PROPOSALS TO IMPLEMENT STANDARDS FOR CONGENITAL HEART DISEASE SERVICES FOR CHILDREN AND ADULTS IN ENGLAND

RESPONSE OF THE NOTTINGHAM AND NOTTINGHAMSHIRE JOINT HEALTH SCRUTINY COMMITTEE

Meeting the standards

1. In what capacity are you responding to the consultation?

- ☐ Current CHD patient
- ☐ Parent, family member or carer of a current CHD patient
- ☐ Member of the public
- ☐ CHD patient representative organisation
- ☐ Voluntary organisation / charity
- ☐ Clinician
- ☐ NHS provider organisation
- ☐ NHS commissioner
- ☐ Industry
- ☐ Other public body
- ☑ Other

If other, please specify.

The Nottingham and Nottinghamshire Joint Health Scrutiny Committee is a Health Overview and Scrutiny Committee, constituted in accordance with relevant legislation. Nottingham City Council and Nottinghamshire County Council have delegated their statutory health scrutiny powers to this Committee for matters which impact on both the areas covered by Nottingham City Council and Nottinghamshire County Council. The Committee is made up of councillors from both local authorities.

The Committee considers the proposals to be a substantial variation of service for the residents of Nottingham and Nottinghamshire and is responding to the consultation in accordance with its role, as set out in legislation, in relation to substantial variations or developments of health services.

2. In which region are you based?

- [ ] Not applicable/regional/national organisation
- [ ] England – North East
- [ ] England – North West
- [ ] England – Yorkshire and The Humber
- [x] England – East Midlands
- [ ] England – West Midlands
- [ ] England – East of England
- [ ] England - London
- [ ] England – South East
- [ ] England – South West
- [ ] Scotland
- [ ] Wales
- [ ] Northern Ireland

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?

- ☐ Strongly support
- ☐ Tend to support
- ☑ Neither support or oppose
- ☐ Tend to oppose
- ☐ Strongly oppose

4. Please explain your response to question 3.

The Committee neither supports nor opposes this statement because it does not consider that this is actually what is being proposed and that the standards are not being applied in a fair or equitable way.

None of the providers who, under the proposals, will be commissioned to provide Level 1 congenital heart disease services currently meet all of the proposed standards and there is an inconsistent approach being taken as to whether they will meet the standards within set timeframes. It is proposed that Level 1 services will continue to be commissioned from Newcastle upon Tyne Hospitals NHS Foundation Trust even though it is acknowledged that it will not meet key standards within the set timeframe. One of the standards that it will not meet is the required caseload which is the same standard that NHS England states that University Hospitals of Leicester will not meet within the set timeframe. Presumably, if NHS England is willing to continue commissioning from Newcastle despite it not reaching the required caseload then it does not consider that this will harm patient safety or have a negative impact on patient outcomes. If a lower caseload will not harm patient safety in Newcastle then it is not clear why NHS England considers that it will do so in Leicester. Alternatively NHS England is willing to commission a service for patients in Newcastle that is inferior to that in other areas of the country. Either way this inconsistency in approach is unfair for patients.

If an exception is being made to allow continued commissioning at Newcastle while NHS England works with them to deliver the standards within a different timeframe it is unfair not to allow a similar exception for Leicester to have additional time and support to meet the required standards.

While NHS England has stated that it does not consider that University Hospitals of Leicester will meet the full standards within the set timescales, it does not provide evidence that other providers will meet those standards. We are not aware of evidence available to Nottingham and Nottinghamshire residents to reassure them that University Hospitals Birmingham NHS

Foundation Trust or Birmingham Children's Hospital NHS Foundation Trust (where the consultation document suggests that most current Leicester patients will be referred to) are more likely to meet the standards than University Hospitals of Leicester. It is not clear what level of scrutiny has been applied to the growth plans of all providers. This evidence may be available within NHS England decision making processes but it is not transparently available within the public consultation process to enable citizens to make an informed view. University Hospitals of Leicester states that it has a growth plan that will enable it to meet the required standards and it seems reasonable that NHS England should work with them, as it has stated it will do with Newcastle, to deliver the standards rather than decommission a well-regarded service, reducing patient choice and requiring patients and their carers to travel further for a service that it is not clear will be significantly better in terms of patient outcomes. The Committee supports the principle of setting standards for services but considers patient outcomes to be the most important measure from a patient's perspective. Surgical survival rates at Leicester are at least as good as expected, in common with most providers, and the most recent Care Quality Commission inspection rated it as Outstanding for effectiveness.

If standards can be applied flexibility, with exceptions allowed, (which is what is being proposed by allowing a different timeframe for implementation by Newcastle) then this calls into question the necessity of those standards in the first place.

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

The standards set expectations for future provision of congenital heart disease services. However for some standards (for example the 3 year period over which the number of operations per surgeon is assessed) the proposals are based on past performance. It is unreasonable to assess a service, and make decisions about its future, based on past performance against a standard that did not exist at the time. Assessment against standards should commence from when the standards came into place not for a period of time before that.

