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BOARD PAPER - NHS ENGLAND

Title:
New Congenital Heart Disease Review: Final Report

From:
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Purpose of Paper:
To describe the findings of the New Congenital Heart Disease Review. The review makes recommendations on a model of care, standards and service specifications, earlier diagnosis and better information. In addition this paper makes proposals for the commissioning and implementation of the review's recommendations.

The Board is invited to:

1. **Agree** the proposed model of care, and standards and service specifications

2. **Agree** the proposals for earlier diagnosis and improvements in information

3. **Note** the analysis of the required service capacity, and

4. **Agree** the proposals for commissioning the service and for implementation, including monitoring and management of adherence to the standards.

New Congenital Heart Disease Review: Final Report
NHS England Board – 23 July 2015

Executive summary

At the request of the Secretary of State, NHS England has conducted a review of congenital heart services. This is a small specialty accounting for just over 1% of NHS England's specialised commissioning budget. Already concentrated in a relatively few centres (for children at least), services in England are good and outcomes have improved over the past ten years. They compare well internationally. However, we heard that previous reviews left stakeholders exhausted and frustrated. The failure to implement recommendations created uncertainty within the specialty, damaged relationships between centres, harmed recruitment and retention and reduced the resilience of services. A number of centres could not meet NHS England's service specification for paediatric congenital heart disease (CHD) services, and occasional practice was widespread. The new CHD review was therefore set up in June 2013 to be as transparent and inclusive as possible, particularly in its use of evidence and data, and to engage as widely as possible. **The background to the review is described in paragraphs 1-15.**

From the outset, stakeholders agreed that we should build consensus around a set of standards which describe services of the highest possible quality, recognising that it might subsequently prove necessary to make tough choices when considering how to put them into practice. The proposed standards cover a wider range of subjects than those they replace, and for the first time cover the whole lifetime pathway of care for people with CHD. The production of the standards has been led by clinicians and patient representatives. **The development of the standards is described in paragraphs 16-21**. The standards envisage a three tier model care with clear roles and responsibilities for each tier. Networks will help local services to work closely with specialist centres, to ensure that patients receive the care they need as close to home as possible. **The proposed model of care is described in paragraph 22.** Taken together the standards fulfil the review's first objective: to develop standards to achieve improved outcomes, minimal variation and improved patient experience for people with congenital heart disease. **Selected aspects of the standards are described in paragraphs 23-67.** This section also includes our work on improving early diagnosis which fulfils the review's sixth objective to improve antenatal and neonatal detection rates. **Our proposals for improving early diagnosis are described in paragraphs 47-58.**

We make proposals for a broader range of timely comparative information to drive quality improvement, enable patients to make more informed choices, and to help us to commission services more effectively. This fulfils the review's fifth objective to establish a system for the provision of information about the performance of congenital heart disease services. **Our proposals for improving the available information are described in paragraphs 68-78.**

Our analysis of future demand suggests that we should plan for continued growth in activity with more rapid growth in procedures for adults with CHD than for children and young people. This reflects the success of the current service which has increased life expectancy, and fulfils the review's second objective to analyse the demand for specialist inpatient congenital heart disease care, now and in the future. **Our analysis of activity levels is described in paragraphs 88-93.**

The main recommendations of the review will be accomplished through commissioning. We are working with clinicians and managers from hospitals to design ways of working that will ensure the standards are met. We have set a target go-live date of 1 April 2016 for contracts against the new standards. This work fulfils the review's third and fourth objectives to make recommendations about the function, form and capacity of services and to make recommendations on the commissioning and change management approach. **Our proposals for commissioning and implementation are described in paragraphs 94-118.**

We have considered the deliverability of the proposals. We conclude that the proposals are affordable, that we can be cautiously optimistic that staff with the right skills will be available to deliver the standards, and that major reconfiguration of specialist services, with the associated risk and upheaval, can probably be avoided. Implementation of the proposals will be complex but we believe it is deliverable. **Our assessment of deliverability is described in paragraphs 119 -134.** We now have the opportunity to put in place CHD services that genuinely achieve the highest possible quality, within the available resources.

The Board is asked to:

- **Agree** the proposed model of care and service standards and specifications. NHS England gave an earlier commitment to make this decision at Board level, and in public.
- **Agree** the proposals for earlier diagnosis and improvements in information.
- **Note** the analysis of the required service capacity and
- **Agree** the proposals for commissioning the service and for implementation, including monitoring and management of adherence to the standards.

New Congenital Heart Disease Review: Final Report

NHS England Board, 23 July 2015

PART ONE: The Review and its proposals

Congenital heart disease

1. Congenital heart disease (CHD) affects up to 9 in every 1,000 babies born in the UK. There is evidence that prevalence is higher among Asian communities. Many cases of congenital heart disease are diagnosed by an ultrasound scan in pregnancy. However, it is not always possible to detect congenital heart defects in this way.

2. Treatment for congenital heart disease depends on the particular anomaly that the patient has. Complex disease may affect the person's ability to exercise and may shorten their life span. Most surgery and interventional procedures do not provide a cure, so people with congenital heart disease often need treatment throughout their life and therefore require specialist review during childhood and adulthood. People with complex heart problems can develop further problems over time and need further surgery or intervention. Less severe problems, such as a hole in the heart, may not need treatment, and are sometimes not detected until later in life when treatment may be a single straightforward procedure.

NHS Services

3. Currently the numbers of NHS operations and other interventional procedures for CHD in England are:

   - for children, provided by 10 hospitals performing 3,880 operations and 1,970 interventional catheter procedures
   - for adults, provided by 24 hospitals performing 1010 operations and 1,430 interventional catheter procedures

   The number of children born with CHD is expected to rise, as the birth rate rises. The number of operations and other interventional procedures has been increasing at three to four times the rate of population growth, and this is expected to continue.

4. There is a history of reviews of congenital heart disease services, dating back to the 2001 report of the public inquiry into concerns about the care of children receiving complex cardiac surgery at the Bristol Royal Infirmary between 1984 and 1995. There have been subsequent reviews each making a series of recommendations, but no co-ordinated programme of change, and concerns have remained.

5. The *Safe and Sustainable* review was launched by the Department of Health (DH) in 2008. At the end of that review, in July 2012, a joint committee of Primary Care Trusts (JCPCT) made a series of decisions on the future of children's congenital heart services in England including a decision to reduce the number of centres providing children's heart surgery from ten to seven. This resulted in two separate challenges – a judicial review (JR) of the decision, and referral to the Secretary of State by some of the relevant Health Overview & Scrutiny Committees. The Secretary of State in turn asked the Independent Reconfiguration Panel (IRP) to consider the JCPCT findings. The review's decisions were overturned and the process was halted, and responsibility handed to the newly created NHS England.

6. Since the end of the *Safe and Sustainable* process congenital heart services have remained a topic of considerable public, media and political interest. Several investigations, separate from the review, have also been initiated.

7. This process of repeated reviewing of CHD services without reaching a proper conclusion left many stakeholders demoralised, frustrated, exhausted and angry with some doubting that there was the will to make the necessary changes happen. The failure to implement definitive decisions has created a sense of uncertainty within the specialty and damaged relationships between centres that have felt they had to compete to survive. This in turn has damaged recruitment and retention, particularly of congenital heart surgeons, which in turn has reduced the resilience of patient services.

8. Despite these problems, outcomes have improved significantly since Bristol. The perceived threat posed to individual centres by the *Safe and Sustainable* process led to investment and development in services. A recent review has shown that UK mortality rates are low[1], fell over the 10 years between 2000 and 2010, and compare favourably with current data from other international databases[2]. About 80% of children with congenital heart disease will now survive into adulthood, with the result that for the first time, the number of adults living with CHD is thought to exceed the number of children and young people. This has consequences for the planning of services, which we examine later in this paper.

The new review

9. In July 2013, after discussions with key stakeholders, NHS England established the New Congenital Heart Disease Review, with formal governance provided by a task and finish group chaired by Professor Sir Malcolm Grant, NHS England's Board Chairman[3]. The review faced many challenges, including:

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[1] See Appendix 5 for more information on current outcomes.

[2] Brown KL, Crowe S, Franklin R, et al. Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010. Open Heart 2015;2:e000157.doi:10.1136/openhrt-2014-000157

[3] For a full description of the governance arrangements see the reference pack, available at: https://www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards/user_uploads/reference-pack.pdf

- Overcoming review fatigue and re-energising stakeholders to take part in a new process;
- Addressing the strained, adversarial and competitive element that had come to dominate relationships between centres and their clinicians;
- An excessive focus on surgery in thinking about how to deliver high quality care for patients;
- A suspicion among patient groups that, whatever the official statistics told us, there was something wrong, at least at some of the centres, and that it was only a matter of time before there was 'another Bristol';
- A view among some stakeholders, politicians, hospitals and patient support groups, that the *Safe and Sustainable* process had been biased from the start;
- A need to address the recommendations of the Judicial Review (JR) and Independent Reconfiguration Panel (IRP);
- A number of centres that could not meet the standards set by the *Safe and Sustainable*;
- A number of centres that lacked resilience, so that the loss of a single consultant could call into question that centre's continued viability; and
- Evidence of widespread occasional practice in interventional cardiology for CHD patients and perhaps also in surgery.

10. Against this background, the Board recognised[4] the need to develop a process which was "as transparent and inclusive as it could be, particularly in the use of evidence and data", and the need to engage "as widely as possible, bringing patients, clinicians and their representatives together in the joint pursuit of an effective and equitable solution, in the interests of all service users now and in the future". The new review has made a conscious attempt to gain the participation of all stakeholders in its work, and to design the process and its recommendations together[5]. Significant efforts have also been made to improve communication and transparency[6] and to manage conflicts of interest[7].

11. The Board recognised that as the sole national commissioner of specialised services NHS England had an opportunity not open to its predecessors to drive service improvement - including reduced variation in access and quality - through national standards for a national service, commissioned through a single model. From the outset therefore the review was designed to deliver improvements for patients by commissioning against a new set of service standards.

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[4] 'New review of congenital heart services', NHS England Board paper, July 2013 available at http://www.england.nhs.uk/2013/05/21/board-1805213/

[5] See Appendix 6 for a summary of our engagement with public, patients and their representatives

[6] See http://www.england.nhs.uk/wp-content/uploads/2013/10/chd-prog-brd-agend-pap.pdf for our publication scheme.

[7] See http://www.england.nhs.uk/wp-content/uploads/2014/01/chd15-tfg-agen-0701.pdf for our policy on managing conflicts of interest.

12. The Board also set a wider scope than previous reviews: for the first time, the whole lifetime pathway of care for people with CHD has been considered, rather than just children's services. The review has also paid attention to the whole range of hospital care rather than just surgery. In preparing the standards NHS England and its clinical advisers have used the best evidence available[8]. Few of these standards are informed by direct clinical evidence, but represent the best advice from expert clinicians and patient representatives. To avoid one of the pitfalls of *Safe and Sustainable* we have been very open about the limitations of the evidence base, explaining where we have had to rely on judgement, and what the basis for that judgement is.

13. We commissioned an independent literature review from the University of Sheffield's School of Health and Related Research (ScHARR) which considered the question "What evidence is there for a relationship between organisational features and patient outcomes in congenital heart disease services?". In addition 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. We also benefited from a great deal of expert advice, both from clinicians and from patients and their families. In spring 2015, our Clinical Advisory Panel (CAP), comprising senior national clinicians from a range of specialties, reviewed the evidence that had become available since the consultation on draft standards undertaken in autumn 2014. Commenting on the evidence, CAP chair Professor Sir Michael Rawlins said:

> *"In my experience, the amount of quantitative scientific evidence available to guide us in deciding how best to organise health services is often much less than we would like. In these circumstances we rely heavily on the views of experts, both specialist clinicians and those who are expert because of their experience of using the services in question. The views of experts, while qualitative rather than quantitative, are also valid and an important source of evidence in our deliberations."*

14. In these ways, and in other aspects of the design and execution of the review, NHS England has sought to learn lessons from *Safe and Sustainable* and specifically the recommendations of the IRP. [9]

15. The review was established as a formal programme of work. These arrangements are described in the reference pack[10] produced at the time of the consultation. The principles, aims and objectives of the review are described in Appendix 1. An interim report was presented to the Board of NHS England in July 2014, entitled:

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[8] For a summary of the evidence see Appendix 7

[9] For a paper covering this see: http://www.england.nhs.uk/wp-content/uploads/2014/11/5-chd-34-nchdr-lessons-learnt.pdf

[10] https://www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards/user_uploads/reference-pack.pdf

‘One Year On: progress of the new CHD review’[11].

New standards and specifications

16. Stakeholders told us from the outset that the key to a successful outcome would be to build consensus around a set of standards. They said that the standards should not be “fudged” – i.e. they should objectively describe the optimal model of care, without regard for the current service arrangements. Professor Sir Bruce Keogh, NHS England’s Medical Director, advised that *“The aim of the review is to ensure that services achieve the highest possible quality within the available resources, now and for future generations… the standards [must] set out what is needed to achieve this”.*

17. Taking Sir Bruce’s challenge, the review has aimed to set out standards for services of the highest possible quality. People told us that this was important, even if it later proved necessary to make tough choices, when considering how to put them into practice and what we can afford within the available resources. The process for developing the standards is described in Appendix 2. The standards and associated service specifications describe the way in which CHD services are to be organised and run. They will ensure that all patients have access to high quality care, and minimise unwarranted variation between centres. They cover a wider range of subjects than earlier standards, reflecting the views of patients about what matters to them. The standards will particularly improve patient experience through: higher levels of support from specialist nurses and psychologists; improved communication and improved management of newly diagnosed patients; transition from children’s to adult services; palliative and end-of-life care. These were all issues which our public and patient groups told us were important but had been neglected.

18. Standards have been set for the following:

Section A: The Network Approach
Section B: Staffing and skills
Section C: Facilities
Section D: Interdependencies
Section E: Training and Education
Section F: Organisation, governance and audit
Section G: Research
Section H: Communication with patients
Section I: Transition
Section J: Pregnancy and Contraception

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[11] Available as part of the reference pack, available at: https://www.engage.england.nhs.uk/consultation/congenital-heart-disease-standards/user_uploads/reference-pack.pdf

Section K: Fetal diagnosis
Section L: Palliative Care and Bereavement
Section M: Dentistry

19. Each standard has an associated implementation timeline. This shows the maximum amount of time, from the go-live date, allowed for hospitals to meet the standard. It does not mean they must wait this long before they meet the standard, indeed it will always be preferable to meet the standard sooner. But it does recognise that some standards will be hard for some hospitals to achieve. Neither does it mean that NHS England will not consider whether the standard has been met until this time. On the contrary, NHS England will require hospitals either to show that they meet the required standards at the go-live date or that they have robust plans in place to do so, where necessary supported by appropriate mitigations to deal the shortfall in the interim.

20. Once the standards and specifications have been approved by the Board, they will become part of NHS England's business as usual systems and processes. This means that they will become the responsibility of the Congenital Heart Services (CHS) Clinical Reference Group (CRG), which will be responsible for considering whether any changes are needed in future. In this way the standards can be kept current. The CRG has clinical members from centres across the country, and public and patient representatives.

21. Mechanisms will be put in place to ensure that the standards are met, unlike the previous situation where standards were not effectively implemented, monitored or managed. These mechanisms are described in more detail later in this paper.

A new model of care

22. We are proposing that across the country services should be organised according to a three tier model, with clear roles and responsibilities for each tier. Networks will help local services to work closely with specialist centres, to ensure that patients receive the care they need in a setting with the right skills and facilities, as close to home as possible. The future CHD service must evolve from one that is largely focused on children, to one that sees a growing number of young people and adults with continuing health needs. It will become difficult for the specialist surgical centres alone to manage the demand, so we must develop new ways of working to future-proof the service. With specialist and local cardiology centres meeting national standards, more care can be safely given locally. The three tiers are:

    Specialist Surgical Centres (level 1): Each network will have at least one (often more) Specialist Surgical Centre. All surgery and most cardiological interventions will be undertaken at these level 1 centres. These centres will provide the most highly specialised diagnostics and care.

Specialist Cardiology Centres (level 2): Not all networks will necessarily include level 2 centres, but because of the increasing number of adults living with CHD, Specialist Adult CHD (ACHD) Centres are expected be more common. The need for level 2 centres will be determined by each network taking account of local circumstances, including the opportunity to improve local access, the need for additional capacity, and the availability of appropriately skilled staff.

Local Cardiology Centres (level 3): Local children's cardiology centres will employ a paediatrician with expertise in cardiology (PEC) to provide ongoing monitoring and care, and run outpatient clinics alongside specialists from the Specialist Surgical Centre. This will mean that more care can be given locally, so children and their families will have less need to travel long distances for their ongoing monitoring and care.

Networks

23. We are proposing that all hospitals providing CHD care must work as part of regional, multi-centre networks, bringing together fetal, children's and adult services. Networks would be hosted by one of the surgical centres involved. Individual surgeons will be based at each surgical centre, as now, with arrangements in place for 24/7 cover. Surgeons and interventionists will need to work in teams of at least four. These teams will span multi-centre networks and will be characterised by shared protocols, joint Multi-Disciplinary Teams (MDTs), a shared approach to sub-specialisation, freedom for surgeons to operate at any of the specialist centres in that network, a shared approach to out of hours rotas, mentorship and joint training, mutual cover and joint audit.

24. This approach would, in effect, create larger "virtual" surgical centres, accruing many of the advantages of larger teams, without necessarily requiring reconfigurations. The precise shape of each network will be determined through the commissioning process.

25. Multi-centre networks offer a range of benefits compared with the current "hub and spoke" (sometimes called "Operational Delivery") type networks:

    - Bigger, multi-centre networks will support larger shared surgical and interventional teams, which will give greater resilience and mutual support than isolated smaller centres, and offer an enhanced opportunity to develop sub-specialisation.
    - Networks can more effectively drive improvement through enhanced training and mentorship, sharing learning and skills, quality assurance and audit.
    - A shared network MDT will discuss all patients being considered for rare, complex or innovative procedures, as well as those whose clinical management is controversial, to optimise patient management.

- Isolated and occasional practice will be eliminated.
- Networks have the opportunity to develop innovative approaches to meeting the standards in ways that individual centres might not be able to achieve working alone.

26. Under these arrangements clinicians will need to undertake minimum levels of surgical/interventional activity to maintain their skills. Networks will need to establish systems to ensure that referrals to and between centres are managed in such a way as to ensure that each clinician is able to achieve their numbers, that each patient receives care from a clinician with the appropriate skills and that the flow of patients appropriately matches the capacity of each institution. The standards also require active management of time from MDT decision to treatment, and monitoring and management of short notice cancellations. This is an important new responsibility for networks that will be essential to achieving the standards, and to manage timely patient access to surgery and interventional cardiology.

27. The innovative models of delivery described need to be supported by appropriate commissioning mechanisms, which themselves may need to innovate. The proposed approach to commissioning is discussed in more detail later in this paper.

Eliminating occasional practice

28. Our analysis shows[12] that occasional practice still exists, that is, small volumes of surgery and interventional cardiology being undertaken in institutions that do not offer specialist expertise in this field. This kind of practice is explicitly ruled out by the standards as it is not in the best interests of patients. Networks will work with the relevant local and regional commissioners to identify and tackle occasional practice.

29. One area of concern was the closure of atrial septal defects (ASDs - a type of hole in the heart) in adults outside the proposed specialist surgical centres. We originally proposed that this should be restricted to level 1 specialist surgical centres. However, following discussions with the professional associations it has been agreed that the standards should be revised to allow ASD closure in patients with an adult diagnosis of CHD, with an ASD without complications, to continue at level 2 specialist ACHD centres providing certain conditions are met. This will ensure that this will always be under network-agreed governance arrangements, that all patients will be discussed at a joint MDT meeting, that all procedures are reported to the NICOR congenital audit, and that the interventionists concerned must undertake a minimum volume of procedures in line with the proposed standards.

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[12] A summary of our analytical work may be found at Appendix 8.

Staffing and skills

30. The standards set out our proposals aimed at ensuring that centres providing care for patients with CHD have the right staffing and skills. We set out proposals for minimum staffing and activity levels for surgeons (covered in more detail below), interventional cardiologists and other members of the MDT, specifications for staffing of catheter labs, electrophysiology, imaging and echocardiography, anaesthesia, intensive care and nursing. This includes paediatric, adult, fetal and transition specialist nurses. It also includes psychology and requirements for administrative support, safeguarding leads and named bereavement officers.

31. We describe what needs to be in place to ensure that there is all year round, 24-hour staffing, including on-call arrangements to ensure consistent high quality care.

32. The standards will require that professionals only provide care that they are competent to give, and make clear that they must seek support from a colleague, and/or refer the patient to another centre, if they do not have the necessary skills. We also include a requirement that all centres and networks must work together to develop and support national, regional and local collaborative arrangements.

33. We expect that there will need to be an increase in the number of some staff groups at some centres and across networks to meet the standards. This includes, for example, surgeons, specialist nurses and psychologists. Networks will need to ensure that each centre has the right staffing levels, and the right skill mix at all times.

Surgical caseloads and size of surgical teams

34. The standards require that consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. Networked surgical centres should have four surgeons. A surgeon must be able to reach the patient bedside at the hospital they are providing cover for within 30 minutes of receiving a call that requires their attendance. This will help secure consistently good outcomes; enable surgical teams to adequately cover children’s and adult services (which may be located in different centres); and reduce the risks associated with fatigue. UK surgeons agree that teams of four surgeons are ideal, but the consensus among them is that three rather than four should be the minimum. However, some leading surgeons have argued that four should be the minimum. The IRP made a specific recommendation that teams should be at least four: *‘Patients should receive congenital heart surgery and interventional cardiology from teams with at least four full-time consultant congenital heart surgeons and appropriate numbers of other specialist staff to sustain a comprehensive range of interventions, round the clock care, training and research.*’

35. Congenital cardiac surgeons must work in teams of at least four surgeons, each of whom must be the primary operator in a minimum of 125 congenital heart operations per year. This will enable surgeons to maintain their skills and will ensure the best possible outcomes for patients. All surgeons agree that the number of operations done by each surgeon is more important than the number of surgeons in a team. Surgeons currently carrying out more than 125 operations are therefore reluctant to reduce their individual caseload to facilitate additional surgeon appointments.

36. The combined effect of these requirements means that they cannot be fully met by all centres currently offering these services, because there is insufficient activity at some centres. While activity is expected to increase, this will not completely resolve the problem.

37. We are clear that we would not want to see teams of four or more in a unit too small to provide each surgeon with sufficient activity levels.

38. There is good evidence, from a large number of studies, for a link between centre size and outcomes from studies. Both surgeon numbers and activity levels are a proxy for centre size. There is also good evidence that individual surgeon operating outcomes for complex procedures are linked to the number of procedures undertaken. However, the evidence does not give precise answers to questions about the optimum size of centres or surgeon caseloads.

39. We are working with hospital managers and specialist doctors to explore how these standards can be best met, noting that there may be a number of potential approaches that could be applied to meeting the surgical standards. These different options go beyond a simplistic view that the standards can only be met by every individual unit having more than 500 cases. For example, multi-centre networks would allow the standard requiring larger surgical and interventional teams to be met at a network rather than centre level providing they met the requirement of genuinely working as a single team as characterised by shared protocols, joint MDTs, a shared approach to sub-specialisation, freedom for surgeons to operate without hindrance at any of the specialist centres in that network, a shared approach to out of hours rotas, mentorship and joint training, mutual cover and joint audit. Our discussions with providers are described in more detail later in this paper.

40. Similar standards exist for interventional cardiology services, with similar challenges for implementation which are also part of the discussion with providers.

Interdependencies

41. We are proposing that specialist children’s cardiac services should only be delivered in settings where a wider range of other specialist children’s services are

also present on the same hospital site. This is recognised in the specific requirements in the standards for co-location of paediatric CHD care with paediatric surgery (D6); paediatric renal (D7); and paediatric gastroenterology (D9). Some centres do not currently have paediatric CHD co-located with other tertiary paediatric services.

42. We found no published evidence on the effects of proximity of other services so the proposed standards are based on expert opinion. Our clinical advisers strongly advocated co-location with other paediatric services, though they recognised that not everyone agrees. They considered that while responsiveness was one important factor, it was not the only thing that mattered. Delivering these services effectively requires the input of the wider paediatric multidisciplinary team, and the interaction between these teams on a daily basis, when co-located, is considered to be of significant benefit to patients.

43. Nonetheless some clinicians argue that co-location is not necessary, and/or that the link between paediatric CHD and adult CHD services is more important than the link between paediatric CHD and other specialist paediatric services. Others emphasise the link with transplant services. In their consultation responses, many stakeholders asked us to recognise “triple co-location” (maternity, paediatric CHD and adult CHD) as the gold standard.

44. Our clinical advisors considered that the proposals for co-location bring the standards for CHD services into line with expectations in other specialist children’s services. Historically most specialist services initially developed as adult services, with paediatric services later “bolted-on,” usually on adult sites. Since that time most other specialist paediatric services have moved to a paediatric environment, including liver transplantation; bone marrow transplant; stem cell/cancer therapy; and gastroenterology. This follows the accepted international norm.

45. Our advisers said that in their view it was not safe to care for children with complex conditions and co-morbidities (a high proportion of whom will need input from other specialties) in settings where other paediatric services were not on site. Having all tertiary specialties on one site means neither the child nor the specialist has to travel with the potential compromises involved in the care environment, access to the full team and equipment, timeliness etc.

46. As with the surgical standards, we are working with hospital managers and specialist doctors to explore how these standards can be best met.

Early diagnosis

47. Stakeholders consistently told us that early diagnosis was an important topic even though it is often overshadowed by the debate about surgical centres. Early detection of CHD improves outcomes because it:

- avoids the complications, morbidity and mortality associated with cardiovascular collapse following delayed diagnosis;
- results in fewer emergency transfers at birth;
- improves family experience throughout the pathway; and
- permits choice of birth place optimising postnatal management.

48. Section K of the proposed standards covers fetal diagnosis and aims to increase early diagnosis of CHD by ensuring that national standards are consistently applied and results reported. The standards will help to ensure that patients receive the same high quality fetal anomaly screening wherever they live and will receive the support, care and information they need if an anomaly is suspected. Where there is a concern that a baby in the womb may have anomalies of the heart, a firm diagnosis will be made as quickly as possible and expert advice and support will be made available at this difficult time.

49. While our proposed service standards will be helpful, they cannot address all the factors affecting early diagnosis. Based on further work undertaken by the review, this will also need better data, commissioning assurance, a sonographer workforce and training review, and potentially the introduction of routine pulse oximetry for new-borns.

50. The Fetal Anomaly Screening Programme (FASP) is the responsibility of Public Health England (PHE)[13]. While FASP's 2010 standards have not been fully implemented across England, more demanding screening requirements were introduced in April 2015 - the three vessel trachea (3VT). Prior to this only 7% of hospitals were undertaking and reporting 3VT views, with slightly more undertaking the view but not reporting.

51. Our proposed standards aim to increase early diagnosis of CHD by ensuring that the national standards set by FASP and the British Congenital Cardiac Association (BCCA)[14] are consistently applied and results reported.

52. FASP's current target is that 50% of detectable cardiac anomalies should be detected. While no fully comprehensive dataset exists, the latest figures from NICOR demonstrate a year-on-year improvement in detection across England, reaching 46.9% in 2013/14 but with considerable variation between areas. While there is an argument for the target to be reviewed and a more demanding target set, there is still a need to "level up" by addressing low rates of detection seen in some parts of the country.

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[13] For further information about FASP see: https://www.gov.uk/fetal-anomaly-screening-programme-overview

[14] Fetal Cardiology Standards, BCCA, 2012 available here: http://www.bcs.com/documents/Fetal_Cardiology_Standards_2012_final_version.pdf

53. Work being led by PHE to develop a national registry (the National Congenital Anomaly and Rare Diseases Registration Service - NCARDRS) will improve our understanding of detection rates by giving full national coverage. This is expected to be achieved by April 2016. Once the register is fully operational, plans should be developed to improve fetal detection rates in those parts of the country with the lowest detection rates.

54. There are longstanding issues with sonographer workforce and training. FASP is delivering training to support the introduction of 3VT over the next 18 – 24 months. This is being supported by training from charities. Ideally, no further screening requirements should be released until firm plans for supporting their implementation, including infrastructure and training, have been developed.

55. Health Education England (HEE) is undertaking a full sonographer workforce analysis, and review of education and training requirements. This review should ensure that basic and specialist training are standardised, and that clear requirements are established for sonographers' continuing professional development. NHS England supports HEE's review and will seek advice from HEE on the requirements for competency to be included in future versions of the CHD standards. Ensuring that those undertaking the screening are appropriately trained is made more complex because a range of different professionals can be involved, and because sonography is not a registered profession.

56. The commissioning of antenatal screening could be improved if the quality of antenatal screening for CHD were measured. Once the 3VT training has been completed, the percentage of scans in which the five cardiac views are successfully captured should be routinely measured and monitored. Congenital heart disease networks should include antenatal screening in their audit programmes. PHE's Quality Assurance (QA) teams will in future undertake assurance visits every three years, to audit training and performance. Regional public health commissioners will work with the QA teams to provide oversight, escalate concerns and incentivise performance.

57. CHD screening is already part of the new-born and infant physical examination (NIPE). Many trusts in England have added pulse oximetry readings to the basic NIPE as further screening for CHD. The National Screening Committee (part of PHE) is piloting pulse oximetry testing in a number of trusts. The pilot will report in March 2016 and make recommendations on wider roll-out.

58. A group has been established, chaired by NHS England's accountable commissioner for CHD, and including the relevant stakeholder groups, to plan and co-ordinate these inter-related pieces of work on improving early diagnosis. The group will monitor progress against plan and manage any risks or issues. Within NHS England they will provide regular updates to the Congenital Heart and Complex Obstetrics CRGs.

Optimising outcomes for rare and complex conditions/procedures

59. Our proposals for bigger surgical teams are intended to ensure that, in every team, the skills are available to perform most operations. Rare and complex cases would be managed either by referral to an appropriate specialist or by inviting a specialist to provide support at the patient's usual centre. Bigger surgical teams working across larger networks will ensure that the great majority of cases can be managed by the network team.

60. A shared network MDT will discuss all patients being considered for rare, complex or innovative procedures, as well as those whose clinical management is controversial. This will optimise management of those patients without requiring us to formally identify which centres should undertake each of the rare complex or innovative procedures, which our clinical advisers tell us would lead to the unhelpful emergence of a two-tier service.

61. The standards require that all congenital cardiac surgeons and consultant interventional cardiologists only undertake procedures for which they have appropriate competence. They set out what needs to happen if a situation arises that the team does not have the skills or experience to deal with. In some cases this will mean that support needs to be brought in from within the network or another specialist surgical centre.

62. We expect that within the larger networks we are exploring, it will be possible to put in place formal agreements that allow consultants to move between the centres within that network (there is already experience of this in the arrangements between Oxford and Southampton). Networks will also have an important role in making sure that the introduction of new techniques is managed appropriately.

63. In situations where a doctor needs to work in a hospital other than their own, outside their network and at short notice, the Certificate of Fitness for Honorary Practice[15] agreed between NHS Employers and the Academy of Medical Royal Colleges (AoMRC) provides a means by which consultants can carry out short-term, ad hoc or urgent activity in another organisation, without the need for an honorary contract of employment. This or a parallel process should be used to ensure that there is no administrative obstacle to clinicians operating effectively at different centres.

Better support and communication for patients

64. Section B of the standards outlines the requirements for a number of staffing groups that patients told us are important in providing support and communication

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[15] Available at: http://www.nhsemployers.org/your-workforce/recruit/employment-checks/certificate-of-fitness-for-honorary-practice

to them, including specialist nurses, psychologists and bereavement officers. We expect to see an increased number of these staff across the country so that patients have consistent levels of support wherever they receive their care.

65. The standards on transition, pregnancy and contraception, fetal care and diagnosis all set expectations of a high degree of support and communication. The need for training for staff in this area is recognised in the training and education standards.

66. Responding to concerns expressed by our patient and public stakeholders, section H sets out in detail the requirement to give the information that patients, families and carers need in a form that makes sense, so that they will have a better understanding of CHD, the care provided and what the options are, and are more able to take part in decisions about their care.

67. Section L of the standards sets out the support patients and their families should receive when their disease is not responsive to curative or life-extending treatment, and the support that must be given to bereaved families and carers at the time of death and afterwards. A key element of these standards is the need for better communication and for discussions with patients and their families/carers to be open, honest and accurate.

Better information

68. Working with a wide range of stakeholders we have undertaken an analysis of information needs, and we make detailed recommendations to improve the usefulness of existing information and to extend the range of information available. These are set out in full in Appendix 3.

69. The primary outcome measure used to monitor congenital heart services is 30 day post-operative mortality in paediatric surgery as reported through the National Congenital Heart Disease Audit (NCHDA) run by NICOR. The NCHDA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

70. NICOR compares each paediatric centre’s actual 30 day survival rate with their risk-adjusted prediction. If a centre’s actual survival rates are below their predicted survival rate, to a statistically significant extent, letters are written to the hospitals involved as well as the relevant professional societies. But under the current arrangements commissioners of the service are not routinely informed or involved in responding to any divergence. We do not consider that this process is defined clearly enough or is sufficiently robust. Without a clear process there is a risk that appropriate action is not taken to address concerns over centres’ mortality rates when they are identified. We are recommending that in future the Accountable Commissioner for the congenital heart services CRG and NHS England’s HQIP contract manager (responsible for the relationship with NICOR) are informed. This

will enable appropriate and well established processes for investigation and intervention (such as Quality Surveillance Groups and Risk Summits) to be initiated if appropriate.

71. NICOR does not currently publish a comparable risk-adjusted centre level analysis for adult survival rates, although the data is collected. Data is not available for longer term outcomes, morbidities or patient experience for either children or adults. As survival rates have improved, longer term measures of outcome are now needed. We are recommending improvements in the available mortality information including longer term measures, analysis of adult mortality, mortality information on a wider range of procedures and diagnosis-based mortality information.

72. We noted above that improvements are needed in the information on antenatal diagnosis. We are recommending that this should include monitoring of antenatal diagnosis rates via the National Congenital Anomalies and Rare Diseases Registration Services, and a pilot of a measure to show how many women receive a complete screen.

73. We are also recommending improvements in information on quality of care including metrics to monitor compliance with standards (e.g. waiting times) and other quality metrics (e.g. infections, complaints) including measures of patient experience. The quality dashboard developed by the CHS CRG is an important vehicle for collecting and making available this information. The CHS CRG is establishing an information sub-group to continue reviewing and improving the Quality Dashboard.

74. We found that the timeliness of information could be improved. By the time of its publication, NCHDA data is between 18 and 24 months old, so any concerns revealed cannot be addressed until considerably after the event. We are recommending more timely reporting so that NICOR produce their annual report on paediatric and adult mortality within six months of the end of the year reported. In time this should move to quarterly reporting.

75. To be useful, information must be presented in an accessible manner appropriate for its different audiences. We recommend that NICOR improves the design and publication of audit data, with specific targeted communication for different groups including a system to inform stakeholders when new reports are published. We are also recommending that once the data is reliable, NHS England should make the Quality Dashboard publicly available. We understand that this should be possible within 18 months.

76. Hospitals told us that the work of compiling and submitting information was already significant and that they would not welcome more onerous requirements. Therefore, rather than increasing the amount of data collected, our focus has been

on making better use of the information already being collected. Whilst our recommendations propose some new measures any additional burden on providers should be counterbalanced by no longer needing to submit other information.

77. The availability of a broader range of more timely comparative information has an important role in driving quality improvement. It will enable patients to make more informed choices and to have a better understanding of what they can expect. It will also help us to commission services more effectively.

78. We have worked closely with NICOR in developing our recommendations, and they are broadly supportive of the proposals, which they expect to include in their development plans for discussion with HQIP.

A system designed to be oriented towards improvement

79. The risk that "uncertainty could compromise the safety, quality, resilience and viability of services until the future configuration of the service is established" has been at the top of the review's risk register since its inception.

80. Completing this review and implementing its recommendations will help restore the stability and confidence of the CHD service, which have been affected by a lingering sense of uncertainty and suspicion, impacting recruitment and retention of clinical staff and damaging relationships between centres.

81. That is important, but not by itself sufficient. Enormous amounts of time, money and energy have been devoted to this and previous CHD reviews. Services for congenital heart disease are a small part of NHS England's portfolio of responsibilities, and by most measures are working well. They will not receive this level of attention again in the foreseeable future so it is important that what is proposed now puts the service on a stable footing, with a self-sustaining approach to improvement, in the interests of patients and service users, many of whom will not have been born yet.

82. We have produced a set of standards that respond to the challenge that NHS England set for itself. They describe how to deliver services of the very highest quality. They are what clinicians and patients have told us is best for patients.

83. Service improvements will result both from the wider range of subjects covered by the new standards, and because mechanisms will be put in place to ensure that the standards are met, unlike the present situation where standards have sometimes been disregarded. Our proposed approach to commissioning and implementation is described in part 2 of this paper.

84. The standards will particularly improve patient experience through higher levels of support from specialist nurses and psychologists, improved communication and improved management of newly diagnosed patients, better managed transition from children's to adult services, and a new focus on palliative and end of life care. These were all issues which our public and patient groups told us were important but neglected.

85. Bigger, multi-centre networks will offer a range of advantages, including larger shared surgical and interventional teams, offering greater resilience and mutual support than isolated smaller centres, and offer an enhanced opportunity to manage rare and complex procedures within each network. Networks can more effectively drive improvement through enhanced training and mentorship, sharing learning and skills, quality assurance and audit. A shared network MDT will discuss all patients being considered for rare, complex or innovative procedures, as well as those whose clinical management is controversial. This will optimise management of these patients without formal designation of sub-specialist centres, which our clinical advisers told us would lead to the unhelpful emergence of a two tier service. Taken together with the requirement for all CHD services to be part of networks, this will eliminate isolated and occasional practice.

86. Networks will be supported by an improved range of information. This will help commissioners hold providers to account, and help patients to make informed choices.

87. Taking these things together (standards, multi-centre networks, peer review, performance management by commissioners, and better more timely information) will result in a system oriented towards driving continual improvement without further external intervention.

PART TWO: Commissioning and Implementation

Service Capacity

88. We have undertaken detailed analysis of historic trends in the delivery of CHD services and modelled likely future demand. The number of operations and other interventional procedures has been increasing at greater than the rate of population growth and this is expected to continue. Our analysis suggests that the main factors behind further growth in CHD activity are:

- Population growth (which is a function of birth rate, migration and life expectancy)
- Increasing proportion of patients who are of Asian and Black ethnicity
- Technical and medical advances
- Increased patient longevity and survival

- Increased expectations of treatment (patients) and willingness to provide treatment (clinicians)
- Increased complexity and severity of patients undergoing treatment.

89. Our projections take account of both population growth and the rising number of procedures per head of population. We cannot forecast either of these with 100% accuracy. However, based on the Office of National Statistics (ONS) 2012 principal population projection[16] and existing trends in the number of procedures per head of population, we expect that there will be growth in the number of procedures that need to be commissioned in the next ten years.

90. For surgery, our estimate for growth is 4.9% by 2018/19 (equivalent to 240 more operations pa) and 11.7% (equivalent to 570 more operations pa) by 2023/24, compared with our 2013/14 baseline. For interventional cardiology, our estimate for growth is 11.0% by 2018/19 and 19.6% by 2023/24 (compared with our 2013/14 baseline).

91. Using different population assumptions,[17] by 2023/24 this could range from 3% to 20% for surgery, and from 14% to 26% for interventional cardiology. This illustrates the high degree of uncertainty of population projections and shows that this is a much bigger factor than the uncertainty over trends in the number of procedures per head of population.

92. Our main projections use ONS national forecasts. Using CCG-based forecasts to understand local variation shows that greater than the national average growth can be expected in London (equivalent to 50 more operations p.a. by 2023/24 compared with the estimate from the national projection) and lower than national average growth in the north (equivalent to 40 fewer operations p.a. by 2023/24 compared with the estimate from the national projection). The difference in growth compared to the national projection in the midlands, south and south west is not considered material.

93. Taking all this together, it is clear that future capacity will need to be able to cope with increased demand, but it is not safe to assume that demand will increase at the same rate across the whole of England, nor that growth will necessarily resolve the challenge of meeting the surgical activity standards everywhere.

How will changes in the CHD service be accomplished?

94. NHS England has always intended that the main recommendations of the review would be accomplished through commissioning[18]. We now have a set of standards

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[16] http://www.ons.gov.uk/ons/publications/re-reference-tables.html?newquery=*&newoffset=0&pageSize=25&edition=tcm%3A77-318453

[17] ONS 2012 high and low population projections

[18] Commissioning is the process of planning, agreeing and monitoring services

that describe how to deliver services of the very highest quality and we have started the process of thinking through our commissioning approach. In doing so we recognise that the standards are rightly challenging, and it will be hard for hospitals to meet all of them.

95. In keeping with the approach adopted throughout the review, we are working with managers and clinicians from the hospitals responsible for delivering services, as part of a group focused on implementation. Any trust identified as being active in surgery or interventional cardiology for patients with CHD, no matter how few or what type of cases they performed, has been invited to be part of the group. This helps ensure that potential new providers of specialist CHD services have had an opportunity to be fully part of the process. We are discussing the wider issues of appropriate engagement and advice during the commissioning phase with the review's three existing groups (patient/public; clinical; provider leadership).

96. As part of this, hospitals have been asked to work collaboratively where previously competition has been the norm and relationships have been strained. New ways of working are being considered. This has been demanding and sometimes uncomfortable for all participants, but there is a shared belief that a solution developed collaboratively will be better than one that is imposed or forced through a formal procurement process. This approach allows clinicians and managers who are responsible for delivering the service on a daily basis to take the lead in designing solutions that they believe will work.

97. The group has agreed to pursue a multi-centre network approach as the most likely to maximise achievement of the proposed standards. Initial network groupings have been explored, but the final groupings are not yet settled. The group has been asked to "strain every sinew" to get as close to meeting the standards as they can. There is a collective recognition that the standards cannot be completely met by all of the centres without changing the way they work. We have asked participants to consider how they could best set themselves up to be able to deliver the standards, or failing that to get as close as possible. Where providers believe that they cannot meet a standard, they have been asked to consider what mitigation they would put in place.

98. This will allow NHS England, as the commissioner responsible for CHD services, to make decisions about whether, with the appropriate mitigations, this produces an acceptable solution, in the best interests of patients. Our commissioning decisions will need to take into account and balance all the main factors, including affordability, impact on other services, access, and patient choice, and not treat the standards as though they exist in isolation.

99. We expect that the process will now begin to move from the present informal approach to a formal commissioning process. Within this we expect to seek formal submissions of the proposed service delivery models in October 2015, for NHS

England to review and make a decision whether to continue with the current commissioning approach in November.

100. Key factors that we will consider in our evaluation of those proposals are expected to be:

- Patient driven including choice
- Meeting the standards and specifications
- Network service model and service integration
- Capacity, activity, access
- Affordability
- Staff/workforce.

101. If it becomes clear that the joint work is not progressing at sufficient pace, or if it is clear that it will not be able to deliver a desirable solution, then in the interests of patients, we would expect to move to a procurement-based solution. A number of alternative procurement approaches exist. It is possible that a differentiated solution may emerge if collaborative working is successful in some parts of the country but not in others.

102. We have set a target go-live date of 1 April 2016 for contracts against the new standards. This will clearly be dependent on the outcome of the informal collaborative work. A more detailed commissioning timetable will be developed by the end of October 2015.

103. Contract duration has not yet been set but is likely to be compatible with standard NHS contract terms. However, contracts will also recognise the need for providers to make a considerable investment of time and energy in developing new ways of working, and that the timescale for achieving one of the standards stretches to five years from the date of go-live.

Commissioning local care

104. Working with clinical representatives from level 3 services we have developed standards for local, level 3 services. We expect that proposals for multi-centre networks will include proposed arrangements for all three tiers of the service and that centres at all three levels will have signed up to the plans.

105. In line with our principles for collaborative commissioning we expect that national standards, policies and specifications will be used within locally designed service models and pathways. These services are delivered in local hospitals as part of wider paediatrics and adult cardiology services commissioned by CCGs. We will develop a collaborative commissioning process to support the commissioning of this part of the service, and agree this with the NHS England’s Collaborative Commissioning Programme Oversight Group.

Implementation

106. Once contracts are let, the final phase of the work, implementation and change, will commence. Simply commissioning against the new standards will not be enough, and we will need to work with the new networks to assess the need for change management and project support, and for national clinical leadership.

107. The established governance and engagement arrangements will need to be reviewed and revised, but our early thinking suggests that it would be wise to maintain national oversight of this work alongside NHS England's established regional commissioning arrangements. There will be a continuing need for ongoing patient and public and clinician advice and communications.

108. The degree of commissioner support to the new arrangements will depend on the degree of change that is required to implement the new agreed delivery model.

Monitoring and managing adherence to the standards

109. We heard from patients and their families that while they were supportive of the idea of setting standards, this would only be worthwhile if systems were put in place to ensure that they were met. Without that they considered our efforts would have been wasted.

110. Agreeing and publishing the final standards and making them a contractual requirement through the service specification will be the first step in ensuring that the standards are met. The initial phase of the commissioning process is then expected to include an assessment of each network's adherence to the standards, and to require that networks and their member hospitals have plans in place to achieve the standards according to the timescale set out in the standards and mitigation in the interim. Commissioners will then monitor provider performance using the quality dashboard.

111. Better information will be important in monitoring implementation of the new standards, and in time, supporting patients to make informed choices about the provision of their care. The quality dashboard will bring together a range of measures that allow commissioners to monitor the service provided, and the implementation of the standards. It will also be a key tool to support networks in improving their outcomes. New measures will become available as NICOR takes forward its development programme.

112. One of the main functions of networks is to ensure that standards are consistently met by all member hospitals. The standards also propose a system of inter-unit peer review where each centre will be required to provide evidence to show that it meets the standards. NHS England will look to support this process through its quality surveillance programme.

113. Commissioning, networks, better information about the quality of services, and peer review are the corner stones of our approach to quality improvement and ensuring that the standards are met. The NHS also has systems in place to deal with concerns relating to individual cases or services, and for regulation to address potential and actual quality and service failures.

Accountability and governance

114. We are in transition from a bespoke review, led by the policy team in NHS England's Commissioning Strategy directorate, to specialised commissioning and implementation led by our Commissioning Operations directorate. This is a process that has already begun and will extend over several months rather than an abrupt change on a single day. Nevertheless it is important to identify the point at which accountability transfers from one National Director to another, and it is recommended that this transfer occurs immediately after the board has made its decisions.

115. While a formal transfer of accountability should occur on this date, many of those working on this issue would continue to do so, and changes to governance and engagement structures should be more evolutionary than revolutionary. Board level oversight will pass at this point from the review's Board Task and Finish Group (solely concerned with the CHD review) to the Board's Specialised Commissioning Committee. A new senior responsible officer (SRO) will need to be appointed.

116. The review's Programme Board is expected to continue, but its focus will shift to commissioning and implementation, with membership, terms of reference and lines of reporting appropriately revised to match. The existing CHD Commissioning Group, an internal NHS England group to ensure a coherent commissioning approach, will become a sub-group of the refreshed Programme Board.

117. The programme team supporting the review will remain in place until the end of September. A budget to support a full programme of work is in place for the full financial year. During July and August the new SRO will consider what resources will need to be deployed to deliver the commissioning phase of the work. A formal programme close and handover will be completed by the end of September. This will include a full revision of the programme's risk register to reflect the post-Board environment and the move into the commissioning phase.

118. To date the process has been nationally led and co-ordinated, with regional provider relationship and contract management. It is recommended that this approach be continued throughout the pre-commissioning and commissioning phases to ensure a nationally consistent approach to managing commissioning, and to reduce the risk of challenge arising from regional variation.

Is it affordable?

119. Our financial analysis[19] estimates the current cost of the CHD service to NHS England as £175m pa (based on 2013/14 figures). Activity is projected to increase whether or not the new standards are implemented. As a result, we forecast that – in today's prices - by 2025/26 expenditure on CHD services will be between £186m and £207m depending on activity growth assumptions

120. Therefore an additional £11m to £33m would need to be made available to commission CHD services to meet increased activity levels, based on the current configuration of providers, even if new standards were not introduced.

121. The proposed standards do not propose changing access criteria or treatment protocols. The great majority of proposed standards have no explicit cost, and most of the small number of standards with an explicit cost (e.g. staffing standards) are already present in the current standards against which we already commission. We therefore expect that the affordability challenge for commissioners will be in meeting the costs of overall activity growth. We expect that the additional income providers receive as activity levels increase will cover, on average, the costs of the wholly new aspects of the standards for providers, without the need to change tariff prices.

122. The standards include detailed expected implementation timescales set by the Congenital Heart Services CRG. These recognise that some aspects of implementation cannot be achieved instantly. Timescales range from immediate to five years. As a result any cost impact on providers will be spread over a number of years.

123. The main capital cost is likely to face those providers that do not currently have paediatric cardiac care co-located with other tertiary paediatrics services, though the pressure to deliver specialised paediatric services from a consolidated paediatric environment does not arise only from this specialty.

124. There will be a cost to establishing multi-centre networks, but fewer networks at wider scale may be more cost effective than asking every surgical centre to take on a bigger role through its local hub-and-spoke network arrangements. Pump-priming the set-up of the new networks should be considered as part of the commissioning for the service.

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[19] Available here: http://www.england.nhs.uk/wp-content/uploads/2015/06/chd-finance.pdf

Are the right staff with the right skills available to deliver the standards?

125. In the autumn 2014 consultation some respondents challenged the NHS to address what they saw as a pressing and ongoing need for staff training, which some believe is the only way the proposed workforce requirements could be met.

126. Where standards call for increased numbers of particular professional groups, we have written to the relevant professional societies and colleges to ask them whether there is a pipeline to supply sufficient staff to meet the standards within the timeframe set out. Their replies note that the precise numbers of staff required will only be known once the final configuration of services is decided and a baseline assessment has been conducted. While changes to the configuration of the service are not planned, if this were to result from the introduction of new standards, a joint approach to managing staff affected by change would be sensible and helpful.

127. With this caveat, the non-medical clinical groups are cautiously optimistic that the availability of suitable staff to fill the posts within the timeline envisaged by the standards will not be a limiting factor. The role of hospital trusts in releasing their staff for further training is noted, as is the role of HEE in ensuring that there is an adequate pipeline of people entering each professional group with the necessary basic training.

128. There has been a higher level of consultant movement than usual in the recent past, including overseas. Successfully filling consultant posts (paediatric cardiology, adult CHD and CHD surgical) will in part be dependent on reducing this loss of expertise. The improved certainty and stability that will result from implementation of the standards should support this outcome. While noting that it is impossible to be certain, the Society of Cardiothoracic Surgeons advises that to the best of their ability to predict the potential needs, they believe there will be enough surgeons available to deliver the service to the new standards.

129. The proposed standards outline a number of expectations for ongoing education and training, and describe an infrastructure to support this within networks. A particular issue has been identified for ultra-sonographers affecting both workforce and training. As previously noted HEE is undertaking a sonographer workforce analysis and review of education and training requirements. NHS England will support HEE in its review, and seek advice from HEE on the requirements for competency to be included in future versions of the standards.

Will the configuration of services change?

130. We are not making any proposals for changes to the configuration of specialist providers at this time. The precise configuration of specialist services will be the result of commissioning the CHD service against the proposed new standards and service specifications.

131. Some hospitals are undertaking very low volume practice (both surgery and interventional cardiology procedures in patients with CHD). We intend to work through our regional teams with CCGs and networks to bring an end to this practice, which we do not consider to be in the best interests of patients. Because of the low volumes involved this is unlikely to have a material impact on the organisations concerned.

132. We do not have evidence that outcomes at any particular unit are consistently below what would be expected. Nevertheless the standards have been developed to describe how to organise services to assure excellence, and as the commissioner NHS England must reserve the right not to commission services from a provider that is so significantly at variance from the standards as to cause safety/quality concerns. Such a decision would only be taken following a risk assessment of the costs and benefits of both closure and non-closure.

Deliverability/risks

133. Implementation of the proposals will be complex but we believe it is deliverable. There is evidence to support the view that the proposals are affordable both for NHS England as commissioner and for service providers; that sufficient staff are available; and that major reconfiguration of specialist services can probably be avoided. However, successful implementation will depend on continued collaborative working between NHS England as commissioner and service providers (and a wide range of other partners). It will also be critically dependent on providers making every effort to attain the standards, and to work together, differently from current practice, to mitigate the risk of non-compliance with any of the standards.

134. We have the opportunity to put in place CHD services that genuinely achieve the highest possible quality, within the available resources, now and for future generations, with better outcomes, consistent standards, increased service resilience, better patient experience, better information and improved early diagnosis. Through our commissioning we can secure a truly national service, with providers working collaboratively, with better information at their disposal in a system better able to drive improvement, and without risky isolated and occasional practice. In doing so we would have held true to the review’s guiding principle, that patients must always come first.

