

**Report of the Paediatric and
Congenital Cardiac Services
Review Group**

December 2003

Chapter 1 Introduction

1. The tragic failures of children's heart surgery in Bristol and inquiries into services at the Royal Brompton and Harefield NHS Trusts signalled the need for a fundamental review of how the NHS cares for children. As part of this, the Government set up a Review Group in January 2001 to make recommendations for the safe organisation of the paediatric and congenital cardiac service. The terms of reference for the Review Group are at annex A.
2. The Review Group was multidisciplinary and included clinical experts, parent and patient representatives, NHS managers and Department of Health officials. All hospitals providing paediatric and congenital cardiac services in England were included in the Group, which also had representation from Wales and Northern Ireland. The Scottish Parliament received papers. Full Membership of the Review Group is listed at annex B.
3. The Review Group began work in March 2001. Its programme included a survey of the 14 hospitals that provide paediatric and congenital cardiac services in England, Wales and Northern Ireland. A multidisciplinary team (including a parent representative) visited all of the hospitals and met with parent and patient groups, clinical staff and managers. A web-site gave updates on Review Group meetings and invited comments. Additionally the Children's Heart Federation organised a specific sounding board event for parents and children in September 2001, which included workshop discussions on a number of key aspects of the paediatric and congenital cardiac service. The Group carried out detailed discussions about standards through subgroups, in plenary meetings and by e-mail. The Group was mindful of the work underway to develop principles and standards for the Children's National Service Framework (NSF) and sought to ensure, as far as possible, that its proposed standards and recommendations reflect those principles.
4. In chapter 2 this report sets out the rationale for the standards we have suggested, including the evidence base for them. Chapter 3 presents the standards themselves. In chapter 4 we consider how future demand for the service might develop and in chapter 5 how this might affect the shape of the service. In chapter 6 we set out proposals for supporting our recommended standards. We also include proposals for the periodic review of the whole service by the proposed Commission for Healthcare Audit and Inspection (CHAI) and for revisiting the standard relating to a minimum number of procedures per centre as further evidence becomes available through the proposed national audit.
5. In offering this report, which has the unanimous backing of all its members, and is endorsed by the Children's Taskforce, the Review Group hopes its recommended standards will ensure that all children and adults with congenital heart disease have access to the highest quality care in the future. The Group believes that a service which operates to these explicit standards will command the confidence of patients and parents; and provides the best chance of preventing the tragic events in Bristol from ever happening again.

6. The Review Group would like to thank all the centres, patients, parents, clinical staff and officials at the Department of Health who have given generously of their time and energy in developing this report.

Chapter 2 Rationale

Introduction

1. The Kennedy report recommended (recommendation 192¹) that:

“National standards should be developed as a matter of priority, for all aspects of the care and treatment of children with congenital heart disease (CHD). The standards should address diagnosis, surgical and other treatments, and continuing care. They should include standards for primary and social care, as well as for hospital care. The standards should also address the needs of those with CHD who grow into adulthood”
2. In developing these standards, the Review Group took as its starting point the Core Principles of the NHS Plan (www.nhs.uk/nationalplan) and the principles developed by the Children’s Taskforce (www.doh.gov.uk/chilrenstaskforce)
3. Many relevant documents and reviews emerged during the review. These include the Evans Report (Brompton and Harefield), the Children and Young People’s Unit’s document “Learning to Listen: Core Principles for the Involvement of Children and Young People”, the core principles for the Children’s National Service Framework (NSF), and, of course, the Kennedy Report and the Government’s response to it. In all these cases, the Group took steps to audit its processes and the proposed standards, for compliance with both letter and spirit of these recommendations. The same goes for a great deal of other work, eg. on consent, critical incident reporting, bereavement support, etc., where these standards proposed here signpost to other extant or forthcoming DH guidance.
4. The Group was also mindful of the developing standards for the fast-tracked module of the Children’s NSF “Children who need acute/hospital services” and worked hard to align its standards with the developing thinking of the External Working Group for this programme. This was greatly assisted by a degree of cross-membership and by shared secretariats.
5. Many of the standards and interventions proposed are based on examples of good practice that we observed on visits to each of the units in England, Wales and Northern Ireland. The visiting team was led by an external clinical expert and included a nurse, a parent and a Department of Health official. (Details of the visiting team are attached at annex D.) Each of the fourteen review visits also included detailed discussion with patients and parents.
6. The visiting team reported back to the Review Group on their findings, and set out the key implications for standards. These standards were developed through consultation within the Review Group and were discussed at various stages in Review Group meetings, in sub-groups and in correspondence.
7. The current order of presentation is an attempt to impose a logical framework on a detailed debate. It derives in part from considering typical care pathways, or patient journeys, through this service. It should not be taken to

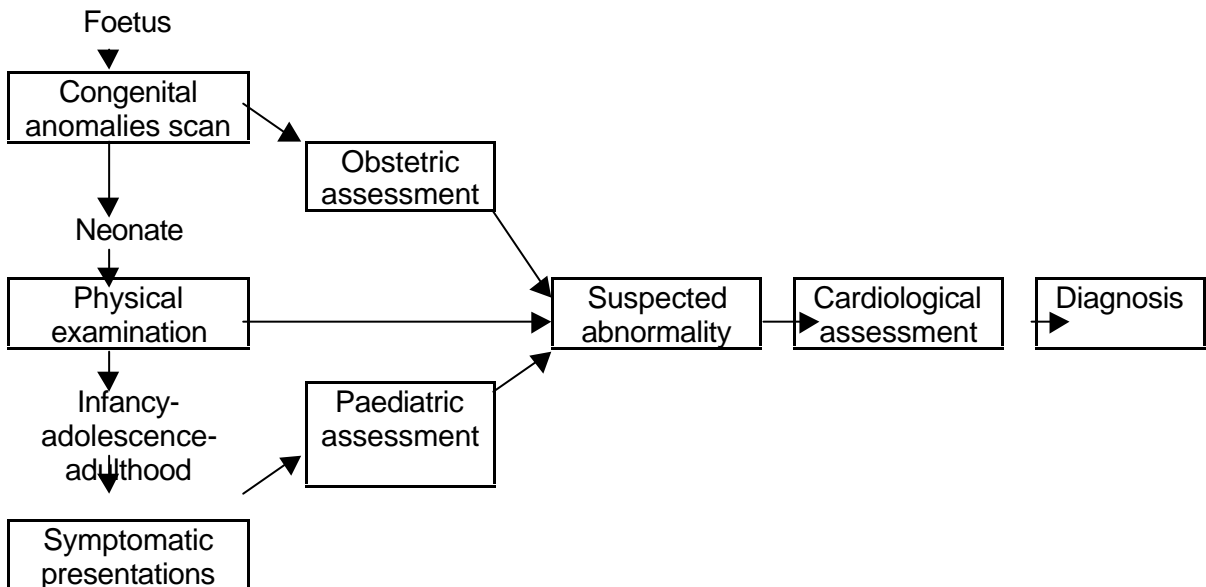
¹ The Kennedy recommendations on healthcare services and treatment for children with congenital heart disease can be found at annex C

represent any order of priority – standard 12 about bereavement support carries the same weight as standard 1 about the clinical team; nor does it indicate the order in which any necessary changes should be undertaken.

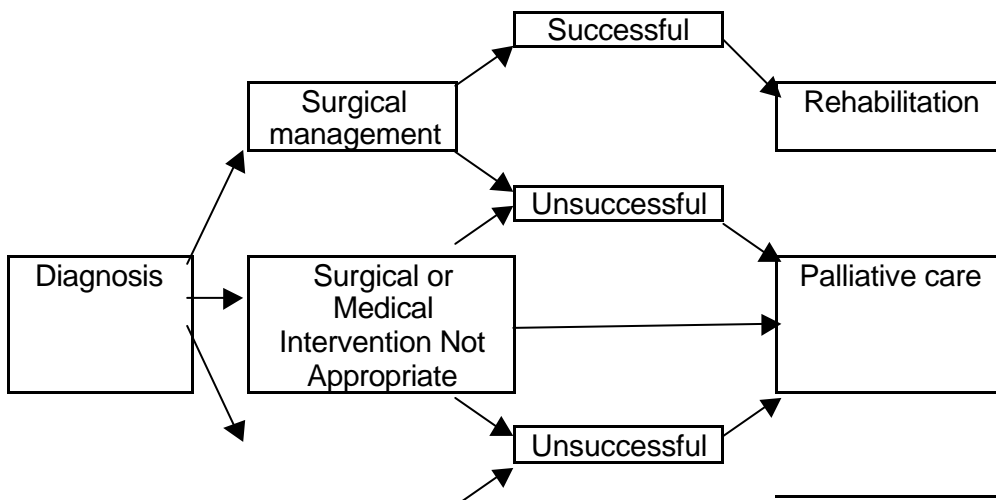
Care pathways

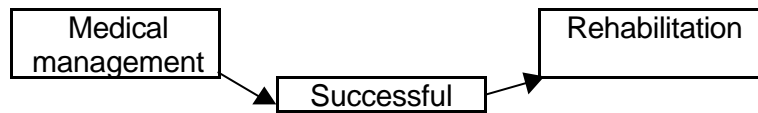
- The Review Group developed two generic care pathways. The first maps out the process from identification of a congenital anomaly to diagnosis, and the second, the process from diagnosis to eventual outcome. A further pathway attempts to identify the points of transition where an individual will move between different services. The Group used these to identify points at which standards might be required (e.g. at points of key transition); and as a reality check to ensure proposed standards covered all the necessary aspects.

Care Pathway 1 – Identification to Diagnosis

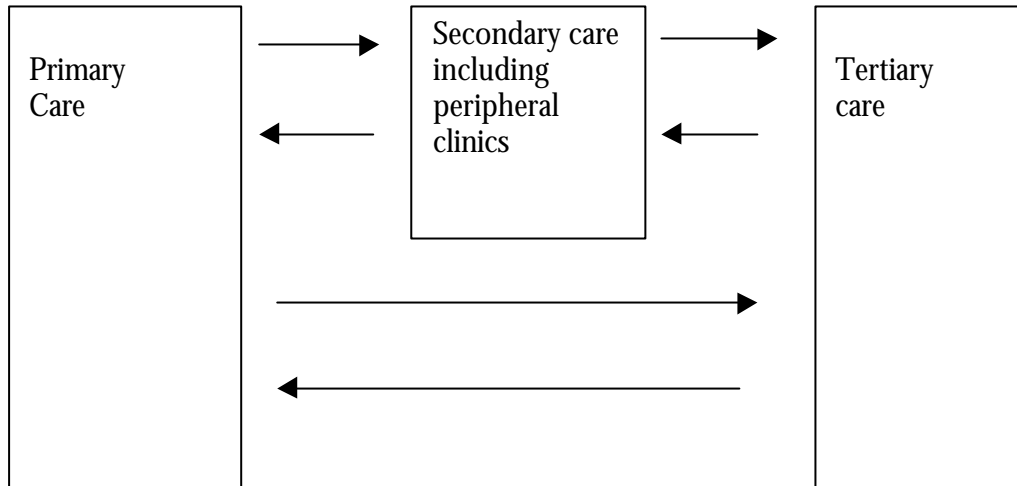


Care Pathway 2 – Diagnosis to Outcome of Intervention

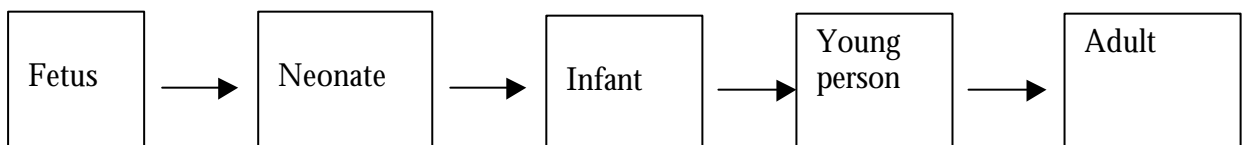




Care pathway 3- Transfer Between Primary, Secondary and Tertiary Services



Care pathway 4- Management of transitions as the child grows



The Standards

The Context of Care

9. There are very different models of organisation across the 14 units. Some units have a mixed practice of paediatric and adult work whereas other units concentrate purely on children. The visiting team did not identify a single preferred model, but did identify certain characteristics that helped to create a successful unit:
 - there needs to be strong support within the Trust as a whole for the paediatric and congenital cardiac service;
 - there needs to be strong leadership and team-working with evidence of continuing efforts to maintain and develop the team;
 - good communication/liaison between different parts of the service is more important than how things are organised geographically although services such as the paediatric intensive care unit, the ward and theatre do need to be close to each other;
 - there needs to be a commitment to care for children in an environment that is appropriate to their needs and stage of development.

