

Consultation on Congenital Heart Disease PAPER C

Summary

NHS England is currently formally consulting on its proposals to implement the national standards for congenital heart disease.

These include the proposal to cease the provision of children's surgery and interventional cardiology at Glenfield Hospital.

Board Members are asked to form a view based upon the information in the paper below for submission to NHS England before the closing date of Monday 17th July 2017.

FOR DISCUSSION AND DECISION

Background

In 2015, NHS England [published new commissioning standards for CHD services](#) following extensive consultation with patients and their families, clinicians and other experts.

Healthwatch Rutland contributed to that consultation by approving the proposed standards. The HWR Board took the view that it supported retention of the unit at Glenfield but not if national standards could not be met.

Hospital trusts providing CHD services were asked to assess themselves against the standards, which came into effect from April 2016, and report back on their plans to meet them within the set time frames.

On 7th July 2016 it announced that, subject to consultation with relevant Trusts and, if appropriate, the wider public, NHS England would work with University Hospitals of Leicester NHS Trust and Royal Brompton & Harefield NHS Foundation Trust to safely transfer CHD surgical and interventional cardiology services to appropriate alternative hospitals. It was stated that neither University Hospitals Leicester or the Royal Brompton Trusts meet the standards and are extremely unlikely to be able to do so. Specialist medical services may be retained in Leicester.

UHL issued a strong rebuttal of the decision followed by a public campaign of protest supported by MPs and other bodies across the whole catchment area.

Consultation on Implementation Proposals

On 9th February 2017, NHS England launched a public consultation on how it will put in place the new standards for hospitals providing congenital heart disease services in England.

The consultation document can be accessed [here](#) and runs from Thursday 9 February to Monday 17th July 2017. It aims to gather as many views as possible from patients, families and clinical experts and will include face to face meetings around the country, webinars and an online survey.

To ensure the best outcomes for patients, the standards set out the need for surgeons to do a minimum of 125 cases per year, the equivalent of three per week. They also require that there should be a minimum of three surgeons in the team to cover the workload 24 hours a day, rising to four surgeons per team by April 2021. To make sure critically ill children receive the full range of support, the standards also specify that specialist children's cardiac services must also only be delivered where there are also a wider range of other paediatric specialities present on the same hospital site.

Professor Huon Gray, National Clinical Director for Heart Disease, NHS England said:

“It's our job to organise services so that every adult and child with congenital heart disease in this country gets not just safe or good care, but excellent care. We've worked hard with patients and clinical professionals to develop a set of standards to achieve this, and heard clearly throughout this process that this would only be worth something for patients if acted upon.

“NHS England has set out how these standards can be put into practice. No final decisions have been made, and whether or not they are carried out in the way we've suggested, is subject to the outcome of public consultation, so we encourage everyone with an interest to get involved.

“We've already been working with the hospitals potentially most affected by our proposals to help them to meet the standards, and look forward to hearing as many views as possible during the consultation.”

In a joint statement, the Royal College of Surgeons and the Society for Cardiothoracic Surgery said:

“We fully support these standards. NHS England must ensure that the standards are applied for the benefit of patients, by ensuring that expertise is concentrated where it is most appropriate. The proposals put forward by NHS England in July 2016 should improve patient outcomes and help address variations in care currently provided.”

All of the documents relating to the consultation can be found at:
www.engage.england.nhs.uk

Action Locally

A range of public meetings have been held including a joint LLR Health and Social Care Scrutiny Committee on 4th March where Mr Huxter who is leading the consultation for NHS England, acknowledged that the areas of difference

at Glenfield over standards had now been reduced to the 125 per surgeon /500 per unit number of cases per annum . Will Huxter attended the Rutland Health and Wellbeing committee on 28th March and the draft minute of that discussion is set out below .

