Quality of paediatric epilepsy care and rates of death and hospital admission among children & young people with epilepsy in England: national longitudinal data-linkage study

Authors

Dougal S. Hargreaves MD(Res)[1,2], Sandeepa Arora M.Econ[1,2], Carolina Viveira MSc[3], Daniel R. Hale PhD[4], Joseph Ward MBBS[3], Christopher Sherlaw-Johnson PhD[2], Professor Russell M. Viner PhD[3], Colin Dunkley MBBS[5], Professor J Helen Cross PhD[3]

Affiliations

[1] Imperial College London. Department of Primary Care & Public Health, St Dunstan's Road, London W6 8RP.

[2] Nuffield Trust, 59 New Cavendish St, Marylebone, London W1G 7LP

[3] UCL Great Ormond Street Institute of Child Health, 30 Guilford Street, London. WC1N 1EH

[4] Heriot Watt University, Edinburgh, Scotland. EH14 4AS

[5] Royal College of Paediatrics & Child Health, 5-11 Theobalds Rd, London WC1X 8SH

Corresponding author

Dr Dougal S. Hargreaves

Address: Imperial College London. Department of Primary Care & Public Health, St Dunstan's Road, London W6 8RP.

Telephone: 07943 746 717

Email: d.hargreaves@imperial.ac.uk

ABSTRACT

Background

Lack of coordinated, high-quality care for children and young people with epilepsies is thought to contribute to preventable hospital admissions and avoidable epilepsy-related deaths, especially around the time of transition to adult services. However, these links have rarely been investigated in large-scale data-linkage studies.

Methods

We accessed unit-level data from Round 1 (2009-11) and Round 2 (2013-14) of the Epilepsy12 national clinical audit and data on death registrations and unplanned hospital admissions. We investigated the association between unit-level performance in involving a paediatrician with epilepsy expertise, Epilepsy Specialist Nurse (ESN), and Paediatric Neurologist (PN) in Round 1 and the proportion of adolescents with epilepsy admitted to each unit who subsequently died during the study period (2009-15). We also investigated whether change in Epilepsy12 performance between the audit rounds was associated with change in the standardised ratio of observed:expected unplanned epilepsy admissions.

Findings

79/1164(6·8%) of patients included in the PN analyses died; 54/1164(4·6%) deaths occurred post-transition. Regression models estimated an absolute reduction of 6.4%(95% CI 1.3-12.7%) in total mortality risk and 5·7%(0·6-10·8%) post-transition mortality risk between units where all versus no eligible patients were seen by a PN. In dichotomised analyses, units where all eligible patients were seen by a PN were estimated to have 4·6%(0·3-8·9%) absolute mortality reduction and 4·6%(1·2-8 ·0%) reduction in post transition deaths compared to other units. There was no significant association between performance on other audit measures and mortality. In units where access to an ESN deteriorated, the standardised ratio of epilepsy admissions increased by a mean of 0·21 (95% CI 0·01-0·42).

Interpretation

Among adolescents with epilepsy, greater involvement of tertiary specialists in paediatric care predicts lower mortality in the period after transition to adult services. Reduced access to an ESN was associated with an increase in paediatric epilepsy admissions.

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RESEARCH IN CONTEXT PANEL

Evidence before this study

The National Institute for Health, Care & Excellence (NICE) has published several comprehensive reviews of the evidence on delivering paediatric epilepsy care, including guidance in 2004 and 2012, an evidence update in 2014, and a surveillance report in 2018. High quality evidence is available to guide choice of anti-epilepsy drug for many types of epilepsy, and appropriate choice of drug is known to reduce mortality risk. In contrast, NICE recommendations regarding the organisation and delivery of paediatric epilepsy services have always been based on Level C evidence (expert opinion), indicating that 'directly applicable clinical studies of good quality are absent or not readily available'.