PART THREE: RECOMMENDATIONS TO THE BOARD

The board is asked to:

135. **agree** the proposed model of care and service standards and specifications, as described in Part 1 of this paper and set out in Appendix 4. The proposed standards and service specifications fulfil objective 1 of the new CHD review. NHS England gave an earlier commitment to make this decision at Board level, and in public.

136. **agree** the proposals relating earlier diagnosis (paras 47-58) and improvements in information (paras 68-78). These fulfil review objectives 5 and 6.

137. **note** the analysis of the required service capacity (paras 88-93). This fulfils objective 2; and

138. **agree** proposals for commissioning the service and for implementation, as set out in Part 2 of this paper, including monitoring and management of adherence to the standards (paras 94-118). These fulfil objectives 3 and 4.

Appendix 1: Principles, aims and objectives

Principles

In July 2013 the board of NHS England agreed the following principles and approach for the new review[20]:

- **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. Notwithstanding the comment above about "retaining what was good", we must have no preconceived notions about the outcome. Wherever there is an assumption it must be made explicit, and justified.

The aim of the review is to "ensure that CHD services achieve the highest possible quality, within the available resources, now and for future generations:

- to secure the best outcomes for all patients, not just lowest mortality but reduced disability & an improved opportunity for survivors to lead better lives;
- to tackle variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care; and
- to deliver 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".[21]

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[20] 'New review of congenital heart services', NHS England Board paper, July 2013 available at http://www.england.nhs.uk/2013/05/21/board-1805213/

The review set six objectives focussed on the new challenge but mindful of the advice given by the Independent Reconfiguration Panel (IRP) at the end of the Safe and Sustainable review. These were agreed by the board of NHS England in January 2014[22]:

Objective 1: to develop standards to give improved outcomes, minimal variation and improved patient experience for people with congenital heart disease;
Objective 2: to analyse the demand for specialist inpatient congenital heart disease care, now and in the future;
Objective 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;
Objective 4: to make recommendations on the commissioning and change management approach including an assessment of workforce and training needs;
Objective 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
Objective 6: to improve antenatal and neonatal detection rates.

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[21] 'New review of congenital heart services', NHS England Board paper, July 2013 available at http://www.england.nhs.uk/2013/05/21/board-1805213/

[22] http://www.england.nhs.uk/wp-content/uploads/2014/01/item7d-board-0114.pdf

Appendix 2: How the standards were developed

In developing the new standards the review built on the *Safe and Sustainable* paediatric standards and a related set of standards for ACHD services that had been developed in parallel but never ratified. These were refreshed, revised and harmonised. This process involved clinicians from all the specialist centres, working with patient representatives and selected clinicians from tier 2 and tier 3 centres. This addressed criticisms that earlier standards did not adequately cover tier 2 and 3 and that not as much attention was paid to medical practice as to surgery. Concerns raised by patient groups, for example about communication and end of life care, were also addressed.

The standards were then considered and refined by the review's Clinical Advisory Panel (CAP) and by the NHS England Congenital Heart Services Clinical Reference Group (CHS CRG). The CRG advised on the implementation timeline for each standard and revised the service specifications (the basis of NHS England's contracts with hospitals that provide these services) in line with the proposed standard.

The standards, specification and model of care were subject to full formal public consultation over 12 weeks between 15 September and 8 December 2014. A consultation document described the proposals[23] and 12 events were delivered across England and Wales by the review team and by partners with the aim of making people aware of the proposed standards, the questions and how they could respond. The review team met patients, families, staff from centres, clinicians from others services, charities local community groups and politicians.

By consultation close 459 responses had been received from a wide variety of stakeholders, including patients themselves, and from right across the country. The responses varied considerably in detail, subject matter and length of response. The responses were independently analysed by 'Dialogue by Design' a specialist in the field which produced a full report[24] summarising the responses to the consultation.

Views on the standards were broadly positive and many people thought they would promote high quality, accessible, patient-centred care. Some told us that they thought they would be particularly beneficial to adults with CHD as this group was not covered by existing standards. Most people added comments and caveats to their responses whether they were for or against. Not everyone agreed with all the proposals and some opposed them. Many of the concerns refer to the challenges of implementation, particularly adequate funding and staffing or a fear that closure of centres would be the result. Views were mixed on level 2 cardiology centres, and some questioned the need for these in every network or even at all.

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[23] Proposed congenital heart disease standards and service specifications: a consultation, NHS England, 2014

[24] http://www.dialoguebydesign.co.uk/wp-content/uploads/2015/03/NHSEngland_CHD_Consultation_Final_Report_201503021.pdf

Responses relating to particular standards were identified from Dialogue by Design's report and by a separate examination of responses by the programme team. The proposed standards were then annotated with all the related comments, and these were then reviewed by a specially convened group of clinicians and patient representatives (involving the two groups that had worked on the standards revision, the CHS CRG and representatives of other related CRGs and known as the JSCRG). This group considered whether any changes were needed to the proposed standards in light of the comments received. The review's Clinical Advisory Panel undertook a full line by line review of the standards and the JSCRG's recommendations. Both the JSCRG and CAP also made a small number of amendments prompted by their own review of the standards rather than the consultation responses.

Following consultation many minor changes were made to the standards. Some of these improve the drafting or remove ambiguity, others add important detail. Only a very small number of material changes have been recommended. These are[25]:

> ***Standard B9(L1) Paediatric and Adult*** : An extension of the time allowed to achieve a 1 in 4 consultant surgical rota from three to five years, but with an additional requirement to achieve 1 in 3 immediately. This is in recognition of the lead time for recruitment and training of surgeons and will allow time for wider networks to evolve.
>
> ***Standard A7(L2) Adult***: Level 2 ACHD centres will be permitted to continue interventional ASD closure provided all standards met. This change, supported by both the British Cardiovascular Intervention Society (BCIS) and British Congenital Cardiac Association (BCCA) will give better access to this service while ensuring that all those providing it are doing so within the new network arrangements, and that isolated and occasional practice will cease.
>
> ***Standards B28(L1) Paediatric and B31(L1) Paediatric and B30(L1) Adult***: The staffing numbers for specialist nurses and practitioner psychologists have been clarified to ensure both an appropriate level of scalability with population size while avoiding reference to the number of patients under the care of a centre or network, recognising that this is not always known with great accuracy.
>
> ***New standard***: The addition of a standard referencing the requirements for accredited perfusion services at level 1 surgical centres.

Some people were concerned that the standards did not include or give sufficient weight to all of the potential issues of CHD care. These comments were considered by the Clinical Advisory Panel which concluded that these did not require further changes to the standards.

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[25] The standard numbers refer to the numbering at the time of consultation. These have since been subject to revision to accommodate additions and deletions.

- Transplantation: the CHS CRG is examining issues relating to access to transplant services for CHD patients. There is a separate specification for transplant services.

- Learning difficulties: the panel considered that the standards covered the needs of patients with learning disabilities.

- Primary care: the panel considered that the standards were appropriately focussed on hospital care and that information flows with primary care were well covered.

- Paediatric Intensive Care: there is a separate specification for paediatric intensive care. The panel considered that it was sufficient for the standards to reference this.

- Psychological needs of patients and families: the panel considered that the standards gave considerable and appropriate attention to the psychological needs of patients and families, and would greatly enhance the provision of psychological support.

The Clinical Advisory Panel agreed that the standards and specifications, as revised following consultation, could be recommended to the review's Board Task and Finish Group.

The recommended standards and specifications were then subject to NHS England's specialised commissioning assurance process before being put forward for consideration by the Board.

Appendix 3: Better information

1. Background

Throughout the review we have heard that work is needed to develop the information provided to both patients and commissioners about the performance of congenital heart disease services. There are also other stakeholders, such as networks, clinicians and managers, who have a legitimate interest in better information on congenital heart disease services. Clinicians, providers, charities and patient groups have all identified that the data currently available regarding congenital heart disease services is not sufficient and that work is needed to develop the accuracy, reliability and usefulness of information about the performance of congenital heart services.

This issue was raised in the Independent Reconfiguration Panel's review of the Safe and Sustainable review which made two specific recommendations relating to information. These were:

- *NHS England must establish a systematic, transparent, authoritative and continuous stream of data and information about the performance of congenital heart services. These data and information should be available to the public and include performance on service standards, mortality and morbidity; and*

- *NHS England and the relevant professional associations should put in place the means to continuously review the pattern of activity and optimise outcomes for the more rare, innovative and complex procedures.*

Responding to this the review set a specific objective relating to information:

- 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.

The primary outcome measure used to monitor congenital heart services is 30 day post-operative mortality measured over a three year rolling period. This is reported through the National Congenital Heart Disease Audit (NCHDA) run by the National Institute for Cardiovascular Outcomes Research (NICOR) which is responsible for managing six national clinical cardiac audits, commissioned by the Healthcare Quality Improvement Partnership (HQIP) until March 2017 on behalf of NHS England. HQIP is responsible for monitoring the performance of NICOR against the terms of this contract.

HQIP was established in April 2008 to promote quality in healthcare, and in particular to increase the impact that clinical audit has on healthcare quality in England and Wales. HQIP is a charity and company limited by guarantee, led by a consortium comprising the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices. A key element of HQIP's work is the commissioning, management and development of the National Clinical Audit and Patient Outcomes programmes on behalf of NHS England. The NHS England Head of Clinical Programmes is responsible for managing NHS England's relationship with HQIP and monitoring HQIP's performance against the terms of their contract with NHS England.

As survival rates improve there is an increased recognition of the need for other measures of quality and more attention to be given to adult congenital heart services. This report makes recommendations to address this need.

2. Rationale

Improving the information on congenital heart services will deliver three clear benefits:

- It will contribute to quality improvement across congenital heart disease services. Better information would enable providers to effectively benchmark themselves against other services within the UK and identify areas of underperformance within their services. It would also highlight examples of good practice across the UK which will more effectively prompt learning across different centres. In addition, measuring performance can promote a healthy competition which often leads to improvements. For example, since the National Congenital Heart Disease Audit (NCHDA) has been collecting information on the antenatal diagnosis of patients who undergo a procedure for congenital heart disease in the first year of life the detection rate has increased from less than a quarter in 2003 to almost half in 2013.[26] As a result of the work of this review better information will be available on congenital heart services which will contribute to quality improvement across a wider range of services.

- It will enable patients to make better informed choices regarding the services available for people with congenital heart disease. Better information on the outcomes, activity and quality of care will provide patients and their families/carers with greater resources when seeking to make appropriate choices regarding the care they receive. For example, improved reporting on centres' surgical activity for rare, complex and innovative procedures will enable patients to identify centres with more experience of these procedures to inform their choice of surgical centre. Making this information more accessible to patients will also improve the ability of patients to access relevant information, presented in a way which can meaningfully inform their decision making.

- It will enable NHS England to commission services more effectively. Better information will enable commissioners to better assess the quality of the services they are commissioning and identify any particular areas of underperformance where further investigation or remedial action is required. For example, better information on adult mortality will enable commissioners to determine if there are

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[26] https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/Antenatal%20Diagnosis?Opendocument

any centres with concerning mortality rates which require further investigation/action.

3. Approach

This work initially involved wide consultation with patient and public groups, clinicians, commissioners, hospital management, academics and international colleagues to better understand the information which is currently available, the work which is going on to develop information and the information which stakeholders want. From this a gap analysis was prepared which highlighted a significant number of areas of information which could be developed. This work has been described in a previous paper[27].

We prioritised these areas according to their importance to key stakeholders and the short to medium term deliverability of the various metrics. The results of this prioritisation were then tested with a variety of stakeholders including those consulted in the initial gap analysis, the Congenital Heart Disease Clinical Reference Group and our Patient and Public, Clinicians and Provider engagement groups. Once the key areas had been identified we worked to ensure that clear, agreed, action plans were in place for each, with appropriate ownership and governance. The key actions which have been agreed are included in the subsequent sections of this report.

We have given priority to improvements that give greatest benefit and which are also considered to be deliverable within the foreseeable future and resources, informed by our discussions with those responsible for providing the data and reporting information. We were regularly told that rather than increasing the data currently being collected, our focus should be on making better use of the information already being collected, and to ensure that the burden on data providers remains appropriate and should not require them to deploy significant extra resources to implement the changes.

4. Mortality

4.1 Current Provision

Mortality information is of primary concern when assessing the quality of congenital heart services. Whether a person with congenital heart disease is likely to survive a procedure or not is the initial question most patients, families, friends and carers have when faced with the possibility of requiring this service. The NCHDA currently measures survival at 30-days for 56 surgical and transcatheter cardiovascular interventions in children for all centres, undertaking major congenital heart disease procedures in England, Scotland, Wales and Republic of Ireland.

NICOR uses Partial Risk Adjustment in Surgery (PRAiS) software to estimate the risk of death within 30 days of a primary surgical procedure, based on specific procedure, age, weight, recorded diagnoses and comorbidities. The PRAiS model can only be applied to

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[27] Objective 5 – Phase 1 Report, New CHD Review, NHS England, 2015

paediatric cardiac surgery and is only used for aggregate analysis of whole centre performance, not individual procedure outcomes. No risk model can adjust for every factor which may impact the outcome of a procedure and as such there are inherent limitations with using risk models as they will not be able to accurately predict the survival rates associated with some of the more complex, and riskiest, cases. Despite these inherent limitations significant work has been undertaken to review and improve the PRAiS model which has enabled meaningful analysis to be performed on 30 day mortality. The development of PRAiS and improvement in data quality has led to a high level of confidence in the 30 day mortality information produced by NICOR.

An application of PRAiS has also been developed which allows all centres to track near real time 30 day mortality outcomes and identify outlier status on a monthly basis. This information is not validated but centres are required to review this and confirm that these have been reviewed via the Transition dashboard. The Quality Dashboard also requires centres to report on most recent 3 year mortality scores using their in house PRAiS data.

NICOR compares each paediatric centre's actual 30 day survival rate with those predicted by the PRAiS software. Both overall centre survival rates (based on PRAiS) and survival rates for individual procedures (with no other factors taken into account) are reviewed to identify if centres have a statistically significant lower survival rate than that predicted either overall or for specific procedures. This process compares a centres performance against the national average (based on 10 years of UK national audit data) and as such cannot be used to tell us whether UK centres as a whole are performing well.[28] However, the raw mortality information which is also published demonstrates that UK survival rates are comparable with the best survival rates internationally and that they have been improving.

If a centre's actual survival rates are below their predicted survival rate, to a statistically significant extent, letters are written to the hospitals involved as well as the relevant professional societies. Commissioners are not formally informed of this or involved in responding to any divergence.

Annual reports are produced by NICOR which report paediatric 30 day mortality rates for the previous three years (e.g. 2014 report would be for the financial years 2010/11, 11/12 and 12/13). The 2014 report, which included information from 1 April 2010 to 31 March 2013, was not published until 25 September 2014. The most recent report which includes information from 1 April 2011 to 31 March 2014 was published on 3 June 2015. A variety of factors contribute to these delays.

Currently the NCHDA does not include a report on adult 30 day mortality. Unadjusted mortality rates can be reviewed through their website, but no analysis or narrative is provided to help this information be interpreted in a meaningful way. The NCHDA website also reports 30 day mortality rates for each procedure to enable a centre's mortality to be reviewed for specific procedures.

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[28] https://www.ucl.ac.uk/operational-research/AnalysisTools/PRAiS

A different approach has been adopted in the US, reporting on operative mortality over a four year rolling period, the definition of which includes any death, regardless of cause, occurring within 30 days after surgery whether in or out of the hospital and any death later than 30 days but during the same hospitalisation.[29] The US Society of Thoracic Surgeons has also developed a different risk model which allows them to report on centres' operative mortality for all ages and not just for paediatric practice.[30]

NHS England currently publishes individual surgeon mortality outcomes for adult cardiac surgery on NHS Choices; however, individual paediatric cardiac and adult congenital heart disease surgeon mortality outcomes are currently not required. NHS England states that publication of surgeon data means consultants' performance can be compared openly for a given specialty to help spread best practice and identify any issues that need investigating.

The potential for publishing mortality outcomes for individual surgeons within congenital heart disease was an area of much discussion with stakeholders, with a number of concerns being voiced. There was concern that publishing individual surgeon mortality rates could lead to additional stress on surgeons and potential risk-averse behaviour where they would be unwilling to operate on patients with a higher risk of mortality. The focus on the surgeon could also be unhelpful as the care of a patient is the responsibility of a much wider team. It was, however, noted that individual surgical outcomes should be reviewed and discussed within the trust to ensure that any areas of concern are identified and addressed. As a result of this no recommendation to implement surgeon specific mortality information is included in this report.

4.2 Recommendations

Adult Mortality

Although adult mortality is reported by procedure on the NCHDA website no analysis of whole centre adult outcomes is performed due to the lack of an adult congenital heart disease risk model. This increases the risk that centres with concerning mortality rates are not identified and appropriate actions to address this are not taken. Although it is recognised that reporting without a risk model is problematic, the risks associated with not analysing and reporting this information are too great to be ignored. For example, without any analysis of this data there is no guarantee that a significantly lower survival rate within an adult centre would even be noticed. It was confirmed that some analysis of adult mortality should be possible prior to the development of the proposed risk model. For example, it may be possible to use the Society of Thoracic Surgeons - European Association for Cardio-Thoracic Surgery Congenital Heart Surgery Mortality Categories

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[29] http://www.sts.org/quality-research-patient-safety/sts-public-reporting-online/explanation-2014-congenital-risk-model

[30] http://www.sts.org/quality-research-patient-safety/sts-public-reporting-online/explanation-2014-congenital-risk-model

(STAT Mortality Categories) to report on raw mortality information by category.[31] This would be an interim measure designed to provide some information and assurance prior to a more robust way of case mix adjusted reporting on the outcome of adult interventions being developed.

This information will provide patients, commissioners and providers with more meaningful information on the most fundamental quality measure for each specialist centre, the survival rates of those undergoing surgical or transcatheter cardiovascular interventions.

- NICOR to publish a non-risk adjusted report on whole centre adult mortality alongside their paediatric mortality reports.
- NICOR to begin developing case mix adjusted reporting on the outcomes of adult interventions

Process and Guidance

The processes for submitting information to the NCHDA were of significant concern to centres. They stated that more guidance on the role of the audit, the processes for submitting information to it and how the data would be used would be beneficial. Without this there is a risk of errors, omissions or inconsistencies in the data submitted and of becoming overly reliant on the experience and expertise of individuals within the centres. A more uniform and accessible mechanism for submitting the data would also reduce the risk of errors or omissions in data submissions and potentially make the submission of data less burdensome. For example, there have been previous occasions where missing information has led to certain cases not being included in the initial analysis of mortality rates which has significantly skewed the centre’s results. A web based submission process can ensure that data is not submitted without all appropriate information being completed.

‘Alert’ and ‘Alarm’ limits are in place for paediatric mortality to enable users of the information to identify centres where there may be concerns over the mortality. Currently any outliers are responded to using the Department of Health’s guidelines from 2011[32]; however, we do not consider that this process is clearly defined or sufficiently robust. Without this there is a risk that appropriate actions are not taken to address concerns over centres’ mortality rates when they are identified. In the current process the commissioners are not informed of any outliers and there is no clear process as to how NHS England would respond were they informed of any outliers. Ensuring that the Accountable Commissioner for the Congenital Heart Services Clinical Reference Group and NHS England’s HQIP contract manager are informed will enable appropriate

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[31] O'Brien SM, Clarke DR, Jacobs JP, Jacobs ML, et al. An empirically based tool for analyzing mortality associated with congenital heart surgery. J Thorac Cardiovasc Surg. 2009;138:1139-53.
For categories see https://www.documentcloud.org/documents/2084695-congenital-heart-surgery-mortality-categories.html

[32] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213767/dh_123888.pdf

commissioners to be informed within NHS England and allow them to initiate processes such as Quality Surveillance Groups and Risk Summits if appropriate.

- NICOR to implement a web based system for providers to submit their data.
- NICOR to provide written guidance to providers to include information on responsibilities, data submission, reporting and what will happen if alert/warning limits are breached.
- HQIP to update their policy on the detection and management of outliers to include a step to inform the Accountable Commissioner for the Congenital Heart Services Clinical Reference Group (CHS CRG) and the HQIP contract manager of any outliers.
- NHS England to develop a consistent process for responding to any outliers

Communication of Information

The timeliness of reporting NCHDA information on mortality has been a significant issue as it means that patients and commissioners are often presented with information which is between 18 and 24 months old. This means that any potential mortality issues the audit identified are not formally addressed and responded to until significantly later. This could result in poor performance continuing unaddressed for a significant period of time and appropriate lessons not being learned due to the delay between the period in question and any review/analysis of it. We understand that six months is the shortest period of time NICOR could report on the results with the current validation process; however, they are exploring other methods of validation to determine the best way of moving to quarterly reporting. Information reported on a quarterly basis would not be able to receive the current level of full validation through on-site validation visits.

As well as having the appropriate information available in a timely manner it is also critical that it is presented in an accessible manner for patients/public, clinicians, provider management and commissioners to increase the likelihood that appropriate conclusions are reached on the basis of this information and that it prompts appropriate actions and change. NICOR are currently working to produce more targeted communication of the NCHDA information. Part of this work needs to include the development of a communication plan to enable information to be disseminated to key stakeholders and them to be informed of any relevant publications. The Clinical Operational Research Unit are also undertaking a project to develop, test and disseminate online resources which will help mortality information be interpreted more clearly and it is important that this work is reviewed and that appropriate learning is taken from this project.

- NICOR to produce their annual report on paediatric and adult mortality within six months of the end of the year reported
- NICOR to report both paediatric and adult risk adjusted mortality on a quarterly basis

- NICOR to improve the design and publication of audit data, with specific targeted communication for; Patients/Public, Providers (Clinical Teams/Units), Commissioners and Trust Boards. This will also include the establishment of a communication strategy for informing stakeholders when reports have been published.
- The Clinical Operational Research Unit (CORU) to complete its project to develop, test, and disseminate online resources for families affected by congenital heart disease in children, the public and the media to facilitate appropriate interpretation of published mortality data following paediatric cardiac surgery.
- The CHS CRG to review the outcome of the CORU project looking at disseminating online resources to determine if it provides any learning regarding how to better communicate information on congenital heart disease outcomes.

Expanded Mortality Information

30 day mortality is considered to be a good metric for evaluating the outcome of a procedure however, with the improvement in intensive care short term survival is becoming less of an issue. Exclusive use of this measure obscures longer term outcomes for patients. The use of 90 day mortality alongside 30 day mortality will provide better information on the survival rates of patients undergoing surgical or catheter procedures and ensure that any significant variances are identified and reviewed.

As well as improving the use and communication of the information currently reported by the NCHDA there is also the need to ensure that the range of information being reported remains appropriate. Currently the 56 procedures against which mortality is reported cover around three quarters of all procedures undertaken. However, this means that for a quarter of procedures it is not possible for patients or commissioners to identify the specific mortality relating to these procedures overall or at each centre. Due to the bespoke nature of some procedures, as well the small volumes of these which are performed, reporting on mortality in a meaningful way is difficult but expanding the number of procedures reported would provide valuable information for patients preparing to undergo these procedures. As well as informing choice this would also enable patients to have more appropriate expectations of likely outcomes. This would provide valuable information on the mortality rates of different centres for more complex procedures. This would reduce the risk of significant variations between centres failing to be identified and responded to in an appropriate way.

The NCHDA’s current reporting of mortality by procedure is a useful quality measure of centre interventional performance. Reporting mortality by diagnosis would provide useful information for patients who are seeking to better understand their diagnosis and the survival rates associated with this. Mortality by diagnosis would also be a more useful way of reporting on longer term outcomes where these are less closely linked to the procedures and more reflect the life course of patients with the condition and the influence of numerous other factors. With 30 day survival rates continuing to improve, due to medical advances relating to both the surgery and intensive care available, longer term outcomes are becoming an increasingly important measure of quality. Patients, families, carers and friends are not particularly reassured by the thought of someone with congenital heart disease surviving 30 days but instead want to know what the long term prospects for someone with this condition are. 30 day mortality has also proved to be a poor discriminator between centres as the differences in 30 day survival rates are relatively small. Reporting on longer term outcomes will provide increasingly important information for patients, families, friends and carers and reduce the risk that poor long term outcomes are not identified and addressed by centres and commissioners.

The Clinical Operational Research Unit (CORU) have recently completed a project, led by Dr Kate Brown of Great Ormond Street, on infant mortality which highlighted that for a distinct group of patients there is a significant risk of out of hospital mortality within a year of their procedure. There is a risk that these deaths are not being appropriately monitored and reviewed to ensure that appropriate learning is taken from these to improve the long term care of these patients. In addition to this, CORU, are also undertaking a project (also led by Dr Brown) to look at the long term outcomes of two congenital heart disease conditions and develop a methodology for analysing and reporting on these. It is important that the findings of this project are reviewed to ensure that any learning on how to analyse and report on long term outcomes is taken forward in continuing to develop reporting on long term outcomes by diagnosis.

- NICOR to report on 90 day mortality alongside 30 day mortality.
- NICOR to review the 56 procedures against which mortality information is provided to ensure as many as possible are included within this list.
- NICOR to report outcomes by diagnosis as well as procedure.
- The CHS CRG information sub-group to add measures to the dashboard relating to out of hospital mortality for high risk procedures.
- The CHS CRG to review the outcome of the CORU project looking at long term outcomes to determine if it provides any learning regarding how to report on longer term outcomes by diagnosis.

4.3 Summary

The NCHDA has established a process which is now able to produce accurate information on 30 day mortality. However, more work is needed to make better use of the information submitted specifically in the area of adult mortality and the mechanisms used for communicating this information in a timely and meaningful way. There has been a lack of clarity in the appropriate way to respond to any outliers resulting from the reports on 30 day mortality and a failure to effectively consider the role of the commissioner, acting as the patients’ representative, in responding to this. With 30 day survival continuing to improve it is essential that we begin the process of developing a methodology for reporting on longer term outcomes by diagnosis to provide meaningful information to patients, families, friends and carers and a means by which quality measures relating to this can be developed for use by centres and commissioners.

5. Quality of Care

5.1 Current Provision

It is becoming increasingly recognised that the use of one overarching indicator - such as mortality in hospital - to reflect the quality of service of a provider is flawed.[33] This factor along with the improvement of survival rates for people with congenital heart disease has resulted in an increased focus on other measures which provide information on the quality of care people receive.

There are three dimensions to quality, all three of which must be present in order to provide a high quality service:

- clinical effectiveness – high quality care is care which is delivered according to the best evidence as to what is clinically effective in improving an individual's health outcomes;
- safety – high quality care is care which is delivered so as to prevent all avoidable harm and risks to the individual's safety; and
- patient experience – high quality care is care which looks to give the individual as positive an experience of receiving and recovering from the care as possible, including being treated according to what that individual wants or needs, and with compassion, dignity and respect. [34]

NHS England has established two dashboards across congenital heart services:

- **The Transition Dashboard** was developed to enable commissioners to test the current health of congenital heart services by collecting specific information on defined operational delivery aspects of Children's Congenital Heart Services in England. It was developed because it was recognised that the system had been under review for a significant period of time and there were concerns that this uncertainty had resulted in instability and strain on congenital heart services. It was designed to identify any early signs of problems within centres and used longitudinally (to analyse whether a centre was getting better or worse) rather than horizontally (to compare centres with other centres). The information provided by these is submitted to commissioners who use it to inform monthly conversations reviewing congenital heart services in each paediatric specialist centre. The Transition Dashboard was rolled out to all units during the course of 2013/14 and is now fully operational.

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[33] Clinical Services Quality Measures (known as Service Level Markers) Principles for developing composite measures (technical/statistical), NHS England, 2014

[34] http://www.england.nhs.uk/wp-content/uploads/2014/03/quality-surv-grp-effective.pdf

- **The Quality Dashboard** for adult and children's services was developed by the Congenital Heart Services Clinical Reference Group (CHS CRG) for congenital heart services as part of NHS England's strategy to provide better information on all specialised services. The Quality Dashboard is intended to provide both commissioners and the public with a broader range of appropriate information to assess the quality of the services being provided by each unit. This is overseen by the Quality Surveillance Team which commissions the service from Methods. Quality Dashboards are at different levels of development with work still being undertaken to develop a portal for submitting data and accessing the outputs.

Public Health England has established the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) which plans to have national coverage by April 2016. This will include all patients diagnosed with congenital heart disease and may provide a useful way of recording any presenting information on long term quality of care. The NCARDRS will provide important information on congenital anomalies and rare diseases to:

- improve our understanding of congenital anomalies and rare diseases and help research into their prevention, causes and treatment;
- look at numbers and trends - for example to understand any changes or any patterns
- give health professionals information to support and monitor their clinical practice leading to improved care for patients;
- support patients and their carers, through the provision of personalised information relevant to their disease;
- help plan and develop NHS services; and
- monitor and evaluate antenatal screening programmes.[35]

5.2 Recommendations

Morbidities

Currently morbidities and surgical complications are reviewed by centres through their mortality and morbidity meetings but, with the exception of a metric relating to complications of cardiology interventions in the Quality Dashboard, these are not reported on a national level. Further development of the Quality Dashboard is still required as it currently includes a measure for complications relating to cardiology interventions but not for surgical interventions. The CHS CRG information sub-group will develop a meaningful way of reporting surgical complications via the Quality Dashboard. With 30 day mortality measures comparable across units it may be that complications provide useful information for commissioners and patients on the quality of centres. For example, a centre may have the same 30 day mortality rates as another but a much higher rate of complications which make the process less safe and may lead to a poorer quality of life. Reporting on complications also increases the likelihood that centres with higher rates of complications learn from the good practice of those with lower rates.

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[35] https://www.gov.uk/the-national-congenital-anomaly-and-rare-disease-registration-service-ncardrs

The Clinical Operational Research Unit at University College London University, led by Dr Victor Tsang and Dr Kate Brown of Great Ormond Street Hospital, is currently undertaking a study to better understand surgical morbidities entitled 'Complications after heart surgery in children'[36]. The project is funded by the National Institute of Health Research (NIHR) and includes representatives from Great Ormond Street Hospital, Evelina Children's Hospital, Bristol's Royal Hospital for Children, Birmingham Children's Hospital, Glasgow's Royal Hospital for Sick Children, The Children's Heart Federation and University College London. The project is planned to run from 1 January 2014 to 30 June 2017. A list of ten morbidities[37], on which information will be collected and analysed, has been agreed by a panel of clinicians and patient representatives to establish whether or not these provide useful and comparable information. A definitions panel has been put in place to establish sufficiently robust definitions for each morbidity. NICOR began collecting the necessary information for some of these morbidities in April 2015. Upon completion of this project the CHS CRG will review the findings of the project in order to determine whether any of these should be incorporated as metrics to be reported on nationally by either the Quality Dashboard or the NCHDA.

This project is an important step towards consideration of a much wider range of metrics which will produce a fuller understanding of quality of care patients receive. The learning from this project should also be used to inform a decision about whether or not a comparable study for adult morbidities should be undertaken. This study will provide useful evidence regarding which measures provide meaningful information on the quality of care received by patients. Establishing appropriate morbidity measures will reduce the risk of variations in the care patients receive, or areas of poor care, failing to be effectively identified and addressed.

- The Clinical Operational Research Unit (CORU) to complete its project to identify paediatric morbidities which could be reported on and test the quality and usefulness of the metrics identified.
- The CHS CRG to review the outcome of the CORU study on paediatric morbidities to review whether or not any of the morbidities identified should be reported via the Quality Dashboard/NCHDA.
- The CHS CRG information sub-group to develop a method for reporting on surgical complications.
- The CHS CRG to decide whether or not work should be undertaken to identify and test metrics relating to adult morbidities.

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[36] http://www.gosh.nhs.uk/medical-information/clinical-specialties/cardiothoracic-surgery-information-parents-and-visitors/research/complications-after-heart-surgery-children

[37] Acute Neurological Event (ANE); Unplanned cardiac reoperation within 30 days; Problems feeding (excluding NEC); Need for renal replacement therapy (excluding ECLS); Major adverse cardiac events or never events; Extra-coporeal Life Support (ECLS); Necrotising enterocolitis (NEC); Surgical site & bloodstream infections; Chylothorax; and Communication between families and clinical team.

Long term outcomes

The Clinical Operational Research Unit's project looking at long term outcomes does not just look at long term mortality but will also investigate measures relating to longer term outcomes. For example, as the audit collects information on interventions it should be possible to analyse and present information on the prevalence and timings of re-interventions. This information should enable patients to better understand the long term impacts of these specific conditions and reveal variation in long term outcomes including the need for re-interventions.

The National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) is initially focussed on providing better information on the identification and diagnosis of people with congenital anomalies including congenital heart disease. It has been established to ensure the registration of congenital abnormalities and rare diseases across the whole of England. Currently, congenital anomaly registration covers 49% of births in England. However, as the register develops it is possible that it will become a useful tool for presenting information on longer term outcomes by diagnosis. For example, in the future it could be used to record information such as surgical interventions or episodes of care which could provide useful information on the long term outcomes of patients. This would provide patients and commissioners with the ability to review aggregated condition specific information on re-interventions / episodes of care to both inform expectations and identify any variations. The CHS CRG will continue to monitor the development of the registration service to determine whether or not this could provide useful information on long term outcomes in the future. Where useful information is identified they will adopt these into the Quality Dashboard or establish a process for reviewing and analysing the information provided by the NCARDRS.

- The Clinical Operational Research Unit (CORU) to complete its project looking at long term outcomes for two congenital heart conditions.
- The CHS CRG to review the outcome of the CORU project looking at long term outcomes to determine if it provides any learning regarding how to report on longer term outcomes by diagnosis.
- The CHS CRG to monitor the progress of the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) and review whether or not useful information on quality of care is available through the register.

Service Measures

For patients requiring rare, complex or innovative procedures the NCHDA does not report on these specific procedures because the low volumes make any reporting statistically meaningless and have associated information governance problems. This means that patients, families, friends and carers have no information on the centres which perform these procedures. Whilst there is no easy solution to the problems associated with reporting the survival rates for these procedures it should be possible to report the activity of each centre relating to these procedures. This would enable patients, families, friends and carers to understand which centres are performing these procedures and the volumes they are performing. This would reduce the risk of centres undertaking procedures which they do not have sufficient experience of and increase the transparency of the services offered by different centres.

NICOR has also been commissioned to identify a small number of Clinical Service Quality Measures (CSQMs) for congenital heart disease which can be used by commissioners and patients to provide a high level view of areas of concern at any of the specialist centres. CSQMs are designed to provide an at-a-glance indication of how well services are performing. In order to reflect the fact that the delivery or care is a holistic process, it is intended to develop these CSQMs as composite measures. Composite indicators measure multi-dimensional concepts which cannot be captured by a single indicator in order to convey information on overall performance. These indicators will then be published via NHS Choices. This process is in its early stage and being overseen by the Programme Manager - Clinical Services Quality Measures (Karina Gajewska) within NHS England.

- NICOR to report activity for at least 95% of all procedures for both adults and children.
- NICOR to develop Clinical Service Quality Measures (CSQMs) for congenital heart disease as part of NHS England’s Clinical Services Quality Measures Programme.

Dashboards

Information was submitted to Methods for reporting via the Quality Dashboard at the end of 14/15 at which point the New Congenital Heart Disease Review examined an example of the information reported by the dashboard and suggested some changes. Metrics were added to measure compliance with the new standards specifically relating to waiting times. Metrics from the Transition Dashboard that provide useful information on quality (for example number of cases of infections and number of formal complaints) were moved into the Quality Dashboard to enable the Transition Dashboard to cease to operate. This will give a single, authoritative, public domain source of information.

As the range of information available to measure the quality of care provided by specialist congenital heart disease centres grows it will be important that the CHS CRG continues to examine which of these provide useful information for patients, commissioners and providers. The creation of an information sub-group of the CHS CRG will help ensure that appropriate attention is given to the development of this dashboard and to providing increasingly useful quality information.

NHS England intends Quality Dashboards to be publicly available and there is a significant desire among patient and public groups for more information on the quality of congenital heart services to be available to everyone. To date no quality dashboards have been made publicly available; however, making this information available increases the likelihood of the data quality improving and will enable patients and their families, carers and friends to better hold centres to account over the quality of their services and compliance with the new standards. NHS England has recently commissioned the development of a portal which will enable NHS Staff to access the dashboard information and submit data to it. Following this a Quality Surveillance Portal will be established as a public facing portal where dashboard information can be viewed by members of the public. It is envisaged it will be 18 months before this is developed.

- The CHS CRG to adopt the revised Quality Dashboard.
- The CHS CRG to establish an information sub-group to continue reviewing the Quality Dashboard.
- The CHS CRG information sub-group to add measures to the dashboard relating to the adult and paediatric PREMS and surgical complications.
- Centres to submit data for each measure which applies to them.
- NHS England commissioners to cease collecting Transition Dashboard information.
- The CHS CRG to monitor and review the Quality Dashboard reports and take appropriate actions to ensure it is in a position to be made publicly available
- NHS England to make the Quality Dashboard publicly available.

Patient Experience

Metrics which report on patients' experience of care are seen as an important marker of the quality of the service and help to establish that the patient is at the centre not just of the care they receive but of the way the quality of their care is measured. The Quality Dashboard for congenital heart disease includes metrics from the adult PREMS survey developed by the Somerville foundation; however, there is no equivalent survey for paediatric congenital heart disease. The adult survey includes questions for both inpatients and outpatients on a range of experience measures such as communication, information provided, staffing, facilities and admission. The adult survey is currently not operational and would benefit from further testing with patients to ensure that the questions are appropriate and lead to meaningful results.

NHS England's Insight & Feedback Team oversees surveys which are being run within NHS England. Disease specific PREMS are currently only in use for a limited number of conditions, for example cancer. A national children's inpatient and day case survey has been designed, tested and co-ordinated by the Co-ordination Centre for the NHS Patient Survey Programme which is based at Picker Institute Europe and works under contract to the Care Quality Commission.[38] This survey is to be undertaken within Trusts but does not include the facility to analyse the data by disease group. There is no funding within NHS England to develop and run a specific congenital heart disease PREMS survey and any resources required for this would need to be found elsewhere.

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[38] http://www.nhssurveys.org/Filestore/CYP14_Guidance_manual_for_in_house_trusts_V2.pdf

There is a real appetite among patient and public groups involved in congenital heart disease to report on PREMS and therefore the New Congenital Heart Disease Review has begun the process of commissioning the development of paediatric PREMS surveys, validate the existing adult survey, create a web based portal for completing the surveys and provide ongoing analysis to centres of the results of these surveys. The New Congenital Heart Disease Review will provide some initial resource to develop this; however, funding for the ongoing hosting and reporting of the results of the survey will need to be provided by the centres. Once the results of the PREMS surveys are being reported key metrics should be included within the Quality Dashboard. The reporting of PREMS reduces the risk that issues impacting patient experience are not identified and increases the degree to which patients are at the centre of the services delivered.

Patient Reported Outcome Measures (PROMS) assess the quality of care delivered to NHS patients from the patient perspective. Currently NHS England has established PROMS covering four clinical procedures which calculate the health gains after surgical treatment using pre- and post-operative surveys. The four procedures are hip replacements, knee replacements, groin hernia and varicose veins. [39] PROMS could also be used to measure longer term quality of life for patients requiring ongoing care and a Cardiovascular Revascularisation Outcomes Questionnaire has also been piloted by NHS England.

We are not recommending implementation of PROMS for CHD as a priority because the lack of an infrastructure for collecting PROMS makes this impractical and stakeholders consider PREMS a higher priority with a greater chance of successful implementation in the short term. The expansion of patient centred outcome measures (PCOMS) may provide congenital heart disease with an opportunity to collect information on patient outcomes in a different way.[40] The CHS CRG should seek to ensure that appropriate learning is taken from NHS England's current development of PCOMS.

- The New Congenital Heart Disease Review to procure a service to develop paediatric PREMS surveys, validate the existing adult survey, create a web based portal for completing the surveys and provide ongoing analysis to centres of the results of these surveys.

5.3 Summary

There is a growing awareness that measures relating to the quality of care provided by centres are increasingly important as survival rates continue to improve. As patients are living for longer their experience of care and longer term outcomes become important measures of the quality of care provided by different centres. Due to this growing awareness work, such as the morbidities project run by CORU and the development of an adult patient experience survey by the Somerville Foundation, has begun to provide

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[39] http://www.england.nhs.uk/statistics/statistical-work-areas/proms/

[40] http://www.england.nhs.uk/2015/02/11/pcoms-cyp/

better information in this area and it is crucial that the projects undertaken in this area are reviewed to ensure that their findings are appropriately incorporated into future measures.

The Quality Dashboard represents a key tool in NHS England's strategy of providing better information on the quality of specialised services and significant work has been done by the CHS CRG to develop this. The range of metrics included has been revised to better reflect the new standards for congenital heart disease and the requirements of patients, commissioners and providers.

The development of PREMS for both adult and paediatric services will provide useful patient centred information on the services provided and enable any perceived issues to be identified and addressed in a timely manner.

Other quality metrics were considered as part of this review. It was decided that length of stay, whilst relatively easy to collect, would not provide meaningful information on the quality of care received as it is not clear whether a longer or shorter length of stay represented better quality of care. This would be true for PICU/ICU length of stay measures as well and monitoring this may not incentivise centres to act in the best interests of patients should longer PICU/ICU stays provide a better quality of care. Other measures such as neurological development measures whilst offering valuable information were deemed as insufficiently developed and too resource intensive to be feasible at the current time. There is no established method for determining the baseline against which neurological development could be monitored and the range of factors which can influence this make it very difficult to establish causality. Significant research would therefore be required to establish a national metric which could provide meaningful information on this. Further discussion of the quality of care areas which were considered as part of this work can be found in a previous paper.[41]

6. Antenatal Diagnosis

6.1 Current Provision

There are currently two ways in which antenatal diagnosis is reported. The first is through the National Congenital Heart Disease Audit (NCHDA) which reports on the percentage of people who undergo a congenital heart disease surgical or catheter intervention within the first year of life that are diagnosed antenatally. This is reported by the specialist centres as part of their audit return with a Yes/No response required to the question of whether they were diagnosed antenatally. No further information on antenatal diagnosis is collected by the audit, for example there is no information on when it was diagnosed or the accuracy of the diagnosis.

The second way which antenatal diagnosis is reported is through the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS). This was

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[41] Objective 5 – Phase 1 Report, New CHD Review, NHS England, 2015

established by Public Health England in April 2015. This is incorporating the work done by the British Isles Network of Congenital Anomaly Registers (BINOCAR) which recorded antenatal diagnosis information but only covered around half of England. The NCARDRS will have greater coverage of antenatal diagnosis as it will record anyone who is diagnosed with congenital heart disease regardless of whether or not they undergo a surgical or catheter intervention in the first year of life. They will also collect more granular information on the identification and diagnosis, for example more information on the screening which the pregnant woman underwent and the detection rate. The NCARDRS expects to have information on antenatal diagnosis which can be effectively analysed and reported from April 2016.

The NCHDA has developed a proposal to expand its fetal dataset to include more information relating to the antenatal diagnosis (for example reason for referral, any other issues identified etc.) and to cover everyone diagnosed with congenital heart disease regardless of whether or not they undergo a surgical or catheter intervention in the first year of life.

Antenatal diagnosis of congenital heart disease relies on appropriate scans being completed in a timely manner. The ultrasound screening test includes five cardiac views of the heart which increase the likelihood of congenital heart disease being identified antenatally. Public Health England’s Fetal Anomaly Screening Programme (FASP) Standards state that 95% of women should undergo the ultrasound screening test once they have accepted the offer and complete it within the timeframe of 18+0 to 23+0 weeks. Work is underway to determine whether a metric which records the percentage of women who undergo the screening test within the appropriate timeframe is possible.

6.2 Recommendations

Diagnosis Metrics

Neither the National Congenital Heart Disease Audit (NCHDA) or the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) is likely to capture every person with congenital heart disease and it is very difficult to identify the proportion of people with congenital heart disease which are included in any register. Cross checking the NCARDRS information with that collected by the audit may provide some useful indicative information as to the completeness of the register. It can also be used to validate some of the information included within the register. As there are now two organisations collecting this information there is a significant risk of duplication which would be increased were NICOR to expand their current fetal dataset. As such, the first step in this process is for NICOR and the NCARDRS to arrange an appropriate data sharing agreement to ensure that the same information is not being collected by both organisations and that appropriate decisions are made about expanding the current information collected on fetal diagnosis.

The NCARDRS has only recently been created. It has recently undertaken a piece of work for FASP examining four congenital heart disease conditions to identify what this information tells them about antenatal detection rates. As this is a work in progress and is not owned by the NHS the Congenital Heart Services Clinical Reference Group should continue to review the work of the NCARDRS to ensure that it is providing appropriate information and that useful information from the register is being reported, reviewed and considered by stakeholders.

- The National Institute for Cardiovascular Outcomes Research and the National Congenital Anomaly and Rare Disease Registration Service to enter into a data sharing agreement.
- Public Health England to develop a robust method of collecting accurate information on antenatal diagnoses of people with congenital heart disease through NCARDRS.
- Public Health England to analyse the antenatal diagnosis rates of four specific congenital heart conditions through the newly established the National Congenital Anomaly and Rare Disease Registration Service.
- The Congenital Heart Services Clinical Reference Group to review the antenatal diagnosis information provided by the National Congenital Anomaly and Rare Disease Registration Service to determine if this would provide additional information on antenatal diagnosis rates to that currently reported by the NCHDA.

Screening Metrics

One of the objectives of antenatal screening for fetal anomaly is to ensure that all eligible women accepting an offer of screening are actually tested. As such the establishment of a metric which can provide information on the proportion of those women who are offered, and accept, the ultrasound screen that actually undergo the complete scan within the timeframe would be very beneficial. However, there are concerns over the availability of the necessary information and the demands this may place on hospitals and so a pilot has been run to assess the usefulness of the information and enable hospitals to feedback on the process. Following this pilot it is hoped that an appropriate way of collecting and reporting this issue will be found and the KPI added to the service specifications from April 2016. Information on screening coverage is essential in order to identify trends and to monitor the effectiveness of service improvements. This metric if introduced will not provide information on the percentage of all pregnant women who are offered a complete screen or accept a complete screen which would also provide useful information on the number of women with access to an appropriate screen.

An Improving Fetal Detection Implementation Oversight Group has been established with representatives from NHS England, Health Education England, Public Health England, providers and patient and public groups to provide oversight of all the recommendations raised in objective 6 of the review. This group will provide oversight and advice in the establishment of metrics relating to antenatal diagnosis. For example this group will be updated on the results of the FASP pilot on ultrasound screen completion and help ensure that appropriate decisions are made on the basis of this pilot.

- Public Health England's Fetal Anomaly Screening Programme (FASP) to complete a pilot to assess the reliability of information on the proportion of women who have completed the ultrasound screen within the timeframe of 18+0 to 23+0 weeks is possible.
- If the FASP pilot on complete screens is successful Public Health England will include a KPI requiring hospitals to report the proportion of women who have completed the ultrasound screen within the timeframe of 18+0 to 23+0 weeks.
- The NHS England Improving Fetal Detection Implementation Oversight Group will review the work relating to antenatal diagnosis to ensure appropriate metrics are established and reported in an accessible format.

6.3 Summary

Antenatal diagnosis continues to be an area of significant interest to patients, commissioners and providers. Better antenatal diagnosis would improve patient care and the ability of centres to effectively plan the care they provide to babies with congenital heart disease. The establishment of the NCARDRS will help provide better information on antenatal diagnosis rates which will drive up the quality of antenatal diagnosis and help identify areas of concern and of good practice. The key driver of improvement in this area will be the completion of appropriate scans and as such being able to monitor this will reduce the risk that areas of concern are not identified and appropriate actions to address these concerns not being taken. In addition it should increase this likelihood that hospitals improve in this area through healthy competition and enable learning to occur from centres with higher completion rates.

7. Implementation

A key driver of the recommendations raised by the report is the ability to implement the changes and significant work has been undertaken to work with the relevant organisations to ensure that clear plans are in place to deliver these recommendations. The key methods of reporting information on congenital heart disease are the National Congenital Heart Disease Audit (NCHDA) and the Quality Dashboard. Both of these are intended to be publicly available ensuring that information is available to all stakeholders including patients, commissioners and providers.

The following sections document which of these recommendations relate to the NCHDA, which relate to the Quality Dashboard and which relate to projects which could provide valuable learning to help better information on congenital heart disease services in the future. Clear deadlines have been agreed for each recommendation and an owner has been specified to enable ongoing review and oversight of progress against these recommendations. A summary of the responsibilities for overseeing each area is also included to ensure there is clarity over the methodology for gaining assurance and addressing any issues relating to the implementation of the recommendations within this report.

7.1 The National Congenital Heart Disease Audit

The following recommendations are being made to improve the NCHDA. NHS England commission Healthcare Quality Improvement Partnership (HQIP) to commission, manage, support and promote national clinical audit programmes. NHS England's contractual arrangement with HQIP is overseen by the Head of Clinical Programmes (Cathy Hassell) on behalf of NHS England's Medical Director (Sir Bruce Keogh). The National Clinical Director Children, Young People and Transition to Adulthood (Dr Jacqueline Cornish) also sits on HQIP's Clinical Outcome Review Programmes' Independent Advisory Group: Child Health.

HQIP commissions the running of six audits by the National Institute for Cardiovascular Outcomes Research (NICOR) including the National Congenital Heart Disease Audit (NCHDA) and are responsible for monitoring NICOR against the terms of this contract.

NICOR then report the information from each of their audits on their website with each audit having a Steering Committee which oversees the work of this audit. The NCHDA Steering Committee chaired by Dr Rodney Franklin, who also acts as the clinical lead, includes representatives from the Society for Cardiothoracic Surgery (SCTS) and the British Congenital Cardiac Association (BCCA).

We have worked closely with NICOR in developing our recommendations, all of which they support.. They have indicated that the changes proposed can be delivered to the timescales set out.. The recommendations included in this report have been agreed with NICOR and HQIP and will be funded through the current arrangements for the provision of the audit. As the ultimate commissioner of the NCHDA this report represents an opportunity for NHS England to set a direction for the audit both for the short term and the next commissioning cycle. The current contract with NICOR is due to expire in April 2017 and work will begin in September 2015 on the new contract for the National Congenital Heart Disease Audit. This gives NHS England the opportunity to work with HQIP to ensure they commission a service which is able to provide high quality information on congenital heart services to patients and commissioners from the most appropriate organisation. The Head of Clinical Programmes (Cathy Hassell) will work with HQIP to ensure the recommendations of this report are reflected in the new contract for the NCHDA.

There are a number of stakeholders who will play an active role in monitoring the progress of the audit and holding NICOR to account for the actions agreed in this report. Specifically it is expected that the Congenital Heart Services Clinical Reference Group will regularly review the information being provided by the NCHDA against this report and escalate any issues to Dr Jacqueline Cornish and Cathy Hassell if necessary.

