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BMJ Open Emergency hospital care for adults with suspected seizures in the NHS in England 2007–2013: a cross-sectional study

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ABSTRACT

Aims To quantify the frequency, characteristics, geographical variation and costs of emergency hospital care for suspected seizures.

Design Cross-sectional study using routinely collected data (Hospital Episode Statistics).

Setting The National Health Service in England 2007–2013.

Participants Adults who attended an emergency department (ED) or were admitted to hospital.

Results In England (population 2011: 53.11 million, 41.77 million adults), suspected seizures gave rise to 50 111 unscheduled admissions per year among adults (≥18 years). This is 47.1% of unscheduled admissions for neurological conditions and 0.71% of all unscheduled admissions. Only a small proportion of admissions for suspected seizures were coded as status epilepticus (3.5%) and there were a very small number of dissociative (non-epileptic) seizures. The median length of stay for each admission was 1 day, the median cost for each admission was £1651 (\$2175) and the total cost of all admissions for suspected seizures in England was £88.2 million (\$116.2 million) per year. 16.8% of patients had more than one admission per year. There was significant geographical variability in the rate of admissions corrected for population age and gender differences and some areas had rates of admission which were consistently higher than the average.

Conclusions Our data show that suspected seizures are the most common neurological cause of admissions to hospital in England, that readmissions are common and that there is significant geographical variability in admission rates. This variability has not previously been reported in the published literature. The cause of the geographical variation is unknown; important factors are likely to include prevalence, deprivation and clinical practice and these require further investigation. Dissociative seizures are not adequately diagnosed during ED attendances and hospital admissions.

INTRODUCTION

Epilepsy is the most common chronic disabling neurological disease worldwide,¹ it is an ambulatory care sensitive condition

Strengths and limitations of this study

- This study is based on Hospital Episode Statistics (HES) data, which includes all attendances at emergency departments (over 93 million) and all inpatient admissions to hospital (over 42 million) in England during a 6-year period (2007–2013).
- This is the first published study of unscheduled admissions for suspected seizures using HES data.
- HES data use ICD-10 for diagnostic coding facilitating comparisons with other national and international studies where ICD-10 is used.
- We have assumed that HES diagnosis codes are accurate compared with gold-standard clinical diagnoses for epilepsy and seizures but further research is required to confirm this.

(ACSC)² and suboptimal ambulatory (routine or scheduled) care can lead to unnecessary emergency care, which is often associated with morbidity and impaired quality of life.³ Estimates vary internationally,^{4–9} but most studies suggest that approximately 70% of people with epilepsy will become free of seizures with optimal treatment. The overall seizure freedom rate achieved in the UK is around 50%.^{10–13} This implies that approximately one in five patients with epilepsy may be having seizures that could be prevented.⁵ In the UK, some epilepsy services are world leading but the quality of care is geographically variable, and patients in many areas do not have access to optimal monitoring and treatment.¹¹ Many patients who have active epilepsy are not under the care of an epilepsy specialist.^{4 14} Epileptic seizures may give rise to potentially avoidable unplanned attendances at hospital emergency departments (EDs) (formerly known as accident and emergency departments, A&E) or admission to hospital, and management decisions may be complex, require expertise, training and guidance.

However, after a seizure, patients are often seen by paramedics, junior doctors and physicians without particular expertise in epilepsy.

Precise estimates vary, but in England (population in 2011: 52.96 million, 42.96 million adults¹⁵), seizures give rise to 60 000 seizure-related ED attendances (2%–3% of all attendances) (113 per 100 000 of the general population per year)¹⁶ and 40 000 hospital admissions (76–148 per 100 000/year) which is 9.5% of all admissions for ACSCs.^{16 17} There were over one million emergency admissions for chronic ACSCs in England in the financial year 2011/2012 and over 600 000 for acute conditions that should not normally require hospital admission.¹⁸ Admissions in both categories have been rising, and suspected seizures are one of the largest contributors to these admissions. We should point out that, although most suspected seizures are epileptic,¹⁴ this is a diagnostically heterogeneous group and other conditions can mimic epilepsy.¹⁹ We use the term ‘suspected seizure’ to encompass how this group of patients usually present to medical practitioners, that is, transient loss of consciousness and convulsions leading observers (usually not medical professionals) to suspect an epileptic seizure and to report this to emergency services.

