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How can paediatric epilepsy services best be delivered in secondary care?

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KEYWORDS
Evidence-based guidelines;
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Summary *Objective*: To produce practical evidence-based guidelines for the management of paediatric epilepsy in secondary care settings. *Design*: Question-specific systematic literature review and local service audit. *Main outcome measures*: Grade of recommendation for specific management issues. *Results*: There is little good quality research to support many existing epilepsy guidelines for secondary care. *Conclusion*: Practical guidelines for the provision of children's epilepsy services can be evidence influenced but until more relevant research is undertaken, not evidence based.

Introduction

Many groups have suggested standards, guidelines and recommendations for management of patients with epilepsy. These often fail to address the particular problems of paediatrics[1], address mainly tertiary care[2] and often do not consider the practical issues of implementation in the NHS. A recent Government publication from the Clinical Standards Advisory Group[3] has provided a comprehensive review and provided recommendations ''that would improve the standards of care provided by the NHS for people with epilepsy''.

There is a paucity of published data about clinical activity and provision of secondary care services for children with epilepsy. As care of children and their families is strikingly different to adult services, there is a clear need for a sensible, efficient and evidence-based provision for this population. This paper provides data from a prospective study of epilepsy in a District General Hospital (DGH). The aim of this study was to review our current practice in all patients attending a DGH, review the literature and hopefully inform the debate on service provision and clinical practice especially in respect of the recent recommendation on standards of service provision[3]. Specific questions are addressed and discussed with reference to the best available evidence.

Methods

York District Hospital is a medium to large sized District Hospital that serves a population catchment area of approximately 300 000. There are 2900 births per year and 52 000 children below the age of 17. There are four general paediatric and one community consultant who each have an additional specialist interest, one of whom has an interest in epilepsy and another in childhood disability.

A prospective study of all patients attending the hospital over a period of 1 year from April 2000 to April 2001 was performed. All five consultants and

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secretaries agreed to participate. All patients with epilepsy, both those with new and existing diagnoses, aged between 3 months and 16 years were included. Epilepsy was defined by the diagnosis being made by the consultant. Patients with febrile convulsions and those with a single seizure of less than 30 minutes duration were not included. Cases were ascertained prospectively from clinic attendances, from ward admissions using hospital diagnostic coding records and from prospective manual checking of ward admission books. Patients who had no hospital attendances or admissions during the period were not included in the review. Data on each case were collected and analysed by R.A.S.

To address the need for auditable standards of care, a series of literature searches was performed on the Cochrane Library and Medline database (using PubMed and OVID interfaces). These searches addressed questions regarding the management of paediatric epilepsy within the secondary care setting, and were produced by consensus between the two authors.

In general, a hierarchical approach was used, based on the Oxford Centre for Evidence-based Medicine Levels of Evidence (www.cebm.net/levels), and where possible a grade of recommendation is appended according to this document.

Results

Epidemiology [How common is it?]

How many cases should we see?

Over 1 year there were 60 newly diagnosed and 151 existing cases of epilepsy seen in the department. Epidemiological data would indicate that if all cases were seen we should expect to see 22—79 (43—152 cases per 100 000 children) new cases of epilepsy per year and have a prevalence of approximately 155—311 (3—6 cases per 1000 population)[4,5]. There are methodological difficulties in studying epilepsy epidemiology[6] and figures extrapolated from epidemiological studies may not always reflect the clinical caseload in a given area especially if only cases of active or treated epilepsy are included[7].

We feel that we have complete ascertainment of cases attending our clinics. We are the only DGH in our area but it is possible that some cases are managed solely in primary care, in other centres or in the adult epilepsy clinic. We are aware of eight cases of epilepsy either seen in another centre or not reviewed during the year of the study (and therefore not included). Most cases seen in the regional centre are on a shared care basis with consultants in our department. A postal survey in the UK reported that 28% of children with epilepsy had not been to a hospital clinic within the last 12 months[3].

