

Safe and Sustainable Consultation Report

**Technical Annex prepared for the Joint Committee of Primary Care
Trusts**

24 August 2011

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1. Introduction

This document details the methodological approach to the consultation on the *Safe and Sustainable* proposals for children's congenital heart services in England. This should be read alongside the document *Safe and Sustainable: Children's congenital heart services in England consultation report*, which summarises the key findings from the consultation.

1.1 The context

In 2008, the NHS Medical Director asked for a review of children's congenital heart services, following two previous reviews in 2001 and 2003 which put forward the case for reducing the number of hospitals that provide children's heart surgery. The subsequent *Safe and Sustainable* Review has developed proposals for 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.

1.2 Partners

The Joint Committee of Primary Care Trusts have conducted a multi-strand, full-scale consultation exercise to investigate the views of the general public and stakeholders towards the *Safe and Sustainable* proposals. Ipsos MORI was commissioned to undertake the analysis of this consultation as an independent body. Communications for the consultation, including all engagement events (see Section 1.3) were carried out by Grayling.

1.3 The consultation process

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 languages¹ 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 languages².
- **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.

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

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

2. Responses to the consultation

2.1 Numbers of responses

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

Table 1

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

It should be noted that the numbers in the table above refer to the number of *responses*, rather than *respondents*, as one respondent may have responded more than once by various methods. For example, one individual may have completed a response form and sent a text message. This will not be apparent in the analysis of the responses. However, it has been possible to identify where more than one text message was sent from the same mobile telephone number – 19,852 sent just one message and 549 sent more than one response³. The hard copy response forms contained unique serial numbers and no duplicates were received. Four forms without serial numbers (which appear to have been downloaded versions of the online form) were received and have been included in the table above. Multiple responses were accepted from individual IP addresses to ensure, for example, that a family sharing a home computer were all able to submit individual responses. In some cases, a large number of responses were received from an individual IP address. There were 14 IP addresses where over 100 responses were received from that one address and the highest number of responses from one IP address was 765, though these were all from different e-mail addresses.

³ Having removed all blank messages

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 participants by audience group is shown in Table 2, and further descriptions of each audience group are given below.

Table 2

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

⁴ Those completing a response form were able to allocate themselves to one or more of these categories

⁵ Those completing a response form were able to allocate themselves to one or more of these categories

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

As can be seen from the table above, respondents providing a personal response included people (50,332) with professional and personal interest in children's heart services. This 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).

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. 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.

2.2 Reporting participant views

While every attempt has been made to classify each participant into the correct category, it is not always clear from the response exactly who is responding or in what capacity. Although the response form contained questions on this, the information is self-classified and often incomplete. For example, a respondent may have stated that they were responding on behalf of an organisation but given little information as to the organisation itself or how the views of members were collected. Nevertheless, with no clear evidence to the contrary, these responses were analysed as organisation responses. Eleven responses where the respondent had indicated that they represented a group or organisation, but then went on to say there was only one member in the group or organisation, were analysed as personal responses.

It must also be borne in mind that a consultation such as this does not comprise the responses of a representative sample of the general public and stakeholders, only of those who chose to respond to the *Safe and Sustainable* consultation. Detailed demographic

information, where this information has been recorded, is given in Appendix C of the consultation report.

3. The consultation questions

The *Safe and Sustainable* consultation document poses questions on three broad areas:

- the suggested new approach to providing children’s congenital heart services
- the proposed standards that have been developed to ensure quality across the services regardless of where patients live
- the proposed options for change.

3.1 Developing the consultation questions

The consultation questions contained in the response form were developed by Ipsos MORI, following briefing on the proposals from the *Safe and Sustainable* team and Grayling to ensure that they reflected all elements of the proposals. The resulting response form included a mix of closed and open questions⁶. The closed questions were designed to produce quantitative data on the proposals. The open questions were designed both to give respondents the opportunity to provide more in-depth explanation of their views and offer further comments as they wished on issues not covered in the closed questions.

Early drafts of the response form were tested through ten cognitive interviews with parents of children with CHD and healthcare professionals with an interest in CHD. These interviews were designed to test whether respondents understood the response form and the wording of the questions and were able to respond in the way that they wished. The results of the testing were fed back into the design process and changes were made to the response form as a result.

3.2 Text message question

As mentioned earlier, respondents were also able to respond via text messaging. They were asked to provide their views on the proposals by texting their response to the following 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?

⁶ The hard copy and online response forms contained identical questions.

4. Methodology for analysing responses

4.1 Analysing the consultation responses

As outlined, there were a number of methods of responding to the public consultation. As such, a number of different processes were employed to ensure that every response was considered fully and could be taken into account by the JCPCT.

As mentioned above, the response form contained both closed and open questions. The responses to the closed questions contained in the response form were captured and processed by Ipsos MORI. Hard copy forms were scanned and the data added to the electronic output from the online forms to produce one dataset containing all responses to the closed questions. This data set was analysed by Ipsos MORI.

Analysis of the open-ended questions in the response form required coding of the data, as did the responses by text message and the written comments submitted via letter and email. Coding is the process by which responses are matched against standard ‘codes’ from a coding frame Ipsos MORI compiled (with sign-off from the *Safe and Sustainable* team) so that their content can be classified and tabulated. These codes were developed from an initial selection of responses, and were added to and updated throughout the duration of the consultation period.

Each of these codes represents a discrete ‘theme’ raised in a number of responses; the complete coding frame should be comprehensive in representing the whole range of opinions and ‘themes’ given in the responses. It was continually developed throughout the duration of the consultation. As further responses were received, they were coded to ensure that any new themes that emerged were captured, and that no nuances were lost. Any one response received may have had a number of codes applied to it if it made more than one point, or addressed more than one theme. Every response was coded individually.

Throughout the main body of the report, reporting of the consultation responses received is based upon the codeframe developed as described above. It must be understood that because people often express the same idea in different ways, the codes must be wide enough in their scope to draw together those responses that are making the same point in different ways. It is also sometimes inevitably the case that responses are sometimes ambiguous and might be intended to put across any one of a number of related but distinct

points. Therefore, it is sometimes necessary when reporting the number of responses making a particular point to express it in somewhat vague terms. This is simply because the coding must ensure that broadly similar responses are not sub-divided too finely if it is to be useful in helping understand what those replying to the consultation have said.

A great deal of time and effort has been put into the responses by contributors to the consultation. For example, many individuals described their personal experiences, particularly in their written comments sent by letter or email. All of these responses have been read, analysed and coded by Ipsos MORI.

In addition, some of the responses from associations, organisations, groups and others that represent the views of a number of people were extremely detailed and wide ranging in nature. Some were much broader in scope than the questions asked in the response form, while others addressed 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 – the codeframe may not have adequately captured the content of these responses. Therefore, all organisation or group 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 to the consultation report.

Below we summarise how responses received via the various methods were recorded and analysed.

Online response form: these were transferred to an Excel file. All responses were logged and loaded into the Ascribe system (a secure web-based system) to be coded.

Hard copy response form: responses were logged and scanned electronically. 'Tick box' responses were captured and verbatim comments loaded into Ascribe to be coded.

Letters and emails sent to the Safe and Sustainable consultation addresses: responses from individuals were captured and loaded into Ascribe to be coded. Responses from organisations were logged and passed on to the JCPCT for their full consideration.

Text messages (SMS): these responses were loaded into Ascribe to be coded.

Hard copies of responses remained securely stored in Ipsos MORI's Harrow offices. Answers to the 'tick box' questions on the response forms were also recorded and matched to the coded data by serial numbers, enabling a more detailed breakdown of data at the final analysis stage.

All open ended responses were coded twice, to verify that the correct code or codes had been applied (and to make amendments as necessary). Once coding was complete, a further series of checks was carried out to ensure that no responses had either been omitted from the analysis or inadvertently double-counted.

The coding and data handling procedures, and the working of the Ascribe software, are set out in more detail in Appendix A.

4.2 Interpreting the consultation responses

It is important to bear in mind the limitations of this form of consultation in measuring the detailed views of the general public and stakeholders. A consultation in which the whole population is offered an opportunity to take part has some obvious advantages over opinion polls and similar exercises as a democratic tool allowing everybody a voice in the decision-making process. However, it is less effective at measuring how widely held particular opinions are, and while some people comment on issues not directly asked in the consultation, it cannot be assumed that others do not hold these opinions.

As noted above, the consultation does not comprise the responses of a representative sample of those in the target audience, only of those who chose to respond to the consultation. It over-represents some demographic groups who were disproportionately likely to respond, and may also over-represent particular points of view in the same way. For a strictly representative view, well-conducted representative sample surveys are more likely to be reliable. Moreover, many consultation responses consisted of a brief free-form response to the proposal document, and will naturally not have expressed in the fullest detail participants' views on every point in question.

It must be understood, therefore, that the consultation as reflected through the report should not be interpreted as if it were a survey or opinion poll. The use of closed questions does allow us to produce quantitative data on the number of people who responded in a set way in relation to a particular aspect of the proposals. However, not all respondents answered every question so the main report discusses the result as a percentage of responses to that question and of everyone who responded to the consultation.

The open questions in the response form and the written comments produce qualitative data, where findings emerge as a number of themes and ideas. Therefore, while some figures relating to these open responses are given in the report, these are to illustrate the relative importance of particular themes. The core focus is on the themes emerging, and no reliable statistical analysis can be undertaken with the data produced. These figures 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 small figures can reflect important themes. The vast majority of responses are spontaneous in nature and as a result, there are a wide range of themes emerging from the consultation. The spontaneous nature of the comments also means that the absolute numbers mentioning a particular theme can be small compared to the total number of responses to the consultation. There are also many blank responses to certain questions, where participants chose not to answer. Often they had a strong view on one aspect of the consultation, and made their views on this clear, but left other questions blank.

List of appendices

Appendices

The **appendices** to this document are:

Appendix A: Technical note on the coding process

Appendix B: Public consultation response form

Appendix C: Public consultation topline

Appendix D: Full codeframe

Appendix E: Numbers of text messages received

Appendix A: Technical note on the coding process

Development of initial coding frame

Coding is the process by which open ended responses are matched against standard ‘codes’ from a coding frame compiled by Ipsos MORI and approved by the team to allow systematic statistical and tabular analysis. The codes within the coding frame represent an amalgam of responses raised by those registering their view and are comprehensive in representing the range of opinions and ‘themes’ given.

The Ipsos MORI coding team drew up an initial code frame using a selection of the first responses. An initial set of codes was created by drawing out the common ‘themes’ and points raised. Each code thus represents a discrete view raised. The draft coding frame was then presented to the Ipsos MORI project team and *Safe and Sustainable* project team and fully approved before the coding process continued. The code frame was continually updated throughout the analysis process to ensure that newly emerging ‘themes’ were captured throughout the duration of the consultation.

Coding using the Ascribe package

Given the scale and complexity of the consultation, Ipsos MORI used the web-based Ascribe coding system to code all open ended responses found within completed questionnaires and other free form responses. Ascribe is a proven system which has been used on numerous large scale projects. The scanned and electronic verbatim responses were uploaded into the Ascribe system, where the coding team worked systematically through the verbatim comments and applied a code to each relevant part(s) of the verbatim comment.

The Ascribe software has the following key features:

- Accurate monitoring of coding progress across the whole process, from scanned image to the coding of responses;
- An ‘organic’ coding frame that can be continually updated and refreshed; not restricting coding and analysis to initial response issues or ‘themes’ which may change as the consultation progresses;
- Resource management features, allowing comparison across coders and question areas. This is of particular importance in maintaining high quality coding

across the whole coding team and allows early identification of areas where additional training may be required; and

- A full audit trail – from the verbatim response to codes applied to that response.

Coders were provided with an electronic file of responses to code within Ascribe. Their screen was split, with the left side showing the response along with the unique identifier, while the right side of the screen showed the full code frame. The coder attached the relevant code or codes to these as appropriate and, where necessary, alerted the supervisor if they believed an additional code might be required.

If there was other information that the coder wished to add they could do so in the 'notes' box on the screen. If a response was difficult to decipher the coder would get a second opinion from their supervisor or a member of the project management team. As a last resort, any comment that was illegible was coded as such and reviewed by the Coding Manager.

Briefing the coding team and quality checking

A dedicated core team of coders worked on the project, all of whom were fully briefed and were conversant with the Ascribe package. This team also worked closely with the project management team.

In addition to the core coding team, a number of senior coders also took a supervisory role throughout and undertook the quality checking of all coding. Using a reliable core team in this way minimises coding variability which retains data quality.

The Ascribe software was controlled on a secure Internet platform, making it totally secure and, at the same time, easy to administer for joint site working.

To ensure consistent and informed coding of the verbatim comments, all coders were fully briefed prior to working on this project. During the first week of starting work, coding was carefully monitored to ensure data consistency and to ensure that all coders were sufficiently competent to work on the project.

The coder briefings included background information and presentations covering the proposals, the consultation process and the issues involved and discussion of the initial coding frame. The briefings were carried out by one of Ipsos MORI's research team members.

The Ascribe package also afforded an effective project management tool, with the coding manager reviewing the work of each individual coder, having discussions with them where there was variance between the codes entered and those expected by the coding manager.

To check and ensure consistency of coding, all coded responses were validated by the coding supervisors, who checked that the correct codes had been applied and made changes where necessary.

Coding additional comments and damaged questionnaires

The scanning machines are programmed to capture responses written in the spaces dedicated to each question on the forms. In some instances, participants had written comments on the forms outside of the scanned areas. In these cases, the additional comments were transcribed manually into Excel and fed into Ascribe.

Similarly, some response forms were unable to pass through the scanners due to being damaged. Responses were transferred manually on to blank forms and fed through the scanners.

Updating the coding frame

An important feature of the Ascribe system is the ability to extend the code frame 'organically' direct from actual verbatim responses throughout the duration of the consultation coding period.

The coding teams raised any new codes during the coding process when it was felt that new themes were being registered. In order to ensure that no detail was lost, coders were briefed to raise codes that reflected the exact sentiment of a response, and these were then collapsed into a smaller number of key themes at the analysis stage. During the initial stages of the coding process, meetings were held between the coding team and Ipsos MORI research team to ensure that a consistent approach was taken to raising new codes and that all extra codes were appropriate and correctly assigned. In particular, the coding frame sought to capture precise nuances of participants' comments in such a way as to be comprehensive.

A second key benefit of the Ascribe system is that it provides the functionality of combining codes, revising old codes and amending existing ones, as appropriate. Thus, the coding frame grew organically throughout the coding process to ensure it captured all of the important 'themes'.

Checking the robustness of the datasets

As already stated, all open ended responses were coded twice. The first time was by the coder and the second time by a senior coder to verify that the correct code or codes had been applied to the open ended responses and to make amendments as necessary. This second verification occurred once the coding frame had been extensively developed, enabling the most appropriate codes to be applied and back-coding of 'other' codes into newer codes where appropriate, using codes which may have not existed at the time the response was originally coded.

Once coding was complete, and all data streams combined, a series of checks were undertaken to ensure that the data set was comprehensive and complete.

