

# NHS services for epilepsy from the patient's perspective: a survey of primary, secondary and tertiary care access throughout the UK

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The aims of this study were to estimate the proportion of patients with epilepsy who made primary care and/or hospital outpatient medical consultations within 1 year; to formulate a model of the explanatory variables that influence whether patients consult or not; and to estimate the frequency of referral to, and waiting time for, hospital outpatient clinics in patients with new-onset seizures. Suggestions are offered for improvement of epilepsy services based on the findings.

A questionnaire was distributed to 3455 unselected patients identified at population level from primary care practices in all NHS regions of the UK.

There were 1652 respondents with epilepsy of all types, irrespective of aetiology, duration or severity. Fifty-two per cent of the whole sample made at least one medical consultation of any type specifically for epilepsy (42.0% primary care, 30.5% hospital, 20.4% both). Most patients with controlled epilepsy (74.5%) had no consultations. Of patients with severe epilepsy, 27.5% made no primary care consultations, 43.4% no hospital consultations and 14.1% no consultations of either type. Gender did not influence the likelihood of either GP or hospital consultations in patients with either controlled or active epilepsy. Increasing seizure frequency was associated with a greater likelihood of one or more hospital consultations for epilepsy, whereas increasing duration of epilepsy was associated with a decreased likelihood of either type of consultation. Age affected consultation rates: of those patients over the age of 65 years, only 29.9% made a medical consultation for epilepsy, compared to 53.8% of young adults. Patients under the age of 17 years were less likely to have consulted a GP and more likely to have consulted a hospital doctor.

Ninety percent of new-onset patients had been referred to a hospital doctor, and the mean wait was 6.5 weeks.

In conclusion, many patients with epilepsy, including severe epilepsy, are not receiving specialist input, and a significant proportion are receiving no medical supervision. The elderly are over-represented in this group. Care tends to be polarized between hospital or primary care, falling short of the ideal of shared care. It will be important to address the influences on consultation seeking in epilepsy, particularly for those patients currently under no medical supervision.

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**Key words:** epilepsy care; health care delivery; health service research; questionnaire; health services needs and demand; Great Britain.

## What is already known on this topic

- Epilepsy affects all age groups and varies widely in severity. Medical care for epilepsy is available at all levels in the NHS but little is known about the factors that influence consultation types or rates.

## What this study adds

- In a large, representative, community-based sample, many patients with severe epilepsy had no primary care consultations within the study period of 1 year.

- Many patients with severe epilepsy did not receive any specialist input into their care.
- A substantial minority of patients with severe epilepsy had no consultations for epilepsy.
- Few patients with controlled epilepsy received regular medical supervision although they were taking antiepileptic drugs.
- Older patients were less likely to receive medical supervision, regardless of seizure frequency or severity.

## INTRODUCTION

Epilepsy is responsible for a large medical and psychosocial burden and makes corresponding demands upon the NHS and society<sup>1,2</sup>. Care for people with epilepsy in the NHS is distributed across all levels and, in hospitals, across several specialities. There is a wide spectrum in the severity of epilepsy and a corresponding variability in the need for overall medical care and the degree of specialist input required in different patients. However, the overall use of medical services by people with epilepsy and the distribution of care between the different service levels and how these factors relate to disease severity are largely unknown. In addition, the medical management of the individual with epilepsy should be shared between primary care and hospital but previous studies have found that shared care is often lacking<sup>3</sup>. Equitable and effective health service planning for epilepsy care will depend upon an understanding of these patterns and the factors that influence the utilization of available services.

We have therefore surveyed consultation patterns for epilepsy and their determinants in people with epilepsy at all levels of the Health Service in a large, nationwide sample. We have examined the patterns of use in relation to clinical need and assessed the degree to which care is shared between the primary and hospital level.

## METHOD

### The questionnaire

The questionnaire and the method of patient sampling have been previously described<sup>4</sup>. In brief, 80 primary care practices distributed questionnaires to 3455 patients receiving prescriptions for antiepileptic drugs (AEDs) for epilepsy, excluding febrile convulsions. All patients who were being prescribed AEDs for epilepsy (apart from febrile convulsions) were in-

cluded and the sample, therefore, is representative of the overall population of patients with epilepsy in the country.