Area	Priority	Recommendations	Deadline	Owner
Antenatal Diagnosis	Improved reporting of Antenatal Diagnosis rates across the country	The National Institute for Cardiovascular Outcomes Research and the National Congenital Anomaly and Rare Disease Registration Service to enter into a data sharing agreement.	September 2015	Jess Tudor-Williams (COO - NICOR) Sarah Stevens (Public Health Consultant - NCARDRS)
Mortality	Improved range of reporting	NICOR to publish a non-risk adjusted report on adult mortality alongside their paediatric mortality reports.	January 2016	Rodney Franklin (NCHDA Clinical Lead - NICOR)
Mortality	Improved communication of information	HQIP to update their policy on the detection and management of outliers to include a step to inform NHS England commissioners. NICOR to ensure the Accountable Commissioner for the Congenital Heart Services Clinical Reference Group (CHS CRG) and the HQIP Contract Manager are informed of any outliers.	January 2016	Jane Ingham (CEO - HQIP) Jess Tudor-Williams (COO - NICOR)
Mortality	Improved use of mortality information	NHS England to develop a consistent process for responding to any outliers	January 2016	Julia Grace (Accountable Commissioner - CHS CRG)
Mortality	Improved consistency and ease of data submission	NICOR to provide written guidance to providers to include information on responsibilities, data submission, reporting and what will happen if alert/warning limits are breached.	April 2016	Rodney Franklin (Clinical Lead – NCHDA)

Mortality	Improved range of mortality reporting	NICOR to report on 90 day mortality alongside 30 day mortality	April 2016	Rodney Franklin (NCHDA Clinical Lead - NICOR)
Quality of Care	Improved coverage of activity	NICOR to report activity for at least 95% of all procedures for both adults and children.	April 2016	Rodney Franklin (NCHDA Clinical Lead - NICOR)
Mortality	Improved coverage of mortality	NICOR to review the 56 procedures against which mortality information is provided to ensure as many as possible are included within this list.	April 2016	Rodney Franklin (NCHDA Clinical Lead - NICOR)
Mortality	Improved consistency and ease of data submission	NICOR to implement a web based system for providers to submit their data.	April 2016	Peter Ludman (National Audit Lead - BCIS)
Mortality	Improved range and comparability of reporting	NICOR to begin developing case mix adjusted reporting on the outcomes of adult interventions	April 2016	Ben Bridgewater (National Adult Cardiac Surgery Audit clinical lead - NICOR) The NCHDA Steering Committee
Mortality	Improved communication of information	NICOR to improve the design and publication of audit data, with specific targeted communication for; Patients/Public, Providers (Clinical Teams/Units), Commissioners and Trust Boards. This will also include the establishment of a communication strategy for informing stakeholders when	July 2016	John Deanfield (Director – NICOR), John Parkinson (CEO – NICOR) & Jess Tudor-Williams (COO - NICOR)

		reports have been published.		
Mortality	Improved timeliness of information	NICOR to produce their annual report on paediatric and adult mortality within six months of the end of the year reported	September 2016	John Deanfield (Director – NICOR), John Parkinson (CEO – NICOR) & Jess Tudor-Williams (COO - NICOR)
Quality of Care	Improved communication of information	NICOR to develop Clinical Service Quality Measures (CSQMs) for congenital heart disease as part of NHS England's Clinical Services Quality Measures Programme.	September 2016	Adam Timmis (Chair of MINAP Academic Group – NICOR) & Mark de Belder (New Technologies lead - NICOR) Karina Gajewska (Programme Manager - Clinical Services Quality Measures)
Mortality	Improved timeliness of information	NICOR to report both paediatric and adult risk adjusted mortality on a quarterly basis	April 2017	John Deanfield, John Parkinson & Jess Tudor-Williams (NICOR)
Mortality	Improved usefulness of information	NICOR to report outcomes by diagnosis as well as procedure	April 2017	Rodney Franklin (NCHDA Clinical Lead - NICOR)

7.2 The Quality Dashboard

The following recommendations are being made to improve the congenital heart disease Quality Dashboard. The Congenital Heart Services Clinical Reference Group (CHS CRG) represents a key group in the development of the provision of better information. It consists of representatives from commissioning, providers and patient and public groups and therefore enables a range of stakeholders to contribute to and assess the information it is developing. Oversight of the CHS CRG lies with the Women and Children Programme of Care Board which will ensure that the CHS CRG continues to review and develop the Quality Dashboard in line with this report.

Methods are responsible for collecting and analysing the Quality Dashboard information on behalf of NHS England and their role is overseen by the Quality Surveillance Team. It is the Quality Surveillance Team's responsibility to monitor the performance of Methods and establish the appropriate infrastructure for the collection and reporting of Quality Dashboards for commissioners and the public.

Area	Priority	Recommendations	Deadline	Owner
Quality of Care	Improved range and quality of information	The CHS CRG to establish an information sub-group to continue reviewing the Quality Dashboard.	September 2015	Graham Stuart (Chair of CHS CRG)
Quality of Care	Improved range of reporting	a. The CHS CRG to adopt the revised Quality Dashboard. b. Centres to submit data for each measure relevant to them.	September 2015	a. CHS CRG b. Provider CHD clinical leads
Quality of Care	Avoidance of information duplication	NHS England commissioners to cease collecting Transition Dashboard information	September 2015	Julia Grace (Accountable Commissioner - CHS CRG)
Mortality/Quality of Care	Improved range of information	The CHS CRG information sub-group to add measures to the dashboard relating	December 2015 Surgical Complications	Chair of the Information Sub Group for the CHS CRG

		to the following areas: - Adult and paediatric PREMS - Out of Hospital Mortality for high risk procedures - Surgical complication	– December 2017	
Quality of Care	Improved communication of information on centre performance	The CHS CRG to monitor and review the Quality Dashboard reports and take appropriate actions to ensure it is in a position to be made publicly available.	September 2016	Chair of the Information Sub Group for the CHS CRG
Quality of Care	Improved communication of information on centre performance	NHS England to make the Quality Dashboard publicly available	January 2017	Sally Edwards (Head of Quality Surveillance Team – NHS England)
Antenatal Diagnosis	Improved range of reporting	The CHS CRG to review the antenatal diagnosis information provided by the National Congenital Anomaly and Rare Disease Registration Service to determine if this would provide additional information on antenatal diagnosis rates to that currently reported by the NCHDA.	September 2017	Chair of the Information Sub Group for the CHS CRG

7.3 Longer term development

Throughout our work we were made aware of a number of areas of information which would provide useful information but where significant additional work was required. We have attempted to gain an understanding of any work currently being undertaken in these areas and, where appropriate, to instigate or support the development of information in these areas. Many of these areas will require significant work prior to useful information being available to patients and commissioners.

Many of these projects have their own governance and oversight structures however, in order to ensure the learning from these is appropriately considered the CHS CRG will continue to monitor the outputs as part of their role to develop the Quality Dashboard. The NHS England Improving Fetal Detection Implementation Oversight Group will provide more operational oversight for those areas relating to antenatal diagnosis and the Information Sub Group of the CHS CRG will be able to engage with many of these other projects prior to any review by the CHS CRG as a whole. Oversight of the CHS CRG lies with the Women and Children Programme of Care Board which ensure that the CHS CRG continues to review and develop the Quality Dashboard in line with this report.

Area	Priority	Actions	Deadline	Owner
Antenatal Diagnosis	Improved range of information	Public Health England's Fetal Anomaly Screening Programme (FASP) to complete a pilot to assess whether or not reliable information on the proportion of women who have completed the ultrasound screen within the timeframe of 18+0 to 23+0 weeks is possible.	September 2015	Annette McHugh (Programme Manager NHS FASP)
Quality of Care	Improved range, quality and accessibility of information	The New Congenital Heart Disease Review to procure a service to develop paediatric PREMS surveys, validate the existing adult survey, create a web based portal for completing the surveys and provide ongoing analysis to centres of the	December 2015	Michael Wilson (Programme Director – New Congenital Heart Disease Review)

		results of these surveys.		
Antenatal Diagnosis	Improved range, quality and accessibility of information	Public Health England to develop a robust method of collecting accurate information on antenatal diagnoses of people with congenital heart disease	April 2016	Sarah Stevens (Public Health Consultant - NCARDRS)
Antenatal Diagnosis	Improved range of information	If the FASP pilot on complete screens is successful Public Health England will include a KPI requiring hospitals to report the proportion of women who have completed the ultrasound screen within the timeframe of 18+0 to 23+0 weeks.	April 2016	Annette McHugh (Programme Manager NHS FASP)
Antenatal Diagnosis	Improved range of information	The NHS England Improving Fetal Detection Implementation Oversight Group will review the work relating to antenatal diagnosis to ensure appropriate metrics are established and reported in an accessible format.	April 2016	Julia Grace (Chair of Detection Implementation Oversight Group)
Quality of Care	Improved range, quality and accessibility of information	The CHS CRG to monitor the progress of the NCARDRS and review whether or not useful information on quality of care is available through the register.	July 2016	Chair of the Information Sub Group for the CHS CRG
Mortality	Improved accessibility of information	Clinical Operational Research Unit to complete its project to develop, test, and disseminate online resources for families	July 2016	Christina Pagel (Lecturer in Operational Research - CORU)

		affected by congenital heart disease in children, the public and the media to facilitate appropriate interpretation of published mortality data following paediatric cardiac surgery.		
Mortality	Improved accessibility of information	The CHS CRG to review the outcome of the CORU project looking at disseminating online resources to determine if it provides any learning regarding how to better communicate information on congenital heart disease outcomes.	July 2016	Chair of the Information Sub Group for the CHS CRG
Mortality/Quality of Care	Improved range of information	The Clinical Operational Research Unit (CORU) to complete its project investigating long term outcomes for two congenital heart conditions.	July 2016	Martin Utley (Director of CORU) Kate Brown (GOSH) GOSH/CORU research team
Mortality/Quality of Care	Improved range of information	The CHS CRG to review the outcome of the CORU project investigating long term outcomes to determine if it provides any learning regarding how to report on longer term outcomes by diagnosis	July 2016	Chair of the Information Sub Group for the CHS CRG
Antenatal Diagnosis	Improved quality of information	Public Health England to analyse the antenatal diagnosis rates of four specific congenital heart conditions through the newly established the National Congenital Anomaly and Rare Disease Registration	April 2017	Annette McHugh (Programme Manager NHS FASP)

		Service		
Quality of Care	Improved range of information	The Clinical Operational Research Unit (CORU) to complete its project to identify paediatric morbidities which could be reported on and test the quality and usefulness of the metrics identified.	September 2017	Martin Utley (Director of CORU) Victor Tsang and Kate Brown (GOSH) GOSH/CORU research team Rodney Franklin (NCHDA Clinical Lead - NICOR)
Quality of Care	Improved range of information	The CHS CRG to review the outcome of the CORU study on paediatric morbidities to review whether or not any of the morbidities identified should be reported via the Quality Dashboard/NCHDA.	September 2017	Chair of the Information Sub Group for the CHS CRG
Quality of Care	Improved range of information	The CHS CRG to decide whether or not work should be undertaken to identify and test metrics relating to adult morbidities.	September 2017	Chair of the Information Sub Group for the CHS CRG

8. Conclusion

The lack of reliable information or appropriate infrastructure for many areas of information makes the challenge of providing better information a significant one. With a lack of additional resource to devote to this the challenge is largely to make better use of the information which is currently being collected or use current infrastructures and processes to collect additional information in a non-labour intensive manner. This report includes a large number of recommendations which can be implemented without significant additional resource and will make a meaningful difference to the ability of NHS England to commission effectively, providers to review the quality of their services and patients, families, friends and carers to make more informed choices regarding their care.

Many of the principles and much of the learning from this paper can be applied to other specialised services within the NHS. Many national audits have not put sufficient energy into ensuring that the information they provide is timely and accessible to patients as well as clinicians/commissioners. There needs to be an increased focus on making better use of the information currently collected within national audits and ensuring that they are clearly patient facing. It is also apparent that through consultation with the users of information and the specialist centres it is possible to establish sources of information which can be of real benefit to patients, commissioners and providers and do not result in onerous data submission requirements for centres.

With a growing emphasis on patient reported metrics - PROMS, PREMS and PCOMS - there is a real need for an established infrastructure for collecting, analysing and reporting information provided by these sources. Without this, establishing robust patient reported measures is likely to only be done on an ad hoc basis and in a resource intensive way.

The recommendations included in this Appendix on better information will help improve outcomes as better information on these areas drives improvement. It will enable variation to be identified and addressed leading to consistently high quality services across the country and it will place patient experience at the heart of the services delivered by establishing key patient experience metrics for the service. This will provide patients and their families with more appropriate and useful information about congenital heart services across England.

Appendix 4: Proposed standards and service specifications

	Paediatric	Implementation timeline
	Specialist Children's Surgical Centres	
A1(L1)	Each Congenital Heart Network will be hosted by an agreed lead provider. The network's host organisation will provide appropriate managerial and administrative support for the effective operation of the network, and ensure that appropriate management and administrative support is provided by all organisations throughout the network. Each network should develop a business plan	Within 6 months
A2(L1)	Each Congenital Heart Network and NHS commissioners will establish a model of care that delivers all aspects of the care and treatment of children and young people with congenital heart disease. The model of care will ensure that all congenital cardiac care including investigation, cardiology and surgery, is carried out only by congenital cardiac specialists (including paediatricians with expertise in congenital (BCCA definition)). The model of care will also ensure that as much care and treatment will be provided as close as possible to home and that travel to the Specialist Children's Surgical Centre only occurs when essential, while ensuring timely access for interventional procedures and the best possible outcomes.	Within 6 months
A3(L1)	Congenital Heart Networks are responsible for the care of patients with CHD across their whole lifetime including prenatal diagnosis, maternity, obstetric and neonatal services, children's services, transition, adult congenital cardiac services and palliative care. Each network must contain at least one Specialist Children's Surgical Centre. Congenital Heart Networks should work closely with other relevant networks including networks for fetal services, maternity services, neonatal services and intensive care services to ensure a joined-up approach with treatment continuity.	Within 6 months
A4(L1)	Specialist Children's Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care;	Immediate

	Paediatric	Implementation timeline
	b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how congenital cardiac surgeons, paediatric cardiologists and paediatricians with expertise in cardiology (PECs) will work across the network, including at the Specialist Children's Surgical Centre, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, according to local circumstances; and f. address how Specialist Children's Surgical Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions.	
A5(L1)	There must be an appropriate mechanism for arranging retrieval and timely repatriation of patients which takes into account the following: a. Clinical transfers must be arranged in a timely manner according to patient need. b. Critically ill children must be transferred/retrieved in accordance with the standards set out within the designation standards for Paediatric Intensive Care services. c. Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care.	Immediate
A6(L1)	There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.	Immediate
A7(L1)	All children and young people transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist Children's Surgical Centres,	Within six months

	Paediatric	Implementation timeline
	representatives of the Congenital Heart Networks and commissioners.	
A8(L1)	Congenital Heart Networks will develop and implement a nationally consistent system of 'patient-held records'.	Within 3 years
	Cardiological Interventions	
A9(L1)	Specialist Children's Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. require all paediatric cardiac surgery, planned therapeutic interventions and diagnostic catheter procedures to take place within a Specialist Children's Surgical Centre; b. allow neonates with *patent ductus arteriosus* to receive surgical ligation in the referring neonatal intensive care unit (level 3)[42] provided that the visiting surgical team is dispatched from a designated Specialist Children's Surgical Centre and is suitably equipped in terms of staff and equipment (this is the sole exception to the requirement that heart surgery must be performed in a designated Specialist Children's Surgical Centre). It will be for each Congenital Heart Network to determine whether this arrangement is optimal (rather than transferring the neonate to the Specialist Children's Surgical Centre) according to local circumstances, including a consideration of clinical governance and local transport issues; c. ensure that emergency balloon atrial septostomy and temporary pacing, if undertaken outside of a Specialist Children's Surgical Centre, can be safely conducted if clinically indicated. Networks will develop clear guidelines that govern this process; d. ensure that patients requiring electrophysiology must be treated in dedicated paediatric services, with paediatric cardiac	Within 3 years

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[42] Neonatal intensive care units (NICUs) are sited alongside specialist obstetric and fetal-maternal medicine services, and provide the whole range of medical neonatal care for their local population, along with additional care for babies and their families referred from the neonatal network. Many NICUs in England are co-located with neonatal surgery services and other specialised services. Medical staff in a NICU should have no clinical responsibilities outside the neonatal and maternity services. A minimum of a 1:1 qualified nurse staff to-baby ratio is provided at all times (some babies may require a higher staff-to-baby ratio for a period of time): Toolkit for High Quality Neonatal Services; DH 2009

	Paediatric	Implementation timeline
	surgical support not adult services; and e. enable access to hybrid procedures (those involving both surgeons and interventional cardiologists) in an appropriate facility either in the Specialist Children's Surgical Centre or in another Specialist Children's Surgical Centre, if the need arises.	
	Non-Cardiac Surgery	
A10(L1)	Each Congenital Heart Network will agree clinical protocols and pathways to care that will ensure 24/7 availability of specialist advice including pre-operative risk assessment by a Congenital Heart team, including paediatric cardiologists and paediatric anaesthetists, for patients requiring anaesthesia for non-cardiac surgery or other investigations, the most appropriate location for that surgery or investigation, and advice to paediatricians across the Congenital Heart Network.	Immediate
	External Relationships	
A11(L1)	Each Specialist Children's Surgical Centre must have a close network relationship with all maternity and fetal medicine services and neonatal services including neonatal transport services, within their network and be able to demonstrate the operation of joint protocols.	Immediate
A12(L1)	Each Specialist Children's Surgical Centre must have a close network relationship with any ACHD providers within their Congenital Heart Network and be able to demonstrate the operation of joint transition protocols.	Immediate
A13(L1)	Each Congenital Heart Network must contain at least one Specialist Children's Surgical Centre in a formal network relationship with the Specialist ACHD surgical service, Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, evidenced by agreed joint referral and care protocols. Each Specialist Children's Surgical Centre must have a formal network relationship with the following, evidenced by agreed joint referral and care protocols: a. the paediatric cardiothoracic transplant centres;	Immediate

	Paediatric	Implementation timeline
	b. the national Pulmonary Hypertension Service; and c. a paediatric cardiac pathologist with expertise in congenital cardiac abnormalities.	
A14(L1)	Children and young people 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 referring specialist is responsible for explaining to the patient and their family the transplant pathway and the risks and benefits of referral and any alternative pathways to inform patient choice. The designated transplant centre is responsible for managing and developing referral, care, treatment and transfer pathways, policies, protocols, and procedures in respect of transplant patients.	Immediate
A15(L1)	Each Specialist Children's Surgical Centre must have a close relationship with all community paediatric services in their network, to ensure the provision of a full range of community paediatric support services particularly for children and young people with complex medical and social needs.	Immediate
	Telemedicine and IT	
A16(L1)	Each Congenital Heart Network will have telemedicine facilities as required to link designated hospitals in the network (Specialist Surgical Centres, Specialist Cardiology Centres and Local Cardiology Centres, according to local circumstances) and with other Congenital Heart Networks. The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals;	Within 3 years

	Paediatric	Implementation timeline
	d. allow timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various paediatric cardiac services; and e. support video-conferencing (eg. Skype) for outpatient consultations from home when appropriate.	
A17(L1)	Each congenital heart network must make arrangements for CHD clinicians and paediatricians (inc. PECs) within the network to be able to access patient records and imaging systems in all Specialist Surgical Centres and Specialist Cardiology Centres in the network.	3 years
	Multidisciplinary Team (MDT)	
A18(L1)	Each Specialist Children's Surgical Centre will have a dedicated specialist multidisciplinary team (MDT) that meets weekly to consider case management. Patients undergoing complex interventions or any surgical interventions must be discussed in an appropriate MDT meeting as defined by the network. All rare, complex and innovative procedures and all cases where the treatment plan is unclear or controversial will be discussed at the network MDT. The attendance and activities of the MDT meeting will be maintained in a register.	Immediate
A19(L1)	Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A20(L1)	The composition of the MDT will 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). An out-of-hours MDT meeting for emergency decision-making will include as a minimum a congenital heart surgeon, a paediatric cardiologist and a paediatric intensivist.	Immediate
A21(L1)	Each Congenital Heart Network will hold regular meetings of the wider clinical team for issues such as agreement of protocols,	Immediate

	Paediatric	Implementation timeline
	review of audit data and monitoring of performance. Meetings will be held at least every six months. Network patient representatives will be invited to participate in these meetings.	
	Network Leadership	
A22(L1)	Each Congenital Heart Network will have a formally appointed Network Clinical Director with responsibility for the network's service overall, who will be supported by clinical leads for surgery, cardiac intervention, fetal cardiology, neonatal, paediatric, adolescent and adult congenital heart disease and anaesthesia. The Network Clinical Director will provide clinical leadership across the network and will be appointed from the network.	Within 6 months
A23(L1)	Each Congenital Heart Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.	Within 6 months
A24(L1)	Each Congenital Heart Network will have a formally appointed Network Manager responsible for the management of the network, and the conduct of network business.	Within 6 months

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
A1(L2)	To ensure that children and young people receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Specialist Children's Cardiology Centres where appropriate.	Within 6 months
A2(L2)	Each Specialist Children's Cardiology Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L2)	Each Specialist Children's Cardiology Centre will adhere to their Congenital Heart Network's clinical protocols and pathways to care for: a. Prenatally diagnosed congenital heart defects If prenatal diagnosis of congenital heart defects has been made or is suspected the mother will be referred to the network fetal cardiac service. Counselling will take place including discussion about the location of the delivery of the baby. b. New-borns with a murmur and otherwise clinically well c. Neonates and infants diagnosed with congenital heart defects Each Specialist Children's Cardiology Centre will provide close monitoring for the development of heart failure, cyanosis or arrhythmias, and their initial management by medical treatment, if appropriate. d. New referrals from GPs and paediatricians Local hospitals will refer children/young people to a Specialist Children's Cardiology Centre/Local Children's Cardiology Centre, as necessary, for the following categories of referrals: • Murmurs • Cyanosis • Chest pain • Palpitations • Syncope or dizziness • Screening because of family history of congenital heart defect, cardiomyopathy or other syndromes • Kawasaki disease e. Ongoing care of children and young people diagnosed with congenital heart defects Local hospitals will refer children/young people to the Specialist Children's Cardiology Centre or Local Children's Cardiology Centre	Within 6 months

	Paediatric	Implementation timescale
	as appropriate, for close monitoring for the development of heart failure or cyanosis, depending on the underlying heart defect, for the monitoring and treatment and control of arrhythmias, and for the adjustment of various cardiac drugs.	
A4(L2)	Specialist Children's Cardiology Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the delivery of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how congenital cardiac surgeons, paediatric cardiologists and paediatricians with expertise in cardiology (PECs) will work across the network, including at the Specialist Children's Surgical Centres, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres according to local circumstances; f. address how Specialist Children's Cardiology Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and g. provide 24/7 cover by consultant paediatric cardiologists for specialist advice.	Immediate
A5(L2)	There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.	Within 6 months
A6(L2)	All children and young people transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will comply with a standard national template developed and agreed by Specialist Children's Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Immediate
	Cardiological Interventions	
A7(L2)	Specialist Children's Cardiology Centres will adhere to their Congenital Heart Network's clinical protocols and pathways of care that will: a. require all paediatric cardiac surgery, planned therapeutic interventions and diagnostic catheter procedures to take place within a	Within 6 months

	Paediatric	Implementation timescale
	Specialist Children's Surgical Centre; and b. ensure that emergency balloon atrial septostomy and emergency temporary pacing, if undertaken in a Specialist Children's Cardiology Centre can be safely conducted if clinically indicated. Networks will develop clear guidelines that govern this process.	
	Non-Cardiac Surgery	
A8(L2)	Specialist Children's Cardiology Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of a pre-operative risk assessment by a Congenital Heart team including paediatric cardiologists and paediatric anaesthetists, for patients requiring anaesthesia for non-cardiac surgery or other investigations, and other specialist advice, including a decision on the most appropriate location for that surgery or investigation.	Immediate
	External Relationships	
A9(L2)	Each Specialist Children's Cardiology Centre must have a close network relationship with all maternity and fetal medicine services, neonatal services including neonatal transport services, within their network and be able to demonstrate the operation of joint protocols.	Immediate
A10(L2)	Each Specialist Children's Cardiology Centre must have a close network relationship with any ACHD providers within their congenital heart network and be able to demonstrate the operation of joint transition protocols.	Immediate
A11(L2)	Each Specialist Children's Cardiology Centre must demonstrate formal working relationships with: a. network Specialist Children's Surgical Centres and Local Children's Cardiology Centres, according to local circumstances; b. the paediatric cardiothoracic transplant centres; c. the national Pulmonary Hypertension Service; and d. a paediatric cardiac pathologist with expertise in congenital cardiac abnormalities.	Within 6 months
A12(L2)	Each Specialist Children's Surgical Centre must have a close relationship with all community paediatric services in their network, to ensure the provision of a full range of community paediatric support services particularly for children and young people with complex medical and social needs.	Immediate
	Telemedicine and IT	

	Paediatric	Implementation timescale
A13(L2)	Each Congenital Heart Network will have telemedicine facilities as required to link with designated hospitals in the network (Specialist Surgical Centres and Local Cardiology Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various paediatric services. e. support video-conferencing (eg. Skype) for outpatient consultations from home when appropriate.	Within 3 years
A14(L2)	Each Specialist Children's Cardiology Centre must cooperate to allow specialist consultants doing outreach clinics and MDT meetings to gain remote access to the Specialist Children's Surgical Centre system, and enable immediate access to patient data.	Immediate
	Multidisciplinary Team (MDT)	
A15(L2)	Each Specialist Children's Cardiology Centre will participate in the weekly network specialist multidisciplinary team (MDT) to consider case management. All patients to be considered for complex interventions or any surgical interventions will be discussed in the network MDT meeting with the Specialist Children's Surgical Centre as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.	Within 1 year
A16(L2)	A designated cardiologist will attend (in person or by VC link) the weekly network MDT, and must also attend the annual network meeting. Job plans for cardiologists will include regular attendance (in person or by VC link) at the weekly network MDT.	Within 1 year
A17(L2)	Staff from the Specialist Children's Cardiology Centre should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A18(L2)	The composition of the MDT will 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).	Immediate
	Network Leadership	

	Paediatric	Implementation timescale
A19(L2)	Each Specialist Children's Cardiology Centre must have a formally nominated nursing Clinical Lead, who has a direct link and collaborative working partnership with the Lead Nurse for the Network. The post holder must have specified time working in paediatric cardiology, with an agreed list of responsibilities. The time available for these responsibilities will be specified by the network.	Within 6 months

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
A1(L3)	To ensure that children and young people receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Local Children's Cardiology Centres. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.	Immediate
A2(L3)	Each Local Children's Cardiology Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L3)	Local Children's Cardiology Centres must belong to a defined Congenital Heart Network and must comply with protocols, including those for shared care and pathways of care as defined as part of network arrangements. Each Local Children's Cardiology Centre will provide pathways of care and management of congenital heart defects agreed with the Congenital Heart Network: a. Prenatally diagnosed congenital heart defects If prenatal diagnosis of congenital heart defects has been made or is suspected the mother will be referred to the network fetal cardiac service. Counselling will take place including discussion about the location of the delivery of the baby. b. New-borns with a murmur and otherwise clinically well c. Neonates and infants diagnosed with congenital heart defects Each Local Children's Cardiology Centre will provide close monitoring for the development of heart failure, cyanosis or arrhythmias, and their initial management by medical treatment, if appropriate. d. New referrals from GPs and paediatricians Following review by the Paediatrician with Expertise in Cardiology, children/young people will be referred to a Specialist Surgical Centre or Children's Cardiology Centre, as necessary, for the following: • Murmurs • Cyanosis • Chest pain • Palpitations • Syncope or dizziness • Screening because of family history of congenital heart defect, cardiomyopathy or other syndromes • Kawasaki disease	Immediate

	Paediatric	Implementation timescale
	e. Ongoing care of children and young people diagnosed with congenital heart defects Local hospitals will refer children/young people to the Local Children's Cardiology Centre as appropriate, for close monitoring for the development of heart failure or cyanosis, depending on the underlying heart defect, for the monitoring and treatment and control of arrhythmias, and for the adjustment of various cardiac drugs.	
A4(L3)	Local Children's Cardiology Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record, and with clear links to 24/7 specialist services; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how congenital cardiac surgeons, paediatric cardiologists and paediatricians with expertise in cardiology (PECs) will work across the network, including at the Specialised Children's Surgical Centre, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, according to local circumstances; f. address how Local Children's Cardiology Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and g. deliver joint clinics between a paediatric cardiologist and a paediatrician with an expertise in cardiology in a Local Children's Cardiology Centre. Local Children's Cardiology Centres will provide weekday cover for CHD advice from a local network of PECs.	Within 1 year
A5(L3)	There will be specific protocols within each Congenital Heart Network for the transfer of children and young people requiring interventional treatment.	Within 6 months

	Paediatric	Implementation timescale
A6(L3)	All children and young people transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist Children's Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Immediate
	Cardiological Interventions	
A7(L3)	Local Children's Cardiology Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will require all paediatric cardiac surgery, planned therapeutic interventions and diagnostic catheter procedures to take place within a Specialist Children's Surgical Centre. Local Children's Cardiology Centres may not undertake any paediatric cardiac surgeries, planned interventional catheter procedures or diagnostic catheter procedures as part of their investigation into congenital heart disease. Local Children's Cardiology Centres may undertake coronary angiography and cardioversion.	Immediate
	Non-Cardiac Surgery	
A8(L3)	Local Children's Cardiology Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure 24/7 availability of pre-operative risk assessment by a Congenital Heart team including a paediatrician with expertise in cardiology and paediatric anaesthetists, in discussion with a paediatric cardiologist, for patients requiring non-cardiac surgery or other investigations, and other specialist advice, including a decision on the most appropriate location for that surgery or investigation.	Immediate
	Emergency Care	
A9(L3)	When children or young people with CHD attend A&E or are admitted, whether for CHD-related problems or not, Local Children's Cardiology Centres will seek advice from the local PEC or a paediatric cardiologist at a specialist centre on appropriate care and management.	Immediate
	External Relationships	
A10(L3)	Each Local Children's Cardiology Centre must demonstrate formal working relationships with the network Specialist Children's Surgical Centres and Specialist Children's Cardiology Centres, according to local circumstances. Other supra-regional services will be accessed via the CHD network.	Immediate

	Paediatric	Implementation timescale
A11(L3)	Local Children's Cardiology Centres must have a close relationship with local community paediatric services, to ensure the provision of a full range of community paediatric support services particularly for children and young people with complex medical and social needs.	Immediate
	Telemedicine and IT	
A12(L3)	Each Local Children's Cardiology Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist Children's Surgical Centres and Specialist Children's Cardiology Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site multidisciplinary team meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.	Within 3 years
A13(L3)	Each Local Children's Cardiology Centre must cooperate to allow specialist consultants doing outreach clinics and multidisciplinary team meetings to gain remote access to the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre system and enable immediate access to patient data.	Within 6 months
	Multidisciplinary Team (MDT)	
A14(L3)	Staff from across the Local Children's Cardiology Centre should be encouraged to attend multidisciplinary (MDT) meetings in person or by video/teleconferencing and participate in the decision-making about their patient, where necessary.	Immediate
A15(L3)	Each designated paediatrician with expertise in cardiology will attend (in person or by VC link) the weekly network MDT meeting at least six times per year, and must also attend the annual network meeting. This requirement will be reflected in job plans.	Within 1 year
A16(L3)	Each designated paediatrician with expertise in cardiology will liaise with other local District General Hospitals, Primary Care and the local cardiac networks, forming a link between them and the Congenital Heart Network.	Within 1 year
A17(L3)	Each Local Children's Cardiology Centre must have identified registered children's nurses with an interest and training in children's and young people's cardiology.	Within 1 year

	Paediatric	Implementation timetable
	Specialist Children's Surgical Centres	
B1(L1)	Each Specialist Children's Surgical Centre 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 paediatric surgery and interventional cardiology cover. A consultant ward round will occur daily. Each Specialist Children's Surgical Centre must provide a 24/7 emergency telephone advice service for patients and their family with urgent concerns about deteriorating health.	Within 6 months
B2(L1)	Consultant interventional paediatric cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either: a. the support of a competent second operator/interventionist must be obtained from within the network or another Specialist Children's Surgical Centre; or b. the child/young person must be referred to an alternative Specialist Children's Surgical Centre where a surgeon/interventionist has the appropriate skills. All rare, complex and innovative procedures and all cases where the treatment plan is unclear or controversial will be discussed at the network MDT.	Immediate
B3(L1)	Arrangements must be in place in each Specialist Children's Surgical Centre both for consultant interventional paediatric cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases.	Immediate
B4(L1)	Consultant interventional paediatric cardiologists and congenital cardiac surgeons will be mentored and supported by a lead interventionist or surgeon. Newly qualified consultants will initially share lists with more experienced colleagues.	Immediate
B5(L1)	Specialist Children's Surgical Centres and networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre-to-centre referrals.	Immediate
B6(L1)	Each Specialist Children's Surgical Centre will have a formally nominated paediatric CHD lead with responsibility for the service at the Specialist Children's Surgical Centre, who supports the Network Clinical Director and works across the network including outreach clinics, with precise duties determined locally.	Within 6 months
B7(L1)	All children and young people requiring investigation and treatment will receive care from staff trained in caring for children and	Immediate

	Paediatric	Implementation timetable
	young people, including safeguarding standards, in accordance with the requirements of their profession and discipline.	
	Surgery	
B8(L1)	All paediatric cardiac surgical cases must be carried out by a specialist congenital cardiac surgical team with expertise and experience in paediatric cardiac disease.	Immediate
B9(L1)	Consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. Each Specialist Children's Surgical Centre must develop out-of-hours arrangements that take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence. The rota will deliver care for both children and adults. If this means that the surgeon is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Rota: 1 in 3 immediate, 1 in 4 within 5 years Other requirements: immediate
B10(L1)	Congenital cardiac surgeons must work in teams of at least four surgeons, each of whom must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Only auditable cases may be counted, as defined by submission to the National Institute for Cardiovascular Outcomes (NICOR). VAD surgery and cardiac transplant surgery may also be counted.	Teams of at least three immediate, teams of at least four within 5 years 125 operations: immediate
B11(L1)	Perfusion services and staffing must be accredited by The College of Clinical Perfusion Scientists of Great Britain and Ireland	Immediate
	Cardiology	
B12(L1)	All paediatric congenital cardiology must be carried out by specialist paediatric cardiologists.	Immediate
B13(L1)	Each Specialist Children's Surgical Centre must be staffed by a minimum of one consultant paediatric cardiologist per half million	Within 3 years

	Paediatric	Implementation timetable
	population served by the network, working flexibly across the network.	
B14L1)	Each Specialist Children's Surgical Centre must deliver 24/7 elective and emergency care, including specialist consultant paediatric cardiology on-call cover for the Specialist Children's Surgical Centre and to provide advice across the network including requests for transfers. Rotas must be no more frequent than 1 in 4. The rota may deliver care for both children and adults. If this means that the cardiologist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Immediate
B15(L1)	Consultant interventional cardiology cover must be provided by consultant interventional paediatric cardiologists providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. This could include interventional cardiologists based at a Specialist Children's Surgical Centre or a Specialist Children's Cardiology Centre. Each Specialist Children's Surgical Centre must develop out-of-hours arrangements that take into account the requirement for interventionists only to undertake procedures for which they have the appropriate competence. The rota will deliver care for both children and adults. If this means that the interventionist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Within 1 year
B16(L1)	Cardiologists employed by the Specialist Children's Cardiology Centre and trained to the appropriate standards in interventional and diagnostic paediatric cardiology shall be provided with appropriate sessions and support at the Specialist Children's Surgical Centre to maintain and develop their specialist skills.	Within 6 months
B17(L1)	Cardiologists performing therapeutic catheterisation in children and young people with congenital heart disease must be the primary operator in a minimum of 50 such procedures per year. The Lead Interventional Cardiologist in a team must be the primary operator in a minimum of 100 such procedures per year, in each case averaged over a three-year period.	Immediate
B18(L1)	Each Specialist Children's Surgical Centre must be staffed by a minimum of one expert electrophysiologist experienced in paediatric cardiac disease. There must be appropriate arrangements for cover by a competent person.	Immediate
B19(L1)	Paediatric electrophysiology procedures must only be undertaken by an expert electrophysiologist experienced in the management of paediatric arrhythmias.	Immediate

	Paediatric	Implementation timetable
B20(L1)	The catheterisation laboratory must comply with the British Congenital Cardiac Association standards for catheterisation and have the following staff to operate safely: a. dedicated and appropriately trained cardiac physiologists; b. a radiographer; c. a 'running' member of staff without other duties and with specific knowledge of the location of equipment required in congenital interventional catheterisation; and d. a nurse with experience of paediatric cardiac catheterisation.	Immediate
B21(L1)	Each Specialist Surgical Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging across the network.	Immediate
B22(L1)	Each Specialist Children's Surgical Centre will have a continuous, immediate and documented availability of specialised cardiac paediatric anaesthetists with full training (in accordance with the Royal College of Anaesthetists' Guidelines and Paediatric Intensive Care Society Standards) and competence in managing paediatric cardiac cases including a specialist paediatric cardiac on-call rota which is separate from the intensive care rota.	Immediate
B23(L1)	At each Specialist Children's Surgical Centre a paediatric cardiologist will act as the lead for Congenital Echocardiography. The lead must be European Association of Cardiovascular Imaging (EACVI) Congenital Heart Disease Echocardiography accredited (or have recognised equivalent accreditation or experience). The lead will have dedicated echocardiography sessions and will have responsibility for training and quality assurance.	Within 6 months
B24(L1)	Each Specialist Surgical Centre will have a team of congenital echocardiography scientists (technicians), with a designated Congenital Echocardiography Scientist (Technician) Lead 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 population served, and whether the service is integrated with ACHD echocardiography.	Immediate
	Intensive Care	
B25(L1)	Paediatric Intensive Care Unit (PICU) consultants with appropriate skills in paediatric cardiac critical care must be available to the	Immediate

	Paediatric	Implementation timetable
	PICU on a 24/7 basis.	
B26(L1)	Paediatric Intensive Care Units and High Dependency care will be staffed in accordance with national standards. Children and young people must be cared for by children's nurses with appropriate training and competencies in paediatric cardiac critical care.	Immediate
	Nursing	
B27(L1)	Each Specialist Children's Surgical Centre must have a formally nominated lead CHD nurse with responsibility for the service at the Specialist Children's Surgical Centre, providing professional and clinical leadership and support to the team of children's cardiac specialist nurses across the network.	Within 6 months
B28(L1)	Nursing care must be provided by a team of nursing staff trained in the care of children and young people who have received cardiac surgery. The paediatric cardiac inpatient nursing team will be led by a senior children's nurse with specialist knowledge and experience in the care of children and young people and in paediatric cardiology and cardiac surgery.	Immediate
B29(L1)	Each Specialist Children's Surgical Centre will employ a minimum of 1 WTE children's cardiac specialist nurse per 600 000 catchment population, whose role will extend throughout the Congenital Heart Network, ensuring that both an in-hospital and outreach service is provided. The precise number, above the minimum seven, and location of these nurses will depend on geography, population and the configuration of the network. Networks must demonstrate that the role of each Children's Cardiac Nurse Specialist meets the minimum requirements of the Royal College of Nursing role description. Included in these numbers will be at least 1 WTE Fetal Cardiac Nurse Specialist, shared with the fetal network, to provide expert information and on-going support to parents who have a fetal diagnosis of congenital heart disease and 1 WTE designated Children's Cardiac Transition Nurse to coordinate the transition process across the network. Each child/young person must have access to a Children's Cardiac Nurse Specialist and complex patients will have a named CCNS responsible for coordinating their care, and who acts as a liaison between the clinical team, the child/young person and parents/carers. There must be regular contact between the named CCNS and high risk children/young people and their families, at a frequency determine by need.	Within 1 year
	Psychology	
B30(L1)	Each Specialist Children's Surgical Centre must employ a minimum of 0.25 WTE practitioner psychologists (with experience of working with CHD) per 100 children and young people undergoing cardiac surgery each year.	Within 3 year

	Paediatric	Implementation timetable
	In addition, 1 WTE practitioner psychologist must be employed for each network. The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network. The lead psychologist should provide training and mentorship to the other psychologists in the network.	
	Administrative Staffing	
B31(L1)	Each Specialist Children's Surgical Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to parents/carers in a timely fashion.	Immediate
B32(L1)	Each Specialist Surgical Centre must have a minimum of 1 WTE dedicated paediatric cardiac surgery/cardiology data collection manager, with at least 1 WTE assistant, responsible for audit and database submissions in accordance with necessary timescales.	Within 6 months
	Other (See also section D: interdependencies for professions and specialties where dedicated sessions are required.)	
B33(L1)	Each Specialist Children's Surgical Centre will have a Lead Doctor and Lead Nurse for safeguarding children and young people.	Immediate
B34(L1)	Each Specialist Surgical Centre will have an identified bereavement officer.	Immediate
B35(L1)	Each Specialist Children's Surgical Centre must have a minimum of 2 WTE dedicated play specialists.	Immediate

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
B1(L2)	Each Specialist Children's Cardiology Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service within legally compliant rotas. A consultant ward round will occur daily.	Immediate
B2(L2)	All children and young people requiring investigation and treatment will receive care from staff trained in caring for children and young people, including safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
	Medical	
B3(L2)	Each Specialist Children's Cardiology Centre must be staffed by a minimum of 4 WTE specialist paediatric cardiologists (in addition to the one consultant paediatric cardiologist per half million population across the network). These cardiologists will work flexibly across the network.	Within 3 years
B4(L2)	Each Specialist Children's Cardiology Centre must provide a specialist paediatric cardiologist on-call rota. Rotas must be no more frequent than 1 in 4.	Immediate
B5(L2)	Each Specialist Children's Cardiology Centre will have a formally nominated Clinical Paediatric Cardiology Lead with responsibility for the service at the Specialist Children's Cardiology Centre, who works across the network including outreach clinics, with precise duties determined locally. Each Specialist Children's Cardiology Centre will have separate clinical leads identified from the relevant specialties, including fetal cardiology and nursing (and ICU and anaesthesia, if such provision exists) who have a direct link and collaborative working partnership with the lead roles in the Specialist Children's Surgical Centre.	Within 6 months
B6(L2)	Cardiologists employed by the Specialist Children's Cardiology Centre and trained to the appropriate standards in interventional and diagnostic paediatric cardiology shall be provided with appropriate sessions and support at the Specialist Children's Surgical Centre to maintain and develop their specialist skills.	Within 6 months
B7(L2)	Paediatric cardiologists based at the Specialist Children's Cardiology Centre who visits the Specialist Children's Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures per year, averaged over a three-year period.	Immediate
B8(L2)	Each Specialist Children's Cardiology Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of	Immediate

	Paediatric	Implementation timescale
	complex cases. There will be shared protocols for cross-sectional imaging across the network.	
B9(L2)	Paediatric Intensive Care Unit (PICU) consultants with appropriate skills in paediatric cardiac critical care must be available to the PICU on a 24/7 basis.	Immediate
	Nursing	
B10(L2)	Specialist Children's Cardiology Centres must have locally designated registered children's nurses with a specialist interest in paediatric cardiology, trained and educated in the assessment, treatment and care of cardiac children and young people.	Immediate
B11(L2)	There must at all times be a minimum of two registered children's nurses allocated to the operational children's cardiology beds who are trained according to the Royal College of Nursing competency framework.	Immediate
B12(L2)	Each Specialist Children's Cardiology Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively.	Immediate
B13(L2)	The network Children's Cardiac Nurse Specialist Team, will support the Specialist Children's Cardiology Centre. An appropriate number of Children's Cardiac Nurse Specialists will be based at the Specialist Children's Cardiology Centre (the number will depend on geography, population and the congenital heart network).	Within 1 year
	Psychology	
B14(L2)	The Network Children's Cardiac Psychologist will support the Specialist Children's Cardiology Centre. An appropriate number of Children's Cardiac Psychology sessions will be based at the Specialist Children's Cardiology Centre (the number will depend on geography, population and the congenital heart network).	Immediate
	Administrative	
B15(L2)	Each Specialist Children's Cardiology Centre must have an identified member of staff to ensure high quality data input to the network database.	Immediate
B16(L2)	Each Specialist Children's Cardiology Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to	Immediate

	Paediatric	Implementation timescale
	parents/carers in a timely fashion.	
	Other	
B17(L2)	Each Specialist Children's Cardiology Centre will have a team of congenital echocardiography scientists (technicians) who should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with ACHD echocardiography.	Immediate
B18(L2)	Each Specialist Children's Cardiology Centre will have a Lead Doctor and Lead Nurse for safeguarding children and young people.	Immediate
B19(L2)	Each Specialist Children's Cardiology Centre will have a dedicated bereavement officer.	Immediate

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
B1(L3)	Each Local Children's Cardiology Centre must be staffed by at least one Consultant Paediatrician with expertise in cardiology (PEC) who is closely involved in the organisation, running of and attendance in the Local Children's Cardiology Centre. Each PEC must have received training in accordance with the Royal College of Paediatrics and Child Health and Royal College of Physicians one-year joint curriculum in paediatric cardiology (or gained equivalent competencies as agreed by the Network Clinical Director). Each PEC must spend a minimum 20% of his/her total job plan (including Supporting Professional Activities) in paediatric cardiology (in accordance with the British Congenital Cardiac Association definitions). Each PEC must be part of a Congenital Heart Network. Each PEC must work with a link/named Consultant Paediatric Cardiologist from either the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre and take responsibility for the running of regular joint paediatric cardiology clinics with the visiting Consultant Paediatric Cardiologist. Each PEC will hold an honorary contract with the Specialist Children's Surgical Centre and/or the Specialist Children's Cardiology Centre and have the opportunity to attend clinical and educational opportunities in order to maintain expertise and facilitate good working relationships there as part of their job plan. All patients under the care of a local children's cardiology centre should have a named paediatrician (ideally a PEC) responsible for coordinating care for children and young people after discharge from a CSSC, for referrals to local services and for communication between health professionals.	Within 1 year
B2(L3)	Local Children's Cardiology Centres must have locally designated registered children's nurses with a specialist interest in paediatric cardiology, trained and educated in the assessment, treatment and care of cardiac children and young people.	Within 1 year
B3(L3)	Each Local Children's Cardiology Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively in the outpatient clinic.	Immediate
B4(L3)	Each Local Children's Cardiology Centre must have a locally designated 0.25 WTE registered children's nurse with a specialist interest to participate in cardiology clinics, provide support to inpatients and deal with requests for telephone advice.	Within 1 year
B5(L3)	The network Children's Cardiac Nurse Specialist Team will provide support, education and a link to the outpatient and ward nursing staff at the Local Children's Cardiology Centre. A local link nurse will be identified who can be a point of contact within the Local Children's Cardiology	Immediate

	Paediatric	Implementation timescale
	Centre.	
B6(L3)	Each Local Children's Cardiology Centre must have an identified member of staff to ensure high quality data input to the network database.	Within 6 months
B7(L3)	Each Local Children's Cardiology Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to parents/carers in a timely fashion.	Immediate
B8(L3)	Each Local Children's Cardiology Centre must have a cardiac physiologist with training in congenital echocardiography.	Within 1 year
B9(L3)	All children and young people requiring investigation and treatment will receive care from staff trained in caring for children and young people, including safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
B10(L3)	Each Local Children's Cardiology Centre will have: a. a Lead Doctor and Lead Nurse for safeguarding children; and b. a dedicated bereavement officer.	Immediate

	Paediatric	Implementation timeline
	Specialist Children's Surgical Centres	
C1(L1)	There must be facilities in place to ensure easy and convenient access for parents/carers. Facilities and support include: a) accommodation for at least two family members to stay; b) the ability for at least one parent/carer to stay with their child in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c) access to refreshments; d) facilities suitable for the storage and preparation of simple meals; e) facilities for parents/carers to play and interact with their child (and their other children); and f) an on-site quiet room completely separate from general family facilities. Family accommodation should be provided without charge.	Within 6 months
C2(L1)	All children and young people must be seen and cared for in an age-appropriate environment, taking into account the particular needs of adolescents and those of children and young people with any learning or physical disability.	Immediate
C3(L1)	Children and young people must have access to general resources including toys, books, magazines, computers, free wifi and other age-appropriate activity coordinated by dedicated play specialist teams.	Immediate
C4(L1)	Specialist Children's Surgical Centres must have a hospital school with teachers. Children and young people must have access to education resources.	Immediate
C5(L1)	There must be facilities, including access to maternity staff, that allow the mothers of new-born babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breastfeeding and the emotional health of the mother and baby.	Immediate
C6(L1)	Parents/carers will be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.	Immediate
C7(L1)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable	Immediate

	Paediatric	Implementation timeline
	and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	
C8(L1)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children's cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C9(L1)	Specialist Children's Surgical Centres should ideally have landing facilities for a helicopter and must have local arrangements for transferring patients from airfields and helipads.	Immediate

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	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
C1(L2)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children's cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C2(L2)	There must be facilities in place to ensure easy and convenient access for parents/carers. Facilities and support include: a) accommodation for at least two family members to stay; b) the ability for at least one parent/carer to stay with their child in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c) access to refreshments; d) facilities suitable for the storage and preparation of simple meals; e) facilities for parents/carers to play and interact with their child (and their other children); and f) an on-site quiet room completely separate from general family facilities. Family accommodation should be provided without charge.	Within 6 months
C3(L2)	All children and young people must be seen and cared for in an age-appropriate environment, taking into account the particular needs of adolescents and those of children and young people with any learning or physical disability.	Immediate
C4(L2)	Children and young people must have access to general resources including toys, books, magazines, computers, free wifi and other age-appropriate activity coordinated by play specialist teams.	Immediate
C5(L2)	Specialist Children's Cardiology Centres must have a hospital school with teachers. Children and young people must have access to education resources.	Immediate
C6(L2)	Parents/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.	Immediate
C7(L2)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
C1(L3)	There must be dedicated child friendly facilities in which practitioner psychologists, cardiac physiologists, children's cardiac nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C2(L3)	There must be facilities in place to ensure easy and convenient access for parents/carers. Facilities and support include: a) accommodation for at least two family members to stay; b) the ability for at least one parent/carer to stay with their child in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c) access to refreshments; d) facilities suitable for the storage and preparation of simple meals; e) facilities for parents/carers to play and interact with their child (and their other children); and f) an on-site quiet room completely separate from general family facilities. Family accommodation must be provided without charge.	Within 6 months
C3(L3)	All children and young people must be seen and cared for in an age-appropriate environment, taking into account the particular needs of adolescents and those of children and young people with any learning or physical disability.	Immediate
C4(L3)	Children and young people must have access to general resources including toys, books, magazines, computers, free wifi and other age-appropriate activity coordinated by play specialist teams.	Immediate
C5(L3)	Children and young people must have access to education resources.	Immediate
C6(L3)	Parents/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.	Immediate
C7(L3)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **must be located on the same hospital site** as **Specialist Children's Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
D1(L1)	Paediatric Cardiology.	Immediate
D2(L1)	Paediatric Airway Team capable of complex airway management (composition of the team will vary between institutions).	Immediate
D3(L1)	Paediatric Intensive Care Unit (PICU): Level 3 paediatric critical care services, capable of multi-organ failure support (delivered in accordance with Paediatric Intensive Care Society Standards and NHS England's service specification for Paediatric Intensive Care). High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing paediatric cardiac patients.	Immediate
D4(L1)	Specialised paediatric cardiac anaesthesia.	Immediate
D5(L1)	Perioperative extracorporeal life support (Non-nationally designated extracorporeal membrane oxygenation (ECMO)).	Immediate
D6(L1)	Paediatric Surgery.	30 minute call to bedside: Immediate Co-location: within 3 years
D7(L1)	Paediatric Nephrology/Renal Replacement Therapy.	30 minute call to bedside: Immediate Co-location: within 3 years
D8(L1)	Paediatric Gastroenterology.	30 minute call to bedside: Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **must be located on the same hospital site** as **Specialist Children's Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
		Co-location: within 3 years
D9(L1)	Each Specialist Children's Surgical Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The range of cardiac physiological investigations must include Electrocardiography (ECG), Holter monitoring, event recording, tilt test, standard exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, as well as standard, contrast, intraoperative, transesophageal and fetal echocardiography. There must be a 24/7 congenital echocardiography service with access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a selection of probes suitable for all age groups, including suitable fetal echo probes, with facilities for advanced techniques including 3D and speckle tracking. Specialist Children's Surgical Centres should be able to undertake cardio-pulmonary exercise testing (CPEX) and the six-minute walk test in children and adolescents; if not provided on site they must have access to these investigations. Specialist Children's Surgical Centres must have access to Isotope Imaging. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network. Specialist Children's Surgical Centres must offer invasive diagnostic investigation and treatment, including: a. catheter intervention; b. electrophysiological intervention; c. pacemaker insertion and extraction; and d. cardiac surgical intervention, including the provision of extracorporeal support of the circulation and hybrid catheter/surgical treatment where clinically indicated). These services must be available 24/7.	Within 6 months

	Paediatric	Implementation timescale
	The following specialties or facilities **should** be located on the same hospital site as Specialist Children's Surgical Centres. They must function as part of the extended multidisciplinary team. Senior decision makers from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. Specialist Children's Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).	
D10(L1)	Whether or not adult and paediatric CHD services are on the same site, congenital heart surgeons, congenital interventional cardiologists and congenital electrophysiologists must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7. [This standard recognises shared staffing and out-of-hours cover.]	Within 1 year
D11(L1)	Adult cardiology interventionist (to provide thrombolysis, clot removal and back-up for catheter lab emergencies including acute dissection).	Immediate
D12(L1)	Vascular Surgery or other surgeon competent to undertake vascular/microvascular repairs in children.	Immediate
D13(L1)	Paediatric Physiotherapy (urgent response required for respiratory physiotherapy).	Immediate
D14(L1)	Multidisciplinary paediatric pain management service.	Immediate
D15(L1)	Bereavement Support, including nurses trained in bereavement support.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed**.** The services must be experienced in caring for patients with congenital heart disease.	
D16(L1)	Paediatric Neurology.	Immediate
D17(L1)	Paediatric Respiratory Medicine.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed**.** The services must be experienced in caring for patients with congenital heart disease.	
D18(L1)	Neonatology.	Immediate
D19(L1)	Clinical Haematology.	Immediate
D20(L1)	Infection control team experienced in the needs of paediatric cardiac surgery patients.	Immediate
D21(L1)	Paediatric Neurosurgery.	Immediate
D22(L1)	Child Psychiatry (with dedicated sessions and 24/7 on call).	Immediate
D23(L1)	Clinical biochemistry (including toxicology).	Immediate
D24(L1)	Pharmacy (with dedicated sessions for CHD and 24/7 on-call for urgent supply and advice).	Immediate
D25(L1)	Paediatric Endocrinology.	Immediate
D26(L1)	Paediatric Orthopaedics.	Immediate
D27(L1)	Plastic surgery.	Immediate
D28(L1)	Microbiology and Infectious diseases.	Immediate
D29(L1)	Safeguarding team/social work (as per national standards).	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities must be able to provide **advice and consultation at least by the next working day.** The services must be experienced in caring for patients with congenital heart disease.	
D30(L1)	Paediatric Ear, Nose and Throat (seven day working week).	Immediate
D31(L1)	General Paediatrics (seven day working week).	Immediate
D32(L1)	Breast Feeding Support (seven day working week).	Immediate
D33(L1)	Obstetrics and Midwifery (seven day working week).	Immediate
D34(L1)	Psychology, with dedicated sessions for CHD.	Immediate
D35(L1)	Paediatric Dietician with dedicated sessions for CHD	Immediate
D36(L1)	Social Work Services.	Immediate
D37(L1)	Clinical Genetics.	Immediate
D38(L1)	Paediatric Dentistry.	Immediate
D39(L1)	Paediatric Immunology.	Immediate
D40(L1)	Dermatology.	Immediate
D41(L1)	Sexual health.	Immediate
D42(L1)	Fetal-maternal medicine.	Immediate
D43(L1)	Paediatric Rheumatology.	Immediate
D44(L1)	Gynaecology.	Immediate
D45(L1)	Paediatric Urology.	Immediate

