NHS

Yorkshire and Humber
Congenital Cardiac
Network

CONGENITAL CARDIAC SERVICE STRATEGY

Version Control

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EXECUTIVE SUMMARY

This strategy has been developed by the Yorkshire and the Humber Regional Congenital Cardiac Network Board. It describes how service for children and adults with abnormalities of the structure of the heart present from birth are cared for in our region. It highlights where standards have been developed to ensure services are the best they can be; and it presents key challenges for the future.

The heart

The heart is an essential organ- without it there is no life. From its formation in the early development of a child in the womb, to the early months of life, the heart changes and grows in a complex and precarious way.

Spotting a problem- before birth

All pregnant women in the region are offered ultrasound screening half way through their pregnancy as part of the antenatal screening programme. This includes viewing the newly formed heart and vessels. Even at this early stage there can have been problems in the process which could result in ill health as soon as the baby is born.

We have worked with the staff that perform these scans to improve the pick-up of abnormalities of the heart.

Working with leads from the PCTs we will work to improve the quality of this screening.

Sometimes, these conditions are treated by fetal cardiologists- experts in the diagnosis and treatment of heart problems in the child in the womb and the newborn. Some mothers are advised to have their labour in a specialist centre where the baby can have treatment immediately after birth.

There is a single fetal cardiology service, provided by Leeds Hospitals which links with fetal medicine services in Sheffield.

The specialist centre provides joint clinics with maternity services to help plan care.

We propose to retain the Leeds service as the fetal cardiology centre.

Spotting a problem- at birth

In some cases, either because a woman chooses not to be screened, or because the abnormality is not noted on scanning- a baby may be born and immediately show signs of a heart abnormality. These signs can range from looking blue, to failing to breathe. Usually the heart has been fine up until birth- but the changes required in those first hours of life to change the heart to be suitable for life outside the womb may not occur.

At this point a paediatrician will identify a problem and arrange for mother and baby to be transferred to a specialist centre.

We have developed a comprehensive transport service for neonates to allow the emergency transfer of babies to the specialist centre.

Spotting a problem- in the first year

Often, babies have normal scans, and are well in the first days after birth but either on first examination, or at the 'six week' check by the GP, a murmur is noted- an extra noise coming from the heart. This can be normal- but may be a sign of an abnormal shape or structure within the heart. Ideally these babies should be seen by an expert in babies hearts- usually with a further ultrasound of the heart- called an echo.

Working with PCTs, we propose to maintain a good standard of local expertise to allow children to be examined soon after birth by a competent paediatrician or specially trained midwife.

The regional paediatric cardiology network- a clinicians forum- has developed guidelines for GPs and hospital staff to standardise the way children with suspected heart problems are managed.

Where possible the first port of call for less serious cases will be a local paediatrician with a special interest. These paediatricians work alongside the paediatric cardiologists from the centre to assess the children before onward referral of those with complex problems.

We propose to offer local access to this intermediate level care- ie between GPs and Generalists, and Paediatricians with a special interest- in clinics which meet standards agreed with experts across the region.

Diagnosis- confirming the problem and initial treatment

In total, each year more than 400 babies are identified as having a heart problem. Less than 100 of these would be considered complex. All babies with abnormal hearts will usually need diagnostic tests involving dye in the heart to allow the experts to identify the exact nature of the problem.

Treatment will be offered either medical, intervention using balloons and tubes called stents- or through some form of heart surgery. At present, all but the most rare procedures can be performed within our region.

There is a national review taking place to agree supra-regional centres for paediatric cardiac surgery. Such centres will support regional cardiac centres and networks for congenital cardiac services.

Although for some children one treatment rectifies the problem and they return to normal- for many repeated treatments are required.

At present, we propose to maintain a single specialist centre at Leeds while the national review progresses. We will develop the Leeds service to best use the time and expertise of the staff- both in the centre, and in out-reach settings.

Ongoing care
Paediatric cardiology services provide ongoing care for babies, children and teenagers with structural heart problems. For simple conditions, the care may continue with a paediatrician with a special interest in cardiology- rather than a full time specialist. This means that children can receive ongoing care closer to home- usually in their local hospital. For more complex conditions the consultant paediatric cardiologist will continue to see the child and family- either at the specialist centre, or where possible, in ‘outreach’ clinics in local hospitals.

We will continue to develop the provision of as much of the ‘consulting room’ part of the service in a local setting- rather than at the centre. This relies on local clinics meeting the agreed standards.

Newly discovered problems in children
If a GP or paediatrician suspects a child has a heart condition later in childhood the child should be seen by a local paediatrician with a special interest. As outlined above, these experts work alongside the cardiologists at the centre.

We are working with GPs to spread the use of the referral guidelines and working to make referral to the local paediatrician with a special interest the norm.

Moving into adulthood
Ongoing care can continue into adulthood- sometimes called Grown-up or Adult Congenital Heart Disease (GUCH or ACHD). This group is growing as treatment and subsequent survival in those with heart disease improves. There are now estimated to be more than 15,000 adults living in the region with some history of congenital heart disease.

General Cardiology services for adults may take on the care of some adults with a congenital cardiac condition but support from an ACHD specialist can always be accessed. For the more complex cases the ACHD specialist team can be seen- either at the centre or in an outreach setting.

We have agreed standards for this specialist centre, based on a national template. We propose to maintain a single centre- in Leeds- and develop a greater number of out-reach locations over time.

When an adult with previously diagnosed congenital heart disease is identified- the ideal is that any treatment- either medically intervention or surgery, is planned, agreed or provided by experts in these conditions.

Advice to family members about inheritance of conditions
A final part of the service for families with one of these conditions is the Inherited Cardiac Conditions (ICC) service. This is a service which brings together cardiologists and clinical geneticists to advise families where the cause of the heart disease may be hereditary. Advice may relate to preparation for pregnancy, screening in pregnancy, and risk of future offspring having the condition.

We have developed a service specification for this service including standards for the teams. We propose to develop two centres with an element of out-reach.

The cardiologists within ICC teams are now developing an expertise in the treatment of children and adults with these conditions- and for some they provide the continuing clinical care.

This is a new division of healthcare and we will work with other cardiologists, GPs and the coroners in the region to develop the service over time.

Support for children and families
It will be clear from this short summary that many patients with identified heart abnormalities will be affected throughout their life- and this will have a significant effect on parents and other family members. Patient support groups and the provision of ongoing support by specialist nurses are vital to manage the day to day strain of living with these conditions.

The service standards all include requirements for specialist or liaison nurses, as well as ensuring appropriate information is given regarding other means of support.

1 Introduction

1.1 Service Scope

This strategy covers the following specialised service areas:

- Paediatric Cardiology (including fetal cardiology)
- Adult Congenital Cardiology
- Congenital Cardiac Surgery (adult and paediatric)

See Appendix A for relevant sections of the National Specialised Services Definitions Set.

1.2 Age range

- All ages

1.3 Care pathway

Entry to the service is via

- Fetal screening
- Newborn screening
- Referrals from GPs / Primary care
- Referrals from Secondary care

1.4 Population covered

This strategy covers the population of the Yorkshire and the Humber region, plus North Derbyshire and Bassetlaw.

Region / Area	Population Figure
Yorkshire and the Humber	5,140,794
Bassetlaw	107,065
Derbyshire county (North)	369,238
Total	**5,617,097**

1.5 Overall aim of the strategy

The strategy provides a framework for commissioning and delivery of Congenital Cardiac services.

