

The response of the Children's Heart Federation to the consultation: Safe and Sustainable - A new vision for children's congenital heart services in England

About Children's Heart Federation

The Children's Heart Federation (CHF) is the leading national charity and the umbrella body for voluntary organisations working to meet the needs of children and young people with congenital and acquired heart conditions (CHD) and their families. Our vision is that all children with heart conditions have both their medical and social needs met so that they can live life to the full.

Working for every family affected by CHD

The charity has 21 member groups which have a focus either on a specific heart condition or have a geographical focus, providing support to families in a region or connected to a particular paediatric cardiac unit. CHF's remit and focus is broader – we provide support for CHD families wherever they are in the country and we campaign, as the 'voice for CHD families', for high quality services for every family affected by CHD. CHF works closely with GUCH P.A., the national organisation for adults with CHD, and while our focus is on children and young people, we are concerned that high quality lifetime CHD services should be available, from before birth to end of life.

Campaigning for higher standards in children's heart care for 10 years

Our mandate in the area of the Safe and Sustainable review is based on parents asking us to press for the introduction of the highest possible standard of heart surgery after the Bristol Inquiry. We have been campaigning for the adoption of the recommendations of the Kennedy Report for the last ten years. Findings from the Oxford Inquiry and Pollock Report last year show that without externally enforcing the standards, including monitoring and reviewing outcomes, units will not necessarily adopt the best practices and perform to the highest standards.

Without changes, the cracks already seen in the children's heart care service will widen – some children will die unnecessarily and some will suffer avoidable side-effects of treatment; without reorganisation, failures of the current service -- long waiting lists for surgery and cancellations -- will persist.

For CHF, no change is not an option. We believe that the standards developed through the NHS Specialised Services Safe and Sustainable review must be brought into practice at the earliest possible opportunity. Whilst pressing for safeguards for children and young people currently receiving treatment who will need further surgery in the future, our primary focus is on making change now to improve the services for the next generation.

To that end, fully backing the aims of the Safe and Sustainable process to achieve excellence in treatment and care for children with CHD wherever they live in the country, we make this response to the consultation *A new vision for children's congenital heart services in England*.

Basis of our response

Our response to the consultation draws on input from:

- CHF Member groups;
- Parents who have contacted us through our information service or at events;
- Points raised through CHF's social media activity;
- Survey about the proposed changes to children's heart surgery commissioned by CHF and delivered by Ipsos MORI in autumn 2009;
- Participating in all the public engagement and consultation events within the Safe and Sustainable review.

As a national charity, we also participate in many discussions about how to improve treatment, support and care for children and young people with CHD at steering groups, committees, specialist meetings and informal settings with a wide range of professionals and practitioners in the field. Our response reflects that wider context.

Key messages

Beyond the message that ‘the time for change is now’, the most important points we wish to draw to the attention of the Joint Committee of Primary Care Trusts (JCPCT), as it reviews the responses from the consultation before deciding on the configuration of the children’s heart care services of the future, are summarised below and developed in the rest of the document:

- **High quality treatment is the top priority for parents;**
- **Parents want equality of access to services;**
- **Needs of acquired heart disease patients can vary from congenital heart patients;**
- **CHF supports implementation of the consensus standards, including the core proposals to:**
 - **Bring surgeons together to work in teams of at least four, performing at least 400 operations per year as a team (ideally up to 600);**
 - **Support and sustain the development of excellent cardiology services in all the units that currently provide specialist children’s heart care, whether or not they continue to offer surgery;**
 - **Develop effective children’s heart networks that provide care as close to the child’s home as possible, including building up the network of paediatricians with expertise in cardiology.**
- **CHF is not supporting any particular unit or configuration option;**
- **Implementation planning must address difficulties caused by the reorganisation (especially where there is increased travel, need for accommodation, need for support during long stays in hospital and need for support for adjustment to new arrangements);**
- **Making data accessible that allow parents to understand the quality of service throughout the system must be a priority.**

CHF’s recommendations about changes we would expect to see as the Safe and Sustainable process moves forward appear in **bold body copy**.

High quality treatment is the top priority for parents

Throughout the Safe and Sustainable review process, many parents have declared in these or very similar words: ‘I would take my child to the ends of the earth to get the best possible surgery’. High quality of life outcomes for their children are a higher priority than access issues in relation to surgery.

We would urge the JCPCT to set in train moves to a configuration that achieves the highest possible outcomes from surgery at all surgical units.

