University Hospitals of Leicester NHS
NHS Trust

Leicester Royal Infirmary
Leicester
LE1 5WW

Direct Dial: 0116 258 8940
Email: john.adler@uhl-tr.nhs.uk
mandy.johnson@uhl-tr.nhs.uk

Tel: 0300 303 1573
Fax: 0116 258 7565
Minicom: 0116 287 9852

Will Huxter
Regional Director of Specialised Commissioning
NHS England
Mezzanine Floor
Southside
105 Victoria St
London
SW1E 6QT

BY EMAIL to will.huxter@nhs.net

5th July 2016

Dear Will,

Re: Outcome of NHS England assessment of CHD services against the new standards.

The East Midlands Congenital Heart Centre (EMCHC) has made excellent progress over the last 18 months through the leadership of our clinicians, the energy and efforts of the whole CHD team, the support of our charities and the closer integration of our partner organisations. We have expanded bed numbers, improved outcomes, invested in staffing, created a new adolescent unit and have briefed architects to create a new single site children's hospital which will both meet your co-location standard and provide a wonderful new environment for the care of all our younger patients.

This progress has all been achieved against a backdrop of many years of uncertainty following the "flawed" decision four years ago to stop Level 1 CHD services in Leicester. It does make me wonder what this service could achieve if NHS England backed these clinicians.

I trust it will therefore come as no surprise when I say that I cannot agree that your decision to "cease commissioning" children's heart surgery in the East Midlands is in any way "in the best interests of patients with congenital heart disease and their families".

I have discussed your assessment in detail with our clinical leadership team and I have set out our response below.

1. We provide a high quality service.

Our most recent clinical outcomes, when compared with current published data, place us alongside the best performing surgical centres in England. Further, we can predict that upon publication of the NICOR data in October 2016 that the clinical outcomes for our patients will be amongst the best in the country. Despite seeing and treating more children than ever before there have been no deaths at the EMCHC within 30 days of surgery in the last year.

Recognising that quality is about more than outcomes (as the latest Bristol Review identified), our same-day cancellation rates and un-planned re-operation rates within 30 days are significantly better than the national average and our patient and family satisfaction rates have increased to 99% over the last year.
All of this is supported by the Care Quality Commission who, in their initial feedback letter following their inspection in June 2016, reported: "*We noted the excellent clinical outcomes for children following cardiac surgery at Glenfield Hospital."*

Our first rebuttal to your assessment of our service is therefore that you want to close a centre beloved of its patients and families despite quality indicators that ought to alert you to the fact that this is a grave mistake.

2. We are on target to meet the number of surgical procedures.

In 2014/15 we carried out 280 surgical cases. In 2015/16 we increased this to 332 cases. Based on current projections of activity we expect to meet the standard of an average of 375 cases per year, with three surgeons over the next three years. To accommodate this additional work this year we expanded our bed-base by 31% (17 beds total) including the provision of an adolescent unit, and a short stay bay at a cost of just under £1million.

All that aside we would remind you again that the evidence for 125 cases being the 'magic number' is selective. As you know, following a worldwide review of literature on behalf of NHS England, the School for Health and Related Research in Sheffield found "that, whilst a relationship between volume and outcome exists, this is unlikely to be a simple, independent and directly causal relationship." In other words, no cut-off relating to surgical volume and better outcomes was identified.

Our second point of rebuttal is that NHS England is therefore proposing to close a top quality service despite the fact that the clinicians working in the service are confident of their ability to perform the required number of procedures. This is compounded by the fact that the premise for the decision is based on an arbitrary number of cases for which there is no scientific evidence. We would encourage you therefore to look at our outcomes, our zero mortality and our actual results.

3. A compromised Paediatric Intensive Care Service.
The East Midlands Congenital Heart Centre supports 12 Paediatric Intensive Care Unit, (PICU) beds at Glenfield Hospital which will obviously be lost if NHS England ceases to commission surgical services. Of equal importance is that as a consequence of losing these beds, the viability of the PICU at the Leicester Royal Infirmary will be compromised. As you are no doubt aware, paediatric intensivists in Leicester work across both units and in common with other units are attracted by the diverse caseload that this offers. The loss of a specialist PICU at the EMCHC, which more than halves the total PICU beds in Leicester, will mean that the children's intensive care will cease to be as attractive a place for our clinical teams to work; we will lose existing staff and find it harder to attract new staff.

Taken together, the two Leicester units provide 30% of the PICU capacity across Birmingham, Leicester and Nottingham; close one and destabilise the other, and even assuming a bed in the region can be found, more children and their families will have to travel further to support one another in a time of crisis.

