

NHS CONSULTATION ON CONGENITAL HEART DISEASE SERVICES



This document provides an overview of the standards that NHS England is proposing for all congenital heart disease (CHD) units with the views of CHSF. A consultation on these standards is now open until **December 8th**. CHSF would encourage you to provide feedback on these to ensure that they produce the best service for patients and their families.

Network Approach

- NHS England (NHSE) has heard different views about congenital heart networks. Some feel that they should have fixed, geographical boundaries, which will manage patient flows, to ensure that all CHD surgeons, in each specialist centre can perform enough operations to meet the standards. Others have said that restricting where patients can go reduces patient choice and means that some would not be allowed to use their nearest centre.
- The proposed standard would ensure that the shape and size of each congenital heart network is determined by local need and circumstances, taking into account geography and transport. There will not be a fixed geographical boundary and they will be expected to have working relationships with national specialists, such as transplant services.

CHSF View

We strongly support patient choice. Networks should be built around patient demand and not to suit the convenience of centres or clinicians. Networks should offer maximum, convenient access to the largest number of people.

There may be a misunderstanding that all outreach clinic sites (local medical centres around the region where specialist cardiac and related staff from the specialist centre in Leeds travel to treat patients) will become local centres. Leeds runs a vast number of outreach clinics and are committed to continuing these. However, not all will become local centres. There is not really anything in the review to assure parents that NHS England supports these sub clinics.

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Staffing and Skills

- The standards propose introducing minimum staffing and activity levels for surgeons, which would include all year round, 24-hour staffing and on-call arrangements.
- NHSE have also heard that families and carers depend on psychological, social spiritual and practical support.
- The proposed standards ensure that all CHD services must provide appropriate support to patients and to their families. This will include bereavement follow up and referral for ongoing emotional support of the family/carers.


- A key aspect of the standards is the need for communication and end of life care discussions with patients and their families to be open, honest and accurate. The standards cover care in hospitals as well as arrangements if a patient wishes to be at home.

CHSF View

CHSF wholeheartedly supports the increase of staff. As a charity we have funded some of these positions for many years. It's clear in the standards that these services are now recognised. We feel NHSE, commissioners and Trusts have a duty to meet the costs of these new positions to ensure greater access for patients in outreach clinics.

Surgical Caseloads and Size of Surgical Teams

- The proposed standard is that surgeons must complete a minimum of 125 congenital heart operations a year averaged over a three year period. Teams of surgeons should be made up of four surgeons, however not all centres have enough work for four. Many centres have teams of three surgeons with good results. Last year Leeds completed 486 operations with three surgeons although is actively seeking to recruit a fourth.
- It is possible that this requirement will mean that the way services are provided will need to change. This might mean fewer surgical centres in future but other solutions might include managing the case load at each centre to ensure sufficient activity or creating regional/national multicentre networks with surgeons working a part of larger surgical teams and working across more than one centre.



Surgeons must complete a minimum of 125 congenital heart operations a year

CHSF View

We accept that there has to be enough activity for each surgeon at a centre to retain their level of experience and competency. There is a genuine debate about the link between volume and outcome, including drawing on international evidence. NHSE should prioritise the interests of patients. This means that the level of staffing provided should support the needs of the local population. The level of cover should meet the demand. Whilst patients will be prepared to travel, that is not a reason to force more to do so than is necessary.

Where local demand is unable to sustain a level of activity compatible with the threshold considered safe for surgical teams, patients should be included in the most convenient networks linked to the nearest sustainable, specialist centre.

Sub-specialisation

- It has been suggested that some centres could be designated as sub-specialist; performing particular operations. This could affect the services that are offered in other centres and would lead to longer journeys for patients.
- Doctors have said that they prefer that support is brought in from within a network or other specialist centre or that a patient is referred to an alternative centre. Current rules which make it difficult for doctors to work in a hospital other than their own, especially at short notice, need to be addressed for this approach to work.
- NHSE is not proposing any formal sub-specialisation designation for any centre and instead proposes that networks need to work together to ensure that surgeons can move between units to support each other as needed.