Added value of this study

By linking national datasets from the Epilepsy12 national clinical audit, Hospital Episode Statistics, and the Office of National Statistics, we performed a novel investigation into the links between quality of paediatric epilepsy care and two key outcomes: all-cause mortality among adolescents with epilepsy and rates of hospital admission for paediatric epilepsy. We found that 7.5 % of adolescents with epilepsy who were admitted to hospital died within the study period (median 4.5 years, range 3.0-6.0 years). Adolescents who were managed within paediatric units that met national guidelines on involving paediatric neurologists were less than half as likely to die in the period following transition to adult services compared to patients who were managed in other units. In absolute terms, fully meeting guidelines for involving paediatric neurologists was associated with 4·6 (95% CI 1·2-8·0) fewer deaths per hundred patients. Units where involvement of an Epilepsy Specialist Nurse (ESN) deteriorated over time experienced a significant increase in standardised epilepsy admissions over the same period.

Implications of all the available evidence

While improving the organisation and delivery of local paediatric epilepsy services will continue to be important, our findings suggest that increasing capacity and involvement of paediatric neurologists

could be an effective strategy to reduce epilepsy-related mortality among young people in England, which is high by international standards, and is known to include many potentially avoidable deaths. While our findings cannot be directly applied to other countries with different health systems, the principle that high quality paediatric care can reduce epilepsy-related mortality is highly relevant globally. Our finding that higher quality healthcare in early/mid adolescence predicts lower mortality in early adulthood deserves further investigation, and may have important wider implications for the care of other long-term conditions,

INTRODUCTION

Epilepsy is estimated to affect over 112,000 children and young people (CYP, 0-24 years), in the UK alone.(1) Quality and coordination of health care are important determinants of outcomes for CYP with epilepsy(2-6); failure to provide consistently high-quality care for CYP with epilepsies has been linked to high rates of over- and under-diagnosis of epilepsy,(1, 7) wide geographical variation in epilepsy admission rates and deaths(8, 9) the presence of avoidable factors in epilepsy-related deaths (4, 10) and higher mortality rates from epilepsy among young people in the UK than comparable countries.(11) Particular concerns have been raised that fragmented or poor quality services often do not meet the needs of adolescents with epilepsy during their transition to adult life, further exacerbating risk among a group who are already at increased risk of death from Sudden Unexpected Death in Epilepsy (SUDEP), injuries, suicide and other causes.(1-3)

In response, national policy initiatives over more than a decade have focussed on defining, facilitating, and incentivising high quality care for CYP with epilepsy, through NICE guidance(12), training,(13) regional networks,(14) the Epilepsy12 national clinical audit,(6) and the Best Practice Tariff (BPT) for paediatric epilepsy.(15) However, the diverse nature of the epilepsies presents challenges in validating standardised, evidence-based quality measures. Despite international endorsement and widespread adoption in NHS policies, the performance measures included in NICE guidance and the Epilepsy12 audit are largely based on expert consensus,(12) with little empirical evidence that improving performance on these measures would reliably reduce mortality or hospital admission, or improve other patient-important outcomes.

The aim of this study is to investigate the relationship between unit performance in three key measures of the Epilepsy12 national clinical audit(6) (involvement of a paediatrician with expertise in epilepsy, an Epilepsy Specialist Nurse (ESN) and, where appropriate, a Paediatric Neurologist (PN)), and two outcome measures that are believed to be both important and sensitive to the quality of paediatric care:

- the proportion of adolescents (10-18 years) admitted to hospital with epilepsy who subsequently died within the study period. For the reasons noted above, we were particularly

interested in the relationship between quality of paediatric care and deaths pre/post transition to adult services.

- rates of unplanned epilepsy-related hospital admissions (0-18 years)

We hypothesised that patients managed in units that performed better in some or all of these three measures would have lower risk of mortality and unplanned hospital admissions.

METHODS

Creation of a dataset with linked, unit-level data on Epilepsy12 performance (Round 1), hospital admissions and death registration.

Data from Round 1 of the Epilepsy 12 national clinical audit were obtained from the Royal College of Paediatrics & Child Health (RCPCH).(6) All paediatric epilepsy services in England were invited to take part in this audit of consecutive new patients who met inclusion criteria (see Table 1). Case notes were reviewed retrospectively for a 12-month period of care prior to the census data in each Trust (either 1st February or 1st May 2011).

Ethics: A dataset combining Hospital Episode Statistics (HES) data(16) and death registrations from the Office for National Statistics (ONS)(17) was approved for the purpose of these analyses and provided by the Health and Social Care Information Centre (HSCIC).

