NATIONAL EPILEPSY 12 AUDIT

RESPONSE to;
FINAL SITE SPECIFIC REPORT: CLINICAL AND SERVICE DESCRIPTOR RESULTS for
PLYMOUTH
PREPARED BY THE ROYAL COLLEGE OF PAEDIATRICS
AND CHILD HEALTH JUNE 2012

Introduction

The National Epilepsy 12 Audit was set up to determine how effectively national recommendations for the management of epilepsies in children and young people (NICE 2004 – updated 2012 and SIGN 2005) are being followed. There has been concern that there has been little evidence of widespread implementation of recommendations and ongoing concern that service provision is variable across the UK.

The UK wide multi-centre collaborative audit critically examined the provision of health care for children and young people (CYP) with suspected epileptic seizures against 12 standard measures in the first 12 months following presentation to district level health services. Included in the audit was feedback from CYP and carers.

One area particularly identified for improvement was the need for greater involvement of paediatric specialist epilepsy nurses in clinical care. 47% of units audited had no input from specialist epilepsy nurse within 12 months of assessment. The importance of access to specialist nurses was first highlighted in the National Sentinel Audit on Epilepsy Related Deaths 2002.

The Healthcare Quality Improvement Partnership in Health Improvement, Scotland funded the RCPCH to conduct the audit which was undertaken by 197 units.

The key aims were:

- To facilitate health providers and commissioners to measure and improve quality of care for CYP with seizures and epilepsy and to;
- Contribute to the continuing improvement of outcomes for those children, young people and families.

Three domains were examined:

1. Service descriptor; paediatric services described details of their service for a specific census date 1 February 2011.

2. A retrospective case note analysis for all children meeting the project including criteria having their first paediatric assessment during the period of 1st August 2009 – 31st January 2010.

3. Patient related experience measure; carers and young people invited to describe experiences of health care.
Results:

Details of service

1. 17% (347/2027) of WTE general paediatric consultants within the UK audit units were reported as having defined expertise in epilepsy. **Plymouth has 2/10 paediatricians with defined expertise in epilepsy one of whom takes the lead for children’s epilepsyservices.**

2. 47% (91/193) of audit units had no epilepsy specialist nurse. **Neither Plymouth Hospitals NHS Trust PHNT or Plymouth PCT employ a children’s specialist epilepsy nurse. Children who are seen at PHNT from Cornwall do have access to a specialist epilepsy nurse as there is a specialist epilepsy nurse employed by Cornwall PCT. The majority of the patients seen at PHNT come from Plymouth with a minority coming from Cornwall and West Devon.**

3. 58% (112/193) of UK units held epilepsy clinics. **The lead consultant for epilepsy in Plymouth hold 1.5-2 epilepsy clinics a week**

4. 18% (35/193) of units had a specific clinic for young people or teenagers with epilepsy **Plymouth has a Transition Clinic held jointly by the lead for children’s epilepsy and a consultant adult neurologist and children are seen at this clinic from the age of 15/16 years. There is no specific clinic for teenagers prior to transition.**

**Epilepsy 12 Indicators**

The performance indicators are included in Appendix 1 and the results from Plymouth in Appendix 2. Plymouth was not found to be an outlier for any of the performers indicators. Two indicators were not applicable to the sample population in Plymouth. Positive findings were that the children identified in the audit with epilepsy were seen by a paediatrician with expertise in epilepsies, there were no contra indications for an EEG examination in any of the children where an EEG was conducted and there was 100% accuracy of diagnosis. Of concern only 1/6 children with epilepsy had epilepsy specialist nurse input by one year. None of the three children meeting the criteria for paediatric neurology referral had input by tertiary care by one year. A syndrome diagnosis was only made in 16.7% this being in the lower quartile range by comparison to the rest of the UK. Only 40% of children where there were indications for an MRI had an MRI performed within one year of presentation.

**RESPONSE**

Unfortunately data capture in Plymouth was not complete as not all patients within the study cohort had their notes obtained before the closing date of the audit.

**Action:** To complete the audit locally to ensure results obtained are representative of the entire cohort.

**Timescale:** 3 months
Service Provision

Children and Young People from Plymouth with epilepsy do not have access to an epilepsy specialist nurse. Epilepsy specialist nurse provision includes care planning, facilitating appropriate participation, risk assessment, school and respite care liaison, first aid and rescue medication training and telephone advice.

<table>
<thead>
<tr>
<th>Action:</th>
<th>To prepare a business case for employment of a specialist epilepsy nurse for those children from Plymouth and West Devon who do not currently have access to the services of an epilepsy nurse.</th>
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| Timescale: | Preparation of Business Case 4 weeks. 
Specialist epilepsy nurse in post 4 months |

Plymouth has a transition clinic for older adolescents with diagnosis of epilepsy but no specific for younger teenagers.

<table>
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<tr>
<th>Action:</th>
<th>To introduce a monthly epilepsy clinic specific for teenagers prior to transition</th>
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<tr>
<td>Timescale:</td>
<td>6months</td>
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Compliance with Epilepsy 12 Performance Indicators.

1. Input of tertiary care – there are national recommended criteria for children with epilepsy who should have been seen by a tertiary neurology specialist. A tertiary neurology clinic is held at Derriford Hospital and at the Child Development Centre with a total of 16-20 clinics per annum. Despite this provision not all children have been seen in a timely manner as evidenced by the audit findings.

<table>
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<tr>
<th>Action:</th>
<th>To identify children with epilepsy who would meet the criteria for referral neurology and who have not been seen with a view to establishing the requirements for additional tertiary neurology input.</th>
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<tr>
<td>Timescale:</td>
<td>8 months</td>
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2. Investigation

There are recommendations for which children with epilepsy should be investigated by the means of a cranial MRI scan. The audit indicated that only 40% (2/5 children) with indications for an MRI scan had a scan by one year.

| Action | 1. The recommendations with regard to MRI scanning should be highlighted to consultants who see children with suspected seizures.  
2. Paediatricians should work with the paediatric anaesthetists and imaging department to obtain more provision for MRI scanning under general anaesthetic. |
| Timescale | 1. Highlighting need – 1 month  
2. Increase in GA sessions – 6 months |

3. Assessment and Classification

The standard of assessment and classification the audit revealed comparative performance with other units in first clinical assessment and seizure classification. Syndrome classification however, was in the lower quartile (not an outlier).

| Action | A proforma to be produced for first clinical assessment providing prompts for clinical assessment diagnosis and investigation. |
| Timescale | 3 months |

There is a plan to repeat the audit in its present form in the next 24 months to seek consistency and assess improvement.

| Action | To participate fully, with complete data collection in the repeat audit. |

Dr Carolyn Adcock – PHNT lead for children’s epilepsy service

Dr Ben Marsh - Lead for Epilepsy 12 audit