Appendix B: Public consultation response form

SAFE AND SUSTAINABLE

REVIEW OF CHILDREN'S CONGENITAL CARDIAC SERVICES IN ENGLAND RESPONSE FORM

HOW TO PROVIDE YOUR COMMENTS

The NHS is currently looking at the best way to provide surgery for children with congenital heart disease (CHD) and is keen to receive your feedback on the proposals. Full details of the Safe and Sustainable review of children's congenital cardiac services in England can be found at www.specialisedservices.nhs.uk/safeandsustainable

YOUR RESPONSE TO THE CONSULTATION

As part of this consultation, we are asking health care professionals, parents of young people with congenital heart disease (CHD), patients, members of the general public and any other interested parties to give us their views and complete this response form. You may add extra sheets if needed. Alternatively, you can provide your views online at www.ipsos-mori.com/safeandsustainable

Please bear in mind this is a consultation, not a 'vote'. We will take responses into account along with a wide range of other information such as the views of clinicians working in children's congenital cardiac services, Royal Colleges and professionals' groups and NHS managers working in this field. We are interested in the overall responses to the tick box questions, and your reasons for your views. If you don't have any comments, please leave the boxes blank.

We have asked Ipsos MORI to undertake the analysis of the response forms on our behalf. The findings will help the NHS in its final decision. As part of this consultation, we will also be hosting a number of consultation events across England and Wales, to get the views of a wider group.

Important: Please do not provide the names of any individuals in the feedback boxes.

Please reply by **1 July 2011** in the envelope supplied or send to the address below. You do not need a stamp.

Freepost RSLT-SRLZ-JYYY
Safe and Sustainable
Ipsos MORI
Research Services House
Elmgrove Road
Harrow
HA1 2QG

Thank you for your help.

The information you provide, including personal information, may be subject to publication or release to other parties or to disclosure under regimes such as the Freedom of Information Act 2000, the Data Protection Act 1998 and the Environmental Information Regulations 2004.

ALL TO ANSWER

Q1 Listed below are the **five Key Principles** which are outlined on pages 13 and 14 in the **Safe and Sustainable Consultation Document**. Please indicate the extent to which you agree or disagree with each of the five Key Principles. PLEASE TICK **ONE BOX** FOR EACH OF THE STATEMENTS BELOW

	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know
a) <u>Children</u> - The need of the child comes first in all considerations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) <u>Quality</u> - All children in England and Wales who need heart surgery must receive the very highest standards of NHS care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) <u>Equity</u> - The same high quality of service must be available to each child regardless of where they live or which hospital provides their care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) <u>Personal service</u> - The care that every congenital heart service plans and delivers must be based around the needs of each child and family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) <u>Close to families' homes where possible</u> - 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ALL TO ANSWER

Q2 What, if any, comments do you have on the five Key Principles? PLEASE **SUMMARISE** YOUR **KEY** COMMENTS IN THE BOX BELOW AND IF YOU ARE COMMENTING ON A SPECIFIC KEY PRINCIPLE OR KEY PRINCIPLES PLEASE INDICATE WHICH ONE(S) YOU ARE COMMENTING ON AND INSERT a, b, c, d AND/OR e NEXT TO YOUR ANSWER

ALL TO ANSWER

Q3 A set of proposed national quality standards have been developed as part of the Safe and Sustainable Review.

It is proposed that each of these national quality standards should be met by all NHS hospitals that are designated as Specialist Surgical Centres by the Safe and Sustainable Review. The Safe and Sustainable Review has set out these standards with reference to seven key themes. Please see pages 34 - 37 in the Safe and Sustainable Consultation Document.

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

PLEASE TICK ONE BOX ONLY FOR EACH OF THE STANDARDS LISTED BELOW

Key Themes...	Strongly support	Tend to support	No views either way	Tend to oppose	Strongly oppose	Don't know
a) Congenital Heart Networks (See pages 37 - 54)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Prenatal diagnosis (See pages 55 - 56)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Specialist Surgical Centre (See pages 57 - 62)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Age Appropriate Care (See pages 63 - 66).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Information and Making Choices (See pages 67 - 68)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) The Family Experience (See pages 69 - 72)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Ensuring Excellent Care (See page 73)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ALL TO ANSWER

Q4 What, if any, comments do you have on these national quality standards?

PLEASE **SUMMARISE** YOUR **KEY** COMMENTS IN THE BOX BELOW AND IF YOU ARE COMMENTING ON A SPECIFIC STANDARD OR STANDARDS PLEASE INDICATE THE NAMES OF THE STANDARD OR STANDARDS YOU ARE COMMENTING ON E.G. A15, C6, C67, ETC.

ALL TO ANSWER

Q5 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.

PLEASE TICK ONE BOX FOR EACH OF THE STATEMENTS BELOW

	Strongly support	Tend to support	No views either way	Tend to oppose	Strongly oppose	Don't know
a) The statement that ‘Without change the service will not be safe or sustainable in the future’ (See pages 18 - 32)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) The proposal to develop Congenital Heart Networks across England (See pages 37 - 54)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) The need for 24/7 care in each of the Specialist Surgical Centres (See pages 57 - 62)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) The statement that ‘research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes’ (See page 18)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) In the future interventional cardiology should be provided only by designated Specialist Surgical Centres (See page 62)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) The proposal that current surgical units that are not designated for surgery in the future may become Children’s Cardiology Centres (See pages 43 - 44)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) The proposal to increase the role of Paediatricians with Expertise in Cardiology in District Children’s Cardiology Services across England (See pages 41 - 42)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ALL TO ANSWER

Q6 What, if any, comments do you have on these elements/statements/proposals?
PLEASE **SUMMARISE** YOUR **KEY** COMMENTS IN THE BOX BELOW AND IF YOU ARE COMMENTING ON SPECIFIC ELEMENTS/STATEMENTS/PROPOSALS PLEASE INDICATE THE ELEMENTS/STATEMENTS/PROPOSALS YOU ARE COMMENTING ON E.G. a, b, c, d, e, f AND/OR g.

THE FOLLOWING SECTION ASKS ABOUT THE PROPOSALS FOR SPECIALIST SURGICAL CENTRES IN LONDON. IT IS PROPOSED THAT TWO LONDON HOSPITALS WILL BE CHOSEN AS SPECIALIST SURGICAL CENTRES.

ALL TO ANSWER

Q7 Before answering this question, please read pages 93 - 96 in the Safe and Sustainable Consultation Document. Do you support the proposal for two Specialist Surgical Centres in London?

PLEASE TICK **ONE BOX ONLY**

- Yes – support the proposal for two Specialist Surgical Centres in London
- No – do **NOT** support the proposal for two Specialist Surgical Centres in London
- Don't know

ALL TO ANSWER

Q8 What, if any, comments do you have on the number of Specialist Surgical Centres in London?
PLEASE **SUMMARISE YOUR KEY COMMENTS IN THE BOX BELOW**

ALL TO ANSWER

Q9 Before answering this question, please read pages 93 - 96 in the Safe and Sustainable Consultation Document.

It is proposed that the two Specialist Surgical Centres in London will be Great Ormond Street Hospital for Children NHS Trust (GOSH) and Evelina Children's Hospital – Guy's and St Thomas' NHS Foundation Trust.

If there were to be only two Specialist Surgical Centres in London, please indicate whether you support this choice (i.e. GOSH and Evelina Children's Hospital), or whether you think that the Royal Brompton & Harefield NHS Foundation Trust should replace one of these other two London hospitals?

PLEASE TICK **ONE BOX ONLY**

- Support the proposal for:
Great Ormond Street Hospital for Children NHS Trust (GOSH)
AND
Evelina Children's Hospital – Guy's and St Thomas' NHS Foundation Trust
- Prefer:
Royal Brompton & Harefield NHS Foundation Trust
AND
Great Ormond Street Hospital for Children NHS Trust (GOSH)
- Prefer:
Royal Brompton & Harefield NHS Foundation Trust
AND
Evelina Children's Hospital – Guy's and St Thomas' NHS Foundation Trust
- None of these
- Don't know

ALL TO ANSWER

Q10 What, if any, comments do you have on the proposals for Specialist Surgical Centres in London?

PLEASE **SUMMARISE** YOUR **KEY** COMMENTS IN THE BOX BELOW

The following section asks about the proposals for Specialist Surgical Centres outside London (i.e. the proposed location of Centres IN ADDITION to the Centres in London).

ALL TO ANSWER

Q11 Before answering this question, please read section 6 pages 97 - 118 in the Safe and Sustainable Consultation Document.

Thinking about the proposals put forward by the NHS for the Safe and Sustainable Review, please indicate the extent to which you support or oppose EACH of the FOUR alternative proposed options A, B, C and D for the location of the Specialist Surgical Centres outside London.

PLEASE TICK ONE BOX FOR EACH OPTION A, B, C AND D

	Strongly support	Tend to support	No views either way	Tend to oppose	Strongly oppose	Don't know
OPTION A						
• Alder Hey Children's NHS Foundation Trust (Liverpool)						
• Birmingham Children's Hospital NHS Foundation Trust						
• University Hospitals Bristol NHS Foundation Trust	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)						
• University Hospitals of Leicester NHS Trust (Glenfield)						
OPTION B						
• Alder Hey Children's NHS Foundation Trust (Liverpool)						
• Birmingham Children's Hospital NHS Foundation Trust						
• University Hospitals Bristol NHS Foundation Trust	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)						
• Southampton University Hospitals NHS Trust						
OPTION C						
• Alder Hey Children's NHS Foundation Trust (Liverpool)						
• Birmingham Children's Hospital NHS Foundation Trust	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• University Hospitals Bristol NHS Foundation Trust						
• The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)						
OPTION D						
• Alder Hey Children's NHS Foundation Trust (Liverpool)						
• Birmingham Children's Hospital NHS Foundation Trust	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• University Hospitals Bristol NHS Foundation Trust						
• Leeds Teaching Hospitals NHS Trust						
Please note that with Option D it is proposed that one of the London centres is Great Ormond Street Hospital for Children NHS Trust (GOSH) because only GOSH and Newcastle provide transplantation services, and that an option without either would not be safe						

ALL TO ANSWER

Q12

And, which ONE of the FOUR alternative proposed options, if any, is your preferred option for the location of the Specialist Surgical Centres outside London?

PLEASE TICK ONE BOX ONLY

OPTION A

Alder Hey Children's NHS Foundation Trust (Liverpool)
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)

OPTION B

Alder Hey Children's NHS Foundation Trust (Liverpool)
Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)
Southampton University Hospitals NHS Trust

OPTION C

Alder Hey Children's NHS Foundation Trust (Liverpool)
Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)

OPTION D

Alder Hey Children's NHS Foundation Trust (Liverpool)
Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
Leeds Teaching Hospitals NHS Trust

Please note that with Option D it is proposed that one of the London centres is Great Ormond Street Hospital for Children NHS Trust (GOSH) because only GOSH and Newcastle provide transplantation services, and that an option without either would not be safe

None of these

Don't know

ANSWER Q13 IF YOU SELECTED ONE OF THE OPTIONS A, B, C OR D AT Q12 – OTHERS GO TO Q14

Q13 Which ONE of the FOUR alternative proposed options would be your next most preferred option for the location of the Specialist Surgical Centres in the future?

PLEASE TICK ONE BOX ONLY. PLEASE DO NOT TICK THE SAME OPTION AS IN Q12

OPTION A

Alder Hey Children's NHS Foundation Trust (Liverpool)
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)

OPTION B

Alder Hey Children's NHS Foundation Trust (Liverpool)
Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)
Southampton University Hospitals NHS Trust

OPTION C

Alder Hey Children's NHS Foundation Trust (Liverpool)
Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)

OPTION D

Alder Hey Children's NHS Foundation Trust (Liverpool)
Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
Leeds Teaching Hospitals NHS Trust

Please note that with Option D it is proposed that one of the London centres is Great Ormond Street Hospital for Children NHS Trust (GOSH) because only GOSH and Newcastle provide transplantation services, and that an option without either would not be safe

None of these

Don't know

ALL TO ANSWER

Q14 What, if any, comments do you have on the proposals for Specialist Surgical Centres outside London? PLEASE **SUMMARISE** YOUR **KEY** COMMENTS IN THE BOX BELOW

PLEASE ANSWER Q15 IF YOU ANSWERED "NONE OF THESE" OR "DON'T KNOW" OR DID NOT ANSWER/LEFT ANSWER BLANK AT Q9 OR Q12

Q15

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

PLEASE TICK AS MANY BOXES AS APPLY

- Alder Hey Children's NHS Foundation Trust (Liverpool)
- 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
- Don't know

PLEASE ANSWER Q16 IF YOU ANSWERED "NONE OF THESE" OR "DON'T KNOW" OR DID NOT ANSWER/LEFT ANSWER BLANK AT Q9 OR Q12

Q16

Please give your reasons for your preferred configuration for the location of the Specialist Surgical Centres in the future (given at Q15).

PLEASE SUMMARISE YOUR KEY COMMENTS IN THE BOX BELOW

ALL TO ANSWER

Q17 Before answering this question, please read section 8 pages 125 - 128 in the Safe and Sustainable Consultation Document.

To what extent do you agree or disagree with the proposals that systems should be implemented to improve the collection, reporting and analysis of mortality and morbidity data?

PLEASE TICK ONE BOX ONLY

- Strongly agree
- Tend to agree
- Neither agree nor disagree
- Tend to disagree
- Strongly disagree
- Don't know

ALL TO ANSWER

Q18 Before answering this question, please read pages 107 - 113 in the Safe and Sustainable Consultation Document.

What, if any, comments do you have about the assumptions we have made concerning how postcodes have been assigned in any of the four options for the Specialist Surgical Centres?

PLEASE **SUMMARISE** YOUR **KEY** COMMENTS IN THE BOX BELOW

BACKGROUND INFORMATION

ALL TO ANSWER

Q19 Are you responding on your own behalf or on behalf of an organisation or group?

PLEASE TICK ONE BOX ONLY

- Providing my own response – CONTINUE TO Q20
- Providing a response on behalf of an organisation or group – GO TO SECTION “Details of your organisation/group” - Q31 ONWARDS

Q20 Which, if any, of the following applies to you?

PLEASE TICK AS MANY BOXES AS APPLY

- I have Congenital Heart Disease (CHD)
- I care for or have cared for a son or daughter with CHD
- I care for or have cared for another family member with CHD
- I care for or have cared for somebody outside of my family with CHD
- I know or knew someone who has, or has had CHD/have been involved with someone with CHD
- I care for or have cared for somebody outside the family with CHD in a professional capacity/as part of my job
- I do not have any experience of caring for someone with CHD
- None of these
- Don't know

Q21 Which, if any, of the following applies to you?

PLEASE TICK AS MANY BOXES AS APPLY

- Member of a voluntary organisation or 3rd Sector organisation or group
- NHS Trust employee
- Member of an Overview and Scrutiny Committee
- Member of Foundation Trust
- Other (PLEASE WRITE IN)

- None of these
- Don't know

Q22 Which, if any, of the following applies to you?

PLEASE TICK AS MANY BOXES AS APPLY

- I currently work in the NHS
- I used to work in the NHS
- I currently work in the independent health sector
- I used to work in the independent health sector
- I do not work in, or have not worked in the NHS or the independent health sector
- Don't know

Q23

Which, if any, of the following applies to you?

PLEASE TICK AS MANY BOXES AS APPLY

I am a...

