



Epilepsy -  
death in the  
shadows

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

**REPORT 2002: SUMMARY**

The National Sentinel Clinical Audit of Epilepsy-Related Death was managed and coordinated by Epilepsy Bereaved. The audit forms one of a series of initiatives to improve epilepsy services conducted under the umbrella organisation of the Joint Epilepsy Council. Participating organisations in the audit included the International League against Epilepsy (British Branch), the Royal College of General Practitioners, the Royal College of Nursing, the Royal College of Paediatrics and Child Health, the Royal College of Pathologists and the Royal College of Psychiatrists (Learning Disability Faculty).

The National Institute for Clinical Excellence (for England and Wales), the Scottish Executive and the Northern Ireland Department of Health, Social Services and Public Safety are associated with the National Sentinel Clinical Audit of Epilepsy-Related Deaths through funding contracts. The funding bodies consider the work of the Audit to be of value to the NHS in all countries in the UK and recommend that it be used to inform decisions on service organisation and delivery.

**Epilepsy Bereaved Online Information ([www.sudep.org](http://www.sudep.org))**

The full report of the National Sentinel Clinical Audit of Epilepsy-Related Death and information resources to support professionals, patients and families are available from the Epilepsy Bereaved website, [www.sudep.org](http://www.sudep.org).

Epilepsy Bereaved commissioned the College of Health to conduct research into the experiences of bereaved relatives who contacted the charity during the period of the audit. A report on this research will also be published on this site during 2002.

The National Audit should be cited as follows:

Hanna N J, Black M, Sander JW, 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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Royal College of General Practitioners



Royal College of Paediatrics and Child Health



Royal College of Pathologists



Royal College of Psychiatrists

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## REPORT 2002: SUMMARY

**Ms N. Jane Hanna** *Director of Epilepsy Bereaved;  
Joint Epilepsy Council representative*

**Dr Marjorie Black** *Consultant forensic pathologist;  
Royal College of Pathologists representative*

**Professor Josemir W. Sander** *Consultant neurologist;  
International League against Epilepsy representative*

**Dr W. Henry Smithson** *General practitioner;  
Royal College of General Practitioners representative*

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

**Professor Stephen Brown** *Consultant neuropsychiatrist;  
Royal College of Psychiatrists (Learning Disability Faculty)  
representative*

**Professor David R. Fish** *Consultant clinical  
neurophysiologist and neurologist; International League against Epilepsy  
representative*

**Produced by Epilepsy Bereaved**

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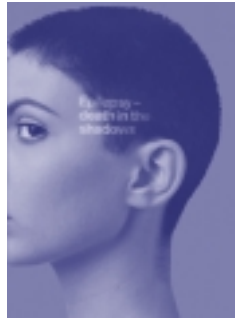
PO Box 112, Wantage, Oxfordshire, OX12 8ER

**Office:** 01235 772850

**Bereavement contact line:** 01235 772852

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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.

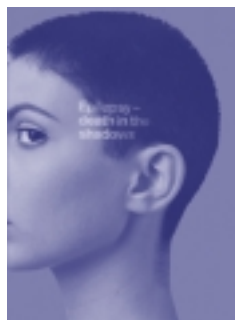
We recommend this report, which will be available widely to the National Health Service. We also give a commitment to consider what can be done to address the weaknesses in care it identifies. By doing this we will demonstrate that by taking action now, lives may be saved.

Sir Liam Donaldson,  
Chief Medical Officer England

Dr Ruth Hall,  
Medical Officer Wales

Dr Mac Armstrong,  
Chief Medical Officer Scotland

Dr Henrietta Campbell,  
Chief Medical Officer Northern Ireland



# 1

## BACKGROUND

Epilepsy, meaning a tendency to have recurrent seizures, is the most common serious neurological condition. 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 (1,2). Each year, in a community of 250,000 people, between 125 and 200 will develop epilepsy (3).

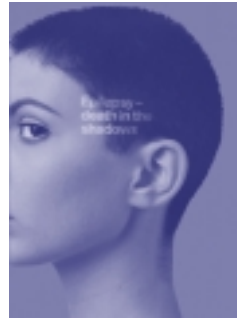
People with epilepsy have a risk of premature death that is 2–3 times higher than in the general population (4). Most premature deaths among people with epilepsy are directly related to the epilepsy itself. Every year in the UK about 1000 people die because of epilepsy, and most of these deaths are associated with seizures. Sudden unexpected death in epilepsy or SUDEP (Box A) is the principal cause of seizure-related death in people with chronic epilepsy and has been estimated to account for about 500 deaths each year. Young adults are most at risk of SUDEP, and most deaths occur at home. Although it is not entirely clear what causes SUDEP, the most important risk factor is the occurrence of seizures – the more frequent the seizures, the higher the risk (5). Since most epilepsy deaths are related to seizures, good seizure control is the key to minimising the risk of death.

### Box A Definition of SUDEP

#### What is SUDEP?

‘SUDEP is the sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning 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 anatomical cause for death.’ (6)

Most people with epilepsy (up to 70%) have the potential to be seizure-free, but five government reports over a 50-year period have drawn attention to the neglect of epilepsy and there has been little action (7). Another problem is the inconsistency with which the causes of death in people with epilepsy are reported – this may be due to a lack of awareness of epilepsy-related death among clinicians, coroners and pathologists (8,9).



## 2

# AUDIT METHODS

The National Sentinel Clinical Audit of Epilepsy-Related Death – reported in summary here – was the result of a call for a confidential enquiry into epilepsy-related deaths. The aim was to establish whether deficiencies in the standard of clinical management, or in the overall healthcare package, could have contributed to the deaths. Two key areas were reviewed:

- investigations into the deaths (pathology)
- general practice and hospital-based care.