We linked unit (clinical service) identifiers within the Epilepsy12 audit to HES Trust identifiers, excluding all units where consistent, one-to-one linkage throughout the study period was not possible. . Differences in case mix prevented direct comparison of admission and mortality rates between tertiary and secondary care services; tertiary centres (defined as any Trust employing a Paediatric Neurologist) were therefore excluded from these analyses. Units with fewer than two eligible patients for a given indicator were also excluded. See Figure 1 for full details of the linking process and exclusions.

Independent/exposure variables (from Epilepsy12 audit data)

The 3 performance measures were the proportions of patients in each unit who, within the 12-month period following their first assessment, were seen by a

- Paediatrician with expertise in epilepsy
- Epilepsy Specialist Nurse (ESN)
- Paediatric Neurologist (PN) (where appropriate - see Table 1 for eligibility criteria)

For the grouped analyses, we allocated units to one of three categories for each performance measure:

- Good performance (100% of patients received the recommended standard of care)
- Moderate performance (50-99%)
- Poor performance (0-49%)

Dependent/outcome variables (from hospital/death registration data)

The primary outcome measure was the proportion of adolescents admitted to participating units with epilepsy who subsequently died within the study period (1st April 2009 – 31st March 2015). Due to long-standing concerns about increased mortality risk following transition from paediatric to adult services, we then disaggregated deaths into those that occurred pre and post transition. Deaths were defined as post-transition if they occurred after the first planned adult appointment or more than 6 months after their last planned paediatric appointment.

In order to study this outcome measure, we used HES data to identify a cohort of adolescent epilepsy patients who met three criteria:

- one or more inpatient admissions for epilepsy (ICD10 codes G40, G41) during the period 1st April 2004 to 31st March 2012
- age between 10 and 18 years at the time of first admission
- last planned paediatric appointment occurred between April 1st, 2009 and March 31st, 2012.

Data linkage to ONS mortality data then identified which members of this cohort died within the study period (1st April 2009 – 31st March 2015).

Analyses

Longitudinal analyses of prospectively-collected, linked data were performed. For each Epilepsy12 performance measure, the total number of patients and deaths in good/moderate/poor performing units were calculated and compared using Fisher's exact test. These analyses were then repeated separately for pre-transition and post-transition deaths.

Next, the association between performance on PN involvement and unit-level mortality (total and post-transition) was calculated using Spearman's Rho (non-parametric test) and unadjusted, ordinary-least-squares, linear regression models (in which unit-level performance was the independent, continuous variable and proportion of patients who died was the dependent variable). To address confounding, subsequent regression models adjusted for population and unit characteristics, as well as healthcare activity (the best available proxy measure for disease severity). Attendance at adult outpatient clinics is known to reflect the quality of preparation for transition and to predict mortality risk (27); planned healthcare activity after transition was therefore added to the other variables in separate models.

Population characteristics

- Mean Index of Multiple Deprivation (IMD) quintile (an area-based measure of socio-economic position)
- Ethnicity (defined as proportion of patients who were White, Mixed ethnicity, Asian, Black, Other ethnicity).

Unit size and structural characteristics

- Number of patients
- Mean transition age
- Does the unit host a paediatric neurology clinic*
- Does the unit have a young people clinic*
- Is there an adult Epilepsy Specialist Nurse*

Healthcare activity pre-transition

- Mean number of inpatient care episodes
- Mean number of outpatient visits
- Mean number of contacts with mental health services

- Mean number of unplanned care episodes

Hospital activity post-transition

- Mean number of inpatient care episodes
- Mean number of contacts with mental health services
- Mean number of unplanned care episodes

Attendance and engagement with adult outpatient services

- Proportion of patients with any adult outpatient visits
- Proportion of patients with adult outpatient visit within 12 months of last paediatric appointment
- Proportion of patients with adult outpatient visit within 6 months of last paediatric appointment.
- Proportion of patients with adult outpatient visit within 6 months of last paediatric appointment and at least two further visits within next 24 months.

Variables marked with an asterisk were binary variables; all others were continuous variables.

Finally, these regression models were repeated, entering unit performance as a dichotomised (100% vs. <100% patients received recommended care) rather than a continuous variable. All models were weighted for size of unit (number of paediatricians). P values <0.05 were considered significant throughout.

