UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

NHS ENGLAND REVIEW OF CONGENITAL HEART DISEASE SERVICES

REPORT TO THE JOINT LLR HEALTH SCRUTINY COMMITTEE

14th MARCH 2017

Introduction

NHS England is conducting a formal public consultation on its proposals to change the configuration of congenital heart disease (CHD) services across England. These proposals would see the de-commissioning (i.e. removal) of at least the surgical service from Leicester and most likely a further loss of services both related to CHD and more widely across the Leicester Children's Hospital.

University Hospitals of Leicester NHS Trust disagrees fundamentally with these proposals, for the following key reasons:

- The outcomes for children being delivered in Leicester are at least as good as those from the other UK centres and compare well globally
- The future sustainability of the service has been secured through the recent appointment of two key substantive clinicians
- We are very close to achieving the required minimum numbers of cases (375) per year) and have a robust plan for further expansion to meet the longer term standard (500 cases)
- We have a robust, funded, plan to meet the requirement that all children's services are on one site, within the required timescale
- NHS England is no longer suggesting that we have material issues with any of the other standards
- The removal of the service in Leicester will leave the East Midlands as the only region in England without a Level 1 (surgical) centre and force children and their families to travel much further for care
- These wholly unnecessary changes also risk destabilising a number of other key services for children, including already stretched paediatric intensive care and the largest ECMO centre in the country.

Consultation response

To assist the Committee's deliberations, the attached document is structured in the same way as the consultation questionnaire. We have set out, for each question, our view of the facts and our response.

The UHL Chief Executive and senior clinical staff will be in attendance at the Committee meeting to answer any questions that members may have.

John Adler

Chief Executive

6th March 2017

Introduction

The University Hospitals of Leicester NHS Trust (UHL) welcomes the consultation into the proposals to implement standards for congenital heart disease (CHD) for children and adults in England. The East Midlands Congenital Heart Centre (EMCHC) currently based at Glenfield Hospital is a high quality Level 1 centre that provides congenital heart surgery, diagnostic and interventional catheter procedures and all related medical CHD services for the population of the East Midlands. We also provide the majority of extracorporeal membrane oxygenation (ECMO) services for the entire UK. Our latest CQC inspection rated EMCHC as good overall with Outstanding for effectiveness. Our latest results below show we are performing above expectations in many areas;

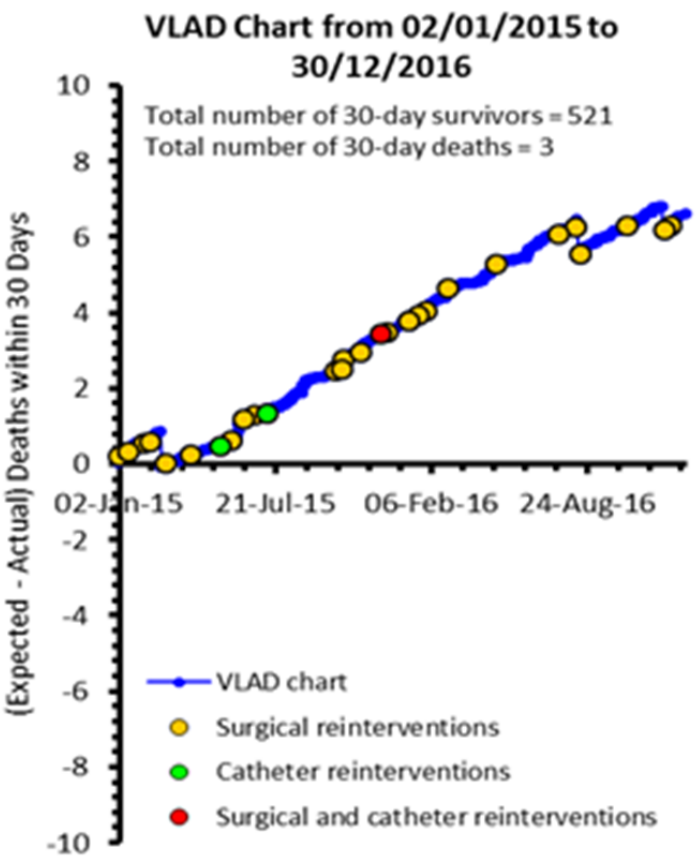
Better than expected surgical survival

Our Risk-adjusted survival following paediatric surgery is statistically significantly better than expected, benchmarked against the nationally recognised PRAiS (partial risk adjustment software) for the previous 2 years.

