Item 5

WOMEN & CHILDREN POC BOARD

29 JULY 2014

ITEM 5 / CONGENITAL HEART DISEASE SPECIFICATIONS

PURPOSE OF PAPER

Advisory Decision Required **(e.g. recommendation of policy)**	**Debate / Co-production** **(e.g. Strategy document)**
✓	☐

CPAG REQUIREMENT

CPAG is asked to:

- Support the financial impact assessment that has been undertaken and recommend that the Directly Commissioned Services Committee approve NHS England to go out to consultation on the specifications.

Report Author:	**JULIA GRACE (CRG ACCOUNTABLE COMMISSIONER FOR CONGENITIAL HEART DISEASE SERVICES), AND** **THE NEW CONGENITAL HEART DISEASE REVIEW TEAM**

GOVERNANCE APPROVAL

CRG	**PoC Board** **(for Specialised Services)**	**Relevant Oversight Group**	**CPAG**	**DCSC**
✓	✓	✓	☐	☐

STAKEHOLDER TESTING

Was this item submitted for Stakeholder consultation?	**Yes** ☐	**No** ☑	**N/A** ☐
Number of Stakeholders consulted?	A wide range of stakeholders have been involved. A report is attached as Annex F	**Number of Stakeholder Responses**	See detail in Annex F

FUNDING IMPLICATIONS

<table>
<tr><th colspan="2">Investment Required</th><th colspan="2">Saving</th></tr>
<tr><td colspan="2">☐</td><td colspan="2">☐</td></tr>
<tr><td>Notes</td><td colspan="3">Specific investment is not required to implement these changes, nor are they expected to generate a saving.

Implementation of the standards will not affect demand for services; they do not introduce new clinical interventions or change the threshold for treatments. If recent trends continue it is expected that whether or not new standards are introduced activity will increase and therefore spending by specialised commissioning will need to increase. It is expected that any increase in cost due to the implementation of the standards can be met within the existing tariff and this increase in spending, therefore no specific investment for these changes is required.

The figures below reflect our best estimate of current service activity and spend and are provided for context.

A financial impact assessment has been completed and can be found at Annex C.</td></tr>
<tr><td>Average Cost of Care Pathway</td><td>Annual current service cost estimate: £110.3m in 2012/13</td><td>No. of Patients to Access/Undergo Procedures during Financial Year</td><td>132,400 episodes of inpatient and outpatient adult and paediatric care in 2012/13</td></tr>
</table>

EXECUTIVE SUMMARY

1. At the meeting of the Women and Children’s POC Board on 29 July 2014 the Board is asked to review and advise on the specifications and impact assessments before they are formally presented for sign-off at the 20 August 2014 meeting and to the 2 September 2014 meeting of the CPAG. Arrangements have been made with the Chair of the Directly Commissioned Services Committee for briefings to be circulated by correspondence in August (due to the cancellation of the quarterly meeting) and approval to be made by Chair’s action, subject to recommendation by CPAG, in early September 2014.

2. In June 2013 the Secretary of State asked NHS England, as the organisation responsible for commissioning congenital heart services, to undertake a new review, learning from the work of the “Safe and Sustainable” review of children’s congenital heart surgery and taking account of the Judicial Review findings and the report of the Independent Reconfiguration Panel (IRP).

3. The review was scoped to include six objectives including: to develop standards to give improved outcomes, minimal variation and improved patient experience for people with congenital heart disease.

4. Working with stakeholders, the review has developed comprehensive service standards covering the whole lifetime pathway of care for congenital heart disease (CHD) patients.

The congenital heart Clinical Reference Group has developed draft specifications aligned to those standards.

5. The proposed new specification for paediatric cardiac services is intended to replace the existing specification. The proposed new specification for adult CHD services is completely new; this area of service is not currently covered by a service specification.
6. Attached to this paper are the two draft specifications and four supporting papers; a financial impact assessment, an equalities analysis, a paper outlining the governance process surrounding the national review and a paper outlining the extensive engagement which has taken place in order to get to develop the standards and service specifications for public consultation.

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WOMEN & CHILDREN POC BOARD

29 JULY 2014

ITEM 5 / CONGENITAL HEART DISEASE SPECIFICATIONS

INTRODUCTION

In June 2013 the Secretary of State announced in Parliament that the Safe and Sustainable proposals for children's congenital heart services could not go ahead in their current form. He went on to say that "it is right we continue with this process, albeit in a different way". He asked NHS England, as the organisation responsible for commissioning congenital heart services, to undertake a new review, learning from the work of the "Safe and Sustainable" review and taking account of the Judicial Review findings and the report of the IRP. The new review was to consider the whole lifetime pathway of care for people with congenital heart disease (CHD), to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources.

The NHS England board set out a number of key principles on which the review would be based:

Patients come first: the new review must have patients and their families at its heart, with a relentless focus on the best outcomes now and for the future. That aim over-rides organisational boundaries.

Retaining what was good from earlier work: although the JCPCT's decision on configuration of children's congenital heart services has been overturned, much else was developed as part of that process and the subsequent implementation programme including a model of care, service standards, and well-developed thinking about network working. Similarly standards for adult services have also been developed and are ready for formal consultation. This work has had extensive clinical and patient input and has the potential to be applicable to whatever service configuration is decided. Therefore NHS England must work with stakeholders to determine how much of this work can be retained.

Transparency and participation: NHS England is committed to openness, transparency and participation. We should work with user, clinical and organisational stakeholders to ensure that we develop an approach to take the work forward that is true to those values. Our work should be grounded in standards, rigour, honesty and transparency.

Evidence: the IRP reflected criticism of the way in which Safe and Sustainable used evidence to support its conclusions. The new review will need to be clear about the nature and limitations of the available evidence, and about any intention to rely on expert opinion in the absence of evidence.

The full board paper can be found here:

http://www.england.nhs.uk/wp-content/uploads/2013/07/180713-item13.pdf

The findings of the judicial review and the report of the IRP can be found here:

http://www.judiciary.gov.uk/judgments/r-v-app-save-our-surgery-limited-v-jt-committee-primary-care-trusts/

http://www.irpanel.org.uk/lib/doc/000%20s&s%20report%2030.04.13.pdf

The review was scoped to include six objectives:

1. to develop standards to give improved outcomes, minimal variation and improved patient experience for people with congenital heart disease;
2. to analyse the demand for specialist inpatient congenital heart disease care, now and in the future;
3. to make recommendations about the function, form and capacity of services needed to meet that demand and meet quality standards, taking account of accessibility and health impact;
4. to make recommendations on the commissioning and change management approach including an assessment of workforce and training needs;
5. to establish a system for the provision of information about the performance of congenital heart disease services to inform the commissioning of these services and patient choice; and
6. to improve antenatal and neonatal detection rates.

Working with stakeholders, the review has developed comprehensive service standards covering the whole lifetime pathway of care for CHD patients. The Clinical Reference Group has developed draft specifications aligned to those standards. An analysis of current and future CHD activity has been prepared and based on this a financial impact assessment has been produced.

Annexed to this paper are the following:

Annex A: Paediatric service specification

Annex B: Adult service specification

Annex C: Financial impact assessment

Annex D: Draft equalities analysis (verified by the NHS England equalities team)

Annex E: Governance paper (to provide assurance that the review programme has been appropriately governed)

Annex F: Engagement paper (to provide details of the review's engagement and advisory groups and the engagement which has taken place to inform the standards)

When the specifications are submitted for formal assurance by the Programme of Care board they will be supported by the standards. At this stage the specifications have been written based on the draft standards. The most recent published version can be found here: http://www.england.nhs.uk/ourwork/qual-clin-lead/chd/meetings/cap/ (see 31 March 2014 meeting).

Final revisions prior to consultation need to made to the standards to take into account the changes recommended by the Clinical Advisory Panel (CAP) at their meeting on 18 June 2014, before they can be published again.

CURRENT POSITION

1. There is a service specification in place for Paediatrics which is included in the current contract for commissioning.

2. There is currently no specification for adult CHD services and it is intented to introduce the specification from April next year.

REVISED SPECIFICATION OVERVIEW

3. The below table details all the changes made in the specification:

PAGE NUMBER	SUMMARY OF AMENDMENTS MADE
Adult specification	New specification developed by congenital heart CRG – no specification to amend or replace.
Paediatric specification	Changes are significant enough to warrant consideration as a new specification rather than to consider as a set of changes.
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Table 1 - Review Specification Summary

OVERVIEW OF STAKEHOLDER TESTING OF PRODUCT

4. A wide range of approaches have been taken to manage the various stakeholder groups of the new CHD review. An engagement paper is attached which provides the details of how the various stakeholders inputted to the development of the standards. See Annex F.

FINANCIAL REVIEW

5. A financial impact assessment has been completed to assess the potential impact on commissioners associated with implementing the draft standards, via the attached service specifications.
6. Specific investment is not required to implement these changes, nor are they expected to generate a saving.
7. Implementation of the standards will not affect demand for services; they do not introduce new clinical interventions or change the threshold for treatments. If recent trends continue it is expected that whether or not new standards are introduced activity will increase and therefore spending by specialised commissioning will need to increase. It is expected that any increase in cost due to the implementation of the standards can be met within the existing tariff and this increase in spending, therefore no specific investment for these changes is required.
8. The financial impact assessment has been produced following advice from NHS England Strategic Finance and Fiona Moore, CPAG financial advisor.
9. The financial impact assessment can be found at Annex C.

IMPACT ASSESSMENT AGAINST THE DECISION MAKING FRAMEWORK

10. The below table details the changes made and considers whether they have an impact, both positive or negatively, against the factors of the decision making framework.

DECISION MAKING FRAMEWORK	DO THE CHANGES TO THE COMMISSIONING PRODUCT ADD OR DETRACT FROM THE EVIDENCE FOR THESE FROM THE CURRENT POSITION AND HOW THESE FACTORS WOULD BE WEIGHTED	COMMENTS/ ADDITIONAL EVIDENCE
DOES IT WORK?		
Severity and ability of patients to benefit	Best practice service standards have been developed. This in intended to drive out variation in levels of care and outcomes. (Standards to be updated before submission in August).	**link to standards once updated**
Clinical safety and risk	The standards, and therefore specifications, have been developed to increase safety and decrease risk in the services.	N/A
Clinical effectiveness & potential for improving health	As above.	N/A
DOES IT ADD VALUE TO SOCIETY?		
Stimulating research and innovation	The standards require that CHD providers are involved in research programmes.	N/A
Needs of patients and society	CHD services have been under review for more than 10 years undermining patient confidence in the service. Providers have sometimes been reluctant to invest in services because of the uncertainty. It is important to bring the review to a successful conclusion to allow the service to move forward on a sound footing and to restore confidence.	N/A
IS IT A REASONABLE COST TO THE PUBLIC?		
Average cost per patient	It is not expected that the changes require specific investment beyond additional funding driven by increased activity.	See financial impact assessment Annex C
Value for money compared to alternatives	Commissioner spend will rise whether or not new standards are introduced due to predicted activity increase. The use of standards implemented through the new service specifications will ensure that commissioners achieve best value for that additional spend.	See financial impact assessment Annex C
IS IT THE BEST WAY OF DELIVERY?		
Best clinical practice in delivering the	The standards have been developed with groups of clinical practitioners to ensure they represent views from experts practising in	**link to standards once updated** See governance (Annex E

service	this field.	and engagement (Annex F) papers
Economic efficiency of provision	At this stage of the review it is not appropriate to consider the remaining objectives on function, form and commissioning and change models. The review is at a point in time where standards are being introduced. The next phase of the process will address how the standards may be delivered and this will include a detailed economic analysis of the potential options for delivery.	N/A
Continuity of provision	At present providers are working to the existing paediatric specification and providers and commissioners will have mechanisms in place to measure performance for adult services including quality dashboards. A transition dashboard is now in place for paediatrics to enable commissioners to monitor the health of the current system and this is subject to ongoing development. Babies born with CHD are amongst the most vulnerable patients cared for by the NHS. Significant gains have been made in improving outcomes with much improved life expectancy. The standards will ensure that all patients benefit from the same high quality care and that occasional and isolated practice is eliminated. Improvements are also expected in quality of life and patient (and family) experience.	http://www.england.nhs.uk/wp-content/uploads/2013/06/e05-paedi-cardi-cardi-surg.pdf
Accessibility and balanced geographic distribution	The review is currently considering the national commissioning position and not the geographic distribution of services, however there are standards that may affect this. Consideration will be made to this in answering the third objective of function and form. Some analysis has been completed to identify how far people are currently travelling to attend specialised surgical centres and will be published in advance of consultation, but no potential changes have been modelled as service reconfiguration is not in scope at this stage.	**input link to analysis pack once published**

Table 2 - Decision Making Framework

NEXT STEPS

11. The specifications will be presented for sign-off at the 20 August 2014 meeting of the Women and Children's POC board and at the 2 September 2014 meeting of the CPAG.

12. Arrangements have been made with the Chair of the Directly Commissioned Services Committee for briefings to be circulated by correspondence in August (due to the cancellation of the quarterly meeting) and approval to be made by Chair's action, subject to recommendation by CPAG, in early September 2014.

13. The full governance process that the review will pass through in order to launch consultation can be found within the governance paper at Annex E.

14. Due to the expected volume of responses to the consultation and the need for independent analysis, the responses to the consultation will be analysed by an external provider. They will analyse the responses and present back in such a away that allows NHS England to identify possible changes required to the standards and therefore specifications.

15. Post-consultation the congenital heart disease review standards groups will be asked to recommend changes to the standards and the CAP will then consider and approve in response to consultation. The CRG will amend the specifications as appropriate. The usual NHS governance process will then be applied.

16. Details of the expected process and governance groups can be found in the attached governance paper at Annex E.

17. Final decisions recommended by the review will be subject to a decision of the NHS England Board, meeting in public.

RECOMMENDATIONS

18. CPAG members are asked to:

- Sign-off the financial impact assessment and equalities analysis and approve the specifications to be put out to public consultation.

POST DECISION ACTION REQUIRED

19. Once final approval has been received the service specifications will be submitted for a full 12 week public consultation, expected to launch in mid September 2014.

APPENDIX ONE

NAME OF ORGANISATION[1]	COMMENTS RECEIVED REGARDING PERIOD OF CONSULTATION REQUIRED	ACTION AND CONCLUSION
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NAME OF ORGANISATION[1]	**COMMENTS RECEIVED REGARDING**	**ACTION AND CONCLUSION**

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[1] **PLEASE NOTE:**

If a response has been submitted from an individual, please keep their identity anonymous.

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Annex A

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	*E05/S/a*
Service	Paediatric Cardiac Services (Congenital Heart)
Commissioner Lead	
Provider Lead	
Period	
Date of Review	

1. Population Needs

This specification will be subject to change in line with the outcome of NHS England's current review of Congenital Heart Services and the standards of care produced as a result of this process. The review is due to report in 2015.

This specification covers all Paediatric Cardiac activity (surgery and cardiology), taking place in the Specialist Surgical Centres (Tier 1 services) and Specialist Children's Cardiology Centres (tier 2 services), including activity undertaken by the Specialist Centres on an outreach basis where it is delivered as part of a provider network. Paediatric Cardiac Services provide all cardiac care for children with heart abnormalities from the point of diagnosis to transition to adult services.
The Congenital Heart Disease Standards include care taking place in Tier 3 services (Local Children's Cardiology Centres). This activity is currently commissioned by Clinical Commissioning Groups and therefore outside the scope of this specification. Nevertheless Tier 3 services are part of the Congenital Cardiac Network of Care and it is expected that Children's Tier 1 and 2 services will work in partnership with Tier 3 providers to ensure all patient care is of a consistent, high quality. Moreover, it is expected that networks will collaborate together to ensure uniformity of care throughout the healthcare system.

This specification includes children with Inherited Cardiology Conditions acknowledging that care for this group must be provided in accordance with the separate specification; A09/s/c.
http://www.england.nhs.uk/wp-content/uploads/2013/06/a09-cardi-inheri-card-con.pdf

1.1 National/local context and evidence base

Background

Congenital heart disease (CHD) is one of the major categories of illness that, if treated, can restore health and improve quality of life. It constitutes the bulk of the paediatric cardiac workload. Currently 6-8 / 1,000 babies born in England will suffer from some form of Congenital Heart Disease (CHD). In 2012 this resulted in 4716 paediatric cardiac surgical procedures. Office of National Statistics 2012 data based on the 2011 Census, shows that the national population has increased at a greater rate than previously estimated, predicting an ongoing increase in the number of paediatric cardiac surgical procedures. Between 2001 and 2011 there has been an increase of 22% in the national birth rate with a corresponding rise in the number of paediatric cardiac surgical procedures taking place of 27%. Of note the increase of 400,000 (13 per cent) under-five-year-olds throughout England and Wales in this period is particularly pronounced in urban city areas.

Current Service Provision

The standards of care developed through the Safe and Sustainable process were approved by the JCPCT and not subsequently challenged by the judicial review or Independent Reconfiguration Panel. Revision of these has been an ongoing process and the draft final version of the standards of care (April 2014) produced by the Congenital Heart Disease Review Standards Group forms the basis of this service specification. Each Standard has an associated time-line within which units must be compliant. These range from immediate compliance to within 3 years and are detailed in the standards document appendix 3.
These standards use a network model of care to provide age appropriate, safe and effective services as locally as possible. Networks for childrens cardiac services should be aligned with those for fetal services and adult congenital services to allow a smooth transition from diagnosis through to adulthood. Within a network the hospitals delivering children's cardiac care are configured in up to three tiers. All must be able to demonstrate compliance with the appropriate tier service standards:

- Tier 1: Specialist Surgical Centre (SSC)
- Tier 2: Specialist Children's Cardiology Centre(s) (CCC)
- Tier 3: Local Children's Cardiology Services (LCCS)

The exact configuration of any individual network will be determined by the outcome of the current Congenital Heart Disease Review due to report in 2015. During the current service review each specialist surgical centre (tier 1) is expected to:

- Maintain appropriate collaborative network relationships between units (Tier 1, 2 and 3) in order to maintain a good outcome for patients
- Provide operational activity data on a monthly basis to Area Team Commissioners i.e. The "Transition Dashboard"
- Communicate consistently with families, staff and referrers regarding the progress of the ongoing review

Evidence Base

Draft Congenital Heart Disease Standards v0.19, Tier 1-3, March 2014.

Paediatric and Congenital Cardiac Services Review (2002),

Chapter 8 (Arrhythmias and Sudden Cardiac Death, 2005) of the National Service Framework for Heart Disease (2000)

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	**Preventing people from dying prematurely**	√
Domain 2	**Enhancing quality of life for people with long-term conditions**	√
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	√
Domain 4	**Ensuring people have a positive experience of care**	√
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	√

The Clinical Reference Group have developed a quality dashboard for implementation in 2014/15. Proposed outcome measures include the following:

- Post Procedural Mortality – Crude annual 30 day and 1 year mortality for individual types of procedure (as published by NICOR). 3 year rolling partial risk adjusted total 30 day mortality.
- 30 day unplanned re-operation/ re intervention rate (NICOR defined procedure)
- Cancellations on day of operation for non clinical reasons
- Post catheter intervention complication rate
- Mothers with suspected CHD in fetus seen within 5 days
- Mothers with suspected CHD in fetus seen by specialist cardiac nurse at diagnosis

The list of quality of care indicators included in the initial iteration of the dashboard is not exhaustive and subject to ongoing revision.

3. Scope

3.1 Aims and objectives of service

The paediatric cardiac service provides all cardiac care for children with heart abnormalities from the point of diagnosis to the transition to adult services.

Service Aims

The service for paediatric congenital heart disease aims to:

- Deliver best outcomes for patient, with lowest mortality, reduced disability and an improved opportunity for a better quality of life for survivors
- Consistently meet the draft standards of care (2014)
- Provide resilient and comprehensive 24/7 care
- Provide age appropriate, safe and effective services as locally as possible
- Ensure that parents and children have co-ordinated care throughout the entire pathway, and feel supported and informed during their cardiac journey.
- Provide good patient experience, including information to patients and their families and consideration of access and support to families when they have to be away from home
- Demonstrate clinical outcomes in line with national and international standards for children with cardiac conditions adjusted for case mix

Service Objectives

The objectives of the service are to improve life expectancy and quality of life for children with Heart Disease by:

- Developing Congenital Cardiac Networks to deliver a standardised model of paediatric heart disease service that meets national quality standards
- Providing high quality, timely and accurate diagnosis
- Agreeing treatment plans with patients and their families
- Undertaking safe and effective paediatric cardiac surgery and catheter intervention.
- Providing appropriate counselling and psychological support to patients and their families
- Supporting patients and their families so they can aspire to a life less hindered by their condition
- Ensuring effective communication between patients, families and service providers that is sensitive to the physical, psychological and emotional needs of the patient and their family
- Ensuring smooth and managed transition from paediatric to adult care
- Providing an individualised palliative care and bereavement service

3.2 Service description/care pathway

This specification covers the following service areas:

- Paediatric congenital heart disease services
- Paediatric acquired heart disease services
- Paediatric cardiac surgery and invasive cardiology services
- Fetal cardiology services
- Paediatric cardiac electrophysiology services
- Paediatric specialist cardiovascular imaging

Service description of Provider Centres within a Children's Congenital Heart Network

The model of care for children with heart disease is based on an overarching principle of a children's cardiac network, which will adopt policies and guidelines agreed across the network relating to patient management pathways within each of the following centres specific care level.

- (Tier 1) A Children's Cardiac Specialist Surgical Centre (SSC)
- (Tier 2) Children's Cardiology Centres (CCCs)
- (Tier 3) Local Children's Cardiology Services (LCCS)

Paediatric Cardiac Networks should be aligned with networks for fetal services and adult congenital services such that the transition from fetus → child, child → adolescent and adolescent → adult, follows a joined up approach with continuity of care. Children's cardiac services will form part of a larger Congenital Heart Network to facilitate seamless transition through the constituent services. It is expected that the regional networks will work in a coordinated manner to ensure equality and standardisation of care throughout the NHS.

The Specialist Surgical Centres will provide active leadership in the Children's Cardiac Networks. They will work with the Specialist Childrens Cardiology Centres and Local Childrens Cardiology Centres within the Network to:

- Manage and develop referral and care pathways
- Manage and develop treatment and transfer pathways
- Develop network policies, protocols, and procedures
- Performance monitor through agreed governance arrangements
- Undertake audit, professional training and development
- Facilitate the development of as much care and treatment as possible close to the child's home
- Manage the transition to adult services
- Continually review the pathways to ensure they provide the best care and support for parents and their children.

Children's Cardiac Specialist Surgical Centres (SSCs) (Tier 1)

- Specialist Surgical Centres (SSCs) will perform all surgical and interventional procedures on children and provide a full range of diagnostic tests for fetal and paediatric patients.
- SSCs will provide assessment and follow-up services for children who live locally.
- Consultant Cardiologists from the SSC will provide an outreach out patient service in conjunction with paediatricians with special expertise in cardiology at Local Children's Cardiology Centres within their network.
- The SSC will host weekly multidisciplinary team meetings to discuss patient management. They will facilitate regular face to face and teleconference attendance by Specialist Children's Cardiology and Local Children's Cardiology Centres.

- SSCs along with other units providing care within a children's cardiac network will hold regular multidisciplinary meetings for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every 6 months.
- SSCs will develop and implement a system of 'patient-held records' that will be used throughout the network ensuring joined up treatment and care.