We note that the vast majority of children who need heart surgery need only one operation. As expertise increases and new approaches to surgery are introduced as the result of implementing the new standards, we would expect fewer children to need more than one operation.

We note the trend to shorter hospital stays following surgery, which can be a shock to parents. **We would expect discharge planning routinely to start much earlier, from the time of admission to hospital or even before.**

We also note that outcomes from surgery do not depend on the skills of the surgeon alone, but include the need for strong clinical leadership and high quality performance across the whole team.

In the light of experience that rebuilding the team at Bristol after the Baby Tragedy was possible, we accept that any of the units currently within the pool of potential surgical centres could provide surgery in the future to an excellent standard. We also note that:

- No units currently comply with all the Safe and Sustainable standards;
- The units that scored lowest for quality in Sir Ian Kennedy's Independent Expert Panel review will have furthest to travel to meet the new service standards;
- Rebuilding the team at Bristol involved radical staffing change;
- It seems counterintuitive to disband a high performing service to achieve quality in the national configuration and we understand that this may be necessary.

As building effective teams often takes several years we would expect implementation plans at all units to safeguard the health of children with CHD during a time of service change. We would expect particular attention to clinical leadership and change management at centres that have the most improvements to make.

As more and more children with heart conditions are surviving into adolescence and adulthood, CHD services need to be planned and function as a lifetime service. **We would expect to see the development of high quality antenatal screening services, eliminating the current variation, in all parts of the country.** We are aware that draft guidelines for GUCH services were issued by the Department of Health in 2008 and are pleased to note that in the next few months these are being reviewed, with a view to designating GUCH centres by the end of the year. **We urge the JCPCT to take the outcome of that review into consideration, specifically in relation to the designation of GUCH surgical centres. We would expect to see transition services being planned with significant input from young people and young adults with CHD.**

One of the most important indicators of a high quality service for parents is that their child should be seen as a unique individual, not an 'NHS number', and his/her specific needs should be recognised by the unit in which he/she is treated. Parents place a very high value on the relationship they build up with the team at their treating unit. With the continuance of cardiology at all centres, this feeling of 'being known' should remain more intact than many parents fear. However, we note that being designated as a surgical unit, with the increase in caseload that entails, will make it harder for centres to maintain the 'personal touch'. **In implementation planning, we would expect surgical units to work with service users to understand which features of their service delivery culture and practice are critical in delivering a high quality care experience. In the light of that knowledge, we would expect surgical units to have ongoing plans to monitor and improve these 'softer' and yet highly valued dimensions of their service.**

Surgery is a particularly stressful event that raises many questions and concerns that patients and their families want to address to the team treating them. Additional distance from the treating centre and treating team make it harder to achieve the familiarisation that is an important part of preparation for surgery. **We would expect best practice about remote pre- and post-operative communication and support between service users and clinical teams to be disseminated and adopted.**

Parents want equality of access to services

Most parents accept that to achieve high quality surgical outcomes involves consolidating surgery into fewer, higher volume units with the consequence that some families will have to travel further for surgery. The campaigns at Southampton and Leeds have highlighted the need for the final configuration decision to reflect accurate, natural patient flows from all parts of a hospital's catchment, bearing in mind that parents may always opt to take their child to a treating centre that is not their nearest unit and taking account of the quality of the local transport infrastructure, impact of severe weather conditions and local rates of population growth or decline. We are persuaded that the patient flow modelling that underpins the review has generally been high and are also glad that additional modelling has been undertaken in key postcode areas because it is important to demonstrate that the process has been fair, accurate and not 'fudged' or 'fixed'.

We appreciate that for macro political reasons, the overall clinical need and configuration for Scotland was not included in the review. If the clinical outcomes rationale of teams of at least four surgeons performing at least 400 operations applies in England, we would expect the same logic to apply in Scotland. We anticipate that applying that rationale would have a knock-on effect for English centres, particularly the Freeman Hospital in Newcastle and would **urge the JCPCT to make their decision mindful of the potential impact of changes to the configuration in Scotland.**

Many parents have concerns about having to travel further to surgical centres. These concerns fall into two main areas:

- Family support;
- Safety for very sick children.

Family support: travelling for surgery involves costs and many logistical challenges (including fares, arranging appropriate transport, accommodation and living expenses, loss of earnings, childcare, support when isolated in an unfamiliar environment). We are particularly concerned about the impact of longer and/or more complicated journeys on CHD families with low incomes, no access to a car, difficulties in using English and on families whose children need to travel most frequently or have the longest stays in hospital.