Suggested Standards:

- DGH epilepsy caseload should be between 55 and 100 new cases/100 000 population per year, with total caseload of approximately 5/1000 population [Grade B]
- All children with epilepsy should be under secondary care [Grade D]

Epilepsy diagnosis [How is it diagnosed?]

Do all patients get an epilepsy diagnosis?

How many patients have epilepsy as only one of their clinical problems?

Are all patients correctly diagnosed?

In our study, 173 cases (82%) of children received an epilepsy diagnosis according to the 1989 ILEA Classification[8]. Of the 79 cases with partial epilepsy, 22 were idiopathic and 57 symptomatic. Of the 70 with generalised epilepsy, 65 were idiopathic and 5 symptomatic, including 4 with Lennox Gastaut Syndrome. Nineteen other cases had been given specific epilepsy syndrome diagnoses. There were five cases that had initially presented with infantile spasms, three of whom were idiopathic. There were a further 38 (18%) who had not had their epilepsy classified, of whom 14 were idiopathic. In a prospective study using the same syndrome classification, a diagnosis was assigned by paediatric neurologists for 99% of 614 children with epilepsy, 57% had localisation-related epilepsy and 28% generalised. In 12—14% of cases, it could not be determined whether the seizures were of a focal or generalised origin[9]. Much has changed since these guidelines on classification were agreed and there is a current review and revision ongoing with a draft available at www.epilepsy.org. The currently proposed diagnostic scheme will make use of standardised terminology and concepts to describe individual patients.

Table 1 gives the associated medical diagnoses in symptomatic cases and serves to illustrate the diversity of associated problems many of which also require considerable expertise to manage, adding to the complexity of care required for these patients. This has particular implications for the practical clinic management of these children (see below).

We cannot say, as it was not a specific aim of this study, for how many of these children the epilepsy

Table 1 Diagnoses in 88 patients with symptomatic epilepsy.

Cerebral palsy	30
Quadriplegia	15
Hemiplegia	9
Athetoid	4
Diplegia	1
Not classified	1
SLD no specific diagnosis	8
Previous encephalitis (2 Herpes, I HUS)	5
Focal cortical dysplasia	4
Chromosome abnormality (9p deletion, inversion chromosome 1, partial trisomy chromosome 8, XYY)	4
Previous meningitis	4
Mesial temporal sclerosis	3
Autism plus SLD	3
3 microcephaly plus SLD	3
CVA	2
2 MLD, no specific diagnosis	2
Angelman's Syndrome	2
Rett's Syndrome	2
Hydrocephalus with shunt	
ATRX Syndrome	
Neurofibromatosis	
Septo-optic dysplasia	
Pfeiffer's Syndrome	
Periventricular leukomalacia	
Aicardi's Syndrome	
Astrocytoma	
Ganglioneuroma	
MRI small? Glioma	
ADEM	
MRI cystic structure	
Hemimegalencephaly	
Leukodystrophy	
Down's Syndrome	
Tuberose sclerosis	

SLD: severe learning difficulty (IQ $<$ 50); MLD (moderate; IQ $=$ 50—75).

is incorrectly diagnosed. While the diagnosis of seizures and epilepsy can be straight forward, it can also be one of the greatest clinical challenges, especially in children[10,11]. The rate of misdiagnosis is a strong argument for specialist neurology care but until adequate resources are available to allow a specialised service for all cases this will not be possible. A way around this could be some form of case note review with specialists for those not referred for a second opinion. A full review of all cases diagnosed is again impractical, but a 'quality control' review may well be beneficial. There are no relevant data to suggest what proportion would be appropriate or feasible.

Suggested Standards:

85% of DGH epilepsy patients should have an ILEA epilepsy diagnosis made within 1 year of diagnosis [Grade D]

Perform a case note review on a sample of cases not referred to a paediatric neurologist [Grade D]

Neurophysiology

How is it investigated?