Our current paediatric 30 day survival after cardiac surgery is 99.4% whereas the national average is 98%

This cannot be described as just 'adequate'.

NB: a VLAD chart shows how many fewer (or more) deaths there are over time compared to what would be expected. Deviation above the 0 line demonstrates better than expected performance.



Consultation Questions

Question 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?

Question 4 Please explain your response to question 3.

NHS England is not doing what it says it is doing

- It is not possible to support or oppose this statement - as this is not what is being proposed
- In the consultation document, NHS England states that none of the centres currently meet all of the standards.
- Moreover, some of the centres who retain commissioning in this proposal currently meet fewer standards than UHL.
- They say that only centres that can meet the full set of standards within set timeframes will be commissioned but don't provide any
  evidence that other centres can do this better than EMCHC

Inconsistency

- NHS England clearly intends to retain commissioning of Newcastle despite the centre not meeting two of their key standards:
  a) The ability to reach the required caseload by 2021 and
  b) Co-location now or in the future.
- The geographic location of Newcastle makes it impossible for them to ever meet the 500 caseload standard without very major shifts in referrals to them from other areas much further away. NHS England has made it very clear that they (at least in theory) will not influence referral pathways and as such NHS England should not be supporting this assumption.
- If it is possible to derogate, and thereby accept that having less cases than required by the standard does not in itself add to patient risk for this centre, then it should also be possible to allow EMCHC additional time to meet the standards, should it be required.
- There is no evidence in the consultation document to demonstrate that NHS England's assessment of the growth plans proposed by other centres are any more or less robust than those proposed by EMCHC. NHS England's concerns regarding the UHL growth plan have not been discussed with the Trust other than simply dismissing our assertions.

NHS England then state that:

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

UHL comments in relation to this are as follows:

Interpretation of the standards

The Trust supports the principles of the standards that were approved by NHS England in April 2016, and in fact had representation from EMCHC on the standards development group. This group debated the standards at length and accepted that their implementation would be challenging which is why realistic timescales were agreed to allow centres the best chance of achieving the standards. At no point was it agreed that the standards would be used to close centres.

NHS England states that we do not meet standard 2.1 and are unlikely to do so in the timescales expected. On the 14th November NHS England wrote to the Trust and stated that;

Standard 2.1 requires a team of at least 3 cardiac surgeons, each of whom must have been the primary operator in a minimum of 125 congenital heart operations per annum as at April 2016, averaged over the previous 3 years (and therefore averaged over that period a minimum of 375 cases per year for the team of surgeons as a whole is required).

The actual wording in the standards document states ‘ averaged over 3 years ‘ not ‘ averaged over the **previous** 3 years ‘

Our understanding of the view of the profession is that the timescales for the implementation would be measured from the date of approval of the standards by NHS England. At no time was it suggested, or accepted, that any of the standards would be applied retrospectively. If this was the case, requirement 2.1 would have immediately excluded a number of centres from ever being given the opportunity to meet the standards. The introduction of an immediate timeframe by NHS England (not the standards committee) therefore was widely interpreted as being measured from April 2016 onwards.

UHL is predicting that in 2016/17 we will have delivered 350 operations in year (93% of 375 targets). Our network growth plan indicates that by 2018/19 the average case load <u>will be</u> 375 operations per year (detail below)
If the standard is interpreted in the way in which we think it was intended UHL will meet the standard within the timeframe

<u>Network growth plan</u> - UHL currently has a close working relationship with many hospitals across the East Midlands. Over the last couple of years we have worked closely with even more of the East Midland's Hospitals to provide CHD clinics and services as close to home as possible. This has already increased the number of CHD patients who have been referred to EMCHC. Based on the success of this strategy and extending it to a wider area, we are able to predict continued growth which will enable us to meet the required standards in the necessary timeframes.

EMCHC growth plans to meet the key standards around case load have been submitted to NHS England on numerous occasions , we have not received any detail explanation as to why NHS England deems our plans not to be robust .
Our growth plan is specifically based on the following assumptions;

- Population growth as per Office of National Statistics (ONS)
- Continuing our growth over the last three years (which has come from robust network relationships, providing satellite clinics in local hospitals, and providing robust , high quality referral pathways and excellent outcomes)
- Higher than average number of procedures per head of population due to the pattern of disease and complexity seen in our regional patient groups
- Expanding our network to three additional hospitals within the East Midlands network that have not traditionally referred a significant number of patients to UHL; despite UHL being the closest centre geographically for these patients.
  Discussions with these centres are underway and very positive; we have acknowledged that it will take time for the network clinicians to see that an equivalent service is on offer and to build relationships. We have therefore been very conservative in the first two years rising to a maximum requirement of only 51 patients in total in 2021 from these three centres.

