The Joint Epilepsy Council welcomes the attention that the Chief Medical Officer has brought, through the Government Action Plan on Epilepsy, to the serious deficiencies in service provision for people with epilepsy and the significant potential for saving of life in this area.

Whilst welcoming the increased profile that the Government has given to epilepsy through the Action Plan, the JEC calls on the Government to improve on the series of initiatives that are planned, to ensure that real action results in benefit for people with epilepsy.

The voluntary sector calls on the government to strengthen the plan by making clear what funds will actually be available to local health organisations to develop epilepsy services and how the government intends to monitor or check whether services have improved and whether lives have been saved.

The Joint Epilepsy Council views the Action Plan as insufficient to tackle the serious shortfalls identified in the National Sentinel Audit of Epilepsy Related Deaths (SUDEP) in May 2002. Whilst we welcome the fact that the Action Plan brings epilepsy to the fore in a number of existing initiatives, the Action Plan is fundamentally flawed in that it does not contain:

- any target for the reduction of epilepsy related deaths
- any proposed means for monitoring the effectiveness of the plan
- any significant injection of funds to deliver improved services.

It is reliant upon recommendations and requests to the Health Service, which, when faced with competing directives for action from the government in other areas of health provision, is unlikely to deliver any significant improvement in care for people with epilepsy and, critically, unlikely to reduce the 400 annual preventable deaths from epilepsy.

We believe there should be a national target of a 40 per cent reduction in epilepsy related deaths within three years.

We are committed to working with the government and health service to deliver improvements in care and remain available to help develop these initiatives into effective plans.

Below we have briefly analysed the various points within the governments action plan and indicated our view on these and how they could be improved.

JEC comments are in the right hand column

### IMPROVING SERVICES FOR PEOPLE WITH EPILEPSY

#### DEPARTMENT OF HEALTH ACTION PLAN IN RESPONSE TO THE NATIONAL CLINICAL AUDIT OF EPILEPSY-RELATED DEATH

**Government Action Plan**

1. Epilepsy is the most common chronic disabling condition of the nervous system affecting around 380,000 people in England. Almost 800 of these people die every year as a result of epilepsy and most of these deaths are associated with seizures.

2. The National Clinical Audit of Epilepsy-related Death (SUDEP audit) published in May 2002 has provided some useful information to improve our understanding of epilepsy deaths. The full report is on the internet at [http://dspace.dial.pipex.com/epilepsybereaved/](http://dspace.dial.pipex.com/epilepsybereaved/), and a summary at [http://www.nice.org.uk/pdf/epilepsyreport.pdf](http://www.nice.org.uk/pdf/epilepsyreport.pdf). The Department of Health welcomes the report and acknowledges the important role played by the voluntary organisation, Epilepsy Bereaved in project managing the audit. We will continue to work with the epilepsy voluntary organisations to ensure that the views of patients/service users and their representatives are fairly represented in the development of epilepsy policy.

3. In his 2001 report, the Chief Medical Officer recommended that an action plan to improve epilepsy services and address the audit findings should be published. The report is available at [http://www.doh.gov.uk/cmo/annualreport2001/index.htm](http://www.doh.gov.uk/cmo/annualreport2001/index.htm). The Department of Health is committed to improving standards of care and support for people with epilepsy and their families. We hope this action plan will be the start of a process of improving awareness and understanding of Sudden Unexpected Death in Epilepsy (SUDEP) and will lead to improved care and services for people with epilepsy. It is intended to address the needs of all groups, including those with learning disabilities.

**JEC Response**
4. The action plan recognises that local health services face many challenges and priorities. It has therefore been developed in a way that complements rather than duplicates existing initiatives and policies. It also recognises the broader context of the Planning and Priorities Framework (PPF) which sets out the current priorities for the NHS, and substantial increases in resources for health and social care which give local health communities the opportunity to plan and deliver services over the next three years with a greater degree of flexibility and autonomy. The document Improvement, Expansion and Reform: The next 3 years’ Priorities and Planning Framework 2003-2006 is available at http://www.doh.gov.uk/planning2003-2006/index.htm.