1.6 Development of the strategy

- Oversight of the process will be via the Congenital Cardiac Network Board
- Patient involvement strategy
- Communication Plan

Key milestones in development of Strategy:

November 2009	Draft Strategy prepared
November 2009	Strategy considered by Strategy Steering Group
December 2009	Strategy considered by Congenital Cardiac Network Board
January 2010	Strategy considered by Strategy Steering Group

2 Background

2.1 What is congenital heart disease?

Congenital heart disease refers to any structural abnormality of the heart or great vessels which has been present since birth.

Congenital heart disease is the most common type of birth defect, with about 8 out of every 1,000 babies being affected by a congenital heart defect of some description. The incidence of congenital heart defects amongst newborns has not changed for many years.

The outlook for congenital heart disease varies depending on the type and severity of the heart defect. However, due to advances in heart surgery, 85% of children with congenital heart disease will now survive into adulthood. Thus the prevalence of congenital heart defects in adults is increasing year on year. Most of these adults have complex health needs and require life-long specialised care. See Appendix B for classification of congenital heart defects by severity.

2.2 Health needs assessment

Although congenital heart disease complicates almost 1% of live births, accurate prevalence data and statistics on the numbers of adults with congenital heart disease is lacking.

Before the advent of cardiac surgery for congenital heart malformations, less than one fifth of children born with such lesions reached adulthood. Most survivors had mild lesions. Exceptionally, some with more severe complex defects survived. The dramatic successes of surgical management and more recently interventional catheterisation in childhood has reversed this poor prognosis so that by the 1980s 85% could be expected to reach adulthood. ‘Total correction’ however is the exception and more often than not, any such interventions are palliative, which means the majority of patients need life-long surveillance and often further medical and/or surgical intervention.

As a result of this change there has also been an increase in the complexity of cases, not only because many will require several, repeat interventions but also because with an aging patient population acquired heart diseases such as ischemic heart disease become more prevalent. Most deaths from congenital heart disease now occur in adults. Knowledge and training in congenital heart disease, adult cardiology and general medicine are required for practitioners in this area.

In an attempt to predict the future care needs of the population with congenital heart disease, a study in a single UK health region reviewed all births over a 10-year period (1985-1994) and extrapolated the results to the United Kingdom as a whole.

For Yorkshire and the Humber, the estimated incidence of congenital heart disease in children in 2010 is as follows:

Moderate/complex	100
Simple	300

The annual increase in numbers of *adults* with congenital heart disease was estimated to be approximately 1600, with some 800 patients per year requiring specialist follow-up.

A commissioning guide for services for young people and grown ups with congenital heart disease 2006 estimates that in 2000 there were over 133,000 adults with congenital heart disease of varying complexity in the UK, and that this could grow to 159, 000 by 2010.

For Yorkshire and the Humber, the prevalence of Adult Congenital Heart Disease by severity in 2010 has been estimated as follows:

	Complex		**Moderate**		**Simple**	
	Prevalence in 2000	Prevalence in 2010	Prevalence in 2000	Prevalence in 2010	Prevalence in 2000	Prevalence in 2010
North East Yorkshire and North Lincolnshire	520	660	1620	1970	2110	2460
West Yorkshire	730	920	2140	2630	2770	3260
South Yorkshire	430	540	1290	1560	1660	1950
Total (Y&H)	**1680**	**2120**	**5050**	**6160**	**6540**	**7670**

2.3 National drivers

Paediatric Congenital Cardiac Services have been under the spotlight since reports began to raise concerns about surgery in Bristol. The recommendations included in the report of the Paediatric and Congenital Cardiac Services Review Group, published in November 2002 (known as the Munro report) have been implemented to a variable degree. Concerns came to a head in 2006 when pressures on paediatric cardiac surgical centres caused Sheila Shribman and Roger Boyle to call a DH sponsored Workshop to discuss the way forward.

This group agreed the following:

- The need for fewer, larger centres nationally
- Need for national standards
- Change should be determined locally

The DH and the Specialised Commissioners considered the implications of this consensus and this resulted in a paper being considered by the NHS Management Board (MB) in May 2008. The MB fully supported a national process to review the provision of paediatric cardiac surgical services with a view to reconfiguration.

The process to achieve this is now called the Safe and Sustainable Paediatric Cardiac Surgery programme. An event to launch draft standards for Paediatric Cardiac Surgery was held on 22nd October 2009.

The drivers for change were identified as:

- Clinical sub-specialisation
- Critical mass of procedures
- Training and development
- Working hours

The National process is focused on Paediatric Cardiac Surgery but acknowledges that Paediatric Interventional Cardiology needs to be co-located in surgical centres and there needs to be clear links to services for adults with congenital cardiac problems (Grown up Congenital Heart disease- GUCH- patients).

Alongside this process, the SCGs in England agreed a process to agree designation standards for GUCH services, led by East of England SCG. This document is in the final stages of development.

In response to the Programme, the SCGs in England have asked providers to report on compliance with the Munro standards and other aspects of congenital cardiac services as part of a baseline assessment. This is due for completion by the end of January 2010.

2.4 Local drivers

- SHA mandate for specialist commissioners to make decisions about specialist services
- There is currently one major centre in Yorkshire and the Humber, which will need support if the region is to have a service in the future
- There is a need to maintain local access where safe to do so
- There is a need to foster collaboration across NHS providers for the benefit of patients in the region
- There is a need to respond to national drivers in ensuring cardiac centres are sustainable in the longer term
- Changes in local paediatric services have resulted in an increase in the support required from the specialist centre. This is unsustainable and the future of paediatric services needs to be planned.
- There is inequity in the current adult and paediatric service, despite pockets of excellence.

3 Current Commissioning Arrangements

3.1 Planning

Services for adults and children are commissioned via the Yorkshire and the Humber SCG. Service planning takes place through cardiac services. The SCG has established the Congenital Cardiac Network Board to advise on future service planning.

3.2 Contract arrangements

The service for adults currently attracts the adult cardiac tariff in some parts of the region, but due to a historical arrangement, some provision attracts a paediatric uplift. The paediatric uplift is considered by many to be appropriate for ACHD services, given that most consultations will involve more investigations than those used in the majority of general cardiology consultations.

Paediatric cardiology activity attracts the standard tariffs for general paediatrics and paediatric cardiology. Work is ongoing to ensure that (i) non-urgent referrals to the specialist paediatric cardiology service are only made after appropriate assessment in secondary care, and (ii) tariffs for paediatric cardiology and general paediatrics are applied consistently and appropriately for activity across the region.

Current congenital cardiology activity (adult and paediatric) is not easily separated from other cardiac activity due to the way it is recorded and coded. Some diagnostics and interventions performed on adults with congenital heart disease may be funded through non-specialised elements of the provider contract.

There is no agreed activity baseline for congenital cardiac services.

3.3 Performance management

There is no mechanism for performance monitoring, partly due to the fact that the service is currently subsumed as part of other cardiology services. As such it is included in reporting to the Performance Management Sub Group of SCG and issues may also be raised as part of contract discussions.

