

Safe and Sustainable Review of Children's Congenital Heart Services in England

Report of the public consultation

Executive summary

This report contains an independent analysis of the responses received to the public consultation on the proposals put forward by the *Safe and Sustainable Review of Children's Congenital Heart Services*. The review has proposed new National Quality Standards and changes to the way in which services are planned and delivered in the future. The consultation ran for four months and received a large number of responses – over 75,000 – from patients, families, health professionals and other groups. Respondents used a number of channels to feed back their views:

- A response form with questions on specific aspects of the proposals, available online and in hard copy;
- Written comments submitted in letters and e-mails; and
- Text messages

There were also consultation events and supplementary qualitative research, both of which are reported on separately. It is important to remember that the results contained in this report are not representative of the population – they only refer to the people and organisations that responded to the consultation.

The suggested new approach

Five Key Principles

Respondents supported the Five Key Principles underpinning the proposals. Around a third of personal respondents and a half of organisations chose not to respond to these questions, but of those responding, around nine in ten respondents supported each of the following principles:

- **Children:** the need of the child comes first in all considerations.
- **Quality:** all children in England and Wales who need heart surgery must receive the very highest standards of NHS care.
- **Equity:** the same high quality of service must be available to each child regardless of where they live or which hospital provides their care.
- **Personal service:** the care that every congenital heart service plans and delivers must be based around the needs of each child and family.

In fact, nearly all respondents agreed with the principles concerning *Quality*, *Equity* and *Personal service*. However, there were slightly lower levels of agreement with the fifth principle:

- **Close to families' homes where possible:** other than surgery and interventional procedures, all relevant cardiac treatment should be provided by competent experts as close as possible to the child's home.

Among those responding, 70% of personal respondents and of 86% organisations agreed with this principle. Written comments suggested that many of those *disagreeing* were particularly concerned that surgery and interventional procedures

have been excluded – they would like to see these also being provided close to home. Some highlighted the impact of increased travel times and the problems this can cause for the patient and their families. Other respondents though suggested that high quality care should always take precedence over ease of access.

Views on different aspects of the new approach

Respondents were also asked for their views on particular elements of the proposals. Again, not all respondents chose to address these questions, showing a greater interest in other aspects of the proposals. Amongst those that did, the majority supported each of the elements, but there were substantial differences between specific aspects.

There was strongest support, amongst both personal respondents and organisations, for **the need for 24/7 care in each centre** (94% of each audience).

There was lowest support for the statement “**without change the service will not be safe or sustainable in the future**” – under half of personal respondents (46%) and two-thirds of organisations (64%) who provided an answer were in support. Many of those disputing this idea believed that all hospitals were safe at the moment and questioned the evidence on which the statement was based.

There was also lower support for the suggestion that there is a **relationship between higher-volume and better clinical outcomes** – 52% of personal respondents and 70% of organisations were in support. Some respondents commented further on this and disagreed with the interpretation of „higher volumes“ if defined at over 400 cases a year. Many of these argued that the evidence showed only that outcomes were worse below a minimum of 200 cases. Others thought there was insufficient evidence on which to base a conclusion.

The majority of respondents agreed with the proposal that systems should be implemented to improve the collection, reporting and analysis of mortality and morbidity data. **Over eight in ten of those responding to the question agreed** (85% of personal respondents and organisations).

National Quality Standards

There was extremely strong support for the National Quality Standards amongst respondents providing an answer. Around nine in ten stated their support for the standards under each of the seven themes:

- Congenital Heart Networks
- Prenatal Diagnosis
- Specialist Surgical Centres
- Age Appropriate Care
- Information and Making Choices
- The Family Experience
- Ensuring Excellent Care

There was particularly strong support for the standards relating to **Ensuring Excellent Care** (93% of personal responses and 94% of organisations).

Only a minority of respondents chose to provide further comments on the National Quality Standards; the majority of these related to the **Specialist Surgical Centre** theme. Again, some respondents discussed the relationship between higher volumes

of cases and better outcomes and put forward their view that the interpretation was incorrect.

