

Congenital Heart Disease: NHS England takes action to deliver consistent and high quality services now and for the future

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Patients with complex, sometimes life-threatening congenital heart disease will benefit from action to ensure core standards of quality and sustainability apply across all specialist services announced today (Friday 8th July) by NHS England.

Congenital heart disease (CHD) services have been the subject of a number of reviews since the public inquiry at Bristol Royal Infirmary in 2001, with the outcome of a further review of a number of children's heart surgery cases at Bristol published last week.

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

Since then, hospital trusts providing CHD services have been 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.

As a result of these assessments, and following further verification with providers, NHS England intends – subject to necessary engagement and service change process in relation to this assessment – to take the following actions to ensure all providers comply with the set standards.

With regard to providers of specialist surgical (Level 1) services:

- Subject to consultation with relevant Trusts and, if appropriate, the wider public, NHS England will also work with Alder Hey Children's Hospital NHS Foundation Trust and Liverpool Heart and Chest Hospital NHS Foundation Trust to safely transfer CHD surgery from Central Manchester University Hospitals NHS Foundation Trust. Specialist medical services may be retained at Central Manchester.
- Subject to consultation with relevant Trusts and, if appropriate, the wider public, NHS England will also 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. 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.

- NHS England will work with Newcastle Hospitals NHS Foundation Trust to ensure progress is made towards meeting the standards and the strategic importance of the link of CHD surgery to the paediatric heart transplant centre is sustainable and resilient.
- NHS England will support and monitor progress at University Hospitals Bristol NHS Foundation Trust, Leeds Teaching Hospitals NHS Trust, University Hospitals Birmingham NHS Foundation Trust, Barts Health NHS Trust, Guy's and St Thomas' NHS Foundation Trust, and University Hospital Southampton NHS Foundation Trust to assist them in their plans to fully meet the standards. In the case of Bristol this will also include addressing specific recommendations set out in the independent report published last week.
- Birmingham Children's Hospital NHS Foundation Trust and Great Ormond Street Hospital for Children NHS Foundation Trust will continue to be commissioned, with ongoing monitoring, as they currently meet all or most of the standards.

NHS England remains concerned as to the level of occasional and isolated practice in specialist medical (Level 2) services, and intends to take the following actions:

- NHS England will work with Blackpool Teaching Hospitals NHS Foundation Trust, University Hospital of South Manchester NHS Foundation Trust, Papworth Hospital NHS Foundation Trust, Nottingham University Hospitals NHS Trust and Imperial College Healthcare NHS Trust to cease occasional and isolated specialist medical practices. Plans will be put in place to transfer services to other appropriate providers.
- NHS England will support and monitor progress at Liverpool Heart and Chest hospital to develop Level 2 and Level 1 services in line with standards and Oxford to assist them in their plans to fully meet the standards.
- Norfolk & Norwich University Hospitals NHS Foundation Trust and Brighton and Sussex University Hospitals NHS Trust will receive ongoing monitoring of their progress towards meeting the standards.

In addition, a small number of hospital trusts not recognised as a specialist centre, but which responded to the self-assessment that they undertook occasional practice/interventions, have been instructed to make arrangements for such patients to be cared for at a specialist centre in future. This process has now all-but

eliminated occasional practice, with follow-up action to be taken against providers if they continue.

Dr Jonathan Fielden, NHS England Director of Specialised Commissioning and Deputy National Medical Director, said: “Patients, families and staff need to be assured of sustainable, high quality services now, and into the future.

“There has been a great deal of uncertainty over the future of congenital heart disease services over the past fifteen years. We owe it to patients, families and staff to end that uncertainty, and to provide clear direction for the safety and quality of this specialist area of medicine going forward.

“A great deal of work has gone into achieving consensus across the board on the standards that providers should meet. We are determined to take all actions necessary to ensure that those standards are met, so that patients get the high quality and safe services that they expect and deserve.

“This is further proof that NHS England as the national commissioner of specialised care is stepping up decisively on behalf of patients now and to sustain quality care for the future.”

Professor Sir Ian Kennedy, who was the chair of the public inquiry at Bristol Royal Infirmary, said: “These are vital services and we have waited 15 years to arrive at a solution which delivers quality and consistency for current and future generations. It is good news for patients that there is finally a clear consensus on the standards that need to be met, and that we are now seeing decisive action to make those standards a reality for every patient in every part of the country.”

Miss Clare Marx, President of the Royal College of Surgeons, said:“Improvements to care for children undergoing heart surgery continue to be needed in spite of improvements since the Bristol Royal Infirmary public inquiry report in 2001. The Royal College of Surgeons strongly supports today’s plans and we hope these changes will now finally happen for the ultimate good of patients. “Units need to be the right size to enable surgical teams to be familiar and skilled in all conditions, treating these patients on a regular basis to maintain their experience and expertise. It’s absolutely critical that teams are sufficiently staffed to provide secure on-call rotas, disseminate new techniques, and train the next generation of specialists.

“The proposals set out today represent a consensus view of what consistent, high quality care should look like across the country. As a profession we are confident

these standards will help reduce variation in care and improve outcomes. Any further delay or obstruction by local parties will prolong uncertainty for the very ill patients who need this surgery.”

Congenital heart disease (CHD) affects up to 9 in every 1,000 babies born in the UK, with differing types of CHD and levels of severity. Some of the more common CHDs include:

- septal defects, commonly referred to as a “hole in the heart”;
- coarctation (or narrowing) of the aorta,
- pulmonary valve stenosis, where the valve controlling blood flow to the lungs is narrower than normal, and;
- transposition of the great arteries, where the pulmonary and aortic valves and the arteries they’re connected to have swapped positions.

Services and surgery – the provision of which is clustered in a small number of specialist centres across England – have progressed significantly over the last few decades, and around 80% of those born with a CHD now survive into adulthood.

However, there has been uncertainty over their future configuration. In an effort to address this uncertainty, in July 2013, after discussions with key stakeholders, NHS England established the New Congenital Heart Disease Review.

The Review had the following aims:

- Securing the best outcomes for all patients – not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives;
- Tackling variation – ensuring that services across the country consistently meet national standards, and are able to offer resilient 24/7 care, and;
- Improving patient experience – including how information is provided to patients and their families, and consideration of access and support for families when they have to be away from home.

On 23 July 2015 the NHS England Board received the review’s report and around two hundred new standards and service specifications which providers of CHD services should meet. These standards began in April 2016, with a five-year trajectory to full compliance.

In order to establish which providers do or can meet the standards in the set time frame, all providers were asked to complete a self-assessment process, the results of which have now been processed and form the basis of the actions set out today.

In 2014/15, the last year for which reliable data exists, the number of operations performed by CHD services was 4,354, and the number of interventional procedures was 3,793.

While some patients will have to travel further to access specialist services as a result of these changes, emergency admissions are rare, and ongoing work aims to ensure that more of a patient's long-term care can be delivered closer to home, meaning fewer trips to specialist centres.

Where the transfer of services goes ahead, NHS England will work with the hospital trusts to ensure that staff are supported.