	Paediatric	**Implementation timescale**
	The following specialties or facilities must be able to provide **advice and consultation at least by the next working day.** The services must be experienced in caring for patients with congenital heart disease.	
D46(L1)	Speech and language, with dedicated sessions for CHD, including swallow assessment with timely access to video fluoroscopy.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities must be located **on the same hospital site** as **Specialist Children's Cardiology Centres.** They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
D1(L2)	Paediatric Cardiology.	Immediate
D2(L2)	Paediatric Airway Team capable of complex airway management (composition of the team will vary between institutions).	Immediate
D3(L2)	Paediatric Intensive Care Unit (PICU): Level 3 paediatric critical care services, capable of multi-organ failure support (delivered in accordance with Paediatric Intensive Care Society Standards and NHS England's service specification for Paediatric Intensive Care. High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing paediatric cardiac patients.	Immediate
D4(L2)	Each Specialist Children's Cardiology Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The exact range of equipment and investigations will be agreed with the network. The range of cardiac physiological investigations must include electrocardiography (ECG), Holter monitoring, event recording, standard exercise testing, ambulatory blood pressure monitoring and pacemaker interrogation and follow up, as well as standard, transesophageal and fetal echocardiography. The availability of contrast echocardiography is desirable. Specialist Children's Cardiology Centres must be able to access contrast echocardiography, tilt testing, cardio-pulmonary exercise testing (CPEX), the six-minute walk test in children and adolescents. There must be 24/7 access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a selection of probes suitable for all age groups, including suitable fetal echo probes. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network. These services must be available 24/7 where clinically indicated.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Cardiology Centres. They must function as part of the extended multidisciplinary team. Senior decision makers from the following services **must** be able to provide emergency bedside care (**call to bedside within 30 minutes**) 24/7.	
D5(L2)	Paediatric Surgery.	Immediate
D6(L2)	Paediatric anaesthetist who works closely with specialist paediatric cardiac anaesthetists in the network.	Immediate
D7(L2)	Paediatric Nephrology.	Immediate
D8(L2)	Paediatric Physiotherapy (urgent response required for respiratory physiotherapy).	Immediate
D9(L2)	Bereavement Support, including nurses trained in bereavement support.	Immediate
D10(L2)	Multidisciplinary paediatric pain management service.	Immediate
D11(L2)	Paediatric Gastroenterology.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Cardiology Centres. Consultants from the following services **must** be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed. The services must be experienced in caring for patients with congenital heart disease.	
D12(L2)	Paediatric Neurology.	Immediate
D13(L2)	Paediatric Respiratory Medicine.	Immediate
D14(L2)	Neonatology.	Immediate

	Paediatric	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist Children's Cardiology Centres. Consultants from the following services **must** be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed. The services must be experienced in caring for patients with congenital heart disease.	
D15(L2)	Paediatric Neurosurgery.	Immediate
D16(L2)	Child Psychiatry with dedicated sessions.	Immediate
D17(L2)	Paediatric Endocrinology.	Immediate
D18(L2)	Paediatric Orthopaedics.	Immediate
D19(L2)	Plastic surgery.	Immediate
D20(L2)	Vascular surgery.	Immediate
D21(L2)	Clinical Haematology.	Immediate
D22(L2)	Infection control nurse experienced in the needs of paediatric cardiac patients.	Immediate
D23(L2)	Clinical Biochemistry (including toxicology).	Immediate
D24(L2)	Pharmacy (24/7 on-call required for urgent supply and advice).	Immediate
D25(L2)	Microbiology and Infectious diseases.	Immediate
D26(L2)	Learning Disability Team.	Immediate
D27(L2)	Safeguarding team/social work (as per national standards).	Immediate

	Paediatric	Implementation timescale
	Advice and consultation must be available from the following specialties at least by the next working day. The services must be experienced in caring for patients with congenital heart disease.	
D28(L2)	Paediatric Ear, Nose and Throat.	Immediate
D29(L2)	General Paediatrics (seven day working week).	Immediate
D30(L2)	Psychology.	Immediate
D31(L2)	Paediatric Dietician.	Immediate
D32(L2)	Breastfeeding Support (seven day working week).	Immediate
D33(L2)	Social Work Services.	Immediate
D34(L2)	Obstetrics and Midwifery (seven day working week).	Immediate
D35(L2)	Clinical Genetics.	Immediate
D36(L2)	Paediatric Dentistry.	Immediate
D37(L2)	Paediatric Immunology.	Immediate
D38(L2)	Fetal-maternal medicine.	Immediate
D39(L2)	Dermatology.	Immediate
D40(L2)	Sexual health.	Immediate
D41(L2)	Paediatric Rheumatology.	Immediate
D42(L2)	Gynaecology.	Immediate

	Paediatric	Implementation timescale
	Advice and consultation must be available from the following specialties at least by the next working day. The services must be experienced in caring for patients with congenital heart disease.	
D43(L2)	Paediatric Urology.	Immediate
D44(L2)	Speech and language, with dedicated sessions for CHD, including swallow assessment with timely access to video fluoroscopy.	Immediate

DRAFT CHD Standards: Section D: Interdependencies
Level 3: Local Children's Cardiology Centres

	Paediatric	**Implementation timescale**
	The following specialties or facilities must be located **on the same hospital site** as **Local Children's Cardiology Centres.**	
D1(L3)	In and Outpatient Paediatric and Adolescent Services.	Immediate
D2(L3)	Prenatal diagnostic services, obstetrics, midwifery and breast-feeding support and neonatal services.	Immediate
D3(L3)	General adult cardiology services.	Immediate
D4(L3)	Urgent advice 24/7 from any relevant services not on site or in the District General Hospital Paediatric service – either from Specialist Cardiology Centres or from Specialist Surgical Centres in accordance with network protocols**.**	Immediate
D5(L3)	Each Local Children's Cardiology Centre must provide standard non-invasive diagnostic imaging capabilities with access, across the network, to CT and MRI scanning. The exact range of equipment and investigations will be agreed with the Network. The range of cardiac physiological investigations to which the Local Children's Cardiology Centre must have access include electrocardiography (ECG), Holter monitoring, event recording, standard exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, 24 hour tapes, event recorders; and ambulatory blood pressure monitoring, as well as standard, and fetal echocardiography. Local Children's Cardiology Centres must be able to access cardio-pulmonary exercise testing (CPEX) and the six-minute walk test in children and adolescents. There must be 24/7 access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a selection of probes suitable for all age groups, including suitable fetal echo probes. There must be the facility to store and transfer digital recordings of radiological and echocardiographic images. Governance arrangements across the Children's Congenital Heart Network must ensure that the training and skills of all echocardiographic practitioners undertaking paediatric echocardiograms are kept up to date.	Immediate

	Paediatric	Implementation timescale
	Specialist Children's Surgical Centre	
E1(L1)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including the care of children, safeguarding, working with children with learning disability, life support, pain management, infection control, end of life, bereavement, breaking bad news and communication.	Immediate
E2(L1)	All members of the cardiac and PICU medical and nursing team will complete mandatory basic training on end-of-life care, breaking bad news and supporting children, young people and their families through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L1)	Nurses working within Specialist Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre, with a formal annual training plan in place.	Within 1 year
E4(L1)	Each Specialist Children's Surgical Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in paediatric cardiology and paediatric cardiac surgery, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum, and to the training of Paediatricians with expertise in cardiology.	Immediate
E5(L1)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children and young people with congenital heart problems. Specialist Children's Surgical Centres must provide resources sufficient to support these educational needs across the network.	Within 6 months
E6(L1)	Specialist Children's Surgical Centres must provide sufficient Cardiac Clinical Nurse Educators to deliver standardised training and competency-based education programmes across the Congenital Heart Network including linked neonatal units. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months

	Paediatric	Implementation timescale
E7 (L1)	Governance arrangements across the Congenital Heart Network must ensure that the training and skills of all echocardiographic practitioners undertaking paediatric echocardiograms are kept up to date.	Within 6 months

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
E1(L2)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including the care of children, safeguarding, working with children with learning disabilities, life support, pain management, infection control, end-of-life care, bereavement, breaking bad news and communication.	Immediate
E2(L2)	All members of the cardiac and PICU medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting children, young people and their families through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L2)	Nurses working within Specialist Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre, with a formal annual training plan in place.	Within 1 year
E4(L2)	Each Specialist Children's Cardiology Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in paediatric cardiology according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.	Immediate
E5(L2)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children and young people with congenital heart problems.	Within 6 months
E6(L2)	Sufficient Clinical Nurse Educators must be provided across each Congenital Heart Network to deliver standardised training and competency-based education programmes. Each Specialist Children's Cardiology Centre must have one clinical educator who is responsible for ensuring the continuing professional development of nursing staff in the Specialist Children's Cardiology Centre. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months
E7 (L2)	Governance arrangements across the Children's Congenital Heart Network must ensure that the training and skills of all echocardiographic	Within 6 months

	Paediatric	Implementation timescale
	practitioners undertaking paediatric echocardiograms are kept up to date.	

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
E1(L3)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including the care of children, safeguarding, working with children with learning disabilities, life support, pain management, infection control, end-of-life care, bereavement, breaking bad news and communication.	Immediate
E2(L3)	All members of the cardiac medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting children, young people and their families through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L3)	Each Local Children's Cardiology Centre must assist the Specialist Children's Surgical Centre in providing core curriculum level training as per the Joint Royal Colleges of Physicians' Training Board curriculum to all specialty doctors within their network catchment area.	Immediate
E4(L3)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children and young people with congenital heart problems.	Within 1 year
E5(L3)	Sufficient Clinical Nurse Educators must be provided across each Congenital Heart Network to deliver standardised training and competency-based education programmes. They will be responsible for ensuring the continuing professional development of nursing staff in the Local Children's Cardiology Centre and community paediatric nurses. The competency-based programme will focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication.	Within 1 year
E6(L3)	Nurses working within Local Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place.	Within 1 year
E7(L3)	Paediatricians with expertise in cardiology (PECs) should have a named cardiologist within the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre who acts as a mentor; this mentor would normally be the link cardiologist.	Immediate

	Paediatric	Implementation timescale
F1(L1)	Each Specialist Children's Surgical Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years as part of the national programme.	Within 1 year
F2(L1)	Each Specialist Children's Surgical Centre must have a dedicated management group for the internal management and coordination of service delivery. The group must comprise the different departments and disciplines delivering the service.	Immediate
F3(L1)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. regular, continuous network clinical audit and quality improvement; b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance; c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents and resultant action plans from all units.	Within 1 year
F4(L1)	Each Specialist Children's Surgical Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist Children's Surgical Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F5(L1)	Each Specialist Children's Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). The database will have seamless links to that of the Specialist and Local Children's Cardiology Centres. Audit of clinical practice should be considered where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Within 6 months
F6(L1)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L1)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Immediate
F8(L1)	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where	Within 6

	Paediatric	Implementation timescale
	possible.	months
F9(L1)	Each Specialist Children's Surgical Centre must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F10(L1)	Each Congenital Heart Network's database must allow analysis by diagnosis to support activity planning.	Immediate
F11(L1)	Each Specialist Children's Surgical Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist Children's Surgical Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Immediate
F12(L1)	Governance arrangements must be in place to ensure that when elective patients are referred to the multidisciplinary team, they are listed in a timely manner. Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F13(L1)	Admission for planned surgery will be booked for a specific date.	Immediate
F14(L1)	All children/young people who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.	Immediate
F15(L1)	Specialist Children's Cardiology Centres and Local Children's Cardiology Centres must be informed of any relevant cancellations and the new date offered.	Immediate
F16(L1)	Last minute cancellations must be recorded and discussed at the multidisciplinary team meeting.	Immediate
F17(L1)	If a child/young person needing a surgical or interventional procedure who has been actively listed can expect to wait longer than three months, all reasonable steps must be taken to offer a range of alternative providers, if this is what the child/young person or parents/carers wish(es). Specialist Children's Cardiology Centres and Local Children's Cardiology Centres must be involved in any relevant discussions.	Immediate
F18(L1)	When a Specialist Children's Surgical Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist Children's Surgical Centre, or Specialist Children's Cardiology Centre if appropriate.	Immediate

	Paediatric	**Implementation timescale**
F19(L1)	A children's cardiac nurse specialist must be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.	Immediate
F20(L1)	Each Specialist Children's Surgical Centre must implement a pain control policy that includes advice on pain management at home.	Immediate
F21(L1)	Advice must be taken from the acute pain team for all children/young people who have uncontrolled severe pain. Particular attention must be given to children/young people who cannot express pain because of their level of speech or understanding, communication difficulties, their illness or disability.	Immediate
F22(L1)	Each Specialist Children's Surgical Centre must be able to demonstrate that clinical and support services are appropriate and sensitive to the needs of neonatal, infant, paediatric and adolescent patients with congenital heart disease and to their families/carers.	Immediate
F23(L1)	Each Specialist Children's Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals.	Immediate
F24(L1)	Each Specialist Children's Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the child/young person's home or other agencies.	Immediate

	Paediatric	Implementation timescale
	Specialist Children's Cardiology Centres	
F1(L2)	Each Specialist Children's Cardiology Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L2)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. regular, continuous network clinical audit and quality improvement; b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance; c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents and resultant action plans from all units. d.	Within 1 year
F3(L2)	Each Specialist Children's Cardiology Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist Children's Cardiology Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L2)	Each Specialist Children's Cardiology Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist Children's Surgical Centre.	Within 6 months
F5(L2)	Each Specialist Children's Cardiology Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L2)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L2)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Within 1 year

	Paediatric	Implementation timescale
F8(L2)	Each Specialist Children's Cardiology Centre must participate in national programmes for audit and must submit data on any emergency procedures, electrophysiology procedures and endocarditis, to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F9(L2)	Each Specialist Children's Cardiology Centre will contribute to the network-wide database by diagnosis to support workload planning.	Immediate
F10(L2)	Each Specialist Children's Cardiology Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist Children's Cardiology Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Within 6 months
F11(L2)	Where cases are referred to the specialist multidisciplinary team for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F12(L2)	When a Specialist Children's Cardiology Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.	Immediate
F13(L2)	Each Specialist Children's Cardiology Centre must be able to demonstrate that clinical and support services are appropriate and sensitive to the needs of neonatal, infant, paediatric and adolescent patients with congenital heart disease and to their families/carers.	Immediate
F14(L2)	Each Specialist Children's Cardiology Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals.	Immediate
F15(L2)	Each Specialist Children's Cardiology Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the child/young person's home or other agencies.	Immediate

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
F1(L3)	Each Local Children's Cardiology Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L3)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. regular continuous network clinical audit and quality improvement; b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance; c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents and resultant action plans from all units.	Within 1 year
F3(L3)	Each Local Children's Cardiology Centre will report on adverse incidents. In addition to contractual and national reporting requirements, Local Children's Cardiology Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L3)	Each Local Children's Cardiology Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist Children's Surgical Centre.	Within 6 months
F5(L3)	Each Local Children's Cardiology Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L3)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L3)	Each Local Children's Cardiology Centre must participate in relevant national programmes for audit and must submit data to the Specialist Children's Surgical or Specialist Children's Cardiology Centre on endocarditis so that this can be submitted to the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate

	Paediatric	Implementation timescale
F8(L3)	Each Local Children's Cardiology Centre will contribute to the network-wide database by diagnosis to support workload planning.	Within 1 year
F9(L3)	Each Local Children's Cardiology Centre must work with the network to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Local Children's Cardiology Centres will follow mandatory National Institute for Health and Care Excellence guidance.	Immediate
F10(L3)	Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F11(L3)	Each Local Children's Cardiology Centre must be able to demonstrate that clinical and support services are appropriate and sensitive to the needs of neonatal, infant, paediatric and adolescent patients with congenital heart disease and to their families/carers.	Immediate

Level 1: Specialist Children's Surgical Centres

	Paediatric	Implementation timescale
G1(L1)	Each Specialist Children's Surgical Centre is expected to participate in research.	Within 6 months
G2(L1)	Each Congenital Heart Network must have, and regularly update, a research strategy and programme that documents current and planned research activity in the field of paediatric cardiac disease and the resource needed to support the activity and objectives for development. This must include a commitment to working in partnership with other Specialist Children's Surgical Centres and Specialist Children's Cardiology Centres, and Local Children's Cardiology Centres as appropriate, in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of children and young people with CHD and their families.	Within 6 months
G3(L1)	Each Congenital Heart Network must demonstrate close links with one or more academic department(s) in Higher Education Institutions.	Immediate
G4(L1)	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	Immediate

DRAFT CHD Standards: Section G: Research
Level 2: Specialist Children’s Cardiology Centres

	Paediatric	Implementation timescale
	Specialist Children’s Cardiology Centres	
G1(L2)	Each Specialist Children’s Cardiology Centre must participate in research.	Immediate
G2(L2)	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	Immediate

DRAFT CHD Standards: Section G: Research
Level 3: Local Children’s Cardiology Centres

	Paediatric	Implementation timescale
	Local Children’s Cardiology Centres	
G1(L3)	Each Local Children’s Cardiology Centre should participate in research.	Immediate
G2(L3)	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	Immediate

	Paediatric	Implementation timescale
H1(L1)	Specialist Children's Surgical Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to participate in decision-making at every stage in the care of the child/young person.	Immediate
H2(L1)	Every family/carer (and young person, as appropriate) must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L1)	Children and young people, family and carers must be helped to understand the patient's condition, the effect it may have on their health and future life, what signs and symptoms should be considered 'normal' for them and the treatment that they will receive, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child/young person, parents' and carers' understanding must be considered. Information provided should include any aspect of life that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. tattoos, piercings and intradermal procedures; f. school and careers; g. travel; h. welfare benefits; i. social services; and j. community services.	Immediate
H4(L1)	When referring patients for further investigation, surgery or cardiological intervention, patient care plans will be determined primarily by the availability of expert care for their condition. The cardiologist must ensure that parents, carers, children and young people are advised of any appropriate choices available as well as the reasons for any recommendations.	Immediate

	Paediatric	Implementation timescale
H5(L1)	Sufficient information must be provided to allow informed decisions to be made, including supporting parents, carers and young people in interpreting publicly available data that support choice. The following should also be described: a. other clinical specialties offered by alternative units, relevant to patients with co-morbidities; b. accessibility of alternative units; c. patient facilities offered by alternative units; d. outcomes at units under consideration; and e. consideration of the closest unit to the patient's home.	Immediate
H6(L1)	Specialist Children's Surgical Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another Specialist Children's Surgical Centre, and in interpreting publically available data that supports patient choice.	Immediate
H7(L1)	Information must be made available to parents and carers in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	Immediate
H8(L1)	Specialist Children's Surgical Centres must demonstrate that arrangements are in place for parents and carers, children and young people to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H9(L1)	The child/young person's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H10(L1)	Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist Children's Surgical Centres must make this feedback openly available, to children, young people, families/carers and the general public, together with outcome of relevant local and national audits.	Immediate

	Paediatric	Implementation timescale
	Specialist Children's Surgical Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made. Specialist Children's Surgical Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	
H11(L1)	Each Specialist Children's Surgical Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients and their parents/carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.	Immediate
H12(L1)	Each child/young person must have access to a Children's Cardiac Nurse Specialist (CCNS) who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the parents/carers and child/young person throughout their care. Children/young people with complex needs must have a named CCNS. CCNS contact details will be given at each attendance at the outpatient clinic.	Immediate
H13(L1)	A Children's Cardiac Nurse Specialist must be available at all outpatient appointments to help explain diagnosis and management of the child's condition and to provide relevant literature.	Within 6 months
H14(L1)	The Children's Cardiac Nurse Specialist will support parents by explaining the diagnosis and management plan of the child's condition, and providing psychosocial support to promote family (and child/young person's) adaptation and adjustment.	Immediate
H15(L1)	The Children's Cardiac Nurse Specialist must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H16(L1)	Where children/young people, parents/carers do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	Immediate
H17(L1)	There must be access (for children/young people and families/carers) to support services including faith support and interpreters.	Immediate

	Paediatric	Implementation timescale
H18(L1)	Copies of all correspondence for GP and local centres must be copied to the parent/carer/young person (as appropriate) in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate
H19(L1)	Parents, carers and all health professionals involved in the child's care (and young people as appropriate) must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H20(L1)	Parents and carers should be offered resuscitation training when appropriate.	Immediate
H21(L1)	Where surgery or intervention is planned, the child/young person and their parents or carers must have the opportunity to visit the Specialist Children's Surgical Centre in advance of admission (as early as possible) to meet the team, including the Children's Cardiac Nurse Specialist that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H22(L1)	Children/young people and their parents/carers must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Consent must be taken in line with GMC guidance.	Immediate
H23(L1)	A Children's Cardiac Nurse Specialist must be available to support parents and children/young people throughout the consent process. When considering treatment options, parents, carers (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H24(L1)	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H25(L1)	Parents, patients and carers must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H26(L1)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care.	Within 6 months

	Paediatric	Implementation timescale
H27(L1)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the young person as appropriate or their family/carers) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed with the family so that their views on future care can be included in the pathway. An ongoing opportunity for the patient and parents to discuss concerns about treatment must be offered.	Immediate

DRAFT CHD Standards: Section H: Communication with patients
Level 2: Specialist Children’s Cardiology Centres

	Paediatric	Implementation timescale
	Specialist Children’s Cardiology Centres	
H1(L2)	Specialist Children’s Cardiology Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to actively participate in decision-making at every stage in the care of the child/young person.	Immediate
H2(L2)	Every family/carer (and young person as appropriate) must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient’s GP.	Immediate
H3(L2)	Children and young people, family and carers must be helped to understand the patient’s condition, the effect it may have on their health and future life, what signs and symptoms should be considered ‘normal’ for them and the treatment that they will receive, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child/young person’s, parents’ and carers’ understanding must be considered. Information provided should include any aspect of life that is relevant to their congenital heart condition, including a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. tattoos, piercings and intradermal procedures; f. school and careers; g. travel; h. welfare benefits; i. social services; and j. community services.	Immediate
H4(L2)	Information must be made available to parents, carers, children and young people in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	Immediate

	Paediatric	Implementation timescale
H5(L2)	Specialist Children's Cardiology Centres must demonstrate that arrangements are in place for parents/carers and children and young people to be given an agreed, written management plan, in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H6(L2)	The child/young person's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H7(L2)	Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist Children's Cardiology Centres must make this feedback openly available to patients, families/carers and the general public, together with outcome of relevant local and national audits. Specialist Children's Cardiology Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made. Specialist Children's Cardiology Centres must demonstrate ongoing structured liaison with patient and patient groups, including evidence of how feedback is formally considered.	Immediate
H8(L2)	Each Specialist Children's Cardiology Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients and their parents/carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.	Immediate
H9(L2)	Each child/young person must have access to a Children's Cardiac Nurse Specialist (CCNS) who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the parents/carers and child/young people throughout their care. Children/young people with complex needs must have a named CCNS. CCNS contact details will be given at each attendance at the outpatient clinic.	Immediate
H10(L2)	A Children's Cardiac Nurse Specialist must be available at all outpatient appointments to help explain the diagnosis and management of the child/young person's condition and to provide relevant literature.	Immediate
H11(L2)	The Children's Cardiac Nurse Specialist will support parents/carers by explaining the diagnosis and management plan of the child/young	Immediate

	Paediatric	Implementation timescale
	person's condition, and providing psychosocial support to promote parental (and child/young person's) adaptation and adjustment.	
H12(L2)	The Children's Cardiac Nurse Specialist must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H13(L2)	Where patients, parents/carers do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters /advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	Immediate
H14(L2)	There must be access (for children/young people and families/carers) to support services including faith support and interpreters.	Immediate
H15(L2)	Copies of all correspondence for GP and local centres must be copied to the parent/carer/young person (as appropriate), in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate
H16(L2)	Parents, carers and all health professionals involved in the child's care (and young people as appropriate) must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L2)	Parents and carers should be offered resuscitation training when appropriate.	Immediate
H18(L2)	Specialist Children's Cardiology Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another centre, and in interpreting publicly available data that supports patient choice.	Immediate
H19(L2)	Where surgery or intervention is planned, Specialist Children's Cardiology Centres must ensure that the child/young person and their parents or carers have the opportunity to visit the Specialist Children's Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H20(L2)	A Children's Cardiac Nurse Specialist must be available to support parents and children / young people throughout the consent process. When considering treatment options parents /carers and (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed	Immediate

	Paediatric	Implementation timescale
	consent.	
H21(L2)	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H22(L2)	Parents, patients and carers must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H23(L2)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision making around care and lifecycle transitions, including transition to adult care.	Within 1 year
H24(L2)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the young person if appropriate or their family) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed with the family so that their views on future care can be included in the pathway. An ongoing opportunity for the patient and parents to discuss concerns about treatment must be offered.	Immediate

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
H1(L3)	Local Children's Cardiology Centres must demonstrate that arrangements are in place that allow parents, carers, children and young people to actively participate in decision-making at every stage in the care of the child/young person.	Immediate
H2(L3)	Every family/carer (and young person as appropriate) must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L3)	Children and young people, family and carers must be helped to understand the patient's condition, the effect it may have on their health and future life, what signs and symptoms should be considered 'normal' for them and the treatment that they will receive, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child/young person's, parents' and carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. tattoos, piercings and intradermal procedures; f. school and careers; g. travel; h. welfare benefits; i. social services; and j. community services.	Immediate
H4(L3)	Information must be made available to parents, carers, children and young people in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	Immediate

	Paediatric	Implementation timescale
H5(L3)	Local Children's Cardiology Centres must demonstrate that arrangements are in place for parents/carers, children and young people to be given an agreed, written management plan, in a language they can understand that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H6(L3)	The child/young person's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H7(L3)	Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Local Children's Cardiology Centres must make this feedback openly available, to children and young people, families/carers and the general public, together with outcome of relevant local and national audits. Local Children's Cardiology Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made. Local Children's Cardiology Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate
H8(L3)	Each Local Children's Cardiology Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients and their parents/carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.	Immediate
H9(L3)	Each child/young person must have access to a Children's Cardiac Nurse Specialist (CCNS) who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the parents/carers and child/young people throughout their care. Children/young people with complex needs must have a named CCNS. CCNS contact details will be given at each attendance at the outpatient clinic.	Within 6 months
H10(L3)	A Children's Cardiac Nurse Specialist must be available at all outpatient appointments to help explain the diagnosis and management of the child/young person's condition and to provide relevant literature.	Within 1 year
H11(L3)	The Children's Cardiac Nurse Specialist will support parents by explaining the diagnosis and management plan of the child/young person's condition, and providing psychosocial support to promote parental (and child's/young person's) adaptation and adjustment.	Immediate

	Paediatric	Implementation timescale
H12(L3)	The Children’s Cardiac Nurse Specialist must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H13(L3)	Where patients, parents/carers do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability ‘passports’ which define their communication needs.	Immediate
H14(L3)	There must be access (for children/young people and families/carers) to support services including faith support and interpreters.	Immediate
H15(L3)	Copies of all correspondence for GP and local centres must be copied to the parent/carer/young person (as appropriate), in plain language to retain in the patient’s personal record in accordance with national guidance.	Immediate
H16(L3)	Parents, carers and all health professionals involved in the child’s care (and young people as appropriate) must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L3)	Parents and carers should be offered resuscitation training when appropriate.	Immediate
H18(L3)	Local Children’s Cardiology Centres must demonstrate that parents, carers and young people are offered support in obtaining further opinions or referral to another centre, and in interpreting publicly available data that supports patient choice.	Immediate
H19(L3)	Where surgery or intervention is planned, Local Children’s Cardiology Centres must ensure that the child/young person and their parents or carers have the opportunity to visit the Specialist Children’s Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H20(L3)	A Children’s Cardiac Nurse Specialist must be available to support parents and children / young people throughout the consent process. When considering treatment options parents /carers and (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate

	Paediatric	Implementation timescale
H21(L3)	Parents and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H22(L3)	Parents, patients and carers must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H23(L3)	A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care. Where this service is not available locally the patient should be referred to the Specialist Surgical Centre or Specialist Children's Cardiology Centre.	Within 1 year
H24(L3)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the young person, as appropriate, or their family) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed with the family so that their views on future care can be included in the pathway. An ongoing opportunity for the child/young person and parents/carers to discuss concerns about treatment must be offered.	Immediate

	Paediatric	Implementation timescale
I1(L1)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L1)	Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.	Immediate
I3(L1)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I4(L1)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.	Immediate
I5(L1)	All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not need long-term follow-up.	Immediate
I6(L1)	Young people, parents and carers must be fully involved and supported in discussions around the clinical issues. The views, opinions and feelings of the young person and family/carers must be fully heard and considered. The young person must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I7(L1)	The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.	Immediate
I8(L1)	All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family. Peer to peer support should also be offered.	Immediate
I9(L1)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging	Immediate

	Paediatric	Implementation timescale
	results and the care plan.	
I10(L1)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Their attention must be drawn to sources of information and support groups.	Immediate
I11(L1)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I12(L1)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Immediate

	Paediatric	Implementation timescale
I1(L2)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L2)	Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.	Immediate
I3(L2)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I4(L2)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.	Immediate
I5(L2)	All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not need long-term follow-up.	Immediate
I6(L2)	Young people, parents and carers must be fully involved and supported in discussions around the clinical issues. The views, opinions and feelings of the young person and family/carers must be fully heard and considered. The young person must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I7(L2)	The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.	Immediate
I8(L2)	All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family. Peer to peer support should also be offered.	Immediate
I9(L2)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging	Immediate

	Paediatric	Implementation timescale
	results and the care plan.	
I10(L2)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Their attention must be drawn to sources of information and support groups.	Immediate
I11(L2)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I12(L2)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Immediate

	Paediatric	Implementation timescale
I1(L3)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L3)	Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.	Immediate
I3(L3)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I4(L3)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.	Immediate
I5(L3)	All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not need long-term follow-up.	Immediate
I6(L3)	Young people, parents and carers must be fully involved and supported in discussions around the clinical issues. The views, opinions and feelings of the young person and family/carers must be fully heard and considered. The young person must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I7(L3)	The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.	Immediate
I8(L3)	All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family. Peer to peer support should also be offered.	Immediate
I9(L3)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate

	Paediatric	Implementation timescale
I10(L3)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Their attention must be drawn to sources of information and support groups.	Immediate
I11(L3)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I12(L3)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.	Within 1 year

	Paediatric	Implementation timescale
	Family Planning Advice	
J1(L1)	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	Immediate
J2(L1)	In line with national curriculum requirements, from age 12, female patients will have access to specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture, developmental level and cognitive ability and taking into account any personal/cultural expectations for the future. Written advice about sexual and reproductive health and safe forms of contraception specific to their condition must be provided as appropriate, in preparation for when this becomes relevant to them. They must have ready 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.	Immediate
J3(L1)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L1)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant paediatric cardiologist and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist.	Immediate
J5(L1)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Within 1 year
	Pregnancy and Planning Pregnancy	
	For patients planning pregnancy or who are pregnant, refer to adult standards; section J: Pregnancy and Contraception for further relevant standards.	

	Paediatric	Implementation timescale
	Family Planning Advice	
J1(L2)	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	Immediate
J2(L2)	In line with national curriculum requirements, from age 12, female patients will have access to specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture, developmental level and cognitive ability and taking into account any personal/cultural expectations for the future. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided as appropriate, in preparation for when this becomes relevant to them. They must have ready 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.	Immediate
J3(L2)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L2)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant paediatric cardiologist and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist.	Immediate
J5(L2)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Immediate
	Pregnancy and Planning Pregnancy	
	For patients planning pregnancy or who are pregnant, refer to adult standards, section J: Pregnancy and Contraception for further relevant standards.	

	Paediatric	Implementation timescale
	Family Planning Advice	
J1(L3)	All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist or paediatrician with expertise in cardiology and a nurse specialist with expertise in pregnancy in congenital heart disease. Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service through an outreach clinic, at the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.	Immediate
J2(L3)	In line with national curriculum requirements, from age 12, female patients will have access to specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture, developmental level and cognitive ability and taking into account any personal/cultural expectations for the future. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided as appropriate, in preparation for when this becomes relevant to them. They must have ready 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.	Immediate
J3(L3)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L3)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant paediatric cardiologist or paediatrician with expertise in cardiology and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist. Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service through an outreach clinic at the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.	Immediate
J5(L3)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Immediate
	Pregnancy and Planning Pregnancy	
	For patients planning pregnancy or who are pregnant, refer to adult standards, section J: Pregnancy and Contraception for further relevant standards.	

	Paediatric	Implementation timescale
K1(L1)	Obstetric services caring for patients with congenital heart disease must offer fetal cardiac diagnosis and management protocols as an integral part of the service offered to patients with congenital heart disease.	Immediate
K2(L1)	All Congenital Heart Networks must work with all providers of maternity and paediatric cardiac services in their network to ensure that NHS Fetal Anomaly Screening Programme standards are consistently met and results reported. There should be feedback to sonographers from fetal cardiac services and obstetricians when they have/have not picked up a fetal anomaly.	Immediate
K3(L1)	Each congenital heart network will agree and establish protocols with obstetric, fetal maternal medicine units, tertiary neonatal units, local neonatal units and paediatrics teams in their Congenital Heart Network for the care and treatment of pregnant women whose fetus has been diagnosed with a major heart condition. The protocols must meet the relevant NHS Fetal Anomaly Screening Programme and British Congenital Cardiac Association Standards.	Immediate
K4(L1)	Mothers whose pregnancies have a high risk of fetal CHD must be offered access to fetal cardiac scanning, the timing of which must be in line with the British Congenital Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.	Immediate
K5 (L1)	All women with a suspected or confirmed fetal cardiac anomaly must be seen by : • an obstetric ultrasound specialist within three working days of the referral being made; and • a fetal cardiology specialist within three days of referral and preferably within two working days if possible. If there is also a suspicion of non-cardiac abnormalities, simultaneous referral must be made to a fetal medicine unit (in accordance with FASP standards). This must not delay referral to a fetal cardiology specialist. (This standard exceeds the requirements of current British Congenital Cardiac Association and NHS Fetal Anomaly Screening Programme (FASP) standards reflecting the concerns of service users.)	Immediate
K6(L1)	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.	Immediate
K7(L1)	Each unit must have designated paediatric cardiology consultant(s) with a special interest and expertise in fetal cardiology, who have fulfilled the training requirements for fetal cardiology as recommended by the paediatric cardiology Specialty Advisory Committee or the Association for European Paediatric Cardiology.	Immediate

	Paediatric	Implementation timescale
K8(L1)	A Fetal Cardiac Nurse Specialist) will be present during the consultation or will contact all prospective parents whose baby has been given an antenatal diagnosis of cardiac disease to provide information and support on the day of diagnosis. Parents must also be given contact details for relevant local and national support groups at this point. The Fetal Cardiac Nurse Specialist (FCNS) must work with the Cardiologist and the fetal medicine team to ensure that condition-specific information, explanation of treatment options, and psychosocial support is provided. The FCNS will act as the point of contact for the family throughout pregnancy for support and further information.	Immediate
K9(L1)	Following the diagnosis of a complex congenital heart condition, the fetal medical team will discuss all the options and ensure that the palliative nature of the treatment options is discussed in a caring and supportive fashion. A named clinician and specialist nurse will be identified. Written information on the pathways discussed and further non-directional information will be given to the parents, including information on support services available. Information about the agreed pathway will be shared with all members of the network (hospital and community) clinical teams.	Immediate
K10(L1)	At diagnosis, a plan must be agreed between the Specialist Children's Surgical Centre, the specialist fetal-maternal unit, the local obstetric unit, the neonatal team, paediatricians and the parents about arrangements for the delivery of the baby. The plan must be updated throughout pregnancy.	Immediate
K11(L1)	In all cases where a baby may require immediate postnatal catheter intervention or surgery, the baby must be delivered at or close to the Specialist Surgical Centre (for example, at a linked obstetric unit). This decision must be explained to the parents. Appropriate contact must be maintained with the local obstetric unit which will continue to be the mother's first port of call in an emergency or in case of preterm delivery.	Immediate
K12(L1)	When the plan is for the delivery of the baby at the local maternity unit, this must include a clear written plan, including timetable for the transfer of the mother and baby to the Specialist Children's Surgical Centre if early intervention or assessment is required. A neonatal team must be present at the time of delivery and be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment, robust arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.	Immediate

	Paediatric	Implementation timescale
K1(L2)	All Congenital Heart Networks must work with all providers of maternity and paediatric cardiac services in their network to ensure that NHS Fetal Anomaly Screening Programme standards are consistently met and results reported. There should be feedback to sonographers from fetal cardiac services and obstetricians when they have/have not picked up a fetal anomaly.	Immediate
K2(L2)	Specialist Children's Cardiology Centres that do not provide a fetal diagnostic cardiology service must work within the protocols defined by the Specialist Children's Surgical Centre in their Congenital Heart Network.	Immediate
K3(L2)	Mothers whose pregnancies have a high risk of fetal CHD must be offered access to fetal cardiac scanning, the timing of which must be in line with the British Congenital Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.	Immediate
K4(L2)	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.	Immediate
K5 (L2)	All women with a suspected or confirmed fetal cardiac anomaly must be seen by : • an obstetric ultrasound specialist within three working days of the referral being made; and • a fetal cardiology specialist within three days of referral and preferably within two working days if possible. If there is also a suspicion of non-cardiac abnormalities, simultaneous referral must be made to a fetal medicine unit (in accordance with FASP standards). This must not delay referral to a fetal cardiology specialist. (This standard exceeds the requirements of current British Congenital Cardiac Association and NHS Fetal Anomaly Screening Programme (FASP) standards reflecting the concerns of service users.)	Immediate
K6(L2)	Each unit must have designated paediatric cardiology consultant(s) with a special interest and expertise in fetal cardiology, who have fulfilled the training requirements for fetal cardiology as recommended by the paediatric cardiology Specialty Advisory Committee or the Association for European Paediatric Cardiology.	Immediate
K7(L2)	A Fetal Cardiac Nurse Specialist will be present during the consultation or will contact all prospective parents whose baby has been given an antenatal diagnosis of cardiac disease to provide information and support on the day of diagnosis. Parents must also be given contact details for relevant local and national support groups at this point. The Fetal Cardiac Nurse Specialist (FCNS) must work with the Cardiologist and the fetal medicine team to ensure that condition-specific information, explanation of treatment options, and psychosocial support is provided. The FCNS will act as the point of contact for the family	Immediate

	Paediatric	Implementation timescale
	throughout pregnancy for support and further information.	
K8(L2)	Following the diagnosis of a complex congenital heart condition, the fetal medical team will discuss all the options and ensure that the palliative nature of the treatment options is discussed in a caring and supportive fashion. A named clinician and specialist nurse will be identified. Written information on the pathways discussed and further non-directional information will be given to the parents, including information on support services available. Information about the agreed pathway will be shared with all members of the network (hospital and community) clinical teams.	Immediate
K9(L2)	At diagnosis, a plan must be agreed with the Specialist Children's Surgical Centre, the specialist fetal-maternal unit, the local obstetric unit, the neonatal team, paediatricians and the parents about arrangements for the delivery of the baby. The plan must be updated throughout pregnancy.	Immediate
K10(L2)	In all cases where a baby may require immediate postnatal catheter intervention or surgery, the baby must be delivered at or close to the Specialist Children's Surgical Centre (for example, at a linked obstetric unit). This decision must be explained to the parents. Appropriate contact must be maintained with their local obstetric unit which will continue to be the mother's first port of call in an emergency or in case of preterm delivery.	Immediate
K11(L2)	When the plan is for the delivery of the baby at the local maternity unit, this must include a clear written plan, including a timetable, for the transfer of the mother and baby to the Specialist Children's Surgical Centre if early intervention or assessment is required. A neonatal team must be present at the time of delivery and be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment, robust arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.	Immediate

DRAFT CHD Standards: Section K: Fetal diagnosis
Level 3: Local Children's Cardiology Centres

	Paediatric	Implementation timescale
K1(L3)	All Congenital Heart Networks must work with all providers of maternity and paediatric cardiac services in their network to ensure that NHS Fetal Anomaly Screening Programme standards are consistently met and results reported. There should be feedback to sonographers from fetal cardiac services and obstetricians when they have/have not picked up a fetal anomaly.	Immediate
K2(L3)	Local Children's Cardiology Centres that do not provide a fetal diagnostic cardiology service must work within the protocols defined by the Specialist Children's Surgical Centre in their Congenital Heart Network.	Immediate
K3(L3)	Mothers whose pregnancies have a high risk of fetal CHD must be offered access to fetal cardiac scanning, the timing of which must be in line with the British Congenial Cardiac Association Fetal Cardiology Standards and adhere to the NHS Fetal Anomaly Screening Programme clinical care pathway for congenital heart disease.	Immediate
K4(L3)	Counselling for congenital cardiac anomalies must be performed by a fetal cardiologist or paediatric cardiologist with experience of fetal cardiology.	Immediate
K5(L3)	A Fetal Cardiac Nurse Specialist will be present during the consultation or will contact all prospective parents whose baby has been given an antenatal diagnosis of cardiac disease to provide information and support on the day of diagnosis. Parents must also be given contact details for relevant local and national support groups at this point. The Fetal Cardiac Nurse Specialist (FCNS) must work in collaboration with the Cardiologist and fetal medicine team to ensure that condition-specific information, explanation of treatment options, and psychosocial support is provided. The FCNS will act as the point of contact for the family throughout pregnancy for support and further information.	Immediate
K6(L3)	At diagnosis a plan must be agreed with the Specialist Children's Surgical Centre, the specialist fetal-maternal unit, the local obstetric unit, the neonatal team, paediatricians and the parents about arrangements for the delivery of the baby. The plan must be updated throughout pregnancy.	Immediate
K7(L3)	In all cases where a baby may require immediate postnatal catheter intervention or surgery, the baby must be delivered at or close to the Specialist Children's Surgical Centre (for example, at a linked obstetric unit). This decision must be explained to the parents. Appropriate contact must be maintained with their local obstetric unit which will continue to be the mother's first port of call in an emergency or in case of preterm delivery.	Immediate

	Paediatric	Implementation timescale
K8(L3)	When the plan is for the delivery of the baby at the local maternity unit, this must include a clear written plan, including timetable for the transfer of the mother and baby to the Specialist Children's Surgical Centre if early intervention or assessment is required. A neonatal team must be present at the time of delivery and be available to care for the baby whilst awaiting transfer. In cases not requiring urgent assessment, robust arrangements for early postnatal cardiac evaluation must be in place prior to delivery, and enacted after delivery.	Immediate

	Paediatric	Implementation timescale
	Palliative Care Note: **Palliative care** is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L1)	Each Specialist Children's Surgical Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral for ongoing emotional support of the family/carers.	Immediate
L2(L1)	Clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L1)	When a child or young person is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the child/young person and their family/carers. These leads may change over time as appropriate.	Immediate
L4(L1)	The lead doctor and named nurse will work together with the palliative care team to ensure the child/young person and their family/carers are supported up to, and beyond death.	Immediate
L5(L1)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the child/young person and their family/carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The potential for organ and tissue donation should be discussed. The family/carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L1)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L1)	Communication and end-of-life care discussions with children, young people and their families/carers must be open, honest and accurate.	Immediate
L8(L1)	The child/young person and their family/carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L1)	For children and young people remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their parents/carers can easily seek answers to questions and express wishes, worries and fears.	Immediate

	Paediatric	Implementation timescale
L10(L1)	The room and environment must be prepared to meet the palliative care needs and wishes of the child/young person and their family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L1)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L1)	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L1)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the child/young person and their family.	Immediate
L14(L1)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local paediatricians, GPs, community children's nurses, out-of-hours GP and ambulance services and the local children's hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L1)	Support for children/young people and their families/carers must continue if they choose to have their end-of-life care in the community. Families/carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L1)	The team supporting a child/young person, and their family/carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the child/young person and their family/carers where possible.	Immediate
L17(L1)	If a family would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L1)	Young people, parents and carers will be offered an opportunity to discuss the donation of organs and tissues with the *Donor* team.	Immediate
L19(L1)	The lead doctor/named nurse will inform the hospital bereavement team that a child is dying. They should only be introduced to the	Immediate

	Paediatric	Implementation timescale
	family/carers before a death has occurred, if they have specifically requested to meet them.	
L20(L1)	Families/carers must be allowed to spend as much time as possible with their child after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of their child.	Immediate
L21(L1)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L1)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L1)	Contact details of agreed, named professionals within the paediatric cardiology team and bereavement team will be provided to the child/young person's family/carers at the time they leave hospital.	Immediate
L24(L1)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a child/young person	
L25(L1)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L1)	Within six weeks of the death, the identified lead doctor will write to offer the opportunity for the family/carers to visit the hospital team to discuss their child's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The family/carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Families who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	Immediate
L27(L1)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the family/carers.	Immediate
L28(L1)	If families/carers are seeking more formal ongoing support, the identified Children's Cardiac Nurse Specialist/named nurse will liaise with appropriate services to arrange this.	Immediate

	Paediatric	Implementation timescale
	Palliative Care Note: **Palliative care** is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L2)	Each Specialist Children's Cardiology Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral for ongoing emotional support of the family/carers.	Immediate
L2(L2)	Clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L2)	When a child or young person is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the child/young person and their family/carers. These leads may change over time as appropriate.	Immediate
L4(L2)	The lead doctor and named nurse will work together with the palliative care team to ensure the child/young person and their family/carers are supported up to, and beyond death.	Immediate
L5(L2)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the child/young person and their family/carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family) The potential for organ and tissue donation should be discussed. The family/carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L2)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L2)	Communication and end-of-life care discussions with children, young people and their families/carers must be open, honest and accurate.	Immediate
L8(L2)	The child/young person and their family/carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L2)	For children and young people remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their parents/carers can easily seek answers to questions and express wishes, worries and fears.	Immediate

	Paediatric	Implementation timescale
L10(L2)	The room and environment must be prepared to meet the palliative care needs and wishes of the child/young person and their family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L2)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L2)	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L2)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the child/young person and their family.	Immediate
L14(L2)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local paediatricians, GPs, community children's nurses, out-of-hours GP and ambulance services and the local children's hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L2)	Support for children/young people and their families/carers must continue if they choose to have their end-of-life care in the community. Families/carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L2)	The team supporting a child/young person, and their family/carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the child/young person and their family/carers where possible.	Immediate
L17(L2)	If a family would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L2)	Young people, parents and carers will be offered an opportunity to discuss the donation of organs and tissues with the *Donor* team.	Immediate
L19(L2)	The lead doctor/named nurse will inform the hospital bereavement team that a child is dying. They should only be introduced to the	Immediate

	Paediatric	Implementation timescale
	family/carers before a death has occurred, if they have specifically requested to meet them.	
L20(L2)	Families/carers must be allowed to spend as much time as possible with their child after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of their child.	Immediate
L21(L2)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L2)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L2)	Contact details of agreed, named professionals within the paediatric cardiology team and bereavement team will be provided to the child/young person's family/carers at the time they leave hospital.	Immediate
L24(L2)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a child/young person	
L25(L2)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L2)	Within six weeks of the death, the identified lead doctor will write to invite the family/carers to visit the hospital team to discuss their child's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The family/carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Families who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	Immediate
L27(L2)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the family/carers.	Immediate
L28(L2)	If families/carers are seeking more formal ongoing support, the identified Children's Cardiac Nurse Specialist/named nurse will liaise with appropriate services to arrange this.	Immediate

	Paediatric	Implementation timescale
	Palliative Care **Note: Palliative care** is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L3)	Each Local Children's Cardiology Centre must provide access to a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the family/carers. Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service at the Specialist Children's Surgical or Specialist Children's Cardiology Centre.	Immediate
L2(L3)	Clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L3)	When a child or young person is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the child/young person and their family/carers. These leads may change over time as appropriate.	Immediate
L4(L3)	The lead doctor and named nurse will work together with the palliative care team to ensure the child/young person and their family/carers are supported up to, and beyond death.	Immediate
L5(L3)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the child/young person and their family/carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The potential for organ and tissue donation should be discussed. The family/carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L3)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L3)	Communication and end-of-life care discussions with children, young people and their families/carers must be open, honest and accurate.	Immediate

	Paediatric	Implementation timescale
L8(L3)	The child/young person and their family/carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L3)	For children and young people remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their parents/carers can easily seek answers to questions and express wishes, worries and fears.	Immediate
L10(L3)	The room and environment must be prepared to meet the palliative care needs and wishes of the child/young person and their family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L3)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L3)	Children/young people and their families/carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L3)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the child/young person and their family.	Immediate
L14(L3)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local paediatricians, GPs, community children's nurses, out-of-hours GP and ambulance services and the local children's hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L3)	Support for children/young people and their families/carers must continue if they choose to have their end-of-life care in the community. Families/carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L3)	The team supporting a child/young person, and their family/carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the child/young person and their family/carers where possible.	Immediate

	Paediatric	**Implementation timescale**
L17(L3)	If a family would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L3)	Young people, parents and carers will be offered an opportunity to discuss the donation of organs and tissues with the *Donor* team.	Immediate
L19(L3)	The lead doctor/named nurse will inform the hospital bereavement team that a child is dying. They should only be introduced to the family/carers before a death has occurred, if they have specifically requested to meet them.	Immediate
L20(L3)	Families/carers must be allowed to spend as much time as possible with their child after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of their child.	Immediate
L21(L3)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L3)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L3)	Contact details of agreed, named professionals within the paediatric cardiology team and bereavement team will be provided to the child/young person's family/carers at the time they leave hospital.	Immediate
L24(L3)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a child/young person	
L25(L3)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L3)	Within six weeks of the death, the identified lead doctor will write to invite the family/carers to visit the hospital team to discuss their child's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The family/carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of	Immediate

	Paediatric	Implementation timescale
	death. Families who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	
L27(L3)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the family/carers.	Immediate
L28(L3)	If families/carers are seeking more formal ongoing support, the identified Children's Cardiac Nurse Specialist/named nurse will liaise with appropriate services to arrange this.	Immediate

DRAFT CHD Standards: Section M: Dental
Level 1: Specialist Children's Surgical Centres

	Paediatric	Implementation timescale
M1(L1)	Children and young people and their parents/carers will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L1)	All children and young people with planned elective cardiac surgery or intervention must have a dental assessment as part of pre-procedure planning to ensure that they are dentally fit for their planned intervention.	Immediate
M3(L1)	All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.	Immediate
M4(L1)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L1)	Specialist Children's Surgical Centres must provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for children and young people with congenital heart disease.	Immediate
M6 (L1)	Specialist Children's Surgical Centres will refer children with CHD to a hospital dental service when local dental services will not provide care.	Immediate

	Paediatric	Implementation timescale
	Specialist Children’s Cardiology Centres	
M1(L2)	Children and young people and their parents/carers will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L2)	The Specialist Children’s Cardiology Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L2)	All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.	Immediate
M4(L2)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L2)	Specialist Children’s Cardiology Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for children and young people with congenital heart disease or refer such patients to the Specialist Children’s Surgical Centre.	Immediate
M6 (L2)	Specialist Children’s Cardiology Centres will refer children with CHD to a hospital dental service when local dental services will not provide care.	Immediate

	Paediatric	Implementation timescale
	Local Children's Cardiology Centres	
M1(L3)	Children and young people and their parents/carers will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L3)	Each Local Children's Cardiology Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L3)	All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.	Immediate
M4(L3)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L3)	Local Children's Cardiology Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for children and young people with congenital heart disease or refer such patients to the Specialist Children's Surgical Centre.	Immediate
M6 (L3)	Local Children's Cardiology Centres will refer children with CHD to a hospital dental service when local dental services will not provide care.	Immediate

SCHEDULE 2 – THE SERVICES

A. Service Specifications

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

1. Population Needs

1.1 National/local context and evidence base

This specification covers all Paediatric Cardiac activity (surgery and cardiology), taking place in the Specialist Children's Surgical Centres (Level 1 services) and Specialist Children's Cardiology Centres (Level 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 Level 3 services (Local Children's Cardiac Centres). This activity is commissioned by Clinical Commissioning Groups and is therefore outside the scope of this specification. Nevertheless Level 3 services are part of the Congenital Heart Network of Care and it is expected that Children's Level 1 and 2 services will work in partnership with Level 3 providers to ensure all patient care is of a consistent, high quality.