York is relatively well served as a DGH in having a consultant neurophysiologist without a long waiting list (Kitson and Shorvon[3] reported that only 39% of relevant Hospital Trusts had EEG facilities but that 95% of hospital-based patients had undergone an EEG). In our sample, 91% of newly diagnosed patients had received an EEG at some point. Overall, 94% of cases had had an EEG of which 73% were abnormal. There were more abnormalities in the EEGs of those with pre-existing epilepsy (82% with one or more recording abnormal) compared with 47% in the new diagnosis group. Nine cases had undergone ambulatory EEG and six video-EEG. Some children did not receive an EEG: of the patients with existing epilepsy, one parent declined the offer, two had severe cerebral palsy, two autism and in one child with severe learning difficulties the EEG was attempted but failed (the only case of a failure to record an EEG).

There is no clear guideline indicating who should undergo an EEG and when. Decisions need to be made on an individual basis as presentations of epilepsy in childhood are quite variable. It is important that the purpose and role of an EEG in the diagnosis of epilepsy is understood. The organisation and provision of paediatric neurophysiology should be considered as an integral component in the development of a managed clinical network[12].

Suggested Standards:

95% of new DGH epilepsy patients should have an EEG within 2 months [Grade D]

They should be reported by a consultant neurophysiologist or neurologist with an interest or training in paediatric encephalography interpretation [Grade D]

Further EEGs may be required in up to 50% of patients [Grade D]

Neuroimaging [How is it investigated]?

Which patients should undergo neuroimaging? Are there any guidelines?

In York, dedicated general anaesthetic (GA) magnetic resonance imaging (MRI) lists are available once every month, with the capacity to scan 48 patients each year. We no longer perform MRI under deep sedation. For those children who do not require GA, further slots are available. In acute cases, CT imaging is available urgently at all times (and may be followed up with an elective MRI scan). The scans are reported by a consultant radiologist with an interest in paediatrics who works in close liaison with paediatric neuroradiology colleagues at the local tertiary centre. Ex-premature infants who have received cranial ultrasound scans that demonstrated abnormalities may not have received other forms of imaging.

In total 49% of our childhood epilepsy population had some form of neuroimaging; 18% of cases received a CT scan (66% were abnormal); 33% an MRI scan (54% were abnormal) and 6% both. In three cases there was an initial normal CT scan with an abnormality detected on subsequent MRI scan. There were 4% who were imaged by cranial ultrasound in the neonatal period of which all were abnormal. Overall, when considering all modalities of neuroimaging, abnormalities were revealed in 64% of cases. There were six patients with symptomatic partial epilepsy in the existing group who had not had any form of neuroimaging, three were older children with cerebral palsy, one had a chromosome abnormality and one had ATRX Syndrome. One patient declined the offer of MRI.

The preferred mode of imaging is MRI as it is clear that it will occasionally detect lesions in otherwise normal patients with normal CT scans[13]. Furthermore, a routine MRI may miss lesions detectable on higher resolution MRI using specific epilepsy protocols.

The decision to perform neuroimaging generally is based on accurate seizure classification and syndrome diagnosis. MRI is the ideal form of imaging and recommended in suspected symptomatic partial epilepsies, specific syndromes, such as West's Syndrome, and in infants less than 12 months, but not recommended in children with primary generalised or benign epilepsies[3,14–19]. The emphasis in decision making now is not considering which patients need a scan, but deciding on those who do not need a scan. Patients who are being considered for epilepsy surgery clearly require more detailed imaging, possibly including functional MRI and isotope studies that need to be performed in specialist centres. It is clear from this that the proportion of children who are scanned (with MRI, or possibly CT) will reflect the caseload in terms of specific diagnoses.

Suggested Standards:

- All patients without a clear diagnosis of primary generalised or benign partial epilepsy syndrome should have an MRI head within 1 year of diagnosis [Grade D]
- They should be reported by a consultant radiologist with an interest in paediatric radiology who also has access to second opinion where necessary [Grade D]

Referrals for second opinion [How is management organised?]