Minute 699 PROPOSALS TO IMPLEMENT CONGENITAL HEART DISEASE SERVICES FOR CHILDREN AND ADULTS IN ENGLAND

Report No. 60/2017 was received from Will Huxter, Regional Director of Specialised Commissioning, NHS England. During discussion the following points were noted:

- a) The consultation process would run from the 9th February until the 5th June 2017.(Later extended because of the election)
- b) It was proposed to implement national service standards at every hospital that provided congenital heart disease (CHD) services. This would result in some hospitals carrying out more CHD surgery while other hospitals would stop this work.
- c) University Hospitals of Leicester (UHL) NHS Trust did not and would not meet the minimum number of cases required by the national service standards – 375 cases by April 2016 and 500 cases by April 2021. It was therefore proposed that surgery and interventional cardiology for children and adults at this hospital should cease.
- d) It was proposed that children and adults who would receive surgery and/or interventional cardiology at University Hospitals of Leicester would in future receive their care at either Birmingham Children’s Hospital NHS Foundation Trust or University Hospitals Birmingham NHS Foundation Trust. Some Leicester patients could also choose Leeds Teaching Hospitals NHS Trust, if this was closer for them than Birmingham, or any other commissioned centre. NHS England would not direct patients to attend particular centres.

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The Chair agreed to take the questions from Mrs K Reynolds and Dr J Higgs

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QUESTION 1 – from Mrs K Reynolds

Can NHS England assure the patients and their families in the East Midlands that the risks associated with the implementation of the proposal to decommission CHD services at Leicester, will NOT exceed any known/ evidenced based risk associated with giving EMCHC sufficient time to meet the standards, as has been offered to Newcastle?

Background:

The East Midlands Congenital Heart Centre (EMCHC,) is a high quality Level 1 centre that provides Congenital Heart Disease (CHD) Surgery and all related medical CHD services for the population of the East Midlands. It also provides the majority of extracorporeal membrane oxygenation (ECMO) services for the entire UK.

Its latest CQC inspection rated the EMCHC as Outstanding for effectiveness. Its latest results show they are performing above expectations in many areas such as Better than Expected Surgical Survival Rates, low waits for surgery and a 99% recommendation rate on Family & Friends Test. The EMCHC is up there with the best, but the constant uncertainty surrounding the unit will undermine the confidence

of both the staff working within the unit and of those clinicians sending patients to it, in case it might not be there in 18 months.

Question:

It is known from National Institute for Cardiovascular Outcomes Research (NICOR) data that the East Midlands already delivers over 500 cases of Congenital Heart Disease (CHD) surgery per annum, and based on Office for National Statistics (ONS) population growth this caseload is expected to rise. The EMCHC believes with time they will be able to facilitate relationships and referrals from within the East Midlands that will meet the 2021 case load standard. The proposal from NHS England will mean significant change for patients in the East Midlands and we all recognise that there are significant risks associated with transition, it rarely goes as smoothly as the proposal suggests and that means it will impact patient care, safety and experience. Can NHS England assure the patients and their families in the East Midlands that the risks associated with the implementation of the proposal to decommission CHD services at Leicester, will NOT exceed any known/ evidenced based risk associated with giving EMCHC sufficient time to meet the standards, as has been offered to Newcastle?

RESPONSE 1 – from Mr Huxter

UHL does not meet the current surgical activity requirement. Based on the latest available data, none of its three surgeons is undertaking more than the minimum 125 operations per year. NHS England's analysis shows that the population within the area for which UHL is the closest L1 centre would be expected to require over 500 operations per year.

We expect that at some point within the next few years UHL will meet the standard that came into effect in April 2016, which will require it to undertake at least 375 operations. We recognise that UHL believes that it will be able to attract referrals that will lead to a level of surgical activity that would meet the 2021 requirement of four surgeons each undertaking 125 operations a year, but it has not provided a robust plan that demonstrates to us how this will be achieved, nor any certainty about when it will be achieved in relation to the requirements of the standards.

Our aim is to assure patients that the care they receive meets the standards. We cannot rely on aspirations or beliefs that are not backed up by robust plans that we can be assured can and will be delivered.

When NHS England's board makes its decisions it will take account of the risks associated with change as well as the benefits of any proposed change.