1.2 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 5-9 / 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.

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, 2015).

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 “Levels” of provider as described in the Standards of Care.

The Standards provide timescales for achievement of each standard ranging from standards that must be achieved immediately to standards which must be achieved within 5 years. The timescale for each standard is provided in the standards document.

Network Care Levels:

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

It is expected that Paediatric and Adult services will work in partnership within the network 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

1.4 Evidence Base

Draft Congenital Heart Disease Standards Level 1-3 (2015)

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**	✓

A quality dashboard is now operational. Currently assessed outcome measures include the following:

- Post Procedural Mortality: 3 year validated partial risk adjusted 30 day mortality after paediatric cardiac surgery
- 1 year rolling unvalidated partial risk adjusted 30 day mortality after paediatric cardiac surgery
- 30 day unplanned re intervention rate following congenital cardiac surgery and catheter intervention (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 Service Aims and Objectives

Service Aims

The Children's Heart Service aims to provide services in line with the agreed standards of care and which operate within a Network Model encompassing care from point of diagnosis to exiting the service. The service will manage all patients diagnosed with heart disease before their 16th birthday, with the exception of some forms of inherited heart disease.

The service for children's heart disease aims to:

- Deliver best outcomes for patients, with lowest mortality, minimal disability and an improved opportunity for a better quality of life for survivors
- Consistently meet the standards of care (2015) and provide resilient 24/7 care
- Communicate effectively with other specialised services as required to ensure high quality care for children with co-morbidities
- 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;
- Systematically measure and act upon patient experience and satisfaction and contribute to patient surveys where they exist
- 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 Congenital Heart Disease by:

- Development of Congenital Heart Networks to deliver a standardised model of care 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; and
- Providing an individualised palliative care and bereavement service.

3.2 Service description/care pathway

Overview

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

The model of care for children with heart disease is based on an overarching principle of a Congenital Heart Network. Working in partnership with the Adult Congenital Heart services the network will adopt policies and guidelines agreed across the network relating to patient management pathways within each of the centre’s specific care levels described below. The Congenital Heart Networks will also be expected to link closely with related networks covering areas such as fetal medicine, maternity, neonatal and paediatric intensive care.

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:

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

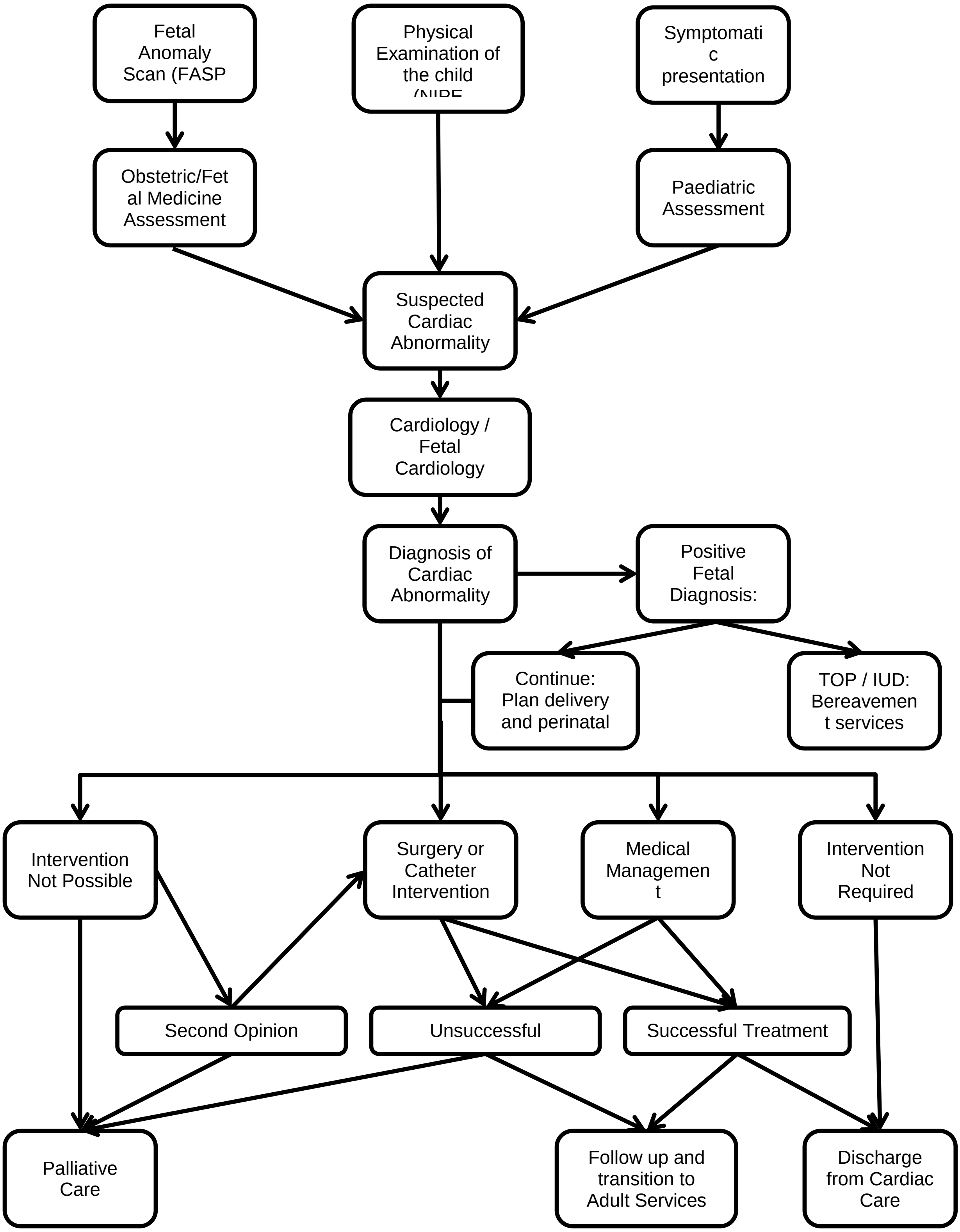
Across the whole Congenital Heart Network there must be facilities in place to ensure easy and convenient access for patients and their families/carers and facilities and where an inpatient stay is needed, support should include:

- Accommodation for parents/carers/siblings 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 (levels 2 & 3)

Patients should be seen in an appropriate paediatric environment, ideally within a dedicated paediatric cardiology ward/OPD space.

Parents or carers and where appropriate patients must be supported to actively participate in decision making at every stage of their care.

Patient care pathway



Referral

Patients enter the paediatric cardiac pathway through:

- Prenatal diagnosis.
- Physical examination of an asymptomatic infant or child (including NIPE).
- 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.

- Upon referral the appropriate paediatric cardiac service will:See referrals within 3 days and preferably within 2 working 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 cardiac nurse specialist)

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.

- The fetal cardiac team will discuss options available to the family in a non-directive, caring and supportive way with direction given to publically available information
- A Fetal Cardiac Nurse Specialist will be present when the diagnosis is explained to the parents, or make contact with them to provide information and support on the day of diagnosis.
- Written information regarding the condition, pathways discussed, available support services including contact details of local and national support groups will be provided.
- A named clinician and specialist nurse will be identified
- 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 SCSC in all cases where the baby may require immediate surgery or catheter intervention.
- A children's cardiac nurse specialist/fetal 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 fetus.

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, 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 specialist 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.
- 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.

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

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

The process of transitioning from paediatric to ACHD care must be initiated no later than 12 years of age taking into account individual circumstances and special needs.

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. Each CHD 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.

- The ACHD service will accept referrals of appropriate young people from the paediatric cardiac services.
- 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.
- Clear care plans (or transition “passports”) must be agreed for further management in a clearly specified setting
- A named children’s cardiac transition nurse will act as a main point of contact and provide support to the young person and their family. They will also function 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
- Peer to peer support should be offered
- 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

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. The potential for organ and tissue donation should be discussed.
- 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 are 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 at a mutually agreed time and location, to offer support.
- When a death occurs in hospital, the processes that follow a death including legal aspects need to be explained verbally, at the family’s pace and backed up with written information. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.
- 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 with the hospital team.
- 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 ongoing treatment, including the seeking of a second opinion, must be

discussed with the family.

Paediatric Congenital Heart Disease MDT

- The management of patients with significant congenital heart disease should be discussed at combined MDT meetings at the SCSC. This includes all patients being considered for a complex catheter intervention, surgery or innovative procedures
- Each MDT discussion must generate a signed record of the discussion and the final outcome.
- When considering patients for complex catheter intervention or surgery (including out of hours and in emergencies) the minimum composition of the MDT is a Congenital Cardiologist, Congenital Surgeon and Specialist Intensivist 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 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.

Communication

- Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient’s GP

- Patients and their carers must be given sufficient information for them to understand and contextualize their congenital heart condition. Information provided should include any aspect of life that is relevant to them including: exercise and sports participation, sex, contraception, pregnancy, dental care, endocarditis prevention, smoking, alcohol and drugs; tattoos, piercings and intradermal procedures, school, career, travel, welfare benefits, social services and community services.

- Sufficient information must be provided to patients and carers to allow informed decisions to be made. This should include help interpreting publicly available data, information on other clinical specialties offered by alternative units (particularly for patients with co-morbidities), accessibility of alternative units, patient facilities offered by alternative units, outcomes at units under consideration and consideration of the closest unit to the patient’s home.

- Patients and Carers must be offered support in obtaining further opinions or referral to another Specialist Children’s Surgical Centre

- Patients and carers must be encouraged to provide feedback on the quality of care and their experience of the service. This feedback should be openly available together with outcome of relevant local and national audits. It should also be taken into account when planning and delivering services.

Governance

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

- Regular continuous clinical audit and quality improvement.
- Regular network multidisciplinary team (MDT) clinical meetings.
- Regular network meetings to review dashboard metrics including PRAiS mediated VLAD outcomes and unplanned re-interventions, discussion of mortality, morbidity, adverse events and resultant action plans.

- Regular network meetings of the wider clinical team (including network patient representatives) at least every 6 months, for issues such as agreement of protocols, review of audit data and monitoring of performance.

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 Children's 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.
- All centres must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiological procedures and endocarditis to the National Congenital Heart Disease Audit (NCHDA) housed within the National Institute for Cardiovascular Outcomes Research (NICOR), as appropriate.
- All centres delivering care to children with cardiac abnormalities will co-operate in developing a national register of research trials and outcomes.

Annual reports

Congenital Heart Networks will produce annual audit and governance reports covering paediatric cardiac services.

3.3 Service Description of Provider Centres within Paediatric Heart Networks

The Network must demonstrate a robust policy for collaboration with other Networks and with NHS commissioners for audit, including formal inter-unit peer review every five years.
The Specialist Children's Surgical Centre will work with the Specialist Children's Cardiology Centres and Local Children's 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; and
- Continually review the pathways to ensure they provide the best care and support for parents and their children.

Specialist Children's Surgical Centres (SCSCs) (Level 1)

- SCSCs will perform all surgical and interventional procedures on children and provide a full range of diagnostic tests for fetal and paediatric patients.
- SCSCs will provide assessment and follow-up services for children who live locally.
- Consultant Cardiologists from the SCSC will provide an outreach outpatient service in conjunction with paediatricians with special expertise in cardiology at Local Children's Cardiology Centres within their network.
- The SCSC 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.
- SCSCs 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 (SCCC) (Level 2)

- The team of Consultant Paediatric Cardiologists will provide all paediatric cardiac medical services including assessment of new referrals and ongoing inpatient and outpatient medical management of children with heart disease.
- Consultant Cardiologists from the SCCC will provide an outreach outpatient 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 SCCC to the SCSC.
- If clinically indicated, emergency balloon atrial septostomy and temporary pacing may be conducted in a SCCC following clear Network guidelines,

Local Children's Cardiology Centres (LCCC) (Level 3))

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

3.4 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). 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 (including patients with congenital heart disease and inherited/ acquired conditions) 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.

4. Applicable Service Standards

Infrastructure requirements

4.1 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 (2015). They have not been included in detail here for brevity.

4.2 Congenital Heart 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.
- Each Congenital Heart Network will have a formally appointed Network Manager responsible for the management of the network, and the conduct of network business.
- Appropriate managerial and administrative support for the effective operation of the network is the joint responsibility of all constituent units.
- Each Network 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.

4.2.1 Specialist Children’s Surgical Centres

- SCSCs must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service, within legally compliant rotas, including 24/7 paediatric surgery and interventional cardiology cover.
- Each SCSC will have a formally nominated paediatric CHD lead who will support the Network Clinical Director. Each SCSC will also have a formally nominated lead CHD nurse. Both will have responsibility for the service at the SCSC, with additional responsibilities across the network.

Surgeons

- Surgical teams must consist of a minimum of four WTE consultant congenital cardiac surgeons. Units will have a period of five 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 complement of 3 WTE consultant congenital cardiac surgeons will be acceptable in the interim.
- SCSCs must provide 24/7 surgical care across the spectrum of neonatal and paediatric surgical emergencies (with the exception of cardiac transplantation) with Consultant call to bedside response time of 30 minutes
- SCSCs 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 (paediatric and ACHD) surgical procedures (auditable cases as defined by submission to NICOR with the addition of VAD implantation procedures and cardiac transplantation) each year, averaged over a three-year period.

Cardiologists

- SCSCs must be staffed by a minimum of 1 consultant paediatric cardiologist per half-million population served by the network, working flexibly across the network
- SCSCs must provide 24/7 elective and emergency care, including specialist consultant paediatric cardiology on-call cover, with rotas no more frequent than 1 in 4 and ensuring a Consultant call to bedside response time of 30 minutes
- A Consultant ward round will occur daily
- Consultant interventional cardiology cover must be 24/7 with a rota no more frequent than 1 in 4. Congenital interventionists based at other hospitals may participate in this rota. 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 SCSC must be staffed by a minimum of one expert electrophysiologist experienced in paediatric cardiac disease with appropriate arrangements for cover by a competent person
- Each SCSC will have a congenital cardiac imaging specialist expert in both cardiac MRI and cardiac CT.
- Each SCSC will have a lead for congenital echocardiography (EACVI accredited or retrospective equivalent experience).
- Each SCSC 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.

Nursing

- Each SCSC 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 SCSC will provide sufficient clinical cardiac nurse educators to deliver competency-based programs for nurses across the network
- Each Congenital Heart Network will employ a minimum of either 7 WTE children's cardiac nurse specialists or 1 per 600,000 of the catchment population (whichever is the larger) distributed across the network according to geography and population. Included in this complement will be at least 1 WTE fetal cardiac nurse specialist and 1 WTE children's cardiac transition nurse

Other

- 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.
- Perfusion services and staffing must be accredited by The College of Clinical Perfusion Scientists of Great Britain and Ireland
- Each SCSC will have a team of congenital echocardiography scientists (technicians), with a designated lead 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.
- Each SCSC must employ practitioner psychologists at a ratio of 0.25 WTE per 100 children undergoing cardiac surgery each year. A further minimum of 1 WTE practitioner psychologist must be employed to support the service across the network.
- The SCSC 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 SCSC 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 SCSC must have a minimum of 2 WTE dedicated play specialists.
- Each SCSC will provide 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 SCCC will have telemedicine facilities to link with the SCSC.
- Each SCSC should have landing facilities for a helicopter and must have local arrangements for transferring patients from airfields and helipads.
- Equipment infrastructure on site: Electrophysiology including three-dimensional mapping ; standard, contrast, intraoperative, transesophageal and fetal echocardiography (echo); cardiac catheterisation laboratory; Magnetic Resonance Imaging (MRI); Computerised Tomography (CT); post-operative extra corporeal life support (Non-nationally designated extracorporeal membrane oxygenation (ECMO)); and access to Isotope Imaging.

Specialist Children's Cardiology Centres (SCCCs)

- Congenital Heart Networks may be supported by one or more SCCC. 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 SCCC 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 SCCC will be staffed by a minimum of 4 WTE Consultant Paediatric Cardiologists, in addition to the 1 WTE per half million of the population covered by the centre.
- Each SCCC will have a designated Clinical Paediatric Cardiology lead with responsibility

for service provision within the SCCC.

- Each SCCC 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 SCSC.
- Leads at the SCCC may also take on a similar role for the Network.
- Interventional cardiologists from the SCCC who undertake procedures at the SCSC must perform at least 50 procedures a year, averaged over a three-year period.

Nursing

- Each SCCC 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 SCCC 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 SCCC 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

- 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.
- Children referred to the SCCC 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 SCCC will have a team of Congenital Echocardiography scientists (technicians) who should have, or be working towards, EACVI accreditation. The number will depend on the configuration of the service.
- The Network Children's Cardiac Psychologist will support the SCCC with an appropriate number of Children's Cardiac Psychology sessions based on site.
- Each SCCC must have an identified member of staff to ensure high quality data input into the network database.
- Each SCCC will provide 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 SCCC will have telemedicine facilities to link with the SCSC.
- SCCC will follow Congenital Heart Network pathways of care and management of congenital heart defects agreed with the SCSC and in line with the congenital heart disease standards (2015).
- Each SCCC 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 Centres (LCCC)

- Congenital Heart Networks will be supported by LCCC. 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.
- LCCC will have a named Consultant Paediatrician with expertise in cardiology (PEC) who must have received training in accordance with the RCPCH/RCP one-year joint curriculum

in paediatric cardiology or gained equivalent competencies as agreed by the Network Clinical Director

- Each PEC must spend a minimum 20% of his/her total job plan (including Supporting Professional Activities) in paediatric cardiology
- Each PEC will hold an honorary contract with the SCSC and/or the SCCC to enhance continued professional development and facilitate good working relationships.
- LCCC will have a locally designated registered children's nurse 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.
- The Network Children's Cardiac Psychologist will support the LCCC with an appropriate number of Children's Cardiac Psychology sessions
- LCCC will provide 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.
- LCCC will follow Congenital Heart Network pathways of care and management of congenital heart defects agreed with the SCSC and in line with the draft congenital heart disease standards (2015).
- LCCC will have telemedicine facilities to link with the SCSC.
- LCCC 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)

SCSCs 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

TBC

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 rolling 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 validated 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 Somerville 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			
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
% Fetal 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
% Fetal 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 NCHDA DQI	Non-compliance with contract General Conditions 8 & 9
Total surgical case load	To be determined after first year	Number of NICOR defined surgical procedures in 1	Non-compliance with contract General

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
	submissions	year	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

	Adult	Implementation timeline
	Specialist ACHD Surgical Centres	
A1(L1)	Each Congenital Heart Network will be hosted by an agreed lead provider. The network's host organisation will provide appropriate managerial and administrative support for the effective operation of the network, and ensure that appropriate management and administrative support is provided by all organisations throughout the network. Each network should develop a business plan	Within 6 months
A2(L1)	Each Congenital Heart Network and NHS commissioners will establish a model of care that delivers all aspects of the care and treatment of patients with congenital heart disease throughout their life. The model of care will ensure that all congenital cardiac care, including investigation, cardiology and surgery, is carried out only by congenital cardiac specialists (including cardiologists with an interest (BCCA definition)). [See Appendix A for definition of adult CHD surgery]. The model of care will also ensure that as much care and treatment will be provided as close as possible to home and that travel to the Specialist ACHD Surgical Centre only occurs when essential, while ensuring timely access for interventional procedures and the best possible outcomes.	Within 6 months
A3(L1)	Congenital Heart Networks are responsible for the care of patients with CHD across their whole lifetime including prenatal diagnosis, maternity and obstetric services, children's services, transition from paediatric congenital cardiac services, adult congenital cardiac services and palliative care. Each network must contain at least one Specialist ACHD Surgical Centre. Congenital Heart Networks should work closely with other relevant networks including networks for adult cardiac, maternity services and intensive care services to ensure a joined-up approach with treatment continuity.	Within 6 months
A4(L1)	Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care;	Immediate

	Adult	Implementation timeline
	b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how congenital cardiac surgeons, specialist ACHD cardiologists and cardiologists with an interest will work across the network, including at the Specialist ACHD Surgical Centre, the Specialist ACHD Centres and Local ACHD Centres, according to local circumstances; and f. address how Specialist ACHD Surgical Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions.	
A5(L1)	There must be an appropriate mechanism for arranging transfer and timely repatriation of patients which takes into account the following: a. Clinical transfers must be arranged in a timely manner according to patient need. b. Acute beds must not be used for this purpose once patients have been deemed fit for discharge from acute cardiac surgical care.	Immediate
A6(L1)	There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.	Immediate
A7(L1)	All patients transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist ACHD Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Within 6 months
A8(L1)	Congenital Heart Networks will develop and implement a nationally consistent system of 'patient-held records'.	Within 3 years

	Adult	Implementation timeline
	Cardiological Interventions	
A9(L1)	Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. require all ACHD surgery, including atrial septal defect closure, to take place within a Specialist ACHD Surgical Centre [see Appendix A for the definition of ACHD Surgery and Interventions]; b. require all therapeutic interventions, except atrial septal defect closure, and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre [see Appendix A for the definition of ACHD Surgery and Interventions]; and c. enable access to hybrid procedures (those involving both surgeons and interventional cardiologists) in an appropriate facility either in the Specialist ACHD Surgical Centre or in another Specialist ACHD Surgical Centre, if the need arises.	Within 6 months
	Non-Cardiac Surgery	
A10(L1)	Each Congenital Heart Network will agree clinical protocols and pathways to care that will ensure 24/7 availability of specialist advice including pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, the most appropriate location for that surgery and advice to non-ACHD cardiologists across the Congenital Heart Network.	Immediate
	External Relationships	
A11(L1)	Each Specialist ACHD Surgical Centre must have a close network relationship with all maternity services within their network and be able to demonstrate the operation of joint protocols.	Immediate
A12(L1)	Each Specialist ACHD Surgical Centre must have a close network relationship with any paediatric CHD providers within their Congenital Heart Network and be able to demonstrate the operation of joint transition protocols.	Immediate
A13(L1)	Each Congenital Heart Network must contain at least one Specialist ACHD Surgical Centre in a formal network relationship with the Specialist Children's Surgical service, Specialist ACHD Centres and Local ACHD Centres, evidenced by agreed joint referral and care protocols. Each Specialist ACHD Surgical Centre must have a formal network relationship with the following, evidenced by agreed joint referral	Immediate

	Adult	Implementation timeline
	and care protocols: a. the cardiothoracic transplant centres including one staffed by transplant surgeons with a congenital practice; b. the national Pulmonary Hypertension Service; and c. a cardiac pathologist with expertise in congenital cardiac abnormalities.	
A14(L1)	Patients who require assessment for heart transplantation (including implantation of a mechanical device as a bridge to heart transplant) must be referred to a cardiothoracic transplant centre. The referring specialist is responsible for explaining to the patient the transplant pathway and the risks and benefits of referral and any alternative pathways, to inform patient choice. The designated transplant centre is responsible for managing and developing referral, care, treatment and transfer pathways, policies, protocols, and procedures in respect of transplant patients.	Immediate
A15(L1)	Each Specialist ACHD Surgical Centre must have a close relationship with all community adult services in their network, to ensure the provision of a full range of community adult support services particularly for patients with complex medical and social needs.	Immediate
	Telemedicine and IT	
A16(L1)	Each Congenital Heart Network will have telemedicine facilities as required to link designated hospitals in the network (Specialist ACHD Surgical Centres, Specialist Cardiology Centres and Local Cardiology Centres, according to local circumstances) and with other Congenital Heart Networks. The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals;	Within 3 years

	Adult	Implementation timeline
	d. allow timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services; and e. support video-conferencing (eg. Skype) for outpatient consultations from home when appropriate	
A17(L1)	Each congenital heart network must make arrangements for CHD clinicians (including cardiologists with an interest in congenital) within the network to be able to access patient records and imaging systems in all Specialist Surgical Centres and Specialist Cardiology Centres in the network.	Immediate
	Multidisciplinary Team (MDT)	
A18(L1)	Each Specialist ACHD Surgical Centre will have a dedicated specialist multidisciplinary team (MDT) that meets weekly to consider case management. Patients undergoing complex interventions or any surgical interventions must be discussed in an appropriate MDT meeting as defined by the network. All rare, complex and innovative procedures and all cases where the treatment plan is unclear or controversial will be discussed at the network MDT. The attendance and activities of the MDT meeting will be maintained in a register.	Immediate
A19(L1)	Staff from across the Congenital Heart Network should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A20(L1)	The composition of the MDT will 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). An out-of-hours MDT meeting for emergency decision-making will include as a minimum a congenital heart surgeon, an ACHD cardiologist and an intensivist.	Immediate

	Adult	Implementation timeline
A21(L1)	Each Congenital Heart Network will hold regular meetings of the wider clinical team for issues such as agreement of protocols, review of audit data and monitoring of performance. Meetings will be held at least every six months. Network patient representatives will be invited to participate in these meetings.	Immediate
	Network Leadership	
A22(L1)	Each Congenital Heart Network will have a formally appointed Network Clinical Director with responsibility for the network's service overall, who will be supported by clinical leads for surgery, cardiac intervention, fetal cardiology, neonatal, paediatric, adolescent and adult congenital heart disease and anaesthesia. The Network Clinical Director will provide clinical leadership across the network and will be appointed from the network.	Within 6 months
A23(L1)	Each Congenital Heart Network will have a formally appointed Lead Nurse who will provide professional and clinical leadership to the nursing team across the network.	Within 6 months
A24(L1)	Each Congenital Heart Network will have a formally appointed Network Manager responsible for the management of the network, and the conduct of network business.	Within 6 months

	Adult	Implementation timescale
	Specialist ACHD Centres	
A1(L2)	To ensure that patients receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Specialist ACHD Centres where appropriate.	Within 6 months
A2(L2)	Each Specialist ACHD Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L2)	Each Specialist ACHD Centre will adhere to their Congenital Heart Network's clinical protocols and pathways to care for: a. New referrals from GPs, cardiologists and local hospitals b. Ongoing care of patients diagnosed with congenital heart defects	Within 6 months
A4(L2)	Specialist ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the delivery of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how congenital cardiac surgeons, specialist ACHD cardiologists will work across the network, including at the Specialist ACHD Surgical Centres, the Specialist ACHD Centres and Local ACHD Centres, according to local circumstances; f. address how Specialist ACHD Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and g. provide 24/7 advice via an on-call rota comprised predominantly of general consultant cardiologists who will have contact details for the on-call ACHD specialists in the network.	Immediate
A5(L2)	There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional	Within 6 months

	Adult	Implementation timescale
	treatment.	
A6(L2)	All patients transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist ACHD Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Immediate
	Cardiological Interventions	
A7(L2)	Specialist ACHD Surgical Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will require all ACHD surgery, including atrial septal defect closure, to take place within a Specialist ACHD Surgical Centre [see Appendix A for the definition of ACHD Surgery and Interventions]. Interventional closures of ASDs will usually be undertaken at a Specialist ACHD Surgical Centre, but ASD closures may be undertaken at a Specialist ACHD Centre providing certain conditions are met: • All interventional ASD closures must only be undertaken under network agreed governance arrangements including oversight by the network lead congenital interventionist. • All cases of ASD must be discussed at a joint MDT meeting with the Specialist ACHD Surgical Centre and the decision made at the MDT where the intervention should be performed and by whom. • ASD closure may be undertaken at a Specialist ACHD Centre only for patients with an adult diagnosis of CHD, with an ASD without additional complicating features. • All procedures must be reported to the NICOR congenital audit. • ASD closures may only to be undertaken at sites where vascular surgeons and cardiac surgeons are available to provide back-up and surgical retrieval of devices • All interventionists must undertake a minimum volume of procedures as required by standard B7(L2). Diagnostic catheterisation will usually be undertaken at a Specialist ACHD Surgical Centre, but it may be undertaken at a Specialist ACHD Centre providing certain conditions are met: • All diagnostic catheterisation must only be undertaken under network agreed governance arrangements. • All diagnostic catheterisation must be discussed at a joint MDT meeting with the Specialist ACHD Surgical Centre and the decision made at the MDT as to whether diagnostic catheterisation is appropriate, and if so where the catheterisation	Within 6 months

	Adult	Implementation timescale
	should be performed and by whom.	
	Non-Cardiac Surgery	
A8(L2)	Specialist ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure the availability of a pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, and other specialist advice, including a decision on the most appropriate location for that surgery.	Immediate
	External Relationships	
A9(L2)	Each Specialist ACHD Centre must have a close network relationship with all maternity services within their network and be able to demonstrate the operation of joint protocols.	Immediate
A10(L2)	Each Specialist ACHD Centre must have a close network relationship with any paediatric CHD providers within their congenital heart network and be able to demonstrate the operation of joint transition protocols.	Immediate
A11(L2)	Each Specialist ACHD Centre must demonstrate formal working relationships with: a. network Specialist ACHD Surgical Centres and Local ACHD Centres, according to local circumstances; b. the cardiothoracic transplant centres, including one staffed by transplant surgeons with a congenital practice; c. the national Pulmonary Hypertension Service; and d. a cardiac pathologist with expertise in congenital cardiac abnormalities.	Within 6 months
A12(L2)	Each Specialist ACHD Surgical Centre must have a close relationship with all community adult services in their network, to ensure the provision of a full range of community adult support services particularly for patients with complex medical and social needs.	Immediate
	Telemedicine and IT	
A13(L2)	Each Congenital Heart Network will have telemedicine facilities as required to link with designated hospitals in the network (Specialist Surgical Centres and Local Cardiology Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to:	Within 3 years

	Adult	Implementation timescale
	a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC MDT meetings; c. handle emergency referrals; allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services; and d. support video-conferencing (eg. Skype) for outpatient consultations from home when appropriate.	
A14(L2)	Each Specialist ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and MDT meetings to gain remote access to the Specialist ACHD Surgical Centre system, and enable immediate access to patient data.	Immediate
	Multidisciplinary Team (MDT)	
A15(L2)	Each Specialist ACHD Centre will participate in the weekly network specialist multidisciplinary team (MDT) to consider case management. All patients to be considered for complex interventions or any surgical interventions will be discussed in the network MDT meeting with the Specialist ACHD Surgical Centre as defined by the local network. The attendance and activities of the MDT meeting will be maintained in a register.	Within 1 year
A16(L2)	A designated cardiologist will attend (in person or by VC link) the weekly network MDT meeting, and must also attend the annual network meeting. Job plans for cardiologists will include regular attendance (in person or by VC link) at the weekly network MDT meeting.	Within 1 year
A17(L2)	Staff from the Specialist Cardiology Centre should be encouraged to attend MDT meetings in person or by video/teleconferencing and participate in the decision-making about their patient where necessary.	Immediate
A18(L2)	The composition of the MDT will 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).	Immediate
A19(L2)	Specialist ACHD Centres will routinely refer patients to their primary network MDT meeting. Exceptions to this principle will include the exercise of patient choice and, when justified by a consideration of the clinical facts of the individual case, the exercise of referrer choice. In all cases when a patient is referred ‘out of network’ the Specialist ACHD Centre must inform the Specialist ACHD Surgical Centre in writing of the reasons for referral.	Immediate

	Adult	Implementation timescale
	Network Leadership	
A20(L2)	Each Specialist ACHD Centre must have a formally nominated nursing Clinical Lead, who has a direct link and collaborative working partnership with the Lead Nurse for the network. The post holder must have specified time working in ACHD cardiology, with an agreed list of responsibilities. The time available for these responsibilities will be specified by the network.	Within 6 months

	Adult	Implementation timescale
	Local ACHD Centres	
A1(L3)	To ensure that patients receive as much non-interventional treatment as close to their home as is safe, Congenital Heart Networks will be supported by Local ACHD Centres. The precise shape of each Congenital Heart Network will be determined by local need and local circumstances, including geography and transport.	Immediate
A2(L3)	Each Local ACHD Centre will provide appropriate managerial and administrative support for the effective operation of the network.	Within 6 months
A3(L3)	Local ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care for: a. New referrals from GPs, cardiologists and local hospitals b. Ongoing care of patients diagnosed with congenital heart defects	Immediate
A4(L3)	Local ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will: a. achieve high quality of care at all stages of a seamless pathway in accordance with the model of care; b. facilitate the development of as much non-surgical care and treatment as close as possible to home; c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient held record or other equivalent electronic care record, and with clear links to 24/7 specialist services; d. facilitate access to second opinions and referrals to other centres/services (reflecting that collectively they provide a national service); e. address how congenital cardiac surgeons, paediatric cardiologists and paediatricians with expertise in cardiology (PECs) will work across the network, including at the Specialised Children's Surgical Centre, the Specialist Children's Cardiology Centres and Local Children's Cardiology Centres, according to local circumstances; f. address how Local ACHD Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions; and	Within 1 year

	Adult	Implementation timescale
	g. deliver joint clinics between a specialist ACHD cardiologist and a cardiologist with an interest in ACHD in a Local ACHD Centre. Local ACHD Centres will provide weekday cover for CHD advice from a local network of consultant cardiologists with expertise in CHD.	
A5(L3)	There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.	Within 6 months
A6(L3)	All patients transferring across or between networks will be accompanied by high quality information, including a health records summary (with responsible clinician's name) and a management plan. The health records summary will be a standard national template developed and agreed by Specialist ACHD Surgical Centres, representatives of the Congenital Heart Networks and commissioners.	Immediate
	Cardiological Interventions	
A7(L3)	Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will require all ACHD surgery, including atrial septal defect closure, therapeutic interventions and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre. Local ACHD Centres may not undertake any ACHD surgeries, planned interventional catheter procedures or diagnostic catheter procedures as part of their investigation into congenital heart disease. [See Appendix A for the definition of ACHD Surgery and Interventions.]	Immediate
	Non-Cardiac Surgery	
A8(L3)	Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure the availability of a pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, and other specialist advice, including a decision on the most appropriate location for that surgery.	Immediate
	Emergency Care	
A9(L3)	When patients with CHD attend A&E or are admitted, whether for CHD-related problems or not, Local ACHD Centres will seek advice from the local cardiologist with expertise in CHD or an ACHD cardiologist at a specialist centre on appropriate care and management.	Immediate

	Adult	Implementation timescale
	External Relationships	
A10(L3)	Each Local ACHD Centre must demonstrate formal working relationships with the network Specialist ACHD Surgical Centres and Specialist ACHD Centre, according to local circumstances. Other supra-regional services will be accessed via the CHD network.	Immediate
A11(L3)	Local ACHD Centres must have a close relationship with local community adult services, to ensure the provision of a full range of community adult support services particularly for patients with complex medical and social needs.	Immediate
	Telemedicine and IT	
A12(L3)	Each Local ACHD Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist ACHD Surgical Centres and Specialist ACHD Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to: a. undertake initial assessments of echocardiograms; b. support participation in multi-site VC multidisciplinary team meetings; c. handle emergency referrals; and d. allow a timely and reliable transfer and receipt of images (including echo, CT, MRI) across the various ACHD services.	Within 3 years
A13(L3)	Each Local ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and multidisciplinary team meetings to gain remote access to their own Specialist ACHD Surgical Centre or Specialist ACHD Centre system and enable immediate access to patient data.	Within 6 months
	Multidisciplinary Team (MDT)	
A14(L3)	Staff from across the Local ACHD Centre should be encouraged to attend multidisciplinary (MDT) meetings in person or by video/teleconferencing and participate in the decision-making about their patient, where necessary.	Immediate

	Adult	Implementation timescale
A15(L3)	Each Local ACHD Centre cardiologist with an interest in ACHD must participate (at least six times per year) in specialist MDT meetings led by the Specialist ACHD Surgical Centre, either in person or via telemedicine facilities, and must also attend the annual network meeting. This requirement will be reflected in job plans.	Within 1 year
A16(L3)	Each cardiologist with an interest in ACHD will liaise with other local District General Hospitals, Primary Care and the local cardiac networks, forming a link between them and the Congenital Heart Network.	Within 1 year
A17(L3)	Each Local ACHD Centre must have identified registered nurses with an interest and training in ACHD.	Within 1 year

	Adult	Implementation timetable
	Specialist ACHD Surgical Centres	
B1(L1)	Each Specialist ACHD Surgical Centre 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 surgery and interventional cardiology cover. A consultant ward round will occur daily.	Within 6 months
B2(L1)	Consultant interventional specialist ACHD cardiologists and congenital cardiac surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either: a. the support of a competent second operator/interventionist must be obtained from within the network or another Specialist ACHD Surgical Centre; or b. the patient must be referred to an alternative Specialist ACHD Surgical Centre where a surgeon/interventionist has the appropriate skills. All rare, complex and innovative procedures and all cases where the treatment plan is unclear or controversial will be discussed at the network MDT.	Immediate
B3(L1)	Arrangements must be in place in each Specialist ACHD Surgical Centre both for consultant interventional specialist ACHD cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases.	Immediate
B4(L1)	Consultant interventional specialist ACHD cardiologists and congenital cardiac surgeons will be mentored and supported by a lead interventionist or surgeon. Newly qualified consultants will initially share lists with more experienced colleagues.	Immediate
B5(L1)	Specialist ACHD Surgical Centres and networks must work together to develop and support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre-to centre referrals.	Immediate
B6(L1)	Each Specialist ACHD Surgical Centre will have a formally nominated ACHD lead with responsibility for the service at the Specialist ACHD Surgical Centre, who supports the Network Clinical Director and works across the network including outreach clinics, with precise duties determined locally.	Within 6 months
B7(L1)	All patients requiring investigation and treatment will receive care from staff trained in safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate

	Adult	**Implementation timetable**
	Surgery	
B8(L1)	All adult congenital cardiac surgical cases must be carried out by a specialist congenital cardiac surgical team with expertise and experience in adult congenital heart disease. [See Appendix A for the definition of what qualifies as ACHD surgery.]	Immediate
B9(L1)	Consultant congenital surgery cover must be provided by consultant congenital surgeons providing 24/7 emergency cover. Rotas must be no more frequent than 1 in 4. Each Specialist ACHD Surgical Centre must develop out-of-hours arrangements that take into account the requirement for surgeons only to undertake procedures for which they have the appropriate competence. The rota will deliver care for both children and adults. If this means that the surgeon is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Rota: 1 in 3 immediate; 1 in 4 within 5 years Other requirements: immediate
B10(L1)	Congenital cardiac surgeons must work in teams of at least four surgeons, each of whom must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Only auditable cases may be counted, as defined by submission to the National Institute for Cardiovascular Outcomes (NICOR).	Teams of at least three: immediate Teams of at least four: within 5 years 125 operations: immediate
B11(L1)	Perfusion services and staffing must be accredited by The College of Clinical Perfusion Scientists of Great Britain and Ireland.	Immediate
	Cardiology	
B12(L1)	All adult congenital cardiology must be carried out by specialist ACHD cardiologists (including cardiologists with a special interest in congenital (BCCA definition)).	Immediate
B13(L1)	Each Specialist ACHD Surgical Centre must be staffed by a minimum of 4 WTE consultant specialist ACHD cardiologists. Each ACHD Cardiologist will have an indicative maximum patient workload of 1,500 per WTE cardiologist.	Within 3 years

	Adult	Implementation timetable
B14(L1)	Each Specialist ACHD Surgical Centre must deliver 24/7 elective and emergency care, including consultant specialist ACHD cardiology on-call cover for the Specialist ACHD Surgical Centre and to provide advice across the network including requests for transfers. Rotas must be no more frequent than 1 in 4. The on-call rota must ensure cover by appropriately trained specialists in care of both children and adults. If this means that the cardiologist is on-call for two hospitals, they must be able to reach the patient bedside at either hospital within 30 minutes of receiving the call.	Immediate
B15(L1)	Each Specialist ACHD Surgical Centre must be staffed by at least two interventional specialist cardiologists (ACHD or paediatrics), who may be included in the number referred to in standard B12(L1).	Within 1 year
B16(L1)	Cardiologists employed by the Specialist ACHD Centre and trained to the appropriate standards in interventional and diagnostic ACHD cardiology shall be provided with appropriate sessions and support at the Specialist ACHD Surgical Centre to maintain and develop their specialist skills.	Within 6 months
B17(L1)	Cardiologists performing therapeutic catheterisation in patients with congenital heart disease must be the primary operator in a minimum of 50 such procedures per year. The Lead Interventional Cardiologist in a team must be the primary operator in a minimum of 100 such procedures per year, in each case averaged over a three-year period.	Immediate
B18(L1)	Each Specialist ACHD Surgical Centre must be staffed by a minimum of one expert electrophysiologist experienced in ACHD. There must be appropriate arrangements for cover by a competent person.	Immediate
B19(L1)	ACHD electrophysiology procedures must only be undertaken by an expert electrophysiologist experienced in the management of arrhythmias with congenital heart disease.	Immediate
B20(L1)	The catheterisation laboratory must comply with the British Congenital Cardiac Association standards for catheterisation and have the following staff to operate safely: a. dedicated and appropriately trained cardiac physiologists; b. a radiographer; c. a ‘running’ member of staff without other duties and with specific knowledge of the location of equipment required in	Immediate

	Adult	Implementation timetable
	congenital interventional catheterisation; and d. a nurse with experience of congenital cardiac catheterisation.	
B21(L1)	Each Specialist Surgical Centre must be staffed by a congenital cardiac imaging specialist who may be a cardiologist or a radiologist, expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging across the network.	Immediate
B22(L1)	Each Specialist ACHD Surgical Centre will have 24/7 anaesthetic support by consultants experienced in the management of ACHD patients.	Immediate
B23(L1)	At each Specialist ACHD Surgical Centre an ACHD cardiologist will act as the lead for Congenital Echocardiography. The lead must be European Association of Cardiovascular Imaging (EACVI) Congenital Heart Disease Echocardiography accredited (or have recognised equivalent accreditation or experience). The lead will have dedicated echocardiography sessions and will have responsibility for training and quality assurance.	Within 6 months
B24(L1)	Each Specialist Surgical Centre will have a team of congenital echocardiography scientists (technicians), with a designated Congenital Echocardiography Scientist (Technician) Lead 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 population served, and whether the service is integrated with paediatric echocardiography.	Within 1 year
	Intensive Care	
B25(L1)	Intensive Care Unit (ICU) consultants with appropriate skills in congenital cardiac critical care must be available to the ICU on a 24/7 basis.	Immediate
B26(L1)	Intensive Care Units and High Dependency care will be staffed in accordance with national standards. Patients must be cared for by nurses with appropriate training and competencies in adult congenital cardiac critical care.	Immediate
	Nursing	

	Adult	Implementation timetable
B27(L1)	Each Specialist ACHD Surgical Centre must have a formally nominated lead ACHD nurse with responsibility for the service at the Specialist ACHD Surgical Centre, providing professional and clinical leadership and support to the team of ACHD specialist nurses across the network.	Within 6 months
B28(L1)	Nursing care must be provided by a team of nursing staff trained in the care of young people and adults who have received cardiac surgery. The ACHD inpatient nursing team will be led by a senior nurse with specialist knowledge and experience of congenital cardiology and cardiac surgery.	Immediate
B29(L1)	Each Specialist ACHD Surgical Centre will employ a minimum of 5 WTE ACHD specialist nurses, whose role will extend throughout the Congenital Heart Network, ensuring that both an in-hospital and outreach service is provided. The precise number, above the minimum five, and location of these nurses will depend on geography, population and the configuration of the network. Each patient must have a named Specialist ACHD Nurse responsible for coordinating their care, and who acts as a liaison between the clinical team, the patient and partner/family or carers.	Within 3 years
B30(L1)	The ACHD nurse specialists will work closely with the Children’s Cardiac Transition Nurse to coordinate the transfer process for each patient.	Within 6 months
	Psychology	
B31(L1)	Each Specialist ACHD Surgical Centre must employ a minimum of 1 WTE practitioner psychologist (with experience of working with CHD). In addition, 1 WTE practitioner psychologist must be employed for each network. The location and precise number of practitioner psychologists will depend on geography, population and the configuration of the network. The lead psychologist should provide training and mentorship to the other psychologists in the network.	Within 1 year
	Administrative Staffing	

	Adult	Implementation timetable
B32(L1)	Each Specialist Surgical Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to patients and partners/family or carers in a timely fashion.	Immediate
B33(L1)	Each Specialist Surgical Centre must have a dedicated congenital cardiac surgery/cardiology data collection manager, responsible for audit and database submissions in accordance with necessary timescales.	Within 6 months
	Other (See also section D: interdependencies for professions and specialties where dedicated sessions are required.)	
B34(L1)	Each Specialist ACHD Surgical Centre will have a Lead Doctor and Lead Nurse for safeguarding vulnerable adults.	Immediate
B35(L1)	Each Specialist Surgical Centre will have an identified bereavement officer.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centres	
B1(L2)	Each Specialist ACHD Centre must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service, 7 days a week within legally compliant rotas. A consultant ward round will occur daily.	Immediate
B2(L2)	All patients requiring investigation and treatment will receive care from staff trained in safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
	Medical	
B3(L2)	Each Specialist ACHD Centre must be staffed by: a. one lead specialist ACHD cardiologist who spends at least 0.8 WTE clinical time on ACHD; and b. 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.	Within 3 years
B4(L2)	Each Specialist ACHD Centre must provide a dedicated consultant-led cardiology on-call rota of 1 in 4 cardiologists comprising congenital and non-congenital cardiologists.	Immediate
B5(L2)	Each Specialist ACHD Centre will have a formally nominated Clinical ACHD Lead with responsibility for the service at the Specialist ACHD Centre, who works across the network including outreach clinics, with precise duties determined locally. Each Specialist ACHD Centre will have separate clinical leads identified from the relevant specialties, including nursing, ICU, and anaesthesia who have a direct link and collaborative working partnership with the lead roles in the Specialist ACHD Surgical Centre.	Within 6 months
B6(L2)	Cardiologists employed by the Specialist ACHD Centre and trained to the appropriate standards in interventional and diagnostic ACHD cardiology shall be provided with appropriate sessions and support at the Specialist ACHD Surgical Centre to maintain and develop their specialist skills.	Within 6 months
B7(L2)	Specialist ACHD Cardiologists performing therapeutic catheterisation in adults with CHD must be the primary operator in a minimum of 50 such procedures per year (while not normally within the definition of CHD, for these purposes, PFO closure is included as a countable procedure), averaged over a three-year period.	Immediate

	Adult	Implementation timescale
B8(L2)	Electrophysiology will usually be undertaken at a Specialist ACHD Surgical Centre, but it may be undertaken at a Specialist ACHD Centre if specifically agreed by a joint MDT meeting with the Specialist ACHD Surgical Centre and under network agreed governance arrangements.	Immediate
B9(L2)	Each Specialist ACHD Centre must be staffed by a congenital cardiac imaging specialist (who may be a cardiologist or a radiologist) expert in both cardiac MRI and cardiac CT. There will be joint reporting (cardiologist and radiologist) and dedicated MDT review of complex cases. There will be shared protocols for cross-sectional imaging across the network.	Immediate
B10(L2)	Intensive Care Unit consultants with appropriate skills in congenital cardiac critical care must be available to the ICU on a 24/7 basis.	Immediate
	Nursing	
B11(L2)	Specialist ACHD Centres must have locally designated registered nurses with a specialist interest in adult congenital heart disease, trained and educated in the assessment, treatment and care of patients with CHD.	Immediate
B12(L2)	Each Specialist ACHD Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively.	Immediate
B13(L2)	Each Specialist ACHD Centre will employ a minimum of 2 WTE specialist ACHD nurses whose role will extend throughout the network. The precise number, above the minimum two, and location of these nurses will depend on geography, population and the configuration of the network.	Within 1 year
	Psychology	
B14(L2)	Each Specialist ACHD Centre must have access to a clinical psychology service that is integrated with the ACHD team. The Network Children's Cardiac Psychologist will support the Specialist ACHD Centre. An appropriate number of ACHD Psychology sessions will be based at the Specialist ACHD Centre (the number will depend on geography, population and the congenital heart network).	Immediate
	Administrative	

	Adult	Implementation timescale
B15(L2)	Each Specialist ACHD Centre must have an identified member of staff to ensure high quality data input to the network database.	Immediate
B16(L2)	Each Specialist ACHD Centre will provide administrative support to ensure availability of medical records, organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to patients, partners/family or carers in a timely fashion.	Immediate
	Other	
B17(L2)	Each Specialist ACHD Centre will have a team of congenital echocardiography scientists (technicians) who should have or be working towards appropriate accreditation. The size of the team will depend on the configuration of the service, the population served, and whether the service is integrated with paediatric echocardiography.	Immediate
B18(L2)	Each Specialist ACHD Centre will have a Lead Doctor and Lead Nurse for safeguarding vulnerable adults.	Immediate
B19(L2)	Each Specialist ACHD Centre will have a dedicated bereavement officer.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
B1(L3)	The Local ACHD Centre must be staffed by at least one consultant cardiologist with an interest in ACHD.	Within 1 year
B2(L3)	Each Local ACHD Centre will provide skilled support to undertake blood pressure and oxygen saturation monitoring accurately and effectively in the outpatient clinic.	Immediate
B3(B3)	Each Local ACHD Centre must have a locally designated 0.25 WTE registered nurse with a specialist interest to participate in ACHD clinics, provide support to inpatients and deal with requests for telephone advice.	Within 1 year
B4(B3)	ACHD Specialist Nurses from the Specialist ACHD Surgical Centre or Specialist ACHD Centre will provide support, education and a link to the outpatient and ward nursing staff at Local ACHD Centres. A local link nurse will be identified who can be a point of contact within the Local ACHD Centre.	Immediate
B5(L3)	Each Local ACHD Centre must have an identified member of staff to ensure high quality data input to the network database.	Within 6 months
B6(L3)	Each Local ACHD Centre will provide administrative support to ensure availability of medical records, to organise clinics, type letters from clinics, arrange investigations, ensure timely results of the investigations, arrange future follow-ups and respond to patients, partners/family or carers in a timely fashion.	Immediate
B7(L3)	Each Local ACHD Centre must have a cardiac physiologist with training in congenital echocardiography.	Within 1 year
B8(L3)	All patients requiring investigation and treatment will receive care from staff trained in safeguarding standards, in accordance with the requirements of their profession and discipline.	Immediate
B9(L3)	The Local ACHD Centre will have: a. a Lead Doctor and Lead Nurse for safeguarding vulnerable adults; and b. a dedicated bereavement officer.	Immediate

	Adult	Implementation timeline
	Specialist ACHD Surgical Centres	
C1(L1)	There must be facilities in place to ensure easy and convenient access for partners/family/carers. Facilities and support include: a) accommodation for partners/family members to stay; b) the ability for at least one parent/carer to stay with any patient with learning disabilities in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c) access to refreshments; d) facilities suitable for the storage and preparation of simple meals; and e) an on-site quiet room completely separate from general facilities Family accommodation should be provided without charge.	Within 6 months
C2(L1)	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient, within a dedicated ACHD ward space, and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability. Each Specialist Surgical Centre must provide a 24/7 emergency telephone advice service for patients with urgent concerns about deteriorating health.	Immediate
C3(L1)	Patients must have access to general resources including books, magazines and free wifi.	Immediate Free wifi: 6 months
C4(L1)	There must be facilities, including access to maternity staff, that allow the mothers of new-born babies who are admitted as emergencies to stay with their baby for reasons of bonding, establishing breastfeeding and the emotional health of the mother and baby.	Immediate
C5(L1)	Patients and their partners/family/carers will be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.	Immediate

	Adult	Implementation timeline
C6(L1)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate
C7(L1)	There must be dedicated room space in which practitioner psychologists, cardiac physiologists, ACHD nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C8(L1)	Specialist ACHD Surgical Centres must have local arrangements for transferring patients from airfields and helipads.	Immediate
C9(L1)	All patients should have access to cardiac rehabilitation facilities.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centres	
C1(L2)	There must be dedicated room space in which practitioner psychologists, cardiac physiologists, ACHD nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C2(L2)	There must be facilities in place to ensure easy and convenient access for partners/ family/carers. Facilities and support include: a) accommodation for partners/family members to stay; b) the ability for at least one parent/carer to stay with any patient with learning disabilities in the ward 24 hours per day (except when this is considered to be clinically inappropriate); c) access to refreshments; d) facilities suitable for the storage and preparation of simple meals; and e) an on-site quiet room completely separate from general facilities. Family accommodation should be provided without charge.	Within 6 months
C3(L2)	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability.	Immediate
C4(L2)	Patients must have access to general resources including books, magazines and free wifi.	Immediate Free wifi: 6 months
C5(L2)	Patients and their partners/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.	Immediate
C6(L2)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate

	Adult	Implementation timescale
C7(L2)	All patients should have access to cardiac rehabilitation facilities.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
C1(L3)	There must be dedicated room space in which practitioner psychologists, cardiac physiologists, ACHD nurse specialists and social work staff conduct diagnostic and therapeutic work.	Immediate
C2(L3)	There must be facilities in place to ensure easy and convenient access for partners/family/carers.	Within 6 months
C3(L3)	All adult patients must be seen in an appropriate adult environment as an outpatient, be accommodated in an exclusively adult environment as an inpatient and offered cultural and age-appropriate cardiac rehabilitation, taking into account any learning or physical disability.	Immediate
C4(L3)	Patients must have access to general resources including books, magazines and free wifi.	Immediate Free wifi: 6 months
C5(L3)	Patients and their partners/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.	Immediate
C6(L3)	If an extended hospital stay is required, any parking charges levied by the hospital or affiliated private parking providers must be reasonable and affordable. Each hospital must have a documented process for providing support with travel arrangements and costs.	Immediate
C7(L3)	All patients should have access to cardiac rehabilitation facilities.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities **must be located on the same hospital site** as **Specialist ACHD Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
D1(L1)	General adult cardiology services, including acute cardiac care unit.	Immediate
D2(L1)	Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).	Immediate
D3(L1)	Intensive Care Unit: Level 3, capable of multi-organ failure support. High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing patients with ACHD.	Immediate
D4(L1)	Specialised congenital cardiac anaesthesia.	Immediate
D5(L1)	Perioperative extracorporeal life support with or without ventricular assist programme. (Non-nationally designated extracorporeal membrane oxygenation (ECMO)).	Immediate
D6(L1)	Adult cardiac surgery.	Immediate
D7(L1)	Vascular services including surgery and interventional radiology.	Immediate
D8(L1)	Each Specialist ACHD Surgical Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The range of cardiac physiological investigations must include Electrocardiography (ECG), Holter monitoring, event recording, tilt test, exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, as well as standard, contrast, intraoperative, transesophageal and fetal echocardiography. Specialist ACHD Surgical Centres should be able to undertake cardio-pulmonary exercise testing (CPEX) and the six-minute walk test; if not provided on site they must have access to these investigations. Specialist ACHD Surgical Centres must have access to Isotope Imaging. Radiological and echocardiographic images must be stored	Within 6 months

	Adult	Implementation timescale
	The following specialties or facilities **must be located on the same hospital site** as **Specialist ACHD Surgical Centres**. They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
	digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network. Specialist ACHD Surgical Centres must offer invasive diagnostic investigation and treatment, including: a. catheter intervention; b. electrophysiological intervention; c. implantable cardioverter defibrillator (ICD) and pacemaker insertion and extraction (including Cardiac Resynchronization Therapy - CRT); and d. cardiac surgical intervention, including the provision of extracorporeal support of the circulation and hybrid catheter/surgical treatment (where clinically indicated). These services must be available 24/7.	

