Referral patterns after a seizure admission in an English region: an opportunity for effective intervention? An observational study of routine hospital data

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ABSTRACT
Objectives: To identify emergency seizure admissions to hospital and their subsequent access to specialist outpatient services.

Design: Algorithmic analysis of anonymised routine hospital data over 7 years using specialist follow-up by 3 months as the target outcome.

Population: All adults resident in Merseyside and Cheshire, England.

Main Outcomes: Whether, and when, access to the specialist advice that might prevent further admissions was offered.

Results: 1.4% of all emergency medical admissions are as a result of seizure. In the following 12 months 35% were readmitted and experienced a mean of 2.3 emergency department visits. Only 27% (48% of those already known to specialists and 13% of those not known) were offered appointments. Subsequent attendance at a specialist clinic is more likely if already known to a clinic, if aged <35 years, if female, or required a longer spell in hospital. Extrapolation from other work suggests 100 000 bed days per annum could be saved.

Conclusions: Most seizure admissions are not being referred for the help that could prevent future admissions. The majority of those that are referred are not seen within an appropriate time frame. Our service structures are not providing an optimum service for people with epilepsy.

Strengths and limitations of this study

- The National Audit of Seizure management in Hospitals (NASH) audit showed that the care of people presenting to hospital following a seizure is variable and that only a quarter of patients were being seen in specialist clinics. One report suggests that length of stay could be halved and readmissions reduced by 80%.
- Using different methods this paper confirms with larger numbers over 7 years, that within 3 months, only 27% of seizure admissions are reaching the specialist advice that could improve their outcome.
- There is a substantial disconnect between the needs of the patients attending emergency services/secondary hospitals and their access to neurology specialists.

INTRODUCTION

Many patients with epilepsy (70%) are seizure free with or without medication, seizure freedom is associated with a better quality of life, however, up to 30% have persistent seizures and require specialist management.1 2 ‘Specialist’ usually means neurologist because of the wide range of therapeutic options, yet most seizures present to emergency departments (EDs) or acute medical units without neurologists, and this paper examines the patient pathways after presenting with a seizure to hospital, and how often patients do get to specialist care.

The second National Audit of Seizure management in Hospitals (NASH)3 described over 4500 attendances at EDs following a seizure, and showed that 66% of patients with known epilepsy were on either monotherapy (48%) or no therapy (18%), that care at hospital was variable, and that only a quarter went on to receive specialist advice. This suggests that opportunities to prevent another seizure are being missed.

Medical emergency admissions (ie, non-surgical) are rising across the UK4 and are more than twice as likely among the most deprived population decile (vs mean deprivation) implying challenges that are medical and social.5 Most acute hospitals receiving
seizure admissions rely on visiting, rather than fulltime, neurology specialists on site, so there are particular organisational challenges getting seizure patients to specialists. A recent report suggests that this matters and described how, from a similar baseline, an active process of early specialist review halved days in hospital and reduced readmissions by 80%.

This analysis of the hospital admission data for Merseyside and Cheshire was performed to provide data to enable more effective planning of seizure services and asked whether:
- The numbers presenting with seizures were consistent and how they compared with trends for other medical emergency presentations,
- Readmission rates were high and how often patients visited hospital EDs,
- Particular factors affected access to specialist help.

METHODS

The Hospital Episodes Statistics (HES) data, for the nine hospitals within Cheshire and Merseyside, contains information on hospital admissions, ED attendances, and outpatient clinic visits. It includes the Index of Multiple Deprivation (IMD) based on home address and either death or discharge details. At discharge, coders working to standard methods create a list of up to 20 International Classification of Diseases, 10th Revision (ICD-10) diagnoses but this does not clarify when a given condition was the prime cause or merely a comorbidity. We have created an algorithm based on knowledge of disease behaviour, clinical pathways, and clinician feedback, using multiple diagnoses from the ICD-10 list to select those where a seizure was likely to be the prime reason for admission.

Inclusion criteria: All emergency admissions to the major medical specialties (not attendances), that were primarily related to presentation with a seizure, in the 7 year period 2006–2013, ie,
- Method of admission was emergency (excluding day and elective cases) AND
- Under care of the major medical specialties (cardiology, respiratory, neurology, etc) AND
- A seizure admission was defined from the discharge diagnosis codes:
  - An epilepsy code (G40, G41) in the first diagnosis position (P1) OR
  - An epilepsy code second or third in the list (AND a supportive symptom or condition code in P1).

For each admission, we recorded the associated readmissions, ED attendances and neurological (code 400) clinic attendances in the year prior, and the year after. To be sure that we were not missing outpatient data, we confirmed with the service that all neurology clinics had been included, whether occurring locally or in the regional centre. Details of the coding lists, and how they were applied, are available in an online supplementary appendix and available from authors.

