

Update on congenital heart disease services for children and adults in the North West



Why are we here?



Our aim in this meeting is to:

- Provide a refresh of main points of NHS England proposals for the future and when decisions will be taken.
- Outline the current North West position and interim arrangements for patients.
- Answer any questions you might have about next steps.



Part One: NHS England national proposals

Michael Wilson, Programme Director, NHS England



Background



- Congenital heart disease (CHD) refers to a heart condition or defect that develops in the womb, before a baby is born.
- There are many different forms of CHD. Some people with CHD do not require surgery or an interventional procedure.
- Advances in care mean that most babies born with CHD now grow up to be adults, living full and active lives.
- CHD services have been the subject of several reviews and enquiries over the past 16 years, but failure to implement recommendations has resulted in uncertainty, damaged relationships and made recruitment and retention difficult.
- While outcomes for CHD surgery are good, overall, care can be improved.

Model of care



Congenital heart disease services are delivered through a three-tiered model of care:

Level 1: Specialist surgical centres deliver the most highly complex diagnostics and care, including all surgery and interventional cardiology.

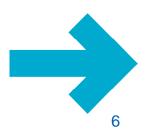
Level 2: Specialist cardiology centres provide the same level of medical care as Level 1 hospitals, but do not provide surgery or complex interventional cardiology.

Level 3: Local cardiology services are involved in diagnosis of CHD and provide routine and follow up care for patients with CHD particularly those with less complex problems.

The standards



- The New Congenital Heart Disease Review, set up in 2013 developed service standards, describing how a good CHD service should be set up, organised and run.
- We developed these standards almost 200 in total over a two-year period, working in partnership with patients, families, carers, surgeons, specialist doctors and nurses, and other stakeholders.
- Consensus was achieved on the standards. They were the subject of public consultation, and were adopted by the NHS England Board in July 2015.



Assessing against the standards England

- In January 2016 we assessed hospitals providing CHD services against a specific number of the standards.
- Central Manchester University Hospitals NHS Foundation Trust (CMFT) did not meet the requirements, was considered unlikely to be able to do so and the national panel considered their arrangements to be a risk.
- The level 1 service in Manchester is for adults only.
- Central Manchester had only one congenital heart surgeon, carrying out around 90 congenital heart operations a year – the standard requires teams of four surgeons each doing more than 125 operations per year.



The proposals



- We are proposing that, in future, we will only commission CHD services from hospitals able to meet the standards within the required timeframes.
- If our proposals were implemented, adult patients who received surgery or interventional cardiology at Central Manchester would be most likely to receive that care from Liverpool Heart and Chest in future.
- Children with CHD in the NW already receive surgery and/or interventional cardiology in Liverpool at Alder Hey.
- Medical care, including some interventional cardiology and most maternity care for women with CHD could continue to be provided at Central Manchester.
- Other non-CHD cardiac services are not affected.

Next steps for the national decision



- Our consultation ended on 17 July 2017. We received over 7,500 responses and we are determined to ensure careful analysis of the very full responses we have received.
- We are awaiting confirmation of some information supplied by provider trusts.
- As part of this process NHS England has asked the North West to work on a local model of care.
- We expect to make a decision on CHD services at our public board meeting on 30 November 2017.





Part Two: The current situation in the North West

Andrew Bibby, Assistant Regional Director of Specialised Commissioning, NHS England North West



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The commissioned service



The following services are currently commissioned by NHS England for the North West region:

- Level 1 paediatric service at Alder Hey (circa 400 surgical cases a year).
- Level 1 adult service commissioned at CMFT (circa 90 surgical cases per year).
- Level 2 services at Liverpool Heart and Chest and Blackpool hospitals.



Current North West position



- CMFT formally notified NHS England of its suspension to adult CHD services in June 2017.
- The single-handed surgeon left, meaning that CMFT could no longer offer surgery and therefore a Level 1 service.
- The national standards outline for surgeons to work in teams of at least four to mitigate risk against service continuity problems.
- These surgeons are highly specialist and scarce (less than 40 nationally).
- As a response NHS England has worked with CMFT and other providers in the North of England to develop an interim service.
- This is to ensure the needs of patients in the North West continue to be met.

What this means for patients



- Adult CHD surgery and interventional cardiology is temporarily provided at Newcastle or Leeds hospitals.
- We have designed an approach where as much care as possible can continue to be provided at CMFT (Manchester Royal Infirmary site).
- We have developed arrangements with the Trust to provide assistance for patients and their families with support for travel.
- We considered the role that Liverpool Heart and Chest could play in the interim, however they do not currently have the required team to provide Level 1 services in the short term.

What this means for patients



CMFT continues to provide the following services:

- Outpatient CHD services, including all diagnostic tests.
- A dedicated adult congenital clinical nurse specialist service and support on site.
- Maternity care for women with adult congenital heart disease and pre-conception counselling.
- All other non-CHD heart surgery services.



Who is doing what...



During the suspension CMFT has been responsible for:

- Coordinating the re-provision of the service with other Trusts.
- Communicating with patients affected.

NHS England is supporting CMFT by:

- Working with all parties in assessing and prioritising current patient need.
- Acknowledging this has been difficult for patients.
- Meeting patients and their representatives to listen and respond to their concerns.

Wider North West CHD services England

- CMFT is not the provider of congenital heart disease services for children.
- Alder Hey Children's Hospital has always been the Level 1 single specialist centre in the North West region for children in need of congenital heart disease surgery.
- The majority of CHD activity is for children.
- Future intentions deliver a service that is seamless between children and adult services.
- There are currently three specialist CHD surgeons already practicing in the North West, based at Alder Hey Children's Hospital in Liverpool.

Next steps locally in the NW



- NHS England is facilitating a joint piece of work involving senior clinicians from CMFT, Liverpool Heart and Chest, Alder Hey, Blackpool, and Wrexham to develop a collective North West model of care for the future.
- We are working up a proposal that seeks to ensure that as much care as can be provided in Manchester, will be provided in Manchester in the future.
- A clinical summit involving patients took place in September to consider how the service works in the future.
- These proposals will feed into the national decision making process in November.

Feedback from patient advocates



"We have been working with NHS England, CMFT and the Liverpool hospitals (as well as the regional centres) to try and work out what the patient journey would be like. The 'patient journey' is how we move from one part of the system to another. The good news is that our clinicians and nurses are in these meetings and all of the hospitals are working together to make this work as quickly as possible so we can start the rebuilding process."

