

Clinical Advisory Panel review of proposed CHD standards

Introduction

The Clinical Advisory Panel (CAP) considered the proposed standards for CHD services at its meeting on 31 March 2014. Following discussion, and with a number of suggested amendments, CAP approved the standards for discussion with stakeholders prior to formal consultation.

This paper summarises views expressed during this pre-consultation period. In particular it reflects views from the review's Children and Young People Events, visits to CHD services across England and Wales, discussions with the review's three engagement and advisory groups and discussions at the CHD Clinical Reference Group. Some comments were also received via the NHS England website. In each case the paper seeks to accurately reflect what was said.

The views expressed are those of the individuals and groups concerned and not the official views of NHS England. Rather they are reported to aid the development of the proposed standards.

SCHARR was commissioned to undertake an independent review of the literature and its findings have been summarised at relevant points of this paper. Their work focused on two questions:

- What is the current evidence for the relationship between institutional and surgeon volume and patient outcomes and how is that relationship influenced by complexity of procedure and by patient case mix?
- How are patient outcomes influenced by proximity to/co-location with other specialist clinical services (e.g. co-location of services such as specialist cardiac paediatric intensive care)?

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

Recommendation

CAP is asked to consider the standards in light of all these contributions and advise whether any amendments need to be made prior to full public consultation.

Section A: The network approach

Children and Young People Events

No specific comments

Visits to CHD services across England and Wales

On our visits to CHD services across England and Wales many centres told us that network working is what makes a difference

What makes networks work?

Networks only succeed when given a lot of time, energy and commitment. All parties have to want them to succeed.

Networks need to be managed and properly resourced - there are leadership, managerial and administrative costs.

Networks are about relationships built over the long term. Having named link consultants with good relationships with local PECs/CWSIs is crucial. Effective network working is very dependent on individual relationships.

Supporting PECs/CWSIs through outreach clinics, working alongside allows them to develop their skills.

Protocols, guidance and shared governance help reduce variation.

Telemedicine and information systems

Effective networks need shared information - clinical IT systems; videoconferencing; telemedicine. There were different views about the importance of being able to share scans.

Regional or national networking

Some centres consider that there is a role for network arrangements at a level above the hub and spoke model described in the standards. Regional networks would allow surgical centres to work more closely together and provide important quality assurance and mutual challenge, enhanced training and research opportunities. There was also support for a national network of surgical centres, and it was considered that developing this might be an NHS England / professional society joint venture.

We heard that some units are not speaking to each other – relationships had been OK but were damaged by the Safe and Sustainable process. Networking between distant centres is a bit better than it was, but with near neighbours it is still strained. This reduces opportunities to learn from each other.

Network boundaries, catchments, competition and choice

We heard concern in some places about boundary issues and how to ensure that each unit gets the 'right number' of patients to meet the minimum requirements of activity for its number of surgeons.

Transplant

A small percentage of CHD will require transplant and access to transplant is limited not just by the number of donors but also by professional views of the potential success.

Donation is the limiting factor with few donors from children. Most children who are transplanted receive adult hearts.

We were told that patients who get to adulthood with CHD will rarely get a transplant because whenever a heart becomes available there will always be other potential recipients in whom the operation would be simpler and in whom better long term outcomes are more likely.

Patient and Public Engagement and Advisory Group

The group emphasised the importance of effective communications between clinicians across networks and nationally.

The group considered that more attention needed to be given to transport and retrieval services (Embrace was raised as an example of best practice).

Provider Engagement and Advisory Group

The group asked for clarity about the proposed model for CHD networks. Were they operational delivery networks? There was a view that while ODN functions of shared pathways and joint working were being described other roles with a greater emphasis on sharing and learning to drive quality were also being described and this might be a different sort of network.

The group considered that it would be possible to describe quality driven relationships

Clinician Engagement and Advisory Group

Network boundaries, catchments, competition and choice

A subgroup considered the question of whether network boundaries should be managed or should emerge as a result of competition and choice. The group considered that unless boundaries were managed it would continue to damage relationships.

They considered that managed boundary networks would be more efficient and would drive costs down. The group therefore advised a more formal statement about this issue.

The group considered how boundaries could be set in a managed scenario (closest, shortest journey time) and how commissioners could enforce these arrangements, for example by not paying for activity where the boundaries were not respected.

Other members of the clinician group considered that patient choice must be allowed which implied competition.

The managed boundary model proposed led to units that would be similarly sized. Some considered that there was a case for at least some units to be larger. Others argued that if units all had to undertake at least 500 cases this meant that the decision not to have bigger units had in effect been taken.

Experience from trauma networks was that managed network boundaries had been effective and well accepted.

Transplant

A sub-group considered the approach to transplant taken in the standards.

They advised that the paediatric standards were fine.

Adults requiring transplant range from simple procedures that can be done in any of the transplant centres to complex patients who can only be done where there is special expertise that are almost all done in Newcastle. In the future we can expect more complex adult demand – a second centre may be required to do this work. There will also be a continued rise in the use of mechanical assist devices both as bridge to transplant and, in time, as destination therapy. Arrangements would also need to cover heart and lung transplant and not just heart transplant as demand for these procedures could be expected to rise.

The group identified a problem in applying the standards – the Newcastle centre is in a sparsely populated region where there won't be enough patients to meet the CHD activity requirements. The group advised that some sort of super network and intelligent commissioning will be needed if the CHD work is not to close the transplant service.

It was proposed that there should be a minor change in wording to differentiate between referral of simple rather than Complex patients:

The proposed adult standard (A2) which stated that *"each specialist ACHD centre must demonstrate formal working relationships with a cardiothoracic transplant centre staffed by transplant surgeons with a congenital practice"* has been modified to read *"each specialist ACHD centre must demonstrate formal working relationships with cardiothoracic transplant centres, including one staffed by transplant surgeons with a congenital practice"*

Clinical Reference Group

Network boundaries, catchments, competition and choice

There was discussion about network boundaries and pathways of care. The discussion noted that there would be a difficulty guaranteeing enough activity at some centres if network boundaries were not defined by commissioners but that the approach had also to recognise that competition/choice is allowed in the NHS and fixed boundaries would be anti-competitive. There was a view that network boundaries should take account of "normal expected" pathway flows. There was not general agreement that boundaries should be fixed.

Congenital networks

The CRG agreed that there should be combined CHD networks covering both children and adults. A clear definition of a "Network" is needed including descriptions of network leadership roles and responsibilities. There should be a single lead clinician across both aspects of the network.

Network development

There would be a need to define pathways of care from the outset recognising that the Network Functions will take time to establish.