- Member of the general public
- Obstetrician
- Midwife
- Sonographer
- Paediatrician with expertise in Cardiology
- Consultant Paediatric Cardiologist
- Consultant Congenital Cardiac Surgeon
- Children's Cardiac Specialist Nurse
- Consultant Intensivist
- Consultant Anaesthetist
- Clinical Psychologist
- Dietician
- A surgeon
- A nurse
- A GP
- Other health care professional
- Other profession (PLEASE WRITE IN)

- None of these
- Prefer not to say

ANSWER Q24 IF YOU HAVE, OR IF YOU CARE FOR OR HAVE CARED FOR A CHILD(REN) WHO HAS HAD CONGENITAL HEART DISEASE – DO NOT ANSWER THIS QUESTION IF YOU CARE FOR OR HAVE CARED FOR A CHILD(REN) WITH CHD IN A PROFESSIONAL CAPACITY (E.G. AS A GP, CONSULTANT, ETC.)

Q24

On how many separate occasions have you, or has a child(ren) you have been caring for had heart surgery or interventional cardiology procedures for their congenital heart disease that has been carried out in hospital?

PLEASE TICK ONE BOX ONLY

- None have had heart surgery or interventional cardiology procedures for their congenital heart disease
- One occasion
- Two to three occasions
- Four or five occasions
- Six or more occasions
- Don't know
- Prefer not to say

ANSWER Q25 IF YOU HAVE, OR IF YOU CARE FOR OR HAVE CARED FOR A CHILD(REN) WHO HAS HAD CONGENITAL HEART DISEASE – DO NOT ANSWER THIS QUESTION IF YOU CARE FOR OR HAVE CARED FOR A CHILD(REN) WITH CHD IN A PROFESSIONAL CAPACITY (E.G. AS A GP, CONSULTANT, ETC.)

Q25 Which hospital or hospitals have provided the primary co-ordination of your care, or the care for the child(ren) you have been caring for who have had heart surgery or interventional cardiology procedures?

PLEASE TICK AS MANY BOXES AS APPLY

- Alder Hey Children's NHS Foundation Trust (Liverpool)
- 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
- University Hospital of Wales
- Oxford Radcliffe Hospitals NHS Trust
- Other (PLEASE WRITE IN)

- Don't know
- Prefer not to say

PERSONAL INFORMATION

We would be grateful if you could answer the following questions so we can establish if we have responses from a cross-section of people, and allow us to analyse the results overall and by these different groups of people. Please remember that the response form and the information you provide may be subject to publication or release to other parties or to disclosure under regimes such as the Freedom of Information Act 2000, the Data Protection Act 1998 and the Environmental Information Regulations Act 2004.

Q26 How old are you?

PLEASE TICK ONE BOX ONLY

- Under 16
- 16-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75 and over
- Prefer not to say

Q27 Are you:

PLEASE TICK ONE BOX ONLY

- Male
- Female
- Prefer not to say

Q28 **What is your ethnic group?** PLEASE TICK ONE BOX ONLY TO BEST DESCRIBE YOUR ETHNIC GROUP OR BACKGROUND

White

- English / Welsh / Scottish / Northern Irish / British
- Irish
- Gypsy or Irish Traveller
- Any other White background, write in

Mixed / multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed / multiple ethnic background, write in

Asian / Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background, write in

Black / African / Caribbean / Black British

- African
- Caribbean
- Any other Black / African / Caribbean background, write in

Any other ethnic group

- Arab
- Any other ethnic group, write in

Prefer not to say

Q29 **Do you consider yourself to have a disability? By disability, we mean “physical or mental impairment which has a substantial and long term adverse effect on your ability to carry out normal day to day activities” (Disability Discrimination Act, 2005).**

PLEASE TICK ONE BOX ONLY

- Yes
- No
- Prefer not to say

Q30 **Please give the first part of your postcode e.g. B19, W4, SE15.**

PLEASE WRITE IN BELOW

DETAILS OF YOUR ORGANISATION OR GROUP

ONLY complete the following section if you are responding on behalf of an organisation or group – please be as detailed as you can. For example, if you are responding on behalf of a group or organisation, please record the name of the group or organisation. Please remember that the response form and the information you provide may be subject to publication or release to other parties or to disclosure under regimes such as the Freedom of Information Act 2000, the Data Protection Act 1998 and the Environmental Information Regulations 2004.

Q31 **What is your name, job position and name and address of organisation/group of the organisation or group on whose behalf you are submitting this response?**

The name and details of your organisation or group may appear in the final report

PLEASE WRITE IN BELOW IN BLOCK CAPITALS

Name:

Job Position:

Name of organisation / group:

Address of organisation / group:

Q32

What category of organisation or group are you representing?

PLEASE TICK ALL BOXES THAT APPLY

- | | |
|---|--|
| <input type="checkbox"/> A professional body (e.g. a Royal College) | <input type="checkbox"/> Trade body |
| <input type="checkbox"/> A hospital | <input type="checkbox"/> Academic organisation |
| <input type="checkbox"/> Charity / voluntary sector group | <input type="checkbox"/> A commissioner |
| <input type="checkbox"/> National patient group | <input type="checkbox"/> Political party/Political group |
| <input type="checkbox"/> Local patient group | <input type="checkbox"/> GP Consortium |
| <input type="checkbox"/> National parent group | <input type="checkbox"/> Strategic Health Authority |
| <input type="checkbox"/> Local parent group | <input type="checkbox"/> Other (PLEASE WRITE IN) |
| <input type="checkbox"/> Local Authority | |
| <input type="checkbox"/> Trade Union | |

Q33

Please write in the total number of members in your organisation or group.

PLEASE WRITE IN BELOW

Q34

Please tell us who the organisation or group represents and, where applicable, how you assembled the views of members:

PLEASE WRITE IN BELOW IN BLOCK CAPITALS

ALL TO READ

Thank you for your comments.

Please reply by 1 July 2011 in the envelope supplied or send to the following address. You do not need a stamp.

Freepost RSLT-SRLZ-JYYY
Safe and Sustainable
Ipsos MORI
Research Services House
Elmgrove Road
Harrow
HA1 2QG

An electronic version and hard copies of the consultation document and Response Form are available in English and Welsh. Braille, and copies in other languages can also be provided on request. Please contact the communications team.

Telephone: 020 7025 7520

Email: nhsspecialisedservices@grayling.com

If you have any queries or complaints regarding the consultation process or consultation documentation content, please contact Jeremy Glyde, Programme Director for Safe and Sustainable in the following ways:

- Write to Safe and Sustainable, NHS Specialised Services, 2nd floor, Southside, 105 Victoria Street, London, SW1E 6QT
- Call the review team on 020 7932 3958
- Email ChildHeart@nsscgs.nhs.uk

Please note that any queries or complaints submitted via this process cannot be counted as part of the formal consultation.

Appendix C: Public consultation topline

Safe and Sustainable Review of Children's Congenital Cardiac Services in England Topline Results

- *The consultation ran from 1 March 2011 to 1 July 2011.*
- *Results are based on all respondents using the response form, either online or hard copy, unless otherwise specified.*
- *The total base size is 50,332 personal respondents and 1,121 organisation respondents.*
- *Please see full codeframe for coded results for open questions.*
- *An asterisk (*) indicates a figure smaller than 0.5% but greater than 0.*
- *Where percentages do not sum to 100, this is due to computer rounding or multiple responses.*

ALL TO ANSWER

- Q1. Listed below are the five Key Principles which are outlined on pages 13 and 14 in the Safe and Sustainable Consultation Document.
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 %	Not stated %
a) <u>Children</u> - The need of the child comes first in all considerations							
Personal response	47	10	7	*	*	*	36
Organisation	40	5	2	0	*	*	53
b) <u>Quality</u> - All children in England and Wales who need heart surgery must receive the very highest standards of NHS care							
Personal response	60	3	1	*	*	*	36
Organisation	45	2	*	0	*	*	53
c) <u>Equity</u> - The same high quality of service must be available to each child regardless of where they live or which hospital provides their care							
Personal response	57	5	1	*	*	*	36
Organisation	43	3	*	*	*	*	53
d) <u>Personal service</u> - The care that every congenital heart service plans and delivers must be based around the needs of each child and family							
Personal response	56	6	1	*	*	*	37
Organisation	42	4	1	*	*	*	53
e) <u>Close to families' homes where possible</u> - 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							
Personal response	35	9	3	9	7	1	37

Organisation	33	7	2	2	2	*	54
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Q2. **What, if any, comments do you have on the five key Principles?**

ALL TO ANSWER

Q3. **A set of proposed national quality standards have been developed as part of the Safe and Sustainable Review.**

It is proposed that each of these national quality standards should be met by all NHS hospitals that are designated as Specialist Surgical Centres by the Safe and Sustainable Review. The Safe and Sustainable Review has set out these standards with reference to seven key themes. Please see pages 34 - 37 in the Safe and Sustainable Consultation Document.

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

PLEASE TICK ONE BOX ONLY FOR EACH OF THE STANDARDS LISTED BELOW

Key Themes...		Strongly support %	Tend to support %	No views either way %	Tend to oppose %	Strongly oppose %	Don't know %	Not stated %
a) Congenital Heart Networks	Personal response	39	11	2	*	*	2	45
	Organisation	27	5	1	*	*	1	66
b) Prenatal diagnosis	Personal response	39	12	2	*	*	2	45
	Organisation	26	6	1	*	0	1	66
c) Specialist Surgical Centre	Personal response	33	16	3	*	1	2	45
	Organisation	25	6	2	*	0	1	66
d) Age Appropriate Care	Personal response	39	11	2	*	*	2	45
	Organisation	26	6	1	*	*	1	66
e) Information and Making Choices	Personal response	38	11	3	*	*	2	45
	Organisation	25	6	2	0	0	1	66
f) The Family Experience	Personal response	39	11	2	*	*	2	45
	Organisation	26	6	1	0	0	1	66
g) Ensuring Excellent Care	Personal response	44	7	1	*	*	2	45
	Organisation	30	3	1	*	0	1	66

ALL TO ANSWER

Q4. **What, if any, comments do you have on these national quality standards?**

ALL TO ANSWER

Q5. 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.

PLEASE TICK ONE BOX FOR EACH OF THE STATEMENTS BELOW

	Strongly support %	Tend to support %	No views either way %	Tend to oppose %	Strongly oppose %	Don't know %	Not stated %
a) The statement that 'Without change the service will not be safe or sustainable in the future'							
Personal response	17	9	9	14	4	3	44
Organisation	14	8	4	5	2	2	65
b) The proposal to develop Congenital Heart Networks across England							
Personal response	24	19	7	1	1	4	45
Organisation	20	9	2	1	1	1	66
c) The need for 24/7 care in each of the Specialist Surgical Centres							
Personal response	46	6	1	*	*	2	45
Organisation	28	4	1	*	*	1	66
d) The statement that 'research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes'							
Personal response	14	14	6	6	12	3	44
Organisation	15	9	3	2	4	2	66
e) In the future interventional cardiology should be provided only by designated Specialist Surgical Centres							
Personal response	22	9	14	3	3	4	45
Organisation	18	7	5	1	1	2	66
f) The proposal that current surgical units that are not designated for surgery in the future may become Children's Cardiology Centres							
Personal response	18	9	18	3	3	4	45
Organisation	14	7	7	2	1	2	67
g) The proposal to increase the role of Paediatricians with Expertise in Cardiology in District Children's Cardiology Services across England							
Personal response	17	11	9	6	8	4	46
Organisation	17	7	4	1	3	2	67

ALL TO ANSWER

Q6. What, if any, comments do you have on these elements/statements/proposals?

THE FOLLOWING SECTION ASKS ABOUT THE PROPOSALS FOR SPECIALIST CENTRES IN LONDON. IT IS PROPOSED THAT TWO LONDON HOSPITALS WILL BE CHOSEN AS SPECIALIST SURGICAL CENTRES.

ALL TO ANSWER

Q7. **Before answering this question, please read pages 93 - 96 in the Safe and Sustainable Consultation Document. Do you support the proposal for two Specialist Surgical Centres in London? PLEASE TICK ONE BOX ONLY**

	Personal response %	Organisation %
Yes – support the proposal for two Specialist Surgical Centres in London	72	54
No – do <u>NOT</u> support the proposal for two Specialist Surgical Centres in London	12	13
Don't know	12	7
Not stated	4	27

ALL TO ANSWER

Q8. **What, if any, comments do you have on the number of Specialist Surgical Centres in London?**

ALL TO ANSWER

Q9. **Before answering this question, please read pages 93 - 96 in the Safe and Sustainable Consultation Document. It is proposed that the two Specialist Surgical Centres in London will be Great Ormond Street Hospital for Children NHS Trust (GOSH) and Evelina Children's Hospital – Guy's and St Thomas' NHS Foundation Trust.**

If there were to be only two Specialist Surgical Centres in London, please indicate whether you support this choice (i.e. GOSH and Evelina Children's Hospital), or whether you think that the Royal Brompton & Harefield NHS Foundation Trust should replace one of these other two London hospitals? PLEASE TICK ONE BOX ONLY

	Personal response %	Organisation %
Support the proposal for: Great Ormond Street Hospital for Children NHS Trust (GOSH) AND Evelina Children's Hospital – Guy's and St Thomas' NHS Foundation Trust	39	17
Prefer: Royal Brompton & Harefield NHS Foundation Trust AND Great Ormond Street Hospital for Children NHS Trust (GOSH)	5	3
Prefer: Royal Brompton & Harefield NHS Foundation Trust AND Evelina Children's Hospital – Guy's and St Thomas' NHS Foundation Trust	10	2
None of these	7	9
Don't know	25	19
Not stated	14	51

ALL TO ANSWER

Q10. **What, if any, comments do you have on the proposals for Specialist Surgical Centres in London?**

THE FOLLOWING SECTION ASKS ABOUT THE PROPOSALS FOR SPECIALIST SURGICAL CENTRES OUTSIDE LONDON (i.e. THE PROPOSED LOCATION OF CENTRES IN ADDITION TO THE CENTRES IN LONDON).