The National Health Service (NHS) in the UK is tax funded and free at the point of delivery. It is the provider of almost all healthcare in the UK, especially emergency care. The emergency care structure in the UK, with universal access to healthcare, and non-overlapping emergency services offers opportunities to study emergency presentations with suspected seizures which do not exist in many other countries. Most NHS services are commissioned locally by geographically based clinical commissioning groups (CCGs) which came into being on 1 April 2013 (they were preceded by primary care trusts (PCTs) which had similar geographical boundaries).²⁰ Hospital Episode Statistics (HES) is a data warehouse containing routinely collected data from all admissions, outpatient appointments and ED attendances at NHS hospitals in England. The data are collected during a patients’ hospital attendance for the purpose of allowing hospitals to be paid for the care that they deliver, but it is also a powerful tool for research. Our aims were to quantify the frequency, the characteristics and the costs of ED attendances and unplanned hospital admissions care for suspected seizures, and to identify geographical variation that may reflect disparities in ambulatory care or emergency care pathways such as ED admission guidelines.

METHODS

Data source and case ascertainment

HES data were accessed by a third-party organisation (Health IQ) that searched the HES A&E database for attendances and the HES inpatient database for unscheduled/emergency inpatient admissions in adults (≥18 years) in the NHS in England during the period 1 April 2007 and 31 March 2013 (six financial years). Six

years of data was judged sufficient to explore readmission rates after the index admission and the cut-off of 31 March 2013 was chosen to avoid any potential disruption from 1 April 2013 as CCGs came into being.

ED data

We used the HES A&E Data Dictionary²¹ central nervous system (CNS) codes (two character and three character): CNS excluding stroke (24), CNS epilepsy (241) and CNS other non-epilepsy (242). We used code 241 as a proxy for our target population of patients with suspected seizures. Although ED is now the preferred term in most countries, this section of the HES data retains its historic title of HES A&E data.

Inpatient data

We searched the inpatient database for admissions (spells) where ≥1 episode (a period under the care of an individual consultant) during the admission/spell had a primary diagnosis code for a disease of the nervous system. Three separate searches were undertaken: (1) admissions where the primary diagnosis was suspected seizure, (2) admissions where the primary diagnosis was a neurological condition other than a suspected seizure (the full list of ICD-10 codes used to generate diagnostic categories are listed in the appendices (see online supplementary file), we used ICD-10 (International Classification of Diseases) chapter six plus two codes from other chapters), (3) admissions where the primary diagnosis was dissociative seizures (DS). The following codes were used in the search for suspected seizures: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions). The following codes which are closely related to suspected seizures were not included: R56.0 (Febrile convulsions), P90 (Convulsions of new born), O15 (eclampsia) and R56.1 (post-traumatic seizures). Stroke/TIA (G45/G56) was not included in any of the searches because these conditions are classified in ICD-10 as cerebrovascular diseases. F44.5 was used for dissociative seizures (DS). We also calculated the number of times patients were readmitted with the same codes over the study period. We calculated the time from first admission to either first readmission or to the end of the study period and plotted this using a Kaplan-Meier curve. We included data on costs for ED attendances and inpatient admissions. The cost of each A&E attendance was based on: (Healthcare Resource Group (HRG) attributed to each attendance) + (Investigation and Treatment cost) x Market Forces Factor (MFF). The cost of each admission was based on: (HRG attributed to each admission + trim point (base) cost + Added Bed days cost) x MFF.

