Proposed changes to service specification for Children's Epilepsy Surgery: Consultation outcome report

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Publications Gateway Reference:	**05867**
Document Purpose	Consultations
Document Name	Proposed changes to service specification for Children's Epilepsy Surgery: Consultation outcome report
Author	Women and Children's Programme of Care Board
Publication Date	18 November 2016
Target Audience	Foundation Trust CEs , Medical Directors, NHS England Regional Directors, Communications Leads, NHS Trust CEs
Additional Circulation List	
Description	This report summarises the outcome of the public consultation held in 2015 on proposed changes to the service specification for Children's Epilepsy Surgery and sets out NHS England's response to the consultation.
Cross Reference	Consultation on children's epilepsy surgery consultation and revised Service Specification for Children's Epilepsy Surgery Service
Superseded Docs (if applicable)	
Action Required	Implement the revised service specification for children's epilepsy surgery
Timing / Deadlines (if applicable)	**By 01 April 2017**
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Document Status

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Proposed changes to the service specification for Children's Epilepsy Surgery (CESS): Consultation outcome report

First published: **18th November 2016**

Prepared by: Specialised Commissioning Directorate

Classification: OFFICIAL

NHS England would like to thank all of the individuals, groups and organisations that supported the public consultation on children's epilepsy services in some way. In particular NHS England would like to thank Epilepsy Action for their help in undertaking an online survey of their members which supported the NHS England public consultation.

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Equality statement

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;
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from, healthcare services and in securing that services are provided in an integrated way where this might reduce health inequalities.

Introduction

1. The Children's Epilepsy Surgery Service (CESS) is commissioned by NHS England to provide specialist pre-surgical evaluation and surgery for children in specialised CESS centres across England.

2. A service specification for CESS (NHS England E09/S/e 2013/1) sets out the standards these children's epilepsy surgery centres have to meet in order to provide this service for children and young people.

3. In 2014, the Paediatric Neurosciences Clinical Reference Group (CRG) proposed changes to the current service 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. CRGs are groups of clinicians, commissioners, public health experts, patients and carers who are the primary source of clinical advice for NHS England on the best ways that specialised services should be provided.

4. The proposed changes would:

    - expand the list of operations to be undertaken in CESS centres in line with national and international expert clinical advice; and
    - mean that all children (aged 0-18) undergo their operations in one of the four CESS centres.

5. NHS England carried out a public consultation on the proposed changes to the service specification from 25 March to 17 June 2015. It sought views from all those with an interest in this important service.

6. At the same time, NHS England commissioned Public Health England (PHE) to undertake an epidemiological assessment on the impact of the changes.

7. This document presents the outcome of the public consultation on proposed changes to the service specification for CESS. The findings of the PHE assessment are published in full on the PHE website. This document also describes how the feedback has been considered by NHS England and outlines the next steps it intends to take.

Background

8. 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.

9. 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.

10. 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 (MDT).

11. 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 mortality associated with continuing seizures, if surgery is carried out at an early stage.

12. 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]

13. In 2010–2011 there were 137 epilepsy surgery operations in children aged 0–18 years, of which 38 were less than 6 years old. 57 of the operations were at Great Ormond Street Hospital (GOSH) and 22 of these were in children under 6 years. Paediatric neuroscience centres outside GOSH were operating on small numbers of children. These operations are not all the same – various complex neurosurgical procedures are appropriate to the needs of different children. It follows that some of these operations were being performed very rarely and this was particularly the case for children under 6 years old.

1.1 Launch of the Children's Epilepsy Surgery Services (CESS)

14. As the recognition of epilepsy surgery outcomes grew, in 2012 the NHS launched the Children's Epilepsy Surgery Services (CESS). This aimed to improve the quality of care for children with complex epilepsy, who might benefit from surgery, by concentrating expertise, and increase the number of children assessed and treated.

15. Four centres were designated to provide surgical services for those children, following a rigorous evaluation process involving independent, international experts. 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.

16. These 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 and Kings College Hospital NHS Foundation Trust
- Alder Hey Children's Hospital NHS Foundation Trust and Central Manchester University Hospitals NHS Foundation Trust

17. The Service Specification for the CESS (NHS England E09/S/e 2013/1), published in 2013, states that all children of any age being considered for epilepsy surgery should be discussed by the multi-disciplinary team (MDT) in the relevant CESS centre, involving local clinicians to agree the management

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[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

plan. For children who are 5 years and under, specialist epilepsy surgery is only to be provided at a designated CESS centre. For children aged 6 years and over, a decision can be made on whether surgery is more appropriately performed either in a CESS centre or in a paediatric neuroscience centre (if the centre meets the agreed service specification and standards).