For children and patients with learning difficulties, parents or carers were asked to help complete the form. Information on seizure frequency and seizure severity was collected in order to stratify the responses to other questions. Seizure severity was assessed with a modified version of the National Hospital Seizure Severity Scale<sup>5</sup> (NHS3). Respondents were classified into three categories of epilepsy; (i) 'new-onset epilepsy' with seizure onset within 2 years; (ii) 'continuing epilepsy' with a duration of epilepsy greater than 2 years and with a seizure within 12 months; (iii) 'controlled epilepsy' with a duration greater than 2 years but no seizure within 12 months.

### Ethical approval

Ethical approval was obtained from the North Thames Multi-centre Research Ethics Committee and from each Local Research Ethics Committee.

### Statistical analysis

Primary care and hospital outpatient medical consultations were analysed separately and combined ('any medical consultations'). Patients were dichotomized into those who had and had not consulted for epilepsy within 12 months. To obtain descriptive statistics, patients were categorized into three age bands (<17, 17–65, >65 years) and, for patients who had a seizure within 12 months, two epilepsy severity bands, mild and severe. Mild epilepsy was defined as an NHS3 score of 15 or less and less than 10 seizures in the preceding 12 months; severe was defined as an NHS3 score of 15 or greater, or more than 10 seizures in the preceding 12 months regardless of the NHS3 score. Five explanatory variables (seizure frequency, NHS3 score, age, gender and duration of epilepsy) were analysed using unmatched, stratified logistic regression fitted by unconditional maximum likelihood. Gender was found to have no appreciable effect and was removed from the final model. For the logistic regression, the continuous variables (seizure severity score, age and duration) were converted to categorical variables. The results were expressed as the adjusted odds ratios for having consulted.

## RESULTS

### Response rates and demographic and epilepsy severity profile

Of 3455 questionnaires distributed by GPs, 1652 (48%) were returned, although some questions were not answered by all respondents. The relevant denominators are shown in the text. The demographic features of the sample have been summarized previously<sup>4</sup>. In 64.3% of patients the epilepsy severity was mild and in 32.5% severe; the remaining 3.2% were unclassified because NHS3 had not been completed.

### Consultation rates

Fifty-two percent (806 out of 1550) had a medical consultation (GP and/or hospital doctor) for epilepsy within 12 months; 42.0% (663 out of 1579) had consulted their GP, 30.5% (491 out of 1612) a hospital doctor and 20.4% (316 out of 1550) consulted both. Consultation rates with stratification by epilepsy severity and seizure frequency are shown in Table 1. The results of the logistic regression analyses for primary care consultations, hospital consultations and 'any medical consultation' (i.e. primary and/or hospital) are shown in Fig. 1a–f. Increasing seizure frequency was associated with an increased likelihood of having had one or more primary care consultations, whereas increasing duration of epilepsy and age less than 17 years or above 65 years (in comparison to 17–65 years) were significantly associated with a decreased likelihood of having had any primary care consultations. Increasing seizure frequency and age less than 17 years were associated with an increased likelihood of having had one or more hospital consultations; age >65 years and duration of epilepsy >15 years were associated with a decreased likelihood. Increasing seizure frequency, seizure severity and age <17 years were associated with an increased likelihood of any medical consultation, whereas increasing duration of epilepsy and age >65 years were associated with a decreased likelihood.

### Consultation patterns in patients with controlled epilepsy

Of the patients with controlled epilepsy, 18.5% (145 out of 782) had one or more primary care consultations in the last 12 months and 10.0% (79 out of 791) had one or more outpatient consultations. Most controlled patients 74.5% (573 out of 769) had no consultations of either type.

### Consultation patterns in patients with severe epilepsy

Amongst patients with severe epilepsy, 27.5% (140 out of 509) had no primary care consultations and 43.4% (227 out of 523) had no hospital consultations for epilepsy within 12 months, 14.1% (70 out of 497) had neither a primary care nor outpatient consultation. Of those who had any type of consultation, 50.8% (217 out of 427) had consulted both the GP and a hospital doctor.

### Patients over 65 years

Amongst patients over 65 years, 29.9% (75 out of 251) had one or more medical consultations of any type for epilepsy within 12 months, in comparison with 53.8% (593 out of 1102) in the 17–65 years group. For primary care consultations the figures were 25.1% (64 out of 255) vs. 45.7% (513 out of 1123), and for hospital consultations 15.3% (40 out of 262) vs. 29.7% (339 out of 1142).