We propose that NHS England should proactively work with University Hospitals of Leicester to support development of its plans to meet the required minimum number of cases (which is the only remaining standard that NHS England states that Leicester will not meet). We understand that its growth plan involves changing usual referral pathways. Representatives of NHS England have told us that referrals are a matter of patient choice and not to be mandated by NHS England. We support the principle of patient choice but believe that most patients make their 'choice' on the basis of their clinician's advice. If a clinician usually refers to one particular provider (perhaps for historical reasons) they will continue to advise patients of this

referral pathway and the length of travel etc. for patients will not be a significant concern for them. Patients will 'choose' on the basis on this advice even though they might actually prefer to be seen closer to home. As councillors we often hear from people that they would rather receive services closer to home and representatives of NHS England acknowledged to us that it is really important for some people to get services locally. The proposals remove this choice for patients in the East Midlands, who will no longer have any Level 1 congenital heart disease services provided in their region. University Hospitals of Leicester has told us that changing referral pathways involves developing new relationships and takes time. Representatives of NHS England told the Committee that they did not consider that they had a role in this – we disagree – and at the very least University Hospitals of Leicester should be allowed time (as Newcastle is) to try and achieve the necessary changes.

Finally, as stated in response to Question 4, the standards should be applied consistently. If one provider is given additional support and a different timeframe that this should be equally applied to all other providers.

Central Manchester University Hospitals NHS Foundation Trust and University Hospitals of Leicester NHS Trust

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?

- ☐ Strongly support
- ☐ Tend to support
- ☑ Neither support or oppose
- ☐ Tend to oppose
- ☐ Strongly oppose

Royal Brompton and Harefield NHS Foundation Trust

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?

- ☐ Strongly support
- ☐ Tend to support
- ☑ Neither support or oppose
- ☐ Tend to oppose
- ☐ Strongly oppose

Newcastle upon Tyne Hospitals NHS Foundation Trust

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 support
- ☐ Tend to support
- ☑ Neither support or oppose
- ☐ Tend to oppose
- ☐ Strongly oppose

Travel

We know that some patients will have to travel further for the most specialised care including surgery if the proposals to cease to commission surgical (level1) services from Central Manchester University Hospitals NHS Foundation Trust (adult service); Royal Brompton & Harefield NHS Foundation Trust (services for adults and children); and University Hospitals of Leicester NHS Trust (services for adults and children) are implemented.

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

- ☐ Yes
- ☑ No

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

We do not consider the assessment of the impact of the proposals on travel for patients and their carers who live in Nottingham and Nottinghamshire to be accurate.

There are good transport links between Nottinghamshire and Leicester, especially with the recently enhanced A46 road. While Birmingham might look relatively close to Nottingham on a map it is less easy to get to. The assessment suggests that children who currently receive treatment at Leicester will have an increased journey time of 14 minutes while adults will have an increased journey time of 32 minutes. Presumably this is based on where current patients live but since individuals born with congenital heart disease are as likely to live in one area as another it does not make sense as a statistic on which to base commissioning decisions.

The increased length of journey will take longer to complete and cost more for individuals. Locally, our hospitals strongly encourage patients and their carers to use public transport to get to hospitals – presumably this is the same in Birmingham. If Nottinghamshire residents used public transport to get to either of the Birmingham providers then it would take much longer than the increased journey time referred to in the assessment. The train journey between Nottingham and Leicester typically takes approximately. 30 minutes. The train journey between Nottingham and Birmingham New Street typically takes approximately 1 hour 15 minutes (that it without taking into account the ongoing travel at either end). One way of encouraging public transport use is increasing parking charges. Due to the journey, residents from Nottingham and Nottinghamshire would be less likely to be able to avoid parking charges. The increased journey time, especially for those in more remote rural areas may also require overnight accommodation. Consideration could be given to mitigating for these unavoidable costs.

It would not be necessary to mitigate for longer journey times if the standards are applied consistently and services continue to be commissioned at University Hospitals of Leicester.

Equalities 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.

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

☐ Yes

☑ No

10. *Please describe any other equality or 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 fully take into account the impact of the levels of deprivation in Nottingham City and some parts of Nottinghamshire County. This impacts on access to transport and the ability of individuals to pay for transport costs to attend medical appointments (which will increase under the proposals). Rural deprivation in parts of the County, such as parts of Bassetlaw, mean that people face challenges in accessing public services and we consider that this will be exacerbated by the proposals.

The assessment does not adequately consider the impact on the existing regional inequity of cardiology services in the UK. The East Midlands already has the least number of cardiologists per head of population of any UK region (Royal College of Physicians census data 2016). If congenital heart surgery and intervention at Leicester closes, it is likely that a proportion of current and future appointments will move away from the East Midlands to Birmingham or Leeds.

Other impacts

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.

