The case for investing in children and young people's epilepsy services

Health Policy team
This information bundle on epilepsy presents interventions to ensure that children and young people with epilepsy receive high quality care and appropriate mental health support. This information was presented to NHS England to inform the development of their long term plan.

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What is the problem?

- The UK Epilepsy12 National Audit Rounds 1 and 2 provided systematic evidence of current UK paediatric epilepsy patient care. The 2014 report showed significant improvement, but there remains a large persisting implementation gap and wide variations in standards of care.
- In 2012, there was 9-fold variation in admission rates for children with epilepsy between different areas. Adjustments for socioeconomic deprivation did not account for this variation.
- The Child Health Review 2013 reported 107 UK deaths for children with epilepsy. One in eight children in the study who died had modifiable contributory findings identified.
- In July 2014, only 22% of Health and Wellbeing boards said their Joint Strategic Needs Assessments included a section on epilepsy. 77% of Clinical Commissioning Groups (CCGs) stated that they had not produced, and had no plans to develop, a written needs assessment of the health and social care needs for people with epilepsy.
- 37% of children with epilepsy have a co-existing mental health disorder. This is a significantly higher prevalence than found in other long-term childhood conditions, such
as diabetes and asthma.
- 72% of children with epilepsy have 'low achievement at school' and 42% of children have 'underachievement' at school\(^5\).

**Numbers**

Epilepsy is the common significant long-term neurological condition of childhood, affecting about 1 in 220 children. We estimate that this is approximately 51,000 children and young people with epilepsy in England (0-16 years old). Seizures and epilepsy account for about 5% of all childhood emergency admissions\(^6\).

**What are the interventions required?**

**Implement NICE Clinical Guideline 137**

NICE recommends a comprehensive whole-system approach to achieving the best outcomes for children and young people with epilepsy. This includes paediatricians with defined expertise, epilepsy specialist nursing (ESN), referral criteria for complex epilepsies to tertiary care, appropriate investigation, avoiding misdiagnosis and appropriate drug and non-drug treatment. Appropriate interventions also includes detecting and managing co-morbidities, mental health and educational problems.

*We want further investment to achieve paediatric epilepsy Best Practice criteria to bridge the gap between current paediatric service delivery in England and that advocated by NICE Clinical Guideline 137.*

**Integrated services designed around paediatric epilepsy patients**

The diagnosis and treatment of mental health problems alongside epilepsy health provision will require integration of some mental health delivery within epilepsy services. 2019 proposed Best Practice criteria has included co-located mental health provision within the established epilepsy clinics. This will require a further uplift of funding over and above the existing best practice price equating to an initial estimate of 1 whole time equivalent (WTE) mental health practitioner per 250 children with epilepsy.

*We want to see integrated services designed around paediatric epilepsy patients so their physical and mental health needs are diagnosed and treated together in a holistic approach.*

**Maintaining and improving implementation of the Epilepsy Best Practice criteria**

In April 2013, the Department of Health introduced an Epilepsy Best Practice Tariff (BPT) for the secondary tier follow-up of children with epilepsies in England and Wales. Successful unites evidence a whole system approach aligning with NICE recommendations and quality standards, and attract enhanced funding.
The scope has developed over time and the recent proposal for 2019-20 now includes integrated mental health support and formalised transition services.

We want the proposed Epilepsy Best Practice criteria to be fully implemented by all relevant trusts in England.

Sufficient epilepsy specialist nurses

A key focus of Epilepsy 12 has been to establish sufficient epilepsy specialist nurse (ESN) provision. The BPT has been designed to remove cost barriers around ESN post creation and maintenance.

Based on the Royal College of Nursing recommended ratio of one ESN to 250 children, then there needs to be a total of 204 whole time equivalent (WTE) ESNs. Epilepsy12 reported 74 nurses in 2012 and 121 in 2014, suggesting a 2014 shortfall of at least 83 WTE ESNs.

