

# Findings of Children's Heart Federation survey of parents' priorities for children's heart surgery services

Presented by Anne Keatley-Clarke, CHF Chief Executive,  
at the NHS Safe and Sustainable Children's Heart Surgery Services Stakeholder Event,  
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## **Children's Heart Federation – representing parents' views**

The Children's Heart Federation consists of 22 groups all with an interest in congenital heart conditions and most are either condition specific or location specific. They are all, with two exceptions led by parents, the exceptions being *GUCH Patients Association* which is led by adults living with congenital heart disease and *Tiny Tickers* led by professional specialising in ante-natal screening.

Children's Heart Federation is tasked with representing the views of its members, a task that can sometimes be very challenging – especially when not all of our members agree. It can, sometimes, be an uncomfortable place to be. However, as far as today is concerned we have almost complete agreement on one matter at this that what every parent wants is excellent care for their child.

## **Satisfaction with current services – concern for the future**

What's more the vast majority of parents whose children have recently or are currently receiving treatment are very satisfied with the care that their heart-child has received.

However some of us are aware that in some places the current service is dependent on the goodwill of existing surgeons and their teams to work demanding rotas that go beyond their contracts in order to provide cover-particularly for emergency surgery.

We don't believe this can continue and have been campaigning for changes to ensure a sustainable service for the heart children of the future which is not reliant on old fashioned working practices that involves surgeons working in relative isolation. We want a service that facilitates the training of new surgeons and enables them to be mentored by more experienced colleagues so that they can safely develop their skills and we want to see them working in centres where there is sufficient clinical volume for the development of new

CHF is federation with  
22 member groups

All parents want  
excellent care for their  
child

85% parents very  
satisfied and 12% fairly  
satisfied with treatment  
child received at main  
surgical centre

Future children's heart  
surgery service must  
enable surgeons to  
build up and maintain  
their skills

technologies and treatment.

We realise that because the number of operations remain constant the current proposals are likely to result in larger but fewer surgical centres. We are aware that this is causing concern to some parents.

Some families may have to travel further but many of our families already travel a significant distance. This map ([see slide 2](#)) shows where the existing centres are – and you can see that it is not a local service – although to families who live close to a centre it will feel local.

### **Organisation of survey**

Aware that parents reactions to the proposals will differ according to their experience, we thought it timely to get the views of as wide a number of parents as possible to ensure that their views are being represented. So, we commissioned Ipsos MORI to undertake the research with parents of heart-children to capture their views on proposed changes to the structure of children's heart surgery services in England.

We distributed by post and email a short self-completion questionnaire to both our own family contacts and the members of the Groups that make-up the Children's Heart Federation and its member organisations. In addition, discussion groups were held at our Federation Day in mid-September. Half our member groups participated, and 5500 questionnaires were sent by post and e-mail. Those receiving the postal questionnaire were also given the option to complete the questionnaire online.

### **Profile of respondents**

Over 1000 replies were received - nearly all from parents, the majority of which were mothers aged between 35-44 years old. The respondents were spread across all regions of the UK, with particular concentrations in the South East (21%), East Midlands (13%) and East of England (11%). Although the proposals only apply to surgical centres in England, a small number of responses were received from Wales (3%), Scotland (2%) and Northern Ireland (1%).

When interpreting the findings from the survey, it is important to remember that postal surveys are liable to 'non-response bias': so, those with stronger

**Level of operations for congenital heart disease in children remaining constant**

**Children's heart surgery service is *not* a local service**

**Independent research agency Ipsos MORI ran and analysed the survey for CHF**

**Findings based on 1013 survey responses and focus group discussions**

**Responses related to all surgical centres in England**

**People with strongest views most likely to reply**

positive or negative views are more likely to reply.

### **High support for changes and agreement with need**

The findings of the research demonstrate overwhelming support for the proposed changes, with more than 73% of parents saying that they agree with the changes (see slide 3).

While agreement with the need for the changes is lower, it is still high at 65%. As would be expected, those who think the changes will have a positive impact were more likely to agree with the changes (88% compared to 11%) and the need for changes (79% compared to 15%) than those who do not.

