



Epilepsy -  
death in the  
shadows

# **National Sentinel Clinical Audit of Epilepsy-Related Death**

**REPORT 2002**



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First Published in May 2002

ISBN 0117028681

Produced by Epilepsy Bereaved  
Registered Charity 1050459

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Printed by The Stationery Office

### **Referencing**

#### **The National Audit should be cited as follows:**

Hanna N J, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, Fish DR  
(2002) The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy-death in the shadows. The Stationery Office.

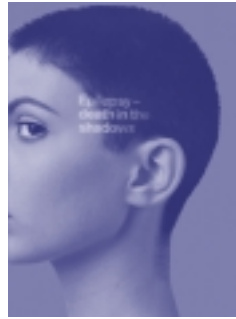
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## FOREWORD

We warmly welcome this landmark report and congratulate Epilepsy Bereaved for its project management of the National Sentinel Clinical Audit of Epilepsy Deaths. We thank Epilepsy Bereaved on behalf of the UK Health Departments for championing sudden unexpected death in epilepsy and for successfully co-ordinating this multidisciplinary and wide-ranging project.

National sentinel audits are comprehensive clinical audits recently introduced in the NHS. This audit of epilepsy deaths will enable health professionals locally to review their practice and address any developmental needs.

Epilepsy is the most common chronic disabling condition of the nervous system affecting around 400,000 people in the UK. Almost 1,000 deaths occur every year as result of the illness and most of them are associated with seizures. There has been a need for some time to better understand and reduce the number of epilepsy deaths.

This important and carefully executed piece of work focuses on that need. It reveals weaknesses in both clinical service and aspects of the treatment infrastructure. It shows that by addressing poor epilepsy management, there is the potential to achieve a reduction in the number of deaths.

The audit was sponsored by the National Institute for Clinical Excellence (NICE), and the health departments of the devolved administrations. A short summary report for England and Wales, published by NICE, is also available. A similar short report is going to be published by Epilepsy Bereaved and this will be disseminated in Scotland and Northern Ireland.

We recommend this report, which will be available widely to the National Health Service. We also give a commitment to consider what can be done to address the weaknesses in care it identifies. By doing this we will demonstrate that by taking action now, lives may be saved.

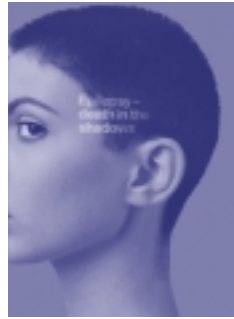
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# EXECUTIVE SUMMARY

## BACKGROUND

People with epilepsy have a risk of premature death that is 2–3 times higher than in the general population (Cockerell *et al.*, 1994). Most premature deaths among people with epilepsy are directly related to the epilepsy itself. Every year in the UK about 1000 people die because of epilepsy, and most of these deaths are associated with seizures. Sudden unexpected death in epilepsy (SUDEP) is the principal cause of death in people with chronic epilepsy and has been estimated to account for about 500 deaths each year. SUDEP is defined as “*sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death.*”

Risk factors for SUDEP include young age, generalised tonic-clonic seizures, uncontrolled epilepsy, learning disability, seizures during sleep, unwitnessed seizures and poor treatment compliance. Of these, the occurrence of seizures is the most significant risk factor and, in virtually all witnessed SUDEP cases, there is evidence of a preceding epileptic seizure. In a recent, case-controlled study, Nilsson *et al.* (1999) reported that people who had not been seizure-free in the previous year had a 23-fold increased risk of SUDEP compared to people with fully-controlled seizures. Furthermore, the risks increased with increasing seizure frequency.

In order to reduce mortality, therefore, there is a need to strive towards optimum seizure control. Although up to 70% of people with epilepsy have the potential to become seizure-free, evidence most recently highlighted by the Chief Medical Officer for England (CMO 2001) suggests that epilepsy management in the UK is sub-optimal. The situation is compounded by inconsistencies in reporting the causes of death in people with epilepsy, possibly related to a lack of awareness of SUDEP.

In 1996, the voluntary organisation *Epilepsy Bereaved* coordinated a symposium for those professionals concerned with SUDEP. A call was made for consideration of a confidential enquiry into epilepsy-related deaths. This resulted in the present National Sentinel Clinical Audit which evaluated the standard of pre-mortem epilepsy care received by

people who had died an epilepsy-related death. The audit also assessed the subsequent investigation of death and contact with the bereaved family.

## **AIMS OF AUDIT**

The aims were to establish whether deficiencies in the standard of clinical management, or the overall healthcare package, could have contributed to deaths (i.e. whether some epilepsy-related deaths are potentially avoidable with improved pre-mortem care) and the quality of post-mortem management (i.e. establishing the cause of death and communicating it to the family/carers).

Three key areas were reviewed:

- investigations into deaths (pathology)
- care prior to death (general practice and secondary care)
- contact with the bereaved family.

## **METHODOLOGY**

The audit was developed by multiprofessional and lay groups, with healthcare professionals drawn mainly from the Royal Colleges of General Practitioners, Nursing, Pathologists, Paediatrics and Child Health, and Psychiatrists (Learning Disability faculty) and from the British Branch of the International League against Epilepsy. A steering group provided strategic, clinical and methodological guidance, while an executive committee (project manager, audit officer and clinical leads from pathology, primary and secondary care) planned audit activity and carried out monitoring. Expert panels in pathology, primary and secondary care supported the clinical leads. The audit officer and five field workers (nurses) were responsible for case identification and data collection and management.

Audit tools were developed by defining the domains and criteria that were relevant in the pathology, primary care and secondary care settings. Criteria for audit were established using published guidelines, literature searches and the views of the expert panels. The draft audit tools were refined by the steering group and piloted.

Criteria for the pathology audit were developed under the following domains: background, post-mortem investigation, further investigations and cause of death. The audit domains in the context of primary and secondary care were: access to care and clinical assessment, investigations, drug treatment and other therapies, continuing care, information and support, and communication between professionals and services.

The audit team sought the advice of the NHS Regions in relation to obtaining cooperation from key individuals in organisations (e.g. trusts and primary care groups) for case ascertainment. The primary method of case ascertainment was through an

agreement with the Office for National Statistics; the General Register Office for Scotland and the General Register Office for Northern Ireland.

The target population for the audit comprised individuals who had died from an epilepsy-related death, in the UK, between September 1999 and August 2000. Although different national methods for data collection and accessibility influenced case capture, the audit was able to address its key goals using data across the UK.

Data collection involved completion of hard copy audit tools. The data were then converted manually into centrally held computerised records. Pathology audit tools were completed from post-mortem, coroner's office and police reports, while primary and secondary care audit tools were completed from case notes. Checks were made to identify data inconsistencies and duplication. The clinical leads and expert panels assessed findings from each arm of the study and assessments were made of overall adequacy of pre-mortem care and post-mortem investigation and certification of death.

## KEY FINDINGS

### Investigation of death

#### *Official data on deaths*

During the study period, there were 2412 deaths reported with epilepsy somewhere on the death certificate. Of these, 1023 were subject to post-mortem. The audit reviewed 439/1023 post-mortems (43%). In addition, the audit reviewed 156/1389 deaths (11%) certified without post-mortem. (For more details see box 1.)

#### *Pathology and certification of deaths*

Of the 439 post-mortem cases audited, 364 (83%) recorded a history of epilepsy and 332 (76%) recorded the circumstances of death, although pathologists indicated non-standardised access to such information.

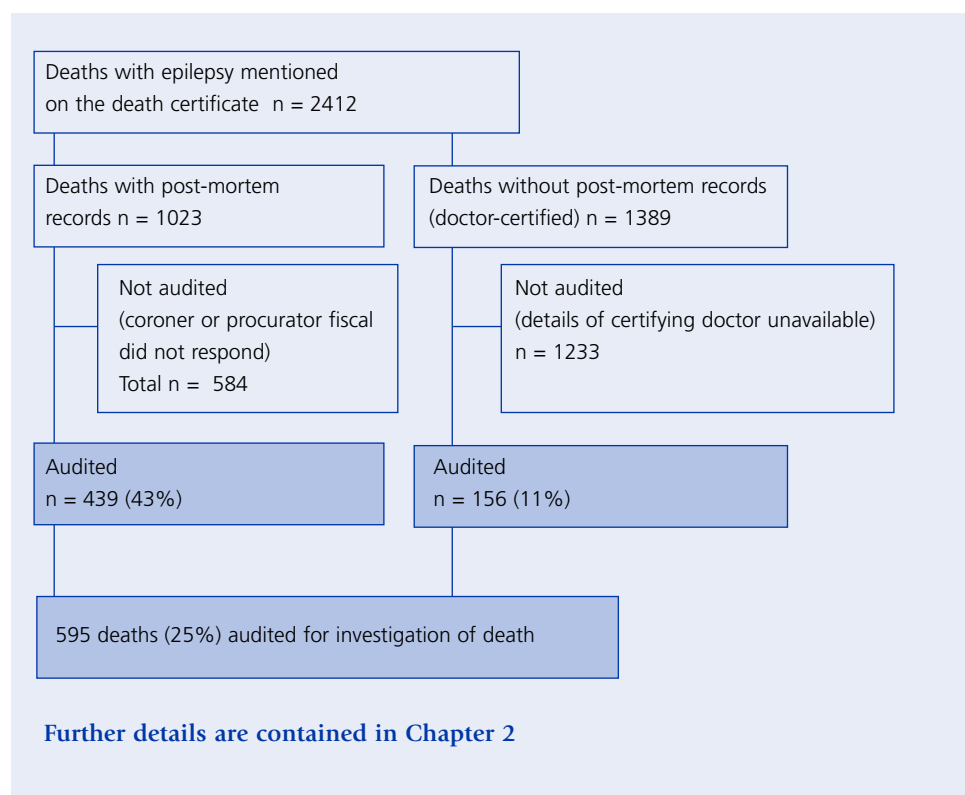
Of the 439 post-mortem examinations performed, 383 (87%) were considered to be inadequate. In 130/383 (34%) inadequately investigated cases, the only area to be considered inadequate was incomplete further investigations.

The external and internal examinations were unsatisfactory in 117/439 cases (27%) and 29/439 cases (7%), respectively. Furthermore, only 62 cases (14%) met the criteria for further investigations (i.e. histology, toxicology and neuropathology). In general, there were no consistent or nationally agreed criteria for, or approach to, further investigations.

Most deaths were confirmed as being in keeping with epilepsy as the cause, but the stated cause of death was inconsistent and sometimes inappropriate. The cause of death was considered to be inadequately stated in the post-mortem report in 178 cases (41%). A cause of death was often cited despite a lack of pathological evidence. Death was categorised as SUDEP in just over 10% of audited post-mortem cases.

**Box 1**

Audit of investigation of deaths



Only one third of pathologists were aware of systems in place to inform relatives about post-mortem examination results.

Of the 156 audited cases where death had been certified without post-mortem, 39 deaths were directly attributed to epilepsy and 38% of these were sudden/unexpected and should have been subject to post-mortem examination.

## Pre-mortem care

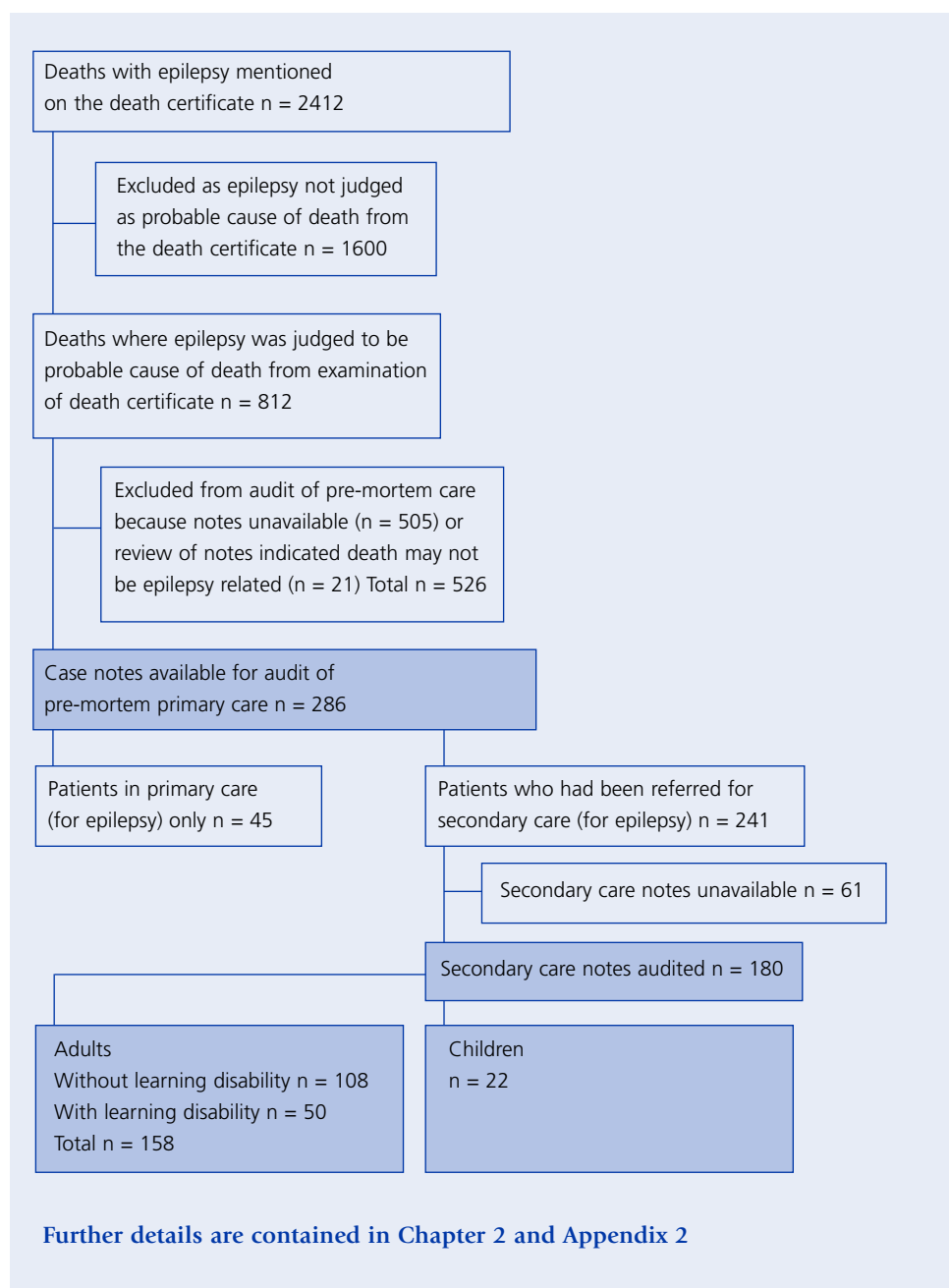
In 812 deaths epilepsy was identified as the primary cause of death (a further 238 were identified as possible). A total of 286 primary care case notes and 180 secondary care case notes were examined for the audit of care before death of people for whom epilepsy was judged to be the main cause of death. (For more details of the deaths audited, see Box 2.)

## Overall findings

Although an audit based on medical records cannot assess non-recorded activity and so the findings may not be entirely comprehensive, the information obtained raises matters of urgent concern.

Access to appropriate specialist care and therapeutic management were significant problems. Furthermore, in general, record-keeping was poor in both primary and secondary care. Shared areas where documentation was a concern were: clinical assessment and information provision and support. Many clinical details were lacking in relation to classification of seizure type and syndrome, seizure triggers, seizure frequency, drug treatment issues and non-drug therapies. There was little documented evidence that

**Box 2**  
Audit of  
pre-mortem care



the hazards of epilepsy (including the risk of death), the importance of adherence to drug regimens and adverse drug effects had been discussed with people with epilepsy and/or their carers. The advice and support of voluntary organisations, specialist epilepsy nurses and counsellors were likewise seldom recorded. Communication problems between professionals were evident both within and between primary and secondary care. There was little documentation of GP or specialist contact with the bereaved family – very few families (10%) were invited to discuss the death.

Specific primary and secondary care issues are described below.

### *Primary care issues*

The audit reviewed the GP case notes of 286 individuals who died, comprising 45 who received their care entirely within general practice and 241 who also received secondary care.

The referral process was analysed for people whose epilepsy was diagnosed recently (that is within 5 years before death; n = 46) and for whom data was available. After a first seizure, most individuals (84%) were referred to secondary care, but waiting times for a specialist appointment were disappointingly long. While 31% of individuals were seen within 1 month from a referral being made to appointment, 15% had to wait more than 6 months. It was not possible to audit from the records whether the referral specialist had a particular field of interest or knowledge of epilepsy. Only half of the population diagnosed in the 5 years before death were initially referred to a neurologist.

There was a low level of clinical information recording in relation to all 286 people who died. Documented evidence of individual, written management plans was lacking. Where these were present, they were often simply a statement of the date for next review or plans for taking a blood sample.

The review process was unstructured and lacking in detail. In the year prior to death, there had been no recorded review of 67% of patients receiving all of their care in general practice. Around 47% of these individuals had not been reviewed in 2 years. A greater percentage of patients who were receiving combined care had been reviewed by either the specialist or the GP (78%). About 31% of these reviews were with the GP and the commonest actions during review were to provide medication or to check drug levels.

Around 29% of individuals had been seen by their GP for non-epilepsy-related problems in the month before death. This would have provided an opportunity for epilepsy review.

Four individuals receiving only primary care had a change in seizure frequency, but were not referred. Of those receiving combined primary/secondary care, 68 individuals (28%) were considered to fulfil the criteria for reassessment (including 11% with a change in seizure frequency), but only 6 (9%) were re-referred.

### *Secondary care issues*

The majority of people with epilepsy receive most of their initial care in secondary care and those whose seizures are not well controlled should receive ongoing care in this setting. Overall, 180 cases were audited (158 adults and 22 children). Clinical review of these deaths suggests that 60% of epilepsy-related deaths were SUDEP and a further 7% were possible SUDEP. These numbers are estimates because of concerns about information available to the audit on the circumstances of death, the events leading up to the death and the adequacy of post-mortem investigations. Only 3% of people who died were recorded as seizure-free at their last hospital appointment and, therefore, most fulfilled the criteria for the need for this level of care on an ongoing basis.

A total of 50 adults (32%) and 15 children (68%) had learning difficulties; 28 adults (18%) had alcohol-related problems and 11 children (50%) had a physical disability. Most of the paediatric deaths occurred in individuals who had seizures that were difficult to control and/or learning or physical disabilities.

Although most adults (93%) were not recorded as seizure-free for at least a year before death, at least 37% of these people were not seen in the year before they died. The reasons for this were unclear in 50% of cases. Three individuals with learning disabilities had been 'lost' in the handover from paediatric to adult care. Around 15% of adults missed at least one appointment. Access to appropriate specialist care was a particular problem in children and in adults with special needs. About 36% of children had inadequate access to a specialist in epilepsy care. Adults with learning difficulties were less likely to see a consultant.

Basic clinical assessments and investigations were poor. In adults, seizure frequency was either not recorded or unclear in 47% of deaths. In children, there was inadequate documentation of classification of seizure type and syndrome and consideration of an underlying cause, and seizure frequency was either not recorded or unclear in 41% of deaths. Nilsson *et al.* (1999) reported that the people at highest risk of SUDEP were those without proper documentation of seizure frequency. It appeared that appropriate investigation was poor in a significant percentage of people who died. For example, in adults, 32% did not have EEGs and of these 43% were under 25 years at diagnosis and should have had an EEG. Investigations were inadequate in 32% of children.

From a review of the audit findings, the expert panel raised concerns about therapeutic management and considered that it was deficient in 20% of adults and 45% of children. Six percent of adults and 18% of children had not been prescribed any antiepilepsy drug (AED) at the time of death, in some cases despite ongoing seizures, and 14% of adults had documented drug adherence problems. Issues relating to therapeutic management included inappropriate choice or combinations of AED, sub-optimal or inappropriate doses, unsupervised or inappropriate management of AED treatment changes, little consideration of alternative or additional AEDs in cases of ongoing seizures and major drug errors.

The expert panel considered that secondary care had been inadequate (or contained at least one major error) in 85 adults (54%) and 17 children (77%). Most of these children and most adults had deficiencies in more than one aspect of care (and in addition to any finding on provision of information and support). The main problems in adults and children with overall inadequate care were access to specialist care (66% of adults and 47% of children), lack of appropriate investigations (25% of adults and 41% of children) and therapeutic management (38% of adults and 59% of children). Overall, 39% of adult deaths and 59% of deaths in children were considered to have been potentially or probably avoidable.

## CONCLUSIONS

It is difficult to establish the true number of epilepsy-related deaths from national data. National statistics are an important source for monitoring public health, setting targets for healthcare policies, and research aimed at reducing epilepsy-related deaths. The results of this audit indicate that because of the high percentage of inadequately investigated epilepsy-related deaths action should be considered to improve the quality of death certification in relation to these deaths.

Epilepsy-related death, particularly SUDEP, is still underestimated by healthcare professionals and this may reflect the mistaken belief that epilepsy is a benign condition. The risk of death associated with epilepsy appeared rarely to have been discussed with patients or their families. There was little documented evidence of contact with bereaved relatives after death. These issues of communication need to be highlighted with all relevant professionals through better education.

There was concern about many aspects of epilepsy management and, frequently, management did not meet published national criteria. There were particular problems in managing epilepsy in people who had associated problems such as learning difficulties.

From the available documentation, the audit found deficiencies in access to and quality of care, communication between clinical staff and between healthcare professionals and patients and their carers, documentation and post-mortem investigation of epilepsy-related deaths.

These system failures need to be addressed when planning professional education, clinical and audit guidance and systems for service delivery. Particular concerns are inadequate access to appropriate epilepsy care; lack of education of healthcare professionals about the principles of epilepsy management and the risks of epilepsy-related deaths; poor communication with patients and their families and between professionals; documentation and post-mortem investigation of epilepsy-related death.

By its very nature, an audit of epilepsy-related deaths should not be assumed to be representative of the care provided to patients in general. Nevertheless, audit can compare clinical care to published best practice guidelines in a systematic way. This clinical audit does not establish that the epilepsy-related deaths were directly caused by inadequate care – but it provides important findings about shortcomings in care that may have contributed to a substantial number of potentially avoidable deaths.

### Further action

The audit report will be disseminated to policymakers and stakeholders to provide strategic guidance for the prevention, investigation and management of epilepsy-related deaths.

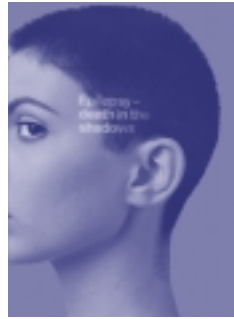


PART I:

**INTRODUCTION  
AND AUDIT  
METHODOLOGY**

Epilepsy –  
death in the  
shadows





## CHAPTER 1

# INTRODUCTION

Epilepsy, meaning a tendency to have recurrent seizures, is the most common serious neurological condition. There are many types of epileptic seizure, and a number of discrete epileptic syndromes have been described. The lifetime risk of developing epilepsy is reported to be 2–5% (Hauser *et al.*, 1991, 1996; Sander and Shorvon, 1996; Bell and Sander, 2001) and at any one time between 1 in 140 and 1 in 200 people in the UK (at least 300,000 people) are being treated for epilepsy (Muir *et al.*, 1996; Wallace *et al.*, 1998). Epilepsy is as common as insulin dependent diabetes and in a community of 250,000 people (the size of most primary care trusts in England) between 125 and 200 will develop epilepsy each year. (Frost *et al.*, 2002). The incidence varies with age; epidemiological research in the UK suggests that a quarter of new cases begin before age 15, about half between the ages of 15 and 60, and about a quarter after the age of 60 (Sander *et al.*, 1990).

Epileptic seizures, especially tonic-clonic seizures, may result in injury or death (Kirby and Sadler, 1995). The diagnosis of epilepsy carries an excess mortality that is 2–3 times higher than that for the general population (Cockerell *et al.*, 1994). In 2000, official statistics reported 951 deaths due to epilepsy in the UK (ONS, 2000; Register General Office for Scotland, 2000; Northern Ireland Statistics and Research Agency, 2000). According to official figures (quoted in Hanna, 1997) the excess death rate found in epilepsy in 1995 was about 4.5 times that found in asthma and this has increased to about 10 times in recent years (from figures quoted in National Asthma Campaign, 2001).

The causes of the excess mortality include:

- underlying disease such as stroke or brain tumour (mainly in newly diagnosed individuals)
- suicide
- accidents resulting from seizures, including drowning
- status epilepticus
- sudden unexpected death in epilepsy (SUDEP).

In chronic epilepsy, SUDEP is the main cause of excess mortality, and in this group of people the mortality rate has been found to be 4.5 times higher than expected, with more than half attributed to SUDEP (Nashef *et al.*, 1995a). In the UK it is estimated that 500 deaths per annum are SUDEP. Young people with severe epilepsy and learning disability may be at even higher risk of SUDEP, with one recent study showing a death rate 15.9 times greater than expected (Nashef *et al.*, 1995b).

### **SUDEP is defined (Nashef, 1997) as:**

**'sudden, unexpected, witnessed or unwitnessed, nontraumatic and nondrowning death in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death.'**

Reported risk factors (Shorvon, 1997) for SUDEP include:

- young age
- generalised tonic-clonic seizures
- uncontrolled epilepsy
- learning disability
- seizures occurring during sleep
- unwitnessed seizures and poor adherence to anti-epileptic drug regimen.

The most significant risk shown by case-controlled studies, however, is the occurrence of seizures, and the risk of SUDEP appears to be directly related to the frequency of seizures (Nilsson *et al.*, 1999). Indeed, most of the excess mortality of epilepsy is related to seizure frequency. In a recent case control study, Nilsson *et al.* (1999) reported that people who had not been seizure free during the year had a 23-fold increased of SUDEP compared to people with fully controlled seizures. Tomson (2000), in a review of published studies, concluded that the risk of SUDEP is 40 times higher in people who continue to have seizures. Sperling *et al.* (1999) found that elimination of seizures after surgery reduced the mortality rate in people with epilepsy to a level indistinguishable from that of the general population. They suggest that uncontrolled seizures are a major risk factor for excess mortality in epilepsy. The reason for this relationship seems to be that most SUDEPs are seizure-related (Shorvon, 1997; Nashef *et al.*, 1998; Nilsson *et al.*, 1999; Langan, 2000).

Optimising the management of epilepsy should therefore reduce the mortality associated with epilepsy. Around 70% of people with epilepsy have the potential to become seizure free (Annegers *et al.*, 1979; Griffin, 1991; Hauser and Annegers, 1993; Cockerell *et al.*,

1997; Wallace *et al.*, 1997; Taylor, 2000). The other 30% will continue to have seizures despite optimum care. There is, unfortunately, ample evidence that the management of epilepsy in the UK is less than optimal (Jacoby *et al.*, 1996). This was most recently highlighted by the Clinical Standards Advisory Group report in 2000 (CSAG, 2000). However, despite attempts to put epilepsy on the NHS commissioning agenda (Brown *et al.*, 1993, 1998) and the issuing in England and Wales of NHS Executive Letter EL95(120) which gave guidance to commissioners, service planners have not focused their attention on this area (Brown and Lee, 1998; Brown *et al.*, 1999).

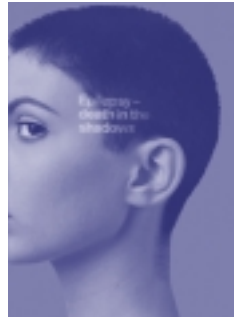
The situation is compounded by inconsistencies in reporting the causes of death in people with epilepsy. This is probably related to a lack of awareness of SUDEP among coroners, pathologists and clinicians (Lip and Brodie, 1992; Coyle *et al.*, 1994, Timmings, 1998) due to a myth which developed during the twentieth century that individual seizures are benign (Nashef and Sander, 1996). After the founding of the charity Epilepsy Bereaved, anecdotal evidence began to appear suggesting that deficiencies in care may play a part in epilepsy-related death, and that at least some of these deaths are potentially avoidable. Research also drew attention to the overall poor quality of support given to bereaved relatives. One risk factor is that of poor medical note-keeping, perhaps representing an inadequate standard of clinical care (Nilsson *et al.*, 1999). There are accepted standards for the clinical care of epilepsy, ranging from primary care through specialist secondary services and covering the overall structure of services and the way in which they should be commissioned (Brown *et al.*, 1993, 1998; Hall *et al.*, 1997; SIGN, 1997; Wallace *et al.*, 1997; Epilepsy Task Force, 1999; Taylor, 2000). The Royal College of Pathologists has also published guidelines with standards for post-mortem examinations (RCPATH, 1993). In 1996 the UK voluntary organisations, most notably Epilepsy Bereaved, cooperated to establish an international symposium that brought together clinicians and researchers involved with SUDEP (Nashef and Brown, 1997). At this meeting a call was made for a confidential enquiry into epilepsy mortality, along the lines of those already in existence for maternal and infant deaths.

Subsequent lobbying by organisations representing clinicians, researchers and the voluntary sector, led by Epilepsy Bereaved, resulted in the present National Sentinel Clinical Audit. The primary purpose of the audit was to assess the standard of epilepsy care received by people who had died of an epilepsy-related death. This included not only clinical standards in the management of epilepsy before death, but also investigation and management of the situation after death. Since deaths are related to seizure occurrence, and this in turn is affected by the standard of clinical care, it was important that deaths should be studied to ascertain and highlight instances where deficiencies in the standard of clinical management or the overall healthcare package may have played a part in causing death. The audit also provided an opportunity to assess the standard of subsequent investigation of cause of death, and the contact with the bereaved family.

This audit of epilepsy-related death is reported in the context of a number of national developments. In England the government announced in 2001 that a National Service Framework for long-term conditions would be developed. In England and Wales NICE have commissioned the development of a clinical guideline for the diagnosis and management of epilepsy in children and adults (due June 2004) and a technology

appraisal of drugs for children and adults (due December 2003). In Scotland the SIGN guidelines on the diagnosis and management of epilepsy are being revised and are due to be published during 2002.