A small number of respondents did provide comments on the other themes, and these often simply stated the perceived importance of the standards and the subject covered by the standards.

Proposals for Specialist Surgical Centres in London

Around three-quarters of respondents supported the proposal for two Specialist Surgical Centres in London. This dropped to just under half of individuals in London itself (47%), with many of these suggesting that all three hospitals in London should retain heart surgery services for children. They noted that all three hospitals provide high quality care and would like to see them work together to deliver services. Some had concerns that two centres in London would not be able to cope with the demand of its population.

On the other hand, some respondents who disagreed with the proposal (particularly those living outside London) suggested that there should only be one centre in London, so that another centre could be situated elsewhere in the country. If there were to be two centres in London, the majority of those responding supported the proposed choice of **Great Ormond Street Hospital for Children NHS Trust (GOSH)** and **Evelina Children's Hospital – Guy's and St Thomas' NHS Foundation Trust** (65% of personal respondents and 56% of organisations). Just under one in ten personal respondents preferred **Royal Brompton and Harefield NHS Foundation Trust and GOSH** (8%) and 16% preferred **Royal Brompton and Evelina**. The pattern for the two alternative options is reversed amongst organisations though, where 11% preferred **Royal Brompton and GOSH** and just 5% preferred **Royal Brompton and Evelina**.

Around half of the comments made here related to the specific hospitals themselves and their merits, particularly **Royal Brompton**. Most people stated their support for the hospital and were positive about the care and service provided. Amongst other things, they named its ground-breaking research, the full range of services and the childhood to adulthood care provided at the hospital. Some also expressed concerns about the risks posed to patients (particularly cystic fibrosis patients) and the negative impact on other services at the hospital if the children's heart surgery service were to cease.

Proposals for Specialist Surgical Centres outside London

Almost all respondents provided views on the proposed options for centres outside London – they were asked for their support or otherwise for each option, then asked which they preferred.

Views on options

Option A received the highest level of support from personal respondents (58%), followed by **Option B** (34%). Amongst organisations though, more respondents supported **Option B** (63% compared to 22% for **Option A**). Ten per cent or fewer of both audiences supported Options C and D.

As might be expected, there were substantial differences in support for each option in different parts of the country. A large proportion of respondents to the consultation

came from the East Midlands and the South Central regions, and their responses have influenced the overall results. Outside these two regions, there was greater support for **Option B** – 43% compared to 35% for Option A), though **Option A** was supported by more respondents in six of the ten regions.

These results were largely replicated when respondents were asked for their *preferred* option. Again, **Option A** was selected by more personal respondents than any other (54% compared to 30% for Option B, 1% for Option C and 8% for Option D). Outside the East Midlands and South Central regions though, **Option B** was again preferred – 33% compared to 27% for Option A).

Organisations clearly expressed a preference for **Option B** (41% compared to 18% for Option A, 1% for Option C and 4% for Option D).

A large number of respondents chose to give further comments on specific hospitals rather than their views on the configurations. Most commonly mentioned were Southampton University Hospitals NHS Trust, Leeds Teaching Hospitals NHS Trust and the University Hospitals of Leicester NHS Trust (Glenfield). Generally respondents referred to the good service they had experienced at each hospital and the high standard of care received there.

Southampton received the most comments – in addition to positive comments about the care received, many respondents also mentioned:

- Its rank as second in the country in the review
- Its location and accessibility for the south of the country (particularly mentioning the Isle of Wight and the Channel islands)
- Its good transport links.

Leeds was also commented on favourably by many respondents who had prior experience of it. Large numbers also mentioned:

- Its ability to provide a range of services in one location
- Its central location and large population served.

Glenfield received similar comments about the standard of care provided at the hospital. In addition, there were comments about:

- The extracorporeal membrane oxygenation (ECMO) facilities provided at the hospital
- Its central location for a large population
- Its good transport links.

However, some respondents did comment further on the options proposed. **Option A** was considered by some respondents to offer the least disruption to patients as it would mean no relocation of specialised services. Others thought that it offered a good geographic spread.