1.2 Proposed changes to the service specification

18. In 2014, the Paediatric Neurosciences Clinical Reference Group (CRG) proposed changes to this service specification.

19. This included additions to the list of operations that should be performed in a CESS centre, as the management of these complex cases is so important.

20. The CRG also proposed 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. This would mean removing the statement from the service specification 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.

21. The reasons for the proposed changes are outlined in the guide to the public consultation. One aim of CESS is to ensure that an increasing number of children aged under 6 undergo epilepsy surgery, as there are good reasons to believe that this would lead to an improvement in their long-term health. This is likely to leave a decreasing number of children aged 6 and over to be referred for surgery, meaning that non-CESS centres would progressively see fewer cases and would have difficulty maintaining their expertise and experience. Children’s epilepsy surgery involves a range of complex procedures and there is good evidence from other areas of surgery that consolidation of cases in specialised surgical centres improves outcomes. 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.

Summary of public consultation

1.3 How we did it

22. From 26 March to 18 June 2015 NHS England sought views on the proposal to change the current service specification so that all children requiring

surgery undergo their operations in one of the four CESS centres, and not in a non-CESS centre.

23. The survey was hosted online alongside the proposed service specification and a guide to the consultation.

24. 641 individual responses were received, representing professional organisations, voluntary organisations and parents/carers. This included support for the proposals from the British Paediatric Neurology Association (BPNA), the Society of British Neurosurgeons (SBNS) and Epilepsy Action.

1.4 What we asked

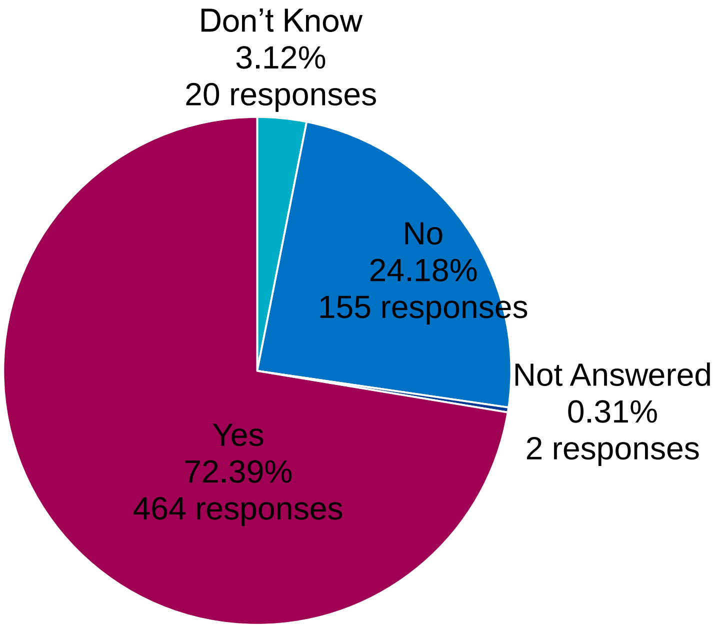
25. The online survey collected responses to five questions.

    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?
    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?
    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?
    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?
    5. Please provide any further comments you may have on the proposed changes.

What you told us

Question 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?

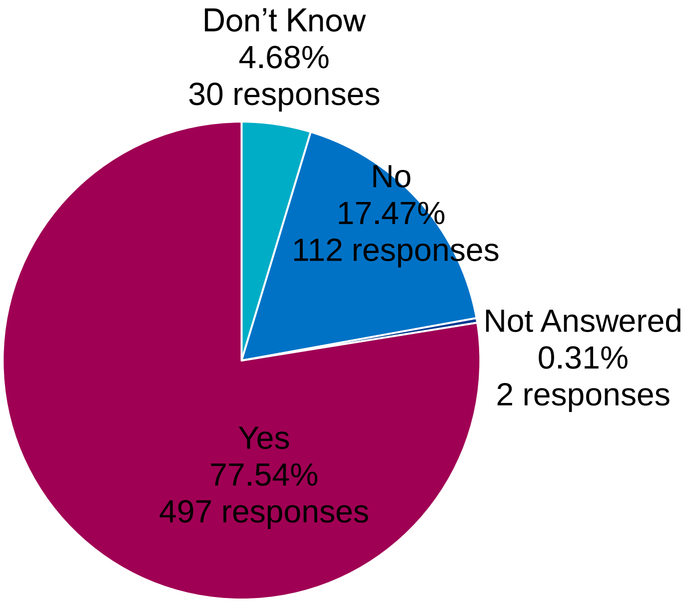
Figure 1: Response to question 1



26. A large majority of respondents (72%) stated that they agreed with the principle that concentrating epilepsy surgery in the four CESS centres is in the best interests of children

Question 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?