For analysis we split patients into two groups who:
A. Had been seen in a neurology clinic in the preceding year (ie, are under active follow-up) (group A),
B. Had not been seen (ie, currently unknown to neurologists)—representing either suspected first seizures or cases not in active follow-up (group B).

The 7-year data were used to examine differences among hospital sites and trends over time.

Comparisons are by simple χ², t, or Spearman Rank tests as appropriate.

Finally, we examined the likelihood of being offered a clinic appointment within 3 months with a multiple logistic regression with age groups (15–34, 35–54, 55–74 and >75), IMD (as quintiles), comorbidity (Charlson Index groups of 0, 1–2 and >2 points), sex, whether discharged to a nursing home, whether they had had a clinic appointment in the previous year, an admission or ED attendance in prior year, hospital stay greater than the median, and hospital attended as dependent variables. We excluded those who died in hospital.

RESULTS

Cohort summary and changes over time

There were 129,933 emergency admissions in 91,508 people per year, with numbers increasing by 2.7% per annum in line with national trends. There were 1767 seizure admissions/year (in 1020 patients) representing 1.36% (interhospital range 1.2–1.6%) of all emergency medical admissions—a proportion that was constant over the 7 years. Table 1 shows that compared with admission for other reasons, seizure admissions were younger (mean age 55 vs 66 years), included more males, and had a shorter length of stay, but were of similar deprivation backgrounds. Other than the rising trend in overall admissions, the patterns in each of the years were similar and so no further between-year comparisons are presented. We present analysis by admission, which includes multiple admissions for some patients. Results are similar to those using the first admission per individual.

Patients known, or not known, to the specialist service and interhospital variability

Table 2 subdivides patients into those who had had a neurology clinic appointment in the prior year (group A), and those who had not (group B) for the central 5 years to include a full year of other activity before and after. There were no significant differences in age, gender, deprivation or admission/clinic rates in the 5-year cohort versus the 7-year cohort.

Compared with group A, group B patients were older (mean age 59 vs 47 years), had longer lengths of stay, were more likely to be discharged to nursing home care, and included more in-hospital deaths (3.7% vs 1.0%), (all p<0.001). But they were less likely to come from deprived areas.

Both groups showed similar high numbers of attendances at the ED in the year before the index admission.
The mean figures hide a skewed dispersion such that 17% (group A) and 9% (group B) had more than six recorded visits. The pattern of frequent ED visits persists in the year after.

The proportion offered a specialist clinic appointments was less than half in group A and only 11% in group B. Of these, 14% and 12% respectively failed to attend. The interhospital range is moderate, but the low rate of access to specialist assessment is consistently different across hospitals at all time points (figure 1).

We cannot tell how many of the 3066 group A patients (34.6%) would have had planned appointments as part of their routine care, but if 80% were offered a 6 month follow-up that could account for a 40% 3 month clinic rate. Similarly we do not know how many of the 5806 group B patients were patients for whom this was the first known seizure and should have been seen within 2 weeks, or were patients with known epilepsy but outside of specialist follow-up.

Table 3 builds on table 2 by subdividing the groups according to whether or not they were current attenders at the specialist neurology clinic.

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**Table 1** Comparison of mean numbers of seizure admissions to all emergency medical admissions, with the ranges across the nine hospitals

|                          | All emergency medical admissions | Range (lowest and highest values for individual hospitals in the region) | Emergency admissions due to a seizure | Range (lowest and highest values for individual hospitals in the region) |
|--------------------------|---------------------------------|------------------------------------------------------------------------|--------------------------------------|------------------------------------------------------------------------|
| Mean admissions/year     | 129 933                         | 5991–23 894                                                           | 1767                                 | 68–381                                                                |
| Mean individuals/year    | 91 508                          | 5116–15 375                                                          | 1020                                 | 214–864                                                              |
| Mean age (years (SD))    | 66 (19.3)                       | n/a                                                                   | 55 (20)                              | n/a                                                                   |
| Sex (% male)             | 46.8                            | 46.0–48.7                                                             | 57.7                                 | 44.3–60.9                                                            |
| Median length of stay (days) | 3 IQR 1–7                      | 1–4                                                                   | 2 IQR 1–6                            | 1–3                                                                   |
| Mean length of stay (days (SD)) | 8.0 (14.3)            | 6.5–9.1                                                               | 5.7 (11.5)                           | 3.5–6.8                                                              |
| Mean IMD rank (SD)       | 10 400 (9809)                   | 5266–21 108                                                           | 10 869 (9810)                        | 5437–19 954                                                          |

IMD, Index of Multiple Deprivation; n/a, not applicable.

