

**Consultation Guide:
Proposed Changes to
the Service
Specification for the
Children's Epilepsy
Surgery Service
(CESS)**



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Consultation Guide: Proposed Changes to the Service Specification for the Children's Epilepsy Surgery Service (CESS)

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Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

Contents

Contents.....	4
1. Introduction	5
2. Background.....	6
3. The proposals	8
4. The case for change	9
5. Why are we consulting?	11
6. Consultation questions.....	12
7. Feedback and next steps	12

1. Introduction

- 1.1. More than 600,000 people in England have epilepsy and there are over 50,000 children and young people aged 18 or under with epilepsy. People with epilepsy are prone to seizures – sudden bursts of intense electrical activity in the brain which cause temporary disruption to the way the brain normally works.
- 1.2. Epilepsy can often develop without an obvious underlying cause, but it may be associated with abnormalities of brain development, and can be the result of damage to the brain by trauma, infection or stroke as well as sometimes being associated with brain tumours. The condition is usually treated with medicines, to try and reduce, or stop, the seizures from happening.
- 1.3. Surgery can also be used to try and stop seizures, to reduce the number of seizures, or to make them less severe. However it is essential that children are carefully selected so that the correct operation is performed and this assessment needs the combined expertise of a multidisciplinary team. Epilepsy surgery in infancy and early childhood is increasingly recommended because it may prevent many years of unnecessary seizures. Surgery can help prevent or reduce the impaired development and behaviour that is sometimes caused by early onset seizures. There is also evidence of better long-term outcomes and a possible reduction in early mortality, if surgery is carried out at an early stage.
- 1.4. The Children’s Epilepsy Surgery Service (CESS) is commissioned by NHS England to provide specialist pre-surgical evaluation and surgery to children in specialised CESS centres across England.
- 1.5. A service specification for CESS sets out the standards those children’s epilepsy surgery centres have to meet in order to provide this service for children and young people.
- 1.6. NHS England, supported by clinical advice from its Paediatric Neurosciences Clinical Reference Group (CRG) wishes to make a number of changes to the current published specification, in order to ensure that the CESS continues to provide a safe, effective and high quality service for all patients requiring this form of surgery.
- 1.7. NHS England’s Clinical Priorities Advisory Group has recommended that the proposed changes should be the subject of a 12 week public consultation. This consultation guide is designed to provide those with an interest in this important service, and who have a view about the proposals, to contribute to the consultation in an informed manner.

2. Background

2.1. There is evidence that more children in England should be considered for epilepsy surgery than are currently being referred. This comes from a population-based study performed in Connecticut, USA, the results of which suggest that around 350 children a year in England would benefit from surgery.¹

2.2. In fact, much smaller numbers were undergoing epilepsy surgery in England:

	0-5 years	6-18 years	Total
All trusts in England	38	99	137
Great Ormond Street Hospital for Children NHS Foundation Trust	22	35	57
Kings College Hospital NHS Foundation Trust	6	7	13
University Hospitals Bristol NHS Foundation Trust	1	11	12
Central Manchester University Hospitals NHS Foundation Trust	2	9	11
Birmingham Children's Hospital NHS Foundation Trust	1	9	10
Alder Hey Children's Hospital NHS Foundation Trust	2	3	5
All remaining trusts	4	25	29

Table 1: Summary of procedures containing epilepsy diagnosis by age. 2010-2011 Hospital Episode Statistics activity. Excludes vagal nerve stimulation and invasive monitoring. (National Cancer Services Analysis Team)

2.3. For comparison, the numbers of children who have epilepsy surgery per year in other European centres are: Bielefeld 40, Utrecht 50, Rome 20-30, Prague 30, and Florence 15 (new centre). In a survey of paediatric epilepsy surgery centres around the world, 42 replied and the average number of children having operations was 49 per centre per year.²

2.4. The CESS was established in November 2012. Four centres in England were designated to provide surgical services for those children who might benefit from surgery, following a rigorous evaluation process involving independent, international experts.

2.5. Prior to this, Great Ormond Street Hospital for Children NHS Foundation Trust in London had been leading the way in the development of children's epilepsy surgery, having established a service in the 1990s, at a time when few centres were performing such complex operations. The development of the CESS, and the designation of the four centres, meant that there was the opportunity to

¹ 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

² American Epilepsy Society, December 2013

provide a high quality service across a wider geographical area. The four CESS centres are:

- Birmingham Children's Hospital NHS Foundation Trust
- University Hospitals Bristol NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust designated with Kings College Hospital NHS Foundation Trust
- Alder Hey Children's Hospital NHS Foundation Trust and Central Manchester University Hospitals NHS Foundation Trust

2.6. The purpose of the designation process was to improve the quality of the services offered to patients by concentrating expertise in the four CESS centres, and to increase the number of children assessed and treated. It is anticipated that the four centres will eventually see around 1,050 referrals each year in total, with around 350 children going on to have surgery.

2.7. To enable the centres to meet this ambition, NHS England has developed plans, in conjunction with the centres, which will allow them to increase their capacity at the same time as meeting the rigorous standards expected for the delivery of a safe epilepsy surgery service for children.