5. The action plan should inform what local health communities do in the short term to address key findings and recommendations of the audit and recommendations in the Chief Medical Officer’s 2001 report. It takes into account two major pieces of work currently in development that will contribute significantly to better epilepsy services:

- The National Institute for Clinical Excellence (NICE) is looking at a range of anti-epileptic drugs for children and adults and is expected to produce guidance by October 2003 which will help address the ‘post-code lottery’ of getting these treatments. It is also developing a clinical guideline for the diagnosis, management and treatment of epilepsy, by June 2004. Further information on NICE is available at http://www.nice.org.uk.

- The National Service Framework for Long-term Conditions (NSF) will have a particular focus on neurological conditions, including epilepsy. We expect to publish the NSF in 2004 with a 10-year implementation programme starting in 2005. Further information on the NSF is available at http://www.doh.gov.uk/nsf/longterm.htm.

Pathology and post mortem investigations

The audit found that it was difficult to establish the number of epilepsy related deaths from national data. It found:

- There are no specific guidelines for the investigation of epilepsy specific death.
- Death certification was of poor quality.
- Two-thirds of pathologists indicated that they had no mechanism to inform relatives about post-mortem results.
- Little evidence of contact with relatives after death with only 10% of families contacted by a specialist and 7% by a GP.

Department of Health response – how we will make improvements

6. There is a range of new and existing strategies in pathology and post mortem services which will help to address shortfalls in current practice and improve information and support for bereaved carers and
families of people with epilepsy:

a. Post mortems have an important role to play in clinical audit and improving care for future patients. The Royal College of Pathologists’ Guidelines on good autopsy practice which were published in September 2002 include a section on neuropathology and epilepsy. In 2003, the College will also be producing evidence-based datasets, including a dataset covering epilepsy-related deaths. These will support improvements in autopsy practice, provide high quality information to improve clinical audit and ensure better management of epilepsy in patients. We will work with the Royal College of Pathologists to promote this work. The College’s website is at http://www.rcpath.org/.

   • A clearer legal framework to support good clinical practice around post mortem examination and wider uses of human tissue.
   • Education and training for all health professionals on appropriate standards of practice.
   • Better education for NHS patients and the public on the value of post-mortems to public health, clinical audit and research.
   • Improved support and advice to families at the time of bereavement, including the development of the role of bereavement advisers within every NHS Trust.

c. The Department of Health is contributing to the Coroners’ Review consultation document and has highlighted concerns around the investigation and certification of epilepsy deaths. The Review is due to report by April 2003, and is expected to recommend:
   • A more modern system for certifying and investigating deaths, including investigation of premature medical deaths such as from epilepsy.
   • Support for the bereaved which is at the heart of a reformed inquest process, with explicit service standards for the provision of information, advice on bereavement counselling, and the involvement of families in key aspects of any post mortem examination decisions.

This work of the Royal College is welcome, but the findings of the National Sentinel Audit indicated that existing guidance from the Royal College was not being followed. The evidence base of any data set will depend crucially on the quality of post mortems. There will be a need for a re-audit of epilepsy deaths to see whether the introduction of further guidance has effected any change.

We welcome this and hope that discussions with the pathology section of the Department of Health will lead to initiatives to improve the experience of families experiencing SUDEP.
**Department of Health response – how we will make improvements**

7. The Department of Health will:
   
a. In early 2003 engage with **NHS and Primary Care Trusts**, **Strategic Health Authorities** to suggest they review local epilepsy services in the light of the audit findings and address any shortfalls as part of their local delivery plans. We will refer them to the Joint Epilepsy Council’s National Statement of Good Practice, which was published in May 2002 and is available at [http://www.jointepilepsycouncil.org.uk/](http://www.jointepilepsycouncil.org.uk/). Paper copies are available from the JEC (contact details below). We will also link this with the Modernisation Agency’s National Primary and Care Trust Development Team (NaTPaCT) competency framework website at [http://www.natpact.nhs.uk/](http://www.natpact.nhs.uk/).

The fact that the government is going to ‘suggest’ the Health Bodies ‘review’ their epilepsy services is a fundamental weakness of the action plan.

