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1 Title: Long term outcomes after epilepsy surgery, a retrospective cohort study
2 linking patient reported outcomes and routine healthcare data.

3

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28

29 **Highlights:**

- 30 • **We conducted a retrospective analysis of post epilepsy surgery outcomes from 3**
31 **different data sources: case notes, patient questionnaires and a national**
32 **anonymized linked health and population databank**
- 33 • **49% of patients were seizure free at last follow up (median follow up of 7 years)**
34 **with 88% having at least a worthwhile improvement in seizure frequency**
35 **following resective epilepsy surgery**
- 36 • **There was a significant increase in quality of life (QOLIE-31-P)**
- 37 • **There was a significant reduction for all cause hospital admissions post-surgery**
38 **and reduction in anti-epileptic drug load post-surgery**

39

40

41

42 **Abstract**

43 **Objective:** To assess the long-term outcomes of epilepsy surgery between 1995–2015 in
44 South Wales, UK, linking case note review, postal questionnaire and routinely-collected
45 healthcare data.

46 **Method:** We identified patients from a departmental database and collected outcome data
47 from patient case notes, a postal questionnaire and the QOLIE-31-P and linked with Welsh
48 routinely-collected data in the Secure Anonymised Information Linkage (SAIL) databank.

49 **Results:** 57 patients were included. Median age at surgery was 34 years (11–70); median 24
50 years (2–56) after onset of habitual seizures. Median follow-up was 7 years (2–19). 28 (49%)
51 patients were free from disabling seizures (Engel Class 1), 9 (16%) experienced rare
52 disabling seizures (Class 2), 13 (23%) had worthwhile improvements (Class 3) and 7 (12%)
53 no improvement (Class 4). There was a 30% mean reduction in total anti-epileptic drug
54 (AED) load at five years post-surgery. 38 (66.7%) patients experienced tonic-clonic seizures
55 pre-surgery versus 8 (14%) at last review. Seizure-free patients self-reported a greater overall
56 quality-of-life (QOLIE-31-P) when compared to those not achieving seizure freedom.
57 Seizure-free individuals scored a mean of 67.6/100 (100 is best), whereas those with
58 continuing seizures scored 46.0/100 ($p < 0.006$). There was a significant decrease in the
59 median rate of hospital admissions for any cause after epilepsy surgery (9.8 days per 1000
60 patient days before surgery compared with 3.9 after $p < 0.005$).

61 **Significance:** Epilepsy surgery was associated with significant improvements in seizures, a
62 reduced AED load and an improved quality-of-life that closely correlated with seizure
63 outcomes and reduced hospital admission rates following surgery. Despite this there was a
64 long delay from onset of habitual seizures to surgery. The importance of long-term follow-up
65 is emphasized in terms of evolving medical needs and health and social care outcomes.

66

67 **Abbreviations:**

68 AEDs, Anti-epileptic drugs; DRE, Drug resistant epilepsy; HS, Hippocampal sclerosis;

69 IGRP, Information Governance Review Panel; QOL, Quality of life; SAIL, Secure

70 Anonymous Information Linkage; VNS, Vagus nerve stimulator.

71

72 **Key words:**

73 Refractory epilepsy, Epilepsy surgery, Seizure cessation, Quality of life, Long-term outcomes

74

75

76 **1 Introduction:**

77 Epilepsy is a chronic condition with a prevalence of 50 million worldwide and an incidence
78 of 2.4 million per annum (1). In Wales, approximately 30,000 people suffer with epilepsy (2).

79 The main treatment of epilepsy is pharmacological intervention with anti-epileptic drugs
80 (AEDs). However, a third to a half of patients develop seizures that are resistant to AEDs,
81 referred to as drug resistant epilepsy (DRE) (3). DRE is commonly defined as a failure to
82 achieve sustained seizure freedom after treatment with at least two appropriately chosen and
83 appropriately used AEDs, in monotherapy or in combination (4-6). The reasons why DRE
84 develops remains unknown (7). **Delineation and surgical resection of epileptogenic brain
85 tissue is a treatment option with a strong evidence base for reducing or halting seizures
86 and reducing AED dependence, along with beneficial outcomes on quality of life (QOL)
87 in appropriately selected and evaluated cases (8-12).**

88 Delay from onset of habitual seizures and drug resistance to surgical treatment is well
89 recognized with intervals of several decades in most case series (11-14). One reason for this
90 delay may be poor knowledge of the available surgical options, and perception of patients,
91 carers and treating physicians. The time to surgery probably impacts on morbidity and
92 mortality (15), and those not proceeding to surgery have been found to be 2.4 times more
93 likely to die than those who did have surgery (16). Life expectancy itself has also been shown
94 to be on average five years longer in operated drug resistant epilepsy compared to those
95 remaining on medical therapy (17).

96 A small number of studies have looked at epilepsy surgery outcomes beyond five years (18-
97 23) with many others only reporting outcomes at three years or less (9, 10, 13). An important
98 outcome, in addition to seizure freedom, is change in AED treatment load post-surgery; one
99 review of outcome studies with more than five years follow up found that less than a quarter
100 of studies included outcomes on AED changes and patient QOL measures (21).