The key point to note here is our growth plan clearly demonstrates our ability to meet the standard within the necessary timescale and INCREASES patient choice not reduces it. We are not asking NHS England to force patients to go where they do not want to – unlike the current NHS England proposals which will require MUCH larger numbers of patients to go out of East Midlands for their care with no choice.

Question 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?

- Apply the standards fairly and as originally intended.- the timescale for 125 cases should be measured from April 2016 onwards, not applied retrospectively.
- Treat all centres equally ensuring their ability to meet the standards is not predicated on the demise of another centre
- Ensure that all patients across the entire East Midlands are offered the choice of attending EMCHC, as an option in addition to the current usual referral pathway from those centres not already usually referring to us. EMCHC's growth plan recognises this will require relationships to be developed further. This will take time.
- Support UHL in the development of these relationships, thus reducing the need for thousands of patients in the East Midlands to be denied care closest to home and the choice of being treated at Glenfield
- Work with UHL to fully understand their growth plan and help implement standard B5 L1 which encourages Network referral to sustain the viability of Level1 centres in a Network
- Remove the cloud of uncertainty from Glenfield, enabling them to continue to build the expertise of their team for the future and put your efforts into celebrating and supporting its success

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?

It is surprising that NHS England has chosen to group these 2 centres together when the situation for each is totally different. It is not possible to answer this question sensibly as the rationale for decommissioning either centre is very different. Asking for a combined response is unfair.

The impact of establishing a Level 2 centre in Manchester with a level 1 (surgical and catheter) centre retained in the North West region is far less than downgrading the service in Leicester and leaving the entire East Midlands region with no Level 1 centre, and where every patient will have to go out of the region for level 1 care

In the consultation document NHS England outlines how Oxford has successfully moved from a Level 1 centre to become a Level 2 centre. Oxford was only performing around 100 surgical cases per year at the time it closed. There were evident concerns about quality where no such concerns exist at EMCHC. This was therefore a significantly smaller process to relocate compared to that from a centre delivering 350 surgical cases a year, >400 catheter cases and all the associated other inpatient procedures for patients from a much wider geography.

UHL stands by its predictions on the impact on other services: fetal medicine, neonatal surgery, neonatal surgery and intensive care, paediatric intensive care and speciality paediatrics, and ECMO, both within UHL and across the wider East Midlands and UK. If these proposals go ahead we believe the only services realistically able to be offered in a Level 2 centre are outpatient clinics and some inpatient drug therapies. Since <1/4 of the East Midlands patients actually live in Leicester, Leicestershire and Rutland, it is not clear why they would be better coming to Leicester for these services rather than being seen in their local (level 3) centres, some of which are very big teaching hospitals in their own right.

Royal Brompton and Harefield NHS Foundation Trust
Question 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.

We believe that this would depend on whether the partnership enabled all surgeons (both adult and Paediatric) to meet the 125 requirement.

Newcastle upon Tyne Hospitals NHS Foundation Trust
Question 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?

We would strongly oppose this ONLY BECAUSE it treats one centre differently from another. If the same approach was applied to all centres equally, then we would support this.
There is major Inconsistency of approach - the geographic location and historical growth information for Newcastle makes it impossible for them to meet the 500 caseload standard without significant shift in referrals to them from other centres.

Irrespective of the rationale for this derogation (exception making) based on the Transplant services offered by Newcastle, it means that NHS England **is** prepared to derogate against the standards. We would argue that the same flexibility should be shown (if necessary) to EMCHC in order to maintain local access for the population of the East Midlands. This cannot be unsafe as if it were then Newcastle would have to be closed.

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 (level 1) 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.

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

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

This travel analysis is clearly wrong.

We have asked for the 'raw data' on which NHS England has based their calculations to enable us to analyse how the figures have been derived. As yet we have not been provided with this. But it is also clear that they have only used a (low) number of patients having surgery elsewhere rather than all the procedures and admissions and clinic appointments that would have to move (>800 pa).