Multidisciplinary Team

The MDT membership is not sufficiently defined. Need to define core members. The group proposed a minimum of three members - congenital cardiologist, congenital surgeon, specialist anaesthetist.

NHS England website – comments

Network boundaries, catchments, competition and choice

One comment stated that in order to attract and retain patients NHS specialised service providers have to listen and adapt to the changing needs of their patients. Those service providers which have implemented continuous improvements and change are those which naturally attract more patients and referring clinicians. This is not something that can be done nationally as the changes necessary often require local support and long term commitment. Any centre which is failing to attract enough patients to successfully employ enough staff to safely run its service and have successful succession planning has to look to itself and ask why. That centre needs to ask what is happening in those centres which are increasing their services naturally and ask what is it that they are doing that we are not.

ScHARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Tier 2 Specialist Cardiology Centres

Children and Young People Events

No specific comments

Visits to CHD services across England and Wales

Where tier 2 paediatric services were running, units considered that they had a valuable role and were confident that as part of networks they could have a positive future.

Clinician Engagement and Advisory Group

The role of tier 2 specialist cardiology centres

A subgroup considered that the limitations on interventional cardiology in tier 2 ACHD centres were too inflexible and that there was the potential for these units to do more. This should be different for ACHD than paediatric CHD because adult cardiologists exist outside SSCs but do not for paediatrics. It was noted that the majority of adult ASD closure is currently undertaken outside specialist surgical centres and that the results are good.

They considered that the flexibility offered by the standard on electrophysiology was more appropriate - this requires that patients are discussed at the MDT. The group considered that this flexibility should be replicated for other forms of intervention / diagnostic catheters and that more should be allowed outside the surgical centre with network agreement. This might include ASD and PFO closure. They also recommended that arrangements for ASDs and PFOs should be consistent to reduce the risk of gaming. It was agreed that as a minimum BCS standards must be met including numbers of interventionists and numbers of procedures undertaken by each. The proposed tier 2 ACHD standards would also need to be met.

Clinical Reference Group

Interventional cardiology in tier 2 specialist ACHD centres*

There was a discussion about the potential for interventional cardiology to be undertaken at tier 2 specialist ACHD centres, for example for the repair of ASDs. Currently the standards require that these are only undertaken at a specialist surgical centre, but interventionists from tier 2 centres (who have been appropriately trained and who meet the minimum volume thresholds) may undertake these procedures at the specialist surgical centre. The group considered that for this to be possible the level 2 unit would need to meet both the level 2 standards and the appropriate requirements for interventional cardiology services described in the tier 1 standards. The requirement for specialist congenital surgical back-up in particular was considered essential and surgical members of the group were of the view that congenital surgeons based at specialist surgical centres would not and could not provide this.

[nb. this record of CRG discussions is subject to ratification by the group]

Long term viability

The CRG expressed concerns about the viability of the Tier 2 Centres – both in achieving the standards on a sustainable basis and a concern that recruitment of high quality staff to these centres may present a problem.

Other issues

- Standards should affirm need for beds based on population/patient activity and provision should be aligned accordingly
- Standards should specify need for dedicated sonographer
- The standard on research needs to be stronger and include requirement for “national research”
- Where fetal diagnostics are provided in tier 2 centres, all staff must have the appropriate specialist expertise in fetal cardiology or refer onto the tier 1 service/specialist fetal centre

NHS England website – comments

No specific comments

ScHARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Tier 3 Local Cardiology Centres / Local Hospitals

Children and Young People Events

Local A&E and paediatric services

- Local units find complex cases very difficult to manage and the parent needs to be the advocate which worries them - particularly if they can't be there all the time
- We heard about a situation when a local unit said her son 'was good for a child with CHD' but the parent knew that he 'wasn't right' - insistence on calling main centre who asked for a lung xray and both lungs had collapsed.
- Patient and the parents in particular have a big advocacy role but too often are not listened to - they are the experts and are seen as overly cautious by the doctors.
- Would be helpful if there was a way to flag these children on the system particularly for the local hospitals - a national database feels rather obvious - so that parents wouldn't be relied on - particularly in stressful situations.

Visits to CHD services across England and Wales

Local CHD Services

We heard about good work in many places to develop role of PECs/CWSIs.

Local tier 3 services are really important both to allow patients to receive more care locally and to ensure that specialist centres can focus on the most complex patients. The growth in the number of adult CHD patients makes the role of local centres even more important – specialist centres would be overwhelmed without the support of good local services.

We heard concerns in a number of places about whether CCGs would see local CHD services as a priority, and therefore a risk that they might not want to fund them.

Local A&E and paediatric services

We were told that local hospitals do not consistently deliver a good service to these patients / families

- Emergency admissions via A&E were cited as difficult
- Do not consistently contact specialist centres for advice
- Appear to not know what they are doing
- Act against the advice of the parents who are expert in their child's condition
- Non specialist staff locally makes parents feel isolated and rely on the specialist centre
- Community and local hospital staff forget that the parents do become experts in their children's health and must be included in care decisions locally - they will know a lot more about the specific aspects of the child's care and 'what's right for their child'
- Many parents say they have to get aggressive to get care for their children locally, for concerns to be taken seriously, phoning surgeons and cardiac consultants desperately looking for them to influence the local care being given.
- Poor consistency in delivery of services close to home: community nurses, health visitors, GPs, prescribing specialist medication, blood tests
- Local hospitals are by passed in favour of specialist centres because of lack of faith in local hospitals to listen to them and call the specialist centre for advice

- Inconsistent GP involvement
- Because baby/child in the congenital heart system, children and babies (and post natal mothers) fall out of the normal health care/social system and struggle to get back in - health visitors, community nurses, midwives, GP's either aren't involved, aren't aware of the child, or are scared of the child and being involved in their health
- Once trust is lost in local DGHs very hard to get back, means parents are dependent on one hospital and surgeon/ specialist nurse and will travel great distances to get to the care they trust
- Unaware of what is available locally to support other family members – particularly siblings

We heard about a number of things that work well

- Open access to their local centres and therefore bypass A&E which has a positive impact
- Some hospitals have good links with the specialist centres and work with the parents as a partner in their child's care
- Handheld notes with patients history and medication that can be shared with other medics
- Experiences where the GP worked in partnership with the specialist centre to deliver local care
- Good IT across the network to support clinicians would be helpful to make these links work even better

Engagement and advisory groups

No specific comments

Clinical Reference Group

Commissioning

The CRG affirmed the importance of tier 3 services which offer the opportunity for many patients to avoid long journeys to specialist centres. However the CRG feels strongly that the activity which takes place in a tier 3 centre should be classified as “specialised” (outreach and PEC/CWSI). A PSAG submission would be required for this with a clear case for change with numbers and potential cost implications. The CRG does not feel that the tariff in tier 3 centres is sufficient to meet the standards.

