

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

Report of the public consultation

24 August 2011

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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.

¹ 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.

1. Overview of the consultation process

1.1 Background

Over the last 50 years surgery for congenital heart problems has grown into one of the most complex areas of modern medicine. Over the last decade or so there have been a number of reviews of children's heart services and calls to reduce the number of hospitals that provide children's heart surgery. In 2008, the NHS Medical Director asked for a review of children's congenital heart services. The *Safe and Sustainable Review* was established and the *Safe and Sustainable* team at NHS Specialised Services managed the review process on behalf of the ten Specialised Commissioning Groups in England and their local Primary Care Trusts. The review has involved engagement with parents, young people and clinicians and expert panel assessment of the quality of current centres. It has proposed new National Quality Standards and changes to the way in which services are planned and delivered. The changes are intended to achieve:

- Improved diagnostic services and follow-up treatment delivered through congenital heart networks
- Better results in surgical centres
- Improved communication between parents and services
- Reduced waiting times
- A highly trained workforce
- The development and use of innovative techniques that improve the quality of care.

In order to make changes to the way services are organised, the NHS has consulted the public for its views. This report contains the main findings from the public consultation. Following the consultation, the Joint Committee of Primary Care Trusts (JCPCT) will be making the final decision on the proposals.

1.2 Structure of this document

This report sets out Ipsos MORI's analysis on the responses received to the public consultation. This first chapter gives details on the background to the consultation, how it was set up and run, and who responded, as well as some points on how to interpret the data.

The following chapters detail the analysis of responses. The public consultation itself was broken down into three key question areas covering:

- The suggested new approach to providing children's congenital heart services
- The proposed standards that have been developed to ensure quality across the service regardless of where the patient lives
- The proposed options for change.

The report is structured around these key areas. For further technical details on the consultation, please see *Safe and Sustainable Consultation Report: Technical Annex*.

1.3 Structure of the consultation

There were a number of channels through which participants could respond to the public consultation, all of which are listed below:

Online response form – responses to specific questions on the proposals, available in 11 languages² on the *Safe and Sustainable* website and hosted by Ipsos MORI.

Hard copy response form – responses to specific questions on the proposals, available in 12 languages³.

Written comments – letters and emails sent to the *Safe and Sustainable* email or postal address. A number of petitions were also submitted by email and post.

Text message – responses to one open question on the proposals.

Ipsos MORI also carried out supplementary qualitative research with parents, children and young people to explore their views and experiences in more depth and research with those from specific ethnic minority communities, designed to ensure that the opinions of under-represented groups would be taken into account. This included 25 group discussions and 18 family interviews. The overall results of the supplementary qualitative research are detailed in a separate report by Ipsos MORI.

² English (from 1 March 2011) and Chinese, Polish, Hindi, Urdu, Gujarati, Punjabi, Bengali, Somali, Farsi, Arabic (from 25 May 2011)

³ English and Welsh (from 1 March 2011) and Chinese, Polish, Hindi, Urdu, Gujarati, Punjabi, Bengali, Somali, Farsi, Arabic (from mid-May 2011)

In addition to the work carried out by Ipsos MORI, consultation events were held across the country to allow people to hear more about the proposals and put their questions to local clinicians and commissioners. A separate report about these events is also available.

The consultation ran from 1 March 2011 to 1 July 2011. All responses dated and received within these dates were treated as valid consultation responses. In addition, to make allowance for any potential delays within the post, all those received through the post after the deadline were accepted as 'on time' if they were postmarked on or before the closing date.

1.4 Responses to the public consultation

There were a total of 77,216 responses received within the consultation period, plus the consultation events, interviews and discussion groups. The number of responses via each means is shown in Table 1.

Table 1 – Responses to the public consultation

Method	Total
Hard Copy Response Forms	36,884
Online Response Forms	14,779
Written comments (letters and emails)	371
Petitions	25
Text messages (excluding blanks)	22,119
Blank text messages	3,038
TOTAL (including blank text messages)	77,216
TOTAL (excluding blank text messages)	74,178

The consultation sought to reach a wide-ranging audience and responses came from both the general public and various stakeholders. Throughout the report, key themes are broken down by audience where appropriate and possible. The total number of responses by audience group is shown in Table 2, and further descriptions of each audience group are given below.

Table 2 – Responses by audience group

Response method	Audience	Total	
Response forms	Personal responses⁴	50,332	
	Member of the general public	31,748	
	Health professional	8,289	
	Other professional	8,204	
	None of these	4,748	
	Not stated (including 'prefer not to say')	2,879	
		Responses on behalf of an organisation or group⁵	1,121
		Hospital	196
		Charity/voluntary group	63
		Local patient group	27
		Local Authority	22
		Professional body	20
		Local parent group	15
		National patient group	10
		Academic organisation	9
		Strategic Health Authority	7
		Commissioner	7
		National parent group	6
		GP consortium	5
		Political party/group	4
		Trade body	1
		Other	62
		Not stated (including 'prefer not to say')	754
		Not stated as personal or organisation	210
	Written comments	Individual	167
		Health professional	36
		Stakeholder	204
MPs & politicians		67	
Health bodies		24	
Overview and Scrutiny Committees (OSC) and Local Involvement Networks (LINKs)		23	
International		21	
Local groups		13	
Hospitals providing children's heart surgery		12	
Groups of NHS staff		12	

⁴ Those completing a response form were able to allocate themselves to one or more of these categories. Please note this data is self-reported.

⁵ Those completing a response form were able to allocate themselves to one or more of these categories. Please note this data is self-reported.

Local Authorities	12
Professional associations and advisory bodies	11
National charities	9

Response forms

As can be seen from Table 2, respondents providing a personal response via the response form (50,332) included people with professional and personal interest in children's heart services. Many of these will have more detailed knowledge of children's heart services. The response form also directed people to the relevant pages of the consultation document, though of course it can not be known to what extent they read or consulted the document.

Respondents using the response form included 1,711 people who have congenital heart disease (CHD) themselves and 10,575 who care for or have cared for someone else with CHD (usually a family member). A further 5,095 respondents care for or have cared for people with CHD as part of their job.

Responses were received from across a wide variety of age ranges, including 928 respondents who were under 16 years of age and 4,208 aged between 16-24, though the largest single age group was 35-44 years old (12,120). The majority of respondents were female (28,683) and 10,279 responses were received from people from ethnic minority backgrounds. Detailed demographic information, where this information has been recorded, is provided in Appendix C.

Those providing responses on behalf of an organisation or group were also asked to provide information on the type of organisation, its size and the way in which views of its members were gathered. Where this information was provided, the organisations varied in size from under five members (six responses) to over 500 (85). The largest had 9,050 members. Methods of assembling members' views included events, ballots or simply asking them. A full list of these organisations is included at Appendix A.

Text responses

A total of 25,157 text messages were received to the *Safe and Sustainable* number; this included 3,038 blank messages. There were also multiple responses received from some mobile phone numbers, though the majority sent just one message (19,852⁶).

⁶ Having removed all blank messages

The text message format means that no demographic information was collected about these respondents. It is also not known whether or not they would have read the consultation document, or how much they would have known about the proposals.

Chapter 6 contains analysis of the text message responses.

Open written responses

Some respondents chose not to use the response form but sent in bespoke written comments via letter and email. A total of 167 were from individuals, including health professionals and patients and their parents. Again, many of these individuals had experience of children's heart services, but it is not known to what extent they had read or consulted the consultation document. Analysis of these responses is included at relevant points throughout this report. Stakeholders returning written comments were classified into ten categories, as shown in Table 2. These included responses from the hospitals currently providing children's heart surgery, national charities and professional associations and advisory bodies.

Campaigns/petitions

Campaign responses and petitions (some with a large volume of signatories) tended to support particular hospitals and were often organised by local groups. While the number of signatories to each is known, very little else is known about these individuals. The campaigns/petitions tended to ask people to show their support for a specific hospital, rather than comment on any other aspect of the proposals. It is not known how much those signing the petition would have known about the proposals or whether they would have read the consultation document. Chapter 8 contains details of these responses.

It is worth noting that it is likely that these local campaigns also generated more responses via other methods, particularly text messages and response forms.

1.5 Interpreting the consultation responses

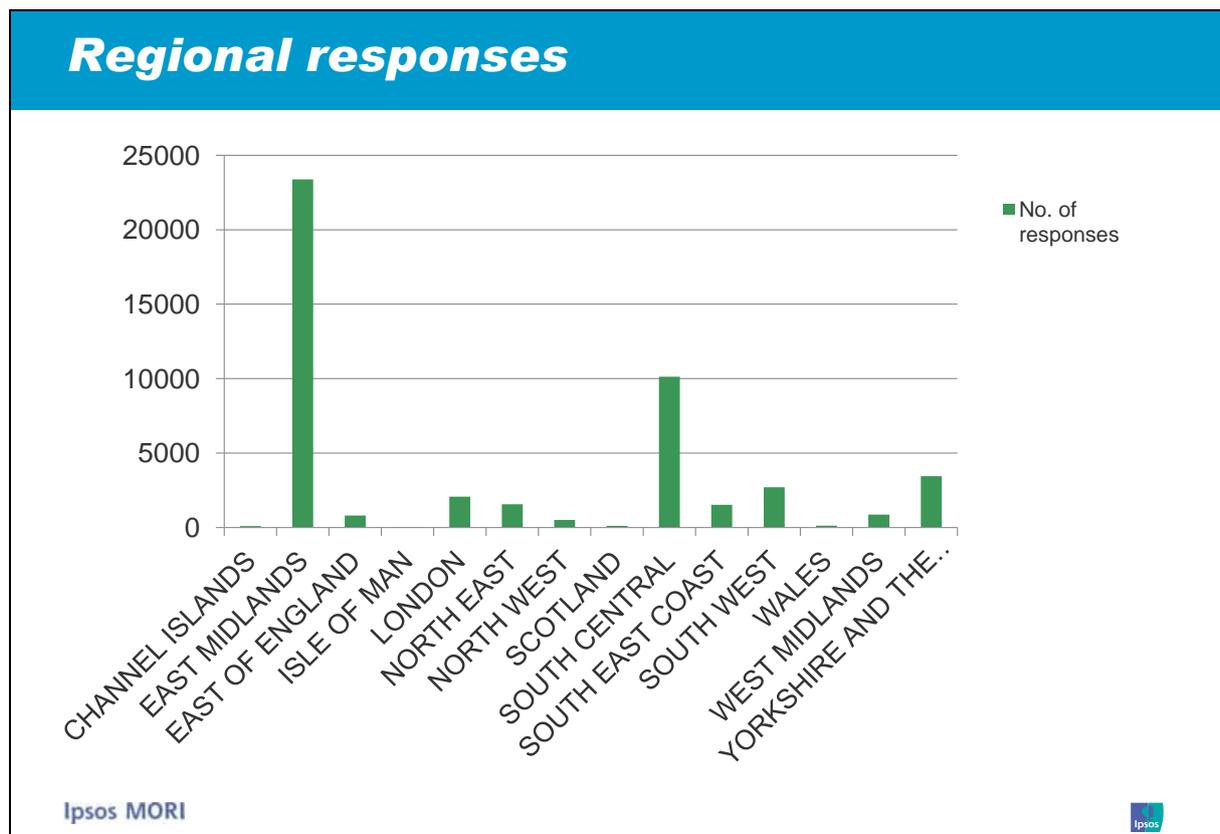
Understanding who has responded

While a consultation exercise is a very valuable way to gather opinions about a wide-ranging topic, there are a number of issues to bear in mind when interpreting the responses.

While the consultation was open to everyone, the respondents were self-selecting, and certain types of people may have been more likely to contribute than others. In this instance, it is possible that those participating were more likely to be engaged with children's

congenital heart services in some way. This means that the responses are not representative of the population as a whole.

In addition, and as mentioned above, it is likely that local campaigns are likely to have increased awareness and encouraged a greater number of responses via all methods of response. It is certainly the case that a greater number of responses have been received from regions where the local unit is perceived as being 'under threat of closure', as can be seen from the chart below. For example, 49% of respondents were from the East Midlands, which accounts for 9% of the population of England.



The campaigns tended to urge people to respond to 'save their hospital' and many were emotive in nature, focusing on the impact of closure of the local unit. It is not known how this may have influenced responses, but it is true that a large number of responses via all methods focused on the options for proposed Specialist Surgical Centres rather than the other aspects of the proposals. It is also clear that respondents often copied specific wording (or part of it) from published responses relating to specific hospitals.

The emotional nature of the topic, evident in many of the responses, is also likely to have contributed to the large number of responses received.

Understanding the different audiences

While attempts are made to draw out the variations between the different audiences, it is important to note that responses are not directly comparable. Across the different elements of the consultation, participants received differing levels of information about the proposals. Some responses therefore are based on more information than others, and may also reflect differing degrees of interest across participants.

Similarly, while every attempt has been made to classify each participant into the correct category for reporting purposes, it is not always clear from the response the specific category to which they belong. The information is self-reported and is often incomplete.

Free text responses

The consultation included a number of open-ended questions which are exploratory in nature and allow respondents to feed back their views in their own words. Respondents were also able to write, email or text their views. Qualitative methods are much-used and well-respected in research. Despite the fact that findings emerge as a number of 'themes' and 'ideas' rather than leading to statistical analysis, this can be just as, if not more, useful in analysing results.

Responses from the open questions and written comments were coded to categorise and group together similar responses and identify the key themes. The vast majority of responses were spontaneous in nature and as a result a wide range of themes emerged from the consultation. The spontaneous nature of the comments also meant that the absolute numbers mentioning a particular topic were often small compared with the total number of responses to the consultation overall. Not all participants chose to answer all questions, as they often had views on certain aspects of the consultation, and made their views on these clear, but left other questions blank. Therefore, there were many blank responses to certain questions.

Some figures relating to the coded responses from the open questions are reported in this document, although they must be treated with caution. While some figures may seem small given the scale of the overall consultation, all those reported on have been highlighted due to their importance relative to other themes, and despite small figures can reflect important themes.

A number of verbatim comments are included to illustrate and highlight key issues that were raised.

2. The suggested new approach

This chapter considers respondents' views on various aspects of the suggested new approach – specifically, the Five Key Principles underpinning the proposals, elements of the proposals such as the need for 24/7 care, and the suggested improvements to the collection of data.

2.1 Five Key Principles

In the *Safe and Sustainable* consultation document, the Five Key Principles underlying the consultation were presented (p13-14):

- **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.
- **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.

Respondents were asked the extent to which they agreed or disagreed with each of these principles. Before answering, respondents were referred to the relevant pages of the consultation document (pages 13 & 14).

Agreement with the principles overall

More than one in three personal respondents to the public consultation (50,332 respondents) did not give an opinion about each of the principles. However, among those who answered these questions, there was strong agreement, particularly with the principles on *Children*, *Quality*, *Equity* and *Personal service*. Of those answering the questions, around nine in ten agreed.

Views towards the fifth principle, that treatment should be *close to families' homes where possible*, were less positive than for the other four principles, though a majority still agreed.

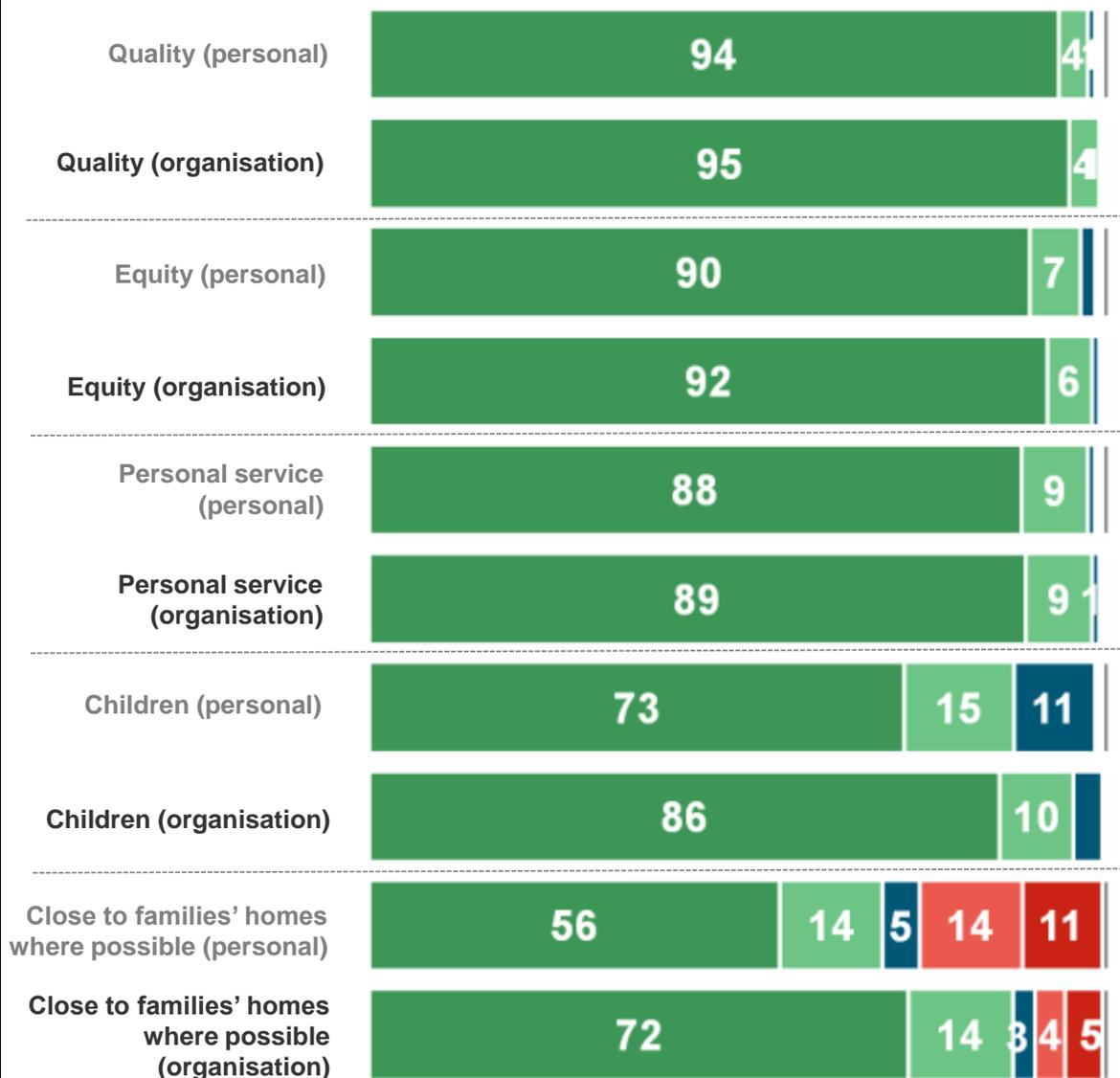
The majority of organisations did not give an opinion about the Five Key Principles. However, levels of agreement were relatively consistent across all five principles, and very few organisations disagreed with each principle.

The following chart shows responses across all five principles. Individual principles are considered in more detail later in this chapter.

The Five Key Principles

Q Please indicate the extent to which you agree or disagree with each of the five key principles.

■ % Strongly agree
 ■ % Tend to agree
 ■ % Neither agree nor disagree
■ % Tend to disagree
 ■ % Strongly disagree
 ■ % Don't know



Base: All respondents providing an answer to each question (approx 32,000 personal respondents and 500 organisation respondents) 1 March – 1 July 2011

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All respondents were also invited to comment on the Five Key Principles in a free text box, where they could report their views either on a specific principle or principles, or their general comments. Of those commenting, 5,118 did not refer to a particular principle – though it is often clear from their comments which principle or principles they had in mind. For example, *quality* was a strong theme to emerge from these responses – 2,272 respondents emphasised the importance of the standard of care provided. This often related to comments that high quality service or patient care was paramount, or all children deserved the best possible care.

“I think that quality is of the highest importance for these services”

Many respondents also mentioned a specific hospital and their support for it. Travel was also high in respondents’ minds, with 1,505 respondents mentioning this aspect – for example, a large number said that ease of access, the location of services, or short travel was necessary or of paramount importance.

“All centres must be easily accessible for families whose children are in need of the specialist care.”

The family was also a key theme emerging, mentioned by 1,128, where respondents talked about the need for families to be close to visit the patient and aid their recovery and the importance of accommodation. The needs of the family as well as the child’s needs were also stressed.

A number of respondents stated that they agreed with all the principles or that they were all equally important. Others started to report priorities, for example, saying that high quality care takes precedence over length of time travelling or location and that the child’s needs come before anything else. In addition, a number made more general comments relating to the proposals, such as that centres should be multi-disciplinary or provide a full range of services under one roof.

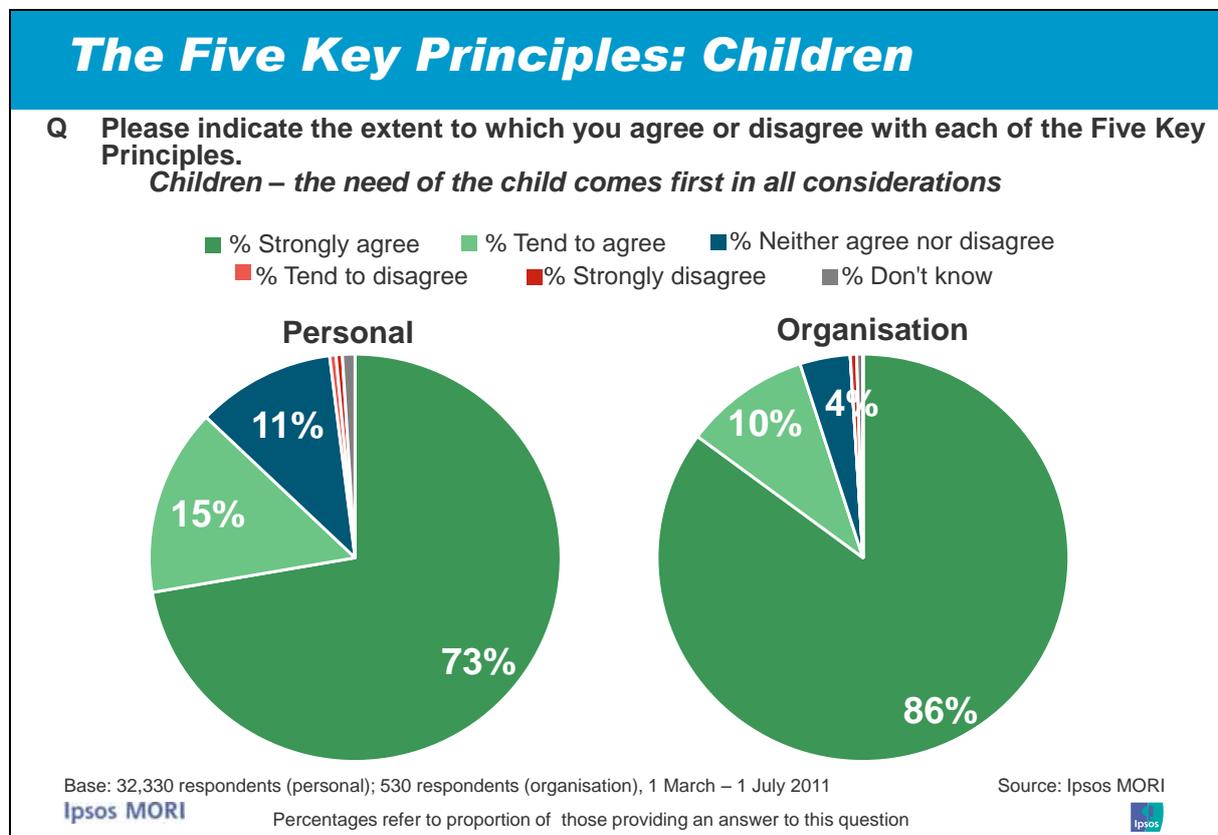
“Quality of specialist care is more important than local access.”

“In all these considerations the child’s physical, social and emotional welfare must come first”.

“I would rather go to a single centre where everything can be done than have to visit lots of different places to see doctors/surgeons and have tests.”

The Five Key Principles – Children

Turning to the first of the key principles – *the need of the child comes first in all considerations* – almost three in five personal respondents agreed with the principle (56%), with approaching half *strongly* agreeing (47%). However, as mentioned above, around one in three did not answer this question (36%) and very few disagreed (fewer than one per cent). Among organisations, more than half did not give an opinion about the principle. Again though, the balance of opinion is similar, if not slightly more likely to be in agreement than among personal respondents, with more than two in five organisations agreeing (45%) and very few disagreeing (fewer than one per cent). **Of those respondents answering this question, around nine in ten agreed with the principle** (88% of personal responses and 96% of organisations).



Levels of agreement varied across different groups of personal respondents largely because some were less likely to have answered the question. For example, only three in ten in the East Midlands agreed with the principle (31%, compared with 57% overall) but almost three in five did not answer the question (57%, compared with 36% overall). Response rates across all other regions were substantially higher, particularly in the North East and Yorkshire and Humber (just 1% and 3% respectively did not answer). In addition, the groups who were less likely to answer this question were those with no experience of caring for someone with CHD (45% not stated), men (43%), respondents under the age of 16 (55%) and those over

75 (49%) and those from a minority ethnic background (63%). In fact respondents in these groups were less likely to have answered any of the questions regarding the new approach covered in this chapter; they were more likely to have only answered questions on the options for the location of specialist surgical centres.

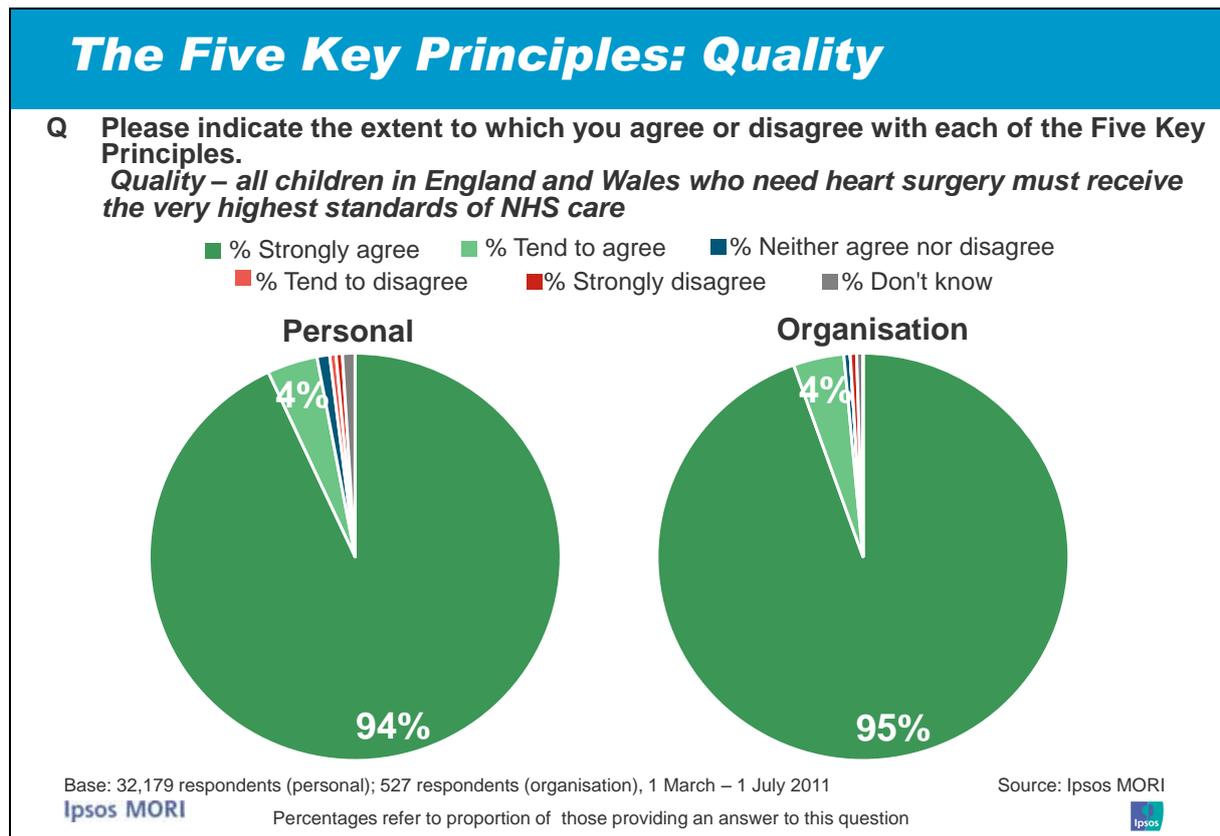
Of the 745 respondents who went on to comment on this principle in their own words, many reiterated that the child's needs have to come before anything else, with some saying that this was the most important of the five principles. Many respondents focused on the needs of the family, often adding a caveat – suggesting that the wider family's needs must also be taken into account. For example, some said that parents having to take time off work should be considered or that the effect on siblings needed to be taken into account. Respondents also mentioned more logistical issues, such as the time and cost involved, as well as the need for accommodation. The cost of travel was mentioned and others said extra costs such as meals and accommodation should be considered. In addition, a number of respondents pointed to the need for easy access to services, with the location and short travel times being important.

“The child is the main concern but the family unit must also be considered in terms of travel, accommodation, work commitments, costs to stay with their child etc.”

Quality was also a theme emerging from some responses to the key principle on *children* – largely the importance of high quality care and safety. Some also mentioned a specific hospital, generally showing their support for that hospital.

The Five Key Principles – Quality

The second key principle underpinning the proposals is that *all children in England and Wales who need heart surgery must receive the very highest standards of NHS care*. There was particularly strong agreement with this principle. Among personal respondents, more than three in five agreed with the principle and fewer than one per cent disagreed. As before, more than one in three did not give an answer to this question (36%). Those responding as organisations were less likely to give an answer to this question – over half did not respond (53%). Levels of support for the principle were again high, with fewer than one per cent disagreeing with it and approaching half agreeing (46%). **Almost all respondents answering the question agreed with the principle** – 98% of personal respondents and 99% of organisations.