### New-onset epilepsy: referral rates and waiting times

Of the 64 people with new-onset epilepsy, who had been diagnosed within the previous year, 51 (79.9%) gave a valid answer when asked if they had been referred to a hospital doctor. Of these, 46 (90.2%) had been. Within this group, the mean waiting time was 6.5 weeks ( $n = 32$ , range 1–20, SD 5.7) and 68.8% had been seen within 8 weeks. Sixty-five percent thought the wait was reasonable ( $n = 40$ ). There was a significant correlation between waiting time and satisfaction with waiting time (Pearson correlation =  $-0.62$ ,  $P = 0.003$ ). Of those waiting 4 weeks or less, 90.0% (18 out of 20) thought the wait was reasonable. Of those waiting 5 weeks or more, only 25% thought the wait was reasonable.

## DISCUSSION

The study was based on a large sample drawn from all NHS regions. Case inclusion depended only upon the prescription of AEDs for a diagnosis of epilepsy (other than febrile convulsions), and thus a wide and unselected spectrum of patients was included. The findings are therefore likely to be an accurate reflection of rates of primary and hospital doctor consultation by all people with epilepsy in the UK. We recognize that relying on patients' recall of visits may have led to some underestimation of consultation rates<sup>6–8</sup>.

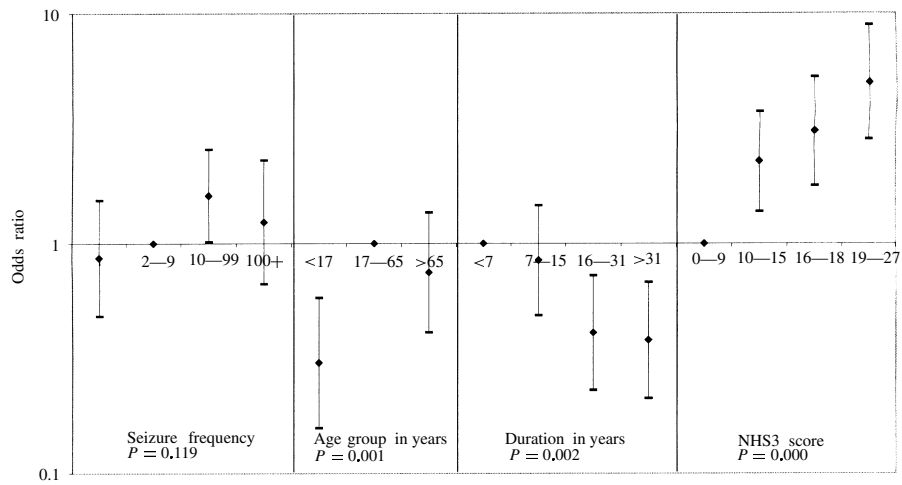


Fig. 1a: Odds ratio for visits to GP,  $n = 553$ .

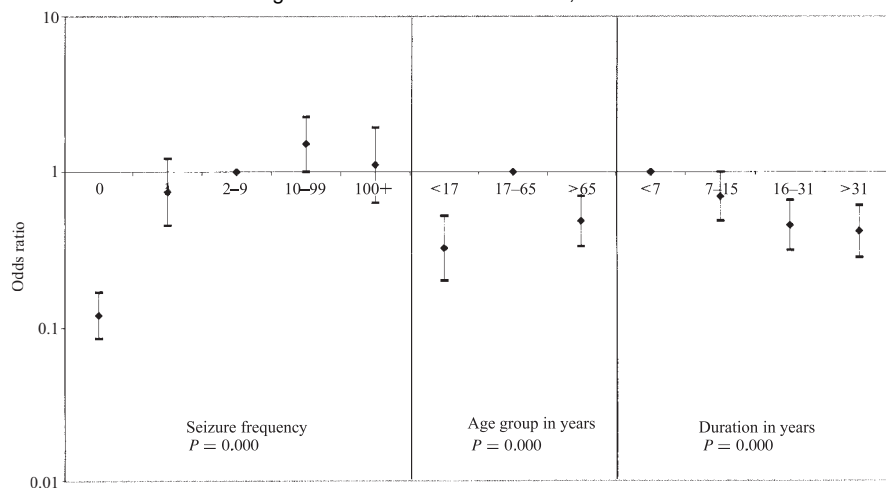


Fig. 1b: Odds ratio for visits to GP (no seizure severity scale),  $n = 1381$ .