The audit was developed using a structured approach (Box B) involving multiprofessional and lay groups. The audit team reviewed the official records of individuals who died of an epilepsy-related death, in the UK, between September 1999 and August 2000. During that time, 2412 deaths were reported where epilepsy was mentioned somewhere on the death certificate.

### Box B

How the audit was developed

#### How was the audit developed?

A steering group provided overall guidance; an executive committee planned and monitored audit activity; an audit officer and five nurses (fieldworkers) identified cases and collected data.

Criteria for standards of care in pathology and primary and secondary care were identified using published guidelines (including references 10–13), literature searches and the views of expert panels in these three areas. Audit tools were developed, and data were collected and analysed.

Panels of experts for review of the audit findings were drawn from pathology, primary and secondary care to reflect the views of clinicians with a particular interest in epilepsy care (panel membership is listed in appendix 1 of the full report).

Full details of the methods used for the audit are presented in the full report which is available from the Epilepsy Bereaved website ([www.sudep.org](http://www.sudep.org)). Copies of the audit tools and criteria are available from Epilepsy Bereaved.

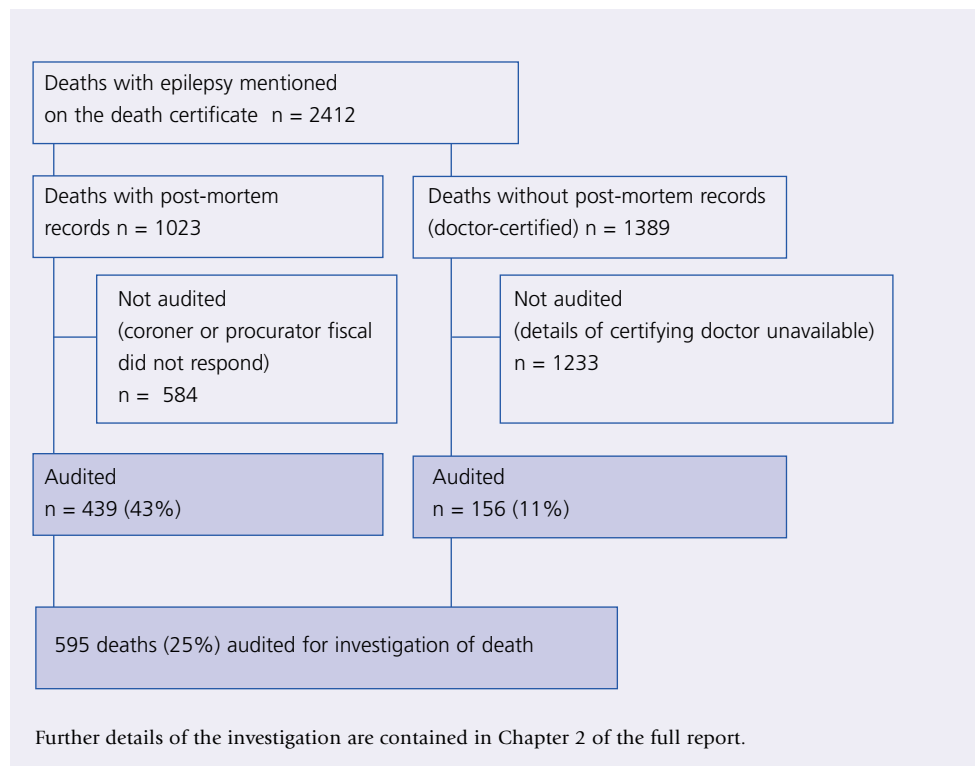
## 2.1 AUDIT OF INVESTIGATION OF DEATH

Of the 2412 deaths with epilepsy on the death certificate, 1023 were subject to post-mortem and 1389 were not.

For the audit of investigation of death, records were examined for 439 (43%) of the 1023 deaths for which there were post-mortem records and for 156 of the 1389 deaths for which there were no post-mortem records (see Box C).

In the pathology audit the areas examined were: background, post-mortem examination, further investigations and cause of death – with information collected from post-mortem reports and coroner’s officer and police reports.