Since the majority of our patients live on the opposite side of Leicester from Birmingham, and it regularly takes more than an hour from Leicester to central Birmingham, these figures don't make sense.

NHS England's analysis suggests that **children** who currently come to EMCHC for treatment will have an average journey time increase of 14 minutes, whilst **adults** from the same region currently travelling to EMCHC will have an increase of 32 minutes! How is this possible? This inconsistency also casts doubt on the accuracy of the remainder of their travel time calculations.

If we assume these travel times are by road, significant numbers of our patients rely on public transport and have no cars of their own. We therefore also challenge that the proposals will only add this very small amount of time onto these journeys.

Patients from the east coast of Lincolnshire who rely on public transport and have an appointment in the morning in Birmingham would need to leave the night before

We accept that parents will drive to the moon and back if it would benefit their child – that is not the point. The question is therefore whether the magnitude of the benefits suggested by these proposals outweighs the risks.

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?
Question 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?

We would suggest a 'no' response to this:
Whilst NHSE have acknowledged some of the 'ethnic minority' issues for East Midlands patients, they appear able to ignore both urban and rural deprivation issues as this is not a statutory duty as it is not a 'protected group'. Despite this, there are very significant levels of both within the East Midlands which we believe have been ignored, not just for travel times but accessibility, family support and social care provision which EMCHC provides in great depth. Congenital Heart Disease is a life-long condition, and our patients have to visit hospital regularly throughout their lives; this is not a one off inconvenience. Whole families will be affected by the proposals.

UHL is the only Level 1 centre in the UK able to offer gender realignment surgery if requested to patients with CHD.

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

Transition Risk

There is a lack of consideration as to what will actually happen as soon as a surgeon or interventional cardiologist leaves during the 'transition period'. There is an assumption that this will be a gradual process but there is no evidence to support this and patients are likely to suddenly be left in a limbo situation with their cardiologists struggling to find them a bed in units with their own current capacity issues.

There is no formed description of how a level 2 centre can or will work across a number of surgical networks, patients in the East Midlands are likely to be referred to 4 other Level 1 centres if these proposals go ahead.

There is an assumption that the current outreach clinic provision will continue / be replicated in the new 'network' but there is no clear description of how this will be provided or indeed resourced. There is no financial incentive for the larger level 1 centres to provide this. The Independent Reconfiguration Panel, (IRP) themselves doubted the validity of the level 2 centre model and this has been ignored.

ECMO

No other centre provides mobile ECMO; all UK ECMO training is provided by EMCHC, and there has been little regard shown for the respiratory ECMO caseload. Caseload (numbers) features as the key 'safety standard' in the CHD review. In theory, all cardiac surgical centres have to be able to undertake ECMO as it may be required after cardiac surgery; in fact the majority of ECMO provided by EMCHC is provided for infants and children with catastrophic respiratory and cardiac failure not related to cardiac surgery. Most of these centres have little or indeed no expertise in this, which is why currently the EMCHC ECMO team travel the country (including to the current surgical centres) to place patients in this situation on ECMO and bring them back to Glenfield for optimal expert care.

NHS England has assumed that the current EMCHC ECMO work can easily and safely be dispersed across all the remaining surgical units and abolishes the mobile ECMO service. This therefore dilutes any residual expertise across the country whereas the proposal for cardiac surgery is to concentrate it! This is in direct contrast to NHS England's own quote from Mr Martin Kostolny highlighted on page 12 of the consultation document and again shows an inconsistency of approach which is not acceptable or fair.

In addition, no account has been taken of the impact of additional bed days and ICU stays for these patients either in one centre or many

Paediatric Intensive Care Unit, (PICU);

Since the Cardiac PICU at Glenfield is already planned to MOVE to the LRI in order to achieve compliance with the co-location standard, NHS England's dismissal of 'closure of the PICU at Glenfield' is both irrelevant and deliberately misleading. The unit at Glenfield is being moved to achieve co-location with the other UHL Children's Hospital services, as required by the CHD standards. It is not therefore being closed and to suggest otherwise is highly inappropriate. To be clear, the service provided by the PICU at Glenfield is only under threat as a direct result of NHS England's proposals.

Our concerns about PICU capacity across the UK (as evidenced by this winter's bed crisis, closure to admission within London etc.), remain entirely valid and have not been addressed by this review.