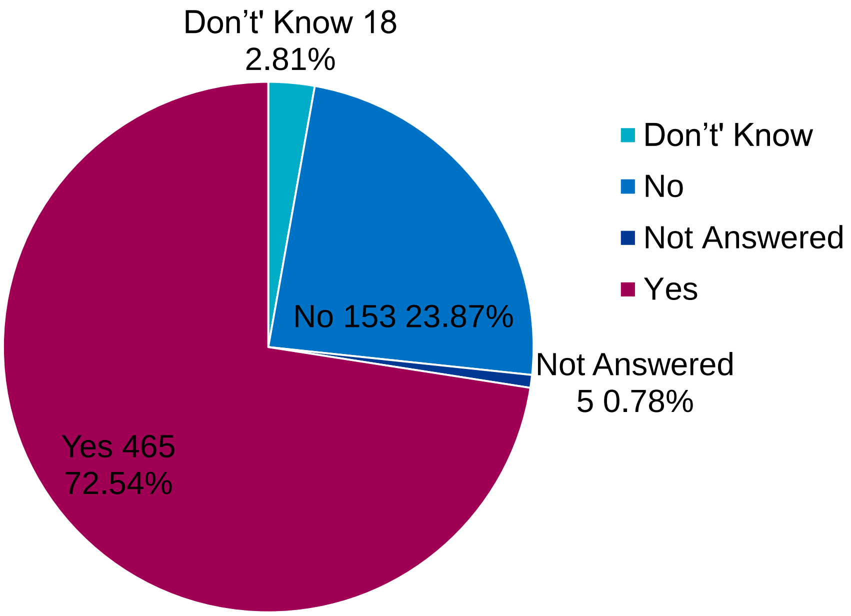
Figure 2: Response to question 2



27. A large majority of respondents (78%) agreed that it is the right thing for all children to have their operations in CESS centres, not just children under 6.

Question 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?

Figure 3: Response to question 3



28. A similar majority of respondents (73%) agreed that it was appropriate that families may have to travel further in order to have the operation that they need.

Question 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?

29. Six key themes were identified from the responses, as detailed in the table below and in Appendix A.

Table 1: Response to question 4

Response theme	Number	Percentage
Theme 1: No or positive impact on health inequalities	275	31.43%
Theme 2: Impact in North East, Yorkshire and Humber	257	29.37%
Theme 3: Impact of centralisation will increase health inequalities	160	18.29%
Theme 4: Comments on the evidence base	104	11.89%
Theme 5: Local services to reduce health inequity	56	6.40%
Theme 6: Other	23	2.63%
Total	**875**	**100%**

Note: The total number of responses is more than the number of individual respondents because a number of people made comments that covered more than one theme.

30. The range of answers to Question 5 is described in Appendix A.

31. Appendix B summarises the results of other activities carried out as part of the consultation, as well as letters received from some NHS organisations and networks.

Summary of Public Health England report

32. NHS England asked Public Health England (PHE) to undertake an assessment to provide independent epidemiological evidence on how children's epilepsy surgery services may change, if the proposed changes to the service specification are implemented.

33. The assessment looked at:

- overview of epilepsy surgery and invasive monitoring – current and projected population trends
- service trends and impacts

- regional and hub access to CESS centres
- current referral pattern and anticipated travel time
- clinically interdependent conditions/services
- emergency admissions for epilepsy and elective epilepsy surgery by deprivation quintile
- current levels of paediatric neurosurgery activity.

34. The PHE report is available to view

1.5 PHE recommendations

34. The PHE report made several 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.
- NHS England should ensure a strong network approach between CESS centres and other paediatric neuroscience centres, with joint MDTs. These MDTs should be for all ages up to 18 years inclusive.
- NHS England should ensure clear transition protocols are robustly implemented for 16–18 year olds.
- For 16–18 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 years
- NHS England should monitor differences in patterns of referrals for paediatric epilepsy surgery between regions.
- NHS England commissioners should ensure that referral pathways for access to children's epilepsy surgery are adhered to and that 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.
- NHS England should ensure that the service specification accounts for interdependencies in the proposed clinical model and the MDT membership. This can be achieved with the support of a strong networked model as per previous recommendations.