2.8. A National Clinical Co-ordinating Group, which includes representatives from the CESS centres, as well as national clinical advisors, has been established. The Group ensures the centres operate in a consistent way across the country in relation to the collection of data and in jointly discussing cases as part of a national CESS multi-disciplinary team, sharing experiences and improving standards nationally.

2.9. In 2010-2011 (prior to the CESS being established) 137 epilepsy surgery operations were carried out in England across all centres, on children and young people aged 18 and under. 38 of the 137 operations were carried out on children aged under six. Fifty seven of the 137 operations were carried out at Great Ormond Street Children's Hospital NHS Foundation Trust, of which 22 were on children aged under six.

2.10. Because so few children aged under six have operations in CESS centres outside of Great Ormond Street Children's Hospital NHS Foundation Trust, it is a requirement that all of these children's cases are discussed with the multi-disciplinary team at Great Ormond Street Hospital. It also a requirement that the CESS national clinical advisors Professor Helen Cross and Mr William Harkness are involved in the planning and execution of these operations whilst local expertise and experience is built up.

2.11. In addition to this, the CESS centre multi-disciplinary teams are responsible for discussing the management of all children being considered for epilepsy surgery with other paediatric neuroscience centres in their network, as set out in the service specification.

2.12. The four CESS centres are making good progress. Activity has increased - in January - June 2013 there were 202 referrals to CESS centres, increasing to

271 referrals in the same period in 2014. Similarly the number of operations for epilepsy (excluding vagal nerve stimulation) performed in the CESS centres increased by 50% from 62 to 93 in those periods.

3. The proposals

3.1. The current service specification, which was adopted in May 2013, sets out a list of operations which should be performed in the four CESS centres.

3.2. The specification states that: *specialist epilepsy surgery should be provided in a CESS centre for children needing the following:*

- *Hemispheric procedures*
- *Invasive EEG monitoring*
- *Surgery for Rasmussen's*
- *Tuberous Sclerosis*
- *Hypothalamic Hamartoma*
- *Sturge Weber Syndrome*
- *Peri-central lesions*
- *Complex temporal lobe surgery*³

3.3. The current service specification also states that:

- *Specialist epilepsy surgery for children who are five years and under will only be provided at a designated centre.*
- *Invasive monitoring and above surgical procedures can be undertaken in a network children's neurosurgical centre if the centre meets the agreed service specifications and standards.*

3.4. Because the list of operations that should be performed in a CESS centre is so important in terms of the management of these complex cases for reasons outlined below, NHS England sought independent expert advice about which operations should be included on it. The list was prepared by the two national clinical advisors to the CESS – Professor Helen Cross and Mr William Harkness, acknowledged experts in the field.

3.5. The list was considered and commented on by two independent international experts, who were part of the evaluation panel that visited and selected the four CESS centres.

3.6. They agreed with the prepared list, which expands the types of operations which should be carried out in a CESS centre. The revised list is:

- Hemispheric procedures
- Invasive EEG monitoring

³ *Complex temporal lobe surgery especially of dominant hemisphere which will require language mapping, depending on complexity and the expertise developed within the area served by the CESS*

- Surgery for Rasmussen's
- Tuberous Sclerosis
- Hypothalamic hamartoma
- Sturge Weber Syndrome
- Peri-central lesions
- Peri-insular lesions
- All temporal lobe resections
- Multilobar resections or disconnections
- Lobar resections
- Cortical resections for malformations of cortical development (e.g. focal cortical dysplasia, polymicrogyria)
- Callosotomy

3.7. The independent experts agreed that children of *any* age having epilepsy surgery procedures shown on the list should have their operations done in one of the four CESS centres.

3.8. They also recommended that a small number of cases may be considered for surgery outside a CESS centre – lesionectomies for glioneuronal tumours, and cavernomas or AVMs where the lesion is in non-eloquent cortex.

3.9. The proposal, therefore, is:

to change the current service specification so that all patients requiring operations as set out in the list shown in para 3.6 above, undergo their operations in one of the four CESS centres, and not in a non-CESS centre.

3.10. This would mean:

- Expanding the list of cases in the service specification as shown in para 3.6 above and
- Removing the statements that children on that list aged six years and older can have their operations in non-CESS centres if those centres meet the agreed service specifications and standards.

4. The case for change

4.1. There is a significant difference between the number of children's epilepsy surgery operations performed at Great Ormond Street Children's Hospital NHS Foundation Trust and those performed in all of the other neurosurgery centres. In order to create a truly world-class children's epilepsy surgery service, providing high quality, safe and effective services it is imperative that the three remaining CESS centres, outside Great Ormond Street Hospital, receive a sufficient number of cases to enable them to increase their experience and expertise. These goals cannot be achieved if expertise and experience are diluted.

4.2. Children aged under six are already required to be referred to a CESS centre. However, most children having surgery in non-CESS centres are older than this.

If there is no change in the service specification there is a danger that the CESS centres will not be referred sufficient numbers to build up their expertise to international standards. .