ALL TO ANSWER

Q11. **Before answering this question, please read section 6 pages 97-118 in the Safe and Sustainable Consultation Document.**

Thinking about the proposals put forward by the NHS for the Safe and Sustainable Review, please indicate the extent to which you support or oppose EACH of the FOUR alternative proposed options A, B, C and D for the location of the Specialist Surgical Centres outside London. PLEASE TICK ONE BOX FOR EACH OPTION A, B, C AND D

	Strongly support %	Tend to support %	No views either way %	Tend to oppose %	Strongly oppose %	Don't know %	Not stated %
OPTION A							
▪ Alder Hey Children's NHS Foundation Trust (Liverpool)							
▪ 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)							
Personal response	56	2	2	2	29	2	8
Organisation	20	2	2	2	47	3	25
OPTION B							
▪ Alder Hey Children's NHS Foundation Trust (Liverpool)							
▪ Birmingham Children's Hospital NHS Foundation Trust							
▪ University Hospitals Bristol NHS Foundation Trust							
▪ The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)							
▪ Southampton University Hospitals NHS Trust							
Personal response	32	2	2	1	53	2	7
Organisation	60	3	3	1	15	1	18
OPTION C							
▪ Alder Hey Children's NHS Foundation Trust (Liverpool)							
▪ Birmingham Children's Hospital NHS Foundation Trust							

<ul style="list-style-type: none"> ▪ University Hospitals Bristol NHS Foundation Trust ▪ The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman) 							
Organisation	3	2	4	2	75	3	12
Personal response	2	3	3	2	59	3	28
OPTION D							
<ul style="list-style-type: none"> ▪ Alder Hey Children's NHS Foundation Trust (Liverpool) ▪ Birmingham Children's Hospital NHS Foundation Trust ▪ University Hospitals Bristol NHS Foundation Trust ▪ Leeds Teaching Hospitals NHS Trust 							
Personal response	9	1	3	2	70	3	12
Organisation	6	1	2	3	55	3	29

ALL TO ANSWER

Q12. **And, which ONE of the FOUR alternative proposed options, if any, is your preferred option for the location of the Specialist Surgical Centres outside London?**
PLEASE TICK ONE BOX ONLY

	Personal response %	Organisation %
OPTION A	54	18
OPTION B	30	41
OPTION C	1	1
OPTION D	8	4
None of these	3	4
Don't know	2	3
Not stated	3	29

ANSWER Q13 IF YOU SELECTED ONE OF THE OPTIONS A, B, C OR D AT Q12 – OTHERS GO TO Q14

Q13. **Which ONE of the FOUR alternative proposed options would be your next most preferred option for the location of the Specialist Surgical Centres in the future?** PLEASE TICK ONE BOX ONLY.
PLEASE DO NOT TICK THE SAME OPTION AS IN Q12

Base: All who selected one of the options A,B,C or D at Q12 (46,391 personal respondents and 728 organisation respondents)

	Personal response %	Organisation %
OPTION A	5	7
OPTION B	6	9
OPTION C	3	5
OPTION D	3	2
None of these	76	59
Don't know	4	4
Not stated	4	14

ALL TO ANSWER

Q14. **What, if any, comments do you have on the proposals for Specialist Surgical Centres outside London?**

PLEASE ANSWER Q15 IF YOU ANSWERED “NONE OF THESE” OR “DON’T KNOW” OR DID NOT ANSWER/LEFT ANSWER BLANK AT Q9 OR Q12

Q15. **Given a choice, which of the following centres would form your preferred configuration for the location of the Specialist Surgical Centres in the future?**

PLEASE TICK AS MANY BOXES AS APPLY

Base: All who answered ‘none of these’ or don’t know’ or did not answer/left answer blank at Q9 or Q12 (24,817 personal respondents and 913 organisation respondents)

	Personal response %	Organisation %
Alder Hey Children’s NHS Foundation Trust (Liverpool)	44	21
Birmingham Children’s Hospital NHS Foundation Trust	43	21
Great Ormond Street Hospital for Children NHS Trust (GOSH)	41	22
Evelina Children’s Hospital – Guy’s and St Thomas’ NHS Foundation Trust	35	18
Southampton University Hospitals NHS Trust	30	16
University Hospitals of Leicester NHS Trust (Glenfield)	28	13
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)	27	12
University Hospitals Bristol NHS Foundation Trust	27	7
Leeds Teaching Hospitals NHS Trust	18	5
Royal Brompton & Harefield NHS Foundation Trust	10	10
Oxford Radcliffe Hospitals NHS Trust	4	2
Don’t know	2	1
Not stated	22	58

PLEASE ANSWER Q16 IF YOU ANSWERED “NONE OF THESE” OR “DON’T KNOW” OR DID NOT ANSWER/LEFT ANSWER BLANK AT Q9 OR Q12

Q16. **Please give your reasons for your preferred configuration for the location of the Specialist Surgical Centres in the future (given at Q15).**

ALL TO ANSWER

Q17. **Before answering this question, please read section 8 pages 125-128 in the Safe and Sustainable Consultation Document.**

To what extent do you agree or disagree with the proposals that systems should be implemented to improve the collection, reporting and analysis of mortality and morbidity data?

PLEASE TICK ONE BOX ONLY

	Personal response %	Organisation %
Strongly agree	53	28
Tend to agree	18	7
Neither agree or disagree	7	2
Tend to disagree	1	1
Strongly disagree	1	1
Don’t know	5	3
Not stated	17	60

ALL TO ANSWER

- Q18. **What, if any, comments do you have about the assumptions we have made concerning how postcodes have been assigned in any of the four options for the Specialist Surgical Centres?**
PLEASE SUMMARISE YOUR KEY COMMENTS IN THE BOX BELOW

BACKGROUND INFORMATION

ALL TO ANSWER

- Q19. **Are you responding on your own behalf or on behalf of an organisation or group?**
PLEASE TICK ONE BOX ONLY

	%	
Providing my own response	97	CONTINUE TO Q20
Providing a response on behalf of an organisation or group	2	GO TO SECTION - "Details of your organisation/group"- Q31 ONWARDS
Not stated	0	

- Q20. **Which, if any, of the following applies to you?**
PLEASE TICK AS MANY BOXES AS APPLY

	Personal response %
I have Congenital Heart Disease (CHD)	3
I care for or have cared for a son or daughter with CHD	10
I care for or have cared for another family member with CHD	8
I care for or have cared for somebody outside of my family with CHD	4
I know or knew someone who has, or has had CHD/have been involved with someone with CHD	26
I care for or have cared for somebody outside the family with CHD in a <u>professional capacity/as part of my job</u>	10
I do not have any experience of caring for someone with CHD	23
None of these	17
Don't know	1
Not stated	6

- Q21. **Which, if any, of the following applies to you?** PLEASE TICK AS MANY BOXES AS APPLY

	Personal response %
NHS Trust employee	17
Member of Foundation Trust	3
Member of a voluntary organisation or 3rd Sector organisation or group	2
Member of an Overview and Scrutiny Committee	*
Other	6
None of these	61
Don't know	3
Not stated	10

Q22. **Which, if any, of the following applies to you?**
PLEASE TICK AS MANY BOXES AS APPLY

	Personal response %
I currently work in the NHS	19
I used to work in the NHS	4
I currently work in the independent health sector	1
I used to work in the independent health sector	1
I do not work in, or have not worked in the NHS or the independent health sector	59
Don't know	7
Not stated	9

Q23. **Which, if any, of the following applies to you?**
PLEASE TICK AS MANY BOXES AS APPLY

	Personal response %
I am a...	
Member of the general public	63
A nurse	6
Midwife	1
A GP	1
A surgeon	*
Consultant Anaesthetists	*
Children's Cardiac Specialist Nurse	*
Consultant Intensivist	*
Obstetrician	*
Clinical Psychologist	*
Sonographer	*
Paediatrician with expertise in Cardiology	*
Dietician	*
Consultant Paediatric Cardiologist	*
Consultant Congenital Cardiac Surgeon	*
Other health care professional	7
Other profession	16
None of these	9
Prefer not to say	2
Not stated	4

ANSWER Q24 IF YOU HAVE, OR IF YOU CARE FOR OR HAVE CARED FOR A CHILD(REN) WHO HAS HAD CONGENITAL HEART DISEASE – DO NOT ANSWER THIS QUESTION IF YOU CARE FOR OR HAVE CARED FOR A CHILD(REN) WITH CHD IN A PROFESSIONAL CAPACITY (E.G. AS A GP, CONSULTANT, ETC.)

Q24. **On how many separate occasions have you, or has a child(ren) you have been caring for had heart surgery or interventional cardiology procedures for their congenital heart disease that has been carried out in hospital? PLEASE TICK ONE BOX ONLY**

Base: All who have, or care or have cared for a child(ren) who has had congenital heart disease (not in a professional capacity) (20,767)

	Personal response %
None have had heart surgery or interventional cardiology procedures for their congenital heart disease	29
One occasion	18
Two to three occasions	18
Four or five occasions	8
Six or more occasions	12
Don't know	6
Prefer not to say	9

ANSWER Q25 IF YOU HAVE, OR IF YOU CARE FOR OR HAVE CARED FOR A CHILD(REN) WHO HAS HAD CONGENITAL HEART DISEASE – DO NOT ANSWER THIS QUESTION IF YOU CARE FOR OR HAVE CARED FOR A CHILD(REN) WITH CHD IN A PROFESSIONAL CAPACITY (E.G. AS A GP, CONSULTANT, ETC.)

Q25. **Which hospital or hospitals have provided the primary co-ordination of your care, or the care for the child(ren) you have been caring for who have had heart surgery or interventional cardiology procedures? PLEASE TICK AS MANY BOXES AS APPLY**

Base: All who have, or care or have cared for a child(ren) who has had congenital heart disease (not in a professional capacity) (26,854)

	Personal response %
University Hospitals of Leicester NHS Trust (Glenfield)	24
Southampton University Hospitals NHS Trust	19
Leeds Teaching Hospitals NHS Trust	8
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)	4
Great Ormond Street Hospital for Children NHS Trust (GOSH)	4
Royal Brompton & Harefield NHS Foundation Trust	4
Evelina Children's Hospital – Guy's and St Thomas' NHS Foundation Trust	3
Birmingham Children's Hospital NHS Foundation Trust	3
Alder Hey Children's NHS Foundation Trust (Liverpool)	2
University Hospitals Bristol NHS Foundation Trust	2
Oxford Radcliffe Hospitals NHS Trust	1
University Hospital of Wales	*
Other	1
Don't know	3
Prefer not to say	5
Question does not apply to me	25
Not stated	7

PERSONAL INFORMATION

We would be grateful if you could answer the following questions so we can establish if we have responses from a cross-section of people, and allow us to analyse the results overall and by these different groups of people. Please remember that the response form and the information you provide may be subject to publication or release to other parties or to disclosure under regimes such as the Freedom of Information Act 2000, the Data Protection Act 1998 and the Environmental Information Regulations Act 2004.

Q26 How old are you?

	%
Under 16	2
16-24	8
25-34	18
35-44	24
45-54	19
55-64	13
65-74	8
75 or over	3
Prefer not to say	2
Not stated	2

Q27 Are you:

	%
Male	38
Female	57
Prefer not to say	2
Not stated	3

Q28 What is your ethnic group?

	%
White	
English/Welsh/Scottish/Northern Irish/British	71
Irish	1
Gypsy or Irish Traveller	*
Any other White background	2
Mixed/multiple ethnic groups	
White and Black Caribbean	*
White and Black African	*
White and Asian	1
Any other mixed/multiple ethnic background	*
Asian/Asian British	
Indian	14
Pakistani	1
Bangladeshi	*
Chinese	*
Any other Asian background	1
Black/African/Caribbean/Black British	
African	1
Caribbean	*
Any other Black/African/Caribbean background	*
Any other ethnic group	
Arab	*
Any other ethnic group	*
Prefer not to say	3

Not stated		3
Q29 Do you consider yourself to have a disability? By disability, we mean “physical or mental impairment which has a substantial and long term adverse effect on your ability to carry out normal day to day activities” (Disability Discrimination Act, 2005).		
		Personal response
		%
Yes		2
No		26
Prefer not to say		1
Not stated		72

DETAILS OF YOUR ORGANISATION OR GROUP

ONLY complete the following section if you are responding on behalf of an organisation or group – please be as detailed as you can. For example, if you are responding on behalf of a group or organisation, please record the name of the group or organisation. Please remember that the response form and the information you provide may be subject to publication or release to other parties or to disclosure under regimes such as the Freedom of Information Act 2000, the Data Protection Act 1998 and the Environmental Information Regulations Act 2004.

Q32 What category of organisation or group are you representing?

	Organisatio n %
A hospital	17
Charity/voluntary sector group	6
Local patient group	2
Local Authority	2
A professional body (e.g. a Royal College)	2
Local parent group	1
National patient group	1
Academic organisation	1
A commissioner	1
Strategic Health Authority	1
National parent group	1
GP Consortium	*
Political party/Political group	*
Trade body	*
Trade Union	0
Other	6
Prefer not to say	1
Not stated	66

Appendix D: Full codeframe

The following tables list the codes used by the Ipsos MORI coding team to code the responses to the public consultation.

Text message Q What do you think about the proposed changes to children's heart services in England, as outlined in the Safe and Sustainable consultation document?	
	Total
Preferred option	17800
Option A	10422
Positive	10233
Option A offers the least disruption/no relocation of services required	5
Support Option A/Option A is the best one	10224
Support A - recommended by the consultation	2
Support A - other	2
Negative	189
Option A is the worst one/oppose A	189
Option B	13714
Positive	13487
Option B offers the least disruption/no relocation of services required	1
Support Option B/Option B is the best one	13486
Support Option B - other	1
Negative	227
Option B is the worst one/oppose B	227
Option C	2468
Positive	2262
Support Option C/Option C is the best one	2262
Negative	206
Option C is the worst one/oppose C	206
Option D	2961
Positive	648
Option D offers the least disruption	6
Support Option D/Option D is the best one	642
Negative	2313
Option D is the worst one/oppose D	2219
Option D not viable as they would have to move transplant and ECMO from the specialised team	173
Subnet: University Hospitals of Leicester NHS Trust (Glenfield)	533
Positive	532
Location/population	23
Glenfield is centrally located/covers a wide region/geographically well placed (includes East Midlands and East Anglia)	12
Glenfield is in a densely populated area/large city/surrounding areas heavily populated	2
Glenfield has easy access/close to motorway/good transport links/good parking	4
Glenfield is accessible by helicopter/has a helipad	1
Glenfield is my nearest centre/closest to my home	7
Facilities	21
Glenfield is able to provide cradle to old age care	4
Glenfield provides ECMO/transplant/specialist facilities	13
Glenfield is a training/teaching hospital	1

Glenfield provides accommodation/facilities for families	1
Glenfield has well developed networks/links (Foetal medicine network, neo-natal network, cardiac network etc)	1
Glenfield treats large numbers of patients	4
Standard of care	70
Glenfield has a good reputation locally/nationally/internationally	5
Glenfield provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	68
Other	3
Glenfield - other positive	2
Glenfield - other neutral	1
Options/possible closure	517
Closing Glenfield would leave numbers of patients/children at risk	9
Glenfield - retaining Glenfield offers least disruption to families	8
Glenfield is in only one of the options/do not agree with this	1
Glenfield: have personal experience of the services (I/family/friend was/is being treated there)	38
Service at Glenfield closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	4
Service at Glenfield closing would impact on expertise/training/research	3
Service at Glenfield should remain open/Glenfield should be included as one of the options/I support Glenfield	502
Service at Glenfield closing would increase travel times for families in the area	10
Negative	1
Glenfield - other negative	1
Subnet: Leeds Teaching Hospitals NHS Trust	699
Positive	695
Location/population	76
Leeds is centrally located/covers a wide region/geographically well placed (including Yorkshire is the biggest county)	25
Leeds is in a densely populated area/large city/surrounding areas heavily populated	49
Leeds has easy access/close to motorway/good transport links/good parking	19
Leeds is my nearest centre/closest to my home	5
Facilities	62
Leeds can already/has the capacity to provide a full range of services in one location	48
Leeds is able to provide cradle to old age care	31
Leeds has well developed networks/links (Foetal medicine network, neo-natal network, cardiac network etc)	22
Leeds treats large numbers of patients	5
Leeds provides accommodation/facilities for families	20
Standard of care	103
Leeds provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	103
Options/possible closure	674
Leeds: closing Leeds would leave numbers of patients/children at risk	11
Leeds: have personal experience of the services (I/family/friend was/is being treated there)	32
Leeds is in only one of the options/do not agree with this	9
Service at Leeds should remain open/Leeds should be included as one of the options/I support Leeds	649
Service at Leeds closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	5
Service at Leeds closing would increase travel times for families in the area	23
Leeds - retaining Leeds offers least disruption to families	5
Leeds - other positive	2
Leeds - other negative	6