	Adult	Implementation timescale
	The following specialties or facilities **should** be located on the same hospital site as Specialist ACHD Surgical Centres. They must function as part of the extended multidisciplinary team. Senior decision makers from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. Specialist ACHD Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).	
D9(L1)	Specialist Paediatric Congenital Cardiac Surgery and Intervention. [This standard recognises shared staffing and out-of-hours cover.]	Immediate
D10(L1)	General Surgery.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities **should** be located on the same hospital site as Specialist ACHD Surgical Centres. They must function as part of the extended multidisciplinary team. Senior decision makers from the following services **must** be able to provide emergency bedside care (call to bedside within **30 minutes**) 24/7. Specialist ACHD Surgical Centres must ensure that facilities are available to allow emergency intervention by these specialties at the surgical centre if clinically indicated (i.e. without transfer).	
D11(L1)	Nephrology/Renal Replacement Therapy.	Immediate
D12(L1)	Gastroenterology.	Immediate
D13(L1)	Physiotherapy (service must be integrated with the ACHD team).	Immediate
D14(L1)	General medicine and provision for diabetes, endocrinology and rheumatology services.	Immediate
D15(L1)	Gynaecology.	Immediate
D16(L1)	Neonatal unit (NICU): Level 3.	Immediate
D17(L1)	Microbiology and infectious diseases.	Immediate
D18(L1)	Obstetric unit with maternal fetal medicine specialist(s).	Immediate
D19(L1)	Respiratory medicine.	Immediate
D20(L1)	Urology.	Immediate
D21(L1)	Pain management service.	Immediate
D22(L1)	Bereavement Support, including nurses trained in bereavement support.	Immediate

	Adult	**Implementation timescale**
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Surgical Centres. Consultants from the following services must be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed**.** The services must be experienced in caring for patients with congenital heart disease.	
D23(L1)	Clinical Haematology.	Immediate
D24(L1)	Clinical biochemistry.	Immediate
D25(L1)	Orthopaedics.	Immediate
D26 (L1)	Acute stroke services.	Immediate
D27(L1)	Neurology.	Immediate
D28(L1)	Neurosurgery.	Immediate
D29L1)	Psychiatry (with dedicated sessions and 24/7 on call).	Immediate

	Adult	**Implementation timescale**
	The following specialties or facilities must be able to provide **advice and consultation at least by the following working day**. The services must be experienced in patients with congenital heart disease.	
D30(L1)	Ear, Nose and Throat.	Immediate
D31(L1)	Psychology.	Immediate
D32(L1)	Dietician.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities must be able to provide **advice and consultation at least by the following working day**. The services must be experienced in patients with congenital heart disease.	
D33(L1)	Clinical Genetics.	Immediate
D34(L1)	Dentistry.	Immediate
D35(L1)	Clinical Immunology.	Immediate
D36(L1)	Dermatology.	Immediate
D37(L1)	Sexual health.	Immediate
D38(L1)	Cardiac rehabilitation.	Immediate
D39(L1)	Occupational therapy.	Immediate
D40 (L1)	Social work services	Immediate

	Adult	Implementation timescale
	The following specialties or facilities must be located **on the same hospital site** as **Specialist ACHD Centres.** They must function as part of the multidisciplinary team. Consultants from the following services must be able to provide emergency bedside care (call to bedside within **30 minutes**).	
D1(L2)	General adult cardiology services, including acute cardiac care unit.	Immediate
D2(L2)	Airway Team capable of complex airway management and emergency tracheostomy (composition of the team will vary between institutions).	Immediate
D3(L2)	Intensive Care Unit: Level 3, staffed by consultant anaesthetists or intensivists experienced in the management of ACHD patients and in perioperative cardiac surgical care. High Dependency beds: Level 2, staffed by medical and nursing teams experienced in managing patients with ACHD.	Immediate
D4(L2)	Each Specialist ACHD Centre must possess the full range of non-invasive diagnostic imaging capabilities including CT and MRI scanning and suitable trained radiological expertise. The range of cardiac physiological investigations must include electrocardiography (ECG), Holter monitoring, event recording, tilt test, exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, as well as standard, contrast, transesophageal and fetal echocardiography. Specialist ACHD Centres should be able to undertake cardio-pulmonary exercise testing (CPEX) and the six-minute walk test; if not provided on site they must have access to these investigations. Radiological and echocardiographic images must be stored digitally in a suitable format and there must be the means to transfer digital images across the Congenital Heart Network. These services must be available 24/7.	Immediate
D5(L2)	Adult cardiac surgery (required if interventional ASD closure is undertaken).	Immediate
D6(L2)	Vascular services including surgery and interventional radiology (required if interventional ASD closure is undertaken).	Immediate

	Adult	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Centres. They must function as part of the extended multidisciplinary team. Senior decision makers from the following services must be able to provide emergency bedside care (**call to bedside within 30 minutes**) 24/7.	
D7(L2)	General Surgery.	Immediate
D8(L2)	Cardiac anaesthetist who works closely with specialist congenital cardiac anaesthetists in the network.	Immediate
D9(L2)	Nephrology.	Immediate
D10(L2)	Physiotherapy (service must be integrated with the ACHD team).	Immediate
D11(L2)	Bereavement Support, including nurses trained in bereavement support.	Immediate
D12(L2)	Pain management service.	Immediate
D13(L2)	Gastroenterology.	Immediate
D14(L2)	Clinical biochemistry.	Immediate
D15(L2)	Clinical Haematology.	Immediate
D16(L2)	Ear nose and throat.	Immediate
D17(L2)	General medicine and provision for diabetes, endocrinology and rheumatology services.	Immediate
D18(L2)	Gynaecology.	Immediate
D19(L2)	Neonatal Intensive Care Unit (NICU): Level 3 – for new-borns of mothers with CHD	Immediate

	Adult	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Centres. They must function as part of the extended multidisciplinary team. Senior decision makers from the following services must be able to provide emergency bedside care (**call to bedside within 30 minutes**) 24/7.	
D20(L2)	Microbiology and infectious diseases.	Immediate
D21(L2)	Obstetric Unit with Maternal Fetal Medicine Specialist/s.	Immediate
D22(L2)	Orthopaedics.	Immediate
D23(L2)	Respiratory medicine.	Immediate
D24(L2)	Urology.	Immediate
D25(L2)	Acute stroke services	Immediate

	Adult	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Centres. Consultants from the following services **must** be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed. The services must be experienced in caring for patients with congenital heart disease.	
D26(L2)	Learning Disability Team.	Immediate
D27(L2)	Neurology.	Immediate
D28(L2)	Neurosurgery.	Immediate

	Adult	Implementation timescale
	The following specialties or facilities **should ideally** be located on the same hospital site as Specialist ACHD Centres. Consultants from the following services **must** be able to provide urgent telephone advice (call to advice within **30 minutes**) and a visit or transfer of care within **four hours** if needed. The services must be experienced in caring for patients with congenital heart disease.	
D29(L2)	Psychiatry.	Immediate

	Adult	Implementation timescale
	Advice and consultation must be available from the following services at least by the following working day. The services must be experienced in patients with congenital heart disease.	
D30(L2)	Clinical Genetics.	Immediate
D31(L2)	Dentistry.	Immediate
D32(L2)	Clinical Immunology.	Immediate
D33(L2)	Dermatology.	Immediate
D34(L2)	Sexual Health.	Immediate
D35(L2)	Cardiac rehabilitation.	Immediate
D36(L2)	Diabetes.	Immediate
D37(L2)	Occupational Therapy.	Immediate
D38(L2)	Palliative Care.	Immediate

DRAFT CHD Standards: Section D: Interdependencies
Level 3: Local ACHD Centres

	Adult	Implementation timescale
	The following specialties or facilities must be located **on the same hospital site** as **Local ACHD Centres.**	
D1(L3)	General adult cardiology services, including acute cardiac care unit.	Immediate
D2(L3)	Urgent advice 24/7 from any relevant services not on site or in the District General Hospital– either from Specialist ACHD Centres or from Specialist ACHD Surgical Centres in accordance with network protocols.	Immediate
D3(L3)	Each Local ACHD Centre must be appropriately staffed to undertake the following investigations: a. blood testing; b. electrocardiogram (ECG) available 24/7; c. transthoracic echocardiogram; d. chest X-ray; e. exercise testing/six-minute walk test; f. 24 hour tapes, event recorders; and g. ambulatory blood pressure monitoring.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Surgical Centres	
E1(L1)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, working with adults with learning disability, life support, pain management, infection control, end of life, bereavement, breaking bad news and communication.	Immediate
E2(L1)	All members of the cardiac and ICU medical and nursing team will complete mandatory basic training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L1)	Nurses working within Specialist ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre, with a formal annual training plan in place.	Within 1 year
E4(L1)	Each Specialist ACHD Surgical Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in ACHD cardiology, ACHD surgery and congenital heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.	Immediate
E5(L1)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems. Specialist ACHD Surgical Centres must provide resources sufficient to support these educational needs across the network.	Within 6 months
E6(L1)	Each Specialist ACHD Surgical Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care, and to deliver standardised training and competency-based education programmes across the Congenital Heart Network. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months

	Adult	Implementation timescale
	Specialist ACHD Centres	
E1(L2)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, working with adults with learning disability, life support, pain management, infection control, end-of-life, bereavement, breaking bad news and communication.	Immediate
E2(L2)	All members of the cardiac and ICU medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L2)	Nurses working within Specialist ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place. Similarly, nurses working within Local ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre, with a formal annual training plan in place.	Within 1 year
E4(L2)	Each Specialist Cardiology Centre must demonstrate a commitment to the training and education of both core and subspecialty level training in in ACHD cardiology and congenital heart disease in pregnancy, according to the latest Joint Royal Colleges of Physicians' Training Board curriculum.	Immediate
E5(L2)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems.	Within 6 months
E6(L2)	Each Specialist ACHD Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at the Specialist ACHD Centre. This individual will work with those at the Specialist ACHD Surgical Centre to deliver standardised training and competency-based education programmes across the Congenital Heart Network. The competency-based programme must focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication. Skills in teaching, research, audit and management will also be part of the programme.	Within 6 months

	Adult	Implementation timescale
	Local ACHD Centres	
E1(L3)	All healthcare professionals must take part in a programme of continuing professional development as required by their registering body and/or professional associations. This should include both specialist education and training and more general training including safeguarding, working with adults with learning disability, life support, pain management, infection control, end-of-life , bereavement, breaking bad news and communication.	Immediate
E2(L3)	All members of the cardiac medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.	Immediate
E3(L3)	Each Local ACHD Centre must assist the Specialist ACHD Surgical Centre in providing core curriculum level training as per the Joint Royal Colleges of Physicians' Training Board curriculum to all adult cardiology trainees within their network catchment area.	Immediate
E4(L3)	Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of patients with congenital heart problems.	Within 1 year
E5(L3)	Each Local ACHD Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at the Local ACHD Centre. This individual will work with those at the Specialist ACHD Surgical Centre to deliver standardised training and competency-based education programmes across the Congenital Heart Network. The competency-based programme will focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication.	Within 1 year
E6(L3)	Nurses working within Local ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place.	Within 1 year
E7(L3)	Cardiologists with an interest in ACHD should have a named cardiologist within the Specialist ACHD Surgical Centre or Specialist ACHD Centre who acts as a mentor; this mentor would normally be the link cardiologist.	Immediate

	Adult	Implementation timescale
F1(L1)	Each Specialist ACHD Surgical Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L1)	Each Specialist ACHD Surgical Centre must have a dedicated management group for the internal management and coordination of service delivery. The group must comprise the different departments and disciplines delivering the service.	Immediate
F3(L1)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. regular continuous network clinical audit and quality improvement; b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance; c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents and resultant action plans from all units.	Within 1 year
F4(L1)	Each Specialist ACHD Surgical Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist ACHD Surgical Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F5(L1)	Each Specialist ACHD Surgical Centre will have a robust internal database and outcome monitoring tool based on standardised national audit coding (EPCC). The database will have seamless links to that of the Specialist and Local ACHD Centres. Audit of clinical practice should be considered where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Within 6 months
F6(L1)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L1)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Immediate

	Adult	Implementation timescale
F8(L1)	Patient outcomes will be assessed with results monitored and compared against national and international outcome statistics, where possible.	Within 6 months
F9(L1)	Each Specialist ACHD Surgical Centre must participate in national programmes for audit and must submit data on all interventions, surgery, electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate
F10(L1)	Each Congenital Heart Network's database must allow analysis by diagnosis to support activity planning.	Immediate
F11(L1)	Each Specialist ACHD Surgical Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist ACHD Surgical Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Immediate
F12(L1)	Governance arrangements must be in place to ensure that when elective patients are referred to the multidisciplinary team, they are listed in a timely manner. Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F13(L1)	Admission for planned surgery will be booked for a specific date.	Immediate
F14(L1)	All patients who have operations cancelled for non-clinical reasons are to be offered another binding date within 28 days.	Immediate
F15(L1)	Specialist ACHD Centres and Local ACHD Centres must be informed of any relevant cancellations and the new date offered.	Immediate
F16(L1)	Last minute cancellations must be recorded and discussed at the multidisciplinary team meeting.	Immediate
F17(L1)	If a patient needing a surgical or interventional procedure who has been actively listed can expect to wait longer than three months, all reasonable steps must be taken to offer a range of alternative providers, if this is what the patient wishes. Specialist ACHD Centres and Local ACHD Centres must be involved in any relevant discussions.	Immediate

	Adult	Implementation timescale
F18(L1)	When a Specialist ACHD Surgical Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist ACHD Surgical Centre or Specialist ACHD Centre, if appropriate.	Immediate
F19(L1)	An ACHD Nurse Specialist must be available to provide support and advice to nursing staff within intensive care, high dependency care and inpatient wards.	Immediate
F20(L1)	Each Specialist ACHD Surgical Centre must implement a pain control policy that includes advice on pain management at home.	Immediate
F21(L1)	Advice must be taken from the acute pain team for all patients who have uncontrolled severe pain. Particular attention must be given to patients who cannot express pain because of their level of speech or understanding, communication difficulties, their illness or disability.	Immediate
F22(L1)	Each Specialist ACHD Surgical Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers, young people and older people with congenital heart disease.	Immediate
F23(L1)	Each Specialist ACHD Surgical Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals.	Immediate
F24(L1)	Each Specialist ACHD Surgical Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the patient's home or other agencies.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centres	
F1(L2)	Each Specialist ACHD Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L2)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. regular continuous network clinical audit and quality improvement; b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance; c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents and resultant action plans from all units.	Within 1 year
F3(L2)	Each Specialist ACHD Centre will report on adverse incidents and action plans. In addition to contractual and national reporting requirements, Specialist ACHD Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L2)	Each Specialist ACHD Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist ACHD Surgical Centre.	Within 6 months
F5(L2)	Each Specialist ACHD Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L2)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L2)	Current risk adjustment models must be used, with regular multidisciplinary team meetings to discuss outcomes with respect to mortality, re-operations and any other nationally agreed measures of morbidity.	Within 1 year
F8(L2)	Each Specialist ACHD Centre must participate in national programmes for audit and must submit data on electrophysiology procedures and endocarditis to the national congenital database in the National Institute for Cardiovascular Outcomes Research,	Immediate

	Adult	Implementation timescale
	including any emerging data requirements for morbidity audit.	
F9(L2)	Each Specialist ACHD Centre will contribute to the network-wide database by diagnosis to support workload planning.	Immediate
F10(L2)	Each Specialist ACHD Centre must demonstrate that processes are in place to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Specialist ACHD Centres will follow mandatory National Institute for Health and Care Excellence (NICE) guidance and work within the constraints set within relevant NICE Interventional Procedures Guidance.	Within 6 months
F11(L2)	Where cases are referred to the specialist multidisciplinary team for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F12(L2)	When a Specialist ACHD Centre cannot admit a patient for whatever reason, or cannot operate, it has a responsibility to source a bed at another Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Immediate
F13(L2)	Each Specialist ACHD Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers, young people and older people with congenital heart disease.	Immediate
F14(L2)	Each Specialist ACHD Centre will provide a psychology service that extends across the network and ensure that patients have access to a psychology appointment: a. by the next working day for inpatients in acute distress; b. within 10 working days for adjustment, adherence or decision-making difficulties that interfere with medical care; or c. within six weeks for all other referrals.	Immediate
F15(L2)	Each Specialist ACHD Centre will demonstrate that it has in place arrangements for psychology follow-up where needed, either through psychology appointments or by referral to other psychologists with experience of CHD closer to the patient’s home or other agencies.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
F1(L3)	Each Local ACHD Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.	Within 1 year
F2(L3)	All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes: a. regular continuous network clinical audit and quality improvement; b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance; c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents and resultant action plans from all units.	Within 1 year
F3(L3)	Each Local ACHD Centre will report on adverse incidents. In addition to contractual and national reporting requirements, Local ACHD Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.	Immediate
F4(L3)	Each Local ACHD Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist ACHD Surgical Centre.	Within 6 months
F5(L3)	Each Local ACHD Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.	Immediate
F6(L3)	Audits must take into account or link with similar audits across the network, other networks and other related specialties.	Immediate
F7(L3)	Each Local ACHD Centre must participate in relevant national programmes for audit and must submit data to the Specialist ACHD Surgical or Specialist ACHD Centre on endocarditis so that this can be submitted to the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.	Immediate

	Adult	Implementation timescale
F8(L3)	Each Local ACHD Centre will contribute to the network-wide database by diagnosis to support workload planning.	Within 1 year
F9(L3)	Each Local ACHD Centre must work with the network to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Local ACHD Centres will follow mandatory National Institute for Health and Care Excellence guidance.	Immediate
F10(L3)	Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.	Immediate
F11(L3)	Each Local ACHD Centre must demonstrate that clinical services and support services are appropriate and sensitive to the needs of teenagers, young people and older people with congenital heart disease.	Immediate

DRAFT CHD Standards: Section G: Research
Level 1: Specialist ACHD Surgical Centres

	Adult	Implementation timescale
G1(L1)	Each Specialist ACHD Surgical Centre is expected to participate in research.	Within 6 months
G2(L1)	Each Congenital Heart Network must have, and regularly update, a research strategy and programme that documents current and planned research activity in the field of ACHD and the resource needed to support the activity and objectives for development. This must include a commitment to working in partnership with other Specialist ACHD Surgical Centres and Specialist ACHD Centres, and Local ACHD Centres as appropriate, in research activity which aims to address issues that are important for the further development and improvement of clinical practice, for the benefit of ACHD patients.	Within 6 months
G3(L1)	Each Congenital Heart Network must demonstrate close links with one or more academic department(s) in Higher Education Institutions.	Immediate
G4(L1)	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centres	
G1(L2)	Each Specialist ACHD Centre must participate in research.	Immediate
G2(L2)	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
G1(L3)	Each Local ACHD Centre should participate in research.	Immediate
G2(L3)	Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.	Immediate

	Adult	Implementation timescale
H1(L1)	Specialist ACHD Surgical Centres must demonstrate that arrangements are in place that allow patients to participate in decision-making at every stage in their care.	Immediate
H2(L1)	Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L1)	Patients and partners, family or carers must be helped to understand the patient's condition and its impact, what signs and symptoms should be considered 'normal' for them, in order to be able to actively participate in decision-making at every stage in their care, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the patient's and partner/family/carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. tattoos, piercings and intradermal procedures; f. careers; g. travel; h. welfare benefits; i. social services; and j. community services.	Immediate
H4(L1)	When referring patients for further investigation, surgery or cardiological intervention, patient care plans will be determined primarily by the availability of expert care for their condition. The cardiologist must ensure that patients are advised of any appropriate choices available as well as the reasons for any recommendations.	Immediate

	Adult	Implementation timescale
H5(L1)	Sufficient information must be provided to allow the patient to make informed decisions, including supporting patients, partners, family or carers in interpreting publicly available data that support choice. The following should also be described: a. other clinical specialties offered by alternative units, relevant to patients with co-morbidities; b. accessibility of alternative units; c. patient facilities offered by alternative units; d. outcomes at units under consideration; and e. consideration of the closest unit to the patient's home.	Immediate
H6(L1)	Specialist ACHD Surgical Centres must demonstrate that patients, partners, family and carers are offered support in obtaining further opinions or referral to another Specialist ACHD Surgical Centre, and in interpreting publicly available ACHD data that supports patient choice.	Immediate
H7(L1)	Information must be made available to patients, partners, family and carers in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	Immediate
H8(L1)	Specialist ACHD Surgical Centres must demonstrate that arrangements are in place for patients, partners, family or carers to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H9(L1)	The patient's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H10(L1)	Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist ACHD Surgical Centres must make this feedback openly available to patients, partners/families/carers and the general	Immediate

	Adult	Implementation timescale
	public, together with outcome of relevant local and national audits. Specialist ACHD Surgical Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients must be informed of the action taken following a complaint or suggestion made. Specialist ACHD Surgical Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	
H11(L1)	Each Specialist ACHD Surgical Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.	Immediate
H12(L1)	Each patient must have access to an ACHD Nurse Specialist who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the patient and partner/family/carers throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.	Immediate
H13(L1)	An ACHD Specialist Nurse must be available at all outpatient appointments to help explain the diagnosis and management of the patient's condition and to provide literature.	Within 6 months
H14(L1)	The ACHD Nurse Specialist will support patients by explaining the diagnosis and management plan of the patient's condition, and providing psychosocial support to promote adaptation and adjustment.	Immediate
H15(L1)	The ACHD Specialist Nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H16(L1)	Where patients do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	Immediate

	Adult	Implementation timescale
H17(L1)	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	Immediate
H18(L1)	Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate
H19(L1)	Patients, partners, family or carers and all health professionals involved in the patient's care must be given details of who and how to contact if they have any questions or concerns. Information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H20(L1)	Partners/family/carers should be offered resuscitation training when appropriate.	Immediate
H21(L1)	Where surgery or intervention is planned, patients and carers must have the opportunity to visit the Specialist ACHD Surgical Centre well in advance of admission (as early as possible) to meet the team, including the ACHD Specialist Nurse that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate
H22(L1)	Patients must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Consent must be taken in line with GMC guidance.	Immediate
H23(L1)	An ACHD Specialist Nurse must be available to support patients and carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H24(L1)	Patients and carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H25(L1)	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H26(L1)	A Practitioner Psychologist experienced in the care of congenital cardiac patients must be available to support patients at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care.	Within 6 months

	Adult	Implementation timescale
H27(L1)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the patient or their family/carers) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed so that their views on future care can be included in the pathway. An ongoing opportunity for the patient to discuss concerns about treatment must be offered.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centre	
H1(L2)	Specialist ACHD Centres must demonstrate that arrangements are in place that allows patients to actively participate in decision-making at every stage in their care.	Immediate
H2(L2)	Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L2)	Patients and partners, family or carers must be helped to understand the patient's condition and its impact, what signs and symptoms should be considered 'normal' for them, in order to be able to actively participate in decision-making at every stage in their care including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the patient's and partner/family/carers' understanding must be considered. Information provided should include any aspect of life that is relevant to their congenital heart condition, including a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. tattoos, piercings and intradermal procedures; f. careers; g. travel; h. welfare benefits; i. social services; and j. community services.	Immediate
H4(L2)	Information must be made available to patients, partners, family or carers in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special	Immediate

	Adult	Implementation timescale
	needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	
H5(L2)	Specialist ACHD Centres must demonstrate that arrangements are in place for patients, partners, family or carers to be given an agreed, written management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H6(L2)	The patient's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H7(L2)	Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist ACHD Centres must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits. Specialist ACHD Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients and partners/family /carers must be informed of the action taken following a complaint or suggestion made. Specialist ACHD Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate
H8(L2)	Each Specialist ACHD Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.	Immediate
H9(L2)	Each patient must have access to an ACHD Nurse Specialist who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the patient and partner/family/carers throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.	Immediate
H10(L2)	An ACHD Specialist Nurse must be available at all outpatient appointments to help explain the diagnosis and management of the patient's condition and to provide relevant literature.	Immediate

	Adult	Implementation timescale
H11(L2)	The ACHD Nurse Specialist will support patients by explaining the diagnosis and management plan of the patient's condition, and providing psychosocial support to promote adaptation and adjustment.	Immediate
H12(L2)	The ACHD Specialist Nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H13(L2)	Where patients do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters /advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.	Immediate
H14(L2)	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	Immediate
H15(L2)	Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient's personal record in accordance with national guidance.	Immediate
H16(L2)	Patients, partners, family and carers and all health professionals involved in the patient's care must be given details of who and how to contact if they have any questions or concerns, including information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L2)	Partners/family/carers should be offered resuscitation training when appropriate.	Immediate
H18(L2)	Specialist ACHD Centres must demonstrate that patients and carers must be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data that supports patient choice.	Immediate
H19(L2)	Where surgery or intervention is planned, Specialist ACHD Centres must ensure that the patient and their partner, family or carers have the opportunity to visit the Specialist ACHD Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate

	Adult	Implementation timescale
H20(L2)	Patients must be given an opportunity to discuss planned surgery or interventions prior to planned dates of admission. Consent must be taken in line with GMC guidance.	Immediate
H21(L2)	An ACHD Specialist Nurse must be available to support patients and their partner, family or carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H22(L2)	Patients and their partner, family or carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H23(L2)	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H24(L2)	A Practitioner Psychologist experienced in the care of congenital cardiac patients must be available to support patients at any stage in their care but particularly at the stage of diagnosis, decision making around care and lifecycle transitions, including transition to adult care.	Within 1 year
H25(L2)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the patient or their family) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed so that their views on future care can be included in the pathway. An ongoing opportunity for the patient to discuss concerns about treatment must be offered.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
H1(L3)	Local ACHD Centres must demonstrate that arrangements are in place that allow patients to actively participate in decision-making at every stage in their care.	Immediate
H2(L3)	Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.	Immediate
H3(L3)	Patients and partners, family or carers must be helped to understand the patient's condition and its impact, what signs and symptoms should be considered 'normal' for them, in order to be able to actively participate in decision-making at every stage in their care including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the patient's and their partner/family/carers' understanding must be considered. Information should include any aspect of care that is relevant to their congenital heart condition, including: a. exercise and sports participation; b. sex, contraception, pregnancy; c. dental care and endocarditis prevention; d. smoking, alcohol and drugs; e. tattoos, piercings and intradermal procedures; f. careers; g. travel; h. welfare benefits; i. social services; and j. community services.	Immediate
H4(L3)	Information must be made available to patients, partners, family and carers in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account	Immediate

	Adult	Implementation timescale
	special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.	
H5(L3)	Local ACHD Centres must demonstrate that arrangements are in place for patients, partners, family and carers to be given an agreed, written management plan in a language they can understand that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.	Immediate
H6(L3)	The patient's management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.	Immediate
H7(L3)	Patients, partners, families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Local ACHD Centres must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits. Local ACHD Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients and their partners/families/carers must be informed of the action taken following a complaint or suggestion made. Local ACHD Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate
H8(L3)	Each Local ACHD Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.	Immediate
H9(L3)	Each patient must have access to an ACHD Nurse Specialist who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the patient and partner/family/carer throughout their care. Patients with complex needs must have a named ACHD Nurse Specialist. ACHD Nurse Specialist contact details will be given at each attendance at the outpatient clinic.	Within 6 months
H10(L3)	An ACHD Specialist Nurse must be available at all outpatient appointments to help explain the diagnosis and management of the patient's condition and to provide relevant literature.	Within 1 year

	Adult	Implementation timescale
H11(L3)	The ACHD Nurse Specialist will support patients by explaining the diagnosis and management plan of the patient’s condition, and providing psychosocial support to promote adaptation and adjustment.	Immediate
H12(L3)	The ACHD Specialist Nurse must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.	Immediate
H13(L3)	Where patients do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability ‘passports’ which define their communication needs.	Immediate
H14(L3)	There must be access (for patients, partners, families and carers) to support services including faith support and interpreters.	Immediate
H15(L3)	Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient’s personal record in accordance with national guidance.	Immediate
H16(L3)	Patients, partners, family or carers and all health professionals involved in the patient’s care must be given details of who and how to contact if they have any questions or concerns, including information on the main signs and symptoms of possible complications or deterioration and what steps to take must be provided when appropriate. Clear arrangements for advice in the case of emergency must be in place.	Immediate
H17(L3)	Partners/family/carers should be offered resuscitation training when appropriate.	Immediate
H18(L3)	Local ACHD Centres must demonstrate that patients and carers must be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data that supports patient choice.	Immediate
H19(L3)	Where surgery or intervention is planned, Local ACHD Centres must ensure that the patient and their partner, family or carers have the opportunity to visit the Specialist ACHD Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.	Immediate

	Adult	Implementation timescale
H20(L3)	An ACHD Specialist Nurse must be available to support patients and their partner, family or carers through the consent process. When considering treatment options, patients and carers need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.	Immediate
H21(L3)	Patients and their partner, family or carers must be given details of available local and national support groups at the earliest opportunity.	Immediate
H22(L3)	Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.	Immediate
H23(L3)	A Practitioner Psychologist experienced in the care of congenital cardiac patients must be available to support patients at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care. Where this service is not available locally the patient should be referred to the Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Within 1 year
H24(L3)	When patients experience an adverse outcome from treatment or care the medical and nursing staff must maintain open and honest communication with the patient and their family. Identification of a lead doctor and nurse (as agreed by the patient or their family) will ensure continuity and consistency of information. A clear plan of ongoing treatment, including the seeking of a second opinion, must be discussed so that their views on future care can be included in the pathway. An ongoing opportunity for the patient to discuss concerns about treatment must be offered.	Immediate

	Adult	Implementation timescale
I1(L1)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L1)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I3(L1)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.	Immediate
I4(L1)	All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse, in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not require long-term follow-up.	Immediate
I5(L1)	Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient's wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I6(L1)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate
I7(L1)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic, they will see an ACHD Specialist Nurse who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle, in language the young person can understand. The Cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The young person will have some independent time to talk with their Specialist ACHD Cardiologist and ACHD Specialist Nurse.	Immediate

	Adult	Implementation timescale
I8(L1)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I9(L1)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.	Immediate

	Adult	Implementation timescale
I1(L2)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L2)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I3(L2)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.	Immediate
I4(L2)	All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse, in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not require long-term follow-up.	Immediate
I5(L2)	Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient's wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I6(L2)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate
I7(L2)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic, they will see an ACHD Specialist Nurse who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle, in language the young person can understand. The Cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The young person will have some independent time to talk with their Specialist ACHD Cardiologist and ACHD Specialist Nurse.	Immediate

	Adult	Implementation timescale
I8(L2)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I9(L2)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.	Immediate

	Adult	Implementation timescale
I1(L3)	Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs. 'Lost to follow-up' rates must be recorded and discussed at the network multidisciplinary team meeting.	Within 1 year
I2(L3)	All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.	Immediate
I3(L3)	There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs.	Immediate
I4(L3)	All patients requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse, in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not require long-term follow-up.	Immediate
I5(L3)	Patients, partners, families and carers must be fully involved and supported in discussions around the clinical issues in accordance with the patient's wishes. The views, opinions and feelings of the patient must be fully heard and considered, and the patient must be offered the opportunity to discuss matters in private, away from their parents/carers if they wish.	Immediate
I6(L3)	All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.	Immediate
I7(L3)	Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Management of young people arriving in the adult service will aim to ensure that they are fully confident in managing their own condition and health care. In the clinic, they will see an ACHD Specialist Nurse who will explain and discuss a range of issues including the impact of their condition, contraception and pregnancy, and lifestyle, in language the young person can understand. The Cardiologist will discuss the treatment plan with the young person and discuss it with their family/carers when appropriate. The	Immediate

	Adult	Implementation timescale
	young person will have some independent time to talk with their Specialist ACHD Cardiologist and ACHD Specialist Nurse.	
I8(L3)	The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.	Immediate
I9(L3)	Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.	Within 1 year

DRAFT CHD Standards: Section J: Pregnancy and Contraception
Level 1: Specialist ACHD Surgical Centres

	Adult	Implementation timescale
	Family Planning Advice	
J1(L1)	All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	Immediate
J2(L1)	All female patients of childbearing age must have access to a service that provides specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Written advice about sexual and reproductive health and safe forms of contraception specific to their condition must be provided. They must have ready 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.	Immediate
J3(L1)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L1)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant ACHD cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist.	Immediate
J5(L1)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Within 1 year
	Pregnancy and Planning Pregnancy	
J6(L1)	Each Specialist ACHD Surgical Centre must be staffed by Specialist ACHD Cardiologists with expertise in pregnancy in congenital heart disease, with arrangements for appropriate cover within the centre.	Immediate
J7(L1)	Patients actively considering pregnancy, for whom pregnancy may carry a moderate or high (class 2-4) risk, must receive joint pre-pregnancy counselling with the cardiologist and a maternal medicine specialist (consultant obstetrician) with expertise in pregnancy in women with congenital heart disease.	Immediate
J8(L1)	A plan for the care of a pregnant woman with congenital heart disease must be developed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease immediately they are pregnant. The plan must be made in conjunction with the obstetric services. This must include access to termination of pregnancy services.	Immediate

	Adult	Implementation timescale
	The individualised care plan must cover the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery. Decisions on place of birth must be made in conjunction with the mother, and sufficient information must be provided to understand any choices. The consequences of such choices must be clear, particularly the impact place of birth may have in relation to the separation of mother and baby immediately postnatally.	
J9(L1)	Pregnant women with congenital heart disease that carries moderate or high (class 2-4) risk and who may require emergency surgery or intervention during pregnancy, must be managed at an obstetric unit at the Specialist ACHD Surgical Centre, or close by (for example at the network linked obstetric unit) during pregnancy, delivery and the puerperium.	Immediate
J10(L1)	Women with moderate or high risk conditions, who are not at risk of requiring such emergency surgery or intervention during pregnancy, may be managed at an obstetric unit outside the Specialist ACHD Surgical Centre with specific network agreement and advice from the specialist centre.	Immediate
J11(L1)	Arrangements need to be made for postnatal follow-up of women and contraceptive advice. Arrangements also need to be made for women to be referred back to their regular long-term follow-up programme once the pregnancy is over.	Immediate
J12(L1)	Each Specialist ACHD Surgical Centre must have a specialist tertiary maternity unit on the same hospital site or in a neighbouring hospital that functions as part of the extended multidisciplinary team. Consultant Obstetricians must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7. Care must be delivered within a dedicated multidisciplinary service staffed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease and an obstetrician with a special interest in maternal medicine who has undergone training in pregnancy in congenital heart disease, and a supporting multidisciplinary team with experience of managing congenital heart disease in pregnancy. The multidisciplinary team must include consultant obstetricians, midwives, consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease.	Immediate
J13(L1)	Regular joint clinics will be provided with the Specialist ACHD Cardiologist with expertise in congenital heart disease in pregnancy, Specialist Obstetrician and with access to an Obstetric Anaesthetist. Regular specialist multidisciplinary team case conferences must take place across the network with additional input including: high-risk obstetrics, cardiac and obstetric anaesthesia,	Immediate

	Adult	Implementation timescale
	haematology, neonatal and fetal medicine, contraception and pre-pregnancy care.	

	Adult	Implementation timescale
	Family Planning Advice	
J1(L2)	All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease.	Immediate
J2(L2)	All female patients of childbearing age must have access to a service that provides specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided. They must have ready 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.	Immediate
J3(L2)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L2)	All male patients must have access to counselling and information about contraception and recurrence risk by an ACHD cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist.	Immediate
J5(L2)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Immediate
	Pregnancy and Planning Pregnancy	
J6(L2)	Each Specialist ACHD Centre must be staffed by Specialist ACHD cardiologists with expertise in pregnancy in congenital heart disease, with arrangements for appropriate cover within the centre.	Immediate
J7(L2)	Patients actively considering pregnancy, for whom pregnancy may carry a moderate or high (class 2-4) risk, must receive joint pre-pregnancy counselling with the cardiologist and a maternal medicine specialist (Consultant Obstetrician) with expertise in pregnancy in women with congenital heart disease.	Immediate
J8(L2)	A plan for the care of a pregnant woman with congenital heart disease must be developed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease immediately they are pregnant. The plan must be made in conjunction with the obstetric services. This must include access to termination of pregnancy services.	Immediate

	Adult	Implementation timescale
	The individualised care plan must cover the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery. Decisions on place of birth must be made in conjunction with the mother, and sufficient information must be provided to understand any choices. The consequences of such choices must be clear, particularly the impact place of birth may have in relation to the separation of mother and baby immediately postnatally.	
J9(L2)	Pregnant women with congenital heart disease that carries moderate or high (class 2-4) risk and who may require emergency surgery or intervention during pregnancy, must be managed at an obstetric unit at the Specialist ACHD Surgical Centre or close by (for example at the network linked obstetric unit), during pregnancy, delivery and the puerperium.	Immediate
J10(L2)	Women with moderate or high risk conditions, who are not at risk of requiring such intervention during pregnancy, may be managed at an obstetric unit outside the Specialist ACHD Surgical Centre with specific network agreement and advice from the specialist centre.	Immediate
J11(L2)	Arrangements need to be made for postnatal follow-up of women and contraceptive advice. Arrangements also need to be made for women to be referred back to their regular long-term follow-up programme once the pregnancy is over.	Immediate
J12(L2)	Each Specialist ACHD Centre must have a specialist tertiary maternity unit on the same hospital site or in a neighbouring hospital that functions as part of the extended multidisciplinary team. Consultants Obstetricians must be able to provide emergency bedside care (call to bedside within 30 minutes) 24/7. Care must be delivered within a dedicated multidisciplinary service staffed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease or an obstetrician with a special interest in maternal medicine who has undergone training in pregnancy in congenital heart disease, and a supporting multidisciplinary team with experience of managing congenital heart disease in pregnancy. The multidisciplinary team must include consultant obstetricians, midwives, consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease.	Immediate
J13(L2)	Regular joint clinics will be provided with the Specialist ACHD Cardiologist with expertise in congenital heart disease in pregnancy, Specialist Obstetrician and with access to an Obstetric Anaesthetist. Regular specialist multidisciplinary team case conferences must take place across the network with additional input including: high-risk obstetrics, cardiac and obstetric anaesthesia,	Immediate

	Adult	Implementation timescale
	haematology, neonatal and fetal medicine, contraception and pre-pregnancy care.	

	Adult	**Implementation timescale**
	Family Planning Advice	
J1(L3)	All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist or cardiologist with special interest in congenital heart disease with expertise in pregnancy in congenital heart disease. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service through an outreach clinic, at the Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Immediate
J2(L3)	All female patients of childbearing age must have access to a service that provides specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease. Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided. They must have ready 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.	Immediate
J3(L3)	Specialist genetic counselling must be available for those with heritable conditions that have a clear genetic basis.	Immediate
J4(L3)	All male patients must have access to counselling and information about contraception and recurrence risk by a consultant ACHD cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service through an outreach clinic at the Specialist ACHD Surgical Centre or Specialist ACHD Centre.	Immediate
J5(L3)	Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.	Immediate
	Pregnancy and Planning Pregnancy	
J6(L3)	A plan for the care of a pregnant woman with congenital heart disease must be developed by a Specialist ACHD Cardiologist with expertise in pregnancy in congenital heart disease at a Specialist ACHD Surgical Centre or Specialist ACHD Centre immediately once they are pregnant. The plan must be made in conjunction with the obstetric services. This must include access to termination of pregnancy services. The individualised care plan must cover the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery.	Immediate

	Adult	Implementation timescale
	Decisions on place of birth must be made in conjunction with the mother, and sufficient information must be provided to understand any choices. The consequences of such choices must be clear, particularly the impact place of birth may have in relation to the separation of mother and baby immediately postnatally.	
J7(L3)	The Local ACHD Centre may care for pregnant women with ACHD in whom pregnancy presents a low maternal risk at the onset of pregnancy. It should be acknowledged that as pregnancy proceeds, complications such as severe pre-eclampsia may alter this risk assessment.	Immediate

	Adult	Implementation timescale
	Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L1)	Each Specialist ACHD Surgical Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers.	Immediate
L2(L1)	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L1)	When a patient is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the patient and their partner/family or carers. These leads may change over time as appropriate.	Immediate
L4(L1)	The lead doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.	Immediate
L5(L1)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the patient and their partner/family or carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The potential for organ and tissue donation should be discussed. The partner/family or carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L1)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L1)	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	Immediate
L8(L1)	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	Immediate

	Adult	Implementation timescale
L9(L1)	For patients remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their partner/family or carers can easily seek answers to questions and express wishes, worries and fears.	Immediate
L10(L1)	The room and environment must be prepared to meet the palliative care needs and wishes of the patient and their partner/family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L1)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L1)	Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L1)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the patient and their partner/family or carers.	Immediate
L14(L1)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local cardiologists, GPs, community nurses, out-of-hours GP and ambulance services and the local hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L1)	Support for patients and their partners/families or carers must continue if they choose to have their end-of-life care in the community. Partners/families or carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L1)	The team supporting a patient, and their partner/family or carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the patient and their partner/family or carers where possible.	Immediate
L17(L1)	If a patient or their partner/family or carers would like to involve the support of members of their home community, the hospital-	Immediate

	Adult	Implementation timescale
	based named nurse, as identified above, will ensure they are invited into the hospital.	
L18(L1)	Patients will be offered an opportunity to discuss the donation of organs and tissues with the *Donor* team.	Immediate
L19(L1)	The lead doctor/named nurse will inform the hospital bereavement team that a patient is dying. They should only be introduced to the partner/family or carers before a death has occurred, if they have specifically requested to meet them.	Immediate
L20(L1)	Partners/families or carers must be allowed to spend as much time as possible with the patient after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of the patient.	Immediate
L21(L1)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L1)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L1)	Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.	Immediate
L24(L1)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a patient	
L25(L1)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L1)	Within six weeks of the death, the identified lead doctor will write to offer the opportunity for the partner/family or carers to visit the hospital team to discuss the patient's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The partner/family or carers will be offered both verbal and written information that explains clearly and accurately the	Immediate

	Adult	Implementation timescale
	treatment plan, any complications and the cause of death. Partners/families or carers who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	
L27(L1)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.	Immediate
L28(L1)	If partners/families or carers are seeking more formal ongoing support, the identified Specialist ACHD Nurse/named nurse will liaise with appropriate services to arrange this.	Immediate

	Adult	Implementation timescale
	Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L2)	Each Specialist ACHD Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers.	Immediate
L2(L2)	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L2)	When a patient is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the patient and their partner/family or carers. These leads may change over time as appropriate.	Immediate
L4(L2)	The lead doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.	Immediate
L5(L2)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the patient and their partner/family or carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The potential for organ and tissue donation should be discussed. The partner/family or carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L2)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate
L7(L2)	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	Immediate
L8(L2)	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	Immediate

	Adult	Implementation timescale
L9(L2)	For patients remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their partner/family or carers can easily seek answers to questions and express wishes, worries and fears.	Immediate
L10(L2)	The room and environment must be prepared to meet the palliative care needs and wishes of the patient and their partner/family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L2)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L2)	Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L2)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the patient and their partner/family or carers.	Immediate
L14(L2)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local cardiologists, GPs, community nurses, out-of-hours GP and ambulance services and the local hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L2)	Support for patients and their partners/families or carers must continue if they choose to have their end-of-life care in the community. Partners/families or carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	
L16(L2)	The team supporting a patient, and their partner/family or carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the patient and their partner/family or carers where possible.	Immediate
L17(L2)	If a patient or their partner/family or carers would like to involve the support of members of their home community, the hospital-	Immediate

	Adult	Implementation timescale
	based named nurse, as identified above, will ensure they are invited into the hospital.	
L18(L2)	Patients will be offered an opportunity to discuss the donation of organs and tissues with the *Donor* team.	Immediate
L19(L2)	The lead doctor/named nurse will inform the hospital bereavement team that a patient is dying. They should only be introduced to the partner/family or carers before a death has occurred, if they have specifically requested to meet them.	Immediate
L20(L2)	Partners/families or carers must be allowed to spend as much time as possible with the patient after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of the patient.	Immediate
L21(L2)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L2)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L2)	Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.	Immediate
L24(L2)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a patient	
L25(L2)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L2)	Within six weeks of the death, the identified lead doctor will write to invite the partner/family or carers to visit the hospital team to discuss the patient's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The partner/family or carers will be offered both verbal and written information that explains clearly and accurately the treatment	Immediate

	Adult	Implementation timescale
	plan, any complications and the cause of death. Partners/families or carers who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	
L27(L2)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.	Immediate
L28(L2)	If partners/families or carers are seeking more formal ongoing support, the identified Specialist ACHD Nurse/named nurse will liaise with appropriate services to arrange this.	Immediate

	Adult	Implementation timescale
	Palliative Care Note: Palliative care is the active, total care of the patients whose disease is not responsive to curative or life-extending treatment.	
L1(L3)	Each Local ACHD Centre must have a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the patient and partner/family or carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the partner/family or carers. Where this is not provided in the Local ACHD Centre, the patient must be offered access to the service at the Specialist ACHD Surgical or Specialist ACHD Centre.	Immediate
L2(L3)	Clinicians should use nationally approved palliative medicine guidance to plan palliative care from the point of diagnosis.	Immediate
L3(L3)	When a patient is identified as needing palliative or end-of-life care, a lead doctor and named nurse will be identified by the multidisciplinary team in consultation with the patient and their partner/family or carers. These leads may change over time as appropriate.	Immediate
L4(L3)	The lead doctor and named nurse will work together with the palliative care team to ensure the patient and their partner/family or carers are supported up to, and beyond death.	Immediate
L5(L3)	An individualised end-of-life plan, including an advanced care plan, will be drawn up in consultation with the patient and their partner/family or carers, and will include personal preferences (e.g. choice to remain in hospital or discharge home/hospice; presence of extended family). The potential for organ and tissue donation should be discussed. The partner/family or carers and all the professionals involved will receive a written summary of this care plan and will be offered regular opportunities to discuss any changes with the lead doctor.	Immediate
L6(L3)	The lead doctor, with the named nurse, will ensure that the agreed end-of-life plan is clearly documented and agreed with all medical, nursing and psychological support team members (including lead clinicians in other treatment units and relevant community services) to ensure that all clinical staff understand the ongoing care and the reasons further active treatment may not be possible.	Immediate

	Adult	Implementation timescale
L7(L3)	Communication and end-of-life care discussions with patients and their partners/families or carers must be open, honest and accurate.	Immediate
L8(L3)	The patient and their partner/family or carers must be offered details of additional non-NHS support services available to them.	Immediate
L9(L3)	For patients remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their partner/family or carers can easily seek answers to questions and express wishes, worries and fears.	Immediate
L10(L3)	The room and environment must be prepared to meet the palliative care needs and wishes of the patient and their partner/family/carers, and allow them the privacy needed to feel that they can express their feelings freely.	Immediate
L11(L3)	All members of the clinical team must be familiar with the bereavement services available in their hospital.	Immediate
L12(L3)	Patients and their partners/families or carers must be made aware of multi-faith staff and facilities within the hospital.	Immediate
	Discharge and out-of-hospital care	
L13(L3)	Any planned discharge must be managed by the named nurse who will coordinate the process and link with the patient and their partner/family or carers.	Immediate
L14(L3)	The lead doctor, with the named nurse, will ensure that the end-of-life plan and discharge plan are shared with relevant community and local hospital services including local cardiologists, GPs, community nurses, out-of-hours GP and ambulance services and the local hospice. Written care plans must be provided for all members of the team. All equipment needed in the home must be available prior to discharge.	Immediate
L15(L3)	Support for patients and their partners/families or carers must continue if they choose to have their end-of-life care in the community. Partners/families or carers must be given written details of how to contact support staff 24/7. Community and outreach provision must be planned prior to discharge.	Immediate
	Management of a Death (whether expected or unexpected)	

	Adult	**Implementation timescale**
L16(L3)	The team supporting a patient, and their partner/family or carers, at the end of their life must adopt a holistic approach that takes into consideration emotional, cultural and spiritual needs, their ability to understand that this is the end of life, and must take account of and respect the wishes of the patient and their partner/family or carers where possible.	Immediate
L17(L3)	If a patient or their partner/family or carers would like to involve the support of members of their home community, the hospital-based named nurse, as identified above, will ensure they are invited into the hospital.	Immediate
L18(L3)	Patients will be offered an opportunity to discuss the donation of organs with the *Donor* team.	Immediate
L19(L3)	The lead doctor/named nurse will inform the hospital bereavement team that a patient is dying. They should only be introduced to the partner/family or carers before a death has occurred, if they have specifically requested to meet them.	Immediate
L20(L3)	Partners/families or carers must be allowed to spend as much time as possible with the patient after their death, supported by nursing and medical staff, as appropriate. It is essential that families have an opportunity to collect memories of the patient.	Immediate
L21(L3)	When a death occurs in hospital, the processes that follow a death need to be explained verbally, at the family's pace and backed up with written information. This will include legal aspects, and the possible need for referral to the coroner and post-mortem. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.	Immediate
L22(L3)	Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.	Immediate
L23(L3)	Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.	Immediate
L24(L3)	Staff involved at the time of a death will have an opportunity to talk through their experience either with senior staff, psychology or other support services, e.g. local bereavement support.	Immediate
	Ongoing support after the death of a patient	

	Adult	Implementation timescale
L25(L3)	Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.	Immediate
L26(L3)	Within six weeks of the death, the identified lead doctor will write to invite the partner/family or carers to visit the hospital team to discuss the patient's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The partner/family or carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Partners/families or carers who wish to visit the hospital before their formal appointment should be made welcome by the ward team.	Immediate
L27(L3)	When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.	Immediate
L28(L3)	If partners/families or carers are seeking more formal ongoing support, the identified Specialist ACHD Nurse/named nurse will liaise with appropriate services to arrange this.	Immediate

Level 1: Specialist ACHD Surgical Centres

	Adult	Implementation timescale
M1(L1)	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L1)	All patients with planned elective cardiac surgery or intervention must have a dental assessment as part of pre-procedure planning to ensure that they are dentally fit for their planned intervention.	Immediate
M3(L1)	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	Immediate
M4(L1)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L1)	Specialist ACHD Surgical Centres must provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for patients with congenital heart disease.	Immediate

	Adult	Implementation timescale
	Specialist ACHD Centres	
M1(L2)	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L2)	The Specialist ACHD Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L2)	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	Immediate
M4(L2)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L2)	Specialist ACHD Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for people with congenital heart disease or refer such patients to the Specialist ACHD Surgical Centre.	Immediate

	Adult	Implementation timescale
	Local ACHD Centres	
M1(L3)	Patients will be given appropriate evidence-based preventive dental advice at time of congenital heart disease diagnosis by the cardiologist or nurse.	Immediate
M2(L3)	Each Local ACHD Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.	Immediate
M3(L3)	All patients at increased risk of endocarditis must have a tailored programme for specialist follow-up.	Immediate
M4(L3)	Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.	Immediate
M5(L3)	Local ACHD Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for people with congenital heart disease or refer such patients to the Specialist ACHD Surgical Centre.	Immediate

SCHEDULE 2 – THE SERVICES

B. 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 (Level 1 services) and Specialist ACHD Centres (Level 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 Level 3 services (Local ACHD Centres). This activity is commissioned by Clinical Commissioning Groups and is therefore outside the scope of this specification. Nevertheless Level 3 services are part of the Congenital Heart Network of Care and it is expected that Adult Level 1 and 2 services will work in partnership with Level 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/
- Heart and Lung Transplantation Service (all ages)
  http://www.england.nhs.uk/wp-content/uploads/2013/06/a18-heart-lung-trans-all.pdf

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 Congenital Heart Network, with agreed pathways and protocols for referral between the three levels. Adult Congenital Heart Services must partner with the Paediatric (and fetal) Cardiac Services within the network 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, 2015).