- 4.3. The current service specification states that all children, of any age, being considered for epilepsy surgery, should be discussed in the multi-disciplinary team of the relevant CESS centre. It would greatly help the work of these teams if there was national agreement about the list of cases that should be operated on in CESS centres whatever the age of the child. Without an agreed list, there is the potential for disagreement between CESS centres and networks about the management of patients.
- 4.4. If non-CESS centres continue to operate on children aged six and over, who require epilepsy surgery, then an assessment process will be required to ensure that they meet the stringent criteria for providing such a service to children and young people.
- 4.5. A key aim of the proposed changes is to ensure that an increasing number of children aged under six undergo epilepsy surgery as there are good reasons to believe that this would lead to an improvement in their long-term health. Epilepsy surgery in infancy and early childhood is increasingly advocated for several reasons: early surgery may prevent many years of unnecessary seizures, early onset seizures are frequently associated with impairments in development and behaviour and these may be reduced by early surgery and there may be a reduction in early mortality. Although the plan is to increase the total number of children having epilepsy surgery, the largest increase should be in young children, leaving a decreasing number of children aged six and over to be referred for surgery. This means that non-CESS centres would, progressively, have less to do, and would have difficulty maintaining their expertise and experience. It is not in the best interests of patients, or their families and carers, to support non-CESS epilepsy surgery centres when their case numbers are already low and are likely to fall.
- 4.6. When the CESS centres were evaluated, their ability to increase capacity was assessed and the expectation is that they will increase their capacity to eventually accommodate more than 350 cases a year between them.
- 4.7. NHS England acknowledges that there may be concerns about the need for patients to travel and about the potential loss of skills in local centres from the concentration of surgery in CESS centres. However the aim is for non-CESS centres to be actively involved in the assessment and follow-up of children undergoing epilepsy surgery, so that the number of visits to CESS centres is limited and non-CESS centres will not lose touch with their patients. The aim is that children are seen in CESS centres for a limited number of assessment visits (the number depending on the complexity of the problem), then have their operations at the CESS centre with subsequent follow up being in their local centre. The CESS centres all have dedicated facilities designed around the needs of the children and they have accommodation for family members at the hospital 24 hours per day.

- 4.8. There is good evidence that concentration of expertise in specialist surgery improves outcome.^{4 5}
- 4.9. The four CESS centres have agreed a rigorous process to collect standardised data about clinical interventions and outcomes. The collection of such data nationally will provide a unique opportunity to record the activity of the CESS centres and compare the outcome of their work with that of centres in other countries. Another important development has been the establishment of a national CESS multi-disciplinary meeting which discusses complex cases, particularly those under 6 years old. The national advisors, and the team at Great Ormond Street Children's Hospital NHS Foundation Trust, are involved in the management of all children aged under six that are being considered for epilepsy surgery in the CESS centres outside Great Ormond Street Hospital. These developments have greatly strengthened the work of the CESS centres and will continue to do so.

5. Why are we consulting?

- 5.1. NHS England is committed to developing its service specifications in an open and transparent way and that specifications developed by NHS England are informed by as wide a range of views as possible.
- 5.2. We would like to hear from anybody with an interest in children's epilepsy surgery.
- 5.3. NHS England seeks to comply with the best practice consultation principles issued by the Cabinet Office in 2012⁶.
- 5.4. NHS England seeks to remain open, engaged and transparent throughout the process for discharging its responsibilities for the direct commissioning of specific health services.
- 5.5. NHS England is committed to promoting equality and reducing health inequalities throughout the health service. Consultation provides the opportunity to gain information about any potential impact on health inequalities which might arise as a result of new or changed processes for making decisions about health services that are directly commissioned by NHS England. This information will feed into an Equality and Health Inequalities Analysis on this programme of work.

⁴ Englot et al J Neurosurg. 2013 Jan;118(1):169-74. doi: 10.3171/2012.9.JNS12776. Epub 2012 Oct 26

⁵ Chowdhury MW, Dagash and Pierro A. A systematic review of the impact of volume of surgery and specialisation on patient outcome. British Journal of Surgery 2007;94:145-161

⁶ They are available in full here:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/60937/Consultation-Principles.pdf

6. Consultation questions

- 6.1. Do you agree with the principle that concentrating epilepsy surgery in the four CESS centres is in the best interests of children who have epilepsy severe enough for surgery to be considered?
- 6.2. Do you agree that it is the right thing for children of all ages to have their operations in CESS centres, not just children aged under six?
- 6.3. Do you think that it is appropriate that children and their families may have to travel further in order to have the operation they need in a centre that is particularly skilled in epilepsy surgery?
- 6.4. Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the proposed changes that we have described?
- 6.5. Please provide any further comments you may have on the proposed changes.

7. Feedback and next steps

- 7.1. The consultation on proposed changes to the children's epilepsy surgery service specification will be open for 90 days from the date consultation starts.
- 7.2. All feedback received during consultation will be considered by Paediatric Neurosciences Clinical Reference Group and by the Women and Children's Programme of Care Board. A short report, setting out the consultation feedback, will be published on the CRG's web page.
- 7.3. A final decision about the development of the service specification will be made by the Specialised Commissioning Oversight Group.