A total of 729 respondents commented further on this principle, referring to it specifically. Around half of those making a comment here simply reiterated that high quality service or patient care was paramount or stated that all children deserve the best possible care and some said that *quality* was the most important principle.

“Quality should be the utmost concern to us all.”

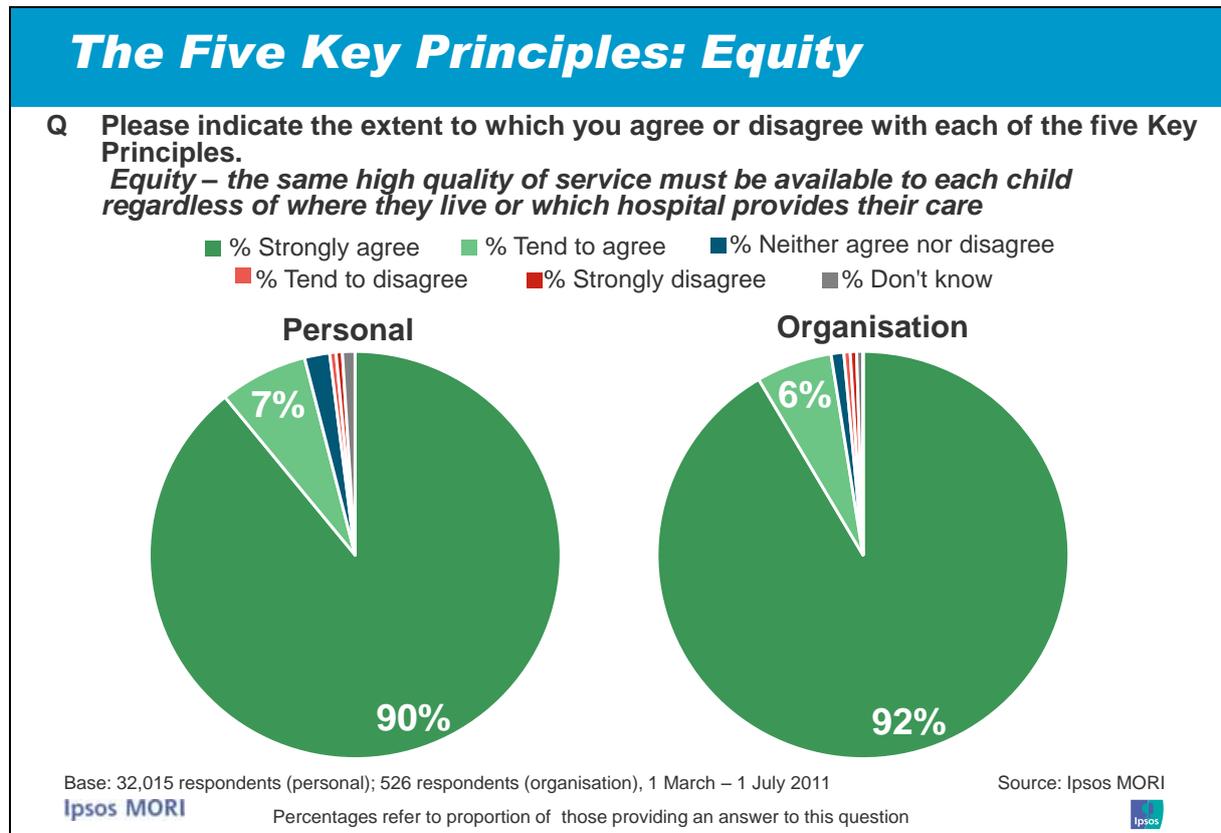
“Providing the highest possible standard of treatment is the most crucial requirement because cardiac care can so easily go wrong in the very young.”

Families and travel were mentioned less frequently, while a number of respondents mentioned something about a specific hospital.

The Five Key Principles – Equity

As seen in relation to the two key principles already discussed, over one in three personal respondents (36%) and over half of organisations (53%) did not give an opinion on the principle of *equity*. According to the principle, *the same high quality of service must be available to each child regardless of where they live or which hospital provides their care*. As before, very few personal respondents or organisations disagreed with this (fewer than one per cent of each), while around three in five personal respondents (62%) and nearly half of

organisations (46%) agreed. Therefore, **of those answering, almost all agreed with the principle** (97% of personal respondents and 98% of organisations).



When asked to comment on the Five Key Principles in their own words, 871 focused on the *Equity* principle. Over half of these discussed the need for centres to be multi-disciplinary or provide a full range of services under one roof.

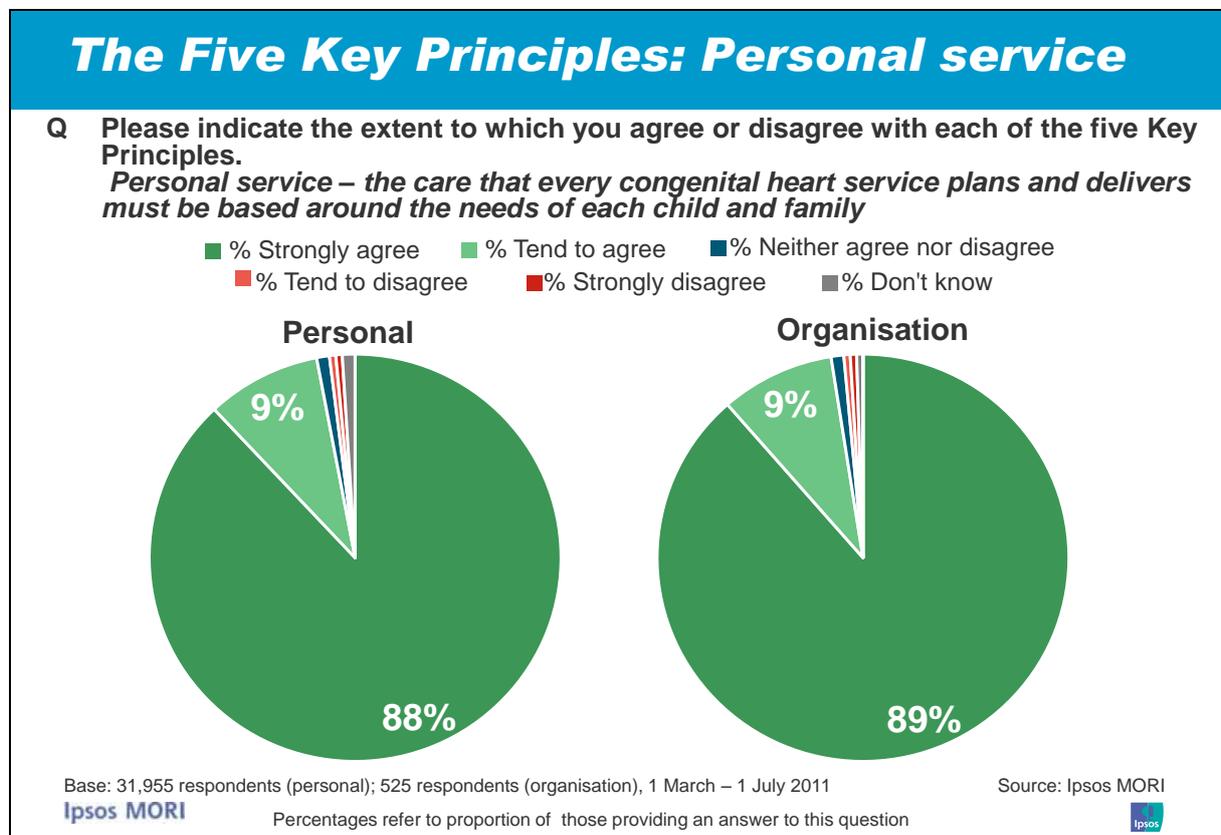
“The same high quality of service must be available to each child in a hospital that is close to where they live.”

“I think that all children requiring cardiac surgery should have access to all other paediatric specialities that they may require all on one site.”

A large number of these were identical (or very similar) in wording, perhaps replicating a published response. A smaller number of respondents restated the importance of high quality care and some said that high quality care should be available to all children.

The Five Key Principles – Personal service

Respondents were also asked to what extent they agreed or disagreed with the key principle on *personal service: the care every congenital heart service plans and delivers must be based around the needs of each child and family*. Levels of agreement were similar to the other principles discussed so far (*Children, Quality and Equity*). More than three in five personal respondents agreed with the principle (62%) and fewer than one per cent disagreed. Again almost two in five did not answer this question (37%). This rose to more than half of organisations (53%). Among organisations, just under half agreed with the principle while, again, fewer than one per cent disagreed. As before then, **almost all respondents providing an answer agreed with the principle** (97% of personal responses and 98% of organisations).



Fewer respondents commented on the principle on *personal service* than on any of the other four principles (330) and fewer said spontaneously that it was the most important principle. Among those who did respond, the importance of the family featured. Many of these believed that the family should be close for the benefit of the child, but they also discussed the needs of the family and the support needed – some specifically mentioned accommodation.

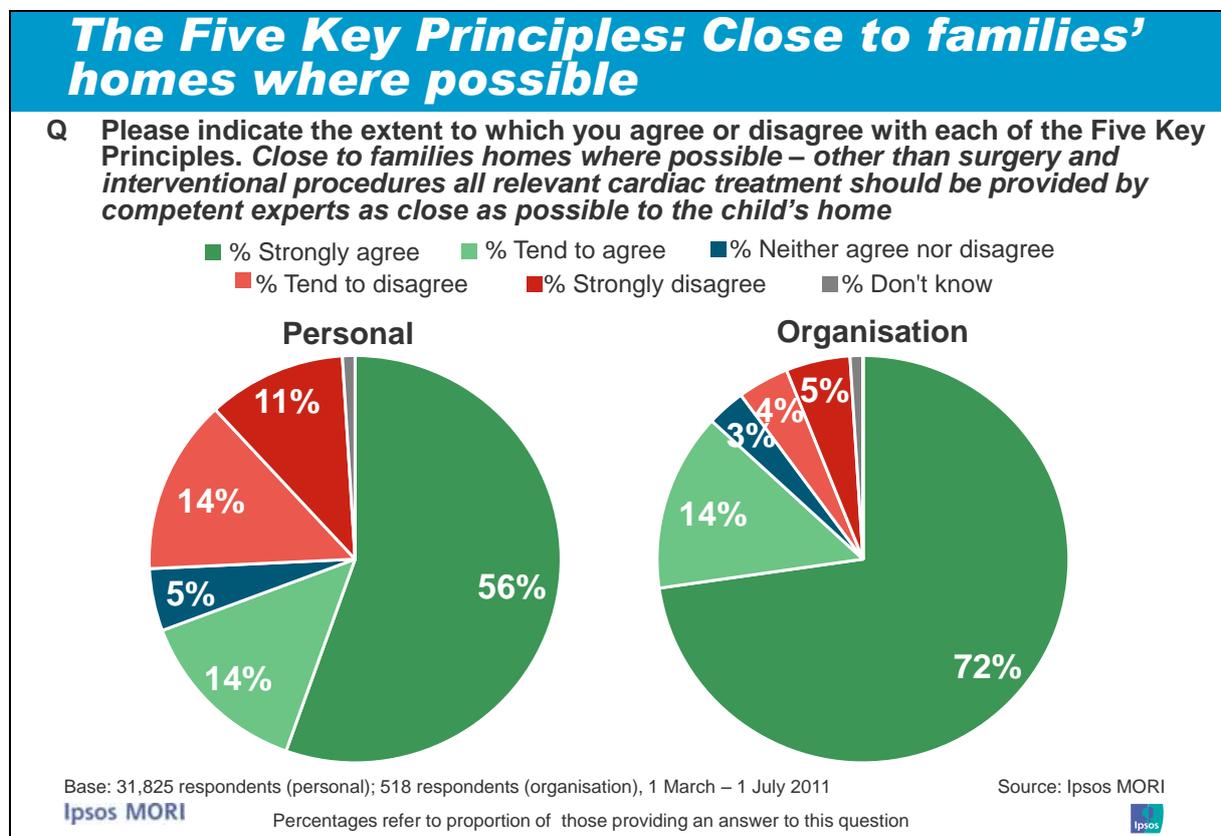
“The child's needs also involve the whole family”

“Each child needs care most relevant to their particular problem with as little disruption to family life as possible.”

Travel (ease of access) and standard of care were mentioned by similar numbers of respondents. As before, many respondents mentioned a specific hospital.

The Five Key Principles – Close to families’ homes where possible

The final principle presented to respondents was services *close to families’ homes where possible*. The principle states that *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*. Of all the five principles asked about, respondents were least likely to agree with this principle. The difference is particularly marked among personal responses. Although a similar proportion have not given an answer as for the other principles (37%), only just over two in five agreed with the principle (44%) and one in six *disagreed* (16%). That said, a higher proportion of respondents still agreed than disagreed with this principle. Among organisations, slightly fewer agreed and slightly more disagreed with this principle than the other principles (40% agreed and four per cent disagreed). **Of those answering therefore, respondents representing an organisation were more likely to agree with the principle – 86% compared to 70% of personal respondents.**



Analysis reveals that some groups were slightly more likely to disagree. Firstly, there appears to be a difference between patient and clinician opinion. Individuals with CHD themselves were most likely to disagree with this principle (21%), while those who cared for people with CHD as a job were least likely to disagree (nine per cent). There were also higher levels of disagreement among those who have had their care or the care of their child primarily co-ordinated by Leeds Teaching Hospital NHS Trust (71%, with only 23% agreeing). In contrast, those receiving care at the Newcastle-Upon-Tyne Hospitals NHS Foundation Trust and Southampton University Hospitals NHS Trust tended to be more supportive of the principle, with almost four in five agreeing with it (79% and 78% respectively). Accordingly, a high proportion of individuals from Yorkshire and Humber disagreed with the principle (72%), while just 2% in the North East disagreed with it and 3% in South Central.

More respondents commenting on the Five Key Principles referred specifically to this principle than to any other (2,139) and their responses suggested that many of those disagreeing with it were particularly concerned that surgery and interventional procedures had been excluded from the commitment to treatment close to home. They agreed that all relevant cardiac treatment should be provided as close to home as possible but also thought that this should apply to surgery and other interventions.

“Surgery, treatment and follow up should ALL be geographically close to patient's home to enable family life to continue to be as usual as possible.”

The majority of the comments made related to travel issues (1,195). Of these, most said that ease of access or the location of services or short travel was necessary, important or paramount, while some said that travelling should be minimised to reduce distress or risk to the child's life, or that it is negligent to force a patient to travel long distances for treatment. Linked to this, respondents said that families need to be close by to visit the patient easily to aid the child's recovery or continue life as normally as possible.

“As someone who grew up with a congenital heart defect I appreciate that I didn't have to travel far for my surgery. The last thing you want to be doing as a sick child is travelling across the country when you shouldn't have to. It also helped my parents who still had to look after my older sister during my spells in hospital.”

Some respondents again said that centres should be multi-disciplinary or provide a full range of services under one roof and many again used identical wording, perhaps copying the wording of a published response. Standard of care was again mentioned frequently, with

many of these suggesting that a high quality of care should take precedence over travel times or the location of the centre.

A smaller number suggested that patients should not be sent to centres further away from home simply to ensure higher volumes at those centres.

2.2 Views on aspects of the new approach

In the response form, respondents were presented with a number of different elements, statements or proposals emerging from the *Safe and Sustainable Review of Children's Congenital Cardiac Services* in England, and asked the extent to which they supported or opposed each one in turn. Before answering, respondents were referred to the relevant pages of the consultation document.

Support for, or opposition to, aspects of the new approach

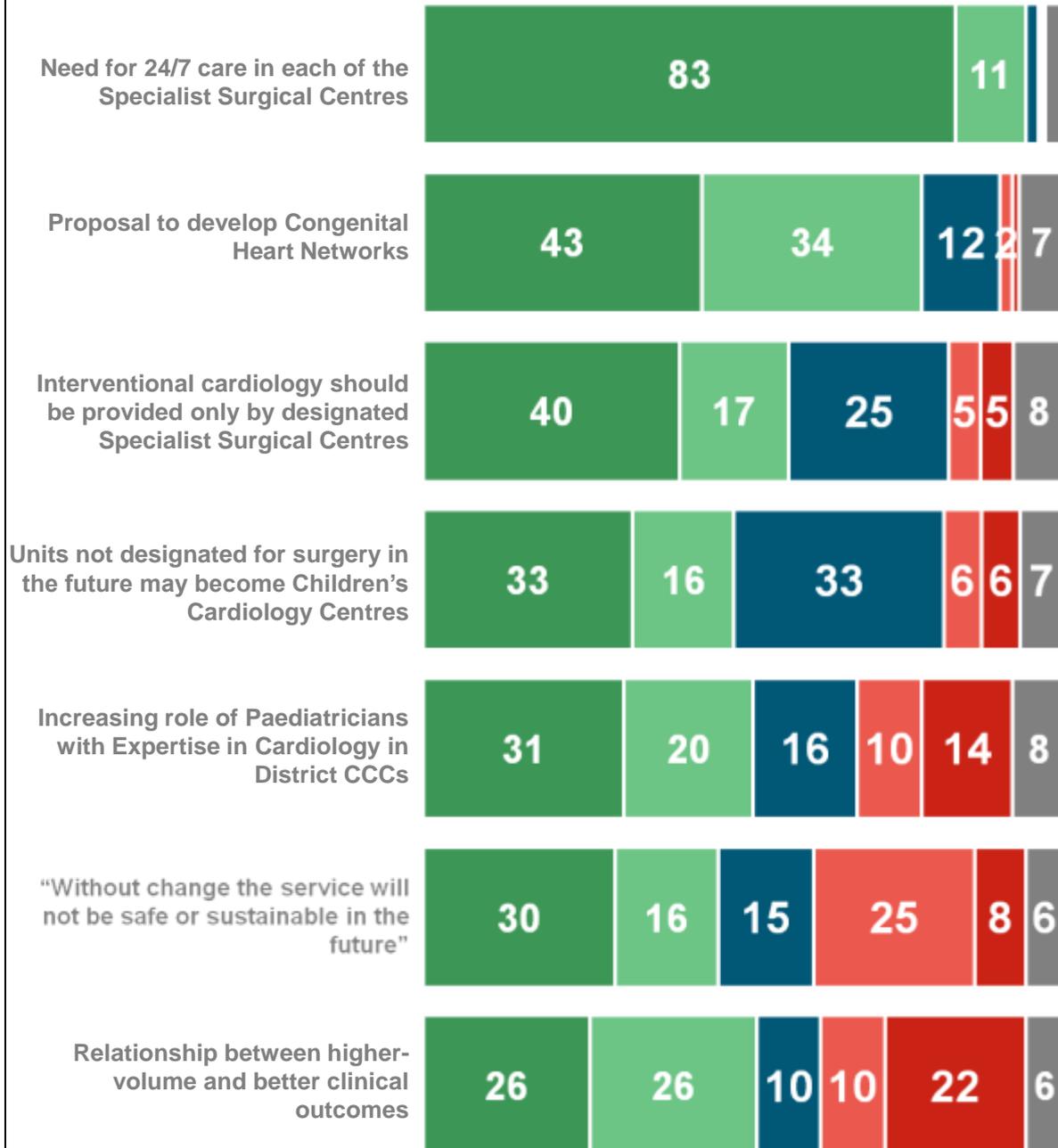
There were differing levels of support across the different elements, statements and proposals put forward in the *Safe and Sustainable Review of Children's Congenital Cardiac Services*. The *need for 24/7 care in each of the Specialist Surgical Centres* garnered most support amongst both personal and organisation respondents. The proposal to develop *Congenital Heart Networks* also generated a high level of support. Around 45% did not give a response to these questions.

The statements that personal respondents were most opposed to were that "*without change the service will not be safe or sustainable in the future*" and that "*research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes*".

Support for the new approach (personal responses)

Q Please indicate the extent to which you support or oppose each of the following elements/statements/proposals of the Safe and Sustainable review of children's congenital cardiac services in England.

■ % Strongly support
 ■ % Tend to support
 ■ % No views either way
■ % Tend to oppose
 ■ % Strongly oppose
 ■ % Don't know



Ipsos MORI

Base: All personal respondents providing an answer to each question (approx 27,000 respondents) 1 March – 1 July 2011

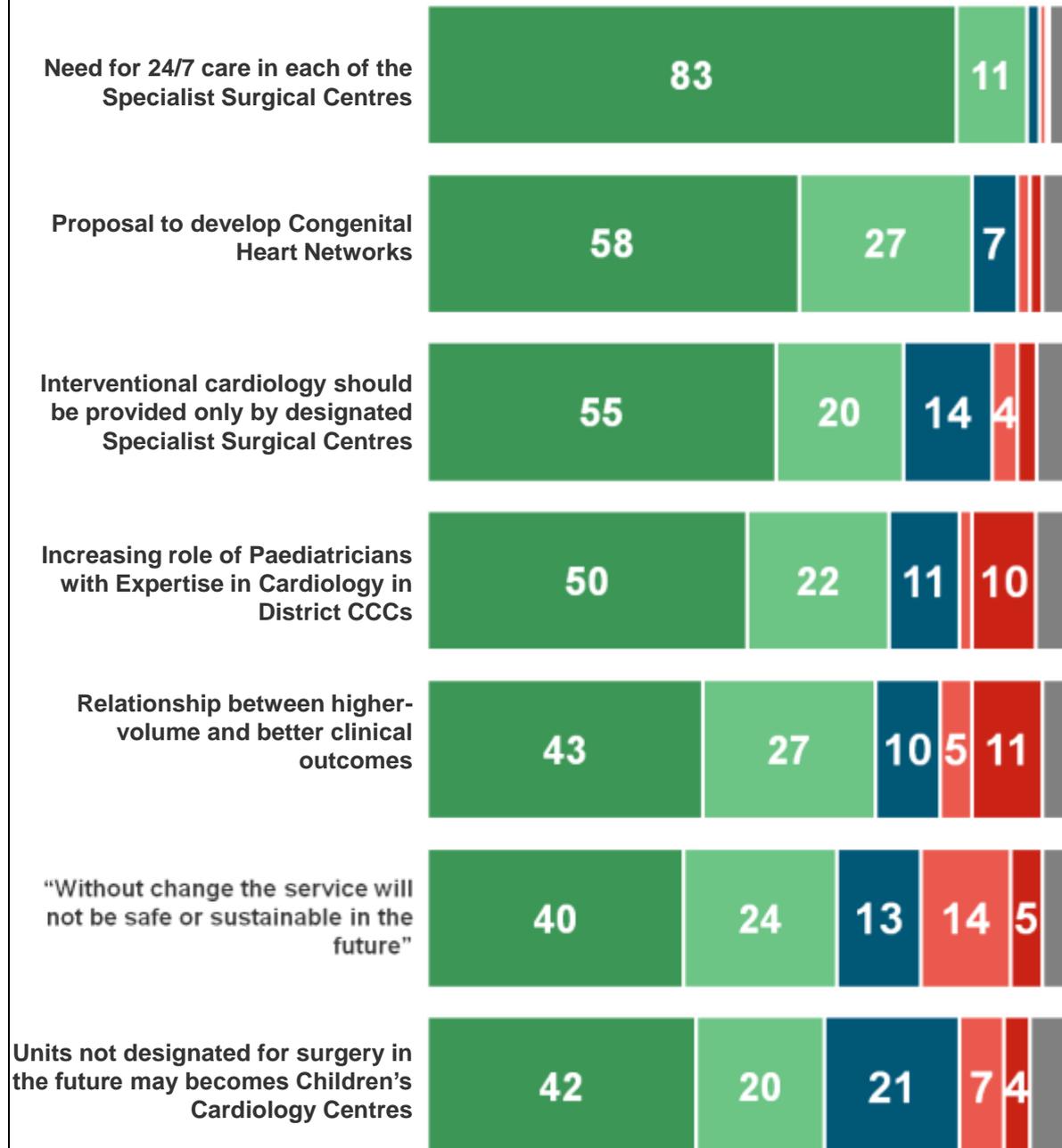


Levels of opposition were lower amongst organisation than personal responses. However, as for personal respondents, organisations were most likely to oppose the statement that *“without change the service will not be safe or sustainable in the future”*.

Support for the new approach (organisation responses)

Q Please indicate the extent to which you support or oppose each of the following elements/statements/proposals of the Safe and Sustainable review of children's congenital cardiac services in England.

■ % Strongly support
 ■ % Tend to support
 ■ % No views either way
■ % Tend to oppose
 ■ % Strongly oppose
 ■ % Don't know



Ipsos MORI Base: All organisation respondents providing an answer to each question (approx 380 respondents) 1 March – 1 July 2011

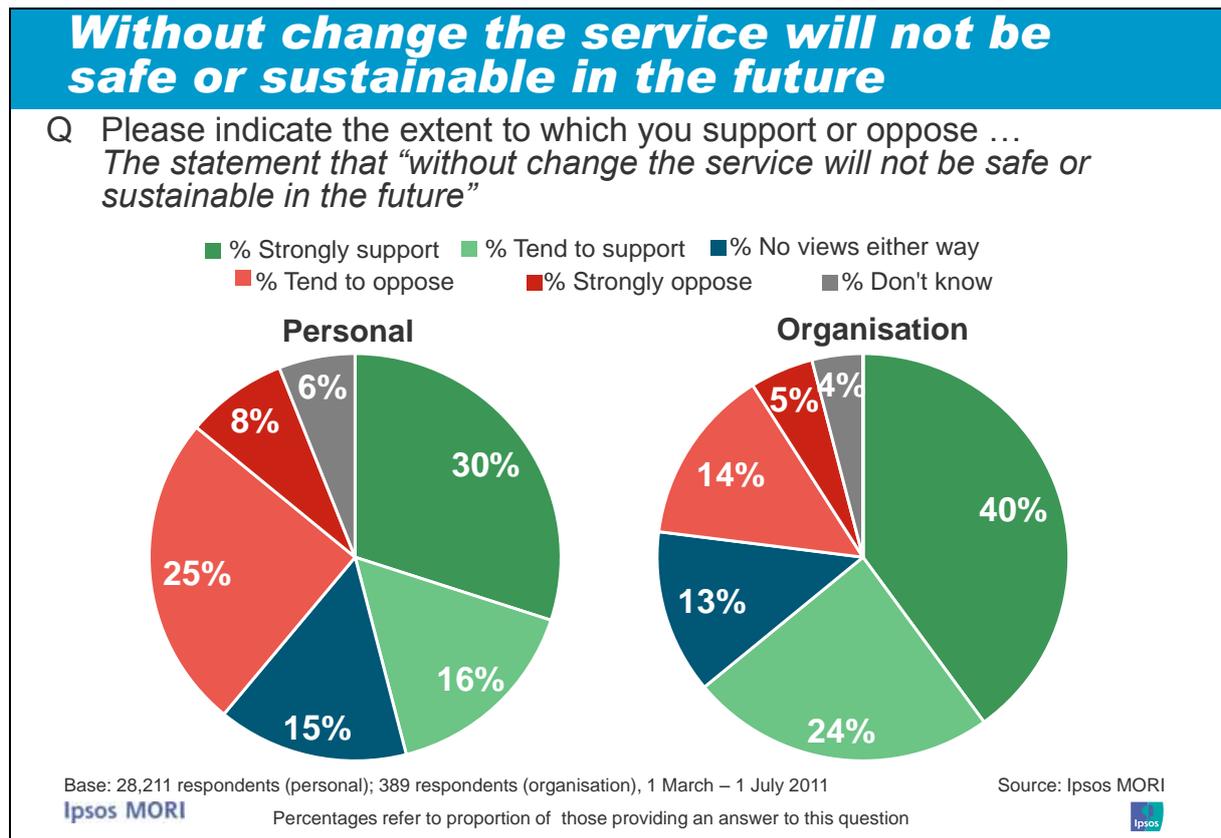


Respondents were then given the opportunity to comment on these elements, statements and proposals. Comments on each specific aspect (where respondents named a particular aspect) are presented separately throughout the rest of this chapter, but some responses did not name a particular proposal, though it is often clear from their response which one(s) they were referring to. Again, standard of care is a key theme that emerged, mentioned by 459 respondents; the largest number within this said that a larger facility or higher volumes do not necessarily mean better standards or outcomes, or that lower volume units do excellent work. The expertise of staff was mentioned by slightly more respondents (472), for example that paediatricians with cardiac knowledge are no replacement for a cardiologist, or that the distinction needs to be maintained. A further issue raised by respondents queried why adult care had been left out of the review. In addition, 180 mentioned the geographical spread and accessibility of services.

The need for change⁷

As already noted, the highest level of opposition was expressed with regard to the statement that “*without change the service will not be safe or sustainable in the future*”. Among personal responses, around one quarter supported the statement (26%) and almost one in five opposed it (18%) – although more than two in five (44%) did not give an answer at all (as is the case for the other six elements, statements or proposals). Among organisations, two in three did not give an answer (65%). More than one in five supported it, but levels of opposition were again highest for this statement (seven per cent). **Amongst those responding to this question there was more support amongst organisations than personal respondents. Around two thirds of organisations (64%) and half of personal respondents (46%) supported it.**

⁷ Respondents were referred to pp18-32 in the consultation document before answering this question.



Opposition was highest among those who have CHD themselves (26%). In addition, individuals from the East Midlands and West Midlands were particularly likely to oppose the statement (24% and 26% respectively).