10. The Kennedy Report recommended (recommendation 196) that any children undergoing a cardiac procedure should be cared for in a paediatric environment. This is also consistent with the NHS Plan and is likely to be amplified in the National Service Framework for Children. Some of the current units are located in children's hospitals; others are within units providing both adult and paediatric services. There was no evidence to suggest one model was inherently superior to any other. The key criterion appeared to be the Trust-wide commitment to a service tailored to meeting the changing needs of the child. Nor was any one model consistently better at handling the transition to adult services.
11. There were few quarrels with the recommendations around establishing maintaining and developing full multi-disciplinary audit, covering mortality and morbidity outcomes; and for results to be published. It clearly makes sense for these developments to build on the established Central Cardiac Audit Database (CCAD). It would be important to ensure that the range of variation was explained in order to avoid "league-table" syndrome. The key aim must be to ensure parents/users of the service are confident that a centre is operating within an acceptable level of safety.
12. Some of the centres visited commented that a degree of culture-change was required around the issue of critical incident reporting (adverse health events). This needs to be seen as a tool for learning and improving practice. In this spirit, the visiting team felt that it was important that the results of critical incidents should be disseminated across the clinical networks and to other centres in order to maximise learning potential.
13. Another recommendation of the Kennedy Report was that procedures undertaken very rarely should only be performed in a maximum of two units. This occasioned a great deal of debate and the Group eventually concluded that such an approach would be unduly restrictive. The visiting team covered this issue in relation to correction of hypoplastic left heart syndrome (judged by the Review Group to be a better touchstone than Truncus Arteriosus) in its questioning, and discovered a number of elements of current good practice:
 - one unit habitually sends all its hypoplastic left hearts to Birmingham for correction;
 - one unit recruited a surgeon who had trained with a world expert, then introduced the procedure in his new unit;
 - one unit invited the world expert to perform a number of corrections with local surgeons assisting and observing; and
 - one unit sent a surgeon to assist a world expert, before bringing the procedure back to base.
14. An alternative suggestion was for a Review Group, similar to the existing SERNIP (Safety and Efficacy Register for New Interventional Procedures) to have responsibility for approving the introduction of any new operation, intervention or medical treatment. This would form part of peer review. The most favoured proposal, however, was for plans to introduce new procedures to be routinely considered in local clinical governance, where Trust management would need to be satisfied that its introduction was justified,

taking into account demand for the procedure, the skills and experience of the local team, the availability of any further supporting resources that might be necessary, and, following consultation with all the other centres, the likely effect on the whole service, and its outcomes, as a whole. In urgent cases, clearly, there would need to be the facility to give post hoc approval.

Information and Consent

15. Many of these proposals are based on the jointly produced booklet *Children's Heart Services – a guide to care standards* (BPCA/CHF/CDCA). One of the consistent themes to emerge from the review visits is the need for more information at diagnosis. Initially patients/parents want to receive relatively simple information but, as they have more time to assimilate the initial diagnosis, they want the opportunity to ask further questions and develop a more sophisticated understanding. Findings from the review visits indicate that patients/parents were generally most content where they felt they had had careful, detailed explanations, repeated as often as requested, with ample opportunity to ask questions. At some units the cardiac liaison nurse was available to sit in on a consultation and support the parents by asking the surgeon/cardiologist relevant questions. Patients/parents felt that it was vitally important that they should also receive written information. Patients/parents tended to want objective, but non-directive information that enabled them to make informed decisions.
16. It is very distressing for a parent to learn that there is no treatment available for their child. It is important to ensure that parents can at least feel certain that everything possible has been done to care for them. Good evidence-based information about why treatment is not appropriate will help them through this process.
17. The Department of Health has issued guidance on consent and this should be consulted for advice on the current law and good practice requirements in seeking consent. This includes what to do when a patient lacks the capacity to give consent to an intervention. The relevant documents (available at www.doh.gov.uk/consent) are:
 - *The Good practice in consent implementation guide*, which contains a model consent policy and four consent forms together with an accompanying information leaflet.
 - *Reference guide to consent for examination or treatment* which provides a comprehensive summary of the current law on consent, and includes requirements of regulatory bodies such as the General Medical Council where these are more stringent.
 - *12 key points on consent: the law in England*, which has been distributed widely to health professionals working in England. This one-page document summarises those aspects of the law on consent which arise on a daily basis.
 - Specific guidance, incorporating both the law and good practice advice, which is available for health professionals working with children, with people with learning disabilities and with older people.

Health professionals should also be aware of any guidance on consent issued by their own regulatory bodies.

18. When a Coroner's Post Mortem is required families should be given a clear explanation about the procedure and their consent will be required before any organs or tissues can be retained for any other purpose. Hospital Post Mortems and any subsequent retention of organs or tissues should be governed by the consent of the family. The Department of Health has recently consulted on a draft code of practice for the handling of communications with families about post mortem examinations together with new draft consent forms to ensure that proper procedures are in place before organs or tissue are removed, retained or used. The documents can be found at www.doh.gov.uk/tissue .

The Patient's Journey

19. The early antenatal identification of congenital abnormalities allows parents the choice about whether to continue the pregnancy. It also allows time for parents to develop a good understanding of the diagnosis and helps to ensure that when they are required to consent to treatment for their child they do so on an informed basis.
20. Early identification of a congenital abnormality also enables medical staff to make decisions, in discussion with the parents, about the management of the pregnancy and arrangements for delivery. Despite this, the Group was conscious of continuing shortfalls in the accuracy of congenital anomalies scanning. The Department of Health has commissioned the National Screening Committee and the National Institute for Clinical Excellence to work on standards for antenatal screening. Screening should comply with these standards as and when they are developed.
21. Referring a patient to a paediatric cardiologist without delay increases the probability that a surgical procedure can be carried out on an elective basis rather than as an emergency. This gives a patient/parent more time to come to terms with the diagnosis, to develop their understanding of the condition and to go through the consent process. It also makes it easier for the paediatric cardiac unit to schedule their surgery.
22. After a great deal of detailed debate, the Review Group agreed that it would include recommendations for minimum numbers of key staff: cardiologists, surgeons and cardiac liaison nurses (see under **Joined up Care**, below); and refer to *Paediatric Intensive Care: A Framework for the Future*, which makes similar recommendations for staffing of paediatric intensive care units. Cardiologist numbers take into account the predicted growth in the number of adults with congenital heart disease (ACHD) by 2010 (see chapter 4) and have been agreed with the British Paediatric Cardiology Association. It was clear to the Group that today's cardiology consultants are hard-pressed. One reason often cited for the reluctance of medical graduates to opt for paediatric cardiology is their perception of this, and their assumption that, in consequence, there will be little in the way of support for trainees. A substantial increase in numbers will do much both to ensure that our proposed quality standards can be achieved in a period of increasing prevalence and to develop a more attractive environment for trainees.

23. The proposed number of surgeons (3 per unit) is based on professional consensus as to what is a manageable on-call rota and would allow for the small increase required by the growing numbers of adults with CHD. A number of other benefits, observed by the visiting team, seem likely to flow from a surgical establishment of this size: ease of succession planning (one moving towards retirement, one learning the craft, one at peak performance); room to diversify eg. two to specialise in infants, one to develop expertise in complex adults; and more time for research.
24. The Group was very mindful throughout of the impact of the European Working Time Directive (WTD) on staffing of health services in the future. While wider debates on the way forward continued, the Group felt that to propose WTD-compliant standards for staffing was beyond its brief. The standards are therefore concerned with what would be necessary under today's circumstances to assure a safe and high quality service. As the service, and particularly the tertiary centres, move towards full implementation, they may find that further adjustment (eg. to on-call rotas) is necessary, which may lead to more imaginative networking of the service. They may also find that many of the changes required to meet these standards provide a good staging post on the way to WTD compliance.
25. The Kennedy Report (recommendation 193) recommended that the standards for the treatment of children with Congenital Heart Disease should stipulate the minimum number of procedures that should be performed by a centre over a given period of time, as a way of ensuring sufficient throughput for surgeons and others to maintain their skills. Although this seems to make sense intuitively, there is limited evidence to support it or to help determine what the minimum level of procedures should be. Surgical results for the past year Central Cardiac Audit Database (CCAD) all fall within a very narrow range, and compare favourably with international results, even though units vary markedly in the number of operations they have carried out over the period.
26. One American study of paediatric congenital cardiac surgery concluded that the mortality risk was lower at an institution performing more than 300 cases annually. It also showed that hospitals that were carrying out fewer than 100 paediatric cardiac procedures annually had "significantly higher mortality rates than hospitals with volumes of 100 or more". This led the Group to two conclusions – that occasional surgical practice, not evident in any of our existing centres, should be ruled out; and that the threshold for cardiac surgery in children should be set at 300 cases per centre per year². In addition, the Group adopted the suggestion in the Kennedy Report (recommendation 194) that a minimum of 4 operating sessions per week would prevent occasional practice for surgeons.
27. The Kennedy report (recommendation 195) also recommended that any centre providing open-heart surgery on young children should have two surgeons trained in paediatric surgery, who should each perform 40-50 open-heart procedures on infants per annum. Again, there is a lack of evidence about the optimal number of procedures per individual surgeon. However,

² The emerging document "The Optimal Structure of a Congenital Heart Surgery Department in Europe", produced by the European Association of Cardiothoracic Surgeons, proposes that centres have at least 2 surgeons and perform a minimum of 250 **congenital** procedures (ie. on children or adults) per year.

there was agreement amongst clinicians, patients, parents and managers within the Review Group that it would seem unsafe for any surgeon to be performing fewer than 40 open-heart procedures a year on neonates and infants. The Group therefore opted to endorse Kennedy's recommendation.