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**Table 2** Proportion of patients offered a neurology appointment following the acute admission according to whether or not they were current attenders at the specialist neurology clinic

|                          | Group A Current attenders (n=3066) | Range of means across hospitals | Group B No recent OPD (n=5806) | Range of means across hospitals |
|--------------------------|-----------------------------------|---------------------------------|---------------------------------|---------------------------------|
| Mean age (years (SD))    | 47                                | 44–50                           | 59*                             | 54–64                           |
| Sex (% male)             | 55.6                              | 44–57                           | 55.9                            | 42–59                           |
| Mean IMD rank            | 9773                              | 5689–20 529                     | 11 296*                         | 5386–19 765                     |
| Mean length of stay (days) | 4.6                              | 3.0–6.2                         | 6.2*                            | 3.7–7.7                         |
| Mean number of ED attendances in the year preceding the acute admission | 3.6                                    | 2.6–4.4                         | 2.6*                            | 0.9–4.4                         |
| Discharged to nursing home (%) | 3.5                                    | 0–5.3                           | 9.0*                            | 0–11.7                          |
| Died in hospital (%)     | 1.0                               | 0–2.1                           | 3.7*                            | 1.5–5                           |
| Mean number of ED attendances in the year following the acute admission | 2.6                                    | 1.6–4.0                         | 2.0*                            | 1.6–4.0                         |
| Mean yearly readmission rate (%) | 43.2                                   | 29–44.6                         | 31.9*                           | 20.8–33.4                       |
| Patients offered specialist clinic within 2 weeks (%) (SD) | 11 (3)                                    | 4–15                            | 2 (1)*                           | 1–2                             |
| Patients offered specialist clinic within 3 months (%) (SD) | 48 (7)                                    | 37–62                           | 11 (2)*                          | 9–14                            |
| Patients offered specialist clinic within 12 months (%) (SD) | 78 (8)                                    | 62–90                           | 21 (4)*                          | 17–27                           |

Mean data for 5 years for region as a whole and then the range across individual hospitals.

*Group B is significantly different (p<0.01) to Group A.

Group B is significantly different from Group A for all variables except gender, ED, emergency department; IMD, Index of Multiple Deprivation; OPD, outpatient department.
Clinic rates in the 5-year cohort versus the 7-year period. The table describes the whole cohort rather than interhospital differences.

Univariate analysis showed that an appointment was more likely in both groups if patients were younger (p<0.001), had a shorter length of stay (p<0.001), had fewer co morbidities, or were female. There was a very weak association with less deprivation. High ED attendance rates (before or after) and readmission rates were not predictive, but those discharged to a nursing care

**Figure 1** Cumulative percentage of patients from each hospital who were offered outpatient specialist appointments according to whether they had been current attenders (upper set of lines) or not (lower group). The arrows describe the interhospital range at the point used for the regression analysis (OPD, outpatient department).

**Table 3** Comparison of patients according to whether or not they were offered a clinic appointment within 3 months (whole cohort—rather than interhospital differences)

|                        | Group A | Range of means across hospitals | Group B | Range of means across hospitals |
|------------------------|---------|---------------------------------|---------|---------------------------------|
| **Current attenders**  | n=3066  |                                 | n=5806  |                                 |
| Mean Age (years (SD)) | 47      | 44–50                           | 59*     | 54–64                           |
| Sex (% male)           | 55.6    | 44–57                           | 55.9    | 42–59                           |
| Mean IMD rank          | 9773    | 5689–20 529                     | 11 296* | 5386–19 765                     |
| Mean Length Of Stay (days) | 4.6   | 3.0–6.2                         | 6.2*    | 3.7–7.7                         |
| Mean number of ED attendances in the year preceding the acute admission | 3.6 | 2.6–4.4                         | 2.6*    | 0.9–4.4                         |
| Died in hospital (%)   | 1.0     | 0–2.1                           | 3.7*    | 1.5–5                           |
| Mean number of ED attendances in the year following the acute admission | 2.6 | 1.6–4.0                         | 2.0*    | 1.6–4.0                         |
| Mean yearly readmission rate (%) | 43.2 | 29–44.6                         | 31.9*   | 20.8–33.4                       |
| Patients offered specialist clinic within 2 weeks (%) (SD) | 11 (3) | 4–15                            | 2 (1)*  | 1–2                             |
| Patients offered specialist clinic within 3 months (%) (SD) | 48 (7) | 37–62                           | 11 (2)* | 9–14                            |
| Patients offered specialist clinic within 12 months (%) (SD) | 78 (8) | 62–90                           | 21 (4)* | 17–27                           |

*Group B is significantly different (p<0.01) to Group A.
ED, emergency department; IMD, Index of Multiple Deprivation; OPD, outpatient department.
home were less likely to have appointments. The patterns noted are the same irrespective of whether the patient attended the clinic.

A multiple logistic regression (table 4) confirmed the univariate picture and provided some quantitation of the interhospital differences. Being part of the clinic system already is a strong predictor of getting another appointment, but more striking is the marked trend for the elderly to not be offered specialist help. The most socially deprived are also relatively excluded.

The regression analyses were also run on group A, and group B separately with very similar results (not presented) save that the age coefficients were a little lower in group A.