The 2001 annual report of the Chief Medical Officer for England highlights the importance of this audit in a chapter entitled 'Epilepsy – deaths in the shadows' (CMO, 2001). He points out that although five government reports over a 50-year period have drawn attention to the neglect of epilepsy, there has been little action and that services for people with epilepsy fall short of what might be expected in modern chronic disease management.



## CHAPTER 2

# AUDIT METHOD

### SETTING AND BACKGROUND OF THE AUDIT

A sample of deaths in England, Wales, Northern Ireland and Scotland during the study period (1 September 1999 to 31 August 2000) was audited for:

- the investigation and certification of deaths where epilepsy was mentioned somewhere on the death certificate, by reference to available reports on post-mortem examination, coroners' officers and police reports, and survey of service provision
- individual care before death of people dying from epilepsy by reference to available case notes
- the context in which care is delivered in acute NHS Trusts and general practices in the UK by a questionnaire survey of service provision. Details of this part of the study can be found in Appendix 3 (The context of care in primary and secondary services).

The remit of the audit included collecting data on deaths to inform the evidence base for the development of professional guidance and delivery of services. The choice to collect data prospectively allowed the study to assess recent deaths and to reflect current practice.

We were not able to include the views of bereaved relatives because a condition of access to national registration data is that audit personnel will not contact relatives of the deceased. However, the views of these families is important, so Epilepsy Bereaved commissioned the College of Health to undertake research into the experiences of bereaved relatives contacting Epilepsy Bereaved during the audit period and that research will be published later during 2002 and be available on the Epilepsy Bereaved website ([www.sudep.org](http://www.sudep.org)).

### PROJECT MANAGEMENT

The project was managed by the director of Epilepsy Bereaved (representing the Joint Epilepsy Council), the first member of a voluntary organisation to manage a clinical sentinel audit.

- a steering group was convened to provide clinical guidance, to oversee the audit and advise the project lead on strategy, audit tool development, data analysis and preparation of the final report. The organisations represented on the steering group and organisations supporting the setting up of the audit are listed in Appendix 1
- an executive committee (comprising the project manager, audit officer and the clinical leads from pathology, primary and secondary care) was responsible for stage-by-stage monitoring and planning of audit activity. The clinical leads were supported by expert panels in pathology, primary and specialist care and by additional expert advice. The members of these committees and specialist panels are listed in Appendix 1
- the audit officer and five field workers were responsible for case identification, data collection and data management
- audit advisors from the Department of Health Science and Clinical Evaluation at the University of York and the School for Health and Related Research (ScHaRR) at the University of Sheffield assisted the executive committee and project manager with methodological and statistical support.

## PREPARATORY AND PILOT PHASE

### Training

The audit team underwent training and familiarisation for 2 weeks at the Royal College of Pathology (3 days), the National Hospital for Neurology and Neurosurgery in London (2 days), University of Birmingham Seizure Clinic (5 days) and the Epilepsy Specialist Unit in Cardiff (1 day). Training was given by the audit officer, epilepsy specialists, the project manager and the clinical leads. It included the background to epilepsy, SUDEP and issues of pre- and post-mortem care. Training also included audit methodology, structure and function of audit tools, and data collection and management.

### Securing cooperation

The success of the audit depended on finding cases of epilepsy-related death and gaining access to the relevant clinical and post-mortem notes. We sought local cooperation by asking advice from NHS Regions, and through correspondence in advance of case ascertainment with coroners, primary care groups and trusts, health boards and hospitals. In addition, we asked organisations to identify local contacts to help with access to records. We carried out a publicity campaign during the audit to inform key professionals by the use of leaflets, articles in professional journals and professional conferences.

### Ethical approval and confidentiality

Two Multi-Centre Research Ethics committees scrutinised the audit proposal. Both independently deemed the project to be audit, so that further ethical approval was unnecessary.

Cases were anonymised by use of coded identifiers. Nominated staff at the National

Society for Epilepsy stored the anonymised data securely.

## Sampling

The target population was everyone who died from an epilepsy-related death during the study period. There were two sample groups within this target population:

- the sample of epilepsy-related death for the audit on the investigation of deaths was drawn from all deaths in the study period with 'epilepsy' stated on the death certificate
- the sample for the audit of pre-mortem care was drawn from deaths where epilepsy was identified as the primary cause of death.

It was impossible to define with confidence the total population who died from epilepsy, because of deficiencies in the accuracy of the stated cause of death, which were identified in the audit of investigation of deaths, and the lack of access to all records for people who died and had epilepsy on the death certificate. The steering group was concerned that the sample used for the audit of pre-mortem care should exclude deaths where epilepsy was not the primary cause of death, and a moderation exercise (see Appendix 2) was conducted to give an estimate of total probable epilepsy deaths and to ensure that deaths that were not primarily related to epilepsy were excluded from the audit of pre-mortem care (Table 2.1).

**Table 2.1**  
Results of moderation exercise  
of deaths

| <i>Moderation by country</i> | <i>Probably due to epilepsy</i> | <i>Possibly due to epilepsy</i> | <i>Unlikely to be due to epilepsy</i> | <i>Total</i> |
|------------------------------|---------------------------------|---------------------------------|---------------------------------------|--------------|
| England and Wales            | 713                             | 232                             | 1115                                  | 2060         |
| Scotland                     | 84                              | 4                               | 195                                   | 283          |
| Northern Ireland             | 15                              | 2                               | 52                                    | 69           |
| All UK                       | 812                             | 238                             | 1362                                  | 2412         |

We considered selecting a sample of deaths stratified for location, acute Trust and coroner or procurator fiscal jurisdiction, but rejected the idea because of the potential geographical variations in care, the relatively small number of deaths and the problems of case ascertainment.

The status of a sentinel audit does not require release of post-mortem reports or medical records, so for access to these we had to rely on the cooperation of clinicians, pathologists, coroners and procurators fiscal involved in each case. Every effort was made to gain cooperation from individuals and organisations, but sampling of cases has inevitably been subject to some selection bias because we depended on securing cooperation from a large number of organisations and professionals before we were allowed to audit. Our aim was to collect data from as many hospitals and GPs as possible, and the final audit sample included 285 GP practices and 94 hospital Trusts

across the UK. The audit team is grateful to the many coroners, pathologists, clinicians and families who gave support to the audit.

Although we accept that there are advantages to a sentinel audit, clarification of the issues of certification and case ascertainment requires a further study with a status ensuring mandatory reporting of deaths and access to notes.

## CRITERIA SETTING AND AUDIT TOOL DEVELOPMENT

The steering group and clinical leads agreed question domains from a search of the evidence and consensus views of the expert panels for each study arm (pathology, primary and secondary care).

Audit tools were developed by defining criteria within the domains in a way relevant to the context of each arm. The leads were responsible for drawing together information from published material and panel discussions. This process was considered a useful method of developing tools with content and construct validity.

The tools were used to collect recorded data only from notes in clinical and pathology records. Professional activity that was not recorded could not be included in the audit. Details of the audit tools and their development are given in Appendix 2.

## CASE ASCERTAINMENT AND RESPONSE TO AUDIT

### Total deaths reported

The primary method of case ascertainment was through a formal agreement with the Office for National Statistics (ONS), and the General Register Offices for Scotland and for Northern Ireland. They agreed to search their databases to identify deaths where epilepsy is mentioned on the death certificate for the study period (Table 2.2).

**Table 2.2**  
Total deaths reported with epilepsy on the death certificate

| Totals             | England and Wales* | Scotland | Northern Ireland | Totals |
|--------------------|--------------------|----------|------------------|--------|
| Death certificates | 2060               | 283      | 69               | 2412   |

\* Individual statistics for Wales were not available to this audit from national registration bodies.

After the first ascertainment of deaths from official national registration bodies, a check was made against deaths reported by families and professionals to Epilepsy Bereaved and deaths known to the University College London Hospitals NHS Trust. Of the 20 deaths known to us that were checked against national registration data, 19 were found on the national registration data reported to the audit. The death not recorded was that of a person who died on holiday and whose death was certified abroad.

## Audit of investigation of deaths with epilepsy mentioned

Case ascertainment is detailed in tables following on audit of investigation of death in relation to all deaths (Table 2.3), the total of post-mortems ordered by coroner or procurator fiscal (Table 2.4) and the total of deaths certified without post-mortem (Table 2.5).

**Table 2.3**  
Audit of investigation of death as percentage of total deaths

|                        | <i>England and Wales</i> | <i>Scotland</i> | <i>Northern Ireland</i> | <i>Totals</i> |
|------------------------|--------------------------|-----------------|-------------------------|---------------|
| Total number of deaths | 2060                     | 283             | 69                      | 2412          |
| Number audited         |                          |                 |                         |               |
| by the investigation   | 397                      | 131             | 67                      | 595           |
| % audited              | 19                       | 46              | 97                      | 25            |

**Table 2.4**  
Audit of post-mortems ordered by coroner/procurator fiscal as percentage of total post-mortems ordered

| <i>Certifier</i>     | <i>England and Wales</i> | <i>Scotland</i> | <i>Northern Ireland</i> | <i>Maximum total post-mortems</i> |
|----------------------|--------------------------|-----------------|-------------------------|-----------------------------------|
| Coroner/procurator   |                          |                 |                         |                                   |
| fiscal post-mortems  | 933                      | 86              | 4                       | 1023                              |
| Audited post-mortems | 379                      | 56              | 4                       | 439                               |
| % audited            | 41                       | 65              | 100                     | 43                                |

The difference in response between countries in respect of deaths certified by coroner or procurator fiscal is explained by the different method for case ascertainment in each country. In England, Wales and Northern Ireland access was dependent on the cooperation of coroners. Coroners are independent judiciary and may provide copies of such documents to persons they consider to be 'properly interested parties'. There are about 131 Coroners (25 of these are full-time) in England and Wales and 7 in Northern Ireland (one full-time). No coroner refused to cooperate in Northern Ireland. In England and Wales 5 coroners did not respond to correspondence, and 12 refused. The main reasons given were that information provided to the coroner was confidential to the limited purpose of their inquiry, or that the coroner was too busy. In Scotland, the Crown Office collected post-mortem reports centrally from procurators fiscal and forwarded the post-mortem reports to the audit.

**Table 2.5**  
Audited deaths certified without post-mortem as percentage of total doctor-certified deaths

|                  | <i>England and Wales</i> | <i>Scotland</i> | <i>Northern Ireland</i> | <i>Total certified</i> |
|------------------|--------------------------|-----------------|-------------------------|------------------------|
| Doctor-certified | 1127                     | 197             | 65*                     | 1389                   |
| Audited records  | 18                       | 75              | 63                      | 156                    |
| % audited        | 2                        | 38              | 97                      | 11                     |

\*In Northern Ireland, 6 deaths were certified by coroner without post-mortem. The audit did not find any other deaths certified by coroner or procurator fiscal without post-mortem, but cannot rule this out.

The difference in response between countries in respect of doctor-certified deaths is explained by the different methods for case ascertainment used in each country. In

Northern Ireland, the Central Health Board had agreed that the audit field worker could have centralised access to primary care records. In Scotland, the General Register Office provided name and contact details of the certifying doctor. In England and Wales the Office for National Statistics did not provide details of the certifying doctor, GP or hospital.

For this reason we were able to audit only 11% of certified deaths. Only 13% of certified deaths without post-mortem were modified as probable epilepsy deaths, compared with 87% of coroner and procurator fiscal post-mortems.

## Audit of care of people dying from epilepsy

**Table 2.6**  
Total number of complete audits

| <i>Total</i>             | <i>England and Wales</i> | <i>Scotland</i> | <i>Northern Ireland</i> | <i>Total</i> |
|--------------------------|--------------------------|-----------------|-------------------------|--------------|
| Probable epilepsy deaths | 713                      | 84              | 15                      | 812          |
| Complete audits          | 156 (22%)                | 56 (67%)        | 15 (100%)               | 227 (28%)    |

Audits were categorised as complete where the medical records on the person who died were audited in relation to medical care received in relation to their epilepsy before death and had also been audited by the pathology arm (Table 2.6). The primary care sample of deaths reported in Part III of this report (286) is larger than the secondary care audit sample (180) because 45 people were managed only in primary care and some additional primary care audits were included where, as a result of difficulties in case capture, we were unable to complete an audit of hospital notes.

The differences in methodology in each country resulted in a considerable variation in access to notes, so the success of the audit in case capture varied significantly. Details of these national variations are given in Appendix 2.

## ASSESSMENT OF RESULTS

Details of data collection and analysis are given in Appendix 2. Expert panels were established to comment on the findings (see Appendix 1). The clinical leads and the expert panels assessed results from each arm of the study. The pathology and specialist care panels also reported on the overall adequacy of post-mortem investigations and pre-mortem care, and their findings are presented in Parts II and III of this report. Data from primary care was sparse, and so comments were made on the aggregated primary care results.

## **PRESENTATION AND DISSEMINATION OF REPORT**

Part II of this report presents findings on the investigation of death and Part III the findings on pre-mortem care. The findings presented are for the UK as a whole, except in relation to the investigation of death, where the different systems employed were reflected in national variations. The audit of pre-mortem care did not identify any significant national differences in audit findings. The clinical leads for pre-mortem care decided that to report individual national findings would compromise confidentiality because of the small numbers of deaths.

This report will be disseminated to policy-makers and stakeholders to inform strategies for the prevention, investigation and management of epilepsy deaths. As well as being available for purchase from bookshops, the full report and all audit tools and questionnaires will also be available to view on the Epilepsy Bereaved web site ([www.sudep.org](http://www.sudep.org)). At the time of publication, a short version will be sent to all professionals and organisations who participated in the audit.



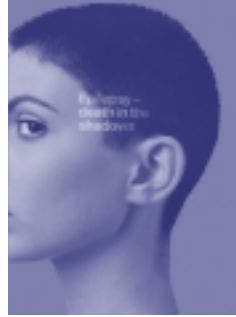


PART II:

# POST-MORTEM AUDIT

Epilepsy –  
death in the  
shadows





## CHAPTER 3

# PATHOLOGY AUDIT

### SUMMARY

The audit identified a total of 2412 deaths between September 1999 and August 2000 where epilepsy was mentioned anywhere on the death certificate. We reviewed 439 (43%) of 1023 post-mortems of people where epilepsy appeared anywhere on the death certificate. The audit also included a sample of 156 (11%) of deaths certified without post-mortem.

The investigation of the majority of the deaths (87%) involving a post-mortem was considered inadequate. The most frequent problem was that further investigations, such as toxicology, histology or neuropathology, were lacking or not standardised. The external and internal examinations were not satisfactory in 117 (27%) and 29 (7%) deaths respectively. Recording of information about the epilepsy and the circumstances of the death were variable, and pathologists indicated variable access to such information. The vast majority of the deaths were confirmed by the audit as being in keeping with epilepsy as the cause. However, whether or not a post-mortem was carried out, the stated cause of death was inconsistent and, in some cases, inappropriate. Two thirds of pathologists indicated that they had no mechanism for communicating their findings to relatives of people who died.

The findings from both the post-mortem examination audit and the doctor-certified deaths highlight the difficulty of establishing the true number of epilepsy-related deaths from certification data. National statistics are an important source for monitoring public health, setting targets for healthcare policies, and research aimed at reducing epilepsy-related deaths, and so it is important to have a high standard of certification in relation to these deaths. The findings support concerns first highlighted nearly 150 years ago (Bacon, 1868) and repeated more recently (Nashef, 1997).

### BACKGROUND TO AUDIT

Doctors can only certify a death where they know the cause. All deaths where the cause of death is in doubt should be reported to the coroner (in England, Wales, Northern

Ireland) or the procurator fiscal (in Scotland). A post-mortem or autopsy is a medical examination of the body of a person who has died and is carried out by a pathologist. If a death has been referred to the coroner or procurator fiscal and they instruct a post-mortem examination, then they arrange and pay for the examination and the consent of the nearest relative is not required.

There are national variations within the UK in relation to the system for the investigation of deaths and essential differences are identified below.

## National variations in the investigation of deaths

### *England and Wales*

Where a doctor attends during the last illness of a person who dies, there is a legal duty to issue a death certificate stating the cause of death. This is delivered to the local registrar of births and deaths. If the cause of death is unknown or, if the deceased was not seen by the certifying doctor in the 14 days before death or after the death, the registrar is legally obliged to refer the death to the coroner.

The coroner has a legal duty to hold an inquest when:

- a death is violent or unnatural
- a death is sudden and its cause is unknown (Coroners Act, 1988, section 8(1)).

A coroner may certify a death without post-mortem where a death is sudden but the cause is known. They may also order a post-mortem and if the cause is found to be natural, they may decide not to hold an inquest. In *R. v Coroner for Inner London North, ex parte Touche* (2000) the Court of Appeal held that a *prima facie* natural death required an inquest where it would not have occurred but for some culpable human failure.

In practice coroners certify nearly a quarter of all deaths in England and Wales, but most of these involve neither an inquest nor any suspicion of violence (Devis and Rooney 1999). They are referred to the coroner usually because they were sudden and unexpected, or because there was no doctor in attendance during the deceased's last illness.

### *Northern Ireland*

In Northern Ireland deaths are referred to a coroner in much the same way as in England and Wales, although the list of formal grounds for referral is more general including 'misadventure' and 'unfair means'. Referrals to the coroner are relatively less common (18% in 1996) and of those referred a significant percentage (37%) are certified without post-mortem (Devis and Rooney, 1999).

### *Scotland*

In Scotland the registrar of deaths is obliged to report to the procurator fiscal any death which falls into a broad range of some 20 categories. These include any unexplained death or where the doctor has been unable to certify a cause of death. The remit of the procurator fiscal is to rule out the risk of homicide or other crime or possible negligence

involved in the death. The procurator fiscal may interview relatives and other witnesses, and may call for a further medical report. The proceedings are conducted informally and in private. The procurator fiscal would normally then instruct a post-mortem examination to be carried out, but this is not obligatory.

There is no equivalent of an inquest in Scotland, but a small number of fatal accident enquiries (less than 100 a year) are conducted when it is considered that there is a public interest issue.

The procurator fiscal is not obliged to establish the precise cause of death in a medical sense, once the possibility of criminal proceedings has been ruled out. After the examination the pathologist issues the medical certificate of cause of death and in most instances the procurator fiscal's investigation is then complete and the body is released for funeral. The pathologist notifies the procurator fiscal on completion of the further investigations and an alteration to the cause of death can then be made.

All deaths categorised as SUDEP, should therefore be the subject of a fiscal enquiry. In recent years there have been a number of fatal accident inquiries into sudden epilepsy deaths.

## Negative autopsy

Although a post-mortem examination is the 'gold standard' for the investigation of death and accuracy of death certification, not all disease can be identified at the time of the examination. This is often referred to as a 'negative autopsy' as no pathology has been identified to account for death. In such cases a number of further investigations may need to be carried out:

- toxicology – the analysis of blood or other specimens for alcohol and drugs
- histology – the examination, under a microscope, of small representative pieces of major organs
- neuropathology – the examination of the brain and nervous system, usually by a pathologist who has special expertise in this field. At the time of the post-mortem the brain is extremely soft and if it is examined at this time valuable information will be lost. Where it is necessary to establish the cause of death, good practice is to retain the brain in a fixative to harden it. This enables the neuropathologist to obtain the best information.

If SUDEP is the cause of death the post-mortem examination (with the exception of injuries associated with a seizure such as a bitten tongue) results in an essentially negative autopsy. Thus full further investigation is essential.

- histology is required to eliminate another microscopic pathology
- toxicology is necessary to rule out an overdose or intoxication. It can also indicate levels of anticonvulsant medication in the blood, although it is recognised that interpretation of such post-mortem levels is complex.

Only if these investigations are undertaken and fail to identify an alternative cause of

death can the death be attributed to SUDEP.

The term SUDEP rather than 'epilepsy' is preferred, as it is now clearly defined and this definition recognises the fact that no positive confirmation of epilepsy as the cause of death is possible as the post-mortem is negative. It also reflects that other pathology can also cause death and result in a negative autopsy. However, the use of the term is recommended in deaths where epilepsy has been diagnosed and the circumstances are typical, as it identifies the death as consistent with being a consequence of the epilepsy.

## Remit of audit

This audit was able to look at the quality of information provided by pathologists to coroners and procurators fiscal and also at the quality of information provided by doctor certifiers. However, it was not possible to audit the decision-making and practices of coroner and procurators fiscal, including the conduct of inquests or fatal accident enquiries, as they are independent judicial officers.

We experienced some problems with access to information, as described in Appendix 2. In summary, access to post-mortem reports, coroner's officers or police reports varied from country to country and in England and Wales from coroner to coroner. Thus, although most coroners and procurators fiscal cooperated with this audit (see chapter 2), there are areas of the country which could not be included.

## Pathology results

A panel of pathologists whose practice includes the investigation of SUDEP and encompassing a variety of experience was established by the Royal College of Pathologists (see Appendix 1) to represent the College in the audit procedure. Domains and criteria for audit were developed by this pathology panel (see Appendix 2). In this section the published evidence for the criteria are listed and the audit findings for each criterion are recorded. A peer review by a pathology panel of the overall adequacy of post-mortem investigations follows the findings.

### Domains and criteria

The domains and criteria for the investigation of death were identified by the pathology panel from evidence in the published literature and guidelines relevant to the investigation of deaths. There are no published guidelines specific to the investigation of epilepsy deaths. Criteria were developed under the following domain areas:

- background
  - demographic details and relevant history should be included in the report
  - circumstances of death
- post-mortem examination
  - external examination: should include weight and height and a full examination including measurement of any injuries

- internal examination: should include description and relevant organ weights of every system, including the central nervous system
- further investigations
  - toxicology and histological examination must be undertaken
  - retention and fixation of the brain is desirable, failing which histological examination would be a minimum requirement
- cause of death
  - the report should include a summary/conclusions and state a cause of death.

### Background

A total of 439 (43%) of post mortem examinations were audited:

- 352 (80%) from England
- 27 (6%) from Wales
- 56 (13%) from Scotland
- 4 (1%) from Northern Ireland

Findings are reported for all deaths (Table 3.1) and for the post-mortem examination audit (Table 3.2). (1029 deaths were investigated by a coroner [in England, Wales, or Northern Ireland] or procurator fiscal [in Scotland] and of those 439 were audited.)

**Table 3.1**  
Findings – all deaths.

| Country           | Total deaths | Coroner/procurator fiscal | Doctor-certified |
|-------------------|--------------|---------------------------|------------------|
| England and Wales | 2060 (85%)   | 933 (45%)                 | 1127 (55%)       |
| Scotland          | 283 (12%)    | 86 (30%)                  | 197 (70%)        |
| Northern Ireland  | 69 (3%)      | 10 (14%)*                 | 59 (86%)         |
| Total             | 2412 (100%)  | 1029 (43%)                | 1389 (57%)       |

\* Six of these were certified without post-mortem.

**Table 3.2**  
Findings – post-mortem examination audit.

| Country           | Total coroner and procurator fiscal post-mortems | Audited post-mortems |
|-------------------|--|----------------------|
| England and Wales | 933 (91%)  | 379 (41%)            |
| Scotland          | 86 (8%)  | 56 (65%)             |
| Northern Ireland  | 4 (1%)   | 4 (100%)             |
| Total             | 1023 (100%)                                      | 439 (43%)            |

### History and demographic details

All deaths had been reported to the coroner or procurator fiscal. In all but 5 deaths (1.5%) in England the pathologist’s details were included in the report. Only in Scotland

did the report indicate that in any substantial number of deaths had the pathologist had access to GP notes or hospital notes (12 and 16 deaths, or 21% and 29% respectively). Access to other information was recorded in 30 deaths (54%) from Scotland and 151 (43%) in England but only 3 (11%) in Wales and in none of the 4 deaths in Northern Ireland.

A history of epilepsy was recorded in the majority of deaths: England 296 (84%), Wales 25 (93%), Northern Ireland 4 (100%) and Scotland 39 (70%). Further details regarding the epilepsy type and frequency of seizures were included in, respectively, only 65 (15%) and 133 (38%) in England, 2 (7%) and 7 (26%) in Wales, 2 (4%) and 10 (18%) in Scotland and 1 and 2 of the four deaths in Northern Ireland. Information about prescribed medication and other medical conditions was documented in 140 (40%) and 208 deaths (59%) in England, 14 (52%) and 22 (82%) in Wales, 18 (32%) and 26 (46%) in Scotland and 3 in Northern Ireland. A history of alcohol abuse was noted in between 13 and 25% of deaths.

### *Circumstances of death*

Particulars of the scene and the circumstances leading up to death were described in most of the deaths investigated in England, Wales and Northern Ireland (281, 24 and 3, or 80%, 89% and 75% respectively) but in only 24 (43%) deaths in Scotland. More detailed information about body position was given for two deaths in Northern Ireland but in 25% or less in the other countries. Witness accounts were rarely included; maximally 4 deaths (7%) in Scotland.

## **Post-mortem examination**

Criteria for assessment of the external examination included measurement of the height and description of post-mortem hypostasis and of injuries. These results are depicted in Figure 3.1 and show that these were documented in a much higher percentage of deaths in Scotland and Northern Ireland than in England and Wales.

The most objective element of the internal examination was recording of organ weights, which occurred in 88–100% of deaths.

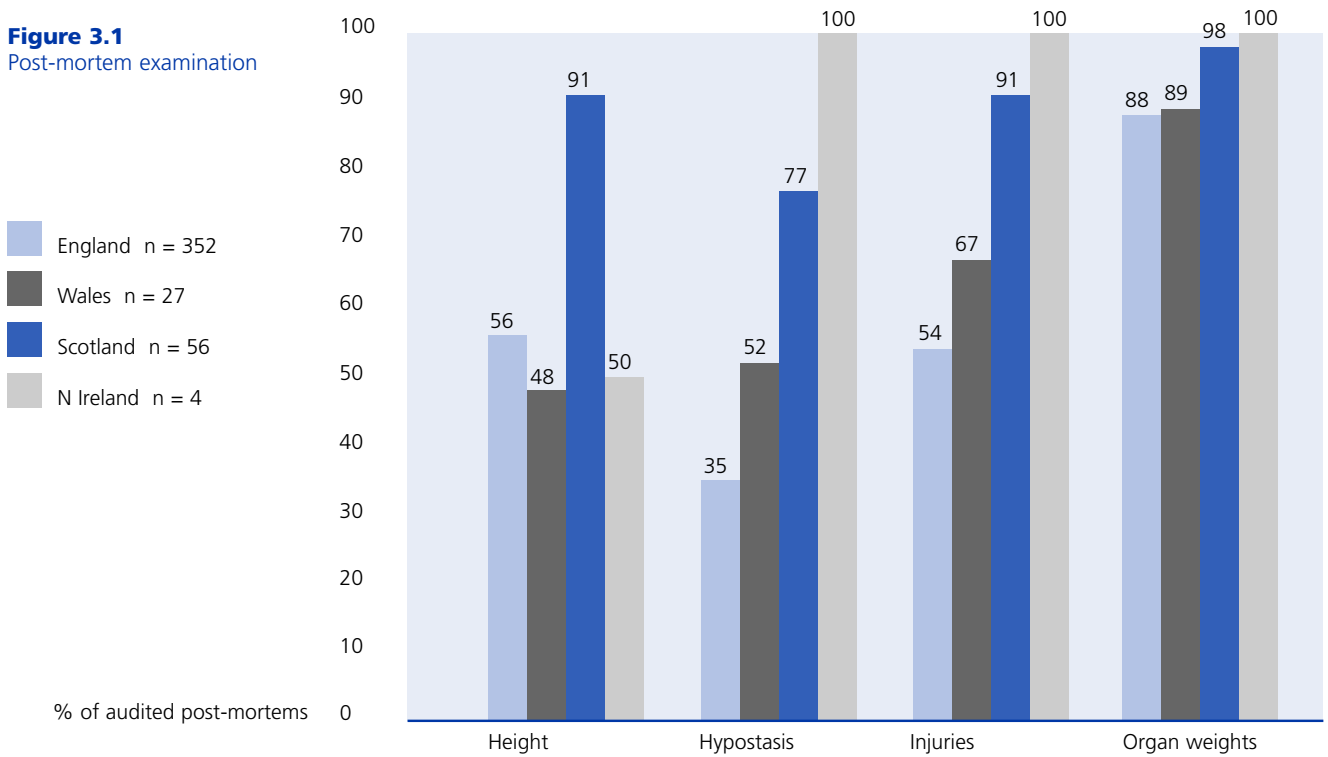
## **Further investigations**

Quantitative analysis of the deaths in which each of the further investigations were carried out is illustrated in Figure 3.2.