Those who believe it is reasonable to ask parents to travel further are also more likely to agree with the changes (87% compared to 29%) and the need for the changes (77% compared to 31%) than those who think it will have a negative impact.

### **Household income influences views**

People on low incomes were less likely to agree with the changes than those who were on higher incomes.

Amongst those with a household income over £50,000, 80% agree with the changes. This falls to 62% of those with incomes under £9,499 and 69% of those whose household income is £9,500 - £17,499.

### **Need for more information**

Parents were asked whether they understood the changes, and if not what needed further explanation. The majority (78%) understood the changes. However a small number of people felt there were issues that needed further explanation and it is useful to look at what the minority say because it highlights the areas of concern.

The issues fell into two groups, the first related to the proposals rather than gaps in knowledge and covered issues such as

- Wanting to know how parents will cope with long distance travel and the stress of being far from home (5%)
- Needing a clear explanation for change because they are happy with the

**More than 73% parents agreed with changes**

**65% respondents agreed with need for changes**

**People on low incomes less likely to agree with changes**

**78% respondents understood the changes**

excellent care they received (3%)

- Understanding but disagreeing with the proposed changes.(2%)

Whereas the second group of issues related to a need for more information about the detail of the proposed changes and how the changes will impact on families and focused on the detail of the proposals and the practicalities the arrangements.

Parents wanted more information on

- How many centres there will be and where
- How the changes will impact on treatment and whether there will be a guarantee of life saving treatments?
- How families' need for support will be met – particularly the additional financial cost of travelling and staying away from home.

A few parents express concerns about the motivation for the reorganisation of the service and wondered whether it was about cost-cutting rather than improving care and outcomes for patients.

### **Good for clinical outcomes** (see slide 4)

When considering the impact of the changes, the vast majority of parents (77%) believe the changes will have a positive impact on clinical outcomes for children with around three in ten believe it will have a very positive effect (29%). Only 6% believe it will have a negative impact on clinical outcomes.

However, amongst those who disagree with the changes, views that it will impact negatively on clinical outcomes are much higher (43% believe it will have a negative impact, compared to just 1% of those who agree with the changes).

Families with children whose main treatment centre is in the South are significantly more likely to believe larger centres will have a negative impact on clinical outcomes than respondents at any other treatment centre. The South includes the centres at Bristol, Oxford and Southampton. Of those being treated in the South, 22% believe it will have a negative impact, compared to 5% being treated in the Midlands and 4% in the North, London and South West. This is a striking difference.

**Concern about cost-cutting**

**77% believe impact will be positive on clinical outcomes**

**6% believe impact will be negative on clinical outcomes**

**Large variance between views of parents from South and other regions**

**Reasonable to travel** (see slide 5)

There was a general consensus that that it is reasonable to expect parents/carers and their child to travel further for treatment, with seven in ten respondents stating this (71%). A minority (18%) believe it is unreasonable.

Eight in every ten family (80%) whose main treatment centre is London say it is reasonable to ask parents to travel further, significantly higher than all other treatment centres excluding the Midlands. Whereas respondents whose main treatment centre is in the South are most likely to feel it is unreasonable, with nearly four in every ten stating this (37%), nevertheless the majority, albeit a smaller one, feel it is reasonable to travel.

The support evident in London may be due to these respondents already travelling to access their services. The number of respondents reporting postcodes in the London area is lower than the number who report their main treatment centre as London (86 compared to 410), suggesting that a large number are travelling into London. If they are already travelling for care they are perhaps more likely to believe it is reasonable to do so as it is routine for them.

Families with a household income is below £9,499 per annum are more likely to believe it is unreasonable to ask parents to travel further, 28% say this compared to 14% of those whose household income is over £30,000 per annum. The number of respondents who earn less than £9,499 per annum was small (60 respondents) and therefore these results should be treated with caution. It does, however, suggest a link a between income and travel, which may be about the ability to travel rather than willingness.

**Biggest problems if fewer, larger centres** (see slide 6)

Parents were then asked what their biggest problems would be if they had to travel further and stay overnight. Some questionnaires enabled parents to choose three options, others just one.

Amongst those who chose up to three options, the main problems were if the centre did not have suitable accommodation for parents (67%) and families (50%) to stay overnight, followed by lack of childcare (35%) and the cost of journey (32%). Difficulty getting more time off work was also an issue for three in ten of families (29%).