NHS England’s response to the feedback

36. Over 70% of respondents agreed:

    - with the principle that concentrating epilepsy surgery in the four CESS centres is in the best interests of children who have epilepsy that can be considered for surgery
    - that it is the right thing for children of all ages to have their operations in CESS centres, not just children aged under six
    - 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.

37. However, a wide range of views was expressed in the qualitative feedback to the question on the impact of the proposed changes on health inequalities. In particular, some feedback drew attention to the impact on geographical areas of England, especially the North East, Yorkshire and Humber. That said, a similar number of respondents felt that the changes would have no or a positive impact.

1.6 How this feedback has been considered

38. Children’s Epilepsy Surgery Services fall under the Women and Children Programme of Care (PoC), one of six National Programmes of Care that cover the whole range specialised services commissioned by NHS England. The PoC boards oversee the development of clinical strategies in these areas.

39. With the large response to the consultation, and the variety of views expressed to the qualitative questions 4 and 5, the Women and Children PoC Board established a service specification working group to review the findings of the public consultation and the Public Health England Epidemiological Assessment.

40. The Women and Children PoC then made a set of recommendations as detailed in the next section.

41. These recommendations have subsequently been considered and approved by the governance structures in NHS England specialised services, the Clinical Priorities Advisory Group and the Specialised Commissioning Oversight Group.

1.7 Recommendations

42. NHS England has concluded that the service specification should be changed as proposed so that:

- the list of operations which should be carried out in the CESS centres is expanded;
- all children requiring operations undergo these in one of the four CESS centres and not in other paediatric neuroscience centres.

43. It came to this conclusion for the following reasons:

- The public consultation demonstrated a high level of agreement.
- Children with severe epilepsy have many problems that put huge strains on their families; the potential improvement after epilepsy surgery should not be underestimated.
- Children's epilepsy surgery involves a range of complex procedures and there is good evidence from other areas of surgery that consolidation of cases in specialised surgical centres improves outcomes.[2]
- The epidemiological assessment undertaken by Public Health England shows that the number of children aged 6-18 having their operations in non-CESS centres is very small. In 2014/15, the proposed change to the service specification would have affected 18 children aged 6-18 per year (18% of those who received surgery). Of these patients, 8 were aged 16-18 years old and might have been referred to the adult neurosurgical service for assessment. Therefore, the proposed service change would impact on 18 patients or fewer (if efforts to identify and refer early continue)
- Concern about the potential impact on quality and outcomes and long term sustainability of the service, if the current service specification remains the same. The intention to move towards epilepsy surgery being undertaken at earlier ages would mean a smaller relative number of children requiring surgery at ages 6 and over. This would further reduce the number of procedures undertaken within non-CESS centres. This would make it difficult for non-CESS centres to maintain their expertise and experience. It is not in the interest of patients to continue surgery in non-CESS centres when their case numbers are already very low and are likely to fall.

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[2] Chowdhury MW, Dagash and Pierro A. A systematic review of the impact of volume of surgery and specialization on patient outcome: British Journal of Surgery 2007; 94:145-161).Englot DJ, Ouyang D

Wang DD et al. Relationship between hospital surgical volume, lobectomy rates, and adverse perioperative events at US epilepsy centres. Journal of Neurosurgery 2013; 118:169-74).

- When the four CESS centres were first selected, the evaluation panel were satisfied that their capacity could be increased to meet an estimated need of 350 cases in England per year. There is no evidence that this will not continue to be the case.

44. However, NHS England has also taken into account the comments from the public consultation and the recommendations of the PHE epidemiological assessment. This has led to the following plans to ensure a strong network approach between CESS centres and local paediatric neuroscience centres:

- Children's Epilepsy Surgery can only be managed with a network approach. There needs to be continued strong engagement and involvement of paediatric neuroscience centres so that early identification and awareness of cases is maximised, and children are able to access epilepsy surgery.
- Paediatric neuroscience centres and other local paediatric services are critical to the patient pathways, particularly in pre- and post-operative work. This can mitigate the impact on children and their families of travel to CESS centres.
- NHS England needs to be able to routinely monitor referral patterns for epilepsy surgery.
- NHS England needs to be assured that these arrangements will be put in place so that changes to the service specification can be fully effective.

1.8 Next steps

45. NHS England expect that the revised service specification will be implemented for **April 2017**

46. NHS England will put a plan in place that describes how commissioners will take into account the measures listed above.