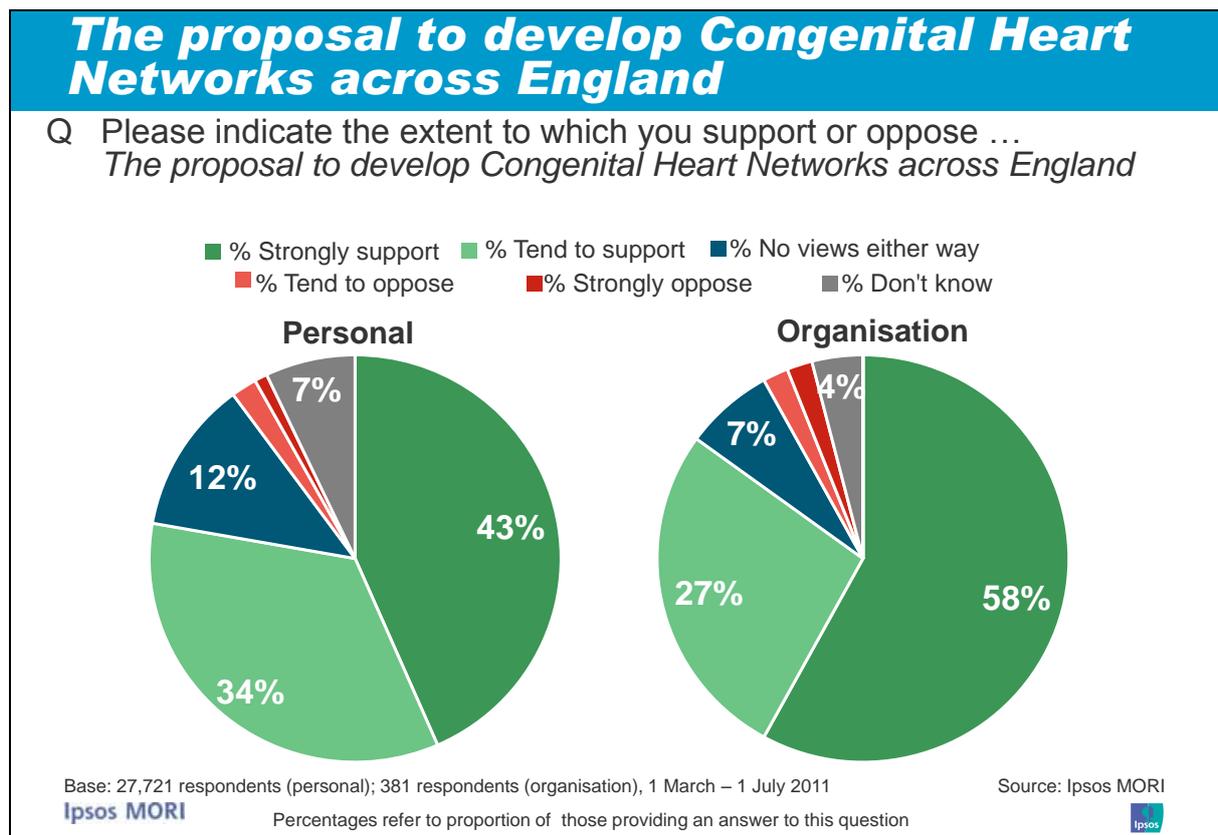
Of those who provided comments about the elements, statements and proposals presented, 715 respondents commented specifically on the statement that “without change the service will not be safe or sustainable in the future”. In particular, some respondents asked whether the service was not safe now (as did a further number of respondents, without referring specifically to the statement). Related to this, respondents said that there was no evidence to show that 400 plus cases of surgery are needed to be safe, and some suggested that all of the hospitals and units are safe.

“In response to Q5(a) are you saying the service provided up until now has not been safe?”

“The current centres are safe. 400+ cases won't make them safer or give better outcomes.”

Congenital Heart Networks⁸

Support for the proposal *to develop Congenital Heart Networks* across England was relatively high in comparison with the other elements, statements and proposals. More than two in five personal respondents supported the proposal (43%) and only two per cent opposed it. Among organisations, almost three in ten supported the proposal (29%) and one per cent opposed it. More organisations than personal respondents did not answer this question (66% compared with 45%). **This means that 77% of personal respondents who did answer the question supported the proposal compared to 85% of organisations.**



Support for Congenital Heart Networks was relatively high across the majority of the different sub-groups responding to the public consultation, with very few differences (although certain groups are less likely to have answered this question).

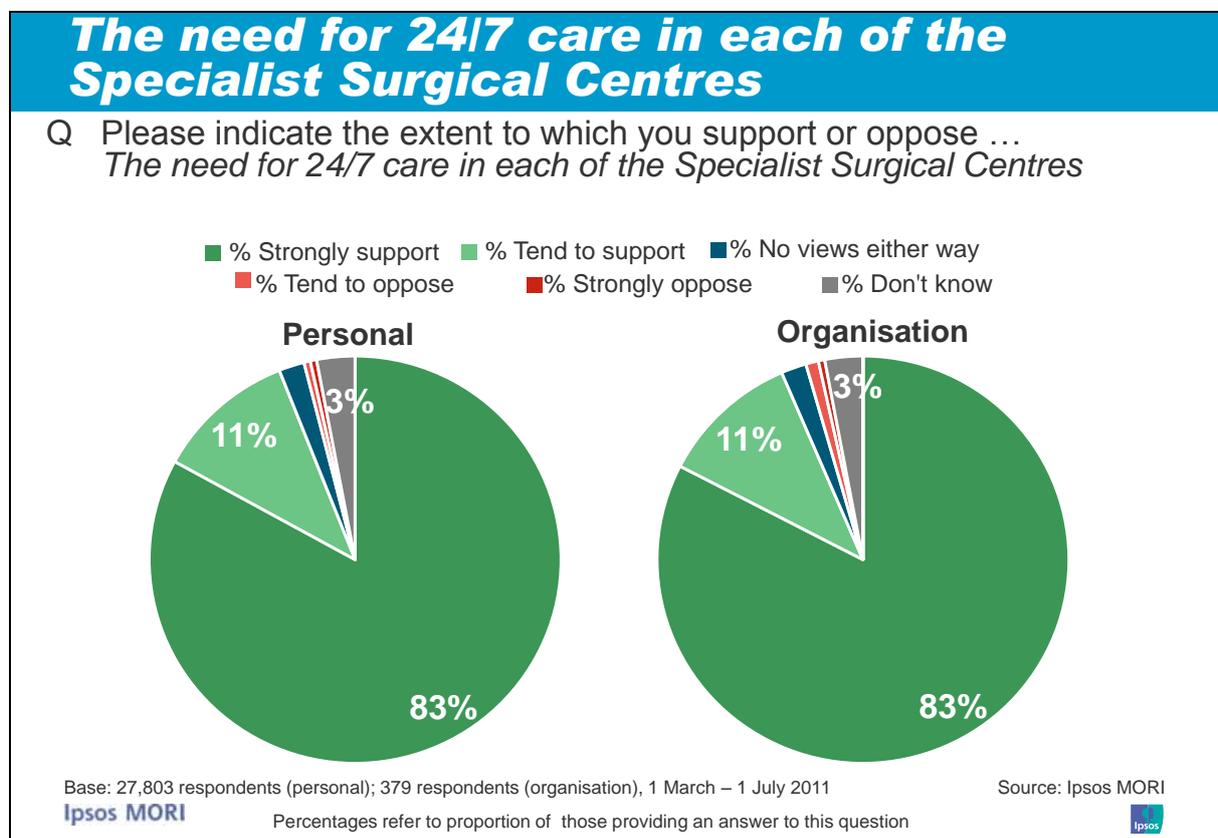
Fewer respondents commented specifically on this proposal than for others (250). Of those commenting, there was a concern that some areas may be left without adequately trained cardiologists. There was also a concern about the networks in terms of quality, how autonomous they might be, and how continuity would be maintained.

⁸ Respondents were referred to pp37-54 in the consultation document before answering this question.

“[I] agree as long as important health professionals do not all move to bigger centres which could result in smaller centres without adequately trained cardiologists”

The need for 24/7 care⁹

The need for 24/7 care in each of the Specialist Surgical Centres generated the highest level of support, among both personal and organisation responses. Fewer than one per cent of each group opposed the need for 24/7 care while half of personal respondents (52%) and one in three organisations (32%) were found to be supportive. Similar proportions as seen for the other elements, statements or proposals did not provide a response (45% of personal respondents and 66% of organisations). **Therefore, support amongst those answering was extremely high – 94% of personal respondents and organisations alike.**



Of those commenting on this element of the consultation (274), most made the suggestion that Glenfield provides this now, with some adding that it has been omitted by the *Safe and Sustainable* team.

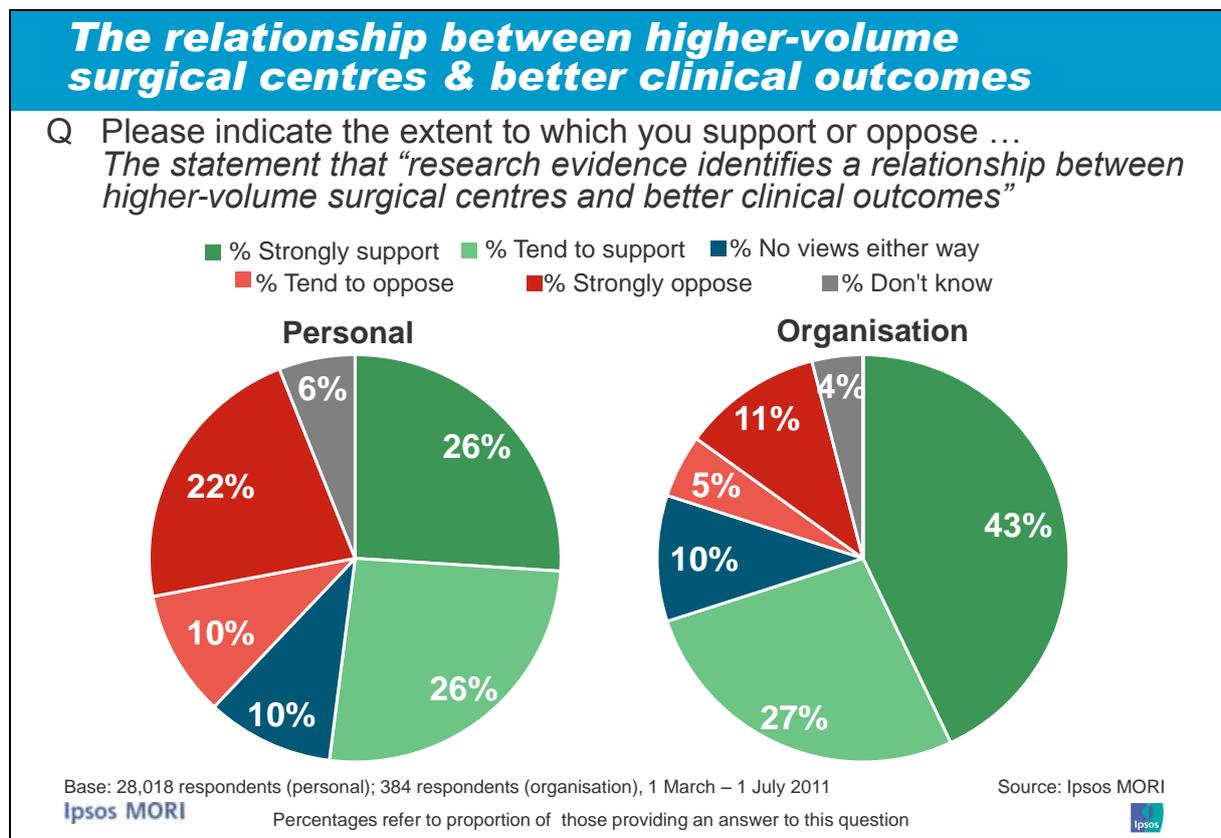
“Glenfield already provides 24/7 care. The S/S appear to have ignored this”

⁹ Respondents were referred to pp57-62 in the consultation document before answering this question.

Other respondents restated, or elaborated further on, the need for 24/7 care.

The relationship between higher-volume centres and clinical outcomes¹⁰

The statement that “research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes” prompted higher levels of opposition, with approaching one in five personal respondents (17%) and one in twenty organisations (five per cent) opposing it. Despite this, a larger proportion of both personal respondents (29%) and organisations (24%) supported the statement than opposed it. **Of those answering, there was higher support amongst organisations – 70% compared to 52% of personal responses.**



Again, there appears to be something of a patient/clinician split – those respondents with CHD themselves were more likely to oppose the statement than those who cared for people with CHD professionally (19% compared with 11%). Opposition was also particularly high among individuals in the East Midlands and West Midlands (both 26%). Linked to this, three in ten of those with links to University Hospitals of Leicester NHS Trust (Glenfield) opposed the statement (30%).

¹⁰ Respondents were referred to p18 in the consultation document before answering this question.

Of the 497 respondents commenting specifically on this statement (by referring to it by letter), around a quarter said that the interpretation of the evidence for higher volumes was incorrect if defined at over 400 cases per year. Others mentioned that there was not enough data to support the statement, that the statement was not correct, that it was disproven by other research, or that quantity did not equal quality – some suggested that higher volumes could actually put quality at risk.

Other respondents did not name a specific statement but their response clearly relates to this particular one. Again, many said that there is no evidence that outcomes improve as the number of operations increase above 200, or that centres carrying out more than 300 to 500 operations have better outcomes. Related to this, respondents specifically mentioned that the European Association of Cardiothoracic Surgeons suggested a minimum of 250 operations per year to include both child and adult congenital cases.

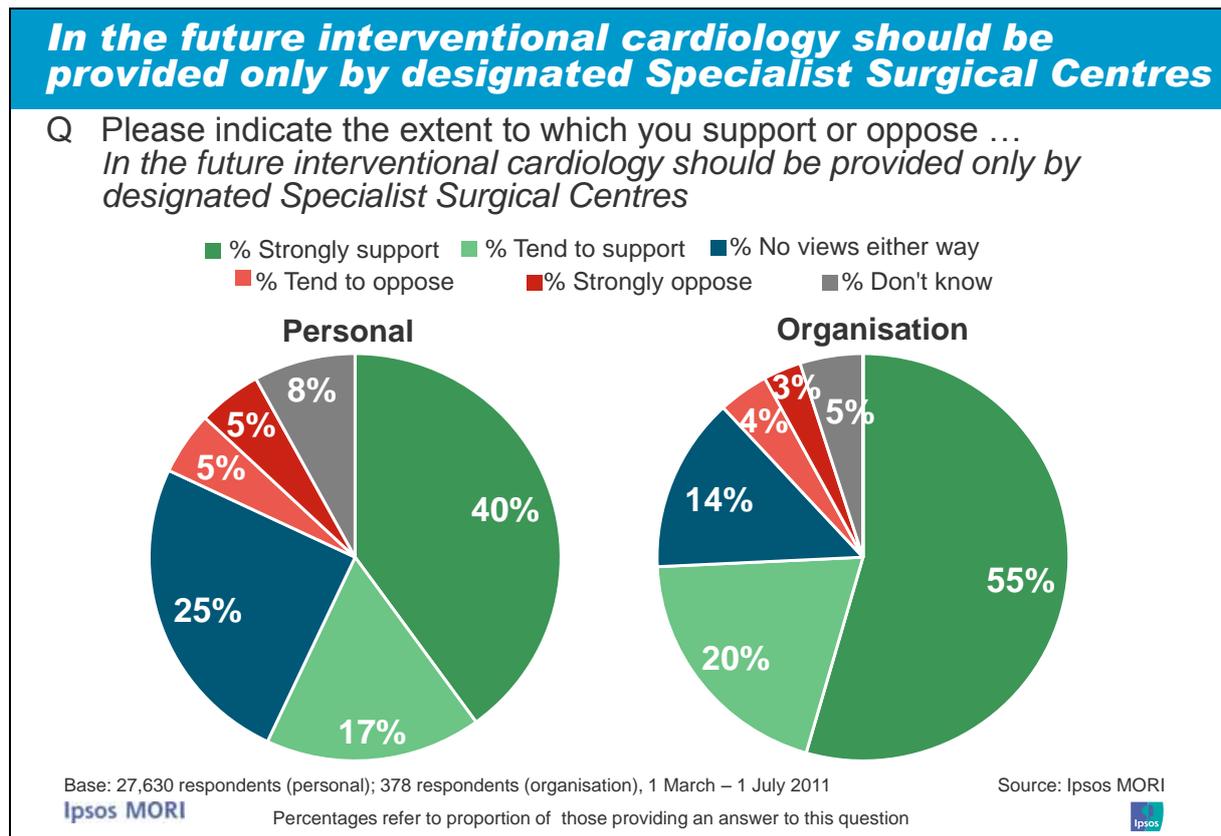
“There is no evidence to show that outcomes improve when the number of operations performed goes above 200, or that the centres performing more than 400 operations are better.”

As highlighted, there was some opposition to the need for each centre to perform 400 cases, with many of these respondents focusing on the lower number of 200 as the minimum. However, as stated earlier, there was a great deal of support for the need for 24/7 care – which leads to the proposal for a minimum of four surgeons and so a minimum of 400 cases at each centre.

Specialist Surgical Centres¹¹

Respondents were asked their views on the proposal that *in the future interventional cardiology should be provided only by designated Specialist Surgical Centres*. As for all these questions, a substantial number of respondents have not provided an answer, but the majority of those responding supported the proposal. Just under half of personal respondents and two thirds of organisations have not answered; three in ten personal respondents have showed their support (31%), with six per cent opposing and one in four organisations were supportive (25%), with only two per cent opposing the proposal. **Of those providing an answer to the question, 57% of personal responses and 75% of organisations supported the proposal.**

¹¹ Respondents were referred to p62 in the consultation document before answering this question.



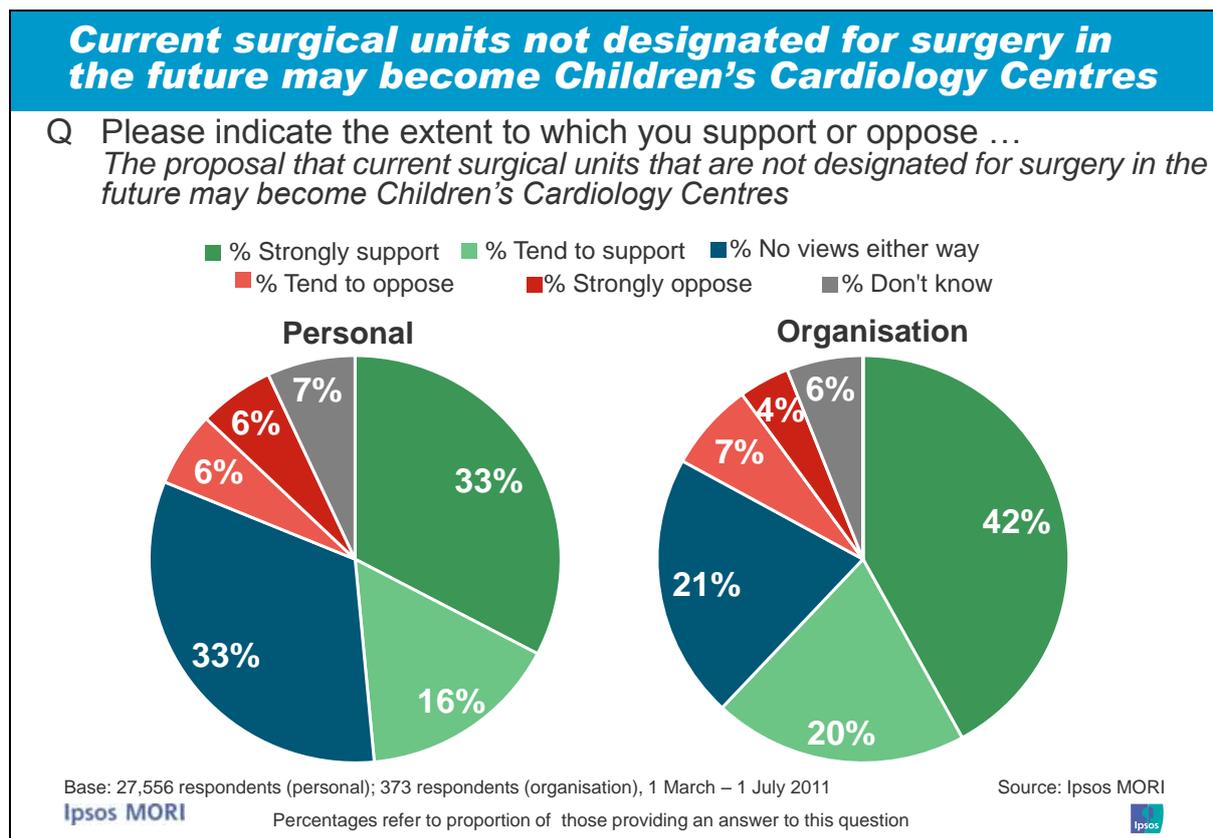
The respondents commenting spontaneously on the proposal tended to query what would happen to the non-surgical centres.

“Has it been considered what will happen to non surgical centres that offer a valuable service now? Just because they don't offer surgery doesn't mean they aren't imperative in their role.”

Children's Cardiology Centres¹²

Another proposal presented to respondents was that *the current surgical units not designated for surgery in the future may become Children's Cardiology Centres*. This proposal was supported by just over one in four personal respondents (27%) and one in five organisations (21%), and opposed by around one in twenty of each (six per cent and four per cent respectively). Large numbers have again not responded, and this means **of those who did provide an answer, 49% of personal respondents and 62% of organisations supported the proposal.**

¹² Respondents were referred to pp43-44 in the consultation document before answering this question.



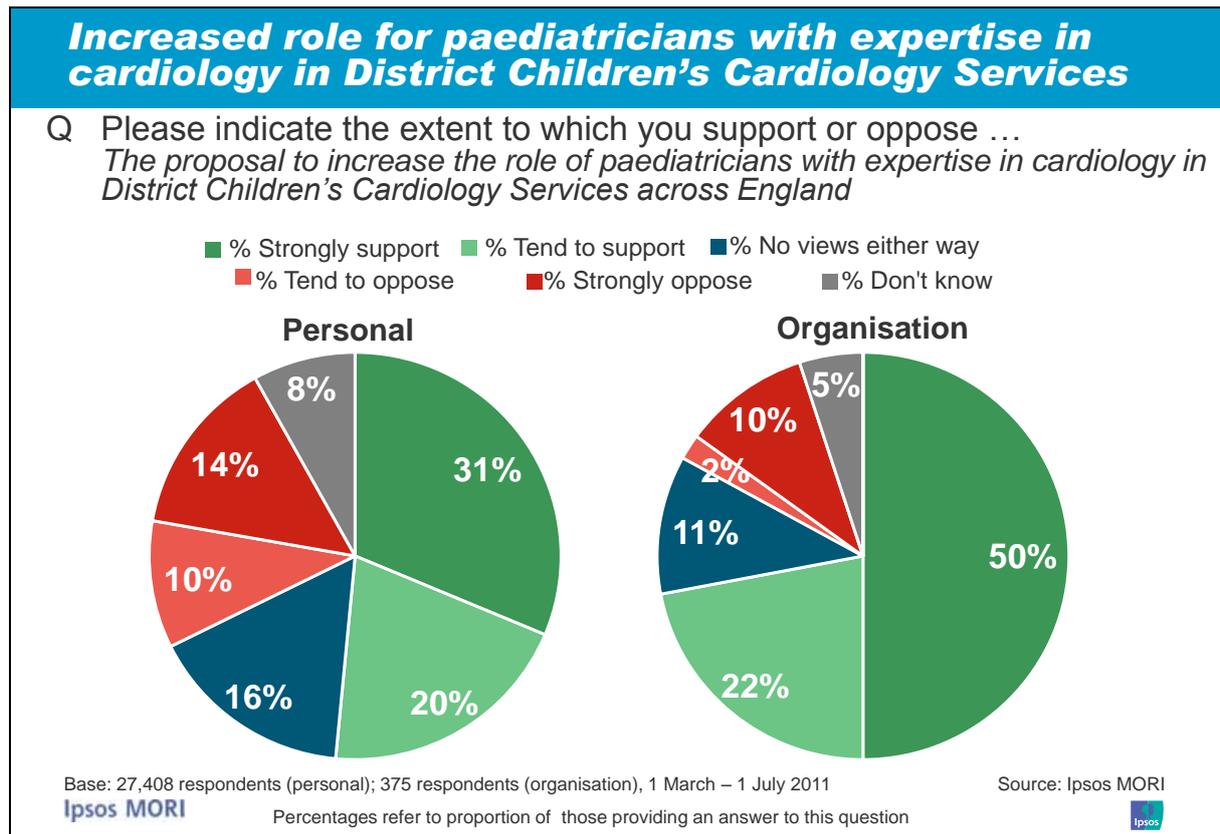
Levels of opposition for the proposal were higher in certain regions – the North East (12%) and London (11%). Opposition was also higher among those with prior experience of Royal Brompton and Harefield NHS Foundation Trust (18%) and Oxford Radcliffe Hospitals NHS Trust (14%).

In response to this proposal, a number of those providing comments mentioned that cardiologists or the most experienced, knowledgeable staff would gravitate to specialist centres, which could result in reduced expertise elsewhere. Others believed there would be no difference between a cardiology centre and a local hospital/district general hospital (DGH).

“What sort of service will we be left with if all the most important health professionals move to bigger centres?”

Developing the role of paediatricians with expertise in cardiology¹³

Almost three in ten personal respondents supported the proposal to *increase the role of paediatricians with expertise in cardiology in District Children's Cardiology Services* across England (28%) and just over one in ten opposed the proposal (13%). Among organisations, levels of opposition were much lower (four per cent), with a similar proportion as personal respondents supporting the proposal (24%). **Of those answering, there was higher support amongst organisations – 72% compared to 51% of personal respondents.**



Again, there was a clear difference in opinion between patients and clinicians; more than one in five respondents with CHD opposed the proposal (22%), while those who cared for people with CHD as part of their job were half as likely to oppose it (11%). There were also strong regional differences among individuals: three-quarters of those in Yorkshire and the Humber opposed the proposal, while in the North East three-quarters supported it (74%). Again linked to this, those with prior links to Leeds Teaching Hospitals NHS Trust were much more likely than others to oppose the proposal (75%).

Many of the 459 respondents who commented further on this proposal focused on their concern that a paediatrician with cardiac knowledge would not be an adequate replacement for a cardiologist, as did a further group of respondents without referring specifically to the

¹³ Respondents were referred to pp41-42 in the consultation document before answering this question.

proposal. Many other respondents who did not name the proposal nevertheless appear to be commenting on it. They raised concerns about having only one paediatrician who specialises in cardiac care: some questioned what would happen if the paediatrician was off sick or on holiday and, similarly, others stated that District Children's Cardiology Services staffed by one paediatrician with a special interest in cardiology would raise very serious clinical risk issues.

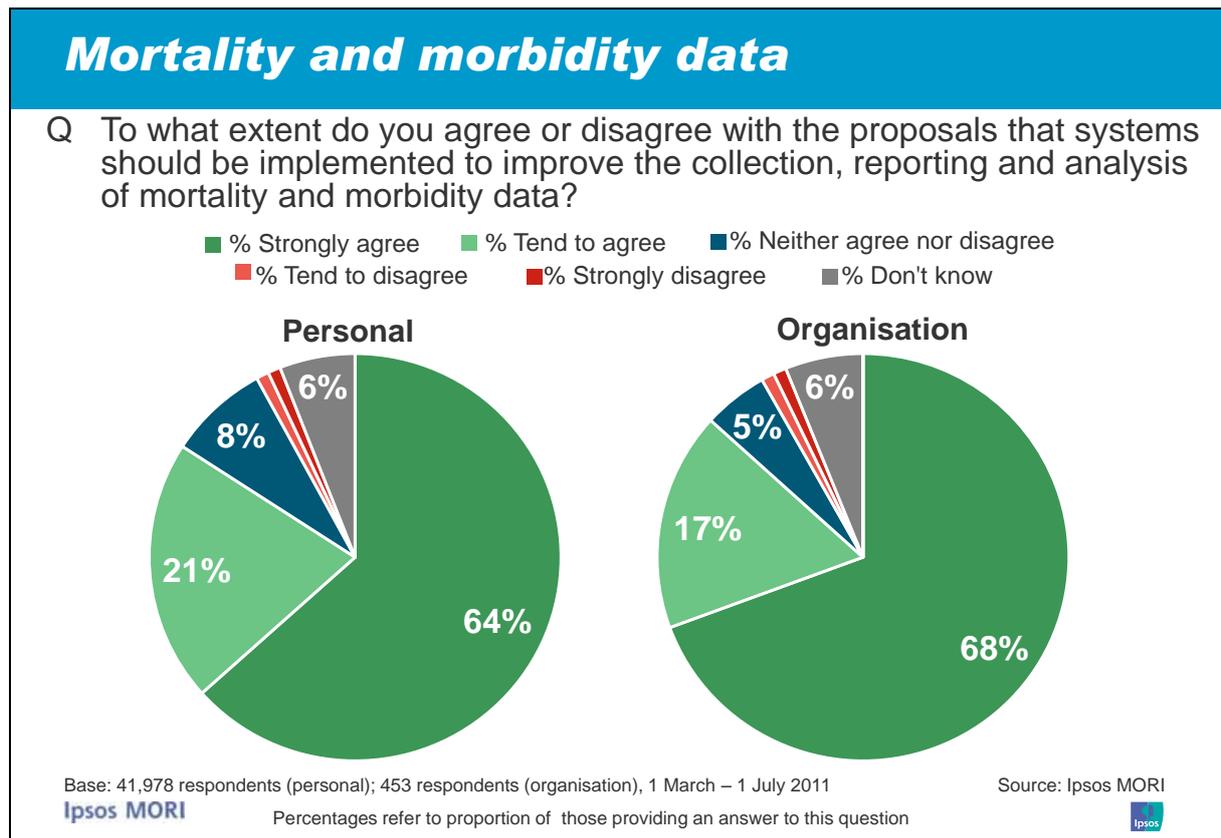
“Whilst an increase in the cardiac knowledge of general paediatricians is obviously of benefit, they cannot and should not be used to replace the knowledge of a cardiologist.”