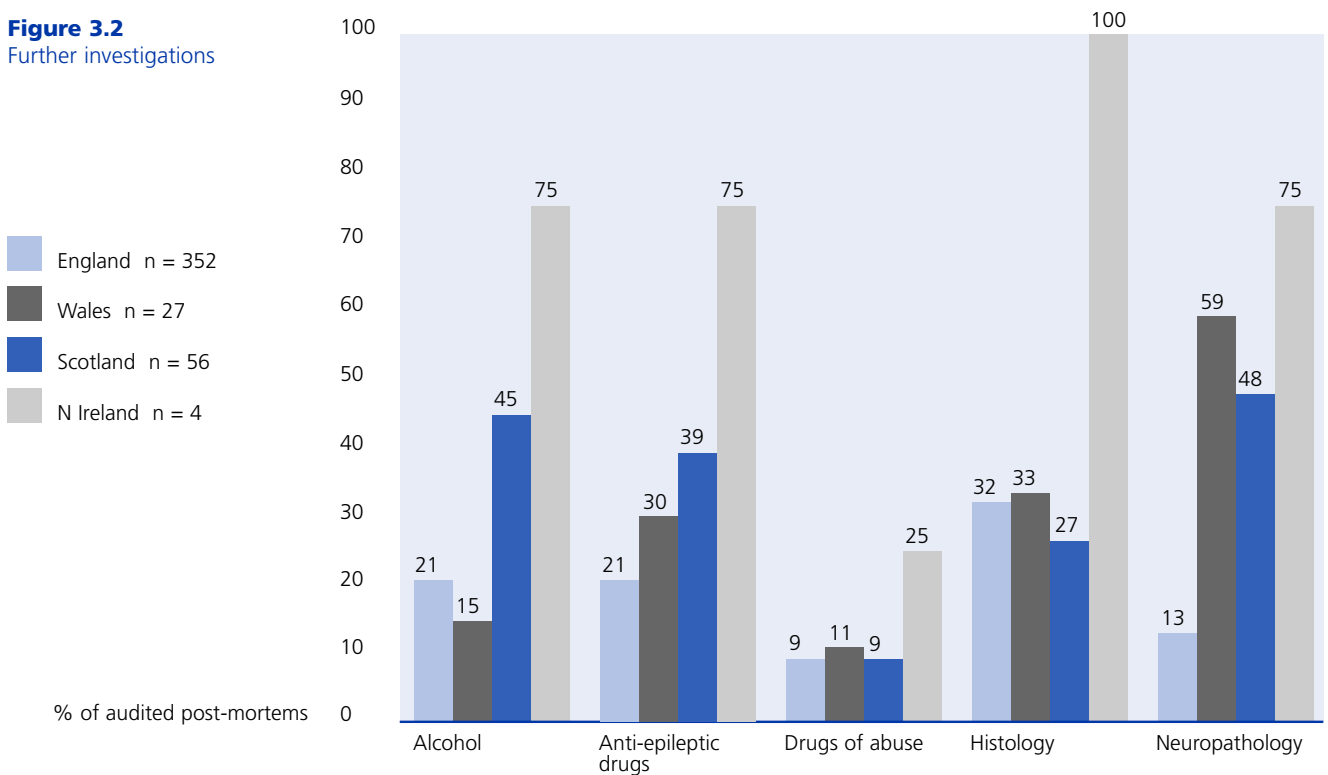
Toxicology was subdivided into alcohol, antiepileptic medication and drugs of abuse where the drugs detected, or analysed for, were indicated. Neuropathology entailed retention of the brain and subsequent examination, not necessarily by a neuropathologist.

With the exception of Northern Ireland, toxicology is most frequently carried out in Scotland and histology is undertaken in approximately one third of deaths throughout the UK. Neuropathology is the most frequently performed investigation in both Scotland and Wales (48% and 59% respectively) in contrast to 13% in England.

**Figure 3.1**  
Post-mortem examination



**Figure 3.2**  
Further investigations



We could only assess further investigations on the information present in the post-mortem report(s) available to the audit. Some toxicology reports indicate only the positive findings, not all the drugs for which analysis was requested, and therefore this information was not always complete. It is also possible that separate, supplementary reports detailing further investigations were not submitted to the audit.

## Cause of death

A variety of terms was used for the cause of death, the most frequent being 'epilepsy' (in 230 deaths). 'Epileptic seizure' was used in 74 deaths, and 'SUDEP' or a variant was used in only 53 deaths. 'Status epilepticus' was the stated cause in 32 deaths. Other terms, including 'unascertained' and 'SADS' (sudden adult death syndrome), were used in a small number of deaths.

An additional cause was given for some deaths: aspiration of gastric contents (22), cardiorespiratory arrest (18), asphyxia (15), hypoxia (14), pulmonary oedema (7) and cerebral ischaemia (6).

## PEER REVIEW OF INVESTIGATION

Peer review was carried out by members of the pathology panel, each post-mortem examination being graded as adequate or inadequate by a panel member individually. If inadequate, the following area (s) of concern were identified:

- external examination
- internal examination
- further investigations
- cause of death.

A panel discussion subsequently took place to confirm uniformity of assessment. If there was concern regarding the accuracy of the audit data, the post-mortem report was available to the lead pathologist for verification.

## Adequate investigation

A post-mortem examination was regarded as adequate only if all four categories mentioned above were acceptable. The post-mortem examinations were considered to be adequate for all four Northern Ireland deaths. For the other countries the percentage found to be adequate varied:

- England      45 (13%)
- Scotland     5 (9%)
- Wales         2 (7%)

A substantial proportion of post-mortem examinations were inadequate only as a result of at least one further investigation not having been done:

The deceased had a history of neurological symptoms but no neuropathological examination was carried out.

A history of phenytoin toxicity but no toxicology performed.

No analysis for alcohol despite a history of alcohol abuse.

A death of a pregnant woman (24 weeks gestation) in which no histology or neuropathology was carried out. A case where the report stated that 'multiple tissues including whole brain and heart retained as per consent' but with no histology included in the report and no indication as to the purpose of retention.

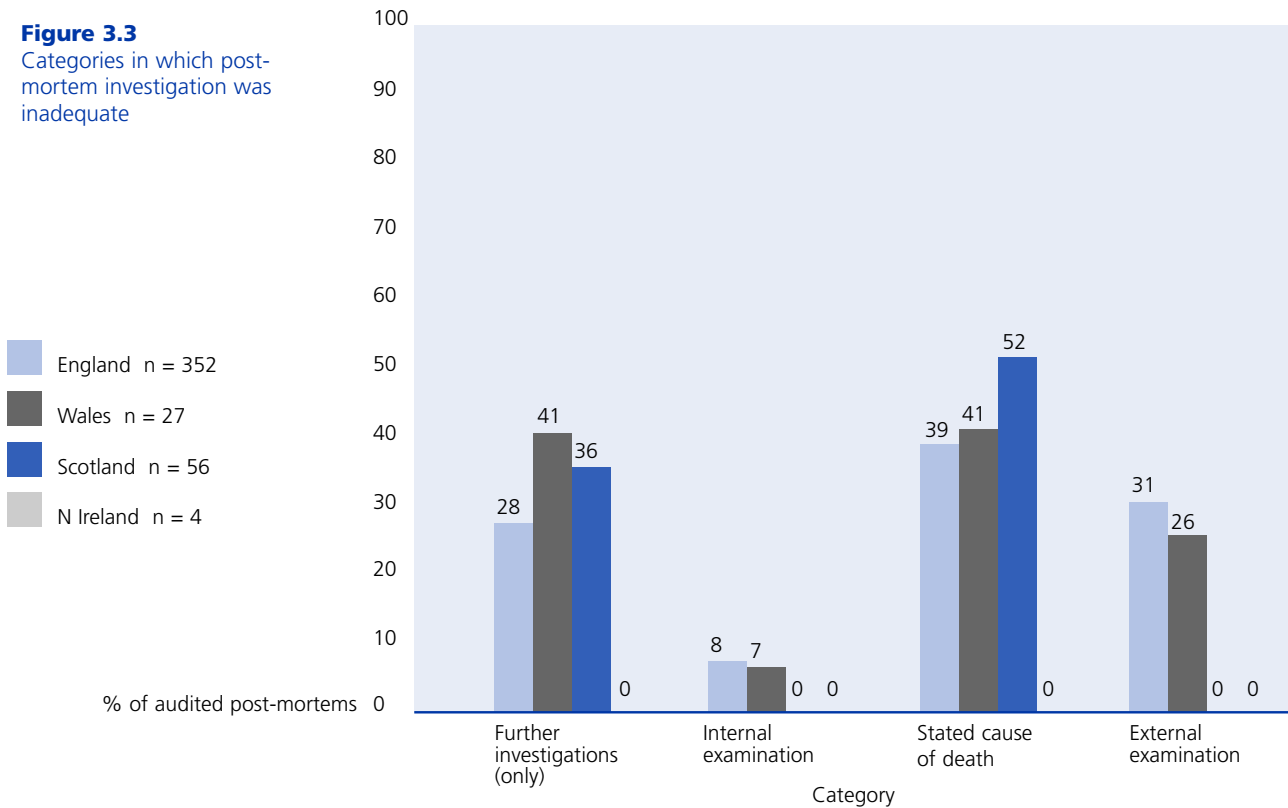
A death where the report included the comment 'the Coroner was sure that the relatives would not wish the brain to be kept so no tissue was retained.'

- England 99 (28%)
- Scotland 20 (36%)
- Wales 11 (41%)

Any toxicological analysis – not necessarily a full screen for alcohol, antiepileptic drugs and drugs of abuse – was accepted. As a consequence of current concerns about organ retention, a subcategory where the only problem was a lack of retention of the brain was included; very few investigations fell into this subcategory – 10 (3%) in England and 2 (4%) in Scotland. In view of this problem, retention of the brain was not considered an absolute requirement if a thorough description was documented and histological examination completed.

For virtually all the other examinations at least one additional category was considered to be inadequate (see Figure 3.3). In only 6 deaths was a lack of further investigations not one of the reasons for an inadequate examination. Examples are illustrated alongside this text.

**Figure 3.3**  
Categories in which post-mortem investigation was inadequate



'Elderly Caucasian female. No obvious operation scars. No marks of external injury.'

'Body was that of a grossly obese young adult white female.'

'A hirsute male.'

The external examination was inadequate in 110 deaths in England (31%) and 7 (26%) in Wales but none from Scotland. In a few instances an incorrect interpretation of findings was the reason for a case being considered inadequate: for example, petechiae within hypostasis described as 'suggestive of asphyxia'. In most cases the problem was the brevity of the description of external examination. Examples of complete external examinations which were considered inadequate are illustrated alongside this text.

The internal examination was inadequate in 27 (8%) of deaths in England and 2 (7%) in Wales, but considered satisfactory in all the Scottish deaths. The usual failing was that the weights of the major organs were not recorded. In a small number of cases the examination was incomplete (e.g. the head was not examined), or there was an incorrect interpretation of the findings (e.g. mottled lungs were described as consistent with asphyxia).

## Cause of death

The cause of death was regarded as inadequately stated in 138 deaths (39%) in England, 11 (41%) in Wales and 29 (52%) in Scotland. The major problems were:

- a cause of death given as status epilepticus or epileptic seizure when the death was unwitnessed or there was no documented seizure
- death attributed to aspiration of gastric contents but aspiration was not witnessed and no food was described in the airways (in such instances confirmation of a vital reaction to the aspirated material on histology is required)
- death attributed to asphyxia on non-specific findings
- co-existing pathology and no apparent rationale for which pathology death is attributed to
- clinical circumstances or post-mortem findings indicate an alternative cause of death
- every medical condition listed whether contributory or not.

Examples are illustrated alongside this text.

A death was certified as SUDEP despite sudden death occurring 15 minutes after the person was last seen to be alive and evidence of significant heart disease that could account for the death (a heart enlarged to 530g and coronary atheroma) and of metastatic carcinoma of the lung.

A death, which was sudden and unwitnessed, occurring after complaining of not feeling well, was certified as '1a status epilepticus due to 1b pulmonary thromboembolus and ischaemic heart disease'.

A sudden, unwitnessed death was certified as epilepsy despite significant cardiac disease (cardiomegaly of 720 g) that could equally account for the death. The heart disease was not mentioned on the certificate.

A death certified as due to coronary atheroma with epilepsy as contributing to death (in Part II) where the deceased was found submerged in the bath and the post-mortem examination describes typical features of drowning.

A person with epilepsy who died after witnessed seizures, and whose death was attributed to hypertensive and ischaemic heart disease with epilepsy mentioned in Part II in addition to diabetes.

Death certificates where every medical condition is listed even if it could not have caused or contributed to death, e.g. 1a multiple organ failure due to 1b epileptic seizure due to 1c uraemia and bronchopneumonia. Under Part II cerebral contusions, renal failure, adenocarcinoma of the prostate, anaemia, ischaemic heart disease, previous myocardial infarction.

## SURVEY OF PATHOLOGISTS

The Royal College of Pathologists supported a survey of pathologists. We sent 195 questionnaires to pathologists who had performed a post-mortem on an audited death, and 1315 to neuropathologists, histopathologists and forensic pathologists (members of the Royal College of Pathologists).

### Audited deaths

A total of 107 questionnaires were returned from pathologists who had performed a post-mortem examination on an audited death (55% response rate).

All responding pathologists were consultants who performed post-mortem examinations on people with epilepsy. Ninety pathologists (84%) had a mixed workload of surgical histology and post-mortems; the remaining 17 stated that their work was principally post-mortem examinations. The range of number of post-mortem examinations performed per year was 30–700 (median 180). The term SUDEP was understood by 94 pathologists (88%) but only one replied that written local guidelines for the investigation of epilepsy deaths existed. Replies from 72 pathologists (67%) indicated that there was no mechanism for discussing the results of the post-mortem with the relatives.

The majority of pathologists reported that they were usually provided with:

- previous medical history – 101 pathologists (94%)
- medication history – 99 pathologists (93%)
- circumstances of the death – 104 pathologists (97%)
- position of the body – 64 pathologists (60%).

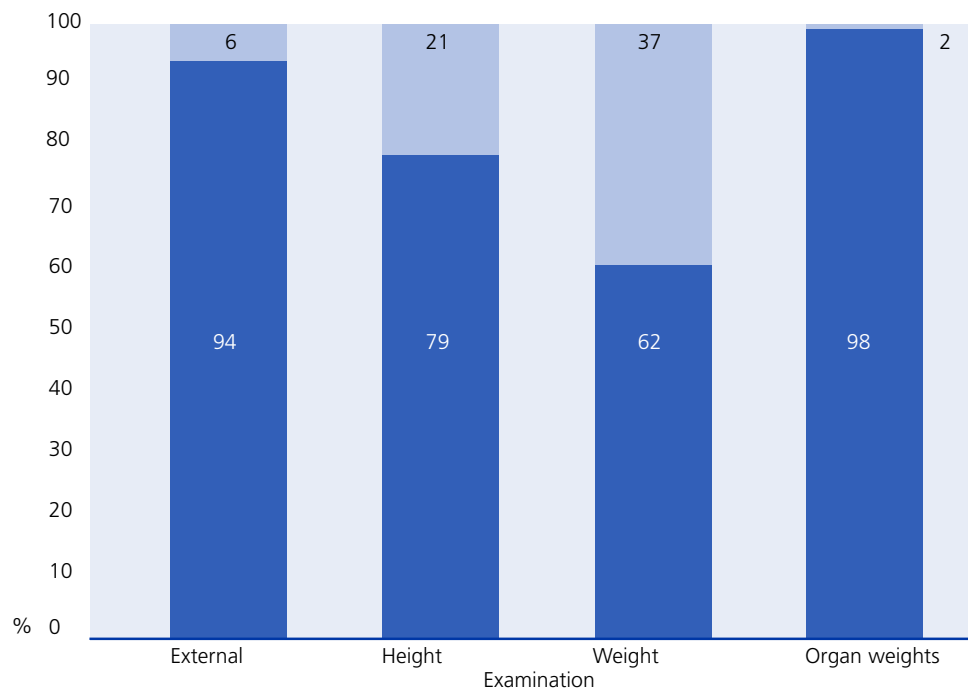
The most frequent source for this information was a coroner’s officer (71 pathologists, 66%) or police report (32 pathologists, 30%).

Access to medical records was less frequent with 35 pathologists (33%) having hospital notes available and 15 (14%) GP notes.

In response to the questions regarding routine post-mortem practice (Figure 3.4), 6 pathologists (6%) indicated that they do not routinely perform a full external examination, 23 (21%) do not record the height and 40 (37%) do not record the weight. A minority of pathologists, 32 (30%), remove the organs themselves but 105 (98%) stated that they routinely weigh the major organs.

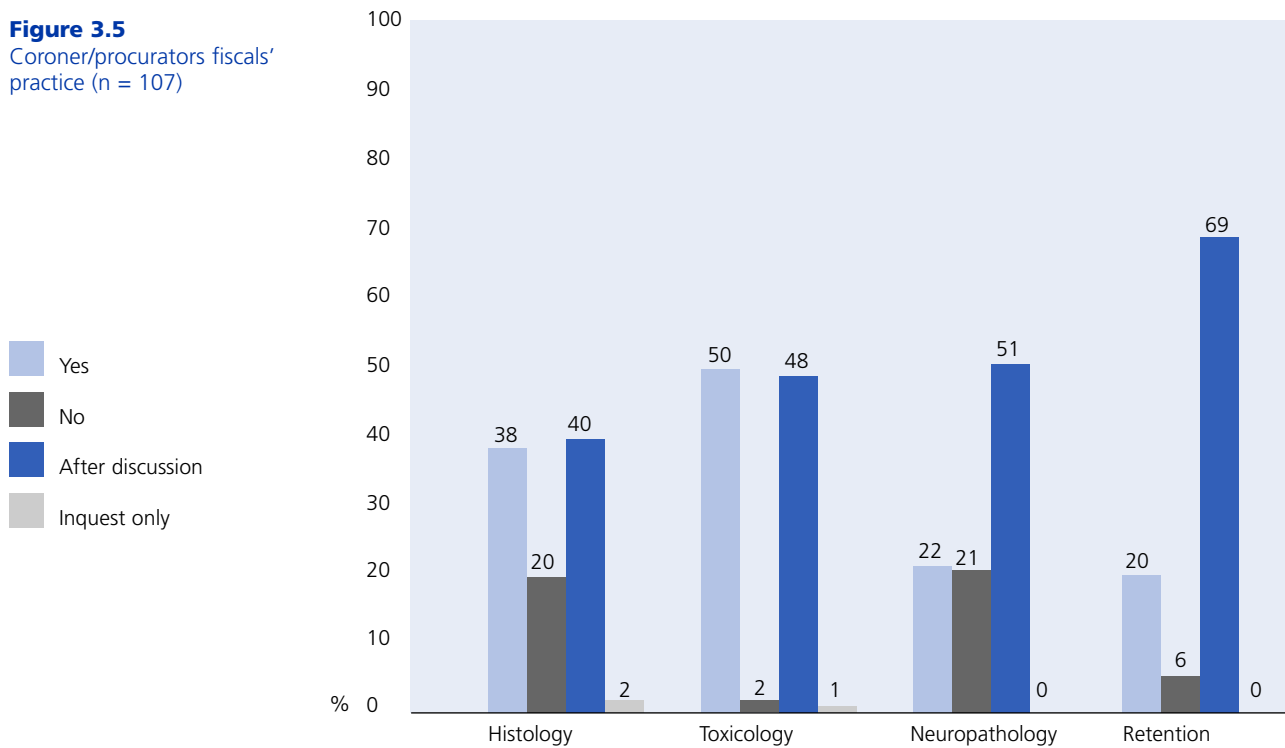
**Figure 3.4**  
Pathologists’ routine practice  
(n = 107)

■ No  
■ Yes



The practice of coroners or procurators fiscal with regard to funding of further investigations or allowing retention of tissues or organs was investigated by asking the pathologist whether each further investigation was authorised automatically, after discussion in inquest cases only or not at all. The findings indicate that coroners or procurators fiscal will authorise and fund, automatically or after discussion, 78% of histology, 98% of toxicology and 73% of neuropathology. Retention of the brain would also be authorised in 89% of such deaths, albeit only after discussion in 69% of cases.

**Figure 3.5**  
Coroner/procurators fiscals' practice (n = 107)



A few pathologists (2% and 1% respectively) said that histology or toxicology was authorised only if there was going to be an inquest. In contrast, 63 pathologists (59%) said they would carry out histology, 71 (66%) would take samples for toxicology and only 21 (20%) would have a neuropathologist examine the brain.

Pathologists who commented highlighted four main areas of concern in post-mortems on possible SUDEP deaths.

- a lack of detailed information available to the pathologist before the post-mortem
- problems persuading the coroner or procurator fiscal to retain the brain and the need to highlight to them its importance in the investigation
- a lack of knowledge of, or access to, interested local neuropathologists and faster fixation methods e.g. microwave fixation
- a need for guidance or information on best practice in the investigation of these deaths.

### Control group of pathologists

A total of 393 pathologists who had not been involved in an audited case also returned a questionnaire – a 30% response rate.

In comparison with those who had performed a post-mortem:

- this group included 6 (1%) who were fully trained but did not hold consultant posts
- a similar percentage, 348 (88%) had a mixed workload of post-mortems and surgical

histology but 48 pathologists (12%) indicated that they did not perform post-mortems on people with epilepsy

- the number of post-mortems performed by an individual pathologist was wider, ranging from 5 to 850 with a lower median of 130
- a smaller percentage of pathologists (296, 75%) were aware of the term SUDEP but a similar 1% (4 pathologists) said local guidelines existed for the investigation of epilepsy deaths
- slightly more pathologists, 141 (35%) were able to discuss findings with relatives
- information was less frequently provided on previous medical history (344, 87%), medication (323, 82%), the circumstances of death (348, 82%) or the position of the body (213, 54%). The replies regarding additional information were similar with slightly fewer pathologists receiving each source
- routine post-mortem practice in this group was similar with respect to external examination and body weight, 16 pathologists (4%) not carrying out an external and 127 (32%) not weighing the deceased. More pathologists (127, 32%), however, did not record the height and a smaller percentage said they recorded organ weights (347, 88%)
- the percentage of pathologists indicating that funding was available for histology and toxicology was less, respectively 71% and 81%, but only 1% fewer indicated problems with funding for neuropathological examination. There was a similar decrease in pathologists indicating that they would request toxicology (198 pathologists, 50%) in contrast to an almost identical percentage indicating they do histology (227 pathologists, 58%) and greater numbers who would request neuropathology (98 replies, 25%).

## DOCTOR-CERTIFIED DEATHS

The audit identified 1389 deaths in people with epilepsy, where the death was certified by a doctor without a post-mortem examination. This figure includes not only deaths where epilepsy was only mentioned under Part II of the certificate as a contributory factor but also deaths that were directly attributed to epilepsy. The moderation exercise (see Appendix 2) categorised only 13% of probable epilepsy deaths as certified without coroner or procurator fiscal post-mortem.

We undertook a limited audit of a sample of 156 (11%) of deaths certified without coroner or procurator fiscal post-mortem. Availability of data and access to it were the primary factors in sample choice. The audit officer audited the medical records of the deceased for evidence in the record of all conditions listed in the certification of death, and transcribed any record describing the circumstances of the death. The numbers of deaths and the distribution of epilepsy as causal or contributory to death as certified are shown in Table 3.3.

**Table 3.3**

Numbers of deaths and the distribution of epilepsy as causal or contributory to death as certified

|                  | <i>Epilepsy as causal to death</i> | <i>Epilepsy as contributory to death</i> |
|------------------|------------------------------------|--|
| Northern Ireland | 13                                 | 50                                       |
| Scotland         | 21                                 | 54                                       |
| England          | 5                                  | 13                                       |
| Total            | 39                                 | 117                                      |

A total of 150 of these 156 deaths were certified by a doctor. Of these 94 were known to be certified by a GP, and 36 by a hospital doctor. In Northern Ireland 6 deaths were certified without post-mortem by a coroner.

Four elements were evaluated:

- on the information available, did the certification appear appropriate?
- was epilepsy certified as the cause of death in a sudden death without post-mortem?
- did epilepsy appear on the death certificate without a recorded diagnosis of epilepsy?
- was epilepsy certified in Part II when it was apparently non-contributory to death?

## Results

- In 14 of the 39 deaths, which were directly attributed to epilepsy (36%), the certification appeared appropriate
- In 15 of these 39 (38%) the death was sudden. In 5 (13%) the circumstances were in keeping with SUDEP. One death was actually certified as SUDEP
- The certified cause of death in the other 38 deaths was status epilepticus or epileptic seizure in 12 cases each and epilepsy in 13. The remaining death was certified as drowning
- In 13 of 50 deaths (26%) where epilepsy was recorded under Part II of the death certificate as contributory, there was no recorded diagnosis of epilepsy in the records
- In 39 of the total 117 (33%) deaths where epilepsy was recorded under Part II on the basis of the cause of death as certified, epilepsy would appear to have no contribution to death.

## DISCUSSION AND CONCLUSIONS

It is worrying that in this audit the investigation of death by pathologists is so often considered inadequate. In England, Wales and Scotland 43% of coroner/procurator fiscal post-mortems were audited and only between 7% and 13% were acceptable in all aspects of external examination, internal examination, further investigations and cause of death.

For between 28% and 41%, however, the only problem was a lack of at least one of the three further investigations (histology, toxicology and neuropathology). In some of these cases the remainder of the post-mortem examination was of a high standard. Regional variations were apparent, with internal and external examinations being particularly poor

in England (8% and 31% respectively) and the adequacy of the stated cause of death being a significant problem in Scotland (52%). Despite widespread concerns about organ retention and its implications for neuropathology, in only 12 deaths was this the only problem with a case.

The pathology service questionnaire did not indicate any major differences between the 107 pathologists involved in an audited case and the 393 who replied who were not: if anything, the responses from the former indicate a better practice.

## Background information

A history of epilepsy was recorded in 83% (364) of all post-mortems. Detailed information about the epilepsy was recorded in the post-mortem reports for a minority of deaths (4–38%), and description of the past medical history and medication was variable (32–82%). This could either reflect that the pathologist did not have the information, or that they were in receipt of it but did not include it in their report. The pathology service questionnaire suggests that the latter is most frequently the case, as 82% or more of responding pathologists indicated that they were usually provided with these details. The audit and the pathology service questionnaire both indicated that hospital or GP notes are not available to the pathologist in most cases, and that the police or the coroner was the source of information. This includes the circumstances of the death, which were described, at least to some extent, in 75% or more of reports. The exception is Scotland where only 43% of reports included this information. As the procurators fiscal will enquire into the circumstances of all deaths in Scotland reported to them, this variability must reflect individual pathologist's practice.

## Post-mortem examination

Of the post-mortem examinations we audited, 73% (322) met the criteria for external examination and 93% (410) met the criteria for internal examination.

The examination, both external and internal, was adequate in 100% of post-mortems in Scotland and Northern Ireland but inadequate in up to 31% in England. For example, in almost 50% of deaths in England height was not recorded, and 21% of the pathologists who replied confirmed that they do not do this (no breakdown by country is available for the pathology service questionnaire). One factor in this may be the greater percentage of post-mortems performed by forensic pathologists in Scotland and Northern Ireland.

The level of further investigation carried out was extremely variable. A possible explanation for this is a lack of funding by a coroner or procurator fiscal, or their refusal to authorise the investigation. However, in responding to the service questionnaire between 71% and 98% of pathologists indicated that funding was available, and 89% replied that retention of the brain would be allowed, albeit often after discussion. It is a matter of concern that the replies to the questionnaire indicated that only 58%, 54% and 24% of all responding pathologists would request histology, toxicology and examination of the brain by a neuropathologist, respectively. It is of equal concern that up to 29% of pathologists indicate that their coroner or procurator fiscal will not authorise or fund a complete post-mortem examination and are therefore instructing an examination which

cannot be adequate in these circumstances.

Only one third of pathologists replying to the service questionnaire said there was a means whereby they could communicate the findings from the post-mortem to families.

## Cause of death

All post-mortems met the criteria for giving a cause of death, but it was noted by the panel that for 178 deaths (41%) the cause of death was inadequately stated. The phrasing of cause of death was very variable, presumably due at least in part to an individual pathologist's preference, and a few pathologists using inadequate terminology could account for the high percentage of poor certification in Scotland. Death was categorised as SUDEP in only just over 10% of the audited cases, although this term has been in use since 1997. Asphyxia and aspiration of gastric contents are still being implicated in death in a significant number of cases where there is no pathological evidence to support such a diagnosis.

For deaths that were certified as being due to epilepsy without a post-mortem examination, approximately one third of the certifications appeared appropriate, e.g. a death occurring in hospital following seizures and hypoxic brain damage or multiple organ failure. One third of these deaths were sudden and/or unwitnessed, so certification as epilepsy or SUDEP cannot be confidently made without a post-mortem examination to exclude unrecognised disease or intoxication. In 26% of the deaths certified as epilepsy having contributed to death, there was no mention of epilepsy in the medical notes. Unless the epilepsy was diagnosed shortly before death, this presumably reflects poor communication between primary and secondary care, or poor recording of information in notes.

The findings from both the post-mortem examination audit and the doctor-certified deaths highlight the difficulty of establishing the true number of epilepsy-related deaths from certification data. A number of deaths, which on certification would appear to be definitely due to epilepsy, have been found to have possible alternative diagnoses. Similarly, some deaths where epilepsy appears under Part II as only contributory, when audited appear – at least possibly – to be epilepsy deaths. In other deaths epilepsy appeared on the death certificate, particularly under Part II as contributory, although it would appear to have had no role in the death.

Accurate death investigation and certification of epilepsy-related deaths is necessary if this is to be a reliable source of data for public health surveillance, research and for effective policy making in relation to the prevention of epilepsy-related deaths.

It has been reported elsewhere that doctors have little training in how to complete medical certificates of the cause of death, and uncertain knowledge of their legal obligations (Devis and Rooney, 1999). Many are unaware of the uses to which their information will be put, including the policy decisions that may ultimately affect their own practice.

This audit was able to draw on a sample of doctor certificates, and the findings identify an area of concern. The key issues identified are the accurate identification of a sequence of events (where present), together with a clear understanding of the nature of the underlying cause of death. Several authors (e.g. Timmings, 1998) emphasise the importance of educating medical professionals in SUDEP such that the cause of death is accurately recorded and that the need for post-mortem investigation is appreciated.

## System for investigation of epilepsy deaths

Concern about investigation and certification of epilepsy deaths were highlighted as early as 1868 in an article in the *Lancet* (Bacon 1868). Coyle *et al.* (1994) suggested that reporting of SUDEPs by coroners was a possible cause for concern. Inconsistencies were observed in post-mortem reports, in both the investigations performed and the observations at time of death. It was noted that there were large differences in the degree of detail recorded with respect to the type and history of epilepsy; in 70% of deaths it was either unknown or unrecorded. The attributed cause of death varied considerably. Disparities were also observed in the coroner's verdicts.

Our audit has found that such disparities continue. The panel noted that the remit of the existing system for investigation of deaths is not designed to address these disparities. In England, Wales and Northern Ireland the primary purpose of the coronial system is to prevent homicide going undetected and to provide a check on legislation affecting public safety. In Scotland, where the remit of the procurator fiscal clearly extends to negligence, the remit still falls short of requiring the identification of a precise medical cause of death. Pathologists carrying out post-mortems for coroners and procurators fiscal often may not have access to medical records to confirm diagnosis and medical history. The need to confirm diagnosis and clinical history is not a priority when the primary purpose of these investigations is legal.