Specific Standards

- Concern was expressed that the standards may be pitched too high, in a way that could deter some local hospitals from trying to deliver this type of service
- Is exercise testing a requirement in a tier 3 service?
- Archiving of documents needs to be the same across all 3 tiers.
- The group recommended that fetal diagnosis should only be undertaken in tier 3 units as part of an out-reach service.

NHS England website – comments

No specific comments

ScHARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Section B: Staffing and skills

Children and Young People Events

Psychology and counselling

There should be a psychologist available for patients – someone to talk to (especially for older children). Genetics often have a counsellor – this should be available to all

It would be good to have someone non-medical in the hospital to talk to – counsellor or youth worker

Specialist Nurses

There should be more Liaison nurses on each ward – they are stretched too thin but a wonderful resource.

Cardiac liaison nurses play an essential role and are seemingly overworked

Play and clowns

Every hospital should have Clown Doctors – children love it – great form of entertainment

Could there be a play therapist on site that could be commissioned?

Practicalities

Where possible there should be a male nurse on each ward

Staff need to be easily identifiable so you know who to talk to – on the uniform, or by colour coding, or a sign in the ward

Patients should be told when there is a shift change so they know there will be a new nurse to look for

Competence

Staff should not be doing procedures they are not trained to do

Clinician mobility

Mobility of staff/doctors/surgeons needs to be encouraged – the current system seems to work in the opposite way

Private practice

Parents wanted to know how we work out whether time that is being spent in private practice is calculated when looking at work ratios. Also need to look at the ratio of people to patients.

Visits to CHD services across England and Wales

Specialist nurses

The role of the specialist nurse is absolutely pivotal for patients. Their role encompasses system navigation, counselling and support, problem resolution, educator. In some places it was noted that because numbers were limited the service that nurse specialists could offer was limited.

Should have liaison nurse in outpatients.

Surgeon numbers and minimum activity levels

Surgeons have mixed views about whether the minimum number of surgeons in a team should be three or four. This was not simply conditioned by the scale of their own unit.

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

Surgeons recognised the importance of being able to access specialist advice and support from other centres. Strained relationships mean that some centres will not contact some other centres. Where surgeons had experience of being asked to assist a colleague at another hospital it had often proved to be frustratingly difficult to sort out the HR clearances needed to do so.

Surgeons all supported a minimum of 125 operations. They told us that this must be seen as a minimum. They are clear that this is a more important determinant of surgical quality than the number of surgeons in a team and that increasing the number of surgeons in a team must never be at the expense of minimum levels of activity. Some surgeons consider that maintaining skills is not just about numbers but also about case mix so some considered that in counting a distinction should be made between short and long procedures.

Some were sceptical that more than a minority of operations are dual surgeon operating so this counting issue could be unimportant.

Some thought that senior surgeons don't need to do so much surgery to maintain skills and that they could do more adult work but would still be competent to tackle paediatric work because of their accumulated experience.

Out of hours

The need for out of hours emergency surgery in this specialty is low (except for transplant centres) so is not considered especially onerous. However it is important that on call arrangements ensure the prompt availability of a surgeon with the skills to deal with whatever problem presents. This is not just a matter of the number of surgeons in a team – the degree of subspecialisation in their surgical practice matters as does the availability of other surgeons when needed. Out of hours these arrangements seem usually to be informal. An alternative approach is to ensure that all surgeons practice across the whole age range.

We heard that most emergencies are arrhythmias. Some difficult arrhythmias might need the ability to bring in a full highly skilled team out of hours to diagnose and manage with interventional techniques.

Scale of units matters to the extent that any unit needs to have sufficient scale to be able to offer the full range of services out of hours that might present as an emergency to that unit out of hours.

Psychology and counselling

Proposals that will ensure greater availability of psychologists are welcome. This must be reflected in the adult standards and not just children's.

We were told that there is a need to connect with social workers to make sure families they are getting benefits they need. In one centre we heard from a specialist social worker who also offered counselling and psychological support.

Play

Play specialists are vital to ensure the child's development does not stop because they are in hospital

Recruitment and retention

Recruitment is challenging in some specialties and some locations. Specific initiatives beyond traditional recruitment practices have been successful.

Specific concerns –

- Nursing – recruitment and retention of highly skilled and qualified nurses is critical and hard but we heard about a number of successful, less traditional approaches; the supply of paediatric nurses was a concern; turnover is high in London – people come for the experience then move on; the availability of PICU nurses was often seen as a capacity limiting factor; nurses are not a mobile workforce so any closures could mean a serious loss of experience and skill to the system; nurses are less flexible now because trained specifically for either paediatric or adult nursing.
- Cardiac surgery – retention was seen to have been adversely affected by the uncertainty. Given the small numbers involved staffing was seen as precarious.
- Scientists, cardiac technicians, physiologists – widespread concerns that curriculum changes resulting from modernising scientific careers meant that appropriate Masters level training is no longer available.
- Cardiologists – concern about whether it will be possible to attract high quality cardiologists to work in level 2 units, particularly in paediatrics.

Clinician engagement and advisory group

One member stated that changing the number of cases to 100 would make little difference to the surgeons but a lot of difference to the networks.

One member stated that it is wrong, especially for adults, to count all cases as equal - some are much more complex.

Provider engagement and advisory group

Recruitment and retention

Attracting cardiologists into Tier 2 services is challenging

There may be different staffing issues in and outside London. Retention seems much more difficult in London – it is more difficult to fill vacancies at lower pay bands in London. It may be easier to fill medical vacancies in London. Competition between units will lead to more staff moves, as some posts are on higher Agenda for Change bandings than others. The group saw value in a dialogue about bandings.

The draft standards propose new requirements for psychologists. While recognising that there is huge variability in availability, there was a concern that resolving this would bring a financial pressure.

There has been little investment in adult services and so it is proving difficult to fill vacancies. This is exacerbated by the fact that there are no standards for adult congenital heart specialists. Need to look at what happened with nursing 10 or 15 years ago - need to link to universities nationally to deliver an adult congenital course.

There may be an issue with ECHO as training has changed and people don't have the same skill set. There is a four year gap because of *Modernising Scientific Careers* – need to look at numbers going in to training as well as bandings. The review team could talk to HEE about the increasing demand for specialists at a time when they are moving towards generalised training rather than specialist. There may be an opportunity to introduce a new training module to Modernising Scientific Careers.

Mobility of staff

The group noted it would be possible to look at getting a passport. In addition, it may be possible to reach agreement for surgeons along the lines of locums in the standards.

