



Welcome...

We must grasp the present opportunity to change and develop children's heart surgery services in England. If we embrace change we can develop services that are better, safer and more sustainable says Professor Sir Bruce Keogh, the NHS Medical Director. Sir Bruce was speaking at the first *Safe and Sustainable* programme stakeholders' conference.

"Almost two hundred parents, clinicians, charity representatives and health service managers gathered in London on 22nd October 2009 for a day-long conference to discuss the future of the children's heart surgery service in England. In my video welcome to the conference I explained that I had commissioned the present review of services because despite the fact that the Kennedy inquiry and the subsequent Monro report had called for service reconfiguration I had seen little progress. Many people are disappointed that progress has been slow, not just professionals but also patient groups, because they feel that services would be better if they were concentrated in fewer centres.

"There are some very significant issues that need to be addressed and they need to be seen not just in the light of improving the services but also ensuring they are safe and sustainable for the longer term and that parents can rely on them. But at the same time, we have to consider the considerable strains that parents have to endure when their children are undergoing very complex surgery and by that I mean issues of travel and accommodation.

"The *Safe and Sustainable* programme will be challenging for everybody. It is going to be challenging for the professionals because they will have to put their own aspirations and ambitions aside, not just for their personal interests, but also for the interests of their institution. The interests of the NHS and the citizens of this country must be paramount.

"In my view the measure of a civilised society is how well it looks after its most vulnerable members. I think that we have a moral, professional and social obligation to develop truly safe and sustainable children's heart surgery services. We must not shy away from this challenge in the face of personal conflict or institutional interest, because failure to solve this will be a stain on the soul of the specialty which we must all share because it would compromise the treatment of the most vulnerable members of the next generation."

Professor Sir Bruce Keogh, KBE
NHS Medical Director

The first *Safe and Sustainable* children's heart surgery services event was designed to engage a range of people from across the country who care about the future of children's heart surgery services in England.

Clinicians, parents and NHS staff had the opportunity to ask questions about the draft service standards and contribute their views in order to shape the work of the programme.



To set the scene for a day of complex discussions, we asked an expert on heart surgery services called Harrison Stedman to address the assembled stakeholders. 11 year-old Harrison was diagnosed with velo-cardio-facial syndrome (VCFS) when he was born and has undergone four serious heart operations and countless cardiac catheter procedures.

Proudly taking centre stage, Harrison told the audience, "I want to know that the doctors and their teams working on me are the best. If I get poorly during the night, I want to know that someone can help me, even if the problem isn't with my heart. I was very poorly during the night after my operation in July. I needed all the doctors who got up to treat me. I want to know that my mum and dad can stay with me in the hospital. I want to have fun things to do when I'm getting better – but no school work please!"

Harrison's father Bernard urged delegates to think about children like Harrison over the course of the day and explained that the quality of the specialised service is more important to parents of children with heart problems than their location. "Most of us have to travel anyway to attend our designated hospital, so the impact to us isn't necessarily negative and as we want to stay with our children, it makes no difference if we need to travel any further."

But Bernard drew a clear distinction between the location of surgical centres and the location of outpatient facilities for more routine procedures. "If some care, particularly the more frequent outpatient and diagnostic work can be localised, then that would be highly beneficial," he said.

Mr Stedman also addressed the importance of supporting clinicians in the decision making process. He said, "Reconfiguration of children's heart services will also have an impact on healthcare professionals. These people will need our support, and we mustn't forget they are people, with families and careers, and change is always disruptive but it is also an opportunity for them. We have to remember who we're making those choices for," he said. And turning towards his son Harrison he said, "he's standing beside me, proudly representing them."

“This is not about whether we should make change but what that change should be...”

One of the keynote sections of the stakeholder conference on 22nd October was the morning session in which Dr Sheila Shribman explained the background to the *Safe and Sustainable* programme and Mr Leslie Hamilton offered his view on why change was essential.

Dr Shribman, National Clinical Director for Children, Young People and Maternity, was the joint chair – along with Professor Roger Boyle, the National Director for Heart Disease – of an important 2006 workshop on children's heart surgery services.

She explained how the *Safe and Sustainable* programme was part of an ongoing process which emerged from the 2006 workshop that was attended by surgeons, cardiologists, patient representatives, professional associations, GUCH (Grown Up Congenital Heart) patients, clinicians and commissioners.

Reflecting on the workshop decisions made in 2006, Dr Shribman reminded delegates that “The concept of fewer and larger centres emerged as a consensus view from the group. There was a clear view that any reconfiguration of services had to be sustainable and we recognised the need for national quality standards and wider quality measures”.

Addressing the concerns of parents on the day who are worried about losing their ‘local’ service, Dr. Shribman explained that while some services are local to some families, it important to focus on the fact that each centre is part of a national service.