Primary and secondary care findings in relation to epilepsy deaths have highlighted problems of access by the people who died to regular review of epilepsy and recording of information. The panel noted the importance of the pathologist having access to standardised information collected from all relevant sources, including family members, on the history of the deceased and the circumstances of death.

The panel noted the existence of alternative systems for the investigation of sudden epilepsy deaths. In Sweden the investigation of sudden and unexpected deaths is the responsibility of a local public health official who may consult medical records and medical personnel before deciding what is the appropriate level of investigation (Devis and Rooney, 1999). In England, the Chief Medical Officer has recently recommended that the number of people who die as a result of epilepsy should be reduced (CMO, 2001) and a European White Paper on Epilepsy has called for national monitoring of mortality data of epilepsy (EUCARE, 2001). National statistics are an important source for monitoring public health, setting targets for healthcare policies, and research aimed at reducing epilepsy-related deaths. The results of this audit indicate that because of the high percentage of inadequately investigated epilepsy-related deaths, action should be considered to improve the quality of death certification in relation to these deaths.



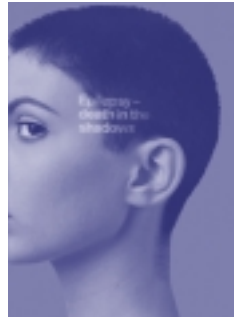


Part III:

# **PRE-MORTEM AUDIT**

Epilepsy –  
death in the  
shadows





## CHAPTER 4

# PRIMARY CARE

People with well-controlled epilepsy can be managed in general practice (Taylor, 2000). General practitioners see the disease in its early stages – which specialists very rarely have the opportunity to do – and can follow it through from the beginning to the end of the illness (Mackenzie, 1939). Management of chronic conditions is a central part of family medicine and aims to:

- prevent complications (rather than attempt a cure)
- encourage people to take responsibility for their condition
- minimise the degree of handicap and help families adjust and adapt (Schofield, 1984).

Protocols for continuing care of asthma, diabetes and ischaemic heart disease have been developed by many practices as a result of successive government White Papers (HMSO, 1989, 1997), but epilepsy has not yet been given such attention.

The audit assessed care by collecting information from GP notes and therefore did not measure non-recorded clinical activity or information available from specialist letters. Although every effort was made to gain access to all sources of clinical material, there may be some clinical information sources not available to the field workers, because of the dual system of computer and handwritten notes that exists in many UK general practices.

Previous audits of epilepsy care have highlighted shortcomings in record-keeping (Goodridge and Shorvon, 1983; Jacoby *et al.*, 1996; Chappell and Hall, 1997), and this audit reflected sparse clinical note-keeping. This chapter sets out criteria, findings and panel comments but the numbers of results vary because of the variable recording of clinical information.

Results were analysed for two populations:

- people with epilepsy who did not receive secondary epilepsy care (group A)
- people with epilepsy who were referred to and received secondary care (group B).

## AUDIT TOOLS

Primary care audit tools were developed using information from available guidelines and literature and primary care panel discussions (see Appendix 2). One tool was adapted to focus on those who were managed in primary care alone and another for those who had received secondary epilepsy care. Both tools were designed to collect data from the records of people who had died of an epilepsy-related cause. Duplication of data collection was minimised by collaborative meetings between representatives from the primary and secondary care panels during tool development.

## AUDIT POPULATIONS

### Group A: the primary care only population

This group of 45 people, of whom 27 (60%) were men, received primary epilepsy care either in general practice or in an accident and emergency department. Their mean age at death was 52 years (minimum 23; maximum 79; SD 13). Thirteen of the group (29%) died within 5 years of diagnosis, and 31 (69%) were aged between 31 and 60 years at death.

With such a small sample one must be cautious about comparisons with the general population, but people born about 52 years ago could expect on average to live to 69 years. The mean age at death of this group of 52 years suggests premature death.

This group received epilepsy care in general practice, but had no secondary care. There were three reasons for this:

- some people died as a result of a first seizure
- some had been referred but died while waiting for a hospital appointment
- some others were not referred for secondary care. The precise reasons for non-referral were difficult to define because of scanty clinical information, but referral may be less likely for those people who had significant co-morbidity (Hall *et al.*, 1997). In this group 3 had dementia (7%), 18 had a history of alcohol abuse (40%) and 7 had learning disabilities (16%).

### Group B: the population referred and seen in secondary care

The field workers gained access to the primary care notes of 241 people who had been referred and received secondary epilepsy care. The mean age at death was 41 years, significantly lower than that in group A. People born about 41 years ago could expect on average to live until 71 years. The panel considered that changes in the NHS in the 5 years before the audit may have influenced care, and so the group was divided into those diagnosed 5 years or less before their death (47 people, 20%) and those diagnosed more than 5 years before death (194 people, 80%). Analysis of these sub-groups showed no difference for :

- type of professional providing epilepsy information
- consultation with their GP within 28 days before death
- lack of investigations
- the type of professional reviewing epilepsy
- adherence to drug treatment and checking of drug level, and associated other health problems.

The referral process was analysed on people diagnosed within 5 years of death, to make results more generalisable to current practice, because of changes in the health service and the problems of access to old GP records.

## AUDIT DOMAINS AND CRITERIA

In the following sections, the characteristics of groups A and B are outlined, the published evidence for each criterion is listed and the audit findings for appropriate populations for each criterion are recorded, followed by panel discussions about the implications of the findings.

The audit domains and criteria in the context of primary care are:

- access and clinical assessment
  - diagnosis and referral
    - contact after first seizure
    - time to specialist appointment
    - choice of specialist
    - specialist referral
  - co-morbidity
- investigations
  - in primary care
- treatment and therapies
  - drug treatment
  - other therapies
- continuing care
  - management plans
  - frequency of review
  - purpose of review

- choice of professional
- information and support for people with epilepsy
- contact with relatives after an epilepsy-related death
- communication between professionals and services.

## RESULTS OF AUDIT

### Access and clinical assessment

#### *Diagnosis and referral*

| Contact after first seizure   |
|---|
| <u>Criteria</u>   |
| <ul style="list-style-type: none"> <li>• Urgent advice required by patient and family (Hall <i>et al.</i>, 1997; LHA, 1999; Taylor, 2000)</li> <li>• No preferred contact identified (all sources)</li> </ul> |

#### Findings

Table 4.1 details first seizure contact for all 45 people in group A. In this group, 9 of the 11 people (82%) with new epilepsy were seen the same day: 8 (73%) attended an accident and emergency department and 3 (27%) attended their GP. Information for newly diagnosed people in group B can be found in Chapter 5.

**Table 4.1**  
Group A: first seizure contact

|                        | N  | %   |
|------------------------|----|-----|
| GP                     | 21 | 47  |
| Accident and emergency | 11 | 24  |
| NHS Direct             | 0  | 0   |
| Ambulance              | 1  | 2   |
| Other                  | 5  | 11  |
| No contact             | 7  | 16  |
| Total                  | 45 | 100 |

#### *Comment*

*The panel agreed that everyone with a new episode should be seen the same day to gather important history from the person concerned or any witnesses, and to allay anxiety. However, some people with partial epilepsy are initially unaware that their symptoms are due to epilepsy. The early recognition and immediate care of people who have a generalised episode and the potential risk of seizures raises the issue of education*

and training for professionals in the ambulance service, accident and emergency and general practice, and for the general public, and the issue of communication between agencies.

### Time to specialist appointment

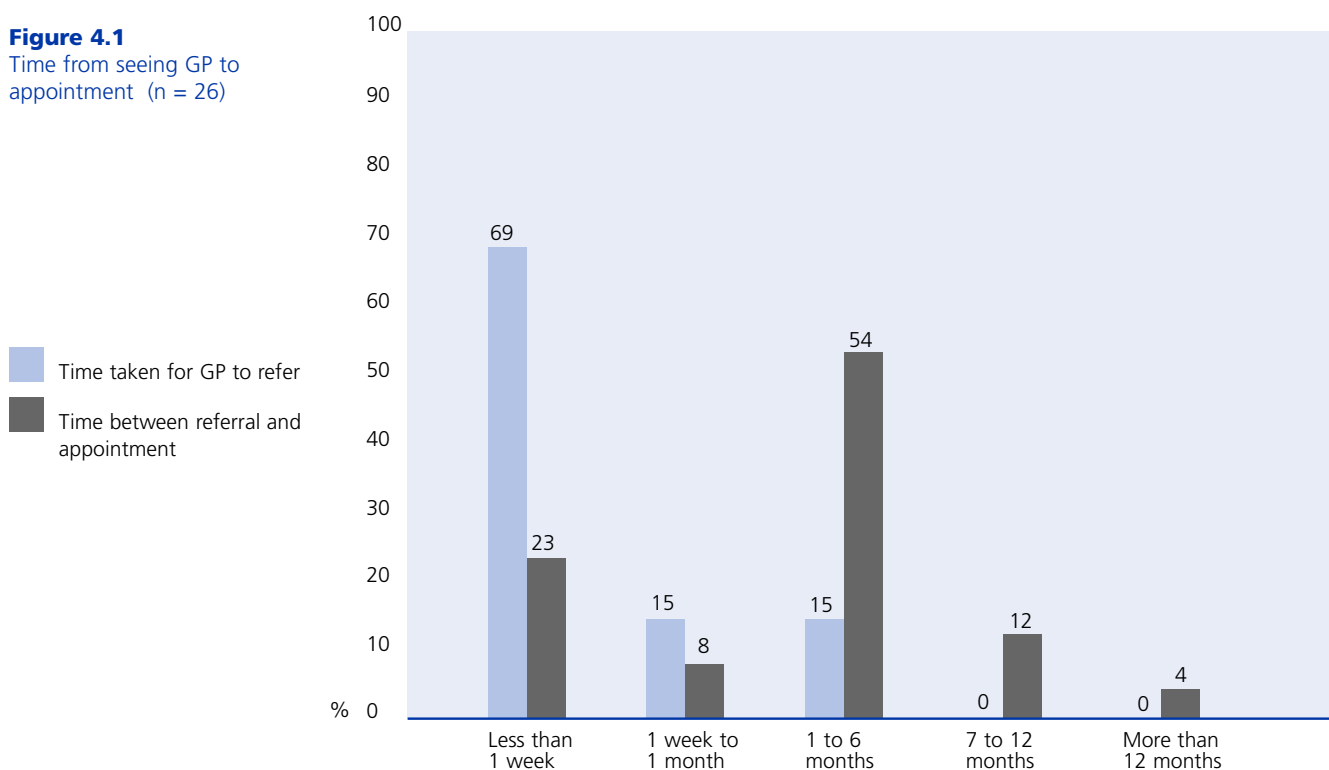
#### Criteria

- within 4 weeks (Hall *et al.*, 1997; Taylor, 2000; LHA, 1999)
- urgently (SIGN, 1997)
- immediately (BAHA, 1998).

### Findings

Information from group B (the group receiving secondary care) was taken only from those with a diagnosis in the 5 years before their death ( $n = 47$  or 20%) to reflect current practice, and to benefit from more accessible data available in this sample. Data about the time taken for the GP to refer was recorded in 26 (55%) cases and revealed 18 (69%) had been referred within a week; but for 4 (15%) it had taken between 1 and 6 months. Data about waiting times revealed 8 (31%) people seen <1 month, 14 (54%) 1–6 months, but 3 (12%) had to wait between 7 and 12 months and 1 (3%) >12 months.

**Figure 4.1**  
Time from seeing GP to appointment ( $n = 26$ )



**Comment**

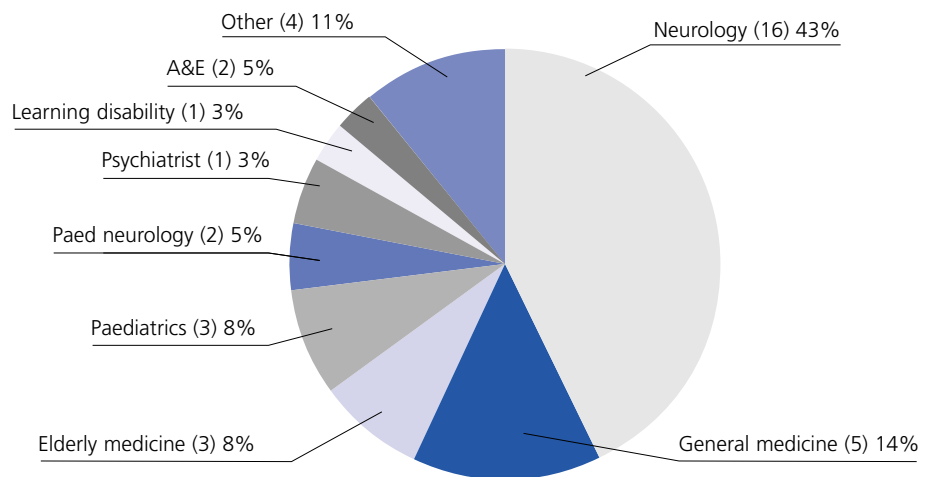
These findings reflect the continuing concern voiced by the panel that if these findings can be generalised, waiting times are too long and access to expert services is difficult. The panel thought that time from referral to appointment where the diagnosis is confirmed and treatment is started should be dependent on seizure severity, but in all cases this should be no more than 4 weeks. Two panel members suggested a 2-week maximum wait, to mirror standards of cancer guidelines. If a prolonged wait is anticipated, then the GP should be able to start antiepileptic medication after consultation with a specialist. The primary care panel support the development of first seizure clinics.

**Choice of specialist**

Criteria

- neurologists (CSAG, 2000)
- specialists with an expertise and an interest (Hall *et al.*, 1997; Taylor, 2000)
- a 'specialist' or 'specialist services' (SIGN, 1997; LHA, 1999; BAHA, 1998).

**Figure 4.2**  
Chosen specialty for initial referral



**Findings**

Data was available from 37 (15%, 95% confidence interval (CI) 11–21) people in group B, of whom 19 (51%) were seen by a neurologist, a psychiatrist or a paediatric neurologist. There was no indication whether these specialists had a particular interest or knowledge of epilepsy.

**Comment**

There was little recorded information on choice of specialist, but if this small sample reflects common practice it remains difficult to access expert epilepsy services. The panel view was that referral should be to either 'specialist services' to reinforce the benefits of a

*multidisciplinary approach, or to a specialist with an interest in the condition. One member felt that if that specialist was not a neurologist, then neurological backup was necessary.*

### Specialist referral

#### Criteria

- all people with epilepsy should generally be referred (Hall *et al.*, 1997; SIGN, 1997; BAHA, 1998; LHA, 1999; CSAG, 2000; Taylor, 2000)
- there may be extenuating circumstances such as co-morbidity or patient choice (Hall *et al.*, 1997; Taylor, 2000)
- indications for re-referral are
  - poor seizure control (Hall *et al.*, 1997; SIGN, 1997; BAHA, 1998; CSAG, 2000; Taylor, 2000)
  - lifestyle issues including pregnancy, status epilepticus, or withdrawal or change of antiepileptic medication (Hall *et al.*, 1997; BAHA, 1998; LHA, 1999; Taylor, 2000)
  - genetic counselling (Hall *et al.*, 1997)
  - consideration of surgery or non-drug therapies (Hall *et al.*, 1997; SIGN, 1997; CSAG, 2000; Taylor, 2000).

#### Findings

*First referral for diagnosis and treatment:* Four people died of their first seizure and were excluded from group A when considering referral in this group. Forty-one (15% of 282) people were not referred and 241 (85% of 282) people were seen in secondary care so, in the total sample of 286, 84% (95% CI 80–88%) of people were referred. In the 'non-referred' group, 3 people were waiting for an outpatient appointment following hospital admission or accident and emergency attendance, one of whom was still waiting 11 months after discharge from hospital.

#### *Comment*

*Everyone should be offered specialist referral, but attendance may depend on patient preference and fitness to attend a specialist clinic. Some elderly people with cerebrovascular disease may be unfit to travel, but if seizure control is not quickly achieved, then referral for exclusion of intracranial pathology is required. People seen at accident and emergency departments should be followed up to ensure that the referral process is optimal and timely.*

*Re-referral:* In group A, 4 cases (9%) showed evidence of a change in seizure frequency or type but none was referred for specialist review.

In Group B, 68 people (28%) fulfilled the criteria for re-referral: 19 (40%) of the 47 diagnosed in the 5 years before death and 49 (25%) of the 194 diagnosed 5 or more years before death. The criteria for re-referral were met for the following reasons:

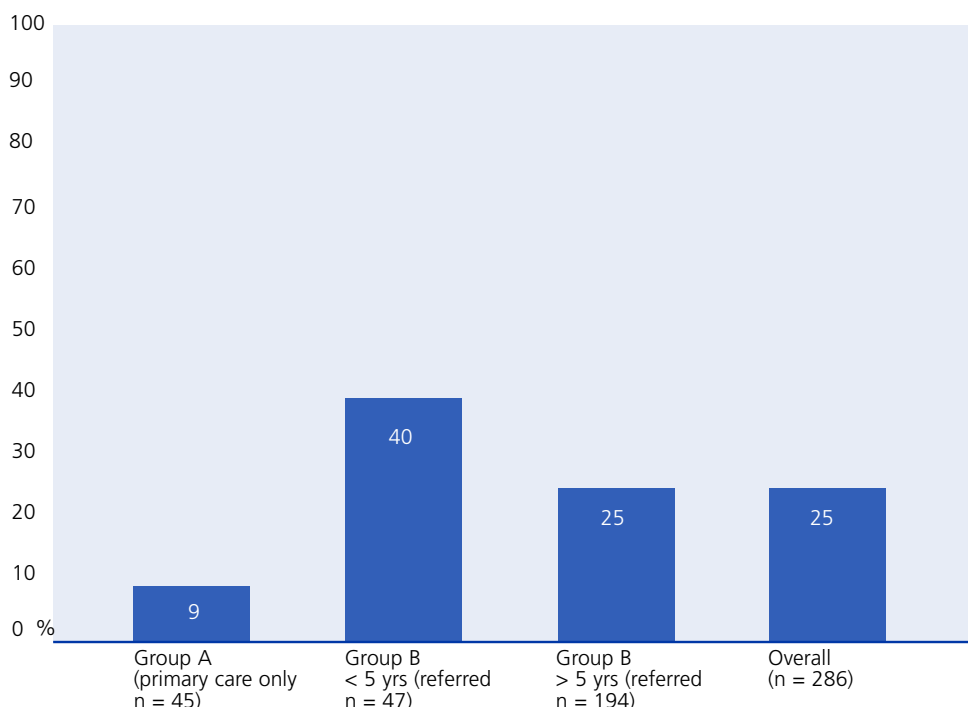
*Seizure change:* 26 (11% of the referred group of 241 patients) had a change in frequency of which 9 (35%) had appropriate action recorded but 7 (27%) were either admitted and discharged or seen in accident and emergency without any action being noted. For 10 (38%), no information was recorded. Also in 14 of the 26 (54%), there was no record of medication change or re-referral. Some cases showed evidence of a breakdown in communication between professionals both between primary and secondary care and between specialist departments;

*Trigger events:* Seventeen people in this group of 26 (65%) had possible trigger events including depression, recent alcohol-related problems or recent fractures. Seven (27%) had a record of appropriate action. Three people (12%) were awaiting a hospital appointment;

*Life events:* One patient (4%) was pregnant. Her notes showed a good management plan and evidence of communication between specialists.

*Summary:* In that group of 68 people where referral was indicated, only 6 (9%) were re-referred, 2 for change in seizure frequency, 1 for a 'change in life event', and 3 'other reasons'.

**Figure 4.3**  
Percentage of people in each group with recorded change in seizure frequency



**Comment**

*Indications for re-referral were not followed in either group. Published guidance should be followed. This issue may be one of professional education for clinicians in general practice and in emergency medicine.*

## Co-morbidity

### Criteria

- likely problems with associated learning disability (Hall *et al.*, 1997; Taylor, 2000)
- alcohol, seizures and antiepileptic medication (Taylor, 2000)
- cerebrovascular disease.

## Findings

Data of co-existing illness was collected in two ways. The audit tools collected data about a medical history of alcohol dependency, ischaemic heart disease and learning disability and of prescriptions for medication for ischaemic heart disease and/or hypertension, asthma or psychiatric conditions (see Table 4.2). Additional disease-specific data was collected for Group B (see Figure 4.4).

*Group A:* Eighteen people (40%) had a history of alcohol abuse, 9 (20%) had ischaemic heart disease and 7 people (16%) were learning disabled. Thirty-six (80%) people had been prescribed one or more medications for conditions other than epilepsy in the year before their death.

*Group B:* Forty-five people (19%) had a history of alcohol abuse, significantly fewer than in group A (95% CI for difference 7–37%). Ten (4%) had ischaemic heart disease, 62 (26%) were learning disabled and 114 (47%) were taking one or more non-epilepsy drugs, significantly fewer than in group A (95% CI for difference 18–44%).

**Table 4.2**  
Medications for conditions other than epilepsy

| Drug               | Group A prescriptions<br>N = 52 (%) | Group B prescriptions<br>N = 155 (%) | Total prescriptions<br>N = 207 (%) |
|--------------------|-------------------------------------|--------------------------------------|------------------------------------|
| IHD                | 9 (17)                              | 14 (9)                               | 23 (11)                            |
| Antibiotics        | 9 (17)                              | 55 (35)                              | 64 (31)                            |
| Asthma/steroids    | 8 (15)                              | 19 (12)                              | 27 (13)                            |
| Psychotropic       | 7 (13)                              | 13 (8)                               | 20 (10)                            |
| Alcohol withdrawal | 11 (21)                             | 16 (10)                              | 27 (13)                            |
| Analgesia          | 8 (15)                              | 25 (16)                              | 33 (16)                            |
| Anti-depressants   | 0 (0)                               | 13 (8)                               | 13 (6)                             |

Information for coronary risk factors was collected and assessed against national data. Coronary risk factors were identified in 75 (26%) people and data for smoking, high blood pressure, obesity and diabetes is shown in Table 4.3. These results have not been compared with accurate standardised comparative data, but the information in Table 4.3 suggests that the study population were leaner than expected, smoked less and had a low

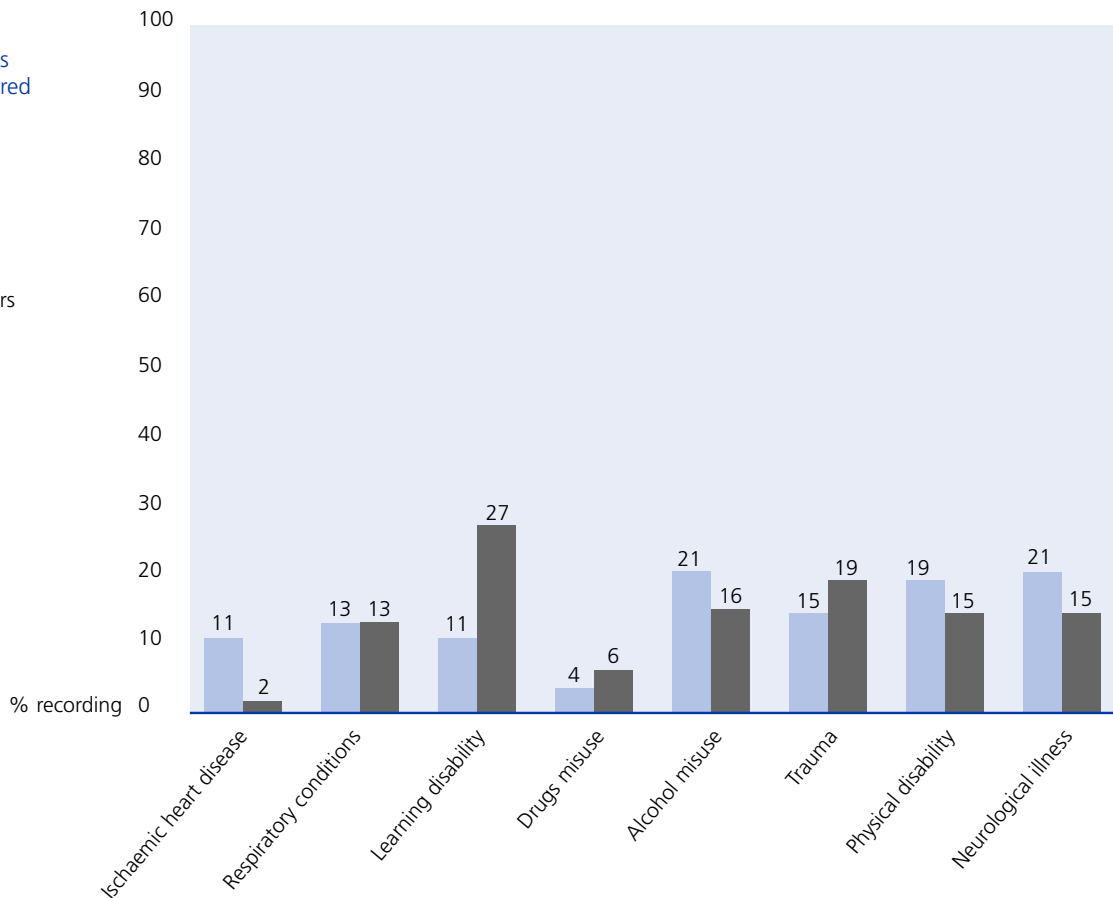
incidence of hypertension and diabetes (www.statistics.gov.uk; www.bhf.org.uk; CMO, 2001). Deaths were therefore unlikely to be due to an excess risk of coronary heart disease.

**Table 4.3**  
Risk factors for coronary heart disease

|                                    | Group A<br>(% of group) | Group B<br>(% of group) | Group A+B<br>(% of A+B) | % of general adult population, 1999<br>(not adjusted for age or gender) |
|------------------------------------|-------------------------|-------------------------|-------------------------|---|
| At least one CHD risk factor       | 5 (1)                   | 70 (29)                 | 75 (26)                 | No data   |
| Hypertension                       | 4 (1)                   | 18 (7)                  | 22 (8)                  | 31–42<br>(age 45–54 years)  |
| Smoker                             | No data                 | 30 (12)                 | No data                 | 27  |
| BMI>28                             | No data                 | 27 (11)                 | No data                 | >20   |
| Diabetes mellitus                  | 0                       | 4 (2)                   | 4 (1)                   | 2.5–3.3   |
| Positive family history CHD/stroke | No data                 | 3 (1)                   | No data                 | no data   |

**Figure 4.4**  
Other health problems recorded for the referred group (n = 241)

■ Dx within 5 yrs  
■ Dx more than 5 yrs



**Comments**

The health profile of these groups was good and so it is unlikely that the deaths were in part due to arterial risk factors. Learning disability, alcohol dependence and cerebrovascular disease present management problems that should be considered in the conclusions.

## Investigations in primary care

### Criteria

- no useful investigations (Hall *et al.*, 1997; Taylor, 2000)
- primary care investigations not mentioned (BAHA, 1998; LHA, 1999; CSAG 2000).

### Findings

The primary care group found that there were no recorded investigations initiated by GPs.

### *Comment*

*For those referred to secondary care, investigations initiated by the GP before diagnosis were infrequent. Only one case was investigated in the population diagnosed in the 5 years before death, and three in the population diagnosed 5 or more years before death.*

*Investigations in primary care such as baseline blood and ECG may be of value if diagnosis is in doubt, but urgent EEG and neuroimaging are the province of secondary care. Open access EEG/MRI was considered helpful by one member of the panel, but to be discouraged by three other members. Investigations were considered unhelpful to confirm epilepsy.*

## Treatment and therapies

### *Drug treatment*

#### Criteria

- initiation by specialist after confirmation of diagnosis (Hall *et al.*, 1997; LHA, 1999)
- may be initiated by GP after taking advice to avoid delay (SIGN, 1997; BAHA, 1998; Taylor, 2000)
- aim for monotherapy if control is good (Hall *et al.*, 1997; BAHA, 1998; CSAG, 2000; Taylor, 2000), or minimum number of drugs (SIGN, 1997) and generally carbamazepine or valproate as first choice drugs (Hall *et al.*, 1997; SIGN, 1997)
- drug serum monitoring: rarely necessary (Taylor, 2000), only useful for phenytoin (Hall *et al.*, 1997) but can give information about adherence (Hall *et al.*, 1997; SIGN, 1997; Taylor, 2000), only performed with a clear indication (SIGN, 1997; BAHA, 1998).

**Findings**

*Group A:* Antiepileptic drug data were recorded for 44 (98%) people, of whom 25 (56%) were on monotherapy, 6 (13%) were on two antiepileptics and 13 (29%) were on no medication, 5 (11%) because death occurred at the first seizure or were awaiting confirmation of diagnosis and 6 (13%) because the drug had been withdrawn either by the patient or because of perceived difficulties due to other agents, particularly alcohol. It was difficult to determine who had started antiepileptic drug treatment.