### Box C Audit of investigation of deaths

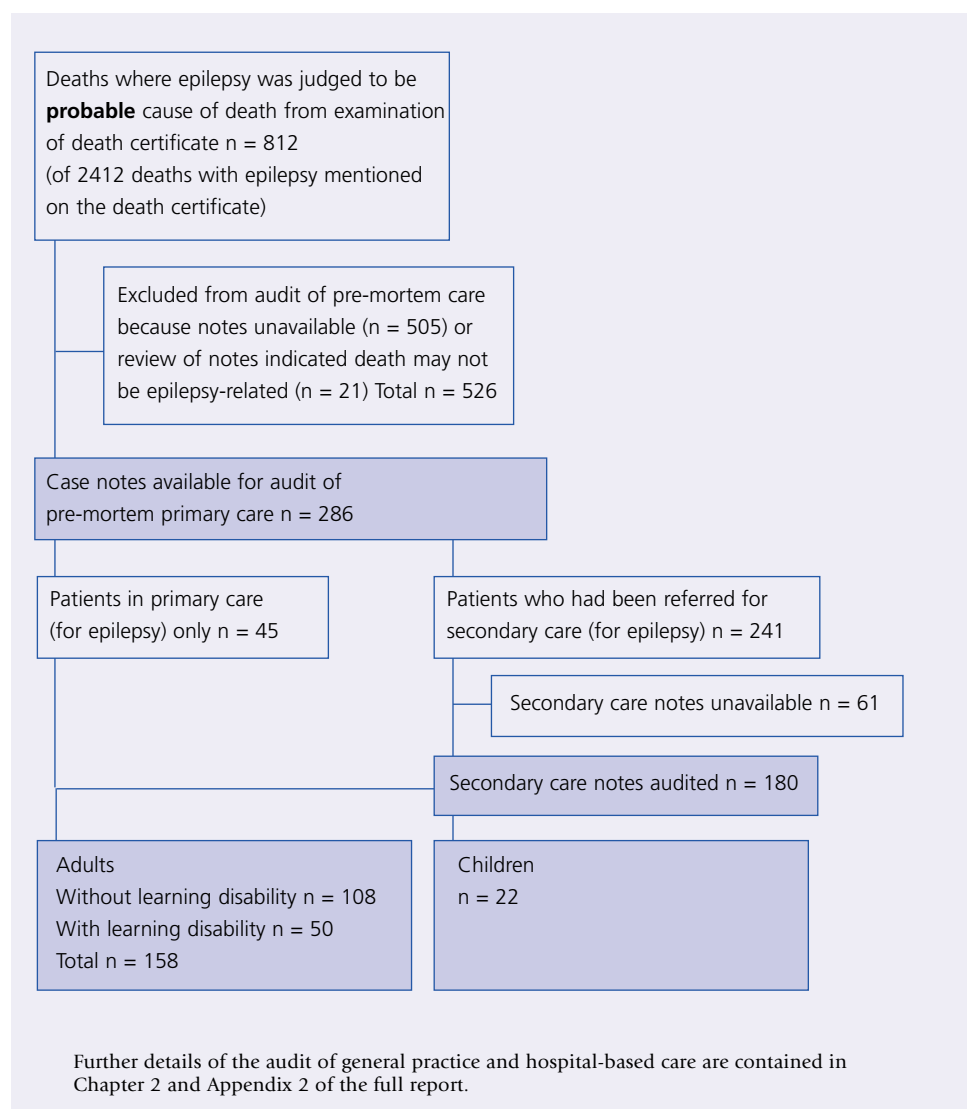


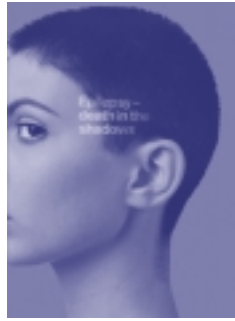
## 2.2 AUDIT OF GENERAL PRACTICE AND HOSPITAL-BASED CARE

For the audit of care before death, a total of 286 primary care case notes and 180 secondary care case notes were examined. (For more details of the cases audited, see Box D.)

In the audit of general practice and secondary care the areas examined were: access to care and clinical assessment, investigations, drug treatment, non-drug therapies, continuing care, information and support, and communication between professionals and services.

### Box D Audit of pre-mortem care





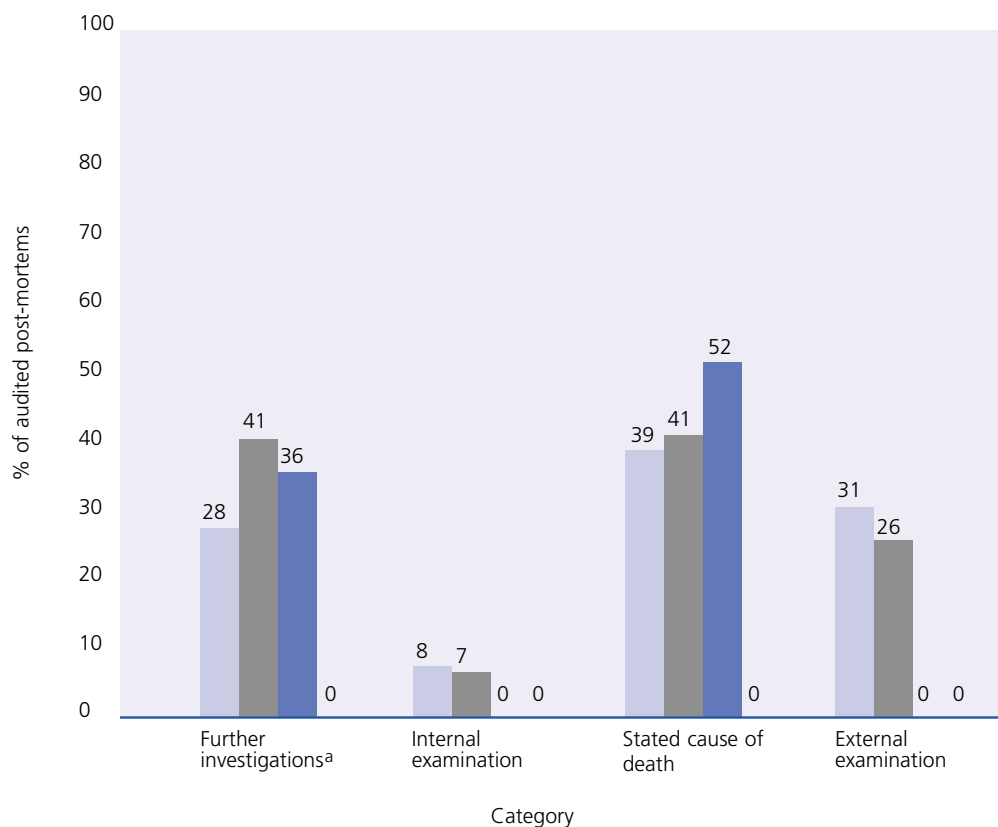
## 3 FINDINGS

### 3.1 INVESTIGATION INTO THE DEATHS

Although most deaths were confirmed as being in keeping with epilepsy as the cause, many (87%, 383/439) of the deaths involving a post-mortem were considered to have been inadequately investigated. Because deaths were not appropriately or adequately investigated it was difficult to establish the true number and/or nature of epilepsy-related deaths in this audit, highlighting a problem of reliance on national certification data in relation to epilepsy deaths. The main problems with post-mortems were with 'further investigations' and the 'stated cause of death' (Figure 1).