How many patients are referred for second opinion? Which patients should be referred to a paediatric neurologist for a second opinion?

In the Yorkshire region at the time of this audit there were 2.5 whole time equivalent paediatric neurologists for a population of 5 million. One paediatric neurologist visits York 6 times per year. Over the year, there are 12–18 new patient slots for all outpatient neurology referrals with 18–30 for follow up. In addition to the shared clinics, advice is available by phone and urgent cases can be referred direct to the regional referral centre. Of the 151 patients with existing epilepsy, 22% had been seen by a paediatric neurologist at some time and 7% were under active review. If one includes the patients with newly diagnosed epilepsy, 15% overall had seen a neurologist and 5% were under active review.

Brown *et al.*[1] stated that 20–40% of patients with epilepsy would require input from a specialist epilepsy service although their recommendations were not specifically for children. There are currently no evidence-based guidelines on which patients should be referred to a paediatric neurologist. The referral rate to specialist paediatric neurologists is, however, inevitably influenced and limited by resources. In the recent National Audit of Epilepsy-related Deaths, 8 of 22 children were considered to have inadequate access to appropriate care[20]. Surgery is increasingly being considered for epilepsy patients. In our study, eight (4%) patients with epilepsy had seen paediatric neurosurgeons in four different regional centres. It has been conservatively estimated that between 5 and 10% of patients with drug-resistant focal epilepsy could be offered surgery[3]. In the context of 30–35% of children requiring add-on anti-epileptic drug (AED) therapy and up to 10–25% of children with epilepsy

being misdiagnosed[11], there is considerable scope for involving paediatric neurologists in the care of these children although it is not possible to define a standard for recommended referral rates to tertiary services.

We believe that if there was a managed network with lead clinicians and adequate support from regional or supra-regional centres with the full range of tertiary epilepsy support services, it would lead to better co-ordinated care for children with severe and complex epilepsy.

Suggested Standard:

All patients who request a second opinion should have access to one [Grade D]

Clinic organisation [How is management organised?]

How should services in a DGH be configured?

Who should manage cases?

What type of clinic?

All five paediatric consultants saw children with epilepsy, the majority seeing the consultant with an interest in the disorder. Some of the consultants saw relatively small numbers of patients. Access to psychology is available by referral to the local Child and Adolescent Mental Health Team with whom there is a weekly liaison meeting[21]. There were a total of 544 outpatient appointments during the year for patients with epilepsy of which 30% of appointments are in the epilepsy clinic, with 55% in general paediatric clinics and 25% in child development clinics (CDC). The majority of children with epilepsy in this study are clearly not being seen in specific clinics, as advised by some recommendations[22]. The mean number of review appointments per case was 2.6 appointments per year, new patients also averaged 2.6 appointments but most were studied for less than a year. We could find no data recommending how often children with epilepsy should be reviewed, nor on the relative benefits of consultant-led versus consultant-delivered management.

The key problem faced currently is of time and resources. If one was to plan a service based on the actual caseload of our department, offering 30 minutes appointments for new and 15 minutes for return appointments (RCPCH recommendations) allowing a 10% non-attendance rate (our departmental average), study leave and annual leave requirements, it would require one and a half clinic sessions every week. If one was to group all new referrals into a 'seizure' clinic it could include 250 new referrals and 2000 follow ups in a year[22] which would require 200 clinics per year or 3 to 4 clinics per week. We could find no evidence to support a recommendation regarding the need for all paroxysmal disorders to be seen in a seizure clinic.

