Proposals to implement standards for Congenital Heart Disease services for children and adults in England

Response of the Leicestershire, Leicester and Rutland Joint Health Scrutiny Committee

1. In what capacity are you responding?

   Other

   If 'other' please specify:

   The Leicestershire, Leicester and Rutland Joint Health Scrutiny Committee, constituted in accordance with relevant legislation is responding to NHS England's proposals, as NHS England is obliged to consult with us in accordance to Regulation 23 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013.

   The committee considers matters which impact on areas covered by Leicester City Council, Leicestershire County Council and Rutland County Council and is made up councillors from all three local authorities.

   The proposals will lead to a substantial variation of services for residents in Leicester, Leicestershire and Rutland and is therefore responding to the consultation as part of Regulation 23 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013 and guidance issued by the Secretary of State for Health.

2. In what region are you based?

   Midlands and East, England

3. NHS England proposes that in future Congenital Heart Disease Services will only be commissioned from hospitals that are able to meet the full set of standards within set timeframes. To what extent do you support or oppose this proposal?

   Neither support or oppose

   Please explain your response:

   Whilst a detailed set of standards for delivering CHD services has been prepared, application of these has not been done in a fair and equitable manner. There is a lack of evidence explaining why a particular subset of the standards has been given greater weight than other standards, suggesting bias for a

predetermined decision, and it is equally unclear as to whether these standards are determined from a strong evidence base.

NHS England has made it clear that none of the Level 1 providers of CHD services currently meet all the standards proposed and some of these providers also currently don't meet what appears to be NHS England's favoured standard, B10 (L1) – *125 operations per surgeon per annum, averaged over three years, undertaken in teams of four surgeons by 2021*. However, it is also accepted by NHS England that some of these trusts will be helped to meet these standards and targets by closures of other units. This is extremely concerning that this is the model being used to achieve, which we have heard, is an arbitrary target. We would like to be clear that the other units are confident that they are able to manage the increased workload that would be created by the closure of some units; this information has not formed part of the consultation documentation.

The Committee has real concerns regarding the lack of scientific research and evidence base supporting the B10 (L1) standard of 125 operations which NHS England states is the amount needed to provide a resilient service, instead it has been explained to us by NHS England that the standard is based on the opinion of a few professionals. We are not clear who these professionals are and whether they have any conflicts of interest which should prevent them from being involved in decision making in this area. Given the lack of robust evidence, we are not clear why this standard is being given such high weighting. It could be argued that it is an activity target rather than a standard, particularly as a centre which does not have quite the volume of activity required is delivering excellent care and outcomes. NHS England again demonstrates an inconsistent approach as the application of this standard is being implemented with immediate effect looking retrospectively, rather than three years from when the standard was introduced in July 2015.

Nonetheless, we do not think the approach taken with Newcastle upon Tyne demonstrates equality in the proposals. Newcastle is being given an unspecified amount of time to achieve targets as it is acknowledged they will not meet them in your timeframe. They will not meet the 125 caseload standard which you believe has an impact on sustainability and safety and a better standard of care, and if you believe they can operate to that 'lower standard' without having an impact on patient safety and patient standards, its seems remarkable that this same principle is not being applied to Leicester, even though they have a robust plan which will actually meet that target in the timeframes when Newcastle will not.

University Hospitals Leicester NHS Trust has put forward a growth plan to NHS England in May which has clear and robust plans to meet the target standard specified in standard B10 (L1) and demonstrated that they have already began to put this plan into place. We understand that NHS England has been considering the growth plan since it was submitted approximately two months ago but that no formal response has been made despite numerous attempts from the Trust to have these talks. We do not understand the reasons for this, given that NHS England has accepted growth from Newcastle and Southampton who do not appear to be making any change to their catchment areas. Glenfield

Hospital is intending to change its catchment area and has already begun to make the necessary links. In our view, this gives additional strength to the growth plan for the East Midlands Congenital Heart Centre.

NHS England has stated that this is the only standard they are concerned about with relation to Glenfield Hospital delivering CHD standards and yet the efforts the trust has put into ensuring they will meet this standard has been completely dismissed whilst other trusts are being given an indefinite time to achieve this, thus showing a real inconsistency in approach.

The Leicestershire, Leicester and Rutland Joint Health Scrutiny Committee recommend that NHS England applies a consistent approach in the application of standards in Level 1 services with all trusts given the same opportunities to improve standards in an equitable and fair manner.

