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England

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# **Epidemiological assessment on proposed change to England's children's epilepsy surgery service specification**

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# 1. Introduction

This report was prepared by Public Health England (PHE) in collaboration with NHS England and was commissioned by NHS England's Women and Children Programme of Care Board. The report should be read in conjunction with NHS England's children's epilepsy surgery consultation response.

The assessment provides independent epidemiological evidence on how children's epilepsy surgery services (CESS) may be affected if the proposed changes to the current service specification are implemented. This assessment will help to inform the Women and Children Programme of Care Board on the next steps required for service improvement. The proposed changes are:

- to expand the list of operations to be undertaken at designated CESS centres
- to change the current service specification so that children of all ages (nought to 18 years inclusive) requiring epilepsy surgery undergo their operations at one of the four designated CESS centres only

PHE worked with commissioners, providers and clinicians to ascertain information and conduct the analysis for this report. Workstream outputs were agreed with NHS England in April 2015 as presented in the table below. Table 1 links each work stream output with its associated conclusion.

**Table 1. Report workstream and associated conclusion**

Workstream output	Associated conclusion
Overview of epilepsy surgery and invasive monitoring – current and projected population trends	Conclusion 1
Service trends and impacts	Conclusion 2
Regional and hub access to CESS centres	Conclusion 3
Current referral pattern and anticipated travel time	Conclusion 4
Clinically interdependent conditions/services	Conclusion 5
Emergency admissions for epilepsy and elective epilepsy surgery by deprivation quintile	Conclusion unable to be drawn therefore not presented in this report
Current levels of all paediatric neurosurgery activity	Conclusion unable to be drawn therefore not presented in this report

## 2. Methodology

Data presented in this assessment has been triangulated from:

- PHE sources
- NHS England sources
- providers of epilepsy surgery services

Our analysis included quantitative data generated from hospital episode statistics (HES), the Office for National Statistics (ONS) and provider-based activity (eg on patient numbers to help calibrate HES analyses using a bespoke proforma). Some qualitative questions were also collated through the bespoke proforma.

In each query we decided to count the number of unique patients rather than procedures in order to assess the anticipated impact of service change at a patient level. Patient counts are based on the unique patient identifier, HES Patient ID (HESID). We asked providers to count unique patients when providing data to us. Our HES methodology is presented in more detail in Appendix 1.