28. In all the standards concerned with minimum numbers of surgical procedures, the Group was mindful of the importance of succession planning, and the working of the surgical team. This is why the minimum is expressed in terms of the whole centre, rather than individual surgeons.
29. No minimum number is proposed for **congenital procedures on adults**. There is neither evidence of outcomes nor professional consensus to support such a minimum. Because this client group is set to grow over the next 10 years, from a small base, the Group wishes the Society of Cardiothoracic Surgeons to review the evidence in 5 years' time and, if necessary, to propose a meaningful minimum.
30. There is currently no evidence that variations in training or experience of anaesthetists have any bearing on outcomes in paediatric and congenital cardiac surgery. This is not surprising, as there have been no studies specifically addressing this issue. There is, however, agreement amongst those involved in this area (patients, parents, and health professionals) that anaesthetists involved in paediatric and congenital cardiac surgery should, like the surgeons and cardiologists, meet minimum standards for training and experience.
31. In the absence of evidence, the Royal College of Anaesthetists consulted the following organisations on the Review Group's behalf:
 - Children's Heart Federation (CHF)
 - Association of Paediatric Anaesthetists (APA)
 - Association of Cardiothoracic Anaesthetists (ACTA)
 - Paediatric Intensive Care Society (PICS)The standards proposed are based on their consensus views. More detail is given in annex E.
32. For cardiology, the Group was guided by the 2000 report of the British Paediatric Cardiology Association (BPCA) which proposed that, to assure competence, interventional cardiologists should undertake a minimum of 40 procedures per year. With the assistance of the BPCA, the Group added to this the concept of the lead interventionist, with key quality assurance responsibilities and the requirement that the lead interventionist should participate in a minimum of 80 procedures per year. The Group wished to encourage the "dual operator" concept, where two cardiologists act together, as a way of cementing teamworking and continuing professional development: hence the use of the term "participate". In such cases, each procedure would count towards the total of each operator.

Joined Up Care

33. The care of patients with a congenital heart condition does not begin and end at the tertiary centre. Apart from a few conditions, where a single surgical correction is all that is necessary, patients continue to need follow-up and/or further surgery for the rest of their lives. For the very many patients who live at some distance from their tertiary centre, therefore, it is essential that their local health services are able to support them. GPs, paediatricians, health visitors, community nurses, etc. need to be able to provide care for conditions both related and unrelated to their underlying heart condition.
34. The review visits indicated that there was considerable variation in the level of support that patients/parents receive from local health services. Many patients and parents spoke of their local health services' inability to provide the support they needed, leaving them little choice but to travel to the tertiary centre.
35. There will, however, always be some situations in which patients/parents will need the direct advice/support of the cardiac centre. A number of the units visited described themselves as offering an immediate access service. This tended to mean a direct telephone number to the ward, the cardiac liaison service, or the cardiologist. This was an aspect of service that patients and parents particularly valued and found very reassuring.
36. Arrangements can be aided by good communication between the cardiac centre and the community team. Thus, the cardiac liaison service has a key role in supporting the community team in providing quality care to the parents/patient. Issuing discharge letters promptly, as well as telephoning the community service prior to discharge, were seen as important. Also patients/parents were appreciative where it was the centre's practice to send them a copy of the discharge letter. As patients/parents move across the service they need to have an understanding of why a transfer to a different level of service is required, how this will be managed and the timescales within which this will occur. Similarly, there is a need for good transfer of information across different levels of the service. Although a number of the units visited were seeking to develop electronic records, it was clear that available IT systems did not yet support the full sharing of information. A promising approach is the use of patient held records. This had recently been introduced by one of the units visited and is particularly empowering to patients/parents. It provides a ready means of explaining to any healthcare professionals the patient's full history.
37. The visiting team observed that the cardiac liaison nurses fulfilled a critical role in helping patients manage the interface between the different levels of service. Ideally the cardiac liaison service needs to be able to provide support within the hospital at outpatients and on the cardiac ward or paediatric intensive care unit, as well as maintaining good links with the community service. A subgroup set itself to define in detail the cardiac liaison role and also proposed some ways to improve the career path for nurses entering the service. A model job description is at annex F. The complete subgroup paper is at www.doh.gov.uk/childcardiac/papers.
38. In full Group discussion, it became clear that the standards ought to allow for the liaison service to be staffed on a competence basis, open to people from

a variety of backgrounds. Some of the tasks identified do not require a nursing professional – although many of them do; nor will it be immediately possible to staff up to the recommended levels solely with nurses, without seriously denuding the cardiac wards in the short-term.

39. As discussions progressed, and particularly during those held with the Children's Taskforce, it became clear that a key worker for each patient/family was also felt to be necessary. This role could form part of the expanded cardiac liaison service, although it might also fall to the patient's GP or to their local paediatrician or cardiologist. The Group did not feel it should be prescriptive, other than to recommend that such a person be identified for each patient. At present, it is clear that for most patients, the key worker is either themselves, or their parent.
40. For both initial consultations and follow-up care, it is convenient for patients not to have to travel to the tertiary centre every time. Although most centres ran a system of peripheral outreach clinics, at least one centre did not; and the quality of service, and degree of involvement of local clinicians, varied greatly. The review visits showed that as a general rule patients/parents were less well supported at outreach clinics than where they attended the tertiary centre. For example, they were less likely to receive written information or details of support groups. Similarly, most of the units did not involve the cardiac liaison service at peripheral clinics although a number had plans to do so.
41. It should be an accepted principle that an outreach clinic should deliver the same quality of care that parents/patients could have received if they had attended a tertiary centre, particularly adequate echo cardiography. To achieve this, there may need to be some rationalisation of where outreach clinics are held. It follows that it will not be possible to provide an adequate level of support to a clinic where it is outside the geographical area covered by the tertiary centre.
42. The concept of the managed clinical network is not a new one; and it seems ideal for the future running of this service. The interventions in the Joined Up Care section therefore aim at establishing these networks, with the tertiary centres taking the lead role, collaborating with other centres to establish the most logical and convenient network of outreach clinics, and helping with training and support to local clinicians, so that they can play their full part in the care of their patients.

Growing up

43. There is evidence from the review visits that parents needed more support in helping teachers to understand the implications of their children's conditions. Problems encountered ranged from unduly protective teachers to a failure to understand why a child was unable to take part in games. Some of the units included school visits, at the request of parents, as part of the cardiac liaison service, and for one centre a school liaison visit was standard practice.
44. Some of the parents interviewed expressed some bitterness at the hurdles they had been forced to overcome in order to secure learning support for their child. There is a clear need for factual information on their child's condition that parents can use to support such an application.

45. The transition to adult services is perhaps the most obvious area where services need to be improved. Models of transition varied across the units visited, but the Group was able to identify some aspects of best practice:
- the age of transition should be flexible;
 - the transition process should be agreed with the patient before it takes place;
 - the patient should be clear where ultimate responsibility for their care lies;
 - joint clinics between the adult and paediatric services can be a means of providing continuity of care across the transition; and
 - the use of nurse counsellors or the cardiac liaison service to support the transition is beneficial.

Any centre providing a congenital heart service for adults should work in close partnership with a paediatric centre. This will aid continuity.

46. The visiting team was told on several occasions when patients now transferred to adult services had been cared for during inpatient stays in the children's wards. This was done for entirely laudable and understandable reasons – the patient and/or parents were familiar and comfortable with the children's ward, staff knew them, etc. The Group agreed that children and young people should be cared for in an environment that meets their developmental needs, is age appropriate and is sensitive to those children and young people with special needs (eg. children with learning difficulties, children with Down's Syndrome etc). However, being also mindful of the need for child protection, the Group recommends that, other than in the most unusual circumstances, no child (under 16) should be cared for on an adult ward and that no one over 18 (Children's Act definition) should be cared for on a paediatric ward. The Group also recommends that centres develop separate accommodation for older children and adolescents. Because of the small numbers involved, it may well be most practicable to provide this through clearly separable parts of the existing children's or adult ward; but these sections must all meet approved quality standards for age appropriate environments.

Support to parents and families

47. All the units visited provided some form of accommodation for parents and all were supportive in enabling parents to stay by their child's bedside (a number of the units had pull-down beds). This was greatly valued by parents.
48. From the review visits it became clear that there was scope for improvement in parents' facilities at some of the centres. For example at one centre, the restaurant closed at 7pm which was seen as being much too early. At another centre the free parking was at a distance from the entrance to the hospital, which caused difficulties where a child was being admitted or discharged.
49. It was also clear from the visits, and from submissions by the Grown Up Congenital Heart Patients' Association (GUCH), that the centres were far from clear on what their provision should be for partners/ visitors/supporters etc who were *not* parents. This is something that needs to be addressed in the

context of developing facilities and services for the growing group of older patients.

50. Proper support when a patient dies is important in helping parents/relatives go through a healthy grieving process. This is a time where getting the practical support on offer right can have a profound effect. For example, at one of the units visited parents who lived some distance from the hospital described how traumatic it was to have to travel back to the hospital area in order to register the death. In some of the units visited bereavement support was provided by the cardiac liaison service. In other areas a separate bereavement counsellor or social worker provided the service. Neither model is inherently superior; whichever is adopted needs to be properly resourced and supported.
51. Where a death has been unexpected, parents/relatives have a strong desire to understand why this has happened. It is important that parents/relatives are given adequate opportunity to talk to the professionals involved in the care of the patient. From the review visits it was clear that openness and honesty were highly valued, with considerable frustration arising wherever it was felt that information had been concealed or withheld.
52. It is recognised that children may need support in coming to terms with their condition or in dealing with the death of a sibling. As a general rule, bereavement support tends to be focused very much on the parents or adult partners. There is a need to ensure that this service also meets the needs of siblings.

Conclusion

53. This summary of the discussions and thought processes of the Review Group is intended to help readers understand the basis and rationale for the standards proposed in the next section.

Chapter 3 – The Standards

THE CONTEXT OF CARE

The Clinical Team

Standard

1. The congenital heart service should function as a team. It should be well led with responsibilities shared appropriately across it. As a result, patients should receive seamless, expert and continuous care that takes account of their changing needs.

Interventions

- 1.1 At the tertiary centre, those delivering paediatric and congenital cardiac care should operate as a team, with responsibilities clearly and openly agreed.
- 1.2 One person within the team should have the lead role, with overall responsibility for maintaining the quality of care, for representing the team and service within the Trust, and for sustaining the continuity of the team, eg. through succession planning. This should be reflected in their job plan.
- 1.3 The team must ensure it has robust arrangements for liaison and co-operative working with other specialties, where a patient needs other treatments. There should be a named person responsible for overseeing and co-ordinating the patient's care management plan. This is especially important for children with complex needs.
- 1.4 The team must ensure it establishes robust liaison and co-operative working with clinicians (paediatricians, GPs, community nurses) who see the patient locally. These will need to vary to fit local situations eg. interests and expertise of local clinicians.

A Quality Service

Standard

2. Clinical practice should be evaluated in a systematic way, ensuring that key lessons are identified and disseminated, and that clear and supportive lines of accountability are in place.

Interventions

- 2.1 All centres should participate in the national audit programme and should ensure that audit is adequately financed and staffed. Over time the data collected should be expanded to include morbidity (especially neurological morbidity), mortality, risk stratification, follow-up and waiting time information. It should also cover the results of interventional catheterisation. There should be a process for audit data to be validated and fed back to centres.
- 2.2 Outreach clinics, and, over time, the whole clinical network, including services supporting patients locally, should form part of the "audit circle" for each service.
- 2.3 All centres should publish annual data on mortality in an agreed format. As systems develop to capture and monitor information on morbidity, these data

should also be made available publicly.