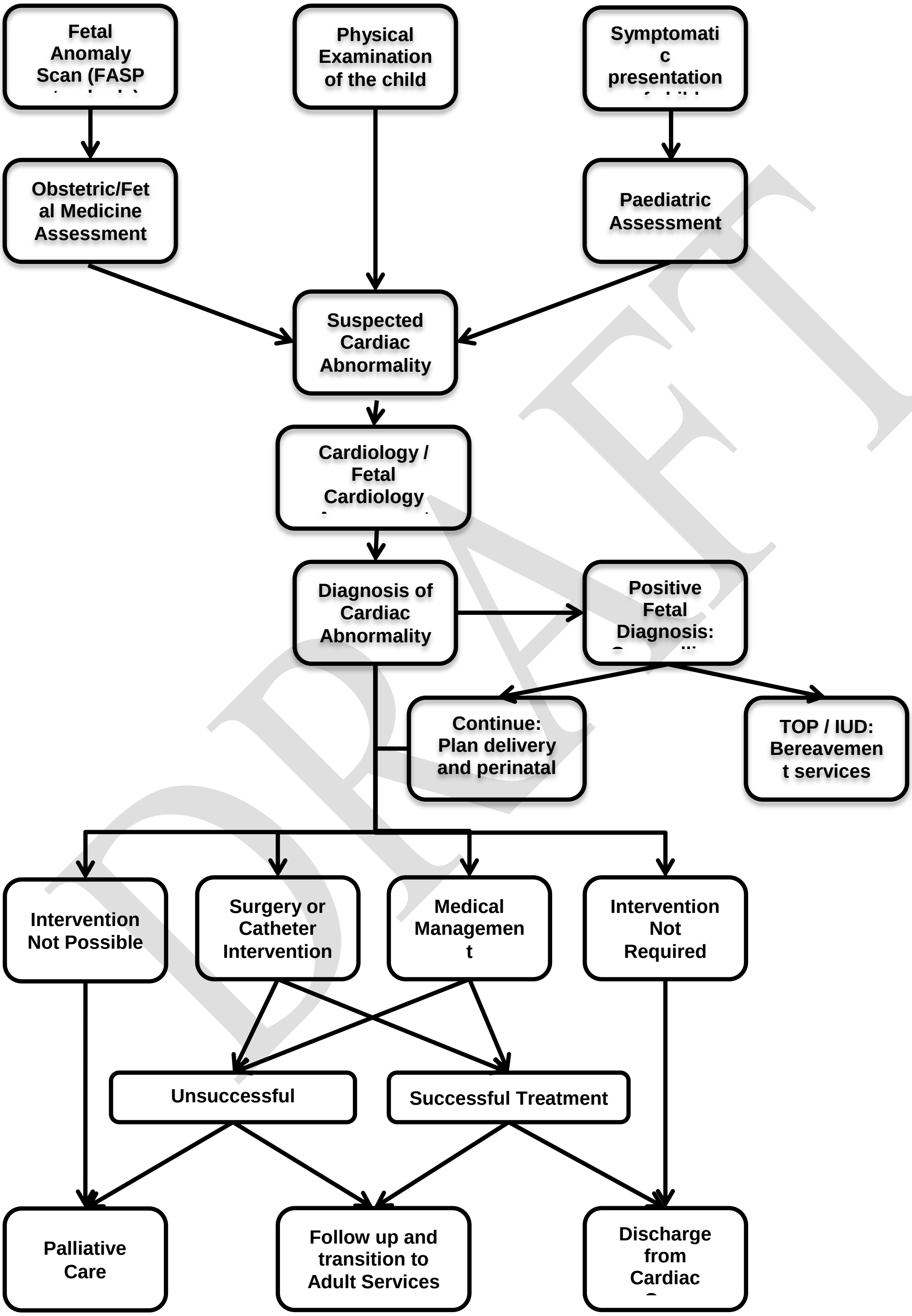
Specialist Children's Cardiology Centres (CCCs) (Tier 2)

- The team of Consultant Paediatric Cardiologists will provide all paediatric cardiac medical services including assessment of new referrals and ongoing in-patient and out-patient medical management of children with heart disease.
- Consultant Cardiologists from the CCC will provide an outreach out-patient service in conjunction with paediatricians with special expertise in cardiology at Local Children's Cardiology Centres within their network.
- Children who need surgical or interventional procedures will be referred by the CCC to the SSC.
- Neonates with Patent Ductus Arteriosus may receive surgical ligation in the CCC providing a suitably equipped surgical team is despatched from a designated SSC.
- If clinically indicated, emergency balloon atrial septostomy and temporary pacing may be conducted in a CCC following clear Network guidelines,

Local Children's Cardiology Services (LCCS) (Tier 3))

- LCCS will be available in some local hospitals. The team will include a Consultant Paediatrician with Expertise in Cardiology.
- Each LCCS will be allocated a named Consultant Paediatric Cardiologist from the CCC or SSC. They will undertake combined outreach clinics regularly at the LCCS and provide a link between the two hospitals.
- Local children with suspected heart disease may initially be referred to the LCCS where inpatient and outpatient management can be undertaken. When a higher level of expertise is needed children will be referred to the CCC or SSC.

Patient care pathway



Referral

Patients enter the paediatric cardiac pathway through:

- Prenatal diagnosis.
- Physical examination of an asymptomatic infant or child.
- Symptomatic infant or child.

Patients are routinely referred through:

- Obstetric Ultrasound Department, Fetal Medicine Department; Obstetrician, Midwife.
- Neonatal /Paediatric Centres; Paediatrician.
- Primary Care; Patient's GP.

The appropriate paediatric cardiac service will:

- See referrals within 3 days following detection of a cardiac abnormality during fetal anomaly scan.
- Screen pregnancies at increased risk of fetal cardiac anomaly.
- Provide 24/7 telephone advice for referral or for patients with an acute illness that may be related to their cardiac abnormality. (Under an agreed provider network).
- Provide inpatient facilities to urgently transfer stabilise and monitor appropriate referrals.
- See routine outpatient referrals within standard NHS waiting time guidelines.
- Where appropriate provide access to and co-ordinate results and assessment from a range of diagnostic tests and from expertise in other specialties.

Initial Care

The appropriate paediatric cardiac service will:

- Establish an accurate and complete diagnosis of congenital heart disease.
- Establish a baseline against which disease progression and response to treatment can be measured.
- Carry out a multidisciplinary team (MDT) assessment of all referred patients with significant congenital heart disease within three months.
- Agree the need for any intervention, either specific or supportive.
- Offer treatment to all patients who might potentially benefit; eligibility for treatment to be determined as set out in relevant guidelines or as clinically indicated.
- Provide age-appropriate verbal, written and/or electronic material in an understandable format about the congenital cardiac condition to patients and their families/carers.
- Provide a clear contact/support pathway for parents /carers (Named Specialist nurse)

Ongoing Care

Prenatal diagnosis

- A fetal cardiologist or a paediatric cardiologist with expertise in fetal cardiology will make or confirm the diagnosis and explain the condition, likely management and prognosis.
- They will discuss options available to the family in a non-directive, caring and supportive way with direction given to publically available information
- A fetal or children's cardiac specialist nurse will be present when the diagnosis is explained to the parents, or make contact with them within 48 hours.
- Written information regarding the condition, pathways discussed, available support services including contact details of local and national support groups will be provided.
- All relevant information will be communicated to network clinical teams involved.
- A management plan for the pregnancy and delivery will be discussed with fetal medicine unit, local obstetric unit, local paediatric team, neonatal team and parents.
- A decision will be made as to whether delivery should be at or close to the SCC in all cases where the baby may require immediate surgery or catheter intervention.
- A children's cardiac nurse specialist telephone advice service will be available for patients and their families/carers, healthcare professionals and non-healthcare and voluntary sector professionals.
- Fetal medicine specialists either at local hospital or specialist centre should ensure there is a complete assessment of the whole baby.

Children with a Confirmed Cardiac Abnormality

The appropriate paediatric cardiac service will:

- Provide regular patient reviews as per national guidelines or clinical practice with written and electronic records of current treatment and patient response.
- Provide access to inpatient and critical care facilities where appropriate.
- Provide access to National specialised services, e.g. pulmonary arterial hypertension (PAH), transplantation, as appropriate.
- Deliver appropriate pharmaceutical therapy.
- Provide patient-centred services, sensitive to the individual's physical, psychological and emotional needs and supported through the provision of patient-appropriate information.
- All patients must have access to a children's cardiac specialist nurse and complex patients will have a named children's cardiac nurse responsible for co-ordinating their care
- Facilitate appropriate shared care arrangements with other paediatric congenital heart disease service providers.
- Provide children's cardiac specialist nurse telephone advice service for patients and their families/carers, healthcare, non-healthcare and voluntary sector professionals.

General Paediatric Care

- All paediatric cardiac service providers will follow the standards outlined in the Specification for Children's' Services (attached as Annex 1 to this Specification).

Leaving the Pathway

Palliative or end-of-life care

The appropriate paediatric cardiac service will:

- Use nationally approved paediatric palliative medicine pathways to plan palliative care.
- Agree a named lead doctor and nurse for any patient entering a palliative care pathway who will ensure the child and their family are supported up to and beyond death.
- Produce a written, agreed, individual, end-of-life care plan after consultation with the child, their family/carers and all healthcare professionals likely to be involved in the care of the child.
- Liaise actively with NHS and non-NHS professionals to ensure access to appropriate palliative or end-of-life services and make the child and their family/carers aware of these.
- Ensure that support for the child and their family/carers continues in the community with access to hospital support 24/7.
- After death, the family should be contacted by a children's cardiac specialist nurse within 1 working week to offer support.
- Within 6 weeks of death the family should be contacted by the lead doctor and offered the opportunity to meet and discuss their child's death at a mutually agreed time and location.
- Generate and publish evidence of effective palliative or end-of-life care for patients / carers.

Adverse Outcomes

- When patients experience an adverse outcome from treatment or care, medical and nursing staff must maintain open and honest communication with patients and their families according to the NHS "Being Open" framework (2009).
- A clear plan of on-going treatment, including the seeking of a second opinion, must be discussed with the family.

Transition from paediatric to adults with congenital heart disease services (ACHD)

The process of transitioning from paediatric to ACHD care will take place between 12 and 18 years of age taking into account individual circumstances.

Paediatric and ACHD centres will develop close working relationships to ensure smooth and effective transition of patients to appropriate facilities, minimising loss of patients to follow up during the process. "Lost to follow up" rates must be recorded and discussed by the network.

- The ACHD service will accept referrals of appropriate young people from the paediatric cardiac network.
- All young people requiring long term congenital cardiac care must be seen at least once by an ACHD cardiologist and ACHD nurse specialist in a specialist MDT transfer clinic or equivalent.
- A children's cardiac transition nurse will act as a liaison between young people,

their carers, the children's cardiac nurse specialist, ACHD nurse specialist and wider multidisciplinary team to facilitate the transition process.
- The network must provide age-appropriate information in an appropriate format to the patients and families/carers, covering the full range of social and health related advice
- Each paediatric/ACHD network must agree and provide formalised operational transition policy consistent with the congenital heart disease standards and with the generic specification for transition produced by the paediatric medicine CRG.

Processes

Paediatric Congenital Heart Disease MDT

- The management of patients with significant congenital heart disease should be discussed at combined MDT meetings at the SSC. This includes all patients being considered for a complex catheter intervention or surgery.
- Each MDT discussion must generate a signed record of the discussion and the final outcome.
- When considering patients for complex catheter intervention or surgery the minimum composition of the MDT is a Congenital Cardiologist, Congenital Surgeon and Specialist Anaesthetist. Otherwise the composition of the MDT should be pathway driven, and adjusted according to the needs of different aspects of the service (for example, assessment, post-operative care, clinic-pathological and audit meetings).
- Staff from across the Congenital Heart Network should be encouraged by the SSC to attend MDT meetings in person or by video/teleconferencing to participate in the decision-making about their patient and for ongoing training and development.
- The attendance and activities of the MDT should be maintained in a register.

Patient registers/database

- All children transferring between services will be accompanied by high quality information, including a health records summary and a management or follow up plan. Note: The health records summary will be a standard national template developed and agreed by the Specialist Surgical Centres, representatives of the Congenital Heart Networks and NHS commissioners.
- There will be written protocols covering communication between clinicians, clinicians and parents / carers and between clinicians and children / young people. The protocols will be developed and agreed with local referring Paediatricians, Paediatric Cardiologists, Children's Cardiac Specialist Nurses, Clinical Psychologists and Patient Groups.
- The SSC must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiological procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research (NICOR).
- All centres delivering care to children with cardiac abnormalities will co-operate in developing a national register of research trials and outcomes.

Annual reports

The Children's Cardiac Networks will produce annual audit and governance reports.

3.3 Population covered

The service outlined in this specification is for patients ordinarily resident in England(*); or otherwise the commissioning responsibility of the NHS in England (as defined in *Who Pays?: Establishing the responsible commissioner* and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges). To ensure equity of access, wherever possible, access to the service should be according to common routes, policies and criteria that do not disadvantage any relevant patient group. It should be noted that around 10% of patients have some form of learning disability. Patients from black and minority ethnic (BME) communities are also found in greater numbers than the general population.

(*) Note: For the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.

Acceptance criteria

- Pregnancy with either suspected fetal heart disease or at high risk of fetal heart disease
- All patients, before the sixteenth birthday at referral, with suspected or confirmed heart disease. In some cases it may be appropriate to offer choice to older teenagers (up to the eighteenth birthday).

Exclusions

The specification excludes:
- Major airway surgery undertaken by Congenital Cardiac Surgical teams

This service specification applies to any patient with a congenital heart condition requiring treatment, and whose condition enters them onto this pathway of care. This pathway may develop before birth in cases with a prenatal diagnosis.

Supra-Regional Services

- Potential candidates for paediatric cardiac transplantation (including implantation of a mechanical support device as a bridge to transplantation) must be referred to a designated paediatric cardiac transplant centre. The designated transplant centre is responsible for managing and developing referral, care, treatment and transfer policies, protocols and procedures in respect of transplant patients.
- Similar arrangements exist for the referral of children and young adults with severe pulmonary hypertension to the national pulmonary hypertension service.

Interdependencies with other services/providers

All units providing care for children with heart disease must conform to the standards for interdependency as laid out in section D of the appropriate Tier of the draft congenital heart disease standards (2014). They have not been included in detail here for brevity.

4. Applicable Service Standards

Infrastructure requirements

Network Requirements

- The exact configuration of an individual network will be agreed locally with area commissioners. The Childrens Cardiac Network will either form part of a larger Congenital Heart Network or be aligned with networks for fetal and adult congenital cardiac services.
- Where the Childrens Cardiac Network is part of a larger Congenital Heart Network the lead roles and infrastructure will be shared. (Subsequently referred to as “Network” to avoid confusion).
- Separate Congenital Heart Networks will not work independently of each other. There will be regular collaboration to ensure equality of care throughout the health service.

Network Staffing

- Each Network will have a formally appointed Network Clinical Director from within the network itself.
- The Network Clinical Director will provide clinical leadership across the network and be responsibility for the network’s service overall.
- The Director will be supported by separate clinical leads for surgery, cardiac intervention, fetal cardiology, paediatric heart disease, adult congenital heart disease, cardiac intensive care and anaesthesia.
- Each Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.
- Appropriate managerial and administrative support for the effective operation of the network is the joint responsibility of all constituent units.

Specialist Surgical Centres

- Each SSC will have a formally nominated Lead Cardiologist who will support the Network Clinical Director. They will be derived from and supported by separate clinical leads for cardiology, surgery, cardiac intervention, echocardiography, cardiac imaging and fetal cardiology. These roles may also extend to those for the network.

Surgeons

- Surgical teams must consist of a minimum of 4 full time consultant congenital cardiac surgeons. Units will have a period of three years to achieve this standard.
- SSCs must provide 24/7 surgical care across the spectrum of neonatal and paediatric surgical emergencies (with the exception of cardiac transplantation)
- A ‘consultant congenital cardiac surgeon’ is defined as having the equivalent of two years dedicated training in a recognised Specialist Congenital Surgical Centre.
- SSCs must enable consultant congenital cardiac surgeons to operate together on complex or rare cases.
- Each congenital cardiac surgeon must perform a minimum of 125 first operator congenital cardiac surgical procedures (auditable cases as defined by submission to NICOR) each year, averaged over a 3 year period.

Cardiologists

- SSCs must be staffed by a minimum of 4 full time consultant congenital interventional cardiologists experienced at paediatric cardiac intervention. This may include congenital interventional cardiologists based at other hospitals.
- Each consultant congenital interventionist must be primary operator in a minimum of 50 congenital procedures per year, averaged over a three year period.
- There must be a designated lead interventionist who must be primary operator in a minimum of 100 procedures per year, averaged over a three year period.
- Each SSC must be staffed by a minimum of one electrophysiologist experienced in paediatric cardiac disease.
- Each SSC will have a congenital cardiac imaging specialist expert in both cardiac MRI and cardiac CT.
- Each SSC will have a lead for congenital echocardiography (EACVI accredited or retrospective equivalent experience).
- Each SSC will have a lead for fetal cardiology who has fulfilled the training requirements for fetal cardiology as recommended by the paediatric cardiology SAC or AEPC. Units will require more than one cardiologist with training in fetal cardiology to meet the requirements of the fetal cardiology standards.
- SSCs must be staffed by a minimum of 1 consultant paediatric cardiologist per half million population served by the network.

Nursing

- Each SSC will have a senior children’s nurse with specialist knowledge and experience in the care of children in paediatric cardiology and cardiac surgery. They will lead a dedicated team of nursing staff trained in the care of children who have received cardiac surgery.
- Each SSC will provide clinical cardiac nurse educators to deliver competency based programs for nurses across the network
- Each congenital cardiac network will have a minimum of 7 WTE children’s cardiac nurse specialists distributed as appropriate across the network.
- Each congenital cardiac network will have at least 1 WTE fetal cardiac nurse specialist.
- Each congenital cardiac network will have at least 1 WTE designated children’s cardiac transition nurse.

Other

- SSCs must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24 hour emergency service, 7 days a week within legally compliant rotas, including 24/7 paediatric interventional cardiology cover. A consultant ward round must occur daily.
- Each SSC will have a team of congenital echocardiography scientists (technicians), with a designated who spends at least half the week on congenital echocardiography-related activity. All scientists should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service.
- The provision of one full time equivalent Practitioner psychologist for each 400 children and young adults undergoing surgery each year and a further 1 WTE for each 5,000 children and young people with CHD.
- Children who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) must be referred to a designated paediatric cardiothoracic transplant centre.
- The SSC will have a paediatric palliative care service able to provide good quality end-of-life care in hospital and with well developed shared-care palliative services with the community.
- Each SSC must have a minimum of 1 WTE dedicated paediatric cardiac data collection manager, with at least 1 WTE assistant, responsible for timely audit and database submissions.
- Each SSC must have a minimum of 2WTE dedicated play specialists
- Equipment infrastructure on site: Electrophysiology, echocardiography (echo), cardiac catheterisation laboratory, Intra-operative echo, transoesphageal echo, Magnetic Resonance Imaging (MRI), Computerised Tomography (CT), post-operative extra corporeal life support (Non-nationally designated ECMO), access to Isotope Imaging.

Specialist Children's Cardiology Centres (CCCs)

- Children's Cardiac Networks may be supported by one or more CCCs. The precise shape of each Congenital Heart Network should be determined by local need and local circumstances, including geography and transport and agreed by Area Team Commissioners.
- Each CCC must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within legally compliant rotas

Cardiologists

- Each CCC will be staffed by a minimum of 4 WTE Consultant Paediatric Cardiologists, increasing by 1 per half million of the population covered by the centre.
- Each CCC will have a designated Clinical Paediatric Cardiology lead with responsibility for service provision within the CCC.
- Each CCC will have separate leads for relevant clinical specialties (e.g. fetal, echocardiography, cardiac intensive care) that will have a direct link and collaborative working partnership with the leads in the SSC.
- Leads at the CCC may also take on a similar role for the Network.

- Interventional cardiologists from the CCC who undertake procedures at the SSC must perform at least 50 procedures a year, averaged over a three year period.
- Paediatric Intensive Care Unit (PICU) Consultants with appropriate skills in paediatric cardiac intensive care must be available to the PICU 24/7, in line with Paediatric Intensive Care Society standards.

Nursing

- Each CCC must have a formally nominated Nursing Clinical Lead who has a direct collaborative working partnership with the Lead Nurse for the network and has specified time working in paediatric cardiology.
- Each CCC must have designated registered children's nurses with a special interest in paediatric cardiology, trained and educated in the care of children and young people with heart disease.
- There must be a minimum of two registered children's nurses allocated to the children's cardiology beds who are trained according to the RCN competency framework.
- An appropriate number of Children's Cardiac Nurse Specialists will be based at the CCC and supported by the team at the Specialist Surgical Centre. Where a fetal cardiology service exists this must be supported by a Children's cardiac nurse specialist with experience in fetal counselling.

Other

- Children referred to the CCC must be seen and cared for in age-appropriate inpatient and outpatient environments, staffed by professionals experienced in the care of children and young people with heart disease.
- Each CCC will have a team of Congenital Echocardiographers who should have, or be working towards, EACVI accreditation. The number will depend on the configuration of the service.
- Each CCC will provide a Clinical Psychology Service for children, and for parents and carers.
- Each CCC must have an identified member of staff to ensure high quality data input into the network database.
- Each CCC will provide outpatient administrative support to ensure availability of medical records, organise clinics, type letters, arrange investigations, ensure timely results of investigations, arrange follow up and respond to parents in a timely fashion.
- Each CCC will have telemedicine facilities to link with the SSC.
- Each CCC will have annual training plans in place, to ensure ongoing education and professional development for all healthcare professionals involved in the care of children with congenital heart problems.
- CCC will follow pathways of care and management of congenital heart defects agreed with the SSC and in line with the draft congenital heart disease standards (2014).
- Each CCC will provide all non-invasive investigations (including electrocardiography, chest radiography, 24-hour ambulatory electrocardiography and blood pressure monitoring, treadmill exercise testing, high quality echocardiography facilities, CT and MRI).

Local Children's Cardiology Services (LCCS)

- Children's Cardiac Networks will be supported by LCCS. The precise shape of each Congenital Heart Network should be determined by local need and local circumstances, including geography and transport and agreed by Area Team Commissioners.
- LCCS will have a named Consultant Paediatrician with expertise in paediatric cardiology (PEC).
- Each PEC must be allocated time in the SSC to provide clinical continuity regarding the management of children under their care, enhance continued professional development and ensure the SSC is made aware of the views or concerns of patients.
- LCCS will have a locally designated registered children's nurses with a specialist interest in children's cardiology, trained and educated in the care of cardiac children and young people. 0.25 WTE must be available to participate in cardiology clinics
- LCCS will provide a Clinical Psychology Service for children, parents and carers.
- LCCS will provide outpatient administrative support to ensure availability of medical records, organise clinics, type letters, arrange investigations, ensure timely results of investigations, arrange follow up and respond to parents in a timely fashion.
- LCCS will follow pathways of care and management of congenital heart defects agreed with the SSC and in line with the draft congenital heart disease standards (2014).
- LCCS will have telemedicine facilities to link with the SSC.
- LCCS will have annual training plans in place, which ensure ongoing education and professional development across the network for all healthcare professionals involved in the care of children with congenital heart problems
- LCCS will provide basic non-invasive investigations (including basic electrocardiography, chest radiography, 24-hour ambulatory electrocardiography and blood pressure monitoring and high quality echocardiography facilities).

5. Applicable quality requirements and CQUIN goals

5.1 Applicable quality requirements (See Schedule 4 Parts A-D)

SSCs must complete the quality dashboard introduced by the congenital cardiac CRG in 2014. The list of quality of care indicators included in the initial iteration of the dashboard is not exhaustive and subject to ongoing revision. Such changes may be introduced prior to 2015.

5.2 Applicable CQUIN goals (See Schedule 4 Part E)

Not applicable.

6. Location of Provider Premises

To be introduced following the outcome of the current congenital cardiac review in 2015.