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 "Levels" of provider as described in the Standards of Care.

The Standards provide timescales for achievement of each standard ranging from standards that must be achieved immediately to standards which must be achieved within 5 years. The timescale for each standard is provided in the standards document.

Network Care Levels:

- Level 1: Specialist ACHD or Children's Surgical Centres
- Level 2: Specialist ACHD or Children's Cardiology Centres
- Level 3: Local ACHD or Children's Cardiology Centres

It is expected that Paediatric and Adult services will work in partnership within the network 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

1.4 Evidence Base

Draft Congenital Heart Disease Standards Levels 1-3, 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**	✓

A quality dashboard is now operational. Currently assessed outcome measures include the following:

- 30 day unplanned re intervention rate following congenital cardiac surgery and catheter intervention (NICOR defined procedure)
- Cancellations on day of operation for non clinical reasons
- Post catheter intervention complication rate

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 and Objectives

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 lifetime 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 (2015) 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

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 live 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 and act upon 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

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 a Congenital Heart Network. Working in partnership with the Paediatric Congenital Heart services the network will adopt policies and guidelines agreed across the network relating to patient management pathways within each of the centre's specific 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:
- Level 1: Specialist ACHD Surgical Centres
- Level 2: Specialist ACHD Centres
- Level 3: Local ACHD Centres

Across the whole Congenital Heart Network there must be facilities in place to ensure easy and convenient access for patients and their families/carers and facilities and where an inpatient stay is needed, 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 (levels 2 & 3)

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.

Patients must be supported to actively participate in decision making at every stage of their care.

Patient Pathway

Although the pathway will be individualised according to the individual patient need, patients will move between the three levels of service described above. Patients with moderate or severe complexity may be cared for either in the Specialist ACHD Centre or the Specialist ACHD 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 levels of care, but move between levels as appropriate and determined by Network protocols and multidisciplinary team (MDT) planning. ACHD patients with complex lesions may be seen in local Level 3 centres in collaboration with a specialist from Level 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.

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.

Adult Congenital Heart Disease MDT

- The management of patients with significant congenital heart disease should be discussed at combined MDT meetings at the Specialist ACHD Surgical Centre. This includes all patients being considered for a complex catheter intervention, surgery or innovative procedures.
- Each MDT discussion must generate a signed record of the discussion and the final outcome.
- When considering patients for complex catheter intervention or surgery (including out of hours and in emergencies) the minimum composition of the MDT is a Congenital Cardiologist, Congenital Surgeon and Specialist Intensivist. 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 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.

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.

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); and
- provide patients and their families/carers with written and/or electronic material relating to the ACHD condition in an appropriate format.

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; and
- ACHD Nurse Specialist telephone advice service for patients and their families/carers, healthcare professionals and non-healthcare and voluntary sector professionals.

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.

Pregnancy and Contraception

All female patients of childbearing age must be offered personalised pre-pregnancy counselling and contraceptive advice by an ACHD cardiologist and a nurse specialist with expertise in pregnancy in congenital heart disease. They must have ready 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 Level 1 and 2 unit.

Male patients must have access to counselling and information about contraception and recurrence risk by a consultant ACHD 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 that have a clear genetic basis. All patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.

Transition from paediatric to adult CHD services

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

The process of transitioning from paediatric to ACHD care must be initiated no later than the 12th birthday taking into account individual circumstances and special needs.
Paediatric and Adult Congenital Heart Network 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 ongoing congenital cardiac care/monitoring must be seen at least once by an ACHD cardiologist and ACHD Specialist Nurse in a specialist MDT transfer clinic or equivalent and be supported by age-appropriate information and lifestyle advice.
- Particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.
- The Children’s Cardiac Transition Nurse will act as a liaison between young people, their carers, the Children’s Cardiac Nurse Specialist, ACHD Specialist Nurse 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 Congenital Heart 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.

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 partner/family/carers are supported up to and beyond death;
- produce a written, agreed, individual, end-of-life care plan;
- discuss the potential for tissues and organ donation;
- 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 partner/family/carers aware of these;
- When a death occurs in hospital, the processes that follow a death including legal aspects need to be explained verbally, at the family’s pace and backed up with written information. Where possible, continuity of care should be maintained, the clinical team working closely with the bereavement team. Help with the registration of the death, transport of the body and sign-posting of funeral services will be offered.
- generate and publish evidence of effective palliative or end-of-life care for patients / carers.

Governance

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

- Regular continuous clinical audit and quality improvement.
- Regular network multidisciplinary team (MDT) 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 network meetings of the wider clinical team (including network patient representatives) at least every 6 months, for issues such as agreement of protocols, review of audit data and monitoring of performance.

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 must:

- ensure there are written protocols covering communication between clinicians, and between clinicians and patients.
- 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)
- co-operate in developing a national register of research trials and outcomes.

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 and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.

Information should include advice relevant to the patient’s condition:

- exercise and sports participation;
- sex, contraception and pregnancy;
- dental care and endocarditis prevention;
- smoking, alcohol and drugs;
- tattoos, piercings and intradermal procedures;
- careers;
- travel;

- welfare benefits;
- social services;
- community services; and
- information on the main signs and symptoms of possible complications or deterioration and what steps to take.

(not an exhaustive list)

Annual reports

The Congenital Heart Network will produce annual audit and governance reports covering ACHD services.

Administration

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

3.3 Service description of Provider Centres within Adult Congenital Heart Networks

Level 1 - Specialist ACHD Surgical Centres

The Specialist ACHD Surgical Centre will deliver all services that Specialist ACHD Centres and Local ACHD Centres provide, as well as providing all ACHD surgery and interventional catheterisation. The Specialist ACHD 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 ACHD Centres.
- Provide leadership for training, development and research across the network.

Level **2 - Specialist ACHD Centres**

Will provide expert ACHD cardiology advice and support to patients to the same standard as that provided by the Specialist ACHD Surgical Centre and will deliver all services provided at the Local ACHD Centres. The Specialist ACHD Centres will provide ongoing management of ACHD patients along with diagnostic services, simple electrophysiology work and management of ACHD in pregnancy. Where agreed by the network a specialist ACHD centre may also undertake transcatheter closure of ASD and PFO. Specialist ACHD 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:

- Ongoing ACHD patient management.
- Broad range of diagnostic services, including invasive and non-invasive imaging, delivered at the same quality as in the Specialist ACHD Surgical Centre.
- Cardiologists employed by the Specialist ACHD Centre and trained to the appropriate standards in interventional and diagnostic ACHD cardiology 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 Centre who visit the Specialist ACHD Surgical Centre to perform 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. Under governance arrangements agreed by the network and after individual case discussion at network MDT, ASD and PFO closure may be undertaken at the Specialist ACHD centre. All other congenital catheter intervention procedures must only be carried out in the Level 1 centre.
- Selected diagnostic catheterisation procedures may be undertaken at the Specialist ACHD centre when agreed at the network MDT.
- Electrophysiology procedures for patients with simple congenital heart lesions may also be carried out at Specialist ACHD Centres if specifically agreed by a joint MDT meeting with the Specialist ACHD Surgical Centre and under network-agreed governance arrangements.
- Ongoing management of pacing.
- Management of ACHD in pregnancy, contraceptive advice and pre-pregnancy planning, with an understanding of when to refer to Level 1 services

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

Will provide ongoing outpatient care for patients with simple defects. They will deliver long-term follow-up/shared care in liaison with the Congenital Heart 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 Level 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 Congenital Heart Network and the Local ACHD 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.

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 BAME communities are also found in greater numbers than the general population.

5. Any acceptance and exclusion criteria and thresholds

5.1 Acceptance Criteria

- All adult patients 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 level of the congenital heart disease standards (2015). 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/competency-based programmes ensuring continuing professional development of nursing staff.

7.1.2 Level 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 four WTE consultant congenital cardiac surgeons. Units will have a period of five 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 complement of 3 WTE consultant congenital cardiac surgeons will be acceptable in the interim.
- Specialist ACHD 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 with the addition of VAD insertion procedures and cardiac transplantation) each year, averaged over a three year period.

Cardiologists

- Specialist surgical centres must be staffed by a minimum of four WTE 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, who may be included in the minimum of four.
- 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 ACHD Surgical Centre must be staffed by a minimum of one expert

electrophysiologist experienced in adult congenital cardiac disease. There must be appropriate arrangements for cover by a competent person

- Each Specialist ACHD Surgical Centre will have a congenital cardiac imaging specialist expert in both cardiac MRI and cardiac CT.
- Each Specialist ACHD Surgical Centre will have a lead for congenital echocardiography (EACVI accredited).

Nursing

- Each Specialist ACHD 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 ACHD Surgical Centre will provide one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care, and to deliver competency-based programs across the network.
- Each Specialist ACHD Surgical Centre will employ a minimum of 5 WTE ACHD specialist nurses whose role will extend 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

- Each Specialist ACHD Surgical Centre will have a Lead Doctor and Nurse for safeguarding vulnerable adults.
- Each Specialist ACHD Surgical Centre will have an identified bereavement officer.
- Perfusion services and staffing must be accredited by The College of Clinical Perfusion Scientists of Great Britain and Ireland
- Each Specialist ACHD Surgical Centre will employ a minimum of two WTE practitioner psychologists, one of whom will have responsibility for delivering services across the network
- Each Specialist ACHD Surgical Centre will have local arrangements for transferring patients from airfields and helipads as required.
- Equipment infrastructure on site: Electrophysiology including three-dimensional mapping; cardiac catheterisation laboratory; , standard, contrast, interoperative, transesophageal and fetal echocardiography; Magnetic Resonance Imaging (MRI); Computerised Tomography (CT); ventricular assist programme with or without post-operative extra corporeal life support (non-nationally designated extracorporeal membrane oxygenation(ECMO)); and access to Isotope Imaging.

7.1.3 Level 2: Specialist ACHD 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 ACHD Lead with responsibility for the service at the Specialist ACHD Centre, 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 undertake ASD/PFO closure locally or visit the Specialist ACHD Surgical Centre to undertake therapeutic catheterisations must perform at least 50 such procedures each year (PFO closure will be countable), averaged over a three-year period.
- Electrophysiology will usually be undertaken at the Surgical Centre but may be undertaken at the Specialist ACHD Centre if agreed at a joint MDT meeting with the Specialist ACHD Surgical Centre and under network-agreed governance arrangements.
- Congenital Heart imaging specialist expert in Cardiac MRI and cardiac CT.
- A minimum of 2 WTE trained specialist designated registered nurses with a specialist interest in ACHD, whose role extends across 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 visiting staff from the Specialist ACHD Surgical 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 Level 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 Specialist ACHD Centre or Specialist ACHD Surgical Centre.
- Designated 0.25 WTE registered nurse with a specialist interest in ACHD to participate in clinics, provide support to inpatients and deal with requests for telephone advice.
- Nurses must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD 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 Specialist ACHD Surgical or Specialist ACHD 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

9. Location of Provider Premises

TBC

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.

Appendix 1

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 be undertaken in either a specialist ACHD surgical centre (L1) or a specialist ACHD centre (L2) to allow joined-up MDT planning.

Interventional closures of ASDs will usually be undertaken at a Specialist ACHD Surgical Centre, but ASD closures may be undertaken at a Specialist ACHD Centre providing certain conditions are met:

- All interventional ASD closures must only be undertaken under network agreed governance arrangements including oversight by the network lead congenital interventionist.
- All cases of ASD must be discussed at a joint MDT meeting with the Specialist ACHD Surgical Centre and the decision made at the MDT where the intervention should be performed and by whom.
- ASD closure may be undertaken at a Specialist ACHD Centre only for patients with an adult diagnosis of CHD, with an ASD without additional complicating features.
- All procedures must be reported to the NICOR congenital audit.
- ASD closures may only to be undertaken at sites where vascular surgeons and cardiac surgeons are available to provide back-up and surgical retrieval of devices
- All interventionists must undertake a minimum volume of procedures as required by the ACHD standards.

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 outpatient 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 Inpatient 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 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
Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm			

Quality Requirement	**Threshold**	**Method of Measurement**	**Consequence of breach**
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 5: Current Outcomes

The UK is one of only three countries with universal participation in national audit of paediatric cardiac surgery, the other two being Sweden and Poland, giving us a good picture of the quality of services right across the country.

NICOR's most recent analysis[43] shows that recent trends in outcomes have been positive, with survival improving in the most recent 18 months[44].

The most recent survival rates for the 10 English centres undertaking paediatric surgery are shown in Table 1.

Table 1: Survival Rates (paediatric surgery 2011-2014) before risk adjustment[45]

	Operations	**Actual Survival (%)**
Guy's and St Thomas	1204	96.8
Leeds General	976	97.6
Liverpool Alder Hey	1146	97.6
Bristol Royal	835	97.7
Newcastle Freeman	678	97.8
Birmingham Children's	1481	98.0
Leicester Glenfield	582	98.1
Southampton	890	98.1
Great Ormond Street	1881	98.4
Royal Brompton	1107	98.9

NICOR's most recent report[46], using a risk adjustment model, showed (figure 1 below) that overall centre survival rates are statistically either as predicted or better than predicted (Birmingham Children's and the Royal Brompton).

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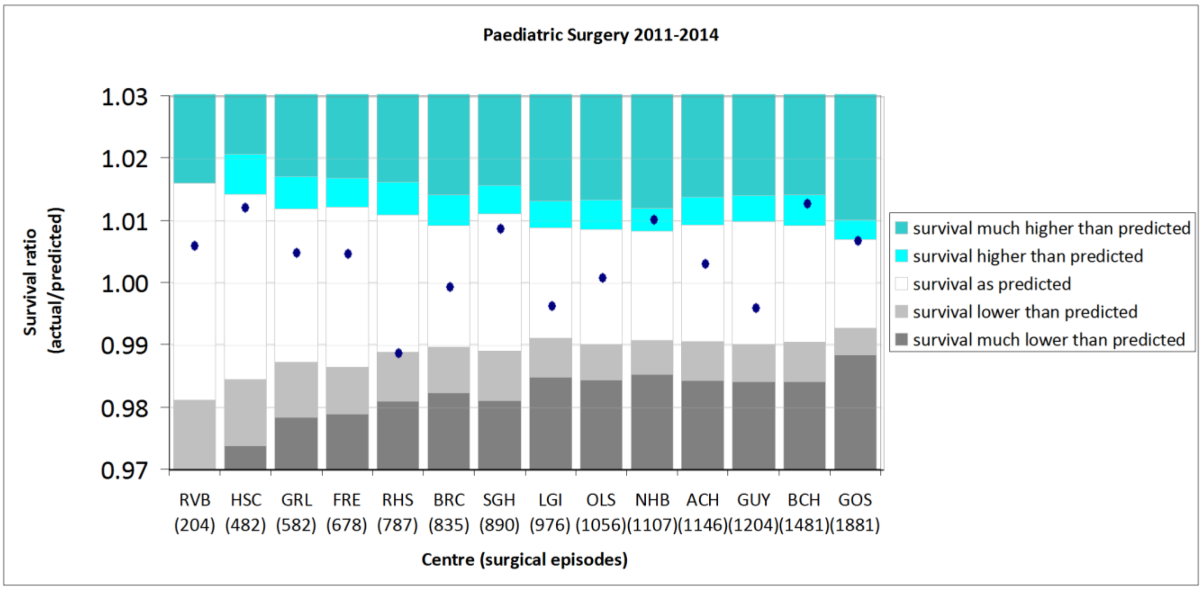
[43] National Congenital Heart Disease Audit Report 2011-2014, NICOR, 2015

[44] National Congenital Heart Disease Audit Report 2011-2014, NICOR, 2015

[45] National Congenital Heart Disease Audit Report 2011-2014, NICOR, 2015

[46] National Congenital Heart Disease Audit Report 2011-2014, NICOR, 2015

Figure 1: Risk adjusted outcome analysis: paediatric cardiac surgery 2011-2014



Key to figure 1	
Code	**Hospital**
RVB	Belfast, Royal Victoria Hospital
HSC	London, Harley Street Clinic
GRL	Leicester, Glenfield Hospital
FRE	Newcastle, Freeman Hospital
RHS	Glasgow, Royal Hospital for Sick Children
BRC	Bristol Royal Hospital for Children
SGH	Southampton, Wessex Cardiothoracic Centre
LGI	Leeds General Infirmary
OLS	Dublin, Our Lady's Children's Hospital
NHB	London, Royal Brompton Hospital
ACH	Liverpool, Alder Hey Hospital
GUY	London, Evelina London Children's Hospital
BCH	Birmingham Children's Hospital
GOS	London, Great Ormond Street Hospital for Children

The dot represents the actual performance of a unit. The shaded bars represent statistical control limits. All centres achieve survival that is as expected or better.

In addition to overall centre outcomes, NICOR also examines performance for 56 specific procedures. There was one outlier for paediatric cardiac surgery[47] and none for paediatric intervention, adult (ACHD) cardiac surgery and adult (ACHD) intervention.

NICOR does not publish a comparable risk adjusted centre level analysis for adult survival rates though the data is collected. NHS statistical analysis[48] of crude survival

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[47] Evelina Children's Hospital for the Norwood procedure. The Evelina Children's Hospital has responded to this alert and published an action plan and NICOR and the professional societies have responded. The review will make recommendations on a more robust and consistent approach to investigating concerns that will involve NHS England as commissioners.

rates did not suggest any providers are clear low outliers compared to the national average, providing some reassurance that there are no obvious safety problems. However as this data is not risk adjusted the analysis is significantly limited and the results should be treated with caution.

An analysis of the ten year trend in 30 day mortality has also been published[49]. This showed that while the number of procedures performed in the UK has increased over the last decade, raw 30-day mortality rate for paediatric cardiac surgical episodes in the UK fell from 4.3% in 2000 to 2.6% in 2009/2010. These rates compare favourably internationally

The drop was seen across the lower three bands of risk (92.9% of surgical episodes) but not in the highest risk band. Case mix has become more complex suggesting a greater proportion of more complex patients in the later years. There is a trend towards earlier definitive repair in infancy. The authors consider that ‘we must now shift our focus [from 30 day mortality] to measures of morbidity, longer term survival and functional outcomes’.

NICOR has also published[50] an analysis of risk factors that could be associated with outcomes, commissioned by the review. This showed that Asian ethnicity had a statistically significant association with outcome at the 95% level. This requires further evaluation and NICOR does not plan to ‘risk adjust’ for Asian ethnicity within the audit without a fuller understanding.

The analysis found no statistically significant links between the other factors explored (deprivation, sex, year, volume, distance from home, weekday or weekend) and 30-day mortality outcome. A trend towards lower mortality was seen at larger case volumes but this was not statistically significant.

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[48] Source: Unpublished NHS England analysis of data from UK providers as reported to NICOR for the years 2010/11 - 12/13 across 46 different procedures. Note that not all ACHD providers report outcomes to NICOR.

[49] Brown et al, Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010, Open Heart 2015;2: doi:10.1136/openhrt-2014-000157

[50] Nicholas O et al, Analysis of candidate risk factors in Paediatric Cardiac Surgery 30-day risk modelling: Ethnicity, Deprivation, Sex, Year, Volume, Distance from home, Weekday or weekend, NICOR, 2015

Appendix 6: Engagement with public, patients and their representatives

At the beginning of the review a single Public and Patient group was created, comprising representatives from national and local charities and support groups. Over 50 groups were invited. The group was chaired by Prof Peter Weissberg, Medical Director of the British Heart Foundation. Some stakeholder groups in particular locations found it difficult to attend the meetings and in these cases we arranged bespoke sessions for briefing and dialogue.

Six meetings of the group have been held to date. Members of this group also took part in a joint meeting group with Clinicians and Provider representatives on three occasions (including one planned for the 13th July).

There were patient and public representatives included in the groups that developed the standards. The standards and service specification were also extensively discussed at the relevant Clinical Reference Group, which includes an expanded number of public & patient representatives (eight). All of these representatives were also invited to consider any necessary amendments post-consultation and five took part in the meeting. Written comments were received from two others.

Hearing from children and young people who use the services

During the Easter holidays in April 2014, nine events were held across the country to specifically engage with young people and ensure that the things that were important to them were addressed in the standards.

Advice and support was taken from young engagement specialists Livity and Fourteen - 19, the latter of whom also provided youth workers to accompany review team members to events to engage with young people. The events were open to all those children and young people who use CHD services. The style was open and friendly, venues were chosen that were child friendly with accessible parking and away from the hospitals. Over 100 children and 60 parents and carers attended the events and added their thoughts to what should be included in the standards of care. Events were as follows:

Monday 7th April	Birmingham – Aston Conference Centre, Aston University
Tuesday 8th April	Liverpool – The Engine Room, Liverpool University Student’s Union
Wednesday 9th April	London - Meeting Room 3A, University of London Union
Thursday 10th April	Bristol – Activity Room 11, Bristol University Student’s Union
Friday 11th April	Southampton - 2 Space, Southampton University Student’s Union
Monday 14th April	Leeds - MINE Venue, Leeds University Student’s Union
Tuesday 15th April	Leicester - Queen’s Hall, Leicester Student’s Union
Wednesday 16th April	Newcastle - The Discovery Museum, Newcastle

Thursday 17th April	Cambridge - Cormack Room, University of Cambridge Centre

A report was developed from the activity with the children and additional comments were gathered from parents and guardians. All these findings were given to the standards groups as they developed the standards. A video was edited of some of the material provided by young people.

Hearing from bereaved parents

We met a number of bereaved parents at our first meeting of patient and public representatives, and hearing about their experience led to the development of a new section in the standards relating to palliative care, end of life care and bereavement.

We sought the advice of and received training from Child Bereavement UK on how we should engage with bereaved parents, and could support their involvement. In August 2014 a meeting took place with parents in Bristol, some of whom were bereaved, or whose children had had poor outcomes. The team also met and talked with a number of bereaved parents at the consultation events.

Reaching stakeholders through the services they use

To widen our engagement with patients and stakeholders currently using the services, time was set aside during the review's programme of visits to CHD units across the country. Many of those who we spoke with were being treated or had relatives being treated in the units and would not have been able to attend events outside the hospital.

Visits and patient and family engagement were done at:

- John Radcliffe Hospital, Oxford April 8th 2014
- Alder Hey Children's Hospital, Liverpool April 15th 2014
- Manchester Royal Infirmary, Manchester April 15th 2014
- Southampton General Hospital, Southampton April 30th 2014
- Royal Brompton Hospital, London May 2nd 2014
- Evelina Children's Hospital, London May 2nd 2014
- Freeman Hospital, Newcastle May 7th 2014
- Leeds General Infirmary, Leeds May 9th 2014
- Birmingham Children's Hospital, Birmingham May 19th 2014
- Bristol Royal Infirmary, Bristol May 20th 2014
- Great Ormond Street Hospital, London May 28th 2014
- Glenfield Hospital, Leicester May 30th 2014
- Cardiff Hospital, Cardiff June 4th 2014
- Blackpool Victoria Hospital, Blackpool July 30th 2014
- Brighton & Sussex Hospital, Brighton August 13th 2014
- Papworth Hospital, Oxford August 15th 2014

The blog

We have published a regular blog throughout the review on the NHS England website with the latest news, papers, discussions, meeting details and forthcoming events so that everything happening in the CHD review was shared and freely available. The blog is written by John Holden, the Director responsible for the review, and has provided an opportunity for comment and conversation for stakeholders.

There are 289 subscribers receiving an alert when the blog is published. The blog has been a tool of engagement particularly for those who are new to the review and we have encouraged those we meet at events to subscribe to the blog to keep up to date with the review. By the end of April 2015 there had been 40 blogs issued.

Ensuring we heard from BME groups

A higher prevalence of CHD has been reported among Asian communities in the UK. We took steps to ensure that all communities were aware of the consultation and had the opportunity to respond. The NHS England Equalities team recommended that we work with the Race Equalities Foundation (REF), who mailed out to their membership about the opportunities to engage online and at consultation events. In particular they connected with the National Black and Minority Ethnic (BME) Transplant Alliance (NBTA), who in turn connected with their membership, as many of the standards that were being developed were applicable to transplant and the aims of the organisation.

We then identified other organisations that connected with BME communities and could help us reach them, by connecting with paediatric CHD units and connecting with local organisations. Organisations contacted included:

- Black Health Agency (Leeds based - northern reach)
- WAITS (Women Active in Today's Society) - Birmingham based, female support organisation that works primarily with harder to reach audiences including BAME women
- Ahmadiyya Muslim Youth Association
- Muslim Health Network
- KHIDMAH
- Newcastle upon Tyne NHS Foundation Trust patient involvement groups
- The Health and Race Equality Forum Newcastle
- The BHA (Black HIV/Aids Forum)

We also contacted hospital trusts and councils in areas with local south Asian communities, including those in Bradford, Leicester, Birmingham, Leeds and Great Ormond Street.

Other languages

Materials were made available in Polish, Punjabi, Hindi, Gujarati, Urdu and Tamil – and we alerted stakeholders as to their availability by email (to all hospitals, local authorities and Health Watches), through the blog and on our website. In addition, because Welsh patients usually undergo CHD surgery in English hospitals, we took Welsh Government advice on consultations in Wales, and written materials were provided in Welsh for the Cardiff consultation event.

Events during consultation

Events were held at a number of cities in England and Wales:

- London – 14th October, 2014
- Newcastle- 16th October, 2014
- Birmingham – 22nd October, 2014
- Leicester - 24th October, 2014
- Leeds – 3rd November, 2014
- Liverpool – 4th November, 2014
- Manchester – 5th November, 2014
- Cambridge – 6th November, 2014
- Oxford – 10th November, 2014
- Cardiff – 11th November, 2014
- Bristol – 12th November, 2014
- Southampton – 13th November, 2014

National and local government and Healthwatch

Meetings and engagement activities were undertaken for MPs and peers, local government officers and councillors; and Healthwatch representatives. Most interest came from those who represented areas that host a CHD specialist unit. Two national meetings of local authority and local Healthwatch representatives were held, in January 2014 and again in October 2015 at the start of the consultation period. This was supplemented with a WebEx. Additionally the team has responded to individual requests for attendance at various Overview and Scrutiny Committees (OSCs).

Meetings also took place in Parliament 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 Bewick, Deputy Medical Director, NHS England, presented at a meeting for MPs after the draft standards had been made public in April 2014

- A drop-in briefing in parliament was held by the review team during the consultation for interested MPs and Peers on the 15 October 2014

Appendix 7: Evidence base for the new standards & specifications

The development of standards has been at the heart of the review; they describe how services should be organised, both adult and paediatric, at each of three levels of the service. Few of these standards are informed by direct clinical evidence, but represent the best advice from expert clinicians and patient representatives.

> “In my experience, the amount of quantitative scientific evidence available to guide us in deciding how best to organise health services is often much less than we would like. In these circumstances we rely heavily on the views of experts, both specialist clinicians and those who are expert because of their experience of using the services in question. The views of experts, while qualitative rather than quantitative, are also valid and an important source of evidence in our deliberations.”
> **Professor Sir Michael Rawlins, Chair, new CHD review Clinical Advisory Panel**

We commissioned a review of the international literature[51] conducted by ScHARR at Sheffield University. Their report focused on two questions:

- What is the current evidence for the relationship between institutional and surgeon volume and patient outcomes and how is that 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 cardiac paediatric intensive care)?

Good data on CHD activity and outcomes is also available from the National Congenital Heart Disease Audit run on behalf of NHS England by the National Institute for Cardiovascular Outcomes Research (NICOR). NICOR was asked to examine its data and to advise what this showed about service factors that could influence outcomes. We have also had extensive support from NHS England analysts, working with a range of data supplied independently, and from CHD clinicians and patient groups.

We have good data on post-operative mortality internationally and on 30 day mortality in this country, but the best data relates only to children’s services, and we have little information about longer term outcomes, morbidity or patient experience. Some believe that it is the lack of broader measures that hinders us in being able to show the benefits of larger scale services, arguing that 30 day mortality is a relatively insensitive indicator of good care. Without the data we cannot know the truth of this argument, but one of the review’s six objectives has been to develop proposals for a wider range of relevant

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[51] Turner J, Preston L, Booth A et al, What evidence is there for a relationship between organisational features and patient outcomes in congenital heart disease services? A rapid review, School for Health and Related Research (ScHARR), University of Sheffield, 2014

timely metrics other than just 30 day mortality, to inform commissioners and support patient choice. These proposals will form part of the report we are bringing to the Board in July.

The evidence from published literature can guide our thinking on the scale of services. But the arguments for size of surgical teams, individual surgeon caseload and our approach to subspecialisation are inferred, and relate to the resilience and reliability of systems rather than to outcomes.

Overall then, there is a body of evidence to support most of the challenging standards, some of it from academic studies, some inferential, some based on expert advice. The nature of the evidence is such however that it does not give precise answers to questions about the organisation of the service, or show what size is too small or what size is big enough, and neither can this data be extrapolated to show what improvements in outcomes might be expected. As a result it cannot tell us whether the benefits gained would outweigh the risks of change – the upheaval, the cost, the upset, specialist care delivered further from some patients' homes[52], the risk of destabilising some units or other services linked to or dependent upon CHD services. This has informed our thinking in seeking to develop solutions that give many of the benefits of working as part of a larger team, without the disruption of reconfiguration.

To avoid one of the pitfalls of *Safe and Sustainable* we have been very open about the limitations of the evidence base, and where we have therefore had to rely on judgement, and what the basis for that judgement is. We have published the minutes of every substantive discussion, bringing the debate into our various engagement groups. As a result, the vast majority of the proposed standards are uncontroversial and widely endorsed. But we readily concede that those standards where there has been most contention have been developed by listening to expert advice and argument, not by proving that there is sufficient weight of evidence from research. Our stakeholders know this and would expect us to be able to show the audit trail for any new proposals we now bring forward.

Evidence for the relationship between unit size and outcomes

The ScHARR literature review[53] identified a substantial number of studies reporting a positive relationship between volume and outcome and concluded that while the evidence demonstrates a relationship between volume and outcome in the majority of studies, this relationship is not consistent. The relationship is stronger for single complex conditions or procedures. It remains unclear whether the impact of volume on outcome is largely a consequence of higher volume units organising and providing a complex service with all the "right" components, or whether it remains an independent factor

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[52] ScHARR reported that two studies examined the relationship between distance from a specialist cardiac centre and mortality and both found no relationship between distance and mortality. NICOR found no association was shown with distance from home

[53] Ibid

directly related to the advantages of dealing with a larger number of cases[54]. The lack of any UK studies to contribute to the review indicates a serious gap in evidence relevant to service provision in the NHS.

Two additional publications[55][56] on volume and outcomes were brought to the attention of the review. They were not included in the ScHARR review because they had not been published at the time it was written. Reviewing these studies CAP concluded that they confirm that generally, greater volumes are associated with better outcomes. They do not, though, conflict with the findings of the ScHAAR review; nor should they lead to changes in the volumes contained within the current set of standards. The study by Kansey et al was however notable in that it was based on European rather than American data.

The ScHARR review confirmed the findings of an earlier literature review[57] carried out for *Safe and Sustainable* which found that the literature confirmed the association of volume with in-hospital mortality, but that precise recommendations on volume thresholds were difficult. This review also found that the relationship was stronger with increasing complexity.

While the data linking larger units with better outcomes is widely accepted, it is not clear over what range this relationship holds. Most of the published evidence comes from the US where units operate across a much wider size range. As a result of the banding of centres into small, medium and large, units bigger than 350 operations per year are classified as large. This means that while studies show better outcomes at larger centres, it is not possible to determine whether even bigger centres would be better still. Much of the published evidence considers only paediatric volumes, and it is also unclear how these numbers should be applied to services that deliver both paediatric and adult services. Our smallest units are currently undertaking around 300 operations annually (240 paediatric operations)[58].

As a result of stronger regulation and a centralised national health service, the UK is already in a far better position than both the US and many European countries in having a consolidated paediatric CHD surgical service – a striking change since the original Kennedy Report, when the surgical centre in Bristol had been undertaking around 47 paediatric operations per year. At the time of the Munro report in 2003, six centres in

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[54] The evidence is equivocal – some studies found lower complication rates in high volume centres; others found no association between volume and complication rates. Two studies found low volume centres were associated with longer length of stay. Two studies also assessed costs and both found a relationship of higher costs associated with low volume centres.

[55] Kansey A , Ebels T, Schreiber C et al Association of Center Volume With Outcomes: Analysis of Verified Data of European Association for Cardio-Thoracic Surgery Congenital Database. Ann Thorac Surg 2014;98:2159–64

[56] Karamlou T et al. Surgeon and Center Volume Influence on Outcomes
After Arterial Switch Operation: Analysis of the STS Congenital Heart Surgery Database. Ann Thorac Surg 2014;98:904–11.

[57] Ewart E, The relationship between volume and outcome in paediatric cardiac surgery, PHRU Oxford, 2009

[58] Sources: National Congenital Heart Disease Audit, NICOR data for 2013-14; NHS England analysis.

England and Wales were doing fewer than 200 cases a year and two were doing fewer than 100. Since that time the paediatric surgical service at Oxford has closed, and in the past year surgical practice has ceased in Belfast.

In the context of the NHS in England, while published evidence gives support to the view that units should undertake at least 350 operations per year, interpretation of this is complicated by analysis of UK outcomes which showed no significant association between annual centre volume and 30-day survival outcome[59]. This complexity was recognised in our consultation document[60] where we stated that "the evidence did not tell us the best size for a specialist surgical centre. As a result our Clinical Advisory Panel told us that … the evidence was broadly supportive of the relationship between volumes and outcomes, but did not provide a compelling argument for change."

Evidence for four surgeons in a team

UK surgeons agree that teams of four surgeons are ideal, and some leading individual surgeons have argued passionately in our meetings for this to be the requirement. But the consensus view of the profession[61] is that three rather than four should be the minimum. This appears to be a change from the position during the *Safe and Sustainable* process when there was a consensus for teams of at least four and which is therefore reflected in the current service specification, in use today. This position was supported by the IRP in their recommendations[62]:

'Patients should receive congenital heart surgery and interventional cardiology from teams with at least four full-time consultant congenital heart surgeons and appropriate numbers of other specialist staff to sustain a comprehensive range of interventions, round the clock care, training and research.'

The arguments in favour of larger teams are inferential rather than directly taken from research evidence. They relate to the pressure on individual surgeons working in smaller teams and the vulnerability of such services to the absence of one member of the team. Larger teams are also more able to subspecialise to handle rare, complex and innovative procedures.

The combination of professional, annual and study leave will mean that members of 3 surgeon teams will spend almost half the year working a 1:2 on call. The Royal College of Surgeons, the Royal College of Anaesthetists, the Royal College of Paediatrics & Child Health and the Royal College of Nursing all told our Clinical Advisory Panel that

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[59] Using data from 13 paediatric surgery centres, NICOR's analysis of 12,186 episodes of care in paediatric heart surgery from April 2009 to March 2012 inclusive showed no significant univariate association between annual centre volume and 30-day survival outcome.

[60] Proposed congenital heart disease standards and service specifications: a consultation, NHS England, 2014

[61] Personal communication from David Barron, Society of Cardio Thoracic Surgeons

[62] Independent Reconfiguration Panel, Advice On Safe And Sustainable Proposals For Children's Congenital Heart Services, 2013

this was not acceptable. Norman Williams (then president of RCS) advised that the pressures this placed on individual surgeons could potentially jeopardise patient safety.

Despite this, surgeons who argue the case for larger surgical teams are not usually motivated by concerns about out-of-hours arrangements or work life balance. Rather, the number of surgeons is used as a proxy for the scale of the unit – perceived advantages being greater sub-specialisation within surgical teams, better supporting facilities and staffing, more attractive units for recruitment, and greater opportunities for training and research. These are not seen as ends in themselves, but as vital contributors to higher quality services that will improve outcomes.

Most of the evidence on the volume/outcome relationship comes from studies that examine centre volumes. Some studies have also examined individual surgeon volumes and most found decreased mortality with increasing surgeon volumes for complex procedures[63,64]. Some English centres, because of their size, see only low numbers of complex cases so that individual surgeons may do only one or two of each per year. Our proposals aim to improve this situation by ensuring that surgeons work in teams of at least four (with at least 500 cases between them, so that each team has higher numbers of complex cases) and by an explicit approach to sub-specialisation aimed at concentrating this work in the hands of fewer surgeons. So our proposed standard maintains the current requirement rather than lowering the bar to a "minimum of three". However, by proposing four surgeons per team, rather than per unit, we create the potential for some flexibility in implementation, which is missing from the current standard.

Evidence for 125 cases per surgeon

Maintaining regular operative experience is fundamental to any surgeon, especially in technically demanding specialties like CHD. Two studies suggest a relationship between individual surgeon volumes and outcomes for adults with CHD - one study found outcome was associated with surgeon volume. Another found a similar association with adult procedure volume indicating the influence of expertise on outcome. The requirement in the proposed standards for a minimum of 125 operations per surgeon has been strongly supported by the Society for Cardiothoracic Surgery, by the community of congenital cardiac surgeons themselves, and by the Royal College of Surgeons.

Inevitably the setting of standards involves 'picking a number', and in the absence of data with a clear inflection point, this number will be arbitrary. That is sometimes the source of criticism but this of course ignores the fact that any number would be arbitrary.

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[63] Turner J, Preston L, Booth A et al, What evidence is there for a relationship between organisational features and patient outcomes in congenital heart disease services? A rapid review, School for Health and Related Research (ScHARR), University of Sheffield, 2014

[64] Karamlou T, Jacobs M, Pasquali S et al, Surgeon and Center Volume Influence on Outcomes After Arterial Switch Operation: Analysis of the STS Congenital Heart Surgery Database, Ann Thorac Surg 2014;98:904–11

Similar numbers have been recommended by earlier reviews: the European Association for Cardio-Thoracic Surgery report[65] recommended that each surgeon should perform 126 cardiac surgical procedures on adults or children; the *Safe and Sustainable* review[66] recommended a minimum of 100 paediatric and ideally 125 paediatric operations per surgeon. Job plans for consultant surgeons include between 1.5 – 2.5 operating days a week and we would expect every surgeon to deliver a minimum of 42 weeks clinical work per year. Thus, even at the most conservative end of the spectrum (and including a minimum of emergency work) a consultant surgeon should expect to do 150 cases minimum[67].

Surgeons have been unanimous is saying that they feel that individual case numbers are the single most important statistic to apply in terms of ‘numbers’, and there is very little argument against 125 being a helpful and achievable minimum standard.

Evidence for four interventional cardiologists in a team /no. of cases per cardiologist
The studies identified in both literature reviews related exclusively to surgical practice. Most studies of catheter procedures have been small in scale and as such the available evidence base on which to make recommendations for treatment is limited. The new proposed standards are based on current professional guidelines[68] and the advice we received from clinicians.

Evidence for paediatric CHD co-location with other paediatric services
The ScHARR review[69] found no evidence on the effects of proximity of other services other than PICU, so the proposed standards are based on expert opinion.

Our clinical advisers strongly supported co-location with other paediatric services, even though they recognised that not everyone agrees. The Clinical Advisory Panel[70] considered that this brought the standards for CHD services into line with expectations in other specialist children’s services. They noted that while responsiveness was important, it was not the only thing that mattered – the interaction between teams on a daily basis was also important. They considered that it was not safe to care for children with complex conditions and co-morbidities (a high proportion of whom will need input from other specialties) in settings where other paediatric services were not on site.

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[65] Optimal Structure of a Congenital Heart Surgery Unit in Europe, Congenital Heart Surgery Committee on behalf of the European Association for Cardio-Thoracic Surgery, 2003

[66] Safe and Sustainable: A new vision for children’s congenital heart services in England, NHS Specialised Services, 2011

[67] Barron D, Personal communication, 2014

[68] Recommendations for therapeutic cardiac catheterisation in paediatric heart disease, British Congenital Cardiac Association, 2012

[69] Ibid

[70] Minutes of CAP, 18 June 2014 http://www.england.nhs.uk/ourwork/qual-clin-lead/chd/meetings/cap/

In consultation[71], the majority of respondents supported our proposals (albeit with comments and suggestions). Patients told us that they need good access to these services, and that there need to be good working relationships between clinical teams, making sure that services work together in the patient's best interest. Some consider that the best way to achieve this is to have all the services on the same site.

Evidence for paediatric CHD and adult CHD interdependency

The new proposed standards require that within a surgical service, adult and paediatric CHD services have a close relationship, and that surgeons and interventionists are able to respond with a call to bedside time of no more than 30 minutes (whether the adult and paediatric services are on the same site or not). This recognises the interdependency and shared staffing of the two parts of the service but does not require co-location. This standard is based on the clinical advice we received.

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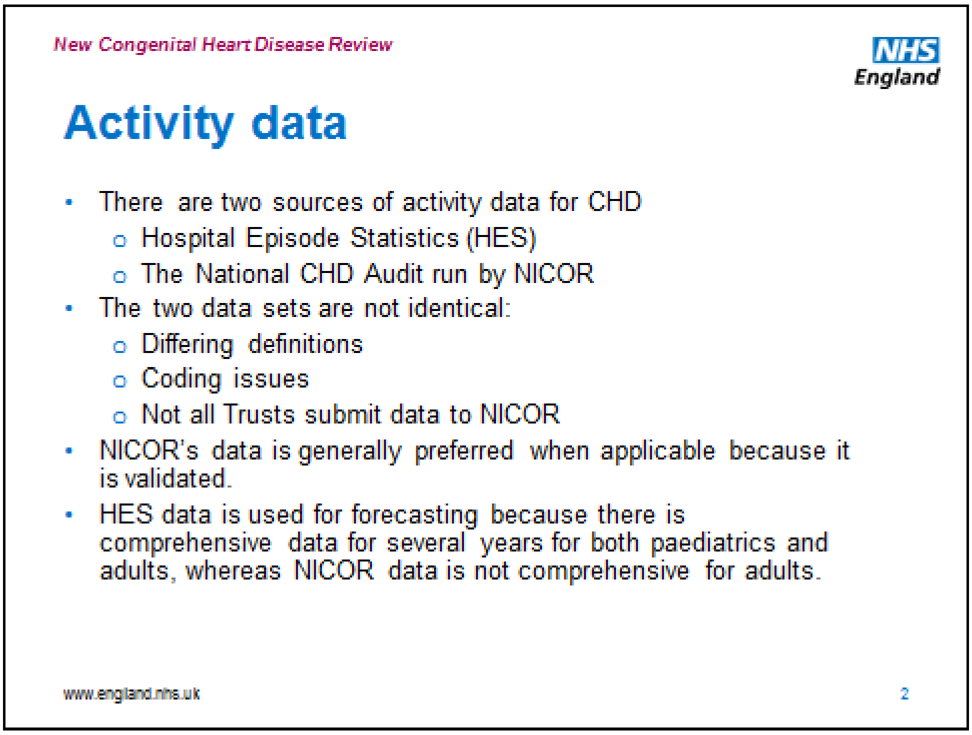
[71] Consultation on draft standards and service specifications for congenital heart disease services, *Dialogue by Design*, 2015.

Appendix 8: Summary of analytical work

New Congenital Heart Disease Review

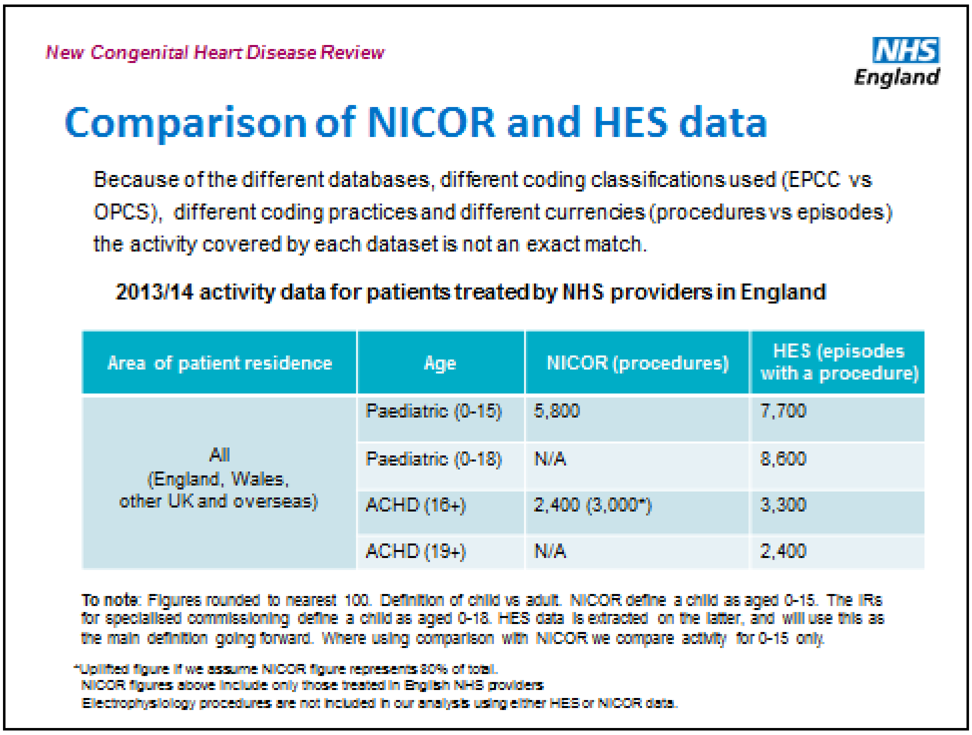
Activity and spend



New Congenital Heart Disease Review

Activity data

- There are two sources of activity data for CHD
  - Hospital Episode Statistics (HES)
  - The National CHD Audit run by NICOR
- The two data sets are not identical:
  - Differing definitions
  - Coding issues
  - Not all Trusts submit data to NICOR
- NICOR's data is generally preferred when applicable because it is validated.
- HES data is used for forecasting because there is comprehensive data for several years for both paediatrics and adults, whereas NICOR data is not comprehensive for adults.



New Congenital Heart Disease Review

NHS England

Comparison of NICOR and HES data

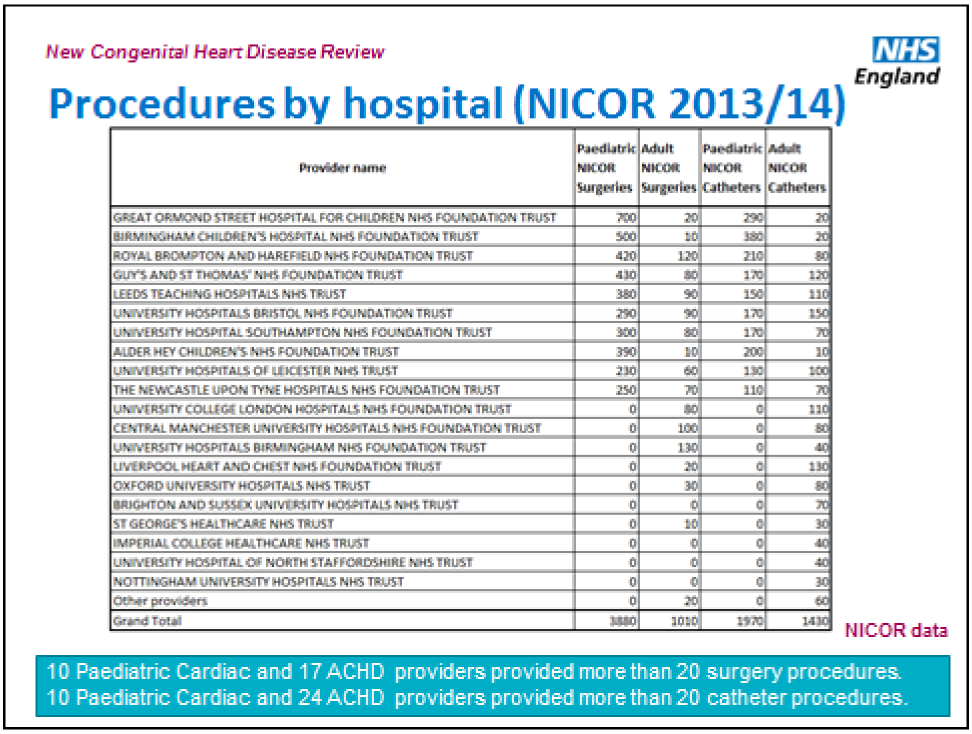
Because of the different databases, different coding classifications used (EPCC vs OPCS), different coding practices and different currencies (procedures vs episodes) the activity covered by each dataset is not an exact match.

2013/14 activity data for patients treated by NHS providers in England

Area of patient residence	Age	NICOR (procedures)	HES (episodes with a procedure)
All (England, Wales, other UK and overseas)	Paediatric (0-15)	5,800	7,700
	Paediatric (0-18)	N/A	8,600
	ACHD (16+)	2,400 (3,000*)	3,300
	ACHD (19+)	N/A	2,400

To note: Figures rounded to nearest 100. Definition of child vs adult. NICOR define a child as aged 0-15. The IRs for specialised commissioning define a child as aged 0-18. HES data is extracted on the latter, and will use this as the main definition going forward. Where using comparison with NICOR we compare activity for 0-15 only.

*Uplifted figure if we assume NICOR figure represents 80% of total.
NICOR figures above include only those treated in English NHS providers
Electrophysiology procedures are not included in our analysis using either HES or NICOR data.



New Congenital Heart Disease Review

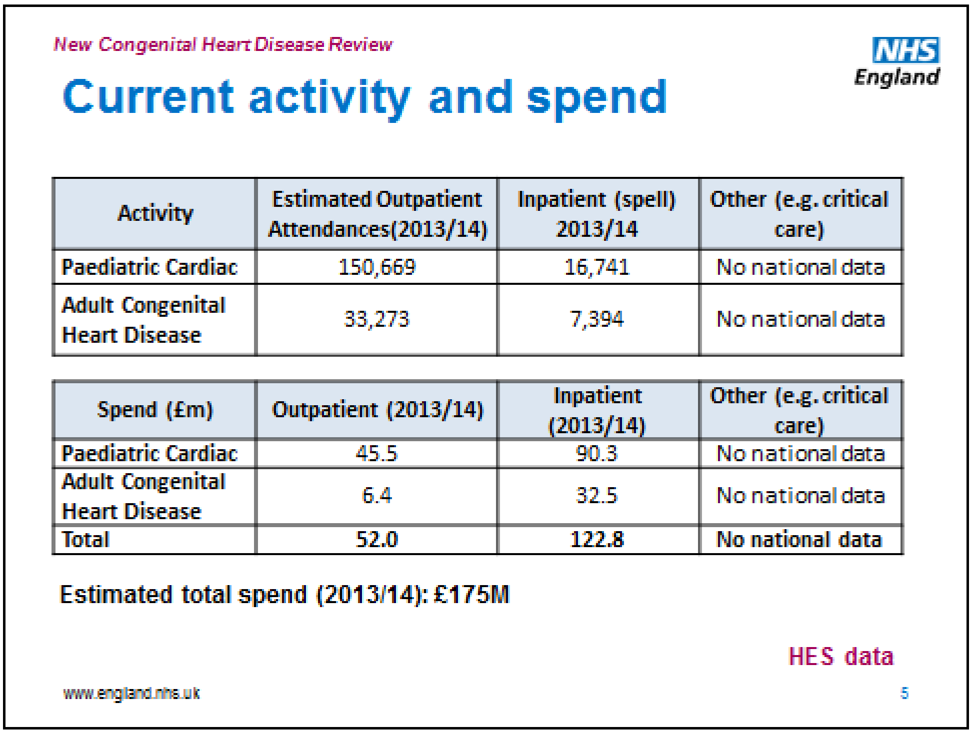
NHS England

Procedures by hospital (NICOR 2013/14)

Provider name	Paediatric NICOR Surgeries	Adult NICOR Surgeries	Paediatric NICOR Catheters	Adult NICOR Catheters
GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST	700	20	290	20
BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST	500	10	380	20
ROYAL BROMPTON AND HAREFIELD NHS FOUNDATION TRUST	420	120	210	80
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	430	80	170	120
LEEDS TEACHING HOSPITALS NHS TRUST	380	90	150	110
UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST	290	90	170	150
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	300	80	170	70
ALDER HEY CHILDREN'S NHS FOUNDATION TRUST	390	10	200	10
UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST	230	60	130	100
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST	250	70	110	70
UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST	0	80	0	110
CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	0	100	0	80
UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST	0	130	0	40
LIVERPOOL HEART AND CHEST NHS FOUNDATION TRUST	0	20	0	130
OXFORD UNIVERSITY HOSPITALS NHS TRUST	0	30	0	80
BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS NHS TRUST	0	0	0	70
ST GEORGE'S HEALTHCARE NHS TRUST	0	10	0	30
IMPERIAL COLLEGE HEALTHCARE NHS TRUST	0	0	0	40
UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE NHS TRUST	0	0	0	40
NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST	0	0	0	30
Other providers	0	20	0	60
Grand Total	3880	1010	1970	1430

NICOR data

10 Paediatric Cardiac and 17 ACHD providers provided more than 20 surgery procedures.
10 Paediatric Cardiac and 24 ACHD providers provided more than 20 catheter procedures.