Admissions measures and analyses

The second set of analyses used longitudinal, linked analyses of prospectively collected data to investigate the association between Epilepsy12 performance and standardised ratios of observed:expected epilepsy admissions in each unit. We examined whether change in unit-level performance between Rounds 1 & 2 of Epilepsy12 was associated with a change in standardised admission ratios over the same period.

We created a dataset with linked data from the two rounds of Epilepsy12 (census dates 1st February/1st May 2011 and 1st January 2014), HES data (2011/12 and 2013/14) and ONS data on population size and socio-economic deprivation. The ONS data were used to derive the denominator of unit-level admission rates (i.e. the hospital catchment population).(18) In addition to the exclusion criteria described above, units were also excluded if their reporting structure for Epilepsy12 changed between

the two audit rounds (for example, if they submitted jointly with another unit in one round). See Figure 1 for details.

Independent/exposure variables (from Epilepsy12 audit data)

The same three Epilepsy12 performance measures were used as for the mortality analyses: proportion of patients with involvement of a paediatrician with expertise in epilepsy, Epilepsy Specialist Nurse (ESN), Paediatric Neurologist (PN) (where appropriate). Units were stratified into three groups for each performance measure based on whether the proportion of patients receiving recommended care in 2013-14 was better, exactly the same, or worse than in 2009-11

Dependent/outcome variables (derived from linked hospital/death registration data)

Changes in unit-level admissions were assessed by comparing the ratio of observed:expected unplanned epilepsy admissions for patients 0-18 years (ICD10 codes for primary reason for admission = G40, G41) in 2011/12 and 2013/14. Expected values were derived from the national admission rate, adjusted for the size, age distribution and socio-economic deprivation of the population served by each hospital, using methods that we have published previously.(19)

Analyses

The mean changes in observed:expected admission ratio for units reporting better/same/worse performance on each measure were calculated, as were the range and distributions of change in performance in each group.

Statistical software

All linkage analyses were performed using Stata version 14 (Stata Corp, College Station, TX). Calculation of observed:expected admission ratios was performed using SAS Version 9.3 (SAS Institute Inc, NC).

Role of the funding source

The Health Foundation had no role in study design; in the collection, analysis, and

interpretation of data; in the writing of the report; and in the decision to submit the paper for publication.

RESULTS

Mortality analyses

Linked mortality data were available for the analyses relating to paediatricians with epilepsy expertise and ESNs from 99 units. A total of 134/1795 (7·5%) patients from these units died during the study period; 46 (2·6%) died pre-transition and 88 (4·9%) died post-transition. In the smaller group of 55 units used for analysis of PN involvement, 79/1164 (6·8%) of patients died; 25 (2·1%) died pre-transition and 54 (4·6%) post-transition.

There was an inverse correlation between unit-level performance on involving a paediatric neurologist and the proportion of patients who died (Spearman's Rho=-0·2767, p=0·041). This association was more significant when restricting to post-transition deaths (Spearman's Rho=-0·3256, p=0·015). No other significant associations were seen.

Regression analyses that adjusted for population, unit and severity characteristics estimated an absolute reduction of 6·4% (95% CI 1·3-12·7%, p=0·046) in total mortality risk and 5·7% (0·6-10·8%, p=0·028) post-transition mortality risk between units where all versus no eligible patients were seen by a PN (see Table 2a and Appendix Figure 1).

Moving to the grouped analyses, Table 3 shows the proportion of epilepsy patients who died by unit performance on Epilepsy12 measures. Patients admitted to units where all eligible patients saw a PN were less likely to die during the follow up period (10/231=4·3%) than their counterparts in other units (69/933=7·4%). This difference reflected a lower number of post-transition deaths (5/231=2·2% vs. 49/933=5·3%), which was of borderline statistical significance (p=0·053 (two-tailed), p=0·027 (one-tailed)). No significant difference was seen for pre-transition deaths (5/231=2·2% vs. 20/933=2·1%), and no significant associations were seen between performance on other audit measures and mortality.

