

Appendix E

Key Clinical Questions

72 key clinical questions were identified by the GDG, of which 52 had adult and child stems. A full literature search and critical appraisal process could not be undertaken for all of these KCQs due to time and resource limitations.

The KCQs were refined, as appropriate, into specific evidence-based questions (EBQs) by the methodology team and these EBQs formed the basis of the literature searching, appraisal and synthesis.^{2326}

Diagnosis

1. Who should establish the diagnosis of epilepsy in adults & children?
2. What are the key features of the history and examination that allow epilepsy to be differentiated from other diagnoses in adults and children?
3. Does home video recording aid in the diagnosis of epilepsy?
4. What is the role of seizure diaries in making a diagnosis of epilepsy?

Investigations

5. What is the role of the EEG in diagnosis?
6. How good is the standard EEG at differentiating between individuals who have had an epileptic seizure and those who have had a non-epileptic seizure?
7. How good is the EEG at differentiating between individuals who have different epilepsy seizure types and epilepsy syndromes?

8. How can the diagnostic yield of the standard interictal EEG be improved?
 - early recording of EEG after seizure
 - repeat EEGs
 - sleep & sleep deprivation
9. What is the role of video-EEG and ambulatory EEG?
10. What is the role of provocation techniques / induction protocols?
11. Does an abnormal EEG predict seizure recurrence?
12. What is the role of neuroimaging in the diagnosis of epilepsy?
13. What is the role of blood tests in the diagnosis of epilepsy?

Classification

14. What classification system should be used in adults and children?
15. What is the role of classification in adults and children?

Pharmacological treatment

16. What AED treatment should be used in adults and children?
17. When should AED treatment in adults/children be started?
18. Who should start AED treatment in adults and children?
19. Who should prescribe continuing AED treatment in adults and children?
20. When should AED treatment be discontinued in adults and children?

21. Who should discontinue AED treatment in adults and children?
22. How should AED treatment be discontinued in adults and children?
23. What is the role of [routine] monitoring in adults and children with epilepsy?
24. What influences AED treatment concordance in adults and children?

Non-pharmacological treatment

25. What non-drug treatments are effective in adults and children with epilepsy?
26. What is the role of the (neuro) psychology assessment in diagnosis and management?

Status epilepticus

27. How should prolonged or serial seizures in adults and children in the community be managed?
28. How should status epilepticus in individuals be managed in secondary care?
29. How should status epilepticus in children be managed in secondary care?
30. How should refractory status epilepticus in individuals be managed in secondary care?
31. How should refractory status epilepticus in children be managed in secondary care?

Special groups – women with epilepsy

32. What are the issues that should be considered when prescribing AEDs in women who may become pregnant or breast feed?
33. What information should be given about the risk of increased seizures?
34. What information should be given about breastfeeding?
35. What is the teratogenicity of AEDs?
36. What are the possible side effects of AEDs in pregnancy?
37. What is the effectiveness of AEDs in pregnant women?
38. What are the dangers of seizures in women who are pregnant?
39. What are the dangers of seizures during labour?
40. What are the dangers of seizures post partum?
41. Does epilepsy increase the risk of complications in pregnancy?
42. What is the best way to care for women during pregnancy and whilst breast feeding?
43. What is the role of drug monitoring when caring for women during pregnancy and whilst breast feeding?
44. What is the role of prenatal monitoring and screening?
45. Do AEDs interact with contraceptives?
46. Are women with epilepsy more likely to have children with epilepsy?
47. When should folic acid be started?
48. Should oral or parenteral vitamin K be used?

49. What is the role, and is there evidence of effectiveness for, joint epilepsy/obstetric clinics?

Special groups- people with learning disabilities

50. Do people with learning disability & epilepsy who receive care from a specialist in learning disability & epilepsy compared with care from a non-specialist have differences in processes and outcomes of care?
51. Are the rates of misdiagnosis higher for people with learning disability & epilepsy when compared with people with epilepsy who do not have learning disabilities?
52. What are the practical difficulties in establishing the diagnosis in this group?
53. Are there a) difficulties in conducting investigations (EEG; neuro-imaging); b) difficulties in interpreting investigations (EEG; neuro-imaging) in people with learning disability & epilepsy when compared with people with epilepsy who do not have learning disabilities?
54. Are there AEDs that are of particular benefit to people with learning disabilities and others which should be avoided?
55. Do people with learning disability & epilepsy have lower rates of remission when compared with people with epilepsy alone?
56. Is there increased mortality in PLD and epilepsy?
57. What management issues in people with learning disabilities do health care practitioners and carers view as important?

Special groups - adolescents

58. Is a different approach to management required in adolescents, particularly around issues of compliance?
59. What is the role of specialist teenage epilepsy clinics?
60. What are the special needs or information requirements of this group?
61. Should the diagnosis of epilepsy be revisited in this group?

Special groups – older people

No additional KCQs identified

Special groups – ethnic minorities

62. Are individuals with epilepsy from minority ethnic groups in the UK more or less likely to experience different outcomes when compared with the general population?
63. Are the information needs different in this group?

Information needs

64. What are the information and counselling needs of people with epilepsy?
65. What is the preferred format, timing and delivery of epilepsy information?
66. What are the outcomes of information giving?

67. What information should be given after a first seizure?
68. What information should be given around investigations?
69. What information should be given on diagnosis?
- Risk assessment
 - Drug treatment
 - Other treatment
 - Remission/Nonremission
 - Refractory epilepsy/surgery

Care process

70. What is the role of primary care/shared care in the management of adults and children with epilepsy?
- structured annual review
 - epilepsy specialist nurses
71. What is the role of secondary/tertiary care in the management of adults and children with epilepsy?
- dedicated epilepsy clinics
 - epilepsy specialist nurses
 - models of care
72. How effective are individual self management plans in adults and children with epilepsy?