- 2.4 Each centre should report on adverse health care events (critical incidents). As well as the national reporting requirements, details should be disseminated across each centre's clinical network and to all the other centres that provide paediatric and congenital cardiac services.
- 2.5 Regular patient experience and satisfaction surveys, and consultation events with patients/parents should form part of the audit process.
- 2.6 Clinical practice should be informed by regular review of research evidence derived from local, national or international sources.
- 2.7 Each centre should pursue an active research strategy related to congenital heart disease and coordinate research effort with other centres to reduce duplication and increase coverage. Research should be conducted in accordance with the NHS Trust Research Governance Policy. Staffing, and other resourcing, for the service should acknowledge the importance of research in maintaining and developing standards of clinical practice, for all disciplines.
- 2.8 Clinical Governance arrangements at sub-speciality level should be sufficient to oversee the introduction of new and rare procedures. This oversight should include arrangements for external peer review eg. by reference to the other centres, where a centre proposes to undertake a procedure that it has not offered before. Where agreement cannot be reached, the Regional Directors of Public Health should be asked to arbitrate

Child-Centred Environment

Standard:

3. Children should be cared for in an environment that recognises their special needs.

Interventions:

- 3.1 The service should demonstrate a commitment to a child-centred environment.
- 3.2 Children who undergo any form of interventional procedure must be cared for in a child-centred environment.
- 3.3 The centre should ensure that the paediatric and congenital cardiac service is informed by best practice within paediatrics (eg. pain management, nutrition for children etc).

INFORMATION AND CONSENT

Standard

4. Patients and parents should be supported in understanding their condition and treatment options, and in giving informed consent at every stage of treatment

Interventions

- 4.1 At each stage of care and on a continuous basis, centres should ensure that patients, parents, families and next of kin are given:

- full information about the condition, likely prognosis, treatment options, likely outcomes of treatment and the possible consequences of decisions about care
 - information about and contact details for local and national support groups
 - information about other forms of support including statutory benefits
 - information in accessible and appropriate formats, always orally and backed-up by written information, and with option of accessing further information if required
 - information that is factual, objective and given in a non-directive way.
- 4.2 Children/young people should receive an explanation of their condition that is appropriate to their age³ and understanding.
- 4.3 Each patient should have an agreed, written care plan/patient record, which they or their parents/family retain. This should include what to do in an emergency, contact numbers and notes of discussions, treatment options agreed and consents (recorded in the care plan by the clinicians and countersigned by the patient/parent/carer). An example of a patient-held record from Liverpool is [enclosed in the plastic wallet at the front of this report].
- 4.4 Each centre should have a written protocol for obtaining further opinions and this should be included in the information patients and parents are given.
- 4.5 Each centre should regard consent to treatment as a process rather than an event and Trusts should refer to DH guidance at www.doh.gov.uk/consent on best practice. Key features include a senior person, visible to the patient/parents, with clear responsibility for overseeing the process; and the opportunity for patients/parents to meet anyone who will be operating or carrying out an intervention on them/their child, before admission for the intervention, unless in an emergency. Where children are concerned, particular reference should be made to *Seeking Consent: working with children* at the same website.
- 4.6 Centres should take particular care when seeking consent to procedures that are new or uncommon, or subject to research. Patients and parents should always be fully informed where this is the case.
- 4.7 At consultations where a diagnosis is confirmed or a treatment plan agreed (including no further treatment), patients/parents should be given the opportunity of a follow-up appointment within 7 days (or longer if the patient/parents prefer), with an appropriate member of the team, to check

³ The wording “appropriate to age and understanding” is used at several points in this paper. By this we mean an assessment should be made of the child/young person’s level of knowledge and understanding prior to receiving explanations about their condition. This will not be a “one off” event and the skills of the multi disciplinary team should be utilised in sharing information with child and family.

their understanding or to seek further information.

- 4.8 As a matter of course, patients/ parents should be able to be accompanied by a friend/supporter at consultations.
- 4.9 The consultant responsible for the patient's care should take overall responsibility both for the quality of the information given and the way it is given.
- 4.10 The centre should also provide expert information to assist an application by the patient/parents for social care services or other support (eg an application for a statement of special educational needs).
- 4.11 There should be an agreed procedure and standardised form for consent for a post mortem examination. A clear explanation should be given to the parent/next of kin of the difference between a coroner's post mortem and a hospital post-mortem. Parents should be fully informed about what will happen to the body of their child and the condition in which it will be returned to them. The DH draft code of practice is at www.doh.gov.uk/tissue.

THE PATIENT'S JOURNEY

Screening, assessment and diagnosis

Standard

5. Screening and diagnosis should identify congenital heart abnormalities, and ensure that patients are referred to the relevant specialist, as early as possible. Accurate diagnosis should follow promptly.

Interventions

- 5.1 All pregnant women should have access to prenatal screening which meets agreed screening standards⁴.
- 5.2 If the standard prenatal scan indicates that the foetus may have a heart problem, the mother should be offered a specialist cardiac scan as soon as possible, and in any case, within 1 week.
- 5.3 All high risk mothers (eg. congenital heart disease in mother, father or previous child, nuchal thickening, etc⁵) should be offered a specialist echo scan at 18 –20 weeks.
- 5.4 If the cardiac scan suggests that the foetus has a cardiac lesion, there should be a full medical assessment within 1 week of the cardiac scan.
- 5.5 Parents who have been told their expected child has a heart condition should have access to non-directive counselling and support to help them interpret the diagnosis and possible outcomes, and decide whether to continue the pregnancy. They should also be given contact details for relevant local and

⁴ The National Screening Committee and the National Institute for Clinical Excellence are working on standards for antenatal screening. Screening should comply with these standards as and when they are developed.

⁵ This list is not exhaustive. The decision about whether to refer for a specialist cardiac scan will depend on the judgement of the obstetrician about what constitutes high risk.

national support groups at this point.

- 5.6 At diagnosis, a plan should be agreed between the parents, maternity unit and paediatric cardiac unit about arrangements for the delivery of the baby. Where the baby is delivered at the DGH (or other local service) this should include arrangements for the transfer of the baby to the tertiary centre. There should be a facility to deliver the baby close to the tertiary centre (eg. at a linked obstetric unit) if necessary.
- 5.7 A paediatrician (or other relevant professional) should examine all newborn babies for signs of heart disease in the first week of life.
- 5.8 Where a GP or other relevant professional, either in following up symptoms, or in the course of opportunistic examination, or the newborn check, is concerned that there may be a heart problem they should arrange for a preliminary assessment by a specialist within 1 week, and a detailed specialist opinion, including likely options for treatment, within 4 weeks.
- 5.9 Patients/parents should be offered information about relevant local and national support groups.

Medical and Surgical Care

Standard

6. Medical and surgical procedures should be carried out in a way that is safe for patients and which maximises quality of care.

Interventions

- 6.1 Each centre providing a paediatric and congenital cardiac service should have a minimum of 1 consultant cardiologist per half million population served. The cardiology team should include expertise in fetal and adult congenital cardiology.
- 6.2 Any patient requiring cardiac catheterisation should receive this within a maximum waiting time of 3 months.
- 6.3 Each centre providing a surgical service should provide interventional cardiology; and this should not be undertaken, other than in an emergency, without on site surgical backup.
- 6.4 Each cardiology team in a centre providing an interventional service should comprise one lead interventionist and one, or two, others. The lead interventionist must participate in a minimum of 80 interventional procedures per year, on average; and the other interventionists should participate in at least 40 procedures per year, on average. Other members of the cardiology team should not carry out interventions.
- 6.5 The lead interventionist should be responsible for assuring the quality of the team's work overall, including involvement in the planning of procedures and the audit of activity; taking steps to eliminate occasional practice; and ensuring that interventionists have received training, and are competent, in the procedures they propose to undertake.

- 6.6 Cardiology teams should also contain a lead in pacing and electrophysiological procedures, who has been trained adequately in those procedures.
- 6.7 Each centre providing a *paediatric* surgical service should carry out a minimum of 300 paediatric surgical procedures per annum, on average, sensibly distributed between the surgeons to avoid occasional practice.
- 6.8 Each centre should have a minimum of 3 cardiac surgeons performing congenital procedures.
- 6.9 Where a centre has a programme of open-heart procedures on children under 1 year, at least 2 of the surgical consultants should be significantly involved with the programme, and the centre should perform a minimum of 80 such procedures per annum on average.
- 6.10 Surgeons should maintain results within an acceptable range of UK average demonstrated by the ongoing national audit of surgical procedures.
- 6.11 Surgeons should avoid occasional practice, and devote a minimum of 4 operating sessions per week, on average, to the congenital service.
- 6.12 Anaesthetists caring for children undergoing congenital cardiac interventions should have received background training in both paediatric and congenital cardiac anaesthesia.
- 6.13 Anaesthetists should undertake at least one session per week, on average, in congenital cardiac anaesthesia.
- 6.14 Post-operative care should be carried out in paediatric intensive care (PIC) units with appropriate facilities in accordance with the document “Framework for the Future” (DH 1997), and sited close to where surgery takes place.
- 6.15 A lead paediatric intensive care (PIC) clinician with 2 years’ recognised PIC training, should be responsible for the development of all aspects of the intensive care service.
- 6.16 Comprehensive cover should be provided by consultants with accredited training and ongoing experience in paediatric intensive care and specific training in congenital heart disease.
- 6.17 Within intensive care, staffing levels should be sufficient to allow 1:1 supervision of the most critically ill children routinely and, where necessary, 2:1. In line with the staffing levels set out in *A Bridge to the Future*⁶ (chapter 3) rotas should include sufficient registered sick children’s nurses with qualifications in intensive care to be at the bedside, or provide supervision and oversight, according to the level of dependency of the children. Some nursing staff should also have experience of, and training in, congenital heart disease.
- 6.18 Each unit should provide High Dependency Care to a standard in line with

⁶ This document can be found at www.doh.gov.uk/pub/docs/doh/bridge.pdf

published guidelines⁷. This may be based in the Cardiac Ward, or linked to the PIC unit, and should be capable of providing 1:2 nurse to patient supervision.

JOINED UP CARE

Going Home

Standard

7. Patients/parents should continue to receive the support and quality of care that will enable them/their child to achieve as complete a recovery as possible, after or between, interventions.

Interventions

- 7.1 An appropriate, integrated and needs-led discharge plan and shared care programme should be agreed with the patient/parents and the community team before discharge. Copies of the plan including 24-hour contact numbers should be given to the community team (including, where relevant, the palliative care team)⁸ and the patient/parents.
- 7.2 A notification of discharge should be sent to the community team no later than 24 hours prior to discharge. This should also be followed up with a telephone call, or in complex cases, through face to face contact with the GP, health visitor or other relevant professional.
- 7.3 Following discharge, there should be a follow-up telephone call by the liaison service to the patient/parents within 2 working days and ongoing contact at agreed intervals, as noted in the patient held record.
- 7.4 Patients/parents should hold their own records in order to ensure that adequate information is available at each stage of the clinical network. These records should be updated at each stage of the process and taken away by the parent/patient. We found the patient-held records used in Liverpool to be a good example.
- 7.5 Patients/parents should have full access to locally provided, high quality community nursing care. These teams should have access to appropriate cardiac care expertise within the clinical network.
- 7.6 Patients/parents should receive full training and support to enable them to care for themselves/their child at home.
- 7.7 There should be an agreed referral process back to the centre for patients/parents requiring specialist advice or support. For urgent cases this should be on an immediate access basis.
- 7.8 A system of follow-up appointments at outpatient and peripheral clinics should be in place. Failure to attend an appointment without explanation should be followed up with the family.
- 7.9 The congenital cardiac service should take responsibility for developing a clinical network that delivers integrated care to the patient in hospital

⁷ This document can be found at www.doh.gov.uk/nsf/paediatr.htm

⁸ The children's palliative care team offer support to patients (and their parents) with life threatening/limiting conditions.