7. Individual Service User Placement

Not applicable

Appendix 1:

Quality standards specific to the service using the following template:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Domain 1: Preventing people dying prematurely			
1 year partial risk adjusted 30 day mortality data	To be determined after first year submissions	NICOR validated submitted annual data	Non-compliance with contract General Conditions 8 & 9
3 year rolling partial risk adjusted 30 day mortality data	To be determined after first year submissions	Unvalidated in house data submitted quarterly	Non-compliance with contract General Conditions 8 & 9
Domain 2: Enhancing the quality of life of people with long-term conditions			
Response to Sommerville Foundation survey on transition to adult care	To be determined after first year submissions	Positive survey responses divided by total responses	Non-compliance with contract General Conditions 8 & 9
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Unplanned reintervention rate within 30 days of catheter intervention	To be determined after first year submissions	Number of reinterventions divided by total number of catheter intervention procedures	Non-compliance with contract General Conditions 8 & 9
1 or more significant procedure related complication after catheter intervention	To be determined after first year submissions	Number of complications divided by total number of catheter intervention procedures	Non-compliance with contract General Conditions 8 & 9
Domain 4: Ensuring that people have a positive experience of care			

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Same day cancellation of elective surgical procedures	To be determined after first year submissions	Number of same day cancellations of elective procedures divided by total number of surgical procedures	Non-compliance with contract General Conditions 8 & 9
% Patients with suspected CHD seen within 3 days of sonographic identification	To be determined after first year submissions	Number seen within 3 days from date of referral divided by total referrals with suspected CHD seen within time period	Non-compliance with contract General Conditions 8 & 9
% Patients with confirmed diagnosis seen by specialist cardiac nurse at time of diagnosis	To be determined after first year submissions	Number seen by specialist cardiac nurse divided by Total diagnoses within time period	Non-compliance with contract General Conditions 8 & 9
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
Data Quality Index (validated from NICOR)	To be determined after first year submissions	Unit NICOR DQI	Non-compliance with contract General Conditions 8 & 9
Total surgical case load	To be determined after first year submissions	Number of NICOR defined surgical procedures in 1 year	Non-compliance with contract General Conditions 8 & 9
Total catheter intervention caseload	To be determined after first year submissions	Number of NICOR defined catheter intervention procedures in 1 year	Non-compliance with contract General Conditions 8 & 9

ANNEX 1 TO SERVICE SPECIFICATION:

PROVISION OF SERVICES TO CHILDREN

Aims and objectives of service

This specification annex applies to all children's services and outlines generic standards and outcomes that would fundamental to all services.

The generic aspects of care:

- The Care of Children in Hospital (Health Services Circular (HSC) 1998/238) requires that:
- Children are admitted to hospital only if the care they require cannot be as well provided at home, in a day clinic or on a day basis in hospital.
- Children requiring admission to hospital are provided with a high standard of medical, nursing and therapeutic care to facilitate speedy recovery and minimize complications and mortality.
- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Children are discharged from hospital as soon as socially and clinically appropriate and full support provided for subsequent home or day care.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child; Accommodation is provided for them to remain with their children overnight if they so wish.

Service description/care pathway

All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease.

Services should therefore be organised and delivered through "integrated pathways of care" (*National Service Framework for children, young people and maternity services*, Department of Health & Department for Education and Skills, 2004)

Paediatric Imaging

All services will be supported by a 3 tier imaging network ('Delivering quality imaging services for children' Department of Health 13732 March 2010).

Within the network:

- It will be clearly defined which imaging test or interventional procedure can be performed and reported at each site
- Robust procedures will be in place for image transfer and review by a specialist radiologist, these will be supported by appropriate contractual and information governance arrangements.

- Robust arrangements will be in place for patient transfer if more complex imaging or intervention is required.
- Common standards, protocols and governance procedures will exist throughout the network.
- All radiologists, and radiographers will have appropriate training, supervision and access to CPD.
- All equipment will be optimised for paediatric use and use specific paediatric software.

Specialist Paediatric Anaesthesia

Wherever and whenever children undergo anaesthesia and surgery, their particular needs must be recognised and they should be managed in separate facilities, and looked after by staff with appropriate experience and training (1). All UK anaesthetists undergo training which provides them with the competencies to care for older babies and children with relatively straightforward surgical conditions and without major co-morbidity. However those working in specialist centres must have undergone additional (specialist) training (2) and should maintain the competencies so acquired (3). These competencies include the care of very young/premature babies, the care of babies and children undergoing complex surgery and/or those with major/complex co-morbidity (including those already requiring intensive care support).

As well as providing an essential co-dependent service for surgery and catheter intervention, specialist anaesthesia and sedation services may be required to facilitate radiological procedures and interventions (for example magnetic resonance imaging (MRI) scans and percutaneous nephrostomy) and medical interventions (for example joint injection and intrathecal chemotherapy), and for assistance with vascular access in babies and children with complex needs such as intravenous feeding.

Specialist acute pain services for babies and children are organised within existing departments of paediatric anaesthesia and include the provision of agreed (hospital wide) guidance for acute pain, the safe administration of complex analgesia regimes including epidural analgesia, and the daily input of specialist anaesthetists and acute pain nurses with expertise in paediatrics.

References:

1. Guidelines for the Provision of Anaesthetic Services (GPAS) Paediatric anaesthetic services. Royal College of Anaesthetists 2010 www.rcoa.ac.uk
2. Certificate of Completion of Training in Anaesthesia 2010
3. Continuing Professional Development matrix level 3

Specialised Child and Adolescent Mental Health Services (CAMHS)

The age profile of children and young people admitted to specialised CAMHS day/in-patient settings is different to the age profile for paediatric units in that it is predominantly adolescents who are admitted to specialised CAMHS in-patient settings, including over-16s. The average length of stay is longer for admissions to mental health units. Children and young people in specialised CAMHS day/in-patient settings generally participate in a structured programme of education and therapeutic activities during their admission.

Taking account of the differences in patient profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following:

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx
- Staffing profiles and training - essential QNIC standards should apply.
- The child / young person’s family are allowed to visit at any time of day taking account of the child / young person’s need to participate in therapeutic activities and education as well as any safeguarding concerns.
- Children and young people are offered appropriate education from the point of admission.
- Parents/carers are involved in the child / young person’s care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Parents/carers who wish to stay overnight are provided with accessible accommodation unless there are safeguarding concerns or this is not in the best interests of the child / young person.

Applicable national standards

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

- There must be at least two Registered Children’s Nurses (RCNs) on duty 24 hours a day in all hospital children’s departments and wards.
- There must be an Registered Children’s Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of 2RCNs in total).

Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes *HBN 23 Hospital Accommodation for Children and Young People* NHS Estates, The Stationary Office 2004.

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children’s Workforce Development Council Induction standards (Outcome 14b *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

Each hospital who admits inpatients must have appropriate medical cover at all times taking account of guidance from relevant expert or professional bodies

(National Minimum Standards for Providers of Independent Healthcare, Department of Health, London 2002)."Facing the Future" Standards, Royal College of Paediatrics and Child Health.

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, including in relation to specific anaesthetic and surgical procedures for children, taking account of guidance from relevant expert or professional bodies (Outcome 14g *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (*Seeking Consent: working with children* Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- Ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them.
- Ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- Ensuring that people who use services are aware of how to raise concerns of abuse.
- Having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.

  Having effective means of receiving and acting upon feedback from people who use services and any other person.
- Taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:
  - having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
  - separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
  - reporting the alleged abuse to the appropriate authority
  - reviewing the person's plan of care to ensure that they are properly supported following the alleged abuse incident.

- Using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- Working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- Taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010

All children and young people who use services must be

- Fully informed of their care, treatment and support.
- Able to take part in decision making to the fullest extent that is possible.
- Asked if they agree for their parents or guardians to be involved in decisions they need to make.

(Outcome 4I *Essential Standards of Quality and Safety*, Care Quality Commission, London 2010)

Key Service Outcomes

General

Implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) leads to better health outcomes for young people and increasing socially responsible life-long use of the NHS. Implementation is expected to contribute to improvements in health inequalities and public health outcomes. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

Transition

Poorly planned transition from young people's to adult-oriented health services can be associated with increased risk of non adherence to treatment and loss to follow-up, which can have serious consequences. When children and young people who use paediatric services are moving to access adult services these should be organised so that all those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

Environment

All hospital settings should meet the *Standards for the Care of Critically Ill Children* (Paediatric Intensive Care Society, London 2010).

The *National Minimum Standards for Providers of Independent Healthcare*, (Department of Health, London 2002) require the following standards:

- **A16.1** Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- **A16.3** Toys and/or books suitable to the child's age are provided.
- **A16.8** There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult patients; the segregated areas contain all necessary equipment for the care of children.
- **A16.9** A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- **A16.10** The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this
- **A16.13** When a child is in hospital for more than five days, play is managed and supervised by a qualified Hospital Play Specialist.
- **A16.14** Children are required to receive education when in hospital for more than five days; the Local Education Authority has an obligation to meet this need and are contacted if necessary.
- **A18.10** There are written procedures for the assessment of pain in children and the provision of appropriate control.

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require:

- A choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs;
- Food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background
- Support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs.
- For the purposes of this regulation, "food and hydration" includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed.
- Providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010)
- All paediatric patients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.
- All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access support from social care, housing, education and other agencies as appropriate
- All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining,

recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 Essential Standards of Quality and Safety, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

- Ensures the medicines given are appropriate and person-centred by taking account of their age, weight and any learning disability
- ensuring that staff handling medicines have the competency and skills needed for children and young people's medicines management
- Ensures that wherever possible, age specific information is available for people about the medicines they are taking, including the risks, including information about the use of unlicensed medicine in paediatrics.

Many children with long term illnesses have a learning or physical disability. Providers should ensure that:

- They are supported to have a health action plan
- Facilities meet the appropriate requirements of the Disability Discrimination Act 1995
- They meet the standards set out in Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. Department of Health Publications, 2006, London

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No.	
Service	Adult Congenital Heart Disease (ACHD)
Commissioner Lead	
Provider Lead	
Period	
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

This specification covers all Adult Congenital Heart Disease (CHD) activity (surgery and cardiology), taking place in the Specialist Adult CHD Surgical Centres (Tier 1 services) and Specialist Adult Cardiology Centres (Tier 2 services), including activity undertaken by the Specialist Centres on an outreach basis where it is delivered as part of a provider network.

The Congenital Heart Disease Standards specify the requirements relating to the care taking place in Tier 3 services (Local Adult CHD Centres). This activity is commissioned by Clinical Commissioning Groups and is therefore outside the scope of this specification. Nevertheless Tier 3 services are part of the Congenital Cardiac Network of Care and it is expected that Adult Tier 1 and 2 services will work in partnership with Tier 3 providers to ensure all patient care is of a consistent, high quality.

This specification excludes the following which are covered by separate service specifications:

- Inherited Cardiology Conditions (A09/s/c) http://www.england.nhs.uk/wp-content/uploads/2013/06/a09-cardi-inheri-card-con.pdf
- Non Congenital Cardiac Surgery (A10/s/a) http://www.england.nhs.uk/wp-content/uploads/2013/06/a10-cardi-surgery-adult.pdf
- Services falling within the Complex Invasive Cardiology CRG as described in the CRG web page: http://www.england.nhs.uk/ourwork/commissioning/spec-services/npc-crg/group-a/a09/

1.2 Background

Adult Congenital Heart Disease (ACHD) affects people aged 16 and over living with a heart defect acquired during fetal development. The demography of Congenital Heart Disease is changing. Largely as a consequence of successful cardiac surgery in childhood, there are increasing numbers of adults with congenital heart disease with a prevalence of more than 4 per 1000 adults. The number of ACHD patients with complex disease is increasing with 10% of the population now falling within the complex group. Congenital heart disease can be diagnosed antenatally, during childhood or may remain undetected until adult life. Most patients with ACHD will require access to expert care and advice throughout their lives. The patient's condition will require regular monitoring, supported by diagnostic investigations. The adult with ACHD may require a variety of interventions including transcatheter intervention, cardiac surgery, invasive electrophysiology and pacing procedures, advanced heart failure management, palliative care and transplantation. The majority of ACHD patients will require on-going follow up and treatment in adult life in a centre with expertise in adult congenital heart disease.

Many ACHD patients will have had palliative surgery or catheter procedures in childhood, others will have undergone definitive repair but may have significant residual hemodynamic lesions and others may have had no specific treatment but require intervention in the future. The transition into ACHD is usually around 16 years of age . Transition to the ACHD service will normally be completed by age 18 and should be managed by expert staff from both paediatric and adult backgrounds in accordance with patient needs, to ensure a smooth transition to adult care.

It is anticipated that there will also be a group of patients who will enter the service as adults having no previous exposure to cardiac services as children..

The model of care is based on an overarching principle of the Adult Congenital Cardiac Network, with agreed pathways and protocols for referral between the three tiers. Adult Congenital Cardiac Networks must in turn partner with the Paediatric (and fetal) Cardiac Networks to ensure that robust and co-ordinated communication, planning and co-operation exists.

1.3 Current Service Provision

Standards of care have been developed through the NHS England Congenital Heart Disease Review and form the basis of this service specification (Congenital Heart Disease Review Standards Group, April 2014).

The Standards of Care are based on the principle of a Network Model. Fetal, Paediatric and Adult services will work together in Congenital Heart Networks to deliver care through three “Tiers” of provider as described in the Standards of Care.

The Standards provide time-lines for achievement of each standard ranging from standards which must be achieved immediately to standards which must be achieved within 3 years. The time line for each standard is provided in the standards document in appendix 3.

Network Care Levels:

- Tier 1: Specialist ACHD or Children’s Surgical Centres
- Tier 2: Specialist ACHD or Children’s Cardiology Centres
- Tier 3: Local ACHD or Children’s Cardiology Centres

It is expected that Paediatric and Adult Networks will work in partnership to deliver high quality, safe and effective services as locally as possible, throughout the patient’s lifetime of care. The exact size and geography of the Network will depend on local need and circumstances and will be determined in partnership with NHS England Commissioners. As much non-interventional treatment as is safe to do so, should be delivered as close to home as possible. It is expected that Networks will collaborate together to ensure uniformity of care throughout the healthcare system

Whilst working to the implementation of Networks of care, service providers will be expected to demonstrate their compliance with the standards in line with the NHS England Service Specification Derogation Policy. During transition to Network arrangements services are expected to:

- Maintain appropriate collaborative network relationships between units (Tier 1 – Tier 3) and with the Paediatric CHD Network in order to maintain a good outcome for patients
- Communicate consistently with families, staff and referrers regarding the progress of the ongoing review

1.4 Evidence Base

Draft Congenital Heart Disease Standards v0.20 Tier 1-3, March 2014.

2013 BCCA/BCS/BCIS Guidelines on Intervention for ACHD
http://www.bcis.org.uk/resources/ACHD_interventions_Oct_20111.doc

DH – 2006 – A Commissioning Guide For Services for Young People and Grown Ups with Congenital Heart Disease (GUCH)
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4134696.pdf

NHS England – April 2013 – Review of Adult Congenital Heart Disease Services – Engagement on Proposed Model of Care and Draft Designation Standards – 11/4/13 – 10/5/13

http://democracy.leeds.gov.uk/documents/s93411/Review%20of%20Adults%20with%20Congenital%20Heart%20Disease%20-%20engagement%20on%20revised%20proposals%20-%20Appendix%201.pdf

May 14 – First View Article – Cardiology in the Young
http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8828368

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	**Preventing people from dying prematurely**	√
Domain 2	**Enhancing quality of life for people with long-term conditions**	√
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	√
Domain 4	**Ensuring people have a positive experience of care**	√
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	√

The Congenital Heart Clinical Reference Group (CRG) has developed a quality dashboard for implementation in 2014/15. The list of quality of care indicators included in the initial iteration of the dashboard is not exhaustive and subject to ongoing revision.

3. Scope

3.1 Service Aims

The Adult Congenital Heart Service aims to provide services in line with the agreed standards of care and which operate within a Network Model encompassing the whole life time of care. The service will manage known ACHD patients transitioning from paediatric services and identify/diagnose adults with congenital heart disease, who are, by definition, aged 16 years and over (recognising that the process of transition to adult services may not be completed until the age of 18 years).

The service for Adult Congenital Heart Disease aims to:

- Deliver best outcomes for patients, with lowest mortality, reduced disability and an improved opportunity for a better quality of life for survivors
- Consistently meet the standards of care (2014) and provide resilient 24/7 care
- Ensure that patients have co-ordinated care throughout the entire pathway, and feel supported and informed during their cardiac journey.
- Provide good patient experience, including information to patients and their families and consideration of access and support to families when they have to be away from home
- Demonstrate clinical outcomes in line with national and international standards for adults with congenital heart disease

3.2 Service Objectives

The objectives of the service are to improve life expectancy and quality of life for adults with Congenital Heart Disease by:

- Development of Congenital Heart Networks to deliver a standardised model of care which meets national service standards
- Providing high quality, timely and accurate diagnosis
- Agreeing treatment plans with patients (and their families)
- Undertaking safe and effective congenital heart surgery and catheter intervention
- Providing appropriate counselling and psychological support to patients and their families
- Ensuring smooth and managed transition from paediatric to adult care
- Supporting patients to manage their ACHD condition independently in order that they can aspire to a life less hindered by their condition
- Ensuring effective communication between patients, families and service providers that is sensitive to the physical, psychological and emotional needs of the patient and their family
- Provide an individualised palliative care and bereavement service
- Systematically measure patient experience and satisfaction and contribute to patient surveys where they exist (e.g. Somerville Foundation Patient Experience Questionnaire)

3.2 Service description/care pathway

3.2.1. Overview

Congenital heart disease is a life-long condition and most patients will require access to specialised care, including monitoring, provided by appropriately trained specialists throughout their lifetime. The model of care for adults with congenital heart disease is based on an overarching principle of an adult congenital heart network. Working in partnership with the Paediatric Congenital Heart Network, the adult network will adopt policies and guidelines agreed across the network relating to patient management pathways within each of the centresspecific care levels described below. The congenital Heart networks will also be expected to link closely with related networks covering areas such as heart and heart/ lung transplantation.

Networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre to centre referrals.

Across an individual Network the units have been categorised into level of care as follows

Network Care Levels:

- Tier 1: Specialist ACHD Surgical Centres

- Tier 2: Specialist ACHD Cardiology Centres
- Tier 3: Local ACHD Centres

Across the whole CHD Network there must be facilities in place to ensure easy and convenient access for patients and their families/carers and facilities and support should include:

- Accommodation for partners/family members to stay (without charge)
- Access to refreshments
- Facilities suitable for the storage and preparation of simple meals; and
- An on-site quiet room completely separate from general facilities

Patients should be seen in an appropriate adult environment, ideally within a dedicated ACHD ward/OPD space and offered cultural and age appropriate cardiac rehabilitation, taking into account any learning or physical disability.

There must be arrangements in place allowing patients to actively participate in decision making at every stage of their care.

3.3. Patient Pathway

Although the pathway will be individualised according to the individual patient need, patients will move between the three tiers of service described above. Patients with moderate or severe complexity may be cared for either in the Specialist Cardiology Centre or the Specialist Surgical Centre and patients with simple congenital lesions may be cared for in their Local ACHD centre. It is not anticipated that patients will follow a linear path through the three tiers of care, but move between tiers as appropriate and determined by Network protocols and MDT planning. ACHD patients with complex lesions may be seen in local Tier 3 centres in collaboration with a specialist from Tier 1 or 2 through joint clinics

Pathways must involve transition from paediatric congenital heart services and have appropriate links with other adult specialties as defined in section 6.

3.3.1 Referrals

Patients will be referred into the Adult Congenital Heart Service from several routes including:

- From Secondary and Tertiary care Consultants (elective or emergency)
- Formal transition from Paediatric Congenital Heart Services
- The patient's GP

Upon referral to the ACHD service, the service will:

- Provide a 24/7 telephone advice and assessment service
- Provide inpatient facilities to stabilise and monitor clinically appropriate patients
- Carry out a core ACHD MDT assessment of all referred patients with a new diagnosis of significant congenital heart disease, within three months for non-urgent referrals
- At point of transfer to the adult service all transition patients from paediatric cardiology will have a formal baseline assessment. This will include detailed

discussion on prognosis, aetiology of condition and potential warning signs which require urgent review.

3.3.2.

Adult Congenital Heart Disease MDT

- The management of patients with significant congenital heart disease should be discussed at combined MDT meetings at the SSC. This includes all patients being considered for a complex catheter intervention or surgery.
- Each MDT discussion must generate a signed record of the discussion and the final outcome.
- When considering patients for complex catheter intervention or surgery the minimum composition of the MDT is a Congenital Cardiologist, Congenital Surgeon and Specialist Anaesthetist. Otherwise the composition of the MDT should be pathway driven, and adjusted according to the needs of different aspects of the service (for example, assessment, post-operative care, clinic-pathological and audit meetings).
- Staff from across the Congenital Heart Network should be encouraged by the SSC to attend MDT meetings in person or by video/teleconferencing to participate in the decision-making about their patient and for ongoing training and development.
- The attendance and activities of the MDT should be maintained in a register.

3.3.3 Service description of Provider Centres within Adult Congenital Heart Networks

Tier 1 - Specialist ACHD Surgical Centres

The Specialist Surgical Centre will deliver all services that Specialist Cardiology Centres and Local Cardiology Centres provide, as well as providing all ACHD surgery and interventional catheterisation. The Surgical Centre will be responsible for developing and agreeing, in partnership with other Network providers, the Network pathways, protocols and governance arrangements for patient care, including self-referrals out of network and second opinions, in line with the agreed standards of care.

Care Delivered in this setting includes:
- All ACHD surgery delivered by trained congenital cardiac surgeons with anaesthetic cover provided by those with appropriate ACHD training.
- ACHD catheter interventions including interventional pacing and electrophysiology delivered by trained congenital interventional cardiologists.
- Hybrid procedures – combined ACHD surgical / ACHD cardiology working.
- Joint surgical procedures - combined ACHD / general cardiothoracic surgical working.
- Joint cardiology procedures – combined ACHD / general cardiology working.
- Complex pacing and ICD procedures.
- Invasive and non-invasive imaging (including echo and dynamic assessment).
- Transition and transfer clinics
- Working links to other specialist areas including heart/ heart-lung transplantation service, genetics, National Pulmonary Hypertension Service.
- Complex patients requiring non-cardiac surgery should be managed in this setting in

order to have access to anaesthetists with ACHD experience.
- Joint management of ACHD patients with high-risk pregnancy.
- Local ACHD services as provided by Specialist ACHD Centres and Local Cardiology Centres
- Provide leadership for training, development and research across the network.

Tier 2 - Specialist ACHD Cardiology Centres

Will provide expert ACHD cardiology advice and support to patients to the same standard as that provided by the Specialist Surgical Centre and will deliver all services provided at the Local Cardiology Centres. The Cardiology Centres will provide on-going management of ACHD patients along with diagnostic services, simple electrophysiology work and management of ACHD in pregnancy. A Specialist ACHD Cardiology Centre will have a Lead Specialist ACHD Cardiologist who spends at least 0.8 WTE clinical time on ACHD and at least one cardiologist committed to ACHD who spends at least 0.5 WTE clinical time on ACHD.

Care Delivered in this setting includes:
- On-going ACHD patient management.
- Broad range of diagnostic services, including invasive and non-invasive imaging, delivered at the same quality as in the Surgical Centre.
- Cardiologists employed by the Specialist ACHD Cardiology Centre and trained to the appropriate standards in ACHD catheter intervention shall be provided with appropriate sessions and support at the Specialist ACHD Surgical Centre to maintain and develop their specialist skills.
- Cardiologists from the Specialist ACHD Cardiology Centre performing therapeutic catheterisation in patients with congenital heart disease must be the primary operator in a minimum of 50 such procedures per year averaged over a three year period. These procedures must only be carried out only in the tier 1 centre.
- Electrophysiology procedures for patients with simple congenital heart lesions may also be carried out at Specialist ACHD Cardiology Centres where there are pre-existing services and appropriate governance arrangements agreed through the Network protocols/pathways
- On-going management of pacing.
- Management of ACHD in pregnancy, contraceptive advice and pre-pregnancy planning, with an understanding of when to refer to Tier 1 services

Tier 3 - Local ACHD Centres (Commissioned by Clinical Commissioning Groups)

Will provide on-going outpatient care for patients with simple defects. They will deliver long term follow-up/shared care in liaison with the CHD Network, local DGHs and primary care. It is anticipated that care will be provided by a local cardiologist with additional training in congenital heart disease in collaboration with a specialist ACHD cardiologist from a Tier 1 or 2 centre, They will refer patients to different settings within the Network according to the agreed protocols/pathways. The Cardiologist with a special interest in ACHD will have a formal liaison role between the ACHD network and the local centre

Care delivered in this setting includes:

- Basic cardiac diagnostic services (ECG and transthoracic Echo)
- Dental management, information and care
- Monitoring of anticoagulation and blood chemistry
- Joint working with palliative care
- Diagnostic catheter procedures, Electrophysiology Procedures and Transesophageal Echocardiogram's if agreed as part of the agreed Network protocols

3.3.3 Definition of Adult Congenital Heart Surgery and Intervention

The definitions of which surgical procedures should only be carried out by accredited Congenital Cardiac Surgeons are attached in appendix 1.