47. For updates on CESS and any latest developments, please visit the paediatric neurosciences section of the NHS England specialised commissioning webpages, sign up to be a registered stakeholder of the clinical reference group or subscribe to the specialised commissioning stakeholder newsletter.

Appendix A: Themes identified in public consultation responses

Responses to question 4 fell into six themes, as described in the following tables.

Table 2: Theme 1 – No or positive impact

Issues raised	Number of responses
Agree with model - will ensure equality and quality of outcomes from the MDT approach	124
Agree - but important for families to have financial and emotional support (place to stay, help with transport. liaison with cultural and local needs)	67
Agree with model - families will travel for expertise	36
Will improve equity - as will be determined by clinical need and all children will be evaluated appropriately	22
CESS should move to children over 6 - as current system creates inequalities in quality	7
Agree with overall model - any impact on health inequalities or the individual can be managed if there are any	6
Agree with model and the numbers for four CESS centres	4
Agree - but will need more investment both in CESS centres and in non-CESS centres to ensure patients are referred, and follow up is appropriate	4
Would be no impact on other neuroscience services as the numbers are small	2
Would support Introducing new techniques and expanding epilepsy surgery	1
Support the growth and development in other CESS centres	1
Need to avoid last minute cancellations to support parents	1
Total	**275**

Table 3: Theme 2 – Impact in North East, Yorkshire and Humber

Issues raised	Number of responses
Inequity of access and this will impact on health inequalities	75
Expertise is already in North East/Yorkshire - existing neuroscience network	36
Travel times (cost and emotional impact on family and child)	32
Dissuade parents from exploring epilepsy surgery as an option/decrease number of children considered for surgery	24
Travel - not just for surgery but for investigations	15

Issues raised	Number of responses
Disadvantage people from a low socio/economic background	15
Less investment in other epilepsy services in the region/loss of local expertise	12
Impact on family life	10
Communication to local teams will lead to poorer outcomes/trust built up with local teams	9
Knock on effect on paediatric neurosurgery more generally	8
North/South divide	7
Increased costs (to the NHS)	5
Disadvantage people from an ethnic background	4
Disadvantage to families with other complex/multiple health needs - including mental health	3
Options for Newcastle patients to go to London should be retained	2
Total	**257**

Table 4: Theme 3 – Impact of centralisation

Issues raised	Number of responses
Centralisation will reduce access (for example as local paediatricians less likely to refer/deskill local services)	50
Inequity of access from travelling time (particularly for those already socially/economically deprived or who have health difficulties)	49
Impact on siblings of parents being away and on family life (economically, socially, emotionally)	16
Dissuade people from exploring surgery options/barrier to accessing services	14
Disadvantage those from ethnic background	5
Will impact upon other (specialist) services - a domino affect	5
Safety of travelling with sick child	4
Undermines existing good provision - in non-CESS centres	4
Patient Choice hasn't been considered	4
Further travel may lead to worse results	3
Care closest to home is most important	3
Lack of 'care of the human being' in a larger/specialist centre	3
Total	**160**

Table 5: Theme 4 – Comments on the evidence base

Issues raised	Number of responses

Issues raised	**Number of responses**
Rationale for only 4 CESS centres – and the current geographical distribution	37
Evidence of capacity - it will reduce beds	21
Needs of older children and transition to adult services within a paediatric setting	17
Increase waiting times/delays in treatment	8
No evidence on health impact - disadvantage those from socially disadvantaged backgrounds and ethnic minorities	7
No evidence of lack of quality/safety in current non-CESS centres	5
Evidence of reduction in epilepsy surgery without a local presence/skill set	4
Lack of scientific evidence for determining model	3
Definition of specialist and what could be provided in a regional centre	2
Total	**104**

Table 6: Theme 5 – Need for local services to reduce impact

Issues raised	**Number of responses**
Need to maintain strong local networks to retain staff skills and prevent inequities of access	30
Importance of investing in local services - therapy/nursing/social care - to provide for patients needs in the local centre	14
Limit travel time and frequency by having pre and post op services locally through a network approach	10
Use of technology (Skype) to ensure links between local and specialist centres	2
Total	**56**

Table 7: Theme 6 – Other

Issues raised	**Number of responses**
Alder Hey and Manchester should operate on all Children (those under 6)	4
Need a service in Southampton	2
Access to rods in UK	1
Lack of patchy services for SLT, OT, physio and psychology	1
Why Epidiolox Trials in UK now critical to Dravet, Lennox and Intractable Epilepsy Syndromes	1
Not great for CO2	1
Young people over 14 may be appropriate to be in an adult	1