(including the DGH) at home or in primary care settings. GPs, local paediatricians, Primary Care Trusts and cardiologists have a key role to play in establishing, maintaining and developing the network.

- 7.10 The tertiary centre should take responsibility for the quality of cardiac care that is provided across the clinical network. It should provide training/support to key staff across the network and be willing to intervene on behalf of the patient if local services are unable or unwilling to provide the necessary care or support.
- 7.11 Each tertiary centre should maintain a cardiac liaison service to support patients and parents throughout the patient journey.
- 7.12 The cardiac liaison service should be resourced and maintained so as to cover the whole clinical network.
- 7.13 The main responsibilities of the cardiac liaison service should be:
- supporting patients/parents by providing and interpreting diagnostic and related information
 - ensuring close liaison with primary care, education, social care and community services
 - being a specialist information and training resource to primary care and community services
 - negotiating, implementing and evaluating agreed care plans
 - being present during consultations, so as to offer further information, interpretation and support
 - supporting patients/parents in their dealings with other health, social care, and education services

A more detailed list of functions is at Annex F.

- 7.14 Precise staffing of the cardiac liaison service will vary with the size of the unit and its network; but the rule of thumb for a unit meeting the standards set out in this Report should be at least 7 whole time equivalents, of whom a majority are likely to be nurses.
- 7.15 A locally-based key worker should be identified for every patient, and family where appropriate. This role might be fulfilled by one of the community-based members of the cardiac liaison team; or a member of the primary health care team; or by the DGH paediatrician or cardiologist. The patient's home PCT will have a role in determining the best way of delivering this function.

Outreach services and the clinical network

Standard

8. Specialist centres should work with local paediatric or cardiology services so that as much cardiac diagnosis and care as possible is provided in a network of locally accessible outreach services. The patient and family should be asked to travel to the specialist centre only when essential.

Interventions

8.1 Each specialist centre should provide outreach clinics in a planned network of designated paediatric and cardiology units within a defined geographical area.

A cardiologist from the specialist centre and the local clinical lead should jointly participate in outreach clinics.

- 8.2 Specialist centres should collaborate to ensure that patients in all areas have equitable access to local cardiology outreach services.
- 8.3 The local outreach services and specialist centres should work to agreed joint clinical protocols.
- 8.4 The specialist centre should provide training and developmental support to the cardiac services in the designated paediatric units.
- 8.5 Each designated paediatric unit should provide basic electrocardiography services for children, including ambulatory and event recording.
- 8.6 Services, including echocardiography, in outreach clinics should be of the same high standard as at the tertiary centre including in the provision of information and cardiac liaison support.
- 8.7 The specialist unit and designated paediatric units should ensure that information provided to children and parents is the same as that available at the specialist centre.

GROWING UP

Age-appropriate care

Standard

9. Patients should receive appropriate care at each stage in their personal development and any changes in location or specialist, because eg. of move to an adult service, should be smoothly managed with the patient's/parents' full understanding and agreement.

Interventions

- 9.1 An integrated and needs led management plan should be agreed for each patient. The management plan should be reviewed at each consultation to ensure that it continues to be relevant to their particular stage of development.
- 9.2 The management plan should recognise the educational needs of older children (eg. outpatients appointment should be scheduled to avoid exam periods).
- 9.3 When a child begins school (or moves to a new school) the cardiac liaison service should be available to provide information to or to visit the school in person at the parent's request, in order to help the teachers and other staff understand the child's condition.
- 9.4 Consultants and parents should make the patient aware and responsible for their condition from an appropriate age. In cases where the parents seem reluctant to let go, the consultant/cardiac liaison service should take particular care to involve the young person in decisions about their treatment.
- 9.5 The paediatric cardiac service should provide information to the young person on relevant life-style issues (eg. body piercing, sex, pregnancy, drug-taking,

career, exercise etc.) at an appropriate stage. Parents should be involved in decisions over the timing of this information.

- 9.6 Young people should have the opportunity to be seen by the consultant for part of the consultation without a parent being present.
- 9.7 The move to adult services should occur at an age agreed with the patient and parents and considered appropriate for the individual patient taking into account their maturity based on mental, emotional and physical factors. The consultant and patient (and parents if still attending the consultation) should agree how the transfer to the adult service should take place and who will be taking over responsibility for their care.
- 9.8 Although transition, in terms of full transfer of care, may be a staged process, there should, as a general rule, be no circumstances in which patients under 16 years old are cared for on an adult ward; nor patients over 18 years old cared for on a children's ward. There should be separate inpatient facilities for young people, including those over 18 with developmental delay.

Services for Adults with Congenital Heart Disease (ACHD)⁹

Standard

10. Young people and adults with congenital heart disease should receive appropriate services depending on the complexity of their condition. It is recognised that these patients fall into two categories: patients with simple lesions and follow-ups; and complex cases, which require care from a dedicated team of more specialist medical services.

Interventions

- 10.1 As a general principle, and to the extent that they are relevant, the standards set out in this paper should also apply to the ACHD service.
- 10.2 For simple cases there should be sufficient units available to ensure that the service is reasonably accessible to all the patients in this category.
- 10.3 For complex cases a smaller number of units is required. These should be in university/teaching centres with both the specialist medical services required and the full range of other specialist services. Routine support for these patients can be provided in units capable of dealing with simple cases but only if their facilities are adequate. Patients accept the fact that complex cases can only be properly treated in a small number of specialist units and that it is necessary to travel to receive proper care.

⁹ Throughout this report, we refer to the two main groups of patients as "children with congenital heart disease" (referring to patients under 16 years of age) and "adults with congenital heart disease", referring to patients 16 yrs and over. We acknowledge and understand other preferred names: "heart children" from the Children's Heart Federation and main parents' groups; "GUCH" (Grown Up Congenital Heart) from the GUCH Patients' Association; and the preference of most clinicians on the group to keep the terms paediatric and adult. We wish to strike a balance between the precision required for meaningful statistics and audit; and the need to consider patients as individuals first.

- 10.4 Surgical statistics of adults with CHD operated on should be kept and audited; and submitted to the Central Cardiac Audit Database (CCAD).

SUPPORT TO PARENTS AND FAMILIES

Facilities for Parents and Families

Standard

11. There should be adequate facilities and accommodation available for parents when a child is admitted to hospital.

Interventions

- 11.1 Parents should be able to remain by their child's bedside as long as their child is admitted. Appropriate accommodation for families (including facilities that will accept siblings) should be available within a reasonable distance of the cardiac ward/paediatric intensive care unit.
- 11.2 Whilst a child is admitted to hospital parents should have on-site access to facilities such as a shower, a kitchen, a lounge/quiet room, somewhere to eat, adequate parking facilities etc.
- 11.3 Special attention should be given to the needs of families accompanying a patient admitted in an emergency, eg. free parking or meal vouchers, private telephones etc.

Bereavement support

Standard

12. Parents/next of kin should be supported after the death of a patient and given information that will help them to understand why the death occurred.

Interventions

- 12.1 Patients should, wherever possible, be allowed to die in a place of their, or their parents' choice.
- 12.2 Bereavement support should be offered to the parents/siblings of a child who is dying. This should continue after the death of the child.
- 12.3 Parents/next of kin should be offered help in dealing with the practical arrangements following the death of the patient/ their child (eg. registering the death, arranging the funeral etc).
- 12.4 Where a death was not expected (eg. surgery was unsuccessful) parents/next of kin should routinely be offered the opportunity to talk to the surgeon, cardiologist, intensivist or other relevant professional.

Chapter 4 – Future Demand for the Service

1. Demographic factors will have a significant impact on demand for the congenital cardiac service over the next ten to fifteen years. The Review Group commissioned work from the Department of Health's Economics and Operational Research Group to quantify this, and to set out the implications for future staffing.

Children Born With Congenital Heart Disease

2. Experts forecast no increase in the number of new cases of congenital heart disease per thousand births per year (epidemiological data from the Scottish, Swedish and Dutch studies¹⁰ support this). The Government Actuary's forecast for the number of live births shows a small increase in the birth rate over the next 10 – 15 years. This means that the overall incidence of congenital heart disease is set to rise slightly. The position is shown in table 1 below.

Table 1: Growth in the Number of Children Born with Congenital Heart Disease¹¹

	2002	2006	2010	2014	2018
Births	572,140	571,402	577,431	590,395	602,436
Heart Disease Patients	4,577	4,571	4619	4,723	4,819

3. Medical progress as a whole means that there are more patients for whom a medical or surgical intervention will be appropriate. Advances in fetal cardiology also mean that more conditions are detectable before birth, which gives parents the choice of whether or not to proceed with the pregnancy and also the opportunity for optimal planning of neonatal interventions.
4. We have assumed that these opposing tendencies are likely to cancel each other out and that the workload from children born with congenital heart disease will remain relatively stable, although increasing very slightly, over the foreseeable future.
5. The prevalence of congenital heart disease, that is, the total number of people living with the disease, will continue to rise, as treatments continue to become more successful. The workload in terms of continuing care for this increasing caseload of patients is, therefore, a growing one.

Adults with Congenital Heart Disease

¹⁰ *Review of Paediatric Cardiac Services in Scotland* (January 1999)
Centralization of Pediatric Heart Surgery in Sweden *Pediatric Cardiology*, (2000) Vol 21 No 4
Heart Surgery and Interventional Cardiology for Children (November 1993) Report of a Committee of the Health Council of the Netherlands

¹¹ Estimates assume that per thousand births there will be eight children born with congenital heart disease

6. There will, by the same token, be significant growth in the number of adults with congenital heart disease. As the range of treatments becomes more successful, more patients are surviving through childhood and into adulthood.

We estimate that by 2010 there will be a 25% increase in the number of adults with congenital heart disease. The position is shown in table 2 below.

Table 2: Growth in Adults with Congenital Heart Disease¹²

	Simple	Complex	Total
2000	122,391	10,323	132,714
2010	150,255	15,483	165,738
% Increase	23%	50%	25%

8. Although much surgical correction takes place in childhood, a proportion of these adults will require further surgery. The analysts looked at staffing levels in services that currently provide an adult congenital service, related to their caseload, and extrapolated to reach a national figure. They estimate that there will therefore need to be an increase in consultant surgeon capacity of between 22% and 30% to meet this need. This translates into a nationwide increase of between 2 and 3 consultant cardiac surgeons, based on whole time equivalents.
9. This required expansion should be achievable within existing plans; but the Group recommends that its estimates are offered to the Department of Health's Care Group Workforce Teams (Coronary Heart Disease and Children) to ensure that they are fed into national workforce planning assumptions.
10. The growth in prevalence, however, means a greater number of "live" cases, who all require follow-up, and some of whom require more frequent active medical intervention. To meet this rising need, there will need to be an increase of around 25% in the number of consultant congenital cardiologists by 2010 in order to meet demand. This will mean approximately 20 more cardiologists. Again, the Group recommends that this analysis be put at the disposal of the appropriate Care Group Workforce Teams.

¹² The number of adult congenital heart disease cases has been estimated using the approach adopted by the British Cardiac Society Working Party on Grown Up Congenital Heart disease.