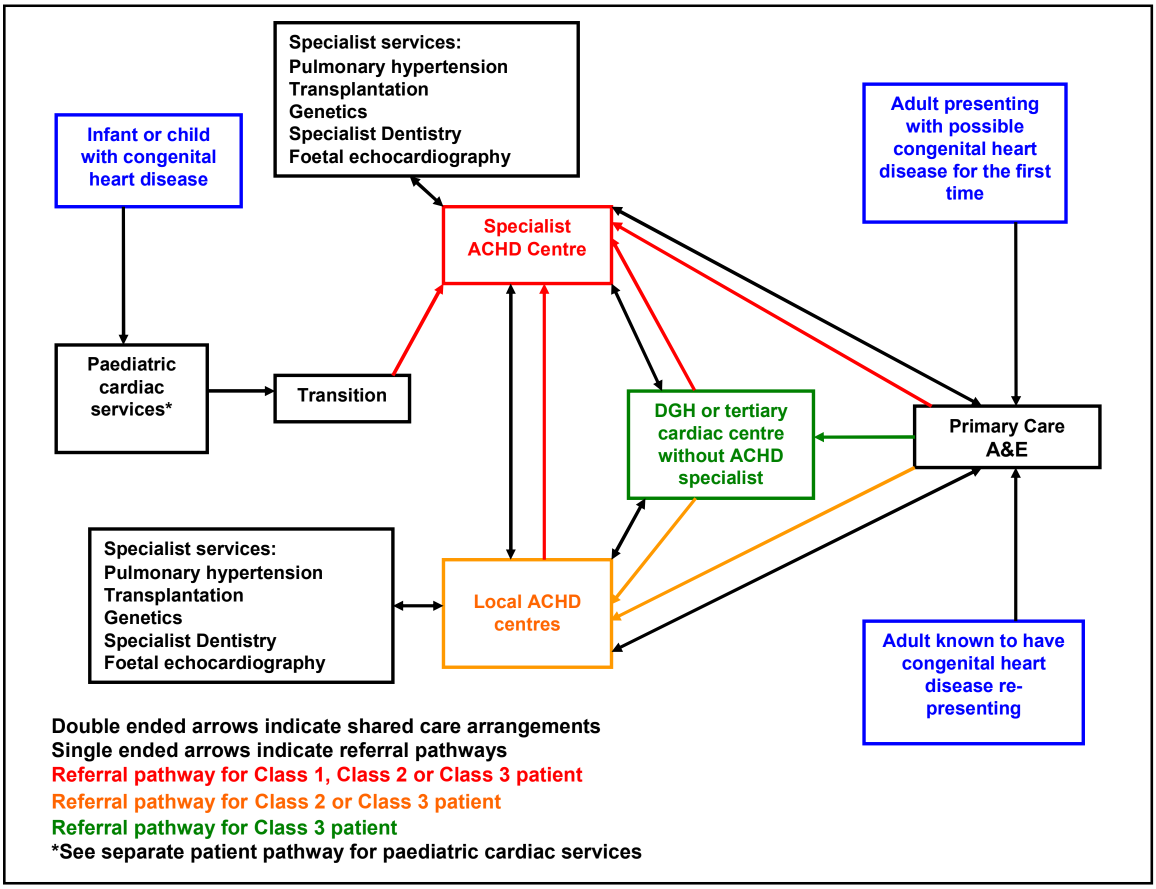
4 Current Service Provision

4.1 Referrals into the service

Referrals come into the service via primary care and secondary care specialists (see section 1.3).

4.2 Adult Provision

Services for adults with congenital heart disease are arranged according to a three tier hub and spoke model. There is currently no formal recognition of this model from commissioners or PCTs.



The three tiers are as follows

- 1 centre providing specialist care including complex surgery and intervention - LTHT
- 2 local centres providing care by local cardiologists with an interest - Sheffield and Hull. Sheffield is supported by all day outreach clinics by the Leeds clinicians 10 x per annum. In both Sheffield and Hull, relatively small numbers of interventional procedures and surgical interventions are taking place each year.
- Local hospitals providing care by local cardiologists.

Patients can currently be referred into any tier of the structure by their GP, emergency department or paediatrician. Reaching the correct level of care for the complexity of disease sometimes requires 2 or 3 further referral steps.

4.3 Paediatric provision

Services for children are provided on an outreach basis via a team of paediatric cardiologists employed by LTHT. Tertiary level outreach clinics are currently provided in 15 Trusts across the region, some of which have a clinic on more than one hospital site. The Congenital Cardiac Network (CCN) has recently completed a comprehensive review of these services.

The review concluded that:

- There is inequity in the existing system, despite pockets of excellence. The service varies significantly across the region in terms of (i) patient pathway, (ii) waiting times and (iii) contracting arrangements.

- The staffing levels in Tertiary care are insufficient to sustain the current system. The reasons for this are (i) changes in local paediatric services have resulted in an increase in support required from the Tertiary centre, and (ii) the European Working Time Directive has imposed an additional limit on capacity at the Tertiary centre.

- Contracting arrangements for the provision of Tertiary level outreach clinics vary significantly across the 15 Trusts.

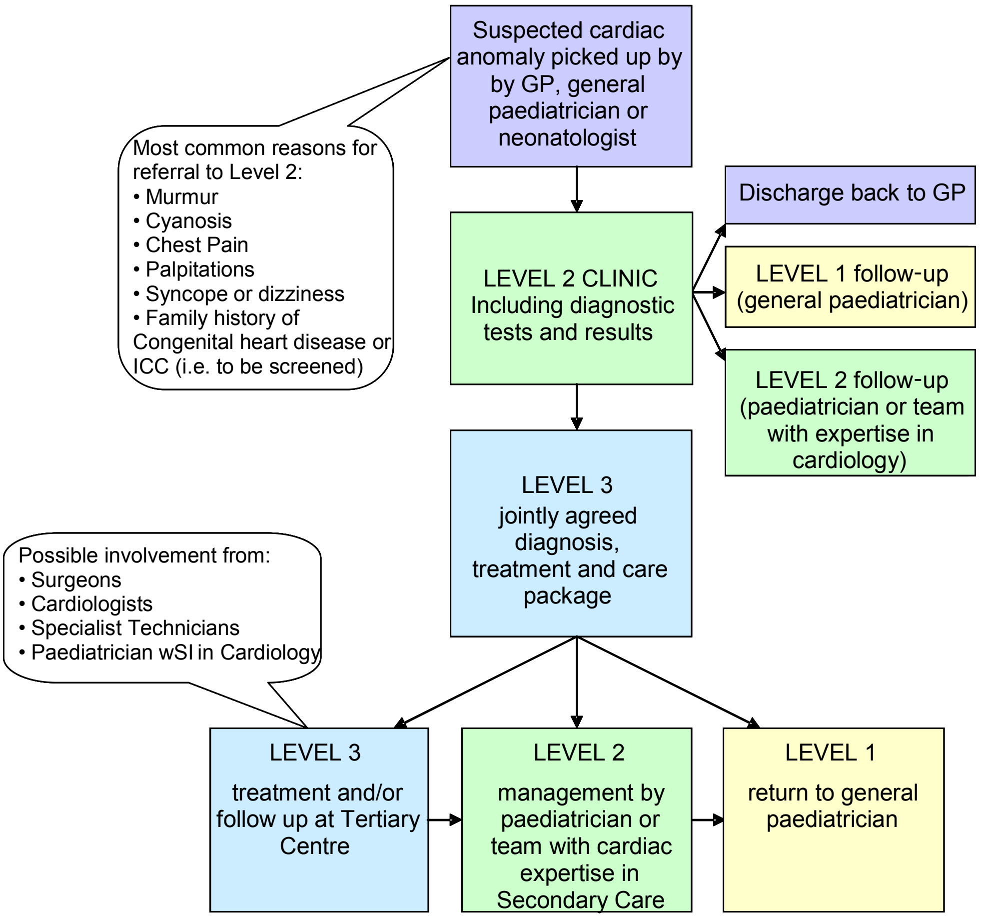
As a result of the review, a set of Clinical Standards have been agreed, covering Secondary and Tertiary level paediatric outpatient services. A set of Referral Guidelines was also developed to aid clinicians in Primary and Secondary care when making cardiology referrals. The guidelines represent a regional clinical consensus.