2.3 Mortality and morbidity data

Improving the collection, reporting and analysis of data¹⁴

When asked to what extent they agreed or disagreed with the proposals that *systems should be implemented to improve the collection, reporting and analysis of mortality and morbidity data*, seven in ten personal respondents said they agreed (71%), with over half *strongly* agreeing (53%). Very few personal respondents disagreed (one per cent). Similarly, among organisations, only one per cent disagreed that the systems should be implemented. Fewer organisations than personal respondents agreed that systems should be implemented to improve the collection, reporting and analysis of mortality and morbidity data (35%), but many more organisations did not give a response (60%). **Of those responding, there were high levels of agreement – 85% of personal responses and organisations.**

¹⁴ Respondents were referred to pp125-128 in the consultation document before answering this question.



There were few differences in levels of disagreement among the various groups of respondents here.

3. National Quality Standards

A set of proposed National Quality Standards, falling under seven key themes, have been developed as part of the *Safe and Sustainable* Review. It is proposed that all hospitals that are designated as Specialist Surgical Centres should meet each of these standards.

Respondents were asked to indicate the extent to which they supported or opposed the National Quality Standards within the key themes:

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

3.1 National Quality Standards – key themes

Views on the new quality standards

The following charts provide an overview of respondents' support for, or opposition to, the proposed National Quality Standards across each of the key themes, broken down by personal and organisation responses. Later sections discuss each of these in more detail.

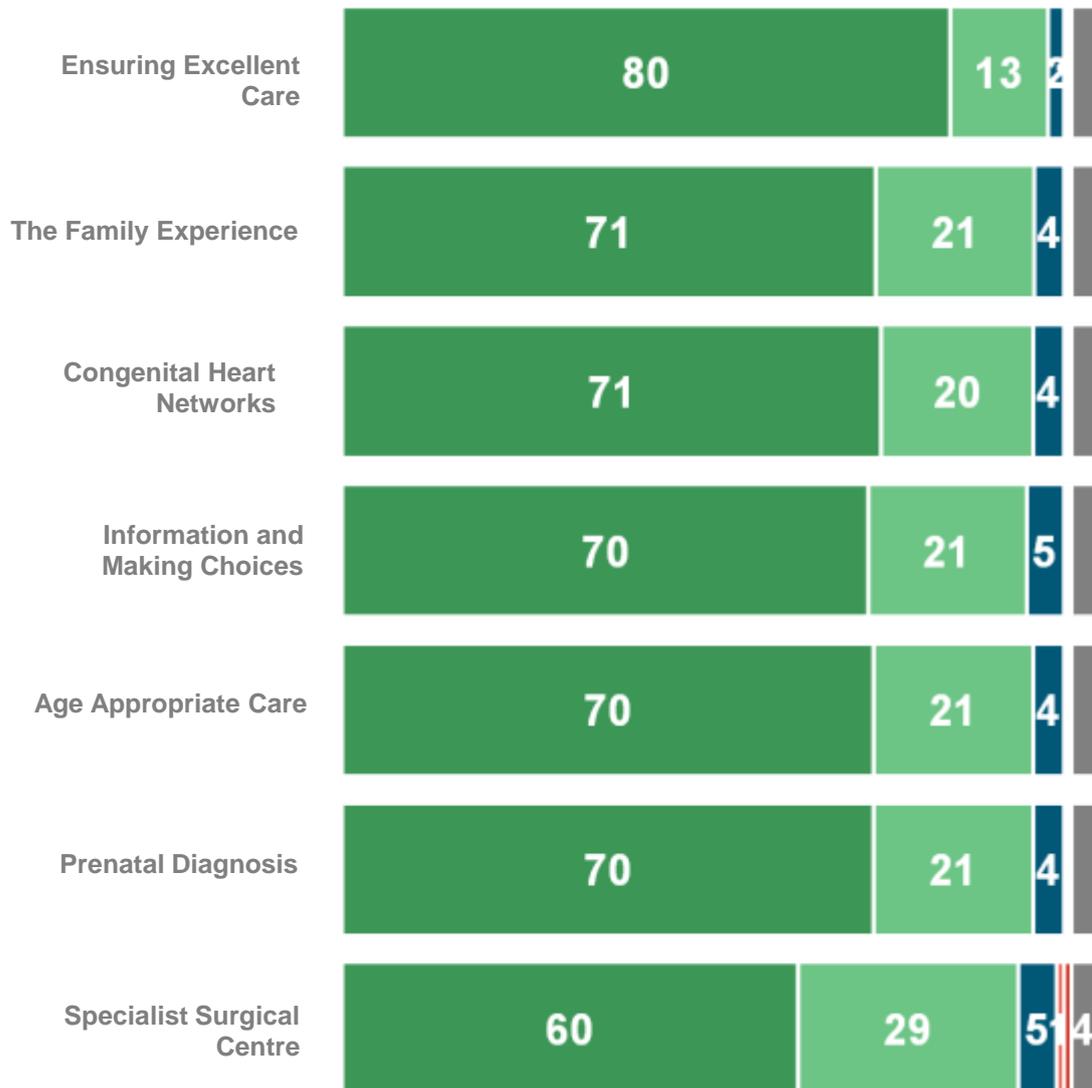
As can be seen, a high proportion of respondents have not provided an answer at this question – particularly those responding on behalf of an organisation or group. However, amongst those that have responded, there was extremely strong support across each of the seven themes.

There was slightly greater support for standards within the *Ensuring Excellent Care* theme – these standards received the highest proportion of respondents saying that they *strongly* supported them. Of people providing an answer to this particular question, over nine in ten showed their support.

National Quality Standards (personal responses)

Q Please indicate the extent to which you support or oppose the national quality standards within each of these seven key themes.

■ % Strongly support
 ■ % Tend to support
 ■ % No views either way
■ % Tend to oppose
 ■ % Strongly oppose
 ■ % Don't know



Ipsos MORI

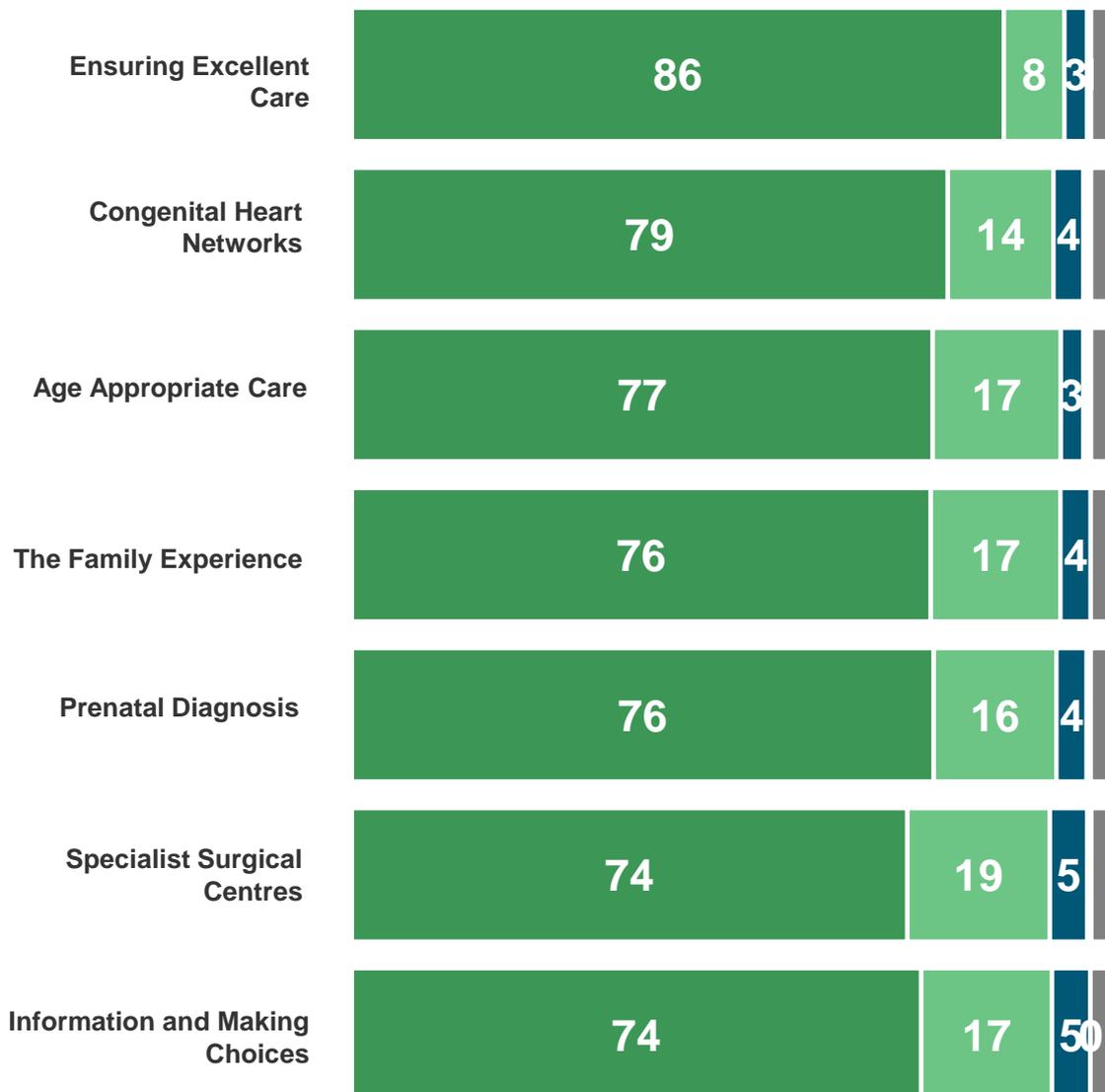
Base: All personal respondents providing an answer to each question (approx 27,000 respondents) 1 March – 1 July 2011



National Quality Standards (organisation responses)

Q Please indicate the extent to which you support or oppose the national quality standards within each of these seven key themes.

■ % Strongly support
 ■ % Tend to support
 ■ % No views either way
■ % Tend to oppose
 ■ % Strongly oppose
 ■ % Don't know



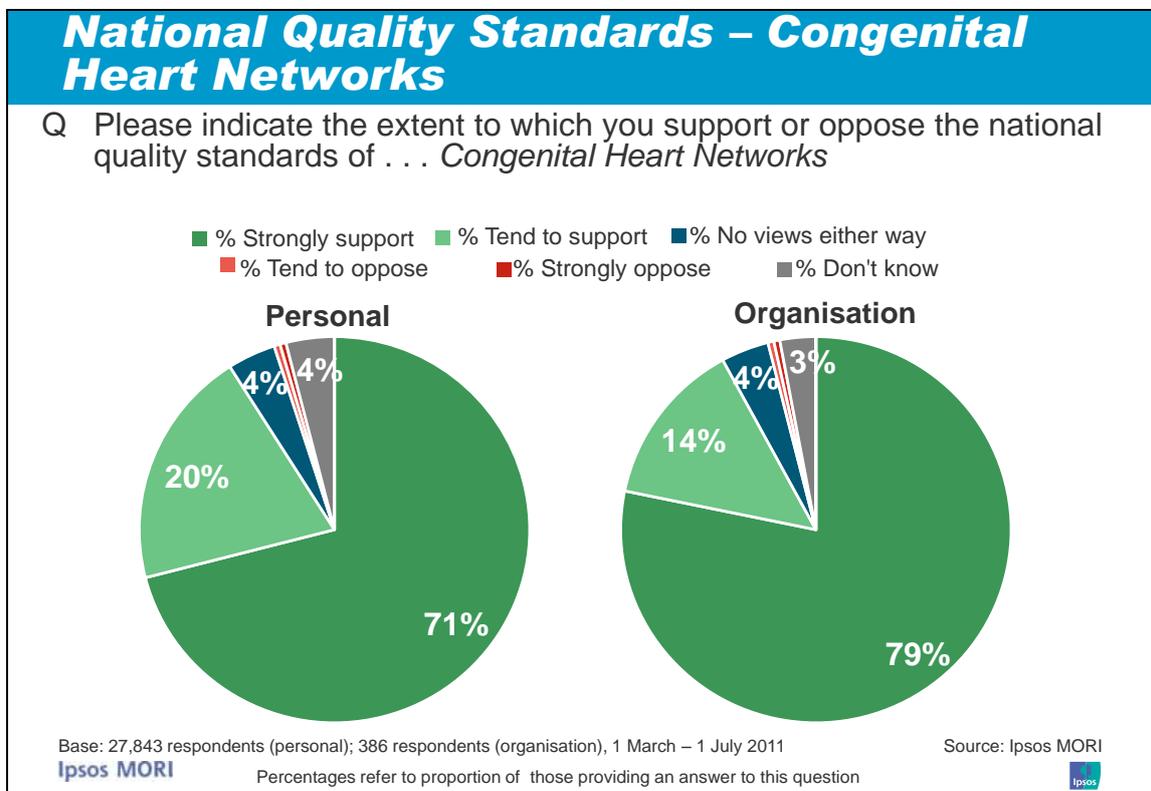
Base: All organisation respondents providing an answer to each question (approx 380 respondents) 1 March – 1 July 2011

The response form also gave respondents the opportunity to comment, in their own words, on the National Quality Standards. Over a thousand respondents did not indicate the particular standard or theme they were commenting on. For example, some respondents reiterated the importance of high quality care above all else (without referring specifically to a standard or theme), though smaller numbers also stated that location is equally important as quality, and finally some showed support for a specific hospital (particularly Southampton). Additionally a number made identical (or similar) comments, perhaps copying a published response; the vast majority of these stated that “gold standard care must be that babies are born in a hospital with a regional specialist neonatal unit on the same site as the cardiac unit to avoid delays in treatment, the need for transfer and to reduce risks”.

National Quality Standards – Congenital Heart Networks¹⁵

Half of personal respondents (51%) either *strongly* or *tended to* support the standards relating to *Congenital Heart Networks*; this compares to a third of organisations (32%). More importantly though, given the high proportion of respondents not giving an answer here, levels of opposition across both groups were extremely low (less than 1% in each case).

Of those providing a response therefore, over nine in ten supported these standards (91% of personal respondents and 93% of organisations).



¹⁵ Respondents were referred to pp37-54 in the consultation document before answering this question.

With such high levels of support, there was very little variation between different groups of respondents; support was high across the board. However, some respondents were more likely not to have provided an answer here – perhaps suggesting a lower interest in this area compared to the proposals surrounding the options for the location of Specialist Surgical Centres, where most respondents did provide responses. These audiences were less likely to have responded across all seven themes. For example, respondents from the East Midlands were less likely than those from elsewhere to have answered this question. Around three in five have not answered (59%). This compares with just 4% of those in Yorkshire and Humber and 7% in the North East.

Respondents from ethnic minority backgrounds were also less likely to have answered this question (65% not stated), as were the youngest and oldest respondents (58% of under 16s and 57% of over 75s not stated).

Of the 246 people that made comments on this key theme, 86 responses stated that Congenital Heart Networks already exist but there is room for improvement.

“Congenital Heart Networks already exist but there is always room for improvement. This can only benefit patients and their families.”

The next most common comment focused on the perceived risk of loss of expert staff associated with the establishment of these networks.

“[Congenital Heart Networks] already exist but there is always room for improvement – but it must not be at the cost of losing specialist consultant cardiac paediatric cardiologists.”

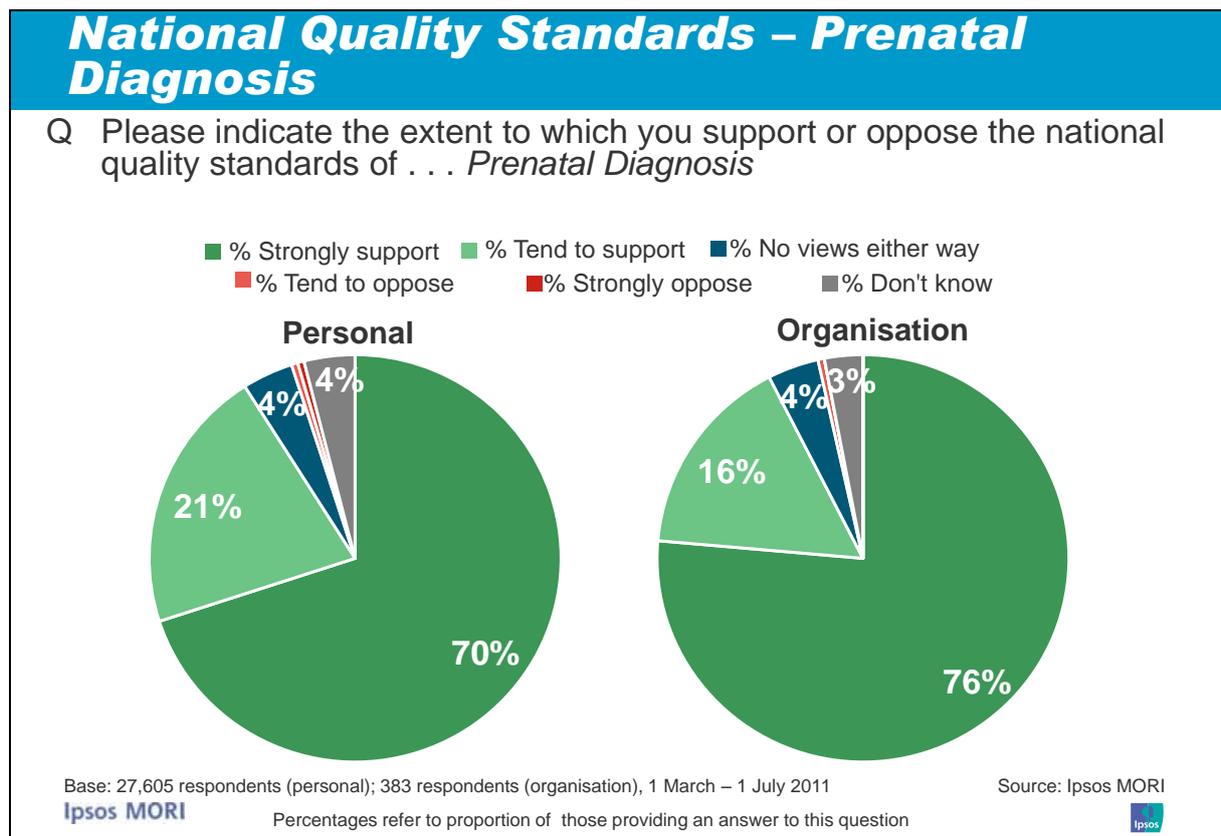
Other comments restated the importance of such networks (and standards relating to these), while a small number referred to existing examples of networks.

National Quality Standards – Prenatal Diagnosis¹⁶

Again, both personal and organisation respondents showed high levels of support for standards relating to *Prenatal Diagnosis*; 50% and 32% did so respectively. Again, levels of opposition were extremely low and a sizeable group did not provide an answer.

Amongst those responding to this question again this means that over nine in ten respondents supported these standards (91% of personal responses and 92% of organisations).

¹⁶ Respondents were referred to pp55-56 in the consultation document before answering this question.



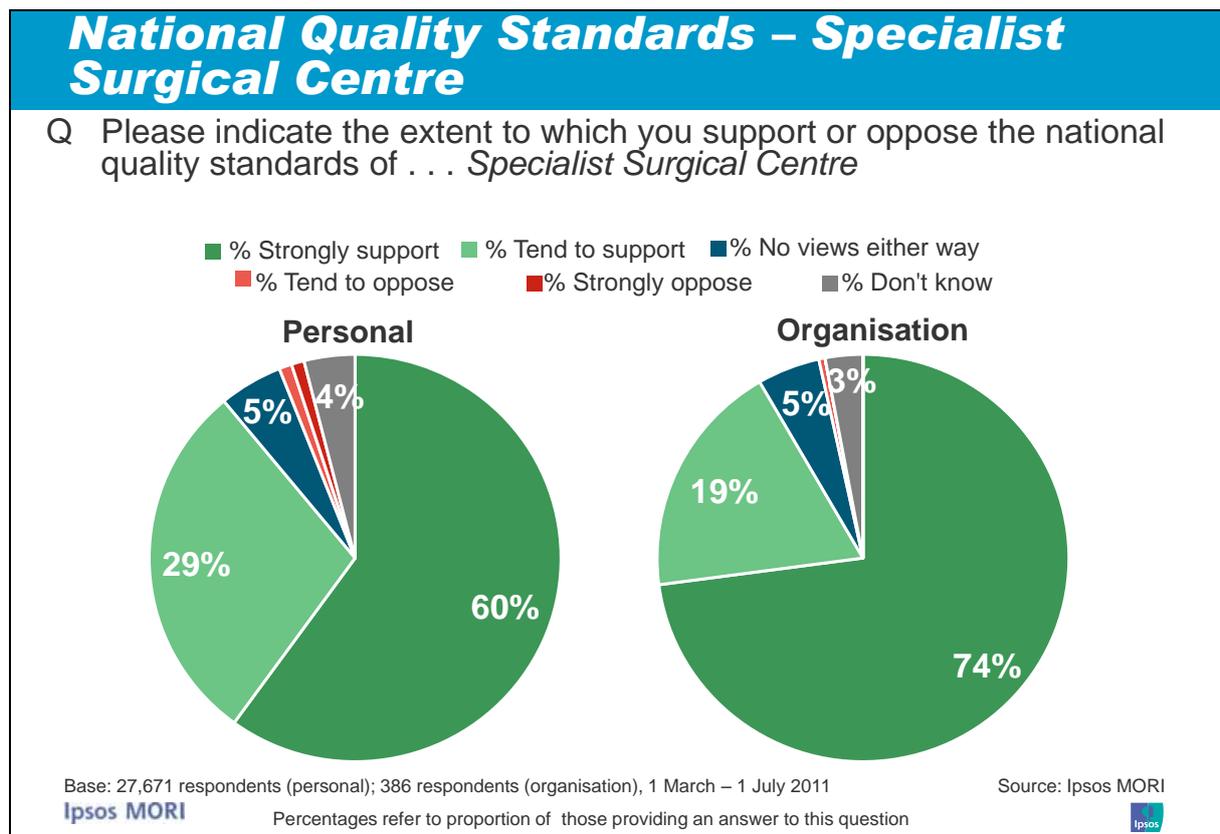
Slightly fewer respondents made comments on the standards relating to *Prenatal Diagnosis* (201), but among those that did, their responses generally stated a belief that prenatal diagnosis was extremely important and would help prepare expectant parents. Other respondents commented that this would allow babies to be born in hospitals where regional neonatal units have specialist cardiac care on site.

“The prenatal scans are of a great help to expectant families. This could give the parents a huge insight of what is to come.”

“Prenatal diagnosis is imperative so that babies can be born in a hospital with the specialist care required...”

National Quality Standards – Specialist Surgical Centre¹⁷

Half of personal respondents (49%) and a third of organisation respondents (32%) supported the National Quality Standards relating to the *Specialist Surgical Centre*. These levels of support were very similar to those regarding *Congenital Heart Networks* and *Prenatal Diagnosis*. However, personal respondents were less likely to *strongly* support this theme (33% vs. 39% in the case of both previous themes). Despite this, **of those providing a response, support remained at around nine in ten (89% of personal respondents and 93% of organisations).**



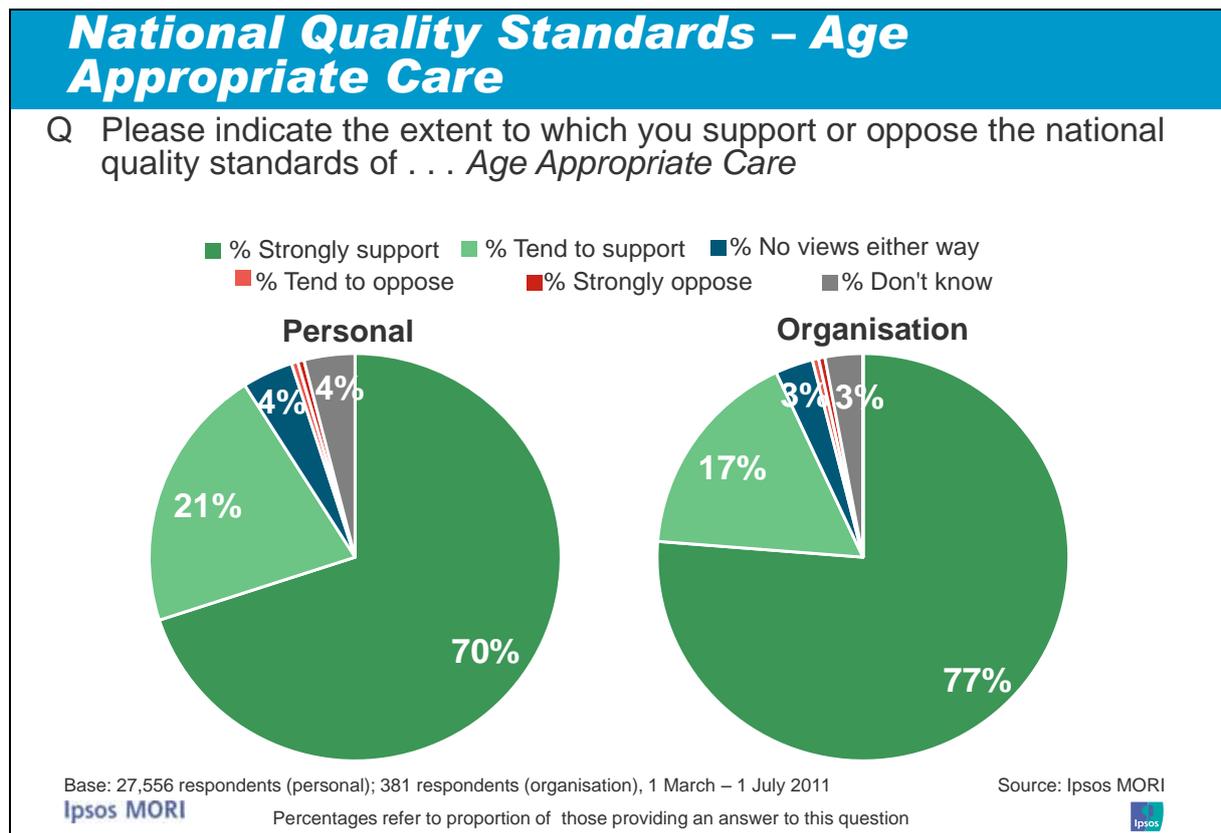
The *Specialist Surgical Centre* theme was the one on which most people commented. Of the 338 respondents who provided comments, around half of these argued that there is insufficient evidence to show that outcomes are better as a result of performing significantly more cases (400+) / with four surgeons. Many of these made the point that the evidence only shows that centres with low numbers / less than 200 have worse outcomes.

“Evidence doesn’t seem to support the suggestion that 400 cases per year by 4 surgeons is safer but very low numbers, i.e. under 200 [per year] might be dangerous.”

¹⁷ Respondents were referred to pp57-62 in the consultation document before answering this question.

National Quality Standards – Age Appropriate Care¹⁸

The National Quality Standards relating to *Age Appropriate Care*, again, received very little opposition. Around half of personal respondents (52%) and a third of organisation respondents (32%) either *strongly* or *tended to* support this theme, and this equates to **91% of personal respondents and 94% of organisations of those who answered this question.**

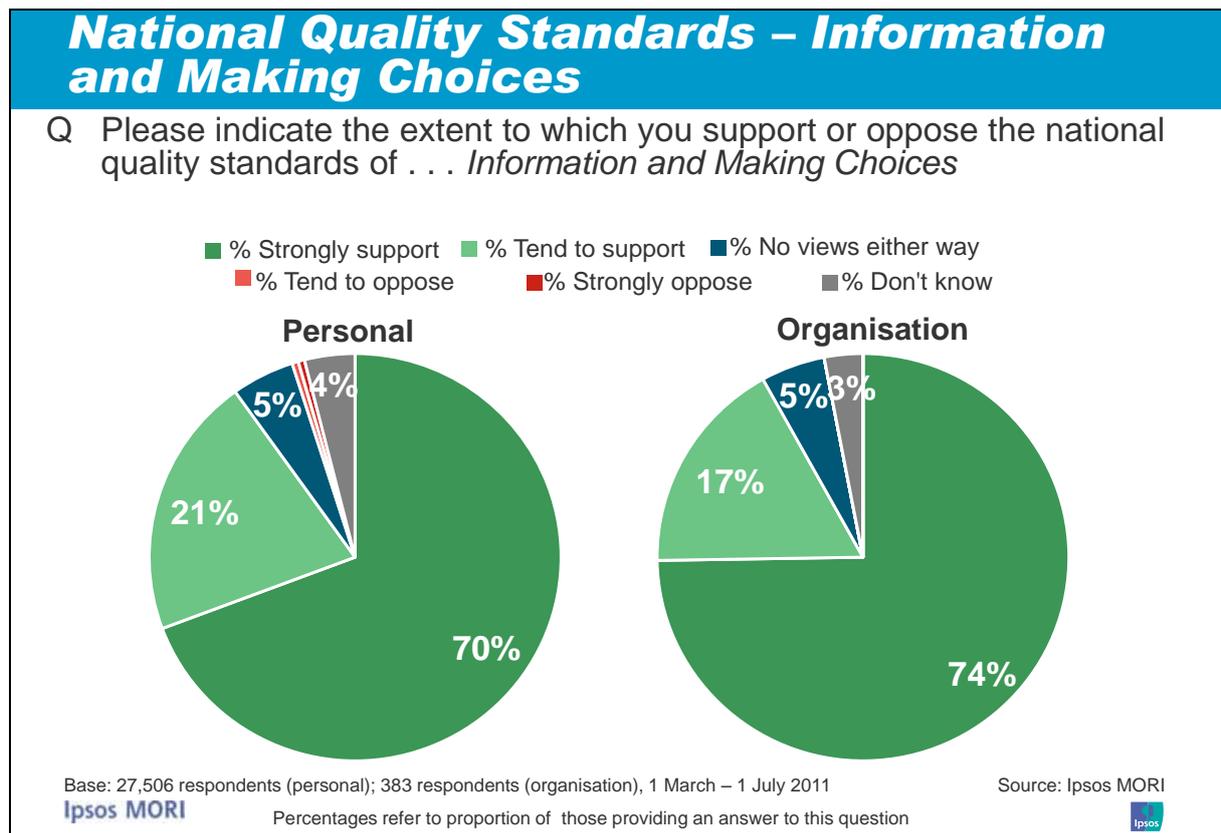


Just 141 respondents provided comments related to *Age Appropriate Care*, the most common being that this was well provided by Glenfield Hospital. Other responses stated the importance of age appropriate care and a small number stressed the value of continuity of care and/or seeing the same doctors from childhood to adulthood.