Finally the analyses were repeated on 3956/5806 patients (68%) in group B, who had had no hospital contact (admission, ED visit, or outpatient clinic) in the prior year, arguing that this subgroup are likely to include a high proportion of ‘first fit’ patients. Their 3-month clinic appointment rate was similar to the rest of group B patients (11.8% vs 12%, not significant).

### DISCUSSION

**Principle findings**

These results, using very different methods, echo the findings of the NASH report; only half (51%) of patients admitted were offered neurology appointments, of which only half were attended. Our headlines are that of the 65% who had not been under specialist review (including the first seizure patients), only 11% are offered a specialist review within 3 months, and only 2% within 2 weeks. Less than half of those already known to specialists are seen within 3 months, which is little better than would have happened anyway. We cannot separate how many were first seizures, but can be certain the National Institute for Health and Care Excellence (NICE) 2-week standard2 is not being met. Even if some of these patients were being seen as ‘ward consults’ by visiting neurologists, one would still expect most to be followed-up to assess the effect of treatment changes.

Our choice of the 3 month timeline was pragmatic, based on numbers available to analyse, but is perhaps too long from a patient viewpoint. A seizure admission is a significant event indicating possible new epilepsy or failure of control. Patients should expect to have therapy discussed, and for that to happen in a timely fashion. The low referral patterns are common to all hospitals, and were similarly widespread in NASH, suggesting this is a generic National Health Service (NHS) problem. It is for others to set the time standards but this is about more than the index admission—as the high readmission and ED attendance rates show.

**Strengths and weaknesses**

Could we be misidentifying the seizure cohort at hospital? We have combined an understanding of the hospital coders’ rules, and knowledge of the clinical behaviours and organisational pathways, to select out those cases that physicians would have considered to be due to a seizure. Our algorithms exclude those admitted primarily for other conditions where epilepsy is a comorbidity and further specialist referral would be unwarranted. Our algorithmic logic accesses more of the coded information and has been shared with specialists to gain their informal approval both of the algorithms and that the numbers have face validity with experience. This approach towards a clinical interpretation of HES has been now been used across conditions in four major specialities (also respiratory, gastroenterology, and renal) and in each has been shared with the respective specialty physicians and been iteratively improved with their feedback. We believe it is closer to the real-life clinical picture than most other published analyses.

We were reassured that other conditions that might have presented as seizure (cancer, stroke or alcoholism) were only present in modest numbers and so cannot

### Table 4

|                                | p Value | OR    | Lower CI | Upper CI |
|--------------------------------|---------|-------|----------|----------|
| **Hospital**                   |         |       |          |          |
| Hospital (9)                   | 0.021   | 1.44  | 1.06     | 1.96     |
| Hospital (1)                   | 0.000   | 1.91  | 1.44     | 2.55     |
| Hospital (2)                   | 0.000   | 2.08  | 1.55     | 2.81     |
| Hospital (3)                   | 0.000   | 2.09  | 1.52     | 2.88     |
| Hospital (4)                   | 0.000   | 2.26  | 1.69     | 3.04     |
| Hospital (5)                   | 0.000   | 2.69  | 2.02     | 3.59     |
| Hospital (6)                   | 0.000   | 2.53  | 1.89     | 3.38     |
| Hospital (7)                   | 0.000   | 3.02  | 2.15     | 4.24     |
| Quintile                      |         |       |          |          |
| Quintile 1 (most deprived)    | 0.079   | 1.16  | 0.984    | 1.36     |
| Quintile 2                     | 0.011   | 1.26  | 1.06     | 1.50     |
| Quintile 3                     | 0.194   | 1.14  | 0.94     | 1.38     |
| Quintile 4                     | 0.000   | 1.76  | 1.41     | 2.19     |
| Quintile 5 (least deprived)   | 0.000   | 3.02  | 2.15     | 4.24     |
| **Age group (years)**          |         |       |          |          |
| >75                            | 0.000   |       |          |          |
| 55–74                          | 0.000   | 2.65  | 2.09     | 3.35     |
| 35–54                          | 0.000   | 3.45  | 2.74     | 4.36     |
| 16–34                          | 0.000   | 6.27  | 4.92     | 7.99     |
| Male                           | 0.000   | 0.79  | 0.71     | 0.89     |
| Long stay (>2 days)            | 0.031   | 0.88  | 0.78     | 0.99     |
| Discharge to nursing home      | 0.000   | 0.55  | 0.39     | 0.76     |
| Admission in prior year        | 0.000   | 1.33  | 1.19     | 1.49     |
| Clinic visits in prior year    | 0.000   | 4.89  | 4.35     | 5.0      |
| Constant                       | 0.000   | 0.043 |          |          |

Each hospital was treated as a separate category.
explain the low referral rates, although the significant number with alcohol codes does imply a need to triage referrals with care.

The data are reported at admission level since each presentation is an opportunity to intervene. Restricting analysis to only the first admission yields similar conclusions from univariate, and multivariate analyses. This may have future impact if ‘referral to specialist’ were to become a marker of appropriate care because it is analytically simpler.