Clinical Reference Group

Surgeon numbers and minimum activity levels

The CRG discussed the appropriate size of surgeon teams. The surgeons were less concerned about this issue than the need to ensure that each surgeon undertakes enough procedures to maintain competence.

They noted that if numbers of surgeons and activity levels were set then network boundaries should be fixed to ensure that these levels are achieved. The timetable for reaching the activity levels required could be critical for some centres that don't reach these levels now but might in 10 years time.

There was agreement that in order to provide on call continuity, cover and back up for illness etc, at least three surgeons at each centre should be an immediate requirement. They noted that most surgeons also agree that four surgeon teams are ideal.

The minimum number of procedures per surgeon is an appropriate standard, and 125 an appropriate minimum.

Out of hours

Given the spread of sub-specialisation which is likely to increase CRG surgeons considered that the number of surgeons was not the only issue. Arrangements needed to ensure the availability of surgeons with the required skills: neonatal surgery (the most frequent out of hours emergencies), complex congenital operations and establishing cardiac ECMO. Emergencies out of hours are however rare.

Specialist nurses

The group considered that the number of specialist nurses in each network should be based on population to ensure that the number would rise in networks with bigger catchments.

Psychology

The group considered that a more prescriptive statement of required psychologist staffing was needed in the adult standards.

NHS England website – comments

Succession planning

One comment from a former congenital heart surgeon stated that larger teams of surgeons was better for succession planning - departure of the senior surgeon through retirement, illness or moving abroad, could lead to significant interruption in continuity of the service. It takes several years to integrate a new surgeon in to the team because new consultants will not have undertaken most of the major procedures when they are appointed. During that period they cannot play a full part in the on-call service.

Two other commenters considered that succession planning was a matter that should be managed by each Trust without the need for a national review to sort it out. Those Trusts that wished to continue to provide a CHD service have to show that they are able to plan and meet all the needs of running the services.

One commenter noted that this approach seemed overly focused on just one individual whereas surgeons work as part of a team and each member of that team provides a crucial role to the individual patients.

ScHARR review

Relationship between volume and outcome - mortality

This review identified a substantial number of studies reporting a positive relationship between volume and outcome. While many of the studies show better patient outcomes when larger volumes of surgery are performed, this was not consistent and not all of the studies showed this.

The relationship between volume and outcome is unlikely to be a simple, independent and directly causal relationship, *but rather be a marker for other process and system factors*. Welke clearly expressed the view that volume is likely to be a surrogate for the processes and characteristics of care systems that produce outcomes and that centre specific quality measures would be more informative than volume thresholds. Pasquali and Vinocur concurred with this view and suggested that service design decisions should be guided by a range of individual centre performance measures and not volume. There are consistent and clear messages within the literature reviewed about the danger of viewing volume in isolation. Furthermore, included studies also caution concerning the likely but as yet poorly understood interaction of volume with the numerous other clinical and structural dimensions that contribute to delivering high quality services and hence good outcomes. With centralisation comes a corresponding increase in volume as more cases are concentrated in fewer centres. It remains unclear whether the impact of volume on outcome is largely a consequence of higher volume units organising and providing a complex service with all the “right” components, or whether it remains an independent factor directly related to the advantages of dealing with a larger number of cases. The lack of any UK studies to contribute to the review indicates a serious gap in evidence relevant to service provision in the NHS.

Despite the growing number of studies on the relationship between volume and outcome few studies have suggested what the optimum size of a CHD centre in terms of volume should be.

ACHD

Two studies found that adult CHD patients had better outcomes when operated on by paediatric surgeons in specialist children's centres.

Two studies suggest a relationship between individual surgeon volumes and outcomes for adults with CHD -one study found outcome was associated with surgeon volume. Another found a similar association with adult procedure volume indicating the influence of expertise on outcome.

Complex conditions

Studies on single conditions or procedures were more likely to identify an effect of volume on mortality but these were focused on high risk conditions, such as Hypoplastic Left Heart Syndrome, and procedures, for example Norwood procedure. Even within these highly selected groups there was considerable variation in effect depending on procedure type and individual centre performance. It is possible that, for example, surgeon volume may be as important as centre volume for these complex cases. Hirsch suggested that a reasonable threshold for referral of children requiring Norwood procedure is centres doing at least 20 procedures a year and 10 procedures a year for arterial switch operation. These studies indicate the potential value of centralising or regionalising highly specialised services for very rare and complex cases.

Relationship between volume and outcomes other than mortality

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

Relationship between distance from specialist centre and outcome

Two studies examined the relationship between distance from a specialist cardiac centre and mortality and both found no relationship between distance and mortality.

National Institute for Cardiovascular Outcomes Research review

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

No association was shown with distance from home.

Section C: Facilities

Children and Young People Events

Teens and young adults

- There need to be forms of entertainment for all ages not just younger children (toys etc. in the waiting room) – to be used as more of a distraction than anything else.
- The playroom needs to be staffed as long as possible so children and young people can have more access to entertainment.

Environment

- The rooms are boring and clinical – they need more of a personality (less intimidating)
- Cleanliness is paramount in all areas of the hospital – for all staff, parents and families
- Facilities for the parents could do with some improvement.

Food

- The standard of food in hospitals needs to be higher – it's when you most need good, healthy, balanced food.
- One parent felt there should not be a McDonalds/Burger King in a heart unit – people are too easily tempted by fast food and it's a main cause/contributor of obesity/heart disease. (other parents had differing views)
- There needs to be a wider variety of food especially for people with:
 - Allergies
 - Intolerances
 - Religious restrictions
- It would be good if the canteen was open later – especially for parents who need to stay overnight in the hospital
- It would be good to have a kitchen on all wards so parents can bring food from home rather than buying everyday
- It would be good if there was somewhere that families can eat together (not fast food)

WiFi

- There needs to be 24 hour access to Wi-Fi for all patients (both in and out) not only for entertainment purposes but so that older children can keep up with school work easily if they have to miss school for operations etc.
- It would also allow siblings to occupy themselves whilst at/waiting at the hospital. It could also benefit parents massively - they would have the opportunity to keep up with work or other family members during their time at the hospital.
- It could also be used as a way of keeping in touch with friends and family whilst in hospital – phones often have no signal in the hospital so Skype/Facebook/messenger programmes would be helpful.

Accessibility

- There needs to be a space where children can put out of use wheelchairs
- There must be easy access for ambulances at the hospitals

Transport

- Not all hospital buses are wheelchair accessible (re: pavements and curbs)
- There isn't enough disabled parking
- It's very expensive to park
- Discount [on parking] is great but needs to be better advertised

School

- Wi-Fi is vital so that children can keep up with school work
- It would be great to run Skype lessons
- There should be a teacher that children can talk to about school work

Visits to CHD services across England and Wales

- The availability of good facilities makes a huge difference to patient and family experience.
- Specific facilities for teenagers and young adults (clinical and social) could be better developed.
- Hospitals should provide a "how to find us/about us" booklet with where to park/eat/sleep in case you use a hospital in a different city – local knowledge is invaluable.
- It is expensive to live in the hospitals – it is expensive to eat in the hospitals.

Engagement and advisory groups

No specific comments

Clinical Reference Group

No specific comments

NHS England website – comments

No specific comments

ScHARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Section D: Interdependencies

Children and Young People Events

No specific comments

Visits to CHD services across England and Wales

When done well, the relationship between maternity services, fetal and paediatric cardiology, fetal medicine, NICU and ACHD cardiology can make a real difference both to the care delivered and to patient experience.

Having services for children and adults all on one site was considered by some to improve efficiency and to promote the sharing of expertise. Having services in the same location is not enough – they must work together with patient needs at the centre. Too often this is not the case in practice. Communication between specialties is not uniformly good

Children with multiple morbidities need access to a range of specialties. It is not always possible to predict which other specialities will be needed. A lot of children require input not from just another specialist medical team but also from nurse specialists, therapists, dietician and so on. If a patient has to wait several days for an opinion that is not considered to be good care or a good service.

Paediatric and adult CHD services must work closely together. There can often be beneficial learning across the age groups. Links are also needed with acquired cardiologists, aortic and mitral surgeons.

Critical care (both childrens and adults)

Capacity in PICU and ITU is often the pinch point. This is mostly about nurses not about estates

Standards for ICU may not be in scope but its importance can't be ignored

Clinician engagement and advisory group

One member suggested that the co-location standards had been set in a collegiate way 'to make sure that everyone can meet them' and there was not enough ambition.

Patient and Public Engagement and advisory group

Considered that co-location with antenatal care was important.

Noted that the delivery of the response times envisaged in the interdependency standards would need robust agreements between hospitals;

Provider engagement and advisory group

Expressed a concern that the CHD interdependency standards no longer followed DH guidance that was still used for other specialties.

Suggested that hospital activity data could be used to show how often other specialties were involved in the care of CHD patients, though it was also noted that the use of other services tended to be strongly influenced by their relative availability.

Noted that services can be next door to each other and not speak to each other – it is about having positive relationships.

Recommended that if triple co-location (ie. childrens CHD with other tertiary children's services, adult CHD with other adult tertiary services, children's CHD with adult CHD) is ideal, this is made clear in the standards.

Clinical Reference Group

Vascular surgery – it was noted that there are no paediatric vascular surgeons and also that in some hospitals other surgeons with suitable expertise are used instead, so recommended that the standard suggested should be amended to require paediatric experience and should say: 'vascular surgeon or other surgeon competent to undertake vascular/micro vascular repairs.'

Paediatric Neurosurgery – the group considered the original standard proposed prior to amendment by CAP was more appropriate i.e. 30 minutes to telephone advice / four hours for bedside care or transfer of care.

NHS England website – comments

No specific comments

ScHARR review

The review found limited evidence on the effects of proximity of other services on mortality or the impact of volume on non-mortality outcomes. One multicentre study compared care in a cardiac PICU with other ICU and found no effect on mortality except for STS-EACTS 3 level cases and primarily in patients undergoing atrioventricular repair and arterial switch operations suggesting that potential benefits may only be applicable to specific patient groups. A second study conducted a single centre before and after study evaluating the impact of introducing a cardiac cardiac PICU and found a reduction in mortality and a bigger effect in reducing morbidity (wound infection and chest re-exploration).

National Institute for Cardiovascular Outcomes Research review

No specific comments

Section E: Training and education

Children and Young People Events

- Parents reported finding that new SHOs and other trainees need to understand better that there is a person not just a procedure. They can be so focused on getting the procedure correct they don't think about listening to the young person and understanding their unexpected expertise
- History taking with new clinicians can be laborious - so standard forms and some kind of hand held records - filofax record - portable record - like the red book - electronic would be preferable

Visits to CHD services across England and Wales

No specific comments

Engagement and advisory groups

No specific comments

Clinical Reference Group

No specific comments

NHS England website – comments

No specific comments

SchARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Section F: Organisation, governance and audit

Children and Young People Events

- Patients should not have to pay for files/patient information to be transferred from one hospital to another
- There need to be stronger links between GPs, hospitals, workplaces and schools so everyone is on the same page regarding the care of the patient

Visits to CHD services across England and Wales

One centre had a highly developed internal data analysis system used to drive quality improvement.

Patient and public engagement and advisory group

It was suggested that an unacceptable number of operations were being cancelled at short notice, causing distress to patients and families. But other group members argued that there is always a risk, in any health system, that surgical capacity will be required to perform more clinically urgent work.

Clinical Reference Group

The CRG considered that while it would take some time to develop robust documented clinical governance frameworks (standard F1) this should be tackled urgently.

The CRG noted that standard F2 requires national reporting of adverse incidents but this does not exist at the moment, though the CRG agrees is extremely important. The methodology for reporting incidents regionally or nationally will need to be agreed and a national system for sharing serious incidents/learning established. The Network function in this regard is not clear.

The CRG discussed alternative models to Peer Review that were effective but potentially less resource intensive.

NHS England website – comments

No specific comments.

ScHARR review

No specific comments.

National Institute for Cardiovascular Outcomes Research review

No specific comments.

Section G: Research

Children and Young People Events

No specific comments.

Visits to CHD services across England and Wales

Many centres emphasised the importance of research and their association with academic institutions. Only some made an explicit link between this and driving improvements in services and outcomes for patients.

Engagement and advisory groups

No specific comments.

Clinical Reference Group

No specific comments.

NHS England website – comments

No specific comments.

SCHARR review

No specific comments.

National Institute for Cardiovascular Outcomes Research review

No specific comments.

Section H: Communication with patients

Children and Young People Events

Communication

- Doctors and nurses need to improve their communication skills
- Communication training should be provided throughout career – like medical training
- From the start they need to establish who they need to talk to – parents/patient
- The way doctors and nurses speak to people with disabilities needs to be improved
- Communication needs to be age specific – knowing your audience
- Get down to the child's level when they are on the bed /chair
- There needs to be more honest communication about the diagnosis
- There needs to be some kind of patient information summary page on the front of each file – so patients don't have to repeat themselves for every clinician
- Children (along with the above point) should have an 'I like/I don't like page that describes their preferences to improve patient experience
 - eg: If I am quiet and not making eye contact then I will be feeling anxious – please come back later
 - eg: I don't like to take my medicine with milk
 - eg: I don't like breakfast so please don't wake me up
- There needs to be a better process for handling delays/cancellations
- There needs to be a register/recording of cancelled operations – re: patients and clinicians
- It's massively beneficial when doctors explain things using diagrams/visual aids/models
- Communication between hospitals is poor and parents become the lynch pin as they are there 24/7 with the child
- Communication standard would be helpful - named consultant for the local area hospitals to refer to
- Life is controlled by fear, ward rounds need more respect for the parents - with personality, apologies and learning to say sorry.
- Patients and parents lose confidence in the staff, parents become neurotic - trust is low when things go wrong
- Need clarity about how to raise complaints or give feedback
- Names on the beds should include mums, dads and guardians – “my name is not “mum””.
- One consultant was intimidating at first but this is a style the family got used to and they have a very good relationship with the consultant now.
- Explain the diagnosis better
- Need a care plan that is common throughout the country

Information

- Need to offer more information to patients – especially regarding transition, consultations and how to live with congenital heart disease.
- Consultation letters that come through are too complicated – they need a glossary or to offer trusted websites for more information
- Patients are unaware to whom you can direct your questions at the Trust

- There needs to be a clear hierarchy within the hospital and a formal process for complaints
- There needs to be a national (or regional at least) register for people with congenital heart disease
- Misdiagnosis is a huge problem for many people with congenital heart disease – local hospitals/GPs need to be aware of symptoms and when necessary they need to refer patients to a specialist centre as soon as possible
- Communicate to patients that there are things they can do whilst in hospital – learning, reading, helping others
- Workshops for children on ‘how the heart works’ or something similar would be good so they know what’s going on from a younger age and can take responsibility for their own care as well
- There needs to be more information given to young people about sex, drugs, alcohol, relationships, contraception, the possibility of children – this needs to be away from parents completely – many teenagers are uncomfortable speaking about any of these things in front of their parents and some don’t even like the idea of speaking with their regular doctors

Pre-op and Post-op care

- There needs to be more support for patients post op – not only dealing with medical issues but also things like depression/anxiety – a psychologist would be good at this point
- Much more explanation about what to expect, post surgical, all about the procedures so people are prepared
- Even individual words matter - parents who are told to say 'Goodbye' to children going to surgery find this very distressing. “Goodnight” has been used as a replacement in some places

Out of hospital

- Follow on care very limited when leaving hospital
- Helping parents prepare for real life - preparation for life stages, schools, what do you say and how do you say it, thinking about making decisions about children and what they can do
- Working out how to get insurance for things like holidays

Visits to CHD services across England and Wales

The review team heard that children are individuals and this needs to be taken into consideration rather than applying a blanket rule – this particularly applies to people with special needs / learning difficulties

Choice

Patient choice was considered controversial by some. Some centres strongly affirmed the right of patients to make informed choices about where they would receive their care. Others favoured significantly constraining choice either because they considered that cardiologists knew where patients would get the best care and would refer accordingly or because constraining choice would make it possible to guarantee activity levels at surgical centres.

Inpatients

Where children have multiple medical needs parents are sometimes left to navigate specialties with no-one in overall control.

When parents don't attend ward rounds and information from the ward round is not passed on they start to feel that they are not being told everything

Communications between departments in a hospital and between clinicians and patients/parents need urgent and thorough improvement - it casts a shadow on good aspects of the care. The review team were told that it's important for the specialist centres to get communication right: – between departments – pharmacy, dietetics, other specialties, and between nursing staff.

This works well when a clinician takes the lead for an individual patient.

Outpatients

When parents see a new doctor they have to explain the child's history again. The clinician may disagree with the last consultation - unsettling for patients.

Facilities not always children / special needs friendly.

Multiple visits sometimes close together to see several specialties are not satisfactory.

It is very helpful when there is a liaison nurse at all clinic appointments

Patients and parents get a lot of complex information at outpatient clinics. It is helpful when everything written down (including medications) to share with health professionals

Discharge from hospital

Transition between hospital and community care is patchy and scary - going from very supported to completely 'on your own'. It helps when hospital and community services connect before discharge and the hospital uses whatever means are available to communicate with local services – eg., red book, email discharge letter to GP, TTO letter.

Arranging to meet community staff in the hospital before discharge – handover meeting with hospital and community staff and family – is also helpful.

Some parents and grandparents had been trained to do CPR so they felt comfortable taking baby home

Being discharged late in the day (whilst waiting for reviews, medications and so on) is bad.

Parents taking a small baby home with a congenital heart disease need a lot of support.

Poor communication between the specialist centre and local services causes unnecessary distress for patients. Arriving home with a new baby after several months in hospital means you have missed some basic things like: registering for child benefit, hearing tests, red book. Red book has a section for complex health needs – not always completed in the hospital – would be a good means of communication.

Parents rely on nurse specialists to liaise with the schools to help the teachers understand the child's condition and therefore what the child is able to do

Provider engagement and advisory group

It was noted that the Somerville Foundation do a survey with patients in adult centres to check that services are addressing expectations. A similar survey for children's services would be helpful.

Clinical Reference Group

Ensure where it refers to patients in the adult standards that carer is added: patient/carers

Top of page 3 – add to standard as follows:

When referring patients for further investigation, surgery or cardiological intervention, patient care plans will be determined primarily by the availability of expert care for their condition. The cardiologist must ensure that patients *and carers* are advised of any appropriate choices available (*including transplantation*) as well as the reasons for any recommendations

H 10 – Should state “plain language” not plain English

NHS England website – comments

No specific comments

ScHARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Section I: Transition

Children and Young People Events

The review team heard that in some cases experiences of transition had been unsatisfactory

- Not enough discussion – need someone to talk to who's been through it/has experience with CHD
- Not enough information given to patients about the transition period
- The Information offered comes in the form of a huge booklet which is daunting to read through
- Process so far poor - no conversations about transition, wasn't going to happen till 21 then suddenly with 2 weeks' notice child was moved without finally seeing the paediatric consultant all rather 'hush, hush'
- Very annoyed when their child was asked whether the old consultant didn't like him as had not said goodbye or anything.
- Poor experience with the cardiac liaison nurse.
- Transition needs to be dealt with better - helping them talk in grown up terms, understanding the technical language, designing the service for young adults.

The review team heard a number of ideas for improving transition

- Needs to be a slow introduction from one to the other – meet the staff first and get to know the building/ward in advance
- There can't be an age limit – each patient is different – some should move early, others late, others never.
- Parents know how it should be done with a slow set up to transition and with the old and new doctor preparing. They can see that things should be different from how they are. and understood that it should be different to how it was
- Needs to be a better guide to transition so that all parties know what to expect.
- With children & adults who have more complex needs there needs to be more support to know how to manage the system, social and health care gets very complicated.
- As children and young people get older they may need support to make their own decisions.
- Transition is difficult if you have other specific problems and managing this in transition is difficult.
- A lot more support is needed to enable transition and it needs to be tailored to the child's specific needs.
- Transition should depend on the individual rather than the age of the person
- Some considered it had been helpful to be at a hospital where the consultants look after adults as well as children
- In a unit offering both paediatric and adult services, parents appreciate the ability to retain the contacts with consultants and the clinicians that they have been involved with.
- Be good to think about how parental involvement is managed within transition
- Managing the transition and engagement with the parents as they get used to a different level of involvement in adult care and different facilities.
- Also needs to be a transition for parents - it's a big change for them as well

- Young adults need lifestyle advice, need to be able to talk to the cardiac liaison nurses about how manage a teen/young adult life about managing their condition.
- When everything is planned around school, and the consultant has explained the handover and families know how many meetings there will be with both teams and when they will go over to adult care, then transition is less worrying.

A lot of people talked about the 'in between' nature of being a teen or young adult and the need for a different approach and distinct facilities

- Transition was an issue for the young people 14 + - stuck between 2 worlds
- The review team heard about a young person who was admitted to an adult cardiac ward with mostly much older men, which was considered totally inappropriate for a young person of 18 who looks no more than 11.
- There should be a transition/young person's ward
- There is a need for something in the middle - teenage services.
- Need help finding further education opportunities, limbo of being over 16 in the educational system.
- Expectations of involvement are high from parents but older teens and young adults often have different ideas.
- Facilities need improving for young adults - like staying in the familiar surroundings in paed but paed not set up to deal with large bodies, having quiet spaces away from babies etc
- An older teen in paed is an oddity.

Some people told us about the particular difficulties of transition for young people with learning difficulties

- For families of young people with learning difficulties transition from paediatric care to adult care was expected to be very difficult as the things they enjoy were more paediatric based

Visits to CHD services across England and Wales

Transition was one of the most talked about subjects. Many centres had made efforts to improve the management of transition. It seems likely that too many patients are still lost to follow up at this stage.

Patients and their families often found the prospect of transition daunting and the experience unsatisfactory. This is only partly to do with the management of transition. Often the problem is the nature of adult services which are organised very differently to children's services, the experience of which can come as a shock.

Transition is especially difficult for patients with learning difficulties. A more flexible approach is needed for these patients and better support for them and their families are needed in adult services.

The review team were told that the CHD standards need to connect with what is happening in transition nationally

Joint working of adult and paediatric teams helps smooth transition for patients, and has the advantage that the clinicians will already know the patient and that the plans will have been developed for care beyond transition.

The review team heard from patients that their relationship with their consultant and nursing staff is very important so transition requires time to build up the trust with new people.

A number of things can help young people transition well:

- Dedicated transition nurses
- Young adult clinics
- Transition days
- To be able to speak to someone who has already gone through it if you want (buddy system)
- Meeting the new consultant and ward staff before transition
- Teenage and young adult wards

Those who had been through transition urged that children and young people were told early about their condition and not to wait until transition as this was an added stress at that time.

Engagement and advisory groups

No specific comments

Clinical Reference Group

Standards need to include further wording regarding flexibility for older children e.g. those with learning disabilities in the paediatric setting to ensure appropriately timed transition.

NHS England website – comments

No specific comments

ScHARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Section J: Pregnancy and contraception

Children and Young People Events

No specific comments

Visits to CHD services across England and Wales

As care of patients with CHD has improved, pregnancy is becoming more commonplace, emphasising the importance of a close relationship between maternity and ACHD services, and the importance of decisions about place of delivery and the levels of CHD cardiology support available.

Clinician engagement and advisory group

A sub-group made a number of editorial improvements to the proposed standards:

- The first section should be re-titled 'Family Planning Advice'
- The standards for adult services use the word co-located to mean 'Women should be cared for at an obstetric unit at or close to (within 30 minutes) the network specialist surgical centre'. This should be spelled out in the standard.
- Standard J11 refers to a maternal medicine specialist. An obstetrician with a specialist interest in maternal medicine would also be an alternative.
- Standard J12 should also mention the obstetrician and midwife as members of the MDT.

Clinical Reference Group

No specific comments

NHS England website – comments

No specific comments

ScHARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Section K: Fetal diagnosis

Children and Young People Events

One parent said that she was glad that she didn't know until birth – she didn't want to be made to make decisions.

Visits to CHD services across England and Wales

Improving rates of fetal diagnosis

Rates of fetal diagnosis vary considerably.

National standards for screening programme to look for CHD at 18-20 weeks were only introduced in 2010. Many places have not yet fully implemented 2010 standards. Some units are struggling just to offer the 20 week scan consistently at all.

New standards are expected next year that will improve detection rates. But standards alone will not solve things. There also needs to be:

- Training for sonographers:
 - There needs to be training and support for sonographers.
 - Sonographer training is underfunded.
 - Can't just do it once - needs regular top up.
 - Feedback on success rates can be helpful
- National anomaly register:
 - Need a national register to know how we're doing.
 - Able to audit performance of units and provide targeted training with scarce resource

Wales has achieved higher levels than many parts of England and there may be important learning.

Ultrasound scanning is packaged within the obstetric tariff. Incentives are not aligned to support improved practice.

The fetal network is really important and needs to be closely linked. A number of services emphasised the importance of close working with in house and neighbouring local fetal medicine clinicians emphasised

CHD detection is a good marker for the overall quality of the ultrasound service.

Diagnosis and support before birth

A lot of parents spoke about their experiences of finding out that their children had congenital heart disease. Parents were sometimes informed as a result of antenatal screening and sometimes the diagnosis was made after the child's birth.

- The review team heard that it was important that enough time and support were given for decision making and planning for delivery.
- The wait between 20 week scan where an anomaly is suspected and specialist scan is a hard time

- The scariest time is when you're pregnant – parents support each other because they know how other people feel
- The review team heard from one parent whose diagnosis changed after more sophisticated tests she was told it might be one thing and she could terminate the pregnancy, then at the next scan there was another diagnosis
- Specialist nurses are very important at this time – easy access is very important. Where detection was in local fetal unit there was not always access to the specialist nurse until after the birth.
- Parents liked the opportunity to speak to other parents and see other children with the same diagnosis
- Parents agreed that they liked to be able to speak to a variety of people including hospital staff, charities and other parents to be able to get as much information as possible.

The review team also spoke to people whose diagnosis was missed antenatally who said that it is not good to miss the diagnosis antenatally. Antenatal detection offers parents the opportunity to speak to relevant people in the health service and to prepare for the birth, to visit the neonatal and paediatric critical care areas and meet the surgeons before birth

Neonatal detection

Experiences when the diagnosis was made after birth were distressing for parents. Where mothers suspected their baby was “not right” they were made to feel neurotic and “fobbed off” in encounters with the health service before the condition is detected. Some of these parents reported that they were told that the symptoms they were describing were characteristics of a normal baby.

This experience was not replicated in the specialist centres where their concerns were taken seriously and acted upon quickly.

Screening for women with CHD

The review team heard that one stop clinics for the high risk women works well

Engagement and advisory groups

No specific comments

Clinical Reference Group

Current standards require that women with a suspected or confirmed fetal cardiac anomaly are seen by a fetal cardiology specialist within five working days of referral and if possible within two days. PPE reps advised that five days is too long from a patient perspective. Similarly having to wait 48 hours for contact with a specialist nurse feels far too long and every effort should be made to limit the wait.

The group also agreed that the ideal would be for women to be able to see both the fetal medicine and fetal cardiology specialists on the same day (while recognising that this may sometimes be difficult to organise and should not be allowed to introduce delay into the process).

NHS England website – comments

No specific comments

SCHARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Section L: Palliative care and bereavement

Children and Young People Events

One mother expressed frustration that during the care of her daughter the term palliative care was being used and no one explained what it meant - 'we're not stupid people - but it wasn't a word we were used to. We asked a nurse what it meant as we had heard it several times. The nurse went quiet and then said she would get a 'doctor'.

Visits to CHD services across England and Wales

No specific comments

Provider engagement and advisory groups

It was agreed that units could start using these standards immediately and that this could give useful feedback and on how they work in practice.

It was noted that the Leeds review and local follow up has produced some good work on culture and communications. The families are keen that lessons are learned and that this work informs future thinking. The offer was made to share this with the group.

Clinical Reference Group

No specific comments

NHS England website – comments

No specific comments

SchARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Section M: Dental

Children and Young People Events

No specific comments

Visits to CHD services across England and Wales

The development of dental standards was welcomed.

Engagement and advisory groups

No specific comments

Clinical Reference Group

No specific comments

NHS England website – comments

No specific comments

SCHARR review

No specific comments

National Institute for Cardiovascular Outcomes Research review

No specific comments

Other issues

PICU

- Inconsistent nurse staffing means that parents feel the need:
 - to be at every handover
 - to tell the nurse about their child at hand over
 - not leave their child – days are very long and there is no chance of doing anything normal like washing their clothes
- Maternity / lactation care is missed as the focus is on the baby.
- The mother would like to be at baby's bedside (particularly difficult in Children's hospitals not on the same site)
- Inconsistent approach to parent involvement in caring for their child – some fully involved in feeds, nappy changing, bathing and others not, therefore are unprepared for the lower staffing levels on the ward
- Step down from critical care wards can be difficult - parents not always informed of or prepared for the ward routine on arrival eg., expectations are they have to provide more hands on care and either don't know that they have to do it, or have not been involved on the PICU and therefore don't know how to do it
- Parents can be up all night and need somewhere to catch a bit of sleep in the day without leaving the hospital

Some things that help are:

- Getting parents involved with baby's care as early as possible
- Communication following ward rounds where parents are not present

Inherited conditions

- The review team were told that inherited conditions cannot be ignored as they use the same resources as CHD.

Care for adults with CHD

- Adult CHD will be enormous in the next 30 years. Must build a network approach because just can't handle it all within a single centre. The need is not for more surgical centres as the big bulk of work is OP and imaging. That needs to be excellent across the network.
- ACHD intervention numbers seem to be steady but ACHD surgery has risen steadily and it would be even higher if there was enough ITU capacity to bring the patients in. 60% of operations are re-dos, many have already had multiple operations. Even those that are not re-dos are not easy because after a life time of abnormal circulation it will be harder to repair than it would have been if done as a child.
- Interventions however need specialist skills and shouldn't be dispersed.
- Follow up probably manages to see 95% of complex patients but there are probably hundreds of less complex patients not being seen regularly.

- Expanded team as part of a strategic plan to cope with rising demand.
- Nurse led OP clinics
- Challenges are: Geography, IT, shared records, growth
- Embedding ACHD service within adult CV services gives open access to other adult cardiology as patients get older for arrhythmia, ischaemia etc.
- Patients find adult services difficult partly because adult services have gaps or the full range of services they need are not all available in one site.

Support groups

Where there was no specific support group associated with a unit, parents felt the lack keenly.

- There needs to be better promotion of support groups (a lot of parents and families weren't even aware of the groups that are available at their trusts)
- It would be good if doctors recommended support groups to families – all the options or specific to the family's needs
- More away days and in hospital activity days should be available to patients and siblings
- It would be great if there was a 'Buddy Scheme' where you could meet older people who have gone through the same or similar things to you – volunteering
- There needs to be stronger connections between charities/support groups and the wards.
- Support networks essential for knowledge and support
- The whole experience can be very isolating
- Other young people with their parents (particularly those who had had diagnosis later in life 10 +) wanted to connect with young people like them that had been through the process of before
- Parents also wanted to connect - it appears that parents with very small children are instantly linked to the charity and support circuit - less so with teenagers
- Would be helpful to have more of a support network.
- It would be good if appointments were grouped by age so that you can meet people of a similar age while at hospital

Continuity of care

- Having the same consultant/surgeon is very important
- Getting to know and being known by hospital staff makes hospital life easier
- Dosing advice is different at local hospitals – there needs to be continuity in all areas
- When doctors give different views and opinions

Life

Many of the children and young people that we met stressed that for them, the most important thing whilst in hospital is maintaining some level of normality. They wanted us to know that even though they have congenital heart disease, they have to stay in hospital and they need to have different procedures and operations throughout their lifetime, all they really want is what everyone wants, to enjoy the life they have.

So, where possible, the hospital/NHS/staff should try and facilitate that through:

- Eating with your family

- Exercising/playing sports
- Seeing/making friends
- Playing/chatting
- Learning – school, studies, exams
- Having boyfriends/girlfriends
- Watching television/listening to the radio
- Having access to social media/internet/online resources
- Home comforts

Ethnicity

NICOR's analysis of data from 13 paediatric surgery centres (12,186 episodes of care in paediatric heart surgery during April 2009 to March 2012 inclusive) showed that Asian ethnicity is associated with poorer outcomes (30 day post-operative mortality). This is a statistically significant finding.

Other categories of ethnicity (Black, Chinese and Other) did not have statistically different risk from the Caucasian category.

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