Dr Shribman went on to discuss the future of children's heart surgery services and said, “There are so many issues for all of us to think about



today, not least the very important subject of staff. I can't stress enough that sustainability of services is the key issue and agreement is now needed urgently but must be created by patients and families, front line NHS staff, and the public all working together. We should not only aspire to excellence but achieve excellence. This is not about whether we should make change but what that change should be.”

Dr Shribman was followed by Mr Leslie Hamilton, President of the Cardiothoracic Society of Surgeons of Great Britain and Ireland, who underlined the need for everyone to be involved in setting the way forward for a world class service and stressed that change was about the service as a whole, not just about individual centres, nor was it financially driven.

He said, “The current situation is not sustainable. We need larger teams in order to cope with increasing specialisation and to provide safe, 24/7 cover. Doctors, nurses and other team members need to maintain their skills and experience and with more resources we will undoubtedly have fewer cancellations and better outcomes.”

Closing the session Mr Hamilton suggested: “We now have an opportunity to set the way for a world class service and that's what we should have at the forefront of our minds today.”

“Informative and useful” event say participants

A large majority of those attending the stakeholder event on 22nd October thought it was well organised and well chaired, that there were sufficient opportunities for general discussion and that they had an opportunity to express their own views. People also felt that speakers were well informed and the venue was an appropriate one.

Participants were specifically asked for their comments at the end of the event and typical of the comments was that from one parent who said they, “appreciated being given the opportunity to come along and be a part of this event.”

Delegates said they found the event had been useful with the rounds table discussions and the outline of the *Safe and Sustainable* process.

One person said it had been a, “very interesting day... well organised and lots of very healthy discussion.” Another said, “This is the beginning of a very important process. It is very important that the views of the few are not heard above the majority.” A third noted that while the event was well presented there was “conflicting evidence and views for the need to change.”

The general consensus view was that the event was informative but a number of people expressed a degree of frustration that the *Safe and Sustainable* programme team couldn't simply get on with the process of change. One participant said, “Too much consultation is as bad as too little. When are we going to be told what is going to be done?”

Transport was a recurring theme throughout the day and parents felt that the issue of cost had to be taken seriously. One parent explained how taking their child to the ‘nearest’ centre had once cost them hundreds of pounds and they had to pay their hotel costs, therefore, accommodation should also be taken into account.

Many participants felt the presentation on the programme timetable was clear and helpful.

“Good opportunity for small group discussion.”

One said it was, “very useful and obviously reflects the desire to make progress on the issues.” But others noted it was a “very tight timetable.”

A range of views were heard throughout the day and one delegate described the round table discussions as not very helpful but the more common view – as expressed by another participant - was that the round table discussions offered an, “excellent opportunity to listen to others’ views.”

Asked what additional information they might find useful, participants identified a number of things including minutes of steering and standards group meetings (these are available on the specialised commissioning website, www.specialisedcommissioning.nhs.uk) and the “case for change” prepared as a distinct document for local discussion. One participant said, We need to recognise that the specialty has come a long way since the Kennedy Report. The case for change now needs to be stated more clearly.

People attending the conference also indicated that they would appreciate more local engagement events and *Safe and Sustainable* Programme Manager, Jeremy Glyde, explained this would indeed be the next step in the engagement process.

“Interesting debate.”



children's heart
FEDERATION

A MORI poll of over a thousand parents, commissioned by the Children's Heart Federation, found that 3 out of 4 parents (73%) felt that the NHS should develop a smaller number of larger specialist centres for children's heart surgery in England. Just 1 in 10 (11%) disagreed with this proposition.

This was one of the key findings from the poll described in a presentation given by Anne Keatley-Clarke, the Chief Executive of the Children's Heart Federation. She said, "At first sight it may seem surprising that parents want fewer heart surgery centres rather than more but the fact is that by bringing specialist paediatric heart consultants together into larger teams parents realise that you get better care, better treatment and better results for their sick children."

The poll also found a general consensus among parents (71%) that families are willing to travel further for specialist treatment that delivers better care and better outcomes.

The presentation of the MORI poll findings was the first real test of parental opinion on this important issue.

Other key findings included:

- A desire for better support for parents who may need to stay overnight with their children
- A need for assistance with the cost of travel
- Help getting time off work.

Asked about priorities for their children, parents rated high survival rates and the need for an experienced team as very important, but the need for a surgical centre close to home as being rather less important.

Mrs Keatley-Clarke said the Children's Heart Federation believes each and every children's heart surgery centre should:

- Have adequate cover across all the cardiac sub-specialisms
- Provide a surgical service 24 hours a day, 7 days a week
- Be governed by agreed national clinical standards
- Offer services that are child and family centred
- Have follow-up care provided as close as possible to the family's home.

"Excellent opportunity to listen to others views."



Mr William Brawn, Chair of the Standards Working Group for the *Safe and Sustainable* children's heart surgery services programme, explained to delegates that his working group had examined existing standards and developed new standards that aim to ensure that children's heart surgery services are of the highest possible quality, are responsive to new developments and are sustainable.