Dichotomised regression analyses showed that units where all eligible patients were seen by a PN had an estimated 4·6% (0·3-8·9%, p=0.038) fewer total deaths and 4·6% (1·2-8·0%, p=0.010) fewer post transition deaths than other units where no or some eligible patients were seen. Units where all eligible patients saw a PN were less likely to report access to an adult Epilepsy Specialist Nurse (6/12 (50·0%) vs. 39/43 (90·7%), p=0·004) and marginally less likely to report having a dedicated young people's clinic (0/12 vs. 12/31 (27·9%), p=0·050). These units also reported higher levels of planned care after transition (a marker for access to, and engagement with, specialist adult neurology services). A significantly higher proportion of patients from these units attended an adult epilepsy clinic within 6 months (57·0 vs. 40·4%, p=0·011), within 12 months (68·9 vs. 55·2%, p=0·015), or at any time within the study follow up period (88·6 vs. 76·7%, p=0·006) and a higher proportion of patients met criteria for successful transition (defined as attending an adult clinic within 6 months of the last paediatric appointment and then attended at least two further appointments within the subsequent 2 years) (45·9 vs. 32·8%, p=0·019).There were no significant differences in other characteristics (see Appendix Table A).

Admissions analyses

Data for unplanned admissions analyses relating to paediatricians with expertise and ESNs were available on 74 units, which accounted for 4,436 epilepsy admissions and served an estimated population of 5·68 million CYP in 2011/12 (4,079 admissions and 5·71 million population in 2013/14). The equivalent figures for analyses relating to paediatric neurologists were 25 units accounting for 1,965 admissions and a population of 2·14 million in 2013/14 (1,817 admissions, 2·17 million population in 2013/14).

Figure 2 presents the change in paediatric epilepsy admission rates over time by change in performance in each audit indicator (worse, same, and better groups). In the 16 units where access to an ESN deteriorated, the standardised ratio of epilepsy admissions increased by a mean of 0·21 (95% CI 0·01-0·42, p=0·043) over the study period. This represents a mean increase of 21% of the expected number of admissions for each unit (taking into account the size and characteristics of the population served). No significant differences in standardised admission rates were seen among units with the same or

better access to ESNs or for any of the subgroups relating to accessing paediatric expertise or paediatric neurologists. Full details of the changes in audit performance and admission rates over time within each group are presented in Table 4.

DISCUSSION

In this national, longitudinal study, 7·5 % of adolescents with epilepsy who were admitted to hospital died within the study period (median 4·5 years, range 3.0-6.0). We found a clinically and statistically significant association between being managed in a paediatric epilepsy unit with good links to a paediatric neurologist and lower mortality risk. In planned subgroup analyses, the link between better audit performance and lower mortality was largely explained by fewer post-transition deaths; no significant association was seen between audit performance and pre-transition deaths.
Units where involvement of an Epilepsy Specialist Nurse (ESN) deteriorated over time experienced a significant increase in standardised epilepsy admissions over the same period. However, units where ESN access improved over time did not experience any matching decrease in epilepsy admissions.

Strengths of this study include the use of prospectively collected, national datasets, which are sufficiently large to allow analysis of the relationship between service-level performance and epilepsy outcomes. Assessing a new patient who meets criteria for involvement of a PN is a relatively rare event for many small or medium size units (46/101 units had one or zero such patients within the data collection period for Round 1 of the Epilepsy12 audit). Large studies using routinely-collected data are therefore likely to be the only feasible way to address these research questions. Data completeness was high in all datasets: Epilepsy12 covers over 95% of paediatric epilepsy units in England, while HES covers 98-99% of paediatric hospital admissions, and the ONS records all registered deaths in England. While 23/101 units were excluded from the admission analyses due to linkage difficulties, this was largely due to hospital mergers or reconfigurations during the study period. As with the exclusion of patients whose care is primarily manged by a tertiary specialist centre (9 units), we believe this is unlikely to introduce significant bias to our findings. However, our findings are clearly less generalisable to patients with specific diagnoses (e.g. absence epilepsies) where unplanned hospital admission is rare or to patients who have not been referred to a paediatric epilepsy unit.