Issues raised	Number of responses
setting and demonstrate pathologies seen in adults	
Local therapy services may be unequally funded which would impact on quality of post-operative follow up	1
Different models in Wales, Scotland and Northern Ireland will lead to inequity	1
Bristol has great standards of care	1
Need a service in Sheffield	1
Need a service in Hull	1
Referrers should have option to refer outside of the regional if the service is not acceptable - maintain competition	1
Before 2013 most surgery undertaken in London - so this is an improvement	1
We are used to travelling in the South West	1
Patients from NUTH would be particularly disadvantaged	1
Potential deaths due to lack of knowledge/transfer	1
Query evidence base for specialist surgeon vs. mixed practice	1
Need for rarer syndromic epilepsy units in a national centre	1
Total	**23**

The table below lists responses to question 5, which asked respondents to provide any further comments they had on the proposed changes.

Table 8: Question 5 – Any further comments

Issues raised	Number of responses
Epilepsy surgery for all children should be concentrated to a small number of centres for best outcomes	78
A 5th centre in the North East/Yorkshire and Humber is needed	35
Relevant local and regional networks will need to be robust and clear - with investment for local services and outreach clinics - including voluntary sector and provision of information	27
Need to minimise the number of visits and travel and invest in high quality family support services	25
Case for only 4 centres needs more justification (both numbers and outcomes)	20
Loss of paediatric expertise will be irreversible - in non-CESS centres - this could destabilise the service, reduce quality and potentially reduce the numbers identified	18
NE has a network in place and is meeting standards	18
Detrimental effect if need for additional time away from home - families should not need to travel - has not been properly assessed	13
Need improvement in identifying patients - current lack of engagement of non-CESS centres has created an inequality and	11

Issues raised	**Number of responses**
reduced the numbers who could benefit from surgery	
Families will be happy to travel for good care	10
Query the methodology of the consultation - hasn't engaged with patients - no data on health impact	8
Provision for young adults - 16 - 19 - who would have been in adult services - needs to be more considered	7
Contrary to drive for services closer to home	7
CESS centres need more investment for increased demands	7
Need more time to analyse effect on the under 5s before a bigger roll out - and impact this has had on increasing numbers	6
Safe and sustainable paediatric neurosurgery has insisted on regional networks - this should follow the same methodology	6
Query using methodology for original designation to apply to this revised service specification	5
Pathway needs to be smoother between CESS centres and locally - referral and post op (e.g. MRI)	5
Impact on training and recruitment for neurosurgeons	5
I was happy with the skills and provision in Sheffield	4
Clarity around who pays for what - local commissioners have to pay for post-operative neuro rehabilitation - CESS centres recommend rehab programme that local care team cannot provide	4
Consideration of amount of therapy needs to be given at CESS centres if capacity were to increase	4
Need professionals who already know them and not just their medical needs but impact on child as a whole	4
Families are already travelling - minimal change	4
Excellent service exists in Leeds	3
Children under 6 should be able to be operated on in both Alder Hey and Manchester and not just Manchester	3
Most likely way of increasing number of children considered for surgery is to have a centre locally	3
Care received at Bristol has been excellent	3
Should simplify the referral process and increase referral rates	3
Can improve collaboration in research and generate innovation	3
Any CESS centre would need to demonstrate the standards required/As long as standards are met service should be provided	2
Need to be clear what procedures could be managed through local neuro-oncology MDT	2
Leeds is more accessible for the large population in Yorkshire and NE	2
Do not agree with the changes	2
Reason for amalgamation is cost - and should be quality	2
A single solution is not the answer	2

