that the diagnosis was made.
3. Identifying epilepsy patients not taking AEDs

Some patients will have epilepsy, but do not have a Read code for AEDs. They will not count towards QOF points, but still have a clinical need for an annual review. A few may receive drugs directly from hospital or in clinical trials and so the AEDs they use are not on the practice computer. Others may have decided not to take AEDs, or have dropped out of follow up. A few may be on non-pharmacological treatment. Many will be patients whose seizures have ceased. Once a year, run a report of patients with a diagnosis of epilepsy that are not on an AED. Again, your computer supplier probably has a pre-set report to help you with this. Most of these patients who have a diagnosis of epilepsy but who are not taking AEDs will benefit from an annual review. After three years of being seizure free, the Read code term ‘history of epilepsy’ (Read code 1473) should be used and the original F25% code deleted.
These reports should be repeated annually.

**Tips for finding a diagnosis of epilepsy**

- The software provided by computer suppliers helps to find patients who should be on the epilepsy register but aren’t. Using this software is the most efficient method of identifying these people but the following tips may also help.

- Be aware that the diagnosis may be:
  - In a consultant’s letter
  - In a discharge summary
  - In an A&E attendance report
  - In a record of consultation.

- The diagnosis may appear in records preceding the first issue of an AED. Remember, drugs may have been issued from a hospital pharmacy and not appear on the GP records for some time after diagnosis.

**Patient identification search**

When conducting a computer search of patients taking AED medication, all the following should be included:

<table>
<thead>
<tr>
<th>Generic</th>
<th>Brand</th>
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<tbody>
<tr>
<td>Carbamazepine</td>
<td>Tegretol®</td>
</tr>
<tr>
<td>Clobazam</td>
<td>Frisium™</td>
</tr>
<tr>
<td>Clonazepam</td>
<td>Rivotril®</td>
</tr>
<tr>
<td>Ethosuximide</td>
<td>Zarontin™</td>
</tr>
<tr>
<td>Gabapentin</td>
<td>Neurontin®</td>
</tr>
<tr>
<td>Lamotrigine</td>
<td>Lamictal™</td>
</tr>
<tr>
<td>Levetiracetam</td>
<td>Keppra® ▼</td>
</tr>
<tr>
<td>Oxcarbazepine</td>
<td>Trileptal® ▼</td>
</tr>
<tr>
<td>Phenobarbitone/phenobarbital</td>
<td>Epanutin™</td>
</tr>
<tr>
<td>Phenytoin</td>
<td>Epilim®</td>
</tr>
<tr>
<td>Pregabalin</td>
<td>Lyrica® ▼</td>
</tr>
<tr>
<td>Primidone</td>
<td>Mysoline™</td>
</tr>
<tr>
<td>Sodium valproate</td>
<td>Epilim®</td>
</tr>
<tr>
<td>Tiagabine</td>
<td>Gabitril®</td>
</tr>
<tr>
<td>Topiramate</td>
<td>Topamax®</td>
</tr>
<tr>
<td>Vigabatrin</td>
<td>Sabril™</td>
</tr>
<tr>
<td>Zonisamide</td>
<td>Zonegran®</td>
</tr>
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</table>
2.2 Practice epilepsy contact record

Practice name: ________________________________________________________

Date audit started: ______________________________________________________

In order to review the success of your improved services for patients with epilepsy, you may find this paper-based record of key outcomes from the audit useful. You will be able to obtain most of these from the computer records, using the appropriate Read codes, but some may require manual inspection of the notes. However, as the average GP (2,000 patients) only has approximately 15 patients with active epilepsy, this should not be too time consuming and will help you to see how services can be improved.

Total number of patients in practice

Total number of patients with a diagnosis of epilepsy

Total number of patients with epilepsy on AEDs

Total number of patients over 16 with epilepsy on AEDs (GMS contract reporting)

Total number of female patients with epilepsy

Total number of patients with learning difficulties (IQ < 70) and epilepsy

Total number of elderly patients (age ≥ 75 years) with epilepsy

Total number of adolescent patients (12–17 years) with epilepsy

Total number of patients contacted for review

Total number of patients who attended review after one request

Total number of patients who attended review after two requests

Total number of patients who attended review after three requests

Total number of patients who did not attend epilepsy review after three requests

The following information will have to be obtained via manual review of the notes

Total number of patients referred for specialist review

Total number of patients referred for advice

Total number of patients referred for medication review due to uncontrolled seizures

Total number of patients referred as seizure-free and want to consider withdrawal

Total number of patients referred for medication review as part of pre-pregnancy counselling

Total number of patients referred due to side effects
3. Inviting patients for review

This section provides tools to aid in the methodical invitation of patients with epilepsy for review. It includes:

- Protocol for inviting patients for review
- Letter of invitation to all patients identified to attend review
- Letter of invitation to non-responders
- Protocol for phoning non-responders
- Letters to confirm the outcome of the telephone call.

These standard letters are designed to be customised to your individual requirements, i.e. practice name, address, date and time of review. When customising these letters, you will also need to make allowances for some patient groups. For example:

- Consider font size for patients with limited eyesight
- Consider the reader’s level of comprehension
- Forward the letter to carers or guardians where appropriate.

Patient groups for whom such allowances should be considered, include:

- Patients with learning difficulties
- Adolescent patients
- Elderly patients
- Patients whose first language is not English.

**Patients with learning difficulties (IQ < 70)**

Letters should be addressed to the patient, and the carer copied in where appropriate. Any letters addressed directly to the patient should be tailored to ensure that they are clear and understandable.

**Adolescent patients (age 12–17)**

Letters should be addressed to the patient from the age of 12 onward, and the guardian copied in. It is important that the patient feels included in any decision-making, as this will soon be their responsibility.

**Elderly patients (age > 75)**

Letters should be tailored to the patients to ensure that they are clear and understandable. The level of comprehension and font size should be considered.

**Patients whose first language is not English**

Letters should be tailored to the individual patient to ensure that they are as clear and understandable as possible. Your PCT should be able to help you with translation services and Epilepsy Action already have some appropriate information leaflets.

Although you are trying to maximise the number of your epilepsy patients who attend review, note that the GMS contract allows patients to be excluded from calculation of points allocation if they refuse to attend review after at least three requests. It is therefore important that a refusal
is recorded on the computer and a letter to the patient, confirming this decision, is advised. Templates for these letters are included.