As with all observational studies, there is a risk of confounding. For the admission analyses, this risk is minimised, as we investigated the association between unit-level changes in performance and unit-level changes in admission rates. For the mortality analyses, we used a longitudinal study design, and were able to adjust for several potential confounders, including population characteristics, size/nature of the service and measures of hospital activity. However, the analyses are limited by lack of individual level data, and hospital activity is clearly an imperfect proxy for disease severity or prognosis. All other things being equal, units seeing sicker patients might be expected to have greater involvement of a PN and to have higher mortality rates than other units. It is therefore possible that our findings underestimate the true association between greater involvement of a PN and lower mortality risk.

Policy implications

Recent policy initiatives and financial incentives to improve the quality of paediatric epilepsy care in the NHS have focused on ensuring that all CYP with epilepsy are seen by a paediatrician with epilepsy expertise and an Epilepsy Specialist Nurse (ESN) (reported by 87% and 59% of patients respectively in the most recent Epilepsy12 audit).(6) Our findings suggest that the additional involvement of a Paediatric Neurologist (PN) in the care of complex patients (reported by 57%) may be of at least equal importance.

However, our study has limited ability to investigate which are the 'key ingredients' of PN involvement which might reduce long-term mortality. Compared to paediatricians working in local paediatric epilepsy units, PNs benefit from extended neurology training, they often have longer consultations with patients, and typically have better access to investigations and multi-disciplinary support. The exact mechanisms through which PN care may mitigates key risk factors such as poor adherence to medication, poor sleep hygiene, mental health problems, and risk behaviours, including alcohol use(2, 3) are therefore unclear. However, our data suggest that better preparation and support for young people to engage with adult neurology teams after transition may be one important mechanism, consistent with previous literature suggesting a protective effect of high-quality developmentally appropriate services during adolescence on future health outcomes.(21-23). .

Our findings regarding the association between ESN involvement and admissions and mortality rates also deserve further investigation. Whereas one previous study reported that increased access to an ESN was associated with a large drop in admission rates,(24) we found no such relationship in our study. However, we did find that units which reported reduced ESN access experienced an increase in admissions over the study period. The lack of a consistent relationship between ESN access and epilepsy admission may reflect changes in the skills or role of ESNs since their presence was incentivised in the Best Practice Tariff (BPT). It may also reflect limitations of the relatively crude performance measure in Epilepsy12, the limited follow up period, and the narrow focus on death and hospital admission as outcomes. Future studies would benefit from including a wider range of patient important outcomes for CYP with epilepsy, for example, educational, occupational, and mental health measures.

While our findings cannot be directly applied to other countries with different health systems, the principle that high quality paediatric care can reduce epilepsy-related mortality is highly relevant globally. Across the world, children with epilepsy face many challenges, including stigma, out-dated beliefs about the causes and effective treatment of epilepsy, and financial barriers to accessing high quality care.(1) Our findings may also have implications for improving adult outcomes of other long-term conditions which present in childhood and adolescence. It is well-recognised that complication rates increase in the immediate period following transition for diabetes, renal disease, and many other long-term conditions.(25-27) Advocates for adolescent health have long argued that adolescence is a second critical window of development when the foundations of adult health are laid down, and when access to high quality services may have long-term benefits.(22, 28) Our findings support this hypothesis, providing evidence that access to higher quality, more developmentally appropriate care in early and mid-adolescence could play an important role in improving adult health outcomes for many long-term conditions.

Conclusion

Through linkage of large, prospectively-collected, national datasets, this study shows that quality of paediatric epilepsy care (specifically the involvement of a paediatric neurologist in the management of complex cases) is an important predictor of mortality risk in the period following transition to an adult

service. We also report evidence that lack of access to an Epilepsy Specialist Nurse is linked to higher admission rates for children with epilepsy. Further work with individual level data linkage and a wider range of outcome measures is needed to inform future design of services and improve epilepsy outcomes.