CHSF View

We support abolishing any rules that restrict doctors working in hospitals other than their own. Apart from preventing greater efficiencies and productivity, it also prevents the greatest degree of patient choice. It is not centres that should be designated as 'specialist', but clinicians. Bricks and mortar can't move, but doctors can and those that have specialist skills should move between units. This ensures that patients have no longer journey times than are necessary.

Facilities

- Centres should provide hospital information booklets; age appropriate facilities; Wi-Fi; catering facilities; schooling; reasonable and affordable parking for long stays; and dedicated room space for therapeutic work.

CHSF View

Top of the list for facilities from our experience or working with children and young people is a good Wi-Fi connection. Other important facilities are parental accommodation and a sufficient sized and resourced play area should be available as this aids recovery greatly. This is fundamental when trying to encourage children to be physically active in preparation for going home. We also believe a quiet/therapeutic room for private or emotional discussions is particularly important. As patients will still need to travel to specialist centres for procedures, such as catheterisations, we feel the Trust and commissioners should be looking at the idea of patient hotels.

Interdependencies and Co-Location

- Specialist congenital services need to work with other services since many patients have other problems and require care from other specialists too. It is widely considered that it is not safe to provide care for children with the most complex congenital heart problems in hospitals where other services are not on the same site.
- There is agreement that some of the services must be on the same hospital site as the CHD service. This is called co-location.
- Triple co-location involves having children's congenital heart surgery, children's congenital heart services and adult congenital heart surgery all on the same site.
- The standards propose that specialist children's cardiac services should only be delivered in settings where a wide range of other specialist children's services are also present on the same site.
- The standards recognise triple co-location as the ideal. Leeds is in this ideal position of having all of its services co-located.



**Specialist
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CHSF View

We strongly support this standard. Co-dependency is vital and the definition of co-location needs to be strictly applied. This must not be watered down or compromised. One of the major problems with the Safe and Sustainable review was the way it sought to bend this objective to make it meet its desired outcome.

The professional body, the British Congenital Cardiac Association, has stated that it is essential to have co-location of foetal, maternity, neonatal services, PICU, children's inpatient services and Adult Congenital Cardiac services all on one site. Recommendation 178 of the Bristol Inquiry in 2002 which led to the Safe and Sustainable Review says: *"Children's acute hospital services should ideally be located in a children's hospital, which*

should be physically as close as possible to an acute general hospital. This should be the preferred model for the future.”

There has been a significant amount of reconfiguration work at LTHT to be able to deliver this gold standard triple co-location, including the move of children’s cardiac services from an isolated site at Killingbeck Hospital in 1997 to the Leeds General Infirmary (LGI) and the more recent centralisation of all children’s inpatient services to the LGI in 2010 to create The Leeds Children’s Hospital.

All our experience tells us having co-located services improves and enhances the patient/parent experience. We have been informed by a huge majority of our parents over the years that they don’t know how they would have coped without having interdependent services. The whole family unit seem to cope better with the situation knowing they can access all services.

Communication with Patients

- Patients and families have said that there needs to be a better way of sharing information across services; they want to be treated with respect and be given the information they need to make decisions.
- The standards will require that patients, families and carers are told about what is happening at all times and are enabled to take part in decisions being made. They will also encourage concerns and complaints to be dealt with in an open and positive way.
- Patients having surgery will be able to visit the centre beforehand.

CHSF View

As we know from our experience at Leeds, having triple co-location can only enhance communication between teams and therefore have a positive impact on patient care. This is something that must be continually monitored and reviewed. An increase in recruitment of liaison nurse specialists as set out by the standards will no doubt aid communications across the service.

Transition

- Moving a patient from children’s to adult services can be difficult and NHSE have heard that transition needs to be planned and personalised. In particular, patients around the age of 14 feel stuck between being a child and adult.
- The standards will ensure that there is joint working between children’s and adult CHD services and a gradual introduction to new staff and the new ward/building.
- The standards also propose that services must have arrangements in place to ensure a seamless pathway of care during transition, and that young people have the help and support they need during the move to adult CHD services.

CHSF View

At Leeds the team is currently looking into developing the transition services by holding information sessions and developing a transition clinic. This is work that CHSF will continue to fund and financially support. Over the coming years we are confident the transition service will go from strength to strength.