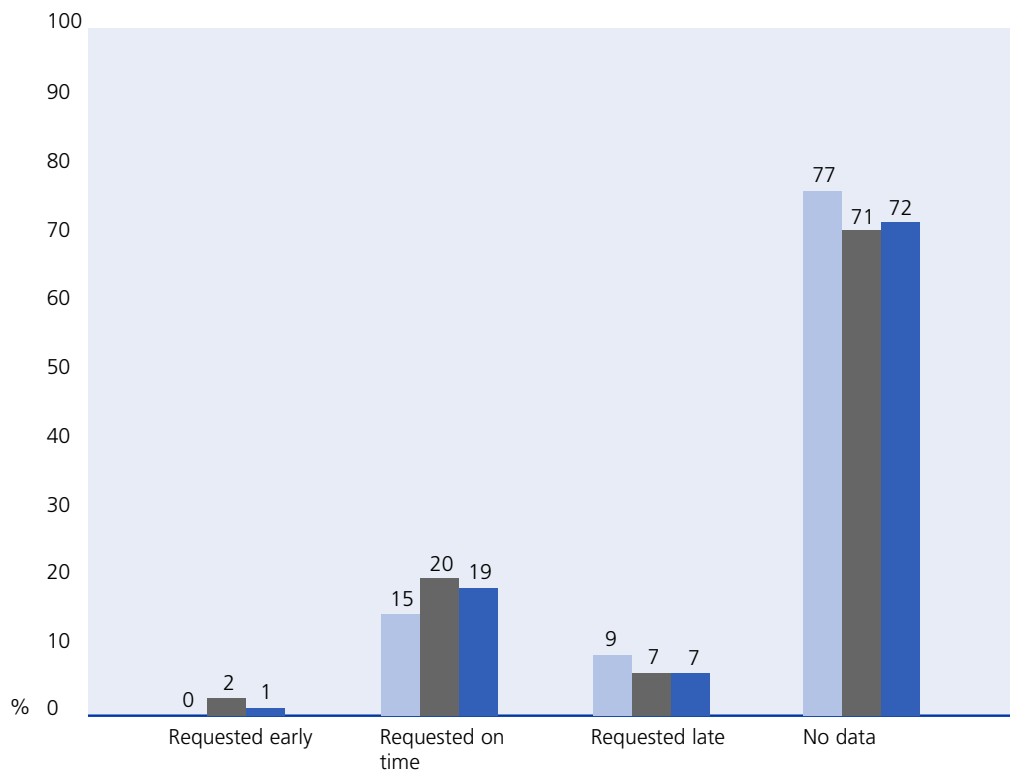
Five people (11%) showed poor drug adherence but records were incomplete in most cases. Antiepileptic drug serum levels had been taken for 11 people (24%) of whom 6 (13%) were for appropriate indications, particularly phenytoin or polytherapy.

Antiepileptic medication had been altered or stopped for 7 people (16%), of whom 4 (9%) followed professional advice. Of these 2 (4%) had their medication reduced or stopped less than 6 months before their death and 2 (4%) had their medication stopped over 1 year before their death, with recurrent seizures in the month before their death. Three people (7%) decided not to take the recommended dose, and 3 (7%) people took their antiepileptic medication irregularly – perhaps because of alcohol problems.

*Group B:* See Figure 4.5 on drug adherence and secondary care for analysis of the use of antiepileptic drugs.

**Figure 4.5**  
Repeat prescription record of adherence to drug treatment for referred group (n = 241)

■ Diagnosed within 5 yrs  
■ Diagnosed more than 5 yrs  
■ Total referred



### Comment

*The panel was split between specialist and GP initiating treatment, but all agreed that monotherapy was the aim if control was good. Serum drug levels are generally unhelpful unless the patient is taking phenytoin, but one panel member works in a locality that recommends annual blood levels for phenytoin, carbamazepine and lamotrigine. Drug information was difficult for the audit team to access, and this may reflect the parallel recording modalities presently used in general practice. No clear information was available in the records about the process of antiepileptic drug initiation.*

### Other therapies

#### Criteria

- non-drug therapies as indicated for seizure control or relief of effects of epilepsy (Hall *et al.*, 1997; Taylor, 2000):
  - vagal nerve stimulation
  - alternative therapist
  - biofeedback
  - dietary restriction
  - psychological therapies
  - other.

### Findings

*Group A:* Three people (7%) had a record of non-drug therapy. Two (4%) received counselling and 1 (2%) received support from the mental health team.

*Group B:* Forty-eight (20%) people had a record of non-drug therapies: 39 (16%) received some form of psychological therapy, 7 (3%) dietary restriction and 2 (1%) had vagal nerve stimulation.

### Comment

*The benefits of psychological support are well documented. The audit tool did not define the psychological modalities used. The panel expected a higher uptake of alternative therapies but it is uncommon for such interventions to be recorded in GP clinical notes.*

## Continuing care

### *Management plan*

#### Criteria

- between patient, GP and specialist (Hall *et al.*, 1997)
- between primary and secondary care (SIGN, 1997; CSAG, 2000).

### Findings

*Group A:* For 5 people (11%) some form of management plan was recorded, but this was simply a statement of next review or a plan to take a further blood sample. There was no evidence of an individual plan drawn up in consultation between the GP and the patient.

*Group B:* This group received secondary care and the secondary care tool examined management in some detail, so the primary care audit tool we used did not collect data of a management plan in the GP notes. Interestingly, all field workers commented on the absence of written epilepsy management plans.

### *Comment*

*A management plan is a good way to reinforce roles and responsibilities of patient, GP and specialist, and to aid communication within the health service. All members thought management plans were valuable but rarely recorded.*

### *Frequency of review*

#### Criteria

- every 6 months (LHA, 1999)
- annually (SIGN, 1997; BAHA, 1998; CSAG, 2000)
- negotiated between doctor and patient (Hall *et al.*, 1997; Taylor, 2000).

### Findings

*Group A:* Fifteen people (33%) had been reviewed by their GP in the year before their death but 30 (67%) had not been reviewed in that time, of whom 21 (47%) had no record of epilepsy monitoring in the 2 years before death. Fifteen (33%) people were seen for non-epilepsy problems by their GP in the 28 days before their death.

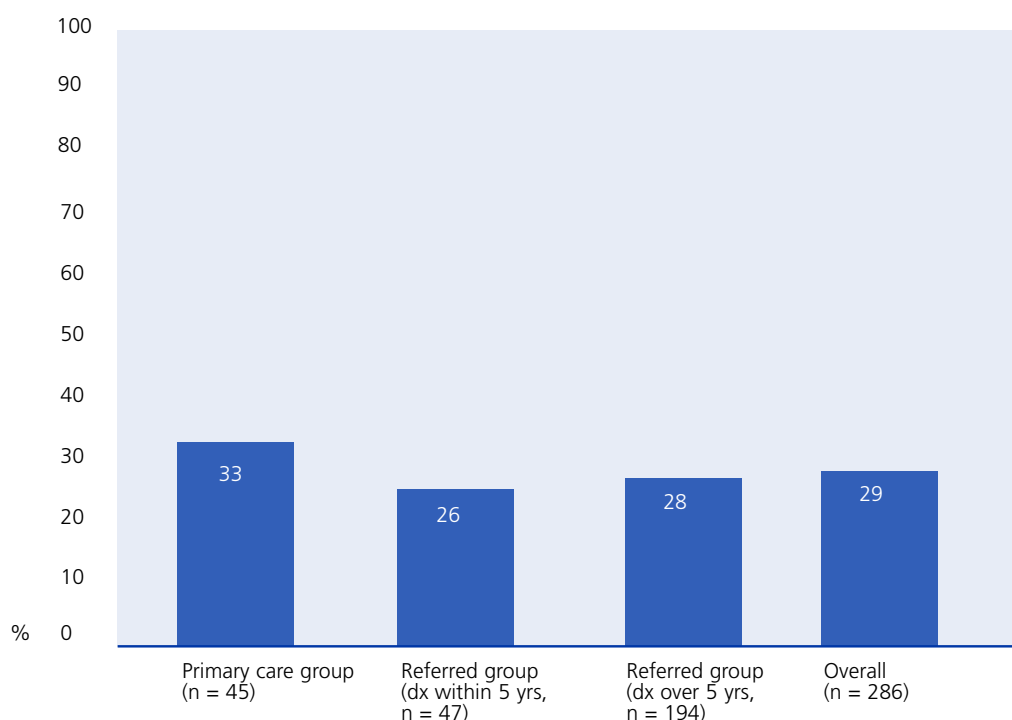
*Group B:* Of those deaths referred 218 (90%) had some evidence of a review and 187 (78%) had a review in the year before their death. Twenty-six (11%) were reviewed in the month before death but 73 (30%) were reviewed more than a year before death of whom

31 (13%) had not been reviewed for more than 3 years before their death. The mean time from review to death was 396 days (range 1–5,183). In the 28 days before death, 67 people (28%) were seen by their GP for problems other than epilepsy.

### Comment

*The panel was split between annual and negotiated review. The pragmatic view was an annual review for people with well-controlled epilepsy, with access to urgent specialist services for people with a change or increased seizure pattern. The opportunity to discuss issues about epilepsy could present when people consult about other problems. Our study has not shown any effect of concurrent illness on epilepsy-related death, but seizure control and drug compliance should be discussed when the patient consults. Figure 4.6 shows the numbers of people who consulted in the 28 days before death in each group.*

**Figure 4.6**  
Percentage of people who were seen in the 28 days before death



### Purpose of review

#### Criteria

- Hall *et al.*, 1997; SIGN 1997; BAHA 1998; CSAG 2000; Taylor 2000:
  - ensure correct diagnosis and seizure type
  - monitor seizure frequency
  - monitor drug side-effects
  - provide information and support
  - consider lifestyle issues.

**Findings**

*Group A:* No information was found concerning the purpose of GP epilepsy review.

*Group B:* A detailed description of review activity was sparse, although it appears that serum blood levels and seizure frequency recording were the main activities in this group. Eighty-seven people (36%) had antiepileptic drug serum levels recorded in the 5 years before their death. Sixty-eight people (28%) had an increase in seizure activity in the 3 months before their death.

**Comment**

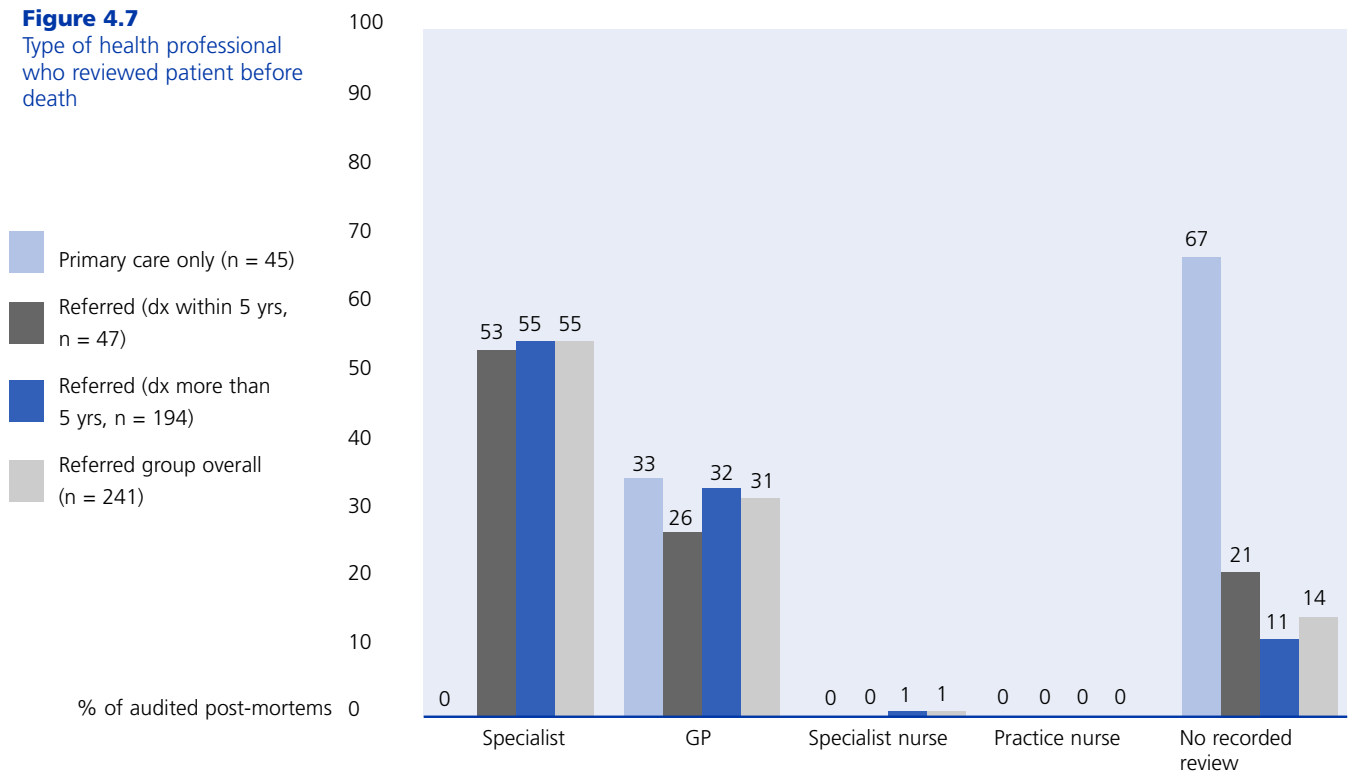
*There is some evidence to suggest that people with epilepsy consult their GP more frequently than people who do not have epilepsy. Drug management programmes in general practice can be used to remind people and the practice of the need for a review. It takes little extra time to structure the consultation to be a more effective review. By doing this, the review process may be of more value to both patient and doctor or nurse.*

*Choice of professional*

**Criteria**

- GP or nurse with an interest (Hall *et al.*, 1997; CSAG, 2000; Taylor, 2000)
- members of the primary care team (SIGN, 1997; BAHA, 1998).

**Figure 4.7**  
Type of health professional who reviewed patient before death



## Findings

*Group A:* Everyone who was reviewed was seen by their GP. No practice nurse or specialist nurse reviews were recorded.

*Group B:* The patient was reviewed by a specialist or a GP in all but 2 cases where they were reviewed by a specialist nurse.

## *Comment*

*The panel supported review by any professional with the necessary interest and training in epilepsy care.*

### Information and support for people with epilepsy

#### Criteria

- provision of information about epilepsy (all sources)
- information about risks of the condition (Hall *et al.*, 1997; BAHA, 1998; Taylor, 2000).

## Findings

*Group A:* One case received information from the GP about epilepsy but not about the risk of death.

*Group B:* Table 4.4 shows that information is most often supplied by the specialist (24%), and then by the GP (8%).

**Table 4.4**

Source of information about epilepsy (n = 241)

| Source                            | <5 years (%) | >5 years (%) | Total (%) |
|-----------------------------------|--------------|--------------|-----------|
| GP                                | 4 (8)        | 16 (8)       | 20 (8)    |
| Specialist                        | 11 (23)      | 47 (24)      | 58 (24)   |
| Practice nurse                    | 0            | 0            | 0         |
| Specialist nurse                  | 2 (4)        | 4 (2)        | 6 (2)     |
| Other                             | 0            | 4 (2)        | 4 (2)     |
| No recorded information provision | 30 (64)      | 123 (63)     | 153 (63)  |

## Findings

There was a record of only 89 people receiving any information on epilepsy. There was a record of only 3 people receiving any information about the risk of death. Although all were among those in group B diagnosed more than 5 years ago, this is not unexpected as this subgroup of 194 includes over two thirds of the overall total sample.

### Comment

Epilepsy information was available to about 25% of both groups, but only three people received information about the risk of death. Information is a priority for people with epilepsy and their families. GPs should link with specialist nurses and voluntary organisations to provide information about epilepsy and the potential impact of the condition. Provision of information should be recorded in the notes and an individual checklist is a useful aid for communication between agencies and professionals.

#### Contact with relatives after an epilepsy-related death

##### Criteria

- GPs should make contact with bereaved relatives (Nashef *et al.*, 1998).

### Findings

*Group A:* Families of 4 (9%) individuals were contacted by the GP after death and 1 (2%) family had an invitation to discuss the death.

*Group B:* Families of 2 (1%) individuals had contact by letter by the GP after death, and 12 (5%) families had an invitation to meet with the GP to discuss the death.

#### Communication between professionals and services

##### Criteria

- communication between professionals is necessary for satisfactory care (Hall *et al.*, 1997; Taylor, 2000).

### Findings

*Group A:* In 15 deaths (33%) there was a suggestion of possible communication failures between professionals; 6 (13%) of poor communication from secondary care to GP, 4 (9%) of poor communication in general practice either with no action being taken following contact with an emergency GP, or no action being recorded after antiepileptic drug blood levels or increased seizure frequency.

In one case awaiting first referral, there was no recorded communication from general practice to secondary care about an increase in seizure frequency and in one other case symptoms of probable secondarily generalised epilepsy were misdiagnosed as snoring and sleep apnoea and so referral was made to an ENT department.

*Group B:* Seven people (3%) were either admitted and discharged or seen in accident

and emergency without any action being noted. In 14 (6%), there was no record of medication change or re-referral after seizure change.

In both groups, there is evidence of a breakdown in communication between professionals both between primary and secondary care and between specialist departments.

### **Comment**

*There is concern about the failure of communication between different sectors of the health service and indeed between clinicians in the same hospital or practice. The audit highlights an educational need for all clinicians involved in epilepsy care (hospital generalists, accident and emergency staff or GPs and nurses in primary care) so that key principles of care are more widely understood.*

## **CONCLUSIONS**

We necessarily collected data from clinical notes and made no assessment of non-recorded clinical activity, so the results may not accurately reflect all actual care. Nevertheless, the audit raised matters of urgent concern. It highlighted evidence of a non-structured review process with a low level of clinical information recording. Although 85% had some evidence of some form of 'epilepsy review' the commonest actions were to provide medication or to check drug levels. There was no evidence of an agreed management plan, few details of seizure type, triggers, issues of drug treatment and other therapies, and there was a low incidence of re-referral for people with changing seizures, life events or possible trigger factors. Information provision was not recorded, about either the condition or the potential risks of epilepsy, and there was little evidence of use of information from the voluntary agencies. There are problems in professional communication between primary and secondary care and between individuals in both settings.

There are issues of access and waiting time for expert advice. The waiting times for confirmation of diagnosis was disappointingly long and only about half the people with epilepsy were referred to a neurologist. Some died while waiting for an outpatient appointment. Difficulties were apparent in delivering care to people with associated problems, particularly alcohol dependence or learning difficulty. The study population showed a lower prevalence than the normal population of coronary risk factors.

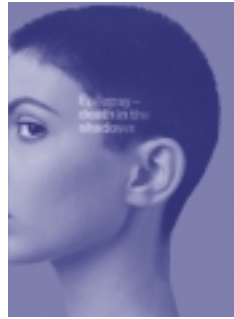
These issues could be addressed by restructuring the diagnostic process:

- resourcing fast-track first seizure clinics
- drawing up agreed individual management plans outlining the roles of professionals in primary and secondary care, voluntary organisations and people and families in monitoring the condition and assessing the risks to the individual.

The ambulance service and NHS Direct must be informed about epilepsy care. Regular structured review must be offered, and clear lines of communication between

professionals in hospitals and general practice should avoid duplication of care. We found no evidence of epilepsy care by either practice or specialist nurses.

Educational initiatives could provide a better understanding of some principles of care resulting in better use of resources, more rapid diagnosis and treatment, more appropriate referral back to secondary care, and clarity in certification of epilepsy death.



## CHAPTER 5

# SECONDARY CARE

Hospitals and specialist centres are where most of the initial investigation, diagnosis and management of a person with epilepsy take place, and where there is continuing management of people whose epilepsy is not well controlled.

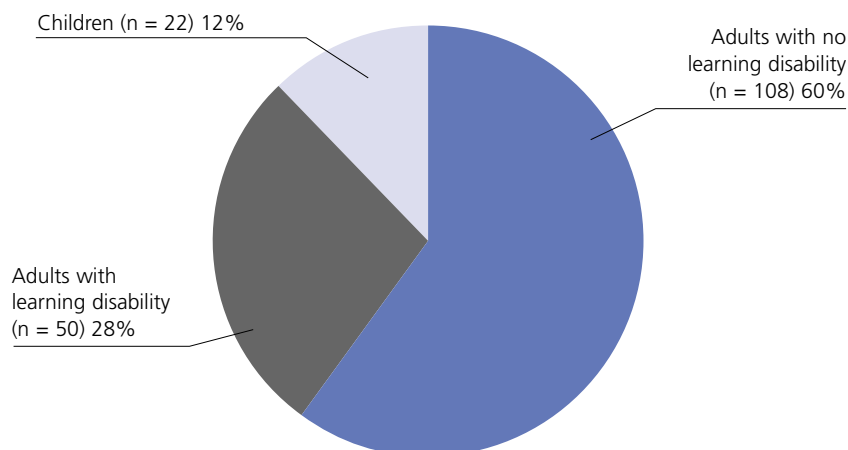
The secondary care audit tool was designed to capture information from hospital records (see Appendix 2). The sample and the domains for audit are described below. The next section reports on audit findings in relation to the adult population, and a later section the findings in relation to children who died. Each part includes the conclusions of a specialist panel on consensus reached in relation to the overall care provided for each person who died. These conclusions augment the audit results, to further inform the evidence base for appropriate guidance and service delivery.

### SAMPLE

We initially assessed 199 epilepsy-related deaths. The sample was checked for inclusion in the audit by the secondary care panel, which had information from all audit tools on the certified cause of death, post-mortem investigations and the medical records. We excluded 19 cases (10%) as having deaths that were not considered epilepsy-related: 4 had acute symptomatic seizures, 4 had probable cardiac deaths, in 2 there was no evidence of epilepsy, 1 died of the disease causing epilepsy, and 8 of unrelated causes. The remaining 180 people, 111 of whom (62%) were male, were included in the analysis (Figure 5.1). Among the 180 were 3 people who had presented previously with a single seizure and where the secondary care panel decided there was sufficient evidence from the audit to include the deaths as epilepsy deaths. Age at death was between 2 and 82 years (mean 37 years, median 36 years).

A clinical review of the sample of 180 deaths audited by secondary care suggested that 60% were SUDEP and a further 7% were possible SUDEP. These numbers are estimates because of concerns about information available to the audit on the circumstances of death, the events leading up to death and the adequacy of post-mortem investigations (see Chapter 3 of this report).

**Figure 5.1**  
180 deaths audited by  
secondary care



For the purposes of further analysis, the total group of adults under specialist care was divided into those with and without evidence of learning disability, because the latter group may have different needs and issues of access or care. Where the results are significantly different the subgroup findings are provided. A subgroup of 28 people with documented alcohol problems were also compared with the remainder, and significant differences are reported here.

## ADULTS: AUDIT DOMAINS AND CRITERIA

The audit domains in the context of secondary care are:

- access to specialist care
  - outpatient clinic and consultant appointment
  - type of specialist
  - access by new patients
  - continuing care for people with epilepsy
  - communication between professionals
- clinical assessment
- investigations
- drug treatment and other therapies
  - when to treat
  - drug treatment
  - adherence to drug regimen
  - surgery
- information and support for people with epilepsy.

Criteria were selected from the Scottish Intercollegiate Guidelines Network (SIGN, 1997) and the Royal College of Physicians guidelines for adults with poorly controlled epilepsy (Wallace *et al.*, 1997). Other sources supporting criteria for audit are cited in the text. Detailed reporting on the development of audit tools and analysis of the results is contained in Chapter 2 and Appendix 2.

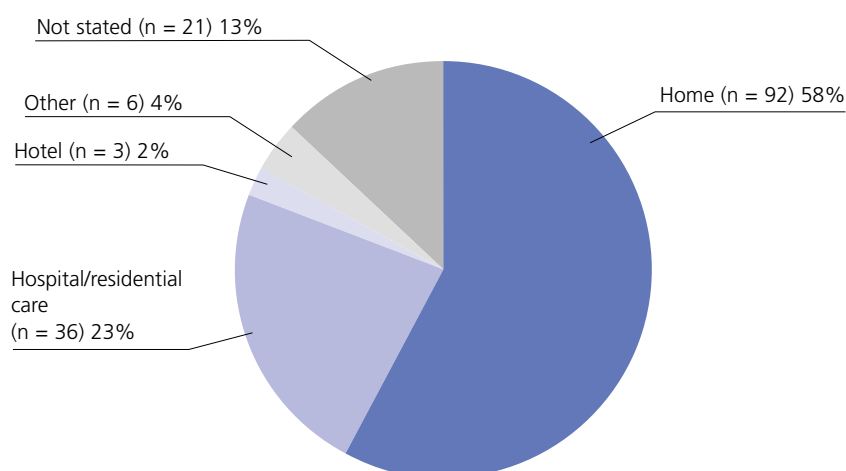
## RESULTS OF AUDIT

### Demography of sample

All adults:

- 158 deaths (100 [63%] male)
- age at death 18–82 years (mean 41 years, median 39 years)
- duration of epilepsy 6 months to 52 years (mean 21 years, median 19 years).

**Figure 5.2**  
Location of death



Data on the location of death is shown in Figure 5.2. Adults with learning disability more often died in hospital or residential care (20/50 (40%) versus 16/108 (15%), 95% confidence interval [CI] for difference 11–40%) and had significantly longer previous history of epilepsy (26 years versus 18 years) and earlier age of onset of seizure (11 years versus 23 years).

#### Access to specialist care

#### *Outpatient clinic and consultant appointments*

##### Criteria

- attendance at an outpatient clinic
- seeing a consultant (Winterton, 1986).

## Findings

In the whole group of 158 adults, 138 (87%) were known to have been seen in outpatients, and 105 (76%) of these saw a consultant at least once in the last three appointments. A further 14 (10%) had seen a consultant previously. People with learning disability had seen a consultant in the last three visits less often (28/43 (65%) versus 77/95 (81%), 95% CI for difference 0–33%).

In the whole adult population there were no documented outpatient attendances for 20 people (13%). For 12 of these there were medical contacts on an inpatient basis, and 8 of these 12 had either seen a consultant, or the case had been discussed with a consultant; 2 of the 12 were in long-term hospital care. Three of the 20 were seen in accident and emergency only, on multiple occasions, and did not see consultants, and 3 appeared to have no contact with secondary care regarding their epilepsy and 2 had repeatedly defaulted appointments. This means that 127 of the 158 (80%) adults had documented evidence that they had ever seen a consultant.

Of the 20 people with no documented outpatient appointments, 10 had recorded alcohol problems. Altogether 28 adults had documented alcohol problems, thus 10/28 or 36% of all those with alcohol problems, compared with 10/130 or 8% of those without alcohol problems, had no record of outpatient attendance (95% CI for difference 10–46%).

### *Type of specialist*

#### Criteria

- specialist with an interest in epilepsy (Brown *et al.*, 1993; SIGN, 1997; Epilepsy Task Force and Joint Epilepsy Council, 1999); Epilepsy Advisory Board, 2000)
- specialised epilepsy unit for a full neurological and psychiatric assessment of anyone suspected of non-epileptic seizures (Wallace *et al.*, 1997).

## Findings

Of the 138 adults seen in outpatients, 14 (10%) had seen a general physician, 3 (2%) had seen a paediatrician and in 11 (8%) the specialty of the doctor seeing the person was not recorded in the notes. One hundred and ten (80%) were known to have been seen in a relevant specialty clinic. Ninety-one (66%) saw a neurologist or neurophysiologist, 11 (8%) saw a psychiatrist, 5 (4%) saw a neurosurgeon, 2 saw a learning disability specialist and 1 saw a paediatric neurologist. We are unable to report a finding on the percentage of people referred to a specialist with a specific interest in epilepsy.

Only 2 of the 43 (5%) adults with learning disability seen in outpatients had evidence that they had seen a specialist with an interest in learning disability, although a further 6 (14%) had seen a psychiatrist, who may have had such an interest.

The notes of three people referred to a diagnosis of non-epileptic attack disorder. Two saw psychiatrists and the third saw a neurologist but had also seen a psychologist. All three may have seen appropriate specialities, but one was lost to follow-up despite ongoing seizures; in one anti-epileptic medication had been stopped and in the other the patient defaulted appointments.

### *Access by new patients*

#### Criteria

- immediate referral (SIGN, 1997)
- 4 weeks (Brown *et al.*, 1993; Epilepsy Task Force and Joint Epilepsy Council, 1999; Epilepsy Advisory Board, 2000).

#### Findings

Four adults (none with learning disability) were new patients who died within a year of the first seizure. All 4 were referred to hospital by their GP the same day, but at least 2 did not meet guidelines for access to a specialist with an interest in epilepsy, and none did so within the criteria for access time.

### *Continuing care for people with epilepsy*

#### Criteria

People with continuing seizures should continue to have access to specialist care (Wallace *et al.*, 1997; SIGN, 1997; CSAG, 2000).

#### Findings

One hundred and forty-seven adults (93%) had continuing seizures or were not known to have been seizure free for at least a year before death (Figure 5.3) and therefore met the criteria for needing continuing access to specialist care. Of these, 127 adults (86%) had documented outpatient attendances. Fifty-four (43%) had last been seen over a year before death and 73 (57%) had been seen in the year before death. In 27 (50%) of people not seen in the year before death we were unable to identify a reason for this lack of follow-up from the notes. Five (9%) had not attended appointments on at least one occasion, and a further 7 (13%) had been discharged. Of the people with learning disability, 3 seemed to have become lost in the transfer from paediatric to adult care. The remaining 12 of those not seen in the year before death include one where the consultant had tried assiduously to follow up the patient, even suggesting domiciliary visits.

Overall, at least 54 (37%) of adults meeting the criteria for needing continuing access were not seen in a specialist clinic in the year prior to death.

*People who fail to attend appointments:* Amongst the 158 adult patients 23 (15%) it was documented that they had not kept appointments at least once. 13 (57%) of these had at least one further appointment sent, but 7 (30%) were sent no further appointments, and in 3 (13%) it was unclear whether any action had been taken.

*People with alcohol problems:* Twenty-eight people (18%) had a record of problems with alcohol. They were almost all men – 26 (93%), compared to 57% of those without alcohol problems. Their age at death ranged from 23 to 65 years (median 43 years). Ten (36%) had no record of outpatient appointments, compared with 8% of those without recorded alcohol problems. Eighteen (64%) had been seen in outpatients, 8 (44% of 18, but only 29% of the total compared with 69 [53%] of those without alcohol problems – 95% CI for difference 6–43%) within a year of death. The maximum time between a last appointment and death was 8 years. Several had had inpatient episodes, emergency admissions (from which they had taken their own discharge) and visits to accident and emergency. Others had failed to keep appointments on several occasions.