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Declaration of interests

All authors declare no conflicts of interest

DH confirms that he had full access to all the data in the study and had final responsibility for the decision to submit for publication

List of Tables and Figures

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Table 1. Key definitions and background information

Epilepsy12 terms	
Paediatric epilepsy unit	All children and young people in England with diagnosed or suspected epilepsy should be under the care of a paediatric epilepsy unit. This is a local unit or service - often part of a general or community paediatric team - and can access specialist support from their regional paediatric neurology service.
Epilepsy12 national clinical audit	The Epilepsy12 audit collects data on patients presenting to each paediatric epilepsy unit in order 'to measure and improve the quality of care for children and young people (CYP) with seizures and epilepsies' Inclusion critera • First EEG during 12-month period during defined period prior to 'census day' • The child had a first paediatric assessment for the paroxysmal episode or episodes during the defined 6-month time prior to census day • Child is older than 1 month and younger than 16 years at first paediatric assessment • The EEG was prompted by the patient having one or more afebrile paroxysmal episodes Exclusion criteria include diagnosis of febrile or acute symptomatic seizures or that first assessment/first year of care were provided across more than one unit.
Hospital Trust	A healthcare provider organisation, which may operate across many geographical sites. Some large Trusts have more than one paediatric epilepsy unit.
Paediatrician with expertise in epilepsy.	A paediatric consultant having: training and continuing education in epilepsies AND peer review of practice AND regular audit of diagnosis. It is recommended that a paediatrician with epilepsy expertise should be involved in the care of all CYP with epilepsy. Epilepsy12 reports the proportion of patients within each unit for whom this happens in practice.
Epilepsy Specialist Nurse (ESN)	A children's nurse with a defined role and specific qualification and/or training in children's epilepsies. It is recommended that ESNs should be involved in the care of all CYP with epilepsy. Epilepsy12 reports the proportion of patients within each unit for whom this happens in practice.
Paediatric neurologist	A consultant with specialist training in paediatric neurology. Paediatric neurologists are typically based at tertiary (specialist) centres, which are excluded from this study. However, it is recommended that local paediatric epilepsy units should involve paediatric neurologists in the care of all CYP with epilepsy who present before their 2nd birthday OR who are prescribed 3 or more maintenance anti-epilepsy drugs within the first 12 months of care. This involvement could be through referral to the specialist centre or through a paediatric neurology outreach clinic. Epilepsy12 reports the proportion of eligible patients in each unit for whom this happens in practice.
Key outcomes and covariates	
Pre-transition deaths	Deaths occurring while under care of a paediatric unit OR within 6 months of last planned paediatric appointment
Post-transition deaths	Deaths occurring while under the care of adult services OR at least 6 months from last planned paediatric appointment
Successful transition	Attending an adult clinic within 6 months of the last paediatric appointment AND then attending at least two further planned appointments within the subsequent 2 years.
Index of Multiple Deprivation (IMD) quintile	A measure of socio-economic deprivation (socio-economic position), derived from the patients' postcode.

Table 2. Unit-level association between performance on involving a paediatric neurologist in the Epilepsy12 national clinical audit and mortality

Panel A: audit performance entered as continuous variable (0-100% of eligible patients saw a paediatric neurologist)

	POST TRANSITION DEATHS				ALL DEATHS			
	Beta	**95% CI**		**P**	**Beta**	**95% CI**		**P**
Unadjusted	-0.040	-0.080	0.000	0.049	-0.030	-0.079	0.019	0.228
Adjusted for population, unit and severity characteristics	-0.057	-0.108	-0.006	0.028	-0.064	-0.127	-0.001	0.046
Additionally adjusted for transition outcomes	-0.048	-0.100	0.004	0.067	-0.057	-0.119	0.004	0.067

Panel B: audit performance entered as a dichotomised variable (0-99 vs. 100% of eligible patients saw a paediatric neurologist)

	POST TRANSITION DEATHS				ALL DEATHS			
	Beta	**95% CI**		**P**	**Beta**	**95% CI**		**P**
Unadjusted	-0.034	-0.063	-0.006	0.02	-0.027	-0.063	0.009	0.14
Adjusted for population, unit and severity characteristics	-0.046	-0.080	-0.012	0.01	-0.046	-0.089	-0.003	0.038
Additionally adjusted for transition outcomes	-0.037	-0.074	0.000	0.049	-0.038	-0.083	0.007	0.095