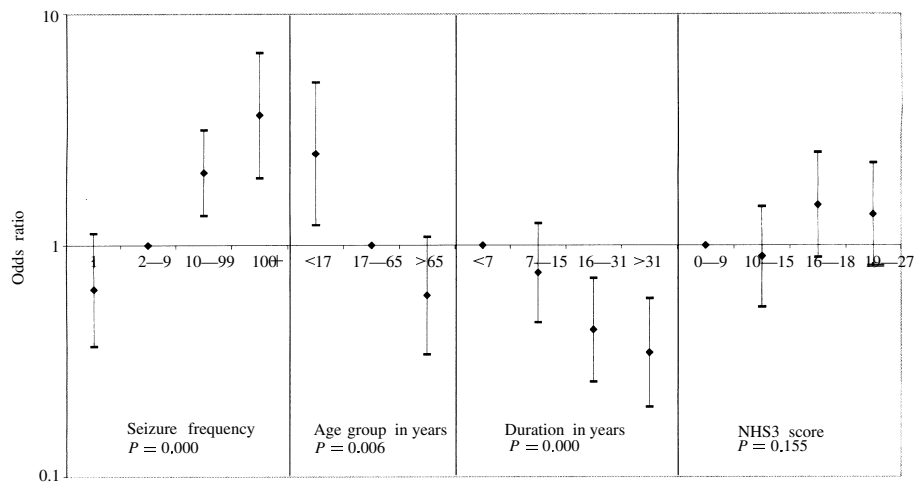


Fig. 1c: Odds ratio for visits to hospital,  $n = 564$ .

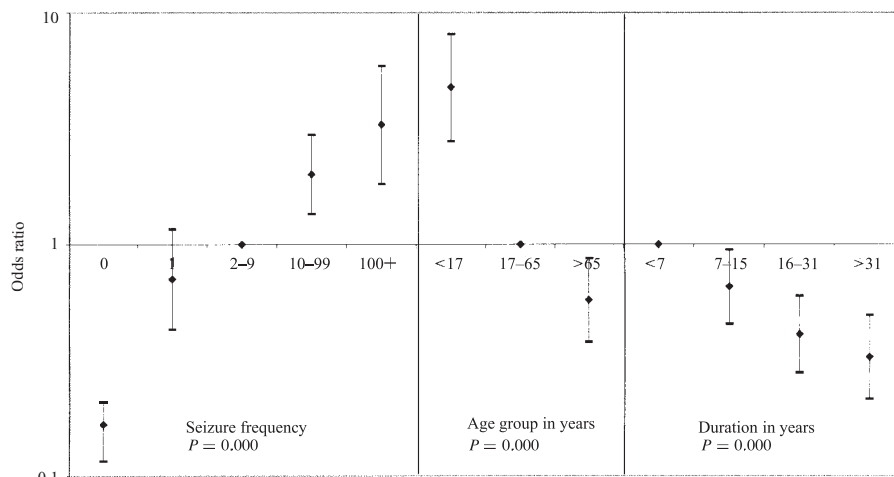


Fig. 1d: Odds ratio for visits to hospital (no seizure severity scale), n = 1405.

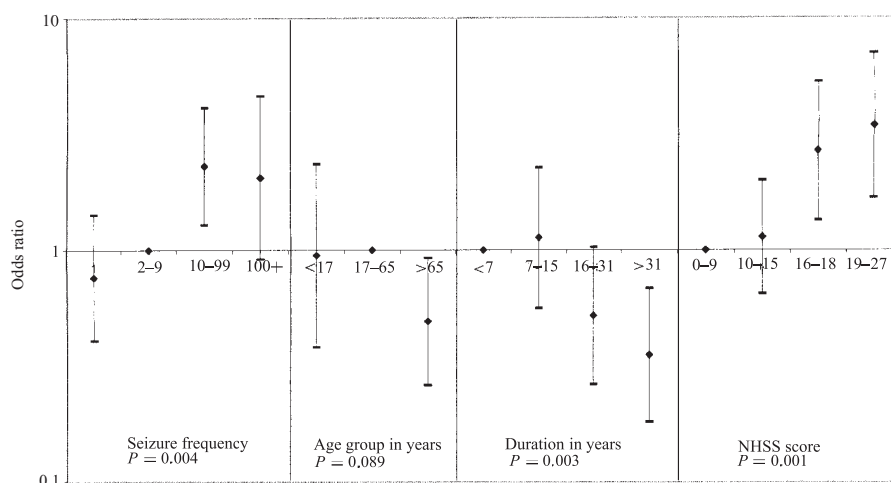


Fig. 1e: Odds ratio for visits to GP or hospital, n = 545.

