



The Brompton Fountain
Royal Brompton & Harefield Family Support Group

Response to the Safe and Sustainable consultation on children's heart services

The Brompton Fountain is an independent charity that supports paediatric patients and their families at the Royal Brompton Hospital. We represent over 3,000 families from across the UK who have had children treated at the hospital for both cardiac and respiratory conditions. This response represents the view of the charity and the families that we represent. It is a collective view that is shared amongst the families who we have worked and talked extensively with over the past months. It is also informed by the participation of the charity in the review leading up to the consultation, during which we had parent representation on the SE regional group meetings.

Summary

We believe that there are many positive aspects to the review that could see an improvement in the level of service provision for many patients. However, as with any complicated review of this nature there are also inherent risks and potential flaws in the reorganisation. We consider it our duty to point out what we see to be significant flaws and risks in these proposals, as well as the consultation and feedback process:

- The questions relating to London on the response form do not present a fair and unbiased appraisal process but relate to a seemingly pre-determined two centre outcome.
- The consultation document provides misleading information regarding London.
- A three centre London solution has not been consulted on, in spite of the fact that it is consistent with all of the standards and requirements of the safe and sustainable review.
- There should have been a further option consulted on based on the most favoured outcome (Option A), but with 3 London centres instead of two.
- The consultation has been conducted in a way that is discriminatory and does not offer equal opportunities of care to all patients.
- The consultation feedback form is written in technical language that is difficult for parents and patients to understand.
- The proposal for Children's Cardiology Centres is ill defined and unsustainable with insufficient workload to justify their existence or attract high level cardiology expertise in the long term.
- There is inadequate risk assessment relating to the proposal to have centres larger than 500 cases.
- There has been an inadequate assessment of critical inter-dependencies of other services.

The Consultation Process

We have a number of concerns regarding the consultation process itself. In the consultation document, and the later released document on London, it was explicitly stated that 'The question of whether two centres in London is the right number will be asked during consultation.' **This question has not been asked.** Not only has the question not been asked, but no option has been provided anywhere to indicate a preference for three centres in London instead of the two that are being consulted on. We therefore find the consultation to be inadequate and to not give a fair and balanced process on which to base representation about the London case. A two centre outcome appears predetermined.

Option B in the consultation is said to include 'the top 7 scoring centres'. It blatantly does not: Royal Brompton came joint fourth in the review process, yet it has been excluded from the 'top 7'.

All the other centres except Royal Brompton are included in one of the four proposals being consulted on (with the exception of Oxford, which has already closed). None of the consultation options include Royal Brompton. **There should have been a further option consulted on based on the most favoured outcome (Option A), but with 3 London centres instead of two.**

We have had extensive feedback from our families and staff at the Royal Brompton that they found the form difficult to understand. It uses highly technical language and frequently frames questions in a way that cannot be understood by a layperson who has not followed the review process.

London

The consultation in respect of London is completely inadequate and does not present a fair and un-biased appraisal process.

In the consultation document, and the later released document on London, it was explicitly stated that 'The question of whether two centres in London is the right number will be asked during consultation.' **This question has not been asked. There is no option to indicate a preference for three centres in London.** There is only provision to agree with the two centre solution, or not. Following this is a highly divisive option that questions whether Royal Brompton should replace one of the other two centres.

The consultation document itself is misleading in the information it presents about London. On p. 93 it says that London has around 1,250 cases per year. This ignores the fact that the favoured options being consulted on will lead to an *increase* in cases being performed in London which will rise to either 1,442 or 1,482. This equates to 480-494 cases per centre, and 120-124 cases per surgeon. **Thus, maintaining three London centres fits perfectly with the standards and requirements for a safe and sustainable service, as outlined in the consultation document.**

The consultation document does not present a consistent or un-biased view. On page 84 it states that 'London requires at least two centres due to the size of the population it covers'. But in a footnote on page 93 it arbitrarily imposes a two centre solution. **A three centre London solution has not been consulted on, in spite of the fact that it is consistent with all of the standards and requirements of the safe and sustainable review.**

Numbers in London have been underestimated because private patients from the UK and overseas / charity patients have not been accounted for. The NHS does not have to pay for these patients, but not counting them is tantamount to saying that these patients do not matter and that it is acceptable to deny the opportunity of good care to people who are not

so fortunate as to have these facilities in their home countries. These cases do contribute to the 'volume' that is such a critical measure of safety and sustainability. **This approach is discriminatory and does not offer equal opportunities of care to all patients.**

Key principles and quality standards of the review

We strongly support the overriding principles that have been used as the basis for this review. In addition we support all of the standards that have been used as the basis for assessment and forward projection. Clearly having a team of surgeons and supporting services provides critical mass and enables development of best practice and will drive up standards. We hope the days of occasional practice are long gone, but nonetheless the recommendation of 4 surgeons is a sensible move.