**Tools**

- 3.1 Protocol: Inviting a patient for review
- 3.2 First letter of invitation for review
- 3.3 Second letter of invitation for review
- 3.4 Protocol: Phoning a patient
- 3.5 Third letter to confirm phone call - attending review
- 3.6 Third letter to confirm phone call - not attending review.
3.1 Protocol: Inviting a patient for review

1. Letter of invitation

Send the first letter of invitation for review. Ensure that it has been tailored to the patient’s needs.

*Tool:*
- 3.2 First letter of invitation for review.

2. Second letter of invitation

If the patient fails to attend review the second letter of invitation should be sent. Again, ensure that it has been tailored to the patient’s needs.

*Tool:*
- 3.3 Second letter of invitation for review.

3. Phone patient/third letter of invitation

If the patient still fails to attend review, they should either be sent a third letter (use the second letter of invitation in the tools) or contacted by telephone and the protocol used.

*Tool:*
- 3.4 Protocol: Phoning a patient.

4. Third letter to confirm phone call

In order to confirm the phone call to the patient, a letter should be sent confirming either their new appointment time or that they will not be attending review. It is important to use this letter, as it is evidence that the patient has been contacted three times. This will be required to exclude them from GMS contract reporting.

*Tools:*
- 3.5 Third letter to confirm phone call - attending review
- 3.6 Third letter to confirm phone call - not attending review.
Dear [Patient name],

As part of a new initiative, our practice is currently working to provide regular review for all our patients with epilepsy. Our aim is to improve standards of care for people with epilepsy in line with best practice.

We have therefore arranged an appointment to review your epilepsy on [date of review] at [time of review]. It is important that your epilepsy is reviewed, so if you are unable to come, please call the surgery on the number below to make another appointment or to discuss any questions you may have.

Your review is an opportunity to check that you are getting the best care you need to control your epilepsy and help you stay healthy. It is also a chance to have any of your questions answered and to discuss any worries you may have.

Even if you feel healthy, regular review of your epilepsy is important as we can discuss new options and changing circumstances. For example:

- New drug options
- Any side effects of your current drugs
- Driving and epilepsy
- Contraception
- Starting a family
- The possibility of stopping treatment.

The appointment will be to see [Practice Nurse or GP name] the [Practice Nurse/GP].

We want to ensure you are getting the best healthcare possible.

Our goal as a practice is to help you live as healthy and full a life as possible.

Thank you for your time and we look forward to seeing you at your review.

Yours sincerely

[Name of healthcare professional responsible for the epilepsy review]

[Contact telephone number]
Dear [Patient name],

We are sorry that you did not respond to a recent opportunity to review your epilepsy. Another appointment has been arranged for you on [date of review] at [time of review].

It is important that your epilepsy is reviewed, so if you are unable to come please call the surgery on the number below to make another appointment or to discuss any questions you may have.

Even if you feel healthy, regular review of your epilepsy is important as we can discuss new options and changing circumstances. For example:

- New drug options
- Any side effects of your current drugs
- Driving and epilepsy
- Contraception
- Starting a family
- The possibility of stopping treatment.

Not only is your review an opportunity to check that you are getting the best care you need to control your epilepsy and help you stay healthy, but it is also a chance to have any of your questions answered and to discuss any worries you may have. These may include issues surrounding employment, driving, contraception or starting a family.

The appointment will be to see [Practice Nurse or GP name] the [Practice Nurse/GP].

We want to ensure you are getting the best healthcare possible.

**Our goal as a practice is to help you live as healthy and full a life as possible.**

Thank you for your time and we look forward to seeing you at your review.

Yours sincerely

[Name of healthcare professional responsible for the epilepsy review]

[Contact telephone number]
3.4 Protocol: Phoning a patient

Some patients with epilepsy do not inform their family or friends that they have the condition. When telephoning the patient, it is vital that you do not pass on any information relating to the patient to others or discuss epilepsy with anyone except the patient. Often when you phone a patient at home, they will not be there. It is generally considered safer not to leave messages and to have the practice phone anonymised so that others using the phone cannot identify that the practice has called. Instead, call again later.

Introduction

Introduce yourself and explain that you are phoning the patient as they are due for a review of their epilepsy and you have not had a response to your previous invitations.

Check convenience

Check that the patient is able to discuss their review at this time. If not then arrange a more convenient time.

Try to discover why the patient has not attended their review

- Did the patient receive their invitations for review?
- Does the patient feel they have had their epilepsy reviewed recently enough? Was this within the last year?
- Are the reviews at an inconvenient time for the patient?
- Does the patient feel that their epilepsy is already well controlled?
- Does the patient have any special circumstances that might make it difficult for them to attend? For example, learning difficulties.
- Did the invitations for review go to the correct person? For example, adolescent patients, patients with learning difficulties and elderly patients may have a carer or guardian who should also be receiving their invitations.
**Explain why it is important to attend their review**

If the patient’s non-attendance does not have a practical solution, explain why it is important for them to have their epilepsy regularly reviewed.

“Even if you feel healthy and you have not had a seizure for a long time, it is important to attend your review as there may be new options to discuss and changing circumstances – for example: the possibility of stopping treatment; changes in driving licence laws; family planning issues [if appropriate].”

“Even if you feel that your epilepsy cannot be improved, there may be options that could improve it – for example: new drug options; improving any side effects; possibility of seeing an epilepsy specialist.”

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**Closing the phone call**

- Thank the patient for their time
- Encourage them to attend in the future by reinforcing the importance of regular review
- Encourage the patient to expect the best control of their epilepsy
- Explain that they should feel free to contact the practice to arrange a review at any time.
Dear [Patient name],

Following our conversation on the phone regarding your epilepsy review, we would like to confirm that you have an appointment on [date of review] at [time of review].

As we explained, it is important that your epilepsy is reviewed. However, we understand if you are unable to keep the appointment, but request that you contact us to let us know. We will then be able to arrange a more convenient time.

Your review is an opportunity to check that you are getting the best care you need to control your epilepsy and help you stay healthy. It is also a chance to have any of your questions answered and to discuss any worries you may have.

The appointment will be to see [Practice Nurse or GP name] the [Practice Nurse/GP].

We want to ensure you are getting the best healthcare possible. **Our goal as a practice is to help you live as healthy and full a life as possible.**

Thank you for your time and we look forward to seeing you at your review.