3.4 Initial Care

The appropriate Adult CHD Service will:

- Establish a baseline against which disease progression and response to treatment can be measured
- Agree the need for any therapeutic intervention, either specific or supportive
- Offer treatment to all patients who might potentially benefit; eligibility for treatment to be determined as set out in relevant guidelines or as clinically indicated
- Provide patients and their families/carers with written and/or electronic material relating to the ACHD condition in an appropriate format

3.5 Ongoing care.

The appropriate Adult CHD Service will hold/provide:

- Regular patient reviews as per national guidelines or clinical practice with written and electronic records of current treatment and patient response
- Access to inpatient and critical care facilities where appropriate
- Access to other specialised services, e.g. PAH, transplantation, etc., as appropriate
- Appropriate access to pharmaceutical therapy
- Patient-centred services, sensitive to the individual's physical, psychological and emotional needs and supported through the provision of patient-appropriate information
- Access to appropriate shared care arrangements with other ACHD service providers.
- Clinical Nurse Specialist telephone advice service for patients and their families/carers, healthcare professionals and non-healthcare and voluntary sector professionals

3.6 Dental Care

The Dental treatment needs of ACHD patients must be identified and addressed prior to referral for any invasive procedure. Any outstanding treatment needs must be shared with the interventional/surgical team. Patients at risk of endocarditis must have a tailored programme for specialised follow up. The Network will have a clear referral pathway for urgent dental assessments.

3.7 Pregnancy and Contraception

All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by a cardiologist with a special interest in congenital heart disease who has expertise in pregnancy care, and where appropriate by a consultant geneticist.. They must have access to appropriate contraception, emergency contraception and termination of pregnancy. The principle of planned future pregnancy as opposed to unplanned and untimely pregnancy should be supported.

A multidisciplinary cardiac obstetric service will be developed in conjunction with each Tier 1 and 2 unit.

Male patients must have access to counselling and information about contraception and recurrence risk by a Consultant Cardiologist and nurse specialist with expertise in congenital heart disease and where appropriate by a consultant geneticist.

Specific genetic counselling must be available for those with heritable conditions. All patients must be offered access to a Practitioner Psychologist as appropriate throughout family planning and pregnancy.

3.8 Transition from paediatric to adult ACHD services

Transition from paediatric to adults with congenital heart disease services (ACHD)

The process of transitioning from paediatric to ACHD care will take place between 12 and 18 years of age taking into account individual circumstances.

Paediatric and Adult Congenital Heart centres will develop close working relationships to ensure smooth and effective transition of patients to appropriate facilities, minimising loss of patients to follow up during the process. “Lost to follow up” rates must be recorded and discussed by the network.

- The ACHD service will accept referrals by of appropriate young people from the paediatric cardiac network.
- All young people requiring on-going congenital cardiac care/monitoring must be seen at least once by an ACHD cardiologist and ACHD nurse specialist in a specialist MDT transfer clinic or equivalent and be supported by age appropriate information and life style advice.
- Particular needs of young people with learning disabilities and their parents/carers must be considered.
- A children’s cardiac transition nurse will act as a liaison between young people, their carers, the children’s cardiac nurse specialist, ACHD nurse specialist and wider multidisciplinary team to facilitate the transition process.

- The network must provide age-appropriate written and/or electronic information to patients and their families/carers, covering the full range of social and health related advice
- Each paediatric/ACHD network must agree and provide formalised operational transition policy consistent with the draft congenital heart disease standards and the generic specification for transition produced by the paediatric medicine CRG.

3.9 Leaving the Pathway - Palliative or end-of-life care

The appropriate cardiac service will:

- Provide symptom control where appropriate for patients with untreatable or degenerative conditions.
- Monitor patient response on a regular basis.
- Use nationally approved palliative medicine pathways to plan care.
- Agree a named lead doctor and nurse for any patient entering a palliative care pathway who will ensure the patient and their family are supported up to and beyond death.
- Produce a written, agreed, individual, end-of-life care plan.
- Liaise actively with NHS and non-NHS professionals to ensure access to appropriate palliative or end-of-life services and make the patient and their family/carers aware of these.
- Generate and publish evidence of effective palliative or end-of-life care for patients / carers.

3.10 Governance

The Network will have a Governance Framework in place which includes arrangements for:

- Clinical audit.
- Regular network multi-disciplinary meetings.
- Regular network meetings including reflection on: mortality, morbidity and adverse incidents.
- Regular audit days including discussion of adverse events and resultant action plans.
- Regular meetings between networks to ensure uniformity of care throughout the healthcare system.

3.11 Patient registers/database

Accurate coding and classification of rare disorders is necessary for determining correct management, providing information on outcome and directing research. The value of such registers to patients is discussed in the chapter ‘Empowering those affected by rare conditions’ in the Department of Health’s 2012 document ‘Consultation on the United Kingdom Plan for Rare Diseases’.

The ACHD Centre will ensure that all patients requiring intervention are invited to have their information collected and entered onto the appropriate national database.

All ACHD Centres will co-operate in developing a national register of research trials and outcomes:

- There will be written protocols covering communication between clinicians, and between clinicians and patients.
- The specialist surgical centres must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiological procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research (NICOR)
- All centres delivering care to adults with congenital cardiac abnormalities will co-operate in developing a national register of research trials and outcomes.

3.12 Patient Information

Patients will be provided with high quality information throughout their care. Patients transferring across or between networks will be accompanied by high quality information including a health records summary and management plan.
Patients/family/carers must be provided with accessible information about the service and the hospital including information about amenities in the local area, travelling, parking and public transport. Information must be made available in a wide range of formats in a clear, understandable, culturally sensitive way and take into account developmental and special needs.

Information should include advice relevant to the patients condition:

- Exercise and sports participation
- Sex, contraception and pregnancy
- Dental care and endocarditis prevention
- Smoking, alcohol and drugs
- Work/Careers
- Travel
- Welfare Benefits
- Social Services
- Community Services
- Potential warning signs which would prompt urgent cardiac assessment

(not an exhaustive list)

3.1 Annual reports

The Adult Congenital Heart Network will produce annual audit and governance reports.

3.14. Administration

All units within the Network will provide appropriate administrative support to ensure timely organisation of system and process across the whole pathway.

4. Population covered

The service outlined in this specification is for patients ordinarily resident in England(*); or otherwise the commissioning responsibility of the NHS in England (as defined in Who Pays?: Establishing the responsible commissioner and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges).

(*) Note: For the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP Practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP Practice in England.

Specifically, the service is commissioned for all ACHD patients and patients referred with a suspected ACHD condition. To ensure Equity of Access, wherever possible, access to the service should be according to common routes, policies and criteria that do not disadvantage any relevant patient group. It should be noted that around 10% of patients have some form of learning disability. Patients from BME communities are also found in greater numbers than the general population.

5. Any acceptance and exclusion criteria and thresholds

5.1 Acceptance Criteria

- Transition patients from paediatric ACHD
- All adult patients newly diagnosed with ACHD

In common with most other types of healthcare provided by the NHS, patients are likely to enter the ACHD model of care via a general hospital or primary care, unless diagnosed during antenatal or post-birth care. In which cases, the proposed model relates to care provided to adults with congenital heart disease who are, by definition, aged 16 years and over (recognising that the process of transition to adult services may not be completed until the age of 18 years).

It is also anticipated that there will also be a group of patients who will enter the service as adults having no previous exposure to cardiac services as children, with congenital heart conditions.

5.2 Exclusions

The specification excludes -

- Patients with congenital syndromes which present with cardiovascular problems in adolescence or adult life e.g. Marfan syndrome, muscular dystrophy or other hereditary conditions may be appropriately looked after by alternative specialists at individual units.

- Adult critical care
- Transplantation
- Pre-implantation Genetic Diagnosis
- Investigational drugs and procedures that are part of a research protocol

6. Interdependencies with other services/providers

All units providing care for adults with congenital heart disease must conform to the standards for interdependency as laid out in section D of the appropriate Tier of the draft congenital heart disease standards (2014). They have not been included in detail here for brevity.

7. Applicable Service Standards

All units delivering care to adults with congenital heart disease should meet the draft standards produced by the Congenital Heart Disease Review Standards Group, April 2014.

7.1 Infrastructure Requirements

The precise shape of each Congenital Heart Network should be determined by local need and local circumstances, including geography and transport and agreed by Area Team Commissioners.

All healthcare professionals in the Network must take part in a programme of continuing professional development as required by their registering body/professional association. This should include specialist education and training and statutory mandatory training.

The Network will have a formal annual training plan in place to ensure ongoing education and professional development. Clinical Nurse Educators must be provided to deliver Network-wide standardised training/competence based programmes ensuring continuing professional development of nursing staff.

7.1.2 Tier 1: Specialist ACHD Surgical Centres

Centres must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within compliant rotas, including 24/7 congenital cardiac surgical and interventional cover. A Consultant ward round will occur daily.

Surgeons

- Surgical teams must consist of a minimum of 4 full time consultant congenital cardiac surgeons. Units will have a period of three years to achieve this standard. Out of hours arrangements must take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence.
- A ‘consultant congenital cardiac surgeon’ is defined as having the equivalent of two years dedicated training in a recognised Specialist Congenital Surgical Centre.
- Specialist Surgical Centres must enable consultant congenital cardiac surgeons to operate together on complex or rare cases.
- Each congenital cardiac surgeon must perform a minimum of 125 first operator congenital cardiac surgical procedures (auditable cases as defined by submission to NICOR) each year, averaged over a 3 year period.

Cardiologists

- Specialist surgical centres must be staffed by a minimum of 4 full time consultant specialist ACHD cardiologists. . Units will have a period of three years to achieve this standard.
- Each Centre must be staffed by at least two interventional specialist cardiologists included in the minimum of 4.
- Each consultant congenital interventionist must be primary operator in a minimum of 50 congenital procedures per year, averaged over a three year period.
- There must be a designated lead interventionist who must be primary operator in a minimum of 100 procedures per year, averaged over a three year period.
- Each specialist surgical centre must be staffed by a minimum of one electrophysiologist experienced in adult cardiac disease.
- Each specialist surgical centre will have a congenital cardiac imaging specialist expert in both cardiac MRI and cardiac CT.
- Each specialist surgical centre will have a lead for congenital echocardiography (EACVI accredited).

Nursing

- Each specialist surgical centre will have a senior nurse with specialist knowledge and experience in the care of patients with congenital heart disease including those undergoing congenital cardiac surgery. They will lead a dedicated team of nursing staff trained in the care of adults undergoing cardiac surgery.
- Each Specialist Surgical Centre will provide Cardiac clinical nurse educators to deliver competency based programs for nurses across the network
- Each congenital cardiac network will have a minimum of 5 WTE adult congenital heart specialist nurses distributed as appropriate across the network.
- Each patient with significant congenital heart disease must have a named specialist ACHD nurse responsible for co-ordinating their care.
- The ACHD nurse specialists will work closely with the Children’s Cardiac Transition Nurse to coordinate the transfer process for each patient.

Other

- Practitioner psychologists employed by the Specialist Children’s Surgical Centre will provide advice to adult patients as required.
- Each Specialist Surgical Centre will have a Lead Doctor and Nurse for safeguarding

vulnerable adults.
- Each Specialist Surgical Centre will have an identified bereavement officer.
- Each Specialist Surgical Centre will have local Arrangements for transferring patients from airfields and helipads as required.
- Equipment infrastructure on site: Electrophysiology including 3 dimensional mapping, transthoracic echocardiography, cardiac catheterisation laboratory, Intra-operative echo, transoesphageal echo, Magnetic Resonance Imaging (MRI), Computerised Tomography (CT), post-operative extra corporeal life support (Non-nationally designated ECMO), access to Isotope Imaging.

7.1.3 Tier 2: Specialist ACHD Cardiology Centres

- A lead specialist ACHD cardiologist who spends at least 0.8 WTE clinical time on ACHD and at least one cardiologist committed to ACHD who spends at least 0.5 WTE clinical time on ACHD (each cardiologist will have an indicative maximum patient workload of 1,500 per WTE Cardiologist).
- Dedicated consultant led cardiology on call rota of 1 in 4 cardiologists comprising congenital and non-congenital cardiologists.
- A formally nominated Clinical Lead who works across the network and separate clinical leads from the relevant specialties including; nursing, ICU, and anaesthesia.
- Cardiologists trained to the appropriate standards in interventional and diagnostic ACHD catheterisation will be provided with appropriate sessions and support at the Specialist ACHD Surgical Centre to maintain and develop their skills
- Specialist ACHD Cardiologists who visit the Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures each year
- Electrophysiology will usually be undertaken at the Surgical Centre but may be undertaken at the Specialist ACHD Cardiology centre if agreed at a joint MDT with the Surgical Centre.
- Congenital Heart imaging specialist expert in Cardiac MRI and cardiac CT.
- A minimum of 2 trained specialist designated registered nurses with a specialist interest in ACHD, whose role extends across the network.
- A formally nominated Nursing Lead who has a collaborative working partnership with the Lead Nurse for the Network.
- Access to a clinical psychology service integrated within the ACHD team.
- Identified member of staff to ensure high quality data input to the network database.
- A team of congenital echocardiography scientists (technicians) who should have/be working towards appropriate accreditation.
- Telemedicine facilities (as determined by the Network).
- Ensure that staff out-reaching from the Surgical or Cardiology Centre have remote access to their own IT systems and enable immediate access to patient data.
- Participation in the weekly Network MDT.

7.1.4 Tier 3: Local ACHD Centres

- At least 1 Consultant Cardiologist with an interest in ACHD.
- Staff should be encouraged to attend Network MDTs to participate in decision making

where necessary (Lead Cardiologist to attend at least 6 times per annum).

- Lead Cardiologist to liaise with other secondary and primary care colleagues linking to the Network appropriately.
- The Cardiologist with an interest should have a named Mentor in either the Cardiology Centre or Surgical Centre.
- Designated 0.25 WTE registered nurse with a specialist interest in ACHD to participate in clinics, provide support to in-patients and deal with requests for telephone advice.
- Nurses must be offered allocated rotational time working in the Surgical Centre or Cardiology Centre to enhance development of clinical knowledge and skills/enable professional development and career progression.
- An identified link nurse as point of contact for the Network.
- Ensure that staff out-reaching from the Surgical or Cardiology Centre have remote access to their own IT systems and enable immediate access to patient data.
- Assist the Network with providing core curriculum level training as per the Royal Colleges of Physicians Training Board within their catchment area.
- Identified member of staff to ensure high quality data input to the network database.
- Telemedicine facilities (as determined by the Network) .
- A Cardiac Physiologist with training in congenital echocardiography.
- Appropriate facilities and staff to undertake: Electrocardiography, Transthoracic Echocardiography, Chest X-Ray, Exercise Testing/six minute walk test, 24 hour tapes, event recorders and ambulatory blood pressure monitoring, theatre facilities/anaesthetic support for provision of specialist dental treatment or arrangements to refer patients on where appropriate.
- Dedicated room space for practitioner psychologists, cardiac nurse specialists and social workers to carry out therapeutic work.
- Facilities in place to ensure easy and convenient access for partners/family/carers.
- Robust reporting arrangements for reporting of adverse incidents and dissemination across the Network as determined by Network Governance Arrangements.
- Robust policy for collaboration with the Network for clinical audit, research and administration.

Core standards relating to the specification include:

- NHS Specialised Services Draft ACHD Standards (2014)
- Safe and Sustainable - Decision Making Business Case (2012)
- Chapter 8 (Arrhythmias and Sudden Cardiac Death, 2005) of the National Service Framework for Heart Disease (2000)
- Adult Congenital Heart Disease Commissioning Guide (2006).

Additional standards for consideration:

The national pulmonary hypertension service and heart and lung transplantation services are a necessary part of a comprehensive service for adults who require specialised cardiology or cardiac surgery services.

The principle that underpins the national guidance is that of age appropriate, safe and effective services as locally as possible, not local services as safely as possible. Care is therefore centralised in specialist centres to ensure depth and breadth of coverage, specialist clinical support and age appropriate care across the age range with defined aspects of care delivered in shared care services outside the specialist surgical centres.

NICE Guidance

- IPG67 Balloon dilatation of pulmonary valve stenosis. June 2004 http://publications.nice.org.uk/balloon-dilatation-of-pulmonary-valve-stenosis-ipg67
- IPG74 Balloon angioplasty with or without stenting for coarctation or recoarctation of the aorta in adults and children: guidance July 2004 http://guidance.nice.org.uk/IPG74
- IPG 86 Endovascular atrial septostomy. August 2004. http://guidance.nice.org.uk/IPG86
- IPG 95 Radiofrequency valvotomy for pulmonary atresia. October 2004 http://publications.nice.org.uk/radiofrequency-valvotomy-for-pulmonary-atresia-ipg95/the-procedure
- IPG 310: Placement of pectus bar for pectus excavatum (also known as MIRPE or the Nuss procedure). August 2009 http://guidance.nice.org.uk/IPG310
- IPG 336. Transcatheter endovascular closure of perimembranous ventricular septal defect.

http://guidance.nice.org.uk/IPG336 March 2010

- NICE guidance on PFO 2010 PFO in divers http://guidance.nice.org.uk/IPG371
- NICE guidelines on PFO closure in stroke 2013 http://guidance.nice.org.uk/IPG472
- Percutaneous Pulmonary Valve Implantation for Right Ventricular Outflow Tract Dysfunction

https://www.nice.org.uk/guidance/IPG436

8. Applicable quality requirements and CQUIN goals

There are no specific Adult Congenital Heart CQUINS (May 2014)

9.. Location of Provider Premises

The Provider’s Premises are located at:

ONLY LIST PROVIDERS IF THERE HAS BEEN A FORMAL DESIGNATION PROCESS.

10. Individual Service User Placement

Insert details including price where appropriate of any individual service user placement e.g. mental health. This is likely to be relevant where the service provides tailored specialist placements. It may also be used to record any specialist equipment that is provided as part of an individual care pathway.

A Definition of ACHD Surgery and Intervention

This is a definition of which Cardiac Surgical Operations should be carried out only by Cardiac Surgeons who are currently revalidated in Congenital Cardiac Surgery* and should be performed only in a designated ACHD Specialist Surgical Centre after approval by that unit's Multidisciplinary Team (MDT). These operations are termed "ACHD Surgery" and the outcomes of these operations will be audited by the UK Congenital Cardiac Audit Database. The referral route for these patients is via the Adult Congenital Cardiologist. Advice, as well as direct clinical care, will be available round the clock from designated ACHD Specialist Surgical Centre teams.

Section A

ACHD surgery includes all cardiac surgery in an adult who:

1. ***Has had cardiac disease diagnosed, operated or intervened on in childhood.***

This includes surgery for the residua or sequelae of interventional management of congenital cardiac lesions.

2. ***Presents with a new primary diagnosis of Congenital Heart Disease.***

This includes Coarctation of the Aorta as well as structural cardiac lesions.

3. ***Is a Woman of Child Bearing Age with congenital heart disease***

All these patients **MUST** be seen by an ACHD Cardiologist and **MUST** be discussed at an ACHD MDT prior to surgery or intervention.

Section B

ACHD surgery does not necessarily include:

1. ***Situations in which the primary cardiac pathology is adult acquired disease***. Any secondary, minor congenital cardiac lesion should be discussed with the "Specialist" ACHD team prior to the decision to operate and a joint procedure (general adult cardiac surgeon and ACHD surgeon) should be considered where recommend by the MDT.

2. ***Surgery for Aortopathy***, which should be carried out by a specialist Aortopathy team which may be a Specialist Surgical Centre ACHD team depending on local arrangements.

3. ***Surgery of the Aortic Valve, including the Bicuspid Aortic Valve***, the overwhelming majority of which will be undertaken by general adult cardiac surgeons. However, in view of the specific expertise of congenital cardiac surgery, careful consideration must be given to the need to refer to a Specialist Surgical Centre ACHD Team, in the following scenarios where a general cardiac surgeon should rarely operate.

a. Patients less than 30 years of age.

b. Patients requiring:

1. Aortic Annulus Enlargement Procedures (Konno)

2. Aortic Autograft Surgery (Ross)

3. Aortic Valve Repair, especially for more complex congenital lesions.

If a patient needs such complex surgery on the aortic valve, then it should be performed by either the ACHD surgeon or general adult cardiac surgeon dependent on the decision of the ACHD MDT and the local arrangements for aortic surgery. Joint consultant (Congenital and General) operating is encouraged. Occasional practice in complex Aortic surgery by a surgeon without appropriately experienced multidisciplinary support is not acceptable.

Section C

Surgery for immediately life threatening presentations of congenital heart disease, which, in less urgent scenarios, would qualify as ACHD surgery:

The risks of transfer to a distant ACHD Specialist Surgical Centre should be balanced against the risks of delaying surgery, where time allows taking advice from the ACHD Specialist Surgical Centre. It is explicitly recognised that Cardiac teams must be supported to act in rare and demanding scenarios (e.g. dissection and endocarditis) where the individual patient is best served by **“Immediate Generalist”** rather than **“Delayed Specialist”** intervention.

** In addition, all Surgeons who achieved CCT in cardiothoracic surgery after 2014 will be required to appear on the GMC Sub-Specialty register of ‘Congenital Cardiac Surgery’.*

Atrial Septal Defect and Patent Foramen Ovale Closures

Atrial Septal Defect

Surgery for Atrial Septal Defects (ASD) should be undertaken by congenital surgeons within an ACHD Specialist Surgical Centre. The argument that this has historically been done by non-congenital surgeons is not relevant as:

a) We are re-designing the service to achieve excellence of care now and in the future

b) Morbidity etc. is a big issue in a low risk situation like ASD

c) Essential for surgical numbers and training

d) The overall aim is to concentrate expertise

As a key issue between surgery and catheter closure is decision making, catheter treatment should also be located in specialised ACHD centre to allow joined-up MDT planning. The advantages of this are around the number of interventional catheterisations, training of ACHD interventionists and facilitation of data collection for national audits within NICOR. **Within the ACHD model of care, ASD closure should only be undertaken in the Specialist Surgical Centre**. This ensures that congenital cardiac surgery co-location is available should it be needed. There should be flexibility within the network to enable cardiologists with skills from Specialist Cardiology Centres to continue to undertake interventional work in Specialist Surgical Centres by local planning.

Patent Foramen Ovale

Closure of PFO is not considered a part of the spectrum of conditions covered by the term ACHD, and the management of PFOs is therefore not covered by this model.

This does not preclude PFO closure from being performed in ACHD services within the congenital heart network.