¹⁸ Respondents were referred to pp63-66 in the consultation document before answering this question.

National Quality Standards – Information and Making Choices¹⁹

Levels of support for standards on *Information and Making Choices* were similar to those under other key themes; half of personal respondents (50%) and a third of organisation respondents (31%) supported them, with low levels of opposition. **Amongst those giving an answer, over nine in ten supported these standards (91% of personal responses and organisations).**

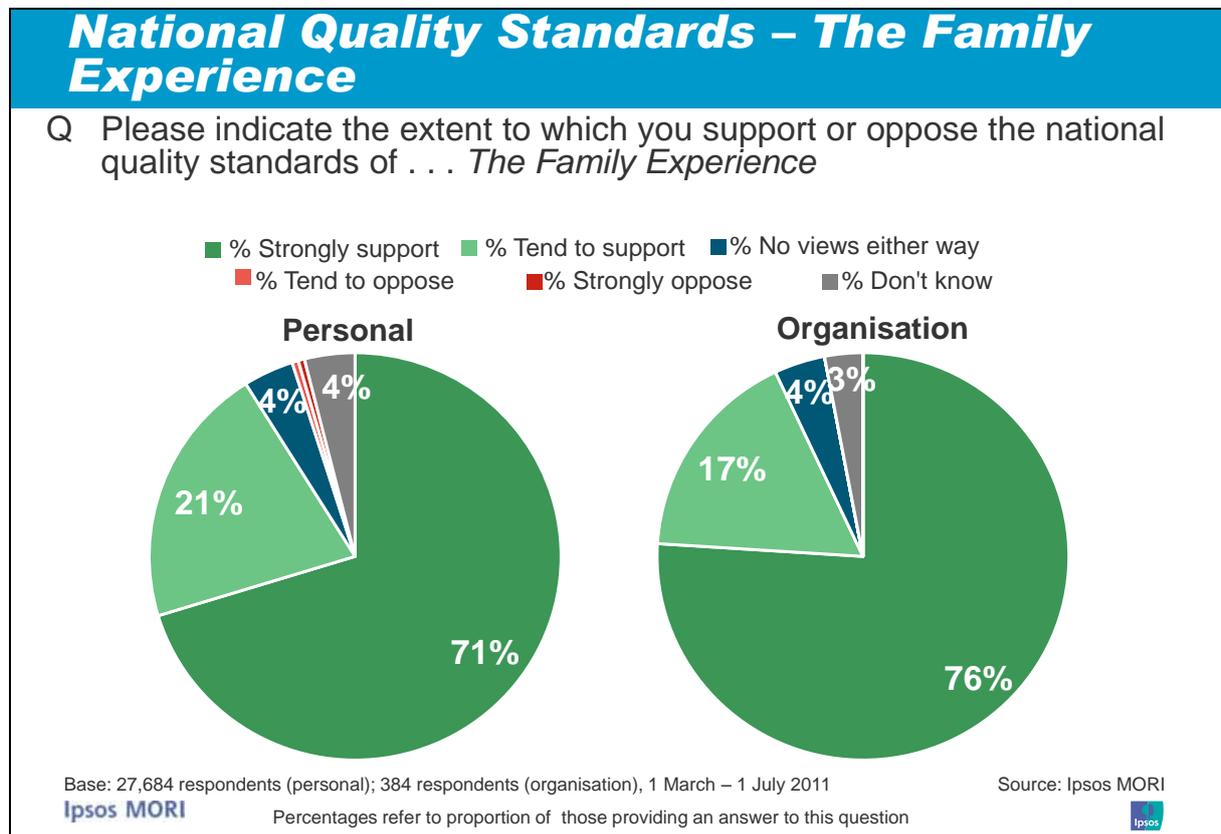


This theme received the lowest number of verbatim comments (71). Those that did provide a response tended to refer to the importance of these standards and noted how important information was for parents and children to point them in the right direction and help them make decisions.

¹⁹ Respondents were referred to pp67-68 in the consultation document before answering this question.

National Quality Standards – The Family Experience²⁰

Around half of personal respondents (50%) and a third of organisation respondents (32%) supported the National Quality Standards relating to *The Family Experience*. Again, very few opposed them. **Nine in ten of those providing a response supported them (92% of personal respondents and 93% of organisations).**



A total of 169 respondents made spontaneous comments on *The Family Experience*. Around a third of these talked about the accommodation at Glenfield, referring to the fact that it is situated on the children’s ward and provides excellent family-centred care/facilities.

“The parents’ rooms at Glenfield Hospital are one of [a] kind. They are attached to the ward and should not be wasted. Parents can be more involved with their child’s recovery and try to maintain a relatively ‘normal’ life, especially where other siblings are concerned, keeping the family together as much as possible.”

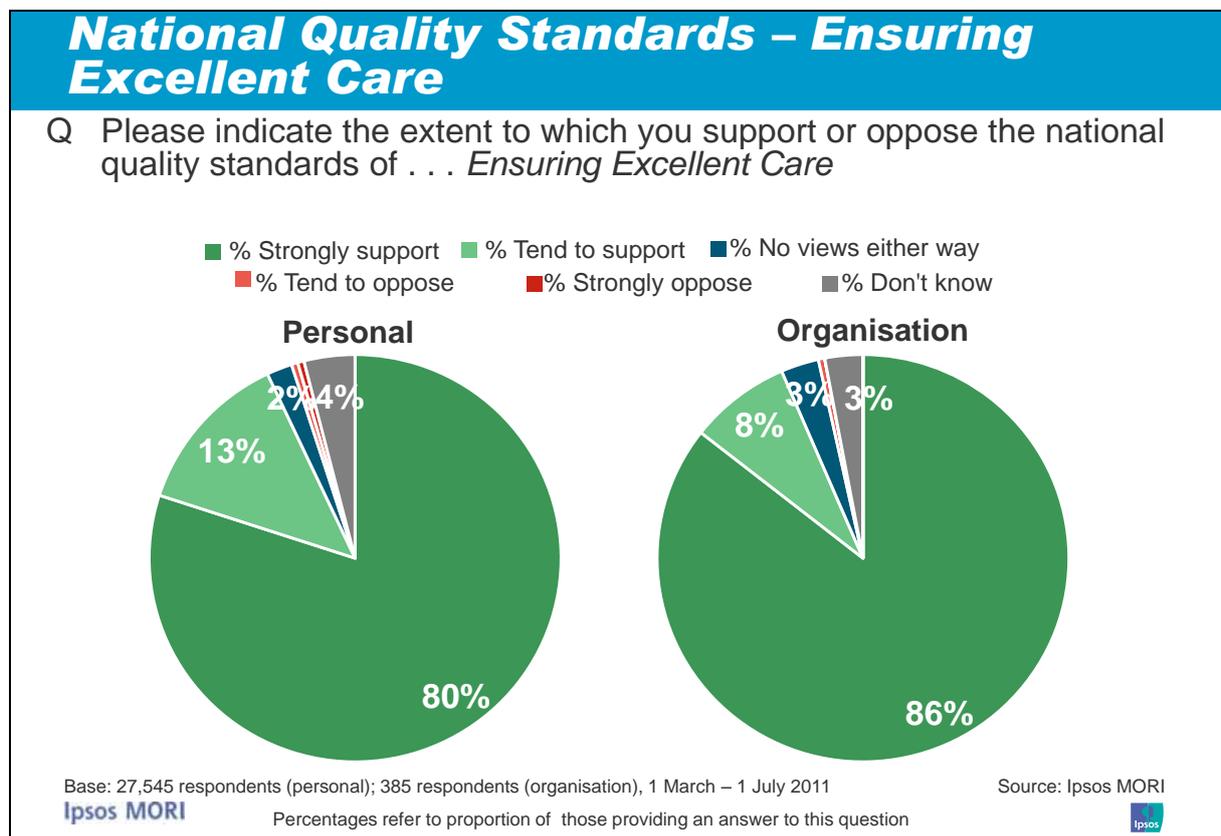
A smaller number of responses made similar comments about other specific hospitals, while others restated the importance of this issue for families.

²⁰ Respondents were referred to pp69-72 in the consultation document before answering this question.

If fewer hospitals, it is imperative to provide facilities for parents to stay with their child. The improved response by the child to their situation is enormous and the reduced stress on the parents is great. Care of the child by the parents (feeding / washing etc) also reduces some of the burden on the nurses.

National Quality Standards – Ensuring Excellent Care²¹

As stated earlier, standards relating to the *Ensuring Excellent Care* key theme appeared to garner strongest support. For personal respondents, they were most likely to *strongly* support them (44% vs. levels from 33% to 39% at other themes). This is also the case for organisation respondents; 30% *strongly* supported this theme compared with between 25% and 27% at the others. As such, **well over nine in ten respondents answering this question supported these standards** (93% of personal respondents – with 80% strongly supporting them – and 94% of organisations – with 86% strongly supporting them).



A total of 121 spontaneous comments on the *Ensuring Excellent Care* theme were made by respondents. Most stated that high quality service/patient care was paramount and that these standards were essential. A small number talked about how improved data would provide more detail on outcomes/quality of future life.

²¹ Respondents were referred to p73 in the consultation document before answering this question.

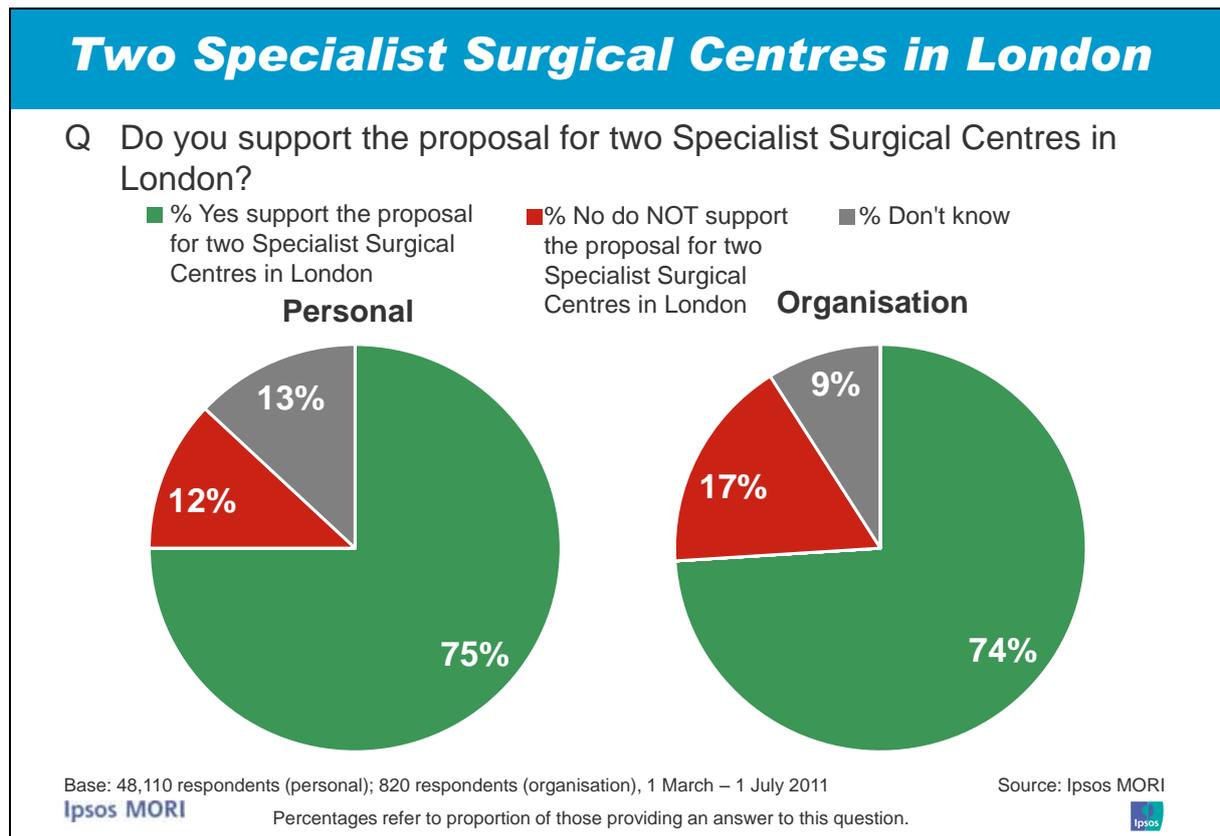
4. Proposals for Specialist Surgical Centres in London

The *Safe and Sustainable Review of Children's Congenital Heart Services* proposes that two Specialist Surgical Centres will be located in London and that these should be Great Ormond Street Hospital and Evelina Children's Hospital. This chapter considers responses on these proposals²².

4.1 Two Specialist Surgical Centres in London

Respondents were asked whether they supported or did not support the proposal for two Specialist Surgical Centres in London. Almost three quarters of personal respondents (72%) supported the proposal, compared to just one in eight (12%) that did not. Only a small number of respondents did not answer this question, so **75% of those responding supported the proposal**. In the case of organisation respondents, just over half (54%) were in support of the proposal and one in eight (13%) did not support it, but over a quarter did not provide an answer to this question. **Among those organisations responding, three quarters (74%) supported the proposal**.

²² Respondents were referred to pp93-96 in the consultation document before answering these questions.



However, there were some sub-groups of respondents who were less likely to support the proposal – in London support fell to 47% and in the North East and Yorkshire and Humber support fell to 34% and 10% respectively. It is clear from comments made to the open-ended question though that respondents in these regions opposed the proposal for different reasons. A total of 1500 respondents (mostly from London) stated that there should be three centres in London. On the other hand, 505 respondents (from across other regions and particularly from those regions furthest from London) thought that there should only be one.

A large number of those calling for three centres outlined the benefits of all London centres working together, leading to better outcomes. Others thought that all of the current surgical units provide high quality services and so should be retained, while smaller numbers were concerned that two centres would not be able to cope with the demand.

“There is a need for all 3 centres in London – surely collaboration between the 3 is the best way to provide the best service for all families accessing the service.”

“I think that to shut one of the current Specialist Surgical Centres would be detrimental to the quality of care provided to the patients.”

On the other hand, reasons for suggesting one centre only in London included the view that one large facility with a full range of services should be sufficient for London. In addition,

many respondents felt that limiting the number in London to one would mean that another centre could provide services elsewhere in the country; this was felt to provide a better geographic spread.

“My answer is based on the distance to travel. Why have two units relatively close together when parents in some parts of the country will have to travel 80+ miles with the cost and disruption that this involves?”

“There should be one centre in London, so more of the UK can have better choice. London is always favoured over the north.”

Some respondents chose to comment on specific hospitals at this question. Royal Brompton received the most mentions (681), followed by GOSH (215) and Evelina Children’s Hospital (145). The majority of comments were positive; in relation to the Royal Brompton these most commonly referred to the quality of care provided there and the strong and close working relationship between the hospital and GOSH.

4.2 Proposals for Specialist Centres in London

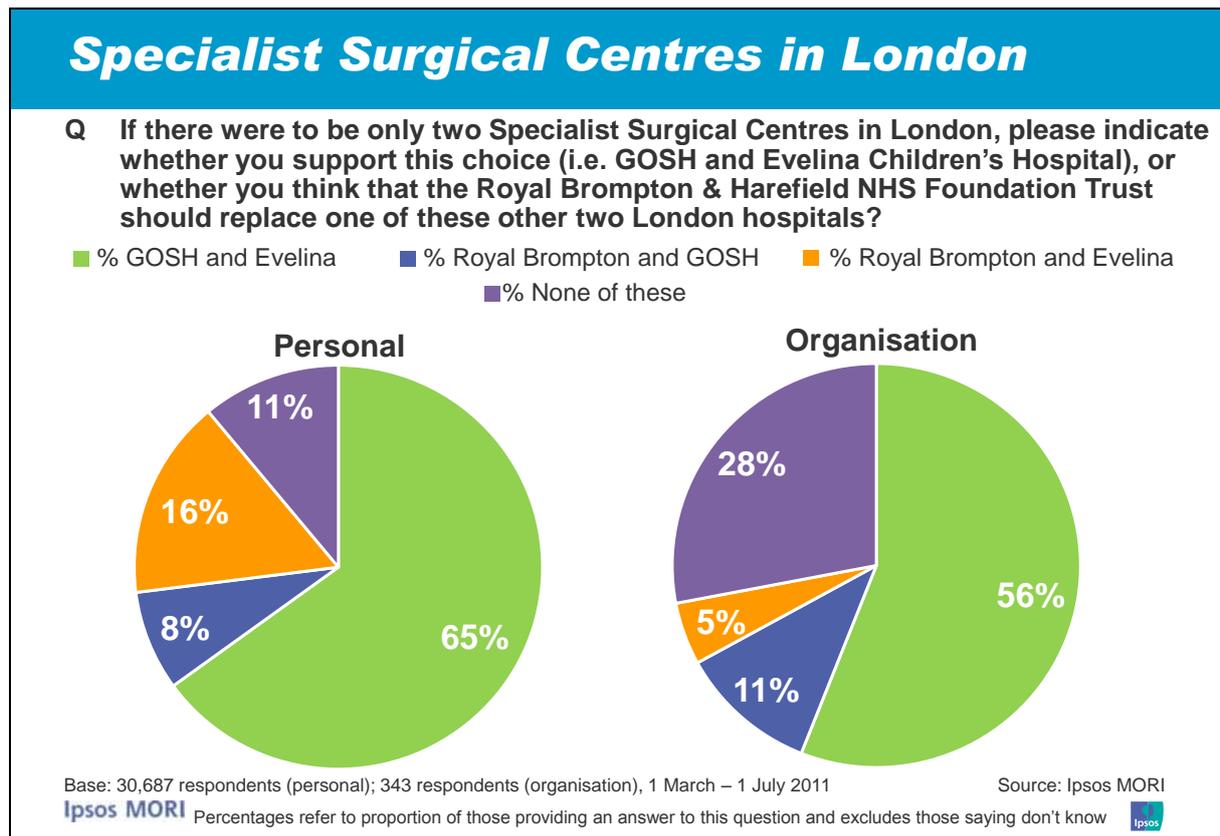
Respondents were also asked, if there were to be only two Specialist Surgical Centres in London, whether they supported the proposal that these should be GOSH and Evelina Children’s Hospital or whether they preferred a different combination.

In the case of personal respondents, two in five (39%) supported GOSH and Evelina, one in twenty (5%) preferred Royal Brompton and GOSH, and one in ten (10%) preferred Royal Brompton and Evelina. Around two in five (39%) however, did not know or did not provide an answer. **Of those responding²³, two thirds supported the proposal (65%),** 8% preferred Royal Brompton and GOSH, 16% preferred Royal Brompton and Evelina while 11% said none of these.

The vast majority of organisations (70%) did not know or did not provide an answer. Again, however, GOSH and Evelina was the most popular combination of the three (17% of organisation respondents in total supported this choice). **Of those responding²⁴, 56% supported the proposal,** 11% preferred Royal Brompton and GOSH, 5% preferred Royal Brompton and Evelina, while 28% said none of these.

²³ This excludes those not stating an answer or saying ‘don’t know’

²⁴ This excludes those not stating an answer or saying ‘don’t know’



In London, a third of individuals supported the proposal (34%), whereas one in ten preferred Royal Brompton and GOSH (12%) and one in twenty preferred Royal Brompton and Evelina (5%). However, nearly two in five respondents said they didn't support any of these options (37%). A further 12% didn't know or did not answer this question.

There was good support for the proposal amongst respondents from the East and West Midlands (47% and 57% respectively), while those in the East of England were more likely than other regions outside London to say they didn't support any of the options (25%).

Amongst respondents with experience of the two proposed surgical centres, support for the proposal rose (to 56% for users of GOSH and 69% of users of Evelina). Amongst respondents with previous experience of Royal Brompton though, just 5% supported the proposal, 30% would prefer Royal Brompton and GOSH and 8% would prefer Royal Brompton and Evelina. However, over half said they didn't support any of the options (51%) and comments at this question showed their preference for retaining all three centres in London.

In terms of hospital-specific verbatim comments provided at this question, Royal Brompton once again received the most mentions (1,813). The vast majority of responses relating to Royal Brompton were positive, with most stating their support for retaining the service at the hospital and some praising the high quality care provided there. A number of perceived

reasons in support of the hospital were offered, and a large proportion of responses referred in particular to the following four aspects:

- They stated that ground breaking research was carried out.
- They suggested that there were four children’s heart surgeons undertaking over 400 operations per year.
- They believed that the hospital had the capacity to provide a full range of services.
- They also referred to the hospital’s ability to provide childhood to adulthood care.

A number of respondents were also concerned that closure of the centre would leave children at risk (with a particular focus on cystic fibrosis patients), and would make other inpatient paediatric services unsustainable.

A small number of respondents also referred to the good working relationship between Royal Brompton and GOSH and suggested that collaboration between the three centres would lead to better outcomes for children.

“Where will cystic fibrosis patients and other children with respiratory problems be cared for if the children’s unit at [Royal Brompton] closes?”

“The Safe and Sustainable review should take into consideration the devastating effects of any closure on the whole children’s unit, including research. No London centre has to close. By developing a joint venture and working closely together, patients will continue to get a high quality service.”

Some of the responses making these points were identical (or very similar) in wording and these may replicate published letters and responses (or extracts from these). A further group of responses discussed legal action taken by Royal Brompton and the view that the review process had been unfair.

Most comments relating to GOSH and Evelina Children’s Hospital were also positive, and similarly, many related to keeping the service open/including the hospital as one of the two Specialist Surgical Centres and the high quality of care that is provided.

“Care should be concentrated at the two best performing units and therefore would support Great Ormond Street and Evelina Children’s Hospital”

“GOSH is the only centre in the UK offering the full range of national cardiac services, some of which could not easily be moved elsewhere. GOSH is the largest centre in the UK for children’s heart surgery it would be absurd to remove its cardiac services”

“The Evelina received the highest overall score largely because of its mortality rates, integrated care within a foundation trust, retrieval service and its ability to deliver high quality care.”

5. *Proposals for Specialist Surgical Centres outside London*

This chapter discusses the views of those who responded to the *Safe and Sustainable* consultation on the proposals for the location of Specialist Surgical Centres outside London. The response forms contained questions asking participants for levels of support or opposition to each of the four options put forward, their preferred option and their preferred configuration if they did not have a preferred option (outside or within London)²⁵.

5.1 Views on options for centres outside London

The four proposed options for the location of Specialist Surgical Centres outside London were outlined in the response form and consultation document. These options are shown in the following table.

Table 3 – Options for the location of Specialist Surgical Centres outside London

Option A	Option B
Alder Hey Children's NHS Foundation Trust (Liverpool)	Alder Hey Children's NHS Foundation Trust (Liverpool)
Birmingham Children's Hospital NHS Foundation Trust	Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust	University Hospitals Bristol NHS Foundation Trust
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)	The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)
University Hospitals of Leicester NHS Trust (Glenfield)	Southampton University Hospitals NHS Trust
Option C	Option D
Alder Hey Children's NHS Foundation Trust (Liverpool)	Alder Hey Children's NHS Foundation Trust (Liverpool)
Birmingham Children's Hospital NHS Foundation Trust	Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS	University Hospitals Bristol NHS

²⁵ Respondents were referred to pp97-118 in the consultation document before answering these questions.

Foundation Trust

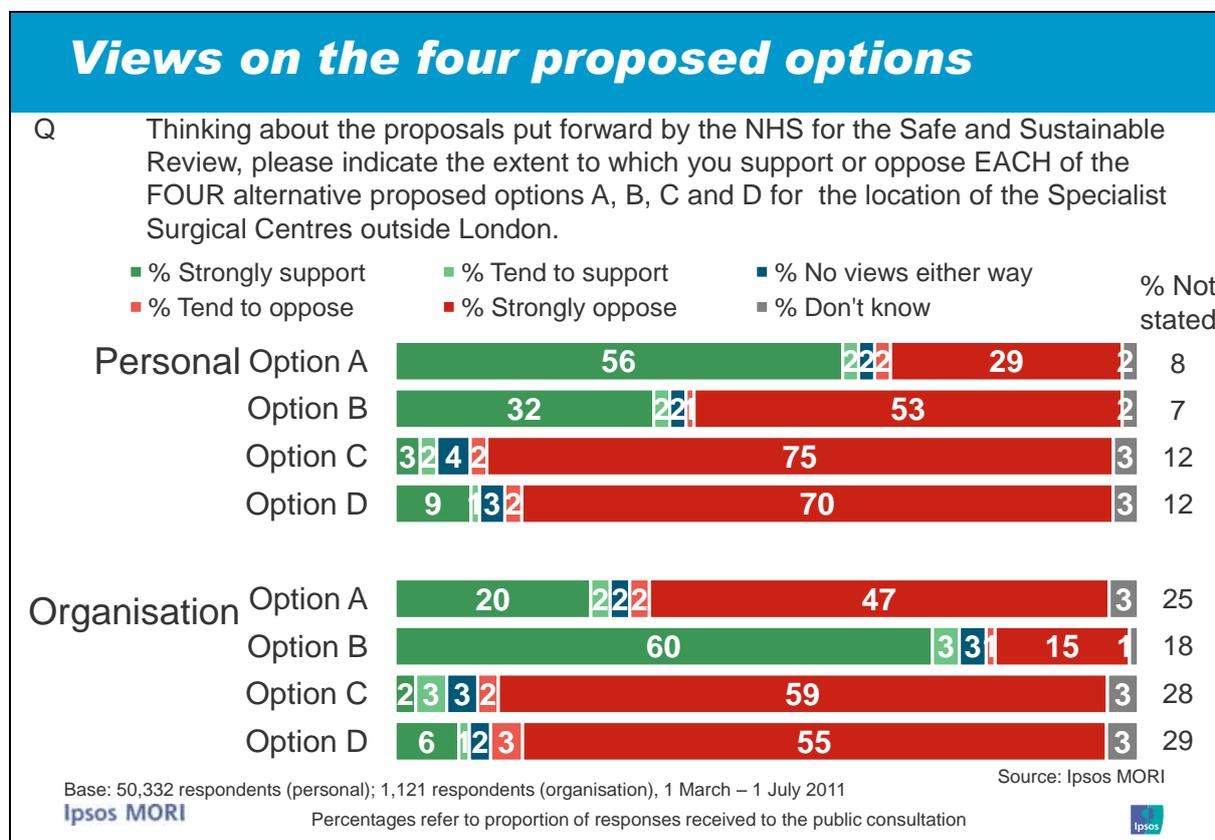
Foundation Trust

The Newcastle-Upon-Tyne Hospitals
NHS Foundation Trust (Freeman)

Leeds Teaching Hospitals NHS Trust

The response form also noted that in relation to Option D it is proposed that one of the London centres is GOSH because only GOSH and Newcastle provide transplantation services, and that an option without either would not be safe.

Those who responded to the consultation via a response form were asked first to rate their support for, or opposition to, each of the four options.



Options A and B were the most commonly supported options both for personal respondents and organisations. However, among personal responses, Option A was the most widely supported, with just under three in five showing their support, while organisations were more likely to support Option B (just over three in five).

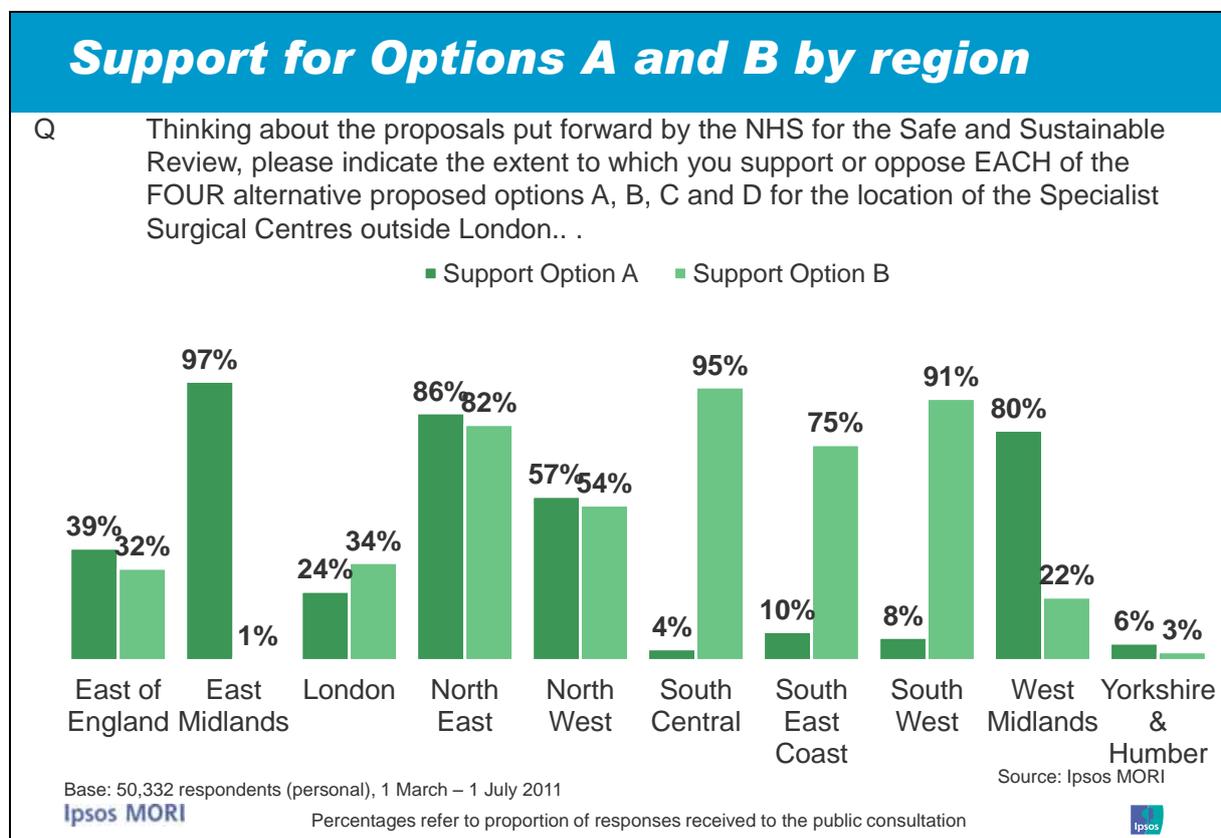
As might be expected, personal responses differ markedly by region. Just under half of the response forms that were received from individuals were from the East Midlands region, and respondents in this region were overwhelmingly likely to support Option A (97%), which is the

only option that includes Glenfield Hospital in Leicester. Indeed, 98% of those individuals who have experienced care at Glenfield supported Option A.

