

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

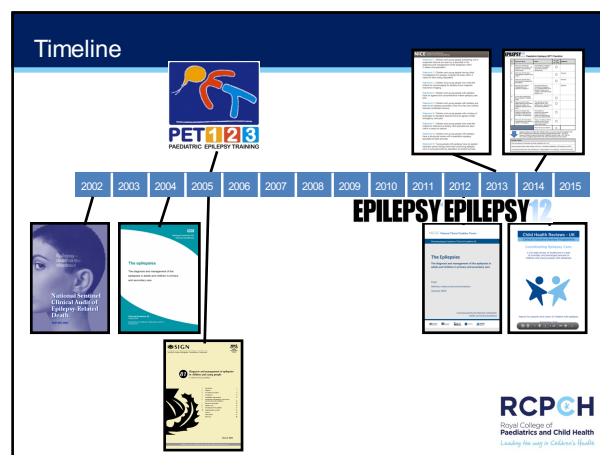
Dr Colin Dunkley  
Consultant Paediatrician

4<sup>th</sup> March 2016

## Outline

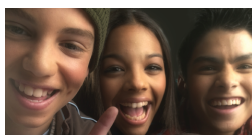
- National picture
- Regional picture
- Local picture

# UK



## Continuing Aims

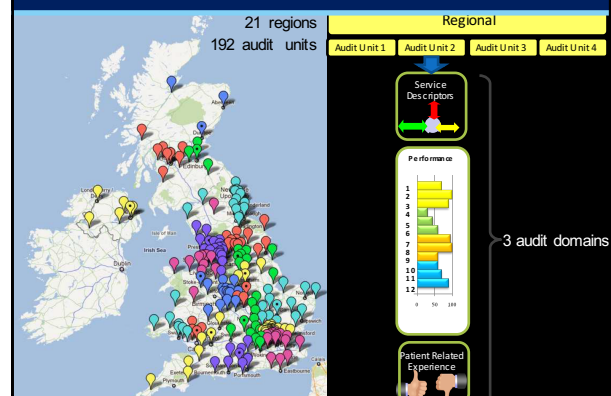
- To facilitate health providers and commissioners to measure and improve quality of care for children and young people with seizures and epilepsies
- To contribute to the continuing improvement of outcomes for those children, young people and their families



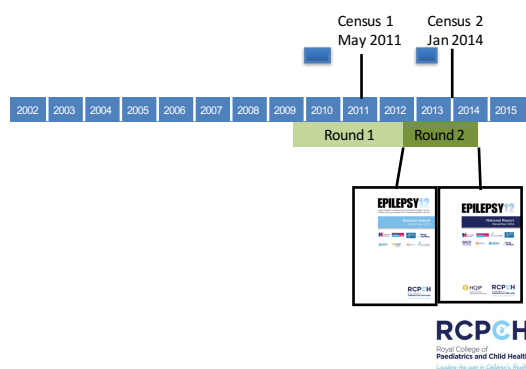
*"12 measures over 12 months"*

**RCPCH**  
Royal College of Paediatrics and Child Health  
Leading the way in Children's Health

## Methods



## Timeline



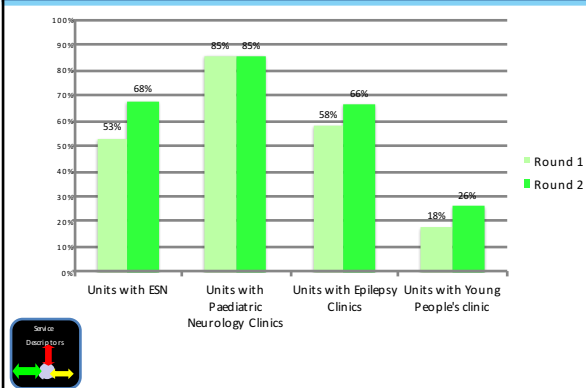
## Numbers and Demographics



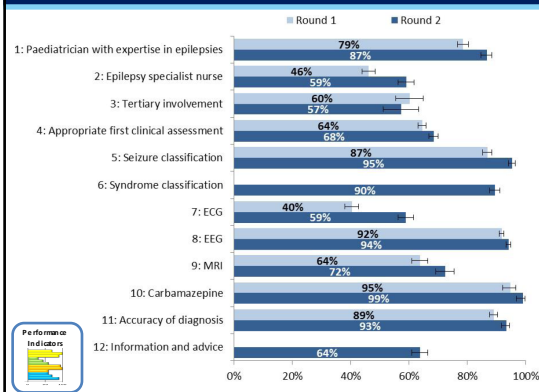
n = 3449 children  
female 45%: male 55%  
acute 45%: non-acute 55%