101 We therefore set out to study the long-term outcomes of epilepsy surgery at our center, that
102 serves a relatively stable population in South Wales, UK. We focused on seizure outcome
103 measures, quality of life, AED use and hospital admissions rates. **We aimed to access three**
104 **separate sources of information for our outcome measures: 1) the patients' clinical**
105 **records, 2) a postal questionnaire including the QOLIE-P31, 3) a national secure**
106 **database of anonymized health and social care records.**

107 **2 Methods**

108 Approval for the study was given by the hospital Continuous Service Improvement Office,
109 Cardiff and Vale University Health Board, Wales, UK. We identified 84 patients from the
110 epilepsy unit departmental database who had undergone resective epilepsy surgery between
111 1995 and 2015. We did not include patients where the primary aim of surgery was tumor
112 resection or those undergoing vagus nerve stimulator (VNS) implantation. We obtained
113 information for 84 patients by reviewing paper case notes and the hospital's online clinical
114 records portal [electronic front end for clinical investigations, attendances and letters (from
115 2008)]. All patients had undergone evaluation with video-EEG telemetry, MRI and pre-
116 operative psychological assessments. Patients operated before 2011 were evaluated with
117 video-EEG telemetry at Kings College Hospital, London, and thereafter all evaluations were
118 undertaken in Cardiff. Patients were operated by one of 2 neurosurgeons [RH (pre-2012) and
119 WG (post-2012)].

120 **2.1 Patient hospital records**

121 From the patient's hospital records we determined changes in seizure frequency and
122 character, time to surgery from initial diagnosis, changes in AEDs and any record of adverse
123 surgical events or psychiatric, cognitive and visual problems (pre-surgical baselines were
124 noted). We used Engel classification to determine seizure outcome at the most recent out-

125 patient appointment, where one is the best outcome and four the worst, with subcategories for
126 each class (appendix 1 – supplementary materials). This has good agreement with the ILAE
127 outcome scale (24) but maintains subcategories for seizure type e.g., focal versus bilateral
128 tonic clonic.

129 2.2 Questionnaire and QOLIE-31-P

130 A questionnaire was developed to identify the patient's current perspective on having
131 experienced epilepsy surgery including their report of seizure frequency (daily, weekly,
132 monthly, yearly and none in the past year), employment and driving status (appendix 2 –
133 supplementary materials). We also included the QOLIE-31-P which was originally developed
134 by Crammer to specifically assess the quality of life of people with epilepsy (25). The
135 QOLIE-31-P takes into account the patients' perception of: levels of energy, emotional toll,
136 daily activities, mental activity, medication effects, seizure attitudes and their feelings on
137 quality of life overall (appendix 3 – supplementary materials). Responses to the QOLIE-31-P
138 were scored according to standard instructions giving an overall score for each patient
139 ranging from 1–100 (100 being the best QOL) (25). Given the large number, type and doses
140 of AEDs to be assessed at different time points over a period of up to 20 years, comparison
141 over time can be difficult. We therefore developed a system to calculate a drug load or
142 burden with respect to the maximum recommended daily dose, as well as recording the total
143 number of AEDs. For each AED, we calculated a ratio of total daily dose taken compared to
144 the maximum recommended daily dose [from British National Formulary, March 2017(26)].
145 Thus, a patient taking the maximum recommended daily dose would score 1, a patient taking
146 50% of daily dose 0.5, and so forth. For example, a patient taking levetiracetam 1250mg BD
147 would score $2500/3000=0.83$ (3000mg being the highest recommended daily dose (26)).

148 2.3 Anonymised linked health care records

149 We used the Secure Anonymous Information Linkage databank (SAIL) (Health Data
150 Research UK, Swansea University) to anonymously link the list of patients having had
151 resective epilepsy surgery to routinely-collected primary care and hospital admission records
152 (27, 28). We included patients who were registered as living in Wales during the periods five
153 years before and after the epilepsy surgery. We recorded the length of stay for all hospital
154 admissions and total time registered as living in Wales before and after surgery excluding one
155 month immediately before and after surgery to exclude specific peri-operative related
156 hospital stays. We compared the rates of admission before and after surgery using a signed
157 Wilcoxon Signed-Rank test.

158 All studies using SAIL data need independent Information Governance Review Panel (IGRP)
159 approval but do not require specific NHS research ethics committee approval. This study
160 obtained IGRP approval ref 0565.

161 3 Results

162 We identified 406 cases as having epilepsy and neurosurgery in our department, from which
163 84 were identified as having resective epilepsy surgery. 64 sets of case notes were available
164 for review. We excluded a further seven cases [three had palliative not resective procedures,
165 two insufficient case notes, and two did not have neurosurgery (incorrectly identified)],
166 leaving a total of 57 patients for patient note review.

167 3.1 Results of hospital record review

168 Of the 57 patients forty-nine were right handed, seven left and one ambidextrous. 51% (29)
169 of patients had a history of febrile seizures, 47% were noted to have not suffered a febrile
170 seizure and one was undocumented. **Patients had a median age at surgery of 34, with the**
171 **median time between onset of habitual seizures and surgery being 24 years (range 2–**

172 **56). It would be important to record the time interval from consideration of epilepsy**
 173 **surgery to the surgery itself. However, we did not have access to these data. As a proxy,**
 174 **we recorded the date of video telemetry in 36 cases, there was a median interval of 12**
 175 **months (range 6-36) between video-telemetry and surgery.**

176

177 Median duration of outpatient follow up after surgery was seven years (range 1–19). **All 57**
 178 **patients had 1 year of follow up, with 40 still being followed up at 5 years, 25 at 7-8**
 179 **years, 22 at 10 years, 13 at 12-13 years and 3 at greater than 15 years.** Lateralization and
 180 histopathological diagnoses are shown in figure 1. We found a significant difference in the
 181 number of patients operated with left (n=28) and right (n=14) hippocampal sclerosis (HS)
 182 $p < 0.02$ (one sample binomial test).