**Figure 1**  
Categories in which post-mortem investigation was inadequate

England n = 352  
 Wales n = 27  
 Scotland n = 56  
 N Ireland n = 4



<sup>a</sup> The post-mortem examination was inadequate only because at least one further investigation had not been done. The values do not include examinations for which there was at least one other inadequacy in addition to inadequate further investigations.

### 3.1.1 Further investigations

Further investigations (Box E) were not carried out or were not standardised. Of 439 post-mortems, 377 (86%) did not include all further investigations listed in Box E. 34% (130/383) of post-mortems were inadequate only because at least one further investigation had not been done (Figure 1 gives national percentages). These investigations are important to eliminate other potential causes of death.

#### Box E

Further investigations during post-mortem

#### **'Further investigations' carried out during post-mortem**

- Toxicology – blood analysis for alcohol and drugs
- Histology – microscopic examination of small pieces of major organs
- Neuropathology – specialist examination of brain and nervous system

### 3.1.2 Stated cause of death

Whether or not a post-mortem was carried out, the cause of death stated was inconsistent and, in some cases, inappropriate. Of the 156 deaths certified without post-mortem, 39 were certified as due to epilepsy. Of these, 38% (15/39) were sudden and/or unwitnessed and should have been subject to post-mortem. The cause of death was inadequately stated in 41% (178/439) of deaths involving a post-mortem.

The main deficiencies in reporting a cause of death were as follows:

- Phrasing of the cause of death. This was very variable (Box F). 'SUDEP', which is a term that has been in use since 1997, was cited in 9% (54/595) of audited cases.
- A cause was often cited (e.g. asphyxia, aspiration of stomach contents, status epilepticus) despite a lack of pathological evidence.
- In some cases, every medical condition the person had was listed on the death certificate, even where this had not contributed to the death.

**Box F**

Terms used to describe the cause of death

### Some terms used to describe the cause of death

- Epilepsy
- Epileptic seizure
- Status epilepticus
- Sudden adult death syndrome (SADS)
- SUDEP
- Unascertained

### 3.1.3 Examination of the body

In a minority of deaths the external or internal examination of the body was considered inadequate (27% [117/439] of external examinations and 7% [29/439] of internal examinations).

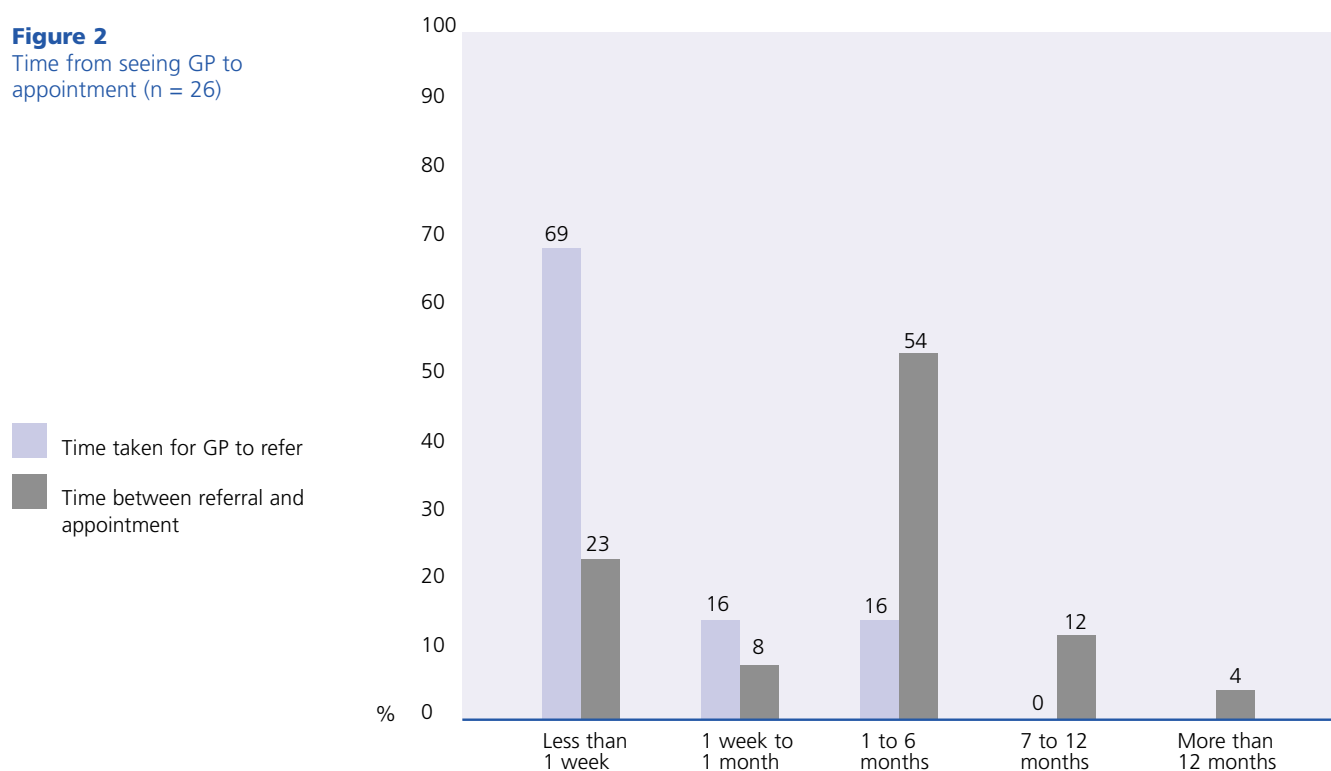
## 3.2 AUDIT OF GENERAL PRACTICE AND HOSPITAL-BASED CARE

### 3.2.1 Referral for specialist care

After a first seizure, individuals are normally referred to secondary care by their GP. Of the 286 people whose GP case notes were audited, 84% (241/286) had been referred.