Geographical variation in seizure/convulsions admissions

We calculated an age and sex directly standardised rate for the number of emergency admissions for each PCT (151 PCTs in total). The numerator of the rate is calculated from HES inpatient data and the denominator is the 2011 PCT population estimate from the Office for National Statistics (ONS).¹ Adjustments were made for

changes to the PCTs in terms of their names and codes and the merger of several trusts. The direct standardisation adjusted for age and sex with age categorised into three groups: 18–34, 35–64 and 65 and over. The age-specific and sex-specific standard population used in the analysis was calculated by grouping the populations of all PCTs from the ONS dataset.²²

To look at the distribution of directly standardised rates and to identify possibly outlying PCTs (low or high admission rates), funnel plots were drawn for each year.²³ The plots show the observed age and sex directly standardised rate for each PCT against the PCT population. In order to identify outliers, an overdispersion model was used to draw control limits around the target outcome—that is, the weighted mean of the directly standardised rates.²⁴ This method allows an overdispersion factor to be calculated that inflates the null variance and allows for any unexplained variation between the PCTs. If all PCTs were included in the estimate of the overdispersion factor, then PCTs that are truly outlying would inflate the parameter unduly and may not appear as outliers. Therefore, when estimating the overdispersion parameter, a trimming approach was adopted to exclude the top and bottom 10% of PCTs (20% \times 151=31) based on their z-score (a scaled difference between the observed rate and the target rate). If no true outliers existed then the estimate of the overdispersion parameter would only be minimally affected by this procedure.

Patient and public involvement

Patients and the public were not involved in this research.

RESULTS

ED HES data

During the study period (2007–2013), 93 806 757 attendances were recorded at ED departments in England, a mean of 15 634 460 attendances per year. There were 146 729 epilepsy (code 241) attendances at ED (mean: 24 455 per year), representing 0.16% of all ED attendances and 0.33% of ED attendances that were given an HES A&E diagnosis code. The average cost of an ED attendance for suspected seizures (code 241) during the study period was £123 (\$172). The total costs related to ED attendances for suspected seizures was £18 047 667 (\$25 174 595) (£123 \times 146 729), an average of £3 007 945 (\$4 195 766) per year.

Inpatient HES data

There were a total of 42 201 775 emergency admissions in the NHS in England between 1 April 2007 and 31 March 2013 (six financial years) of which 638 150 (1.5%) were for neurological conditions (after exclusions). A total of 300 668 (47.1%) neurological admissions were for suspected seizures making this by far the most common neurological cause for unscheduled admissions (0.71% of unscheduled admissions for all causes). **Figure 1** shows the number of unscheduled neurological admissions by

diagnosis. There were 1074 emergency admissions coded as dissociative convulsions (F44.5) during the study period (mean 179/annum).

Suspected seizures accounted for a mean of 50 111 admissions per year, representing 0.71% (range 0.67%–0.74%) of unscheduled admissions for all causes during the study period. 54.3% of the admissions for epilepsy/seizure/convulsion were coded as G40 (epilepsy), 42.2% were coded R56.8 (other and unspecified convulsions) and 3.5% were coded G41 (status epilepticus). 93.4% of admissions were via A&E and 3.6% were via general practitioners. More men (54.6%) than women (45.4%) had unplanned hospital admissions with these diagnostic codes. The median length of stay was 1 day (IQR=0–3, range 0–988). The median cost per admission was £1651 (\$21 750) (IQR £1091–1858, range £0–£217 998) and the mean total cost per year was £88 217 138 (\$116 224 315) (during the study period).

Readmissions

Over the 6-year study period, 83.2% of patients had one admission per year and 16.8% had more than one admission per year (12.1% had two admissions per year, 3.4% had three admissions per year and 1.3% had more than three admissions per year). **Figure 2** shows Kaplan-Meier survival curves for time to first readmission. The curve indicates that overall there was a probability of 0.20 of readmission during the first year of the study and a 0.34 probability of readmission during the 6-year study period. The probability of readmission (first year, full 6 years) for each ICD10 code (coding of first admission) was G40 (0.22/0.38), G41 (0.13/0.23) and R56.8 (0.11/0.18).

Geographical variability in admissions

The weighted mean number of admissions for suspected seizures per 100 000 over the study period was 121.0. **Figure 3A** shows a funnel plot of standardised admission rates for suspected seizures (G40+G41+R56.8) for each PCT (**figure 3B,C** show rates for individual ICD-10 codes). **Figure 3A** demonstrates that four PCTs (2.6%) were identified as being outliers more than 3 SDs above the mean, when less than 1 would have been expected if PCTs were all behaving the same, and no PCT was found to be more than 3 SDs below the mean. Data on individual PCTs are available in the appendices (see online supplementary file).