Issues raised	Number of responses
Need to send the specialist surgeons to hospitals around the country	2
May have discouraged us from accessing the surgery	2
There are 6 CESS centres not 4	2
Will increase costs - due to travel	2
Ill thought through - doesn't put family and child at the centre	2
Need adequate support for the Southwest	2
Need to ensure that referral practices of clinicians are appraised - in non-CESS centres - and all cases are being referred	2
Need to consider impact on other services in the non-CESS centres	2
Whole provision needs review	1
Bristol provides the best care in SW	1
Are there plans to move to centres for Adult Epilepsy?	1
Up until 2012 NE was doing for resective surgery than any other unit outside GOSH	1
Manchester have asked for help from the Sheffield service, so why are patients from NE to go to Manchester	1
Concerned that the algorithm for epilepsy surgery does not require a child to be seen by a paediatric neurologist before being referred to a CESS	1
Keep specialist smaller centres open - like Ryegate	1
CESS model already causes additional unnecessary suffering and this will increase it further	1
Defeats the purpose of improving access to specialised services	1
Southampton has comparable outcomes	1
Unsafe to travel far away from home - ad may require additional support	1
No evidence between CESS outcome and number of procedures performed	1
Experts in other countries with opposing views should be equally cited	1
Sheffield and Leeds are committed to working together to provide a service	1
Opportunity costs not adequately factored in	1
Not adequate consideration of non-direct costs to families and patients	1
Need to meet psychological needs of the family too	1
Impact of moving to 4 centres has been positive and no need for additional centres - main focus should be on improvement of outcomes	1
Good work in non-CESS centres - unfair concentration of resources - consider a central, national MDT	1
Current standard of care received is excellent	1

Issues raised	**Number of responses**
Why is this being discussed so soon after the national agreement	1
Where is the funding coming from?	1
Will the optimum age for surgery be missed?	1
Standards need to be agreed	1
Need to consider a global waiting list so families are redirected and can be seen sooner	1
Need to build up services outside of London, based on expertise of each centre	1
There is capacity to expand the current service	1
Excellent service in Birmingham	1
Excellent service in Alder Hey	1
Poor experience in Airedale and LGI	1
Current loop hole represents a clinical risk	1
Surgeons who are trained are no longer allowed to do the operations they have been trained to do	1
Surgery for children above 6 age group could be provided by experiences surgeons in an allied CESS centre.	1
Non CESS centres need to be allied with CESS centre in their network	1
Wales should be integrated into the four CESS centres	1
Current centres are not referring to Bristol - which may impact on the viability of Bristol	1
Expertise within CESS centres should also be concentrated	1
What is important is best and easiest access for patients	1
In 2014 only 111 CESS operation is carried out in England - activity is not increasing	1
Total	**416**

Additional comments on other elements of the proposed service specification:

- The service specification could mention that increasing surgery will be cost effective as will reduce long term drug costs
- The impact mustn't be decrease in capacity or decrease in number being assessed for surgery
- Specification could be stronger if it referenced the impact on outcomes of delays in surgery
- Need to strengthen the evidence that children should be considered earlier rather than later in the process
- Service specification could be clearer about the length of time that should be built into the care pathway
- Consideration needs to be given to simplifying the referral process - how will referrals from secondary care be increased?

- Potential bottleneck in completing pre-surgical assessments - need to ensure centres manage their through put
- Should include plans to increase the volume of pre-surgical assessments performed
- Service specification should say more about transition - particularly that planning ought to start when a child is 14 years old
- Patient choice should be considered in the service specification
- Relevant sections in evidence should be referenced or quoted
- Roles of MDT should be clarified
- Layout is not always clear
- Consistent in use of acronyms
- Diagram on page 17 is too small
- Final paragraph on page 13 needs revising
- Service specification is too prescriptive
- No mention of pre or post-surgery assessments
- Current spec is contradictory - leading to conflicts between major centres and their network partners
- No mention of MDT professionals - very medically orientated

Appendix B: Summary of other consultation activities

Epilepsy Action Survey

As part of the overall consultation exercise, NHS England asked Epilepsy Action to engage with children and the parents of children with epilepsy living in England. They did this via an online survey using SNAP survey software and the respondents were recruited through Epilepsy Action's website, social networking sites and an e-newsletter. The Epilepsy Action survey covered the questions set out in the NHS England consultation exercise.

Epilepsy Action surveyed 125 people (2 children and 123 parents of children with epilepsy). They received the following responses.

Do you agree with the idea that providing epilepsy surgery only at four CESS centres is in the best interests of children who are being considered for epilepsy surgery?

Strongly agree	31 (25%)
Agree	26 (21%)
Neutral	32 (26%)
Disagree	20 (16%)
Strongly disagree	8 (6%)
Don't know	8 (6%)

Do you agree that all children under the age of 18 should have their surgery at a CESS centre, not just children under six?

Strongly agree	56 (45%)
Agree	34 (27%)
Neutral	22 (18%)
Disagree	4 (3%)
Strongly disagree	5 (4%)
Don't know	8 (3%)

Do you think that going to a more specialist centre is worth the extra travelling?

Strongly agree	53 (42%)
Agree	47 (38%)
Neutral	10 (8%)

Disagree	7 (6%)
Strongly disagree	5 (4%)
Don’t know	3 (2%)

Do you think any particular groups of people will be at a disadvantage if the proposed changes go ahead?