There is agreement among commissioners, managers and clinicians across the region that the patient pathway shown below is the most appropriate way to deliver the service. Some Trusts are already working according to this model. However, some Trusts would need to make significant changes in order to deliver this model.

The CCN Board recently considered the options for future delivery of this service. They concluded that maintaining the status quo would continue to result in:

- Inadequate triage of patients
- An increase in the ‘secondary level’ workload for tertiary care
- Growing unmanaged demand
- Lack of assurance of service quality
- Inequity due to lack of consistent patient pathway (e.g. avoidable referrals)
- An increase in waiting times for tertiary services

On this basis, the Specialist Commissioning Group (SCG) have agreed to undertake to designate providers of paediatric cardiology services (at secondary and tertiary levels of care) based on the clinical standards described above.



LEVEL 3 is specialist (Tertiary) level care and involves a paediatric cardiologist
LEVEL 2 is Secondary level care from a paediatrician or team with expertise in cardiology
LEVEL 1 is any other care at Secondary level

4.4 Fetal Cardiology provision

The Fetal Cardiology service is currently provided by one Fetal Cardiology Consultant, supported by a Paediatric Cardiothoracic Surgeon, a Consultant Sonographer and a second highly specialised Sonographer and 2 Cardiac Liaison nurses.

The service receives referrals from GPs, Midwives and DGH Obstetricians into a "Low risk" outpatient Clinic which is Consultant Sonographer led. Referrals come from the same sources as well as Tertiary Fetal medicine Units (Leeds and Sheffield) to a Consultant Fetal Cardiologist led clinic (any level of risk). Referrals are made for a variety of Maternal, Fetal and Familial indications.

After being seen in the Fetal Cardiology clinic the patients are managed in the following way:

1. Normal Fetal Cardiology review – these cases are referred back to the DGH Obstetrics team, midwife or GP for normal pregnancy management.

2. Abnormal Fetal Cardiology review (no structural abnormality) e.g. Fetal ectopic beats – these cases are referred back to the DGH obstetrics team, midwife or GP for surveillance and / or management of specific risk.

3. Abnormal Fetal Cardiology review (structural abnormality) – these cases are referred to the Fetal Medicine service in Leeds or Sheffield for further investigation and management, or referred back to the DGH Obstetrics team.

N.B. When severe CHD is diagnosed in the fetus, 1 or 2 further appointments are made in the Fetal Cardiology clinic to assess the progression of the abnormality and also to plane delivery. There is an option for discussion jointly with the Cardiothoracic surgeon.

Delivery of Fetuses with Congenital heart disease following antenatal diagnosis

The aim is to deliver babies in Leeds where it is felt that outcome would be improved by urgent Paediatric Cardiology assessment. This decision is made on a case by case basis.

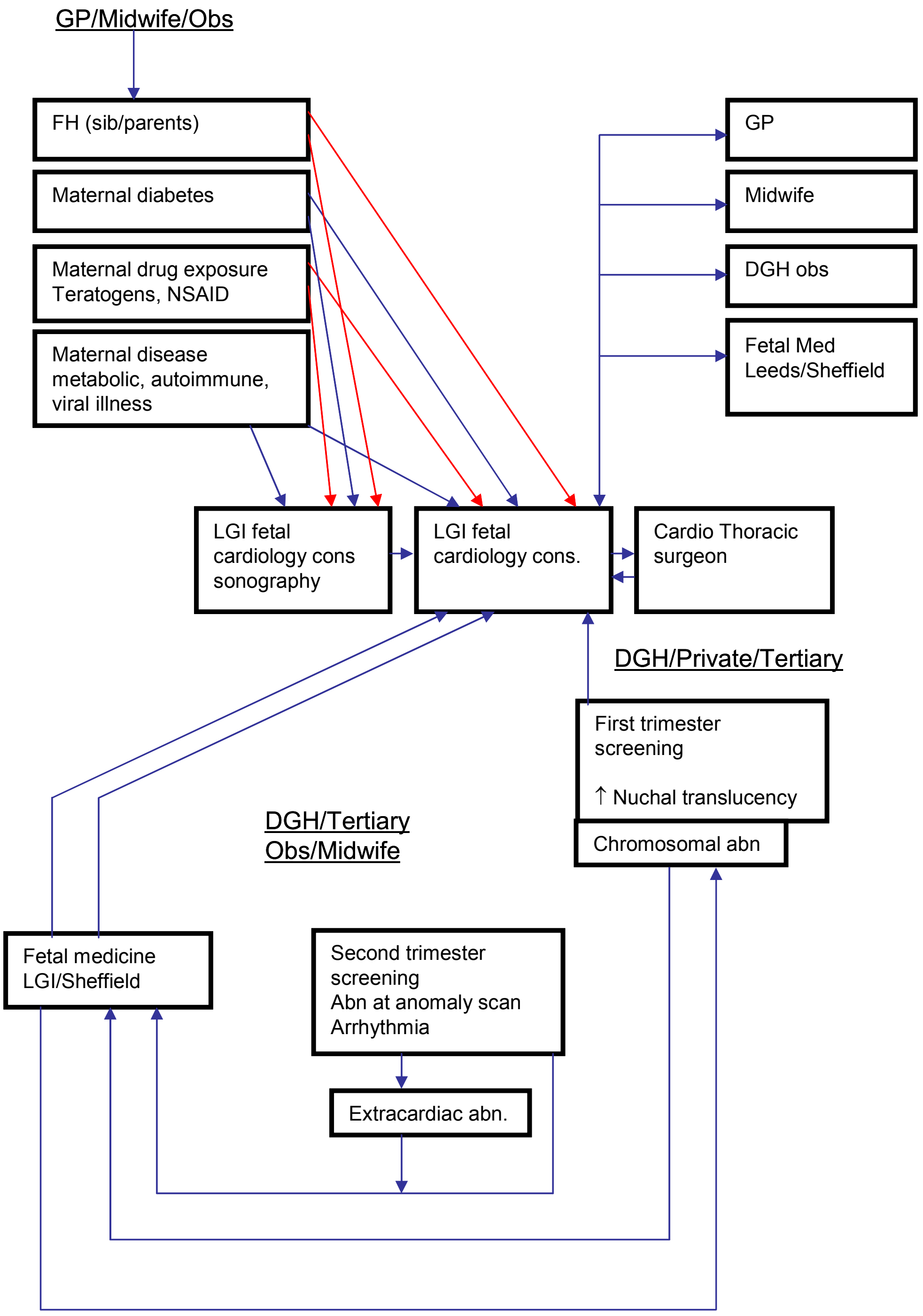
Advantages to Delivery in Leeds

- On site for rapid access to the Paediatric Cardiology Team
- Eliminates the need for neonatal transfer
- Reduced time to intervention if necessitated
- Reduces separation of mother from baby