Data

HES data were provided by Health IQ (a real world data company that has access to HES data), in an aggregated, non-identifiable and suppressed format in line with NHS Digital guidelines.

DISCUSSION

Inpatient admissions for suspected seizures

Our data show that suspected seizures are the most common neurological cause of admission to hospital in

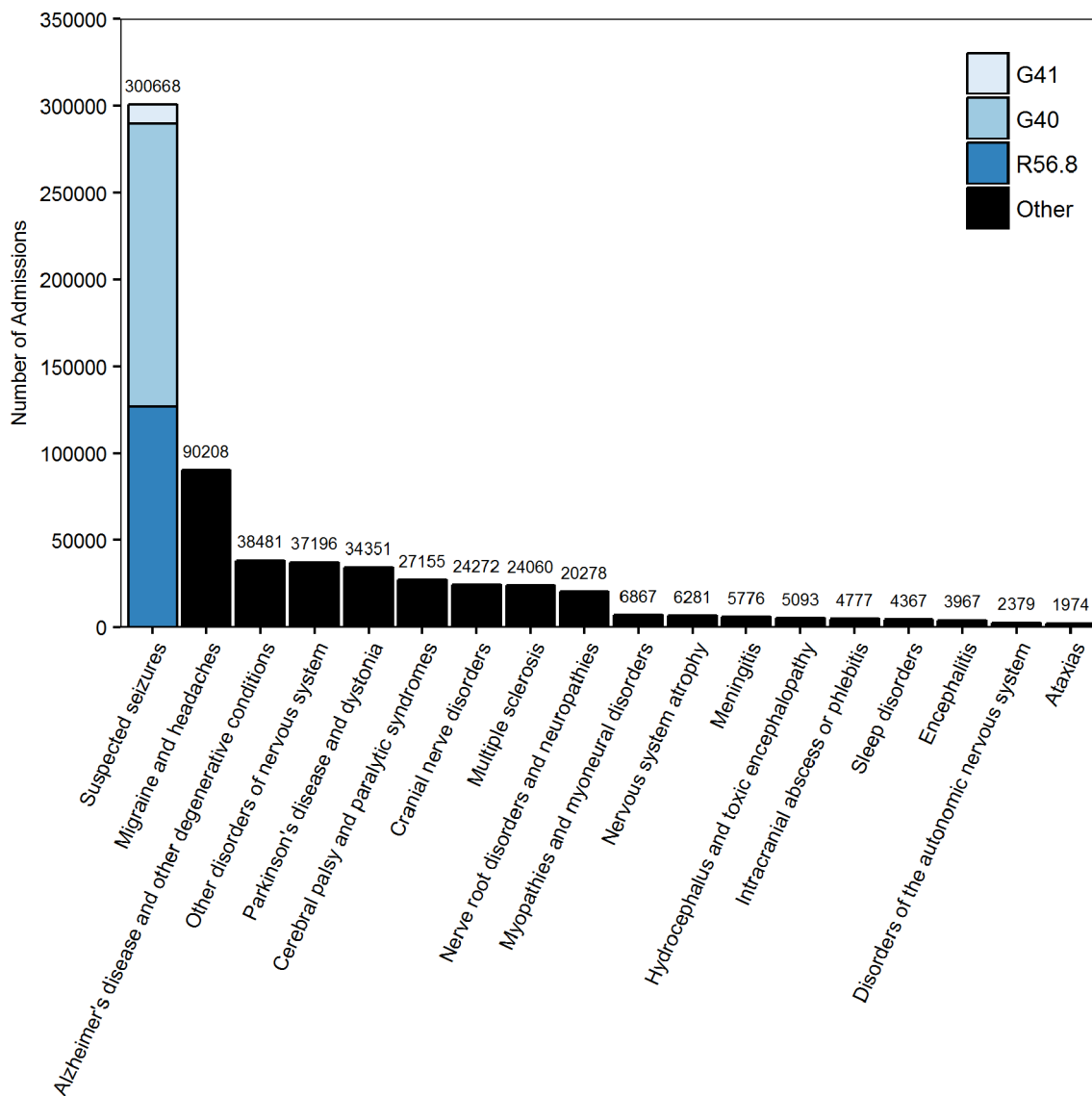


Figure 1 Neurological diagnoses ranked by number of emergency hospital admissions between 31 April 2007 and 31 March 2013. Suspected seizures=G40+G41+R56.8.