Appendix Two

Quality standards specific to the service using the following template:

Quality Requirement	**Threshold**	**Method of Measurement**	**Consequence of breach**
Domain 1: Preventing people dying prematurely			
Pending			
Domain 2: Enhancing the quality of life of people with long-term conditions			
Response to Somerville Patient Survey on out-patient care	To be determined after first year submissions	Positive survey responses divided by total responses	Non-compliance with contract General Conditions 8 & 9
Domain 3: Helping people to recover from episodes of ill-health or following injury			
Unplanned reintervention rate within 30 days of catheter intervention	To be determined after first year submissions	Number of re-interventions divided by total number of catheter intervention procedures	Non-compliance with contract General Conditions 8 & 9
1 or more significant procedure related complication after catheter intervention	To be determined after first year submissions	Number of complications divided by total number of catheter intervention procedures	Non-compliance with contract General Conditions 8 & 9
Domain 4: Ensuring that people have a positive experience of care			
Response to Somerville Patient Survey on In-patient care	To be determined after first year submissions	Positive survey responses divided by total responses	Non-compliance with contract General Conditions 8 & 9
Adequate information provided at discharge	To be determined after first year submissions	Positive survey responses divided by total responses	Non-compliance with contract General Conditions 8 & 9
Same day	To be determined	Number of same	Non-compliance

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
cancellation of elective surgical procedures	after first year submissions	day cancellations of elective procedures divided by total number of surgical procedures	with contract General Conditions 8 & 9
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			
Total surgical case load	To be determined after first year submissions	Number of NICOR defined surgical procedures in 1 year	Non-compliance with contract General Conditions 8 & 9
Total catheter intervention caseload	To be determined after first year submissions	Number of NICOR defined catheter intervention procedures in 1 year	Non-compliance with contract General Conditions 8 & 9

Appendix 3

Standards

Draft financial impact assessment of draft new standards for paediatric cardiac and adult congenital heart disease services

1. Background

Babies born with congenital heart disease (CHD) are amongst the most vulnerable patients the NHS cares for. We must ensure that CHD patients receive the best care we can provide from diagnosis and early treatment through to lifelong care and support.

Although relatively small in terms of numbers and expenditure, congenital heart disease is of huge public and political interest. It is a bellwether of the health service, and 14 years after the Kennedy Report, of the ability of commissioners to effect change in the interests of patients. Confidence in the service has been undermined by many years of repeated review and investigation (even though services in England are considered to be as good as those in any country in the world). Investment in the service has been held back because of continuing uncertainty. It is therefore important that this review is brought to a successful conclusion.

2. Introduction

New standards for congenital heart disease services are proposed for consultation. These will ensure consistent best practice across all providers in terms of how services should be organised and delivered but do not introduce new clinical interventions or change the threshold for treatment.

If recent trends continue it is expected that, whether or not new standards are introduced, activity will increase and therefore spending by Specialised Commissioning will need to increase. The reimbursement to providers for the costs of most elements of clinical care covered by the consultation falls within the scope of Payment by Results (PbR). The costs of providing the service to the new standards should therefore be met by providers from the additional funding they receive through the tariff system as activity levels increase.

The approach taken in this assessment is to consider the current and projected costs that are likely to be required from Specialised Commissioning budgets to meet expected demands using current tariff prices and future activity projections. Future changes in tariff prices reflecting wider system approaches to inflationary and other cost pressures as well as efficiency improvements have been excluded. The consideration of the net impact on providers is not within the scope of this consultation, and thus this assessment.

Consideration of the net impact on providers is not within the scope of this consultation. However, it is noted that the number of procedures undertaken at individual centres has an impact on their efficiency and thus the overall cost of these services. As this is outside the scope of the consultation it has not been considered further here.

At this stage in the consultation process, the objective is to consider the proposals described in the main part of the consultation document to help inform the responses from the consultees. Once a preferred option is confirmed using the financial information presented here, the implementation of this option can be further considered and the preparation of a more detailed financial Business Case will be appropriate.

3. Current CHD Commissioning Spend

The start point for an assessment of future activity and spend is the current estimated level of both. Establishing this has been hampered by a lack of nationally available data and consistency in the identification by commissioners and providers of the relevant activity and associated cost to commissioners.

The base period chosen is 2012/13 as this is the most recent full year for which Hospital Episode Statistics (HES) and Secondary Uses Service (SUS) data are available.

The best information available to NHS England on total paediatric cardiac and adult congenital heart disease specialised activity and spend is that identified through SUS. NHS England is working on improved data flows in this area but this data represents the best estimate currently available. It is important to note that these estimates will underestimate total activity and spend on these services as they do not include spend on the following: high-cost devices (e.g. pacemakers), critical care (e.g. paediatric intensive care), any activity paid for by local prices, and adult CHD outpatient activity. There are also a number of caveats around the quality of the data that is included:

- *Coverage*: The Identification Rules (IR) are used to identify specialised activity within SUS data. However, not all specialised activity can be flagged by the IR, owing to a significant amount that either doesn't flow through SUS or requires cross-referencing with a range of external datasets (to which NHS England has extremely limited access).
- *Source*: Any SUS data underpinning this analysis has been sourced from the PbR-Mart extract, provided by the Health and Social Care Information Centre (HSCIC). This data is freeze data and may contain provider errors that have not been corrected during the reconciliation period. Any coding errors in provider-submitted fields and inconsistencies will remain.
- *Data Enhancements*: The NHS England Analytical Service has enhanced the SUS data to maximise quality and the amount of specialised activity identified. While improving the value of intelligence produced, these enhancements will result in difficulties reconciling the data back to national SUS extracts or local activity data processed by Data Services for Commissioners Regional Offices. Modifications have been applied to the IR to maximise the amount of activity that can be identified and designated as specialised, however these do not account for local deviations in the IR. The data has also been subjected to a light deduplicated algorithm, which removes a limited amount of erroneous data.

As noted above this dataset does not identify adult CHD outpatient activity separately from other adult heart disease-related outpatient activity. To provide an estimate of the activity and thus commissioner expenditure it has been assumed that the ratio of outpatient to inpatient activity is 50% of the paediatric ratio reflecting the lower intensity of ongoing care for these patients. An alternative population-based approach, following a long term condition model, is not possible as the number of adult patients in such a cohort cannot be identified from the data available. The total activity in 2012-13 has been summarised as:

	Outpatient	**Inpatient**	**Other (e.g. critical care)**
Paediatric cardiac	91,500	10,800	No national data
Adult congenital heart diseases	24,900 (assumption)	5,500	No national data

The costs to Commissioners have been calculated using SUS data submitted by providers. The SUS data for 2012/13 and covers all spells for both procedural and non-procedural based CHD activity that have been paid via national Payment by Results tariff. For paediatric activity the data shows the figures for outpatient and inpatient episodes. However for adult activity outpatient episodes for congenital heart disease are not separately identifiable from outpatient activity for other cardiac conditions and an estimate has therefore had to be made based on an assumed relationship between inpatient and outpatient episodes.

The total spend in 2012-13 has been summarised as:

£m	**Outpatient**	**Inpatient**	**Other (e.g. critical care)**
Paediatric Cardiac	20.5	62.1	Unknown
Adult congenital heart disease	3.4	24.0	Unknown
Total	23.9	86.1	Unknown

Note: this baseline underestimates total spend on CHD services so as a result the increases in funding required may be higher than suggested above.

The costs to providers are not directly available however the PbR tariffs are based on the data sent providers that shows the full cost of providing their services including a share of all the overheads of the relevant organisation. The PbR tariff should therefore reasonably represent the average costs incurred by providers.

From the limited information available it is clear that the current quality standards, as required by the existing paediatric CHD service specification have not been uniformly implemented by all providers. Where this is not the case, providers will need to invest in staff and other resources in order to meet those elements of the standards that are defined by the resources required for a service, as opposed to those defined by outputs/outcomes. Providers cannot expect any additional income in the short term as the PbR tariff is intended to reflect the current standards, though over the medium term any additional investment could be expected to be reflected in an increase in the baseline cost and thus tariff, though this would not result in a material change in the tariffs. These costs would not be attributable to the proposed new service specification and standards.

4. Costs associated with the proposals

The principal costs associated with achieving the proposed quality standards arise from increased levels of staffing and from establishing networks.

Many of these costs are already inherent in the existing paediatric service specification, and therefore should not be attributed to the new standards. This includes:

- **Staffing**: additional congenital surgeons, paediatric cardiologists, paediatric nurse specialists and nurse educators.
- **Networks**: most costs including lead clinicians, lead nurses, network meetings etc.

As has already been noted elsewhere, given the projected rise in activity levels, it can be assumed that additional staff will be needed and that the associated costs would be met by the rise in income recovered by providers as a result of this higher activity (see section 5 below). Because of the way in which the standards have been written, the number of surgeons is expected to rise only in line with rises in activity levels. Additional surgeons who were unable to meet the minimum activity levels required would not be supported.

Some of the costs of the proposed new standards are however wholly new and are not included in the existing paediatric specification. This includes:

- Psychologists
- Adult CHD (ACHD) specialist nurses

Detailed costs have not been prepared because of the absence of an accurate baseline for comparison. It is known however that existing staffing levels vary considerably between providers. Commissioners would argue that the uplift in expenditure by providers is modest in the context of overall spend, lifts all providers to the same levels of staffing achieved by the best and that any additional costs should be covered by providers as a result of higher activity levels (see section 5 below).

The implementation of the new standards is not expected to result in new expenditure by either patients or their careers.

5. Benefits associated with the proposals

Commissioning against the standards will have wide ranging benefits for patients, their families, NHS England and other commissioners, and also to provider organisations.

Patients and their families

Effective implementation of the standards will provide assurance to patients and their families that the care they receive will be of a consistently high quality wherever they live in England. It will be delivered in the context of a specialist network dedicated to improving quality, with decisions about their care taken by an appropriate multidisciplinary team and delivered by specialist staff who are supported to maintain their skills and knowledge in specialist centres with the right equipment and close links to the other services they might need.

Effective implementation of the standards will also ensure that patients receive the information they need to participate actively in decisions about their care. It will be provided in a way that they can understand. They will receive the support they need throughout their care, from diagnosis through to end of life.

Commissioners

Adoption of the standards through the service specifications will give commissioners the tools they need to hold providers to account for the quality of care they deliver and to be able to take action if standards are not met. As a result, variation between providers will be reduced and occasional practice will be eliminated thereby addressing an obvious risk to patient safety.

As activity continues to rise, commissioners will be assured that additional expenditure is directed to services of increasing quality and not just quantity.

Providers

Providers will benefit from increased clarity about what is expected of them, and will be able to confidently plan for the future. Relationships between providers will be improved by working as part of formal managed networks. Further, improved information and support to patients will result in fewer complaints, time consuming investigations and potentially costly litigation.

6. Impact of changes to pathways

The implementation of the new standards is intended to increase the quality of the care provided to patients. This will improve the quality of their outcomes and their experience of that care.

The new standards are not expected to directly result in changes to the number, frequency or type of intervention, admission, outpatient attendance or investigation. There is no evidence to support assumptions that the standards will either increase or decrease overall costs.

7. Future levels of activity and expenditure

The need to ensure that consultant paediatric surgeons and their teams undertake a minimum of 125 operations per year limits the number of surgeons that can meet that target under the current levels of activity. The period over which this can translate into a minimum of 4 surgeons per congenital surgical centre depends on the growth rate in the relevant activity.

The PbR tariff paid to providers covers both variable and fixed costs. Therefore an increase in activity will increase the contribution to the fixed overheads of the provider, which will not increase at the same rate. An increase in activity will therefore provide an additional source of funds for providers to invest in the resources required to meet the standards set out in this consultation. The sufficiency of this funding will depend on the amount of additional activity, the proportion of the tariff consumed by variable costs and the level of investment required to meet the standards.

7.1. Future projections of activity

A decision has been made to use HES data for the activity modelling, and this has been triangulated with data from the congenital audit run by the National Institute of Cardiovascular Outcomes Research (NICOR) where possible. This approach has been used for the following reasons:

- HES data is available for both Paediatric and Adult CHD, whereas NICOR's data on adults activity is incomplete.
- The Identification Rule (IR) definitions can be applied to HES, particularly for adults, and it is this definition that is used to calculate payments for specialised services through the National Tariff system and that will drive future levels of Specialised Commissioning funding.
- As with all HES data there is a risk that providers do not code activity in a consistent manner, though in this instance this is not considered to pose a significant threat to the validity of the data when considered at a national level

Detailed analysis of historic trends in specialist inpatient activity for paediatric cardiac and adult CHD services (i.e. procedure-based activity; surgery and catheter interventions) has been used to identify a pattern of growth. This financial assessment considers all CHD activity which includes non-procedural based activity as well as activity which includes a surgical or catheter procedure, e.g. critical care, diagnostic tests and outpatient appointments. We have assumed that the relationship between specialist inpatient activity and all other CHD activity will remain stable and therefore the growth rates for all activity will follow the trend identified for specialist inpatient activity.

Scenario modelling based on Office of National Statistics (ONS) population projections and historic trends in activity per head of the patient population suggests that up to 2025:

Paediatric cardiac activity: 0.4% to 1% per annum up to 2025/6

- Could be expected to grow by 0.4% per annum as a result of Population changes
- Up to a further 0.6% per annum could be expected to arise from increasing activity per Head of Population

To note: These figure are very sensitive to ONS birth rate projections which have been previously underestimated – under ONS high projections we would be looking at 1% per annum as a result of Population changes and up to a further 1% per annum could be expected to arise from increasing activity per Head of Population – giving a range of between 1% and 2% pa. This sensitivity is considered below in scenarios 1b and 2b.

Adult congenital activity increase will be between 0.7% and 4% per annum up to 2025/6

- ACHD activity could be expected to grow by 0.7% annum as a result of Population changes
- Up to a further 3.3% per annum could be expected to arise from increasing activity rates per Head of Population

Assumptions:

- Activity per head will continue to grow as it has in the past following a linear trend
- Population will grow as per ONS's 2012-based principal population projections
- There will be no changes to Clinical Thresholds or Pathways arising from the implementation of the new quality standards (i.e. any changes will be at levels consistent with changes seen in the past)
- The current case mix of interventions will not change (for example the relative proportion of surgical and cardiology interventions)

Based on evidence from data analysis, academic literature and speaking to clinicians, it is expected that the main drivers of CHD activity have been and will be:

1. Population growth (which is a function of birth rate, migration and life expectancy)
2. Increasing prevalence of CHD within the population as a result of an increase in the proportion of patients who are of Asian and Black ethnicity for whom CHD is more likely to occur and in whom more serious manifestations of CHD are more common
3. Advances in medical techniques and new technology
4. Increased patient longevity and survival
5. Increased complexity and severity of patients (possibly also driven itself by 2, 3, 4 and 5 above)

As 30-day post-operative survival rates are already very high the new quality standards are not expected to improve them. Improvements in long-term survival and quality of life are expected but in the absence of any longitudinal studies of this cohort of patients there is no evidence currently available as to the longer term impact on survival rates of the increase in intervention rates over the past 10 years.

Given the uncertainty over future growth rates, as described above, two scenarios have been developed, firstly where growth reflects only projected population growth and secondly where growth reflects the continuation of the average historic growth rates (2003/4-2012/13 for paediatric activity, 2006/7-2012/13 for ACHD activity – due to data issues). The historic trend has been broadly linear, and therefore the rate of growth in the future is assumed to be linear under both scenarios.

Scenario 1 – Population growth only

		Growth	**2012-13**	**2025-26**
Paediatric	**Outpatients**	0.4%	91,500	96,400
	Inpatients	0.4%	10,800	11,400
Adult	**Outpatients**	0.7%	24,900	27,300
	Inpatients	0.7%	5,500	6,100

Scenario 2 – Population growth + Average historic growth rates

		Growth	**2012-13**	**2025-26**
Paediatric	**Outpatients**	1.0%	91,500	104,100
	Inpatients	1.0%	10,800	12,300
Adult	**Outpatients**	4.0%	24,900	41,500
	Inpatients	4.0%	5,500	9,200

7.2. Future projections of spend

Applying our activity growth assumptions (from section 5.1 above) to our estimate of baseline spend (section 2 above) allows us to generate our financial forecast for the adult congenital heart disease and paediatric cardiac specialised services from the perspective of commissioners paying for services under PbR.

This estimate considers only services paid for under PbR and in order to demonstrate more clearly the impact of activity growth, takes no account of deflation/inflation in PbR tariffs.

The following table presents a summary of estimates for baseline and projected commissioning spend by 2025/26 for the two activity growth scenarios presented.

Scenario 1 – Population growth only

£m		**Growth (per annum)**	**2012-13**	**2025-26**
Paediatric	**Outpatients**	0.4%	20.5	21.6
	Inpatients	0.4%	62.1	65.4
Adult	**Outpatients**	0.7%	3.7	4.1
	Inpatients	0.7%	24.0	26.2
TOTAL			**110.3**	**117.3**

Scenario 2 – Population growth + Average historic growth rates

£m		Growth (per annum)	2012-13	2025-26
Paediatric	**Outpatients**	1.0%	20.5	23.3
	Inpatients	1.0%	62.1	70.7
Adult	**Outpatients**	4.0%	3.7	6.2
	Inpatients	4.0%	24.0	39.9
TOTAL			**110.3**	**140.1**

For providers the financial impact in the intervening years will involve a linear increase for variable costs and series of step changes in cost for semi-variable costs and fixed costs. The detail of the calculation of these spending projections is available in Annex A.

By 2024/15 it is expected that additional funding within a range of £7.0m to £29.8m will need to be made available to commission CHD services to meet increased activity levels based on current configuration of providers.

8. Affordability

The implementation of the proposed quality standards is not currently estimated to result in new investment by commissioners, however the early stage in the development of the implementation plans and the assumptions that underpin them mean that more work is required later in the development and assessment process to confirm the expected actual financial impact.

Furthermore this review has not considered any actions providers could take beyond the scope of the standards to mitigate this financial pressure.

Affordability for commissioners:
The increase in commissioner expenditure for the population-only growth model appears to be within the likely increase in overall NHS funding given that it excludes the impact of any QIPP initiatives undertaken by commissioners.

The increase in commissioner expenditure for the population plus historic growth model is likely to be above the likely increase in overall NHS funding. In these circumstances options to increase affordability would be:

- additional Quality, Innovation, Productivity and Prevention (QIPP) schemes to reduce demand and reduce provider expenditure (in order to reduce the PbR tariff); or
- commissioners to increase the share of their budgets that are directed to CHD; or
- measures to increase efficiency, such as reducing the number of networks (for example, creating multi-centre networks) or reducing the number of surgical centres.

Affordability for providers:
The projected increase in activity will provide an additional contribution to semi-fixed costs and overheads built into the current PbR tariffs. These funds could be directed in a way so as to meet the new standards.

The principal additional cost to providers of the new standards is the investment in increasing the number of surgeons and their medical teams.

It is not possible to provide an exact estimate of the number of additional surgeons required. The number of surgeons at each centre remains fluid. Operative activity levels vary considerably between surgeons. There may be changes in the way services are delivered that affects the number of surgeons required. However for the purposes of prudent accounting, the 'worst case' would be to ensure that there were teams of four surgeons at each of the ten specialist surgical centres that currently account for around 80% of paediatric and adult specialist inpatient activity. The IRP reported that in October 2012 there were 34 surgeons practising in England with a maximum of four surgeons at each centre at that time. This would therefore require an increase of six further surgeons. NHS finance teams have historically assumed an estimated cost of an additional consultant (together with their associated supporting staff) to be £500k for the purposes of business planning, or £3m (£500k*6 additional surgeons) in this instance.

The table below shows that even with this investment, providers would still have significant remaining income as a result of rising activity to cover semi-fixed costs and the costs of the proposed standards. As has been discussed, the position for any individual provider may be different but cannot be determined at this stage.

The number of surgeons will only rise as and when activity rises because of the need to maintain surgical skills reflected in the standards. This means that there will be a lag between the increase in the activity and the surgical capacity, which further means that providers will have the additional income from that increased activity before they have to increase these staff costs. At the highest rate of growth projected (Population and Rate per Head), the table below demonstrates that after costs for additional surgeons are taken into account (estimated at £500k per Surgeon) and the variable costs associated with the increased activity, *on average* each of the 10 specialist centres retains up to £1.6m to meet additional internal costs arising. As has been discussed, the position for any individual provider may be different but cannot be determined at this stage, currently around 20% of activity occurs outside of these specialist centres and this would need to be considered.

Provider Cost Impact 2025/6

	1a	1b	2a	2b
	£000	£000	£000	£000
Income from additional activity	£7,000	£14,000	£29,800	£42,700
Costs of 9 additional surgeons and team	-£4,500	-£4,500	-£4,500	-£4,500
(£ ****k per surgeon/team)				
Variable costs @ 30%	-£2,100	-£4,200	-£8,900	-£12,800
Remaining income available for semi-fixed costs and proposed standards	£400	£5,300	£16,400	£25,400

Note: numbers may not sum due to rounding

Scenarios:
1a - Population Growth only (principal paediatric pop growth)
1b - Population growth only (high paediatric pop growth) – sensitivity upper bound
2a - Population growth + historic activity increase (principal paediatric pop growth)
2b - Population growth + historic activity increase (high paediatric pop growth) - sensitivity upper bound

This allows for investment to meet the costs of:

- developing Education and Training and Networks
- ACHD Specialist Nurses
- Psychologists
- Offices and administrative support
- IT development and analytical support

8.1. Efficiency and Value for Money

As has been demonstrated, based on available information, the future of congenital heart disease services following the introduction of the new standards for CHD services:

- Will show expected increases in the quality of care of the patient's experience
- Will show improved health outcomes for patients
- Will show improved levers for commissioners to increase quality
- Will show improved clarity for providers as well as reduced adverse events and complaints
- Will not change the expected number of interventions on the various clinical pathways
- Requires more suitably trained Consultant Surgeons to undertake the additional activity
- Requires existing providers to respond with improvements to quality of service delivery and to increase resources where necessary - the costs of which will be available to them from additional tariff income
- Is estimated to require additional funding of £9m to £37m by 2024/25 to meet activity increases regardless of whether or not the standards are introduced.

A lack of suitable data on patient quality of life has not allowed a quality-adjusted life year (QALY) based calculation to undertake an economic assessment of the value of the proposed changes

The financial assessment has not considered the impact of potential changes to the number, location or capacity of individual providers as this is not in scope of this assessment. However, the opportunity to consider such cost mitigation strategies is available if desired at later stages in the review process. This may involve changes to the location, co-location and distribution of facilities and specialist staff for hospital based CHD activity. Implementation of the standards at a smaller number of centres could be expected to be more efficient as the required number of consultant surgeons, specialist nurses etc. across the country would be lower. Thus, increased volumes of activity could be performed within a lower overall funding cost thus introducing an opportunity to reduce additional funding if so desired. Non-recurrent funding would be required to complete a reconfiguration of services. This financial assessment has not addressed the magnitude or incidence of costs or benefits of reconfiguration, as it is outside scope.

9. Conclusions

The proposed standards of care for CHD services will improve the quality of patient outcomes and patient and carer experience without changes to the existing patient pathways.

Many of the items in the new specification that could be expected to drive costs for individual providers are already included in the existing paediatric specifications and they are not relevant costs for commissioners.

Activity is projected to increase whether or not the new quality standards are implemented. The actual rate of increase will reflect population growth and potentially would exceed this should the recent trend interventions continue.

The additional activity should increase the income of providers and this is expected to cover, on average, the costs of the wholly new aspects of the standards for providers.

10. Recommendations

The approval for the consultation process for the new standards should proceed to the next stage as we do not expect the proposed standards would require material extra funding beyond that needed in the 'Do Nothing' scenario given the existing service specification for specialist paediatric cardiac services and the projected increase in activity for both paediatric and adult CHD services.