The Committee also recommends that the weighting given to standards that are not robustly supported by evidence be reconsidered. The drivers for change should be improvements in patient care and outcomes, rather than volume and activity.

4. Three hospital trusts have been assessed as not able to fully meet the standards within set timeframes. NHS England proposes that surgical (level 1) services are no longer commissioned from these trusts:

   - Central Manchester University Hospitals NHS Foundation Trust (adult service)
   - Royal Brompton & Harefield NHS Foundation Trust (services for adults and children)
   - University Hospitals of Leicester NHS Trust (services for adults and children)

   Can you think of any viable actions that could be taken to support one or more of these trusts to meet the standards within the set timeframes?

   As stated in the previous question, the standards need to be applied equally across all trusts, with all of them receiving the same timeframes and support to meet the standards of care that have been detailed by NHS England and with the same level of scrutiny being applied to all of them as currently it is apparent some centres are being favoured over others.

   Also, as mentioned previously that the timeframe for the standards is nonsensical as they are being applied retrospectively and performance is being judged on the past, before the standards were even in place. It is not fair to assess such a crucial service to the residents of Leicester, Leicestershire and Rutland based on old data when there has been a clear plan to meet the targets imposed since those standards have been set and it is from that date that performance should be measured against a fair set of targets built from a strong evidence base.

The Leicestershire, Leicester and Rutland Joint Health Scrutiny Committee recommend that NHS England consider if all the targets in their identified standards are based on sound scientific evidence. The Committee also recommends that UHL should be supported to deliver its growth plan by changing referral pathways that they have identified in order to meet the specified targets and given the same timeframe that will be applied to all other trusts – no one trust should be given preferential treatment.

Central Manchester and Leicester

5. If Central Manchester and Leicester no longer provide surgical (level 1) services, NHS England will seek to commission specialist medical services (level 2) from them, as long as the hospitals meet the standards for a level 2 service. To what extent do you support or oppose this proposal?

   Neither support or oppose

Royal Brompton

6. The Royal Brompton could meet the standards for providing surgical (level 1) services for adults by working in partnership with another hospital that provides surgical (level 1) services for children. As an alternative to decommissioning the adult services, NHS England would like to support this way of working. To what extent do you support or oppose the proposal that the Royal Brompton provide an adult only (level 1) service?

   Neither support or oppose

Newcastle

7. NHS England is proposing to continue to commission surgical (level 1) services from Newcastle Upon Tyne Hospitals NHS Foundation Trust, whilst working with them to deliver the standards within a different timeframe. To what extent do you support or oppose this proposal?

   Strongly oppose

Travel

8. Do you think our assessment of the impact of our proposals on patient travel is accurate?

   No

9. What more might be done to avoid, reduce or compensate for longer journeys where these occur?

   The Leicestershire, Leicester and Rutland Joint Health Scrutiny Committee do not believe that NHS England's assessment of the impact on travel for patients across the whole of the East Midlands region is accurate.

   The formulaic approach used which determines an average increase in journey time takes no consideration of many factors such as use of public transport, traffic and road links particularly in more remote regions in Leicestershire and Rutland as well as the increased austerity some families face and the extra costs of travelling further for them.

   The Committee has also heard directly from patients and it is clear all the 'human' factors for a patient are disregarded in NHS England's assessment. Some families have more than one child and there is a significant risk that families will be regularly separated by having to attend surgeries and outpatient appointments at an increased distance, likely to include overnight stays on a regular basis. We are not referring to a one off visit; this is a regular inconvenience that is unnecessary when there is an outstanding service that can be delivered more locally to them and this is completely missed in the consultation analysis for travel.

   Some families spoke to the committee about the impact on mental health of parents and family members that having a child or family member with CHD needs has on the whole family and the increased tension this will have when they must travel and be without wider family support for longer periods. These factors should not be ignored and should rightfully be considered when considering the impacts of travelling further as this is not the opinions of professionals or our Committee members but come from the people that experience this themselves every single day.

Equality and Health Inequalities

We want to make sure we understand how different people will be affected by our proposals so that CHD services are appropriate and accessible to all and meet different people's needs.

10. In our report, we have assessed the equality and health inequality impacts of these proposals. Do you think our assessment is accurate?

    No

11. Please describe any other health inequality impacts which you think we should consider, and what more might be done to avoid, reduce or compensate for the impacts we have identified and any others?

