

CHILDREN'S EPILEPSEY SURGERY SERVICES BACKGROUND AND TIMELINE

Introduction

The current proposals around Children's Epilepsy Surgery Services have their origins in the *Safe and Sustainable Review of Children's Neurosurgery Services*, which first emerged in October 2009 and commenced with a national stakeholder event in November 2009.

Councillor Mark Dobson, Chair of Leeds' Health Scrutiny Board at that time, attended the initial stakeholder event. Since the initial discussion, there has been on-going consideration of children's epilepsy surgery services. Given the passage of time, this has involved a number of different Scrutiny Board Chairs and members. The details in the below timeline aims to provide a succinct summary of the various discussions and events.

It should be noted that work around the *Safe and Sustainable Review of Children's Neurosurgery Services* initially took place in parallel to the *Safe and Sustainable Review of Children's Congenital Heart Surgery Services* – although each review was working to different timescales.

Timeline

Date	Summary of event
December 2011	<p>Briefing to joint meeting of Health Scrutiny Chairs (Yorkshire and the Humber) where, in terms of children's epilepsy surgery, members were assured the process aimed to increase capacity for surgery in children 5-years-old and under.</p> <p>With the assurance provided, there was limited support around establishing a formal joint scrutiny committee to oversee the outcome of the review and potential changes to services.</p>
January 2012	<p>Scrutiny Board meeting on 25 January 2012 that considered the briefing note provided by NHS Specialised Services and the outcome of the joint meeting of Health Scrutiny Chairs.</p> <p>The Scrutiny Board expressed a desire to consider the proposed framework and standards documents, which were highlighted by NHS Specialised Services at the meeting.</p>
May 2012	<p>Scrutiny Board meeting on 16 May 2012 that considered the proposed framework and standards documents (highlighted in January 2012). The documents were supplemented by a further briefing note provided by NHS North of England Specialised Commissioning Group.</p> <p>On behalf of the Scrutiny Board, the Chair provided a formal response on 21 May 2012, which included:</p> <p><i>In terms of the specific implications for Leeds (and the wider Yorkshire and Humber region), the Scrutiny Board was assured and welcomed the confirmation that a 'North of England' network solution had been discounted. The Scrutiny Board believed this would be in the interest of patients – for example, in terms of travel and access and the support available to patients and their families.</i></p>

Date	Summary of event
July 2013	<p>Scrutiny Board meeting on 31 July 2013 that considered a formal 'request for scrutiny' regarding proposals around children's epilepsy surgery. The request for scrutiny was submitted by a Consultant Paediatric Neurologist from Leeds Teaching Hospitals NHS Trust.</p> <p>The Scrutiny Board considered details of the request presented at that time and discussed a number of issues, including:</p> <ul style="list-style-type: none"> • The potential shift from procuring 'additional capacity' for children's epilepsy surgery to successful providers being consider the 'sole' providers of services; • The consideration of 'patient's needs' and 'geographical distribution' within the procurement process; • The consistency of the procurement process; • Concerns associated with the overall '<i>Safe and Sustainable</i>' programme. <p>The Scrutiny Board agreed to incorporate the request into its work schedule for 2013/14.</p>
March 2014	<p>Letter from the Chair of the Scrutiny Board (4 March 2014) inviting NHS England to comment on the concerns highlighted during discussion of the 'request for scrutiny' in July 2013.</p>
April 2014	<p>NHS England response (11 April 2014) to the letter from the Chair of the Scrutiny Board.</p>
April 2014	<p>Scrutiny Board meeting on 30 April 2014 that considered the information presented in NHS England's response to the Chair of the Scrutiny Board.</p> <p>Concerns were expressed that, despite the relatively small number of children/ families likely to be affected, the existing provision of epilepsy surgery for children under 6 did not sufficiently reflect the population profile or geography of Yorkshire and the Humber. There was also concern that the lack of provision might be seen as an erosion of services and have a negative impact on other service areas, including other neuroscience services, at Leeds Teaching Hospitals NHS Trust.</p> <p>The Scrutiny Board agreed to maintain an overview of the provision of Children's Epilepsy Surgery Services.</p>
July / August 2014	<p>Various email exchanges on behalf of the Chair of the Scrutiny Board and NHS England regarding specialised services in general and specifically Children's Epilepsy Surgery services.</p>
March 2015	<p>Chair of the Scrutiny Board (Health and Wellbeing and Adult Social Care) became aware of NHS England's consultation: <i>Proposed Changes to the Service Specification for the Children's Epilepsy Surgery Service (CESS)</i>.</p> <p>It should be noted this was not specifically drawn to the attention of the Scrutiny Board by NHS England (as required by legislation).</p>