We would expect implementation planning to include work on relieving travel-related stress:

- **Alternatives to public transport being made available where needed to CHD families without use of a car, including hospital car schemes;**
- **Gathering and disseminating information about sources of funding to help with hospitalisation-related costs;**
- **Planning specifically to support the few families in each region who will need to spend long times and/or make frequent visits to a more distant surgical unit. As these numbers should be predictable looking at case mix, we would expect work on developing funds and care pathways to support long-stay families and those who use services often, so that support is available without delay and for as long as required;**
- **Disseminating learning about how to provide good quality support to families during periods of distant and/or extended hospitalisation from services in which travelling and extended stays are the norm, such as the transplantation service.**

Safety for very sick children: many parents are not persuaded by the standards around retrieval because their experience of ambulance services is that vehicles are poorly equipped for children and the attending staff lack age- and condition-specific knowledge. Whilst CHF is happy to accept the configuration planning based on the Paediatric Intensive Care Society's retrieval standards, **we expect to see the resourcing to meet the standards to address deficits in equipment and staffing.**

Some parents are unclear about the practice of stabilising a critically ill child before it is moved to the appropriate centre for specialist treatment and are concerned that the timescale is unnecessarily long and puts their child at greater risk. **We urge that parents are involved in modelling emergency care pathways as early as possible in the implementation process and that the learning from that modelling is very well disseminated.**

Needs of acquired heart disease patients can vary from congenital heart patients

For much of the Safe and Sustainable review, materials have described it as a review of ‘congenital heart services’. While many of the Safe and Sustainable proposals are generalisable to children and young people with congenital and acquired heart conditions, the requirements of patients with acquired heart conditions are different in some respects – particularly around diagnosis and the use of devices.

We would expect implementation plans to respond to the specific needs of children and young people with acquired heart conditions.

CHF supports implementation of the consensus standards

We note that since at least 2006, there has been very broad sign-up across the relevant professional bodies and parent groups to the principle of bringing surgeons together to work in larger teams handling higher volumes of cases. Tension has arisen at the point of moving from the principle to the specifics of which units should continue to provide surgery.

Surgeons working in larger teams: we support the proposal to bring surgeons together to work in teams of at least four, performing at least 400 operations per year as a team (ideally up to 600) on the basis of the rationale made in the consultation document. We believe that larger teams offer the potential for sub-specialisation that is critically important in the treatment of rarer conditions.

We understand that there is a live debate about whether the rarest conditions should be designated to be treated at a subset of the units, following the precedent of heart transplantation, to ensure high enough clinical volumes at those units to get the best outcomes. **CHF does not take a view on this matter, but would expect the Safe and Sustainable programme to draw on the expertise of more specialist organisations, such as Little Hearts Matter.** In relation to the dissemination of new techniques, we note that unregulated occasional practice has been a disturbing feature of children’s heart surgery in this country. We applaud the desire to innovate and recognise that some patients’ lives have been saved because one unit has been prepared to try out a technique that is not available elsewhere. At the same time, **we would expect to see innovation occurring within a proper context of planned research and peer review, so that applying new techniques is never ‘dabbling’.**

We note that new consultant surgeons these days will not necessarily have had the opportunity to build up as much hands-on surgical practice as former cohorts of new consultant surgeons. **We understand that David Barron is leading the work on developing an accredited training programme for surgeons and we would expect to see this in place as soon as possible.**

Support and sustain the development of excellent cardiology services: we share the concern that has been raised (for example by Ted Baker at the Oxford Consultation event) that more work is needed to describe and specify how the Children’s Cardiology Centres would work. We are persuaded by the precedents of Cardiff, Manchester and Edinburgh that cardiology centres can provide effective, specialist cardiology care without the presence of surgery.

We would seek clarification as early as possible about whether or not interventional cardiology will be provided in non-surgical units and, if it is not, what the plans are for reviewing that decision over time in the light of developments in this field. We would expect the relevant professional bodies to work on the detailed service specifications for Children’s Cardiology Centres, job profiles for non-interventional cardiologists and professional development plans that ensure that health-

care professionals normally based outside surgical centres can keep up their expertise, to avoid the development of a two-tier cardiology service. We would expect clinical leadership across the network to be strong to ensure effective co-ordination of care at every level.

Develop effective children's heart networks: one of the most exciting aspects of the proposed reconfiguration is the development of networks of support at community level.