### **Comment**

*Although most of the adults receiving specialist care who died from epilepsy had reasonable access to secondary care, the audit showed up deficiencies in several areas.*

*Existing guidance requires continuing access to specialist care for people with epilepsy. Guidance is not explicit, however, on frequency of review and criteria for discharge of patients, including criteria for managing people who did not attend appointments. Findings from this audit highlight that there were problems in these areas.*

*People lost to follow-up: Only 73 adults (50% of all adults meeting criteria for needing continuing access) were known to have been seen in outpatients in the year before their death. It appears at least 27 (18%) of all adults were lost to follow-up. Additionally it appears that a further 3 adults, all with learning disability, had been 'lost' in the handover from paediatric to adult care (see below). The secondary care panel was most concerned that such a high percentage of people were not being followed up, and was especially concerned where it became apparent that the GP had not re-referred when the control or type of seizure changed (see Chapter 4: primary care results on 'specialist referral' and Figure 4.3). Future guidelines on the management of people with epilepsy should consider this issue.*

*Management of people not attending: The handling of the 23 (15%) adults who did not attend appointments appears to have been variable. People who fail to attend may waste valuable resources and clinic time, but frequently there was no documentation to suggest that proper effort had been made to establish why the person had not attended, or to send a further appointment.*

*People with problems of social exclusion: It appeared that some people with alcohol problems were receiving less well-structured care. People with epilepsy and other problems tend to need more care than those without. Local and national guidelines and audit should address the delivery of suitable 'packages of care' for these people, including cooperation between secondary care, primary care and social services.*

*Handover to adult care: Three (6%) of adults with learning disability had become*

'lost' in the handover from paediatric to adult care. Local processes need to ensure that the people, primary care physicians and the adult specialist team concerned are aware of the transfer.

### Communication between professionals

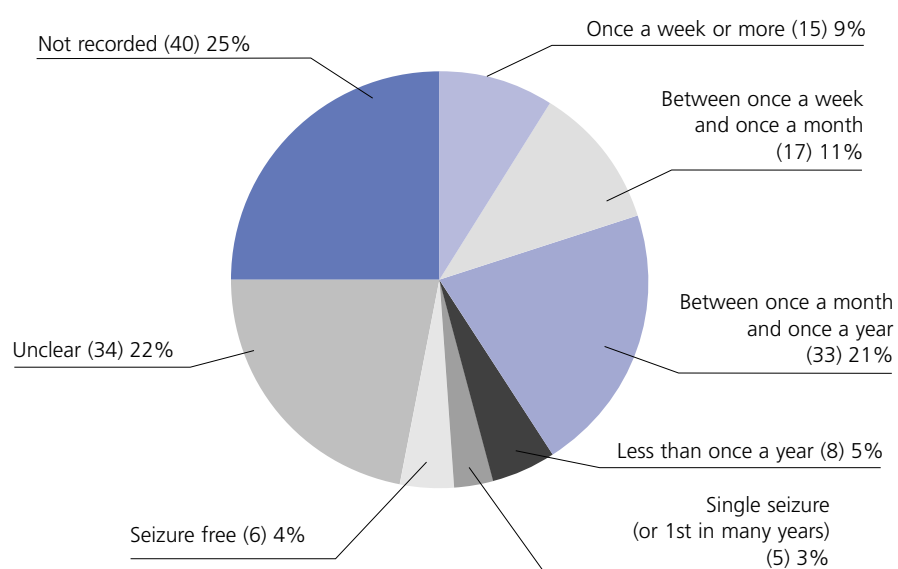
The Royal College of Physicians guidelines (Wallace *et al.*, 1997) acknowledge that GPs cannot be expected to be expert in the management of epilepsy, and therefore 'specialists must ensure that their letters give clear instructions regarding the management of medication, potential side-effects and any monitoring that is required between hospital visits. Information about the nature and likely prognosis of the epilepsy, the results of investigations, and any accompanying medical, psychiatric or psychological problems should also be included'. The audit of secondary care notes did not provide reassurance that this had usually happened for people who died from epilepsy. It should also be considered in developing education, guidelines and local audit of epilepsy care, for example to ensure that each patient has a clear management plan communicated to the GP, especially those who are no longer being seen in secondary care.

#### Clinical assessment

##### Criteria

The basis of the record for use in the care of all people with epilepsy should include a detailed history including witness account or description of seizure and medical history including frequency of seizures (SIGN, 1997).

**Figure 5.3**  
Frequency of seizures



### **Findings**

In the whole group of 158 adults there was a witness account or description of seizure in 130 (82%) and the seizure frequency at the last consultation was documented for 118 (75%).

Those described as 'unclear' used such words as 'continuing' or 'frequent' (12 cases) or may have described very recent or isolated seizure activity only (17 cases). Others included some where more than one seizure type was described, but only one seizure frequency was stated. 11(7%) of adults were recorded as being seizure free for a year prior to their last recorded appointment. These included 6 who were recorded as seizure free and 5 of 8 patients who were recorded as experiencing seizures less than once a year.

### ***Comment***

*It is a fundamental requirement to obtain and document a witnessed account of seizures in all people with epilepsy, and to record the seizure frequency at each visit. Failure to achieve the former requirement in 18% of cases and the latter in at least 25% is cause for concern. Nilsson et al. (1999) reported that the people at highest risk of SUDEP were those without proper documentation of seizure frequency. This may have been a surrogate for less than optimum clinical care. These deficiencies in history-taking or documentation, especially in such a high-risk cohort, need to be considered when education, guidelines, and audit programmes are developed.*

## Investigations

### **Criteria for imaging**

- (Wallace *et al.*, 1997): Best practice is to carry out MRI in all people with epilepsy, with the exception of people who had a definite electroclinical diagnosis of idiopathic generalised epilepsy, or benign epilepsy of childhood with centrotemporal spikes. It is particularly indicated in people with one or more of the following:
  - evidence of a partial onset on history or EEG, at any age
  - onset of unclassified or apparently generalised seizures in the first year of life or adulthood
  - evidence of a focal fixed deficit on neurological or neuropsychological examination
  - difficulty obtaining control of seizures with first-line antiepileptic drugs
  - loss of control of seizures with antiepileptic drugs or a change in the pattern of seizures, which may imply a progressive underlying lesion
  - progressive neurological deficit.

- SIGN (1997)
  - The choice of brain imaging will depend on costs and availability. CT scanning is presently more widely available, but where resources permit MRI is preferred
  - MRI is indicated in the assessment of people with intractable epilepsy.

### Findings

In the whole group of 158, 38 had MRI (24%), and 63 (40%) had CT scanning but no MRI. Fifty-seven (36%) had no imaging of any kind. Of these, at least 19 (33%) should have had scanning according to the guidelines and in 15 others the records did not include sufficient details of the seizures to assess the need for imaging. Ten probably did not need imaging, according to the guidelines. Two people did not co-operate with imaging and 2 died before the scan appointment. In a further 2 cases the scan was cancelled or not attended.

There was no clear or consistent reason among the records of the remaining 7 patients to account for the lack of imaging.

Significantly more adults without learning disability had MRI scanning (33/108 (31%) compared with 5/50 (10%), 95% CI for difference 7–32%). However, this was compensated for by more CT scans among people with learning disability, so that the proportion who should have had imaging but did not get it was similar between the two groups (13/108 adults without learning disability compared with 6/50 adults with learning disability, both 12%), and people with learning disability are often less able to tolerate MRI.

### Criteria for EEG: (SIGN, 1997)

- all people under 25 years at diagnosis should have an EEG
- in people over 25 years, EEG is not necessary in establishing a diagnosis if a clear clinical history is available. If the diagnosis is not clear from the clinical history both EEG and brain imaging should be performed.

### Findings

In the whole group of 158 adults, 107 had EEGs (68%, 95% CI 60–75%). Fifty-one did not have EEGs (32%).

Of these, 22 (43%) were under 25 at diagnosis and in 13 (25%) the need is unclear because of lack of recorded information on history or seizure description or syndrome.

### Comment

*A substantial proportion of people failed to have appropriate investigations to determine the cause or type of their epilepsy. These factors may affect the choice of management strategies because different types of epilepsy vary in their response to specific antiepileptic drugs, and some findings will prompt earlier consideration of epilepsy surgery. We cannot ascertain from this audit to what extent such failures related to problems with medical education, processes of care or local inadequacies in facilities, but the use of appropriate investigation could be readily monitored through local audit.*

#### Drug treatment and other therapies

##### *When to treat*

##### Criteria

People with unprovoked generalised tonic-clonic seizures should be offered treatment after the first seizure if the seizures are associated with previous myoclonic and/or absence seizures. Otherwise decision to treat depends on seizure frequency, severity, and patient preference (SIGN, 1997).

### Findings

Nine people (6%) were not treated with antiepileptic drugs for the following reasons:

*Infrequent seizures:* Two were recorded as having infrequent seizures. There was no recorded discussion with these people of the hazards of seizures, or of the fact that seizures could be fatal.

*Diagnostic doubt:* One patient was not taking antiepileptic drugs because the recorded diagnosis was non-epileptic seizures (although the other two patients with potential diagnosis of non-epileptic attacks were treated with antiepileptic drugs).

*Individual reasons:* One patient was resistant to taking antiepileptic drugs, but there is no record that information about this was provided. One patient had self-discharged from hospital. This person had been informed of trigger factors and of the hazards of epilepsy. One had previously overdosed on antiepileptic drugs.

*Single seizures:* One was waiting for a specialist opinion. The history is insufficiently documented for us to know whether antiepileptic drugs should have been started after the first seizure. One was seen by a consultant neurologist shortly after the first seizure, several years before death. The seizure was attributed to alcohol withdrawal and no antiepileptic drug treatment was recommended, although advice was given about alcohol. The patient was not followed up and it is therefore not clear whether there were recurrences of seizures. One patient with another neurological disease had a first seizure

2 years before death. This was attributed to alcohol withdrawal and no antiepileptic drugs were recommended. There was no follow-up in the audited notes, although the patient may have been followed up for the other neurological disease.

### **Comment**

*The potential consequences of not treating epileptic seizures include SUDEP. The risks of not treating seizures need to be balanced against the risks of antiepileptic drugs and underline the need for ongoing specialist assessment and repeated review – which may include inpatient observation and supervised changes to antiepileptic drugs in patients with problems, diagnostic doubt or possible non-epileptic attacks.*

*The cohort of audited secondary adult care included three adults who may have died during only their second seizure. Such occurrences were also identified in the primary care audit. The sample of epilepsy deaths included approximately 22% of the UK total of probable epilepsy deaths during the course of a full year. The finding of three deaths during second seizures in this sample may seem small (approximately 30,000 people each year in the UK will have their second seizure) but the extreme severity of this outcome suggests that further monitoring of second seizure deaths is necessary to inform the decision making process whether or not to commence antiepileptic drugs after a first seizure.*

### *Drug treatment*

#### Criteria

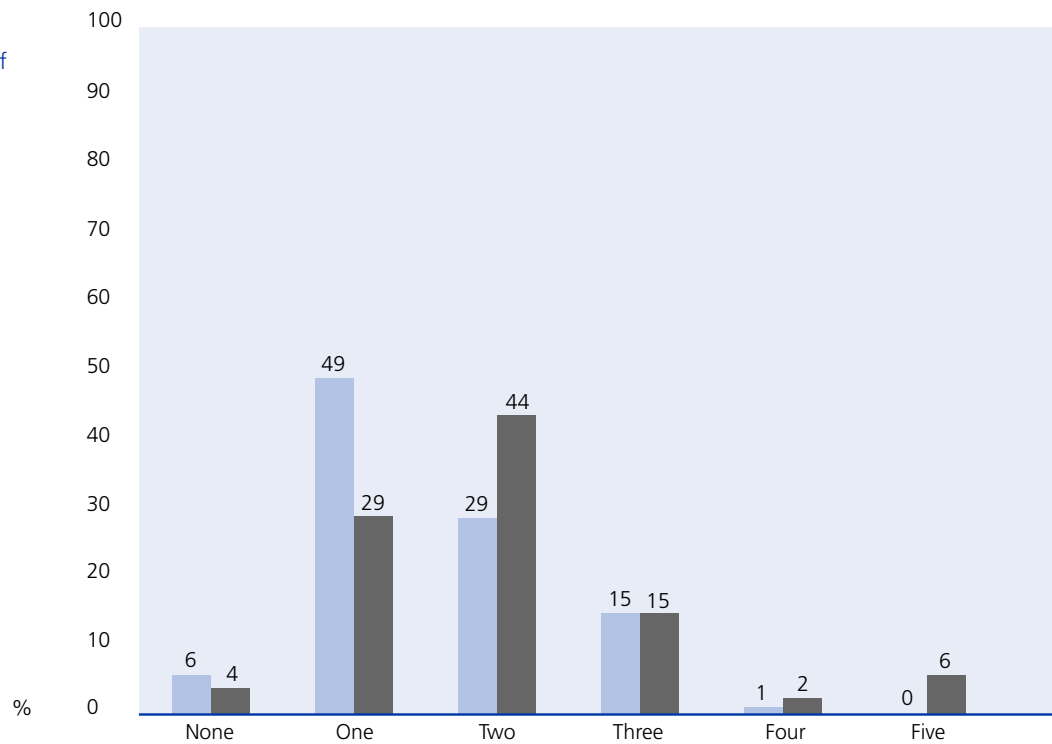
- aim should be to control through use of appropriate first-line drug (SIGN, 1997)
- where the first choice or choices of antiepileptic drugs have been unsuccessful the specialist team should carefully consider other alternative monotherapy or reasoned polytherapy (Mattson, 1985, 1992; Turnbull, 1985; Richens, 1994; Heller, 1995). The next choice of drug depends on seizure type and syndrome (Wallace *et al.*, 1997; SIGN, 1997)
- aim to maintain patient on the minimum number of drugs required to achieve adequate symptom control (SIGN, 1997).

### Findings

Results on whether people were treated and the number of drugs they were taking at the time of death are reported in Figure 5.4. In two cases it was not possible to establish whether or not the patient was on antiepileptic drugs at the time of death. The appropriateness of medications was audited by the specialist panel; in 32 (20%) deaths there was consensus that medications were inappropriate.

**Figure 5.4**  
Numbers of drugs at time of death (percentage taking)

■ Adults without learning disability n = 108  
■ Adults with learning disability n = 48



People with learning disability were taking significantly more drugs as shown in Figure 5.4. In particular, they were more likely to be taking two or more drugs: 32/48 (67%) versus 48/108 (44%), (95% CI for difference 5–37%). The increased use of polytherapy in people with learning disability may have been due to more severe epilepsy.

### Adherence to drug regimen

#### Criteria

- adherence to drug regimen should be reviewed (Wallace *et al.*, 1997)
- the importance of adherence to drug regimen should be stressed (Wallace *et al.*, 1997).

#### Findings

Of the whole group of 158 adults, 22 (14%) had documented problems with adherence to drug regimen. For 8 of these 22 people (36%) it was documented that information had been provided on the importance of taking antiepileptic drugs, but only 2 of them had documented discussion about the hazards of seizures and none had documentation that the patient or family had been informed that seizures could be fatal. Problems with non-adherence were not significantly different in people with learning disability (4/50 (8%) versus 18/108 (17%)).

#### Comment

*The importance of poor seizure control as a risk factor for SUDEP indicate the need to provide optimum effective treatment. Decisions made by physicians not to prescribe or*

*optimise antiepileptic drugs, or decisions by people with epilepsy not to comply fully with recommendations need to be properly informed.*

*Of 22 adults with documented poor adherence to drug regimen, only 36% had information on the importance of taking antiepileptic drugs documented in the notes, only two had documented information about the hazards of seizures, and none that seizures could be fatal. Conflicting evidence exists regarding the contribution of non-compliance to SUDEP. Earnest et al. (1992) suggested that SUDEP is associated with sub-therapeutic post-mortem serum levels of antiepileptic drugs, but Opeskin et al. (1999) found no difference in serum antiepileptic drug levels between people who had died from SUDEP and those with epilepsy who had died from other causes. Although we have no direct evidence that non-adherence to drug regimen led to the death of these subjects, compliance might well have been better, and decisions more openly informed, if the hazards of seizures and the potential for fatal seizures had been addressed.*

## *Surgery*

### Criteria

People who continue to be drug resistant, and who are willing to consider surgery, should be referred for assessment for epilepsy surgery (SIGN, 1997). In most cases a patient will be experiencing more than two seizures per month (Wallace *et al.*, 1997). The guidelines further suggest that people with partial seizures with no history of secondarily generalised seizures are likely to be particularly good surgical candidates.

### Findings

Twenty-seven adults (10 with learning disability) had at least two seizures per month. (It should be noted that in 40 cases seizure frequency was not stated, and in 34 cases it was not clear enough to be able to calculate this.) Eight were considered for surgery. One patient declined surgery and in 4 the specialist felt that surgery was unsuitable. One was waiting for a test or referral at the time of death, and 1 died in the post-operative period. There was no further information for the eighth person.

Of the 19 adults with at least two seizures per month who were not considered for surgery, 7 probably had generalised seizures. In 4 there is no seizure description or syndrome. The other 8 probably had partial onset of seizures, and therefore might have benefited from presurgical assessment.

### *Comment*

*The possibility of epilepsy surgery should be considered in patients with medically intractable partial seizures, and if an individual patient is not referred to an expert team for such consideration the reasons for that decision should be documented in the notes. This can be readily audited. As CSAG recommended all epilepsy clinics should have formal links with tertiary services.*

### Information and support for people with epilepsy

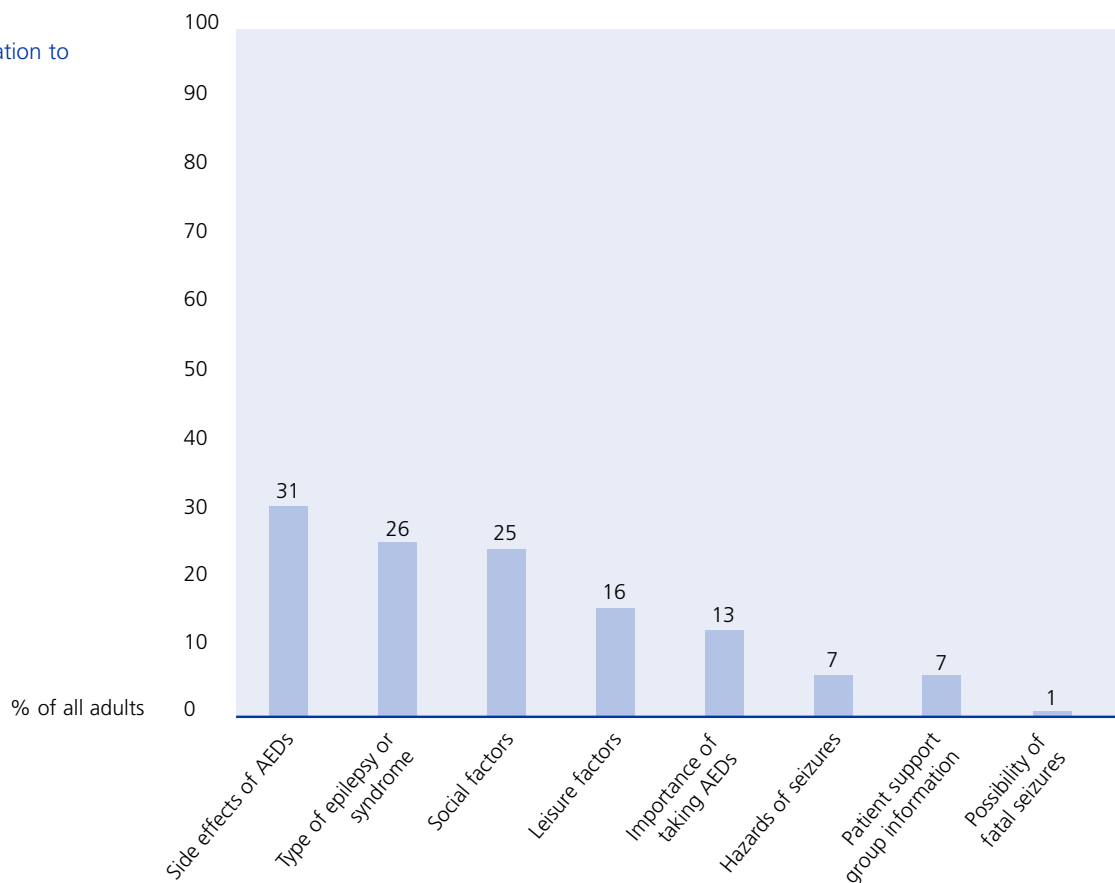
**Criteria**

- full information about diagnosis and potential implications should be provided (Cooper, 1986; Riddale, 1996; Wallace *et al.*, 1997). Continuing information and education should include a checklist of key issues to discuss with the patient recorded in the notes and available to the patient
- up-to-date literature on all matters related to their condition should be readily available to people with epilepsy (Wallace *et al.*, 1997)
- the risks of SUDEP should be considered in the information needs of people with epilepsy and carers (SIGN, 1997)
- integrated epilepsy care should include specialist epilepsy nursing (CSAG, 1999). Information and support needs of people with epilepsy and carers should be explored and access should be provided to other sources of support (Riddale, 1996; SIGN, 1997; Wallace *et al.*, 1997; Brown *et al.*, 1998; Epilepsy Task Force, 1999).

**Findings**

In 65 adult patients (41%, 95% CI 34–50%) there was no documented information provision.

**Figure 5.5**  
Provision of information to adults (n = 158)



Recorded discussions with people or written information provided was more likely in relation to topics of side-effects of medications (31%), type of epilepsy (26%) and social issues (25%) (Figure 5.5). Information provision was less likely in relation to leisure issues (16%), the importance of taking medication (13%), the risks of seizures (7%) and particularly that seizures could be fatal (1% (2 people)). The provision of information was similarly poor in those with and without learning disability.

Thirteen (8%) of the people who died had seen an epilepsy specialist nurse and 1 had seen an epilepsy counsellor in the year before their death. In the same time 5 (3%) had seen a psychologist and 12 (8%) had been provided with information on sources of patient support.

### **Comment**

*Communication with patients and carers is fundamental, especially in severe chronic conditions with multiple treatment options, so that they can make informed decisions about relevant medical or surgical strategies or lifestyle issues that may influence or be influenced by such information, and take proper control of their own life. Consequently we were very disappointed that there was so little information in the medical notes to suggest that such discussion had taken place. Although it is well recognised that lack of clinic time may preclude the clinician from writing down all that was discussed, the virtual complete absence in so many notes was a matter of real concern. Royal College of Physicians (RCP) guidance establishes as good practice that a counselling checklist is included in the medical record and is made available to the patient.*

*The nature of any information provided, when it was documented, is also of interest. RCP guidance requires people to be fully involved in decisions about their treatment and SIGN guidance lists SUDEP as a topic to be considered in people's information needs. Someone's decisions may be influenced by whether risk has been discussed with them, and the way in which risks are explained.*

*Most of the people who died were not known to be seizure free in the year before death and the findings in this chapter included 22 people with documented non-adherence to drug regimen, 1 who declined medications, 1 who declined surgery and 1 who did not attend an imaging appointment.*

*CSAG suggested that epilepsy specialist nurses could provide information for people, but we found little evidence that this happened. Very few adults had seen an epilepsy specialist nurse or counsellor in the year before death, or been given information about other sources of support, whether in the voluntary sector or otherwise.*

*The finding in this audit about the paucity of information and lack of support offered through specialist counselling or through access to the voluntary sector mirrors the findings of previous reports including CSAG (2000).*

*Epilepsy can have far-reaching psychological and social consequences, and still carries a considerable social stigma. Adverse psychological reactions can readily develop including hiding the diagnosis, overprotection from families and from others, and the taking of undue risks. Birnbach (1991) found that people with premature epilepsy-related death more frequently used denial as a psychological defence mechanism. Our audit found*

*that very few people who died of epilepsy were fully informed about the condition and its potential implications, and did not have access to information and support necessary to participate fully in decisions that affected them.*

*The paucity of information provision needs to be taken fully into account in the development of training programmes for undergraduates, postgraduates and associated professions dealing with people with epilepsy. It should also be considered in national/local guidelines and local audit processes: for example, inclusion of such information during consultations evidenced by the recording of it in the notes and sharing of information with patients.*

#### **Criteria**

After a sudden death the specialist should write to bereaved relatives with an open offer of a meeting (Nashef *et al.*, 1998).

#### **Finding**

In 8 deaths (5%) there was a record of an invitation by the specialist to meet with the family of a person who died.

#### ***Comment***

*Although it is possible that some specialists were not aware of the deaths of patients it is of concern that an invitation to meet the bereaved family was rarely recorded. Frameworks of care for patients with epilepsy should include details of post-mortem processes for contact with bereaved carers/families in the event of an epilepsy related death so that there is an open sharing of information and understanding of the events leading up to and the circumstances of death. This is particularly important when the death is sudden and unexpected because families experience bewilderment, isolation and prolonged distress (Nashef *et al.*, 1998).*

## **SECONDARY CARE PANEL REPORT ON OVERALL CARE**

### **Method**

The rationale for the peer review by the expert panel was to provide:

- an expert consensus on the adequacy of the overall care provided in relation to each person who died in order to inform appropriate guidance setting and service delivery
- a consensus on the potential for preventative strategies by a review of whether seizure control could have been substantially improved, and thereby the likelihood of SUDEP reduced (i.e. deaths that were potentially avoidable). Research evidence confirms that the majority of epilepsy deaths are seizure-related. Although it is not possible to establish in each case whether a death was definitely avoidable, the panel

assessed on the balance of probabilities whether deaths were likely to have been avoidable after reviewing the risk profile of each patient that died and overall seizure management

- expert interpretation of data on the audit tools in relation to where parts of the medical record were transcribed on to the audit tools (e.g. recorded descriptions of seizures); details and reasons for decisions and actions taken in relation to complex areas of epilepsy management (e.g. drug therapies and in respect of issues of communication between professionals).

A copy of the completed audit tool that was based on a review of all the available hospital medical case notes was sent to three members of the secondary care panel (see Appendix 1 for membership). At least one of these members was a specialist practising in the country where the person who died was treated. All audit tools relating to adults with learning disability were also sent to a fourth panel member specialising in learning disability. The clinicians assessed the completed audit tool for each adult and submitted an independent summary. After the submission of the three separate and independent evaluations on all the secondary care adult cases, a panel discussion took place to arrive at a single consensus evaluation for each of the adult cases. The panel met to discuss in depth the data available on each patient to agree a consensus opinion and grade each case according to whether specialist care was adequate, inadequate or included a major deficiency that could have itself substantially affected seizure control. In addition, some cases were categorised as unclear where it was considered that the data from the audit tool was too limited to reach a conclusion. Each case was also classified according to whether the death was unavoidable, potentially avoidable or probably avoidable based on the likelihood that optimum care would have substantially improved seizure control. The panel was provided with a summary sheet of findings from the pathology audit on the investigation of the death and with findings from primary care. They also had access to analysis of the treatment of each subject according to existing guidelines. Main concerns were classified under domains of problems of access, the diagnosis including the history taken, investigations, and treatments.

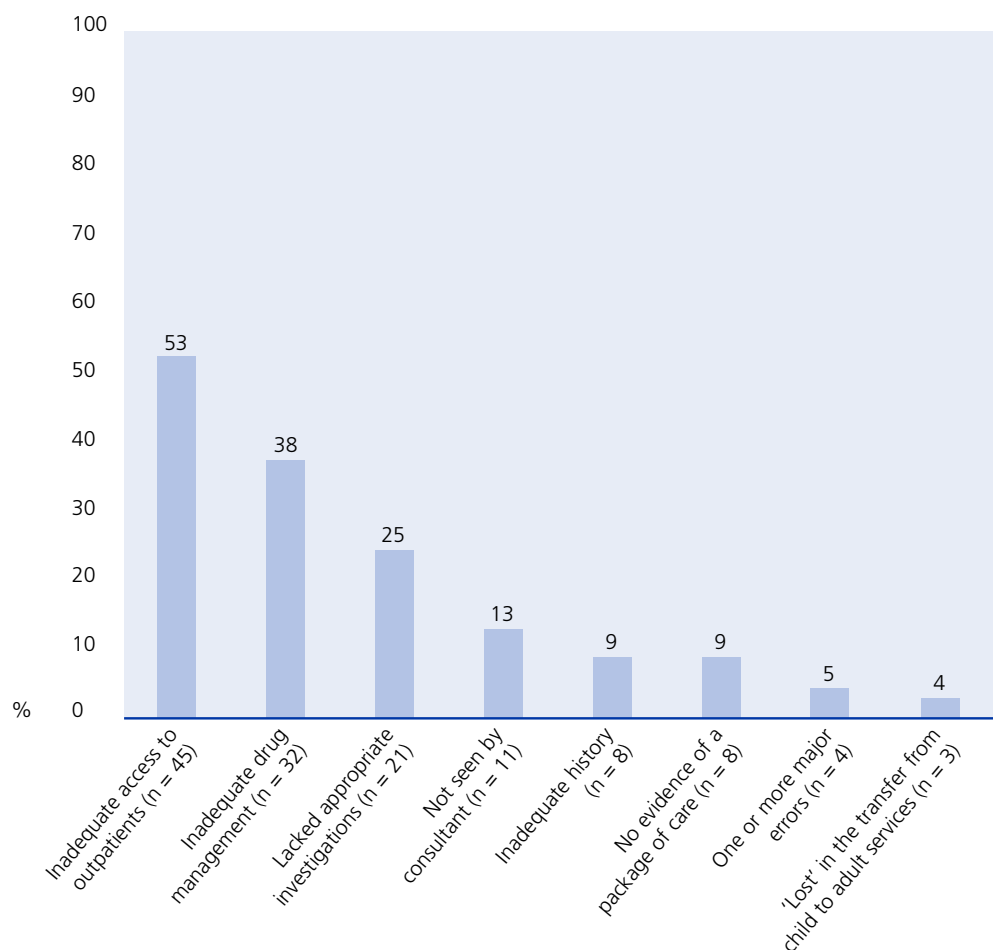
All cases that were categorised as inadequate were checked after the panel meeting against criteria from existing guidance relating to these domains.

## Main findings

Of 158 adult cases, the panel classified 63 (40%) as having had adequate care, and 81 (51%) as having had inadequate care but without a single major error (defined by the panel as a gross or potentially catastrophic error that could well have adversely affected seizure control). Four (3%) cases had had one or more major errors that could well have adversely affected seizure control, and in 10 (6%) the care was unclear.

Altogether, death was felt to be unavoidable in 60 (38%), potentially avoidable in 47 (30%), probably avoidable in 15 (9%). In 36 (23%) the circumstances were unclear. In those for whom the panel thought care was inadequate, they felt that death was unavoidable in 11 (14%), potentially avoidable in 44 (54%), probably avoidable in 8 (10%) and unclear in 18 (22%).