QUESTION 2 – from Dr J Higgo

At the meeting NHS England held on 9th March at Tigers Conference Facilities in Leicester, as part of the Consultation, a number of questions were raised. Mr Huxter indicated he would provide answers. It is my understanding that no answers have been received as of 24/3/17. As the questions were on key areas of information answers are required to give a balanced picture and so will allow carers members of the public full participation in the Consultation. Just one example of an outstanding reply, Mr Huxter said he would make available the data used to calculate travel time, which is very important for those living in Rutland and the East Midlands as the figures quoted in their Consultation document would be impossible to meet even in light traffic. I ask for Mr Huxter's assurance that a prompt response will be forthcoming

RESPONSE 2 – from Mr Huxter

We calculated the travel times by looking at all the patients admitted for surgery

relating to congenital heart disease in England between 2006/07 and 2014/15. We looked at where those patients lived and calculated their journey time to their current level 1 centre. We then calculated their journey time to their nearest centre if our proposals were to be implemented. From these figures we calculated average (median) journey times and the maximum travel time experienced by 90% of patients.

We then compared journey times for the current arrangement of services and for the arrangement of services if our proposals are implemented (i.e. without level 1 services in Manchester, Leicester and at the Royal Brompton in London).

Patient locations were based on the MSOA of residence rather than their actual address. Super Output Areas are a geography used by government for statistical comparison. Middle Layer Super Output Areas (MSOAs) have an average population size of 7,500. We used MSOAs rather than actual addresses because of information governance restrictions on the use of patient identifiable data.

Information on admissions was taken from the HES dataset (Hospital Episode Statistics: the NHS standard data source for information about hospital activity). We used HES because this gave us both the means to identify hospital activity as related to CHD (using procedure and diagnosis codes) and the means to derive the MSOA in which the patients were resident.

The journey times used in the calculations were from Google Maps (using the Google Maps API - Application Programming Interface). In considering these journey time calculations it is worth remembering that not all patients currently receive their care from their closest centre. So when looking at how journey times would change if our proposals are implemented, those patients currently using a centre that is not their closest would, in our calculations, see a reduced travel time if that centre ceased providing L1 care, because we assume they would in future go to their nearest centre. And those patients living near a centre that could cease providing L1 care, but who currently travel elsewhere for their care, would be modelled as having no change in their journey time, because we assume that they would not change centre.

During discussion the following points were noted:

e) The family members of patients were the ones undertaking numerous visits to and from hospitals. Had public transport been taken into account when calculating travel times? The availability of public transport could be problematic in rural areas such as Rutland. Mr Huxter acknowledged this, and confirmed that NHS England would look at public transport as well as car journey time when looking at the impact of its proposals.

f) While all hospitals providing CHD services must meet the national standards or cease this work, there was one exception – Newcastle upon Tyne Hospitals NHS Foundation Trust – where it is proposed that the Trust is given longer to meet the standards. This was because the hospital had a unique, strategic position in delivering care for CHD patients with advanced heart failure and one of only two providers of paediatric heart transplantation.

g) Population growth had been taken into account when calculating catchment area numbers but not all patients attend the hospital located within their catchment area.

h) Emergency ambulance transportation was discussed as the current EMAS figures

for Rutland were not as good as preferred. Travel times would take even longer if access to CHD services was now further away.

i) The national CHD standards include overnight accommodation for parents, and capacity would be increased accordingly at sites which would be undertaking additional work if the current proposals were implemented. What impact would these proposed changes have on the Sustainability and Transformation Plan? Both projects have different timescales but they need to be joined up as they will both have an impact on each other.

j) The area was a rural area with a low population so it could not meet the national service standards. It was therefore being penalised for being a rural area. Mr Huxter disputed this. He pointed out that there was sufficient activity in the East Midlands for Leicester to meet the standards, but that roughly 1 in 3 patients from the East Midlands choose to access care at other centres.

AGREED:

1. The Board **NOTED** the report on the Proposals to Implement Standards for Congenital Heart Disease for Children and Adults in England – Consultation Document from NHS England.
2. The Board **AGREED** that it would provide formal feedback to NHS England via the Chair of the Rutland Health and Wellbeing Board.