

**SUBMISSION TO THE LEICESTERSHIRE AND RUTLAND JOINT HEALTH
SCRUTINY COMMITTEE**

LEICESTER MERCURY PATIENT PANEL

27th JUNE 2017

**PROPOSED CLOSURE OF THE EAST MIDLANDS CONGENITAL HEART
CENTRE**

The Leicester Mercury Patient Panel (LMPP) is a group of individuals from Leicester, Leicestershire and Rutland who draw together a range of expertise and experience in health and social care and who seek to promote patients' interest in local care. These individuals are independent, unpaid volunteers and are not accountable to any organisation, including organisations within the health and social care system.

The Leicester Mercury Patient Panel has sought to understand the reasons and evidence base underpinning NHS England's stated wish to decommission tier 1 services (including all surgery) from the East Midlands Congenital Heart Centre (EMCHC). We have issued a series of requests for information from NHS England within the provisions of the 2000 Freedom of Information Act. Unfortunately, we have acquired limited knowledge through these exchanges as NHS England has declined to respond to many questions posed with relevant information.

As an example of our frustration with the lack of information provided we have asked, on two occasions, for the membership of the group or committee which made the decision to indicate that NHS England was minded to decommission tier 1 services from the East Midlands Congenital Heart Centre. On each occasion, NHS England has declined to give the name of the committee making the decision and its membership. In its second response, NHS England denied there was a group or committee which had judged that services should be decommissioned but instead stated "The judgement that NHS England should cease commissioning level 1 CHD services from UHL (and others) was reached by senior clinical staff in Specialised Commissioning". NHS England have therefore refused to tell us who was responsible for the decision and it follows that, as there was no group or committee responsible, there was no agenda, minutes or accompanying papers. This seems to us an extraordinary state of affairs given the grave significance of NHS England's judgement for patients throughout the region.

NHS England delayed their responses to us so that we did not receive answers to our questions within the 20 working days provided by the Freedom of Information legislation. On one occasion, NHS England took 45 working days to respond to our FOI request. Despite these delays, NHS England sent inaccurate and outdated information on the grounds that they first drafted their responses several weeks before they sent them. Several responses to our questions were inaccurate because they did not incorporate relevant information supplied to NHS England by the Trust. Overall, the Panel gained the impression that NHS England was either deliberately withholding accurate information or did not have arrangements in place to provide the public with accurate information in a timely way.

There is a dispute between NHS England on the one hand and the Trust and local patients on the other as to whether the standards were to have been achieved by April 2016 or by April 2019. We have asked NHS England to provide written evidence to demonstrate that the standards would be measured retrospectively. NHS England has supplied us with no documentation which demonstrates their approach to measuring against standards was the one agreed in 2015. Despite asserting they are not measuring standards retrospectively, they supplied in their response to us the figures for 2012/13, 2013/14, 2014/15 as well as for 2015/16.

NHS England signalled its intention to decommission tier 1 services from the EMCHC before it had undertaken, completed and considered the outcomes of comprehensive reviews into paediatric surgery and paediatric intensive care services and extra-corporeal membrane oxygenation (ECMO) services. Indeed it did not even embark on these reviews until several months after its announcement of that it was minded to close surgery at EMCHC.

NHS England embarked on the public consultation with no impact assessment available for consideration by the public. This again gave the impression that NHS England had rushed into a decision to signal its intention to decommission tier 1 services without thinking through all the consequences and without having all the relevant information at its disposal.

In everyday language, the word 'standards' implies a quality of care to be achieved; consequently it has been our fear that members of the public, on hearing NHS England statements that the EMCHC is not 'meeting standards' would infer that the quality of care provided at the EMCHC is insufficiently good. Of course this is not the case; we know that the quality of care is good because the outcomes are good. The general public will not immediately understand that, when using the word 'standard,' NHS England does not mean quality of care but instead means a particular input – primarily here the numbers of procedures undertaken by each surgeon – which only loosely and even somewhat dubiously relates to the actual quality of care given. We consider that the announcement by NHS England last July to signal its intention to decommission services could have had a destabilising impact on the EMCHC, potentially undermining confidence in the quality of the service, thereby making it more difficult for the Trust to increase the number of patients it treats.

On substantive issues, we make just two observations. The proposal to close the EMCHC as a surgical centre goes beyond regionalisation and would leave families in the whole Eastern side of England between Newcastle and London with no congenital heart surgery provision. In addition we note that NHS England is not consistent in its expectations of compliance with the standards across all Trusts. We believe the explanation given has not convinced patients and public in Leicester, Leicestershire and Rutland that different providers are being treated equitably.

Overall our experience has been that NHS England has not been as forthcoming in providing us with the evidence we sought to justify the intended closure of surgery at the EMCHC as we would have expected. As a result we remain unconvinced that the proposed termination of surgery at the EMCHC is good for patient and their families or that the implications, including for its associated services such as ECMO, have been properly thought through.