There is evidence that such requests are ineffective; NHS Executive Letter, January 1996, EL(95) 120 asked commissioners and providers to work towards good practice in service delivery for their epilepsy population. A follow-up survey of Health Authorities two years later revealed little progress with a lack of commitment to develop epilepsy services (Brown et al, Seizure 1999 Apr; 8(2):128-131).

The Chief Medical Officer has recognised that epilepsy is a ‘special case’, (You and Yours, February 20th) because it suffers a triple jeopardy from stigma, lack of interest by clinicians and lack of interest from service managers.
b. We will discuss with the Modernisation Agency a range of initiatives aimed at improving neurology services, including epilepsy. These include:

- investing £1.2 million in a two-year project to improve quality and access in neurology services starting in April 2003. The project will aim to design and deliver modern, high quality, patient focused and accessible neurology care which will benefit people with epilepsy;

It is common knowledge today that Health Authorities are struggling to meet the requirements of existing targets in health service improvement from the government, in particular in areas such as reducing waiting lists, complying with guidance from NICE etc.

We believe the Action Plan should require PCTs to review their health service provision for epilepsy and require the appointment of a named senior clinician to take responsibility for Epilepsy Services.

We welcome the acknowledgement that the JEC National Statement of Good Practice presents good example of how services should be delivered and feel Government should provide this to each PCT alongside a requirement to review.

The JEC Statement does not however take account of SUDEP and the findings in the National Audit, so we would wish to highlight the need for any review to take account of the Audit Report, most particularly risk management and SUDEP.

Whilst we welcome any investment in Neurology Services we have not received any detail as to how this money will be spent and we feel £1.2 million pounds is wholly inadequate to improve Epilepsy Services:

We would like clarification as to how this money is to be allocated.

One of the main findings of the National Sentinel Audit was failure in clinical care for patients – see page 5 of the government’s action plan.

Government figures note 380,000 people have epilepsy. Whilst no exact figures are available it is estimated that 8 million people have neurological conditions.

Even if the money is to be targeted at epilepsy, £1.2 million between all these people is insufficient to correct the identified and acknowledged inadequacies in care.

Investing solely in Neurology Services will also not benefit people with epilepsy with learning disabilities who tend to be treated outside neurology departments. It should be noted all the children surveyed in the audit who died had learning or other disabilities.

We believe there should be specific investment in neurologists, specialist nurses and other clinicians trained in epilepsy care and management.

We appreciate that doubling the number of epilepsy specialists in the short-term to achieve 1:100,000 population might not be possible, but there needs to be an acceleration in these posts.

In any event, epilepsy clinical networks using the skills of an expanded number of epilepsy specialist nurses and lead GPs is seen as the way forward by the epilepsy voluntary sector.
• asking NaTPaCT to support Primary Care Trusts in tackling this agenda; and,

• liaising with the neurology professional organisations and the Royal College of General Practitioners to produce a specific framework to help develop more general practitioners and nurses with a special interest in neurology.


i. The Disabled Child module will set generic standards aiming to improve multi-agency support for disabled children including those with epilepsy.

ii. The maternity module of the NSF will ensure that general health education programmes stress the importance of contact with health services early in and throughout pregnancy and more active follow-up of women who regularly fail to attend appointments. It will include epilepsy as an example of managing a long-term condition in pregnancy. It will take into account fully recommendations in the Confidential Enquiries into Maternal Deaths in the United Kingdom: Why Mothers Die 1997-1999 which identified 9 deaths from epilepsy. This is available at http://www.cemd.org.uk.

d. The NSF for Long-term Conditions (NSF) will have a particular focus on neurological conditions, including epilepsy. Publication of the NSF is currently planned for 2004 with a 10-year implementation programme starting in 2005. Further information is available at http://www.doh.gov.uk/nsf/longterm.htm.

JEC Response

Epilepsy clinical networks are being taken forward in Scotland and under consideration in Wales. Neurology clinical networks using neurology specialist nurses would not be acceptable.

We welcome the suggestion to ask NaTPaCT to support primary care trusts but believe this should be a requirement not a request.