71% believe it is reasonable to expect travel to surgical centre

18% believe it is unreasonable to expect travel

Parents travelling to London centres more accepting of travel

Low income families less supportive of increased travel

Top five problems if travelling further:

- Overnight accommodation for parents
- Overnight accommodation for families
- Childcare
- Increased time off work
- Cost of travel

Those who disagree with the changes were more likely to cite the cost of the journey (48%), difficulty getting time off work (50%), and not having a car (14% compared to 7% of all the replies) as some of the biggest problems.

Those who felt it was unreasonable to ask parents to travel further were significantly more likely to report difficulties getting more time off work as a problem, with 42% stating this as a problem compared to 25% of those who felt it was reasonable.

Those who were only able to choose one option also saw accommodation as a key issue (see slide 7). Over half chose the centre not having suitable accommodation for parents (54%), while nearly three in ten (29%) said not having suitable accommodation for families would be the biggest problem. These comparisons demonstrate the importance of suitable accommodation, but also show that childcare and finances are also important.

### **Priorities around surgery** (see slide 8)

In order to establish a feeling for what the most important considerations around surgery were, parents were asked to rate a number of factors around the period of time during and immediately after the child's surgery for importance, on a scale of 1 to 10.

The mean scores show parent's main priorities:

- Most important is "the surgical team's good record of survival and quality of life outcomes for patients five years on from their surgery".

This is closely followed by

- "the need for their child to be treated by a surgical team who have performed similar surgical procedures in the past 12 months" and
- Provision of "24 hour, 7 days a week service",

The only option presented to receive a mean score of less than 8 was that "the surgical centre is near to the child's home", with a mean score of 5.9. However, those who disagree with the changes and the need for the changes rated "the surgical centre is near to the child's home" significantly higher than those who agree.

**Accommodation is biggest single problem**

**Priorities around surgery:**

- Survival and quality of life
- Experienced team
- Suitable accommodation
- 24 hour, 7 days a week surgical service
- Facilities for mothers of newborn babies
- Other specialists on hand
- Environment suits child's age
- Surgical centre close to home

Those who believe the changes will have a negative impact and that it is unreasonable to ask parents to travel further also gave a significantly higher score (8.2 and 8.1 respectively).

### **Priorities after surgery** (see slide 9)

Parents were also asked to choose their top three options which are the most important and rank them in order.

Communication between services appears to be the key issue: "Surgical centres and local units share information and communicate well" ranked highly as did the "provision of a smooth transition to adult services".

Older parents, those aged over 45 were more likely to rate the transition option highly, probably because they are most likely to have children going through transition, or have had children who have already gone through it.

Those who disagree with the changes and who believe they will have a negative impact are more likely to rate "follow up care is provided close to the child's home" higher.

Similarly, those who disagree with the need for the changes rate follow up care more highly than those who agree with the need for change.

This indicates that concerns around follow up care may be a driver for disagreeing with the changes and underlines the importance of ensuring information is given around what services will remain locally.

### **Other important issues** (see slide 10)

Finally, parents were asked if there were any issues important to them that had been missed from those given. The majority (65%) did not give an answer to this. However it is helpful to look at the responses that were given because it identifies areas of concern.

Communication again emerges as a particular concern, both explicitly identified and implied in answers such as "having the same staff as before" and "having a person to seek advice".

#### **Priorities after surgery:**

- **Surgical centres and local units share information and communicate well**
- **For older children, centres work jointly with adult cardiologists to ease transition to adult services**
- **Follow up care close to child's home**
- **Healthcare professional talks to child's school**

#### **Other important issues:**

- **Good links between local services/ parents/children and centres**
- **Support/counselling for family**
- **Better sharing/receiving of information**
- **Travel stress**
- **Contact number for nurse support**
- **Continuity of care**
- **Accommodation affordable and close**
- **Larger centres impersonal**
- **Good aftercare**

**Treatment centres** (see slide 11)

Parents and carers of children with heart conditions were asked to complete an additional set of questions about their experience of current and past treatment.

They were first asked what their main centre of treatment was.