11. *Do you think our description of the other known impacts is accurate?*

☐ Yes

☑ No

12. *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 consultation document does not clarify whether University Hospitals of

Leicester will continue to be commissioned as a Level 2 site and what these services will look like, how they will operate, pathways and communication routes to Level 1 services and wider networks. These arrangements should be in place prior to the decommissioning of Level 1 services so that risks to patient care are minimised during the transition period. The consultation document focuses on the impact of patients receiving congenital heart surgery and there has been insufficient regard given to the impact on the larger number of patients requiring specialist medical follow up. We understand that in the adult population in Nottingham, there are approximately 50 patients under specialised follow-up for every one patient going forward for heart surgery. These patients require expertise that is only possible if the cardiologist providing it is regularly working in a centre providing surgery and catheter interventions. Although NHS England has estimated the number of patients requiring surgery who will have to travel out of region, this is not matched by consideration of the sustainability of expertise required to provide appropriate specialist medical adult congenital heart disease services in the East Midlands.

If Level 1 services are decommissioned from University Hospitals of Leicester then consideration needs to be given the service received by patients during the transition period. It is likely that existing staff will look for alternative employment and it is likely to be challenging to recruit to vacancies for a service being decommissioned. The consultation document and our conversation with representatives of NHS England do not demonstrate that sufficient consideration has been given to service provision during this transition period.

The consultation document suggests that most people who currently receive Level 1 services at Leicester will access services at either University Hospitals Birmingham NHS Foundation Trust or Birmingham Children's Hospital NHS Foundation Trust. It reports that University Hospitals Birmingham will require capital investment in order to provide the additional capacity required. The financial pressures facing the NHS are widely reported and, given that context, we are surprised that NHS England is proposing to decommission an existing service only to require significant financial investment to provide an equivalent service elsewhere that also costs patients more to access. The consultation document states that University Hospitals Birmingham has identified sufficient funding. We do not feel that the consultation document demonstrates sufficient consideration has been given to the risks associated with funding being available and able to be spent within required timescales. Greater reassurance is required that the physical changes required will be made prior to the Level 1 services being decommissioned so that existing and new patients at UHB are not negatively impacted upon; and risks identification and mitigation plans in place if not. We are not aware of evidence of assessment of projected waiting times at University Hospitals Birmingham or Birmingham Children's Hospital, have been undertaken.

The consultation document acknowledges that there will be wider impacts as a result of decommissioning Level 1 services at Leicester, including the loss of ECMO services from Leicester – currently the only centre in the UK able to provide mobile ECMO; the provider of all UK ECMO training; and the provider of a significant respiratory ECMO caseload; and paediatric intensive care beds. We feel that insufficient consideration has been given to both the local and national implications of dispersing and diluting the considerable ECMO expertise provided by Leicester. Last year there were national reports of paediatric intensive care bed shortages so it is surprising that NHS England is proposing an option that will reduce bed availability further. Given the close interrelationships between these services and congenital heart disease services it is surprising that a decision is being taken before the national review of PICU and ECMO has reported. The two decisions should dovetail not pre-empt one another. An understanding of future ECMO and PICU needs should be informing this decision not having that review constrained by having options removed by this decision.

Any other comments

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

The consultation document includes an unnumbered question between Question 5 and 6 which groups together proposal to decommission Level 1 congenital heart disease services at Central Manchester and Leicester. The context set out in the consultation document for these two providers is different and the implications of proposals for each is different. Therefore it is surprising that these have been combined together into one question and allow for one response. As a Committee representing Nottingham and Nottinghamshire residents we neither support or oppose the proposal in relation to Manchester but do have a view on the proposal for Leicester. The consultation does not enable us to distinguish between these two different positions. Requiring a combined response is unreasonable. In analysing the responses it will not be possible to tell whether respondents are referring to the proposal for Manchester, Leicester (for which they might have differing views) or both. Therefore it is suggested that this question should be disregarded.

Downgrading the service in Leicester from Level 1 to Level 2 will leave the East Midlands without a Level 1 centre – we do not support this. Based on information provided to us by providers we are also concerned about the viability of Level 2 service in Leicester without Level 1.

We are aware of concerns about the consultation that has been carried out on the proposals. NHS England has included a long list of public meetings being held as part of the consultation. This includes meetings of health overview and scrutiny committees. These are not ‘public meetings’ in the sense that members of the public can speak and/or ask questions but rather

meetings held in public for the committee to be consulted in accordance with its statutory role. We consider that it is misleading to imply that these meetings form part of the public consultation process. We understand that where public meetings have been arranged by NHS England as part of the consultation process the number of people able to attend has been limited. Nottingham University Hospitals NHS Trust has also informed us that they are concerned that consultation has been poor. We understand that information has been requested from the Trust at short notice and not from relevant clinicians; and that concerns that the Trust has raised specific to Nottingham and the East Midlands have not been addressed by NHS England. This is disappointing and potentially undermines confidence in the consultation process.