**What does this imply?**

The data from NASH suggested more could be done, and experience from Ireland showed that early specialist referral reduced 1 year readmissions from 45% to 9% and halved ‘bed day’ use. These two adjectives are important. Few general physicians or general practitioners are able to keep up with the diagnostic tools and range of treatments now available to manage epilepsy. It has become a specialist area even within neurology. The urgency to refer may be reduced as many seizures will be recovering by the time they are seen in hospital. However, the fact that only 11% of patients were offered a specialist appointment is almost a ‘denial of NHS service’ for those patients. For those known to the system a 48% appointment rate is only marginally higher than should be expected with planned care.

While some epilepsy manifests as repeated seizures despite best therapy, two-thirds of the admissions we report were not referred for help. This implies a significant cohort of ‘forgotten people.’ The regression analysis points to an apparent systematic ageism with referrals being particularly unlikely if aged over 75. There is insufficient clinical information in this data set to investigate the reasons, but it is common to each hospital site and warrants further study. Our cohort had a high readmission rate (32% with at least 1 admission in the following 12 months), a mean length of stay of 5 days and many other visits to the ED in the year before hospitalisation. If early referral were half as effective as the alternative of discharge in Ireland, there would be huge savings for the NHS but, more importantly, this group of patients might still be recovering by the time they are seen in hospital.

Neurology services

Neurology services operate from regional centres from which specialists visit the acute hospitals. The relationships of visiting specialists to their visited hospitals vary. In a previous study we showed that mortality due to acute kidney injury was very markedly lower when renal specialists were based in the hospital. The reasons are still being elucidated but it is likely that the specialists’ commitment to the acute ‘take,’ grand rounds and other activities, and the knowledge gained by juniors rotating through the renal wards, has effects on their colleagues that improve the management of issues like fluid balance. Most junior staff have little contact with visiting neurologists and most neurologists have no responsibility to the acute medical take. But to reorganise hospital systems that have been in place for many years without causing chaos elsewhere is not easy. Even the mechanisms for referral into a specialist service are often indirect, depending on primary care to make a decision on appropriateness of referral, with or without a prompt from the discharge letter. But our data show it is not happening for most patients.

This disconnect between service organisation and clinical need has been highlighted in a recent editorial, which strongly advocates that the tertiary neurology units should reach out into the world of acute medicine. But changing clinical pathways requires clinical collaboration across health sectors, but it has to be facilitated by the funders and planners of care. Thus establishing epilepsy clinic capacity so patients can be seen quickly, for example, 2 weeks, requires having enough specialists available and the funding to run those clinics. Moving resources around a healthcare system is never easy but how else is the significant cohort of patients with epilepsy with frequent presentations to hospital going to be enabled to access the specialist services that could help them?

Sharing these data with commissioners and epilepsy specialists in our region has already stimulated two projects to improve the clinical referral pathway. There is a general agreement that 2 or more nights in hospital is unnecessary for most patients—the alternative of discharge with early specialist appointment is likely to be better for, and preferable to, most patients. A very crude estimation is that translating the Irish experience to England would save over 100 000 bed days per year. This would make good health and economic sense for the NHS but, more importantly, this group of patients are largely of working age and reducing their seizure (and admission) rates could significantly improve their well-being, their chances of gaining work, and a better quality of social and family life.

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This project has not used any personal data but has analysed anonymised downloads of NHS records. The outputs will be part of ongoing NHS performance monitoring.

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Additional data is available by emailing RG: ruth.grainger2@nhs.net.

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Correction

Grainger R, Pearson M, Dixon P, et al. Referral patterns after a seizure admission in an English region: an opportunity for effective intervention? An observational study of routine hospital data. *BMJ Open* 2016;6:e010100.

In the abstract the third sentence of the results section states:

“Subsequent attendance at a specialist clinic is more likely if already known to a clinic, if aged <35 years, if female, or required a *longer* spell in hospital.”

The word *longer* should have been *shorter*. The regression is correct in the main body of text and table.

In addition, tables 2 and 3 include different legends and footnotes (correctly) but contain identical data. The data from table 2 appears twice. The correct data for table 3 is given below.