There is no detail as to what form this assistance will take.

Change will depend on engagement of GPs, which is a major challenge currently for the PCTs, and on the provision of sufficient resources.

We would want to ensure that primary care professionals were at the heart of this initiative, which would require specific incentives.

Again we welcome the stated commitment to develop more GPs and nurses with an interest in neurology but note that it is an interest in neurology that is mentioned, not epilepsy, and that further there are no funds committed to implement this.

We are concerned that there is no mention here of the role epilepsy specialist nurses.

We believe all people with epilepsy should have an annual review with their GP or a specialist and that the Action Plan should contain a commitment to ensuring this is available.

We welcome the proposed NSF for children but have not been consulted about any specific commitment within it to improve epilepsy services. The Audit identified a serious problem that in relation to children with learning disabilities management of their epilepsy was neglected. We question how the module will address this?

We welcome the proposals in relation to the NSF Maternity Module.

The acknowledgement of the particular issues surrounding epilepsy and pregnancy is welcomed, but we would like to see detail on initiatives e.g. relating to training of professionals managing women with epilepsy in pregnancy in SUDEP and risk management.

We welcome the proposed NSF for Long Term conditions but cannot see how this is a response to the National Sentinel Audit as it is an ongoing initiative.

The NSF will deliberately not address any condition specific issues and is to be implemented over 10 years from 2004, during which time another 4,000 preventable deaths could have occurred.
**Government Action Plan**

e. The Department of Health strategy *Pharmacy in the Future* (2000) aims to ensure that people get quick and easy access to their medicines and high quality pharmaceutical care. This is available at [http://www.doh.gov.uk/pharmacyfuture/index.htm](http://www.doh.gov.uk/pharmacyfuture/index.htm). We have set up a number of programmes to support this strategy which will also benefit people with epilepsy.

i. Clinicians involved in the epilepsy audit will be invited to participate in future *Medicines Management Services (MMS) Programme* collaborative workshops for PCTs. This will lead to better awareness about managing epilepsy medication among GPs, pharmacists and other practice staff so that people with epilepsy are more involved in their care and get better health outcomes. Further information on medicines management at [http://www.doh.gov.uk/pharmacyfuture/medicinesmanagement.htm](http://www.doh.gov.uk/pharmacyfuture/medicinesmanagement.htm).

ii. The *Task Force on Medicines Partnership* is a two-year initiative aiming to help patients benefit from their medication by exploring how to improve partnership between patients and health care professionals. Over the next year we expect the Taskforce will:
   - prioritise epilepsy in its projects;
   - pilot professional development for neurologists, epilepsy specialist nurses and clinical pharmacists around shared decision making with patients in relation to medicines; and,
   - look at individual patient experience.

iii. We have established a *Medicines Management Group* to identify generic medicines management issues across the Renal, Diabetes and Long-term Conditions NSFs. It will produce guidance on the effective use of medicines by spring 2003 which will provide case studies and examples of good practice to help PCTs and Acute Trusts develop medicines management programmes.

f. We have commissioned the *National Institute for Clinical Excellence (NICE)* to look at a range of new anti-epileptic drugs for children and adults and an appraisal is due in October 2003. NICE is also developing a clinical guideline for the diagnosis, management and treatment of epilepsy which is due to be published in June 2004.

**JEC Response**

We welcome the *Pharmacy in the Future Strategy* but cannot see how this is a response to the National Sentinel Audit as it is an ongoing initiative.

We do believe pharmacists can play a significant role in assisting the management of a condition like epilepsy and would welcome the opportunity to engage in the debate as to how this can be done effectively.

We welcome the *Medicines Management Services (MMS) Programme* but need more detail on how clinicians will be engaged on these workshops and what profile epilepsy and SUDEP will have.

We believe that incentives will be required to encourage GPs to attend and are unclear if this has been considered.

There is no indication of what outcomes are expected from the workshops and how they will be carried forward.

Further, we are concerned that only clinicians involved in the audit will be invited to participate, given the commitment in this action plan to involving representatives from the voluntary sector we believe they too should be involved in the workshops.