Leeds - Other neutral	2
Negative	4
Leeds scored poorly in the review/lower than other services	2
Leeds should not be one of the options/support the closure of services at Leeds	1
Leeds has poor access/limited transport links/poor parking/confusing road infrastructure	1
Subnet: Birmingham Children's Hospital NHS Foundation Trust	3
Positive	2
Service at Birmingham should remain open/should be included as one of the options/I support Birmingham	2
Negative	1
Birmingham is not well placed/too far away from larger centres/poor location	1
Subnet: The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman)	2047
Positive	2044
Location/population	216
Newcastle is in a densely populated area/large city/surrounding areas heavily populated	3
Newcastle has easy access/close to motorway/good transport links/good parking	2
Newcastle is my nearest centre/closest to my home	17
Newcastle is centrally located/covers a wide region/geographically well placed (including Scotland, Northern Ireland and Isle of Man)	197
Facilities	27
Newcastle can already/has the capacity to provide a full range of services in one location	4
Newcastle provides ECMO/transplant/specialist facilities	8
Newcastle is able to provide cradle to old age care	4
Newcastle treats large numbers of patients	13
Standard of care	577
Newcastle has a good reputation locally/nationally/internationally	74
Newcastle provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	547
Options/possible closure	2009
Newcastle: have personal experience of the services (I/family/friend was/is being treated there)	221
Newcastle: closing Newcastle would leave numbers of patients/children at risk	80
Service at Newcastle closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	3
Service at Newcastle should remain open/should be included as one of the options/I support Newcastle	1935
Service at Newcastle closing would impact on expertise/training/research	12
Service at Newcastle closing would increase travel times for families in the area	123
Newcastle - other positive	7
Newcastle - other negative	3
Newcastle - other neutral	7
Negative	3
Newcastle is not well placed/too far away from larger centres/poor location	2
Newcastle should not be one of the options/support the closure of services Newcastle	1
Subnet: Southampton University Hospitals NHS Trust	459
Positive	459
Location/population	37
Southampton is in a densely populated area/large city/surrounding areas heavily populated	1
Southampton is centrally located/covers a wide region/geographically well placed (including Isle of Wight and Channel Islands)	32
Southampton has easy access/close to motorway/good transport links/good parking	4
Southampton is my nearest centre/closest to my home	5
Facilities	4

Southampton is a training/teaching hospital	1
Southampton treats large numbers of patients	3
Standard of care	124
Southampton has a good reputation locally/nationally/internationally	7
Southampton provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	113
Southampton works in partnership with Oxford/has a network model with Oxford	8
Options/possible closure	433
Closing Southampton would leave numbers of patients/children at risk	18
Southampton is ranked 2nd in the country/in the performance review/has excellent results	92
Service at Southampton closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	1
Southampton is in only one of the options/do not agree with this	12
Service at Southampton should remain open/should be included as one of the options/I support Southampton	369
Service at Southampton closing would increase travel times for families in the area	38
Southampton: have personal experience of the services (I/family/friend was/is being treated there)	69
Southampton - other positive	2
Southampton - other negative	2
Southampton - other neutral	1
Subnet: University Hospitals Bristol NHS Foundation Trust	8
Positive	5
Bristol has easy access/close to motorway/good transport links/good parking	1
Bristol provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	2
Bristol : have personal experience of the services (I/family/friend was/is being treated there)	3
Service at Bristol should remain open/should be included as one of the options/I support Bristol	4
Service at Bristol closing would increase travel times for families in the area	1
Negative	4
Bristol should not be one of the options/support the closure of services at Bristol	1
Bristol is not well placed/too far away from larger centres/poor location	3
Subnet: Alder Hey Children's NHS Foundation Trust (Liverpool)	13
Positive	13
Liverpool provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	8
Liverpool is centrally located/covers a wide region/geographically well placed (including Isle of Man and Wales)	3
Liverpool : have personal experience of the services (I/family/friend was/is being treated there)	2
Service at Liverpool should remain open/should be included as one of the options/I support Liverpool	13
Negative	1
Liverpool - other neutral	1
Subnet: Oxford Radcliffe Hospitals NHS Trust	5
Positive	5
Service at Oxford should remain open/should be included as one of the options/should resume surgery/I support Oxford	4
Oxford - other positive	2
Oxford - other neutral	1
Subnet - Royal Brompton & Harefield	17
Royal Brompton provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	8
Royal Brompton: have personal experience of the services (I/family/friend was/is being treated there)	5

Service at Royal Brompton should remain open/should be included as one of the options/I support Royal Brompton	15
Royal Brompton has a good reputation locally/nationally/internationally	1
Closing Royal Brompton would leave numbers of patients/children at risk/adult care/other services may have to close	5
Subnet - Evelina Children's Hospital - Guy's and St Thomas NHS Foundation Trust	1
Service at Evelina should remain open/should be included as one of the options/I support Evelina	1
Subnet - Great Ormond Street Hospital for Children NHS Trust (GOSH)	8
GOSH provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	1
GOSH : have personal experience of the services (I/family/friend was/is being treated there)	2
Service at GOSH should remain open/should be included as one of the options/I support GOSH	5
GOSH - other positive	1
GOSH - other negative	1
SUBNET: Unspecified hospitals	416
Location/population	29
Unspec hospital has easy access/close to motorway/good transport links/good parking	2
Unspec hospital is centrally located/covers a wide region/geographically well placed	21
Unspec hospital is my nearest centre/closest to my home (least disruptive)	7
Facilities	1
Unspec hospital can already/has the capacity to provide a full range of services in one location	1
Standard of care	102
Unspec hospital has a good reputation locally/nationally/internationally	8
Unspec hospital provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	101
Options/possible closure	392
Service at (unspecified) should remain open/should be included as one of the options/I support this hospital (unspec)	352
Unspecified Service - retaining service offers least disruption to families	3
Unspecified Service: cuts down costs for families/parents visiting/taking children to hospital etc	1
Service at (unspecified hospital) closing would increase travel times for families in the area	30
Unspec hospital - Have personal experience of the services (I/family/friend was/is being treated there)	75
Closing (unspecified hospital) would leave numbers of patients/children at risk	10
Unspec hospital - other positive	1
Unspec hospital - other negative	1
Unspec hospital - other neutral	2
Unspec hospital - other positive	2
OTHER	10
Support other hospital or other location (Manchester, Cardiff etc)	10
General unspecific comments	1584
Geographical spread	252
All of the options are too far away from me/us (any location/not London)	0
Centres should be close to motorway/good transport links/these have the best links/easy parking/transport options	5
Midlands needs two centres/Midlands has a bigger population than London/should have 2 centres also	4
Needs to/should be should be based on geographical spread/locations/fair spread across the country/this is the best geographical spread/best locations/access	124
Needs to be closest to my/child's/family home as possible/this is closest to my house/causes least disruption/stress	5

Need to be located close to centres of high population/closest to the most amount of people/near to large cities/population centres	7
Poor options for people living in the East/East Midlands of England/the East/East Midlands needs to be covered East Midlands needs a centre/service/facilities	2
Poor options for people living in the North of England/UK/Scotland/the North needs to be covered/cover the North	80
Poor options for people living in the South of England (including Channel Islands/IOW)/the South needs to be covered/covers the South	22
Provides a workable model for Northern units	1
Spread/options/facilities/centres should be regional, not national	3
Allows retrieval of patients from anywhere in the UK (including IOW) within the stipulated time	1
Well developed networks/co-location of other service (Foetal medicine network, neonatal network, cardiac network etc) should not be lost/need to be developed/maintained	1
Other location/facility numbers in areas type comments	11
Standard of care	933
Care will suffer for those not near services/long distance travel will put lives at risk	92
Quality of service takes precedence over location/length of travel	14
Quality/expertise/reputation (include high scoring facilities) should be the key/is paramount in determining which centres/facilities should be included/these centres represent the best quality/services/facilities/expertise/they are the best/'Safe and Sustainable'	800
Should be based on what is best for children and families	34
Other care related comments	5
Facilities	462
Accommodation facilities/parent services must be available/these centres have accommodations/parent facilities	2
Centres that can already/have the capacity to provide a full range of services in one location should be the most important factor/co-location is paramount/important/these facilities have co location of services	4
Centres should be appropriately funded	11
Centres should be appropriately managed	1
Don't close any/keep all hospitals/facilities open/stay as they are/all are important	372
Ensures equity of provision/equality for patients/should be equity for all patients	10
Keep(s) ECMO and Transplantation (specialist) services in their current location(s) (merge 210/211 and Option A relocation of services)	37
More facilities the better/need as many services as possible	30
This option would mean least disruption to families/important for the services to be least disruptive to families	20
This option/these facilities are able to provide cradle (childhood) to old age care (adulthood)	2
Two transplant facilities is important/needed/necessary/do not agree with 1 transplant centre/retain both transplant centres/Newcastle and GOSH	1
Other Comments	105
Alder Hey/Liverpool and Birmingham are included in all the options/I selected Alder Hey and Birmingham because they are in all the options	2
Facilities outside of London are important/surgery outside of London is crucial for all	1
Patient choice is a fundamental principle of NHS	2
Support 1 London centre/configuration with 1 London facility/centre	2
Support 2 London centres/configuration with 2 London facilities/centre	2
Support 3 London centres/all three London Centres should be retained/should work in close collaboration	1
Support configuration with 5/6/7 - more centres outside London	9
This is the option that retains centres without having to waste money on developing further services/this is more cost effective as they already have facilities in place/most economical	26

We must not allow political decisions to be made/politics must not play a part in the options/Govt should rethink	43
Other personal costs comments (travel costs/accommodation costs etc)	17
Misc	1279
Agree with proposals/make sense/sound good/they are vital etc - general positive comments	129
Disagree with proposals/lacks common sense/joined up thinking/don't agree with any options - general negative comments about all of the options	615
Disagree - This is just a cost cutting exercise/disgraceful when the government wastes money elsewhere (wars, immigrants, drugs etc)	129
Disagree - This will cost lives/impact negatively children's health	114
Consultation document does not provide enough/appropriate information	4
Options are based on inaccurate data/false choices/inappropriate weighting	10
There is no evidence that carrying out 400 procedures per year leads to better outcomes	3
All centres considered in the review, with the exception of Oxford, were shown to be safe	1
Other negative comments on the consultation/review process/document - narrow/over-simplistic	7
Nothing/no answer/see previous answer	130
Don't know/know nothing about these hospitals	26
Other - Negative comments	56
Other - Neutral comments	46
Other - Positive comments	9

Q.2 What, if any, comments do you have on the five Key Principles?	
	Total
Total	51663
UNSPECIFIED CODES (no principle given) (NET)	5118
Standard of care (NET)	2272
UN: High quality service/patient care is paramount/all children deserve the best possible care Including survival rates	1360
UN: High quality/excellent care/services/surgery/treatment takes precedence over length of travel/location	581
UN: High quality service/patient care and location are of equal importance	226
UN: High quality care and hospitals being close to home is necessary to alleviate stress on families	95
UN: Patients/children should be cared for by professionals that they know/ (continuity of care)	59
UN: Safety is necessary/important/paramount	51
UN: Specialists should be involved in all stages of care/including coordination of care close by or at a distance	49
Travel (NET)	1505
UN: Ease of access/location of hospitals/facilities/services/short travel is necessary/important/paramount	1214
UN: Travelling should be minimized to reduce distress/risk to the child's life/its negligent to force a child/patient to travel long distances for treatment	277
UN: Cost of travel/transport should be considered	144
UN: Centres/Services should be located in the most densely populated areas An even geographical spread of centres	64
UN: Travel should be minimized to keep familiar surroundings and trusted care professionals	25

Other non specific hospital comments (NET)	1164
UN: Centres should be multi-disciplinary/provide a full range of services under one roof	551
UN: Hospitals with high ranking/standard of care/expertise should be safeguarded/retained	200
UN: Shouldn't be closing any hospitals/keep all facilities open/it's ridiculous to close any hospitals	123
UN: Remaining Cardiology centres would lose the ability to carry out emergency procedures	98
UN: Should not be sent to remote units just to give those units enough work to stay open (400 operation minimum)	67
UN: All centres should have the same expertise/expert care/services	50
UN: Support the service/facilities at unspecified/unspecified hospital provides excellent/high quality services/care/treatment/should remain open	43
UN: Support option D/only option ensures all centres will have a minimum of 400 operations	35
UN: Centres should be large regional super sites (with concentrated expertise and quality) rather than small local facilities	32
UN: Changes are not needed/system is fine as it is/why fix what isn't broken?	24
UN: Disagree with reducing the number of centres	20
UN: Unspecified hospital - have personal experience of the services (I/family/friend was treated there)	20
UN: ECMO facility is essential in child heart centres	11
UN: Poorly rating centres should work to raise standards	11
UN: Highly ranked centres should be included in more of the options	7
UN: London based hospitals should be cut/unfair they already have 2	4
Families(subnet) (NET)	1128
UN: Families (and extended family/friends) need to be close by to visit the patient/child easily/aids in child's recovery/reduces stress/to continue life as normal as possible	490
UN: Accommodation for families is essential/accommodation services at hospitals is necessary/important/paramount	367
UN: Other siblings needs should be considered	170
UN: The needs of the family are just as important as that of the child/patient	166
UN: Parents having to take time off work should be considered	113
UN: Support for families	102
UN: Needs should be specific to each child/family	35
UN: Families/children must be part of the decision making process	31
Hospitals mentioned (NET)	1115
Southampton University Hospitals NHS Trust (NET)	495
UN: Support the service/facilities at Southampton/Southampton provides excellent/high quality services/care/treatment/should remain open/positive personal experience	494
UN: Southampton - have personal negative experience of the services (I/family/friend was treated there)	1
University hospitals of Leicester NHS Trust (Glenfield) (NET)	207
UN: Support the service/facilities at Glenfield/Glenfield provides excellent/high quality services/care/treatment/should remain open/positive personal experience	207
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman) (NET)	153
UN: Support the service/facilities at Newcastle/Newcastle provides excellent/high quality services/care/treatment/should remain open/positive personal experience	153
Royal Brompton (NET)	120
UN: Support the service/facilities at Royal Brompton/Royal Brompton provides excellent/high quality services/care/treatment/should remain open/positive personal experience	120
Leeds Teaching Hospitals NHS Trust (NET)	94
UN: Support the service/facilities at Leeds/Leeds provides excellent/high quality services/care/treatment/should remain open/positive personal experience	93