The referral process was analysed for people whose epilepsy was diagnosed recently (that is, within 5 years before death; n=47). Information on referral and waiting times was available for 26 of these individuals. Of these, 69% (18/26) had been referred by their GP within 1 week; but for 15% (4/26) it had taken between 1 and 6 months to be referred by their GP. Waiting times for a specialist appointment were long, with 15% (4/26) of individuals having to wait more than 6 months (Figure 2).

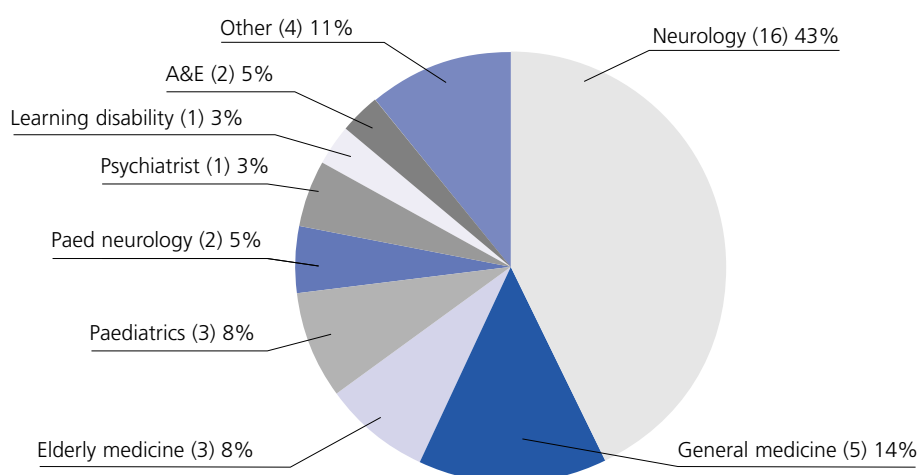
**Figure 2**  
Time from seeing GP to appointment (n = 26)



### 3.2.2 Referral specialty

Referral should be to a specialist with an interest in epilepsy (12). Just under half (18/37) of individuals diagnosed in the 5 years before death were initially referred to an adult or paediatric neurologist (Figure 3).

**Figure 3**  
Chosen specialty for initial referral

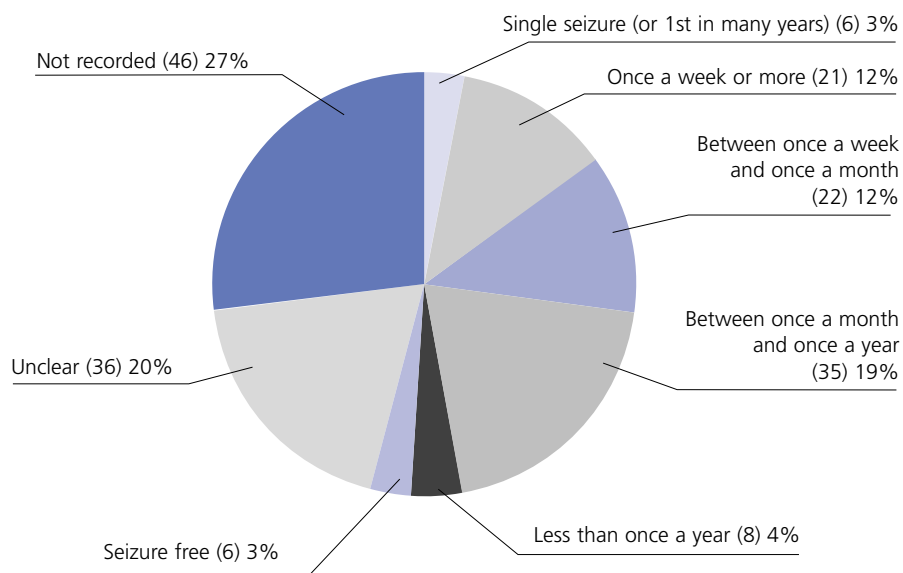


There was documented evidence that 80% (127/158) of the adults and 77% (17/22) of children whose secondary care notes were audited had seen a consultant at some time during their secondary care. The case notes indicated that 66% (91/138) of all adults seen in outpatients had seen a neurologist during at least one of their last three appointments; 35% (7/20) of all children seen in outpatients had seen a paediatric neurologist during at least one of their last three appointments.

### 3.2.3 Seizure status

- Of the people whose deaths were included in the audit of secondary care, 3% were recorded as seizure-free at their last hospital appointment (Figure 4).
- None of the 22 children whose secondary care notes were audited were known to be seizure-free in the year before they died.
- Primary care notes indicated that 11% (26/241) of patients referred to secondary care had evidence of an increase in seizure activity in the three months before death.