Yes	69 (55%)
No	26 (21%)
Don’t know	30 (24%)

Of those who answered yes, the comments included:

- the changes might have a large impact on families with a low income, in receipt of benefits or where one or more parents are unemployed
- the full cost burden on families has not been realised
- distance and or lack of transport could be a barrier. The cost of public transport or the difficulties of using public transport with a child with special needs may also stop families considering surgery.

Other themes raised in the survey included:

- families with more than one child – having a child in hospital can have an impact on managing the care of other children in the family
- time off work - the ability to hold down a job when large periods of time off are needed to facilitate hospital stays and appointments. Travelling further will result in increased time off required.
- support networks – travelling further away may mean that a family’s extended support network cannot be around to provide care and assistance.

NHS England workshop

NHS England ran a patient and public workshop on the 10 June 2015 with an event in London and a simultaneous webcast available online. Two parents attended in person along with a patient and public voice representative. One representative of Epilepsy Action joined online.

The consultation questions were posed to the group and the following responses were received.

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?

- Yes, but there is a need to provide the right information to parents to help them make an informed choice. It is also important that follow-up treatment is standardised.
- It would help parents to talk to other parents whose children have been through this operation to help them with making informed choices.

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?

- Yes, but again it is important that parents are provided with information about why this.

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?

- Yes. The complexity of the surgery means that you would want to travel for the right expertise. Parents need to know though that the travelling is not a one-off and that there may need to be between 2 and 3 visits before the surgery takes place. It is also important that parents have somewhere to stay. Local follow-up is very important and having a coordinated approach with local services is essential.

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

- There is a cost to parents who have to travel long distances to get their children to the designated centres. There are also associated accommodation costs and having to take time off work and making arrangements for other children in the family to be looked after. It is important that all of this is explained to parents.

Leeds Scrutiny Board

Representatives from NHS England Specialised Commissioning (North) attended the Leeds City Council Scrutiny Board (Health and Wellbeing and Adult Social Care) on 24 March 2015. The Scrutiny Board considered the information and discussed a number of issues at the meeting, including:

- limitations in NHS England’s approach to involving and engaging a wide range of stakeholders in relation to specialised services – including local authority health scrutiny bodies
- concern regarding NHS England’s reliance on a web-based approach to public consultation
- the lack of any ‘impact assessment’ to help facilitate wider public participation in the consultation process
- concern that previously reported anxieties around the designation of CESS centres appeared to be becoming reality – despite previous assurances provided to the Scrutiny Board
- the potential impact on children and families across the North East of England
- the potential impact on services to adults
- the future sustainability of the North East Network without a designated CESS centre
- a lack of clear evidence to support any improved outcomes within CESS centres
- concern that there was insufficient information available to enable the Scrutiny Board to make a fully informed consultation response

Letter received from Oxford and Southampton Children’s Hospitals Network

The Oxford and Southampton Children’s Hospital Network wrote a letter in response to the consultation on the proposed new specification. The letter highlighted several points:

- historic partnerships and excellent working relationships between Wessex Clinicians and Great Ormond Street Hospital
- robust networking arrangements across Thames Valley and Wessex regions
- the case for widening the criteria for CESS centres to children over 6 years old and the rationale for the decision to choose only four centres to provide CESS
- confirmation that the Children’s Hospitals Network would like to continue providing this service to over 6 year olds, in line with the CESS service specification

Letter received from Wessex Paediatric Neurosciences Clinical Network (WPNCN)

The Wessex Paediatric Neuroscience Clinical Network wrote a letter in response to the consultation which set out:

- the history of CESS undertaken in Southampton from 2001–2009 and benefit to children and their families
- concern that the evidence that larger services provide better outcomes is very thin and taken from extrapolation from services whose catchment populations are different from regional UK services
- the standards-based approach to paediatric neurosurgery based on the importance of networks
- concern that the current CESS configuration has decreased access to surgery compared with the expected trajectory for CESS
- lack of evidence of a relationship between threshold volume and outcomes
- assumption that adult epilepsy surgery experience is irrelevant is without supportive evidence
- assertion that more procedures in young children will mean fewer procedures in older children is not supported
- fragility of the current configuration of 4 CESS centres and lack of flexibility for the system to adapt
- additional cost for families to travel further.

The letter explains that Wessex would be happy to adopt a network approach to high-quality CESS available across Wessex and the wider region. It requests that commissioners move to a standards-based approach that is working well for other paediatric neurosurgery.