A Cochrane Review[23] of epilepsy clinics versus general neurology or medical clinics found no trials of suitable quality to review. Morrow[24,25] in a comparison of adult general versus adult specialist epilepsy clinic found that patients attending the specialist clinic were more likely to be followed up, to be seen more often and to receive a greater continuity of care than those attending a general neurology clinic. We could find no similar study involving children, but a recent audit by Mar *et al*.[26] reported an increase in knowledge of epilepsy in parents and children attending a specialist epilepsy as opposed to general clinic. Williams *et al*.[27] also reported on the benefits of establishing a multidisciplinary clinic for children. Kitson and Shorvon[3] reported that at general clinics only 17% of clinicians had access to epilepsy specialist nurses compared to 58% of clinicians at specialist clinics.

As epilepsy management is increasingly complex, it makes sense that there should be a lead clinician in each DGH managing the majority if not all cases of epilepsy and that this person should interact closely with neurological colleagues in a tertiary centre possibly as part of a 'managed network'[12]. It would also be feasible for smaller DGHs to work together to jointly provide a combined epilepsy clinic for a larger locality as part of such a network. There may be training issues for existing departments who do not have a consultant with an interest or training in epilepsy and for newly qualified general paediatricians who do not receive neurology training.

Suggested Standard:

The majority of cases should be managed by a lead clinician in a multidisciplinary epilepsy clinic in a DGH (CSAG) [Grade D]

Epilepsy nurses [What treatments are used?]

Are children's epilepsy nurses useful?

Which kind of patients should have access to an epilepsy nurse?

Should all departments that manage children with epilepsy have an epilepsy nurse?

Only 42% of patients had seen the paediatric epilepsy nurse, with a higher proportion of those

seeing the consultant with an interest in epilepsy being referred to the nurse (similar finding as Webb *et al.*[14]). At the time of this study the epilepsy nurse was only funded part time for 1 session per week by a pharmaceutical company. She has the Diploma of Epilepsy Care from the Metropolitan University of Leeds.

There is a paucity of research evidence to support the introduction of epilepsy nursing services. A Cochrane Review of specialist epilepsy nurses[28] concluded that there was no evidence that specialist epilepsy nurses improve outcomes for adults with epilepsy, but the confidence intervals are wide and do not exclude significant benefit (level 1a-). There are a number of audits of patient and parental views that indicate dissatisfaction with the amount and quality of information provided[14,27,29] or that they would prefer to speak to someone other than a doctor about the condition[3,30]. There are also a number of publications available reporting on the benefits of establishing such a service mainly in relation to adult services[3,31–34] but also for children[35]. This highlights a difficulty in producing evidence-based recommendations for health services organisation: funding and research resources are not available to rigorously investigate potential changes in services. What research is undertaken is often 'spare time', unfunded, and descriptive. Kitson and Shorvon[3] reported that 58% of 77 paediatric neurologists and paediatricians who ran epilepsy clinics had epilepsy nurses in their clinics and that only 70% were funded by the NHS. The key roles for the epilepsy nurse that emerge from these studies are not that of taking over the role of the doctor but of enhancing the overall care by providing continuity, information giving, liaison, support, administration and education. A DGH may not need to employ a full time epilepsy nurse, dependent upon the population served, but for useful continuity it would need to be at least 0.5 WTE.

It is our view that a key person in epilepsy management could be the epilepsy nurse. We feel that all patients should be seen by the epilepsy nurse with the specific aim of increasing patients and parent knowledge and understanding of epilepsy and co-ordinating care. This will be especially useful if patients are being seen by several consultants, in a number of different clinics.

Suggested Standard:

All patients and their families should have the opportunity to see a specialist epilepsy nurse [Grade C]

Antiepileptic drug usage [What treatments are used?]

Which drugs are being used?

Should there be an agreed protocol?

Which drugs should be used for which patients?

In this study, we have looked at the AEDs prescribed to the patients at their first outpatient appointment in the year. Whilst following each patient through their prescription year would have yielded a richer dataset to examine, the physical constraints on the study team (q.v.) restricted us to examining this defined event.