183 The type of surgery is summarized in table 1.

184

Type of Surgery	Number of patients
Anterior temporal lobectomy	40 (27 left, 13 right)
Selective amygdalohippocampectomy	7 (5 left, 2 right)
Lesionectomy	10. Temporal, n=4: Epidermoid x2, DNET x2 Frontal, n=4: Ganglioglioma, Epidermoid, cortical dysplasia x2 Parietal, n=1: DNET Occipital, n=1: Ganglioglioma

185

186 Table 1: Type of surgical procedure undertaken. DNET; Dysembryoplastic Neuroepithelial
 187 Tumor

188

189 *3.1.1 Post-operative seizure outcomes*

190 49% (28) of patients were at Engel class 1 (free from disabling seizures), 16%(9) class 2,
191 23%(13) class 3 and 12%(7) at class 4 (no worthwhile improvement) (figure 2a) at last follow
192 up (median 7-years). Figure 2b demonstrates the change in time of Engle class of those
193 patients who were followed up at 1, 5, and 7-8 years (N= 57, 40, 25 respectively) A more
194 detailed breakdown of seizure type and frequency before and at one year following surgery
195 was also determined (figure 2c), and of seizure type and frequency at long term follow up
196 (figure 2d).

197 *3.1.2 Post-operative morbidity outcomes*

198 **10.5% (6) patients suffered surgical site infections with three requiring cranioplasty** and
199 one requiring an intensive treatment unit (ITU) admission. Three patients experienced
200 psychiatric events post-surgery that required inpatient stays. One of these required
201 involuntary detention under the mental health act after attempting suicide by violent means.
202 **40% (23) patients experienced at least partial upper quadrantanopia visual impairment**
203 on formal testing.

204 *3.1.3 Anti-epileptic drug usage*

205 Patient follow up data reduced with increasing time post-surgery, and therefore, total drug
206 consumption was calculated per capita (Figure 3). The mean number of AEDs pre-surgery
207 was 2.35, at last clinic appointment this figure had dropped to 1.83, a reduction of 22%. Of
208 the 20 patients who stopped AEDs entirely, only three remained seizure free with the
209 remaining 17 restarting AED treatment for seizure recurrence. Of the three seizure-free
210 patients, two stopped their AEDs, both stopped medication one year post-surgery and had
211 follow up at three and five years post operatively. **The third patient attempted to come off**
212 **medication at four years but unfortunately relapsed on this attempt and restarted**
213 **carbamazepine. However, after a second attempt at medication withdrawal they**

214 **remained seizure free at follow up, 13 years after surgery. Of the remaining 54 patients,**
215 **33 (61%) were on a reduced total AED load compared to pre-surgery, 13 were on the**
216 **same and eight were on a greater AED load.**

217 3.2 Results of postal questionnaire

218 **Of the 84 patients identified, 34 (40%) returned postal questionnaire and QOLIE-P31**
219 **forms, all completing both questionnaire and QOLIE-P31.** Four responses to the QOLIE-
220 P31 were excluded due to incomplete responses to the questions obviating score calculations.
221 Results of the questionnaire are summarized in table 2.

222 Table 2: Questionnaire responses for employment, driving and seizure status.

	Yes	No
Employment (Full or part time)	12	22
Driving	7	27
Seizure free	21	13

223
224 The seven patients who returned to drive did so at a mean of 3.5 years post-surgery.
225 Patients' questionnaire responses to seizure frequency can be seen in figure 2d. Two patients
226 (6%) experienced no reduction in seizure frequency, with the rest experiencing at least a one
227 class reduction. 13 (40%) patients reported seizure freedom. No patients reported worsening
228 seizures however, 3 patients reported that their QOL had decreased. 26 (76%) of the 34
229 patients reported that their QOL has improved to some extent (Figure 5).

230 3.3 QOLIE-P31 questionnaire

231 Scores were calculated from the 30 complete responses. The final score is a scale ranging
232 from 0–100, with a score of 100 being the best possible QOL. The mean score was 55.2 (s.d.
233 21.7). Those free of seizures scored a mean of 67.9 whereas those who did not achieve

234 seizure freedom scored 46.1, a difference of 21.6 (95% CI 7.0,37.9) $p < 0.006$ (Mann-Whitney
235 U).

236 3.4 Results of anonymized healthcare data

237 We were able to link 34 patients with routinely-collected healthcare data before and after
238 surgery. The proportion of men, mean age at diagnosis and age at surgery were 38%, 10
239 years and 36 years respectively in this sub-group.

240 There was a significant decrease in the median rate of hospital admissions for any cause
241 when comparing the five years after surgery with the five years immediately prior to surgery
242 (3.89 days per 1,000 patient days after surgery compared with 9.84 days per 1,000 days
243 before surgery $p < 0.005$) see figure 6.

244

245

246 **4.1 Discussion**

247 We conducted an evaluation of long-term outcomes in patients having undergone epilepsy
248 surgery in Cardiff, UK. We found that 49% of patients were free of disabling seizures (Engel
249 class 1) at their most recent outpatient visit, a median of seven years post-surgery (Range 2–
250 19). Our seizure outcome findings are similar to those reported by others five years post-
251 surgery, (18-23). The majority of patients were taking fewer AEDs following surgery.
252 QOLIE-P31 scores were significantly higher in those who achieved seizure freedom
253 compared to those who did not. There was close correlation between seizure outcomes,
254 subjective quality of life questionnaire responses and QOLIE-P31 scores in the postal
255 questionnaire/QOLIE-P31 cohort. The majority of patients responding to the questionnaire
256 reported a positive outcome after epilepsy surgery, even if not seizure free post-surgery. We
257 found a measurable reduction in total AED dosing following surgery, using a metric of ‘AED
258 load’, along with the total number of AEDs taken per person. We were able to link 34 of the
259 patients (60% of cohort) with 5 years of routinely-collected anonymized healthcare data
260 before and after surgery that showed a significant reduction in all hospital stays after surgery
261 for this cohort.

262 We found significantly more left HS resections when compared to right HS resections in our
263 series. This has also been reported by other centers. (29) The reasons are unclear, and we do
264 not know the overall prevalence of all HS in our epilepsy population, though a higher
265 prevalence of left compared to right HS has been reported by others (30, 31). We postulate
266 that left HS could have been more likely to come to surgery because of more debilitating
267 seizures (with loss of awareness), compared to right HS (32), or more likely to be present or
268 be under follow at tertiary centers for the same reason.