Outside the East Midlands, support for Option A dropped to 23%, though there was also widespread support among those who live in the North East (86% supported Option A) and the West Midlands (80%).

In contrast, 95% of those in South Central supported Option B (which includes Southampton). Indeed, 97% of those who have experienced care at Southampton supported Option B. Outside the South Central region, support dropped to 19%, though there was strong support for it in the South West (91%) and in the South East Coast region (75%).

The following chart shows how support for Options A and B varied by region.



Respondents from the East Midlands and South Central regions clearly have the strongest views either way and are affecting the results overall. If these regions are excluded from the analysis, the picture changes slightly. Outside these two regions, Option B received the highest level of support (43% compared to 35% for Option A).

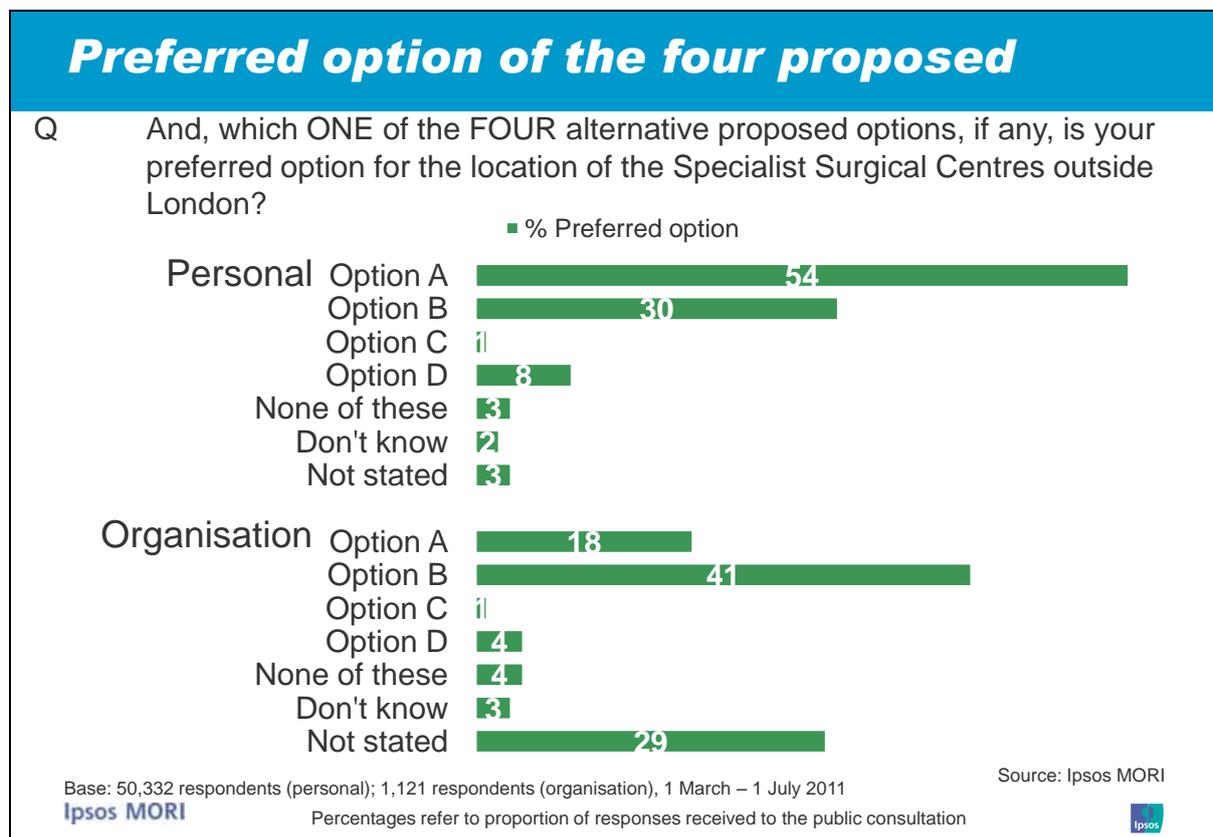
Option C received the lowest level of support – around one in twenty responses from personal respondents and organisations supported this option. Support of Option D was slightly higher, and was highly concentrated among individuals based in Yorkshire and

Humber: 92% of individuals based in this region supported Option D (which includes Leeds Teaching Hospitals).

There were also differences of opinion between clinicians and patients regarding Options A and B. While respondents with CHD themselves were more likely to support Option A (45% vs. 41% for Option B), clinicians were more likely to support Option B (52% vs. 40% for Option A).

5.2 Preferred options

There was a similar pattern when those completing a response form were asked for their one preferred option. Option A and B were the most commonly preferred, with most of those responding personally preferring Option A and most of those responding on behalf of an organisation preferring Option B.

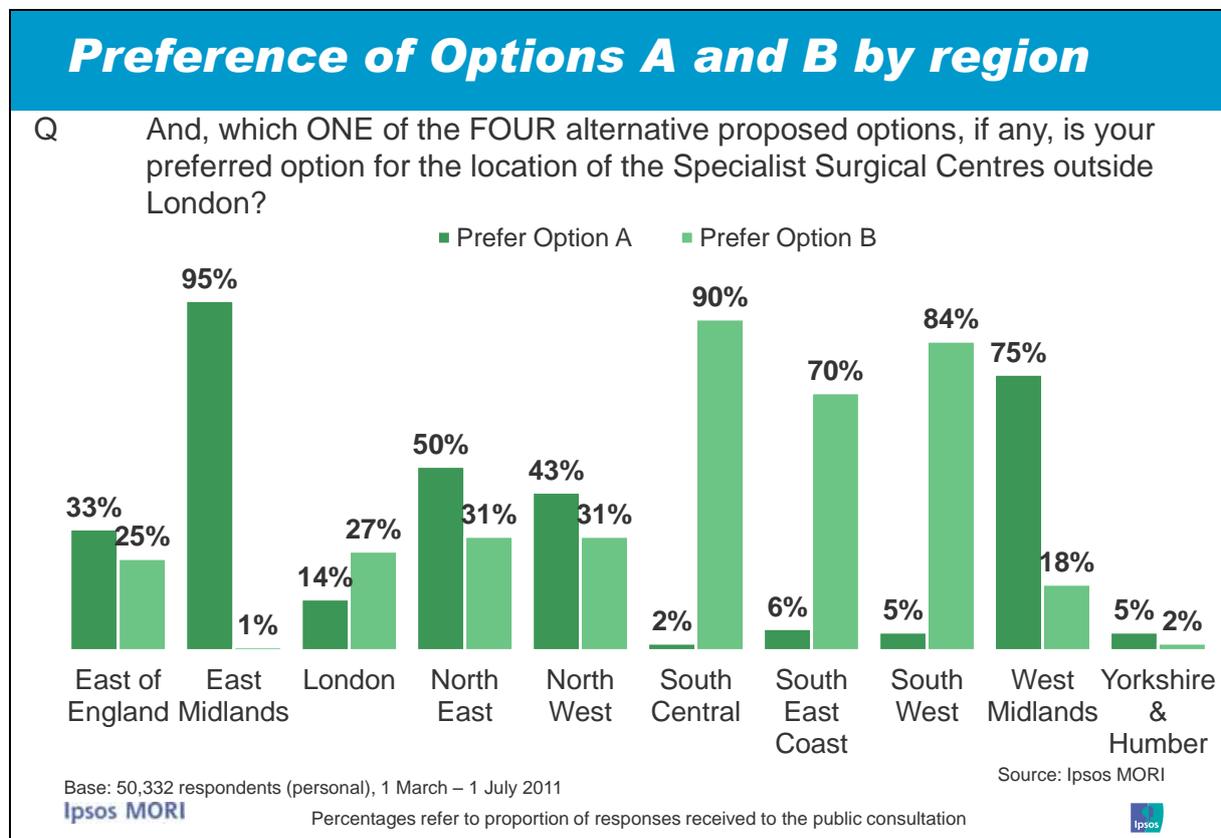


As with support, region was key. Those who responded from the East Midlands and the West Midlands were overwhelmingly likely to prefer Option A (with preference levels of 95% and 75% respectively), and those in the south of the country were especially likely to support Option B (with preference in South Central, South West and South East Coast – 90%, 84% and 70% respectively).

Again, the large number of respondents from the East Midlands (and to some extent South Central) has affected the overall results. Outside of the East Midlands, preference for Option A dropped to 18%. Outside of the South Central region, preference for Option B dropped to 14%. If both regions are excluded from the analysis, Option B was preferred (33% compared to 27% for Option A).

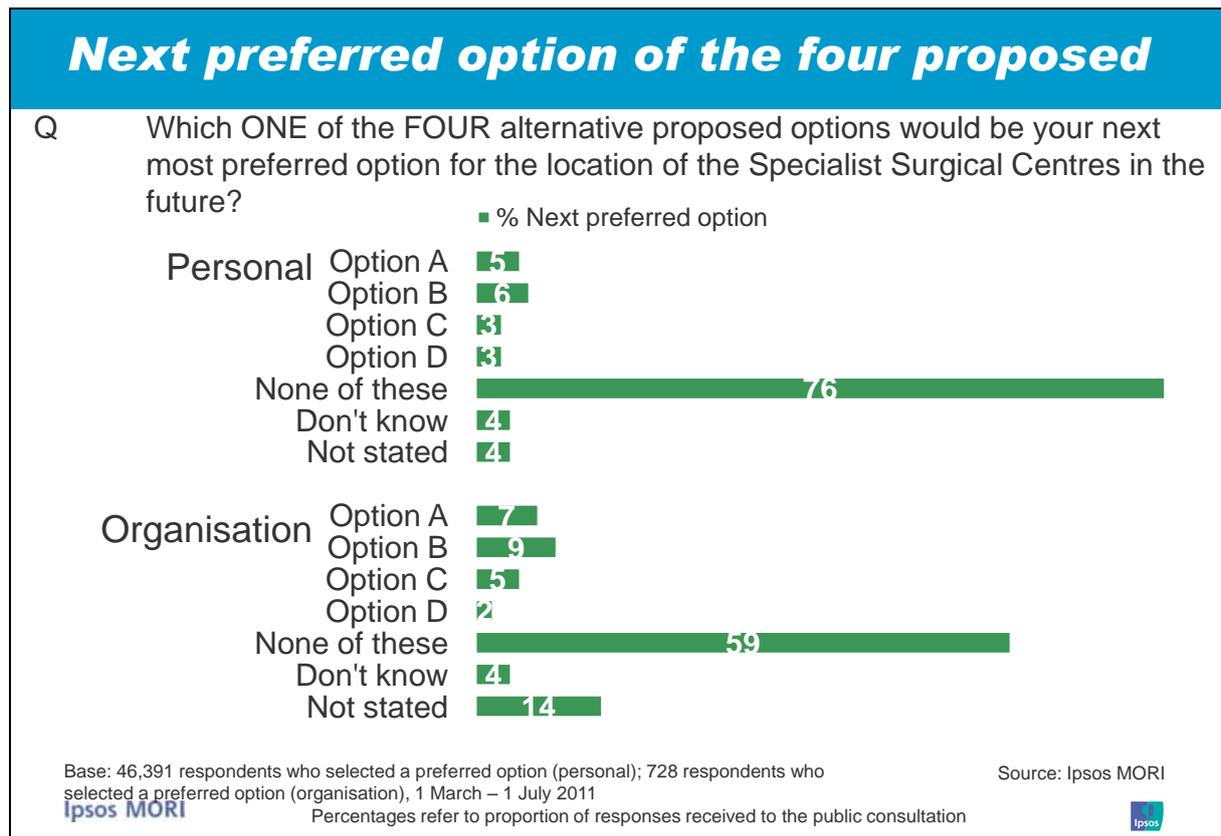
Preference for Option D was overwhelmingly concentrated among those who responded from Yorkshire and Humber: 90% of those from this region supported Option D.

Only one per cent of those who responded preferred Option C as their first choice, though again those in the north were more likely to show favour: 13% of those who responded from the North East and seven per cent from the North West preferred this option.



Aside from region there were no large differences in the demographics and wider views of those preferring each option.

Few respondents had a next preferred option after giving a first preference. This can be seen in the following chart – fewer than one in ten of those who gave a first preference were willing to give a next preference to any of the other options.



Given that few gave a second preference after their first preferred option, combining the two sets of responses makes very little difference to the overall picture. The regional pattern is also maintained.

When asked for any comments on the proposals for Specialist Surgical Centres outside London, respondents were likely to refer to their views or experiences of specific hospitals, showing their support for them, rather than express views on overall configurations.²⁶ This was also the area of the proposals that received the most comments in the letters and emails that respondents submitted. The three hospitals that received the most comments were Southampton, Leeds and Glenfield.

Generally, the comments on the hospitals mostly centred on perceptions and experiences of the quality of care, the facilities and the good reputation of the hospital. References to the convenience of the location, proximity to a large population centre and need for a good geographical spread of centres were also common, though generally less so than comments about the hospitals themselves.

²⁶ All figures referring to the number of responses to the open questions in this chapter combine responses from the questions about the proposed options and preferred configurations (questions 14 & 16 in the response form).

Respondents were overwhelmingly positive about Southampton hospital: of the 3,099 comments on Southampton, 3,084 were positive. Southampton was also the hospital that received the most positive comments in the letters and emails submitted. Many respondents referred to Southampton's results and its rank as second in the country in the performance review. There were also comments on Southampton's high standards of care and staff.

“Southampton Paediatric Cardiac is 2nd best in the UK, the staff are committed, dedicated...Losing it is not an option to be considered.”

“Southampton is a great unit, with an excellent record for paediatric cardiac surgery... I feel that the quality of the service provided is paramount, and this review should concentrate on where excellence is provided when deciding where continued cardiac care is delivered.”

“I believe Southampton should be included in the specialist centres because of its outstanding reputation and results for cardiac surgery.”

Many respondents commented on the benefits of Southampton's location. These mainly referred to the belief that Southampton was well located to service a wide area, including the Isle of Wight and Channel Islands. A smaller number mentioned Southampton's good transport links and parking.

“Southampton hospital should be used as a specialist surgical centre as it provides an excellent service already and is central and relatively easy to get to from all of the South and South West region.”

“All options except Option B are a logistical nightmare for any south coast family, we're talking heart surgery, not a trip to the dentist, Southampton is key to the whole south coast, Isle of Wight and Channel Islands all other options would mean journey times of 2.5 hours plus.”

There were 1,819 comments made about Leeds Teaching Hospitals, and again most were supportive. The most commonly expressed factors related to its services and its facilities, including its ability to provide a range of services in one location, and its location. There were also many positive comments about the standards of care at Leeds and its high quality practices and staff.

“Leeds is the only one outside of London to have all key services in-house, enabling such additional surgeries to be undertaken under one roof, saving time and additional later surgery.”

“Leeds has all services from foetal medicine to adulthood under one roof.”

“Leeds covers 14 million people within a two hour travel time, it’s central.”

“Leeds is already a centre of excellence due to the large numbers of complex cases treated and large population served.”

Comments made about Glenfield hospital were also overwhelmingly positive: 1,114 out of the 1,466 comments on Glenfield made here were positive, while others talked about the impact of closure. Many of these respondents referred to the standard of care, the high quality services and staff and made positive assessments of Glenfield’s facilities. There were also comments on Glenfield’s extracorporeal membrane oxygenation (ECMO) facility and other general comments (i.e. not specific to Glenfield) about the need to keep ECMO facilities in their current location. Many also feared the impact on Glenfield’s training/research service should it not be included as a centre.

“I feel that Glenfield, Leicester should stay open as a Specialist Surgical Centre due to the excellent reputation and care given.”

“Leicester’s Glenfield hospital is a fantastic hospital. Dedicated staff and excellent treatment.”

“Glenfield has a renowned ECMO centre and a world class service, and this expertise should be retained.”

Location was important to some – respondents stated that Glenfield is centrally located for a wide region (including East Midlands and East Anglia) and is in a densely populated area. Some also commented on Leicester’s good transport links and parking.

“Option A is best: Glenfield Hospital's location outside Leicester avoids city centre parking and is easily reached via the M1 motorway.”

There was a similar spread in responses on the proposals and configuration of centres more generally. The standard of care tended to be the most widely commented upon issue regarding the proposals; many respondents stressed that quality, expertise and reputation of hospitals should be paramount when selecting centres. There were 10,867 comments in total on the standard of care and it featured frequently amongst the letters and emails submitted as well.

“Strongly in support of those centres ranked highest for quality and excellence, according to Professor Sir Ian Kennedy's report, 2010.”

“Quality outcomes should be the deciding factor.”

“The quality of the service provided and care for patients should be the absolute priority - the best possible care should continue to be available to children and their families, in centres that already provide the best service.”

Location considerations were also widely commented upon, though less commonly so than standards of care. There were 8,348 comments on this, with the most common being the importance of a good and fair geographical spread of centre locations to ensure widest, best and quickest access. Travel time for patients in the north of the country was also a common concern.

“For sure having more specialist surgical centres outside London would help the families of children treated. Their location should be as more various as possible, to decrease the distance from home of as many families as possible.”

“There needs to be cross country easy access, not some areas with long distances to travel.”

“If at all possible there need to be at least two specialist heart hospitals in the north, south, east, west so treatment can be done as close to the patient’s home as possible.”

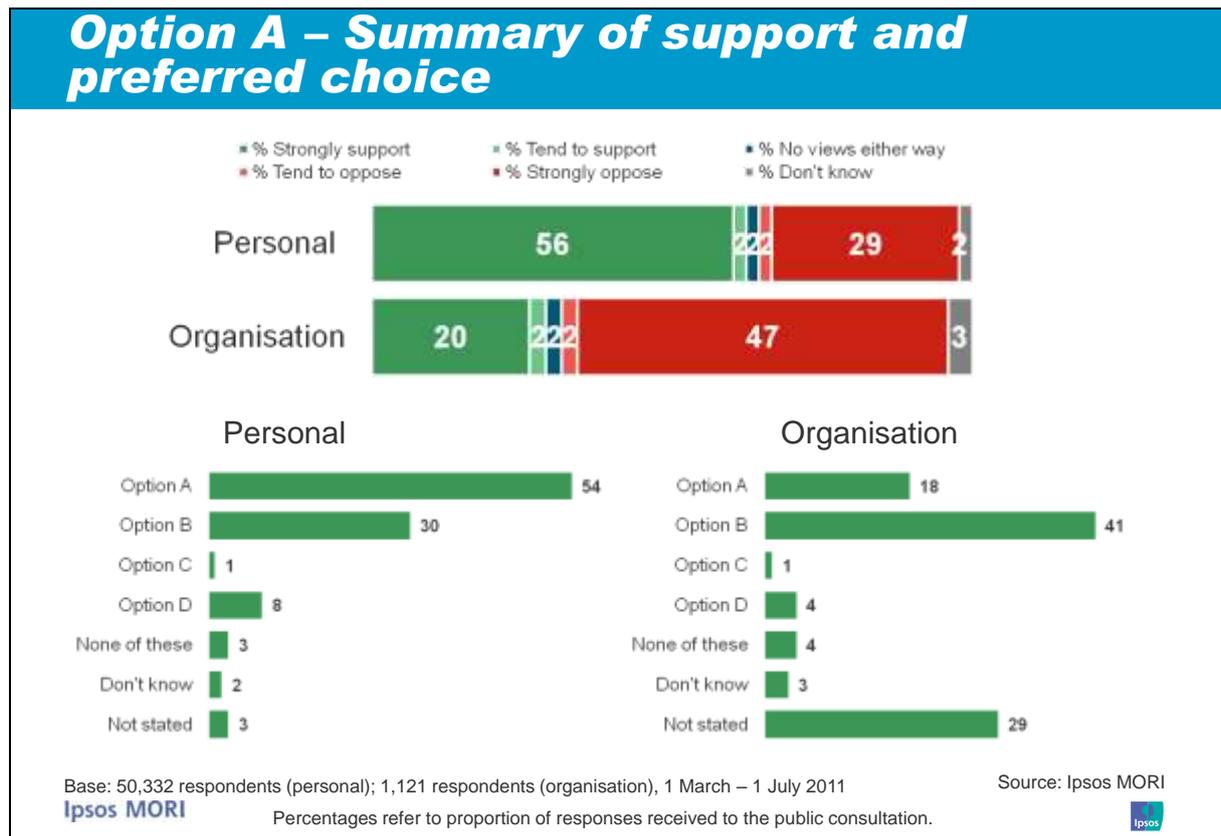
Some respondents also discussed the facilities and services available at proposed centres (4,102 in total), such as retrieval of patients within the stipulated time, reaching the minimum 400 operations (this includes a group of responses using identical wording (or very similar) supporting Option D) and having the least impact on PICU (Paediatric Intensive Care Unit) services.

“Option B is the only option that maintains the best quality centres, and allows all children with CHD to be retrieved within stipulated times.”

“It offers the least overall loss of paediatric intensive care beds in the country.”

5.3 Views on Option A

The pattern of support for Option A, outlined earlier in this chapter, can be seen in the following chart, with more support among personal responses to the consultation than among those responding on behalf of an organisation.



Aside from region and hospital use, as outlined, support for Option A was otherwise consistent across most sub-groups. However, a large proportion of those who preferred Royal Brompton and Evelina as the two London centres (91%) also preferred Option A for outside London.

Most of the spontaneous comments made about Option A were positive (822 comments about Option A were positive). Most respondents stated that it provided the best coverage for the country and often referred to Glenfield as being easily accessible for the population centres within the East Midlands. Many also thought that it offered the least disruption and relocation of services.

“I’ve chosen Option A for accessibility to most of population, and best to keep specialist services like ECMO in current location with experienced team.”

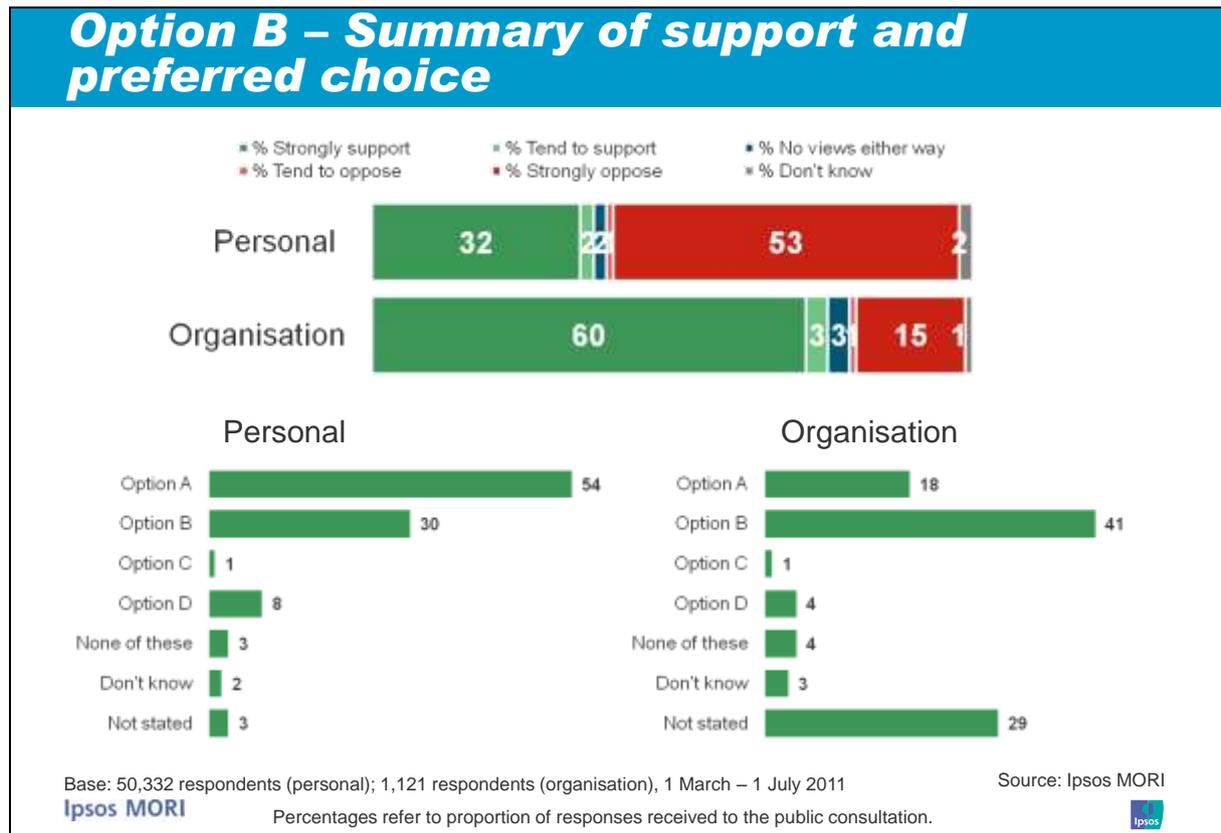
“Option A is the only choice. Specialised services should stay where they currently are. It takes years to build the expertise in these services.”

However, many commented that if Option A were selected it would require Leeds Hospital to be involved in four networks, and they were worried about whether this would be a workable solution. This accounts for a very large proportion of the 288 negative comments on Option A (265).

“Option A for example requires Leeds to be involved in 4 networks, which could cause communication difficulties and confusion for patients, reducing the quality of patient care.”

5.4 Views on Option B

In contrast to Option A, support and preference for Option B was the majority view among organisations, though still one in three personal respondents supported Option B.



As with Option A, region and hospital use were the major discriminators of support and preference for Option B.

There were far more positive verbatim comments made about Option B by those submitting a response form than was the case for Option A, and indeed for any other option. There were 6,030 positive comments overall. Option B also received the most support in the letters and emails submitted.

Comments included a group of identical (or very similar) responses in which respondents stated that Option B should be selected as it consists of the highest scoring centres, including those that already perform complex surgery and that it provides good access to patients nationally.

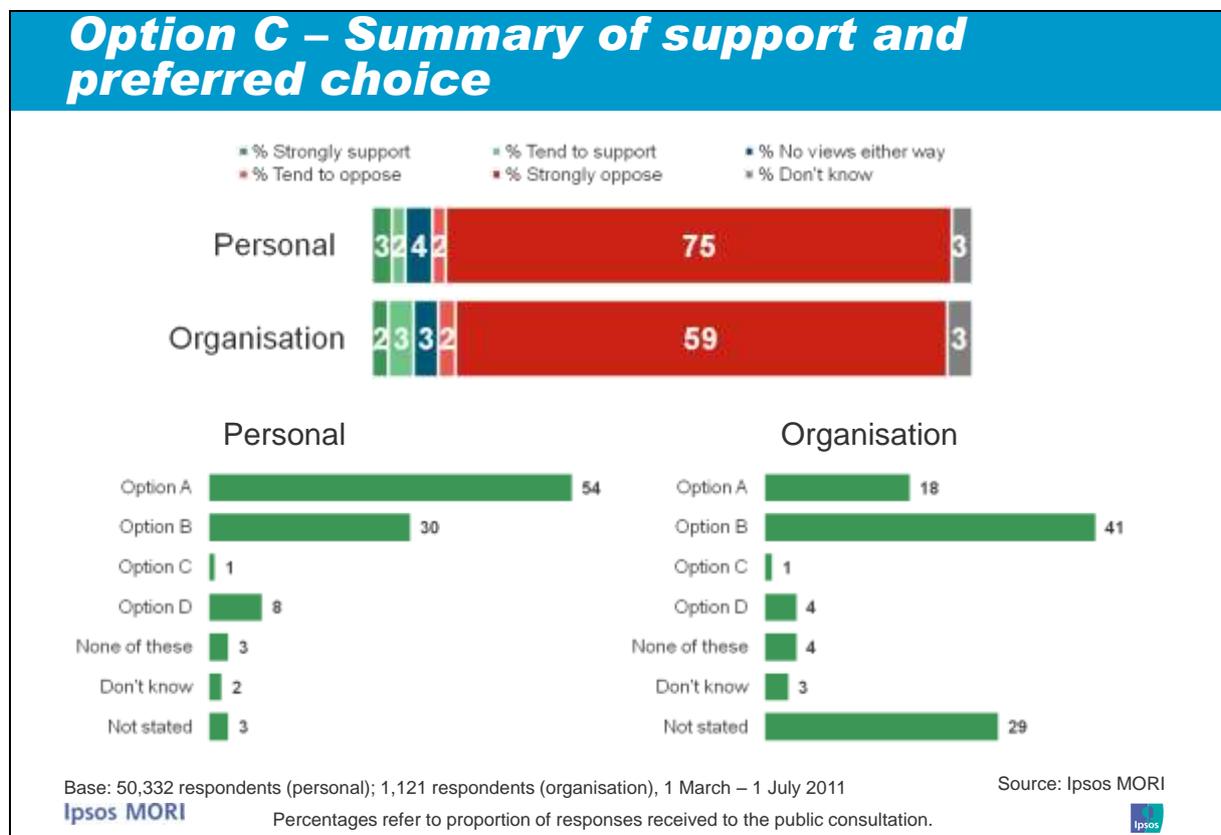
“Option B has centres scoring highest for quality; centres with best surgery survival rates; has centres which already undertake complex surgery; and provide excellent access to patients from all parts of the country.”