Chapter 5 – Implications for Service Development

1. One of the findings of the Review is that all of the 14 paediatric and congenital cardiac units in England, Wales and Northern Ireland provide a good quality service. The results of the 2001 audit of mortality indicate that no unit currently has a mortality rate following surgery that is statistically significantly higher than other units. No service re-organisation is therefore required on immediate safety grounds.
2. However, we acknowledge that the various centres are not equally good on other aspects of quality. This was confirmed by the visiting team. We would hope, therefore, that these standards would provide a firm basis for continuing to improve the quality of the service. Although our suggested standards will have significant implications for the fourteen centres, certain of these standards can be seen as key.

Paediatric Intensive Care

3. The Review process has highlighted a number of issues concerning paediatric intensive care. At some of the centres it was noted that there was:
 - a lack of senior paediatric intensive care cover;
 - a lack of qualified paediatric intensive care nurses; and
 - an apparent lack of integration of the specialist cardiac intensive care unit with the main paediatric intensive care unit.
4. It is expected that all intensive care facilities offering care to children should meet the standards set out in the document "Framework for the Future" (DoH 1997).
5. We suggest that in addition there should be:
 - paediatric intensivist cover available twenty-four hours a day;
 - evidence of integration of specialist and mainstream paediatric intensive care units as demonstrated by: staff rotation, development of shared clinical protocols, shared guidelines on audit and professional development; and
 - further skills development of paediatric and adult intensive care nurses in caring for children with cardiac conditions.
6. This could be achieved across the service with some reorganisation in a number of units.

Number of Surgeons Per Centre

7. We have suggested that each centre should have a minimum of three paediatric cardiac surgeons. Table 3 below indicates that this is the case in only two centres:

Table 3: Number of Surgeons Per Centre at 30 June 2001

Unit	Number of Consultant Surgeons
Belfast	2
Birmingham	2
Bristol	2
Cardiff	N/A
Great Ormond Street	4*
Guy's and St Thomas'	2
Leeds	2
Leicester	2
Liverpool	1
Manchester	N/A
Oxford	2
Newcastle	2
Royal Brompton	3*
Southampton	2

* Includes one academic consultant

8. This does not necessarily imply a large overall increase in the number of paediatric cardiac surgeons nationwide. There would be scope for services to collaborate in new ways/merge in order to meet this standard.

Number of Cardiologists Per Centre

9. We have suggested that there should be a consultant paediatric cardiologist per half million of the population served. As of July 2001 there were 67 consultant paediatric cardiologists in post. This would imply an increase of about 30 cardiologists. (This would be in addition to the 20 cardiologists required to meet the increased adult congenital workload discussed in chapter 4.) The issue of how we can develop this additional capacity is addressed in chapter 6.

Minimum Number of Procedures per Centre

10. Table 4 below shows the current number of surgical procedures in each centre:

Table 4: Average Number of Paediatric Cardiac Operations Per Centre Per Year Over the Period 1998/99, 1999/2000, 2000/01¹³

<i>Unit</i>	<i>Total Open</i>	<i>Total Closed</i>	<i>All Operations</i>
Great Ormond Street	386	132	517
Brompton	301	117	419
Birmingham	383	85	468
Liverpool	231	131	362
Guy's and St Thomas'	205	62	268
Leeds	180	56	236
Bristol	143	70	213
Southampton	148	59	208
Leicester	101	73	174
Newcastle	93	62	155
Oxford	71	45	115
Belfast	61	22	84
Cardiff*			
Manchester*			

* Cardiff and Manchester do not currently undertake surgery.

Observations and Suggestions

11. No one clear way has emerged to ensure the organisation of such complex services in all parts of the country. We put forward the following to stimulate debate. We have based our suggestions on the four geographical zones into which the centres that currently provide a paediatric and congenital cardiac service naturally fall. These are:

The North – Liverpool, Leeds, Newcastle and Manchester;

The Midlands – Birmingham and Leicester;

London - Great Ormond Street, Guy's and St Thomas' and the Royal Brompton; and

The South and South West – Bristol, Southampton and Oxford.

The North – Liverpool, Leeds, Newcastle and Manchester

12. Three centres perform cardiac surgery in the North of England – Liverpool, Leeds and Newcastle. Liverpool also serves the northern parts of Wales. Newcastle is an ECMO centre and is one of two centres that provides a children's cardiac transplant service, for which it also takes patients from Northern Ireland. Additionally, Manchester provides cardiology services but does not undertake surgery.

¹³ The figures in the table have been averaged over three years. Due to rounding some rows do not sum

13. On the basis of current surgical workload and likely future demand, it seems unlikely that all three centres would be able to meet the proposed standards. One option would be to reduce the number of surgical centres to 2, with cardiological services continuing to be provided by all 4. In terms of access there may be a case for one service in the North West and one in the North East.

The Midlands – Birmingham and Leicester

14. Two centres serve the Midlands – Birmingham and Leicester. A key consideration for the service at Leicester is that it has the largest ECMO centre in the country and undertakes 50% of the national workload. ECMO is dependent on the presence of paediatric cardiac services.
15. Birmingham, on the other hand, undertakes a significantly higher number of surgical procedures. In view of their close geographical proximity, there is already a case for some form of collaboration between Birmingham and Leicester or even concentration of services on one site.

London – Great Ormond Street, Guys and St Thomas' and the Royal Brompton

16. London is a good example of an area where existing centres could collaborate. Based on current surgical workload volumes, the three centres should have sufficient caseload collectively for them all to meet our suggested standard relating to the minimum number of procedures. In the longer term, the proposal to introduce more logical referral patterns in London and the South East (see para 19) may mean there is scope for further collaboration.
17. Some of the factors that will be relevant to any discussions about possible collaboration in London are:
- Great Ormond Street is an ECMO centre and provides Children's Transplant Services
 - The Royal Brompton has a plan for children's services to move to the Paddington basin site (within the next 5-6 years). This would be shared with St Mary's. At present, the Royal Brompton is unable to provide the full range of paediatric specialities on site.
 - Guy's and St Thomas's plan to concentrate all children's services in the new Children's Hospital at the St Thomas' site (planned to open in 2004).

South and South West – Bristol, Southampton and Oxford

18. The centre at Bristol provides much of the cardiac surgery for the South West and already has a partnership arrangement with the cardiology centre at Cardiff to provide surgical services for patients from South Wales. Southampton similarly covers much of the South of England. Oxford covers part of central southern England and the South Midlands and already has collaborative working arrangements with Great Ormond Street and Southampton.
19. On the basis of current surgical workload and likely future demand, all three centres would be unlikely to be able to undertake the minimum number of procedures we suggest, with Oxford's workload volumes being much lower than those of the other two centres. There is scope to amend the referral

patterns in the South of England to at least enable the centres at Bristol and Southampton to attract an adequate number of patients to allow for the level of procedures we would like to see .

20. Parents and paediatricians from Oxford have said that they would prefer to be referred to London if the service at Oxford were no longer to provide surgery. In the normal course of events we would expect patients to go to their nearest centre, which may be Birmingham and which in many cases parents will no doubt find more convenient, but referral practices should also respect parents' preferences.

Referral Patterns

- 21 We suggest that under the leadership of the Director of Health and Social Care for London, centres and commissioners, together with centres in other regions, should consider action to establish more logical referral patterns for London and the South East, including the development of managed clinical networks for defined geographical areas. Patient and parent representatives should be included in these discussions. Clearly all centres will specialise in certain procedures and there will continue to be some patients that need to be referred out of their area if specialist input from another centre is required. However, it is unlikely to be appropriate for London centres to run out-patient clinics, for example, in Wales, when other centres could provide an equally high quality but more convenient service for parents and patients and which would enable the high quality services in Bristol and Southampton to meet our proposed standards.

Recommendation

22. Planning and managing service development is key to the future of paediatric and congenital services. We suggest therefore that the 4 national Directors of Health and Social Care should take the lead in such work in their areas. Building on the work and evidence collected by this Review, we recommend that they should ensure that centres work together with staff, patient/parent groups and commissioners (and colleagues in Wales and Northern Ireland where appropriate) to agree a development plan for the overall service. The development plan should include an implementation timetable, revenue and capital costings as well as supporting option appraisals.
23. It was not part of the remit of this Review to look at the impact on other children's services in individual centres of any final decisions to expand or change the paediatric and congenital cardiac service in individual centres. Such an assessment should form part of the option appraisal for each centre.

Chapter 6 – Actions to Support Implementation

Introduction

1. If, after wider consultation, the proposed standards in this report were to be adopted, a number of actions would need to be taken to support their implementation. These fall into two main categories: actions to help develop the capacity of the paediatric and congenital cardiac service (paragraphs 2 – 16) and aspects of the service where specific improvement is required (17-33). This chapter therefore proposes next steps.

Training of Paediatric and Congenital Cardiologists

2. As at July 2001 there were 67 paediatric cardiologists in post. Because of the growth in the adult congenital caseload (see chapter 4), it is estimated that by 2010 there will need to be an increase of approximately 20 paediatric cardiologists. In addition, to achieve 1 paediatric cardiologist per half a million of the population would mean a further 30 cardiologists.
3. There are already initiatives in place to improve the recruitment and retention of cardiologists. By 2010 it has been estimated that these will have led to a 25% increase in the number of cardiologists. However, this would still leave a significant shortfall.
4. Some of the reasons why trainees may choose not to enter paediatric cardiology are:
 - the negative publicity surrounding the Bristol Royal Infirmary and other inquiries;
 - the fact that paediatric cardiology is a particularly stressful speciality;
 - fewer opportunities for private practice in paediatrics than in adult work; and
 - poor facilities compared to what can be available overseas.
5. In order to ensure that there are sufficient paediatric cardiologists for the future, we suggest that a national training programme, taking on 5 trainees per year, be established. It would seem appropriate to ask the Department of Health's Care Group Workforce Team (Children) to take this forward. A plan should be in place by 2003.
6. Issues of recruitment and retention should also be considered in any service development plans that are drawn up.

Training of Paediatric and Congenital Cardiac Surgeons

7. In July 2001 there were 24 paediatric cardiac surgeons in post. In view of the expected increase in the adult congenital workload, discussed at chapter 4, we anticipate a need for a further 2 or 3 surgeons by 2010.
8. Obtaining the required increase in surgeons should be relatively easy to manage. However, it should be recognised that the reasons why trainees may not choose to become paediatric cardiologists (discussed in paragraph 4) apply equally to paediatric cardiac surgeons. It is recommended, therefore, that any decisions about service development should also consider the ability of centres nationally to sustain a reasonable training programme.

Maintenance of Small Specialities

9. There is already an acknowledged national shortage of paediatric pathologists. This restricts the number of hospital post-mortems that can be carried out and thus the lessons that can be learned from the death of a child. At the same time, small specialities such as paediatric cardiac morphology, electrophysiology, and perfusionists are also under pressure.
10. We recommend that within its remit the Department of Health's Care Workforce Group (Children) should address the issue of maintaining these small specialities. This should also be a factor for consideration in local discussions about future development of the service.

Maintenance of the Research Agenda

11. All of the 14 centres in England, Wales and Northern Ireland have a programme of research. Maintenance of adequate research capacity is essential to promote continued innovation in the paediatric and congenital cardiac field and to ongoing improvements in-patient care. Any changes to the service should have regard to the need to build in this capacity. Our suggestion for 3 surgeons per centre would help with the maintenance of research programmes.