Yours sincerely

[Name of nurse responsible for the epilepsy review]

[Contact telephone number]
Dear [Patient name]

Following our conversation on the phone regarding your epilepsy review, we understand that you have chosen not to attend. However, should you ever change your mind, please do not hesitate to contact us and we will be very willing to arrange a review for you.

It is important to remember that even if you feel healthy, there are many ways that a review of your epilepsy could improve your quality of life. By reviewing your treatment it may be possible to:

- Reduce the number of seizures you are having
- Improve any side effects of medication
- Consider alternative treatment options
- Discuss any specific issues or queries you may have.

If you have any queries, or require any further information regarding your epilepsy, we will be very happy to help you. Please feel free to give us a ring.

**Our goal as a practice is to help you live as healthy and full a life as possible.**

Thank you for your time and we look forward to seeing you at some future time.

Yours sincerely

[Name of nurse responsible for the epilepsy review]
4. Patient review

This section provides an outline of the issues that should be covered during the review. These issues include seizures, medication, concordance, side effects, driving and employment, contraception and pregnancy (where relevant).

The patient review checklist takes you through all the issues that should be covered in an epilepsy review. It also provides guidance on when a patient may benefit from a referral for specialist review and suggests additional information that could be provided to the patient.

There are several methods of recording the details of the annual review. Easily the best and simplest method is to use your computer supplier’s pre-set software. All major suppliers have built in templates for an annual epilepsy review which ensure that the correct Read codes are used. However, these templates are set at minimal level. They can be supplemented by using the free text boxes incorporated in them, or by making additional records, or by using templates that have been developed in house.

Many practices are still mainly paper based, and may wish to use the paper recording sheet. Alternatively, you may wish to make all your notes on this paper version, which can be kept in the notes, or used as a check list for writing the information into the notes. It can then be attached to the letter of referral, if referring the patient to a specialist. The information will have to be transferred to the computer records as Read codes and you will have to make sure that exactly the right Read codes are used. More details on Read codes and the quality indicators for epilepsy in the GMS contract are given in Section 6 of this toolkit.

When reviewing patients with epilepsy, for the purposes of reporting on the GMS contract, only those patients over the age of 16 need to be included. However, it is recommended that ALL patients, including patients under 16, with a diagnosis of epilepsy should receive annual review. Therefore this toolkit has been designed to facilitate the review of these patients as well.

The GMS contract recognises that seizure control is often under the influence of factors outside the general practitioner’s control. It is therefore expected that exception reporting in the epilepsy data set will be more common than in other chronic conditions. Tool 6.2 covers this in more detail.

This section also includes a list of leaflets, booklets and other information that could be provided to the patient. A checklist is included to enable you to identify any topics of information that need to be provided to the patient, carer or guardian. A list of useful addresses where patients can get information and support has also been included. This can be copied and handed out.

The patient, carer or guardian should fill in the patient feedback form after the review has taken place. This will enable you to improve your service if required and can be used when compiling a practice report.

Tools

- 4.1 Patient review checklist
- 4.2 Seizure diary
- 4.3 Checklist: Information for patients and carers
- 4.4 Useful addresses
- 4.5 Patient feedback form.
4.1 Patient review checklist

All treatment changes must be carried out in conjunction with patient wishes and under medical supervision.

General

Complete the patient’s details.

<table>
<thead>
<tr>
<th>Patient ID number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
</tr>
<tr>
<td>Address</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Over 16? Please tick:</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td></td>
</tr>
</tbody>
</table>

Date of review

Seizures

Ask the patient to describe their seizures. If they have different types describe each separately. If the name of the seizures is unknown describe what happens, i.e. loss of consciousness, movements or wandering, sense of taste, fear or smell, memory disturbance, chewing or swallowing, incontinence of bladder or bowel.

<table>
<thead>
<tr>
<th>Type 1</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 2</td>
<td></td>
</tr>
<tr>
<td>Type 3</td>
<td></td>
</tr>
</tbody>
</table>

How many of each type of seizure does the patient have a year/month/week (indicate period)?

<table>
<thead>
<tr>
<th>Type 1</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 2</td>
<td></td>
</tr>
<tr>
<td>Type 3</td>
<td></td>
</tr>
</tbody>
</table>

Date of last seizure

- People who experience seizures that have not been recently reviewed (within the last 12 months) by an epilepsy specialist may benefit from a specialist opinion.
- People who have not experienced any seizures for two years may benefit from a specialist review of their diagnosis of epilepsy.10
- A seizure diary is a very useful tool for the patient to complete. See Tool 4.2 in this section for a suggested format.
**Medication**

Indicate what medication(s) the patient is taking and on what dosage.

<table>
<thead>
<tr>
<th>Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carbamazepine (Tegretol®)</td>
</tr>
<tr>
<td>Clobazam (Frisium™)</td>
</tr>
<tr>
<td>Clonazepam (Rivotril®)</td>
</tr>
<tr>
<td>Ethosuximide (Zarontin™)</td>
</tr>
<tr>
<td>Gabapentin (Neurontin®)</td>
</tr>
<tr>
<td>Lamotrigine (Lamictal™)</td>
</tr>
<tr>
<td>Levetiracetam (Keppra®▼)</td>
</tr>
<tr>
<td>Oxcarbazepine (Trileptal®▼)</td>
</tr>
<tr>
<td>Pregabalin (Lyrica® ▼)</td>
</tr>
<tr>
<td>Phenobarbitone/Phenobarbital</td>
</tr>
<tr>
<td>Phenytoin (Epanutin™)</td>
</tr>
<tr>
<td>Primidone (Mysoline™)</td>
</tr>
<tr>
<td>Sodium Valproate (Epilim®)</td>
</tr>
<tr>
<td>Tiagabine (Gabitril®)</td>
</tr>
<tr>
<td>Topiramate (Topamax®)</td>
</tr>
<tr>
<td>Vigabatrin (Sabril™)</td>
</tr>
<tr>
<td>Zonisamide (Zonegran®)</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

**Concordance**

Try to assess how compliant the patient is with their medication.

<table>
<thead>
<tr>
<th>How often does the patient miss tablets?</th>
<th>Never</th>
<th>Once a month</th>
<th>Once a week</th>
<th>Once a day</th>
<th>Reasons given for missing medication</th>
</tr>
</thead>
</table>

- Where patients are not taking their medication in accordance with the prescription, it is important to explore the reasons behind this. This should be done in a non-confrontational way and the implications discussed. Patients will often have very good reasons for not adhering to prescribed medicine, which make good sense to them.
- People who are non-adherent to prescribed medication may require a specialist review for the purpose of exploring the reasons behind this.
- Non-adherence to prescribed medication is recognised to be an important cause of poor seizure control.\textsuperscript{11,12}
**Consider providing for the patient**

- Epilepsy Action booklet: Treatment.