**Figure 4**  
Seizure frequency (adults and children n = 180)



### 3.2.4 Hospital visits

- At least 37% (54/147) of adults who were not recorded as being seizure-free had not been seen in the year before they died.
- Around 15% (23/158) of adults had missed at least one of their last three appointments but there was no standard way in which these missed appointments were managed. Of the 23 adults who had missed at least one appointment, 57% (13/23) had been sent at least one further appointment and 30% (7/23) were not sent any further appointments; it was unclear what action had been taken in 13% (3/23) cases.

- Although all children were seen in secondary care in the year before death, it was considered that 36% (8/22) of children had inadequate access to appropriate care. The main deficiency was lack of access to appropriate specialist care for children who had learning and/or physical disabilities and frequent seizures.

### 3.2.5 Re-referral

The audit of all of the primary care case notes showed a lack of re-referral by the GP for individuals fulfilling the criteria for reassessment. Among the 241 individuals receiving combined GP/specialist care, the GP notes suggested that 28% (68/241) fulfilled the criteria for re-referral. Of these 68, only 9% (6) were re-referred. Although four individuals receiving all of their care through the GP had a change in seizure frequency, none was referred.

### 3.2.6 Special needs

There were particular concerns about access to specialist care for people with special needs. For example, only 5% (2/43) of the adults with learning disability seen in outpatients had evidence that they had seen a specialist with an interest in learning disability and 6% (3/50) of adults with learning disability had been lost to follow-up in the transfer from paediatric to adult care.

### 3.2.7 Clinical assessments

Documentation of clinical assessments was variable throughout primary and secondary care. Many details were lacking in relation to classification of seizure type and syndrome, seizure triggers, seizure frequency, drug treatment issues and non-drug therapies. For example, in 47% (74/158) of adults and 36% (8/22) of children whose secondary care case notes were audited seizure frequency had either not been recorded or was unclear.

### 3.2.8 Hospital investigations

- Secondary care notes did not report a scan for 57 adult patients (57/158, 36%) – at least 19 of these should have had one according to existing guidance (11,12).
- There was no documented report of an EEG for 51 (32%) of the adult patients – at least 22 of these should have had one because they were aged under 25 at the age of diagnosis (12).
- no brain scan or EEG was documented for seven (32%) of the 22 children whose secondary care notes were audited, although all of these children should probably have undergone these investigations.

### 3.2.9 Drug management

- Most adults (76% [119/156; data unavailable for 2 adults]) were receiving one or two anti-epilepsy drugs (AEDs). However, 6% (9/156) of adults and 18% (4/22) of children were not receiving any anti-epilepsy medication when they died.
- Drug management was inadequate in 20% (32/158) of adults and 45% (10/22) of children. Problem areas of drug management are shown in Box G.

**Box G**

Problem areas of drug management

### Problem areas of drug management

- No medication prescribed despite ongoing seizures
- Inappropriate choice of AED<sup>a</sup>
- Inappropriate combinations of AEDs
- Doses too low or inappropriate
- Unsupervised/inappropriate management of AED changes
- Little consideration of alternative or additional AEDs in cases of ongoing seizures
- Major drug errors (e.g. abrupt cessation of treatment)

<sup>a</sup> AED = anti-epileptic drug

- In secondary care 14% (22/158) of adults had a problem adhering to their drug regimen.
- In primary care 27% (65/241) of those referred had a documented medication record. Of those with a drug record, 26% (17/65) ordered their medication later than anticipated, indicating poor adherence.

### 3.2.10 Patient review through primary care

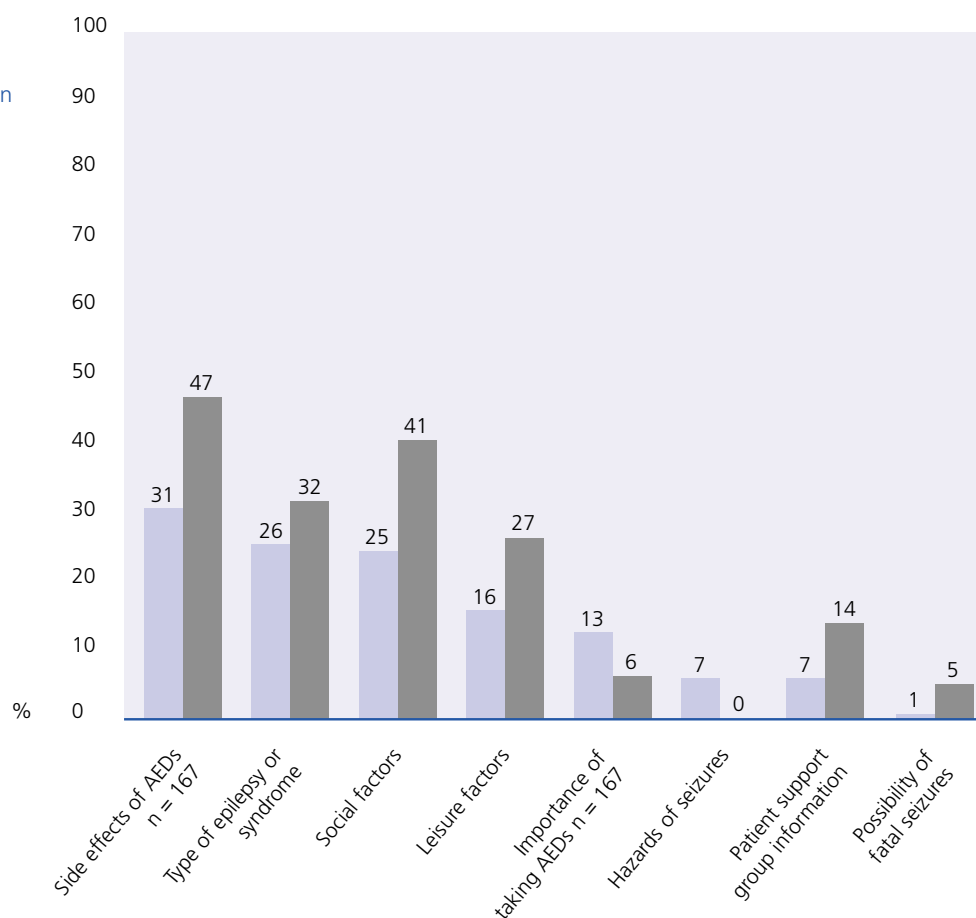
- From the audit of all the primary care case notes there was evidence that the review process in primary care was unstructured and lacking in detail.
- Of patients who were also receiving secondary care, there was evidence that 78% (187/241) had been reviewed by either the GP or specialist in the year prior to death and 31% (75/241) had been seen by the GP at their last review.
- In the year before they died, there was documented evidence that only 33% (15/45) of those who received all of their care through the GP had been reviewed.
- Most GP reviews were only to provide medication or to check blood drug levels.
- 29% (82/286) of individuals whose primary care notes were audited had been seen by their GP for non-epilepsy-related problems in the month before they died, which would have been a good opportunity for the GP to talk about their epilepsy.
- In at least 13% (36/286) of deaths there were communication failures with no action recorded following contact by a patient with A&E or an emergency GP, or following recordings of increased seizure frequency.