Advantages to Local Delivery

- Leeds is the Regional Neonatal Unit therefore the demand for beds is high
- Delivery may need to be induced early (higher incidence of instrumental delivery)
- Family Support is more readily available
- It is important to build up links with local Paediatrics for ongoing support
- Builds up Local expertise

Pathway for Fetal Cardiology



4.5 Paediatric and Adult Congenital Surgery provision

Most referrals to the Paediatric and Adult Congenital Cardiac Surgery Service are made via the Leeds Teaching Hospitals Trust (LTHT) tertiary (level 3) Paediatric and Adult Congenital Cardiologists. Each individual referral is presented in the LTHT weekly multidisciplinary meeting. The MDT is made up of all the key stakeholders including Paediatric and Congenital Cardiologists, Paediatric and Congenital Cardiac Surgeons, Radiologists, Anaesthetists / Intensivists and Specialist Nurses.

A consensus treatment plan for each individual patient is made. This may either be:

(i) a continuation of Cardiology management either in a level 2 or level 3 centre,
(ii) further diagnostic imaging which could include Echo, Angiography, MRI and CT scans
(iii) a Surgical referral which would be made acutely or electively.

The elective patients are seen by accepting surgeons in their LTHT Outpatient clinics. Where appropriate they are added to the surgical waiting list to assess fitness for surgery and consent for surgery. The Surgeon may refer for further investigations, medical opinions or to a Dentist, prior to adding the patient to the surgical waiting list.

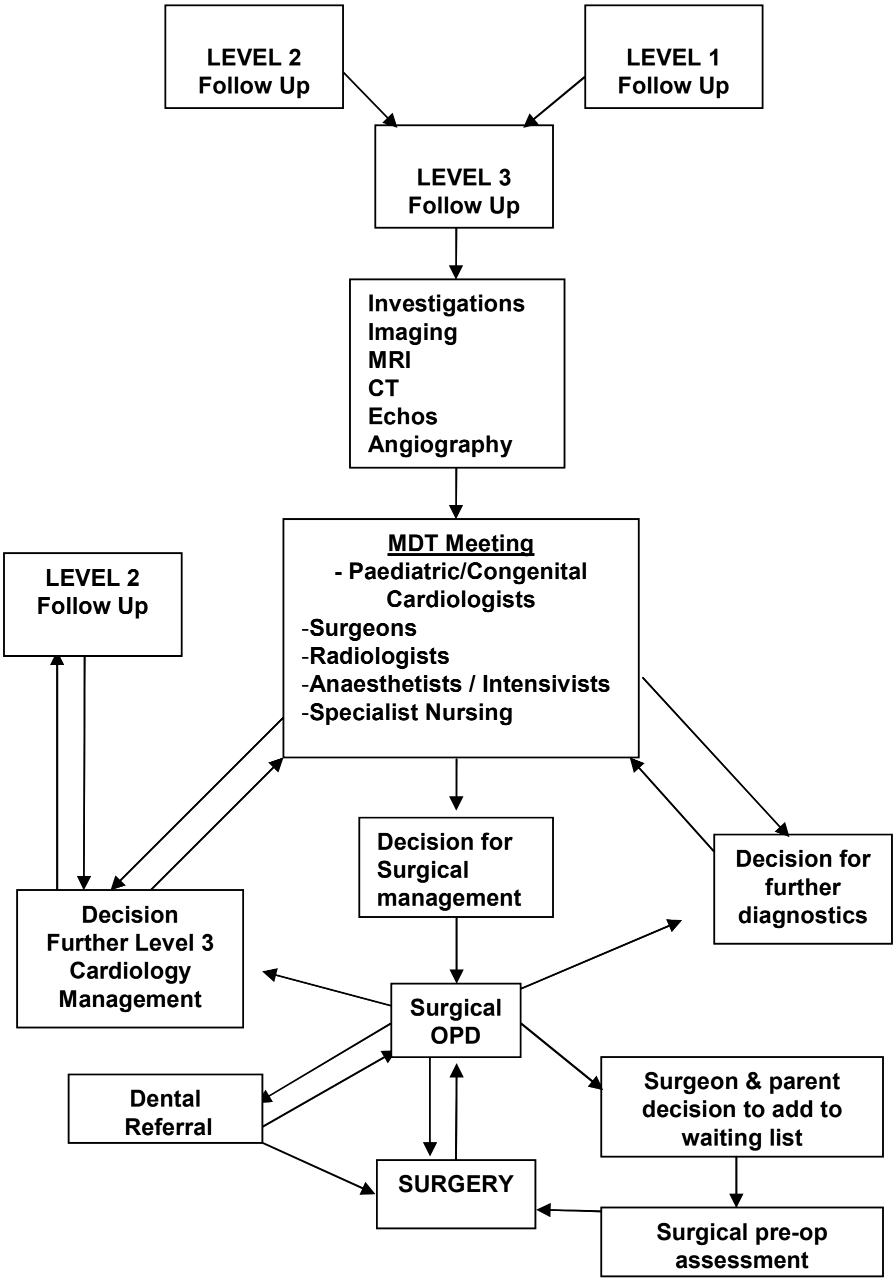
On very few occasions individual Surgeons will receive direct referrals for a surgical opinion. These referrals are discussed in the MDT meeting and, again, a consensus treatment plan for the individual is be reached. This will usually include referrals to one of the Paediatric or Adult Congenital Cardiologists for further assessment.

Access to acute surgery is provided via a 1:3 rota by the Paediatric and Adult Congenital Cardiac Surgeons employed by LTHT.

Some elements of the current surgical service lead to last minute cancellations of surgery which is unsatisfactory for patients, and leads to ineffective and inefficient use of resources. Particular areas of difficulty are Theatre staffing and access to Adult and PICU beds (again, related largely to Nurse staffing).

The pathway for surgical services is shown on the following page.