There were fewer negative comments than was the case for Option A – only 52 negative comments were made about Option B. However, prominent among these was the belief that Option B is illogical and unsustainable on the grounds of being too southern biased (as it includes Bristol and Southampton among the centres).

“Considering the geography I cannot understand the logic of proposing a unit in Southampton, one in Bristol and two in London.”

5.5 Views on Option C

The low level of support for Option C among those who submitted a response form can be seen in the chart below. It is reflected in low levels giving Option C as a preference. Only four per cent of personal responses and organisations chose Option C as one of their two preferred options. This possibly reflects that Option C does not contain a proposed Specialist Surgical Centre location that is not also contained in another option.

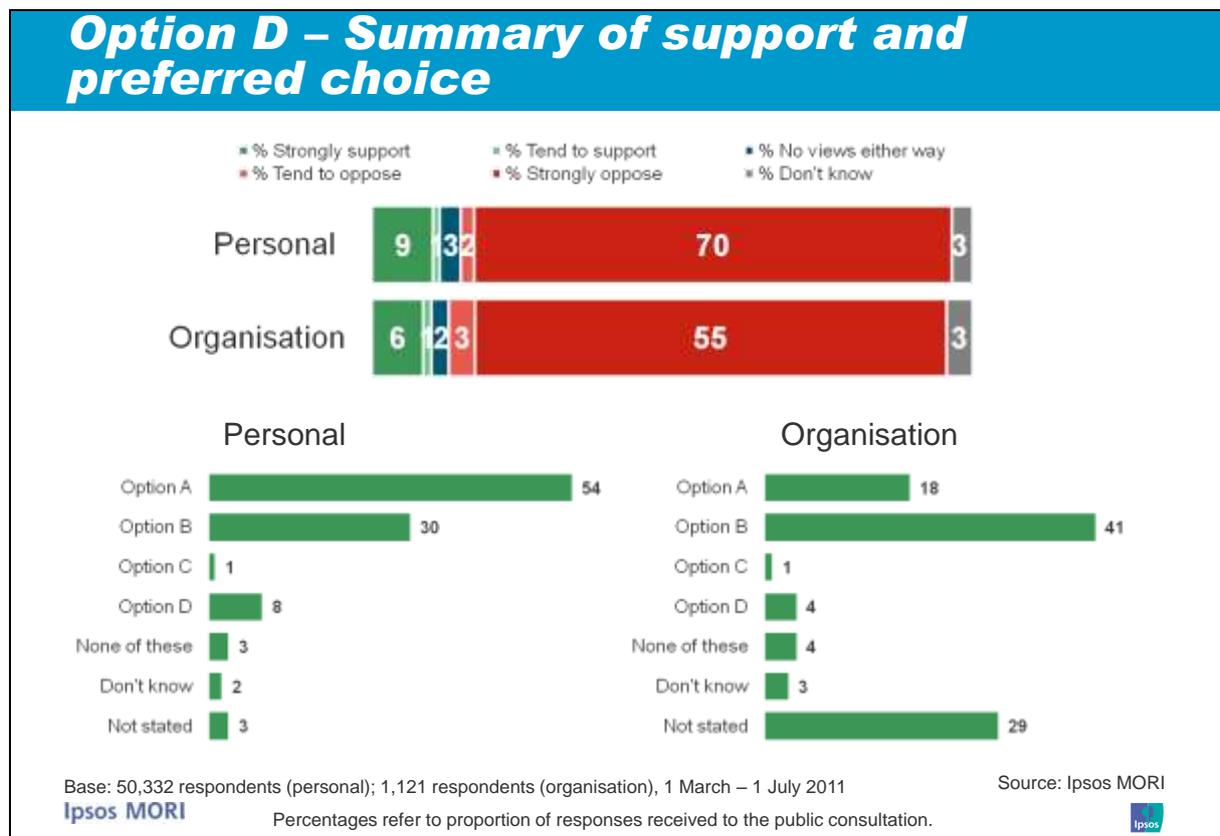


Relatively few respondents spontaneously commented on Option C – just 48 comments were made in total. Of these, there were more negative than positive and most referred to there being too few centres in Option C in the respondents’ view.

“Option C has only 6 centres nationally.”

5.6 Views on Option D

Relatively few of those who submitted a *Safe and Sustainable* response form supported or preferred Option D, though it did have greater levels of support than Option C.



Support for Option D came largely from people in the Yorkshire and Humberside region, as mentioned, and it is also the case that users of Leeds Hospital were particularly likely to prefer Option D – 91% of these people who responded to the consultation preferred this option.

As with Options A and B, the comments on Option D were overwhelmingly positive – 681 positive vs. 66 negative. However, two prominent issues were among the negative comments: the view that Option D had too few centres, and that the option was not viable due to having to move transplant and ECMO services away from the specialised team.

“Option A would mean that services such as ECMO and paediatric transplant would not have to relocate. I am concerned that Option D would mean that transplant services would have to be re-established.”

There was also a group of identical (or similar) responses expressing support for Option D on the grounds that it was the only option that would mean that all centres would meet the minimum number of cases required; some of these qualified the statement – they said that it was the only option meeting the requirement without patients travelling to a unit other than the one closest to them.

“Only option D allows all the units to perform the minimum of 400 operations with children going to their nearest unit.”

5.7 Preferred configuration

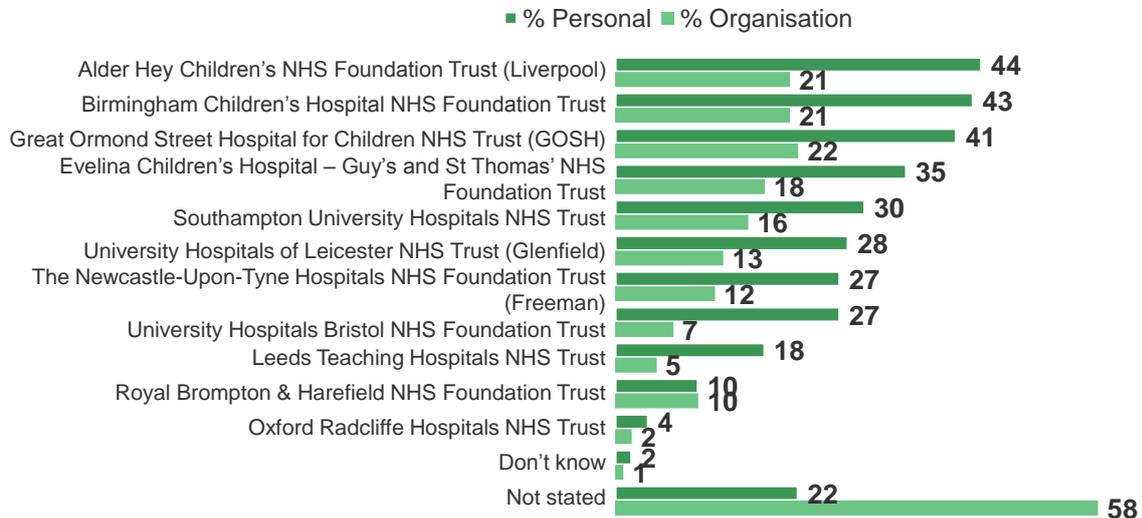
Those who did not express a preference for the location of centres inside and outside of London were asked an additional question wherein they selected their preferred configuration of locations of centres across England.

Alder Hey, Birmingham (each of which are in each of the four proposed options) and GOSH were the three most commonly selected locations among these respondents, both for personal responses and those representing organisations.

Leeds, Brompton and Oxford were in fewest of these respondents' configurations, and Bristol received relatively little preference from responses on behalf of organisations.

Preferred configuration

Q Given a choice, which of the following centres would form your preferred configuration for the location of the Specialist Surgical Centres in the future?



Base: 24,817 respondents who said don't know or none of these at preferred option (personal); 913 respondents who said don't know or none of these at preferred option (organisation), 1 March – 1 July 2011
 Source: Ipsos MORI
 Percentages refer to proportion of responses received to the public consultation

There was a strong correlation between prior experience of a hospital and its selection in the configuration. At least 70% of users of each hospital included that hospital in their configuration in every case apart from Oxford (where 39% of users included it in their configuration).

Inclusion of hospitals in the configuration was also strongly related to the respondent's region. For example, 96% of those in Yorkshire and Humberside who answered this question included Leeds Hospital in their configuration.

A vast number of different configurations were preferred by respondents answering this question; 854 different configurations in total were suggested, though some were single centre configurations and others simply chose one of the existing options:

- Many entered only a single centre location here – with most selecting only Leicester, only Southampton or only Newcastle.
- The most commonly selected configuration consisted of the hospitals in Option D – more than 2,500 selected this configuration. Those based in Yorkshire and Humberside were especially likely to select these.
- Slightly fewer than 2,000 selected the Option B centres (without Bristol)

- More than 1,000 selected the Option A centres, though they were split roughly 50-50 between not including any London centres and including the two proposed London centres.
- The most common configuration not framed around an existing option was all three London centres plus Alder Hey and Birmingham (1,086).
- Slightly fewer than 300 respondents included all of the listed centres in their configuration.

The following table shows the nine most commonly selected configurations of centres (though three configurations only contain one hospital).

Table 4 – Most commonly selected configurations of Specialist Surgical Centres

Configuration	Number of respondents selected by	Comments
<i>Base: 24,817 respondents who said don't know or none of these at preferred option (personal) and 913 respondents who said don't know or none of these at preferred option (organisation), 1 March – 1 July 2011</i>		<i>n</i>
University Hospitals of Leicester NHS Trust (Glenfield)	3847	
Alder Hey Children's NHS Foundation Trust (Liverpool)	2631	Option D plus the proposed London centres
Birmingham Children's Hospital NHS Foundation Trust		
University Hospitals Bristol NHS Foundation Trust		
Leeds Teaching Hospitals NHS Trust		
Great Ormond Street Hospital for Children NHS Trust (GOSH)		
Evelina Children's Hospital - Guy's and St Thomas' NHS Foundation Trust		
Southampton University Hospitals NHS Trust	2240	
Alder Hey Children's NHS Foundation Trust (Liverpool)	1947	Option B without Bristol, plus the proposed London centres
Birmingham Children's Hospital NHS Foundation Trust		
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)		
Southampton University Hospitals NHS Trust		
Great Ormond Street Hospital for Children NHS Trust (GOSH)		
Evelina Children's Hospital - Guy's and St Thomas' NHS Foundation Trust		
Alder Hey Children's NHS Foundation Trust (Liverpool)	1086	All three London centres plus Alder Hey and Birmingham
Birmingham Children's Hospital NHS Foundation Trust		
Great Ormond Street Hospital for Children NHS Trust (GOSH)		
Evelina Children's Hospital - Guy's and St Thomas' NHS Foundation Trust		
Royal Brompton & Harefield NHS Foundation Trust		
Alder Hey Children's NHS Foundation Trust (Liverpool)	637	Option A without any in London
Birmingham Children's Hospital NHS Foundation Trust		
University Hospitals Bristol NHS Foundation Trust		
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)		
University Hospitals of Leicester NHS Trust (Glenfield)		
Alder Hey Children's NHS Foundation Trust (Liverpool)	527	Option A with the proposed London centres
Birmingham Children's Hospital NHS Foundation Trust		
University Hospitals Bristol NHS Foundation Trust		
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)		
University Hospitals of Leicester NHS Trust (Glenfield)		
Great Ormond Street Hospital for Children NHS Trust (GOSH)		
Evelina Children's Hospital - Guy's and St Thomas' NHS Foundation Trust		
Alder Hey Children's NHS Foundation Trust (Liverpool)	296	All centres
Birmingham Children's Hospital NHS Foundation Trust		
University Hospitals Bristol NHS Foundation Trust		
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)		
University Hospitals of Leicester NHS Trust (Glenfield)		
Leeds Teaching Hospitals NHS Trust		
Southampton University Hospitals NHS Trust		
Great Ormond Street Hospital for Children NHS Trust (GOSH)		
Evelina Children's Hospital - Guy's and St Thomas' NHS Foundation Trust		
Royal Brompton & Harefield NHS Foundation Trust		
Oxford Radcliffe Hospitals NHS Trust		
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)	292	

Source: Ipsos MORI

5.8 Assumptions on how postcodes have been assigned

Respondents were also asked in the response form what, if any, comments they had about the assumptions made concerning how postcodes have been assigned in any of the four options for the Specialist Surgical Centres.

More than 10,000 comments were made by respondents, and the majority given by those who answered were negative (7,885). The most common point made was that the assumptions ignore patient/parent/family choice, and the feeling that these people should have a say in where the patient is treated (5947).

Shouldn't parents (and children) have the right to choose where they go?

Patient choice is a fundamental principle of the NHS. Patients will travel to quality centres which have good survival rates.

Others suggested that the assumptions made were wrong, with postcodes being allocated incorrectly in some cases. Some respondents said they were illogical and particularly referred to the fact that options A, B and C required patients to travel further than their nearest unit.

Other respondents stated their concerns about increased travel times; many of these believed the assumptions would result in higher mortality rates and greater harm if people have to travel further.

Any option that involves patients travelling further than necessary, at greater inconvenience, cost and at a potential of further harm, should not be considered.

However, on the other hand, large numbers discussed the importance of the quality of care provided, often saying that it should take precedence over travel issues. Many stated that the quality of the centres needed to be the decisive factor.

I would travel across the world for the best treatment. It is about quality not distance.

We want quality service - and are prepared to travel for it.

A large number of responses also referred in identical (or very similar) wording to the Oxford-Southampton model as a good example of partnership working.

6. Text message responses

As part of the public consultation, the general public were given the opportunity to voice their opinions via text message; this was included to help encourage a wider range of responses, particularly from younger respondents. Respondents were asked one open-ended question: “*What do you think about the proposed changes to children's heart services in England, as outlined in the Safe and Sustainable consultation document?*”. As such, the responses received included comments on all aspects of the proposals. The responses have been coded and this chapter contains the qualitative analysis of those responses.

6.1 Numbers of text messages received

As previously stated, a total of 25,157 text messages were received from 23,518 unique telephone numbers; this total includes 3,038 blank messages. Focusing just on the text messages that were not blank, the majority sent just one message (19,852), 558 sent two and smaller numbers sent more. The highest number of responses received from one ‘phone number was 30.

Where respondents sent more than one text message, some were simply sending identical responses (e.g. of those ‘phone numbers from which two messages were sent, 149 sent identical messages). However, a larger proportion chose to send additional responses or longer responses that were split over two separate messages (due mainly to reaching the word limit for one message).

6.2 Discussion of response themes

The text responses received covered a number of overall themes but most commonly offered support for a particular option or an individual hospital. A smaller number of responses provided opinions on what specifically should or should not take priority in making decisions (geographical locations, facilities, standard of care, etc.) and views on the proposals in general.

Support for, or opposition to, each of the Options A - D

The majority of text messages contained preference for (and/or opposition to) one or more of Options A – D (17,800), with the majority referring to Options A or B. As can be seen from Table 5 below, Option B received the most support (13,487 messages), followed by Option A (10,233). A minority of responses opposed each of Options A-C, while more messages opposed Option D than supported it (2,313 opposed it from 2,961 messages).

Table 5 – support for, or opposition to, each of the options

	Support	Oppose	Total
Option A	10,233	189	10,422
Option B	13,487	227	13,714
Option C	2,262	206	2,468
Option D	648	2,313	2,961

In many cases, respondents did not offer a reason for their support of a particular option (beyond it containing their preferred hospital – see later in this chapter). However a small number of respondents expanded on their views regarding Option D – a few said they supported it because it offers the least disruption, but most said it was not viable as ECMO and transplant services would need to be relocated.

Support for, or opposition to, each of the hospitals

Some respondents texted in their views on whether a particular hospital should operate as a Specialist Surgical Centre in the future. These responses were overwhelmingly positive in nature, although a minority took issue with the location of other hospitals when discussing the possible closure of their preferred centre, objecting to the increased travel times they would face.

The largest number of responses received referred to the Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman) (2,047), with the majority stating that the service should remain open. Some gave further reasons for their support – often mentioning the hospital's central location and/or proximity to highly populated areas.

Many respondents who had some experience of the hospital specifically praised the hospital's standard of care, mentioning its high quality and highlighting its good reputation locally, nationally and internationally.

The second highest number of responses (699) referred to Leeds Teaching Hospitals NHS Trust and again the vast majority stated support for retaining the service. Respondents referred to the high standard of care provided at the hospital, with small numbers stating that it had the capacity to provide a full range of services.

A total of 533 responses referred to University Hospitals of Leicester NHS Trust (Glenfield), again with the majority supporting its future inclusion as a Specialist Surgical Centre. Again, the quality of care provided was praised and suggested as a reason to retain heart surgery services. A small number also mentioned the hospital's facilities, particularly referring to its ECMO facility.

Southampton University Hospitals NHS Trust was mentioned in 459 responses, with most calling for the surgical unit to remain open. Again large numbers referred to the high standard of care at the hospital, and some specifically highlighted the fact that it has been ranked second in the country. A small number also highlighted its partnership with Oxford as an example of a working network model.

Small numbers also referred to University Hospitals Bristol NHS Foundation Trust, Alder Hey Children's NHS Foundation Trust, Birmingham Children's Hospital NHS Foundation Trust, Oxford Radcliffe Hospitals NHS Trust and the three London hospitals.

Priorities

As discussed, most of the text responses referred to a particular option or hospital. However a minority offered further opinions on the decision making process. Three factors emerged as perceived priorities: standard of care (933), facilities (462) and location/geographical spread (252).

The majority of responses mentioning standard of care highlighted quality, expertise and reputation as paramount in determining which centres to keep open. A few responses also specifically stated that standard of care should take precedence over location.

The majority of responses mentioning facilities specifically stated that no centres should be closed and some argued that centres should be retained rather than wasting money on the development of further services. A small number specifically argued that ECMO facilities should be a paramount concern, stating that they should remain where they are currently.

General opinions of the proposals

Some respondents also made general comments on the proposals, with most being negative. These included respondents who didn't agree with any of the options, or just disagreed with the proposals as a whole (615); some others thought it was just a cost-cutting exercise while others expressed concern about the risk to patients. Further responses contained positive comments about the proposals and offered general support for them.

7. Stakeholder responses

Written responses (via email or letter) that came from associations, organisations, groups and others that represented the views of a number of people were treated as stakeholder views. These were in addition to the responses from organisations and groups that were sent on the standard response form and which are included in the analysis of the results of the consultation.

Some of these responses are much wider in scope than the questions asked in the response form, while others address one specific aspect of the proposals in a great deal of detail. A definitive picture of these responses can only be gained by reading their submission in full. All stakeholder responses submitted via email and letter were logged by Ipsos MORI and forwarded on to the *Safe and Sustainable* Steering Group and JCPCT for their full consideration. They were made available on 21st July 2011 and published on the *Safe and Sustainable* website thereafter.

A full list of these responses is appended at Appendix A.

8. ***Petitions and campaign responses***

A total of 25 petitions and campaign responses were received. The following table lists each of these, indicating what each was supporting and listing the number of signatories. Where the number of signatories was included with the submission, the table lists this number. Where the number was not included with the submission, the signatories were counted by Ipsos MORI.

Table 6 – Petitions and campaigns

	Petition/campaign on behalf/in support of	Number of signatories
A	Option A and specifically Glenfield Hospital, University Hospitals of Leicester NHS Trust	6,223
B	Option A and specifically Glenfield Hospital, University Hospitals of Leicester NHS Trust	53
C	Their Hearts in Your Hands from Alder Hey Children's NHS Foundation Trust	48
D	Royal Brompton & Harefield NHS Foundation Trust from The Brompton Fountain	117
E	Save Ocean Ward (Southampton University Hospitals NHS Trust) i-petition from Wessex Children's Heart Circle	5,169 ²⁷
F	Glenfield Hospital, University Hospitals of Leicester NHS Trust and Option A	407
G	Glenfield Hospital, University Hospitals of Leicester NHS Trust from Heart Link	47,258 ²⁸
H	The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)	1,228

²⁷ Stated number of responses received with petition (not verified by Ipsos MORI – may contain duplicates)

²⁸ Stated number of responses received with petition (not verified by Ipsos MORI – may contain duplicates)

I	Leeds Teaching Hospitals NHS Trust from Rotherham NHS Fellowship	24
J	Leeds Teaching Hospitals NHS Trust from Children's Heart Surgery Fund	445,945 ²⁹
K	Glenfield Hospital, University Hospitals of Leicester NHS Trust from Zuffar Haq	463
L	Their Hearts in Your Hands from Alder Hey Children's NHS Foundation Trust	1,727
M	The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)	267
N	Glenfield Hospital, University Hospitals of Leicester NHS Trust	53
O	Oxford Radcliffe Hospitals NHS Trust	3,677 ³⁰
P	Leeds Teaching Hospitals NHS Trust and Option D from Children's Heart Surgery Fund	4,297
Q	The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)	173
R	Southampton University Hospitals NHS Trust – Have a heart Daily Echo campaign	240,094 ³¹
S	Southampton University Hospitals NHS Trust – save our heart unit website	310 ³²
T	Leeds Teaching Hospital NHS Trust	873
U	Leeds Teaching Hospital NHS Trust	834

²⁹ Approximate figure – counted but not verified by Ipsos MORI (may contain duplicates)

³⁰ Stated number of responses received with petition (not verified by Ipsos MORI – may contain duplicates)

³¹ Stated number of responses received with petition (not verified by Ipsos MORI – may contain duplicates)

³² Stated number of responses received with petition (not verified by Ipsos MORI – may contain duplicates)

V	Leeds Teaching Hospital NHS Trust	31
W	Leeds Teaching Hospital NHS Trust	104
X	Leeds Teaching Hospital NHS Trust from the Children's Heart Surgery Fund	933
Y	Glenfield Hospital, University Hospitals of Leicester NHS Trust from the Voice of the People of Glenfield	570 ³³

As can be seen, these petitions and campaigns have focused on supporting a specific heart surgery unit (and a relevant option). In addition to forming responses in their own right, it is likely that these campaigns have influenced responses via other methods by raising awareness and encouraging people to respond to the consultation. However, it is difficult to quantify their impact.

Four of the petitions/campaigns also allowed signatories to post their own comments or respond to specific questions about the proposals. All of these comments have been read by Ipsos MORI and are summarised below so that they may be taken into account by the JCPCT.

Petition C – Alder Hey Children's NHS Foundation Trust postcards

Petition C consisted of a postcard produced by Alder Hey Children's Hospital which asked patients and parents four questions and included space for them to write their own comments. Children were encouraged to include a drawing.

As in other petitions, there were a great deal of comments about the excellent service provided at the hospital. Many of the children's drawings also contained thanks to the staff at Alder Hey.

The first question posed asked for views on the proposal to reduce the number of hospitals providing surgery. There was qualified support for this proposal. Some appreciated that it would lead to more experienced and specialist staff, but there were concerns about potential increased travel times and financial hardship for families where parents have to take time off work for example. Respondents stressed the need for practical and financial help for families

³³ Stated number of responses received with petition (not verified by Ipsos MORI – may contain duplicates)

and warned that travelling to centres further away from home would make the experience more traumatic.

A small number stated strong opposition to the proposal. They thought that more, if not all, hospitals should provide children's heart surgery.

The second question posed asked for comments on Congenital Heart Networks and received very few comments beyond agreement that the networks were a good idea. Respondents believed the networks would co-ordinate care and welcomed increased co-operation and communication between services.

In answer to the third question posed on the National Quality Standards, there was general agreement, particularly with those relating to prenatal diagnosis. Other suggestions include:

- Distance and access
- The transition to adult care
- Patient (or parent) reported outcomes
- Cancer care
- Advice and support during pregnancy about the risks of cardiac problems.

Finally, respondents to the petition were asked whether they supported Alder Hey and the North West network. All those answering this question said they did. They mentioned the staff and resources in place that are already up and running.

Petition E – Wessex Children's Heart Circle i petition (Southampton)

Petition E allowed signatories to post comments. Most chose just to sign their name to the petition, but some also added further comments. Participants included patients, parents, families and other interested members of the public.

Comments generally expressed disbelief that the unit at Southampton could be closed – many people recalled their own good experiences of the hospital or the fact that the unit has saved the life of a member of their family or a child they know. But much of the disbelief also emanated from those who said the unit was one of the best in the country – many referred to the fact that it was ranked second in the country in the performance review. They found it difficult to understand why any high performing service should be closed. Others referred more specifically to the options put forward and questioned the wisdom of closing the heart

unit at Southampton while a lower performing unit stays open. Most stressed that quality should be the deciding factor.

Others though, talked about cuts in the NHS, believing that the proposals were being put forward to save money and expressed their anger that any children's service, but particularly a high performing one, could be closed.

A smaller number outlined the impact of closing the unit at Southampton – and increased travelling times for patients in the south of England. Some referred specifically to the impact on patients and families from the Isle of Wight and the Channel Islands.

Petition S – Southampton University Hospitals NHS Trust website comments

Petition S was formed of a list of comments posted on a website from patients, parents, users of other services at the hospital and other local interested members of the public.

In addition to stating their support for the unit at Southampton and calling for it to be saved, many of the comments related personal experiences of the unit. The quality of care received was praised and many referred to the staff and named specific clinicians who they said provided excellent care. A large number stated their belief that it was the best in the country, with some highlighting that it was ranked second in the country in the review. There were references to the importance of the services provided at Southampton, with respondents noting that it was one of a very small number to have the expertise to perform complex procedures. Some argued that patients shouldn't be moved to "*poorer performing*" units simply to provide a geographical spread across the country.

Many talked about the impact of closing the unit, particularly the effect of travelling longer distances for those in the south of the country. Some commented on the strain this would place on the family and the potential impact on the patient's recovery. Some were concerned that it would put children's lives at risk and would be disruptive to existing patients. However there was also recognition that other families in other parts of the country would be going through similar things – and questions as to why any units should be closing, A small number linked this to a perceived need to save money.

Petition X – Children's Heart Surgery Fund postcards (Leeds)

Petition X consisted of a postcard produced by the Children's Heart Surgery Fund which allowed children (and some adults) to write in their words why they were "not happy that people want to close the children's heart wards in Leeds".

Many of the messages focused on the large numbers of children who had been treated at the hospital (with many receiving life saving treatment) – and some talked specifically of friends and family (particularly siblings) that had been patients there.

Some of the children expressed their concerns that closing the unit would lead to children not receiving the treatment they needed in the future. A number of these mentioned a risk to children's lives.

The other issue most frequently mentioned was the unit's location and the increased distances that families would have to travel if it was closed. Some of these respondents said that Leeds was the only service locally and that it served a large population. Large numbers said that travelling further for treatment would cause families more inconvenience and place all the family under stress; again, some referred to the risk to patients of increased travel times. Many of the children said that they personally did not want to travel further for treatment.

Appendices

The appendices to this report are:

Appendix A: Responses from organisations

Appendix B: Petitions/campaigns

Appendix C: Demographics

Appendix A: Responses from organisations

Responses by letter and email (not via the response form)

The organisations and groups that submitted responses by letter and email are listed below, categorised into ten groups. Some of these have submitted more than one response.