As the chart below shows, responses were received from all the main centres in England, with the majority coming from the London hospitals (Evelina Hospital, Great Ormond Street and Royal Brompton).

They were then asked how satisfied they were with the treatment their child had received at this centre.

**Satisfaction with care high** (see slide 12)

The vast majority of parents are satisfied with the treatment their child received (98% say either fairly satisfied or very satisfied), and over eight in ten very satisfied (85%). Only 1% of parents are dissatisfied.

Satisfaction with how their *other needs* were met is also high at 92%.

**Findings from focus groups at Federation Day**

In addition to the survey, discussion groups were also held at CHF’s annual “Federation Day” conference in London on 12 September 2009. The second half of our conference was given over to discussion of the proposed changes to children’s heart surgical services.

This began with an introduction from the Safe and Sustainable Programme Manager, Jeremy Glyde, about the Safe and Sustainable Paediatric Cardiac Surgery Services programme.

Following this, conference participants were divided into three groups to discuss their thoughts on the changes in more detail. These groups were based on knowledge, with participants divided into healthcare professionals, parent activists and parents.

The Activist Group were generally parents, or former patients, who were

Majority of responses from London treatment centres

Only 1% parents dissatisfied with child's treatment

Focus groups of healthcare professionals, parent activists/representatives and parents



already active in CHF campaigning activities and were familiar with the proposals. The parent group consisted of parents of heart children who were not participating in CHF's campaigning activities and were relatively unfamiliar with the proposals.

The Discussion Groups were led by researchers from Ipsos MORI and while representatives from the Specialist Commissioning Group and staff from Children's Heart Federation observed, they did not participate in the discussions. Participants were guaranteed anonymity – that no comments would be traceable to them in Ipsos MORI's report.

**Views varied between the three groups**

Participants' views on the proposed changes vary between the three groups, which is to be expected given their different levels of knowledge and the different motivations between parents and healthcare professionals.

Activists are the most accepting of the three groups and view the proposals as a necessary change to improve services. There is more uncertainty amongst healthcare professionals and parents. Amongst healthcare professionals there is a general sense that the case for change has not been proven and they want to see more evidence to prove outcomes would improve and that the financial implications have been fully thought through before they fully support it.

**Closeness to surgical centre influenced parents' views**

A similar uncertainty and desire for more information was seen amongst parents, but this was a less evident theme. The parents group was particularly divided on how they viewed the proposed changes, whereas activists and healthcare professionals tended to be more in agreement with each other. Amongst the parent participants, there was an evident split of views that in part seemed to depend on how close an individual lived to their current treatment centre. Those who are currently living very close to their surgical centre were more concerned about the proposals and opposed to any change which might, in their view, jeopardise the care they currently receive.

In contrast, those families who already travel some distance to reach their surgical centre were less opposed to the proposals in general, although still concerned about how they would work in practice. They were open to the idea but wanted more information about the detail of the proposals, the reasons

**Activists most accepting of proposals**

**Healthcare professionals and some parents felt case for change not proven**

**Parents who already travel were more open to idea of travelling**

behind it, and how it will impact on care.

It is perhaps not surprising that those who potentially face the most change are more concerned about the impact of the proposals. It is this group who do not currently travel to their centre and benefit from having the full range of services close to their homes who will be most affected if surgery moves from their centre.

Crucial to these parents is not just that the centre is close to their home, but that they and their child have a very strong personal tie with the centre, beyond simply the treatment it provides. Parents in the group who currently live close to their centre were concerned that they would lose personal relationships which are very important to them and help them cope with their child's condition. Moving to an alien environment where they do not know the nurses or surgeons is a difficult prospect to deal with and one which causes anxiety. Particular mention here was made of Cardiac Liaison Nurses, and what would happen to their role under the new proposals.

### **Key considerations for future plans**

Having established general perceptions of the proposals, the groups discussed the key considerations taken into account when designing the future plans for children's heart surgical services. While the groups were looking at the proposals from different perspectives a general consensus across the groups is evident.

The impact of a reduction in surgical centres on the **skills and knowledge** of healthcare professionals working in these centres was raised by all groups, but was particularly important for the healthcare professional group. While one of the stated aims of the proposed changes is to improve the skills and knowledge of surgical teams, there was concern amongst participants that things might get worse, at least in the short to medium-term.