Date	Summary of event
April 2015	<p>Scrutiny Board meeting on 24 April 2015 that considered NHS England's consultation: <i>Proposed Changes to the Service Specification for the Children's Epilepsy Surgery Service (CESS)</i>. A number of issues were raised including:</p> <ul style="list-style-type: none"> • Proposals included all children's epilepsy surgery being undertaken in one of the currently designated Children's Epilepsy Surgery Services (CESS) centres. • The proposals would impact on children 0-18 years. • It was proposed to extend the list of procedures undertaken by the CESS centres. • The number of procedures likely to be involved was in the region of 320-350 per annum. • There were patient safety issues that needed to be considered. • Confirmed that an impact assessment was being undertaken during the public consultation. • The North East England Paediatric Neuroscience Network had been formed since the original designation of CESS centres – but was the only network not to include a designated CESS centre. • The designation of CESS centres had not led to an increase in surgical interventions, as originally planned. • Concerns regarding the potential distances children and their families may be expected to travel. • The annual number of investigations was in the order of 3-4 times greater than the number of surgical interventions – therefore the number of children and families affected was likely to be greater. • Risks that current expertise in the network would be lost to CESS centres. <p>The Scrutiny Board raised a number of issues, including:</p> <ul style="list-style-type: none"> • 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 and understanding of any likely implications. • 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.
June 2015	<p>Submission of Scrutiny Board response to the CESS consultation and proposals. <u>CESS consultation closed on 18 June 2015.</u></p>

Date	Summary of event
September 2015	Progress update requested. NHSE asked to provide a written update and invited to attend a meeting with members of the Scrutiny Board in October 2015. Specific request on the status and availability of the impact (epidemiological) assessment.
October 2015	NHSE briefing note provided. Briefing note outlining NHSE was considering its response to the public consultation and epidemiological assessment – expected to be available December 2015/ January 2016. NHSE unable to attend the meeting
November 2015	Specialised Commissioning in the North – Stakeholder Bulletin: <i>‘The Children’s Epilepsy Surgery Services consultation received a significant level of feedback and the Programme of Care (POC) board is currently considering the options in the NHS England response.’</i>
December 2015	Position update requested. NHSE confirmed CESS consultation outcome had not yet been finalised or published.
February 2016	Position update on CESS requested. Followed up in March 2016 following a regional scrutiny event in Leeds.
March 2016	NHSE responded as follows: <i>‘The expected publication of the outcome of the Children’s Epilepsy Surgery Service Review is now likely to be early May. The review documentation is not yet complete. When it is, the report must go to the NHS England Board Committee before it can be shared externally and can only be released once they have given approval to do so.’</i>
June 2016	Further CESS position update requested. Requested details of the public consultation analysis report and epidemiological assessment. NHSE responded as follows: <i>‘NHS England needs to make a final decision on the proposed changes to the specification so that epilepsy surgery for children aged 6 and over is undertaken in a designated CESS centre. There was a high level of support for the proposed changes in the public consultation and there is good clinical evidence that consolidation of cases in specialised surgical centres improves outcomes. However the public consultation has also raised some complex commissioning issues and the chair of the national Women and Children’s Programme of Care board is working with the national specialised commissioning Senior Management Team to ensure that the appropriate process and governance are in place for NHS England to make the final decision. Once the decision has been made, the outcome of the consultation and the Public Health England epidemiological impact assessment will be published.’</i>
May 2016	Leeds Health & Wellbeing Board letter requesting consideration to commission 5 th CESS centre in North East England.

Date	Summary of event
June 2016	Concerns raised by various stakeholders regarding lack of progress following the CESS consultation, which closed 12 months earlier (i.e. June 2015).
August 2016	Letter to Mr Robert Cornall – Regional Clinical Director for Specialised Commissioning (North) – setting out concerns regarding lack of progress / decision in relation to CESS and requesting provision of the consultation analysis report and Public Health England’s epidemiological assessment.
August 2016	Letter from Mr Robert Cornall – setting out assurance regarding NHSE decision making processes and timescales.
September 2016	Exchange of correspondence with NHSE – further exchange of correspondence with NHSE. NHSE stated decision to be made at Specialised Commissioning Sub-Committee on 27 September 2016.
October 2016	Scrutiny Board agenda item – meeting on 4 October 2016. NHSE invited to attend. Verbal feedback that decision made at the Specialised Commissioning Sub-Committee on 27 September 2016, but a formal announcement was expected by 11 October 2016.
October 2016	Scrutiny Board agenda item – meeting on 25 October 2016. NHSE invited to attend. Feedback prior to the meeting that the formal announcement had not been made. No future date provided.

Steven Courtney
Principal Scrutiny Adviser
October 2016