**Side effects**

Does the patient experience any of the following side effects?

<table>
<thead>
<tr>
<th>Drug name(s):</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drowsiness/lethargy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of concentration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aggression/agitation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visual disturbance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tremor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight gain</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight loss</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hair loss</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unwanted hair growth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Menstrual disturbances</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headache</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ataxia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gum swelling</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- People who experience side effects from medication may benefit from a medication review by an epilepsy specialist. Patients must be fully involved in decisions about their treatment: their views on treatment, such as achieving the right balance between side effects and seizure control, should be taken into account when considering medication changes.13

**Consider providing for the patient**

- Epilepsy Action booklet: Treatment.
Driving and Employment
Does the patient drive and are they in employment? Do they need any advice on these issues?

<table>
<thead>
<tr>
<th>Driving</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does the patient drive?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Counselling on regulations given</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Employment**

<table>
<thead>
<tr>
<th>Employment</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the patient currently in employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits advice given</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability Employment Advisor (DEA) information given</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Consider providing for the patient

- Epilepsy Action leaflets/booklets: Driving and Employment
- Local contacts with employment/disability employment services and benefit agencies.

Female patients only

**Women of childbearing potential**

<table>
<thead>
<tr>
<th>Women of childbearing potential</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is the patient a woman of childbearing potential?*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the patient planning a pregnancy?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If yes, have you referred the patient for specialist advice (e.g. teratogenicity, folic acid supplementation, seizure management)?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Women with epilepsy should be offered specialist advice and information at an appropriate time following diagnosis, even if they are not considering pregnancy at the time.⁶,⁷,¹³

Consider providing for the patient

- Epilepsy Action booklet: Women.
**Contraception**

Does the patient use any of the following forms of contraception?

<table>
<thead>
<tr>
<th>N/A</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Barrier</td>
<td></td>
</tr>
<tr>
<td>Combined oral contraceptive (COC)</td>
<td></td>
</tr>
<tr>
<td>Depot (If yes, how often?)</td>
<td></td>
</tr>
<tr>
<td>Intrauterine contraceptive device (IUCD)</td>
<td></td>
</tr>
<tr>
<td>Advice given</td>
<td></td>
</tr>
</tbody>
</table>

- When the COC is given with an enzyme-inducing AED (see Table 5 in Information booklet) one containing a minimum of 50 µg of oestrogen should be used.6,7
- Women should be warned that the efficacy of the COC is reduced and barrier methods of contraception should also be used if maximal contraceptive effect is required.6,7
- If breakthrough bleeding occurs with 50 µg of oestrogen the dose should be increased and “tricycling” (i.e. taking three packs of the high dose COC consecutively and reducing pill-free days to four) of the COC should be considered.6,7
- For women taking lamotrigine, hormonal contraception should only be used as the sole method of contraception if there is no other alternative. If the COC is chosen as the sole method of contraception, women should be advised to promptly notify their physician if they experience changes in menstrual pattern, as this may be an indication of decreased contraceptive efficacy.14
- Depot injections of progesterone (Depo-Provera) may be considered by women with epilepsy. If enzyme-inducing AEDs are being taken at the same time, NICE and SIGN recommend that the injection is repeated every 10 weeks instead of the usual 12-week interval, to ensure adequate contraceptive protection.6,7,15
Referral to specialist epilepsy clinic

Make a record of the patient's next epilepsy appointment.

<table>
<thead>
<tr>
<th>Has the patient been given an appointment for their next epilepsy review?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has the patient been referred to an epilepsy clinic?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments

Write any additional information of note concerning the patient's lifestyle and epilepsy.

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
4.2 Seizure diary

What is this diary for?
To help you record when your seizures occur and what form they take. The completed diary pages will then help your doctor plan your treatment to achieve the best possible control of your epilepsy.
**How do I use this diary?**

You may need to rely on a witness’s account to complete this section.

The first step is to identify as simply as possible the types of seizure that you experience. Use letters to represent each type ranging from A as the least severe to D as the most severe. **Ideally your doctor or nurse will help you with this.**

For example:

- A Strange taste in mouth
- B Become vague, mumble, search around floor
- C A+B followed by collapse and convulsion
- D Absence or muscle jerks seizures, involving the whole body (tonic–clonic)

**Types of seizure experienced**

As everyone’s experience of epilepsy is slightly different, write down your own personal classification. This will help create a useful diary record. Remember A is the least severe, D is the most severe seizure.

A
B
C
D

**What do I need to record in my diary?**

The more information you include in your diary, the more useful it will be for your doctor:

- Fill in the month at the top of the page.
- Record in the awake and asleep columns the number of seizures that you experience using your letters A, B, C or D and the number you experience.
- Note the time the seizure has occurred.
- In the triggers column, write any ‘trigger factors’ that you feel you may have experienced before the seizure. For example, ‘missed medication’, ‘I was feeling very low’, ‘had a stressful day’ or ‘period’.
- In the notes column write in the treatment that you are taking and the dosage.
- Record any medicine other than your AEDs that you are taking, whether on prescription or something you have purchased yourself, including the dose, frequency and how long you have taken it.
- Write in any other things that may affect your health or mood. For example, if you are feeling run-down or stressed, if you have exams to take, if there is anything that has particularly distressed you, or you are feeling in a good mood or bad mood. All of these can have a significant effect on the frequency or severity of your seizures.
The example below should make this clear:

**Month January**

<table>
<thead>
<tr>
<th>Date</th>
<th>Asleep</th>
<th>Awake</th>
<th>Time</th>
<th>Triggers</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>2A</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>4A</td>
<td>1B</td>
<td>09:40</td>
<td>Had several late nights recently</td>
<td>Very tired, grumpy</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>2B</td>
<td></td>
<td></td>
<td><strong>Period</strong></td>
<td>Took paracetamol 2x500mg three times today</td>
</tr>
<tr>
<td>6</td>
<td>1A</td>
<td></td>
<td>20:37</td>
<td></td>
<td>Been trying to diet and have missed out on meals</td>
</tr>
</tbody>
</table>
# SEIZURE DIARY

- **Month:**

<table>
<thead>
<tr>
<th>Date</th>
<th>Asleep</th>
<th>Awake</th>
<th>Time</th>
<th>Triggers</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2</td>
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<td>31</td>
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<tr>
<td><strong>Total</strong></td>
<td></td>
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</tbody>
</table>
4.3 Checklist: Information for patients and carers

NICE and SIGN recommend that patients be given appropriate information. The following is a checklist that can be used to identify what information to give patients and carers. Epilepsy Action produces a range of leaflets that can be used in primary care to increase patients’/carers’ knowledge of epilepsy. If the patient requires some of the more detailed information included in this list, then referral to a specialist should be considered.