n = 2335

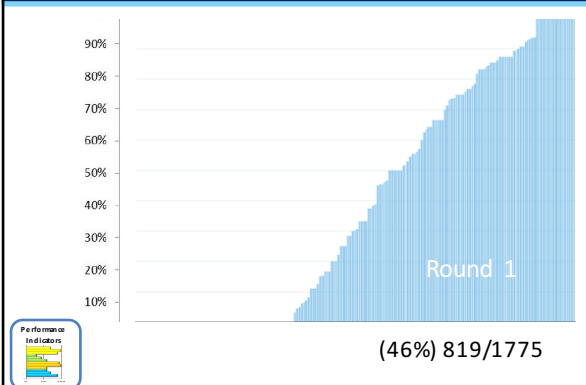
## Service Descriptors



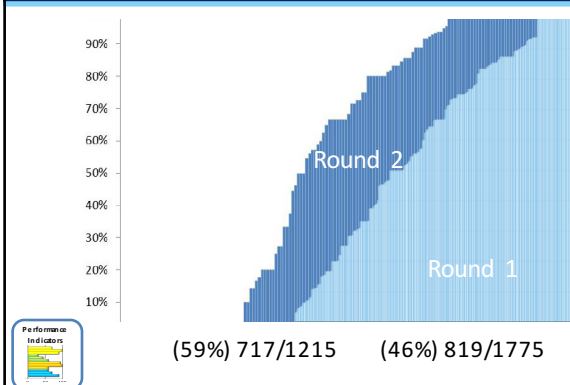
## 12 Performance Indicators

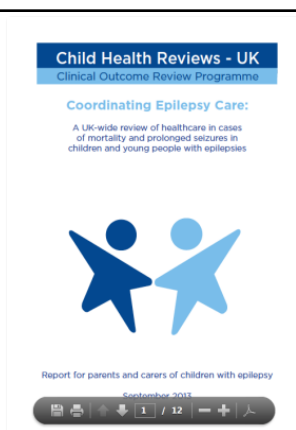


## Epilepsy Specialist Nurse Input



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## Child Health Review 2013

- 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

## Child Health Review 2013

**Key finding 1:** In spite of the severity of these children's health needs, this review has emphasised that the care provided by parents and professionals working together provides the best possible quality of care.

**Key finding 5:** Early, thorough and ongoing discussions with children and young people and their parents or carers are crucially important. This is clearly emphasised in both NICE and SIGN guidelines. However, although such discussions may be taking place, there was a paucity of documentation around these.

**Key finding 12:** Children with epilepsies who die do so from a variety of causes, with over half of the children in this review dying of causes other than their epilepsy. This can lead to multiple professionals being involved in the child's care, allowing it to become fragmented. This further highlights the need for a single clinician taking charge of the coordination of the child's care.

## Child Health Review 2013

### Recommendation 3

Clinical teams looking after children and young people with epilepsies should consider introducing an 'epilepsy passport' for all children as a means of improving communication and clarity around ongoing management.

### Recommendation 6

Ambulance Trusts should consider updating their protocols for seizure management in children and young people to recommend the use of buccal midazolam as the first line treatment for prolonged seizures. This should be backed up with appropriate training of all ambulance crews in the use of buccal midazolam and provision of buccal midazolam to all ambulance crews.

### Recommendation 7

Emergency departments should ensure that children and young people presenting with prolonged seizures are treated according to current NICE and APLS guidance through appropriate departmental guidelines, training of staff and audit.



Please return passport form  
valued to read all 4 pages

**PERSONAL AND BACKGROUND INFORMATION**

Full name:  Date of previous seizure(s):

Date of birth:  Gender:  Age at diagnosis:  or seizure:

Emergency contact 1:

Emergency contact 2:

Emergency contact 3:

Emergency contact 4:

Emergency contact 5:

Emergency contact 6:

Emergency contact 7:

Emergency contact 8:

Emergency contact 9:

Emergency contact 10:

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## 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



### Risk planning...

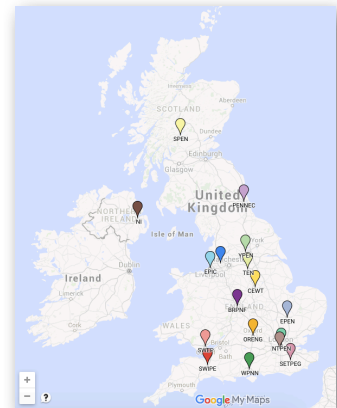
#### All need...

- Appropriate advice on seizure control
- First aid advice
- Discussion about their risks
- Participation advice...  
Bath, swimming, heights, cycling, driving advice



### OPEN UK

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



## EAST MIDLANDS



### 'Epilepsy - To - Go'


#### Comprehensive Care Plan Resources

PEPO - Paediatric Epilepsies Plan Overview (NEW!)  
aid to summarise of ongoing care and communication  
CEWT letter template v4  
dictate letters using a suggested format/dataset  
Seizure Diary  
give to patients for seizure(s) documentation  
Seizure Description  
give to parents/carers/schools to aid witness description  
Drug Dosage Plans  
help communicate drug escalation plans  
Home Video Instructions  
help improve quality of home video  
Neurology investigations checklist  
list of potential tests for some epilepsies  
Ketogenic Diet Monitoring  
record results for children on ketogenic diet  
Epilepsy data collection form  
summarise relevant clinical data  
Patient Information Checklist  
Manage the information needs of young people  
Epilepsies Treatment Summary (NEW!)  
Table to help document previous and ongoing AEDs

[www.cewt.org.uk](http://www.cewt.org.uk)

**PEPO**

- ✓ Care Tracking 'start to finish' care
- ✓ Record and prompt self-management and journey through adolescence



The form is titled 'PEPO Pediatric Epilepsy Plan Overview' and is a comprehensive tracking tool for pediatric epilepsy care. It includes sections for 'Child or young person details', 'At diagnosis', 'Initial seizure planning', 'Ongoing care', 'Further seizure planning', 'Young people (Self-Management)', and 'Adult Services'. It features various checkboxes and fields for recording clinical data and management plans.

## SHERWOOD FOREST

### Recent local changes

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

Sherwood Forest Hospitals   
NHS Foundation Trust



### 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!