    The assessment does not take into consideration the high levels of deprivation faced in our region, particularly in large parts of Leicester city which has some of

the most deprived areas in the country, as well as parts of the County and Rutland. The added costs of travel etc which are only set to increase under the proposals on these families will impact them negatively where some maybe choosing to eat over travel to an appointment.

We also know that BME groups are more at risk for CHD services and that populations particularly in the inner city areas of Leicester, Nottingham and Derby and also many other parts of the outer regions have high populations of BME groups which will be negatively impacted by the proposals.

Whilst Equality Impact Assessments (EIAs) have been carried out, they have been done on a national basis as NHS England states this is a national review. However, this national review has a local impact and EIAs should be conducted more locally so NHS England can understand the 'real' equalities impact in a region like the East Midlands, where even across the region there are differing needs of people. For example, Leicester City has a young population in comparison to much of the country and COPD and related diseases are on the increase and therefore future projections might suggest more of a need for services like CHD and this example could be translated across many parts of the region with differing equalities needs.

Other Impacts

12. We want to make sure that the proposed changes, if they are implemented, happen as smoothly as possible for patients and their families/carers so it is important that we understand other impacts of our proposals. Do you think our description of the other known impacts is accurate?

    No

13. Please describe any other impacts which you think we should consider, and what more might be done to avoid, reduce or compensate for the impacts we have identified and any others?

    The Independent Reconfiguration Panel (IRP) clearly recommended that the reviews of ECMO (Extracorporeal Membrane Oxygenation) and PICU (Paediatric Intensive Care Units) should be considered as part of the review of CHD services. We do not believe this has been done in the correct manner. It is becoming clear that by removing Level 1 CHD services from Glenfield Hospital it will become unviable that the ECMO and PICU units will remain at Glenfield Hospital.

    NHS England has acknowledged Newcastle's specialism in delivering heart transplant services but has dismissed the specialist knowledge of the ECMO centre in Leicester which is the only mobile unit in the UK, which provides all the training for the rest of the UK. We believe that insufficient consideration has been given to the local and national impact of the ECMO unit at Glenfield hospital and the crucial specialism that will be lost from the dispersal of services and this was being diluted by NHS England and it should be thought of in the

same way as the heart transplant service at Newcastle Hospital. Also, given the relationship of CHD with PICU and ECMO and the ruling from the IRP it is surprising that the proposals are being put forward before the reviews of PICU and ECMO are reported.

NHS England's proposal would result in an entire region not having CHD surgical services; this would be the only region not to have these services and would leave a large geographical gap across the country. NHS England has suggested that Glenfield could perform Level 2 services as part of the proposals which would still offer a service in the East Midlands. However UHL have clearly stated that the viability of this is unlikely because it will affect their ability to perform Level 2 services without a Level 1 service as other proposed Level 2 centres are partnered with a Level 1 centre. Currently no model of what a Level 2 service would look like exists which makes it hard to determine if this is a viable option before Level 1 services are decommissioned.

NHS England proposes that most of Leicester's patients will receive Level 1 CHD services in Birmingham. It clearly states that University Hospitals Birmingham will require capital funds in order to meet the additional capacity. We have also recently heard that Newcastle will need to pay in the region £100m to consolidate the heart services onto one site. With the NHS already facing significant financial pressures, this is both a concern and a surprise that NHS England have opted to put forward these proposals which could lead to a period of instability for patients and casts doubts on Birmingham's ability to cope with the extra demand. This seems even more ridiculous as an option when you have a great CHD centre in Leicester which also has room for expansion if needed and will not require the extra capital cost.

There is also an assumption that Birmingham and Leeds as the two nearest centres to the East Midlands will be able to take patients from the East Midlands. There is no guarantee that this is possible as if they are at capacity patients will have to travel further. Also, it would be fair to assume that patient waiting times will increase which again takes away from the patient experience.

Committee members have asked serious questions about the predictive growth of the population and the increase in CHD conditions on the proposals which were not answered effectively and need to be considered. Once a centre is closed it is much more difficult to reopen it than to retain it and help it meet the standards required. We have also questioned where the extra staff will come from for the centres that need to expand to take on patients as there is an incorrect assumption that staff will want to move and we already know that it is hard to recruit staff across all sectors of the NHS.