UN: Leeds - have personal negative experience of the services (I/family/friend was treated there)	1
Great Ormond Street Hospital (GOSH) (NET)	29
UN: Support the service/facilities at GOSH/GOSH provides excellent/high quality services/care/treatment/should remain open/positive personal experience	29
Evelina hospital (NET)	18
UN: Support the service/facilities at Evelina/Evelina provides excellent/high quality services/care/treatment/should remain open/positive personal experience	18
Alder Hey (Liverpool) (NET)	9
UN: Support the service/facilities at Alder Hey/Alder Hey provides excellent/high quality services/care/treatment/should remain open/positive personal experience	9
Birmingham Children's Hospital (NET)	1
UN: Support the service/facilities at Birmingham/Birmingham provides excellent/high quality services/care/treatment/should remain open/positive personal experience	1
E: CLOSE TO FAMILIES HOME WHERE POSSIBLE (NET)	2139
Travel(subnet) (NET)	1195
E: Ease of access/location of hospitals/facilities/services/short travel is necessary/important/paramount	1020
E: Travelling should be minimized to reduce distress/risk to the child's life/its negligent to force a child/patient to travel long distances for treatment	227
E: Cost of travel/transport should be considered	57
E: Centres/Services should be located in the most densely populated areas	21
E: Should be close to home otherwise reduces patient choice/may get sent to units far away	14
Hospitals mentioned(subnet) (NET)	767
Other unspecified hospital comments (NET)	603
E: Centres should be multi-disciplinary/provide a full range of services under one roof/Don't split sites up	424
E: Should not be sent to remote units just to give those units enough work to stay open (400 operation minimum)	186
E: Support option D/only option that ensures all centres will have a minimum of 400 operations	162
E: Hospitals with high ranking/standard of care/expertise should be safeguarded	28
E: All centres should have the same expertise/expert care/services	22
Southampton University Hospitals NHS Trust (NET)	96
E: Support the service/facilities at Southampton/Southampton provides excellent/high quality services/care/treatment/should remain open/positive personal experience	96
University hospitals of Leicester NHS Trust (Glenfield) (NET)	53
E: Support the service/facilities at Glenfield/Glenfield provides excellent/high quality services/care/treatment/should remain open/positive personal experience	53
Leeds Teaching Hospitals NHS Trust (NET)	28
E: Support the service/facilities at Leeds/Leeds provides excellent/high quality services/care/treatment/should remain open/positive personal experience	28
Birmingham Children's Hospital (NET)	1
E: Support the service/facilities at Birmingham/Birmingham provides excellent/high quality services/care/treatment/should remain open/positive personal experience	1
Standard of care(subnet) (NET)	411
E: High quality/excellent care/services/surgery/treatment takes precedence over length of travel/location	242
E: High quality service/patient care is paramount/all children deserve the best possible care	75
E: High quality care and hospitals being close to home is necessary to alleviate stress on families	50
E: High quality service/patient care and location are of equal importance	40
E: Patients/children should be cared for by professionals that they know	17
E: Safety is necessary/important/paramount	4

Families(subnet) (NET)	363
E: Families (and extended family/friends) need to be close by to visit the patient/child easily/aids in child's recovery/reduces stress/to continue life as normal as possible	264
E: Other siblings needs should be considered	69
E: Accommodation for families is essential/accommodation services at hospitals is necessary/important/paramount	45
E: Support for the family	27
E: Parents having to take time off work should be considered	19
E: The needs of the family are just as important as that of the child/patient	15
E: Families/children must be part of the decision making process	10
E: Needs should be specific to each child/family	9
Other(subnet) (NET)	341
E: Remaining Cardiology centres would lose the ability to carry out emergency procedures - (negative E code)	149
E: Option E/I chose option E/(CLOSE TO HOME is the most important principle)	48
E: Close to home is not always possible/unrealistic/not everyone lives near populated areas use when people say 'we live in X place/4 hours from anywhere'	47
E: Additional costs should be considered (e.g. accommodation, meals)	26
E: Child's needs come before anything else/are of top priority/children are our future	22
E: Do not agree with option E Option E is not important	15
E: Adult congenital services on the same site brings additional benefits to services/ensures continuity of care from childhood to adulthood	15
E: There should be good trust/relationships between parents/doctors/surgeons/nurses	10
E: Other E negative mentions	7
E: It is important to avoid a post code lottery	4
C: EQUITY (the same high quality of service must be available to each child regardless of where they live or which hospital provides their care) (NET)	871
Hospitals mentioned(subnet) (NET)	710
Other unspecified Hospital comments (NET)	530
C: Centres should be multi-disciplinary/provide a full range of services under one roof	514
C: Hospitals with high ranking/standard of care/expertise should be safeguarded	16
Other(subnet) (NET)	250
C: Adult congenital services on the same site brings additional benefits to services/ensures continuity of care from childhood/continuity of care into adulthood is important/essential	124
C: Option C/I chose option C (EQUITY is the most important principle)	67
C: Important to have equitable access across the country - review	19
C: Childs needs come before anything else/are of top priority/children are our future	17
C: It is important to avoid a post code lottery	14
C: Do not agree with how the questions are being asked/consultation is biased/questions are loaded	10
Southampton University Hospitals NHS Trust (NET)	35
C: Support the service/facilities at Southampton/Southampton provides excellent/high quality services/care/treatment/should remain open/positive personal experience	35
Leeds Teaching Hospitals NHS Trust (NET)	17
C: Support the service/facilities at Leeds/Leeds provides excellent/high quality services/care/treatment/should remain open/positive personal experience	17
University hospitals of Leicester NHS Trust (Glenfield) (NET)	12
C: Support the service/facilities at Glenfield/Glenfield provides excellent/high quality services/care/treatment/should remain open/positive personal experience	12
Standard of care(subnet) (NET)	143
C: High quality service/patient care is paramount/all children deserve the best possible care	93
C: High quality/excellent care/services/surgery/treatment takes precedence over length of travel/location	29
C: High quality service/patient care and location are of equal importance	18

C: High quality care and hospitals being close to home is necessary to alleviate stress on families	4
C: Safety is necessary/important/paramount	3
Travel(subnet) (NET)	82
C: Ease of access/location of hospitals/facilities/services/short travel is necessary/important/paramount	65
C: Travelling should be minimized to reduce distress/risk to the child's life/its negligent to force a child/patient to travel long distances for treatment	14
C: Cost of travel/transport should be considered	9
Families(subnet) (NET)	46
C: Families need to be close by to visit the patient/child easily/aids in child's recovery/reduces stress/to continue life as normal as possible	19
C: Accommodation for families is essential/accommodation facilities at services is necessary/important/paramount	11
C: The needs of the family are just as important as that of the child/patient	10
C: Support for the family	6
C: Other siblings needs should be considered	3
C: Families/children must be part of the decision making process	2
A: CHILDREN (all those responding to A -the needs of the child come first) (NET)	745
Other(subnet) (NET)	444
A: Child's needs come before anything else/are of top priority/children are our future	285
A: Additional costs should be considered (e.g. accommodation, meals) Finance	144
A: Option A/I chose option A (CHILDREN is the most important principle)	70
A: Is this affordable/will the finance be available	9
A: Adult congenital services on the same site brings additional benefits to services/ensures continuity of care from childhood to adulthood	4
A: It is important to avoid a post code lottery (only use if they say 'postcode lottery')	2
Families(subnet) (NET)	375
A: Parents having to take time off work should be considered Plus other work related content regarding parents.	200
A: The needs of the family are just as important as that of the child/patient	190
A: Other siblings needs should be considered	158
A: Families need to be close by to visit the patient/child easily/aids in child's recovery/reduces stress/to continue life as normal as possible	75
A: Support for the family	46
A: Accommodation for families is essential/accommodation facilities at services is necessary/important/paramount	23
A: Families/children must be part of the decision making process	8
A: Needs should be specific to each child/family	8
Travel(subnet) (NET)	257
A: Ease of access/location of hospitals/facilities/services/short travel is necessary/important/paramount Close to children's homes is vital/spread around the country	164
A: Cost of travel/transport should be considered Expense related content	127
A: Travelling should be minimized to reduce distress/risk to the child's life/its negligent to force a child/patient to travel long distances for treatment	22
A: Travel should be minimized to keep familiar surroundings and trusted care professionals	5
Standard of care(subnet) (NET)	90
A: High quality/excellent service/patient care is necessary/important/paramount/all children deserve the best possible care	67
A: High quality/excellent care/services/surgery/treatment takes precedence over length of travel/location families will travel to get the best treatment	13
A: High quality/excellent service/patient care and location are of equal importance Ease of access to the best possible care	12
A: Safety is necessary/important/paramount	3

Hospitals mentioned(subnet) (NET)	88
Other unspecified Hospital comments (NET)	34
A: Centres should be multi-disciplinary/provide a full range of services under one roof	17
A: Hospitals with high ranking/standard of care/expertise should be safeguarded	9
A: Support the service/facilities at unspecified hospital/unspecified hospital provides excellent/high quality services/treatment/should remain open/positive personal experience	6
A: There should be good trust/relationships between parents/doctors/surgeons/nurses	2
University hospitals of Leicester NHS Trust (Glenfield) (NET)	32
A: Support the service/facilities at Glenfield/Glenfield provides excellent/high quality services/care/should remain open/positive personal experience. supportive comments	32
Southampton University Hospitals NHS Trust (NET)	16
A: Support the service/facilities at Southampton/Southampton provides excellent/high quality services/care/treatment/should remain open/positive personal experience.	16
Leeds Teaching Hospitals NHS Trust (NET)	6
A: Support the service/facilities at Leeds/Leeds provides excellent/high quality services/care/treatment/should remain open/positive personal experience	6
Birmingham Children's Hospital (NET)	1
A: Support the service/facilities at Birmingham/Birmingham provides excellent/high quality services/care/treatment/should remain open/positive personal experience	1
MISC codes (NET)	731
All are important/relevant/equal importance/agree with all of them/'Safe & Sustainable' safe and sensible/I support them/strongly support	540
Do not agree with how the questions are being asked/consultation is biased/questions are loaded - negative mentions of review process	114
Agree with the principle (s) but don't see how they'll work/not sure how realistic the they are	80
Answers referring to another question	2
Other (NET)	730
UN: Childs needs come before anything else/are of top priority/children are our future	388
UN: Additional costs should be considered (e.g. accommodation, meals, loss of earnings)	103
UN: Adult congenital services on the same site brings additional benefits to services/ensures continuity of care from childhood to adulthood	93
UN: Isle of Wight should have been included/IOW overlooked/long travel time to London/Option B is best	68
UN: Is this affordable/will the finance be available	51
UN: There should be good trust/relationships between parents/doctors/surgeons/nurses	19
UN: Changes in heart services will have a negative knock on effect on other services	19
UN: It is important to avoid a post code lottery	15
UN: Scotland should be included/considered	11
UN: Transplants should have been included	4
UN: Ireland should be included	3
UN: More money needs to be spent on children's heart care rather than other self inflicted problems (smoking, drug addiction, obesity etc)	1
B: QUALITY (All children who need heart surgery must receive the very highest standards of NHS care) (NET)	729
Standard of care(subnet) (NET)	372
B: High quality service/patient care is paramount/all children deserve the best possible care	313
B: High quality/excellent care/services/surgery/treatment takes precedence over length of travel/location	50
B: High quality service/patient care and location are of equal importance	10
B: High quality care and hospitals being close to home is necessary to alleviate stress on families	8
B: Safety is necessary/important/paramount	4
Other(subnet) (NET)	254

B: Option B/I chose option B (QUALITY is the most important principle)	220
B: Childs needs come before anything else/are of top priority/children are our future	25
B: It is important to avoid a post code lottery	6
B: Adult congenital services on the same site brings additional benefits to services/ensures continuity of care from childhood to adulthood	3
Hospitals mentioned(subnet) (NET)	181
Southampton University Hospitals NHS Trust (NET)	93
B: Support the service/facilities at Southampton/Southampton provides excellent/high quality services/care/treatment/should remain open/positive personal experience	93
Other unspecified hospital comments (NET)	63
B: Hospitals with high ranking/standard of care/expertise should be safeguarded	45
B: Centres should be multi-disciplinary/provide a full range of services under one roof	14
B: All centres should have a good ECMO service	5
The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman) (NET)	12
B: Support the service/facilities at Newcastle/Newcastle provides excellent/high quality services/care/treatment/should remain open/positive personal experience	12
University hospitals of Leicester NHS Trust (Glenfield) (NET)	12
B: Support the service/facilities at Glenfield/Glenfield provides excellent/high quality services/care/treatment/should remain open/positive personal experience	12
Leeds Teaching Hospitals NHS Trust (NET)	5
B: Support the service/facilities at Leeds/Leeds provides excellent/high quality services/care/treatment/should remain open/positive personal experience	5
Great Ormond Street Hospital (GOSH) (NET)	1
B: Support the service/facilities at GOSH/GOSH provides excellent/high quality services/care/treatment/should remain open/positive personal experience	1
Families(subnet) (NET)	42
B: Accommodation for families is essential/accommodation facilities at services is necessary/important/paramount	25
B: Families need to be close by to visit the patient/child easily/aids in child's recovery/reduces stress/to continue life as normal as possible	14
B: Support for the family	5
B: The needs of the family are just as important as that of the child/patient	4
Travel(subnet) (NET)	34
B: Ease of access/location of hospitals/facilities/services/short travel is necessary/important/paramount	28
B: Cost of travel/transport should be considered	6
B: Travelling should be minimized to reduce distress/risk to the child's life/its negligent to force a child/patient to travel long distances for treatment	5
D: PERSONAL SERVICE (NET)	330
Families(subnet) (NET)	105
D: Families need to be close by to visit the patient/child easily/aids in child's recovery/reduces stress/to continue life as normal as possible	29
D: The needs of the family are just as important as that of the child/patient	28
D: Accommodation for families is essential/accommodation facilities at services is necessary/important/paramount	25
D: Support for the family	22
D: Needs should be specific to each child/family	17
D: Other siblings needs should be considered	9
D: Families/children must be part of the decision making process	1
Hospitals mentioned(subnet) (NET)	86
Other unspecified hospital comments (NET)	37
D: Centres should be multi-disciplinary/provide a full range of services under one roof	17
D: Hospitals with high ranking/standard of care/expertise should be safeguarded	8
D: Support the service/facilities at unspecified/unspecified hospital provides excellent/high quality services/care/treatment/should remain open	5
D: Disagree with reducing the number of centres	4

D: All centres should have the same expertise/expert care/services	3
Southampton University Hospitals NHS Trust (NET)	29
D: Support the service/facilities at Southampton/Southampton provides excellent/high quality services/care/treatment/should remain open/positive personal experience	29
Leeds Teaching Hospitals NHS Trust (NET)	13
D: Support the service/facilities at Leeds/Leeds provides excellent/high quality services/care/treatment/should remain open/positive personal experience	13
University hospitals of Leicester NHS Trust (Glenfield) (NET)	10
D: Support the service/facilities at Glenfield/Glenfield provides excellent/high quality services/care/treatment/should remain open/positive personal experience	10
Standard of care(subnet) (NET)	83
D: High quality service/patient care is paramount/all children deserve the best possible care	41
D: High quality/excellent care/services/surgery/treatment takes precedence over length of travel/location	14
D: High quality service/patient care and location are of equal importance	12
D: Patients/children should be cared for by professionals that they know	10
D: High quality care and hospitals being close to home is necessary to alleviate stress on families	7
Other(subnet) (NET)	80
D: Option D/I chose option D (PERSONAL SERVICE is the most important principle)	31
D: Childs needs come before anything else/are of top priority/children are our future	29
D: There should be good trust/relationships between parents/doctors/surgeons/nurses	12
D: Adult congenital services on the same site brings additional benefits to services/ensures continuity of care from childhood to adulthood	5
D: Do not agree with option D (PERSONAL SERVICE is the most important principle)	5
Travel(subnet) (NET)	72
D: Ease of access/location of hospitals/facilities/services/short travel is necessary/important/paramount	53
D: Travelling should be minimized to reduce distress/risk to the child's life/its negligent to force a child/patient to travel long distances for treatment	21
D: Cost of travel/transport should be considered	5
Other positive comments	27
Other negative comments	150
Other neutral comments	206
Don't know	2