Parents frequently express anxiety that at primary care level (particularly among GPs and health visitors), in A&E departments and where a child needs treatment that may impact on his/her heart condition (e.g. an operation to correct a squint) there is poor understanding of CHD.

We hear far too many stories of late diagnoses when non-cardiac healthcare professionals miss or do not act on tell-tale symptoms. Children with acquired heart disease and those not picked up antenatally are most likely to be missed. **We would expect to see specialist units providing necessary cardiac skills- and awareness-training to non-cardiac healthcare professionals in the community, so that heart conditions are diagnosed as early as possible and treated as effectively as possible. We would also expect the necessary investment and planning to enable access to good local diagnostic facilities.**

We would expect to see funding and planning focused on building up the cohort of paediatricians with an expertise in cardiology as quickly as possible. We would expect their work to be supported by the necessary telemedicine and records-sharing technology, so that they can advise more generalist healthcare colleagues and collaborate with cardiac specialists. The ambition for children's heart care must be that wherever the child presents in the healthcare system, at that moment and moving forward, his/her cardiac needs can be managed in a timely and appropriate way to achieve the best possible clinical outcome.

We would also expect to see investment in developing the network of children's cardiac nurses working in the community.

Continuity and consistency of care as children move between treating teams and different service providers is vitally important to parents. This is a particular concern where children have complex co-existing conditions -- such as a heart problem, digestive problems, breathing difficulties and a learning difficulty – for which they come under the care of several different teams. Parents expect that clinicians within institutions and between institutions should communicate with each other well – and, unfortunately, in this key aspect of care management, often feel let down. **We would expect to see the co-ordination responsibilities for clinicians (cardiologists, paediatricians and specialist nurses) to be clarified, to ensure clear lines of communication and accountability.**

Crucially, as the primary providers of care, care management, transport and advocacy for young CHD patients, we would expect parents to be treated as part of the local care team and for them to have direct access to cardiologists, other professionals and information about their child's condition and treatment as needed.

CHF is not supporting any particular unit or configuration option

While we support the implementation of the Safe and Sustainable standards, CHF is neither aligned with any particular unit nor supporting any particular configuration option. As a national charity working on behalf of all children with CHD, it has not been appropriate for us to back any campaign in favour of a particular unit.

Some of our member groups are supporting a particular option and have responded separately, in detail, to the consultation (for example Little Hearts Matter and Wessex Children's Heart Circle support Option B); other groups (for example HeartLine Association and Downs Heart Group) have not expressed support for a particular option but wish to see standards improved across the heart care network, in line with the campaigning activity of many years, other groups (like South West Children's Heart Circle

which highlights the good practice at Bristol or the Children's Heart Unit Fund which promotes the work of the Freeman Hospital) are supporting the service provided by the unit with which they have particular links and support improvement across the whole network.

Many parents have a strong loyalty to the unit where their child has been treated and so will support the option that they feel gives that the unit the best chance of continuing to offer surgery. CHF respects the views of those parents and their right to express them. At the same time, we believe that it is vital that the decision regarding the reconfiguration should be based on the creation of a national service with clear managed networks rather than the continuation of the present regionally-based surgical services with ad hoc referral pathways.

The length of the review process has caused a high degree of uncertainty and anxiety among parents about where their children will be treated. Whatever the JCPCT's decision about the configuration of services, **we would urge the Safe and Sustainable team to ensure that families receive clear information as soon as possible about the impact on their child's care pathway** (bearing in mind their right to patient choice). **We suggest that particular attention is paid to communications during the transition period, with a central helpline and/or information and advice-giving service at each of the current units, so that parents have an authoritative and caring contact point to air their concerns. Parents should be involved in planning this service** and, if supported to increase its capacity, CHF could provide such a contact point. With hindsight from the Bristol Tragedy, we would anticipate the need for counselling support to be available for some parents who feel that have made a 'wrong decision' around the treatment for their child.

Implementation planning must address difficulties caused by the reorganisation

Frustrating as it has been for some parents, we accept that detailed planning of many aspects of the service is not possible until the configuration is agreed. We have already highlighted examples (see *Family Support*) of issues that will need addressing during implementation.

One specific support need is for families whose children require ongoing care from a surgical centre that is different from their current unit, particularly when the child has a learning difficulty that makes it hard for them to adjust to change. Seven out of ten children with CHD have a learning difficulty or developmental delay, so communication to support them in understanding their care now and in the future requires particular expertise and skill, both directly with the children and also supporting parents as the child's main advocate and care co-ordinator.