The University of Leicester is a leader in cardiovascular science research and has had national recognition and awards for its work. We have heard from the University the importance of the CHD service at Glenfield Hospital and the impact that it has on the important research that it conducts into cardiovascular disease. This wider impact should also be considered as the important work of the university in not only training and supporting people into the workplace for CHD but the research they conduct and how it will be negatively impacted

following the removal of CHD services in Leicester as part of NHS England's proposals.

14. Do you have any other comments about the proposals?

The Leicestershire, Leicester and Rutland Joint Health Scrutiny Committee is disappointed that as part of Question 5, Manchester and Leicester Trusts have been put together. These are two different trusts with different determining factors and whilst our committee has no view on Manchester we have a clear one with regards to Leicester and are opposed to NHS England's plans to decommission Level 1 CHD Services from Glenfield Hospital.

Public consultation has been questionable throughout this process with public meetings only allowing people to participate on a first come first serve basis with a restriction to the number of people that could attend. Also, scrutiny committees were listed as public meetings, they are meetings open to the public and not public meetings which does not allow the public the opportunity to ask direct questions of NHS England and these should not be included as part of NHS England's consultation.

NHS England has also been slow to respond to questions and queries raised by members of the public and they should find a better means to feedback to them. Having an open and transparent consultation is paramount and should be a priority to NHS England as it is these people that are directly affected by what NHS England are proposing.

We have heard directly from patients/carers about the importance to them of continuity of care and staying at the hospital where they have begun treatment. This is another forgotten factor that has not been considered. It seems that, rather than giving the sites the time to meet the standards, the review is unnecessarily unsettling patients that are already receiving outstanding care. The review has not thought about current patients at sites that are being proposed to be decommissioned and how they will be affected if services are decommissioned, again negatively impacting on the patient experience.

Whilst NHS England is working to a different set of standards, UHL's CHD unit was rated as 'outstanding' by the CQC; the only one in the country to do so and this should not go unrecognised. Again, if this review is truly about the quality of care as NHS England say it is and the resilience of a service, there is very little to doubt the outstanding service being provided at Glenfield hospital.

A simple adjustment to catchment areas or making links with surgeons at hospitals nearby would enable UHL to increase the number of operations it performs to meet NHS England's standard of 125 operations per surgeon per year, with 375 by 2019 and 500 by 2021. However, rather than supporting this in the same way other Trusts are being supported to reach necessary standards, NHS England have consistently stated that it isn't for them to mandate to patients where to have surgery at a particular centre and that it was for parents/patients to determine where they wished to receive treatment. However

we dispute this as it is NHS England's responsibility to organise these services and whilst they do not choose where a patient is treated these proposals are seeking to determine where they are not treated and thus NHS England is effectively limiting patient choice

The timescale of this review has been drawn out once again and there appears to be no determined date for a decision. This is irresponsible given the detrimental effect that the uncertainty of such proposals have on patients, clinicians and staff alike. We do not consider this to be acceptable practice; the timescales for change should always be communicated as part of a consultation process. We urge for a decision to be made in a timely manner with a clear timeline of events given.

It is also unclear who will make the decision and the Leicestershire, Leicester and Rutland Joint Health Scrutiny Committee would like reassurances that it will be made impartially and without bias. Clinicians and Trusts that are set to benefit as part of these proposals should not be part of the decision making process. There already questions around the determination of these proposals as many members of the original Safe and Sustainable Review have either remained on the Programme Board or in some cases have moved to Trusts that are in the scope of the review. Also, clinicians that have been part of the process to conduct self-assessments and formulate the consultation document are from some of the affected trusts. Such situations could breach conflict of interest rules and the credibility of the review and NHS England's decision making could be undermined if assurance is not given that no conflict of interest exists.

NHS England should consider the detailed growth plan that UHL has proposed and work with them to support them to meet the necessary targets. It is unclear as to why NHS England did not accept UHL's original growth plan as no reasoning has been given, in the same way no reasoning has been given as to why they have accepted growth plans from Newcastle and Southampton given there has been no indication they are making any change to their catchment areas. NHS England should facilitate meaningful dialogue with UHL to develop its caseload and catchment area.

The Leicestershire, Leicester and Rutland Joint Health Scrutiny Committee would like to emphasise that this is not about numbers and the patient experience should be heard and the emotional needs of the child, patient, parents, carers and family members should be considered. The Committee feels that NHS England is defending the indefensible and that it should realise that following this consultation, it should drop its proposals and instead develop a policy that helps support all trusts in an equitable manner, to reach the standards required. No more unnecessary public funds should be used to support this review any further.