**General epilepsy information**
- Explanation of what epilepsy is*
- Probable cause
- Explanation of investigative procedures
- Classification of seizures
- Syndrome
- Epidemiology
- Prognosis*
- Genetics
- Sudden Unexpected Death in Epilepsy (SUDEP)*
- Recurrence risks – what to do if your child has another seizure

**Anti-epileptic drugs (AEDs)**
- Choice of drug*
- Efficacy*
- Side effects*
- Concordance and adherence*
- Drug interactions*
- Free prescriptions*
- Missed doses

**Seizure triggers**
- Lack of sleep*
- Alcohol and recreational drugs*
- Stress*
- Photosensitivity

**First Aid**
- General guidelines*
- Status epilepticus

**Support organisations**
- Addresses and telephone numbers of national and local epilepsy organisations* (see Tool 4.4)

| *These items are considered essential information. The other information should be given when it is relevant. |

**Issues for women**
- Contraception*
- Pre-conception*
- Pregnancy and breastfeeding*
- Menopause

**Lifestyle**
- Driving regulations*
- Employment
- Education (e.g. guidance for teachers)
- Leisure
- Relationships
- Safety in the home*
- Parenting
- Safety and appropriate restrictions for children and young people
- Alarms and monitors
- Identity bracelets
- Free prescriptions
- Financial allowances
- Multiagency support for family (education, social work, voluntary sector etc)
- Parentline (organisation to support those experiencing parenting difficulties)

**Possible psychosocial consequences**
- Perceived stigma*
- Memory loss*
- Depression
- Anxiety
- Maintaining mental well being
- Self esteem*
- Sexual difficulties
- Behaviour problems in children and young people
It is important to ensure that the information is provided in an appropriate format. Consider appropriate:

- Language
- Use of audiotapes (eg. Typetalk/Minicom)
- Text size
- Level of comprehension.

The following information is available from Epilepsy Action. These are available by calling the helpline on 0808 800 500 or can be downloaded as PDFs from www.epilepsy.org.uk/downloads. In addition, Epilepsy Action produces a number of other fact sheets and can supply additional resources about epilepsy as videos, CD ROMs etc.

### Information booklets

<table>
<thead>
<tr>
<th>Subject</th>
<th>Code for ordering</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children</td>
<td>B002</td>
</tr>
<tr>
<td>Difficult to control epilepsy - adults (winter 2003)</td>
<td>B097</td>
</tr>
<tr>
<td>Difficult to control epilepsy - children (winter 2003)</td>
<td>B098</td>
</tr>
<tr>
<td>Education</td>
<td>B006</td>
</tr>
<tr>
<td>Employment</td>
<td>B016</td>
</tr>
<tr>
<td>Epilepsy and Everyone</td>
<td>B001</td>
</tr>
<tr>
<td>Epilepsy Passport</td>
<td>B018</td>
</tr>
<tr>
<td>Memory Problems and Epilepsy</td>
<td>B099</td>
</tr>
<tr>
<td>New to Epilepsy</td>
<td>B047</td>
</tr>
<tr>
<td>New to Epilepsy - A Parent's Guide</td>
<td>B028</td>
</tr>
<tr>
<td>New to Epilepsy - Later in Life</td>
<td>B003</td>
</tr>
<tr>
<td>Raising awareness and young people</td>
<td>B024</td>
</tr>
<tr>
<td>Treatment</td>
<td>B004</td>
</tr>
<tr>
<td>Women</td>
<td>B017</td>
</tr>
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</table>

### Information sheets

<table>
<thead>
<tr>
<th>Subject</th>
<th>Code for ordering</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol &amp; Recreational Drugs</td>
<td>B012</td>
</tr>
<tr>
<td>Driving</td>
<td>B005</td>
</tr>
<tr>
<td>EEG Test</td>
<td>B035</td>
</tr>
<tr>
<td>Learning Disabilities</td>
<td>B010</td>
</tr>
<tr>
<td>Photosensitive Epilepsy</td>
<td>B007</td>
</tr>
<tr>
<td>Subject</td>
<td>Code for ordering</td>
</tr>
<tr>
<td>-----------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Safety</td>
<td>B015</td>
</tr>
<tr>
<td>Seizures Explained</td>
<td>B037</td>
</tr>
<tr>
<td>Sport &amp; Leisure</td>
<td>B014</td>
</tr>
<tr>
<td>SUDEP</td>
<td>F006</td>
</tr>
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</table>

**Information for young people**

<table>
<thead>
<tr>
<th>Subject</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Upfront</td>
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</tr>
</tbody>
</table>

**Other Language Factsheets**

<table>
<thead>
<tr>
<th>Subject</th>
<th>Code for ordering</th>
</tr>
</thead>
<tbody>
<tr>
<td>New to Epilepsy (Bengali)</td>
<td>OL04</td>
</tr>
<tr>
<td>New to Epilepsy (Gujarati)</td>
<td>OL06</td>
</tr>
<tr>
<td>New to Epilepsy (Hindu)</td>
<td>OL07</td>
</tr>
<tr>
<td>New to Epilepsy (Punjabi)</td>
<td>OL05</td>
</tr>
</tbody>
</table>
4.4 Useful addresses

This is a list of useful contact details and web-based information for patients with epilepsy and their carers or guardians.