269 Previous studies have reported AED use and seizure freedom (21, 33), we found it
270 additionally helpful to develop a measure of AED burden as an outcome measure.

271 This showed a 30% reduction in drug dosage five years post-surgery in comparison to pre-
272 surgery. Previous literature has drawn associations with the AEDs themselves reducing QOL
273 (34) and AED cessation improving cognition (35). In our cohort 20 of the 57 patients had a
274 trial of complete AED withdrawal, and of those, only three remained seizure free and off
275 AEDs, this may reflect local practice of reducing to low dose single AED in preference to
276 recommending complete withdrawal, the latter generally occurring only in patients who were
277 seizure free and requesting to stop all AEDs.

278 Patients' subjective interpretation of their health seems to correlate with their clinical picture,
279 with 14.7% reporting no change or a decrease in their QOL on their questionnaire responses
280 with a similar percentage as those who class as Engel IV (Figure 2a). Although, these were
281 not necessary the same individuals, as responses and case notes could not be linked due to
282 questionnaires being anonymized at the start of data collection. Those completely seizure free
283 reported a significant difference in their QOLIE-P31 compared to those not seizure free
284 ($P < 0.006$). Of the 19 patients who returned their questionnaire who were still experiencing
285 seizures, 12 still described their QOL 'much improved' or 'very much improved' following
286 surgery, demonstrating the importance of recording patient's opinions and QOL measures in
287 addition to Engel scores.

288 **Although a majority of patients reported an increase in QOL post-surgery, many**
289 **burdens of their chronic disease including higher cognitive functioning persist. This**
290 **may explain why our patients' employment levels post-surgery remain low. Of the 38**
291 **patients in whom we had records for both pre and post-surgery neuropsychometry**
292 **testing, only 13% (5) had mild improvements to verbal memory. A majority showed**
293 **similar performance or a mild reduction in verbal memory compared to pre-surgery**
294 **testing. Age at surgery and duration of epilepsy are also likely factors in predicting**
295 **post-operative employment. Career prospects have been shown to be optimal when**

296 **surgery is performed at a young age with minimal time between habitual seizure and**
297 **referral (36). The median time of 24 years to surgery in our cohort was a likely factor in**
298 **low rates of employment after surgery even if seizure free.**

299

300 **Despite nearly 50% of our cohort being seizure free at their most recent outpatient**
301 **appointment, only 21% (7) were driving based on questionnaire responses. A previous**
302 **systematic review found wide variation in driving status post-surgery (7-65%), age at**
303 **surgery was a factor (37). National variation in transport links also likely contributes.**

304

305 **Previous studies have noted a wide range of visual field defects (VFD) (6-76%) following**
306 **temporal lobectomy or selective mesial resection. One report found that of the nearly**
307 **75% who experienced VFD, 48% had driving-relevant VFD (38, 39). 40% of our total**
308 **cohort were documented as having post-surgical VFD although the extent of the deficit**
309 **and impact on driving was not recorded. Questionnaires responses suggested ongoing**
310 **anxiety associated with driving. Many spent decades adapting their life to manage**
311 **without the need for driving and there was a sentiment of not wanting to ‘tempt fate’.**

312

313 **The goal of epilepsy surgery is to achieve long-term seizure freedom. The achievement**
314 **of seizure freedom is not a static event. Previous studies have found a correlation**
315 **between long term seizure freedom and absence of focal seizures with retained**
316 **awareness in the first 2 post-operative years (12)(40). In our cohort, eight patients who**
317 **were seizure free at one-year post-surgery experienced seizures in some capacity at five**
318 **years post-surgery. Our measure of AED load showed a continued fall until at least**
319 **eight years post-surgery. Had our follow up period been shorter, cases of relapse would**

320 **have remained unrecorded, and the extent of reduced AEDs would also have been**
321 **missed, emphasizing the need for longer term follow up.**

322

323 **Given the benefits of timely epilepsy surgery, it is important to highlight the need to**
324 **reduce the time taken to refer to epilepsy surgery. The reasons for delay are likely a**
325 **combination of the need for better information amongst the neurology community and**
326 **adequate resources. One study of 796 neurologists found over half would wait a year**
327 **before a surgical referral in those suffering from refractory epilepsy, over 75% felt the**
328 **greatest barrier was a lack of resources (41). Furthermore, the time to surgery after**
329 **initial pre-surgical evaluation is important and steps in the surgery pathway need to be**
330 **streamlined as far as possible.**

331

332 Linking our surgical cohort to the SAIL database of routinely-collected health care data
333 showed a clear reduction in hospital admissions as a marker of health care utilization post-
334 surgery. This represents an additional cost saving when coupled with the reduction in AED
335 costs.

336 Our study had limitations, mainly the retrospective data collection and the incomplete data
337 capture. This could have introduced bias, e.g., unavailable clinical notes in those lost to
338 follow-up, who perhaps had better seizure outcomes, subjective interpretation during clinical
339 assessments, and those who returned questionnaires, with only a 40% response rate being
340 biased toward those reporting improved (or otherwise QOL), or biased by their experience of
341 epilepsy surgery. Trying to ascertain why some in our cohort failed to achieve seizure
342 freedom is limited by sample size and retrospective review. Trying to establish causality as to
343 which pre-surgical factors could be a marker to surgical failure remains challenging. We
344 were also only able to link 60% of the patients with 10 years of their routinely-collected data

345 mostly due to incomplete historic data and lack of linkage due to changes of addresses
346 outside Wales. Nevertheless, we show significant changes in the factors we were able to
347 measure and demonstrate this as a way forward for future studies of post-operative epilepsy
348 surgery outcomes. **Finally, our cohort predominantly consisted of lesional temporal**
349 **epilepsy cases with hippocampal sclerosis and those with other cortically based lesions.**
350 **It is known that best surgical outcomes are seen in lesional temporal lobe cases and**
351 **future studies are needed to address outcomes from more complex epilepsy surgical**
352 **procedures (42).**

353

354

355 **5.1 Conclusion**

356 In summary, we demonstrate the demographics and benefits of epilepsy surgery in terms of
357 seizure outcomes, quality of life and health care utilization. We, as elsewhere, note a long
358 delay from diagnosis to surgery, and continued work is needed to improve this, in addition to
359 continued monitoring of long-term outcomes after epilepsy surgery.