Development of the Cardiac Liaison Service

12. The cardiac liaison service is fundamental to the development of a high quality paediatric and congenital cardiac service. The current cardiac liaison service is universally appreciated by parents and patients. Where criticisms were made of this service it was generally along the lines of too few staff, or their being overstretched.
13. Cardiac liaison staff have a key role to play in supporting parents and patients at numerous points along the patient journey. (Our suggested role for the cardiac liaison service is outlined at annex F). One specific area for development is the support that parents and patients receive in the community, especially with a view to ensuring that patients and parents receive high quality care after discharge from the tertiary centre.
14. There are currently 22 cardiac liaison nurses in England. The Review Group proposes that in order to perform the range of duties set out at annex F, centres would require, on average, a team of 7 cardiac liaison staff. (This is based on an assessment of the amount of time that cardiac liaison nurses currently spend on specific tasks and extrapolating from this the amount of time that would be required to meet the range of duties outlined at annex F.) This would mean an increase of 50 staff (based on whole time equivalents) across the service as a whole.
15. The cardiac liaison staff that are currently in post are highly qualified, typically nurses at G or H grade with many years' experience of cardiology. We recognise that expanding the cardiac liaison services by 50 posts could deprive paediatric cardiology and other services of much needed experience. Whilst many of these additional posts will be filled by nurses, there should be a multi-disciplinary approach to the expansion of the service, that recognises the input of other professionals. Thus, the cardiac liaison service should include social workers, case managers, bereavement counsellors and psychologists. Similarly there is scope for more junior nurses, at grade E or

thereabouts, to work in the cardiac liaison service, as part of their rotational training, under the team leadership of a senior cardiac liaison nurse.

16. In future, we envisage that cardiac liaison nurses should have a clearer leadership role within the team. A lead cardiac liaison nurse should, therefore, be a qualified children's nurse with considerable experience or qualification in cardiac nursing and experience/qualification in community care. Within cardiac liaison nursing it is recommended that competence based courses are developed which have transferable academic and professional value across the UK. The Review Group recommends that there be agreed course content and standards for all qualifications to assist with this aim and funding of sufficient course places. Again, the Department of Health's Care Group Workforce Team (Children) should be asked to take this forward.

The Community Service

17. As discussed earlier in the Report (chapter 2 paragraphs 33 to 42) local health services need to be able to provide care for patients' conditions both related and unrelated to their underlying heart condition. Both patients and parents expressed most dissatisfaction with this aspect of the service.
18. We recommend that future plans for service changes and developments should be for whole networks. This would mean empowering and funding the tertiary centre to develop clinical networks that can provide the whole spectrum of care. The tertiary centre should provide training and support to local paediatricians, GPs, health visitors and other key professionals to ensure that good levels of care are available locally. We propose that all centres should conduct an audit of their existing clinical network, as part of the general review of services, to identify areas where improved planning and support is required.
19. As mentioned earlier, the clinical network should be supported by an expanded cardiac liaison service. This will help ensure that good links are formed with professionals both in the community and in other sectors such as social care and education. We recommend that the additional cardiac staffing proposed at paragraph 14 above should be in post by 2006 and that developing the community based aspects of the service should be a priority for how they are used.
20. Patients and parents also expressed concern that the service provided in a peripheral clinic is less comprehensive than they would receive at the tertiary centre. As a core principle we propose that care in a peripheral clinic should be of the same standard, including in the provision of information and cardiac liaison support, as would be provided at the specialist centre. We recommend that every centre should review their peripheral clinics as part of the general review of services with a view to ensuring that all meet this requirement.

Discharge of Children with Neurological Damage

21. The inquiry into services at the Royal Brompton and Harefield Hospitals commented that the Department of Health should ensure that:
“...families of children who are neurologically damaged in the course of medical treatment have the benefit of dedicated liaison services allowing them to access support services easily when the need arises”
(recommendation 74).

22. We endorse this recommendation and propose that when a child with neurological damage is discharged from hospital, the cardiac liaison service, along with other professionals in the multi-disciplinary team, should develop a comprehensive care plan to support the patient and their family in the community. As well as medical and nursing care the plan should also include educational and social services support. The plan should identify a key worker who will be responsible for liaising on behalf of the family and ensuring that they have access to the full range of support available.

Patient- Held Records

23. Patient-held records provide a ready means of explaining a patient's full cardiac history to any healthcare professional involved in their care. It also addresses the potential problem of delays at the specialist centre in issuing discharge letters and other communications across the NHS and related services.
24. Pending the full introduction of a system of electronic records, that can be accessed by all healthcare professionals involved in the care of a patient, the Review Group proposes that each centre should develop a system of patient held records. These should be genuine records that are updated by the clinician at each outpatient visit or other intervention and include an explanation of the patient's heart condition and its implications that can be understood by a non-specialist. They should provide a meaningful record to patients and parents, enabling them to participate fully in discussions about the treatment plan. For hospitals that record patient notes electronically, the patient held record should include an up-to-date printout of the electronic record. Centres that do not already have a system of patient-held records in place that meets the above criteria might wish to consider that used at Alder Hey as an example of good practice. This should be implemented without delay.

Audit Arrangements

25. Key to the maintenance of high standards is the systematic monitoring and auditing of outcomes data. Given that the paediatric and congenital cardiac service is a relatively small speciality, we recommend that this should be run on a national basis. The Central Cardiac Audit Database (CCAD), which already collects data on mortality, seems ideally placed and skilled to take on this role. We recommend that the Department of Health should continue to provide funding to cover the costs of the CCAD for the foreseeable future. We also recommend that the Department should meet the cost of dedicated audit staff and systems in the tertiary centres for a two-year transitional period until the new arrangements have bedded down. As for other trust audits, funding should then be provided by participating units in the normal way.
26. In the first instance the audit should focus on mortality data, which should be adjusted for risk and complexity, using the most up-to-date measures available. Information should be fed back to all the centres on a regular basis and examined in the centres' audit meetings. Over time the audit should be extended to include morbidity, long-term follow-up of social functioning and educational attainment.
27. In addition to normal trust procedures, and the requirement to report to the National Patient Safety Agency, clinicians should ensure that details of critical incidents are circulated immediately to colleagues in other centres.

28. The new national audit database system should be supported by a stakeholders' council including parents, patients and professionals, as well as the UK Health Departments. It should be responsible for monitoring the audit programme and reporting annually on progress.

Next Steps

29. To ensure that we have got all our proposals right, we suggest that there should be a three-month consultation period following the publication of the Review Group's report. This would provide the opportunity for a wider range of professional groups, patients, NHS managers and the public to comment on the feasibility of our proposals and to express views on our suggestions for the development of the service outlined in chapter 5.
30. In the light of final decisions on the Review, we suggest that the four national Directors of Health & Social Care, in collaboration with local representatives (staff in centres, commissioners, parent and patient groups), should agree plans for the development of the service in those areas for which they are mostly responsible (i.e. the geographical zones described in chapter 5 do not directly map onto the areas covered by the national directors).
31. We further suggest that a peer group of all centres (similar to the group that produced this report) should convene again in 5 years' time to:
 - review the evidence-base, particularly around links between outcome and the number of procedures, including in relation to outcomes for adult congenital heart disease; and
 - act as a reference group to a full review of the national paediatric and congenital cardiac service by the planned Commission for Healthcare, Audit and Inspection.
32. We would like to see the Department of Health and the Society of Cardiothoracic Surgeons and the British Paediatric Cardiac Association overseeing this work.
33. Finally, we suggest that the new Commission for Healthcare Audit and Inspection should be asked to review the whole national service within 5 years. The review should look at the safety and effectiveness of the service as a whole. In particular it should assess progress in implementing the final decisions emerging on this report, and look at the robustness of audit procedures that have been put in place.

Paediatric and Congenital Cardiac Services Review Group –
October 2002

Annex A – Terms of Reference

Paediatric & Congenital Cardiac Services Review Terms of Reference

20th March 2001

1. Reporting through the Children's Taskforce the Review will:
 - 1.1 Assess the likely need for services, taking account of the relevant epidemiology and the possible effects of antenatal screening, looking ten to twenty years ahead
 - 1.2 Review current service provision, activity and outcomes in the context of current evidence of effectiveness
 - 1.3 Consider likely changes needed to the current organisation and delivery of paediatric and congenital cardiology and cardiac surgery services in England and Northern Ireland, involving Wales and Scotland in the review process
 - 1.4 Make recommendations to Department of Health Ministers to ensure high quality, patient-focused effective, efficient, accessible and safe services for children, adolescents and adults with congenital heart disease and their families as part of the NHS Modernisation Programme
2. In doing this the Review will need to:
 - 2.1 Take into account the published findings of the Inquiries at Brompton/Harefield Hospitals and the Bristol Royal Infirmary when they are available, and the Alder Hey Hospital and the Framework for the Future reports
 - 2.2 Take into account the views of patients and their parents and carers
 - 2.3 Recommend criteria and standards, based on best available evidence, which should govern service delivery
 - 2.4 Apply the criteria to advise on optimum service configurations to achieve or maintain these standards
 - 2.5 Take account of the impact that changes in configurations might have on other services, especially intensive care, general primary and secondary services for children and other specialist children's services
 - 2.6 Consider the likely human and other resources required for future services

- 2.7 Propose advice for commissioners on what should be included in a national specification to cover these services
3. The Review will report by January 2002 (subsequently amended with agreement from Ministers to October)

Annex B – Review Group Members

Paediatric and Congenital Cardiac Services Review Group (PCCSR) Members

Role	Name	Location
Cardiologist	Nick Archer	Oxford Radcliffe Hospitals
Cardiac Morphologist	Robert Anderson	Institute of Child Health
Cardiologist	Edward Baker	Guy's Hospital
Manager for Children's Services	Ian Barrington	United Bristol Healthcare NHS Trust
Trust CE	Tony Bell	Royal Liverpool Children's NHS Trust
Anaesthetist	Rob Bingham	Great Ormond Street
Surgeon	Bill Brawn	Birmingham Children's Hospital
Paediatric Cardiologist	Dr Brian Craig	Royal Group of Hospitals & Dental Hospital HSS Trust
User	Michael Cumper	Grown Ups with Congenital Heart Disease
Specialist nurse	Lesley Ferguson	Guy's Hospital
Cardiologist	John Gibbs	Leeds General Infirmary
Surgeon	Leslie Hamilton	Freeman Hospital, Newcastle
Joint Chair	David Hewlett	Department of Health
Senior commissioner	John James	Kensington & Chelsea & Westminster Health Authority
Primary Care Trust CE	Lise Llewellyn	South Peterborough Primary Care Trust
Paediatrician	Andrew Long	Farnborough Hospital
Joint Chair - Surgeon	James Monro	Southampton General Hospital
Paediatric Cardiac Surgeon	Ash Pawade	Bristol Royal Hospital for Children
Intensivist	Charles Ralston	Birmingham Children's Hospital
Trust CE	Peter Reading	University Hospitals of Leicester NHS Trust
Cardiologist	Philip Rees	Great Ormond Street
Director of Children's Services	Len Richards	Manchester Children's University Hospitals NHS Trust
Clinical Director of Paediatrics	Babulal Sethia	Royal Brompton & Harefield NHS Trust
Parent	Maria Shortis	Constructive Dialogue for Clinical Accountability
Parent	John Spall	Children's Heart Federation
Cardiac liaison nurse	Paddy Walsh	Freeman Hospital, Newcastle

Officials		
National Clinical Director for Children and Chair of the Children's Taskforce	Professor Albert Aynsley-Green	Department of Health
National Director for Heart Disease	Roger Boyle	Department of Health
CHD Team	Helen Bellairs	Department of Health
Scotland	Kathy Collins	National Services Division
Statistics	Anne Emery	Department of Health
Commissioning Team	Helen Forgacs	Department of Health
Children's Taskforce	Barbara Herts	Department of Health
Economic & Operations Research	David Hughes	Department of Health
Northern Ireland	Miriam McCarthy	DHSS-PS NI
Statistics	Greg Phillpotts	Department of Health
Team Leader - Child Health	Jane Scott	Department of Health
Wales	Gillian Todd	Specialist Health Services Commission for Wales
Head of Children's Services	Kathryn Tyson	Department of Health
Secretariat	Michele Armstrong	Department of Health
Secretariat	Paul Hughes	Department of Health

Annex C - The Kennedy Report's recommendations on healthcare services and treatment for children with congenital heart disease

Recommendation 192

National standards should be developed, as a matter of priority, for all aspects of the care and treatment of children with congenital heart disease (CHD). The standards should address diagnosis, surgical and other treatments, and continuing care. They should include standards for primary and social care, as well as for hospital care. The standards should also address the needs of those with CHD who grow into adulthood.