**Epilepsy Action**
New Anstey House
Gate Way Drive
Yeadon
Leeds
LS19 7XY
Helpline: 0808 800 5050
Tel: 0113 210 8800
Free Fax: 0808 800 5555
Email: helpline@epilepsy.org.uk
Website: www.epilepsy.org.uk

**Epilepsy Scotland**
48 Govan Road
Glasgow
G51 1JL
Helpline: 0808 800 2 200
Tel: 0141 427 4911
Fax: 0141 419 1709
Email: enquiries@epilepsyscotland.org.uk
Website: www.epilepsyscotland.org.uk

Both Epilepsy Action and Epilepsy Scotland produce a range of leaflets available to healthcare professionals, people with epilepsy and their carers

**The National Society for Epilepsy**
Chesham Lane
Chalfont St Peter
Bucks
SL9 ORJ
Helpline: 01494 601400
Tel: 01494 601300
Fax: 01494 871927
Website: www.epilepsynse.org.uk

**Epilepsy Pregnancy Register**
Tel: 0800 3891248

**Epilepsy Bereaved** (for the relatives of people who have died from epilepsy)
PO Box 112
Wantage
Oxon
OX12 8XT
Bereavement Support Contact Line - 24 hour answering service: 01235 772852
Tel: 01235 772850
Website: www.sudep.org

**NHS Direct**
Website:
England: www.nhsdirect.nhs.uk
Wales: www.nhsdirect.wales.nhs.uk
Tel: 0845 46 47
4.5 Patient feedback form

Name................................................................. Date..........................

When was the last time that you saw a doctor about your epilepsy?

Do you consider your epilepsy to be well controlled?

Yes No

Do you know what type of epilepsy you have?

Yes No

Would you like more information about epilepsy?

Yes No

If yes, what would you like more information on?

Who has provided you with information about epilepsy in the past?

Has today’s review of your epilepsy been useful?

Yes No

Please give reasons for your answer

Do you have any suggestions about how the practice might improve the service provided for people with epilepsy?
5. Referral

Once the patient review is completed, it may be apparent that the patient’s epilepsy management could benefit from a specialist review.

Topics that might have been identified as potential areas for discussion include:

- Diagnosis review
- Seizure control
- Medication review
- Side effects of medication
- Contraception
- Pre-conceptual counselling
- Pregnancy.

This resource includes a standard letter that can be used to request a specialist epilepsy review. If you have used the patient review checklist (Tool 4.1) to take notes during the review, this can be attached to the letter of referral in order to give the specialist the information they require. If, however, notes have been made straight into the computer you can attach a printout of the epilepsy review and the relevant notes you have made. All computer suppliers offer software that includes preset referral letters that can be adapted to the practice requirements, and you may which to use these.

Copying the patient in on communications concerning their epilepsy will enable the patient to feel more in control of their condition, and they will be less likely to be lost to follow-up.

This letter should be customised to your individual requirements.

Tool

- 5.1 Epilepsy specialist referral letter
Dear [Name of specialist]

Request for specialist epilepsy review of:

[Patient name]
[Patient DOB]
[Patient address]

[Attach a copy of the patient review checklist or computer records report]

In line with the GMS contract, I have reviewed this patient who has [insert type of seizure]. Following a consultation with the above named patient, it was felt that his/her epilepsy management required specialist review due to the following:

[The following details should also be included:

- Past medical history
- Social history, job, driving, smoking, alcohol
- Past AED history
- Past epilepsy investigations and results
- Past consultants seen
- Other current, non-AED medication
- Allergies]

I would be grateful if you could review this patient in your clinic.

Yours sincerely

[Signed GP]
6. Reporting for the GMS contract

The GMS contract provides a major focus on quality and outcomes. Practices have the opportunity to receive additional funding to support aspiration to and achievement of a range of quality standards. Practices are rewarded for delivering quality care, with extra incentives to encourage even higher standards. There are four main components in the quality framework:

- Clinical standards covering coronary heart disease, stroke or transient ischaemic attacks, hypertension, diabetes, chronic obstructive pulmonary disease, epilepsy, cancer, mental health, hypothyroidism and asthma
- Organisational standards covering records and information about patients, information for patients, education and training, practice management and medicines management
- Experience of patients covering the services provided, how they are provided and patients’ involvement in the service development plans
- Additional services.

This section explains the reporting of epilepsy management in the GMS contract in more detail. It includes:

- An outline of the quality indicators for epilepsy
- Information on the relevant Read codes for reporting outcomes in epilepsy management
- A list of criteria for reporting patients as exempt from inclusion (exclusion reporting).

Reporting for the GMS contract requires the use of the Read code system, which is the current recommended national standard coding system in general practice (see Section 6.2).

Section 2 explains how Read codes are used when setting up a register of patients with epilepsy. Several new codes have been introduced to facilitate GMS reporting. These are listed in this section, but if you require more detail on Read codes or an update on the current situation, please refer to the NHS Information Authority website (http://www.nhsia.nhs.uk/terms/pages/default.asp)

Tools

- 6.1 GMS quality indicators – epilepsy
- 6.2 Exception reporting
- 6.3 Read codes.
6.1 GMS quality indicators – epilepsy

The establishment of disease registers is an important feature of the quality and outcomes framework (QOF). The GMS contract encourages the compilation of a register of patients receiving drug treatment for epilepsy and sets three quality indicators for ongoing management with financial rewards. These quality indicators aim to encourage the establishment and delivery of a structured management system for patients with epilepsy in primary care.

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Points</th>
<th>Maximum threshold</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Records</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EPILEPSY 1. The practice can produce a register of patients receiving drug treatment for epilepsy</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Ongoing management</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EPILEPSY 2. The percentage of patients age 16 and over on drug treatment for epilepsy who have a record of seizure frequency in the previous 15 months</td>
<td>4</td>
<td>90%</td>
</tr>
<tr>
<td>EPILEPSY 3. The percentage of patients age 16 and over on drug treatment for epilepsy who have a record of medication review in the previous 15 months</td>
<td>4</td>
<td>90%</td>
</tr>
<tr>
<td>EPILEPSY 4. The percentage of patients age 16 and over on drug treatment for epilepsy who have been seizure-free for last 12 months recorded in last 15 months</td>
<td>6</td>
<td>70%</td>
</tr>
</tbody>
</table>

**Indicator 1: Records**

**Epilepsy indicator 1**

2 points

*The practice can produce a register of patients receiving drug treatment for epilepsy*

The different elements of this toolkit can be used to fulfil the GMS contract quality indicators. Section 2 gives information on how to produce a register of patients receiving drug treatment for epilepsy. Although initially much work will have to be done to ensure that this register is accurate, once it has been established, annual maintenance is not too difficult. Following the process outlined in Section 2 will help practices to establish this register.