**Figure 5.6**  
Main reasons care was considered inadequate (85 adult deaths)



### *Inadequate care or major errors*

The specialist panel considered that 85 (54%) people who died had received inadequate care or had major errors in their care. They reached consensus on the main causes of inadequate care in these deaths. Of these 85 people:

- 45 (53%) had inadequate access to outpatients, and an additional 11 (13%) had no documented access to a consultant
- for 8 (9%) the history was inadequately documented in the notes, and for 21 (25%), appropriate investigations do not seem to have been instigated
- therapeutic management was considered inadequate for 32 (38%) people. For 2 people it seems that no antiepileptic drug had been advised, despite ongoing seizures. For 1 of these it was said that the seizures were infrequent. For 8 people the panel thought the drugs used were inappropriate for the seizure type or syndrome described, including 2 who were on carbamazepine for myoclonic jerks (this drug may exacerbate myoclonic epilepsy). For 6 people changes in antiepileptic medication were managed inappropriately, either in view of the kinetic properties of the drugs, or because changes were made too rapidly. For 1 person the antiepileptic drug treatment was suboptimal, because the doses used were small and likely to be subtherapeutic. Additionally, in 7 cases, despite ongoing seizures, there is not evidence that trying a second antiepileptic drug was considered. A further 3 cases had major drug errors (see below). For the remaining 5 people other problems

included unsupervised changes to medication and inappropriate doses or drug combinations

- for 8 people (9%) with various other needs, the panel saw no evidence of a package of care. A further 3 (4%) appear to have become 'lost' in the transfer from paediatric to adult care
- in 4 (5%) there were one or major errors. Three of these centred on drug management issues, including abrupt cessation of treatment and withholding therapy for no clear reasons. In one other death an incorrect diagnosis was made, with insufficient care being taken to perform investigations.

## Check against existing criteria

The cases that were regarded as inadequate or as containing major errors by the peer review panel were checked against existing guidance criteria in six key areas. The guidance checked was:

- having seen a consultant
- having seizure frequency documented at the time of the last consultation
- having a seizure description in the notes
- having had an EEG if appropriate
- having had neuroimaging if appropriate
- having antiepileptic drugs which went against the guidance of the BNF.

Twenty five out of 85 (29%) failed to meet the criteria for one of the guidelines, 25 (29%) failed to meet two guidelines, 10 (12%) failed to meet three guidelines, 4 (5%) failed to meet four guidelines, and one was deficient against five guidelines.

Twenty of the cases viewed as inadequate by the expert review panel did not specifically fail any of the guidance criteria above, but were considered substandard in other areas. Seven (7/20, 35%) cases were felt not to have followed accepted practice regarding antiepileptic drugs. Three of these (3/7, 43%) had poorly coordinated changes in their antiepileptic medication and 2 had inappropriate combinations of antiepileptic drugs. Two are detailed in the description of major errors (above). Thirteen people (13/20, 65%) were considered to have had inadequate access to care. Three of these did not keep appointments, but no further appointments were sent. Two were discharged, 1 with ongoing seizures and 1 who had only been seizure free for a few months. Six were lost to follow-up, and 1 case had not been successfully handed over from paediatric to adult care. One further patient had frequent inpatient episodes but no outpatient appointments.

The panel review of overall care therefore added support to the audit findings of care. For many patients there were deficiencies of care, although only four deaths were categorised as having gross errors and this finding was reassuring. In a substantial number of cases improved clinical care could reasonably have expected to have led to better seizure control and reduced risk of SUDEP.

## CHILDREN: RESULTS OF AUDIT

### Criteria

The limited nature of published guidance on the management of children with epilepsy meant that this part of the audit could only report in an extremely limited way in relation to nationally agreed clinical guidance. The panel assessed the appropriateness of treatment for each subject, including whether the antiepileptic drug treatment was appropriate for the type of epilepsy, and whether surgery or alternative treatments had been considered. In those children presenting with refractory severe epilepsy, the panel looked for evidence of consideration of referral to a specialist with a special interest, e.g. neurologist, paediatric neurologist or specialist with an interest in learning difficulty, as recommended by the Winterton report (Winterton, 1986).

### Audit tool

The secondary care audit tool was modified for the paediatric cases. Standards and guidelines published in the UK on the specific management of paediatric epilepsy were very limited. They consisted of an audit of children presenting with a possible diagnosis of epilepsy (Appleton *et al.*, 1998) and guidelines on when to undertake brain imaging in children with epilepsy (BPA, 1995). Additional 'evidence' on which the secondary care (paediatric) audit tool was designed included those guidelines produced within the centres of the members of the steering and expert groups of the audit team and also a consensus expert opinion of these members. For each child a secondary care (paediatric) audit tool was subsequently completed based on a review of all the available hospital medical case notes. A copy of the completed audit tool was sent to the paediatric panel (see Appendix 1 for membership). Each of the three clinicians assessed the completed audit tool for each child and submitted an independent summary that focused on three areas:

- adequacy of medical care before death and at the time of death
- circumstances of the child's death
- documentation of issues of holistic management.

Each clinician also commented on the quantity and quality of the overall documentation within the hospital medical case notes.

After the submission of the three separate and independent evaluations on all the paediatric cases, a panel discussion took place to arrive at a single consensus evaluation for each of the paediatric cases.

The final stage of the audit involved discussion of the single consensus paediatric evaluation with access to the primary care audit tool and the post-mortem audit tool for each of the paediatric cases, and consultation with two consultant neurologists for the paediatric cases in England and Wales and three consultant neurologists for the

paediatric cases in Scotland. This consultation resulted in a final evaluation on the paediatric cases, which, as in the preceding stages, focused on:

- adequacy of medical care before death and at the time of death
- circumstances of the child's death
- documentation of issues of holistic management.

## Sample

Eighty one children with epilepsy who died before their 18th birthday were reported to the National Sentinel Audit Secretariat during the study period (1 September 1999 to 31 August 2000). Complete audit tool data were available for 22 of these 81 children. These 22 children therefore constituted the paediatric cases in this audit.

## Findings

### *Demography of sample*

- 22 children (11 girls)
- age range at death: 2–17 years
- all children had experienced their first seizure by 12 years of age
- 9 of the 22 children had experienced their first seizure by 1 year of age
- 11 children had died at home (1 in a friend's home); 9 had died in hospital (accident and emergency department in 1) and place of death was not stated for the remaining 2
- 15 of the 22 children (68%) had learning disability (mild in 3, moderate in 4, severe in 3, and not specified in 5)
- 11 of the 22 children (50%) had physical difficulties (most commonly described as 'cerebral palsy').

Although 21 of the 22 completed paediatric secondary care audit tools included an eyewitness account or description of the child's typical seizure, in only 15 was the specific seizure type documented and the specific type of epilepsy (or epilepsy syndrome) was documented in only 7. The possible, probable or known cause of the epilepsy was documented for only 8 children. No children were known to be seizure free in the year prior to their death. 1 child died in a second seizure; 15 were recorded as having on-going seizures (seizures were experienced at least once a week by 6 children, at least once a month by 5 children and at least once a year by 2). Seizure frequency was not recorded at the last consultation for 6 (27%) children and was unclear in a further 2 (9%). Four (18%) children were not prescribed anti-epileptic medication at the time of death.

There was documented evidence that 17 children (77%) had never seen a consultant. Two of the 22 children had been seen only in the accident and emergency department and not in a hospital outpatient department. The other 20 had attended at least one outpatient appointment because of their epilepsy. All 20 children had been seen in an

outpatient clinic within 1 year of death, 17 (85%) within 6 months of death and 14 (70%) within 3 months of death. Only seven children (35%) had seen a paediatric neurologist at any of their last three appointments.

### *Care before death and at the time of death*

The overall adequacy of medical care (if this included the management of an acute seizure in hospital in the period immediately before death) was assessed using the following criteria:

- whether the patient had access to a consultant paediatrician or, when indicated by the child's history, to an expert in paediatric epilepsy (i.e. a consultant paediatric neurologist)
- whether the child had undergone appropriate investigations – specifically an EEG or neuroimaging (CT or MRI)
- whether the child had access to specialist investigations
- whether the child had received appropriate antiepileptic medication and dosages to treat the epilepsy
- whether the child had received appropriate management of an acute seizure in the hospital (accident and emergency department and/or the intensive care unit).

The panel considered the medical care to be adequate for 3 of the 22 children (14%). Two children (9%) could not be satisfactorily assessed because of inadequate information in the audit tools. For 17 children (77%) care was considered to have not met the required standard, for the following reasons:

- inadequate access for 8 children; 2 had never seen a consultant paediatrician and 6 children had never seen a consultant paediatric neurologist despite experiencing frequent seizures, and these seizures occurring in children with learning disability, physical difficulties or both. One child died while on the waiting list (over 12 months) for access to detailed investigations for possible epilepsy surgery
- inadequate investigations for 7 children; either no EEGs undertaken or EEGs undertaken many years earlier and not repeated despite a change in the frequency or character of the seizures and no brain scans (CT or MRI) ever undertaken in children where a scan should have been performed
- inadequate antiepileptic drug management for 10 children; 2 were not prescribed an antiepileptic drug by a hospital doctor, despite having frequent seizures. One of these children had a seizure lasting many minutes in the outpatient department which was witnessed by the consultant but medication was not prescribed; 4 children were considered to have been prescribed an inappropriate drug for the type of seizure (or seizures) that the child was described as having in the medical case notes; 4 were considered to have been prescribed inappropriately low or high doses of antiepileptic drugs on the basis of the child's age and weight (where the weight was documented in the medical case notes).

It must be emphasised that a number of the 17 children whose overall medical care was considered to be inadequate had inadequate care in not just one, but two or more of the categories outlined above.

### *Circumstances of death*

On the basis of the information provided in the three audit tool questionnaires (primary care, secondary care and post-mortem tools) the panel expressed an opinion on the circumstances of the child's death. They considered that the death was probably unavoidable in 6 of the 22 children (27%), potentially or possibly avoidable for medical reasons in 11 of them (50%), potentially or possibly avoidable for other reasons in 1, probably avoidable in 1 and unclear with no opinion possible because of incomplete information in 3 children (14%).

Of the 17 children for whom it was considered that the medical care did not reach the set standards, the deaths of these children were considered to have been probably unavoidable in 3 (18%), probably avoidable in 1, potentially or possibly avoidable for medical reasons in 11 (65%), potentially or possibly avoidable for non-medical reasons in 1. For the 1 remaining child an opinion could not be reached because of incomplete information.

### *Documentation of issues of holistic management*

A final audit of the medical case notes was undertaken to try and evaluate how much information and general counselling was given to the family (and, where appropriate, the children themselves). The following summarises the number of children and areas of discussion or topics where this information appeared to have been given:

- type of epilepsy (7 children, 32%)
- educational issues (11 children, 50%)
- social factors (9 children, 41%)
- leisure activities (6 children, 27%)
- potential hazards of seizures (no children)
- the possibility that seizures may be fatal (1 child, 5%)
- importance of taking antiepileptic medication regularly (1 of the 17 children receiving antiepileptic medication, 6%)
- potential side-effects of antiepileptic medication (8 of 17 children, 47%)
- informing families of the existence of national voluntary support groups or charities (3 children, 14%)
- regarding contact with bereaved relatives following the death of a child, there was evidence that 10 (45%) families had been contacted by the specialist.

### **Comment**

*Eighty one children with epilepsy died during the period. The majority of the 22 children included in this audit had refractory epilepsy and frequent seizures and also had additional physical and learning difficulties. It was surprising and disappointing that a number of these children had never been seen by a consultant paediatrician or that there had been no discussion with or referral to a specialist in paediatric epilepsy (a paediatric neurologist). The lack of any documented paediatric neurology input into the care of a number of these children was considered to have had a potentially significant impact on their overall care and therefore, potentially, on the circumstances of their death.*

*The scarcity of documented communication and discussion on a range of holistic issues was also disappointing and again reflected adversely on the overall care given to these children during life and to their families after the death. Although the issue of adolescence – and specifically the transition from paediatric to adult care – was not formally addressed in the paediatric audit, it is important to emphasise that adolescence and early adulthood is an important period, not only because it is the time of development of independence and autonomy but also because it appears to be a particularly high risk period in terms of SUDEP. Management should therefore be optimal during the adolescence and early adulthood of a person with epilepsy.*

*The small number of children audited in no way minimises or invalidates the audit findings. There is no reason to suspect that these patients are not representative of the remaining 59 patients who died during the study period and were not audited.*

## **SUMMARY**

People with epilepsy are at increased risk of sudden death. In virtually all witnessed cases there is evidence of a preceding epileptic seizure. In a key case controlled research study on SUDEP, Nilsson *et al.* (1999) reported that people who had not been seizure free in the previous year had a 23-fold increased risk of SUDEP compared to people with fully controlled seizures, and the risks increased with increasing seizure frequency. These findings emphasise the need to strive towards optimum seizure control to reduce mortality.

The audit of secondary care provided to adults and children who died a seizure-related death examined whether specific factors relating to access, investigation, treatment or communications met agreed criteria before death, whether the overall quality of care was satisfactory, and therefore what proportion of these deaths might have been avoidable.

### **Adults**

- access to specialist care was inadequate in a substantial proportion of people due to delays, failure to receive consultant advice, care by an inappropriate specialty or inadequate follow-up
- basic clinical assessment and utilisation of appropriate investigations were often inadequate

- most people were receiving antiepileptic drugs at the time of death but in some the choice or dose were suboptimal and a small number were on no medication without clear clinical justification for that decision
- our greatest concern was the very poor documentation of adequate information given to people with epilepsy and carers. Despite the frequent occurrence of known high risk factors for SUDEP evident in this cohort:
  - only 1% of case notes indicated that this possibility had been discussed with the patient or carers
  - only 7% that other hazards had been discussed
  - only 12% that the importance of adherence with antiepileptic drug medication had been discussed
- without this information people with epilepsy and carers cannot make informed decisions about treatment and lifestyle options
- there was little evidence of any contact with families after death.

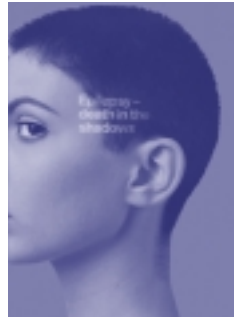
## Children

Any conclusions from this audit of paediatric deaths must obviously be made with some caution because of the small number of children (22) and at times limited data available from the audit tools. It is important to emphasise that the consensus opinions of the expert group were based exclusively on the written information contained in the three audit tool questionnaires and therefore the primary and secondary care medical case notes and post-mortem reports. With these caveats in mind, the following conclusions seem appropriate:

- most deaths occurred in children whose seizures were difficult to control, or who had accompanying learning or physical disabilities. In this cohort it appeared that overall care was inadequate for most of the children, and this was predominantly related to limited access for specialist epilepsy advice and potentially inappropriate medication
- basic documentation in the notes appeared poor, particularly regarding classification of seizure type and syndrome, consideration of an underlying cause and holistic aspects of management
- the overall care was considered to be inadequate in most of the children (77%) and this was predominantly related to limited access for specialist epilepsy advice (consultant paediatric neurologists) and potentially inappropriate antiepileptic medication
- over half (59%) of these 22 deaths may have been possibly or potentially avoidable.

Medical education programmes, national and local, guidelines and audit measures need to take account of these deficiencies to improve both adult and paediatric practice.





## APPENDIX 1

# CONTRIBUTORS AND ACKNOWLEDGEMENTS

### AUDIT STEERING GROUP

Dr Richard Appleton *Consultant paediatric neurologist; Royal College of Paediatrics and Child Health representative*

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### Expert working panels

#### *Moderation*

The steering group appointed a panel consisting of Professor Josemir Sander, Professor David Fish, Dr Marjorie Black, Professor Stephen Brown and Dr Henry Smithson to review the certification data supplied on cases ascertained through the national registration offices. The purpose of the panel was to provide a preliminary view about the national data and allow the cases released by national registration offices to be divided into three groups: likely, possible or unlikely.

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*Secondary care – children:* Dr Richard Appleton

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## AUDIT WORKSHOP PARTICIPANTS

Consultation on the audit report included an invitation to organisations represented on the steering group and other interested stakeholders to attend a workshop during November 2001. We would like to thank the following people who attended a workshop to provide a forum for authors of the report to discuss the audit findings and the content of the audit report:

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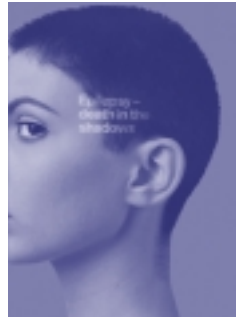
## ACKNOWLEDGEMENTS

- The photograph used on the cover of this report is by kind permission of the Chief Medical Officer for England.

We would also like to thank

- All relatives of people who died during the period of the audit who contacted Epilepsy Bereaved and wished to assist. Thanks also to the office and family support team of Epilepsy Bereaved who made it possible for relatives to give information to the audit team.
- The Crown Office in Scotland and the Central Health Board in Northern Ireland for authorising and facilitating access to records and to all staff in coroner's offices, pathology departments, GP practices, hospitals and health authorities who co-operated and contributed to data collection.
- The Royal College of Pathologists, the National Hospital for Neurology and Neurosurgery, University of Birmingham Seizure Clinic and University Hospital of Wales, Cardiff for providing training facilities
- Additional organisations that supported the bid or the work of this audit. These included the Royal College of Physicians, the Scottish Royal Colleges, the Association of British Neurologists and the Epilepsy Specialist Nurses Association.
- All those who took the time to comment on draft audit tools, questionnaires and the draft report.





## APPENDIX 2

# METHODOLOGY

### PROJECT MANAGEMENT

The steering group included representatives from:

- Department of Health
- Department of Health, Social Services and Public Safety (Northern Ireland)
- Epilepsy Bereaved
- International League against Epilepsy (British Branch)
- Royal College of General Practitioners
- Royal College of Nursing
- Royal College of Pathologists
- Royal College of Pathologist Clinical Audit Department (to January 2001)
- Royal College of Paediatrics and Child Health
- Royal College of Psychiatrists (Faculty of Learning Disability)
- Public Health Resource Unit (from March 2001)
- Scottish Executive
- Welsh Office of Research and Development

The Royal College of Physicians, the Scottish Royal Colleges and the Association of British Neurologists supported the setting up of the audit.

An executive committee (comprising the project manager, audit officer and the clinical leads from pathology, primary and secondary care) was responsible for stage-by-stage monitoring and planning of audit activity. The clinical leads were supported by expert panels in pathology, primary and specialist care and by additional expert advice.

The audit officer was seconded from the audit department of the Royal College of Pathology from April 1999 until January 2001 and the final stages of the project were

coordinated from March 2001 by a senior researcher at the Public Health Research Unit in Oxford. Five nurses were appointed as audit field workers from autumn 1999 to spring 2001. Two were full time, 1 each for the north and south of England; 3 worked part time in Scotland, Wales and Northern Ireland. Two had experience as epilepsy specialist nurses; 2 in neurology and one in research.

## **MODERATION EXERCISE**

A moderation panel made up of all 5 clinical leads reviewed 20% of cases where epilepsy was noted as an underlying condition on Part II of the death certificate. It was considered that deaths of all cases in this sample were more likely to have died from conditions other than epilepsy, and that given our lack of automatic access to case notes the study would risk causing unnecessary distress if professionals or health authorities sought consent from next of kin to examine records where epilepsy was an unlikely cause of death. Part II cases were therefore discarded from the pre-mortem study. The panel then reviewed the certificate information on Part I of the death certificate and decided the criteria for the study sample.

Two clinical leads then reviewed each certified death, and these were divided into probable, possible and unlikely epilepsy deaths. The data collected from medical records and post-mortem reports on a sample of deaths from probable epilepsy deaths, were reviewed again by primary and specialist expert panels (Appendix 1) and 19 secondary cases and 5 primary cases were excluded because of doubtful attribution.

## **AUDIT TOOLS**

### **Audit tool development**

Criteria for audit were developed using published guidelines, results of a literature search and the views of the pathology, primary care and specialist panels. Draft tools were discussed at a steering group meeting and refined to avoid duplication. The audit tool for the investigation of death was piloted using a sample of post-mortem reports of people who were certified as dying from epilepsy. The audit tools for pre-mortem care were piloted using case notes from a GP practice and a hospital trust with the full knowledge and consent of the patients. With consent from relatives, the pilot also included a sample of records of people who had died from epilepsy. It was not possible to pilot audit tools with deaths ascertained through the audit because the audit did not begin to receive national registration data until April 2000 and access to all notes took on average 4 months.

### **Evidence base**

#### *Investigation of death audit tool evidence base*

An audit tool was developed for the audit of post-mortem examination into epilepsy

deaths. The pathology panel noted the absence of specific national guidance in relation to the investigation of epilepsy deaths and developed the audit tool from all available guidance and evidence. An audit form was also developed for deaths certified without post-mortem, which collected data from case notes on evidence in the notes of the stated causes of death in the death certificate. The judicial system and process for the conduct of inquests or fatal accident enquiries was beyond the jurisdiction of this audit.

The material used for the pathology tool and certification form included guidelines from Royal College of Pathologists (RCPATH, 1993) and the Association of Clinical Pathologists (ACP, 2000), as well as the terminology and definitions proposed by Nashef (1997).

### *Primary care tool evidence base*

- SIGN (1997)
- Taylor (1996)
- Hall *et al.* (1997)
- BAHA (1998)
- Leeds Health Authority (1999)
- Brown *et al.* (1993)
- Epilepsy Task Force and JEC (1998)
- Epilepsy Task Force (1999)

A further guideline review was carried out after completion of data collection and some additional publications were identified:

- CSAG (2000)
- Taylor (2000)

A Medline-Embase search (keywords: epilepsy-guidelines-management-primary care-general practice-service provision) identified papers on epilepsy care in accident and emergency departments, a drug treatment decision support tool, management recommendations from the USA, epilepsy specialist nurses, views of patients on service provision, and guidelines for women with epilepsy. These papers suggested the need for epilepsy expertise, an agreed management plan and the benefits of specialist nurses.

### *Secondary care evidence base*

- Winterton (1986)
- Wallace *et al.* (1997)
- SIGN (1997)

A further guideline review was carried out after completion of data collection and the publication of CSAG (2000). The audit had access to the results of the CSAG literature search and some additional papers were identified from an updated Medline-Embase

search in August 2001. The specialist care panel noted that there was very limited published guidance in relation to children with epilepsy. A paediatric panel was established to reach consensus on criteria for audit from available evidence and the results are reported in Chapter 5 (secondary care).

## Checking validity and reliability of audit tools

A high degree of construct and content validity was sought by basing tool development on published literature and steering group and panel discussions for all arms.

Reliability was assessed by field worker exercises and matching primary and secondary data collection. In a development and training exercise before the main study, sets of medical records (6 primary care, 6 secondary care and 12 pathology) were audited once by each of 3 audit officers. The inter-observer proportion of agreements was 72% for the primary care tool, 81% for the secondary care tool, and 94% for the pathology tool. These proportions considerably overestimate true inter-observer reliability, as the data were not available to obtain kappa (chance-corrected agreement) values. At the end of the exercise all disagreements were reviewed and resolved by the audit officers and leads, using the full case notes. Thus reliability was likely to be lower at this point than it was in the main study.

After the audit was completed, a sample of 22 cases with completed primary and secondary care audit tools was reviewed by the relevant clinical lead, to check for agreement between the two tools within question domains and assess internal tool reliability. Compared with the complete case notes of 5 items common to both audit tools, 88% of items were accurately recorded by the primary care tool, and 95% by the secondary care tool. Most of the errors were concentrated in two items: the date of last review and antiepilepsy medication, with 55% and 72% agreement respectively. Even the last of these represents a kappa value of 0.60, which is usually taken to represent good agreement (Altman, 1991).

## AUDIT OF CARE OF PEOPLE DYING FROM EPILEPSY

### National variations in case capture

#### *England and Wales*

In England and Wales case capture was entirely dependent on securing the initial cooperation of the coroner and then securing consent from the relevant GP, health authority and hospital Trust.

The audit was not provided with contact details of GPs or hospitals, so it was not possible to locate where medical care was provided unless coroners assisted the audit or bereaved families initiated contact with us. The audit made every attempt to contact GPs. In England we were able to disseminate information on the audit to every GP practice.

Further, where we did not have GP details, health authorities and boards were contacted with a request to identify and pass on a letter of request to GPs.

Health authorities and Trusts required next of kin consent for release of the medical record. This included some cases where there were no known next of kin. The audit agreement with the Office for National Statistics prevented us from contacting next of kin directly. Seven medical records were lost or destroyed.

### *Scotland*

The General Register Office provided details of the GP as well as the certifying doctor, and our audit field worker was able to request records directly from the GP. Access to primary care records was normally directly from the appropriate health board following written consent by the GP. In Scotland 11 GPs did not respond, 1 refused to co-operate and 1 required next of kin consent. In 3 cases where otherwise we would have had access, medical records were lost or destroyed.

### *Northern Ireland*

We had authority to access primary care records centrally; the audit field worker was able to locate the hospital records, and was given access to these by hospital Trusts.

## **DATA COLLECTION AND ANALYSIS**

Data collection involved completion of hard copy audit tools by audit staff, and was completed on all sites known to the audit as holding relevant records.

### **Pathology**

Audit tools were completed from post-mortem reports and coroner's officer and police reports where available, and included 58 data items. An audit tool for deaths certified without post-mortem completed from patients' notes included 6 data items.

### **Primary care**

Audit tools were completed from case notes and included 57 data items. Data for patients who had not received secondary care for their epilepsy were collected using tool 1 and data for patients who had been referred and received secondary epilepsy care were collected using tool 2.

### **Secondary care**

Audit tools were completed from case notes and included 101 data items. Data were entered manually on to Microsoft Excel software. The audit officer's office at the Royal College of Pathologists provided the central office site for the project during the data collection phase of the audit. Data collected in the field and entered in Excel was collected electronically and regularly from the audit officers' computer files so that at all

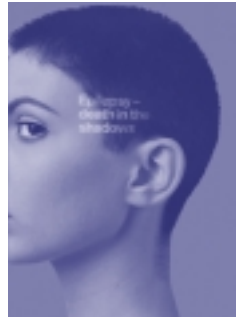
times there was a central record of data. After data collection was completed all hard copies were kept by an audit research officer at the National Society for Epilepsy, which acted as a central office site for all audit tools. Data was transferred into SPSS. Edit checks were run so that data inconsistencies and duplicate entries could be identified and addressed. Data entered, before and after data cleaning, were checked against hard copy audit tools.

## Data analysis

The clinical leads and the panels assessed results from each arm of the study and findings were recorded under the following headings:

- pathology:
  - background history
  - post-mortem external examination
  - post-mortem internal examination
  - further investigations
  - cause of death.
- pre-mortem care:
  - access and clinical assessment
  - investigations
  - treatment and therapies
  - continuing care
  - information and support for patients
  - professional communication.

Data were analysed using Excel (pathology and primary care) and SPSS (secondary care). Proportions were compared with chi-squared tests, with a linear trend component or exact test where appropriate. StatsDirect was used to obtain exact confidence intervals for proportions and differences in proportions (primary and secondary care). Confidence intervals are not given in the text for non-significant differences (5% significance level). Many percentages are based on small numbers, so even where confidence intervals are not given, they are not necessarily a reliable guide to future proportions. Ages were compared between groups using Mann-Whitney tests.



## APPENDIX 3

# THE CONTEXT OF CARE IN PRIMARY AND SECONDARY CARE SERVICES

## PRIMARY CARE

### Method

We carried out a postal survey of 285 general practices linked to the case note audit. Following the audit of records, a questionnaire designed by the primary care arm of the audit was sent to the senior partner. Copies of all audit tools and questionnaires used in the audit are available on [www.sudep.org](http://www.sudep.org)

The questionnaire sought data on epilepsy management, prescribing and access to specialist care.

### Response

Of the 285 practices surveyed, 112 (39%) responded.

#### *About the practices*

- the practices ranged in size from 1,250 to 14,500 patients, with a median of 6,330
- the number of full-time GP principals in the practice varied between none at all (2) and 10 (1). There were 17 (15%) single-handed practices and 55 (49%) had 2 or 3 full-time partners. One (9,750 practice population) had 7 part-time principals and 1 (1300 practice population) had 2 part-time principals
- 32 (29%) had 1 or more part-time principals in the practice
- 34 (30%) are training practices.

## Results: the key areas for epilepsy care

### *Disease management*

- 62 (55%) of the practices have a disease register for epilepsy
- 23 (21%) have a disease management protocol
- 9 (8%) have a GP in the practice with special interest in epilepsy
- 4 (3%) have an epilepsy clinic in the practice, and a further practice was about to start one. Of the 4 practices that have a clinic, 1 is run by a specialist nurse, 1 by a GP and practice nurse, and 1 by a practice nurse only (The fourth practice did not provide details.)
- the practices with an epilepsy clinic varied in list size between 2,900 and 12,000 patients.

### *Audit*

- 34 practices (28%) had carried out an epilepsy-related audit at some time. A further 6 (8%) said they were planning one in the next year
- of the practices that said they had carried out an audit, 21 (62%) said that the results had altered epilepsy care.

The changes described in practice were wide ranging and included improving monitoring and review, setting up an epilepsy clinic, improved information and education, more regular review and redesigning review protocols (including liaison with specialist services), increase in the use of modern antiepileptic drugs, and improved record keeping (such as starting an epilepsy continuation card in the notes).

However, one commented on the difficulties of developing services:

'We attempted to set up a clinic with a dedicated nurse. However, there were so many DNAs [missed appointments] and the patients were reluctant to come.'