Some were concerned though that it would require Leeds to be involved in four networks. Many respondents offering further comment thought that **Option B** offered the best solution in that it included the centres scoring highest for quality and which were able to undertake complex surgery. Others thought that it offered the best access for patients from different parts of the country. However, some thought it did not cover the north of the country sufficiently well.

The level of support for **Option C** was low, and few respondents offered further comments on it. Those who did provide a response tended to say that the number of centres in the configuration was too low.

Some respondents commented positively on **Option D** – in particular that it would ensure that all centres would perform the minimum 400 cases a year. However, other respondents disliked it as having too few centres and because it would mean that transplant and ECMO services would need to be relocated.

Finally, respondents were also asked for any comments on the assumptions made concerning how postcodes have been assigned in any of the four options. The majority of comments received were negative – the most common of which stated that the assumptions ignore patient choice.

The importance of quality

The **quality of care** provided was the most frequently mentioned issue for respondents discussing either specific hospitals or the options more generally. In fact, quality of care featured heavily throughout the consultation responses, at each of the questions posed in the response form and in the letters and emails that were submitted. There was a strong belief amongst many that quality should be the deciding factor in service planning.

However, **location** was also a common concern, with many arguing that there should be an equitable geographical spread of locations across the country. Some respondents noted the difficulties that families would face if they had to travel further for surgery.

Preferred configuration

Where respondents did not express a preference for any of the proposed options, they chose their own preferred configuration of centres. Many respondents simply selected the one hospital they wanted to provide services (most commonly Glenfield and Southampton). The only configuration that was selected frequently – and wasn't formed of one of the proposed options – consisted of **all three London centres plus Alder Hey Children's NHS Foundation Trust and Birmingham Children's Hospital NHS Foundation Trust**.

Text message responses

The majority of text messages received during the consultation contained support for (and, in a small number of cases, opposition to) each of the proposed options. **Option B** received the highest number of text messages in support (13,487), followed by **Option A** (10,233). The remaining two options were referenced in far fewer messages.

A number of respondents also showed their support for particular hospitals in their text messages. Almost half of these referred to **Newcastle**, followed by **Leeds**, **Leicester** and **Southampton**. Although generally much shorter in length, the reasons given were very similar to those submitted via other methods of response.

Petitions and campaign responses

A total of 25 petitions or campaign responses, some with a very large number of signatories, were received to the consultation. These tended to show support for a specific hospital or option. In particular:

- Almost half a million people (445,945) signed a petition to save heart surgery services in **Leeds**.
 - Almost a quarter of a million people (240,094) signed a petition in support of **Southampton**.
 - Around fifty thousand people (47,258) signed a petition in support of **Glenfield**.
- Other petitions and campaigns also supported these three hospitals and Newcastle, Royal Brompton, Alder Hey and Oxford Radcliffe.

Key findings

- There were over 75,000 responses to the consultation via the various methods of response, with most using the response form¹.
- Over 20% of the responses received via the response form were from individuals from minority ethnic backgrounds.
- There was strong support amongst these respondents for the Key Principles.
- There was strong support for the need for 24/7 care in each of the Specialist Surgical Centres.
- There was strong agreement that systems should be implemented to improve the collection, reporting and analysis of mortality and morbidity data.
- Three-quarters of respondents supported the proposal for two Specialist Surgical Centres in London (75% of personal respondents and 74% of organisations responding).
- Almost half of respondents from London supported the proposal for two Specialist Surgical Centres in London (47% of those responding).
- The majority supported the proposed choice of Great Ormond Street Hospital for Children NHS Trust and Evelina Children's Hospital (65% of personal respondents and 56% of organisations responding).
- Option A received the highest level of support from personal respondents (58%) followed by Option B (34%). The majority of respondents to the consultation were from the East Midlands and South Central regions. Outside these two regions, more respondents supported Option B, as did organisations.
- There were lower levels of support for Options C and D, with Option D receiving most support from respondents in the Yorkshire and Humber region.

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