Section 2 enables the identification of ALL patients with a diagnosis of epilepsy, as the NICE and SIGN guidelines recommend that all these patients receive annual review. However, for the purposes of the GMS contract point scoring, only those patients with a diagnosis of epilepsy, on AEDs, over the age of 16 will be included.
Patient review

All people with epilepsy should, where possible, receive an annual review to assess seizure control, side effects experienced and psychosocial issues.\textsuperscript{4-8} Using the protocol provided in Section 3, practices will be able to invite patients for review. Remember that patients may be excluded from calculation of points allocation if they decline to attend review after at least three requests (Exception reporting. See Tool 6.2). Even then, it is possible to perform an opportunistic epilepsy review when they attend the surgery for a consultation on another topic. The on screen prompts provided by supplier software helps to alert the GP or nurse that an epilepsy review has not been done yet, and assists them to collect the correct information using the correct Read codes.

How does annual review relate to the indicators?

The GMS contract notes that epilepsy is often poorly managed in general practice, and there are insufficient specialist resources to provide specialist supervision for most patients. However, it also states that although few types of epilepsy are preventable, much of the morbidity that results could be prevented by appropriate clinical management.\textsuperscript{3}

To help improve clinical management, the GMS contract states that the following information should be recorded in the annual review of all patients with epilepsy (see Section 4):

- Seizure type and frequency, including date of last seizure
- Anti-epileptic drug therapy and dosage
- Any adverse drug reactions arising from anti-epileptic drug therapy
- Key indicators of the quality of care, i.e. topics discussed and plans for future review.

All these criteria are covered in the patient review checklist (Tool 4.1).

Indicators 2-4: Ongoing management

Recording seizure frequency

<table>
<thead>
<tr>
<th>Epilepsy indicator 2</th>
<th>4 points</th>
<th>Payment stages 25-90%</th>
</tr>
</thead>
<tbody>
<tr>
<td>The percentage of patients aged 16 and over on drug treatment for epilepsy who have a record of seizure frequency in the previous 15 months</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Read codes have been developed to record seizure frequency (see Section 6.3).

If patients have had any seizures in the past 12 months, discuss with them the possibility of referral to an epilepsy specialist for adjustments to the dose of their medication or consideration of epilepsy surgery. The date of last seizure needs recording as a date. If patients have been seizure-free for more than two years, there is a possibility that with specialist advice, they could stop their medication. However, adults with a driving licence often prefer to remain on medication\textsuperscript{6} rather than not drive during the withdrawal phase and for six months after cessation of treatment or risk losing their licence if they have another seizure.\textsuperscript{16} Withdrawal of medication must be carried out in small decrements over a long period. Information on referral is included in Section 5.
Medication review

**Epilepsy indicator 3**

<table>
<thead>
<tr>
<th>4 points</th>
<th>Payment stages 25-90%</th>
</tr>
</thead>
<tbody>
<tr>
<td>The percentage of patients age 16 and over on drug treatment for epilepsy who have a record of medication review in the previous 15 months</td>
<td></td>
</tr>
</tbody>
</table>

Read codes for epilepsy medication review and other medication-related issues are listed in Section 6.3.

Drugs and doses of AEDs need checking during the patient review as their regimens can be complex. It is important to check exactly what the patient is taking, record it on the computer and note any anomalies. If the patient is continuing to have seizures, discuss referral to an epilepsy specialist (see Section 5). Ask the patient if they are experiencing any side effects – if these are intolerable, discuss referral to an epilepsy specialist. Section 4 takes you through the steps of the medication review.

Achieving seizure control

**Epilepsy indicator 4**

<table>
<thead>
<tr>
<th>6 points</th>
<th>Payment stages 25-70%</th>
</tr>
</thead>
<tbody>
<tr>
<td>The percentage of patients aged 16 and over on drug treatment for epilepsy who have been seizure free for the last 12 months recorded in the last 15 months</td>
<td></td>
</tr>
</tbody>
</table>

With effective management, up to 70 per cent of people with active epilepsy could become seizure-free. Using this toolkit can help you and your practice to work towards that goal. However, the GMS contract recognises that seizure control is often under the influence of factors outside the GP’s control, and therefore the GMS contract recognises that many patients will be exception reported for this indicator. Some patients prefer not to take AEDs at all, or prefer to take a reduced, less effective dose which gives them less side effects. Some patients are unable to take their medication consistently enough to control their seizures, whilst others develop sensitivities to AEDs. Some patients have seizures which cannot be controlled despite maximal input from epilepsy specialists. Others do not wish to take part in an epilepsy review. A very small number will have a serious competing pathology such as a terminal illness which make carrying out an epilepsy review irrelevant. Some reasons for making an exception report for this indicator are listed in Section 6.2 Exception reporting). Read codes useful for exception reporting are listed in Section 6.3.

6.2 Exception reporting

To ensure that practices do not lose out on quality payments through factors beyond their control despite providing a quality service, an annual system of exception reporting is being put in place. Under the GMS contract it is noted that exception reporting is expected to be more common in epilepsy than in other chronic conditions (e.g. for brain-damaged patients whose seizures cannot be controlled, patients who find the side effects of medication intolerable, etc.). Useful Read codes for recording exceptions from epilepsy quality indicators are listed in Section 6.3.
The following general criteria have been set for exception reporting:

<table>
<thead>
<tr>
<th>Criteria for exception reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Application to epilepsy</strong></td>
</tr>
<tr>
<td>a. Patients who have been recorded as refusing to attend review who have been invited on at least three occasions during the preceding 12 months</td>
</tr>
<tr>
<td>b. Patients for whom it is not appropriate to review the chronic disease parameters due to particular circumstances e.g. terminal illness, extreme frailty</td>
</tr>
<tr>
<td>c. Patients newly diagnosed within the practice or who have recently registered with the practice, who should have measurements made within three months and delivery of clinical standards within nine months e.g. blood pressure or cholesterol measurements within target levels</td>
</tr>
<tr>
<td>d. Patients who are on maximum tolerated doses of medication whose management remains suboptimal</td>
</tr>
<tr>
<td>e. Patients for whom prescribing a medication is not clinically appropriate e.g. those who have an allergy, another contraindication, or have experienced an adverse reaction</td>
</tr>
<tr>
<td>f. Where a patient has not tolerated medication</td>
</tr>
<tr>
<td>g. Where a patient does not agree to investigation or treatment (informed dissent), and this has been recorded in their medical records</td>
</tr>
<tr>
<td>h. Where the patient has a supervening condition that makes treatment of their condition inappropriate e.g. cholesterol reduction where the patient has liver disease</td>
</tr>
</tbody>
</table>

Clinicians should note, in the clinical record of the patient, justification for all excepted patients. However, it should be remembered that just because a patient with epilepsy is excepted, it does not mean that they will not benefit from an annual review.
6.3 Read codes

Read codes are the recommended national standard coding system in general practice. There are two Read code systems in active use in the NHS – 4-byte and 5-byte. Read codes will be replaced by the SNOMED coding system in the next few years as part of the National Plan for Information Technology (NPfIT).