## 3. Surgery and invasive monitoring – current and projected population trends

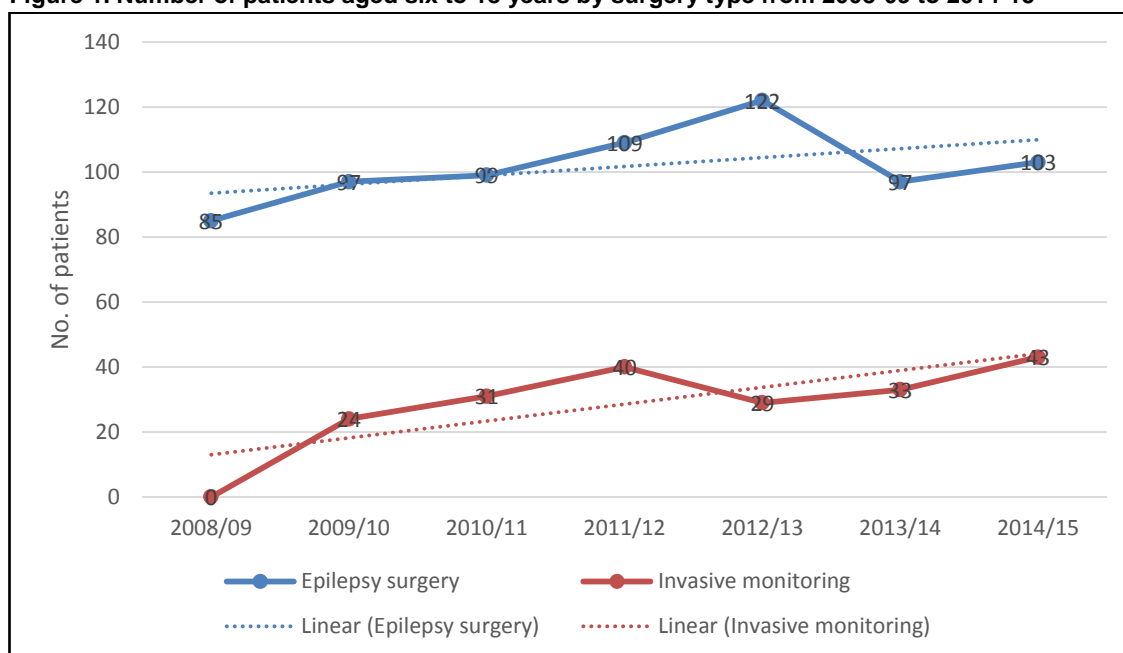
### What we did

HES data was extracted on the numbers of unique patients undergoing epilepsy surgery and invasive monitoring over the seven years between 2008-09 and 2014-15 (figure 1). We also calculated expected numbers of patients aged from nought to 18 years undergoing epilepsy surgery (table 2) and invasive monitoring (table 3) in 2037 based on ONS population projections.

### Key points (figure 1 below)

- epilepsy surgery (elective and non-elective): steady increase in patient numbers, but decrease in 2013-14 (this may be due to better selection of patients hence an increase in invasive monitoring in the same period is seen) and small increase in 2014-15
- invasive monitoring: increase from nought in 2008-09 to 43 patients in 2014-15

**Figure 1. Number of patients aged six to 18 years by surgery type from 2008-09 to 2014-15**



Source: HES, Health and Social Care Information Centre

**Table 2. Expected numbers of patients aged nought to 18 years for epilepsy surgery based on population projections**

NHS England commissioning hub region	Epilepsy surgery patient numbers 2014-15	Crude epilepsy surgery rate per 100,000	Expected epilepsy surgery patient numbers in 2037
England	147	1.21	160
East Midlands	14	1.33	15
East of England	16	1.18	18
London	18	0.91	22
North East and Cumbria	*	-	*
North West	9	0.60	9
South East	*	-	*
South West	19	1.93	21
Wessex	7	0.65	7
West Midlands	21	1.59	22
Yorkshire and Humber	16	1.30	17

Note: Due to information governance purposes, patient numbers of six or fewer in this instance are suppressed

Source: ONS, HES, Health and Social Care Information Centre

**Table 3. Expected numbers of patients aged nought to 18 years for invasive monitoring based on population projections**

NHS England commissioning hub region	Invasive monitoring patient numbers 2014-15	Crude invasive monitoring rate per 100,000	Expected invasive monitoring patient numbers in 2037
England	60	0.49	65
East Midlands	9	0.86	10
East of England	7	0.52	8
London	6	0.30	7
North East and Cumbria	*	-	*
North West	6	0.40	6
South East	*	-	*
South West	10	1.01	11
Wessex	*	-	*
West Midlands	11	0.83	12
Yorkshire and Humber	*	-	*

**Note:** Due to information governance purposes, patient numbers of five or fewer are suppressed

**Source:** ONS, HES, Health and Social Care Information Centre

## Conclusion 1

- 147 children aged nought to 18 years underwent surgery for epilepsy in 2014-15, of these 103 were aged six to 18 inclusive
- 60 children aged nought to 18 years underwent invasive monitoring in 2014-15, of these 43 were aged six to 18 inclusive
- despite increases in activity seen up to 2012-13 for epilepsy surgery and an overall increase in invasive monitoring (figure 1) for children six to 18 years old, modelling for population changes suggests there is no evidence that an overall significant increase in surgical caseload will occur in England (tables 2 and 3)
- for service planning purposes NHS England extrapolated evidence from a population-based study performed in Connecticut, USA, which suggested that around 350 children per year would benefit from epilepsy surgery (Berg AT, Mathern GW, Bronen RA et al, 2009). This is the best available data, therefore a good model for service planning purposes

- PHE concludes that any increase in patient numbers will most likely be due to a change in referral practice

### Recommendations

- NHS England should continue to monitor activity patterns for epilepsy surgery and this will be facilitated through the ORION database
- CESS centres with the support of NHS England commissioners should work with paediatric neurologists to ensure that early identification and awareness of referral criteria is maximised

## 4. Service trends and impacts

### What we did

HES data was extracted on the numbers of unique patients undergoing epilepsy surgery. We cut the data into two time frames 'pre-CESS' (19 months) and 'post-CESS' (29 months) to account for the impact of the current service specification which designated CESS centres for children under six years old on 1 November 2012. Although data for 2014-15 is included within the 'post-CESS' time period, we separated data out for this year in some instances in order to obtain a better understanding of service utilisation.