Paediatric and Adult Congenital Cardiac Surgical Pathway



5 Assessment of Current Provision

5.1 *Adult Congenital Cardiac Services*

5.1.1 Linked services

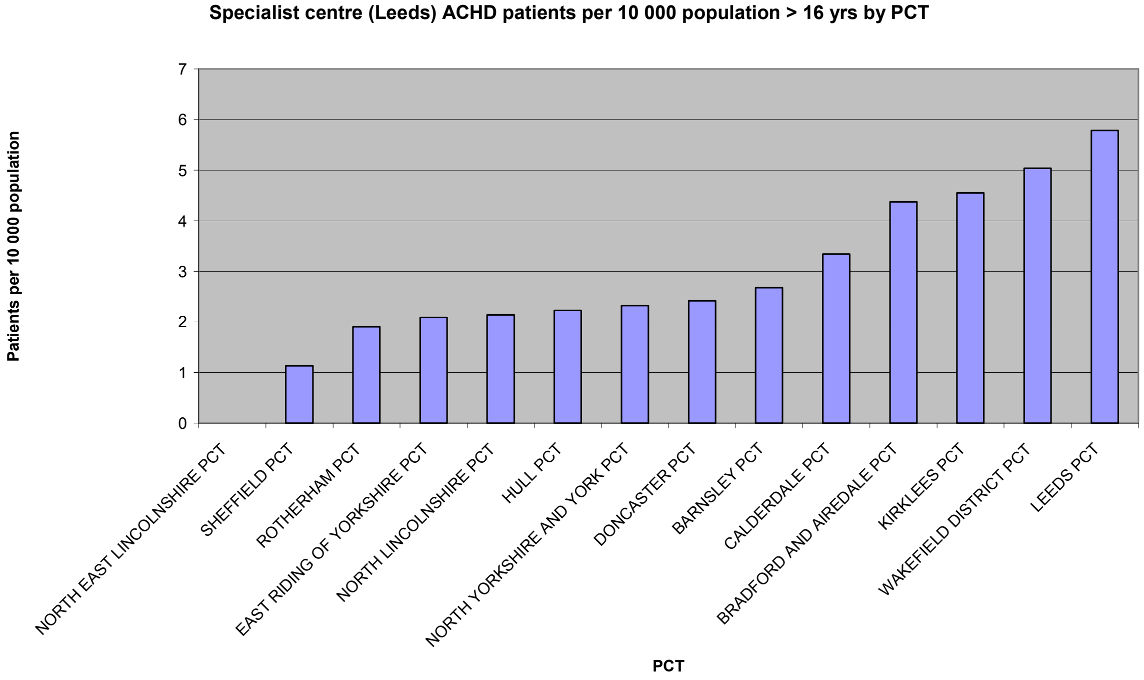
The linkage of these services is currently led by rather informal arrangements between individual clinicians. There are guidelines based on national and international publications published on the ACHD website detailing when and where it is appropriate to refer patients, but these are often not followed. Patients often travel through various 'tiers' of referral before receiving the specialist advice they require. There are difficulties with shared care arrangements in some hospitals. There are difficulties for the specialist centre in LTHT providing 24/7 cover for acute problems which arise in this patient group.

5.1.2 As local as is safe

There is currently provision of specialist ACHD cardiologist input in Leeds and via an outreach clinic in Sheffield. The east coast is served by a cardiologist with an interest based in Hull. There are problems accessing diagnostic tests in many trusts, necessitating patients travelling many miles to the specialist centre for simple tests which are offered routinely in their local hospitals. A better geographical spread of access to specialist cardiologists should be attainable.

5.1.3 Equity of Access to specialist services

There is clear evidence of inequity of access for patients across the region to specialist ACHD services.



5.1.4 Should not destabilise central services

There is a requirement for services in the specialist centre to be safe and sustainable. This requires a certain number of medical and support staff, for example, to be able to provide 24/7 cover. With current staffing levels, this is unachievable.

5.1.5 Strong transition points

Patients are often ‘lost to follow up’ at points of transition from one part of the service to another. This is particularly noticeable on transition from paediatric to adult services. The specialist centre currently has a DNA rate of between 15 and 20%, demonstrating the requirement to improve. Feedback from patients suggested that particular consideration should be given to transition points, particularly from paediatric to adult services, to ensure that patients are adequately informed about the process, and that they do not experience a ‘gap’ in service.

5.1.6 Should meet National Standards

Current regional ACHD services do not meet national standards or indicators of high quality care as set out in ‘the GUCH guide’, or the most recent ‘Designation of Specialist Service providers for GUCH’ in a myriad of ways. One of the fundamental principles is that ‘All adult patients with a congenital heart defect should see a specialist in adult congenital heart disease at least once’. Currently this standard is not met. Other than the specialist nursing care provided by the specialist centre in Leeds, there is no specialist nurse support in the region. There are small numbers of surgical and interventional procedures taking place outside the specialist centre, sometimes by single handed operators with no access to MDT discussion. There is very limited access to specialist psychology services, physiotherapy, or counselling across the whole region.

5.1.7 Good value for money

Patients should be referred to the correct clinician as soon as it is suspected that they have a congenital heart defect. This prevents a costly chain of appointments. Patients should receive the highest possible quality of care, and costly surgical and catheter based interventions should all be discussed in an MDT to reduce the chances of unnecessary or multiple attempted procedures.

5.1.8 Communication

Feedback from patients suggests that the way the clinicians involved in their care communicate with them is equally as important as the clinical and organisational aspects of their pathway. Information and advice should be communicated in as ‘positive’ a way as possible, and messages tailored to the individual.

Patients also pinpointed communication between the different levels of care (e.g. specialist service to district general hospital or GP, and vice versa) as a common source of confusion and distress. The communication channels should regularly be reviewed to ensure that delays are minimised and that patients are kept informed at every stage.

5.2 *Paediatric Cardiac Services*

5.2.1 Linked Services

A paediatric cardiac network meeting takes place every 6 months. This informal network of clinicians and managers has developed over the last 7 years, with representation from all the outreach hospitals (but not yet those hospitals without outreach clinics). It will continue to run to ensure direct communication between hospitals and between managers, commissioners and clinicians. The group is a valuable resource with active involvement from all hospitals. The group actively encourages and supports the instigation and presentation of network wide audit projects and the development of clinical guidelines for use across the network.

5.2.2 As local as is safe

The recommendations of the Paediatric and Congenital Cardiac Services Review Group (2003) were that as much specialist cardiac care should be undertaken locally as is possible (provided that safety requirements can be met). The current service offers a comprehensive series of outreach clinics carried out by tertiary centre cardiologists, with clinics held at all referring Trusts. Most clinics are held at least monthly, but due to shortage of tertiary cardiologists there are some hospitals with less frequent clinics resulting in very large clinics and / or long waits to be seen or children having to travel to Leeds to be seen in clinics which are already overbooked. The current National standards state that travel to the tertiary centre should only be necessary for specialist aspects of care.

The Congenital Cardiac Network has conducted a comprehensive review of paediatric outpatient services. As a result of this work, the Yorkshire and Humber Specialised Commissioning Group have agreed to designate paediatric cardiology services at tertiary and secondary levels of care.

5.2.3 Equity of Access to specialist services

Waiting times for outreach clinics currently vary across the region, although all referring hospitals have immediate access to care in the tertiary centre in Leeds. There is very variable local access to secondary cardiac care with only the minority of outreach hospitals having a local paediatrician or secondary care team with specific expertise in cardiology - a great asset to rapid assessment for acute and elective cardiac patients. In centres with such local expertise referrals to specialist tertiary cardiac outreach clinics are usually much reduced, resulting in greater efficiency of the outreach clinics and more appropriate use of the specialised skills of the tertiary cardiologist.

5.2.4 Should not destabilise central services

As for ACHD services, there is a requirement for paediatric services in the specialist centre to be safe and sustainable. This requires a certain number of medical and support staff, for example, to be able to provide 24/7 cover.

5.2.5 Strong transition points

See section 5.12.5.

5.2.6 Should meet National Standards

National standards exist for a wide range of aspects of paediatric cardiac services in addition to those above. Many of the standards set out in the report of the Paediatric and Congenital Cardiac Services Review Group (2003) are already met. However, the service falls well short of those more recently agreed for outpatient clinics in terms of time allocation to each patient and is still well behind the national recommendation of a minimum of two paediatric cardiologists per million population served. The service currently treats the great majority of patients within the recommended timescales but does occasionally breach these targets. The most recent recommendations of the "Safe and Sustainable" paediatric cardiac standards from the DH specify very high standards for compliance with the European Working Time Directive, with round the clock specialist care including therapeutic catheterisation, electrophysiology and surgery. The service cannot currently meet these standards. The strategy will include measures to eliminate the waiting lists, ensuring all children are treated in a timely and well-planned way, as well as an assessment of how the latest standards might be met, in liaison with local and neighbouring specialist commissioning groups.