Notes
A beta coefficient of -0.040 indicates an absolute reduction of 4.0% (95% CI 0.0-8.0%) in total mortality risk between units where all versus no eligible patients were seen by a paediatric neurologist. (i.e. 4.0 fewer deaths per hundred patients). Variables included in each model are listed below.
Population characteristics: Mean Index of Multiple Deprivation (IMD) quintile; Ethnicity (defined as proportion of patients who were White, Mixed ethnicity, Asian, Black, Other ethnicity.
Unit characteristics: Number of patients; mean transition age; hosts paediatric neurology clinic; young people clinic; adult epilepsy specialist nurse.
Pre transition healthcare activity: Mean number of inpatient care episodes; Mean number of outpatient visits; Mean number of contacts with mental health services; Mean number of unplanned care episodes. Post transition hospital activity: Mean number of inpatient care episodes; Mean number of contacts with mental health services; Mean number of unplanned care episodes.
Transition outcomes: Proportion of patients with any adult outpatient visits; Proportion of patients with adult outpatient visit within 12 months of last paediatric appointment; Proportion of patients with adult outpatient visit within 6 months of last paediatric appointment; Proportion of patients with adult outpatient visit within 6 months of last paediatric appointment and at least two further visits within next 24 months.

Table 3. Proportion of epilepsy patients who died, by unit performance on Epilepsy12 measures

	Epilepsy12 performance	N patients	N units	Deaths pre transition		Deaths post transition		Total deaths	
				N	%	N	%	N	%
Proportion seen by paediatrician with expertise	Good (100%)	263	18	6	2·3%	14	5·3%	20	7·6%
	Moderate (50- 99%)	1017	48	28	2·8%	51	5·0%	79	7·8%
	Poor (0-49%)	515	33	12	2·3%	23	4·5%	35	6·8%
	Total	1795	99	46	2.6%	88	4.9%	134	7.5%
Proportion seen by Epilepsy Specialist Nurse (ESN)	Good (100%)	1104	64	28	2·5%	51	4·6%	79	7·2%
	Moderate (50-99%)	638	30	18	2·8%	33	5·2%	51	8·0%
	Poor (0-49%)	53	5	0	0·0%	4	7·5%	4	7·5%
	Total	1795	99	46	2.6%	88	4.9%	134	7.5%
Proportion of eligible patients seen by paediatric neurologist	Good (100%)	231	12	5	2·2%	5	2·2%	10	4·3%
	Moderate (50-99%)	549	27	12	2·2%	28	5·1%	40	7·3%
	Poor (0-49%)	384	16	8	2·1%	21	5·5%	29	7·6%
	Total	1164	55	25	2.1%	54	4.6%	79	6.8%

Notes. Numbers for the PN analyses differ as 44 units had sufficient patients to be included in the in the paediatrician with expertise and ESN analyses but too few eligible patients for the PN analyses (see Figure 1).

Table 4. Changes in epilepsy admission rates 2011/12 - 2013/14, by change in performance between Rounds 1 & 2 of the Epilepsy12 national clinical audit.

		Change in Epilepsy12 performance				Change in standardised admission ratio		
		Median	**Minimum**	**Maximum**	**N**	**Mean**	**95% CI**	
Paediatrician with epilepsy expertise	Worse	-20.0%	-100.0%	-6.5%	15	0.10	-0.06	0.26
	Same	0.0%	0.0%	0.0%	19	0.04	-0.11	0.20
	Better	16.7%	3.4%	100.0%	40	0.06	-0.05	0.18
Epilepsy Specialist Nurse	Worse	-14.3%	-83.3%	-2.0%	16	0.21	0.01	0.42
	Same	0.0%	0.0%	0.0%	19	-0.07	-0.20	0.06
	Better	25.0%	2.4%	100.0%	39	0.06	-0.04	0.17
Paediatric neurologist	Worse	-42.9%	-100.0%	-16.7%	14	-0.04	-0.27	0.18
	Same	0.0%	0.0%	0.0%	2	0.33	-0.28	0.95
	Better	30.0%	6.7%	50.0%	9	0.27	-0.06	0.61

Notes
This table presents the number of units reporting worse, same, and better performance for each indicator in Round 2 of the Epilepsy12 audit, compared to Round 1. The minimum, maximum and median percentage point increases in performance within each group are shown, as well as the mean difference in observed:expected admission ratio. For each unit, the difference in standardised admission ratios reflects the trajectory of paediatric epilepsy admission in each unit, relative to the trajectory that would be expected given national trends over the study period and any changes in the size and/or composition of the catchment population. Weighted mean differences for all units in each category are presented.