England. We have deliberately used the term suspected seizure rather than epilepsy because of the uncertainty around the diagnosis of seizures and epilepsy.¹⁹ The cause of many seizures and other paroxysmal events involving collapse and loss of consciousness remain uncertain even after hospital admission and review by a specialist. This is further complicated by the difficulty distinguishing epileptic seizures from dissociative seizures,^{25 26} inconsistencies between International League Against Epilepsy (ILAE) classifications and ICD-10 categories, and the transposition of doctors notes by hospital coders into ICD-10 codes. We used ICD-10 codes, G40, G41 and R56.8 to identify patients with suspected seizures. The same (or almost the same) ICD-10 codes have been used in other large studies of variation in admissions and quality of care for suspected seizures.^{16 27 28} There is evidence that HES diagnostic coding is accurate overall, but there is significant variability among the published studies.²⁹ Research from Canada shows that the diagnosis of epilepsy (G40

and G41) by hospital coders is specific but that the use of R56.8 is required to improve sensitivity—at the cost of reducing overall specificity.³⁰ There have been no similar studies in the UK looking specifically at seizures/epilepsy, that is, comparing HES ICD-10 diagnosis codes with a gold-standard diagnosis.

The only previously published study using HES data²⁷ which is directly comparable to this study showed that seizures gave rise to 1.36% (interhospital range 1.2%–1.6%) of all emergency admissions²⁷ which is approximately twice the rate that we found (0.71%; range 0.67%–0.74%). Grainger *et al* included patients using primary and secondary diagnoses whereas our study exclusively used the primary diagnosis. Grainger *et al* also used the diagnosis code for the last episode in the spell, that is, the discharge diagnosis. These two methodological differences probably account for the discrepancy in the results between their study and ours. There have been no published studies modelling the effects of different