New Congenital Heart Disease Review

NHS England

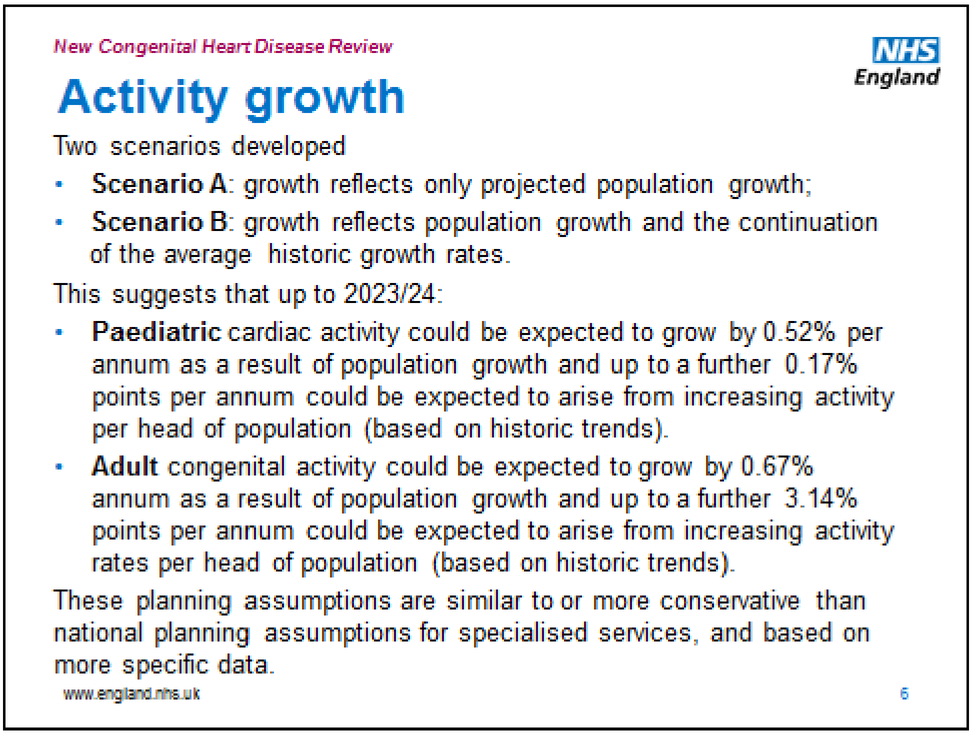
Current activity and spend

Activity	Estimated Outpatient Attendances(2013/14)	Inpatient (spell) 2013/14	Other (e.g. critical care)
Paediatric Cardiac	150,669	16,741	No national data
Adult Congenital Heart Disease	33,273	7,394	No national data

Spend (£m)	Outpatient (2013/14)	Inpatient (2013/14)	Other (e.g. critical care)
Paediatric Cardiac	45.5	90.3	No national data
Adult Congenital Heart Disease	6.4	32.5	No national data
Total	**52.0**	**122.8**	**No national data**

Estimated total spend (2013/14): £175M

HES data



New Congenital Heart Disease Review

NHS England

Activity growth

Two scenarios developed

- **Scenario A**: growth reflects only projected population growth;
- **Scenario B**: growth reflects population growth and the continuation of the average historic growth rates.

This suggests that up to 2023/24:

- **Paediatric** cardiac activity could be expected to grow by 0.52% per annum as a result of population growth and up to a further 0.17% points per annum could be expected to arise from increasing activity per head of population (based on historic trends).
- **Adult** congenital activity could be expected to grow by 0.67% annum as a result of population growth and up to a further 3.14% points per annum could be expected to arise from increasing activity rates per head of population (based on historic trends).

These planning assumptions are similar to or more conservative than national planning assumptions for specialised services, and based on more specific data.

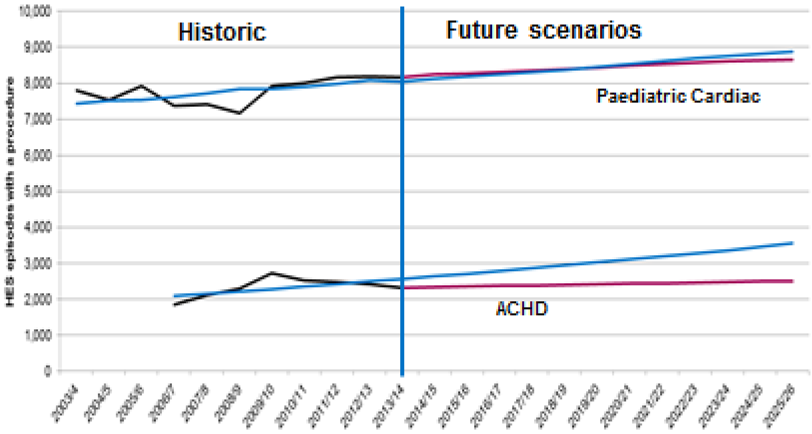
New Congenital Heart Disease Review

NHS England

Activity growth

Future projections of activity, for England and Wales

The red line represents scenario A, the blue line scenario B.



www.england.nhs.uk

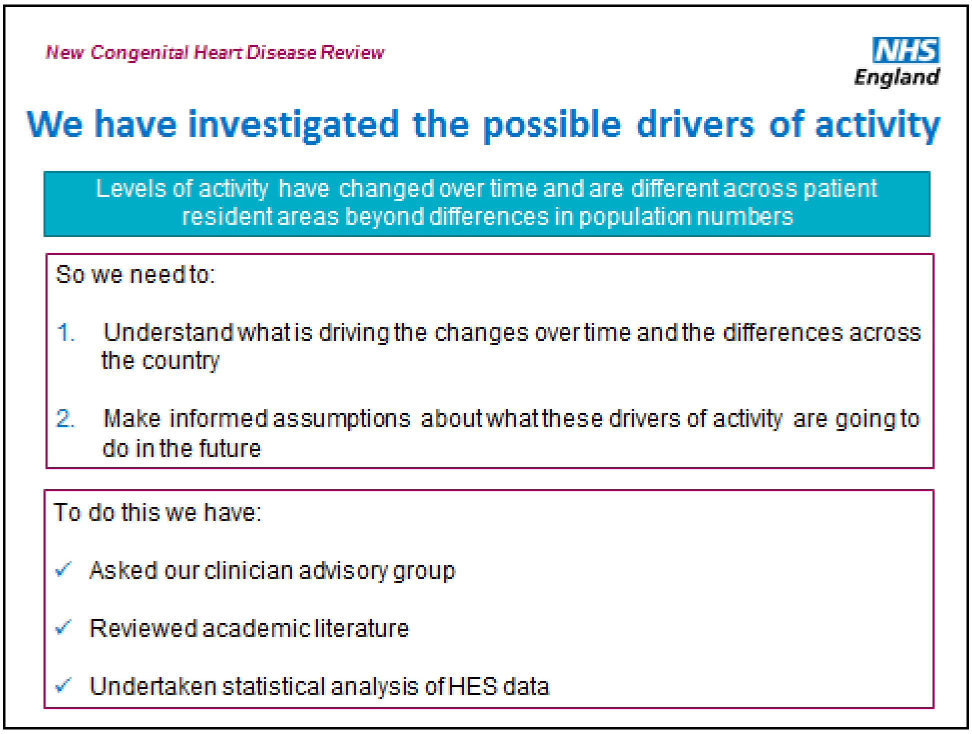
HES data: IR and clinical guidance applied

New Congenital Heart Disease Review

NHS England

Activity drivers

June 2015



New Congenital Heart Disease Review

NHS England

We have investigated the possible drivers of activity

Levels of activity have changed over time and are different across patient resident areas beyond differences in population numbers

So we need to:

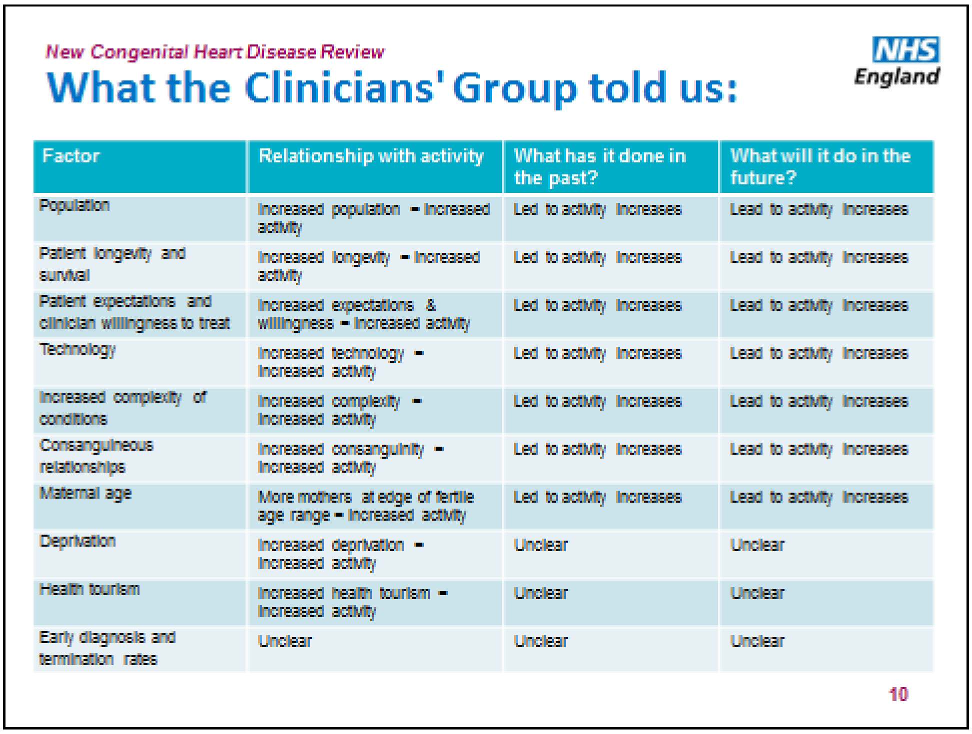
1. Understand what is driving the changes over time and the differences across the country
2. Make informed assumptions about what these drivers of activity are going to do in the future

To do this we have:

✓ Asked our clinician advisory group

✓ Reviewed academic literature

✓ Undertaken statistical analysis of HES data

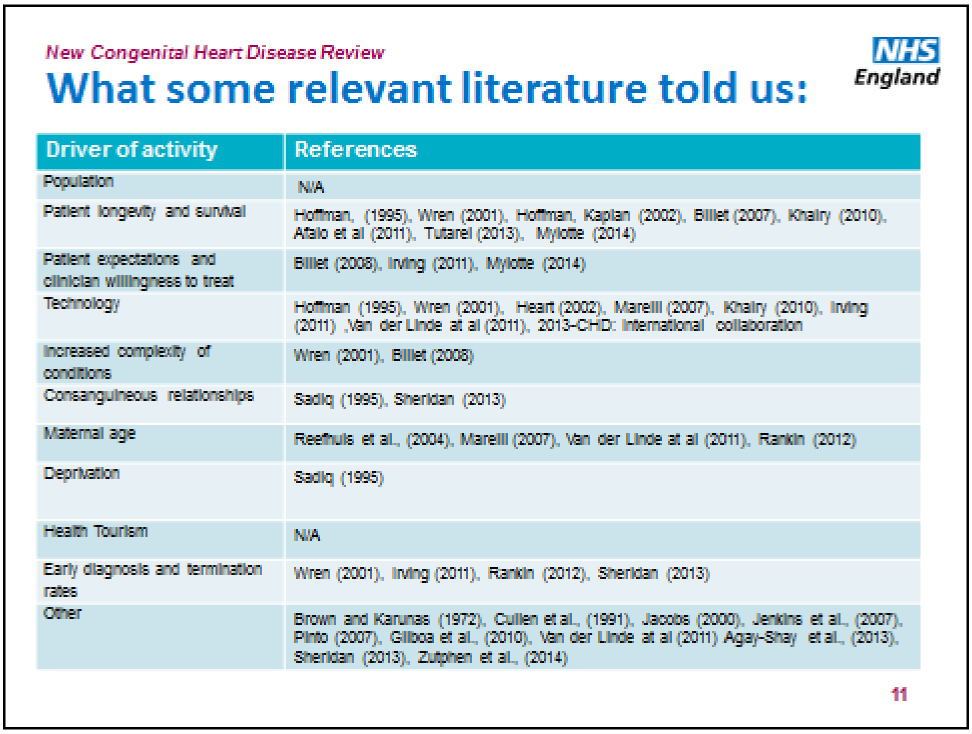


New Congenital Heart Disease Review

NHS England

What the Clinicians' Group told us:

Factor	Relationship with activity	What has it done in the past?	What will it do in the future?
Population	Increased population = increased activity	Led to activity increases	Lead to activity increases
Patient longevity and survival	Increased longevity = increased activity	Led to activity increases	Lead to activity increases
Patient expectations and clinician willingness to treat	Increased expectations & willingness = increased activity	Led to activity increases	Lead to activity increases
Technology	Increased technology = increased activity	Led to activity increases	Lead to activity increases
Increased complexity of conditions	Increased complexity = increased activity	Led to activity increases	Lead to activity increases
Consanguineous relationships	Increased consanguinity = increased activity	Led to activity increases	Lead to activity increases
Maternal age	More mothers at edge of fertile age range = increased activity	Led to activity increases	Lead to activity increases
Deprivation	Increased deprivation = increased activity	Unclear	Unclear
Health tourism	Increased health tourism = increased activity	Unclear	Unclear
Early diagnosis and termination rates	Unclear	Unclear	Unclear

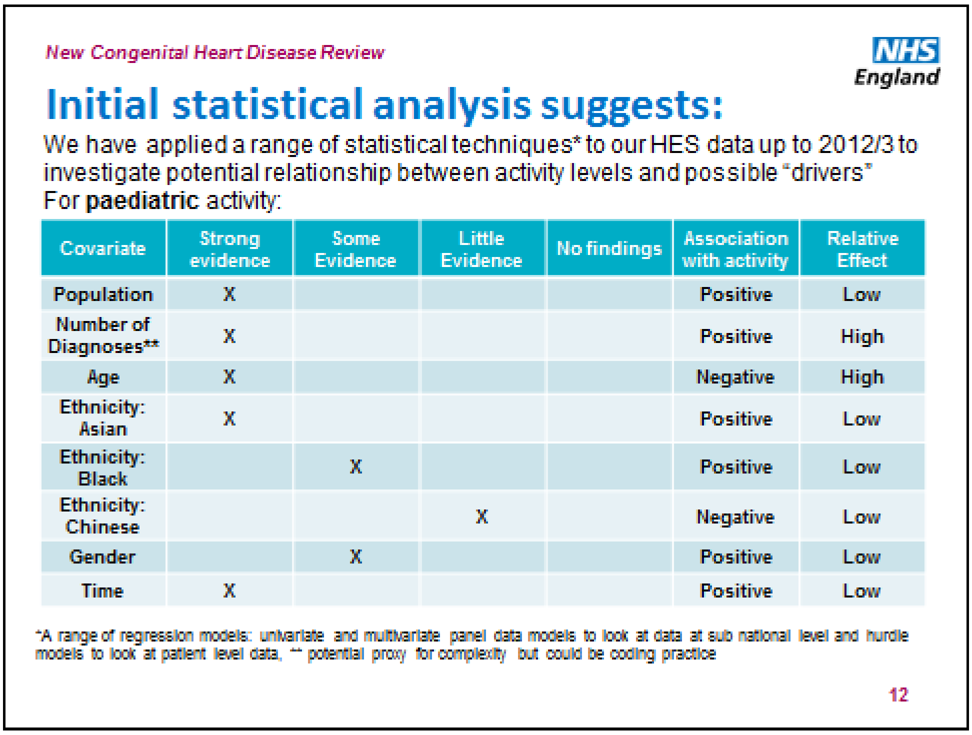


New Congenital Heart Disease Review

NHS England

What some relevant literature told us:

Driver of activity	References
Population	N/A
Patient longevity and survival	Hoffman, (1995), Wren (2001), Hoffman, Kaplan (2002), Billet (2007), Khairy (2010), Afalo et al (2011), Tutarel (2013), Mylotte (2014)
Patient expectations and clinician willingness to treat	Billet (2008), Irving (2011), Mylotte (2014)
Technology	Hoffman (1995), Wren (2001), Heart (2002), Marelli (2007), Khairy (2010), Irving (2011) ,Van der Linde at al (2011), 2013-CHD: International collaboration
Increased complexity of conditions	Wren (2001), Billet (2008)
Consanguineous relationships	Sadiq (1995), Sheridan (2013)
Maternal age	Reefhuis et al., (2004), Marelli (2007), Van der Linde at al (2011), Rankin (2012)
Deprivation	Sadiq (1995)
Health Tourism	N/A
Early diagnosis and termination rates	Wren (2001), Irving (2011), Rankin (2012), Sheridan (2013)
Other	Brown and Karunas (1972), Cullen et al., (1991), Jacobs (2000), Jenkins et al., (2007), Pinto (2007), Gilboa et al., (2010), Van der Linde at al (2011) Agay-Shay et al., (2013), Sheridan (2013), Zutphen et al., (2014)



New Congenital Heart Disease Review

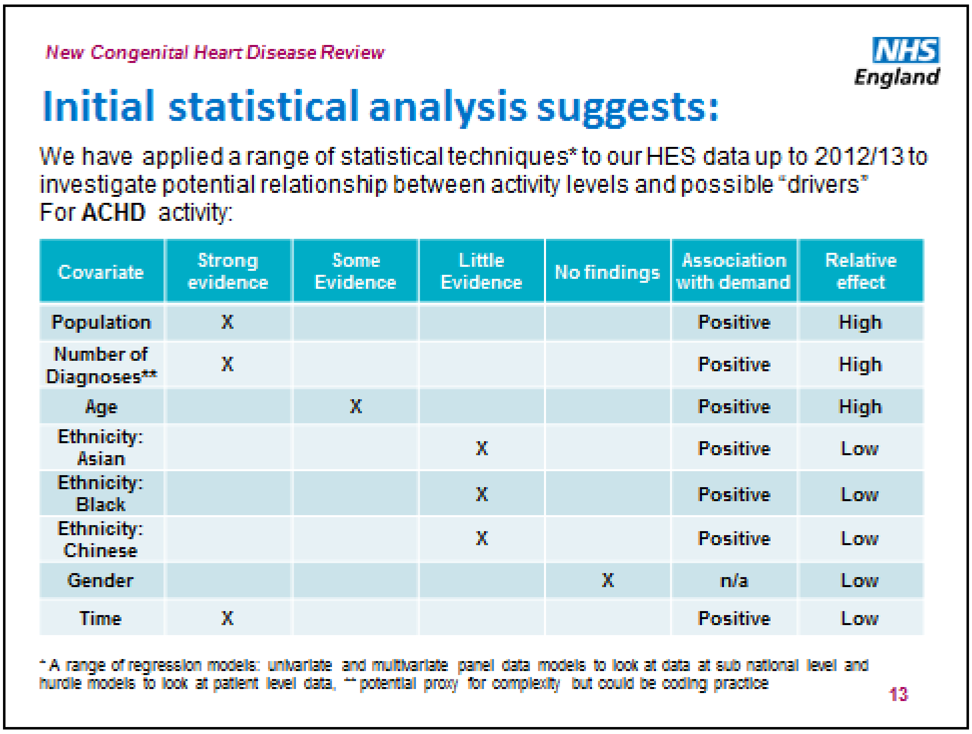
NHS England

Initial statistical analysis suggests:

We have applied a range of statistical techniques* to our HES data up to 2012/3 to investigate potential relationship between activity levels and possible "drivers"
For **paediatric** activity:

Covariate	Strong evidence	Some Evidence	Little Evidence	No findings	Association with activity	Relative Effect
Population	X				Positive	Low
Number of Diagnoses**	X				Positive	High
Age	X				Negative	High
Ethnicity: Asian	X				Positive	Low
Ethnicity: Black		X			Positive	Low
Ethnicity: Chinese			X		Negative	Low
Gender		X			Positive	Low
Time	X				Positive	Low

*A range of regression models: univariate and multivariate panel data models to look at data at sub national level and hurdle models to look at patient level data, ** potential proxy for complexity but could be coding practice



New Congenital Heart Disease Review

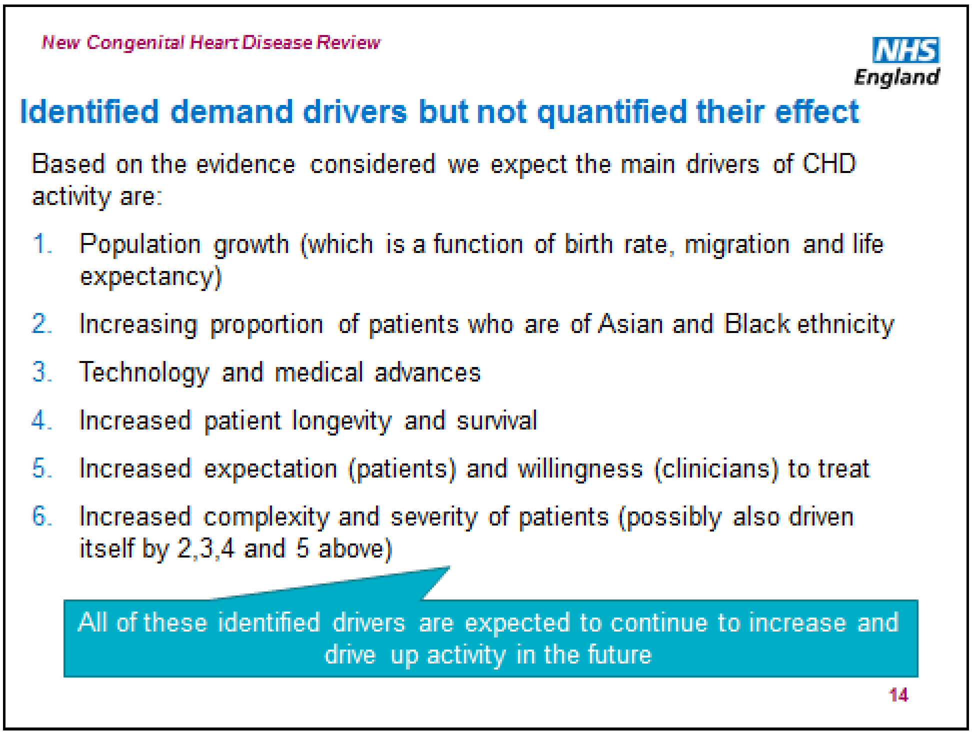
NHS England

Initial statistical analysis suggests:

We have applied a range of statistical techniques* to our HES data up to 2012/13 to investigate potential relationship between activity levels and possible "drivers"
For **ACHD** activity:

Covariate	Strong evidence	Some Evidence	Little Evidence	No findings	Association with demand	Relative effect
Population	X				Positive	High
Number of Diagnoses**	X				Positive	High
Age		X			Positive	High
Ethnicity: Asian			X		Positive	Low
Ethnicity: Black			X		Positive	Low
Ethnicity: Chinese			X		Positive	Low
Gender				X	n/a	Low
Time	X				Positive	Low

* A range of regression models: univariate and multivariate panel data models to look at data at sub national level and hurdle models to look at patient level data, ** potential proxy for complexity but could be coding practice



New Congenital Heart Disease Review

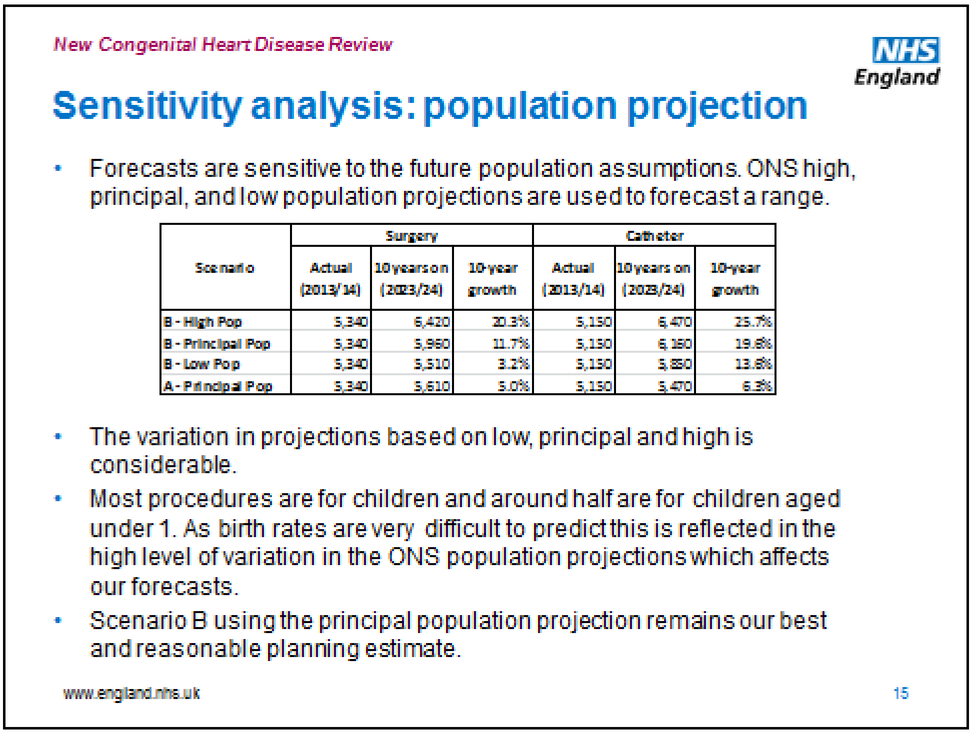
NHS England

Identified demand drivers but not quantified their effect

Based on the evidence considered we expect the main drivers of CHD activity are:

1. Population growth (which is a function of birth rate, migration and life expectancy)
2. Increasing proportion of patients who are of Asian and Black ethnicity
3. Technology and medical advances
4. Increased patient longevity and survival
5. Increased expectation (patients) and willingness (clinicians) to treat
6. Increased complexity and severity of patients (possibly also driven itself by 2,3,4 and 5 above)

All of these identified drivers are expected to continue to increase and drive up activity in the future



New Congenital Heart Disease Review

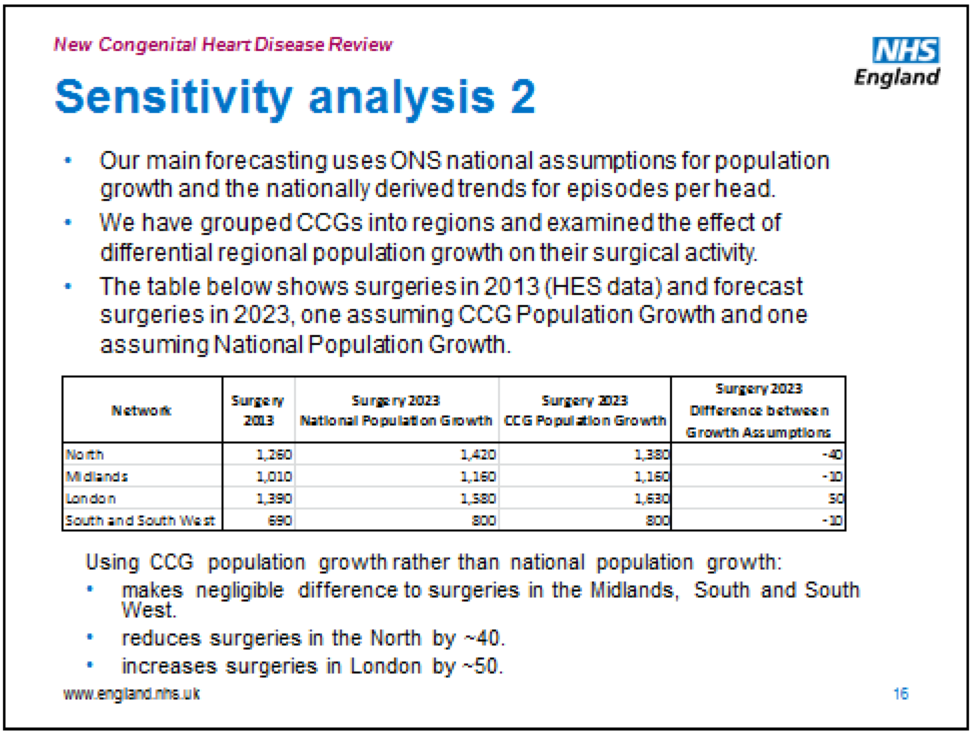
NHS England

Sensitivity analysis: population projection

- Forecasts are sensitive to the future population assumptions. ONS high, principal, and low population projections are used to forecast a range.

Scenario	Surgery			Catheter		
	Actual (2013/14)	10 years on (2023/24)	10-year growth	Actual (2013/14)	10 years on (2023/24)	10-year growth
B - High Pop	5,340	6,420	20.3%	5,150	6,470	25.7%
B - Principal Pop	5,340	5,960	11.7%	5,150	6,160	19.6%
B - Low Pop	5,340	5,510	3.2%	5,150	5,850	13.6%
A - Principal Pop	5,340	5,610	5.0%	5,150	5,470	6.3%

- The variation in projections based on low, principal and high is considerable.
- Most procedures are for children and around half are for children aged under 1. As birth rates are very difficult to predict this is reflected in the high level of variation in the ONS population projections which affects our forecasts.
- Scenario B using the principal population projection remains our best and reasonable planning estimate.



New Congenital Heart Disease Review

NHS England

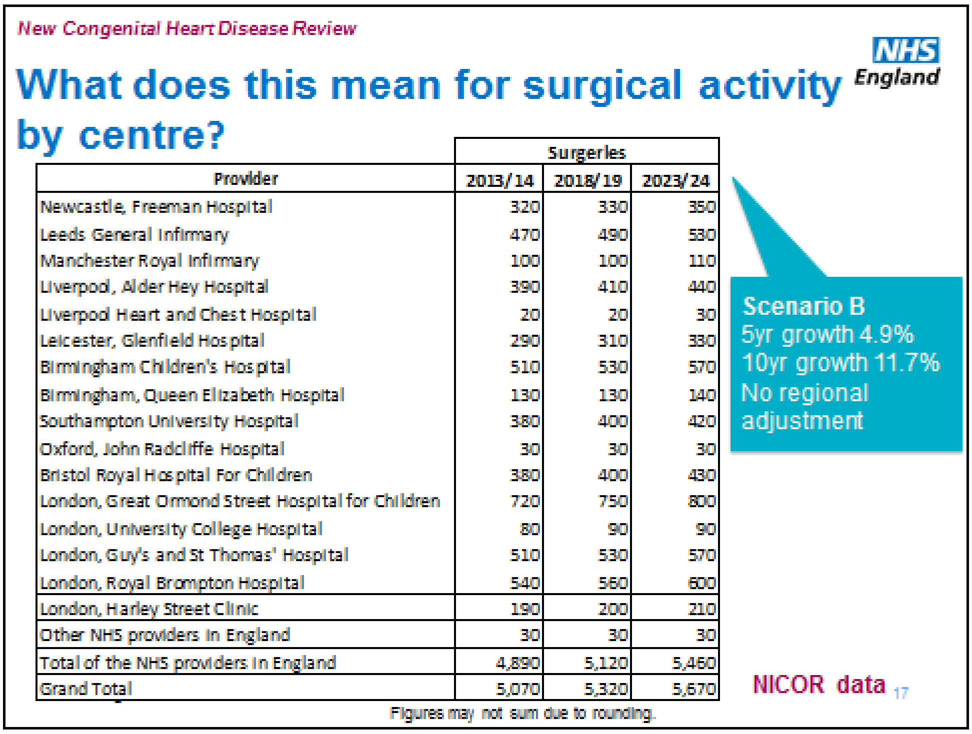
Sensitivity analysis 2

- Our main forecasting uses ONS national assumptions for population growth and the nationally derived trends for episodes per head.
- We have grouped CCGs into regions and examined the effect of differential regional population growth on their surgical activity.
- The table below shows surgeries in 2013 (HES data) and forecast surgeries in 2023, one assuming CCG Population Growth and one assuming National Population Growth.

Network	Surgery 2013	Surgery 2023 National Population Growth	Surgery 2023 CCG Population Growth	Surgery 2023 Difference between Growth Assumptions
North	1,260	1,420	1,380	-40
Midlands	1,010	1,160	1,160	-10
London	1,390	1,580	1,630	50
South and South West	690	800	800	-10

Using CCG population growth rather than national population growth:

- makes negligible difference to surgeries in the Midlands, South and South West.
- reduces surgeries in the North by ~40.
- increases surgeries in London by ~50.



New Congenital Heart Disease Review

NHS England

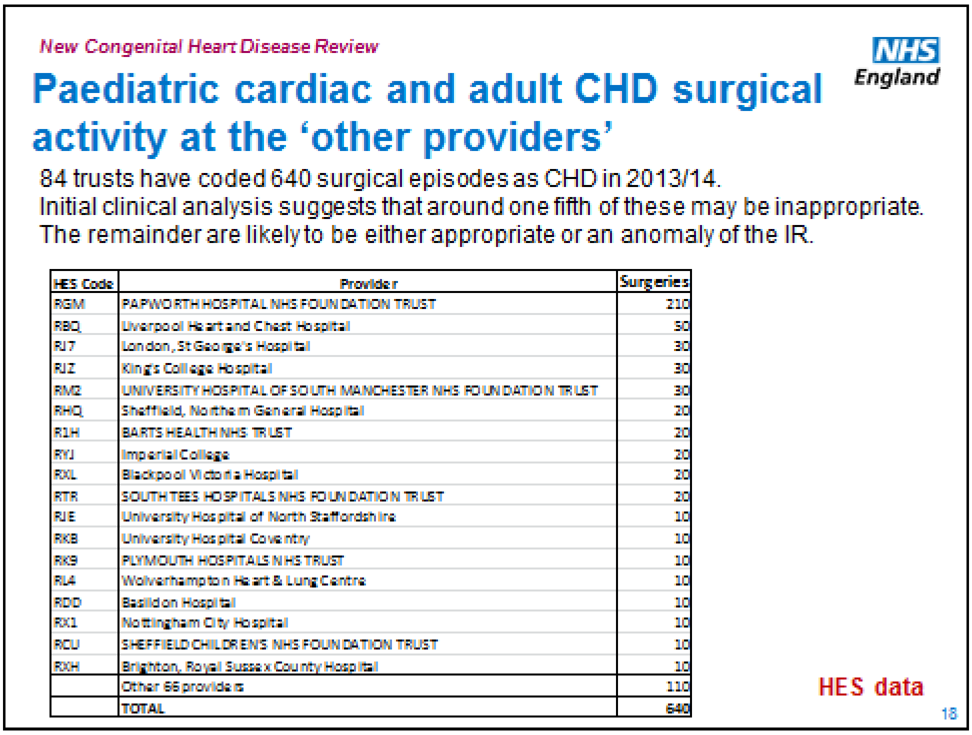
What does this mean for surgical activity by centre?

Provider	Surgeries 2013/14	2018/19	2023/24
Newcastle, Freeman Hospital	320	330	350
Leeds General Infirmary	470	490	530
Manchester Royal Infirmary	100	100	110
Liverpool, Alder Hey Hospital	390	410	440
Liverpool Heart and Chest Hospital	20	20	30
Leicester, Glenfield Hospital	290	310	330
Birmingham Children's Hospital	510	530	570
Birmingham, Queen Elizabeth Hospital	130	130	140
Southampton University Hospital	380	400	420
Oxford, John Radcliffe Hospital	30	30	30
Bristol Royal Hospital For Children	380	400	430
London, Great Ormond Street Hospital for Children	720	750	800
London, University College Hospital	80	90	90
London, Guy's and St Thomas' Hospital	510	530	570
London, Royal Brompton Hospital	540	560	600
London, Harley Street Clinic	190	200	210
Other NHS providers in England	30	30	30
Total of the NHS providers in England	4,890	5,120	5,460
Grand Total	5,070	5,320	5,670

Figures may not sum due to rounding.

Scenario B
5yr growth 4.9%
10yr growth 11.7%
No regional adjustment

NICOR data



New Congenital Heart Disease Review

NHS England

Paediatric cardiac and adult CHD surgical activity at the 'other providers'

84 trusts have coded 640 surgical episodes as CHD in 2013/14.
Initial clinical analysis suggests that around one fifth of these may be inappropriate.
The remainder are likely to be either appropriate or an anomaly of the IR.

HES Code	Provider	Surgeries
RGM	PAPWORTH HOSPITAL NHS FOUNDATION TRUST	210
RBQ	Liverpool Heart and Chest Hospital	50
RJ7	London, St George's Hospital	30
RJZ	King's College Hospital	30
RM2	UNIVERSITY HOSPITAL OF SOUTH MANCHESTER NHS FOUNDATION TRUST	30
RHQ	Sheffield, Northern General Hospital	20
R1H	BARTS HEALTH NHS TRUST	20
RYJ	Imperial College	20
RXL	Blackpool Victoria Hospital	20
RTR	SOUTH TEES HOSPITALS NHS FOUNDATION TRUST	20
RJE	University Hospital of North Staffordshire	10
RKB	University Hospital Coventry	10
RK9	PLYMOUTH HOSPITALS NHS TRUST	10
RL4	Wolverhampton Heart & Lung Centre	10
RDD	Basildon Hospital	10
RX1	Nottingham City Hospital	10
RCU	SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST	10
RXH	Brighton, Royal Sussex County Hospital	10
	Other 66 providers	110
	TOTAL	640

HES data

New Congenital Heart Disease Review

NHS England

What does this mean for catheter activity by centre?

Provider	Catheters 2013/14	2018/19	2023/24
Newcastle, Freeman Hospital	180	200	210
Leeds General Infirmary	260	280	300
Manchester Royal Infirmary	80	90	100
Liverpool, Alder Hey Hospital	200	220	240
Liverpool Heart and Chest Hospital	130	150	160
Leicester, Glenfield Hospital	230	260	280
Birmingham Children's Hospital	390	430	470
Birmingham, Queen Elizabeth Hospital	40	40	40
Southampton University Hospital	240	270	290
Oxford, John Radcliffe Hospital	90	90	100
Bristol Royal Hospital For Children	310	350	370
London, Great Ormond Street Hospital for Children	300	340	360
London, University College Hospital	110	120	130
London, Guy's and St Thomas' Hospital	300	330	360
London, Royal Brompton Hospital	280	310	340
London, Harley Street Clinic	90	100	100
Other NHS providers in England	260	290	320
Total of the NHS providers in England	3,400	3,770	4,060
Grand Total	3,480	3,870	4,170

Figures may not sum due to rounding.

Scenario B
5yr growth 11.0%
10yr growth 19.6%
No regional adjustment

NICOR data

New Congenital Heart Disease Review

NHS England

Paediatric cardiac and adult CHD catheter activity at the 'other providers'

64 trusts have coded 860 surgical episodes as CHD in 2013/14. This may represent isolated and occasional practice, coding problems or both.

HES Code	Provider	Catheters
RBQ	LIVERPOOL HEART AND CHEST NHS FOUNDATION TRUST	140
RGM	PAPWORTH HOSPITAL NHS FOUNDATION TRUST	100
RXH	BRIGHTON AND SUSSEX UNIVERSITY HOSPITALS NHS TRUST	70
RYJ	IMPERIAL COLLEGE HEALTHCARE NHS TRUST	60
RJE	UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE NHS TRUST	50
RM2	UNIVERSITY HOSPITAL OF SOUTH MANCHESTER NHS FOUNDATION TRUST	50
RJZ	KING'S COLLEGE HOSPITAL NHS FOUNDATION TRUST	40
RX1	NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST	40
RJ7	ST GEORGE'S HEALTHCARE NHS TRUST	30
R1H	BARTS HEALTH NHS TRUST	30
RWA	HULL AND EAST YORKSHIRE HOSPITALS NHS TRUST	30
RL4	THE ROYAL WOLVERHAMPTON NHS TRUST	20
RXL	BLACKPOOL TEACHING HOSPITALS NHS FOUNDATION TRUST	20
RKB	UNIVERSITY HOSPITALS COVENTRY AND WARWICKSHIRE NHS TRUST	20
RHQ	SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST	20
RR1	HEART OF ENGLAND NHS FOUNDATION TRUST	10
RDD	BASILDON AND THURROCK UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	10
RDZ	THE ROYAL BOURNEMOUTH AND CHRISTCHURCH HOSPITALS NHS FOUNDATION TRUST	10
RGT	CAMBRIDGE UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	10
RM1	NORFOLK AND NORWICH UNIVERSITY HOSPITALS NHS FOUNDATION TRUST	10
	Other 44 providers	100
	TOTAL	860

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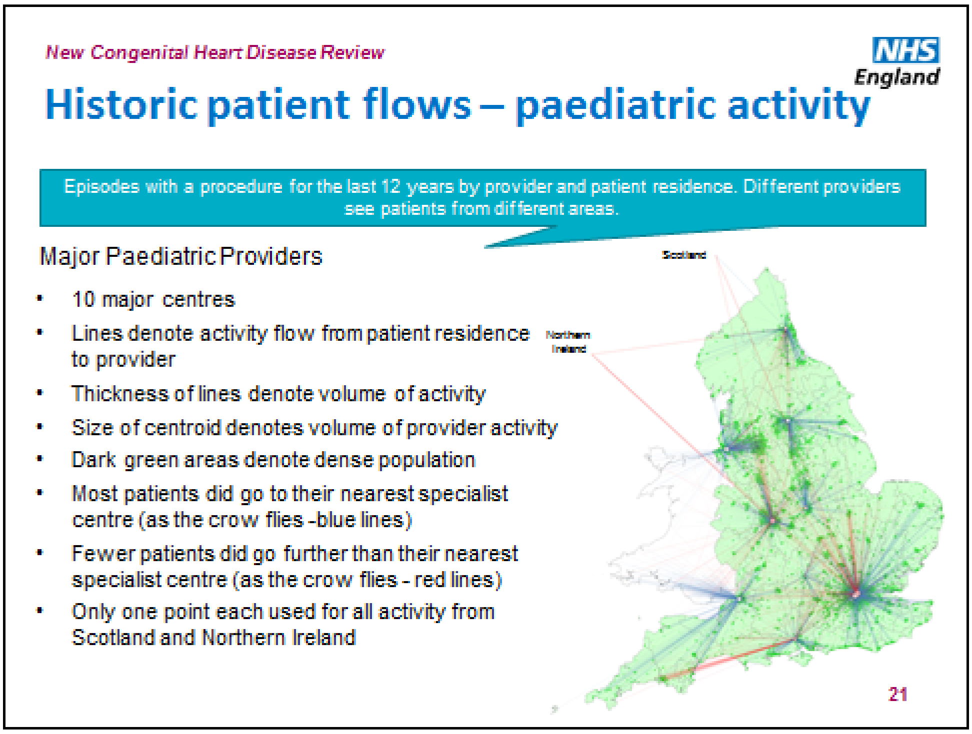
Figures may not sum due to rounding.

HES data



New Congenital Heart Disease Review

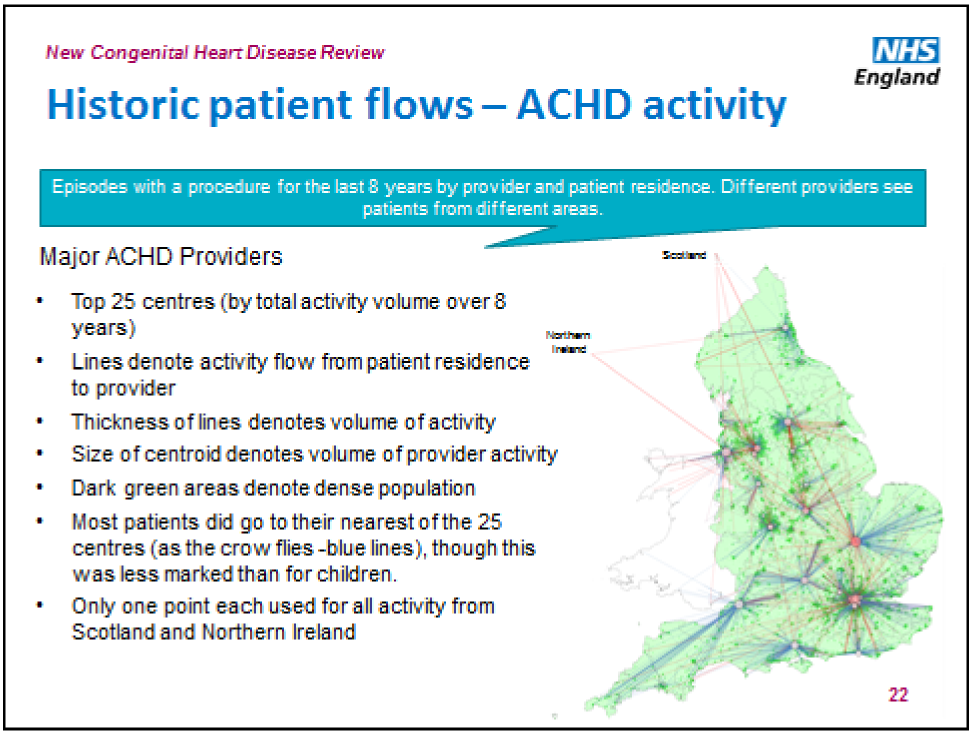
NHS England

Historic patient flows – paediatric activity

Episodes with a procedure for the last 12 years by provider and patient residence. Different providers see patients from different areas.

Major Paediatric Providers

- 10 major centres
- Lines denote activity flow from patient residence to provider
- Thickness of lines denote volume of activity
- Size of centroid denotes volume of provider activity
- Dark green areas denote dense population
- Most patients did go to their nearest specialist centre (as the crow flies -blue lines)
- Fewer patients did go further than their nearest specialist centre (as the crow flies - red lines)
- Only one point each used for all activity from Scotland and Northern Ireland



New Congenital Heart Disease Review

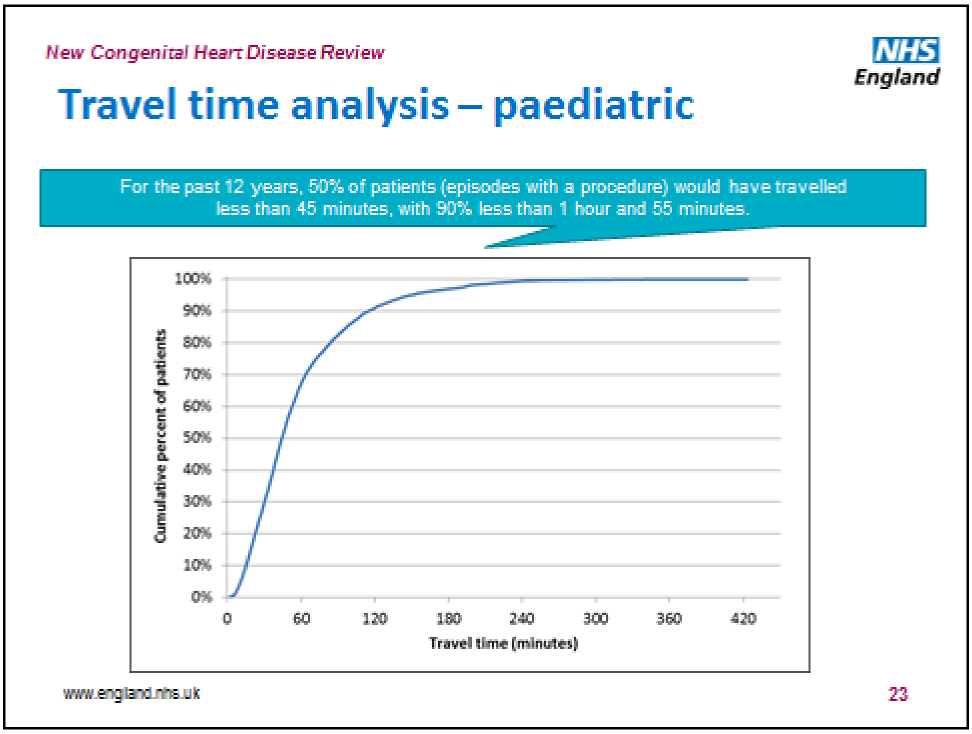
NHS England

Historic patient flows – ACHD activity

Episodes with a procedure for the last 8 years by provider and patient residence. Different providers see patients from different areas.

Major ACHD Providers

- Top 25 centres (by total activity volume over 8 years)
- Lines denote activity flow from patient residence to provider
- Thickness of lines denotes volume of activity
- Size of centroid denotes volume of provider activity
- Dark green areas denote dense population
- Most patients did go to their nearest of the 25 centres (as the crow flies -blue lines), though this was less marked than for children.
- Only one point each used for all activity from Scotland and Northern Ireland

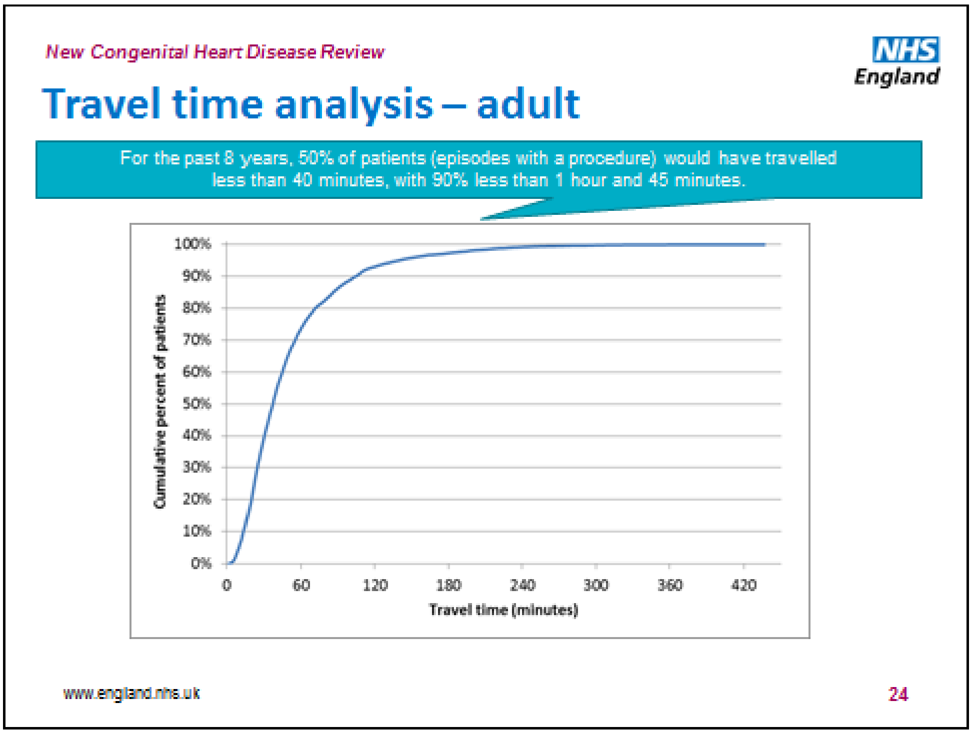


New Congenital Heart Disease Review

NHS England

Travel time analysis – paediatric

For the past 12 years, 50% of patients (episodes with a procedure) would have travelled less than 45 minutes, with 90% less than 1 hour and 55 minutes.



New Congenital Heart Disease Review

NHS England

Travel time analysis – adult

For the past 8 years, 50% of patients (episodes with a procedure) would have travelled less than 40 minutes, with 90% less than 1 hour and 45 minutes.