### 3.2.11 Information provision

- There was little written evidence in secondary care to suggest that epilepsy and its management, and in particular the hazards of epilepsy (including the risk of death), had been discussed with individuals (Figure 5).

**Figure 5**  
Information documented as provided to adults and children in secondary care n = 180

■ All adults n = 158  
■ Children n = 22



- Primary care notes indicated that 31% (89/286) of individuals with epilepsy had some recorded information provision on epilepsy from a health professional in primary or secondary care. Only 1% (3/286) had documented that information had been given on the risk that seizures could be fatal, even amongst most of the individuals in this audit whose epilepsy required ongoing care and who had many apparent risk factors.
- The help of specialist epilepsy nurses and counsellors was rarely recorded and may not have been used.
- Rarely was there any indication that the individual or their carer/family had been told about voluntary organisations and patient advocacy support groups. Consequently, they might not have been able to take advantage of the advice and support that these organisations could have provided.
- Although at least 14% (22/158; secondary care audit) of adults had a problem adhering to their drug regimen, there was little to suggest that this important issue was discussed with patients. Further, only 9% (2/22) had documented information about the hazards of seizures and none about the risk of death.

### 3.2.12 Contact with relatives after death

From the records audited, there was little documented evidence of contact with relatives after a death. About 10% (18/180; secondary care audit) of families of people who died were contacted after the death by the specialist. (Only 5% [8/158] of families of adults were contacted compared with 45% [10/22] of families of children who died.) Only 7% (19/286, primary care audit) of all families were contacted by the GP after the death. Contact with relatives is particularly important in relation to epilepsy deaths because many deaths are sudden and unexpected and families experience bewilderment, isolation and prolonged distress (14).

### 3.2.13 Estimate of SUDEP deaths

Results of a review of the clinical circumstances of deaths reported in this audit suggests that approximately 60% of all epilepsy deaths were SUDEP and a further 7% were possible SUDEP. This is an estimate only and could not be confirmed because of the inadequacy of post-mortem investigations reported in this audit.

## 3.3 PANEL REVIEW OF OVERALL QUALITY OF CARE

### 3.3.1 Secondary care

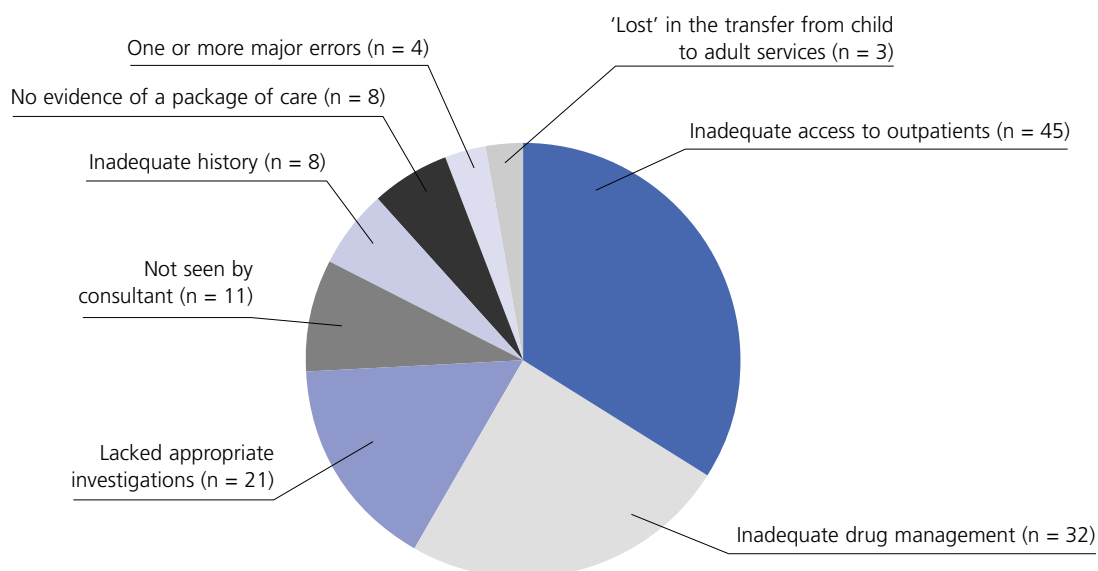
An expert panel reviewed the specific findings from the audit of secondary care and judged the overall quality of care received by individuals.