Since the timescales for the national PICU, specialised surgery and ECMO review do not line up with the CHD process, it is totally inappropriate for NHS England to prejudge the impact on PICU services or to expect patients and families to be reassured by these proposals and comment accordingly.

We remain very concerned about the ability of a retained non-cardiac PICU at the LRI to retain and recruit appropriately expert staff in the mid to longer term. Most other PICUs that do not have cardiac surgery do have some other highly specialised surgical programmes such as major trauma or neurosurgery to provide a background level of high expertise activity to maintain activity and focus between the periods of seasonal high intensity respiratory problems that are what cause the capacity issues year on year.

Reputation and workforce;

NHS England has dismissed our concerns on this on the basis of the effect on the entire trust not the Children's Hospital component. They have also ignored the loss of expertise to CHILDRENS SPECIALITIES as a whole. Not just in PICU but across the entire Children's Hospital. EMCHC has an excellent reputation for training both in paediatric cardiology and ECMO; there is no evidence of any credible plan to re-provide this elsewhere.

FETAL and maternal medicine and cardiology;

NHS England accept that this will be severely impacted but make no comment as to whether or not this matters. Loss of these services will mean that women have to travel much further, repeatedly, during pregnancy if they or their baby has CHD. Not only is this an unnecessary strain of itself but it is clear that this may alter their decision making about continuation of pregnancy or not.

Cost - It may not be about saving money – it may end up costing more money. Those centres potentially receiving additional patients will need to find funding to provide the infrastructure to meet the capacity. There is very limited capital investment available in the NHS currently, which will provide uncertainty and delay to capital development plans. If transition is not as smooth as NHS England hope, there is a real danger that the physical facilities will not be available in time to cope with increases in patient numbers at the remaining centres. We would challenge the capital requirements estimated to accommodate the additional capacity from EMCHC.

Any other comments

Question 13; Do you have any other comments about the proposals?

'Adequate' – Prof Huon Gray fears that without action the service will be left to be 'adequate'. This is implying that EMCHC and RBH are in some way currently 'only adequate' or indeed 'less than adequate' which is not the case. Even if it refers to the CHD speciality as a whole rather than these centres in particular, since the events in Bristol in 1991 and the subsequent reviews, the CHD speciality has actually been transformed and in fact should be seen as a major success story for the NHS. It is already far from merely 'adequate' National Mortality rates have gone from 14% to 2%

- UHL mortality rates have gone from 13% - 0.6%
- The number of CHD centres has gone from 17 to 10
- Occasional practice has gone from 190 cases to 5 case
- All existing UK Paediatric cardiac surgical centres are LARGE by international standards and UK cardiac surgical mortality is amongst the lowest in the world.

Crucial information needed to inform the consultation - The review into ECMO services is a crucial aspect of this consultation and it is inappropriate that the results of that review are not part of this consultation process. This was a recommendation from the previous Independent Review Panel following the Safe and Sustainable review.

FOCUS on surgical number - Caseload has featured as the key standard in the CHD review. NHS England assumptions are that the current ECMO caseload for ECMO delivered by EMCHC can easily and safely be dispersed across the remaining cardiac surgical centres, all of whom in theory can undertake ECMO as it may be required after cardiac surgery.

It is a huge assumption that the ECMO currently provided by EMCHC (over 50% of the UK requirements) will be able to be delivered by the units spread across the country. They are proposing

to dilute ECMO practice whilst using further concentration of cardiac surgical practice as a rationale for service reconfiguration.

This is in direct contrast to NHS England's own quote from Mr Martin Kostolony highlighted on page 12 of the consultation document and again shows an inconsistency of approach which is not acceptable or fair.

Specialist knowledge - The assumption that there will be appropriately trained clinical and nursing staff available to deliver this specialist care across all of the units is severely challenged by the fact that the majority of ECMO provided by EMCHC is provided for children with catastrophic respiratory and cardiac failure not related to cardiac surgery and in which other Level 1 centres have little or indeed no expertise (This is currently evidenced by the fact the EMCHC ECMO team travel the country including to the current surgical centres to place patients in this situation on ECMO and bring them back to Glenfield for optimal expert care) Replicating this expertise will be as difficult as expecting all centres to deliver transplant surgery – the key rationale for the derogation being applied to Newcastle.

This is an initial response to the consultation document and questions. UHL will be responding in detail to NHS England before the end of the consultation period