We would expect service users (parents and CHD patients) and the voluntary sector organisations that support them to have an integral role, as equal partners with clinicians and managers, in the planning and monitoring of the services. We would urge the Safe and Sustainable team to pay particular attention to involving representatives of the frequently marginalised groups identified through the health impact assessment as especially vulnerable to service changes (e.g. black and minority ethnic groups, people with low literacy, economically deprived service users, families of children with complex co-morbidities).

Making data accessible that allow parents to understand the quality of service

CHF warmly welcomes the drive of this review towards more comprehensive collection and publication of data that describe the outcomes of the children's heart care service.

We note that some children die before surgery and that currently, these deaths do not show up 'on the radar' of the national cardiac audit database. In order to prevent any avoidable pre-surgery deaths, **we urge that improvement planning for the children's heart care service of the future should include a review of pre-surgery deaths.**

CHF has been very disappointed by the lack of transparency in the some parts of the children's heart care service over the lifetime of this review. We have observed some clinicians portraying the results from their unit as exemplary when they have not been and we have seen some clinicians and trusts scaremongering about the impact of the proposed changes.

Individual parents and groups of parents who have no other comparator than their experience of their own unit tend to be very trusting. They are desperate to believe that they are making the right choices for their children and that the service at their unit is exemplary, even if it is not. When the Bristol tragedy came to light, some parents were quoted in the media angrily defending their unit against 'unfair' criticism. We have seen the same behaviour surrounding Oxford.

CHF understands the loyalty parents feel towards their unit and supports the right of every hospital-linked group to campaign to save their service. We believe and are glad that for most children, in most places, most of the time, the quality of children's heart care is very, very good. But this is not good enough. Through all our information sources, we are aware that the children's heart care system is not always safe and it certainly isn't sustainable. Indeed, some of CHF's member organisations have criticised CHF for colluding with the message that the existing service is safe at the start of the Safe and Sustainable review, when clearly the service is not completely safe. Without unnecessarily alarming parents, we now act decisively when we become aware of potentially unsafe working practices within the national service.

In the absence of morbidity data that enable comparisons in terms of quality of life after surgery, CHF has listened carefully to what clinicians say, usually off the record, about variance in quality across the service. Professor Sir Roger Boyle caused a sharp intake of breath when he publically stated what has often been privately reiterated - that there are children's heart surgery units where he would not want to send a member of his family. If services are sub-standard, action must be taken to protect children. When CHF has followed through on concerns raised through triangulating information from our groups, helpline and clinicians speaking 'off the record', we have met with hostility and a closing of ranks by professionals.

Whilst we understand the impulse not to criticise 'one's own', CHF asserts that professional loyalty must make way to protect children. Problems at Bristol were known for 12 years before they were brought into the open, during which time children died and were damaged by substandard treatment. This culture is unacceptable. Although this review has focused on surgery, we note the critical role of the cardiologist as the referrer to a surgical service. If cardiologists had stopped referring into Bristol when concerns about the quality of surgery began to emerge, the scale of the tragedy would have been greatly reduced. **In the future we would expect cardiologists to stop referring into a unit if there are serious doubts about the quality of surgery for any particular procedure that a child may need.**

In our role as a provider of information to parents, including information about the performance of different units (we refer parents to the CCAD database), we have been told that performance data should not be made public because parents would not understand it and would misinterpret it.

To move forward, we expect more detailed surgical outcomes data – to include re-operation rates and morbidity data - to be collected and published in ways parents can understand, to allow them to make informed decisions about where their child should be treated, as a matter of priority.

Having noted above the professional loyalties shown during this review, we must also highlight unhelpful and unsavoury cut-throat behaviours. Clinicians (and parents) have commented on the 'nastiness' of the adversarial stance adopted in some quarters. Once the decision is taken about the configuration of services, there will be a lot of team-building to do.

To conclude, we would reiterate our key point that implementation of the standards should begin as soon as possible. We have gone on record to urge everyone - politicians, clinicians, health service managers and parents -- not to stall this vital change process but to see it through to the end. Necessity has been the mother of creative thinking and practical collaboration in the new working arrangements between Oxford and Southampton. Learning from other change programmes, including the creation of the cancer and stroke networks, demonstrates that where there is a will, there is a way. At the centre of the implementation process, we **would expect to see attention paid to creating and sustaining a culture of collaboration across the national paediatric cardiac service for the benefit of those it serves: children and young people with heart conditions and their families.**