Date: **Wednesday 19 June 2002**

Venue: **Committee Room 2, National Assembly for Wales**

Title: **National Sentinel Clinical Audit of Epilepsy related deaths**

Purpose

1. This paper reports to HSSC on the results of the consultation on the National Sentinel Clinical Audit of Epilepsy Related Deaths report. The audit was developed by multi-professional and lay groups, with healthcare professionals drawn mainly from the Royal Colleges of General Practitioners, Nursing, Pathologists, Paediatrics and Child Health, and Psychiatrists and from the British Branch of the International League against Epilepsy. A steering group provided strategic, clinical and methodological guidance, while an executive committee 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 were responsible for case identification and data collection and management.

2. 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.

3. 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.

Background

4. 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.

5. 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.

6. The audit was sponsored by the National Institute for Clinical Excellence (NICE). A short summary report for England and Wales, published by NICE, is also available.

7. 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.

8. National sentinel audits are comprehensive clinical audits recently introduced in the NHS. Epilepsy Bereaved was commissioned by all 4 UK Health Departments to project management of a National Sentinel Clinical Audit of Epilepsy Deaths. It is expected that audit of epilepsy deaths will enable health professionals locally to compare their practice against agreed national standards and address any developmental needs in clinical practice.

9. 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. Proportionally this equates to 59 deaths p.a. in Wales, 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.

10. National audit of sudden unexpected death in epilepsy reveals 59% of child deaths and 39% of adult deaths were potentially avoidable. People with epilepsy have a risk of premature death that is 2-3 times higher than in the general population. Sudden unexpected death in epilepsy 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. Although it is not clear what causes these deaths, the most important risk factor is the occurrence of seizures - the more frequent the seizure, the higher the risk. However, most people with epilepsy (up to 70%) have the potential to be seizure free if their condition is appropriately managed.

11. Figures obtained through the audit were reviewed by an expert panel, which concluded that:

- 59% (13/22) of deaths in children were potentially or probably avoidable.

Care provided was deficient in 77%(17/22) of children, due to:

- Inadequate drug management (45%);
- Inadequate access to specialist care, for example access to outpatients or being seen by a consultant (36%);
- Inadequate investigation, for example an EEG or brain scans (32%).
- 39% (62/158) of deaths in adults were potentially or probably avoidable.
- Care provided was deficient in 54% (85/158) of adults, due to:
    - Inadequate access to specialist care, for example access to outpatients or being seen by a consultant (35%);
    - Inadequate drug management (20%);

- Lack of appropriate investigation, for example and EEG or brain scan (13%).

12. The audit was led by Epilepsy Bereaved and funded by NICE (on behalf of the NHS in England and Wales) and by the Government agencies for Scotland and Northern Ireland. It also included the International League against Epilepsy (British Branch), the Royal College of GPs, the Royal College of Nursing, the Royal College of Paediatrics and Child Health, the Royal College of Pathologists and the Royal College of Psychiatrists

13. A short summary report for England and Wales, published by NICE, is available at http://www.nice.org.uk/pdf/epilepsyreport.pdf. For ease of reference a copy of the short summary report is attached.

14. The National Institute for Clinical Excellence will address issues raised by the audit when developing a clinical guideline on the management of epilepsy in children and adults (expected to be published June 2004). The audit findings will also be used to inform the Institute's appraisal of drugs used to manage epilepsy in children and adults (expected to be published by September 2003).

15. All 4 Chief Medical Officers in the UK signed the foreword to the report, which will be available widely to the National Health Service. In that foreword a commitment was given to consider what could be done to address the weaknesses in care it identified. It is hoped that by taking action now, lives may be saved. This is a difficult problem and it would be wrong to imply that we can put resource and training deficiencies right overnight. However, the shortfalls in standards of care, for whatever reason, are clearly unacceptable and we shall work with the other UK administrations to see how best these can be remedied.

16. Officials attended the launch of the SUDEP report, chaired by Baroness Joyce Gould and held at the House of Lords. It was a small gathering, mostly members of Epilepsy Bereaved, panel members and the Press. Overall the message was very clear, patients and their carers should be told that epilepsy can be fatal and that it is important to take medication as prescribed.

Summary / Recommendations

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

18. The Chief Medical Officer for England has recommended that within 3 months of completion of this audit an action plan should be in place in England to cut the level of preventable epilepsy-related deaths.

19. The conclusions from this audit of epilepsy-related deaths will be taken into account in the following NICE guidance to the NHS in England and Wales:

- guideline on the diagnosis and management of epilepsy in children and adults, which is expected to be published in May 2004

- technology appraisal of drugs in epilepsy in children and adults, which is due to be completed in December 2003

Conclusion of the Report

20. It was difficult to establish the true number of epilepsy-related deaths from certification data. This must cast doubt on the reliability of national statistics as a source for public health surveillance, public policy targets or research aimed at reducing epilepsy mortality.

21. 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.

22. 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.

23. 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.

24. These system failures need to be addressed when planning professional education, clinical and audit guidance and systems for service delivery. In conclusion, poor epilepsy management results in a substantial number of potentially avoidable deaths.

Compliance

25. The National Health Services Act 1977 (Section 1) covers the duty to promote a comprehensive health services and provides or secures provision of services. These powers were transferred to the Assembly under the Transfer of Functions Order 1999 and are delegated to the Assembly Minister for Health and Social Services.

26. The Government of Wales Act 1998 provides the Assembly with the power to do anything to facilitate, or conducive or incidental to, the exercise of any of its functions (Section 40) and to incur expenditure (Section 85, Paragraph 2) and to attach conditions to the giving of financial assistance by the Assembly (Section 85, Paragraph 3). There are no issues of regularity of propriety. The Assembly Compliance Office has seen this paper and is content.

Action for Subject Committee

27. The Committee is asked to note the position

Jane Hutt
Minister for Health & Social Services

Contact Point

John Sweeney, Primary and Community Health Division, or Dr Sarah Watkins, Health Professional may be contacted for further information if required.