NHS England should continue to implement the Best Practice criteria to leverage improvements to ensure ESN numbers follow a reasonable trajectory towards sufficient ESNs using current funding structures.

Improve transition to adult services

Significant changes towards improving transitional care for children with epilepsy can be achieved by re-organising epilepsy clinics to include designated young people's clinics and clear handover process with no significant additional cost.

We want to see more services ensure smooth transition for children and young people with epilepsy from paediatric to adult services. NHS England has a role to play in enabling this to happen by identifying services that are doing this well and disseminating this learning to other services across England.

Economic evidence and data

We want to see evidence and data gathered about the health, social and educational costs attributable to the gap between recommended practice and current service provision specifically for children and young people with epilepsy.

This will help inform future development of paediatric epilepsy services and expected return on investment.

MICE study

The National Institute for Health Research has funded a study entitled Mental Health Interventions for Children with Epilepsy (MICE). This trial aims to establish brief, focused, evidence-based interventions to children with epilepsy and their mental health needs. The interventions will be delivered by staff already working in the epilepsy service, who will receive additional training in telephone-based psychological interventions (for example, anxiety, depression, challenging behaviour). The staff will be supervised by experienced clinicians (clinical psychologists).

The MICE trial is based on a pilot study which shows that there are existing cost-effective
evidence-based interventions that can be delivered to improve the mental health of children with epilepsy.

We recommend that NHS England looks closely at the results of the trial including its economic evaluation component to ascertain future cost savings for the NHS.

What is the expected return on investment?

If the interventions outlines in the section above were implemented, many of the costs outlined below could be significantly reduced.

NICE Clinical Guideline 137 estimated annual (indirect and direct) cost of epilepsy in England (adults and children) is £2 billion7.

The cost of misdiagnosis of epilepsy for UK adults and children is around £268 million per year. In England, there are 69,000 people living with unnecessary seizures and 74,000 people taking drugs they do not need8.

The presence of mental health problems is causally responsible for a significant part of the excess costs. There is a strong economic case for integrating physical and mental health throughout the life course, especially in those with long term conditions. Resolving minor, mental ill health complaints will save money in the long-term (eg by reducing hospital admissions and unnecessary investigations). Studies have shown the presence of comorbid mental ill health to increase costs of care for long-term physical health conditions by around 45-75%, even after the severity of the physical ill health has been controlled.

Between 12 and 18% of NHS spending each year is on long term conditions (this figure is for children and adults combined). This equates to around £8-13 billion. Long term conditions are linked to poor mental health, usually depression or anxiety and around 4.5 million people in England are affected by this multi-morbidity. Around £1 in every £8 spent on long term conditions is linked to poor mental health and wellbeing. Wider costs include reduced employment, economic productivity and reduced productivity. Work by the King’s Fund has shown that depression increases the cost of care for patients with long term conditions by at least 45%, or from £3,910 to £5,670 per year and that at least £11 billion of NHS expenditure can be linked to just two aspects of the relationship between physical and mental health - namely, mental health co-morbidities and medically unexplained symptoms, among people with long term conditions.

Joined up services for medically unexplained symptoms has been seen to save money as around 15-30% of primary consultations fall in this category and investigation of these symptoms leads to a cost of around £3 billion every year in England. A study looking at the cost of medical or surgical paediatric hospital days preventable by psychiatric treatment found that around 10% of total days for 572 inpatients in a large children's hospital were potentially preventable by psychiatric treatment, representing a potential large saving across the categories.

Many of these economic studies focus on adults but the effects begin in childhood and continue throughout the life-course and there is increasingly a large body of evidence for the effectiveness and cost-effectiveness of mental health interventions in paediatric practice.

• 2. RCPCH (2013) Coordinating Epilepsy Care: a UK-wide review of healthcare in cases of mortality and prolonged seizures in children and young people with epilepsies HQIP: London