360

361

362

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478 **Table and figure legends**

479

480 **Figure 1.** The histological causes of the epilepsy in our cohort of 57 patients.

481

482 **Figure 2. a).** Post-operative outcomes at most recent outpatient clinic (median follow up 7
483 years) - Engel classification. (see appendix 1). **b)** Engle classification of patients at 1, 5 and
484 7-8 years after their surgery. **c)** The type and frequency of seizures, pre-surgery and one year
485 after surgery. **d)** Type and frequency of seizures, against patient number and percentage at
486 their last outpatient clinic.

487

488 **Figure 3.** Drug use per capita in the years following surgery. The number on the Y axis refers
489 to the average anti-epileptic drug score per capita. AEDs were scaled, where 1 is the
490 maximum dose of single drug as recommended by the British National formulary (March
491 2017). Patients scores were added together to give an overall number and per capita
492 calculated.

493

494 **Figure 4.** Subjective QOL questionnaire responses ranging from one to 13 years post-
495 surgery.

496

497 **Figure 5.** Box and whisker plot showing the difference in quality of life of those who
498 achieved seizure freedom following surgery and those who did not.

499

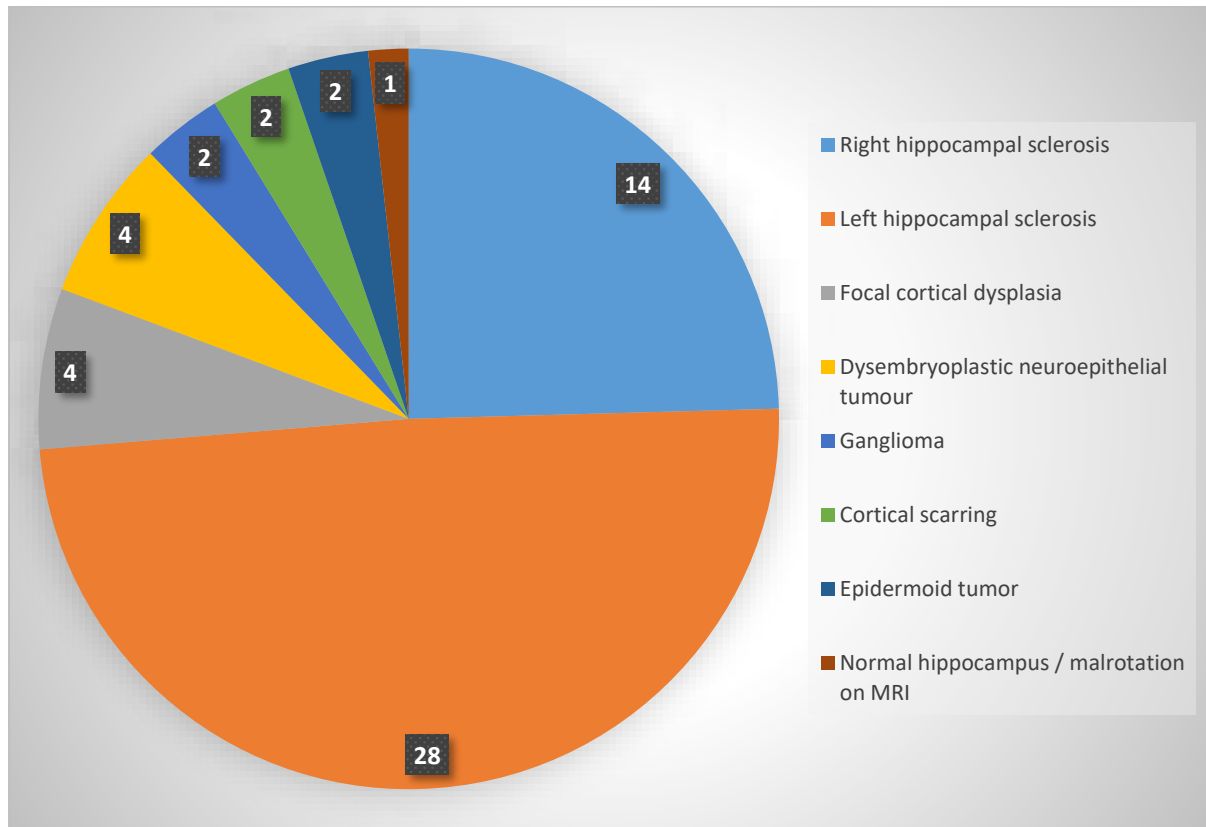
500 **Figure 6.** Box and whisker plot of admission rates per 1,000 days for the five years before
501 and after surgery. The median hospital admission rates were 9.84 per 1,000 patient days
502 before surgery vs 3.89 per 1,000 patient days after surgery.