Introducing the draft working document, which had been circulated widely in September, Mr Brawn explained why it was important that stakeholders have the opportunity to contribute to the

development of the standards. He said, "We want to enable parents and children to be able to make decisions for themselves and part of this process is to involve everyone. I think the care we provide is excellent but there are areas which can be improved. There is no harm in aiming for excellence."

The draft standards cover a range of areas across the patient pathway, from prenatal screening to transition to GUCH services.

In the group discussion that followed the importance of locally based services was raised several times and a paediatrician said, "Whilst standard H talks about the clinical team it doesn't talk about local services which I believe are vital."



There was general agreement that the standards document should include more detail about the roles of nurses and general

"Lots of thoughts and ideas shared."

paediatricians with expertise in cardiology.

One speaker said, "We all agree there should be a certain number of minimum procedures carried out in each unit and we all agree there should be a certain amount of surgeons within each unit – the problem is we can't agree what that number should be." This triggered a discussion on what the minimum number of paediatric surgeons per centre should be and a general consensus of a 1:4 rota for surgeons emerged.

Other themes that emerged were:

- Relationship with GUCH services
- How will reconfiguration improve waiting times?
- The effect of reconfiguration on inter-dependent services
- Low volume specialities, such as ECMO (Extracorporeal Membrane Oxygenation) and transplantation
- Role of the Cardiac Liaison Nurse
- Neonatal intensive care
- Need for clearly defined patient pathway, from antenatal screening to GUCH services.

“Honest discussion” says steering group chair

At the end of the 22nd October conference Dr Patricia Hamilton, the Chair of the *Safe and Sustainable* steering group and Director of Medical Education for England, summarised some of the main points that had emerged in discussion over the course of the day.

She said, “We have been honest and upfront about our starting position, which was that we are building on the work that has been done in previous inquiries, workshops and reviews. Our starting point was that those reviews had showed that it was sensible to organise children’s cardiac services into fewer and larger centres.” But she said she had also wanted to test this with stakeholders and to take into account any alternative views.

Dr Hamilton said that some things that emerged in discussion were ‘absolutely unarguable’ such as the need for better support for families with travel and accommodation.

She also said the impact on interdependent specialties and GUCH services – both now and in the future – was something that could not be ignored.

Referring to difficult discussions around minimum numbers of surgeons Dr Hamilton said that a message that consultant surgeons do not want to be on call more often than in a 1:4 rota had been heard. She said that this might be the right figure for today but we need to think more carefully about the figure for five years time and for ten years time, when working patterns and expectations will be different.

Dr Hamilton said that while the child and the family were at the centre of everything we do, it was also clear that the impact on staff of changing the configuration of surgery centres would be substantial and she said, “We must not underestimate the impact on morale that we are having right now.”

She noted that while some people felt the case for change hadn’t been fully made “other people feel very strongly that the case for change has been made for some time.”

Dr Hamilton was very clear that no decisions had yet been made on the future of individual centres. She said that there were no pre-determined outcomes and that there is a need to take into account the wider national picture.

Dr Hamilton said the conference had heard a lot about local services being strengthened. She strongly supported the emphasis upon services rather than centres and said, “We are talking about a world class service, not just world class centres, and the service means starting from local paediatricians all the way out to the surgical centres. We are all part of a world class service.”

In thanking everyone for their contribution over the course of the day Dr Hamilton said she hoped that when the next stakeholder discussion takes place, “we will have made progress together.” She also reminded people that Sir Bruce Keogh had made it clear that “no change” was not an option. It is not whether we change but how.



What happens next?

"I thought the stakeholder event was a success in allowing a range of people from across the country to have the opportunity to have their say. I was pleased with how interactive the event was. The programme means a lot to everyone who cares about children's heart surgery services and it was always going to be an emotive day when discussing such a sensitive issue.

"But it is not enough to just give people their say. We are making sure that all of the views expressed on the day, and in separate correspondence with us, are being fed into the development of the standards and the work of the programme generally. We encourage people to write in and continue to contribute.



"We need to ensure that these voices are not only heard but are answered and that we all have the opportunity for meaningful dialogue. At the very least I want all parents to be reassured about the integrity and transparency of the process for delivering recommendations for change.

"With this in mind Dr Patricia Hamilton, the Chair of the Steering Group, has asked me to think creatively about how we work with the parents and carers of children with heart conditions in the development of the *Safe and Sustainable* programme. By the time this newsletter is circulated I will already have approached those parents who attended the event for their views on how we take forward ideas such as 'Parent Engagement Groups'.

"Clearly, while there are many parents across the country who are supportive of the aims of the *Safe and Sustainable* programme, there are those who have misgivings about the process and who doubt the need for reconfiguration. These doubts and concerns were voiced loudly, and this was entirely appropriate and in keeping with the aims of the day.

"In addition, the national stakeholder event was just the first of a number of events that will take place in the future and I look forward to continuing open and constructive dialogue."

Jeremy Glyde

Safe and Sustainable Programme Manager

Please send us your views. You can do so in the following ways:

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