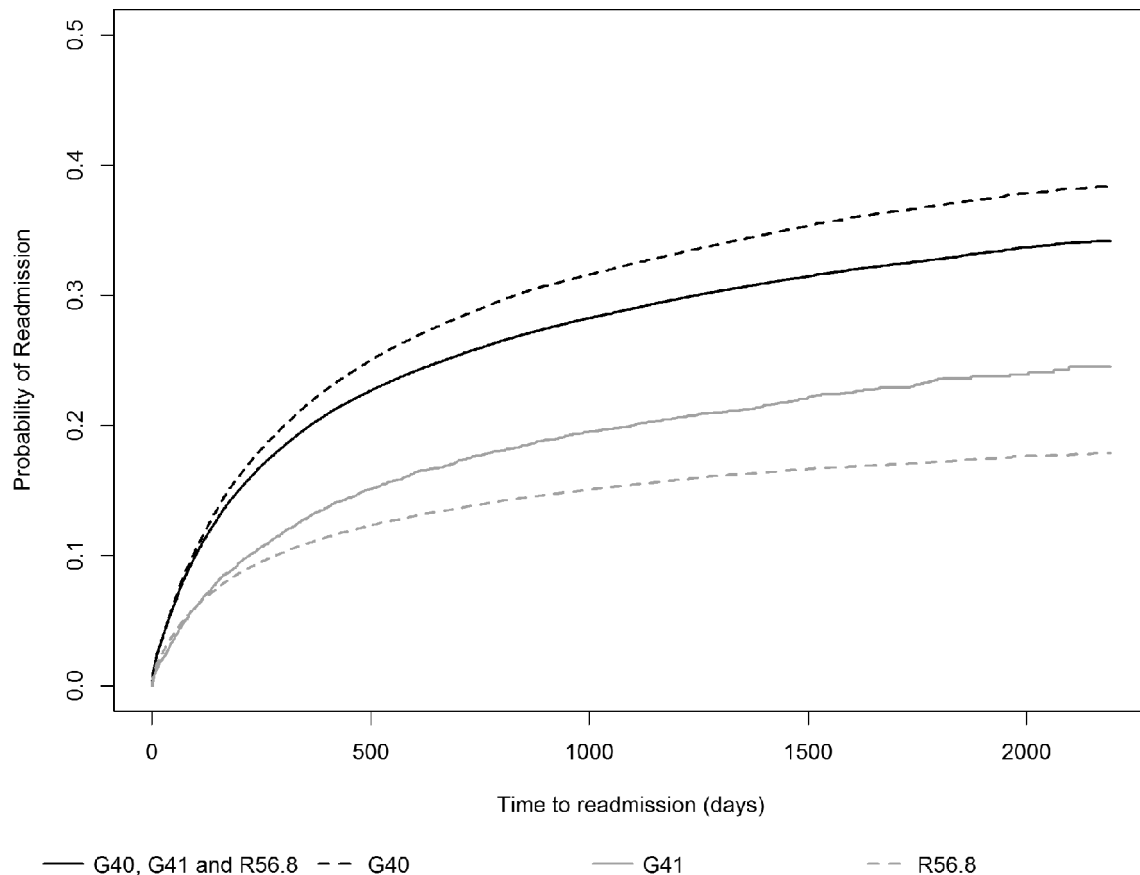


Figure 2 Kaplan-Meier plots showing the time to first readmission after a suspected seizure when the first admission was for G40+G41+R56.8, G40, G41, R56.8. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions).

methods of case ascertainment on admissions rates in terms of primary and secondary diagnoses but there is likely to be a trade-off between sensitivity and specificity using the different methods. We propose that, based on the current evidence, G40+G41+R56.8 is the best combination of codes to identify patients with suspected seizures. But we conclude that further research is required on the optimal method of identifying admissions for suspected seizures in terms of ICD-10 codes, primary±secondary diagnoses and episodes/spells.

Readmissions

After an admission to hospital for a suspected seizure (or an attendance at ED), the aim of management should be to make an accurate diagnosis, manage urgent/emergency problems, optimise ongoing medical treatment (including referral to specialist outpatient services) and provide advice on self-care to reduce the risk of readmission after discharge. Active epilepsy should trigger review by an epilepsy specialist to prevent further seizures and/or to refine the patients emergency care plan but this opportunity is often missed^{14 16 19 31 32} and patients therefore remain at risk of further seizures and the associated morbidity,³³ mortality³⁴ and health services costs^{35 36} of poorly controlled epilepsy. Our data show that 22.4% of patients had more than one admission per year and that

overall there was a 34% chance of readmission after a suspected seizure within 6 years which provides further evidence of potentially avoidable admissions and poor quality care. However, quantification of avoidable admissions using HES data is complicated by the diagnostic uncertainty and the difficulty distinguishing between those cases that are truly ambulatory care sensitive (eg, suboptimally treated patients with active epilepsy) and those which are not (eg, intractable epilepsy, first epileptic seizures which do not meet the criteria for epilepsy³⁷ and many more). Some national performance indicators are predicated on the notion that good quality scheduled care can prevent all admissions for seizures^{28 38 39} which makes their validity doubtful.

Geographical variability and service provision

There is significant geographical variability in the directly standardised admission rates and there are four geographical areas (PCTs) whose mean rate throughout the study period is greater than 3 SDs from the mean. This variability has not previously been reported in the published literature. Our research was not designed to investigate potential causes of the variability and the expected or optimal rate of hospital admissions per 100 000 is unknown. Factors which are likely to influence admission rates for suspected seizures are the, prevalence