**Table 3** Comparison of patients according to whether or not they were offered a clinic appointment within 3 months (whole cohort – rather than inter-hospital differences)

| GROUP A: Patients “known” to the specialist team (n=3066) | GROUP B: Patients who are new or not under follow-up (n=5806) |
|-----------------------------------------------|-----------------------------------------------|
| Not offered neurology clinic appointment | Offered neurology clinic appointment | Not offered neurology clinic appointment | Offered neurology clinic appointment |
| Number of patients (% of group) | 1621 (53%) | 1445 (47%) | 5153 (89%) | 653 (11%) |
| DNA rate at the given clinic (%) | n/a | 14.3 | n/a | 11.5 |
| Number of patients actually seen (% of group) | n/a | 1238 (40%) | n/a | 581 (10%) |
| Co-morbidity (% with Charlson score ≥1) | 123 (7.6%) | 75 (5.2%) | 904 (17.5%) | 65 (10%) |
| Mean age (years (SD)) | 49.2 (17.3) | 43.7 (16.6) | 60.7 (19.7) | 47.3 (18.4) |
| Sex (% male) | 57.6 | 53.1 | 55 | 53.6 |
| Mean Length of Stay (days) | 5.3 | 3.9 | 6.5 | 3.8 |
| Mean IMD rank | 9545 | 10 025 | 11 279 | 11 466 |
| Mean number of ED visits in prior year | 3.4 | 3.8 | 2.6 | 2.4 |
| Mean readmission rate in the year after | 38.4% | 48.5% | 30.1% | 35.0% |
| Mean number of ED visits in the year after | 3.4 | 2.9 | 2.0 | 2.2 |
| Discharged to nursing home (%) | 4.4 | 2.4 | 9.8 | 2.8 |

*Group B is significantly different from Group A, p<0.01.
ED, emergency department; IMD, Index of Multiple Deprivation; OPD, outpatient department.*

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[CrossMark](https://doi.org/10.1136/bmjopen-2015-010100corr1)
APPENDIX 1

SEIZURES PROCEDURE

All original analysis/syntax located at CISSU S:\Information\Ruth\Seizures\Original data.

Seizures data extracted from staging inpatients dataset:
- 01/04/2006 – 31/03/2013 all episodes where:

Admission method is in the list

| Emergency Admission | Description |
|---------------------|-------------|
| 21                  | Accident and emergency or dental casualty department of the Health Care Provider |
| 22                  | GENERAL PRACTITIONER: after a request for immediate admission has been made direct to a Hospital Provider, i.e. not through a Bed bureau, by a GENERAL PRACTITIONER or deputy |
| 23                  | Bed bureau |
| 24                  | Consultant Clinic, of this or another Health Care Provider |
| 28                  | Other means, examples are: ***
- admitted from the Accident and Emergency Department of another provider where they had not been admitted
- transfer of an admitted PATIENT from another Hospital Provider in an emergency
- baby born at home as intended |

Where medical specialty is in the list

| Specialty Code | Specialty |
|----------------|-----------|
| 192            | Critical Care Medicine |
| 300            | General Medicine |
| 301            | Gastroenterology |
| 302            | Endocrinology |
| 303            | Clinical Haematology |
| 314            | Rehabilitation |
| 315            | Palliative Medicine |
| 320            | Cardiology |
| 330            | Dermatology |
| 340            | Respiratory Medicine |
| 361            | Nephrology |
| 370            | Medical Oncology |
| 400            | Neurology |
Where the last episode in the spell indicator is

“1. This episode is the last episode in the hospital provider spell”

Where $x_{\text{transaction\_flag}} = \text{null}$

Where any of the 1st 15 ICD10 codes are in the list (SEIZURE CODES)

| Code | Description |
|------|-------------|
| G400 | LOCAL-RELATED (PART) IDIOPATH EPILEP/EPILEPT SYND WITH SEIZ O |
| G401 | LOCAL-RELATED (PART) SYMPTOM EPILEPSY/EPILEPTIC SYND WITH SI |
| G402 | LOCAL-RELATED (PART) SYMPTOM EPILEPSY/EPILEP SYND W/ COMPLE |
| G403 | GENERALIZED IDIOPATHIC EPILEPSY AND EPILEPTIC SYNDROMES |
| G404 | OTHER GENERALIZED EPILEPSY AND EPILEPTIC SYNDROMES |
| G405 | SPECIAL EPILEPTIC SYNDROMES |
| G406 | GRAND MAL SEIZURES, UNSPECIFIED (WITH OR WITHOUT PETIT MAL) |
| G407 | PETIT MAL, UNSPECIFIED, WITHOUT GRAND MAL SEIZURES |
| G408 | OTHER EPILEPSY |
| G409 | EPILEPSY, UNSPECIFIED |
| G410 | GRAND MAL STATUS EPILEPTICUS |
| G411 | PETIT MAL STATUS EPILEPTICUS |
| G412 | COMPLEX PARTIAL STATUS EPILEPTICUS |
| G418 | OTHER STATUS EPILEPTICUS |
| G419 | STATUS EPILEPTICUS, UNSPECIFIED |
| R568 | OTHER UNSPECIFIED CONVULSION |

Where hospital trust code is in the list

| Code | Description |
|------|-------------|
| RBL | WIRRAL UNIVERSITY TEACHING HOSPITAL NHS FOUNDATION TRUST |
| RBN | ST HELENS AND KNOWSLEY HOSPITALS NHS TRUST |
| RBT | MID CHESHIRE HOSPITALS NHS FOUNDATION TRUST |
Dataset produces a file containing 33,194 admissions

