26 June 2017

Submission to the Leicester, Leicestershire And Rutland Joint Health Scrutiny Committee
27th June 2017

Proposed Downgrading of the East Midlands Congenital Heart Centre

This is a response by Healthwatch Leicester City, Healthwatch Leicestershire and Healthwatch Rutland to the proposals made by NHS England for Congential Heart Disease Serivces.

In July 2016 NHSE announced it was minded to cease commissioning Congenital Heart Disease (CHD) Surgical Services at the Glenfield Unit as it considered it would not meet national standards in the required timeframe. We have discussed the original draft standards developed in 2012, after the Safe and Sustainable Review. There was strong support for national standards, recognising that this stance clearly creates a dilemma if a local unit fails to meet these standards.

Following discussion with University Hospitals Leicester (UHL), it is our understanding that the remaining sticking point across all the standards is whether the Glenfield Unit will reach the requisite number of cases in the timescale required. At this time, it is impossible to know whether NHS England's forecast, or the UHL's prediction will prove correct. It does however appear retrograde to dismantle an established unit with high quality outcomes without firmer evidence that it will not reach the number required in the timescale set.

The process of setting standards and then implementing them reveals different units across the country are at various stages of development and we believe there should be flexibility in recognising that some units have further to travel than others in reaching the requisite standards. We believes the issue could be addressed by allowing sufficient extension to the deadline to allow UHL to increase its catchment area and so its caseload. NHSE has already found this to be a viable alternative, as an extension has been granted to Newcastle. We see no reason why this could not be done for the Glenfield Unit.

Additionally, we are concerned that the assumptions made in predicting travel patterns is not sound and would ask for that to be revisited for example the low availability of public transport in a rural area such as Rutland had not been factored in. Excessive travel times is not just an issue for the patient it is very relevant to the frequent visits that parents and family members make. There appears to be a high reliance placed on the availability of accommodation near to

the hospital being available to parents. However, with other children to care for and work commitments to be maintained it may not be possible for both or even one parent to stay. Assumptions made about where patients would go if the Glenfield Unit was not available lacked an evidence base and may not reflect future patient flows resulting in inaccurate prediction of travel times – this is a serious flaw in the rationale and proposed plans.

We believe that the review has underestimated the "unravelling effect" of taking services out prematurely and the impact that will have on other key services. The two paediatric intensive care units at UHL are an essential part of the provision of Paediatric Intensive Care Unit (PICU) cots for the East Midlands as a whole. A loss will have both a regional and national impact as PICU cots are already under severe pressure.

UHL provides cardiac and respiratory Extracorporeal Membrane Oxygenation (ECMO) for children and is the only provider offering mobile ECMO (which allows children to be transferred between hospitals on ECMO). If the proposals go ahead, UHL would no longer be able to provide cardiac or respiratory ECMO for children or mobile ECMO for children. This would affect approximately 55 children a year.

The Newcastle Unit is rightly in our opinion being given extra time and support to achieve the Standards because in addition to CHD Surgical Services they undertake approximately 20 to 25 paediatric heart transplants per year and the risk posed to transplant services by removing the CHD Surgical Services is considered too great. Yet the risk to the approximate 55 children reliant on Glenfield's specialist ECMO services has not been considered. We want parity on this and an explanation why an extension cannot be granted given the service is treating the most vulnerable in our society?

In conclusion we believes that:

1. NHSE should allow UHL additional time to meet the national standards, as has been given to Newcastle.

2. That transport assumptions should be reviewed as they appear to be flawed. These cover the assumptions made about where families would choose to go and the impact of poor public transport on communities particularly in rural areas.

3. That the review should consider the "unravelling effect" of taking services out prematurely and the impact that will have on other key services.

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