ANNEX A

Figure 1: Activity and Expenditure Forecast Population Growth

SCENARIO 1a - POPULATION GROWTH ONLY (paediatric low growth)														
ADULTS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention														
Total projected growth		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Activity	5,534	5,573	5,612	5,651	5,691	5,730	5,771	5,811	5,852	5,893	5,934	5,975	6,017	6,059
Expenditure	£23,962,792	£24,130,532	£24,299,445	£24,469,541	£24,640,828	£24,813,314	£24,987,007	£25,161,916	£25,338,050	£25,515,416	£25,694,024	£25,873,882	£26,054,999	£26,237,384
Outpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention														
Total projected growth		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Activity (est)	24,903	25,077	25,253	25,430	25,608	25,787	25,967	26,149	26,332	26,517	26,702	26,889	27,077	27,267
Expenditure	£3,735,450	£3,761,598	£3,787,929	£3,814,445	£3,841,146	£3,868,034	£3,895,110	£3,922,376	£3,949,833	£3,977,481	£4,005,324	£4,033,361	£4,061,595	£4,090,026
Total adult expenditure	£27,698,242	£27,892,130	£28,087,375	£28,283,986	£28,481,974	£28,681,348	£28,882,117	£29,084,292	£29,287,882	£29,492,897	£29,699,348	£29,907,243	£30,116,594	£30,327,410
PAEDIATRICS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Rate of intervention														
Total projected growth		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Activity	10,839	10,882	10,926	10,970	11,013	11,058	11,102	11,146	11,191	11,236	11,280	11,326	11,371	11,416
Expenditure	£62,103,081	£62,351,493	£62,600,899	£62,851,303	£63,102,708	£63,355,119	£63,608,539	£63,862,974	£64,118,425	£64,374,899	£64,632,399	£64,890,928	£65,150,492	£65,411,094
Outpatients														
Population increase		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Rate of intervention														
Total projected growth		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Activity	91,498	91,864	92,231	92,600	92,971	93,343	93,716	94,091	94,467	94,845	95,225	95,605	95,988	96,372
Expenditure	£20,469,865	£20,551,744	£20,633,951	£20,716,487	£20,799,353	£20,882,551	£20,966,081	£21,049,945	£21,134,145	£21,218,681	£21,303,556	£21,388,770	£21,474,326	£21,560,223
Total paediatric expenditure	£82,572,946	£82,903,238	£83,234,851	£83,567,790	£83,902,061	£84,237,670	£84,574,620	£84,912,919	£85,252,570	£85,593,581	£85,935,955	£86,279,699	£86,624,818	£86,971,317
TOTAL EXPENDITURE	**£110,271,188**	**£110,795,367**	**£111,322,225**	**£111,851,776**	**£112,384,035**	**£112,919,017**	**£113,456,738**	**£113,997,211**	**£114,540,453**	**£115,086,478**	**£115,635,303**	**£116,186,942**	**£116,741,411**	**£117,298,727**

SCENARIO 1b - POPULATION GROWTH ONLY (paediatric high growth)														
ADULTS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention														
Total projected growth		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Activity	5,534	5,573	5,612	5,651	5,691	5,730	5,771	5,811	5,852	5,893	5,934	5,975	6,017	6,059
Expenditure	£23,962,792	£24,130,532	£24,299,445	£24,469,541	£24,640,828	£24,813,314	£24,987,007	£25,161,916	£25,338,050	£25,515,416	£25,694,024	£25,873,882	£26,054,999	£26,237,384
Outpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention														
Total projected growth		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Activity (est)	24,903	25,077	25,253	25,430	25,608	25,787	25,967	26,149	26,332	26,517	26,702	26,889	27,077	27,267
Expenditure	£3,735,450	£3,761,598	£3,787,929	£3,814,445	£3,841,146	£3,868,034	£3,895,110	£3,922,376	£3,949,833	£3,977,481	£4,005,324	£4,033,361	£4,061,595	£4,090,026
Total adult expenditure	£27,698,242	£27,892,130	£28,087,375	£28,283,986	£28,481,974	£28,681,348	£28,882,117	£29,084,292	£29,287,882	£29,492,897	£29,699,348	£29,907,243	£30,116,594	£30,327,410
PAEDIATRICS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Rate of intervention														
Total projected growth		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Activity	10,839	10,947	11,057	11,167	11,279	11,392	11,506	11,621	11,737	11,854	11,973	12,093	12,214	12,336
Expenditure	£62,103,081	£62,724,112	£63,351,353	£63,984,866	£64,624,715	£65,270,962	£65,923,672	£66,582,909	£67,248,738	£67,921,225	£68,600,437	£69,286,442	£69,979,306	£70,679,099
Outpatients														
Population increase		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Rate of intervention														
Total projected growth		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Activity	91,498	92,413	93,337	94,270	95,213	96,165	97,127	98,098	99,079	100,070	101,071	102,081	103,102	104,133
Expenditure	£20,469,865	£20,674,564	£20,881,309	£21,090,122	£21,301,024	£21,514,034	£21,729,174	£21,946,466	£22,165,931	£22,387,590	£22,611,466	£22,837,580	£23,065,956	£23,296,616
Total paediatric expenditure	£82,572,946	£83,398,675	£84,232,662	£85,074,989	£85,925,739	£86,784,996	£87,652,846	£88,529,375	£89,414,668	£90,308,815	£91,211,903	£92,124,022	£93,045,262	£93,975,715
TOTAL EXPENDITURE	**£110,271,188**	**£111,290,805**	**£112,320,037**	**£113,358,975**	**£114,407,713**	**£115,466,344**	**£116,534,963**	**£117,613,667**	**£118,702,551**	**£119,801,712**	**£120,911,251**	**£122,031,265**	**£123,161,856**	**£124,303,125**

Figure 2: Activity and Expenditure Forecast Population Growth and Rate per Head Increase

SCENARIO 2a - POPULATION GROWTH + INCREASED INTERVENTION RATE (paediatric low growth)														
ADULTS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention		*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*
Total projected growth		*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*
Activity	5,534	5,755	5,986	6,225	6,474	6,733	7,002	7,282	7,574	7,877	8,192	8,519	8,860	9,215
Expenditure	£23,962,792	£24,921,304	£25,918,156	£26,954,882	£28,033,077	£29,154,400	£30,320,576	£31,533,400	£32,794,735	£34,106,525	£35,470,786	£36,889,617	£38,365,202	£39,899,810
Outpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention		*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*
Total projected growth		*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*
Activity (est)	24,903	25,899	26,935	28,012	29,133	30,298	31,510	32,771	34,081	35,445	36,863	38,337	39,871	41,465
Expenditure	£3,735,450	£3,884,868	£4,040,263	£4,201,873	£4,369,948	£4,544,746	£4,726,536	£4,915,597	£5,112,221	£5,316,710	£5,529,379	£5,750,554	£5,980,576	£6,219,799
Total adult expenditure	£27,698,242	£28,806,172	£29,958,419	£31,156,755	£32,403,026	£33,699,147	£35,047,112	£36,448,997	£37,906,957	£39,423,235	£41,000,164	£42,640,171	£44,345,778	£46,119,609
PAEDIATRICS														
Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Rate of intervention		*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*
Total projected growth		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Activity	10,839	10,947	11,057	11,167	11,279	11,392	11,506	11,621	11,737	11,854	11,973	12,093	12,214	12,336
Expenditure	£62,103,081	£62,724,112	£63,351,353	£63,984,866	£64,624,715	£65,270,962	£65,923,672	£66,582,909	£67,248,738	£67,921,225	£68,600,437	£69,286,442	£69,979,306	£70,679,099
Outpatients														
Population increase		*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*	*0.4%*
Rate of intervention		*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*	*0.6%*
Total projected growth		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Activity	91,498	92,413	93,337	94,270	95,213	96,165	97,127	98,098	99,079	100,070	101,071	102,081	103,102	104,133
Expenditure	£20,469,865	£20,674,564	£20,881,309	£21,090,122	£21,301,024	£21,514,034	£21,729,174	£21,946,466	£22,165,931	£22,387,590	£22,611,466	£22,837,580	£23,065,956	£23,296,616
Total paediatric expenditure	£82,572,946	£83,398,675	£84,232,662	£85,074,989	£85,925,739	£86,784,996	£87,652,846	£88,529,375	£89,414,668	£90,308,815	£91,211,903	£92,124,022	£93,045,262	£93,975,715
TOTAL EXPENDITURE	**£110,271,188**	**£112,204,847**	**£114,191,081**	**£116,231,744**	**£118,328,764**	**£120,484,143**	**£122,699,958**	**£124,978,371**	**£127,321,625**	**£129,732,050**	**£132,212,068**	**£134,764,193**	**£137,391,040**	**£140,095,324**

SCENARIO 2b - POPULATION GROWTH + INCREASED INTERVENTION RATE (paediatric high growth)

ADULTS

Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention		*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*
Total projected growth		*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*
Activity	5,534	5,755	5,986	6,225	6,474	6,733	7,002	7,282	7,574	7,877	8,192	8,519	8,860	9,215
Expenditure	£23,962,792	£24,921,304	£25,918,156	£26,954,882	£28,033,077	£29,154,400	£30,320,576	£31,533,400	£32,794,735	£34,106,525	£35,470,786	£36,889,617	£38,365,202	£39,899,810
Outpatients														
Population increase		*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*	*0.7%*
Rate of intervention		*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*	*3.3%*
Total projected growth		*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*	*4.0%*
Activity (est)	24,903	25,899	26,935	28,012	29,133	30,298	31,510	32,771	34,081	35,445	36,863	38,337	39,871	41,465
Expenditure	£3,735,450	£3,884,868	£4,040,263	£4,201,873	£4,369,948	£4,544,746	£4,726,536	£4,915,597	£5,112,221	£5,316,710	£5,529,379	£5,750,554	£5,980,576	£6,219,799
Total adult expenditure	£27,698,242	£28,806,172	£29,958,419	£31,156,755	£32,403,026	£33,699,147	£35,047,112	£36,448,997	£37,906,957	£39,423,235	£41,000,164	£42,640,171	£44,345,778	£46,119,609

PAEDIATRICS

Year	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23	2023/24	2024/25	2025/26
Inpatients														
Population increase		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Rate of intervention		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Total projected growth		*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*
Activity	10,839	11,056	11,277	11,502	11,732	11,967	12,206	12,451	12,700	12,954	13,213	13,477	13,746	14,021
Expenditure	£62,103,081	£63,345,143	£64,612,045	£65,904,286	£67,222,372	£68,566,820	£69,938,156	£71,336,919	£72,763,657	£74,218,931	£75,703,309	£77,217,375	£78,761,723	£80,336,957
Outpatients														
Population increase		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Rate of intervention		*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*	*1.0%*
Total projected growth		*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*	*2.0%*
Activity	91,498	93,328	95,195	97,098	99,040	101,021	103,042	105,102	107,204	109,349	111,536	113,766	116,042	118,362
Expenditure	£20,469,865	£20,879,262	£21,296,848	£21,722,784	£22,157,240	£22,600,385	£23,052,393	£23,513,441	£23,983,709	£24,463,384	£24,952,651	£25,451,704	£25,960,738	£26,479,953
Total paediatric expenditure	£82,572,946	£84,224,405	£85,908,893	£87,627,071	£89,379,612	£91,167,205	£92,990,549	£94,850,360	£96,747,367	£98,682,314	£100,655,960	£102,669,080	£104,722,461	£106,816,910
TOTAL EXPENDITURE	**£110,271,188**	**£113,030,577**	**£115,867,312**	**£118,783,826**	**£121,782,638**	**£124,866,351**	**£128,037,661**	**£131,299,356**	**£134,654,324**	**£138,105,549**	**£141,656,125**	**£145,309,251**	**£149,068,239**	**£152,936,519**

Draft national standards and service specifications for congenital heart disease services: draft equality analysis

Equality and diversity are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have given due regard to the need to:

- reduce health inequalities in access and outcomes of healthcare services, integrate services where this may reduce health inequalities;
- eliminate discrimination, harassment and victimisation; and
- advance equality of opportunity and foster good relations between people who share a relevant protected characteristic (as cited in the Equality Act 2010) and those who do not share it.

What are the intended outcomes of this work?

Congenital heart disease is a term for a range of birth defects that affect the normal workings of the heart. The treatment for congenital heart disease depends on the defect. Mild defects, such as an atrial septal defect (a hole in the heart), often do not need to be treated, as they may improve on their own and may not cause any further problems, or will just need regular monitoring by a cardiologist.

If the defect is significant and is causing problems, surgery (or sometimes a less invasive procedure) may be required. Modern surgical techniques can often restore most or all of the heart's normal function.

However, people with congenital heart disease often do need treatment over their life and therefore require specialist review during childhood and adulthood. This is because people with complex heart problems can develop further problems with their heart rhythm or valves over time.

The new Congenital Heart Disease review

The new Congenital Heart Disease (CHD) review ("the review") was set up in June 2013 to consider the whole lifetime pathway of care for people with CHD to achieve:

- 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 so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care; and
- great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home.

The development of national standards to be applied through a national service specification is at the heart of the review's approach. This reflects the views of stakeholders from across the spectrum and is recognised in the review's objectives.

The review's six objectives:

1. **to develop standards to give improved outcomes, minimal variation and improved patient experience for people with CHD;**
2. to analyse demand for specialist inpatient CHD care, now and in the future;
3. to make recommendations on function, form and capacity of services needed to meet that demand, taking account of accessibility and health impact;
4. to make recommendations on the commissioning and change management approach including an assessment of workforce and training needs;
5. to establish a system for the provision of information about the performance of CHD services to inform the commissioning of these services and patient choice; and
6. to improve antenatal and neonatal detection rates.

Draft service standards and specifications
We are consulting on draft standards and specifications for CHD services for children and adults (there is currently a set of standards and a service specification in place for children's services but standards only exist in draft form for adults).

This equality analysis sets out the evidence we have considered as we have worked with others to develop these standards.

Draft standards
The draft standards cover the following:
- the network approach;
- staffing and skills;
- facilities;
- interdependencies;
- training and education;
- organisation, governance and audit;
- research;
- communication with patients;
- transition;
- pregnancy and contraception;
- fetal diagnosis;
- palliative care and bereavement; and
- dentistry.

We are producing standards and specifications which will enable commissioners to describe and commission an excellent service, within the available resource, and which will help ensure that services are all meeting the same criteria and in doing this, reduce inequalities in CHD service provision and outcomes.

While some standards could have a bearing on how/where services are delivered (insofar as they make proposals as to surgeon numbers, caseloads and mixes, interdependencies and sub-specialisation), there is no predetermined outcome about the configuration of provider units. We await responses from the consultation to inform the final form of the standards, and the future consideration of the subsequent shape of services.

Scope of this equality analysis

It is important to stress that the work on objectives 2-6 above is **not** the subject of the current consultation or this equality analysis, but our future work will be informed by what we hear in consultation.

Future thinking on, for example, function, form and capacity will be subject to the equality duty, in so far as it relates to the configuration of services to meet demand. We will consider feedback to this consultation, alongside future evidence and where appropriate, further equality analyses would be produced. Furthermore, as the sole national Commissioner, NHS England will need to ensure monitoring of the duty as part of contract management with service providers.

We hope that this draft equality analysis will demonstrate the information that has informed our thinking so far, and provide an opportunity for stakeholders, and the general public alike, to share this and to enhance their own understanding and ours, by:

- **considering and commenting on the evidence we have included, and**
- **helping us to fill in the gaps.**

Who will be affected by this work?

It is estimated that across England and Wales between 5 and 9 in every 1,000 pregnancies, or 1 in every 110 to 200, have some form of CHD. This includes pregnancies which lead to live or still births, those which die before birth and those which are terminated. This is based on information collected by the British Isles Network of Congenital Anomaly Registers (BINOCAR[1]) and cited by the British Heart Foundation[2], which currently only covers 36% of births in England and Wales. In 2011, the average for the six geographical areas covered is 6.1 per 1000 births, but this ranges from 4.5 in one area to 9.1 in another. BINOCAR does not cover key areas such as London. Some academic literature (which varies in scope) also suggests rates of around 5 to 8 per 1000[3].

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[1] *Table 1.1 and 5.1, "Congenital Anomaly Statistics 2011, England and Wales",* BINOCAR, September 2013, found at: http://www.binocar.org/content/Annual%20report%202011_FINAL_040913.pdf

[2] *Children and young people: Statistics 2013* (2013) Townsend N, Bhatnagar P, Wickrama singhe K, Williams J, Vujcich D, Rayner M, British Heart Foundation: London found at: http://www.bhf.org.uk/publications/view-publication.aspx?ps=1002326

[3] "*Trends in hospital admissions, in-hospital case fatality and population mortality from congenital heart disease in England 1994- 2004",* Billet J, Majeed A, Gatzoulis M, Cowie M (2008) Heart, (2008) Mar; 94(3): 342-8,
*"Comorbidity, healthcare utilisation and process of care measures in patients with congenital heart diseasein the UK: cross-sectional, population based study with case-control analysis***".** Billet J, Cowie MR, Gatzoulis MA, Vonder Muhil if, Majeed A (2008) Heart, 2008 Sep; 94(9): 1194-9
"*Survival with congenital heart disease and need for follow up in adult life*", Wren C, O'Sullivan JJ (2001) Heart, 2001 Apr; 438-43

There is limited evidence available on how this birth incidence is changing over time, but it is expected to be fairly stable. For a given rate of incidence, as more babies are born, the numbers of babies born with some form of CHD will increase. This, together with people with CHD living longer, means that the number of people living with CHD is increasing.

As well as people with CHD, this work will affect their families and carers, all members of the multidisciplinary clinical teams who support patients with CHD, and hospital managers, in particular those with specialist CHD units. Paediatric cardiac services also care for children with acquired and inherited cardiac diseases (although CHD accounts for most of their work). These children and their families and carers will also be affected.

Evidence

Our evidence has come from a range of sources. Key sources of evidence for the review in general, and the standards in particular, have been advice from:

- patients;
- clinicians;
- provider leaders;
- academics and other experts; and
- the wider public through correspondence and responses to our blog.

We have gathered evidence from:

- our patients' and public, providers' and clinicians' engagement and advisory groups;
- the groups that have developed the draft CHD standards;
- the Clinical Advisory Panel;
- visits to 13 Trusts with specialist CHD units where we had the opportunity to meet staff and patients; and
- nine meetings across England with children and young people.

A report is available at http://www.england.nhs.uk/wp-content/uploads/2014/07/chd-cap-6.pdf.

To inform our thinking on standards and the other objectives of the review, we have put in place other pieces of work to gather evidence. This has been done in parallel with the work of the review's lead analyst who has been progressing work on Objective 2 (including interrogating Hospital Episodes Statistics (HES) data).

We have also commissioned a systematic literature review; and asked the National Institute for Cardiovascular Outcomes Research (NICOR) to investigate their data.

Systematic literature review (papers since 2003 or earlier if few papers)
The independent systematic literature review, undertaken by The University of Sheffield, School of Health and Related Research (ScHARR) on our behalf, aimed to understand how organisational factors may affect patient outcomes focusing on:

- What is the current evidence for the relationship between institutional and surgeon volume and patient outcomes, and how is the relationship influenced by complexity of procedure and by patient case mix?

- How are patient outcomes influenced by proximity to/co-location with other specialist clinical services (e.g. co-location of services such as specialist paediatric intensive care)?

National Institute for Cardiovascular Outcomes Research - data analysis
The National Institute for Cardiovascular Outcomes Research (NICOR) was asked to examine its data and to advise on what this showed about service factors that could influence outcomes. Although the final write-up of this work is not yet available, NICOR has kindly supplied a summary of the main findings and these have been incorporated in this paper.

NICOR run the Congenital Heart Disease Audit using patient information collected by the Central Cardiac Audit Database (CCAD). We asked them to consider whether the information collected could be used to further understand the relationship between certain organisational or patient factors and patient outcomes. NICOR have helped us understand better the association between 30-day mortality rates in relation to ethnicity and social deprivation.

We see the gathering of evidence as part and parcel of our continuing work.

To this end, we propose to hold further engagement and advisory meetings and targeted work with some groups that share protected characteristics: BAME communities; people with learning disabilities and adults with CHD.

In the following sections we consider what impact our proposed standards for congenital heart disease might have on each of the nine protected characteristics:

- Age
- Disability
- Gender reassignment
- Marriage and civil partnership
- Pregnancy and maternity
- Race
- Religion and belief
- Sex
- Sexual orientation

We have also considered carers and geographical variations.

Age

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

Changing CHD population

CHD related episodes by age and as percentage of total (2012/13 HES data)

Age band	Age	Episodes	% total
Neonate	0 to 30 days	1297	12%
Infant	30 to 365 days	2318	21%
Child 1 -16	1 to 16 years	4296	39%
Child 17-18	17 to 18 years	695	6%
Adult 19-64	19 to 64 years	1856	17%
Adult 65+	65 years+	600	5%
Unknown	N/A	25	0%

Note: includes all episodes in NHS England providers for all patients (not just England and Wales)

Mortality from CHD has decreased over the past 30 years; between 1979-1983 and 2004-2008, absolute numbers of deaths from CHD in children under 15 years declined by 83% in the UK[4]. As the birth prevalence of CHD is thought to have remained more stable over this time period[5], it can be inferred that a large part of this decline in mortality is due to improved survival. Knowles *et al*. found that while deaths rates in the first year of life have been reducing throughout the period studied, drops in mortality in all age groups has only been observed for birth cohorts originating after 1989[6].

There is a suggestion from our own analysis and what we have heard that there has been an increase in demand for adult congenital heart disease care, not just among people in their twenties (i.e. birth cohorts originating after 1989).

Whereas in the past, mortality rates were higher in the early days and months, now more children in the UK with CHD benefit from advances in paediatric cardiac surgery and intensive care, and receive treatment and reach adulthood. The greatest decline in deaths from congenital heart disease has occurred in those aged less than one year.

This means that in the future, as more people survive, we are likely to see the service moving from one that is centred around children to one that is treating a growing number of young people and adults, who will continue to have (often complex) health needs.

This has consequences for the way in which services are delivered (and what sort of services are delivered) for both children and young people (and their different needs and expectations) through to transition for young people into adult services.

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[4] *Mortality with congenital heart defects in England and Wales, 1959-2009: exploring technological change through period and birth cohort analysis* Knowles RL, Bull C, Wren C, Dezateux C (2012) Arch Dis Child, 2012 Oct: 97(10): 861-5

[5] *Temporal variability in birth prevalence of cardiovascular malformations* Wren C, Richmond S, Donaldson L (2000). Heart; 83: 414-9

[6] Op. cit.

For many defects treated in childhood, further problems can develop later in life which then require medical care or further surgery[7].

In *Children and young people: Statistics 2013*[8]*,* the British Heart Foundation notes: ‘Treatment of adults with congenital heart disease is relatively new as more children with congenital heart defects receive treatment and reach adulthood. As a result of the success of paediatric cardiology and cardiac surgery over the last four decades, it is thought that more adults with congenital heart disease will require medical care than children[9]’ (page 15).

The report authors go on to highlight the importance of ensuring that facilities are adequate at transition.

Age and CHD: What we have heard during pre-consultation

Increasing need for adult congenital heart disease services
We have heard that there is a need for increasing capacity in adult congenital heart disease services and that some centres are expanding facilities and recruiting new staff.

Age-sensitive services
During pre-consultation, we have heard from patients, families and carers that services need to be age-sensitive and that effective transition is vital. This relates to effective and appropriate communication, but also to the facilities provided.

Young people have told us that they would like more information about sex and relationships and this needs to be away from parents – many teenagers are uncomfortable speaking about any of these things in front of their parents and some don’t even like the idea of speaking with their regular doctors.

Our draft standards emphasise, in several places, the importance of open, honest communication in ways that are appropriate to the patient’s needs. In addition we have also developed specific standards on:

- communication with patients;
- transition; and
- pregnancy and contraception.

We believe that the standards will have a positive impact on the experience and outcomes of all children and adults with CHD. For the first time services will be nationally commissioned using common service specifications across all ages.

We welcome more information/evidence.

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[7] *Care and Treatment for congenital heart defects* (2011) American Heart Association http://heart.org/HEARTORG/Conditions/CongenitalHeartDefects

[8] *Children and young people: Statistics 2013* (2013) Townsend N, Bhatnagar P, Wickrama singhe K, Williams J, Vujcich D, Rayner M, British Heart Foundation: London

[9] *Task force on the management of grown up congenital heart disease of the European Society of Cardiology* (2003) European Heart Journal; 24: 1035-1084

Disability

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

Children and adults with congenital heart disease are at an increased risk of developing further problems. Many children with congenital heart disease experience delays in their development. For example, they may take longer to start walking or talking. They may also have lifelong problems with physical coordination.