- Validation complete on main datasets, to ensure level of discharges are consistent over the 7 year dataset period

| Year       | % of dataset |
|------------|--------------|
| 2006/2007  | 12.56%       |
| 2007/2008  | 12.89%       |
| 2008/2009  | 13.30%       |
| 2009/2010  | 14.99%       |
| 2010/2011  | 15.27%       |
| 2011/2012  | 15.20%       |
| 2012/2013  | 15.79%       |
| (blank)    | 0.00%        |
| Grand Total| 100.00%      |

- This main dataset referenced above was then queried to produce a list of diagnosis codes appearing in P1, the diagnosis codes were then clinically evaluated by MGP to determine whether they were relevant to epilepsy or not. See appendix 1 for the full list of diagnosis codes in P1. This then allowed for the data to be categorised into 4 main groups

1) DEFINITE SEIZURE – Seizure code in position 1 with relevant secondary or R568 in position 1 with a seizure code in later position
2) PROBABLE SEIZURE – Seizure code in later position and a probable linked diagnosis in position 1
3) POSSIBLE SEIZURE – Seizure code in later position and a possible linked diagnosis in position 1
4) DEFINITELY NOT SEIZURE – Seizure code in later position but no linked diagnosis in position 1

| Year       | Definite | Probable | Possible | Not relevant | Blank | Grand Total |
|------------|----------|----------|----------|--------------|-------|-------------|
| 2006/2007  | 1232     | 442      | 688      | 1785         | 22    | 4169        |
| 2007/2008  | 1155     | 514      | 784      | 1796         | 29    | 4278        |
| 2008/2009  | 1257     | 485      | 807      | 1839         | 28    | 4416        |
| 2009/2010  | 1256     | 596      | 932      | 2161         | 30    | 4975        |
| 2010/2011  | 1306     | 551      | 1033     | 2155         | 24    | 5069        |
| 2011/2012  | 1230     | 601      | 1052     | 2132         | 31    | 5046        |
| 2012/2013  | 1258     | 588      | 1094     | 2247         | 54    | 5241        |
| Grand Total| 8694     | 3777     | 6390     | 14115        | 218   | 33194       |
ADDING DATA FROM OTHER DATA SOURCES

- The admissions dataset for definite and probable seizures was linked to the A&E dataset, also saved in CISSU S:\Information\Ruth\Seizures\Original data. The staging inpatients table was linked to staging A&E where HESID is the same in both tables and the A&E arrival date is within one year of the admission date.
- The admissions dataset for definite and probable seizures was linked to the outpatients dataset, also saved in CISSU S:\Information\Ruth\Seizures\Original data. The staging inpatients table was linked to staging outpatients where HESID is the same in both tables and the outpatient clinic date is within one year of the admission date and the outpatient treatment function is ‘400’ (neurology).

VALIDATIONS, EXCLUSIONS AND CHANGES TO THE DATASET

VALIDATIONS

All fields in the dataset had frequencies run on them to understand what was contained, so that we could change or exclude any corrupt data

- Of the 12,471 definite and probable seizures, there were 162 records missing a HESID, these have been included in the number of admissions but discounted from any analysis at patient level. Records without a HESID have also been excluded from A&E and outpatient analysis as the record will not have matched with an A&E or outpatient clinic.
- There were 98 records at the Walton Centre, these have been left in the dataset but removed from any summary analysis.

DUPLICATES

- It is important to check the Data Quality of the dataset and to check for duplicates. This was completed by creating a concatenated field of HESID and discharge date and spell ID, no duplicates were identified as they were removed during the query in the statement x_transaction_flag=null.

ADDING ADDITIONAL FIELDS

- CATEGORY – Identifies the admission as a definite, probable, possible or not relevant to epilepsy
- FINYEAR - Contains the financial year of the discharge date.
- UNIQUE ADMISSION – Identifies a unique admission when linking data to A&E and outpatient records as admissions will duplicate by the number of A&E attendances or outpatient clinics
- TIME TO CLINIC – Clinic date minus discharge date or if clinic date < discharge date then admission date minus clinic date
- TIME TO A&E – A&E date minus discharge date or if A&E < discharge date then admission date minus A&E arrival