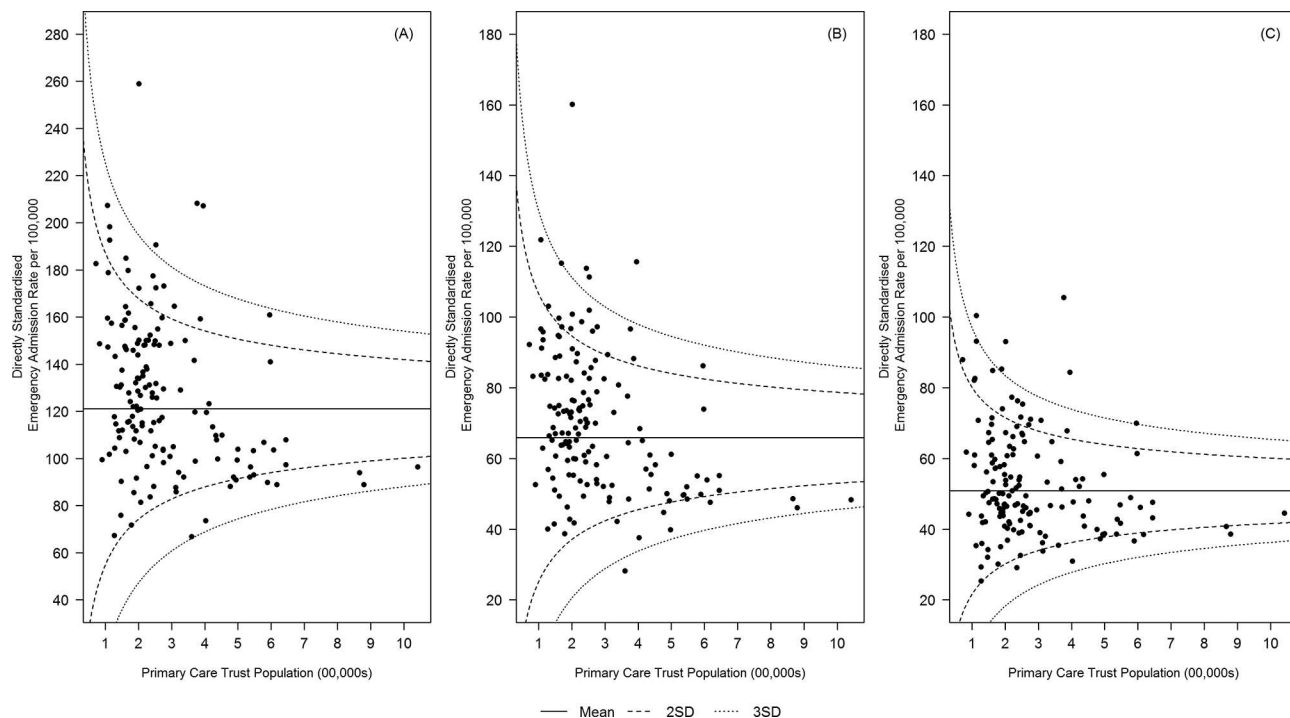


Figure 3 Funnel plots showing the directly standardised emergency admission rate per 100 000 of the adult population 2007–2013 in each PCT. (A) G40+G41+R56.8, (B) G40, (C) R56.8. Each dot represents a PCT, the solid line shows the weighted mean for the standardised admission rate, and the dashed and dotted line shows 2 and 3 SD from the mean, respectively. ICD-10 codes: G40 (epilepsy), G41 (status epilepticus) and R56.8 (other and unspecified convulsions). There was not enough data to age–sex standardise the G41 diagnosis code.

of epilepsy, deprivation, the quality of ambulatory care and local practice in the emergency care system such as care pathways (including the accessibility of neurological advice) and ED discharge protocols. The four outliers (≥ 3 SDs above the mean) are postindustrial areas in the North of England which is consistent with the hypothesis that deprivation is an important factor. Further research is required to investigate the causes of the variability demonstrated in this study. Comparison of rates of admissions for suspected seizures should be compared with all-cause admissions in future studies.

The study period for our data set ends on 31 March 2013 and is based on PCTs. CCGs came into being on 01 April 2013 and although the geographical boundaries of many PCTs were identical to the CCGs that replaced them, some were different, and furthermore the initial configuration of CCGs has subsequently been changed. As such our PCT-based data are not directly comparable with current CCGs, but this does not detract from the conclusion that there is significant geographical variability and commissioners may wish to review the up-to-date data.