Some children with congenital heart disease also have learning difficulties. These are thought to be caused by a poor oxygen supply during early life, which affects the development of the brain.

Natural intelligence is usually unaffected, but some children often perform well below the academic level they would be expected to reach. This is because of problems such as:

- impaired memory;
- problems expressing themselves using language;
- problems understanding the language of others;
- low attention span and difficulty concentrating;
- poor planning abilities; and
- poor impulse control – acting rashly without thinking about the possible consequences.

Recent research has found that children who have had surgery for transposition of the great arteries have significant problems related to a concept known as theory of mind (TOM). TOM is the ability to understand other people's mental states and recognise that they may differ from your own. In other words, to recognise that everyone has their own set of desires, intentions, beliefs, emotions, perspective, likes and dislikes. In simple terms, TOM is the ability to see the world through another person's eyes. An inability to recognise other people's mental states can lead to problems with social interaction and behaviour in later life.

Congenital heart disease as a complication of Down's syndrome

Around 50% of children with Down's syndrome have a congenital heart defect and around 60% of children with Down's syndrome who are born with a heart defect require treatment in hospital.

Septal defects account for 9 out of 10 cases of congenital heart disease in people with Down's syndrome. A septal defect is a hole inside one of the walls that separate the four chambers of the heart, often referred to as a 'hole in the heart'.

Less common but serious types of congenital heart disease in people with Down's syndrome include:

- tetralogy of Fallot (accounts for 6% of cases); and
- patent ductus arteriosus (accounts for around 4% of cases).

As noted above in relation to age, it is possible that in complex congenital heart disease cases, further problems (which could include a disability) will develop later in life that will require medical care or further surgery[10].

Disability and CHD: What we have heard during pre-consultation

We heard about the importance of ensuring the standards respect the needs of people with disabilities.

We have proposed standards that address the needs of all patients and have included particular standards that relate to learning disability, for example in relation to:

- communication with patients; and
- transition.

We believe that the standards will have a positive impact on the experience and outcomes of all children and adults with CHD, a number of whom have a disability. For the first time services will be nationally commissioned using common service specifications across all ages.

We welcome more information/evidence.

Gender reassignment (including transgender)

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

We have not identified any specific evidence relating to gender reassignment (including transgender) and CHD.

We welcome more information/evidence.

Marriage and civil partnership

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

We have not identified any specific evidence relating to marriage and civil partnership and CHD.

We welcome more information/evidence.

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[10] *Care and Treatment for congenital heart defects* (2011) American Heart Association http://heart.org/HEARTORG/Conditions/CongenitalHeartDefects

Pregnancy and maternity

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

Cardiac disease is a leading cause of maternal death in pregnancy[11].

The Royal College of Obstetricians and Gynaecologists (RCOG) published a Good Practice guideline in 2011 which noted that pregnancy carries increased risks for women with congenital heart disease and particular efforts should be made to prevent any unwanted pregnancies. In particular teenage girls with congenital heart disease should have access to a specialist who can advise on contraception and later in life on preconception counselling. RCOG also noted the importance of ensuring that women with CHD:

- who go to their GP or midwife for advice are referred promptly to an appropriate high-risk pregnancy and heart disease team and see a cardiologist to establish how well the heart is working and discuss how pregnancy may impact their health.

- who want to become pregnant or who are pregnant visit their obstetrician and ideally should talk to them jointly with a cardiologist.

Fetal diagnosis

We are undertaking separate work (Objective 6) to improve fetal diagnosis of congenital heart disease.

Pregnancy and maternity and CHD: What we have heard during consultation

We have heard that there is a possibility that increased fetal diagnoses could in some cases increase terminations and reduce activity. But in other cases, it could increase the chance of survival and increase activity.

We have also heard that as a consequence of better care for people with congenital heart disease, more are going on to have their own children. This means that it is very important that there are close links between maternity services and ACHD services, and that deliveries are planned for safety.

We have developed specific standards on:
- pregnancy and contraception; and
- fetal diagnosis.

We believe that the proposed standards alongside our work to improve antenatal and neonatal detection rates (Objective 6) will have a positive impact on the experience and outcomes of women with CHD who are considering pregnancy, are pregnant or are receiving maternity care. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

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[11] Royal College of Obstetricians and Gynaecologists (2011)

Race

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

CHD related episodes by ethnicity and as percentage of total (2012/3 HES data)

Ethnicity (%)	**Specialist inpatient Episodes**	**Specialist inpatient Patients**	**ONS 2011 Census**
Paediatric cardiac			
White	66%	66%	79%
Black	4%	4%	5%
White and Black	2%	1%	N/A
Asian	10%	10%	9%
White and Asian	1%	1%	N/A
Chinese and other	3%	3%	1%
Any other mixed	1%	1%	6%
Not Known	4%	4%	N/A
Not Stated	10%	11%	N/A
Ethnicity (%)	**Specialist inpatient Episodes**	**Specialist inpatient Patients**	**ONS 2011 Census**
ACHD			
White	79 %	79%	88%
Black	2%	2%	3%
White and Black	0%	0%	N/A
Asian	5%	5%	7%
White and Asian	0%	0%	N/A
Chinese and other	2%	2%	1%
Any other mixed	0%	0%	2%
Not Known	5 %	5 %	N/A
Not Stated	7%	7%	N/A

Note: ONS 2011 census do not use the same ethnic groups as HES so not directly comparable but give some sense of how the ethnic mix of activity for specialist inpatient CHD care compares to the general population of England and Wales.

The HES data above indicates that the majority of CHD episodes are among those patients classified as white, followed by those patients classified as Asian.

Ethnicity and prevalence

Research dating back to the 1980s[12] and 1990s[13] demonstrated higher prevalence among Asian communities in various UK cities including Manchester and Leeds, and in the West Midlands. In the 1980s research links were made between CHD and consanguinity in the Asian Muslim population. More recently in *Consanguinity and the risk of congenital heart*

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[12] Gatrad AR, Reap AP, Watson GH Consanguinity and complex cardiac anomalies with situs ambiguous, *Arch.Dis Child 1984; 59: 242-5*

[13] Sadiq M, Stumper O, Wright JGC, de Giovanni JV, Billingham C, Silove ED Influence of ethnic origin on the pattern of congenital heart defects in the first year of life *Br Heart J 1995; 73: 173-176*

disease, (2012)[14] JT Shieh *et al.* undertook a systematic review of consanguinity in CHD, focusing on non-syndromic disease, with the methodologies and results from studies of different ethnic populations compared. They found that the majority of studies support the view that consanguinity increases prevalence of CHD, but found only three population-based studies controlled for potential socio-demographic confounding. The results suggested that the risk for CHD is increased in consanguineous unions in the studied populations, principally at first cousin level and closer.

For more precise risk estimates a better understanding of the underlying disease factors is needed. It has been suggested that we should consider whether and how to raise awareness of the risk of CHD within these communities.

Ethnicity and outcomes

We asked NICOR to see whether there was any link between ethnicity and the 30-day outcome after paediatric surgery. NICOR have used a 2009-12 dataset and a Partial Risk Adjustment in Surgery (PRAiS) model[15] recalibrated to evaluate the candidate risk factors for ethnicity. The PRAiS model assigns risk of death by 30 days after the first surgical operation (29 different specific procedures) in 30-day episodes of surgical management. NICOR's analysis of data from 13 paediatric surgery centres (12,186 episodes of care in paediatric heart surgery during April 2009 to March 2012 inclusive) showed that Asian ethnicity is associated with poorer outcomes (30-day post-operative mortality). This is a statistically significant finding. Other categories of ethnicity (Black, Chinese and Other) did not have statistically different risk from the Caucasian category.

Other factors beyond simple ethnicity may play a factor in this finding, such as deprivation and a higher incidence of consanguinity which is associated with more complex congenital heart disease and therefore less good outcomes.

Race and CHD: What we have heard during pre-consultation

We believe that the standards will have a positive impact on the experience and outcomes of children and adults from ethnic minorities with CHD. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

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[14] Am J Med Genet A. 2012 May;158A(5):1236-41. doi: 10.1002/ajmg.a.35272. Epub 2012 Apr 9.

[15] (Sonya Crowe, Kate L. Brown, Christina Pagel, Nagarajan Muthialu, David Cunningham, John Gibbs, Catherine Bull, Rodney Franklin, Martin Utley, Victor T. Tsang**, Development of a diagnosis- and procedure-based risk model for 30-day outcome after paediatric cardiac surgery**, The Journal of Thoracic and Cardiovascular Surgery, Volume 145, Issue 5, May 2013, Pages 1270-1278, ISSN 0022-5223, http://dx.doi.org/10.1016/j.jtcvs.2012.06.023)

Religion or belief

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

We have not identified any specific literature relating to religion or belief and CHD.

Religion or belief and CHD: What we have heard during pre-consultation

We heard that religion and belief and culture could make it difficult for some people to engage with us in an open forum.

We welcome more information/evidence.

Sex

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

CHD-related episodes by gender and as percentage of total (2012/13 HES data)

Gender	**%**	**%**
Paediatric cardiac	**Episodes**	**Patients**
Male	56	55
Female	44	45
ACHD	**Episodes**	**Patients**
Male	50	50
Female	50	50

In terms of activity levels the HES data above shows that there are more episodes for males than females in paediatric cardiac procedures but the number evens out in adulthood.

In terms of outcomes, there is no evidence that outcomes differ by gender – based on analysis by NICOR – no statistical association between 30-day mortality and patient gender has been identified[16]. However, *Children and young people: Statistics 2013* (2013) notes that in children under five years of age, 3.5% of all deaths in boys and 4.8% of all deaths in girls are from congenital heart disease.

We have not identified any specific literature relating to gender and CHD.

Gender and CHD: What we have heard during pre-consultation

We did not identify any key messages about gender.

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[16] Source: NICOR

We believe that the standards will have a positive impact on the experience and outcomes of children and adults of both sexes with CHD. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

Sexual orientation

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

We have not identified any specific evidence relating to sexual orientation and CHD.

Sexual orientation and CHD: What we have heard during pre-consultation

Young people have told us that they would like more information about sex and relationships and this need to be away from parents – many teenagers are uncomfortable speaking about any of these things in front of their parents and some don't even like the idea of speaking with their regular doctors. Our draft standards emphasise, in several places, the importance of open, honest communication in ways that are appropriate to the patient's needs.

We welcome more information/evidence.

Carers

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

It will be important to ensure that parents and carers of children with CHD have access to the information and any psychological support they might need.

Carers and CHD: What we have heard during pre-consultation

In addition, we have heard how important it is for parents and carers to be supported, particularly when they are away from home. They have told us about difficulties with finding their way round new hospitals, finding accommodation and eating balanced meals. They have also told us about problems with car parking.

We have also heard how important it is to have support for end of life and poor outcomes. This means having identified support structures that encourage and enable open and honest communication with families and carers at that time.

We have developed specific standards on:
- facilities; and
- palliative care and bereavement.

We believe that the standards will have a positive impact on the experience and outcomes for families and carers, ensuring that they are recognised and appropriately supported in their care of children and adults with CHD. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

Geographical variation

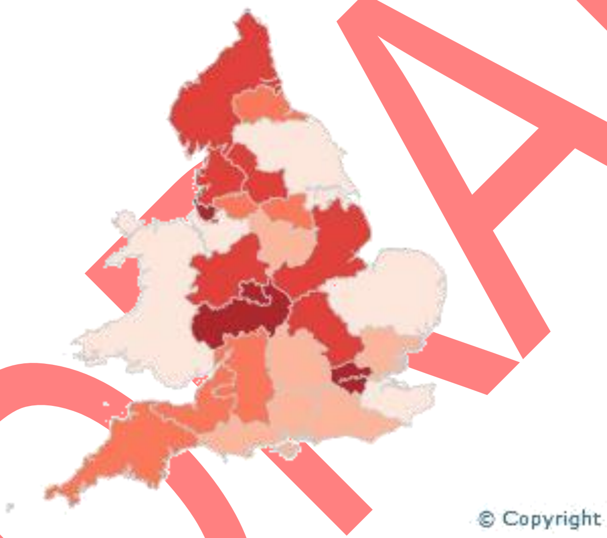
While not a protected characteristic, we have looked at CHD-related episodes (specialist inpatient activity) by area as percentage of total, and episodes per head of population (2012/3 HES data)

Area Team of patient residence	% of all specialist inpatient episodes	Specialist inpatient episodes per 100,000 (0-18) population	Specialist inpatient episodes per 100,000 (19+) population
Durham, Darlington and Tees	2%	60.0	4.9
Cumbria, Northumberland, Tyne and Wear	3%	69.0	3.9
Lancashire	3%	67.3	5.4
Greater Manchester	5%	63.1	6.3
Cheshire, Warrington and Wirral	2%	56.4	5.9
Merseyside	3%	72.4	10.5
West Yorkshire	4%	69.9	6.6
South Yorkshire and Bassetlaw	2%	59.8	3.4
North Yorkshire and Humber	2%	54.8	4.3
Leicestershire and Lincolnshire	3%	69.9	5.8
Hertfordshire and The South Midlands	5%	67.8	5.3
Derbyshire and Nottinghamshire	3%	59.7	5.1
Birmingham and The Black Country	6%	86.6	4.8
Shropshire and Staffordshire	3%	69.5	6.7
Arden, Herefordshire and Worcestershire	3%	72.2	5.7
East Anglia	4%	55.4	7.6
Essex	3%	59.5	3.9
London	16%	70.8	5.4
Kent and Medway	2%	53.7	4.5
Surrey and Sussex	4%	59.4	6.0
Thames Valley	3%	56.5	6.4
Wessex	4%	59.5	4.6
Bath, Gloucestershire, Swindon and Wiltshire	3%	59.8	8.8
Bristol, North Somerset, Somerset and South Gloucestershire	3%	63.9	6.9
Devon, Cornwall and Isles Of Scilly	3%	60.1	6.6

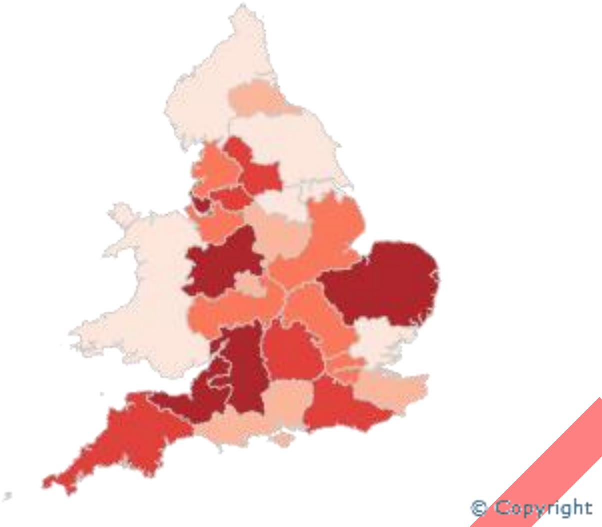
Wales	4%	52.6	2.0
Other (Scotland, N.I, Overseas etc.)	2%	N/A	N/A
Unknown	3%	N/A	N/A

The HES data above indicates that activity is fairly evenly spread across the country with the exception of London which has a much larger population, and Birmingham and Greater Manchester who are also slightly higher. However, once we account for different populations in each area we can see there is much more variation across the country in terms of relative activity. The episodes per 100,000 population show some differences from Wales at 52.6 and Kent and Medway at 53.7 to Merseyside at 72.4 to Birmingham and the Black Country at 86.6 (all paediatric services). In the case of adult services, the episodes per 100,000 population show differences from Wales at 2 and Essex at 3.9 to Bath, Gloucestershire, Swindon and Wiltshire at 8.8 and Merseyside at 10.5. This is demonstrated in the maps below; the darker the colour the higher the relative activity in that area.

<u>Paediatric (0-18) 2012/13 HES specialist inpatient episodes per 100,000 population, by Area Team of patient residence (activity per head so controlled for different population sizes)</u>



ACHD (19+) 2012/13 HES specialist inpatient episodes per 100,000 population, by Area Team of patient residence (activity per head so controlled for different population sizes)



Geographical variation and CHD: What we have heard during pre-consultation

The evidence we have received in relation to geographical variation has been limited. Where geography has been raised it has been in relation to how services are delivered now and how they might be delivered in the future. The focus has been on whether existing units will meet the standards and what it means to staff and patients if not; and travel times now and in the future.

We have noted the feedback we have received during pre-consultation on the concerns about how services will be delivered in the future, and will use this to inform our thinking in relation to future work on Objectives 3, 4 and 5.

We welcome more information.

Engagement and Involvement

Over the past 12 months we have been working with a wide range of stakeholders to develop the current draft standards. We have worked with and spoken to:

- children and young people with CHD and their parents and carers;
- adults with CHD and their parents and carers;
- groups representing people with CHD;
- clinicians and other members of the multidisciplinary team;
- providers; and
- local authorities and Healthwatch.

As well as regular meetings of formal engagement and advisory groups, we have undertaken visits to all specialist units, led by Professor Deirdre Kelly, Chair of the Clinician Group. During these visits, members of the new CHD review team had an opportunity to speak to clinical staff, and patients and their families. We also ran nine dedicated events for children and young people around the country.

The draft standards have been central to our engagement and involvement work from the outset and have informed the development of the draft service specifications. For the past year we have been working with experts to develop the draft standards, and then testing them out with our engagement and advisory groups and a wider audience.

We have adopted an approach of openness and transparency and all our papers are published on the NHS England Congenital Heart Disease Review website and John Holden's blog. Blog 23 contained the then-current version of the standards and so was open to everyone to see.

Launch of the consultation is the next step in the process and our work on engagement and involvement is ongoing. We plan to arrange four further regional visits during consultation and to do some targeted work with the stakeholders with an interest in the following protected characteristics:

- Age (specifically adults with CHD, with whom we have had less contact than children and young people)
- Disability (in particular, learning disability)
- Race

Summary of analysis

The evidence and engagement activity considered above has highlighted ways in which, subject to consultation and final agreement, our standards can help improve the way in which services are delivered to all those with CHD, including those in protected groups.

This is particularly so in relation to:

- Age
- Disability
- Pregnancy and maternity
- Race

The links between the standards and their impact on other protected groups is not so obvious. We hope to better understand how the standards might be used to support other protected groups through focused activities during the consultation – and also increase our understanding of the needs of adults with congenital heart disease.

The standards and the service specifications will, once agreed, set the framework through which CHD services will be delivered. It will be important for providers to ensure that they have regard to the equality duty in the provision of these CHD services.

Eliminating discrimination, harassment and victimisation

The draft standards apply to CHD services for children and adults – we currently only have agreed standards and a service specification for CHD services for children. The new draft standards will ensure that everyone with CHD gets the best possible care whatever their age, thereby improving the consistency of our approach with adults.

Advancing equality of opportunity

The draft standards apply to CHD services wherever they are delivered in the country. They apply to all services (levels 1, 2 and 3). The draft standards will help ensure that all services are working to the same aims – and that people with CHD can receive a consistently high quality service.

Promoting good relations between groups

The standards will provide a consistent approach for all those with CHD in protected groups.

Our work to date has also enabled us to identify some areas that are common to all groups (and not solely applicable to CHD services) and improvements in these areas will benefit all:

- Effective communications
- Information sharing between professionals
- Transition

Evidence- based decision making

Our engagement and involvement to date has been invaluable in enabling us to develop the current draft standards and to hear from a wide range of people. It has at the same time allowed us to develop our thinking in relation to protected groups and to identify some gaps in relation to our understanding of whether people with CHD in some protected groups have a voice and are being heard.

Our work with children and young people and meeting patients and families at the hospitals we visited gave us a particular insight into issues around age (specifically children and young people, and the transition into adult services) disability, pregnancy and maternity, and race.

It has highlighted issues relating to three protected groups that would benefit from further consideration and research:

- How CHD services will develop to meet changing needs as the number of adults with CHD exceeds the number of children with CHD.

- The reason for the prevalence of CHD in some Asian communities and poorer outcomes at 30 days after first surgical procedure.

- How CHD services can best be developed to meet the needs of patients with a disability, in particular learning disability.

We are also keen during consultation to hear from people who can provide further evidence to inform our thinking in relation to those protected groups not mentioned above.

Sharing this draft equality analysis

As part of our assurance, this draft analysis will be shared with our programme board, the Specialised Commissioning Oversight Group, Programme of Care Board for Women and Children, the Clinical Priorities Advisory Group and the Directly Commissioned Services Committee.

The draft equality analysis will form part of the reference document that will accompany the consultation document, draft standards and service specifications.

As such it will be included in our communications and engagement activity at launch. We will send it to our engagement and advisory groups, our Clinical Advisory Panel and blog followers.

For your records **Name of person(s) who carried out this draft analysis:**	Penny Allsop
Name of Sponsor Director:	John Holden, Director of System Policy
Date analysis was completed:	July 2014
Review date:	TBC post-consultation

New Congenital Heart Disease Review

Item 5 **Annex E**

Governance Paper

Purpose

1. This paper provides assurance to the new Congenital Heart Disease (CHD) review Programme Board, Women and Children's Programme of Care (POC) Board, Clinical Priorities Advisory (CPAG) and Directly Commissioned Services Committee (DCSC) that the relevant and necessary governance has been in place during the development of the standards and specifications for congenital heart services.

Governance arrangements to date

2. The standards of care for patients with congenital heart disease from detection to end of life were created by specially formed groups of clinicians and patient representatives on behalf of a Clinical Advisory Panel (CAP) convened for the purposes of the review to advise the Board of NHS England. The CAP considered views from a wide range of stakeholders (see engagement paper, Item 6 Annex F).

3. The service specifications have been created and approved by the congenital heart disease Clinical Reference Group (CRG).

4. The overarching programme has been assured by a monthly-meeting Programme Board and a Task and Finish Group of the NHS England Board.

5. These groups are shown as the decision-making bodies in figure 1 below, along with links to the terms of reference for the various groups. Membership lists can be found in Annex A.

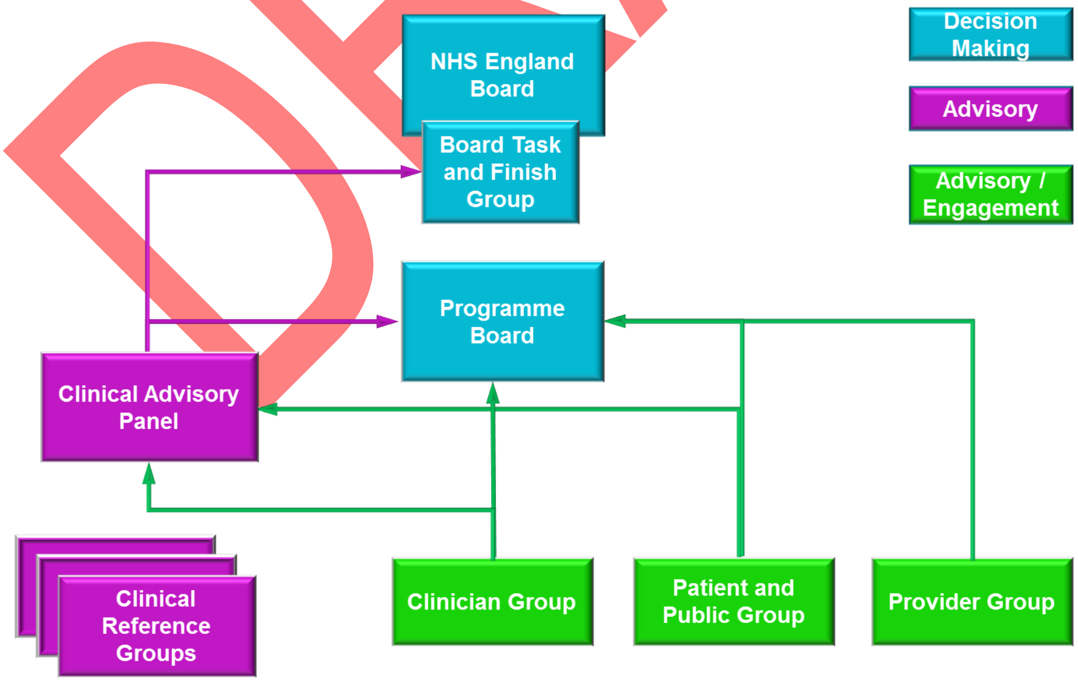


Figure 1

Board Task and Finish Group Terms of Reference
Programme Board Terms of Reference
Clinical Advisory Panel Terms of Reference

6. The CAP met on 18 June 2014 to review the standards. They considered the views expressed during pre-consultation and made amendments as necessary. Final approval for consultation will be given by correspondence by 8 August 2014.