### Conclusion 2

The requirement that epilepsy surgery for children **under six years** be undertaken at designated CESS centres from 1 November 2012 has resulted in an increased proportion of cases undertaken at these centres:

- 93% of children under six between November 2012 and March 2015 had their surgery at a CESS centre. In absolute numbers, 99 out of 106 children under six between November 2012 and March 2015 had their surgery at a CESS centre. Seven children had their surgery at a non-CESS centre
- this compares to 81% pre November 2012, or 55 out of 68 patients
- in 2014-15, 44 out of 46 (96%) patients were operated on at a CESS centre

For **six to 18-year olds**, there has been no change in the proportion of children having surgery at a CESS centre post November 2012:

- 80% of children aged six to 18 between November 2012 and March 2015 had their surgery at a CESS centre. In absolute numbers, 195 out of 244 children aged six to 18 between November 2012 and March 2015 had their surgery at a CESS centre.



Forty-nine children had their surgery at a non-CESS or other paediatric neuroscience centre

- this compares to 77% pre November 2012, or 141 out of 184 patients
- in 2014-15, 84 out of 103 (82%) patients were operated on at a CESS centre
- based on the 2014-15 data, **the proposed service change would impact on 18 patients or fewer (if efforts to refer early continue)**

For **16 to 18-year olds** there has been an increase in the proportion having surgery at a **non-CESS** centre:

- 33% of children aged 16 to 18 between November 2012 and March 2015 had their surgery at a non-CESS centre. In absolute numbers, 18 out of 54 children aged 16 to 18 between November 2012 and March 2015 had their surgery at a non-CESS centre. Thirty-three children had their surgery at a CESS centre and three at other paediatric neuroscience centres
- this compares to 20% pre November 2012, or nine out of 45 patients
- this may be due to patients opting to follow the adult pathway as opposed to the paediatric pathway
- in 2014-15, eight out of 22 (36%) patients were operated on at a non-CESS centre, the rest were operated at a CESS centre
- based on 2014-15 data, **the impact of this service change would affect eight patients in this age group**

Out of the 103 patients who underwent epilepsy surgery aged six to 18 years in 2014-15, 18 cases were undertaken at a non-CESS centre. Of these 18 cases, eight were aged between 16 to 18 years. Evidence shows that there are small numbers of cases aged six to 18 years undertaken at non-CESS centres.

## Recommendations

- NHS England should ensure a strong network approach between CESS centres and non-CESS/other paediatric neuroscience centres, with joint multi disciplinary teams (MDTs). These MDTs should be for all ages up to 18 years inclusive
- NHS England should ensure clear transition protocols are robustly implemented for 16 to 18-year olds
- for 16 to 18-year olds, CESS centres should continue (in line with the service specification) to demonstrate clear working relationships with adult epilepsy surgery units. Planning the transition from children's to adult services should be initiated at least by age 16

## 5. Regional and hub access to CESS centres

### What we did

HES data was extracted on the numbers of unique patients undergoing epilepsy surgery in different NHS England commissioning regions and commissioning hubs. We attempted to generate regional prevalence of epilepsy prevalence in children using data from the Clinical Practice Research Datalink (CPRD).

### Conclusion 3

- regional analyses are confounded by the small numbers having epilepsy surgery
- between regions there are differing proportions of surgery taking place at CESS centres versus non-CESS/other paediatric neuroscience centres
- data on regional epilepsy prevalence in children is not available, however, from other service reviews, often distance/proximity to a specialist centre influences awareness of referral pathways and has an impact on referrals

### Recommendations

- NHS England should monitor differences in patterns of referrals for paediatric epilepsy surgery between regions

## 6. Current referral pattern and anticipated travel times

### What we did

HES data was extracted on the numbers of unique patients undergoing epilepsy surgery. We worked out how many of these patients fall outside a 90-minute travel time from a CESS centre. We also mapped where patients live and which provider operated on them (figure 2).

