

1 APPENDIX C

2 Research Recommendations from 2004 guideline

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- 5 ▪ Large, population based studies are needed to assess current rates of misdiagnosis in
6 both adults and children with epilepsy.

 - 7 ▪ Diagnostic studies are needed to establish the utility, sensitivity and specificity of
8 structured questionnaires compared with a defined 'gold standard' to help medical
9 practitioners differentiate between the common causes of attack disorders in adults
10 and children.

 - 11 ▪ Economic evaluations are needed on the cost-effectiveness of investigations for the
12 diagnosis of epilepsy in both adults and children. Economic evaluations that consider
13 the incremental cost effectiveness of performing specific number of EEGs, or the
14 cost effectiveness of video EEG as compared to EEG or MRI are needed to inform
15 practice.

 - 16 ▪ Economic evaluations are needed into the cost effectiveness of training programmes
17 for healthcare professionals (general practitioners, nurses and specialists) involved in
18 the diagnosis of epilepsy.

 - 19 ▪ Diagnostic studies are needed to establish the utility, sensitivity and specificity of 24
20 hour ambulatory EEG, compared to standard and sleep/induced/deprived EEG in the
21 diagnosis of suspected epilepsy and epilepsy syndromes.

 - 22 ▪ Large, population based cohort studies are needed to further investigate the
23 prognosis of epilepsy in children, with a specific emphasis on the proportion of
24 children who become refractory to drug therapy and become candidates for surgery.

 - 25 ▪ The use of steroids in the treatment of nonconvulsive status epilepticus should be
26 evaluated in adequately powered RCTs that report all relevant clinical outcomes.

 - 27 ▪ RCTs are needed to establish the relative effectiveness of epilepsy clinics, in
28 particular for special groups, when compared with usual care.

 - 29 ▪ The use of epilepsy specialist nurses in primary and secondary care and GPs with a
30 special interest in epilepsy should be evaluated in adequately powered RCTs that
31 report all relevant clinical outcomes for individuals with epilepsy.

 - 32 ▪ Qualitative studies are needed to explore both the process and outcome of risk
33 communication in the consultation between healthcare practitioners and the
34 individual with epilepsy and their carers. These should include the perspectives of all
35 relevant parties.

- 1 ▪ Qualitative studies are needed to determine the experiences of individuals from
2 black and minority ethnic groups with epilepsy in relation to their health needs and
3 beliefs and the role of healthcare professionals in providing culturally sensitive care.
- 4 ▪ Qualitative and quantitative studies are needed to determine the experience of
5 individuals with learning disabilities and in particular, to compare outcomes for
6 people with epilepsy and learning disabilities managed by different groups of
7 clinicians.
- 8 ▪ Qualitative studies are needed about the information needs of individuals with
9 epilepsy with respect to SUDEP. The research should focus on different groups of
10 individuals, particularly children and their families.
- 11 ▪ A large RCT of longer-term clinical outcomes and cost-effectiveness of standard and
12 new antiepileptic drugs (SANAD) has been sponsored by the NHS R&D Health
13 Technology Appraisal Programme. The study will compare monotherapy with
14 clinicians' first-choice standard drug with appropriate comparators from the newer
15 AEDs.
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