#### *Adults*

The panel considered that care had deficiencies for 54% (85/158) of adults (Figure 6). There tended to be deficiencies in more than one aspect of care. The panel considered that the main deficiencies in epilepsy management in these 158 adults, excluding lack of information and support, were:

- inadequate access to specialist care 35% (56/158)
  - access to outpatients 28% (45/158)
  - not seen by consultant 7% (11/158)
- inadequate drug management (20%, 32/158)
- lack of appropriate investigations (13%, 21/158)
- no evidence of a package of care (5%, 8/158)
- inadequate recording of history (5%, 8/158)
- patient 'lost' in transfer from child to adult services (2%, 3/158)
- one or more major clinical management errors (5%, 4/158)

**Figure 6**  
Distribution of inadequacies of care in adults (85 of 158 deaths)



Note: the distribution is shown for the 85 adults whose care was judged to have had at least one inadequacy; for some adults, care had more than one inadequacy

Overall, 39% (62/158) of adult deaths were considered by the expert panel to have been potentially or probably avoidable.

### *Children*

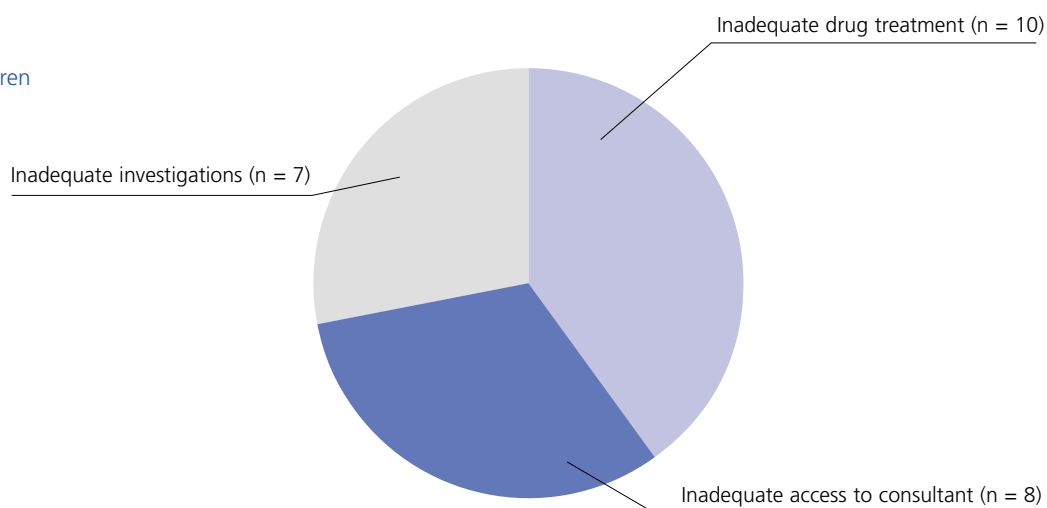
The panel considered that care had deficiencies in 77% (17/22) of children. There tended to be deficiencies in more than one aspect of care. The panel considered that the main deficiencies in epilepsy management in these 22 children, excluding lack of information and support, were:

- inadequate drug management (45%, 10/22)
- inadequate access to specialist care (36%, 8/22)
- inadequate investigations (32%, 7/22).

Overall, 59% (13/22) of deaths in children were considered by the expert panel to have been potentially or probably avoidable.

**Figure 7**

Main reasons that care was considered inadequate in children (17 deaths)



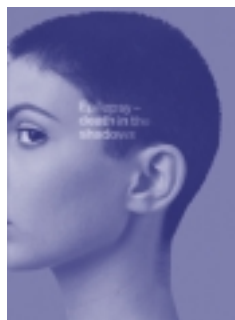
Note: the distribution is shown for the 17 children whose care was judged to have had at least one inadequacy; for some children, care had more than one inadequacy

### 3.3.2 Primary care

Detailed information in primary care records was sparse and for this reason judgements of overall quality of care were not made in relation to individual patients who died. The primary care panel considered the main inadequacies in primary care management were:

- lack of timely access to skilled specialists
- sparse evidence of structured management plans
- triggers for referral were sometimes missed
- professional communication failures.

For example, only 31% (8/26) were seen within 4 weeks by a specialist; only 8% (6/72) of patients with indications for re-referral were referred to secondary care and there were concerns about communication in 13% (36/286).



## 4

# CONCLUSIONS

### 4.1 AUDIT OF INVESTIGATION OF DEATHS

It was difficult to establish the true number and/or nature 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.

### 4.2 Audit of general practice and hospital-based care

In general, record keeping was very poor throughout primary and secondary care. Although an audit based on case notes cannot assess non-recorded activity and so the findings may not be entirely comprehensive, the information obtained raises matters of urgent concern.

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 the death. These issues 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 are particular problems in managing epilepsy in people who have associated problems such as learning difficulties.

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

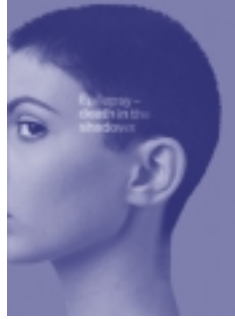
The audit highlights the need for education of healthcare professionals and organisations responsible for epilepsy services about the principles of epilepsy management and the risks of epilepsy-related deaths and the need for support to these services.

These system failures need to be addressed when planning professional education, clinical and audit guidance and systems for service delivery. 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, an 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**

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



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