



BPSU surveillance of Deaths in Children with Epilepsy (excluding Scotland) commences in October 2016

Epilepsy is the most common long-term disabling condition of the nervous system affecting around 600,000 people in the UK. People with epilepsy are 2 to 3 times more likely to die early than the general population. Children with epilepsy may die from a number of causes including sudden unexplained death in epilepsy (SUDEP). Different studies with different cohorts show that SUDEP is responsible for anything between 2% to 18% of all deaths in patients with epilepsy.

The risk in children remains uncertain but is thought to be considerably less. Although the causes of SUDEP are undetermined, the most important risk factor in adults seems to be frequency of seizures. Young people with severe epilepsy and learning disability may be at even higher risk of SUDEP, with one previous study showing a death rate almost 16 times greater than expected. A prospective pilot study is much needed, to determine the size of the problem of death in children affected by epilepsy, to compare the differences between SUDEP and other causes of epilepsy deaths, and to allow future studies in this field.

The BPSU has a well-established system in place for active national surveillance of rare childhood conditions. BPSU surveillance of deaths in children with epilepsy will be undertaken for 13 months, commencing October 2016. There will be an initial case notification questionnaire, which will be used to collate information of the reported cases. The results of the study will be used to calculate incidence figures for this rare outcome of epilepsy, and provide information regarding the demographic characteristics of affected children. The study will contribute to our understanding of current public health policy and measures in place for prevention of deaths in children diagnosed with epilepsy.

We would like to:

- To estimate the current incidence of death in children under 16 years of age with epilepsy in the UK.
- To undertake a comprehensive descriptive study of deaths in epilepsy in UK children over a 13 months surveillance period.
- To compare characteristics of deaths from SUDEP to deaths in children with epilepsy from other causes.
- To develop appropriate information for young people with epilepsy and their families about incidence of SUDEP and characteristics of epilepsy deaths.

Duration: BPSU surveillance will be undertaken for 13 months, starting in October 2016 and concluding in October 2017.

Case definition: Please report any child who dies aged between 1 month and 16 years of age who also has the simultaneous diagnosis of epilepsy. The child must have had seizures or been treated with antiepileptic medication within the last 5 years.

Please report all suspected cases, even if the results of investigations are pending. Please report to the BPSU even if you believe the case may have been reported from elsewhere.

Website: www.rcpch.ac.uk/bpsu/epilepsy

Funding: This study is being funded by SUDEP Action (www.sudep.org).

Ethical approval: This study has been approved by the London Central REC (Ref: 16/LO/1265) and has been granted Section 251 CAG permission (Ref: 16/CAG/0093).

Further information: If you would like any advice regarding the eligibility of a particular case for inclusion in the study please contact:

Dr Omar Abdel-Mannan, NIHR Academic Clinical Fellow, Population, Policy and Practice Programme, UCL Institute of Child Health, 30 Guilford Street, London WC1N 1EH

Tel: 0771 774 7012 **Email:** ich.bpsu.sudep@ucl.ac.uk