Next steps

7. Prior to launching public consultation on the standards and specifications the review will go through the following process:
    - 22 July: **Specialised Commissioning Oversight Group** (SCOG) (to update on the review and engage with area and regional team colleagues)
    - 28 July: **Programme Board** (approval to apply to POC/CPAG/DCSC and approval of the content of the consultation documents)
    - 29 July: **Programme of Care Board** (to review draft specifications and update on impact assessment progress)
    - Early August: **Clinical Advisory Panel** (advice to the programme board on the alignment between standards and specifications by correspondence)
    - Mid-Aug: **Directly Commissioned Services Committee** (DCSC) (briefing by correspondence)
    - 20 Aug: **Programme of Care Board** (for approval/recommendation to CPAG)
    - 1 Sept: **Task and Finish Group of the Board** (briefing and approval to consult, subject to the remaining governance groups)
    - 2 Sept: **Clinical Priorities Advisory Group** (for approval/recommendation to DCSC)
    - 5 Sept: **DCSC** (approval by Chair's action)
    - 8 Sept: **Programme Board** (final approval to launch consultation)

8. Once the consultation closes the review expects the following next steps:
    - Analysis of the responses
    - Identification of required changes to the standards by the standards groups
    - Recommendation of changes made to the CAP
    - Sign-off on changes to the standards made by the CAP
    - Revisions to the specifications made by the CRG (Chair is a member of CAP)
    - Amended specifications to be subject to the specialised commissioning governance process, as defined by the Specialised Commissioning Taskforce
    - Public response to consultation published

9. Final decisions on the work of the review will be taken by the full NHS England Board meeting in public.

Annex A: Membership Lists

Task and Finish Group Members:

- Professor Sir Malcolm Grant, NHS England Chair (Chair);
- Margaret Casely-Hayford, NHS England Non-Executive Director;
- Ian Dodge, National Director: Commissioning Strategy;
- Professor Sir Bruce Keogh, National Medical Director; and
- Ed Smith, NHS England Non-Executive Director

Programme Board Members (as at 17 July 2014):

- Ian Dodge, National Director: Commissioning Strategy (Chair);
- John Holden, Director of System Policy (Vice Chair);
- Wayne Bartlett-Syree, Assistant Head of Planning and Delivery (Specialised Commissioning)
- Eleri de Gilbert, Area Team representative, Area Team Director (South Yorkshire and Bassetlaw area team);
- Sam Higginson, Finance representative, Director of Strategic Finance;
- Chris Hopson, Chair of the review’s Provider Group;
- Will Huxter, Regional Team representative, Head of Specialised Commissioning (London);
- Professor Deirdre Kelly, Chair of the review’s Clinician Group;
- Professor Sir Bruce Keogh, National Medical Director;
- Michael Macdonnell, Head of Strategy, Specialised Commissioning Taskforce;
- Mr James Palmer, National Clinical Director, Specialised Services;
- Linda Prosser, Area Team representative, Director of Commissioning (Bristol, North Somerset, Somerset and South Gloucestershire area team);
- Professor Sir Michael Rawlins, Chair of the Clinical Advisory Panel;
- Professor Peter Weissberg, Chair of the review’s Patient and Public Group;
- Giles Wilmore, Director for Patient & Public Voice & Information;
- Michael Wilson, review Programme Director; and
- two CCG representatives, to be identified.

CAP Members:

- Professor Sir Michael Rawlins, President, Royal Society of Medicine (Chair);
- Mr David Barron, Society of Cardiothoracic Surgery;
- Dr J-P van Besouw, Royal College of Anaesthetists;
- Dr Hilary Cass, Royal College of Paediatrics and Child Health;
- Dr Jacqueline Cornish, National Clinical Director for Children and Young
- People (NHS England);
- Professor John Deanfield, Chair of Adult with Congenital Heart Disease Advisory Group;
- Professor Huon Gray, National Clinical Director for Cardiac Care (NHS
- England);
- Professor Deirdre Kelly, Chair of the review’s Clinician Group;
- Dr Rob Martin, British Congenital Cardiac Association;
- Dr Andy Mitchell, Regional Medical Director (London), (NHS England);

- Professor Pedro del Nido, International Advisor;
- Mr James Palmer, National Clinical Director for Specialised Services (NHS
- England);
- Mr James Roxburgh, Society for Cardiothoracic Surgery;
- Dr Tony Salmon, Chair of the review’s Standards Sub-group;
- Fiona Smith, Royal College of Nursing;
- Professor Terence Stephenson, Academy of Medical Royal Colleges;
- Dr Graham Stuart, Chair of the Clinical Reference Group for Congenital Heart Services;
- Professor Peter Weissberg, Chair of the review’s Patient and Public Group; and
- Professor Norman Williams, Royal College of Surgeons

Congenital Heart Disease Clinical Reference Group (CRG) members:

- Graham Stuart, National Clinical Director Co-Chair
- Julia Grace, Accountable Commissioner

Senate representatives

- John O’Sullivan, North East (N1)
- Vaikom Mahadevan, Greater Manchester, Lancashire and S Cumbria (N2)
- Ram Dhannapuneni, Cheshire and Mersey (N3)
- Kate English, Yorkshire and Humber (N4)
- David Barron, West Midlands (M1)
- Giles Peek, East Midlands (M2)
- Clive Lewis, East of England (M3)
- Duncan Macrae, London NW (L1)
- Martin Elliot, London NE (L2)
- Gurleen Sharland, London S (L3)
- Mark Turner, South West (S1)
- Trevor Richens, Wessex (S2)
- Satish Adwani, Thames Valley (S3)
- David Hildick-Smith, South East Coast (S4)

Professional organisation representatives

- Gill Harte, Royal College of Nursing
- Rob Henderson, British Cardiovascular Society
- Andy Tometzki, British Congenital Cardiac Association
- Andrew Wolf, Association of Paediatric Anaesthetists of Great Britain and Ireland

Patient and carer representatives

- Jonathan Arnold
- Lois Brown
- Michael Cumper
- Penny Green
- Hazel Greig-Midlane
- Suzanne Hutchinson
- Anne Keatley-Clarke
- Samantha Lloyd

Engagement Paper

Introduction

1. This paper provides assurance to the new Congenital Heart Disease (CHD) review Programme Board, Women and Children's Programme of Care (POC) Board, Clinical Priorities Advisory (CPAG) and Directly Commissioned Services Committee (DCSC) that the necessary engagement has been carried out with all relevant individuals and groups in developing the standards, and that the views of stakeholders have been taken into account.

Action taken to date: Developing the standards and specifications

2. The standards of care for patients with CHD from detection to end of life were created by specially formed groups of clinicians and patient representatives. They have been reviewed by the Congenital Heart Disease Clinical Reference Group (CRG). See Annex A for CRG membership.

3. In March 2014 the standards were made public and have since been widely discussed as detailed below. Following this period of pre-consultation engagement, all comments received were considered by the Clinical Advisory Panel (CAP) and amendments made to the standards as necessary. The paper submitted to the CAP summarising what we heard pre-consultation can be found here: http://www.england.nhs.uk/wp-content/uploads/2014/07/chd-cap-6.pdf.

4. The CRG has prepared the service specifications to reflect the standards.

Action taken to date: Stakeholder Engagement

Engagement and advisory groups

5. The review has held regular meetings with its three engagement and advisory groups. All members received papers for meetings and blog alerts whether or not they attend a meeting. The following meetings have taken place:
   - five meetings of the patient and public group (with representation from national and local charities related to congenital heart disease and learning disabilities);
   - four meetings of the provider group (with representation from all providers of congenital heart services); and
   - four meetings of the clinicians' group (with representation from all trusts that offer congenital heart disease services).

   The standards have been discussed by each group and their views taken into account.

6. An additional visit has been made to Southampton representatives as they were unable to attend the main meetings due to timings.

7. These groups are shown as the engagement and advisory bodies in figure 1 below. Membership lists can be found in Annex B.

8. Each engagement and advisory groups has an independent chair (listed below). The chairs represent the views of their engagement and advisory groups at the Programme Board and CAP.

9. Chairs:
   - Chair, Clinician Group: Professor Deirdre Kelly, Professor of Paediatric Hepatology, Birmingham Children's Hospital,
     - Member of Programme Board and CAP

   - Chair, Patient and Public Group: Professor Peter Weissberg, Medical Director, British Heart Foundation,
     - Member of the Programme Board and CAP

   - Chair, Provider Group: Chris Hopson, Chief Executive, Foundation Trust Network,
     - Member of the Programme Board

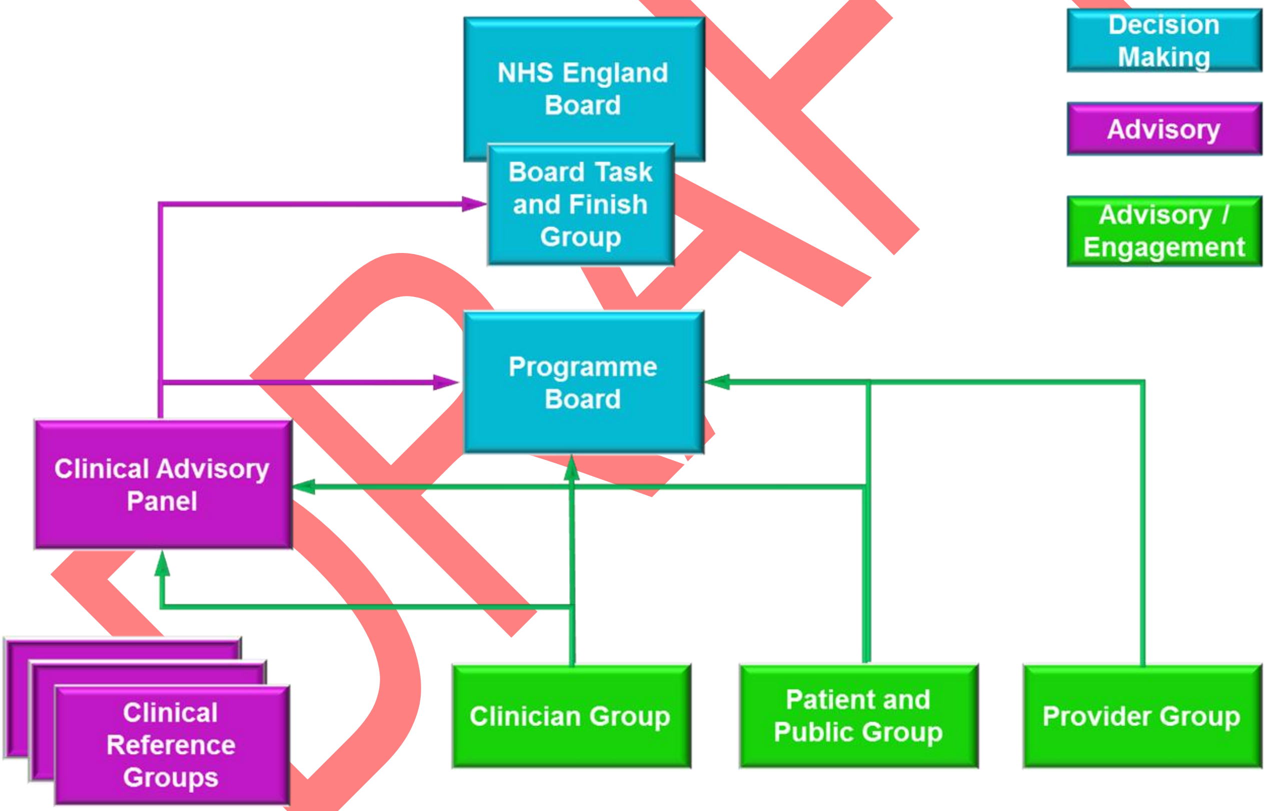


Figure 1: Governance and Engagement Structure

<u>Children and young people</u>

10. Nine events were held at venues around the country during the school holidays, for children and young people with congenital heart disease and their families, to ask them what mattered to them about CHD services. Over 100 children and young people aged between 2 and 24 years attended with their siblings and parents.

11. A parent/patient response form was used to gather comments and opinions on the draft standards.

12. Their views relating to standards were considered by CAP in their review of the standards.

Hospital visits

13. Professor Deirdre Kelly (Chair of the review's Clinician Group) supported by the review team undertook 13 visits to specialist services around the country including sessions with staff as well as with patients and families. The review team engaged directly with over 150 patients and families: adult patients, children and young people, parents of children of all ages in addition to hundreds of hospital staff.

14. Comments relevant to the standards were considered by CAP in their review of the standards.

Government, Local Authorities and Healthwatch

15. The review team has carried out the following engagement activities with government, local authorities and Healthwatch:
    - Two meetings at the House of Commons for interested MPs and Peers –
        - Professor Sir Bruce Keogh, NHS England Medical Director, presented at the All Party Parliamentary Group (APPG) to highlight the approach being taken to develop the standards in October 2013
        - Dr Mike Berwick, Deputy Medical Director, NHS England, presented at a meeting for MPs after the draft standards had been made public in April 2014
    - A combined meeting of local authorities and local Healthwatch groups connected with paediatric and adult services was also held in central England
    - A WebEx event was held for local authorities and Healthwatch
    - The team has responded to individual requests for Joint Overview and Scrutiny Committees and Overview and Scrutiny Committees attendance
    - Attendee lists can be found in Annex C

Next steps and plans for consultation

Regional Events

16. There will be a number of exhibition style events across the country to allow as wide an audience as possible to review the draft standards and respond to the consultation.

Engagement and advisory groups

17. A joint meeting of the three engagement and advisory groups to discuss current draft standards is arranged for 25 July.

18. We will offer the three engagement groups - Clinicians, Providers and Patient & Public – further opportunities to meet during the consultation process.

19. We plan to hold an additional event for all these groups to gather, listen to each other and share what they have been hearing during the consultation period. It will be run towards the end of consultation so that all attendees can report back what has been learnt / heard at the other events including stakeholder events and the regional events.

Hospital visits

20. There are three further visits planned to non-specialist adult CHD providers.

MPs, Peers, Local Authorities and Healthwatch

21. Prior to consultation all local and national government representatives will be informed of the forthcoming consultation at least three weeks in advance.

22. We are planning a further event for Local Government and Healthwatch during consultation.

23. We are having ongoing conversations with the Local Government Association, Centre for Public Scrutiny and Healthwatch England.

24. NHS England will respond to requests to attend JOSCs and OSCs during consultation.

25. There will be a briefing event for MPs and Peers during consultation.

Learning disabled adults

26. We plan to gather opinions on what matters to people with learning disabilities through existing routes rather than running specific events. It is likely that stakeholders who work with young people and adults with learning disabilities will incorporate questions and discussions about the standards, within already planned and existing events, to enable contribution to the consultation process.

Black and Minority Ethnic groups

27. Initial work with faith groups has not provided clear links to those in the communities that have an interest in CHD, but work continues with the providers who serve communities including significant numbers of people from ethnic groups more affected by CHD (see Draft Equality Analysis, Item 6 Annex D) to develop routes by which they are able to contribute to the process. This may include specific events during consultation or providing materials or spokespersons to events being run within these communities to encourage contributions to the review.

Bereaved parents

28. Parents who are bereaved may find contributing to the consultation difficult. The review has linked with the Child Bereavement Trust to assist in engaging bereaved parents during consultation: this may be through an event for bereaved parents

and/or using online and electronic methods of discussing comment and offering contributions. Members of the review team will meet with bereaved parents from the Bristol area at their invitation to seek their views.

Adults with CHD

29. Work is being undertaken to establish whether there is a requirement or desire to hold an event specifically for adults with CHD during the consultation period as this group has been relatively under-represented in the meetings held by the review to date.

Annex A: Congenital Heart Disease Clinical Reference Group members

National Clinical Director Co-Chair	**Accountable Commissioner**
Graham Stuart	Julia Grace, Leicester
Senate	**Representative**
North East (N1)	John O'Sullivan
Greater Manchester, Lancashire and S Cumbria (N2)	Vaikom Mahadevan
Cheshire and Mersey (N3)	Ram Dhannapuneni
Yorkshire and Humber (N4)	Kate English
West Midlands (M1)	David Barron
East Midlands (M2)	Giles Peek
East of England (M3)	Clive Lewis
London NW (L1)	Duncan Macrae
London NE (L2)	Martin Elliot
London S (L3)	Gurleen Sharland
South West (S1)	Mark Turner
Wessex (S2)	Trevor Richens
Thames Valley (S3)	Satish Adwani
South East Coast (S4)	David Hildick-Smith
Association of Paediatric Anaesthetists of Great Britain and Ireland	Andrew Wolf
British Congenital Cardiac Association	Andy Tometzki
British Cardiovascular Society	Rob Henderson
Royal College of Nursing	Gill Harte
Patient and carer representatives	
Samantha LLoyd	Lois Brown
Michael Cumper	Hazel Greig-Midlane
Suzanne Hutchinson	Jonathan Arnold
Penny Green	Anne Keatley-Clarke

Annex B: Engagement and Advisory Membership Lists

Clinician and Provider Engagement and Advisory Group
Alder Hey Children's NHS Foundation Trust
Barts Health NHS Trust
Basildon & Thurrock University Hospitals NHS Foundation Trust
Belfast Health and Social Care Trust
Birmingham Children's Hospital NHS Foundation Trust
Blackpool Teaching Hospitals NHS Foundation Trust
Brighton and Sussex University Hospitals NHS Trust
Cardiff and Vale University Health Board
Central Manchester University Hospitals NHS Foundation Trust
Great Ormond Street Hospital for Children NHS Foundation Trust
Guy's and St Thomas' NHS Foundation Trust
Hull and East Yorkshire Hospitals NHS Trust
King's College Hospital NHS Foundation Trust
Leeds Teaching Hospitals NHS Trust
Liverpool Heart and Chest Hospital NHS Foundation Trust
Newcastle upon Tyne Hospitals NHS Foundation Trust
NHS Greater Glasgow and Clyde
Nottingham University Hospitals NHS Trust
Oxford University Hospitals NHS Trust
Papworth Hospital NHS Foundation Trust
Plymouth Hospitals NHS Trust
Royal Brompton and Harefield NHS Foundation Trust
Royal Wolverhampton NHS Trust
Sheffield Teaching Hospitals NHS Foundation Trust
St George's Healthcare NHS Trust
University College London Hospitals NHS Foundation Trust
University Hospital of South Manchester NHS Foundation Trust
University Hospital Southampton NHS Foundation Trust

University Hospitals Birmingham NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
University Hospitals of Leicester NHS Trust

Royal Colleges and Societies
Academy of Medical Royal Colleges
Association of Cardiothoracic anaesthetists
British Cardiovascular intervention Society
British Cardiovascular Society
British Congenital Cardiac Association
British Heart Rhythm Society
British Maternal and Fetal Medicine Society
British Psychological Society
Cardiothoracic advisory group
CATS
Extracorporeal life support association (ELSO)
Faculty of Intensive Care Medicine
Fetal Anomaly Screening Programme
PICS (Paediatric intensive care society)
Royal College of Nursing
Royal College of Obstetricians & Gynaecologists
Royal College of Paediatrics and Child Health
Royal College of Surgeons of England
Society for Cardiothoracic Surgery (STCS)

Clinical Reference Groups
Adult Critical Care CRG
Cardiac Surgery CRG
Complex invasive Cardiology CRG
Congenital heart services CRG
Fetal Medicine CRG

Heart and Lung Transplantation CRG
Neonatal critical care CRG
Specialised Maternity Services CRG
Paediatric Intensive Care CRG

Patient and Public Engagement and Advisory Group
Amelia Matters
Antenatal Results and Choices (ARC)
Asthma UK
Ben Williams Trust
BHA *(formerly the Black Health Agency)*
British Cardiac Patients Association
British Heart Foundation
Cardiac Risk in the Young (CRY)
Cardio and Vascular Coalition (CVC)
Cardiomyopathy Association
Children’s Heart Unit Fund
Children's Heart Association
Children's Heart Foundation (CHF)
Children's Heart Support Network
Children's Heart Surgery Fund
Children's Heartbeat Trust
Cystic Fibrosis Trust
Down's Heart Group
Ebsteins Society
Elyon's Heart Foundation (EHF)
Evelina Children’s Heart Organisation (ECHO)
Families of Oceanward
Fragile Hearts
Heart Link
Heart Rhythm UK

Heartline Families
Hearts 4 Teens
Heatlhwatch England
ICD Patient and Family Heart Support Group
Keep the Freeman Children's Heart Unit Open
KEEPTHEBEAT
Lagan's Foundation
Little Hearts Matter
Marfan Trust
Max Appeal !
National Voices
Oxford Heart Valve Bank
Race Equality Foundation
SADS UK Sudden Arrhythmic Death Syndrome
South Asian Health Foundation
South West Children’s Heart Circle
The 22Crew
The Afiya Trust
The Brompton Fountain
The Somerville Foundation
Tiny Tickers
To Transplant and Beyond
Transplant Support Network
UK Health Forum *(formerly National Heart Forum)*
Wessex Children’s Heart Circle
Young at Heart
Young Hearts

Annex C: Council Representatives

Council	Name	Position
Leeds City Council	Cllr Lisa Mulherin	Executive Member for Health & Wellbeing
Leeds City Council	Cllr John Illingworth	Chair of Health Scrutiny at Leeds City Council
Leeds City Council	Steven Courtney	Principal Scrutiny Advisor to the Leeds Health Scrutiny Board
Birmingham City Council	Cllr Susan Barnett	Chair of the Health and Adult Social Care Overview & Scrutiny Committee.
Leicestershire County Council	Cllr Ernie White	Chair of the Health & Wellbeing Board
Leicester City Council	Cllr Michael Cooke	Chair of Health and Wellbeing Scrutiny Commission
Southampton City Council	Cllr Dave Shields	Cabinet member for Health also Chair of the Health & Wellbeing Board
Southampton City Council	Cllr Paul Lewzey	Back bench member of the Health & Wellbeing Board
Southampton City Council	Jessica North	Senior Communications Officer, Public Health
Manchester City Council	Ged Devereux	Senior Strategy Manager, Public Health
Westminster City Council	Mark Ewbank	Scrutiny officer
Oxfordshire County Council	Claire Phillips	Senior Policy and Performance Officer
Cambridgeshire County Council	Jane Belman	Scrutiny and Improvement Officer
Cambridgeshire County Council	Cllr Kevin Reynolds	Member of Adults Wellbeing and Health OSC
Lincolnshire County Council	Cllr Christine Talbot	Chairman Health Scrutiny Committee

Lincolnshire County Council	Simon Evans	Health Scrutiny Committee

Healthwatch Representatives

Council	Name	Position
Manchester	Neil Walbran	Chief Officer
Birmingham	Paul Devlin	Chief Executive Officer
Leeds	Pat Newdall	Healthwatch officer
Leicestershire	Eric Charlesworth	LLR representative on the UHL Board and the East Leicestershire and Rutland Clinical Commissioning Group
Leicester	David Barsby	Policy & Partnership Officer
Liverpool	Edwin Morgan	Chair of Liverpool Healthwatch
Oxfordshire	Larry Sanders	Chairman
Healthwatch	Shona Johnstone	Public Policy and Partnerships Manager