Our third rebuttal is simply that given the national crisis in PICU capacity highlighted by last week's report into the Bristol service, the decision to remove beds from the system and destabilise the remaining Leicester PICU seems at best misguided and at worst, reckless.

4. The worst possible domino effect.

If NHS England closes the EMCHC service the PICU at the Glenfield is lost and the Royal's is compromised. Without a suitably sustainable children's intensive care service there will be an inevitable domino effect on other specialist paediatric services which require intensive care capacity to function safely. These include include: children's general surgery, ear nose and throat surgery, metabolic medicine, fetal and respiratory medicine (for long term ventilated children), children's cancer and finally our neonatal units. In addition, those neighbouring hospitals currently supported by the specialist teams in Leicester will no longer be able to look for support for their more complex patients from their nearest specialist trust. These these include hospitals in Burton, Coventry, Kettering, Northampton and Peterborough.

Our fourth rebuttal is that if NHS England closes the children's heart service in Leicester you should be aware that you are essentially undermining the vast majority of other specialist services for children in the East Midlands.

5. Extra Corporeal Membrane Oxygenation (ECMO) Service.

Leicester's paediatric respiratory ECMO service is the largest in the country accounting for 50% of all capacity nationally. As NHS England is aware, Leicester pioneered ECMO in the UK and as a consequence there are many children and adults alive today who have our clinicians to thank for a second chance of life. (In fact, survival following respiratory ECMO treatment in Leicester last year was 15% higher than for patients treated elsewhere). The EMCHC ECMO unit is also the only unit providing a national transport service which stabilises patients at their local hospital before transporting them to a specialist centre. Obviously the decision to close the Leicester surgical service would also result in the closure of the ECMO service, as the doctors working in one also work in the other. This would mean that decades of experience, knowledge and innovation would be lost.

Our fifth rebuttal is that when assessing our surgical service NHS England stressed the importance of achieving a certain critical mass of patients. It therefore strikes us as either peculiar or convenient for those making the decisions on our future that this same principle does not apply when considering ECMO*.*

In summary the East Midlands Congenital Heart Centre is not a service which has stood still for the last four years, since the time of the last discredited review. We are confident that our clinical outcomes are now amongst the best in the country. We have invested in our people and our infrastructure and we have a vision to take the service to the next level within a new children's hospital.

With that in mind we are frankly incensed by the fact that NHS England can say in their press statement, following the latest critical review into children's cardiac services elsewhere that "We will be working closely with Bristol and other centres to support their plans to meet these standards in full." On the same day that we receive a letter saying that our service will close, with no sign of equivalent support.

If NHS England was genuinely seeking to support other centres we would expect, for example, that you would broker conversations that meant that children were treated in their <u>nearest</u> specialist hospital and in doing so, put an end to the ridiculous state of affairs where children in *North*amptonshire are referred to a centre in *South*ampton for no better reason than it was ever thus. If active commissioning of this kind took place then the 500 cases in 5 years' time standard would be achievable in Leicester. If intelligent commissioning of this kind is not within the remit of NHS England, we fail to see what value you add other than to arbitrarily ratify standards irrespective of the consequences.

I recognise that you will find this letter unwelcome but I must caution you against thinking that we are being parochial. If I thought for a moment that my medical and nursing colleagues were motivated simply by a desire to maintain the status quo, the conversation would be different. They are not and as such my Board and I will not sit by whilst NHS England destroys a fabulous service. **For the avoidance of doubt, we reject your stated intention to cease commissioning level 1 CHD services from us and we will use all the means at our disposal to reverse this intention.**

As requested, we have undertaken a factual accuracy check of your assessment of our compliance against the standards and our response to this is attached, together with an evidence file.

When we spoke on the telephone on 3rd July, we noted that the communication process around these decisions had thus far been less than satisfactory and you apologised for this. You also undertook to inform providers in advance of any further announcements so that we can brief our staff and local stakeholders. I understand from Paul Watson, Regional Director – Midlands and East for NHS England, that there is a plan in place to make announcements on Friday, with an embargoed release to a wide range of stakeholders (including providers) at 10am on Thursday. If that plan goes ahead, you will need to ensure that providers are notified **in advance of the wider release** so that we can brief our staff. The reason is that, given the profile of the issue, there is no chance of the embargo holding. This will apply whenever you actually make any announcements. I would of course encourage you not to move with such haste but that is ultimately your decision.

Finally, you say in your letter that "uncertainty about the future has been unsettling for staff and for patients and their families". Of course it has and we have been managing that uncertainty for years and yet still produce wonderful results for our children and families. If you truly want to put that "uncertainty to an end", it is in your gift but it will require you to listen to us and support us as active commissioners.

Yours sincerely

John Adler
Chief Executive