Q.4 What, if any, comments do you have on these national quality standards?	
	Total
Total	51663
UNSPECIFIED THEMES (NET)	1529
Standard of care (NET)	717
UN: High quality service/patient care is important/necessary/paramount/all children deserve the best possible care/should not depend on postcode/wealth/status	296
UN: Support for families/keeping families informed/family experience is important/necessary/paramount/including psychological support/cardiac liaison nurses	95
UN: Continuity of care is important/seeing the same doctors/using the same facilities from childhood to adulthood	48
UN: Surgical/clinical expertise/experience/excellence is important/necessary/important/networks need clinical leadership	42

UN: The importance of prenatal diagnosis should not be underestimated/is important/necessary/paramount	41
UN: High quality care takes precedence over length of travel/location	31
UN: Good communication across the networks is vital/there is a risk of communication errors with congenital heart networks	27
UN: Age appropriate care is important/necessary/paramount	25
UN: Specialist surgical treatment centres are paramount/a good idea/will ensure the best possible care	24
UN: Size does not necessarily mean better standards/higher volumes does not mean better outcomes/quantity does not equal quality/too many cases may exceed a surgeon's capabilities	23
UN: Have concerns about the future effects on staff/shortage of qualified staff/recruitment problems/may lead to cuts in staff/reduction in calibre of staff/expertise leaving the NHS	22
UN: Concerns that large centres may dilute the services/may mean lack of personal attention/loss of continuity in staff	21
UN: A network of expertise/concept of congenital heart networks is important/necessary/paramount	19
UN: Congenital heart networks already exist but there is room for improvement	17
UN: Important to look at survival/mortality rates/outcomes should be assessed geographically	16
UN: Prenatal diagnosis is so valuable to parents/being prepared/warned	15
UN: Expertise is better concentrated in fewer/larger units/facilities/with sufficient number of cases	14
UN: Care of the child/child welfare/quality of service comes before the needs of the family	14
UN: Should be a GUCH facility on the same site to ensure smooth transition into adult services	14
UN: Provision for emergency services/catheter procedures must be available/would not be safe/would risk lives otherwise	13
UN: Local community/general hospitals/GPs need to be trained/equipped to spot defects/problems	12
UN: A paediatrician with cardiac knowledge/increase of paediatricians with cardiac knowledge is no replacement for a cardiologist	11
UN: Ongoing training for staff is important/necessary/essential/need more paediatricians with expertise in cardiology	10
UN: Individual needs must be considered/needs of the child come first	9
UN: More information/help is needed by parents/vital that parents make an informed choice	8
UN: Must not be at the cost of losing specialist consultant/cardiac cardiologists	7
UN: Prenatal diagnosis must improve in order to reduce morbidity/improve maternity/parental/family experience	7
UN: The needs of disabled people/those with mental illness/learning difficulties must be considered	6
UN: Safety of children/patient is important/necessary/paramount	6
UN: Good quality services should not be moved/closed/should be supported	5
UN: Centres with low numbers means that surgeons are unable to maintain/improve skills/need sufficient throughput	5
UN: Age appropriate care is easier to carry out if there is joined up care at the same centre	4
UN: Access to a counsellor/psychologist/family psychotherapist is important/necessary/paramount	4
UN: 24/7 care must be available to treat cardiac conditions	4
UN: Networks do not necessarily lead to quality/procedures are priority	3
UN: Is the service not safe now?	3
UN: Pre-natal diagnosis is very subjective/easy to see why some parents would not want it/can cause anxiety/scans may not be accurate	3

UN: Congenital heart networks can only benefit parents/families	2
UN: Development of congenital heart networks must not be at the cost of losing specialist consultant/cardiac cardiologist	2
UN: Children should be referred to a centre best able to meet their needs/not necessarily based on geography	2
UN: Age appropriate care does not necessarily lead to quality	1
UN: Improved data will provide more detail on outcomes/quality of future life	1
UN: Other negative care mentions	11
UN: Other neutral care mentions	14
UN: Other positive care mentions	2
Specific Hospitals (NET)	434
UN: Support the service/facilities at Southampton/Southampton meets all the standards/provides excellent/high quality services/care/treatment	148
UN: Support the service/facilities at Glenfield (Leicester)/Glenfield meets all the standards/provides excellent/high quality services/care/treatment/should remain open	90
UN: Support the service/facilities at Leeds/Leeds meets all the standards/provides excellent/high quality services/care/treatment/should remain open/positive personal experience	63
UN: Support the service/facilities at Brompton/Brompton meets all the standards/provides excellent/high quality services/care/treatment/should remain open/positive personal experience	52
UN: Support the service/facilities at Freeman/Freeman meets all the standards/provides excellent/high quality services/care/treatment/should remain open/positive personal experience	40
UN: Support the service/facilities at unspecified location/unspecified hospital meets all the standards/provides excellent/high quality services/care/treatment	23
UN: Support the service/facilities at Evelina/Evelina meets all the standards/provides excellent/high quality services/care/treatment/should remain open/positive personal experience	14
UN: Support the service/facilities at GOSH/GOSH meets all the standards/provides excellent/high quality services/care/treatment/should remain open/positive personal experience	6
UN: Support the service/facilities at Alder Hey (Liverpool)/Alder Hey meets all the standards/provides excellent/high quality services	2
Other (NET)	403
UN: There is no evidence that outcomes are better by performing significantly more cases (400+)/with 4 surgeons	193
UN: There is evidence to suggest that performing low numbers/ less than 200 cases lead to worse outcomes	160
UN: Hospitals with high ranking/standard of care/expertise should be safeguarded/retained/those that are not should be closed	43
UN: Do not agree with closure of any hospitals/keep all facilities open/it's ridiculous to close any hospitals/more are needed/existing centres should be improved	41
UN: Funds need to be provided/will there be funding?/will need to be saved from other sources/funding may be withdrawn/investment needed to provide sustainability	17
UN: Patient/family choice of provider is necessary/important/paramount	13
UN: Other services may suffer as a result (i.e. Elderly care)	12
UN: Where will the funding come from to implement these measures?/only achievable if properly financed	11
UN: There is always room for improvement/change/system should be flexible to allow for change	10
UN: Congenital heart networks already exist but there is room for improvement	9
UN: Decisions should be based on where existing facilities exist with expertise	9
UN: The number of procedures taken into consideration should include procedures such as ECMO etc/procedures on adults	8
UN: Choices should not be for political/financial/reasons/services must not suffer because of politics	8

UN: Disagree with reducing the number of centres/service will not be sustainable	8
UN: There is no evidence to suggest that higher numbers are safer/provide better outcomes	7
UN: Surgeons should be able to offer a range of operations of high quality & good outcomes/good surgical outcomes should dictate choices, not numbers	7
UN: Families/children must be part of the decision making process	7
UN: Sounds good/is it realistic/can it be delivered	7
UN: The standards should not over-ride the needs of children and their family	4
UN: There is no evidence to suggest that lower numbers/fewer surgeons are not safe	3
UN: Higher numbers of cases will improve good outcomes	2
UN: Safe & Sustainable is not a good scheme	1
Location/accessibility (NET)	172
UN: Ease of access/location of hospitals/short travel is paramount	104
UN: Care/treatment/facilities/services need to be accessible to all children/patients/people/families	30
UN: Family's access to the patient is important for their welfare	13
UN: High quality/excellent service/patient care and location are of equal importance	12
UN: Facilities close to home reduce costs for families to visit	10
UN: Access needed for patients in Scotland/Ireland/will see increase in travel	10
UN: Need to be located close to centres of high population/closest to the most amount of people/near to large cities/population centre's/these are closest to the most amount of people	7
UN: Other location mentions	4
UN: There should be no reduction in the choice of location	3
UN: Good geographical spread is necessary/8 centres would be better/more centres preferable	2
Facilities (NET)	108
UN: It is necessary/important/paramount for all cardiac/surgical/treatment/facilities (including support networks/outpatient clinics) to be at one site	71
UN: Accommodation for families is essential/accommodation facilities at hospitals is important	20
UN: Work to improve existing facilities (rather than wholesale change)	9
UN: ECMO facility is important/necessary/paramount	5
UN: Size of the facility does not necessarily mean better standards	4
UN: Hospitals of choice should be meeting all of these requirements	3
MISC (NET)	493
Agree with all themes/goals/all are of equal importance/will provide best outcomes for children/ensure high quality care	182
Other negative comments about the consultation/document/review process	102
National standards are important/necessary/good idea/should strive for excellence/to ensure continuity of care/delivered by all centres	87
Standards are good/are they achievable/ensuring compliance is difficult/are there penalties for non-compliance	20
Questionnaire is confusing/poorly constructed/questions are leading/biased	18
National standards are imperative to equal care across the board	17
This is up to the experts to decide/trust expert opinion/not qualified to comment	17
Concerns about how implementation/transition will be regulated/monitored/proper inspection needs to be implemented	17
Principles/goals/standards are inadequate/need to be looked into further/poorly researched/data is inaccurate	10
No change for change's sake/current system if fine	9
Standards are good as long as they do not become bureaucratic/tick boxing exercises	9
Standards are good but proven expertise/track records must be taken into account	8
Other conditional mentions of standards	8
Other negative mentions of standards	7

Difficult to interpret as relating to quality/argument not made that these factors enhance quality	6
Decisions need to be evidence based/where is the evidence/this is asserted but there is no evidence/empirical research is required	5
Other positive comments about consultation/review process/document	4
NHS must not be privatised	2
Standards should be administered in existing centres/no correlation between raising standards and reducing centres	1
C: SPECIALIST SURGICAL CENTRE (NET)	338
C: There is no evidence that outcomes are better by performing significantly more cases (400+)/with 4 surgeons/do not agree with this	121
C: Centres with low numbers/fewer surgeons/less than 200 are not good/do not have good outcomes/evidence suggests that centres with less than 200 are not as good	86
C: C/standard C is important/essential	31
C: Provision for emergency services/catheter procedures must be available/would not be safe/would risk lives otherwise	27
C: Larger/higher number of procedures does not necessarily mean better/safer outcomes/quantity does not equal quality/too many cases may exceed a surgeon's capabilities	21
C: Ease of access/location of hospitals/short travel is important/paramount	21
C: Specialist surgical treatment centres are paramount/a good idea/will ensure the best possible care	20
C: Adequate skills training and experience must be maintained/need to perform sufficient procedures to maintain skills	13
C: Southampton/Oxford partnership is a model of excellence/conducts a large number of procedures	10
C: Support the service/facilities at Glenfield/Glenfield provides excellent/high quality services/care/treatment/should remain open/positive personal experience	10
C: Evidence does not support the cases proposed/where does the evidence come from	9
C: Must have complete service on one site/should be a 'one stop shop'/be able to provide every procedure	8
C: Staffing levels must be maintained/to ensure adequate level of care	8
C: Surgical/clinical expertise/experience/excellence is important/necessary/important	8
C: Good geographical spread is necessary/8 centres would be better/more centres preferable	7
C: Concerns that large centres may dilute the services/may mean lack of personal attention/loss of continuity in staff	7
C: High quality service/patient care is important/necessary/paramount/all children deserve the best possible care/should not depend on postcode/wealth/status	6
C: Support the service/facilities at Brompton/Brompton provides excellent/high quality services/care/treatment/should remain open/positive personal experience	6
C: Configuration/retention of services must be based on clinical/surgical excellence/expertise/experience	5
C: Where is the evidence for saying that larger centres have better outcomes/does not necessarily follow that high numbers of procedures mean better care	5
C: All hospitals should meet the highest standards/should share good practice and information	4
C: Cannot support specialist surgical centres if isolated from cardiac centres/will only work if not isolated from cardiac centres	4
C: Centres should be able to provide ECMO	3
C: Surgeons at Southampton operate on both children and adults/perform larger number of procedures	3
C: Only support Specialist Surgical Centres if it is based on evidence that suggests under 200 cases per year would be an unsafe and not specialist centre	2
C: Centres with low numbers means that surgeons are unable to maintain/improve skills	2
C: High quality service/patient care and location are of equal importance	1

C: Will require adequate investment	1
C: Can only support if impact on family is minimal	1
C: Low numbers of procedures/with many surgeons is wasteful	1
C: Need to be located close to centres of high population/closest to the most amount of people/near to large cities/population centres/these are closest to the most amount of people	1
C: Support the decrease in care centres if it means higher standards of care/optimisation of resources	1
C: Other C mentions	21
C: Other negative C mentions	23
C: Other C positive mentions	7
A: CONGENITAL HEART NETWORKS (NET)	246
A: Congenital heart networks already exist but there is room for improvement	86
A: Must not be at the cost of losing specialist consultant/cardiac cardiologists	32
A: A network of expertise is important/necessary	25
A: A /standard A is important/essential	19
A: Communication is already a concern across the NHS/communication is paramount to improving services	14
A: In the majority of centres the network already exists/outpatient clinics are run at local hospitals	10
A: Southampton is linked with Oxford/replicate the Oxford/Southampton model/excellent model of joint care	9
A: Do not like the idea of a child being transferred after surgery from specialist care to local cardiology centre	8
A: Yorks/Humber has a well developed network arrangement/care is delivered close to home	8
A: Paediatricians will require formalised training/CPD requirement to keep up-to-date/skills will need to be maintained	8
A: Leeds has this already	4
A: Sufficient weight needs to be given to the transition between child and adult care facilities	4
A: Glenfield has this already	4
A: Brompton works alongside GOSH	3
A: There is room for improvement	3
A: This can only benefit parents/families	3
A: Concerns about the training and regulation of paediatricians with specialism in cardiology	2
A: Is the service not safe now?	1
A: Freeman's are doing this already	1
A: Other A mentions	22
A: Other A negative mentions	46
A: Other A positive mentions	3
B: PRE-NATAL DIAGNOSIS (NET)	201
B: Prenatal diagnosis/scans would help all expectant parents/would be pre-warned/prepared	44
B: Prenatal diagnosis is important/necessary/paramount/vital	38
B: Babies should be born in hospitals where regional neonatal units should have specialist cardiac care on site/avoids delays in treatment	35
B: B/standard B is important/essential	18
B: Prenatal diagnosis must improve in order to reduce morbidity/improve maternity/parental/family experience	13
B: Prenatal diagnosis can save lives/be of benefit/offers the best outcomes	10
B: Support the service/facilities at Leeds/Leeds provides excellent/high quality services/care/treatment/should remain open/positive personal experience	7
B: Concerns that pre-natal diagnosis will lead to pregnancies being terminated	6