About half of the sample had not consulted either their GP or a hospital doctor in the last year. Although most of these patients had no seizures within 12 months, all were, by definition, taking AEDs. Whilst patients with controlled epilepsy do not, in general, require hospital supervision, it is an agreed quality standard that such patients should see their GP at least annually and may on occasions require a hospital consultation. Eighty percent fell below this standard.

Furthermore, although most patients with severe epilepsy had consulted either their GP or a hospital doctor, 14% had received no medical supervision. About half (50.8%) of those that had received any medical supervision had seen both their GP and a hospital doctor, suggesting that, as found in previous studies<sup>7</sup>, care tends to be polarized rather than shared. The increasing complexity of medical care for epilepsy and the often chronic course of the condition make shared care imperative to optimal management. Other studies have found, however, that many primary care doctors feel that their knowledge of epilepsy is limited

and this, together with insufficient consultation time, means that primary care input into the care of people with epilepsy may be restricted and tends to be fragmented and unstructured<sup>8,10-12</sup>.

Patients with severe, chronic epilepsy should be under regular expert supervision. However, we found that nearly half of patients (43.4%) with severe epilepsy had not had a hospital consultation in the last year. A substantial proportion of patients who are not currently under specialist supervision might have much to gain from specialist appraisal, particularly in view of major developments in the investigation of epilepsy and its medical and surgical treatment.

Waiting times for hospital referral have been another concern of previous studies<sup>3</sup>. It is widely agreed that all patients with suspected new-onset epilepsy should be seen by an epilepsy specialist for confirmation of the diagnosis and, if necessary, investigations to clarify the aetiology. As well as these medical considerations, it is often the case that the patient and their family may only begin to adjust to the diagnosis when it has been

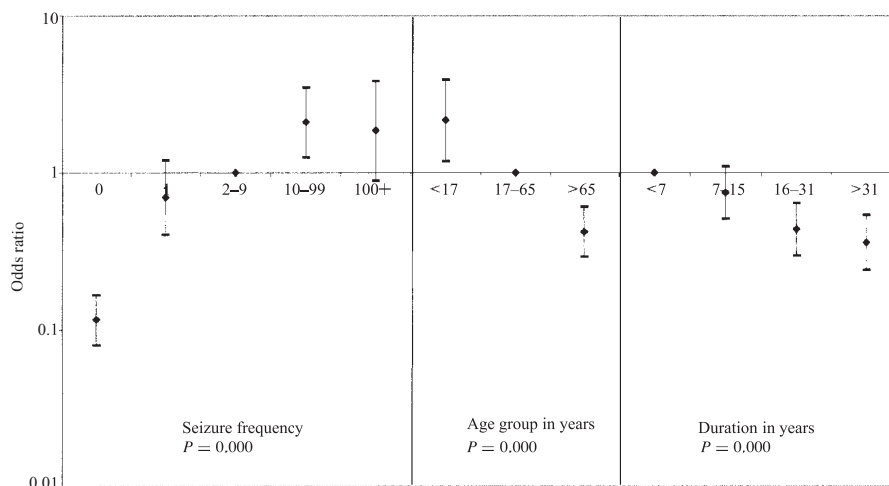


Fig. 1f: Odds ratio for visits to GP or hospital (no seizure severity scale),  $n = 1359$ .

Figs. 1a–f: Logistic regression models for medical consultations specifically for epilepsy within 12 months. In each plot the odds ratio for consulting (i.e. one or more consultations) associated with the variables is represented by a marker; the vertical bars extending from it represent the 95% confidence intervals for the odds ratios. All the variables are categorical. For each variable, the largest group was used as the reference group. The latter is represented by a marker without confidence intervals. The y-axis is logarithmic. Plots (a) and (b) show the findings for GP consultations, plots (c) and (d) for hospital consultations and plots (e) and (f) for any type (i.e. GP or hospital) of consultation. In each case, two plots are shown. The first includes only patients with continuing epilepsy (i.e. one or more seizures within the last 12 months) and seizure severity is included in the model; the second includes all patients (i.e. continuing epilepsy and controlled epilepsy with no seizures within 12 months) and therefore does not include the seizure severity variable, as patients with controlled epilepsy were not asked to complete the National Hospital Seizure Severity Scale.

Table 1: Proportion of patients who had one or more consultations for epilepsy within 12 months, with stratification by epilepsy severity and seizure frequency. Primary care consultations, hospital consultations, and both combined are shown separately. Only patients who returned valid answers to the questions asking about GP and hospital consultations for epilepsy are included in the table.