We do, however, have concerns around the upper limit of cases considered to be safe and sustainable. The largest centres operating in the UK at present are Birmingham and GOS, who are both around the 500-mark. No centre in this country has experience of going much beyond this level. While we are aware that some international centres do significantly more than this, we consider that there are considerable risks associated with any transition to a much higher numbers of cases. Based on the timetable for implementation this will have to occur very quickly and we consider this to have further associated risks. There is no information regarding how these risks may be mitigated or managed during the short time scale for implementation proposed.

The optimal number of cases for any centre with 4 surgeons is logically around the 400-500 mark, with approximately 100-125 cases per surgeon. Going above this threatens diseconomies of scale. We therefore question the quoted upper limit of 800 cases and we do not think it wise to go beyond 500 unless there are exceptional reasons. Further concern to this has arisen following the Emirates public consultation event, where Dr. Leslie Hamilton suggested the upper limit could be 1000 or more. We consider this to be completely unacceptable.

Service Provision

With regard to the development of clinical networks, this is probably the area where we can see most additional benefit to patients as a result of this review, particularly those who are more dependent on outreach clinics and local District General Hospitals. We are strongly supportive of having a paediatrician with expertise in cardiology based in local hospitals, as well as a strong network of locally based cardiac liaison nurses. We would like to see the role of cardiac liaison nurses formalised within the network proposals. These will form important primary contacts within outreach areas.

There is however one area where the proposed network model does not make any sense, and that is the proposed Children's Cardiology Centres. Their role is ill-defined as it is not clear what services will be provided in these centres. Without surgery or intervention there is not much that can be done beyond outpatients and some diagnostics. Without the direct co-location with the critical mass of a surgical centre, this risks falling back to isolated practice.

There is no clear distinction as to what a 'Children's Cardiology Centre' could provide over and above the District General Hospital paediatrician with expertise in cardiology. Would this then mean that for patients who attend District General Hospital hospitals that are satellites of Children's Cardiology Centres, they would have to go through two layers of referral before reaching the surgical centre? We believe this could lead to unnecessary and potentially dangerous delays.

We believe that the proposed Children’s Cardiology Centres are unviable as stand-alone centres, with insufficient workload to justify their existence or attract high level cardiology expertise in the long term.

Regarding interventional cardiology, it is not clear from the report whether this includes diagnostic catheters. We are adamant that ALL interventional cardiology including diagnostics MUST be undertaken in a surgical centre. There is unambiguous evidence from Sweden that any type of catheter without surgical backup is unsafe and will lead to unnecessary deaths.

Interdependent services

The review has failed to adequately assess critical interdependencies of other services. The evaluation of interdependencies has been extraordinarily superficial. In specific regard to Royal Brompton it is simply stated that because the unit exists primarily to serve cardiac patients, “... this presents limited risk to local and national paediatric intensive care provision.” This simplistic approach fails to ascertain what other services are dependent on intensive care provision. In the case of Royal Brompton this is primarily their cystic fibrosis unit. This is the largest cystic fibrosis unit in Europe and since the intensive care unit would be unviable on withdrawal of cardiac surgery, the cystic fibrosis unit would also become unviable, as would the whole of their paediatric department.

We are pleased to hear that there will be a further independent review on the impact to the cystic fibrosis unit at Royal Brompton and we look forward to the outcome of this review. This serves to illustrate that there are flaws in this review process.

Other UK centres

As a charity that represents one of the London centres, we do not consider it appropriate to present an opinion relating to the other UK centres. However, we have identified geographical anomalies in one of the proposed configurations. In option B, we believe that some families would not be well served by the proposed configuration of postcodes included under the Southampton catchment. Families in the BN, RH, GU, SL, HP or OX postcodes may be better served by the London centres since many transport links operate radially from London. This will of course depend on precise location and individual preference.

Further to this, we do of course believe that the principles we state above in relation to risk and cardiac networks relate to the rest of the UK as well.