We welcome the *Task Force on Medicines Partnership*.

We particularly welcome the fact that the government has an expectation that epilepsy will be prioritised in this scheme, however we would submit this should be a requirement.

We believe if this scheme is effective, and suitably resourced, it could be help manage epilepsy for patients.

We are unclear as to the potential impact on epilepsy management of this initiative and would ask for clarification.

We welcome the attention that is being given to epilepsy in the NICE technology appraisals but cannot comment upon the outcomes until they are available.

We would anticipate that the widest range of anti-epileptic medication is made available to clinicians for people with epilepsy.

*In relation to the Clinical Guideline Development we*
g. We recognise that workforce recruitment, education and training issues are important if we want to improve neurology services. We have already set up a group to look at workforce and training issues for the Long-term Conditions NSF. The group will make sure we have the right workforce in place to support the NSF over its 10-year implementation period.

We welcome the government’s commitment to ensuring that there is a suitable workforce in place to implement the NSF, however we are not aware of any funds to ensure this occurs.

We would also reiterate our earlier point that the NSF is non-condition specific and there are acute shortage of trained neurologists in England with specialist training in epilepsy.

Neurologists who do not have a special interest in epilepsy are not necessarily best placed to treat the condition.

The misdiagnosis rate for epilepsy is an unacceptable 20 to 40 per cent and 30 per cent of people with active epilepsy are not being treated by a specialist.

As a target we believe all people with a possible diagnosis of epilepsy should be seen by a specialist with an interest in epilepsy within 28 days.

• The government’s own figures note there are approximately 372 neurologists in the UK.
• The Association of British Neurologists calculates for the population of the UK there should be approximately 600.
• Further there are only approximately 69 trained Paediatric Neurologists in the UK of whom only about half have an interest in epilepsy.
• The British Paediatric Neurologists Association calculates as a minimum 150 Paediatric Neurologists are required to provide a comprehensive services, of which at least half should have an interest in epilepsy.
• It is estimated that approximately 1,200 epilepsy specialist nurses are required compared to the current provision of approximately 150.
• There is an acute shortage of technicians to enable the necessary EEG, MRI, CT and other investigations
h. MRI (Magnetic Resonance Imaging) and CT (Computed Tomography) scanning are not used for the primary diagnosis of epilepsy, but can play an important role when considering treatment options. Diagnostic equipment being provided through centrally funded programmes, including MRI and CT scanners, will benefit all patient groups that are imaged in each hospital, including those with epilepsy. By the end of 2004, central programmes will have provided a total of approximately 100 MRI scanners and 200 CT scanners for the NHS.

i. The Expert Patient: A new Approach to Disease Management for the 21st Century sets out our commitment to using people’s expertise and experience of their conditions by encouraging them to work in partnership with health care professionals to manage their condition. This is available at http://www.doh.gov.uk/cmo/ep-report.pdf. People with epilepsy can expect to benefit from this programme through, for example reduced levels of stress and anxiety and improved control of medicine taking. We will look at the feasibility of developing a disease-specific module for epilepsy in the next phase of this work.

Information provision

Department of Health – how we will make improvements

The audit found deficiencies in communication between healthcare professionals, patients, their carers and families. There was little evidence that epilepsy management and hazards such as the risk of death had been discussed with patients, their families and carers by any healthcare professional in primary or secondary care.

8. The Department of Health recognises that working in partnership to improve epilepsy services depends on the provision of good quality information for service users and their families, health and social care professionals and the public. We will improve the provision of information by:

a. Working with the epilepsy voluntary organisations to produce a patient information leaflet on epilepsy, which will address the need to improve awareness, particularly around managing risks of the condition. We will provide resources for this work in the next financial year (2003/04).

b. Providing £288,600 Section 64 funding over the next three years to the National Society for Epilepsy (NSE) to expand its Epilepsy Information Network. This will provide improved information and support to epilepsy patients and their families, a key need.

JEC Response

We welcome the investment in diagnostic equipment although we are unclear at the moment if this is an adequate level of investment.