Participants raised the issue of whether all staff will be expected/willing to relocate to new centres, and if they are not how the services will cope with a reduction in trained and experienced staff. Healthcare professionals were particularly worried that nurses may not be willing to move or may not be offered re-location expenses and this would undermine care as highly experienced paediatric cardiac nurses leave the teams.

**Strong personal tie with centre very highly valued**

**Concern that expertise would be lost**

**Doubt that staff would relocate**

These concerns were also evident amongst the parent group, who worried that surgeons will leave the service rather than move and therefore pool of experienced surgeons would shrink.

The parents also asked about whether more funding would be available to train surgeons and some parents felt that rather than close centres, it would be better to train more surgeons to work in the existing centres.

Some felt that there were likely to be a future increase in children requiring surgery and cutting the number of centres would leave them unable to deal with this increase.

Parents were also concerned about how the decision of which services to close would be made and wondered how they could be sure the process was independent and fair to all.

**Capacity issues, waiting times and cancellations**

There were concerns about the impact the proposals might have on waiting times and availability of beds. Healthcare professionals raised the issue of funding and whether the new centres would have the investment they needed to cope with increased numbers of patients.

For example, would there be investment to increase bed availability both in the centre and also related services such as paediatric intensive care. Without this investment parents were worried that the centres would not be able to provide the necessary standard of care. This concern is also linked with the skills and knowledge issue, in that if some staff choose not to move, the centres could find themselves with fewer staff to provide care.

Some parents feared that the changes could lead to increased waiting times, increased cancellations and a generally reduced service. They were worried about the impact cancellations will have on heart-children and their parents if they are travelling further for that treatment.

Parents explained that cancellations are always unwelcome, but if you are travelling long distances and surgery is cancelled at short notice the impact is far greater than if you live close to a centre. Parents and children will still have

**Suggestion to build up rather than close existing teams**

**Concern for equity**

**Need for guaranteed investment in beds and related services**

**Cancellations have greater impact when families have to travel**

had to meet the cost of the travel, take time off work, arrange childcare for other children, and undertaken the journey only to have to go back home again.

Parents were very keen that if the proposals go ahead a commitment is given to make the necessary investment guarantee cancellations are rare.

### **Communication and joint working**

Communication and joint working was an important issue to all groups and seen as central to making any reduction in surgical centres work.

Healthcare professionals were concerned that some information systems currently in use don't allow information sharing between different hospitals and GPs, patients care would therefore be more difficult as a result.

Some centres still rely on paper files and without a shared computer-based system healthcare professionals feel this will make transfer of records difficult and therefore potentially compromise care.

The Cardiac Liaison Nurses were particularly concerned about how they would be able to provide support in the way they do currently because it will be harder to contact/liaise with if the surgery team if they are no longer on site.

Parents and activists were also concerned about communication and how it would work if surgery is not taking place in the same centre as follow up care. The activist group were particularly concerned that the proposals will assume the surgical centre is at the centre of the service hub and all other aspects of care will be seen as spokes coming off this hub. They argue that in fact the child's paediatrician needs to be seen as the hub into which all other services feed in, as this is the closest point of contact to the child and the care must be centred on the child. They were also concerned about the care of children with multiple and complex needs.

Those in the parent group who live close to their surgical centre explained that currently if their child has any non-heart related problems that require medical intervention they can easily have a qualified heart surgeon on hand to assist should the intervention cause complications with their heart.

They were extremely concerned that if their centre was further away this help would not be available and if something should go wrong there would be

**Information systems are not yet robust enough**

**Cardiac Liaison service**

**Paediatrician should be hub**

**Provision for emergencies**

nobody with the experience to fix the complications and their child could be severely harmed as a result.

There is also concern over whether adult cardiac services will be located in the same centres as child services, and the impact this could have on the transition between services for older children.

Some participants felt strongly that the proposals may impact on the ability to provide care which is centred around the needs of the child and his/her family. The parents also highlighted the importance of all aspects of care, such as access to dieticians, pharmacists or physiotherapists, not just the surgery, and raised concerns that some of this could be lost.