Of the new patients, 32% had no treatment started during the period of study. In the 58% where treatment was started, nearly nine-tenths (88%) were commenced on standard first line treatment (sodium valproate or carbamazepine). In the remaining five patients there were specific reasons for not using these two drugs. In three teenage girls lamotrigine was prescribed. A further patient was prescribed vigabatrin for infantile spasms, and one was given ethosuximide for absence epilepsy. Only 7% of existing patients were on no treatment.

The number of AEDs for each existing patient at the first appointment during the period of the study may be regarded as a quality marker, as over treatment should be avoided. 22% were on two drugs and reassuringly only 3% were on three drugs and none on four or more. The number of drugs tried in individual patients is a reflection of the difficulty in achieving control in some cases. In 20% of cases patients had been tried on four or more AEDs and 7% on seven or more. In some cases where no medication has been effective and most options have been tried, it may be considered a reasonable option to withhold drug treatments.

One of our patients with severe myoclonic infancy had a vagal nerve stimulator. None of our patients has used a ketogenic diet although two were on a waiting list at the regional centre.

Carpay *et al.* audited the use of anticonvulsants prospectively in a cohort of 494 children with epilepsy. Treatment was initially withheld in 29% of the children and after 2 years, 17% still had not received any anticonvulsant drugs. There were no serious complications from withholding treatment. Of the children treated with AEDs, 60% were still using the first anticonvulsant after 2 years, 80% received monotherapy and 20% polytherapy.

A recent audit of epilepsy-related deaths, however, indicated that 4 of 22 children who died were on no treatment and in 10 of the 22 cases there was deemed to be inadequate drug management. Webb *et al.*[14] audited use of drugs in the management of epilepsy using three standards. These are consen-

sus guidelines that could be adopted in a DGH to audit epilepsy.

It should be possible to produce some nationally agreed guidelines on which anticonvulsants should be used in paediatric practice for the different types of epilepsy. One example is the drug advice information available on the National Epilepsy Association Web site by Richard Appleton (www.e-epilepsy.org.uk). Although these would have to be regularly updated they could lead to an improvement in epilepsy AED management. Although there is not a strong evidence base, this should not be a reason for not attempting to agree a consensus and could stimulate future research. A similar process has occurred for Asthma Management.

At the moment in our department an audit of prescribing would have to be done manually (as in this study). If an up to date epilepsy database of all patients or an electronic prescribing system was used, this would facilitate audit of drug use in epilepsy.

Suggested Standards:

- Only 20% of children should be on two or more AEDs.
- No patient should be on more than two AEDs without shared care with a paediatric neurologist.
- Patients not responding to two AEDs used appropriately should be referred to a paediatric neurologist [Grade D]

Hospital admissions [How is outcome measured?]

During the year of the study, there were 41 hospital ward admissions in 25 patients who had a pre-existing diagnosis of epilepsy (1 patient had 5 admissions). Six of these patients had nine admissions in status epilepticus (one with three episodes). Of the 60 new cases, 28 patients had been admitted on 45 occasions. (This included one patient with nine admissions and another with four.) Eight 'new' patients had nine episodes of status epilepticus.

This demonstrates that an acute hospital admission is still a common presentation of new cases of epilepsy (47% of cases) and therefore still within the area of general paediatrics. 16% of cases with pre-existing epilepsy also re-presented to the ward with recurrences of epilepsy severe enough—be that medical or socially severe—to be admitted. Smith *et al.*[36] reviewed children presenting to a DGH accident and emergency department, 26% of the cases they reviewed were for children with pre-existing epilepsy. It would be tempting to use hospital admission rate as a standard for epilepsy service provision but there is not enough evidence to be able to use this as a recommendation.

Frequency of seizures [How is outcome measured?]

Is seizure frequency being recorded?

Is there an agreed method of assessing epilepsy severity?

The seizure count was taken on the first clinic visit of the period of study. It was possible to record this from 95% of case notes indicating a high standard of note keeping. Seizure severity scales have been described[37] but are not widely used. Currently, there is no universally used classification of seizure frequency or severity for children. Tables 2 and 3 indicate the recorded seizure frequency for the patients with known epilepsy and those with a new diagnosis. Those with daily seizures were having absence seizures.