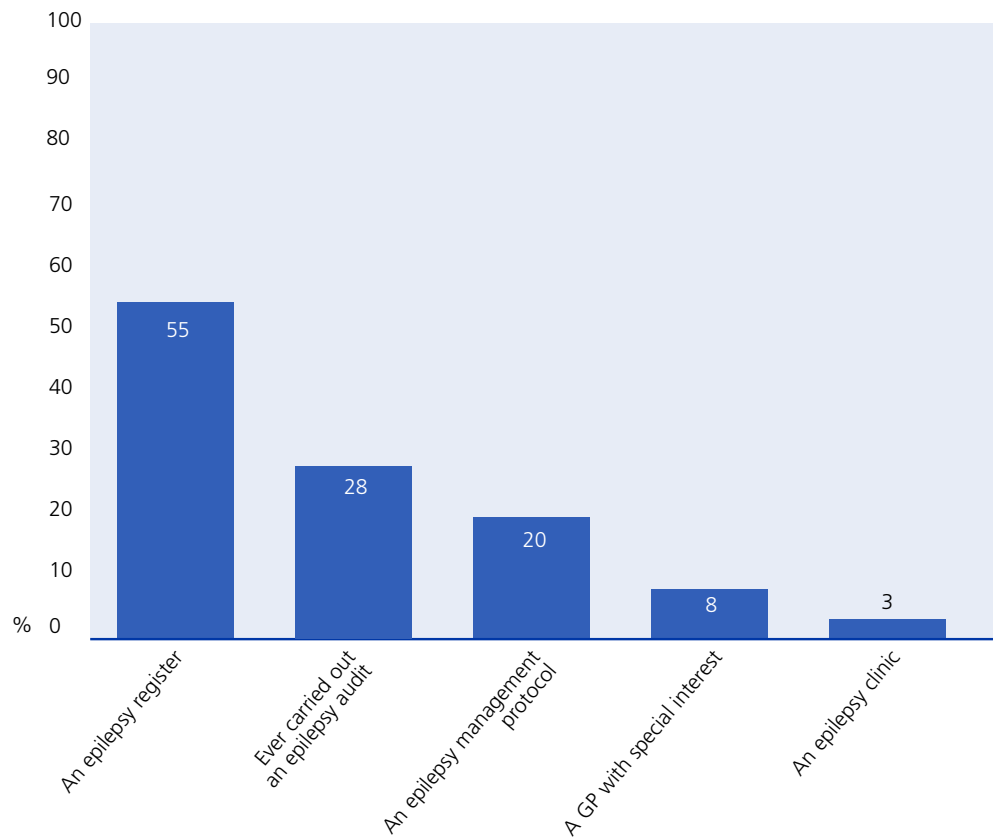
### *Repeat prescribing*

- all the practices are computerised, with one having an additional card index system
- all practices that responded give repeat prescriptions for antiepileptic medication. Fifty-two (46%) prescribe for 28–31 days' supply. Five (4%) prescribe for more than 60 days' supply
- in just over half the sample (n = 60, 54%) the most common number of repeat prescriptions allowed was 4–6. Six (5%) allow more than 12 repeats before review.

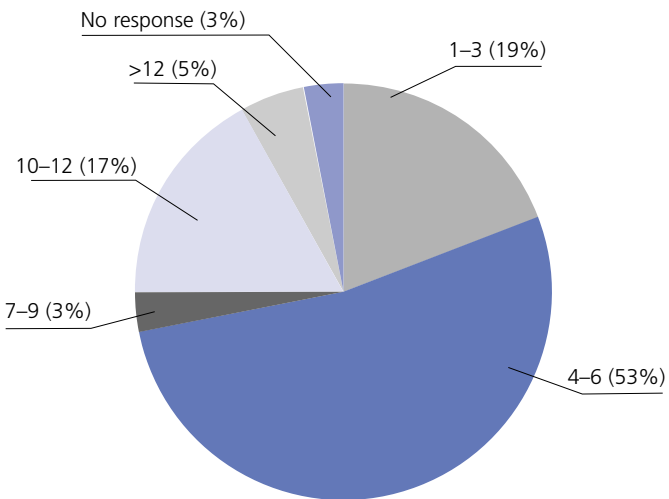
One respondent commented:

'A major difficulty is the understandable unwillingness of epileptics to attend for annual review without being prompted, when they are free of fits.'

**Figure A3.1**  
Epilepsy care in general practices (n = 112)



**Figure A3.2**  
Usual number of repeat prescriptions for antiepileptic drugs before review or reauthorisation (n = 112)



*Access to secondary care*

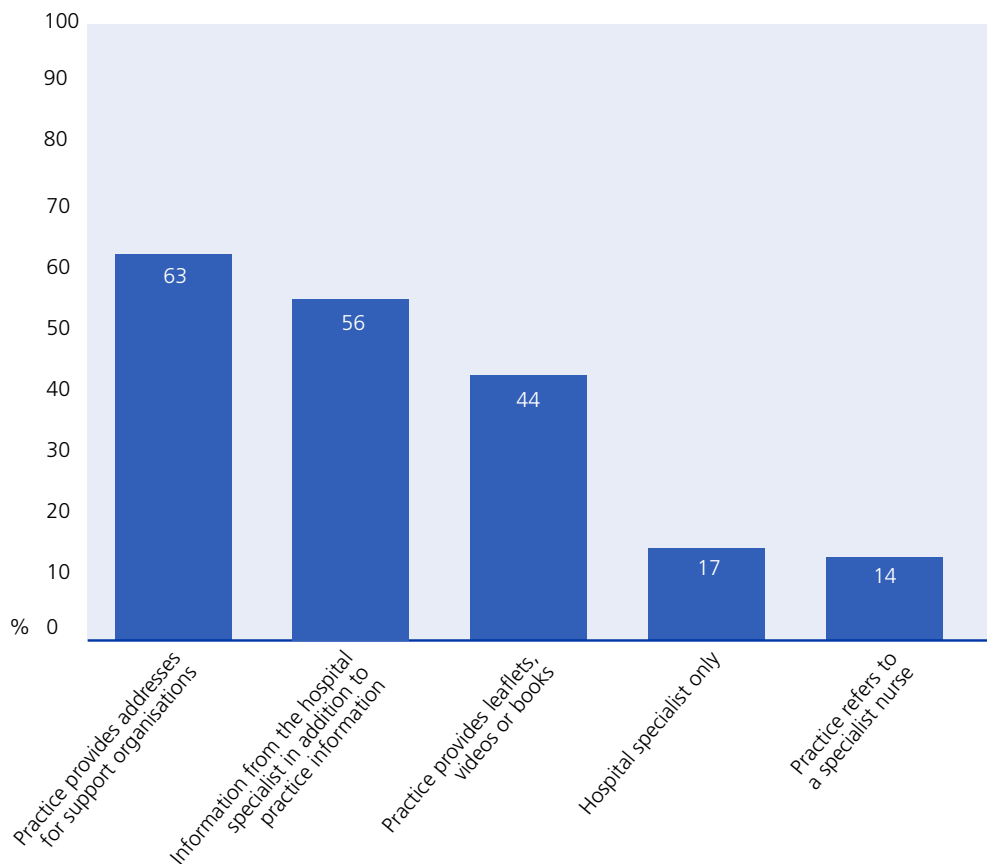
There was a poor response to the questions about waiting times. Twenty-five (22%) did not reply to the questions about waiting times for adults, and 31 (28%) to those about waiting times for children. Two respondents (2%) quoted waiting times of over a year, but 78 (90%) of those who responded said their patients were seen within 6 months. Of these, 40 (46%) were seen with 3 months and 11 (12%) within 1 month.

- nearly three-quarters do not have access to a specialist adult clinic at the local acute Trust. Just under half initially refer an adult to a neurologist
- 79 (70%) said that children with suspected epilepsy are usually seen within 12 weeks by a paediatrician
- 51 (45%) said that the children are usually seen in 4 weeks or less
- 89 (79%) said that there is not a specific children’s epilepsy clinic available at their local Trust; 8 (7%) were not sure or did not reply. Thus only 15 (13%) appear to have access to a specialist children’s epilepsy clinic.

*Information for people with epilepsy and their carers*

- 82 practices (73%) provided information, referral to a specialist nurse or contact details for support organisations
- 19 (17%) said that the person would get information from the hospital specialist only and 11 (10%) did not respond.

**Figure A3.3**  
Provision of information and support in primary care  
(n = 112)



**SECONDARY CARE**

**Method**

A questionnaire was sent to all NHS Trusts in the UK that had cooperated in the audit of

the medical records of people dying from epilepsy. The questionnaire was designed by the secondary care arm of the audit and was based on the questionnaire on Trust services published in *Adults with Poorly Controlled Epilepsy* (Wallace *et al.*, 1997). In addition service issues were also identified and used from:

- Clinical Standards Advisory Group on Epilepsy (CSAG, 2000)
- *Diagnosis and Management of Epilepsy in Adults* (SIGN, 1997)
- Epilepsy Task Force Service Development Kit (Epilepsy Task Force, 1999)
- Developments in the UK service provision for people with epilepsy (Brown and Lee, 1998)
- *Epilepsy Care: making it happen*. Epilepsy Advisory Board, Leeds.

Trusts were approached via a named contact, identified by the Trust for the purpose of the audit. This was sometimes the Medical Director of the Trust, but more usually the lead neurologist. In total, 94 questionnaires were sent to Trusts involved in the case note audit. A reminder was sent after 1 month.

Questionnaires were sent to a further 112 Trusts that had not taken part in the case note audit. Information on whether any of these Trusts had any epilepsy-related deaths during the audit period was not available to this audit (see Chapter 2). These Trusts were identified from two sources:

- Trusts that had provided a contact name for the purposes of the audit in response to a written request during 1999, but had not participated in the medical records audit
- Trusts identified from the *Medical Directory 2000* as having a neurology department or neurologist post.

These Trusts were contacted by phone (unless the Trust listing was clearly concerned with the provision of a service unrelated to epilepsy or neurology), and asked whether they provided secondary or tertiary services for people with epilepsy. If this was confirmed, a questionnaire was sent to a named contact identified by the Trust or, failing this, the Medical Director of the Trust.

In total, 206 questionnaires were sent to NHS Trusts providing specialist care for people with epilepsy.

## Responses

Of the 206 questionnaires sent out, 126 (61%) were returned.

### *About the Trusts*

- 71 Trusts (56%) provide epilepsy services for adult patients, people with learning disability and children
- 26 (21%) provide epilepsy services for adults only, including people with learning disability

- 13 (10%) provide epilepsy services for adults and children, excluding people with learning disability
- 7 (6%) provide epilepsy services for adults only, excluding people with learning disability
- 4 (3%) were specialist children's hospitals and 5 (4%) specialised in the care of people with learning disability
- the median catchment population was 250,00–500,000, ranging from less than 100,000 (3 Trusts) to 4.5–7 million (3 Trusts).

## Results

### *Policies, procedures and protocols*

Forty one Trusts (33%) said that they had written guidance, protocols or procedures for the management of epilepsy. Twenty four provided further information, with 4 stating that protocols existed only for the management of status epilepticus.

Approval is via a variety of approaches:

- 'Clinical Guidelines assessment panel'
- 'Only indirectly – in accepting SIGN guidelines'
- 'Medical Audit Advisory Group (MAAG) steering group in public health'

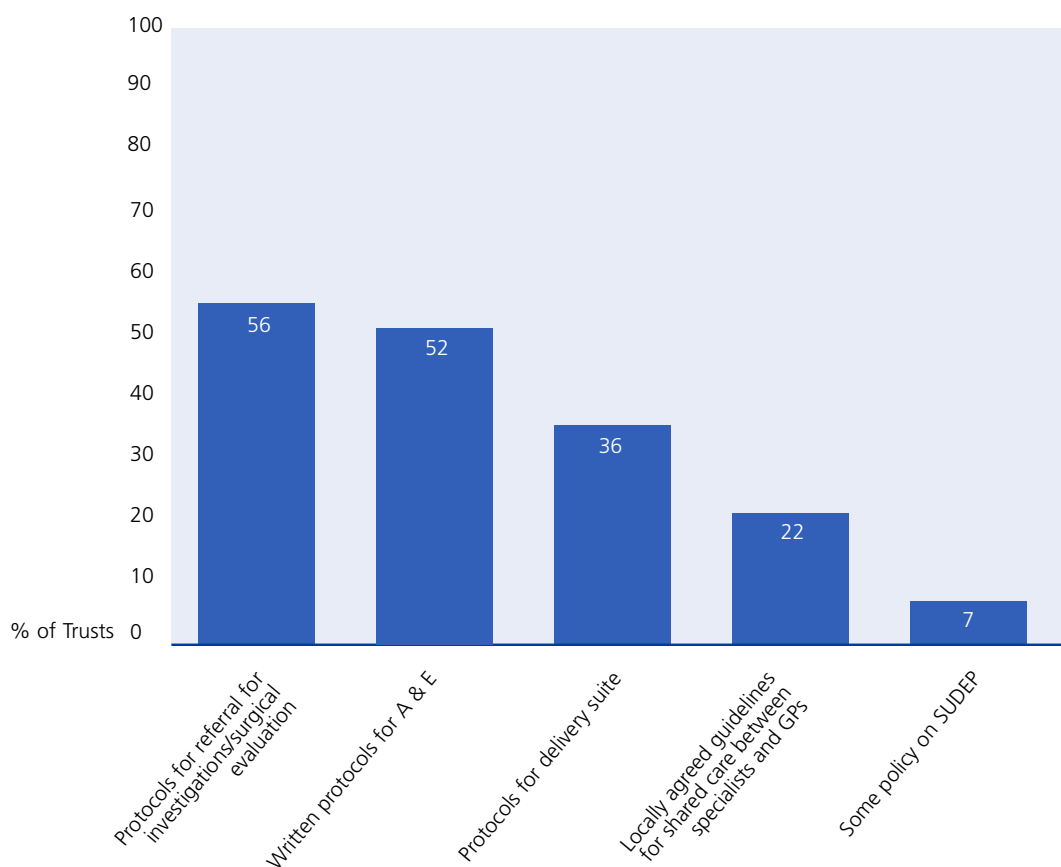
And driven by a variety of people:

- 'Consensus'
- 'Review by the consultant neurologist'
- 'Guidelines for antiepileptic drugs are drawn up by a consultant with an interest in epilepsy'
- 'Developed by epileptologist'

Trusts were asked to include copies of protocols, policies and procedures with their reply. Policies came from England (32), Wales (1) and Scotland (3). None was received from Northern Ireland, although there were two unidentified documents, one from a general NHS Trust and one from a paediatric hospital. Most were protocols for status epilepticus in accident and emergency or labour wards. There was one county-wide policy.

- 9 (7%) Trusts have some policy on SUDEP.
- 27 (21%) have locally agreed guidelines between specialists and GPs for the clinical management of patients across the primary/secondary care interface.
- 65 (52%) have written protocols for accident and emergency.
- 70 (56%) have protocols for referral for investigations and surgical evaluation.
- 45 (36%) have protocols for labour wards.
- A few said protocols existed for status epilepticus only.

**Figure A3.4**  
NHS Trust policies and protocols  
(n = 126)



### Getting into the system

Eighty-three Trusts (66%) said that they see urgent cases within 4 weeks. Some have a 'first seizure' clinic, others have arrangements for fast tracking patients into general clinics.

- 'There is no formal 'fast' clinic. However, we aim to see 'new' in 6–8 weeks.'
- 'I run a first seizure service. I can see people within 3 weeks of their first attack.'
- 'On receipt of an urgent letter, fax or telephone call patient is seen within the next 5 working days if felt to be urgent. Otherwise, waiting time for a new 'routine' appointment is 2–6 weeks.'
- 'Seen within 4 weeks of referral – possibility of doing EEG same day. Patient sees consultant within 6–8 months unless marked "urgent".'
- "'First fitters'" attending casualty are referred to first-fit clinic (seen within 3–4 weeks generally). From a GP, referrals to the first-fit clinic have an EEG on the same day often.'
- 8 Trusts (6%) said that they see routine patients within 4 weeks; however, 10 (8%) have patients waiting for a year or more.
- Where expertise is not available in the Trust, 70 (56%) have a procedure for onward referral where applicable. However, there was a great deal of variation.

## Management/process of care

### Medical care

- 76 (60%) have at least one consultant with specific responsibility for adult epilepsy services. Most are consultant neurologists.
- 43 (34%) have a consultant paediatrician responsible for children’s services, usually a consultant paediatric neurologist or paediatrician.
- 56 (47%) have a dedicated epilepsy service within the Trust.

### Clinical nurse specialist

- 54 Trusts (43%) have a clinical nurse specialist (CNS) attached to the hospital. They were equally divided between clinical grades G and H.
- The CNSs liaise with employers, self-help groups and social services. Thirteen (24%) have set up epilepsy registers with GPs.

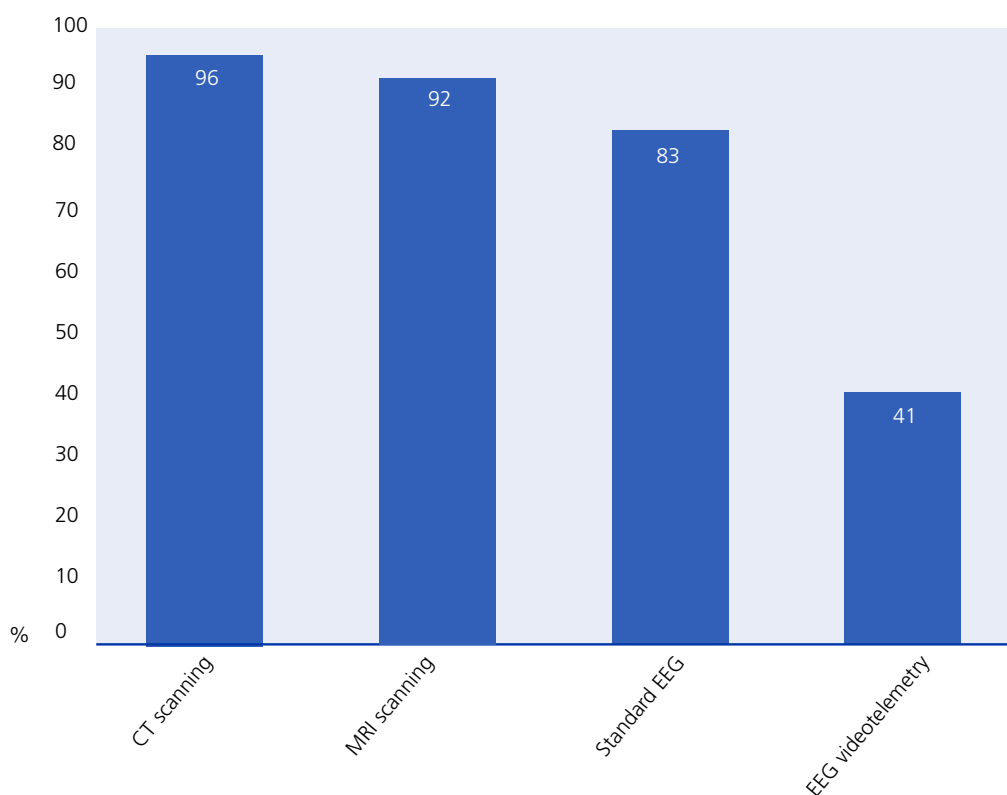
## Investigations

### Scanning

Nearly all Trusts have access to MRI and CT scanning: 110 (92%) and 121 (96%) respectively.

- the average waiting time for an MRI scan is around 3 months
- 99 Trusts (83%) have access to standard EEG
- 52 Trusts (41%) have access to EEG videotelemetry.

**Figure A3.5**  
Percentage of Trusts with access to EEG and scanning (n = 126)



### Surgery

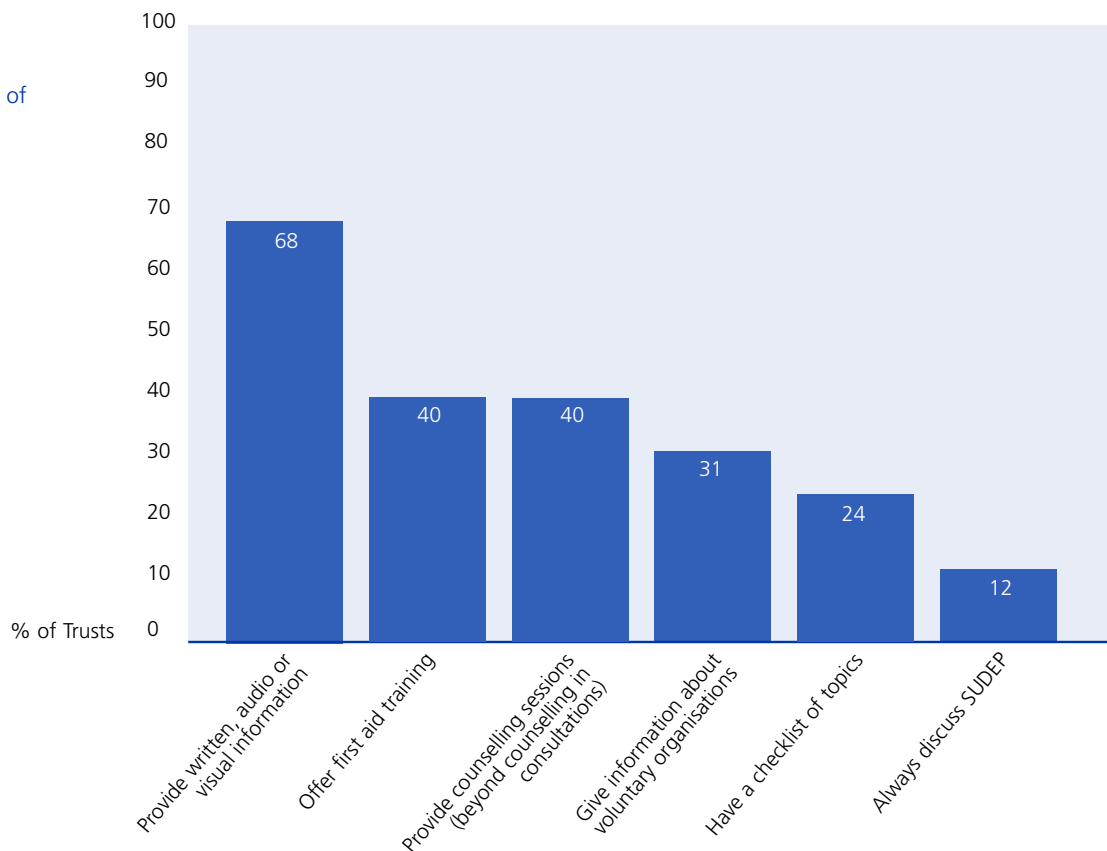
- 40 (32%) of those who replied said that they have epilepsy surgery available as part of the Trust’s service.
- 34 (27%) keep a register of surgery cases and outcome.

### Information for people with epilepsy and their carers

Thirty Trusts (24%) have a checklist of issues to be discussed with patients, available for inclusion in the patient’s notes. This aims to remind members of the healthcare team of patients’ information and educational needs. Some said that SUDEP was included on the checklist, but in addition some of those who did not have a specific list said that they always discussed SUDEP with their patients. Of those who answered this question, 15 (22%) said that they discussed SUDEP.

- first aid training for carers responding to seizures is offered by 51 (40%) of respondents. This is usually provided by the epilepsy specialist nurse
- 39 Trusts (31%) give information about voluntary organisations (again this includes some of those who do not have a checklist)
- 82 Trusts (68%) provide written, audio or visual information for patients and carers
- 51 Trusts (40%) say that they provide counselling sessions, in addition to the counselling offered in a routine medical consultation.

**Figure A3.6**  
NHS Trust policies and protocols on provision of information



## Monitoring and audit

Trusts were asked what epilepsy-related audits had been carried out in the last 3 years within the categories of:-

- aspects of organisation/processes of care
- adequacy of medical records
- clinical outcomes
- consumer surveys.

Examples of audits undertaken included:

- processes of care
- hospital vs. practice nurses' review of epilepsy patients
- the epilepsy clinic
- the teenage clinic service
- consumer surveys
- information received at epilepsy clinic
- satisfaction/information retention
- organisational
- resources used by first seizure clinic
- clinical outcomes
- audit of use of new antiepileptic drugs.
- vagal nerve stimulus.

One Trust, however, made the following comment:

'Large regional audit prevented by ridiculous 'new' regulations regarding so-called patient confidentiality/Caldicott, etc.'

## Difficulties experienced in the last 3 years

The final questions asked Trusts for general comments they had on any difficulties they had experienced in the last 3 years; firstly with supporting their existing epilepsy service and secondly with funding proposals for the development of their epilepsy service. In practice, the two questions were answered as one.

Comments were nearly almost universally related to funding and resource issues.

### *The service as a whole*

'There is a significant lack of neurological resources at all levels – too few consultant neurologists, no clinical neurophysiologists, few inpatient beds, few junior staff – all the services are stretched.'

'There essentially is no epilepsy service. I have been trying to establish an epilepsy nurse post, but there is currently no funding available.'

'Funding adequate secretariat services for general neurology clinics (including a substantial number of new and follow-up cases with epilepsy) is a problem.'

'No difficulty, we used drug company money to set up 'first fit' clinic.'

### *Specialist nurse posts*

'We have found difficulty finding funding for our Epilepsy Nurse Specialist.'

'Struggled for money for the nurse specialist – only just got permanent funding and we need at least two more nurses to help.'

### *Doctors and others*

'The Outpatient clinic is about to be increased. A specialist epilepsy clinic is planned if the desired candidate applies for, and is appointed, to a forthcoming post.'

'With retirement of present consultant in 5 years' time (and no plans for a replacement), the service is slowly being run down.'

### *Management and commissioning*

'We have tried for funding for an epilepsy service. The Trust has not supported our efforts.'

'The Health Authority and PCG/PCT have failed to regard supporting the epilepsy service as a significant priority.'

### *Other comments*

#### Staying in the system

'Some GPs will not cooperate with shared care protocol.'

'Although we do not have a fast-track referral policy for review patients, we do encourage patients to contact the epilepsy specialist nurse or consultant, so that concerns or problems can be addressed within 24 hours. GPs are also encouraged to do this.'

'No [fast track or formal system], but patients are asked to contact the unit directly or indirectly through their carers or community staff and often they are accommodated in clinic within 2 weeks.'

'The nurse specialist may see someone at home if necessary, so that they are seen quicker.'

### Falling out of the system

'There are difficulties in organising separate services for the learning disabled with epilepsy – discussions are in progress following the completion of our audit.'

'We are not an epilepsy service, but work with surrounding providers is fragmented and the stigma of "psych patient" seems to impair patients' access to other services, neurology and epilepsy in particular.'

'There is no psychiatrist with an interest in non-epileptic attacks.'

'There is essentially no epilepsy service.'

### Demand

'The Epilepsy Team has attracted patients from outside our own area. Also because there is now a specific interest in epilepsy and a protocol for referral, our referral rate has increased and there is now more demand. Extra clinics have been carried out to address this problem.'

'The service is currently reliant on one consultant providing the outpatient clinic for a population previously treated by two consultants.'

'Demand far in excess of staff and facilities available.'

## **EXAMPLES OF LOCAL POLICIES SENT TO THE AUDIT**

- *Avon Health Authority* has a very comprehensive and easy to read guideline document for epilepsy service in primary care.
- *Bradford Community Health NHS Trust* provide clear patient information.
- *Calderdale and Kirklees Hospital* has a very clear and concise treatment protocol, including a useful clinic review tick box.
- *Horizon NHS Trust (Learning Disabilities)* in Hertfordshire provided a specific procedure guideline on the management of epileptic seizure, including preventing an epileptic seizure progressing to status epilepticus.
- *The Isle of White Health Authority's* Guidelines on the Management of Epilepsy in Primary Care has a clear patient checklist for advising newly diagnosed patients and carers.
- *Kettering and Northampton General Hospitals (NHS Trusts)* both included a referral form and a copy of an assessment form for the GP to use with patients.
- *Lothian Primary Care NHS Trust* has a good format for its service guideline, covering the whole organisation.

- *Northampton Health Authority* has a comprehensive document, which covers service guidelines, treatment protocols/clinical guideline and guidance for the provision of patient/carer information.
- *Southampton and South West Hampshire* have clear and comprehensive Primary Care Guidelines for the management of Epilepsy (produced jointly by Southampton and South West Hampshire Medical Audit Advisory Group (MAAG), Southampton Community Health Services NHS Trust and Southampton University Hospitals NHS Trust), is very clear and comprehensive.
- *South Cheshire Community Health Care Trust's* Guidelines for managing epilepsy in adults is very easy to read and understand. It makes good use of flowcharts.

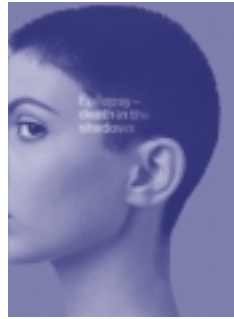
## SUMMARY

Contextual information about the organisation of services was collected via postal questionnaires to general practices and NHS Trusts. This also provided an opportunity for clinicians to describe their usual practice and to raise concerns they have about current or future services.

There was a 39% response rate to the primary care survey of a small sample of practices so findings have to be regarded with care. 55% of responding practices had an epilepsy register and 20% a disease management protocol for epilepsy. 30% carried out epilepsy audit and reported that the audit had the potential to change practice. The survey confirms long waiting times to specialist care with only 12% reporting access within 1 month, although waiting times for children were shorter. Nearly three quarters do not have access to a specialist adult clinic at the local acute Trust and only 13% reported access to a specialist children's clinic. Over 70% of practices felt able to provide information and access to support services.

There was a 61% response by Trusts to the secondary care survey. A third of Trusts said that written guidance, protocols or procedures for the management of epilepsy existed. The survey confirmed difficulty with access. 40% of Trusts did not have at least one consultant with specific responsibility for adult epilepsy services and 66% did not have a consultant paediatrician responsible for children's services. 66% reported seeing urgent cases within 4 weeks. The survey suggests a variation in availability of information and support to patients. Only 43% of Trusts had a clinical nurse specialist, some of whom were not epilepsy specialist nurses.





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## **WEB SITES**

[www.sudep.org](http://www.sudep.org)

Web sites referred to in chapter 4:

[www.bhf.org.uk/hearthealth/zindex.html](http://www.bhf.org.uk/hearthealth/zindex.html)

[www.statistics.gov.uk/statbase](http://www.statistics.gov.uk/statbase)

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