ANALYSIS

- All initial basic analysis has been done using Excel pivot tables
| Row Labels | Description                                                                 | Definite | Probable |
|------------|------------------------------------------------------------------------------|----------|----------|
| G400       | LOCAL-RELATED (PART) IDIOPATH EPILEP/EPILEP SYND WITH SEIZ O                 | 1        | 0        |
| G401       | LOCAL-RELATED (PART) SYMPTOM EPILEPSY/EPILEPTIC SYND WITH SI                 | 1        | 0        |
| G402       | LOCAL-RELATED (PART) SYMPTOM EPILEPSY/ EPILEP SYND W/ COMPLE                | 1        | 0        |
| G403       | GENERALIZED IDIOPATHIC EPILEPSY AND EPILEPTIC SYNDROMES                     | 1        | 0        |
| G404       | OTHER GENERALIZED EPILEPSY AND EPILEPTIC SYNDROMES                           | 1        | 0        |
| G405       | SPECIAL EPILEPTIC SYNDROMES                                                  | 1        | 0        |
| G406       | GRAND MAL SEIZURES, UNSPECIFIED (WITH OR WITHOUT PETIT MAL)                | 1        | 0        |
| G407       | PETIT MAL, UNSPECIFIED, WITHOUT GRAND MAL SEIZURES                          | 1        | 0        |
| G408       | OTHER EPILEPSY                                                               | 1        | 0        |
| G409       | EPILEPSY, UNSPECIFIED                                                        | 1        | 0        |
| G410       | GRAND MAL STATUS EPILEPTICUS                                                 | 1        | 0        |
| G411       | PETIT MAL STATUS EPILEPTICUS                                                 | 1        | 0        |
| G412       | COMPLEX PARTIAL STATUS EPILEPTICUS                                           | 1        | 0        |
| G418       | OTHER STATUS EPILEPTICUS                                                     | 1        | 0        |
| G419       | STATUS EPILEPTICUS, UNSPECIFIED                                              | 1        | 0        |
| R568       | OTHER AND UNSPECIFIED CONVULSIONS                                            | 1        | 0        |
| F019       | VASCULAR DEMENTIA, UNSPECIFIED                                               | 0        | 1        |
| F100       | MENTAL AND BEHAVIOURAL DISORDERS DUE TO ACUTE INTOXICATION WITH              | 0        | 1        |
| F101       | MENTAL AND BEHAVIOURAL DISORDERS DUE TO HARMFUL USE OF ALCOHOL              | 0        | 1        |
| F102       | MENTAL AND BEHAVIOURAL DISORDERS DUE TO ALCOHOL DEPENDENCE                  | 0        | 1        |
| F103       | MENTAL AND BEHAVIOURAL DISORDERS DUE TO WITHDRAWAL OF ALCOHO                | 0        | 1        |
| F104       | MENTAL AND BEHAVIOURAL DISORDERS AND DELIRIUM DUE TO WITHDRAWAL             | 0        | 1        |
| F419       | ANXIETY DISORDER, UNSPECIFIED                                                | 0        | 1        |
| G439       | MIGRAINE, UNSPECIFIED                                                        | 0        | 1        |
| H538       | OTHER VISUAL DISTURBANCES                                                    | 0        | 1        |
| J690       | PNEUMONITIS DUE TO FOOD AND VOMIT                                            | 0        | 1        |
| K292       | ALCOHOLIC GASTRITIS                                                          | 0        | 1        |
| R402       | COMA, UNSPECIFIED                                                            | 0        | 1        |
| R410       | DISORIENTATION, UNSPECIFIED                                                  | 0        | 1        |
| R418       | OTHER & UNSPEC SYMPTOMS & SIGNS INVOLVING COGNITIVE FUNCTION                 | 0        | 1        |
| R42X       | DIZZINESS AND GIDDINESS                                                      | 0        | 1        |
| R451       | RESTLESSNESS AND AGITATION                                                   | 0        | 1        |
| R51X       | HEADACHE                                                                     | 0        | 1        |
| R55X       | SYNCOPE AND COLLAPSE                                                         | 0        | 1        |
| R600       | LOCALIZED ODEMA                                                              | 0        | 1        |
| R798       | OTHER SPECIFIED ABNORMAL FINDINGS OF BLOOD CHEMISTRY                        | 0        | 1        |
| S000       | SUPERFICIAL INJURY OF SCALP                                                  | 0        | 1        |
| S001       | CONTUSION OF EYELID AND PERIOCULAR AREA                                       | 0        | 1        |
| S008       | SUPERFICIAL INJURY OF OTHER PARTS OF HEAD                                    | 0        | 1        |
| S009       | SUPERFICIAL INJURY OF HEAD, PART UNSPECIFIED                                 | 0        | 1        |
| S010       | OPEN WOUND OF SCALP                                                          | 0        | 1        |
| Code  | Description                                                        | Count |
|-------|-------------------------------------------------------------------|-------|
| S018  | OPEN WOUND OF OTHER PARTS OF HEAD                                  | 0     |
| S019  | OPEN WOUND OF HEAD, PART UNSPECIFIED                              | 0     |
| S099  | UNSPECIFIED INJURY OF HEAD                                        | 0     |
| S308  | OTHER SUPERFICIAL INJURIES OF ABDOMEN, LOWER BACK AND PELVIS      | 0     |
| Z038  | OBSERVATION FOR OTHER SUSPECTED DISEASES AND CONDITIONS            | 0     |
| Z739  | PROBLEM RELATED TO LIFE-MANAGEMENT DIFFICULTY, UNSPECIFIED        | 0     |