### Conclusion 4

- several communities in the North East, East of England and South West appear to be affected more by the distance required to travel to a CESS centre (measured as >90 min travel time from CESS centre)

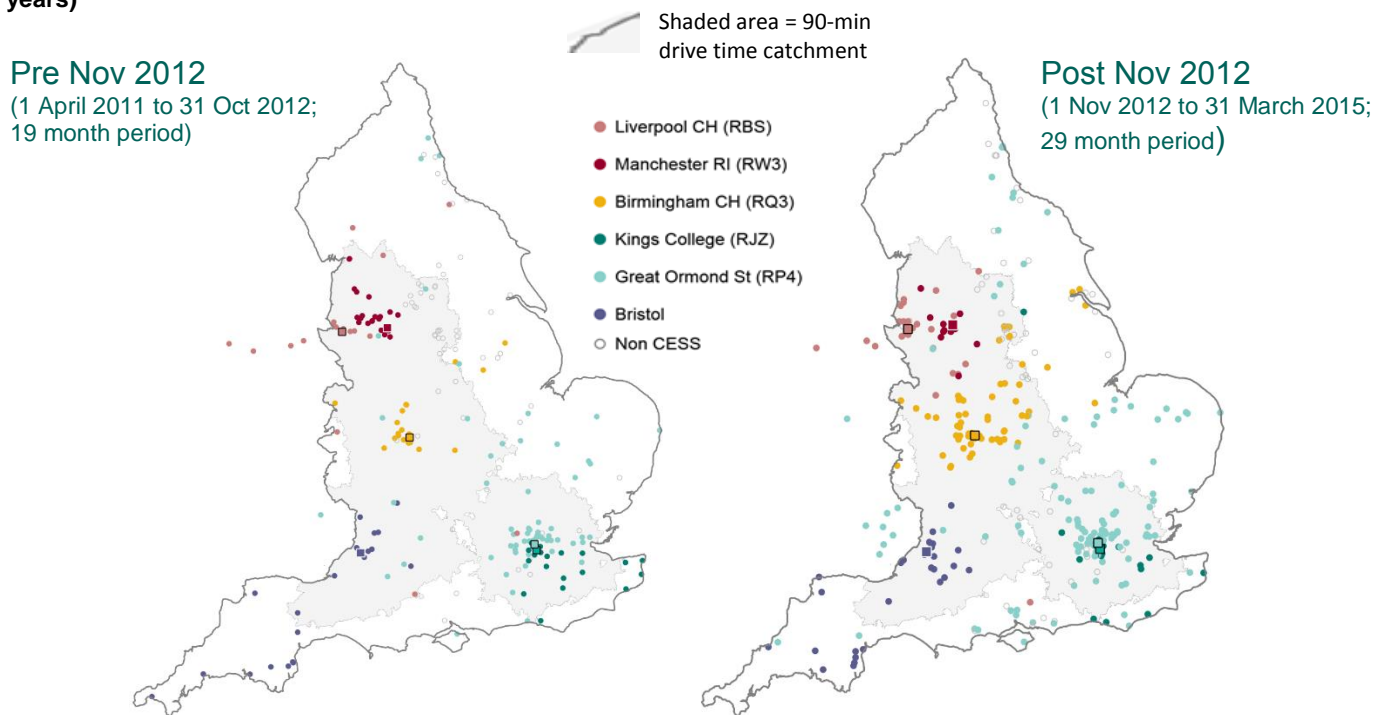
- in these areas, analyses show that the majority of these patients have had surgery at Great Ormond Street Hospital in London
- the majority of these epilepsy surgery operations are elective, not emergency
- the impact of increased distance and travel times is therefore likely to be one of patient and family experience of care further away from home

### Recommendations

- NHS England commissioners should ensure that referral pathways for access to children's epilepsy surgery are adhered to and that non-CESS and other paediatric neuroscience centres are referring to their designated CESS centre, while also considering patient choice
- NHS England should consider ways to minimise travel and provide support to patients and their families where travel is required

Figure 2 below shows the spread of epilepsy surgery cases undertaken by different providers in England over a four-year period. This time period has been split into pre-CESS (19 months) and post-CESS (29 months). Each dot represents at least one patient who lives within that lower layer super output area (LSOA). It is not possible to represent volume of patients within each LSOA due to information governance restrictions. This figure shows that Great Ormond Street Hospital continues to be a leading centre for epilepsy surgery and serves a wider population than that of London and South East of England.