As a target we would suggest that all people with a potential diagnosis of epilepsy should be able to have an EEG an MRI scan within 4 weeks of referral and that sufficient equipment and staffing should be provided to enable this to happen.

We welcome the Expert Patient programme and the suggestion of an epilepsy module but again note the programme is not a response to National Sentinel Audit findings.

We welcome the commitment to provide funding for information provision, however are surprised that the government feel there is a shortfall of literature available, except perhaps in languages other than English.

A Risk Management Leaflet was produced by the JEC in response to the National Sentinel Audit.

The principal issue is not a lack of information about the condition but about clinicians making this available to their patients and discussing the implications with them.

We would welcome the opportunity to discuss with the government funding for dissemination of information leaflets.

We believe the government should be requiring clinicians to provide appropriate information to their patients as part of the consultation process and funding the production and dissemination of an adequate quantity of such leaflets.

We welcome the award of the Section 64 grant and will endeavour to work with the NSE and other charities to ensure this is used as effectively as
identified in the audit. The NSE will work closely with other epilepsy charities to develop this strand of work. This is in addition to the £122,000 Section 64 grant awarded in 2002 which supports the NSE’s Living Well Project. This provides locally-based, short-term courses for people with epilepsy to promote self-help and self-management techniques so that they can take control of their lives in spite of their epilepsy.

c. Suggesting that NHS Direct Online review and update the epilepsy information in its Health Encyclopaedia regularly. We will also consider possible links to other websites targeted at specific groups of people with epilepsy, e.g. those with learning disability. The NHS Direct Online website is at http://www.nhndirect.nhs.uk.

d. Taking advantage of a NHS Direct Online and Medicines Partnership Taskforce project improving medicines information for patients. This will result in the development of clearer information on medicines for conditions including epilepsy.

e. Implementing the copying letters to patients initiative which is a key recommendation in paragraph 10.3 of the NHS Plan (available at http://www.doh.gov.uk/nhsplan/default.htm). This is about giving people more information about the treatment that is being planned for them. It will help improve the quality of the patient and clinician relationship by improving communications between them. We are proposing to issue guidelines, including a toolkit, in spring 2003. Full implementation is expected by April 2004.

f. Engaging with the Royal Colleges to raise awareness of the audit, particularly highlighting the issue of informing patients about epilepsy management and the risks associated with their condition.

9. The epilepsy voluntary organisations have an important role to play in providing information and support. There are over 20 of these and details of some of them are below:

- Joint Epilepsy Council
  website - http://www.jointepilepsycouncil.org.uk/
  e-mail – sharon.jec@btconnect.com
  telephone – 01943 871852

- Epilepsy Action
  website - http://www.epilepsy.org.uk
  freephone helpline - 0808 800 5050
  e-mail - helpline@epilepsy.org.uk

- Epilepsy Bereaved
  website - http://www.sudep.org
  e-mail - epilepsybereaved@dial.pipex.com
  general enquiries - 01235 772850
  bereavement support line - 01235 772852

- Mersey Region Epilepsy Association
  helpline – 0151 298 2666
  e-mail – epilepsy@mrea.demon.co.uk

We welcome the suggestion to NHS Direct Online but would be surprised if this were not the case at present.

We welcome the suggestion to NHS Direct Online.

We welcome the initiative, but note it is not a response to the National Sentinel Audit.

We welcome the initiative to engage with the Royal Colleges, although there is no detail as to what form this may take and in what way the government will ensure this results in action to improve management of epilepsy.

We welcome the recognition of the role of the voluntary organisations and the financial support some have received.

However, we do not believe that the role of voluntary organisations should be substitute for effective delivery by the Health Service in the area of information provision and support.

The voluntary organisations have grown up over the years to fill the void left by the inadequacies within the health service.

The voluntary sector did offer to monitor the outcomes of the Action Plan and are disappointed that the government rejected the bid for funding by the JEC to undertake this work.
Government Action Plan

- National Society for Epilepsy
  website: http://www.epilepsynse.org.uk/pages/index/home
  telephone: 01494 601300

Hard copies of the report can be ordered shortly by emailing doh@prolog.uk.com