Recommendation 193

With regard to paediatric cardiac surgery, the standards should stipulate the minimum number of procedures which must be performed in a hospital over a given period of time in order to have the best opportunity of achieving good outcomes for children. PCS must not be undertaken in hospitals which do not meet the minimum number of procedures. Considerations of ease of access to a hospital should not be taken into account in determining whether PCS should be undertaken at that hospital.

Recommendation 194

With regard to those surgeons who undertake paediatric cardiac surgery, although not stipulating the number of operating sessions sufficient to maintain competence, it may be that four sessions a week should be the minimum number required. Agreement on this should be reached as a matter of urgency after appropriate consultation.

Recommendation 195

With regard to the very particular circumstances of open-heart surgery on very young children (including neo-nates and infants), we stipulate that the following standard should apply unless, within six months of the publication of this Report, this standard is varied by the DoH having taken the advice of relevant experts: there must, in any unit providing open-heart surgery on very young children, be two surgeons trained in paediatric surgery who must each undertake between 40 and 50 open-heart operations a year.

Recommendation 196

The national standards should stipulate that children with CHD who undergo any form of interventional procedure must be cared for in a paediatric environment. This means that all healthcare professionals who care for these children must be trained and qualified in paediatric care. It also means that children must be cared for in a setting with facilities and equipment designed for children. There must also be access on the same site as where any surgery is performed to a paediatric intensive care unit, supported by trained intensivists.

Recommendation 197

Surgical services for children with very rare congenital heart conditions, such as Truncus Arteriosus, or involving procedures undertaken very rarely, should only be performed in a maximum of two units, validated as such on the advice of experts. Such arrangements should be subject to periodic review.

Recommendation 198

An investigation should be conducted as a matter of urgency to ensure that PCS is not currently being carried out where the low volume of patients or other factors make it unsafe to perform such surgery.

Annex D – Membership of the Visiting Team

Role	Name	Location
Notetaker	Michele Armstrong	Department of Health
Nurse Representative	William Booth	Clinical Nurse Manager, Bristol Royal Hospital for Children
Nurse Representative	Andy Darbyshire	Consultant Nurse, Alder Hey Hospital
Team Leader	Dr Mike Godman (Former Chairman of the British Paediatric Cardiac Association)	Association, Consultant Cardiologist, King Fahd Hospital
DH Representative	David Hewlett	Department of Health
DH Representative	Katrina McNamara	Department of Health
Notetaker	Sophie Rees	Department of Health
DH Representative	Jane Scott	Department of Health
Parent Representative	Maria Shortis	Constructive Dialogue for Clinical Accountability
Parent Representative	John Spall	Children's Heart Federation
DH Representative	Kathryn Tyson	Department of Health

Annex E – Standards for training and experience of anaesthetists

There is currently no evidence that variations in training or experience of anaesthetists has any bearing on outcomes in paediatric and congenital cardiac surgery. This is not surprising as there have been no studies specifically addressing this issue.

There is, however, agreement amongst those involved in this area (patients, parents, and health professionals) that anaesthetists involved in paediatric and congenital cardiac surgery should, like the surgeons and cardiologists, have minimum standards for training and experience.

Since there is no objective evidence, this document is based on consensus views of those with experience of paediatric and congenital cardiac surgery, including the patients and parents. In the preparation of these standards the Royal College of Anaesthetists consulted the following organisations:

Children's Heart Federation (CHF)

Association of Paediatric Anaesthetists (APA)

Association of Cardiothoracic Anaesthetists (ACTA)

Paediatric Intensive Care Society (PICS)

These standards are intended for those involved in anaesthesia for corrective surgery in paediatric and/or congenital cardiac disease. They are not intended to be applied in full to anaesthetists caring for individuals with congenital cardiac disease undergoing other types of surgery.

Training

All training should be undertaken in recognised training centres and should involve continuous supervision and assessment.

Anaesthetists intending to undertake anaesthesia for paediatric and congenital cardiac surgery should receive background training in both paediatric and cardiac anaesthesia unless they intend to solely practice in the adult congenital field. They should attain the following competencies *in addition* to those listed under paediatric and cardiac anaesthesia in the Royal College of Anaesthetists "CCST IN ANAESTHESIA: III Competency Based Specialist Registrar; Year 1 and 2".

Knowledge and understanding of:

- Paediatric and congenital cardiac physiology
- Paediatric and congenital cardiac investigation including the interpretation of cardiac catheterisation data and transthoracic and transoesophageal echocardiography
- The main techniques and aims of paediatric and congenital cardiac surgery
- The variation in basic techniques of anaesthesia necessary for different types of congenital cardiac physiology
- The techniques of anaesthesia for open and closed congenital cardiac surgery including the safe use of invasive monitoring
- The techniques of cardiopulmonary bypass employed in paediatric and congenital surgery
- The principles and practice of intensive care following paediatric and congenital surgery
- The basic indications and use of ECMO and VADs

Skills

- Pre-operative assessment in patients with congenital cardiac disease
- Induction and maintenance of anaesthesia in patients with different types of congenital cardiac disease; particularly balanced shunts, outflow tract obstruction and myocardial dysfunction
- Appropriate use of invasive monitoring and interpretation of data obtained
- Use of cardio-active drugs in congenital cardiac disease
- Safe and effective use of post-operative analgesia drugs and techniques

Attitudes and behaviour

- Ability to communicate sensitively and effectively with the patients and their families
- Ability to communicate effectively with surgical colleagues and other members of the operating theatre team
- Full participation in multi-disciplinary clinical audit
- Commitment to continued professional development

Ongoing Experience

As stated above, there is no evidence available to support a minimum level of experience necessary to maintain expertise in the above competencies. A consensus view, however, is that it would be unlikely that competence would be maintained with less than an average of one session a week in paediatric and/or congenital cardiac anaesthesia.

It is recognised that experience in allied areas of practice such as paediatric (cardiac) intensive care and anaesthesia for cardiac catheterisation would augment, but not supplant, experience in the cardiac operating theatre.

Annex F – The Role of the Cardiac Liaison Service

DIAGNOSIS Prenatal

All prospective parents whose baby has been given an antenatal diagnosis of cardiac disease should have access to information, support and counselling from the Cardiac Liaison Services (CLS) at the earliest opportunity. This support should be available between referral and foetal appointment and continue between diagnosis and birth. Support should also be available during “immediate surgery”. Written information detailing services and support available throughout the patient’s journey should be provided to families at this time.

DIAGNOSIS Post natal

The CLS should liaise with primary care on the family situation and be present at out patient/peripheral clinics to explain the diagnosis, provide literature, management of condition, act as a contact point if parents are concerned and give the option of receiving copies of the letters sent to GPs.

AWAITING TREATMENT

The CLS should be available to deal with issues raised/advice sought by children/young people and parents in managing the condition, the care plan, liaison with primary care, etc.

TREATMENT: Pre-admission

Cardiac Liaison Nurses (CLNs) or other members of the CLS should be able to see children/young people and parents either at home, in a pre admission clinic or on a planned visit to the unit. The CLS will be available to explain treatment, hospital routines, accommodation requirements, family, social and financial issues and to provide child-centred information and preparation for admission when required.

TREATMENT: On admission

The CLS should be available daily on the ward for those children/young people and families who require support.

Consent

The CLS should be available to parents throughout the consent process.

Operation /procedure

The CLS should be available to support the family, if requested.

Post operative

During the postoperative period the CLS should be available to provide support to the family if requested and help prepare the child/young person and their family for discharge.

DISCHARGE

The CLS should work in partnership with ward staff to negotiate and agree a discharge plan and parents should meet with the CLS before discharge and ensure their understanding of community arrangements. Parents should have copy of the discharge plan, information about prescribed medication and be aware of how to contact the unit. The CLS should work in partnership with community services and other professionals to ensure that community services and support are mobilised and that secondary and associated conditions are understood by all and care plans agreed for these. In complex/palliative care cases the keyworker (who may be the

Cardiac Liaison Nurse - CLN) should initiate a case conference with the primary care team and parents and work in partnership to provide care and support.

CONTINUING CARE

The CLS should contact all children/families within one week of discharge from the tertiary centre to evaluate the agreed discharge plan and check that it is meeting the needs of the child and the family. The need for a home visit or further follow up telephone support should be assessed at this time. CLNs should attend out patient and peripheral clinics to provide continuing support and ensure care plans are updated and understood by parents.

The CLN should act as a specialist information resource to other professionals in primary care, secondary care, social services, schools and voluntary services. When required the CLN should have ongoing liaison with these services to support them to meet the needs of the child and family.

Every child/young person/family should have a keyworker, who makes themselves well known to all professionals in the caring and support team. The name and contact details of the current keyworker should be known and readily accessible to the child/young person/family and all professionals.

The CLN may be the most appropriate person to undertake the role of keyworker but the child/young person/family should be able to choose the keyworker from the professionals involved wherever possible. As the child/young person/family's needs change they should be able to change their keyworker as appropriate.

TRANSITION TO ADULT SERVICE

It is recognised that CLNs have an important role to play in transitional care and they should discuss timing/implications of transition with parents and children/young people. Maintaining close links and working in partnership with adult congenital services will facilitate a smooth and "seamless" transfer by appropriate support e.g. by accompanying the patient on their first attendance at adult outpatients.

BEREAVEMENT

The CLS should be available to support children, young people, parents, siblings and families through the dying process. When death occurs they can ensure practical/emotional support is available and may assist parents with practicalities/options. The CLS should work in partnership with other bereavement services to ensure the availability of continuing bereavement support.

CONTINUING CARE

The CLS should follow up recently discharged children/young people and their families and carers to ensure satisfactory services are being provided and take the opportunity to deal with anxieties. Ongoing telephone contact with the patient's family should be maintained and visits should be arranged where circumstances require. CLNs should attend out patient/peripheral clinics to provide continuing support and ensure care plans are updated and understood by parents. Ongoing liaison with community services (e.g. primary and community care, social services, education) can ensure that the child's and family's needs are met. In some cases visits to community services/ family/school may be appropriate, with the parents' agreement, to facilitate the ongoing care of the child/young person.