Groups of NHS Staff

Paediatric Critical Care Network, North, East and West Yorkshire
 Paediatric Intensive Care Forum, Western Sussex Hospitals
 Paediatricians in East Kent, East Kent Hospitals University NHS Trust
 Paediatricians St Peter's, Ashford and St Peter's Hospitals NHS Trust
 Salisbury Paediatricians, Salisbury NHS Foundation Trust
 Sheffield Children's NHS Foundation Trust, Senior Clinical Staff
 St Mary's Paediatricians, Isle of Wight NHS
 Wessex Fetal and Maternal Medicine Network, Southampton University Hospitals NHS Trust
 Wessex Paediatricians, Salisbury NHS Foundation Trust
 Wessex Trauma Network
 Yorkshire & Humber Congenital Cardiac Network
 Yorkshire, Humber & North Trent Paediatric Cardiology Clinical Network Paediatricians

Health Bodies

Brighton and Sussex University Hospitals NHS Trust
 Central Manchester University Hospitals NHS Foundation Trust
 Chesterfield Royal Hospital NHS Foundation Trust
 Dartford and Gravesham NHS Trust
 Dorset County Hospital NHS Foundation Trust
 East Sussex Healthcare NHS Trust
 Epsom and St Helier University Hospitals NHS Trust
 Hull and East Yorkshire Hospitals NHS Trust
 King's College Hospital NHS Foundation Trust
 Lewisham Healthcare NHS Trust - Children & Young People Directorate
 Maidstone and Tunbridge Wells NHS Trust
 The Mid Yorkshire Hospitals NHS Trust
 North Tees and Hartlepool NHS Foundation Trust
 Oxford Health NHS Foundation Trust
 The Royal Marsden NHS Foundation Trust
 Salisbury NHS Foundation Trust
 Sheffield Children's NHS Foundation Trust
 Sheffield Teaching Hospitals NHS Foundation Trust
 Solent NHS Trust
 NHS South Central Strategic Health Authority
 Southern Health NHS Foundation Trust
 Surrey and Sussex Healthcare NHS Trust
 York Teaching Hospital NHS Foundation Trust

International

Prof. Joseph J. Amato
 Prof. Ottavio Alfieri MD
 Prof. Salah-Eldin Amry

Torkel Aberg
 Prof Manindra R. Baral
 Heidi M. Connolly MD
 Neville Conway FRCP
 Francis Fontan MD
 Prof. Dr Siegfried Hagl
 Thomas Higgins MD
 Marshall L. Jacobs MD
 Jersey General Hospital Paediatric Services
 Michael J. Landzberg MD
 Douglas J Mathisen MD
 Barbara Mulder MD, PhD
 Prof. Giovanni Stellin
 Marko Turina MD
 Prof. Pascal Vouhe
 Andrew S. Weschler MD, FACS, FAHA, FACC
 Prof. William G. Williams MD, FRCSC

Local Authorities

Amesbury Town Council
 Association of North East Councils
 Craven District Council
 Eastleigh Borough Council
 Hampshire County Council
 Hillingdon Council
 Isle of Wight Council
 Newcastle City Council
 Northumberland County Council
 Rotherham Metropolitan Borough Council
 Southampton City Council
 West Oxfordshire District Council

Local Groups

The Ben Williams Trust
 The Brompton Fountain - Royal Brompton & Harefield Family Support Group
 The Community Voice
 Children's Heart Surgery Fund
 Families of Ocean Ward
 Guy's & St Thomas' Charity
 Harefield Tenants and Residents' Association
 Heart Link
 Parent Representatives with Children with Cystic Fibrosis - Paediatric Cardiac Surgery
 Parent Representatives – SE zonal group
 Ruislip Residents' Association
 Wessex Children's Heart Circle
 Young Hearts

MPs & Politicians

Stuart Andrew MP
 Tony Arbour JP AM
 Jennette Arnold AM
 Norman Baker MP
 Ed Balls MP
 Cllr Richard Barnes AM
 John Bercow MP

Nicola Blackwood MP
Godfrey Bloom MEP
Andrew Boff AM
Victoria Borwick AM
Steve Brine MP
N H Brown MP
David Cameron MP
James Cleverly AM
Philip Davies MP
John Denham MP
Richard Drax MP
Michael Dugher MP
John Glen MP
Justine Greening MP
Greg Hands MP
John Healey MP
Stephen Hepburn MP
Damian Hinds MP
Mark Hoban MP
Kate Hoey MP
George Hollingbery MP
Gerald Howarth MP
Simon Hughes MP
Boris Johnson Mayor of London
Cllr Darren Johnson AM
Liz Kendall MP
Sadiq Khan MP
David Lammy MP
Dr Julian Lewis MP
Kit Malthouse AM
John Mann MP
Cllr Shelagh Marshall
Catherine McKinnell MP
Ian Mearns MP
David Miliband MP
Maria Miller MP
Austin Mitchell MP
Penny Mordaunt MP
Nicky Morgan MP
Caroline Nokes MP
Steve O'Connell AM
Guy Opperman MP
Stephen Phillips MP
Andrew Robathan MP
Linda Riordan MP
Valerie Shawcross AM
Alec Shelbrooke MP
Andy Slaughter MP
Andrew Smith MP
Gareth Thomas MP
Richard Tracey AM
David Tredinnick MP
David Ward MP
Dr Alan Whitehead MP
Rob Wilson MP

Rosie Winterton MP
Yorkshire and Humber, North Derbyshire and North Lincolnshire MPs

National Charities

Asthma UK
British Heart Foundation
Cardiac Risk in the Young
Children's Heart Federation
Cystic Fibrosis Trust
Down's Heart Group
Grown up Congenital Heart Patients' Association
Little Hearts Matter
Resuscitation Council (UK)

OSCs & LINKs

Borough of Poole Council OSC
Bournemouth Borough Council HOSC
Dorset County Council Health Scrutiny Committee
Hampshire County Council HOSC
Isle of Wight Council OSC
Joint HOSC Yorkshire & Humber
Leicestershire LINK
Leicestershire LINK and Leicester City LINK
North Lincolnshire Council's People Scrutiny Panel
Oxfordshire Joint Health Overview and Scrutiny Committee
Royal Borough of Kensington and Chelsea OSC
Somerset County Council Scrutiny Committee
South East Health Scrutiny Network
South Gloucestershire Health Scrutiny Select Committee
Southampton HOSC
Southampton LINK
Walsall Council OSC
West Berkshire LINK
Wiltshire Council OSC
Wokingham LINK

Professional Associations and Advisory Bodies

The Association of Cardiothoracic Anaesthetists
Association of Paediatric Anaesthetists of Great Britain and Ireland
British Congenital Cardiac Association
British Maternal & Fetal Medicine Society
The British Psychological Society
NHS Blood and Transplant
NHS Scotland NSD
NHS Screening Programmes
The Paediatric Intensive Care Society
Royal College of Paediatrics and Child Health

Proposed centres for the location of Specialist Surgical Centres

Alder Hey Children's NHS Foundation Trust
Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
Great Ormond Street Hospital for Children NHS Trust
Guy's & St Thomas' NHS Foundation Trust (Evelina Children's Hospital)
The Leeds Teaching Hospitals NHS Trust

University Hospitals of Leicester NHS Trust (Chair)
 University Hospitals of Leicester NHS Trust
 The Newcastle Upon Tyne Hospitals NHS Foundation Trust
 Oxford Radcliffe Hospitals NHS Trust
 Royal Brompton & Harefield NHS Foundation Trust
 Southampton University Hospitals NHS Trust

Responses using the response form

A number of respondents using the response form stated that they were representing an organisation or group. Where they gave the name of that organisation or group, this is listed below (where this was legible). It is not known whether these respondents were **formally** responding on behalf of that organisation or group, or how they assembled the views of other members. While this information was asked, it was not always supplied and where information was provided, it was self reported.

More than one response was submitted on behalf of some of these organisations.

Many other respondents who stated that they were responding on behalf of an organisation or group did not provide any information or did not specify exactly which organisation they were representing. For example, some said they were representing a hospital or particular department with no further information. Others said they were representing their family or local community. These responses have been included as organisations in the analysis in this report, but are not listed here.

ACC
 Acute Care Diu
 Age Concern Hampshire
 Age Uil Washington
 Airedale NHS Foundation Trust
 Aj Salaam Trust
 Alder Hey Children's NHS Foundation Trust
 Ambulatory Care
 Arnold Lodge
 The Arrhythmia Alliance
 Ashford and St Peter's Hospital
 Ashleigh Clinic
 Association of Paediatric Chartered Physiotherapist
 Association of Paediatric Anaesthetists of Great Britain and Ireland
 Association of Verwood Residents
 Atlas Windows
 Baitul Mukarram Mosque
 Balestone Parish Council
 Beales Plc
 Beaumont Leys
 Sir Alan Beith MP
 Belper Town Juniors
 Bernard Medical Centre
 Birmingham Children's Hospital NHS Foundation Trust
 Blackpool Teaching Hospitals Trust
 Bliss
 Bournemouth Borough Council
 BP

Brighton and Sussex University Hospitals
 British Society for Heart Failure
 British Transplantation Society
 Broomfield SILC
 Broomley and Stocksfield Parish Council
 BT
 Buckinghamshire NHS Trust
 Buckinghamshire Public Health OSC
 BUPA Care Services
 CAMHS NHS Trust
 Cancer Care for Children
 Cancer Sciences
 Carlton Parish Council
 Centre Neonatal Transport Service
 Chadwell Heath Health Centre
 Change for Life
 Children's Heart Surgery Fund
 County Durham Link
 Cross Sectional Imaging, Southampton General Hospital
 Cumbria Health and Well-Being Scrutiny Committee
 Darlington Borough Council
 Department of Paediatrics, Northampton
 Derby City Council
 Derby Hospital
 Directordane Group
 Doncaster and Bassetlaw Foundation Trust
 Dorset County Hospital NHS Foundation Trust
 Down's Heart Group
 Dr Evans and Partners
 Dudley Group of Hospitals NHS Trust
 E.S.Smith and Sons
 East Cheshire NHS Trust
 East Lindsey District Council
 East Midlands Councils
 The Ebsteins Society
 Edvantage Group
 Equals
 Ethiopian Christian Fellowship
 Evelina Children's Heart Organisation
 Evelina Children's Hospital
 Forum for Independent Research
 Freeman Hospital
 Friends SGH
 Frimley Park Hospital
 FSO
 Gateshead LINK
 Gelder and Kitchen LLP
 The General Hospital Jersey
 Glenfield Cardiac Centre
 Glenfield Hospital
 Great Ormond Street Hospital for Children NHS Trust
 Great Western Hospital Swindon
 Guys and St Thomas NHS Trust
 Halifax & District Irish Society
 Hampshire SFYC

Harefield Hospital Re-Beat Club
 Havant Health Centre
 Health Scrutiny Committee For Lincolnshire
 Heart Link
 Hertfordshire LINK (Health Watch)
 The HI
 Hillingdon Association of Voluntary Services
 Hillingdon Play Association
 HMC
 Home Office
 Honorary Police
 Horsham District Council
 Hotel and Restaurant Group
 HSBC Bank
 Huncote F.C.
 HV Solutions Ltd
 Hywel Dda Local Health Board
 Ickle Angels Day Nursery
 Imperial College
 Indian Overseas Congress, Leicester
 The International Guild of Nurses and Carers
 INWL PCTs
 IoW Branch Asthma Uk
 IoW NHS PCT
 Islamic Education Trust
 Isle of Wight Local Safeguarding Children Board
 J&V Field 8 YGC
 Jame Masjid
 John Lewis
 John Radcliffe Hospital
 Johnson and Johnson
 Johnsons
 Kayospruce Ltd
 Kingston Pathfinder Consortium
 Kirkburton Health Centre
 Labour Group
 Ladies Section Kibworth Golf Club
 Leeds Neonatal Service
 Leeds Partnerships NHS Foundation Trust
 Leeds SoH
 Leeds Teaching Hospitals NHS Trust
 Leeds/Southampton Trusts
 Leicester City and Leicestershire
 Leicester City Council
 Leicester General Hospital
 Leicester Royal Infirmary
 Leicester Sikh Centre
 Leicestershire Centre for Integrated Living
 Leicestershire Muslim Kokni Assa
 Leicestershire, Leicester and Rutland Health Overview and Scrutiny Committee
 Leicester Day Trust
 Leicester Host Lions Club
 Lewisham Healthcare NHS Trust
 LGI
 Lincoln County Hospital

Linde Castle
 Little Cuckoos Pre-School
 Little Hearts Matter
 Liverpool Women's NHS Foundation Trust
 Lloyds TSB
 LMC Kirklees
 Lynemouth Parish Council
 Magna Carter School
 Majles-E Dawat-UI Haq Uk
 Market Bosworth Rotary Club
 Masjid Al Huda
 Masjid Ali Charitable Trust
 Masjid Arahman
 Masjide Ishaa-Atul Quran
 Mombasa Khalifa Welfare Trust
 MCRN East
 Medirest Compass
 Medway On Call Care
 Members Forum, GOSH
 Metool
 Mid Essex Hospitals NHS Trust
 Middlesbrough LINK
 Mill Lane J I and Ey School
 Mm Mangrol Muslim Society
 Mothers Network
 Narborough Read Islam Centre
 Neonatal & Paediatric Pharmacists Group
 Neuro LTU
 New Life Centre Church
 Newcastle-Upon-Tyne Hospitals NHS Trust
 Newcross Hospital Wolverhampton
 Newtown Linford Parish Council
 NHS Bournemouth and Poole Consortium
 NHS DMU University
 NHS IM&T
 NHS National Services Scotland
 NHS Southwest London
 NHS Specialised Services
 NHSTA/FIRH/Scorpio Ltd
 Noon Product Ltd
 Norham Parish Council
 Norman Underwood Ltd
 North East Regional Joint Health Overview and Scrutiny Committee
 North Trent Neonatal Network
 North Tyneside Link
 Northampton Healthcare NHS Trust
 Northern Road Surgery
 Nottingham and Nottinghamshire Joint Health Scrutiny Committee
 NSPCT/Bank GH
 Oadby & Wigston Muslim Association
 Oadby Golf Club
 Oak Refrigeration
 The Oakley Overton Partnership
 Orpington College
 Oxford Radcliffe Trust

PAH
 PDM
 Pennine Acute Hospitals
 Percy Arms Hotel
 Peterborough and Stamford NHS Foundation Trust
 Peterborough City Hospital
 Pick Everland
 Poole Hospital
 Portsmouth Feto-Maternal Medicine Consultants
 Portsmouth Health Overview & Scrutiny Panel
 Portsmouth Hospitals NHS Trust
 Portswood Ward Lib Dem Focus Team
 Princess Anne Hospital
 Priory Hospital Marchwood
 Queens Medical Centre
 Radcliffe NHS Trust
 Rainbow Trust Children's Charity
 RCGP
 The Red and Green Practice
 Response Envelopes Limited
 RLC Foundation Trust
 Rolls Royce
 Ronald McDonald House Charities
 Rotary Club of the New Forest
 The Rotherham NHS Foundation Trust
 Royal Bank of Canada
 Royal Brompton & Harefield NHS Foundation Trust
 Royal Liverpool Children's NHS Foundation Trust
 Royal United Hospital, Bath
 Royal Wolverhampton Hospitals NHS Trust
 Rycote Microphone Windshields
 S O S Royal Brompton
 SADS UK
 Safeguarding Unit
 Salisbury NHS Trust
 The Salvation Army
 Santander
 Save Our Heart Unit
 Save Our Surgery
 Save Our Surgery Fighting For The Hearts of Yorkshire Kids
 SBL Travel
 SCH
 Sector Design and Marketing Ltd
 Securitas
 The Sedman Family, Leicester
 Serco
 Sherwood Forest Hospitals NHS Foundation
 Shk Moosa
 Shoreham Housing
 Sinden Family
 Sixpenny Handley & Chalke Valley Practice
 Solent NHS Trust
 Solihull NHS Care Trust
 South and Eastern Health Trust
 South Central Cardiovascular Network

South Central Strategic Health Authority
 South Wigston Health Centre
 Southampton City Council
 Southampton General Hospital
 Southampton Itchen
 Southampton University Hospitals NHS Trust
 Southend University Hospital Trust
 Southern Water
 Spire Healthcare
 Spire Southampton Hospital
 The Square Residents Group
 St George's Healthcare NHS Trust
 St Mary's Hospital Isle of Wight
 St Mary's Hospital
 States of Jersey Ambulance Service
 Sterile Services
 Stone School
 Sunderland City Council's Children, Young People and Learning Scrutiny Committee
 Sunlight Centre
 Sunshine and Smiles - Leeds Down Syndrome Support Network
 The Surati Muslim Khalifa Society
 Surrey and Sussex Healthcare NHS Trust
 Sweetpeas Parent & Toddler Group
 Tadi Bis
 Take Heart at Leeds General Infirmary
 Tayebah Community and Education Centre
 Tin Arts Limited
 Toynbee School
 UHB South Wales
 Unison
 United Families Welfare Society
 University of Surrey
 University Hospitals Bristol NHS Foundation Trust
 University Hospitals of Leicester NHS Trust
 University of Oxford
 University of Southampton
 Valsad District Muslim Jamat
 VIP Childcare Services Ltd
 Voluntary Action Leicestershire
 Wakefield District Link
 Warrington and Halton Hospitals Foundation Trust
 Waterside Ladies Hockey Club
 Welsh Health Specialised Services
 Wessex Children's Heart Circle
 Wessex Heartbeat
 West Bretton Junior and Infant School
 West London University
 Western Sussex Hospitals NHS Trust
 Westfield Junior School
 Alan Whitehead MP
 Wigston Magna Civic Society
 Winchester & Eastleigh Healthcare NHS Trust
 Windsor House Group Practice
 Women's Health Concern
 WTCRF

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York District Hospital NHS Foundation Trust
Yorkshire Neonatal Network
Young Hearts
ZI

Appendix B: Petitions and campaigns

The text of each petition/campaign that was received is detailed here.

Petition A

Why I support 'option A' in the Safe and Sustainable review of children's heart surgery.

Option A places Glenfield Hospital in Leicester as the surgical centre covering Eastern Central England. It includes Birmingham, Newcastle, Bristol and Liverpool to cover the other regions and Great Ormond St and Evelina at Guy's and St Thomas in London.

Option A achieved the highest overall score from the review panel against standards of Quality, Accessibility, Deliverability and Sustainability.

Option A is the only combination of surgical centres that provides a truly sustainable coverage of the population centres in the UK. All the other options are flawed by insufficient provision or inaccessible services.

Option A is the only option that ensures Glenfield's World-Leading ECMO service for infants and children with severe respiratory failure will survive and continue to provide the care, training and research for which it is justifiably famous.

Option A will enable Glenfield to provide surgical services for the UK's fastest growing population base in the East Midlands, which together with Coventry, Derby, Sheffield and Doncaster (all with Option A's footprint) will bring projected surgical referrals to well over 400. Glenfield has a track record of delivering excellence and I believe they are very capable of excelling when asked to achieve this.

Petition B

Why I support 'option A' in the Safe and Sustainable review of children's heart surgery

Option A is

1. Glenfield Hospital in Leicester
2. Birmingham Children Hospital
3. Freeman Hospital in Newcastle
4. Alder Hey in Liverpool
5. Bristol Children Hospital
6. Great Ormond Street in London
7. Evelina at Guy's and St Thomas in London

Option A achieved the highest overall score from the review panel against standards of Quality, Accessibility, Deliverability and Sustainability.

Option A is the only combination of surgical centres that provides a truly sustainable coverage of the population centres in the UK.

Option A is the only option that ensures Glenfield's World-Leading ECMO service will survive.

Option A will enable Glenfield to provide surgical services for the UK's fastest growing population base.

Petition C

Q1. What do you think about fewer hospitals performing more children and young people's heart operations?

Q2. Do you think heart networks are a good idea?

Q3. Do you think these are the right standards? Are there other areas you think we should be recommending standards on?

Q4. Do you support Alder Hey and the North West network?

Petition D

Petition to Save Royal Brompton Hospital's Children's Cardiac Services

Don't let Royal Brompton's children's heart surgery stop. A review of children's heart services in England has recommended that Royal Brompton's cardiac surgery for children should stop. This is in spite of the fact that Royal Brompton's treatment is among safest in the country, and feedback from patients and their families is very positive. Please help us to fight these plans by signing this petition. YOUR SUPPORT CAN MAKE A DIFFERENCE. Further information can be found at www.thebromptonfoundation.org.uk.

We, the undersigned, agree with the content of this petition, and fully support the campaign to prevent the closure of children's heart services at Royal Brompton Hospital, which will have a devastating effect on the care of hundreds of children and their families, as well as the lives of many hundreds of adults who receive care from this wonderful hospital. Thank you for your support.

Petition E

Southampton's Paediatric Cardiac Unit has proven that it has experience, resources, ability and plans in place to adapt to the growing changes that the Safe & Sustainable Review would bring. The unit at Southampton has received the highest accolades for many years and the review itself indicates this is the second best performing children's heart surgery centre in the country. The Southampton Unit should not be considered for closure when units in the lowest end of ranking are deemed to be safe. By signing this petition you are asking that the countries second best children's heart surgery unit is not closed in favour of lower performing units.

Petition F

We give our support to Glenfield Hospital and vote for Option A in the Safe and Sustainable campaign.

Petition G

We the undersigned give our support to the continuation of Children's Surgery and Cardiac Services at The Glenfield Hospital, Groby Road, Leicester.

Petition H

Warning . . .!!! Be aware, that the children's heart unit in Newcastle is in danger of closing. This is in favour of another unit elsewhere in the country. We cannot be without this unit in the northeast. At any time a child with heart problems may need treatment potentially lasting for many years.

Petition I

Petition to support the campaign against the relocation of Paediatric Cardiac Surgery from Leeds to Newcastle.

Petition J

"Fighting for the Hearts of Yorkshire Kids". As Director of Children's Heart Surgery Fund, Sharon Cheng, I appeal to you today for your help to save our Heart Surgery Service in Leeds by signing this petition. Your signature will go a long way to helping us fight our cause and in turn prevent our valued service from closure, thus keeping the children of Yorkshire and surrounding areas safer here in our newly registered "Children's Hospital".

Petition K

Health campaigner Zuffar Haq is fighting for the future of children's heart surgery at Glenfield Hospital, Leicester.

Glenfield Hospital only appears in one of the four options for future children's heart surgery.

Zuffar Haq and the local Lib Dems want to keep the unit here in Leicester.

I the undersigned call on the NHS to keep children's heart services at Glenfield Hospital in Leicester.

Please also respond to the consultation at www.specialisedservices.nhs.uk

Petition L

We, the undersigned want to express our support for the North West Cardiac Network and Alder Hey Hospital as the cardiac surgical centre for the North. We also support the principles that are set out in the Safe and Sustainable review of paediatric cardiac surgery.

Petition M

Freeman Hospital, Newcastle upon Tyne Cardiothoracic Department. NHS has declared that this hospital is one of three that may be closed in the near future for their new hospitals of excellence. It sounds like a good idea but what happens to the people who travel from all over to have their operations at Freeman by their own choosing.

After watching Horizon on BBC1 last week, a programme that delved into the problems regarding the heart, the young doctor visited America and saw the work they are carrying out there. He also visited a research centre in London and finally decided to visit a hospital that was renowned for Pioneer Surgery. Yes, it was Freeman, so what logical reason has the NHS to close such a fantastic department, and what happens to all the patients who are dependent upon urgent treatment, when a possible journey to a hospital, say in Leeds or Liverpool, would mean they could possibly die before they could get the necessary treatment.

I can speak about this from experience. My grandson is one of these patients. He was born in 2004 and at five weeks old was taken to Durham University Hospital where it was discovered he had a hole in the heart. Transferred to Freeman it was found that not only was there a hole in the heart but he also had a leaking valve and congenital corrected transposition.

At five weeks old a minor operation was carried out to fit a band to the leaking valve and his parents were told that he would need major surgery in the near future.

He progressed very well and he was three years old when he had eight hour pioneer surgery to rebuild his heart.

Three weeks later he was fine, home, and became headline news in the local newspapers and local television. The following day the story broke on national news in both the media and TV.

He was to have a pacemaker fitted but unfortunately the team realised that a pacemaker would not rectify the problems he was suffering. At five years old after many tests he underwent further major surgery. Operated on Monday and fit enough to return home on Saturday, thanks to the fantastic surgery once again.

In October last year he suffered a stroke and was immediately admitted to Ward 23 where he was treated. Thankfully to these ingenious and skilful people, yet again, our boy recovered fully.

Unfortunately this will not be the end of him, he, along with lots of other children and adults rely totally upon this hospital for their care and follow-up treatment. For many a long distance travel to another hospital may incur expenses they can not afford and take up too much time, time they do not have.

For all cardiothoracic patients, this has to be seriously considered. Or, is it just a case that the people of North and North East of England do not matter although we have the resourceful people they will be poached away from us. Keep Freeman Open

IF AFTER READING THIS YOU AGREE, PLEASE SIGN THE PETITION

Petition N

Children's Heart Surgery in the East Midlands at Glenfield Hospital. I have received a request from Dr Doug Skehan to support the continuation of this service at Glenfield.

Petition O

Petition to Save Oxford Children's Heart Surgery Unit. There is currently a Safe and Sustainable Review happening concerning the 11 specialised Children's Heart Surgery Units throughout the United Kingdom. 4 or 5 units will close. Oxford and Southampton (who Oxford patients are currently attending) are both under threat.

Without local heart services, there will be a devastating knock on effect on the rest of the children's services offered at Oxford.

Would you risk your child's life if he/she required urgent emergency surgery after a car accident? Under the new proposals children are expected to travel to London or Bristol. This decision doesn't just affect heart children but those without heart conditions. Those healthy children who one day catch a virus and are rushed to hospital needing urgent surgery to repair a badly damaged heart.

Show your support for local services and for your children and your children's children

Petition P

Save Our Surgery "Fighting for the Hearts of Yorkshire Kids". Leeds Children's Hospital is the only Children's Heart Centre in Yorkshire – serving Yorkshire and the Humber and North Derbyshire. The unit WILL close without your help.

I am deeply concerned about the threat of closure to the Leeds Children's Congenital Heart Surgery Unit.

The Leeds Unit covers the whole of Yorkshire & Humber region and some areas within North Derbyshire. This equates to a total population, within a 2 hour drive time to Leeds, or around 14 million.

Leeds offers lifespan care, fetal, maternity, neonatal, all children's services, dental and adult congenital services, co-located under one roof. This provides patients with a Gold Standard of care, from antenatal diagnosis through to adulthood.

Where care is already provided on one site it should NOT be broken up into separate hospitals, which is what would happen to services for the patients of Yorkshire & the Humber, under the current options available.

Any option that expects patients to travel further than necessary, at a greater inconvenience, at greater cost and at a potential greater harm should not be considered.

I strongly support option D or any alternative option that includes Leeds.

Petition Q

To the Secretary of State and Health Petition for the Freeman Hospital Children Health Unit

As residents of Newcastle upon Tyne, we are horrified about the proposal to close the Freeman Hospital Children's Heart Unit as it stands at present. It is one of the most successful in the country and also situated in the North East of England and renowned throughout the world.

What would be the sense of breaking up this successful team that has been built up over two decades or more. Parents of children who have been treated at the Freeman Hospital, are more than satisfied and also raise funds to assist the unit and keep the good atmosphere that surrounds this service.

People in the North East, North West, Scotland and Northern Ireland deserve the Freeman Hospital Children's Heart Unit and should not have to be transferred to further out of the ways areas with sick children.

We call on the Government to keep the unit open and invest in its future.

Petition R

Save Southampton's Cardiac unit dailyecho.co.uk/have_a_heart

Petition S

On 18 April 2011 the save our heart unit website (www.saveourheartunit.org) was launched to give parents and supporters of the Southampton University Hospitals NHS Trust campaign an opportunity to find out more about the Safe and Sustainable review into paediatric heart surgery, what they could do to support the campaign and to leave comments on the review.

Petition T

Yorkshire and the Humber Heart Surgery Service – we the undersigned fully support the Children’s Heart Surgery Unit in the Yorkshire Heart Centre at Leeds General Infirmary and wish to prevent its closure.

Petition U

Save Children’s Heart Surgery at Leeds. Children’s heart surgery at Leeds General Infirmary is under threat in order to cut costs and make fewer but more specialised centres.

Should this happen, it will have a massive impact on many families across Yorkshire who may then have to travel to Newcastle or London in order for their children to undergo heart operations.

This could lead to less support from family and friends, added costs and most seriously the health of the heart child could be at risk due to increased distances to receive the required care.

We hope to try and stop this from happening and hope with as many signatures on these petitions as possible, our voices may be heard.

Please help us by signing this form, it will mean so much to the families involved.

Petition V

We the below mentioned people implore the government to think again with regards the closure of Leeds General Infirmary Paediatric Cardiology Unit:

We the below mentioned people oppose the closure of Leeds General Infirmary Cardiology Unit:

Petition W

Asgar Khan and your local Labour team will be campaigning to save the closure of the Children Heart Surgery Services at Leeds General Infirmary. Please help by signing the petition.

Petition X

Dear Mr Cameron

I am not happy that people want to close the children’s heart wards in Leeds because...

Please can you stop this?

Thank you

Petition Y

You may be aware that our children's heart service at the Glenfield Hospital in Leicester is under threat of closure as part of a national review which aims to reduce the number of centres providing this kind of specialist surgery.

This review is nearing the end of the public consultation period and we need to get together and make our voices be heard, for the people in the East Midlands and beyond.

Please sign this petition and help us to "Hold on to our hearts" Thanks you.

Appendix C: Demographic information

Demographic information, where this information has been recorded, is given below, although it is important to bear in mind that this is just a subset of the consultation participants and cannot be taken to be representative of the consultation participants in general. (It should be noted that all percentages referred to below are rounded to the nearest whole number, and that when two or more such figures are added, it can create rounding error; the rounded figures given in a column, therefore, may not sum to exactly 100%.)

Comparative figures for the population of England (where available) are also provided.³⁴

Table A1

Consultation responses by gender			
Gender	Number of responses	% of responses giving gender	% of population in England
Male	19,258	40	49
Female	28,683	60	51
<i>Stating gender</i>	47,941		
<i>Not stated (where question asked)</i>	2,391		
Total	50,332		

Source: Ipsos MORI

³⁴ Source: Census 2001, mid-year estimates 2010

Table A2

Consultation responses by age			
Age	Number of responses	% of responses giving age	% of population in England
Under 16	928	2	19
16-24	4,208	9	12
25-34	9,216	19	13
35-44	12,120	25	14
45-54	9,605	20	15
55-64	6,466	13	12
65-74	3,817	8	9
75+	1,744	4	8
<i>Stating age</i>	48,104		
<i>Not stated (where question asked)</i>	2,228		
Total	50,332		

Source: Ipsos MORI

Table A3

Consultation responses by experience		
Experience	Number of responses	% of responses giving experience
Have CHD	1,711	4
Care for someone else with CHD	10,575	25
Know someone with CHD	13,095	31
Care for someone with CHD in professional capacity	5,095	12
No experience of caring for someone with CHD	11,487	27
<i>Stating experience</i>	41,963	
<i>Not stated (where question asked)</i>	8,369	
Total	50,332	

Source: Ipsos MORI

Table A4

Consultation responses by region			
Region	Number of responses	% of responses giving region	% of population in England
London	2,072	4	15
South East	1,531	3	16
South Central	10,126	21	(South East and South Central regions)
Channel Islands	100	*	
East of England	811	2	11
South West	2,705	6	10
East Midlands	23,378	49	9
West Midlands	873	2	10
North East	1,569	3	5

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North West	510	1	13
Yorkshire and Humber	3,446	7	10
Wales	122	*	
Scotland	115	*	
Isle of Man	2	*	

<i>Stating region</i>	47,360
<i>Not stated (where question asked)</i>	2,972
Total	50,332

Source: Ipsos MORI

Table A5

Consultation responses by ethnicity

Ethnicity	Number of responses	% of responses stating ethnicity	% of population in England ³⁵
White	37,063	78	91
Mixed	703	1	1
Asian or Asian British	8,786	19	5
Black or Black British	642	1	2
Other	148	*	1
<i>Stating ethnicity</i>	47,342		
<i>Not stated (where question asked)</i>	2,990		
Total	50,332		

Source: Ipsos MORI

³⁵ This data is taken from the 2001 census.