Underdiagnosis of Dissociative Seizures

The EPIC 2¹⁴ study showed that 7.4% of all inpatient admissions in a UK centre which resulted from a 999 call for a suspected seizure were caused by dissociative seizures (DS) (ICD-10 code F44.5, also known as PNES or manifestations of non-epileptic attack disorder, NEAD).¹⁴ Based on these data, we would estimate 22 250 (7.4% \times 3 006 668) (3709 per year) admissions during the study period for DS but in our

study the ICD-10 code for DS identified only 1074 admissions in total (179/annum). Despite the fact that the nosology of DS is controversial and a number of different terms are used in the medical literature there is only one ICD-10 code for DS/PNES/NEAD, so it seems that miscoding is unlikely to be the cause of this discrepancy. The unexpectedly low number of cases coded as being admitted with DS adds to the evidence of underdiagnosis of DS by doctors in acute medical settings and of the misdiagnosis of DS as epileptic seizures.^{40–44} In addition to case reports and case series of patients with DS receiving inappropriate emergency treatment for status epilepticus, other indirect evidence for this problem comes from primary care studies demonstrating that non-expert diagnoses of epilepsy are regularly inaccurate and studies based in secondary care demonstrating that the mean diagnostic delay of DS is several years, with most patients with DS initially receiving treatment for epilepsy.^{45–47} It may be that many patients who were admitted during the study period with a DS were actually coded using G40, G41 or R56.8. More research is required to accurately quantify the number of unplanned hospital admissions with DS, but as the management of DS is very different from that of epileptic seizures, this observation provokes concern that the ED management of psychogenic seizures may be suboptimal.

A&E data

The HES A&E data dictionary uses a crude system of 58 diagnosis codes (at three-character level). Coding is done by individual clinicians many of who are junior doctors

who have not had any training for this role. Using the HES A&E diagnosis code 241 (CNS epilepsy) for case ascertainment shows an average of 24 455 attendances per year that is significantly less than the number of admissions for suspected seizures based on the inpatient data. Many A&E attendances were classified as 'unknown' or 'diagnosis not classifiable' and it is not clear how the other two HES A&E neurology codes relate to the diagnosis of epilepsy. We conclude that HES A&E data are not of sufficient quality to make robust estimates of the number of attendances related to suspected seizures. The Emergency Care Data Set will supersede the current ED data and diagnosis codes will be based on the Systematized Nomenclature of Medicine - Clinical Terms (SNOMED-CT) diagnostic codes⁴⁸ which may improve the quality of the data.⁴⁹ Until the issues with data quality in ED are resolved this will remain an important data gap which undermines attempts to undertake high-quality research, plan services and to evaluate service innovations.

Implications for clinical care and public health in the UK and internationally

Epileptic seizures are usually self-limiting and in themselves are not medical emergencies but they account for a large number of emergency admissions many of which are potentially preventable. Important and potentially modifiable factors which give rise to unnecessary admissions are the quality of ambulatory care, advanced care planning and the configuration of emergency care pathways. Approximately one in five patients with epilepsy are having regular seizures which could be prevented with optimal treatment. Improvements in seizure freedom rates would in turn be likely to reduce the number of unscheduled admissions. Care planning for patients with intractable epilepsy in the form of an emergency care plan shared with relatives, friends and carers may reduce demand on emergency services. Emergency care pathways, designed to identify patients that can be safely managed without emergency attendance/admission to hospital and to divert them to urgent but scheduled appointments in specialised services may improve care and reduce unnecessary admissions. Our research is based on data from the NHS in England and is inevitably context-specific, but research from other European countries shows similar problems with quality of ambulatory care for epilepsy, variability in services and high costs from potentially avoidable admissions.^{50 51} Prevalence of epilepsy and the incidence of seizures has much wider determinants than healthcare provision. Alcohol, deprivation and comorbidities linked with seizures, such as cerebrovascular disease, are all relevant and require a public health approach to tackle them.

Contributors The idea for the study came from RAG. JMD was the chief investigator and he worked with the other authors (RJ, MR, JH, MJC, RM and RAG) to develop the protocol. JMD, JH and RJ took the lead with data analysis. JMD took the lead with writing the manuscript and the other authors (RJ, MR, JH, MJC, RM and RAG) contributed to the manuscript and approved the final version.

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Patient consent Not required.

Ethics approval The work was approved by the University of Sheffield research ethics committee (project number 001932).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No unpublished data from this study are available.

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