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Date: 11<sup>th</sup> April 2014

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***Sent via email***

Councillor John Illingworth  
Chair  
Leeds Overview and Scrutiny Committee  
3rd Floor (East)  
Civic Hall  
Leeds  
LS1 1UR

Dear Cllr John Illingworth,

**Re: Paediatric Neurosciences – Paediatric Epilepsy**

Thank you for your letter to Andy Buck dated 4<sup>th</sup> March concerning children's epilepsy surgery. As the responsible commissioner for these services within Yorkshire and Humber, your correspondence has been passed to me to respond.

I thought it would be helpful to structure our response into three key areas: the background and context; key issues raised within the request for further scrutiny and NHS England's response to these; and the development of the Paediatric Neurosciences Network, which underpins the way forward.

**Background**

Following a national procurement process that concluded in May 2012 four providers were identified to provide Children's Epilepsy Surgery Service (CESS)

1. Birmingham Children's Hospital NHS Foundation Trust
2. North Bristol NHS Trust with University Hospitals Bristol NHS Foundation Trust
3. Great Ormond Street Hospital for Children NHS Trust (GOSH)
4. Alder Hey Children's NHS Foundation Trust with Central Manchester University Hospitals NHS Foundation Trust

Sheffield THFT, Newcastle THFT and Leeds THT initially worked on a bid to become a centre, but due to difficulties in the three Trusts reaching an agreed proposal, the bid did not go forward.

The nationally agreed model of care for children's epilepsy surgery was set out in a letter to all Trusts in September 2012. This model determined that:

- Surgery for children aged six years and over may be appropriately performed locally but must be with the prior agreement of the relevant CESS and on a case by case basis.
- All cases being considered for epilepsy surgery must be discussed by the multidisciplinary team (MDT) in the relevant CESS centre.
- Epilepsy surgery being considered for children aged 5 years and under must only be undertaken by the relevant CESS.
- In Y&H there would be the expectation that referrals would be made to Alder Hey/Manchester, on the basis that
  - this will offer a more easily assessable service to children and families and,
  - with the establishment of Children's Neuroscience Networks, provide an opportunity for the development of effective clinical relationships across the North of England

### **Key issues raised within the request for scrutiny (made by LTHT in July 2013)**

In July 2013, clinicians from Leeds Teaching Hospitals NHS Trust brought a number of concerns to the attention of the OSC. They included:

- the failure of NHS England to formally consult on proposals
- a perception that the procurement process had been deeply flawed
- a concern that all epilepsy surgery would be commissioned from the 4 designated centres only
- a concern that children previously treated in Leeds would need to travel to London/Liverpool/Manchester for surgery

In response to the above points, NHS England would state the following:

- NHS England were not legally required to publicly consult, as this did not constitute a major service change, rather it was a change to treatment thresholds, and there is no legal requirement to consult on changes to clinical criteria for referral
- The national procurement process had been undertaken within a framework which NHS England considered to be legally robust
- The change only affects children under 5 years old requiring epilepsy surgery, and does not mean that all surgery will be undertaken elsewhere. Data submitted to NHS England by LTHT for the period 01.04.12 to 30.09.13 (18m) stated there was a total of 3 children aged 0-5 who received procedure for epilepsy at LTHT during that time. This would equate on average to 2 children per year who would be referred to Liverpool/Manchester
- It is true that children under 5 years old that require epilepsy surgery will have to travel for treatment, however as described above, the anticipation is that this will only affect on average 2 patients per year.
- Furthermore, this change is based on a fundamental principle that through effective network development (see below), the aspects of the treatment undertaken in the centre will be limited to the surgery and complex interventions only, with as much of the pathway being retained locally as possible.

### **Paediatric Neurosciences Operational Delivery Network**

Crucial to the effectiveness of the above arrangements is the development of a North East Paediatric Neurosciences Operational Delivery Network (NEPNN). This will ensure clinically effective pathways are in place for all children with neurological needs, an element of which are the necessary relationships with CESS centres to ensure that the best clinical outcomes are achieved for children under 5 years old requiring epilepsy surgery.

Clinical and management colleagues from Sheffield Children's NHS Foundation Trust, Newcastle upon Tyne Hospitals Trust and Leeds Teaching Hospitals Trust have agreed that representatives from the three Trusts would come together as an Interim Executive Management Group to:

- Work with commissioning staff from South Yorkshire and Bassetlaw Area Team and Cumbria, Northumberland, Tyne and Wear Area Team to explore hosting arrangements for the Network (subsequently recommended that this should be Sheffield Children's Foundation Trust).
- Develop a vision for the Network
- Agree the Principles that will underpin the Network
- Agree the Executive Group Membership for the Network
- Agree the scope and core membership of the Network
- Agree the skill mix and support required to make the Network a success.

A workshop is scheduled for 2 May 2014 that will outline the arrangements for going live with NEPNN, host arrangements and work programme. The Interim Executive Management Group has already agreed a vision and a set of principles for the NEPNN, and worked through the NEPNN Executive Group Membership should be, the scope of and key resources required to support the NEPNN. It is felt that this network is developing successfully.

I hope the above information provides sufficient assurance at this stage to the Overview and Scrutiny Committee; please do not hesitate to contact me if any further detail or discussion is required.

Yours sincerely



Cathy Edwards  
Director of Commissioning  
NHS England (South Yorkshire & Bassetlaw)

Cc.	Stephen Courtney	Principle Scrutiny Advisor, Leeds OSC
	Andy Buck	NHS England Director (West Yorkshire Area Team)
	Mark Smith	Chief Operating Officer, Leeds Teaching Hospitals NHS Trust