Delivering standards within resources

- NHSE expects the extra costs of meeting the standards to be funded through increased activity as demand for services grows. The funding will come, as now, through the national tariff. There will be no extra resources to implement the standards.

CHSF View

The overriding rule is that funding should follow the patients. There can be no justification for doing otherwise. Where the demand is, funding should enable the appropriate facilities to be provided. This should be the only determinant. People and facilities can move, and should do, instead of expecting patients and families to move unnecessarily.

This has not been the case in the past with a significant disparity in specialist commissioning funding. Yorkshire has been a significant loser, especially when measured on a per capita basis, compared to some other regions.

Those units starting at a disadvantage in terms of facilities and resources are not going to catch up, or at least not quickly, if they only can rely on increased activity for their extra funding. NHSE should appraise where resources have gone and the facilities each unit has, and where necessary allocate funding to ensure that there is a level playing field for when the new contracts start. If the standards are to be applied without extra resources overall, then resources need to be re-allocated to meet the anticipated demand.

Those units with the highest current and forecast demand should receive the investment required for equipment and facilities.

Where there is a historic disparity in tariffs (about paid per procedure), this should be corrected to create a level playing field.

There is added significant concern that Specialist Commissioning have recently reduced tariffs without any warning. This means that there is less income for the same amount of work. If they do this again, the units who have had the least amount of investment over the years will be worse off. Also, there is a problem for those units, like Leeds, that are not foundation trusts. They have less scope to fund changes needed to meet the standards in the short term. Leeds may not be untypical with its current finances in deficit. Units like this will be at a clear disadvantage. For example, one of the standards is to have a hybrid theatre that will cost millions of pounds for which Leeds is currently trying to raise the money. Given that the Trust is over £40m in the red, it is unlikely it will be able to fund this and the Unit will be heavily dependent on voluntary donations.

Leeds is on track to perform over 400 operations this year and will need four surgeons to meet current needs, let alone the growing demand that will come from the forecast increase in population, especially from the South Asian community. Even in the short term, Leeds will easily exceed the 500 procedures figure.

Fetal Diagnosis

The standards propose that patients will receive the same high quality, fetal anomaly screening wherever they live.

All networks that work with maternity and paediatric cardiac services must ensure that standards set out by the Fetal Anomaly Screening Programme and British Congenital Cardiac Association are met.

CHSF

Triple co-location ensures the Leeds centre can provide this again enhancing the patient experience for example a mother can currently have a fetal diagnosis deliver and both be cared for in the same hospital.

Making it happen

It is expected that standards will be finalised during 2015/16 for delivery in 2016/17.

There should be a system of inter-unit peer review where each centre will be required to provide evidence to show that it meets the standards.

CHSF

With regards to peer review, healing rifts between units will take time. Any sort of peer review must be carried out in a fair and constructive way. The process must be agreed by each unit. As the Verita report stated, the Safe and Sustainable process pitted units against each other, therefore moving towards a peer review situation is going to take some time, work and support.

Conclusion

What does not come out of the review is the pre-eminence of patients' interests, especially over the question of access.

The fundamental criteria is that doctors and facilities should go to where the patients are. Doctors, facilities and funding should follow the patients, not the other way round.

Patients should have to travel as short a distance as possible. For children's heart surgery, as well as shorter travel distances for sick children helping to save lives, it is a great benefit to patients' families who have to be with their children very regularly or constantly. The easier this is, and the minimum disruption given to family life, the greater the benefit to the patient.

Access to units should therefore be a key component of the standards.

Before a final decision is reached, the Review needs to conduct a Health Impact Assessment along with the recommendations.

The consultation documents must be made available in the most common languages of children using the heart surgery units the most, e.g. Punjabi and Urdu.

The Review team should publish a regional and demographic breakdown of forecast future demand.

How To Respond

The consultation is open until **5pm on Monday 8th December**.

A full copy of the consultation document is available at:

https://www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards/user_uploads/chd-consultation-doc-fin.pdf

You can respond to the consultation at:

<https://www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards>