A report of visits to providers of Congenital Heart Disease services by Professor Deirdre Kelly

Preface

Between April and August 2014 I had the privilege of leading the visits to providers of CHD services. The report that follows describes what the team and I saw and heard. The visits were not an inspection but were part of a pre-consultation engagement prior to public consultation on the new combined standards for the management of fetal, paediatric and adult congenital heart disease in England. This report summarises the general themes emerging from the visits and highlights good practice, what might be done differently, challenges and opportunities for the service but in this preface I wanted to set out some personal reflections. Most of all I was impressed with the high quality of clinical work, motivation and dedication of teams across England and Wales.

Strengths

Although all units provide good clinical care for their patients and have similar outcomes in terms of mortality I noted that each had areas of particular strength that seem important in delivering a high quality service:

1. **Leadership**
   Clarity of leadership, often supported by strong executive management support and investment, clearly made a difference to the morale and functioning of the service. Leadership can come from key clinicians or managers, including the Chief Executive.

2. **Multidisciplinary teams**
   Good relationships between specialists and the wider multidisciplinary team, particularly with clinicians at outreach or network centres, were a particular strength which contributed to a smooth and seamless patient pathway.

   Those units with a strong motivated multidisciplinary team, which included social work, psychology, nutrition and a transition team, tended to provide a more rounded patient experience which was strongly valued.

3. **Specialist Nurses**
   I was particularly impressed with the key role played by specialist nurses who included Advanced Nurse Practitioners, Liaison Nurses, and Transition Nurses.

   Units that had invested in significant numbers of specialist nurses demonstrated a more cohesive patient pathway which was strongly supported and appreciated by families. Specialist Nurses provided the main communication between the clinical team and families in many cases which was especially vital for transition.

4. **Networks**
   I noted that the key to an effective network was adequate resource and management
support. Clarity of roles, responsibilities and good working relationships are essential to ensure effective networking.

5. **Patient Experience**
Some units were more focused on ensuring a holistic patient experience than others. These units tended to have more specialist nurses, a stronger multidisciplinary team and on site family support either through social work, psychology or support groups.

**Challenges**

1. **Facilities**
I saw many high quality facilities, both adult and paediatric, but in a number of units the facilities were not “child friendly” or lacked adolescent facilities reducing the patient experience.

2. **Network Development**
In some areas network arrangements with referring hospitals, their local hospitals or with other collaborative centres seemed less good. Defined pathways of care and network working would be beneficial.

3. **Relationships**
I heard many comments about poor relationships following on from previous reviews. This reduced the ability of centres to work collaboratively or seek second opinions. This is not in the patients' interest.

4. **Transition Services**
The quality of transition varied between units and was dependent on the presence of key workers, transition nurses and good relationships between paediatric and adult sites. This was particularly an issue for patients moving to different units and for patients with learning disabilities for whom additional provision needs to be made.

5. **Level 2 Specialist Cardiology Centres**
We visited a number of these centres, some of which had previously had cardiac surgery on site. We were impressed with the motivation and dedication of the teams. The success of these units depended very much on strong networking and the quality of relationships with the surgical centre.

I heard a lot about specific issues with the role of interventional cardiology in level 2 specialist ACHD centres. Resolution is needed about how these centres will network with the surgical centre in future.

6. **Workforce**
Many units commented on workforce issues, e.g. training cardiologists/cardiac surgeons, the need for additional psychologists and specialist nurses.

There was concern that the new guidelines and curriculum for scientists (perfusionists and technicians) would reduce the expertise and workforce required.
With regard to antenatal detection for CHD, there was significant concern about the need to train sonographers for antenatal detection of congenital heart disease.

7. Constraints
There were many common constraints across the units.

- **Retrieval capacity**
  The necessity for good retrieval services for both neonates and children were highlighted with a need to co-ordinate existing retrieval networks.

- **PICU Capacity**
  All units were concerned about PICU capacity, particularly in winter. This was particularly relevant for those units which carried out mechanical assist or bridge to transplant and those who performed ECMO procedures.

- **Scrutiny**
  Many units commented on the adverse effect of being under constant review and constant scrutiny.

**Introduction**

The new Congenital Heart Disease (CHD) review Team from NHS England visited the specialist adult and children’s congenital heart centres and adult cardiology centres. 16 centres in England and Cardiff were visited between 8 April and 15 August 2014 with the specific aim of communicating directly with clinicians and patients and their families about the review process and for the review team to better understand the review from the local team’s perspective.

To do this the review team:

- met with multidisciplinary clinical teams and managers, to hear about each individual unit and the work they do, areas in which they excel, current challenges they are facing and how they manage interdependencies with other services;

- met with patients, parents and local patient groups to hear about their experiences and concerns; and

- gave an update on the work of the review and answered questions in relation to the review.

It was an opportunity for the review team to engage with members of the teams and to be able to hear what specific issues were relevant about the service and what the review needs to address. It also provided an opportunity to consider the standards in the light of what we heard.
The visits were not an inspection but were part of a pre-consultation engagement prior to public consultation of the new combined standards for the management of fetal, paediatric and adult congenital heart disease in England.

The visits provided a first-hand opportunity to learn what was most important to those delivering services and to those using them.

**Description of the programme of visits**

**Units visited**
The review team led by Professor Deirdre Kelly visited a total of 16 centres: ten specialist paediatric cardiac surgical centres in England, three adult CHD surgical centres and three specialist CHD cardiology centres. Although the review is an NHS England review of services provided in England, the specialist cardiology centre in Cardiff was included in the visits, at their invitation, because of the close working relationship with the service in Bristol.

The visits all had the same basic agenda as suggested by the review team which was tailored by the local team to suit their organisation. The number of hospital staff and patient and public representatives varied with each unit visited. We spoke to over 150 patients and their families as well as many clinical staff and their managers and their feedback is summarised within this paper.

_The suggested agenda for each visit was as follows:_

**Presentations**

**Unit team:** an opportunity for the unit team to give an update about their service, the work they do and how it affects the Trust, CHD team and patients, as well as areas in which they excel, current challenges and how they manage interdependencies with other services.

**NHS England CHD review team:** an opportunity for Professor Deirdre Kelly to give the latest update on the review progress with an opportunity for questions and discussions.

**Tour of congenital heart unit:** an opportunity to meet the multidisciplinary team within the unit.

**Meeting with patients and parents:** an opportunity to update patients and parents about the review and to listen to their views about good patient experience and what could be improved.

**First round of Trust Visits**
Alder Hey Children’s Hospital NHS Foundation Trust
Birmingham Children’s Hospital, Birmingham Children’s Hospital NHS Foundation Trust
and Queen Elizabeth Hospital, University Hospitals Birmingham NHS Foundation Trust
Bristol Royal Infirmary, University Hospitals Bristol NHS Foundation Trust
Evelina London, Guy’s and St Thomas’ Hospitals NHS Foundation Trust
Freeman Hospital, Newcastle upon Tyne Hospitals NHS Foundation Trust
Glennfield Hospital, University Hospitals of Leicester NHS Trust
Great Ormond Street Hospital, Great Ormond Street Hospital for Children NHS Foundation Trust and The Heart Hospital, University College London Hospitals NHS Foundation Trust
John Radcliffe Hospital, Oxford University Hospital NHS Trust
Leeds General Infirmary, Leeds Teaching Hospitals NHS Trust
Manchester Royal Infirmary, Central Manchester University Hospitals NHS Foundation Trust
Royal Brompton Hospital, Royal Brompton & Harefield NHS Foundation Trust
Southampton University Hospital, Southampton NHS Foundation Trust
University Hospital of Wales, Cardiff and Vale University Health Board

Second round of Trust visits
Blackpool Victoria Hospital, The Blackpool, Fylde and Wyre Hospitals NHS Foundation Trust
Papworth Hospital, Papworth Hospital NHS Foundation Trust
Royal Sussex County Hospital, Brighton and Sussex University Hospitals NHS Trust

What we heard

This is a summary of what we heard; it does not necessarily reflect NHS England’s official position or imply our agreement.

This paper summarises the general themes emerging from the visits and highlights good practice, what might be done differently, challenges and opportunities for the service.

We have gone into great detail to reflect the many individual conversations that we had with staff, governors, patients and families as they told us what made the difference to their ability to deliver good care and to their lives.

The team were impressed with the high quality of clinical work, motivation and dedication of teams across England and Wales. The patients and families hold their clinical teams in high esteem.

Part one: feedback from first round of Trust visits

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

Networks only succeed when given a lot of time, energy and commitment. All parties have to want them to succeed. The team noted that the key to an effective network was
adequate resource and management support. Clarity of roles, responsibilities and good working relationships is essential to ensure effective networking.

Networks are about relationships built over the long term and effective network working is very dependent on individual relationships. Having named link consultants with good relationships with local paediatricians with expertise in cardiology (PECs) and Cardiologists with special interest (CWSIs) is crucial.

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

Protocols, guidance and shared governance help reduce variation. There is a need to define pathways of care and network working to ensure good network arrangements between the specialist centres and their referral hospitals, their local hospitals or with other collaborative centres.

**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.
Level 2 Specialist Cardiology Centres
Where level 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.

Level 3 Local Cardiology Centres/Local Hospitals

Local CHD Services
We heard about good work in many places to develop the role of PECs/CWSIs. Local level 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 there is poor consistency in delivery of services close to home: community nurses, health visitors, GP involvement, prescribing specialist medication, blood tests. Because the baby/child is in the congenital heart system, children and babies (and postnatal mothers) fall out of the normal health care/social system and struggle to get back in – health visitors, community nurses, midwives, GPs either aren’t involved, aren’t aware of the child, or are scared of the child and being involved in their health. Families are unaware of what is available locally to support other family members – particularly siblings.

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 and at times the staff did not appear to not know what they are doing or would act against the advice of the parents who are expert in their child’s condition.

Local hospitals do not consistently contact specialist centres for advice. 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. Lack of specialist staff locally makes parents feel isolated and rely on the specialist centre.

Once trust is lost in local hospitals it is very hard to get back, and means parents are dependent on one hospital and surgeon/specialist nurse and will travel great distances to get to the care they trust. Therefore local hospitals are bypassed in favour of specialist centres because of lack of faith in local hospitals to listen to them and families call the specialist centre for advice.
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 patient’s 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

Staffing and skills

**Specialist nurses**
The team was particularly impressed with the key role played by specialist nurses, which included Advanced Nurse Practitioners, Liaison Nurses, and Transition Nurses. Their roles help families navigate the health service, they provide counselling and support, resolve problems and educate. Specialist Nurses provided the main communication between the clinical team and families in many cases which was especially vital for transition. Parents also 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.

In some places it was noted that because numbers were limited the service that nurse specialists could offer was limited.

We heard that it was important to patients and families to have a liaison nurse in outpatients.

Units that had invested in significant numbers of specialist nurses demonstrated a more cohesive patient pathway which was strongly supported and appreciated by families. Those units that had not invested significantly in specialist nurses, psychology or a strong multidisciplinary team tended to have less focus on patient experience and provided less holistic care.

**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.

We heard concerns that the standards could push centres to do things they are not really capable of doing to keep up appearances or to make sure their case numbers are high enough. To avoid this there would need to be mechanisms in place to ensure that units are able to build up capability and competence safely over time rather than chasing case numbers or types.

**Cover for annual leave**
We heard that sometimes it is not clear who is in charge of the patient when the consultant is away on leave and that there needs to be a clear direction of care in times of absence.

**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.

**Sonographers**
With regard to antenatal detection for CHD, there was significant concern about the need to train sonographers for antenatal detection of congenital heart disease.
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 and many units commented on this. There were also concerns about the training pipeline. 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; there were concerns about the ability to recruit extra specialist nurses. We were told that it was important that there was the right number of nurses on cardiac wards with specialist training but also basic training such as recognition of the deteriorating patient.
- **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 new guidelines and curriculum changes resulting from Modernising Scientific Careers meant that appropriate Masters level training is no longer available which would reduce the expertise and workforce required.
- **Psychologists** – there were concerns about the need to recruit additional psychologists.
- **Cardiologists** – concern about whether it will be possible to attract high quality cardiologists to work in level 2 units, particularly in paediatrics.

Facilities
The availability of good facilities makes a huge difference to patient and family experience. We saw many high quality facilities and clinical care, both adult and paediatric but in a number of units the facilities were not “child friendly”. Specific facilities for teenagers and young adults (clinical and social) could be better developed.

Some families said that hospitals could usefully 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 eat and live in the hospitals. Some hospitals provided good facilities for parents to be able to eat nutritious food as well as reducing the cost of living in hospital.

**Interdependencies**

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. But simply 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.

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

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.

**Combined Adults and Paediatric Units**

The team visited a number of units with fetal, paediatric and adult services on site providing a single congenital heart disease service ranging from fetus to child to adult. It was suggested that this approach had significant advantages for the patient pathway and experience with continuity between the services.

**Critical care (both children's 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 the importance of ICU was often emphasised.

**Organisation, governance and audit**

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

We heard concerns about how robust the proposed governance arrangements might be, and whether risk would be appropriately managed. The standards should address how units should manage risk when they come under pressure, for example when PICU beds are full.

We heard support for the publication of data to allow patients to compare units/surgeons but concern about how accessible and easy to use this would be.
The standards require centres have to report adverse incidents. We heard concern that more needed to be done to define this process – both what counts as an adverse incident for the purposes of reporting and to whom are they reported? How would a culture of openness and candour be fostered? Who then investigates and is the investigation properly independent?

We heard that when investigations were necessary they were often prolonged and families did not always feel that they were kept informed. This was important even when there was nothing to report. With that in mind there was agreement that the draft standards regarding reporting of adverse incidents, in addition to the use of a robust database with links across the network.

**Research**

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.

**Communication with patients**

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 told us they 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 to be consistently good – where this is not the case it requires urgent and thorough improvement, because poor communication undermines other good aspects of the care. The review team were told that it is 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**

Some parents said that when they see a new doctor they have to explain the child’s history again. The clinician may disagree with the last consultation – this is unsettling for patients and families.
Facilities are not always children/special needs friendly.

Multiple visits sometimes occur close together to see several specialties; this is not satisfactory from the patient’s perspective.

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 is written down (including medications) to share with health professionals.

**Discharge from hospital**

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 can cause unnecessary distress for patients. Arriving home with a new baby after several months in hospital means that parents and the baby have missed some basic things like: registering for child benefit, taking hearing tests, and being given the “red book”. The red book has a section for complex health needs – not always completed in the hospital – which would be a good means of communication.

It helps when hospital and community services connect before discharge: arranging for the family to meet community staff in the hospital where possible before discharge. Being discharged late in the day whilst waiting for reviews, medications and so on also causes distress.

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

**Transition**

The reported quality of transition services varied between units and we were told was dependent on the presence of key workers/transition nurses/good relationships between paediatric and adult sites. This was particularly an issue for patients moving to geographically distant units. 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. The review team were told that the CHD standards need to connect with what is happening in transition nationally.

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

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 were identified which 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.

**Learning difficulties**
Transition is especially difficult for patients with learning difficulties and their families. We heard that a more flexible approach is needed for these patients and they need better support in adult services.

**Pregnancy and contraception**
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.

**Fetal diagnosis**

*Improving rates of fetal diagnosis*
Rates of fetal diagnosis vary considerably. National standards for a screening programme to look for CHD at 18-20 weeks were introduced in 2010, but in some areas these have not yet been fully implemented. Some locations/units are struggling just to offer the 20 week scan consistently at all.

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

- Training for sonographers:
  - There needs to be training and support for sonographers.
  - Adequate funding for Sonographer training.
  - 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 initially told it might be one diagnosis and that she could terminate the pregnancy, then at the next scan there was another diagnosis and different advice.
- 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 was 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 high risk women work well

Palliative care and bereavement
We also heard about experiences when there were poor outcomes for patients, in some cases the death of a child. Care of the parents and families at those times is needed more than ever and we were told that this was not always consistently given.

We were told how important it was that parents and families were informed of the prognosis and be part of any discussions about end of life care.

We heard how important it is for grieving parents to have their loss acknowledged by hospital staff, and that this did not always happen. There was agreement with the addition of bereavement standards particularly in relation to training on end of life care, breaking bad news and supporting children, young people and their families through loss.

Dental
The development of dental standards was welcomed.

Other issues
Making it happen
We heard concern about how the standards would be enforced. The point was made that having standards by itself achieves nothing unless they are effectively implemented. We were told that there needed to be further consideration of how people were held to account for delivering the standards – networks, peer review and so on are all very well, but do the standards have real teeth? How would trusts be held to account and by whom?

We were told that patients and families should be made aware of the standards they can expect and these should be shared with them in a timely manner.

Paediatric Intensive Care Unit (PICU)
We heard that inconsistent nurse staffing on PICU means that parents feel they must be present at every handover to provide continuity, so as a result some parents felt unable to leave their child; the days are very long and there is no chance of doing anything normal like washing their clothes. Parents may be up all night and need somewhere to sleep in the day without leaving the hospital.

The mother would like to be at baby’s bedside (particularly difficult in Children’s hospitals not on the same site) and maternity/lactation care is missed as the focus is on the baby.

There is an inconsistent approach to parent involvement in caring for their child – some fully involved in feeds, nappy changing, bathing and others not, therefore they are unprepared for the lower staffing levels on the ward. Step down from critical care wards can be difficult - parents are not always informed of or prepared for the ward routine on arrival, e.g. expectations are that 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.
Some things that may 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 must be included as they use the same resources as CHD.

**Care for adults with CHD**
We heard that:
- The numbers of patients with Adult CHD will increase in the next 30 years. It is important to build a network approach because it is not possible to handle it all within a single centre. The main need is for outpatient management and imaging, not for more surgical centres.
- 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 repeat operations, many have already had multiple operations. Repeat operations are not easy because of multiple surgical procedures.
- Interventions need specialist skills and should be centralised.
- 95% of complex patients are followed up but less complex patients are not 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 the full range of services they need are not all available in one site, or are not provided at all.

**Support groups**
When there was no specific support group associated with a unit, parents felt the lack keenly.
- There needs to be a stronger connection 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 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.
Part 2: Feedback from second round of visits

Model of Care

The role of level 2 Specialist ACHD Centres

We heard from several centres (during the visits and at the Clinicians’ Group) that there was a rationale for allowing Level 2 specialist ACHD centres to continue to carry out interventions on adults with recently diagnosed congenital heart disease (in contrast to adult survivors of childhood congenital heart disease) providing this was in the context of a congenital heart network, and that all patients were discussed at the network MDT (multidisciplinary team) meeting. While the need for MDT discussion was acknowledged, we heard that this did not happen at all centres currently.

These centres considered that continuing to provide interventional cardiology at level 2 specialist ACHD centres would be safe in this limited group of patients. They noted that the need for surgical back-up was extremely rare, and that in their experience, if a surgeon was needed this would be a vascular surgeon rather than a congenital heart surgeon. They also stated that the majority of cases were currently done outside the specialist surgical centres and that the specialist surgical centres would struggle to cope with the volume of demand if the proposed standards were enforced.

All those we spoke to agreed that level 2 centres should only undertake procedures in straightforward cases:

- Level 2 centres should only undertake simpler procedures – mainly uncomplicated ASD repair in adults with recently diagnosed disease
- Patients who had been diagnosed in childhood and had previous surgery or intervention in childhood would only receive their care at the specialist surgical centre.

We were told that in addition to interventional cardiology, level 2 ACHD centres have an important role in the ongoing care of ACHD patients. We heard that level 2 centres are needed to provide this service as the number of adults living with CHD continues to rise. In addition it is more convenient and provided local access for patients.

We heard that not all adults with CHD are being followed up by cardiologists with expertise in congenital heart disease. Some are being cared for by general cardiologists in local hospitals; others have been lost to follow-up, suggesting there could be significant unmet need.

We heard there were mixed experiences of ongoing support. Adults with lifelong congenital heart disease were generally supported by the local service, whereas those considered to have more minor conditions diagnosed in adulthood were not always so well cared for.

Where this support was available, patients appreciated being able to receive their care locally, particularly for follow up and after transition. We heard that patients who transitioned from surgical centres in London often preferred to be followed up locally. The
medical teams spoke about the outreach clinics and network arrangements that allow this to happen.

Patients felt that local centres provided them with continuity and remembered them when they came back. They had easy access to the nurse – especially by email which reduced time wasted trying to call them, or waiting for them to call back. In other cases however, there was no access to nurse specialist support.

Those with more minor conditions did not see their condition as minor, in fact were very fearful of a “heart” condition that made major impact on their lives. Patients we spoke to felt that the service and support they received from the hospital teams was good but that there were no clear channels for advice/information outside the team.

We heard positive stories about the care received by women with CHD during pregnancy.

**Next steps**

The review team were extremely grateful for the opportunity to visit the units and for the input received as summarised above. The outputs from the visits are an important contribution to the standards.

Feedback from the first round of visits was included in the paper “Clinical Advisory Panel review of proposed CHD standards” and considered by the Clinical Advisory Panel (CAP) at its meeting on 18 June 2014 when the standards for consultation were agreed.

A number of visits took place after the date of the CAP meeting to agree standards for consultation. What we heard on those visits was therefore not taken into account when CAP made its recommendations, but will be considered when CAP next meets.

**The Programme Board is asked to:**

- note the content of Professor Kelly’s report.