Although one potential marker of epilepsy severity, assessing control is far more complex than simply counting seizure frequency. A key aspect of management with each patient and their family is to come to mutually agreed goals for treatment. In ideal circumstances, this would be complete control of seizures using one AED with no side effects, a normal quality of life and a patient and family

Table 2 Frequency of seizures for 151 existing patients (frequency recorded at first appointment of the year).

Category	Number of patients (%)
Seizure free for at least 12 months	50 (33%)
Seizures less than monthly	36 (24%)
Seizures occurring at least monthly	58 (38%)
Not recorded	7 (5%)

Table 3 Seizure frequency in newly diagnosed patients at the time of diagnosis.

Category	Number of patients
Status epilepticus	2
2 seizures	9
3 seizures	12
4 seizures	5
Several seizures? No	20
Weekly seizures	5
Daily seizures	7

who fully understand their condition as well as to reduce epilepsy morbidity and mortality. Parents and clinicians may not always agree on epilepsy management decisions as they may have differing perceptions and beliefs[38]. Compromises from achieving complete seizure freedom may be acceptable in some cases. Because of the variability of case mix between clinics, it would be difficult to set a target proportion of cases achieving seizure freedom for a defined period as a standard although current available data would indicate that at any one time one third of cases would be seizure free[1].

Suggested Standards:

- Each case should have explicit, agreed treatment goals [Grade D]
- Recording seizure frequency, severity and effect on the child's life will assist in managing expectations [Grade D]

Audit [How is outcome assessed?]

Are there audit standards?

Do they indicate good quality care?

If met, would they lead to an improvement in outcome?

There have been a number of published audits of paediatric epilepsy management. Appleton *et al*.[39] audited the management of new referrals and commented that, despite being a national project supported by the British Paediatric Neurology Association, response was low with only 50 patients included. Stewart *et al*.[40] audited the views of 48 parents on standards of care, the majority of which expressed dissatisfaction with outpatient care and attitude of staff in schools. Kwong *et al*.[41] showed that parents of children with epilepsy disclosed major misunderstandings of the disease and its medical and psychosocial treatment. Robinson *et al*.[30] audited a newly established epilepsy clinic in a tertiary referral centre using a structured questionnaire administered to parents and where appropriate children. A high degree of satisfaction was obtained, however, specific questions about additional resources implied a large number of unmet needs. Williams *et al*.[27] using a questionnaire determined that the best quality predictor using parental rating of a multidisciplinary epilepsy clinic for children was the amount of information given concerning the diagnosis and treatment of epilepsy. Webb *et al*.[14] have audited epilepsy care in a sample of patients against a series of guidelines agreed by physicians in the hospital and indicated that the audit process can demonstrate an increase in the numbers of cases reaching certain agreed management criteria. They stated in their discussion that two potentially useful standards not audited were those in whom a specialised neurology opinion should be sought and those who were misdiagnosed as having epilepsy. Both are more difficult to audit from clinical notes and both more contentious, although they are clinically very important.

This is the first prospective study that provides actual clinical data on all children attending a DGH with epilepsy and these data will be of interest to those planning services for children. We aimed to produce some standards for epilepsy services in secondary care. Although, the standards we propose are largely based on poor quality evidence and are arbitrary, they are based on recommendations from previously published reports and what we believe are realistic and achievable using data from an average sized UK DGH. We would like to propose that our standards could be considered when planning a practical, achievable and evidence-supported framework for providing high-quality care for children with epilepsy. Until further research is published, there will be no evidence base available on which to base such standards of care.

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R.A.S. collected the data, wrote the manuscript and performed some literature searches. R.S.P. also wrote and revised the manuscript and performed most of the literature searches. R.A.S. is the guarantor of the paper.

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