Currently the NHS uses a system called QMAS which externally interrogates the practice computer through a modem and extracts the Read codes that the practice has entered in patient notes. This information is completely anonymous as no patient identifiers are included and is used to calculate payments due to the practice under the QOF component of the new contract.

Each Read code has a unique four or five digit alphanumeric code. The first character (which can be a letter or a number) of the Read code generally represents the chapter heading; for example, codes relating to the nervous system and sense organ diseases begin with the letter F. Read codes are arranged hierarchically, with the level of detail increasing as more digits are added. The hierarchical approach is intended to help users to find related terms and decide on an appropriate level of detail. For example the Read code for epilepsy is F25.\ldots, where the dots represent unused spaces.

Read codes should be recorded at the level of detail that is clinically meaningful and useful, i.e. it is not always necessary to record to the fifth level of the hierarchy. However, if detail is not entered, it will not be possible to analyse in greater depth later. At a minimum, three character codes may be sufficient.

With the increasing use of electronic patient records, the GMS contract guidance recommends the use of NHS standard Read codes as detailed in the Dataset and Business Rules. This is to ensure that practices will store electronic information against the same codes, which are the only ones recognised within the GMS contract reporting system.

To ensure availability of high quality clinical information it is essential that those collecting and recording the data fully understand and are competent in the use of Read codes. To keep the register up to date, some training may have to be carried out on accurate data entry in the practice. All new diagnoses of epilepsy will need an appropriate Read code entry. The practice needs to decide how this is ensured. If this does not happen, the accuracy of the register will deteriorate over the years. Additionally, when carrying out annual review of your patients with epilepsy, the register should be updated to keep it accurate. Practices should contact their software supplier for up-to-date templates. All software suppliers now have epilepsy templates which can collect the information needed for the QOF requirements and which ensures that the correct Read codes are used. Epilepsy Action hopes to host templates for the most common software packages on its website (http://www.epilepsy.org.uk/gpresource) when they become available.

Further information on Read codes for the Quality and Outcomes Framework of the GMS contract is provided at http://www.bma.org.uk/ap.nsf/Content/NewReadCodes04?OpenDocument&Highlight=2,read,codes. Support for users of SNOMED CT and all versions of Read codes are provided at the NHS Information Authority website (http://www.nhsia.nhs.uk/terms/pages/default.asp).
**GMS contract codes for Epilepsy**\(^{9,19}\)

The following lists the Read codes currently included in the Quality Indicators specification. There are many other epilepsy related Read codes not included in the Quality indicators but which practices may wish to use if setting up bespoke templates. The full set of current Read codes can be obtained from the NHS Information Agency (www.nhsia.nhs.uk).

The ‘%’ sign determines whether the Read code is hierarchical or not. When viewing the criteria, any Read code with % or with no full-stop means that it is searched together with any of its sub-level codes.

Any Read code with a full-stop or without a % sign searches only the code and does not include hierarchical codes.

**EPILEPSY 1. The practice can produce a register of patients receiving drug treatment for epilepsy in the last six months**

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>F25%</td>
<td>Epilepsy</td>
</tr>
<tr>
<td>F25..</td>
<td>Epilepsy</td>
</tr>
<tr>
<td>F1321</td>
<td>Progressive myoclonic epilepsy</td>
</tr>
<tr>
<td>SC200</td>
<td>Traumatic epilepsy</td>
</tr>
</tbody>
</table>

Also include those who have a therapy entry of AEDs (include drugs from Section 4.8 of the BNF, dn%) in the last six months.

**Epilepsy Exceptions**

9h61. Excepted from epilepsy quality indicators: Patient unsuitable

9h62. Excepted from epilepsy quality indicators: Informed dissent

**EPILEPSY 2. Patients age 16 and over on drug treatment for epilepsy who have a record of seizure frequency in the previous 15 months (4 points 90%)**

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>667S</td>
<td>Fit frequency</td>
</tr>
<tr>
<td>667F</td>
<td>Seizure free &gt;12 months</td>
</tr>
<tr>
<td>667P</td>
<td>No seizures on treatment</td>
</tr>
<tr>
<td>667Q</td>
<td>1–12 seizures a year</td>
</tr>
<tr>
<td>667R</td>
<td>2–4 seizures a month</td>
</tr>
<tr>
<td>667S</td>
<td>1–7 seizures a week</td>
</tr>
<tr>
<td>667T</td>
<td>Daily seizures</td>
</tr>
<tr>
<td>667V</td>
<td>Many seizures a day</td>
</tr>
</tbody>
</table>
**EPILEPSY 3. Patients age 16 and over on drug treatment for epilepsy who have a record of medication review in the previous 15 months**

- 8B1F Epilepsy medication review
- 6677 Epilepsy drug side effects
- 6678 Epilepsy treatment changed
- 6679 Epilepsy treatment started
- 667A Epilepsy treatment stopped

**EPILEPSY 4. Patients age 16 and over on drug treatment for epilepsy who have been seizure-free for last 12 months recorded in last 15 months**

- 667F Seizure free > 12 months
- 21260 Epilepsy resolved (NB. This is a five-byte code that can only be used in five-byte systems)

**Epileptic seizure-free exception**

- 8BL3 Patient on maximal tolerated anticonvulsant therapy
References

Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work includes:
• providing information to anyone with an interest in epilepsy
• improving the understanding of epilepsy in schools and raising educational standards
• working to give people with epilepsy a fair chance of finding and keeping a job
• raising standards of care through contact with doctors, nurses, social workers, government and other organisations
• promoting equality of access to quality care

Epilepsy Action has a network of local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

Join us...
You can help us in our vital work by becoming a member. All members receive our magazine Epilepsy Today, free cover under our unique personal accident insurance scheme and access to our services and conferences.

Getting more information
Call our Freephone Helpline on 0808 800 5050
Freefax 0808 800 5555
Email helpline@epilepsy.org.uk