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506 **Figure 1.**



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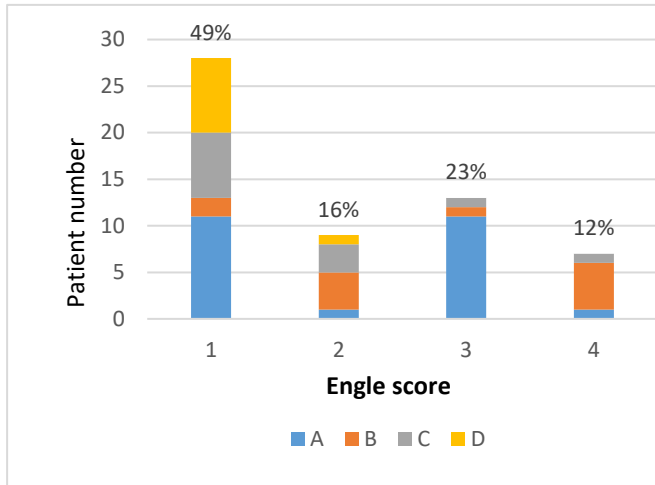
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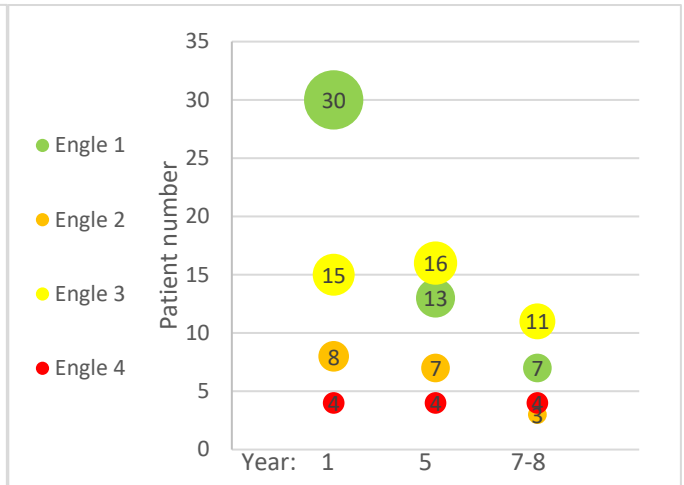
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511 **Figure 2**

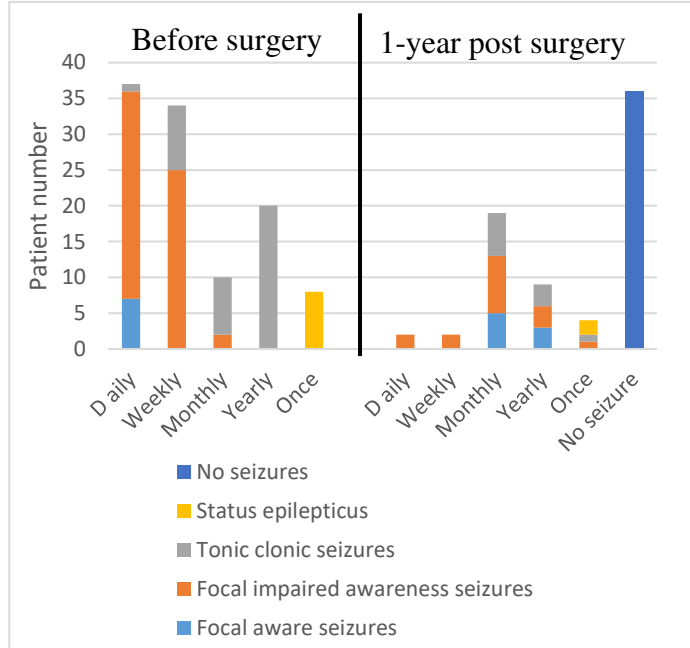
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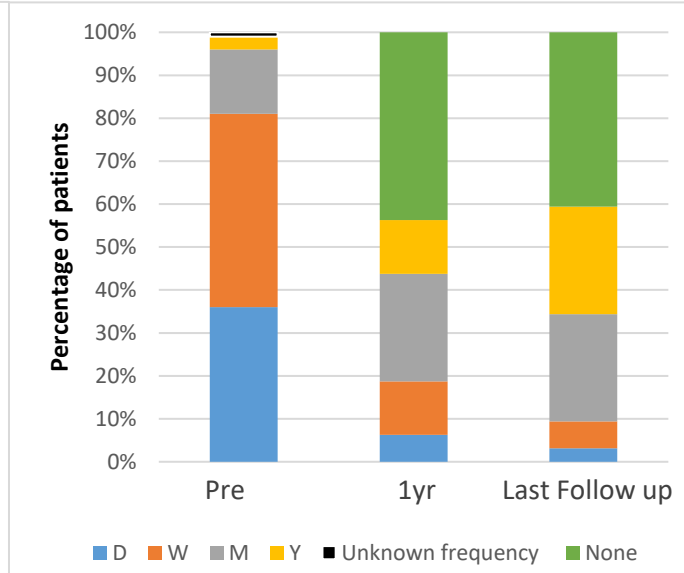
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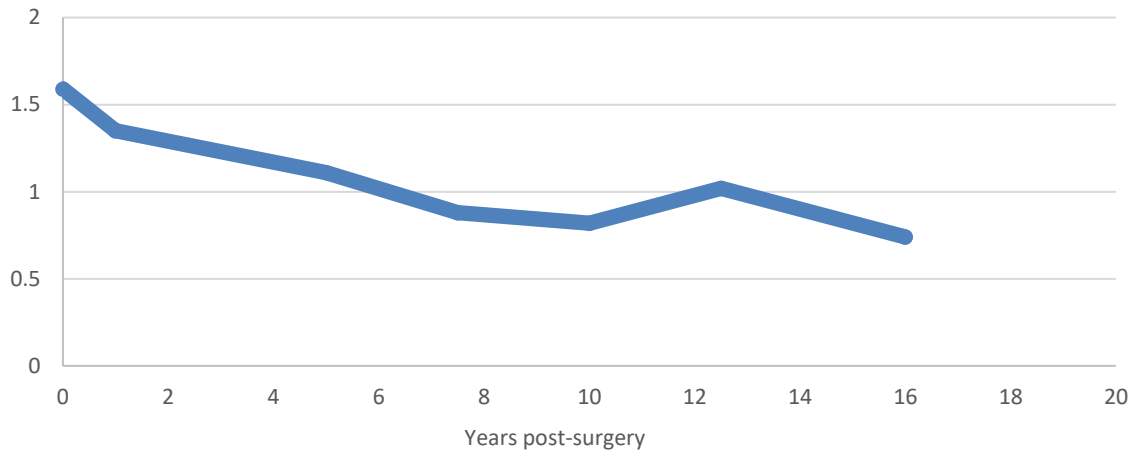
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530 **Figure 3.**

