Preventing Deaths in Children with Epilepsy - what progress can we expect?

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Outline

- National picture
- Regional picture
- Local picture

UK

Continuing Aims

- To facilitate health providers and commissioners to measure and improve quality of care for children and young people with seizures and epilepsies
- To contribute to the continuing improvement of outcomes for those children, young people and their families

“12 measures over 12 months”

Timeline

Methods
**Timeline**

- Census 1: May 2011
- Census 2: Jan 2014

**Numbers and Demographics**

- n = 3449 children
  - Female 45%; Male 55%
  - Acute 45%; Non-acute 55%
- n = 2335

**Service Descriptors**

- Units with ESN: 45% in Round 1, 51% in Round 2
- Units with Paediatric Neurology Clinics: 46% in Round 1, 49% in Round 2
- Units with Epilepsy Clinics: 48% in Round 1, 50% in Round 2
- Units with Young People's clinic: 35% in Round 1, 30% in Round 2

**12 Performance Indicators**

1. Paediatric with expertise in epilepsy: 43% in Round 1, 72% in Round 2
2. Epilepsy specialist nurse: 60% in Round 1, 90% in Round 2
3. Tertiary involvement: 60% in Round 1, 95% in Round 2
4. Appropriate first clinical assessment: 50% in Round 1, 90% in Round 2
5. Seizure classification: 46% in Round 1, 70% in Round 2
6. Syndrome classification: 60% in Round 1, 90% in Round 2
7. EEG: 46% in Round 1, 70% in Round 2
8. MRI: 50% in Round 1, 90% in Round 2
9. Carbamazepine: 46% in Round 1, 90% in Round 2
10. Accuracy of diagnosis: 60% in Round 1, 90% in Round 2
11. Information and advice: 80% in Round 1, 90% in Round 2

**Epilepsy Specialist Nurse Input**

- Round 1: (46%) 819/1775
- Round 2: (59%) 717/1215
The review was based on children with epilepsies aged 1-17 years UK who died (of any cause) or who received intensive or high dependency care for prolonged seizures 2012-2013:

- 33 children who died
- 17 children receiving intensive care
- 19 receiving high dependency care
Epilepsy and Risks

Risk planning

- Children and young people with epilepsy need tailored information about risks of
  - Physical injury
  - Prolonged convulsions and status epilepticus
  - Death including SUDEP

- Advice to mitigate the risks should be given on individual basis

OPEN UK

- Organisation of Paediatric Epilepsy Networks UK
- Agreed with NHS England 2015
- Create UK wide collaborative multi-professional framework and stakeholder group
PEPO

- Care Tracking ‘start to finish’ care
- Record and prompt self-management and journey through adolescence

Recent local changes

- Seeing children in designated epilepsy clinics
- Young person's epilepsy clinic
- Peer review
- “Talking risks” and “SUDEP risk reduction”

Summary

- We need to join up research findings and audit data with actual clinical care
- We should be learning how to improve care...from all children with epilepsy...
  ...for all children with epilepsy
- Epilepsy is coming out of the shadows...there is evidence of improvement...but we have a long way to go!