Follow-up care was a hot topic for parents especially. All groups worried about what services will remain local and what will move, should the changes go ahead. Not knowing how often people might have to travel to access treatment and what kinds of treatment they could access locally is a key issue. Participants are currently unclear on whether centres will close down completely, and if not what centres will be left. Some participants in the parents group were reluctant to have to travel long distances to have shunts or catheters put in, while others already did this and were therefore used to doing so.

Some of the healthcare professionals also speculated that there may be less motivation or opportunity for local staff to keep up to date with developments in paediatric heart services if the specialist teams move further away. They were concerned that this in turn would potentially impact on the level of care available locally.

Financial support for families was major concern in all three groups, with all recognising the financial impact travelling further for treatment could have on parents of children with heart conditions. The key areas of concern around the financial impact are:

- Cost of travelling
- Car parking charges – which have already been addressed
- Accommodation charges
- Impact on earnings of time off work.

**Transition**

**Child-centred services**

**Follow-up care and support services beyond the surgical centre**

**Financial support for families**

Participants in the activist group feel that some parents would need support to meet these costs.

As well as finances, the issue of logistics around accommodation was also an important issue. This was a central consideration for the parent group who saw appropriate accommodation as vital to ensuring that parents were able to travel further for their child's surgery. They described the key characteristics for accommodation to provide the best environment and support for families.

These are:

- On-ward facilities for parents to stay with a child if needed such as drop-down beds that can be brought out of the wall at night for parents to sleep on.
- Off-ward facilities for longer-term stays to allow parents to stay close to their child and have somewhere private to stay. Ideally these facilities would still be close to where the child is.
- Family accommodation so both parents and siblings can stay close to the heart-child.
- Hospital wards to be designed around the needs of the child, rather than adapted adult wards such as child-specific wards designed to have fewer beds than an adult ward in order to allow greater personalisation of the bed area, providing space for pictures, toys, etc. in order to make the child feel more comfortable in hospital.
- Cubicles to allow children and their family privacy on the ward.

#### **More and clearer information needed**

Clearly the proposed changes to children's heart surgery services are still in development stage. The results from the survey indicate that there is a large amount of support for the proposed changes but there is a need for more information.

The discussions held at our conference underline the need for more information. Given that this is a pre-consultation survey this is understandable, and the results will be valuable in indicating what information those affected need, and what needs to be taken into consideration when developing the proposals.

While there is a majority support for the changes, we must remember that there is also a minority who are not supportive who are particularly concerned

**Key characteristics for accommodation**

**Programme still at early stage**

about the impact of the changes on children and families. The findings from the survey suggest that which treatment centre a parent currently attends may influence their opinions of the proposals.

We need to work with parents from the most concerned centres in order to allow them to raise their concerns and see how they might be addressed. However, it is also important to ensure parents are aware what the boundaries of the consultation are, i.e. what is open for negotiation, what may change based on their input, and what is not open to discussion.

The strong undercurrent of concern is evident in the discussion groups where some participants were convinced that the changes will be bad for quality of care for their child.

Both the survey results and the discussion groups show some of these concerns are also shared by those who are more supportive of the proposed changes. Being as clear as possible as soon as possible about how many centres will remain open and where they will be, what services will remain locally, what support will be available for parents and how communication between local services and the centres will help greatly.

The main areas that will need to be addressed in the consultation are: suitable accommodation, childcare for other children, travel costs and arranging time off work. These are also areas where parents and carers who already travel a distance which requires an overnight stay are likely to require support, even if the centre numbers do not change.

**CHF's view of a good service** (see slide 14)

Finally, I thought I would leave you with our thoughts on what a good service looks like and remind you, amidst discussions on hub and spokes and whether a surgical unit is the centre of a heart service or not, that in fact the real centre are our heart children. The service needs to be designed around them.

Heart children, particularly those with complex conditions need good access to a cardiology service that has active involvement from paediatricians and which is willing and able communicate well with the other services that feature in that child's life. Heart Surgery is only part, admittedly at time a very major part of that support and I have expanded that service in my diagram because that it

**Child-centred**

**Cardiology and paediatrics are key**

was we are talking about today, but it is the cardiology service that is responsible for the ongoing care and it needs to be the cardiology service that needs to be closer to the family of a heart-child.