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Anti-
Epileptic
Drug
Dose



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535 **Figure 4.**

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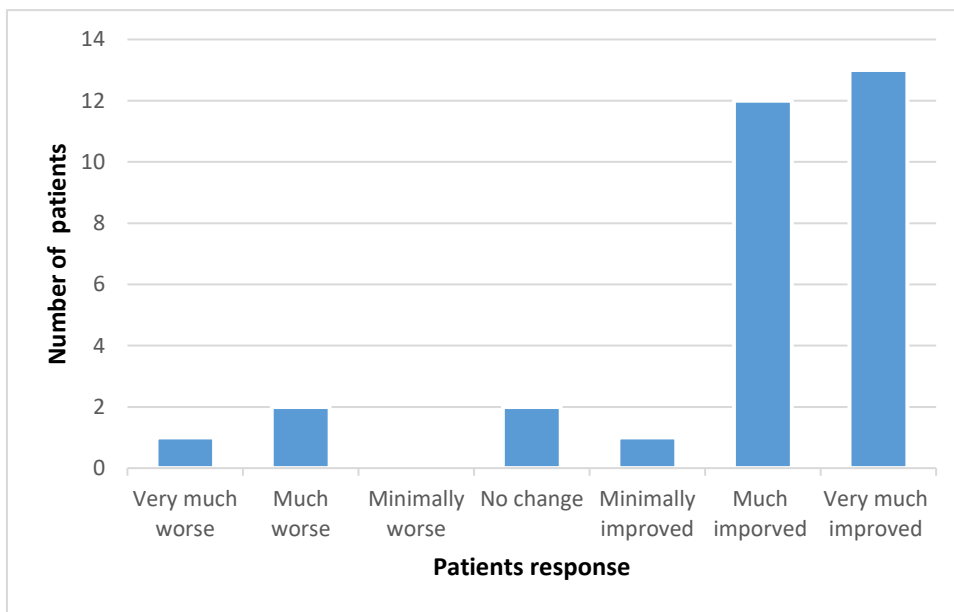
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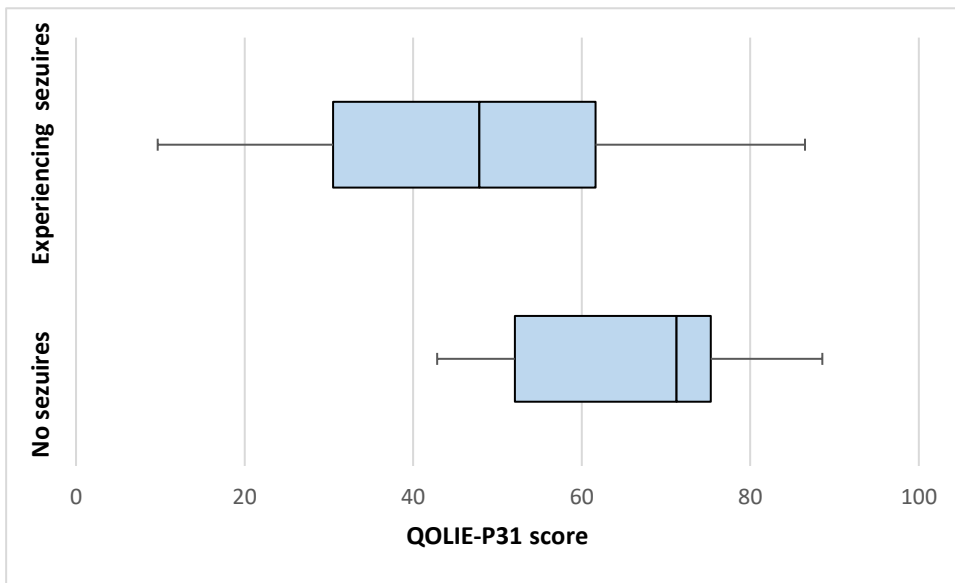
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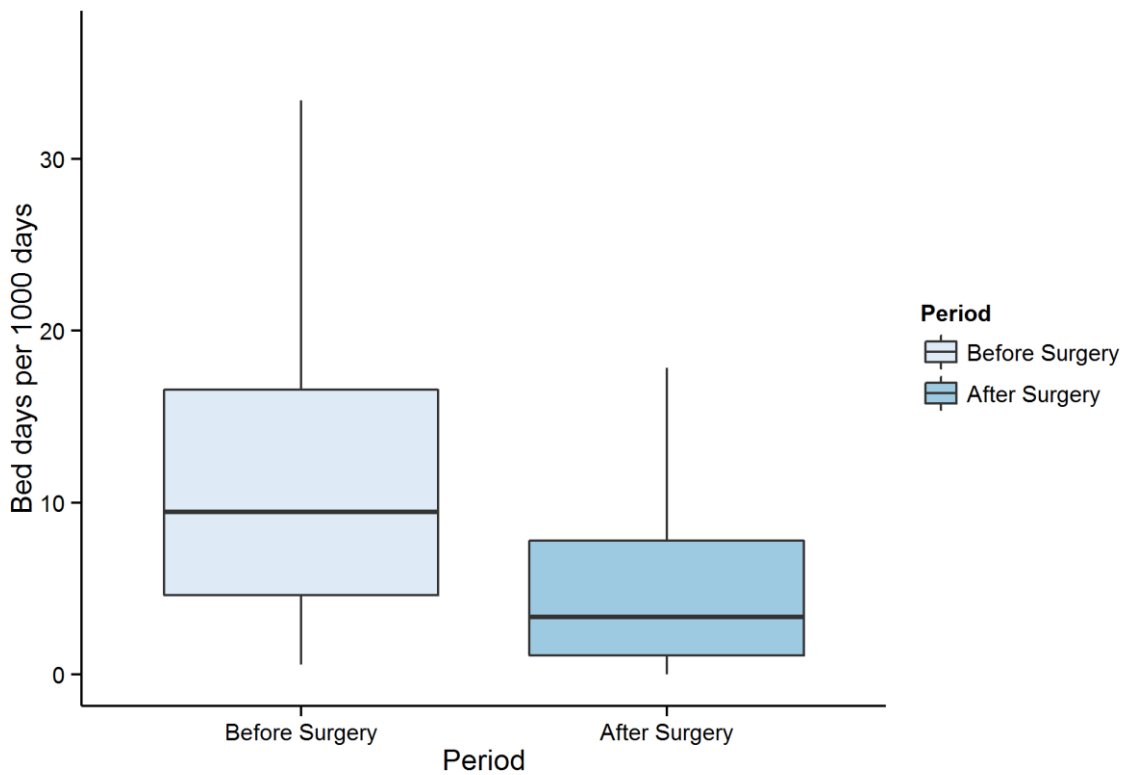
549 **Figure 5.**