5.2.7 Good value for money

The principle issues around value for money include more efficient use of operating theatres in Leeds and the very large number of children with no cardiac abnormality currently seen by tertiary cardiologists. In liaison with LTH and local hospitals, new ways of working should be explored to address these issues. The results of a recent audit of new referrals centrally and in the outreach clinics should guide practice change; in particular, streamlining referral practices from primary care to avoid unnecessary referrals. Patients should be referred to the correct clinician as soon as it is suspected that they have a congenital heart defect. This prevents a costly chain of appointments. Patients should receive the highest possible quality of care, and costly surgical and catheter based interventions should all be discussed in an MDT format to reduce the chances of unnecessary or multiple attempted procedures.

5.3 *Adult / Paediatric Congenital Cardiac Surgery*

5.3.1 Linked services

Linkages in the Paediatric and Adult Congenital Cardiac surgery are strength, but shared care arrangements could be further improved. Clarity is required regarding the range of procedures that should be undertaken within the specialist centre and those provided by other hospitals.

5.3.2 As local as is safe

Paediatric and Adult Congenital Cardiac surgery is predominantly provided on the LTHT site (see 5.3.1). There are a small number of patients that will be discussed in the LTHT MDT meeting, the outcome of which will be to refer to another Paediatric Congenital Cardiac Surgery Centre. This would either be for a second opinion or for specific conditions e.g. Hypoplastic Left Heart Syndrome. The two centres most commonly referred to are Birmingham Children’s NHS Trust and Guys & St Thomas’s NHS Trust.

5.3.3 Equity of Access to specialist services

LTHT has 3 Paediatric Congenital Cardiac Surgeons who have a range of surgical practice, therefore the waiting times vary both for for individual surgeons and particular surgical techniques. This leads to waiting times in excess of 18 weeks for a small number of patients. Measures should be taken to ensure that all patients receive treatment in a timely manner.

5.3.4 Should not destabilise central services

The need to provide a wide range of specialist services and personnel in order to support a Paediatric and Adult Congenital surgery programme supports a centralised model in order to maintain clinical outcomes and cost effective service provisions.

5.3.5 Strong transition points

The strength of the LTHT Paediatric and Adult Congenital Surgery Service is that the 3 Surgeons within the service have a full range of congenital practice from Neonates through to adulthood, all within the LTHT site.

5.3.6 Should meet National Standards

National standards exist for a wide range of aspects of paediatric cardiac services in addition to those above. Many of the standards set out in the report of the Paediatric and Congenital Cardiac Services

Review Group (2003) are already met. Assessment against the “Safe and Sustainable” paediatric cardiac standards is underway.

5.3.7 Good value for money

Value for money in Paediatric and Adult Congenital Cardiac Surgery services could be improved by more efficient use of resources. Some elements of the service lead to last minute cancellations of surgery which, as well as being very unsatisfactory for patients, leads to ineffective and inefficient use of resources. Particular areas of difficulty are Theatre staffing including experienced Nurses, Operating Department Practitioners and Anaesthetic staff. Access to Adult and PICU beds is also limited, and this, again, is related largely to Nurse staffing. If the recruitment and retention for these staff groups were addressed, resource utilisation would improve and last minute cancelled operations would reduce.

6 Future Planning Assumptions

6.1 Health Needs Assessment (HNA)

Across the UK providers and commissioners of adult congenital cardiac services should anticipate and plan for a steady increase in demand within the next 5 to 10 years (see also section 2.2). This is a reflection of the improving survival rates of adults with congenital heart disease.

No significant increase in demand for paediatric cardiology is anticipated. However, it is possible that there will be an increase in the frequency of intervention in older children.

6.2 Population demographics

It is reasonable to assume that demographics and population size will not affect demand for congenital services significantly within the next 5 to 10 years.

6.3 Other influences on demand

- Changes in clinical and surgical practices
- Screening (e.g. for neuromuscular conditions)
- Cardiac input for survivors of childhood cancers

7 Future Commissioning Arrangements

There are three main options for the future commissioning of congenital cardiac services:

- Lead provider with one contract
- Lead provider and a small number of contracts
- Status quo

8 Priorities

The Congenital Cardiac Network Board has identified the following priorities:

Priority 1
To continue to support and develop the ‘clinical’ network to facilitate integrated service delivery: effectively linking all areas of care; primary care, local secondary care and specialist care and where relevant ‘supra’ specialist care.

Priority 2
To support the SCG process of designation of ‘level 2’ services for children to ensure that there is efficient and effective delivery of care at a local hospital level, so that children are offered the clinical care that is appropriate to their condition.

Priority 3
To support Leeds Teaching Hospitals (LTHT) as the main centre for congenital heart disease services (paediatric cardiology, adult congenital cardiology and congenital cardiac surgery) for the Yorkshire and the Humber region.

Priority 4
To support other provider Trusts (Hull and East Yorkshire Hospitals (HEYNHST) and Sheffield Teaching Hospitals (STHT) by clearly defining the services that should be provided at LTHT and also which services should be provided at HEYNHST and STHT, via the development of service specifications.

Priority 5
To ensure that there is an effective means of appraising key developments that may impact on the development of the service or how it is delivered - ‘horizon scanning’.

This could include but is not limited to; political (e.g. national structural changes, or changes to the wider network of services such as those that may result from the national Safe and Sustainable review), changes in clinical practice or medical technology, social or demographic changes.

9 Outcome Measures

Patient Outcomes:
The purpose of this strategy is to

- Increase the personalisation of services for children and adults with congenital cardiac conditions
- Improve the patient experience of users of the services

We will measure progress on this through

  - Patient satisfaction surveys
  - Focus group assessment of progress

The aim of the strategy is to improve patient satisfaction in all areas.

Process Outcomes:
The purpose of this strategy is to

- Provide the right care, to the right person, at the right time
- Achieve national access time targets (e.g. 18 weeks)

We will measure progress on this through

  - Percentage of cases discussed at appropriate MDT
  - Waiting time monitoring
  - Audit of patient pathway
  - Root cause analysis of deaths and untoward incidents

The aim of the strategy is to minimise waste of clinical resources and maximise the quality of patient contact.

Clinical Outcomes:
The purpose of this strategy is to

- Ensure the availability of services which have outcomes comparable to best practise in England
- Reduction inequity in access to services

We will measure progress on this through

  - Procedure specific survival rates
  - Activity data by PCT and sub-PCT with comparison to national data

The aim of the strategy is to save lives and reduce ill health for all patients in the region.