**Figure 2. Children's epilepsy surgery within a 90-minute drive time from a CESS centre (patients aged nought to 18 years)**



Source: HES, Health and Social Care Information Centre

## 7. Clinically interdependent conditions/services

### What we did

HES data was extracted to include all patients who had epilepsy surgery in 2013-14 and 2014-15, aged six to 18 years inclusive. For these patients, details of previous hospital admissions were extracted within the 12-month period prior to their operation.

### Conclusion 5

- interdependencies: the data shows that there is an overlap with specialist oncology services which is also supported from the provider feedback

### Recommendations

- NHS England should ensure that the service specification accounts for interdependencies in the proposed clinical model and the MDT membership
- the above can be achieved with the support of a strong networked model as per previous recommendations

## 8. References

Berg AT, Mathern GW, Bronen RA et al. Frequency, prognosis and surgical treatment of structural abnormalities seen with magnetic resonance imaging in childhood epilepsy. *Brain* 2009;132;2785-2797

# Appendix 1: Methodology of epidemiological assessment

## What we counted

We decided to count the number of unique patients in each query. Patient counts are based on the unique patient identifier, hospital episode statistics patient identifier (HESID). This identifier is derived from a patient's date of birth, postcode, sex, local patient identifier and NHS number, using a standard algorithm.

Note: where data are incomplete, HESID might wrongly link episodes or fail to recognise episodes for the same patient. Care is therefore needed, especially where the data includes duplicate records. Patient counts that are summed across a table where patients may have episodes in more than one cell may lead to duplication.

Where data are presented as \* it is too small (5 patients or fewer) to be shared for information governance purposes.

## Time periods

We decided to look at hospital episode statistics (HES) data between 2011-12 and 2014-15. We cut the data into three time frames below.

Time frame one: 1 April 2011 to 31 October 2012 (19 months)

Time frame two: 1 November 2012 to 31 March 2014 (17 months)

Time frame three: 1 April 2014 to 31 March 2015 (12 months)

Time frame one is before CESS centres were established and is described as 'pre-CESS'. Time frames two and three are described as 'post-CESS'. We separated out 2014-15 data in some instances as HES data is provisional for this time period, and often underreports.

## Geography

Geography varied by query. We cut the data by provider, NHS England commissioning region and NHS England commissioning hub.

## Provider codes

A single valid code was used which means all hospitals within each trust were included.

## Age groups

We chose to separate three age groups of children and young people aged nought to 18 years inclusive:

- Nought to five years inclusive – surgery already undertaken at CESS centres solely
- Six to 18 years inclusive – surgery proposed to be undertaken at CESS centres solely
- 16 to 18 years inclusive – patients in this age group may decide to follow the 'adult' pathway and choose to have their surgery at a wider number of centres

### Coding strategy

For the diagnosis code, we chose G40 (epilepsy) from the international classification of diseases 10 (ICD-10). The procedural codes are listed in the table below and are derived from the Operating Procedure Codes (OPCS) Classification of Interventions and Procedures.

Surgery type	Coding method
Epilepsy surgery	Count distinct patients WHERE any diagnosis position = 'G40' and any procedure position = A01, A02, A03, A075, A076, A077, A078, A079 and start age <19 years
Invasive monitoring	Count distinct patients WHERE any diagnosis position = 'G40' and any procedure position = A11 and start age <19 years
Vagal nerve stimulation (VNS)	Count distinct patients WHERE any diagnosis position = 'G40' and any procedure position = A09 and start age <19 years
Neurosurgery*	Count distinct patients WHERE any procedure position between A00 and A81 and start age <19 years

\*There was not a diagnosis code associated with 'Neurosurgery' as the purpose of this measure was to measure gross neurosurgery activity at centres, and not just limit to patients with a diagnosis of epilepsy.