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559 **Figure 6.**

Comparison of admission rates before and after surgery



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563 **Acknowledgements**

564

565 **This study makes use of anonymised data held in the Secure Anonymised Information**
566 **Linkage (SAIL) system. We would like to acknowledge all the data providers who make**
567 **anonymised data available for research. We thank our patients for their participation in**
568 **the survey and support from the Wales Epilepsy Unit.**

569 **Appendix 1: Engel classification score.**

Class I. Free from disabling seizures

- A. Completely seizure free since surgery
 - B. Non disabling simple partial seizures only since surgery
 - C. Some disabling seizures after surgery, but free from disabling seizures for ≥ 2 years
 - D. Generalized convulsions w/AED discontinuation only
-

570

Class II. Rare disabling seizures (almost seizure free)

- A. Initially free from disabling seizures, but still has rare seizures
 - B. Rare disabling seizures since surgery
 - C. Occasional disabling seizures since surgery, but rare seizures for the last 2 years
 - D. Nocturnal seizures only
-

571

Class III. Worthwhile improvement

- A. Worthwhile seizure reduction
 - B. Prolonged seizure-free intervals amounting to $>50\%$ of follow-up period, but not <2 years
-

572

Class IV. No worthwhile improvement

A. Significant seizure reduction

B. No appreciable change

C. Seizures worse

573

Appendix 2: Patient questionnaire:

Service Evaluation of Epilepsy Surgery in Wales

Patient Questionnaire

We would be grateful if you could take a couple of minutes to answer this questionnaire. Your answers will help us evaluate and improve the current services available to people with epilepsy in Wales.

Please tell us your full name, date of birth and address:

Full name:

.....

Date of birth:

.....

Address:

.....

When did you have surgery for your epilepsy?

.....

Where did you have surgery for your epilepsy?

.....

How old were you when you were diagnosed with epilepsy?

.....

Are you right-handed or left-handed?

.....

Epileptic Seizures

How frequent were your seizures before surgery?

- Every month
- Every week
- Every day

-
- Once or twice a year

Please tell us what kind of seizures these were:

.....

How frequent were your seizures in the first year after surgery?

- Every month
- Every week
- Every day
- Once or twice a year
- Never

Please tell us what kind of seizures these were:

.....

How frequent have your seizures been in the last year?

- Every month
- Every week
- Every day
- Once or twice a year
- Never

If 'never', please tell us when was the last time you had a seizure and describe what kind of seizure you had:

.....

Antiepileptic Medication

If you can, please tell us the **number** and **names** of the medications you were taking for your epilepsy in the year **before** surgery:

.....

If you can, please tell us the **number** and **names** of the medications you were taking for your epilepsy in the year **after** surgery:

.....

What medications are you taking for your epilepsy now?

.....

Did you have any complications following surgery for your epilepsy?

.....

Driving

Do you currently drive?

- Yes
- No

If you answered 'yes' to the previous question or have previously driven, please tell us how soon after your operation were you able to drive?

.....

Employment/Education

What is your current employment status?

- Full-time employment
- Part-time employment
- Unemployed
- In higher education

Please tell us your job and how your career has been influenced by your epilepsy

.....

Global Impression of Change and Quality of Life

Over the past year, how have you felt compared to before you had surgery for your epilepsy? (please tick the box that best describes your condition):

- Very much improved
- Much improved
- Minimally improved
- No change
- Minimally worse
- Much worse
- Very much worse

How has the quality of your life changed since you had surgery for your epilepsy?

- Very much improved
- Much improved
- Minimally improved
- No change
- Minimally worse
- Much worse
- Very much worse

Is there anything else you would like to tell us?

.....

If you are happy for your comments to be included (anonymously) in any publication, please indicate so here:

- I am happy for my comments to be used in any publication
- I do want my comments to be used in any final publication

Are you happy for us to contact you by telephone if further information is required?

- Yes
- No

My preferred phone number is

.....

and preferred contact time

.....

Thank you for taking the time to answer and return this questionnaire. We would appreciate if you could also answer the ‘Quality of Life in Epilepsy’ questionnaire. Your responses will be anonymised and will help us to review the outcomes of epilepsy surgery.

574 **Appendix 3: QOLIE 31-P**

575