Ruth Lund
March 2011
Review date: March 2012

Appendix A: Specialised Services Definitions

Congenital Cardiac services for are included in the Cardiac Specialised Services National Definition Set: 13 (SSNDS)[1] as follows:

Codes for congenital heart disease		
ICD10		
Q20	Congenital malformations of cardiac chambers and connections	Q20.0 to 20.9 inclusive
Q21	Congenital malformations of cardiac septa	Q21.0 to 21.9 inclusive
Q22	Congenital malformations of pulmonary and tricuspid valves	Q22.0 to 22.9 inclusive
Q23	Congenital malformations of aortic and mitral valves	Q23.0 to 23.9 inclusive
Q24	Other congenital malformations of the heart	Q24.0 to 24.9 inclusive
Q25	Congenital malformations of great arteries	Q25.0 to 25.9 inclusive
Q26	Congenital malformations of great veins	Q26.0 to 26.9 inclusive
OPCS		
K04	Repair of tetralogy of fallot	K04.1 to 04.9 inclusive
K05	Atrial inversion operations for transposition of great vessels	K05.1 to 05.9 inclusive
K06	Other repair of transposition of great arteries	K06.1 to 06.9 inclusive
K07	Correction of total anomalous pulmonary venous connection	K07.1 to 07.9 inclusive
K08	Repair of double outlet valve	K08.1 to 08.9 inclusive
K09	Repair of defect of atrioventricular septum	K09.1 to 09.9 inclusive
K10	Closure of defect of interarterial septum	K10.1 to 10.9 inclusive
K11	Repair of defect of interventricular septum	K11.1 to 11.9 inclusive
K12	Closure of defect of unspecified septum of heart	K12.1 to 12.9 inclusive
K13	Transluminal closure of (congenital) defect of septum	K13.3 and 13.4
K14	Other open operations on septum of heart	K14.1 to 14.9 inclusive
K15	Closed operations on septum of heart	K15.1 to 15.9 inclusive
K16	Other therapeutic transluminal operations on septum of heart	K16.5
K17	Repair of univentricular heart	K17.1 to 17.9 inclusive
K18	Creation of valved cardiac conduit	K18.1 to 18.9 inclusive
K19	Creation of other cardiac conduit	K19.1 to 19.9 inclusive
K20	Refashioning of atrium	K20.1 to 20.9 inclusive
L01	Open operations for combined abnormality of great vessels	L01.1 to 01.9 inclusive
L02	Open correction of patent ductus arteriosus	L02.1 to 02.9 inclusive
L03	Transluminal operations on abnormality of great vessel	L03.1
L04	Open operations on both pulmonary arteries	L04.1 to 04.9 inclusive
L05	Creation of shunt to pulmonary artery from aorta using interposition tube prosthesis	L05.1 to 05.9 inclusive
L06	Other connection to pulmonary artery	L06.1 to 06.9 inclusive

	from aorta	
L07	Creation of shunt to pulmonary artery from subclavian artery using interposition tube prosthesis	L07.1 to 07.9 inclusive
L08	Other connection to pulmonary artery from subclavian artery	L08.1 to 08.9 inclusive
L09	Other connection to pulmonary artery	L09.1 to 09.9 inclusive
L10	Repair of pulmonary artery	L10.1 to 10.9 inclusive
L12	Other open operations on pulmonary artery	L12.1 to 12.9 inclusive
L13	Transluminal operations on pulmonary artery	L13.1 to 13.9 inclusive with/without stent (L76.1 to L76.9)
L69	Operations on major systemic to pulmonary collateral arteries	L69.1 to 69.9 inclusive Coiling/occlusion of collaterals
No code	Mustard and Senning baffle leak closure	
No code	Mustard and Senning baffle stenosis angioplasty/stenting	

The success of diagnostic and treatment strategies over the last 20 years has resulted in most patients with congenital heart disease surviving to adulthood. The majority require ongoing follow up and treatment in adult life in a centre with expertise in adult congenital heart disease. Many of these patients have had palliative surgery or catheter procedures in childhood, others will have undergone definitive repair but have significant residual haemodynamic lesions and other may have had no specific treatment but may require intervention in the future. The transition from paediatric to the adult congenital service is supported by joint clinics between the paediatric specialist centre and the adult specialist centre to ensure a smooth transition to adult care.

Adult congenital heart disease specialist centres provide diagnostic and interventional services for teenagers and adults with congenital heart disease, which include:

- Out-patient clinics
- Expert imaging assessment (echo, MRI, CT and nuclear)
- Diagnostic and interventional cardiac catheterisation
- Corrective and palliative cardiac surgery
- Device therapy
- Radiofrequency ablation of arrhythmias following congenital heart disease surgery
- Advice on pregnancy/delivery and family planning issues

The Department of Health Adult Congenital Heart Disease Commissioning Guide (May 2006) suggests a hub and spoke service model, concentrating expertise in a small number of specialist centres and developing local centres which provide shared care under protocols agreed with the specialist centre. The Guide lists the facilities and skills needed at specialist and at local centres.

Cardiac services for Children are also included in the Cardiac Specialised Services National Definition Set: 23 (SSNDS) as follows:

All paediatric cardiology and paediatric cardiothoracic surgical services are specialised activities. This includes ECMO services for heart failure. Please note that neonatal ECMO services for severe respiratory failure for children up to 6 months are National Specialist Commissioning Advisory Group (NSCAG) designated and funded services.

Paediatric cardiothoracic services provide an integrated medical, surgical and intensive care service for the fetus, neonate, infant, child and adolescent with heart disease. Close integration is required with the specialised services provided for adults with congenital heart disease.

Paediatric thoracic surgery is performed by either a cardiothoracic surgeon or, less often, and adult thoracic surgeon with paediatric expertise, or in some centres a general paediatric surgeon.

Appendix B: Classification of congenital heart lesions according to severity

Class 1 - Most complex lesions (specialist centre)
Single ventricle physiology
Fontan physiology
Pulmonary atresia with MAPCAs or conduit
Tetralogy of fallot with electrical or significant valvar sequelae
Systemic right ventricles (Mustards / Sennings / ccTGA)
Unrepaired ASDs with right heart dilatation for consideration of closure
VSD (repaired or unrepaired) with significant AR or complicated haemodynamics
Unrepaired AVSDs (without Eisenmengers physiology) for consideration of repair
Patients with conduits (repaired truncus arteriosus, Rastelli operations, Pulmonary atresia)
Complex LVOT obstruction in women of child bearing age
Unrepaired coarctation
Repaired coarctation with significant sequela
Ebsteins anomaly
Unstable Eisenmenger patients
Double chambered right ventricle
Post Ross operation
Metal valve replacements in women contemplating pregnancy
Patients for assessment for surgical or percutaneous intervention
Known patients with new onset arrhythmias or new unexplained symptoms

Class 2 - moderately complex lesions (local ACHD centre)
Stable Eisenmengers
ASDs closed or not requiring closure
Unrepaired VSDs unless complicated haemodynamics
Repaired AVSDs with good haemodynamic result
Moderate pulmonary stenosis / regurgitation
Repaired tetralogy of Fallot with good haemodynamic result
Aortic stenosis
Repaired coarctation without aortic obstruction or aneurysm formation
Discrete Sub AS
Marfans syndrome
Mild Ebsteins anomaly

Class 3 - least complex (simple) lesions (local cardiology department)
Mild to moderate pulmonary stenosis
Repaired atrial and ventricular septal defects
Ventricular septal defects
Mild to moderate pulmonary regurgitation
Congenital aortic stenosis
Repaired total or partial anomalous pulmonary venous drainage
Marfans syndrome

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[1] http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Commissioningspecialisedservices/Specialisedservicesdefinition/index.htm