	Seizure frequency	$n$	Proportion of patients with one or more consultation		
			Primary care	Outpatient	Primary care and/or outpatient
<b>Mild epilepsy</b>					
No seizures	0	802	19.2%	11.0%	26.6%
Continuing epilepsy	1	69	49.3%	31.9%	59.4%
	2–9	136	55.1%	41.9%	69.1%
	Total	205	53.2%	38.5%	65.9%
Total		1007	26.1%	16.6%	34.6%
<b>Severe epilepsy</b>					
	1	39	66.7%	33.3%	74.4%
	2–9	112	81.3%	50.9%	91.1%
	10–99	253	73.5%	57.3%	85.0%
	≥100	93	65.6%	69.9%	87.1%
Total		497	73.2%	56.6%	85.9%

expertly clarified and explained, and necessary investigations performed. We found that most (but not all) were referred to a hospital doctor at the onset of symptoms, and that the mean wait was 6.5 weeks, with 69% of patients being seen within 8 weeks. These waiting times are less than those for neurological referrals in general; our informal enquiries suggested that this is because most neurologists will fast-track patients with new-onset epilepsy. These results do not, however, provide grounds for complacency. Even in new patients, a third are waiting for 6 weeks or more, and

the waiting times for referral in continuing epilepsy are much longer. The extent to which long waiting times inhibit referral or attendance cannot be gauged from our results, but the fact remains that large numbers of patients with continuing epilepsy are not attending hospital. Waiting times for referrals to specialist epilepsy clinics are particularly long. A survey of 250 trusts in 1997 revealed that only 28% of epilepsy clinics had mean waiting times of under 4 weeks<sup>13</sup>.

As might be expected, our regression analysis of the factors that may influence whether or not people

with epilepsy consult doctors revealed that seizure frequency was strongly related to hospital consultations. However, the analysis also revealed that elderly patients and patients with a longer duration of epilepsy were less likely to have consulted either their GP or a hospital doctor. Lack of medical supervision of older patients with epilepsy is likely to become an increasingly prominent issue in our ageing population, particularly as the incidence of epilepsy is known to rise steeply in the elderly and the frequent existence of co-morbidity poses particular problems in this group. In comparison to older patients, those under 17 years were more likely to have had a hospital consultation but less likely to have consulted the GP. This is in accord with patient preference and professional guidelines<sup>6,7</sup>.

It will be important in the future to further investigate the determinants of medical supervision, especially in the group of people with severe epilepsy who consulted neither their GP nor a hospital doctor (14% in this study).

We found little difference in consultation rates between males and females and, although older patients were significantly less likely to have consulted, age can account for only a small proportion of the patients who had not made any consultations.

This is the largest study of epilepsy services utilization in the UK to date and it was based on all NHS regions. Whilst we have shown in another paper<sup>4</sup> that patient satisfaction is high, we have also demonstrated some major shortfalls in the level of medical supervision of patients with epilepsy. In general, shared care is not being effectively implemented, too few patients are receiving specialist input into their care, and a substantial proportion of patients are under no medical supervision at all. An alarming proportion of elderly patients with epilepsy fall into the latter group, and this is likely to be an increasing problem in the future.

Although satisfaction with the accessibility of primary care in the UK is high<sup>4</sup>, it is commonly perceived by patients that the GP has a limited knowledge of epilepsy and this belief is also common amongst GPs themselves<sup>10</sup>. A tighter integration of hospital and primary care is required. This will require an improvement in communication between epilepsy specialists and GPs, with the provision of management guidelines for commonly occurring problems in epilepsy. We have previously suggested that an increase in the provision of specialist epilepsy nurses would contribute to improving the quality and equity of epilepsy care<sup>4</sup>. In addition, we believe that care for epilepsy should be concentrated within specialized epilepsy centres. In the past decade, a new interest in epilepsy has developed in the UK. This has been accompanied by a range of new treatments, new modes of investigation,

the development of epilepsy surgery, and the general desire of neurologists to be more involved in ongoing management and supportive care. This is a welcome change for patients with epilepsy, and the opportunity should be seized to improve the structure of service provision. This trend should go hand in hand with a strengthening of general practice and an emphasis on shared care.

## CONFLICT OF INTEREST/FUNDING

This work was funded by The Clinical Standards Advisory Group (CSAG).

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