B: Paediatric/cardiac expertise is important for children diagnosed with heart problems during childhood (as opposed to pre-natally)	6
B: Pre-natal care is one of the greatest areas of inequity/must be targeted directly and robustly	4
B: Southampton already does this	4
B: Support the service/facilities at Glenfield/Glenfield provides excellent/high quality services/care/treatment/should remain open/positive personal experience	3
B: Ease of access/location of hospitals/short travel is paramount	3
B: Personal experience of this/my child was diagnosed pre-natally/would have been at risk	3
B: Prenatal diagnosis depends on obstetric/radiological pathway improvement	3
B: High quality care takes precedence over length of travel/location	2
B: Specialist treatment centres are important/necessary/paramount	2
B: Pre-natal diagnosis is very subjective/easy to see why some parents would not want it/can cause anxiety/scans may not be accurate	2
B: Access to a counsellor/psychologist/cardiac liaison nurse is important/necessary/paramount	2
B: Freeman's already doing this	1
B: There is room for improvement in heart networks	1
B: No evidence to suggest that this is safer	1
B: Other B mentions	18
B: Other B negative mentions	9
B: Other positive B mentions	2
F: THE FAMILY EXPERIENCE (NET)	169
F: Accommodation at Glenfield is on the children's ward/provides excellent family centred care/facilities/through Heartlink	58
F: Accommodation for families is essential/accommodation facilities at hospitals is important	33
F: Family experience is vital/must not be underestimated	19
F: Network of support is important/families need to be informed/involved/cardiac liaison nurses needed	17
F: Ease of access/location of hospitals/short travel is paramount	15
F: F/standard F is important/essential	15
F: Family's access to the patient is important for their welfare	10
F: This is well provided for by Southampton	9
F: This is well provided by Leeds	6
F: Family facilities (nsf) are essential	4
F: Care of the child/child welfare/quality of service comes before the needs of the family	2
F: Access to a counsellor/psychologist/family psychotherapist is important/necessary/paramount	2
F: This is well provided for by Brompton	2
F: Hospitals with necessary specialist skills must be located to the greatest density of population	1
F: Other facilities e.g. ease of parking are vital	1
F: This is well provided for by Freemans, Newcastle	1
F: Other F mentions	14
F: Other F negative mentions	12
F: Other F positive mentions	3
D: AGE APPROPRIATE CARE (NET)	141
D: This is well provided by Glenfield/only proper inter-hospital transitional care pathway	37
D: Continuity of care is important/seeing the same doctors from childhood to adulthood/makes the transition easier	22
D: Age appropriate care is important/necessary/paramount	15
D: D/standard D is important/essential	15

D: Would prefer to see centres providing everything from pre-natal to adult (including interventions) under one roof	14
D: Why are GUCH services not being considered at the same time/will lead to a disjointed service/split sites will reduce quality	13
D: Other D mentions	10
D: This is well provided by Southampton	7
D: Other D negative mentions	7
D: Age appropriate care should be available to everyone with no age limit/important to recognise the total spectrum of children's ages	5
D: This is well provided for by Leeds	4
D: This is well provided by the Royal Brompton	3
D: Age appropriate not always relevant as children develop at different rates	2
D: Young children need the constant support of their parents	2
D: This is well provided for by Freemans, Newcastle	2
D: Works well in a general/local hospital/continuation of care difficult in a children's hospital	2
D: This is well provided by GOSH	1
G: ENSURING EXCELLENT CARE (NET)	121
G: G/standard G is important/essential	33
G: High quality service/patient care is paramount/all children deserve the best possible care	30
G: Improved data will provide more detail on outcomes/quality of future life	18
G: I support Southampton General hospital/excellent hospital/rated 2nd highest/has network with Oxford	13
G: Other G neutral mentions	12
G: Other G negative mentions	9
G: This is well provided for at Glenfield/including ECMO	7
G: Hospitals with high ranking/standard of care/expertise should be safeguarded/retained	6
G: Data collection/bureaucracy should not be at the cost of patient care	3
G: Ease of access/location of hospitals/short travel is paramount	3
G: Existing congenital heart networks should be improved, not displaced	2
G: Other G positive mentions	2
G: Network support imperative due to population numbers	1
G: Families/children must be part of the decision making process	1
G: This can only be achieved if the top four ranking centres in the Kennedy review are the final designated centres	1
E: INFORMATION AND MAKING CHOICES (NET)	71
E: More information/help is needed by parents/vital that parents make an informed choice	16
E: Other E mentions	14
E: E/standard E is important/essential	13
E: Other negative E mentions	11
E: This is good for parents and children to point in the right direction/to be able to make decisions	5
E: Removing/closing down units removes parent choice/do not understand how the reduction in number of units improves choice	4
E: This is well provided for by Southampton	3
E: This is well provided for by Leeds	2
E: Choice is not always a good thing/leads to difficult decisions during difficult times/parents/patients should not be given a choice/all centres should be of equally high standards	2
E: This is well provided for by Freemans, Newcastle	1
E: Reduction in number of units does not create an open competitive market	1
E: This is well provided for by Brompton	1
E: This is well provided for by Glenfield	1

E: Other E positive mentions	1
OPTIONS (NET)	37
I choose Option B/Option B supports all these standards/themes/services/Option B provides quality	16
I choose Option A/Option A supports/delivers all these standards/themes/services	12
I choose Option D/Option D supports all these standards/themes/services/Option D provides quality	2
I choose Unspecified Option/Unspecified Option supports/delivers all these standards/themes/services/Unspecified Option provides quality	2
Other options mentions	1
Other negative option mentions	5
Other	69
Other positive mentions	5
Other negative comments	25
Don't know	12

Q.6 What, if any, comments do you have on these elements/statements/proposals?	
	Total
Total	51663
General unspecified comments (no proposal given) (NET)	1434
Expertise (NET)	472
UN: A paediatrician with cardiac knowledge/increase of paediatricians with cardiac knowledge is no replacement for a cardiologist/the distinction needs to be maintained	148
UN: Cardiologists/most experienced/knowledgeable staff will gravitate to specialist centres/leave other areas without adequately trained cardiologists/quality will be affected	85
UN: Need more paediatric cardiac specialists/good to increase knowledge of cardiology/training and development will be important/often frontline for diagnosis	63
UN: The interpretation of the evidence for higher volumes is incorrect if defined at over 400 cases per year/no evidence to support this/outcomes plateau at 250	30
UN: Future interventional cardiology/procedures should be provided by designated specialists whether in a surgical centre or current centres/need to provide for emergency care	23
UN: Expertise is better concentrated in fewer/larger units/facilities	22
UN: There will be no difference between a cardiology centre and a local hospital/district general hospital (DGH)	19
UN: Complexity of surgery is a factor/centres doing more complex surgery may have worse outcomes/some procedures should only be performed in particular centres	18
UN: Without specialist medical staff the system will not be sustainable/concern as to whether there are sufficient health professionals to staff centres	17
UN: Surgical/clinical expertise/experience/excellence is important/necessary/important	13
UN: Specialist surgical treatment centres are paramount/a good idea/will ensure the best possible care	13
UN: Surgery and catheterisation/interventional services should not be split/need to be carried out by specialists/limit risk to child	13
UN: There is an argument for better coverage by specialists/surgeons travelling around/tertiary visiting specialists/outreach clinics	13

UN: Local link is vital to ensure early referral to specialists/adequate local and accessible provision/expertise would need to be provided	12
UN: Interventional/diagnostic cardiology/procedures should not be concentrated in a few large centres/leads to cancellations/increased waiting lists/loss of skills/risk to child	12
UN: Without access to emergency/interventional services, the cardiology centre will be no more than a clinic/will become de-skilled	10
UN: Paediatric cardiology expertise would suffer/negative effect on on child heart surgery training/may lead to misdiagnosis	8
UN: Team work/co-operation produces good outcomes/has been shown to be the key to good outcomes	7
UN: Better outcomes are achieved when teams have sufficient volumes of activity to maintain expertise	6
UN: Staff working in the cardiology centres will become de-skilled if separated from treatments	5
UN: The more practice a surgeon/medical staff has the more expertise is gained/evidence shows that skills used consistently ensure better clinical outcomes	4
UN: More important to consider the outcomes of surgery from each unit/surgeon as it stands as a measure of the quality of the service in that unit	2
UN: Should include the full range of surgery (including interventional procedures) currently carried out by each centre in the figures	1
UN: Other expertise mentions	21
UN: Other negative expertise mentions	12
UN: Other positive expertise mentions	5
Standard of care (NET)	459
UN: Size of facility does not necessarily mean better standards/higher volumes does not mean better outcomes/quantity does not equal quality/lower volume units do excellent work	139
UN: Glenfield provides 24/7 now/but has been omitted by the S&S team	64
UN: Hospitals with high ranking/standard of care/expertise should be safeguarded/retained/should not be based on geography/postcode/each hospital should be judged on its own merit	52
UN: High quality/excellent care is important/necessary/paramount/all children deserve the best possible care/should not depend on postcode/wealth/status	46
UN: 24/7 care must be available to treat cardiac conditions/all patients	26
UN: High quality/excellent care takes precedence over travelling/location	19
UN: Outcomes plateau when 250 is reached/research suggest between 200-400 to maintain outcomes	19
UN: Concerns that large centres/multiple points of contact/may dilute the services/may mean lack of personal attention/loss of continuity in staff	17
UN: Good communication is important to ensure high levels of paediatric patient care/good communication is necessary for success of networks	17
UN: Good centres/surgeons perform procedures on adults as well/there needs to be a continuum of care/adult cardiac surgeons can perform on children/have the experience and equipment	15
UN: Concern over quality of networks/provision left/too autonomous/not integrated	13
UN: Important to look at survival/mortality rates	13
UN: Why have transplants not been included in this review/all should have transplant units/transplants needs protection	9
UN: Clinical outcomes are the most important issue/are paramount	6
UN: Evidence suggests that low numbers/less than 200 leads to worse outcomes/are unsafe	5

UN: Large units do not do well/they split up	5
UN: Leicester has the ECMO/only mobile ECMO unit	4
UN: What will happen to the non surgical centres?	3
UN: New research/research from US does not agree with statement that large volumes lead to better outcomes	2
UN: ECMO facility is important/necessary/paramount	2
UN: Safety is necessary/important/paramount	2
UN: Access to a psychologist/emotional support is important/necessary/paramount	1
UN: Care will be compromised without consultant cover	1
UN: Other care mentions	20
UN: Other negative care mentions	15
UN: Other positive care mentions	2
Specific hospital (NET)	345
UN: Support the service/facilities at Southampton/Southampton meets all the standards/provides excellent/high quality services/care/treatment	139
UN: Support the service/facilities at Glenfield/Glenfield provides excellent/high quality services/care/treatment/should remain open/positive personal experience	64
UN: Support the service/facilities at the Royal Brompton/the Royal Brompton provides excellent/high quality services/care/treatment	52
UN: Support the service/facilities at the Freeman/the Freeman provides excellent/high quality services/care/treatment/should remain open/positive personal experience	38
UN: Support the service/facilities at Leeds/Leeds provides excellent/ high quality services/care/treatment/should remain open/positive personal experience	33
UN: Support the service/facilities at unspecified hospital/unspecified hospital provides excellent/high quality services/care/treatment/should remain open/positive personal experience	9
UN: Support the service/facilities at GOSH/GOSH provides excellent/high quality services/care/treatment/should remain open/positive personal experience	8
UN: Support the service/facilities at Evelina/Evelina provides excellent/high quality services/care/treatment/should remain open/positive personal experience	6
UN: Support the service/facilities at Bristol/Bristol provides excellent/high quality services/care/treatment/should remain open/positive personal experience	3
Facilities/services (NET)	218
UN: Is the service not safe now?	150
UN: Cardiologists(and relevant facilities) and surgeons (and relevant facilities) need to be close/located together/co-location of specialist surgery units and cardiology centres	32
UN: The system/structure works fine as it is/doesn't need change/already safe	21
UN: There needs to be sufficient staff/resources to support changes/sustainable for the future	5
UN: The development of 'networks' should not prejudice the clinical networks that already exist/function well	4
UN: The service is not/will not be safe in the future	2
UN: The proposal does not focus on the needs of the child/patient	1
UN: Current system is sustainable	1
UN: Services should be provided at as many hospitals as possible	1
UN: Other negative facilities/services	1
UN: Other positive facilities/services	1

Locations/geographical spread (NET)	180
UN: Care/treatment/facilities/services need to be accessible to all children/patients/people/families/should be local/to alleviate stress on patients and families	62
UN: Ease of access/location of hospitals/short travel is paramount/sick children should not be transferred from hospital to hospital/retrieval times important	41
UN: Need the best geographical spread/standards of care evenly distributed throughout	23
UN: Children's Cardiology Centres should be located alongside Specialist Surgical Centres/all paediatric services 'under one roof'/a multi disciplinary approach	17
UN: Child's needs must be met near home	13
UN: Need to be located close to centre's of high population/closest to the most amount of people/near to large cities/population centre's/these are closest to the most amount of people	11
UN: High quality/excellent care and location/close to home are of equal importance	8
UN: Care has to be taken for patients from Scotland/travel time must be taken into account/Scotland should be included	7
UN: Accommodation for families is essential/accommodation facilities at hospitals is important	4
UN: Inadequate consideration has been given to population growth, particularly within the Asian community	3
UN: Has account been taken of the Welsh Assembly's decision to establish a children's hospital for Wales/need to include Wales	2
UN: Ireland should be included	2
UN: Other location mentions	3
UN: Other negative location mentions	2
Costs (NET)	54
UN: Funds need to be provided/will there be funding?/will need to be saved from other sources/funding may be withdrawn/investment needed to provide sustainability	31
UN: Costs/money should not be a barrier/money needs to be spent/should not be a money saving exercise	6
UN: Need to be wary of costs of new developments	3
UN: Other cost/resource issues	15
Statement A: 'Without change the service will not be safe or sustainable in the future' (NET)	715
A: Is the service not safe now?	294
A: There is no evidence to support that 400+ cases of surgery are needed to be safe	114
A: S&S team have concluded that all hospitals are safe	83
A: All units are safe/service is safe/according to the review/except Oxford	71
A: No change for change sake/political/financial reasons/changes must benefit patients/medical field	54
A: No/not enough research/data/evidence to support this statement	33
A: Southampton is safe and sustainable now/has excellent survival rates	22
A: Change is needed/necessary/important/to re-assess and improve/for the right reasons	19
A: The system/structure works fine as it is/doesn't need change	16
A: A/statement A is important/essential	16
A: Hospitals with high ranking/standard of care/expertise should be safeguarded/retained/should not be based on geography/postcode	14

A: All are safe, not all are sustainable	11
A: Glenfield is safe and sustainable now/does not need to change	10
A: To be sustainable, there is an argument for better coverage by surgeons/more surgeons/surgeons travelling around/tertiary visiting specialists	7
A: Do not recognise this as a valid reflection of the service/it is safe as it is/do not agree with the statement	7
A: Why is it not sustainable/just need more staff/equipment/increased funding/better management will maintain sustainability	6
A: Inadequate consideration has been given to population growth/density/particularly within the Asian/non Caucasian community	4
A: Freeman is safe and sustainable now/does not need to change	4
A: Team work/co-operation has been shown to be the key to good outcomes	3
A: Close down poorly performing centres	2
A: Neither agree nor disagree	2
A: Proposal is not safe or sustainable/removes surgical cover/will not be able to retain best staff	2
A: Other A mentions	30
A: Other negative A mentions	32
A: Other positive A mentions	4
Statement D 'Research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes' (NET)	497
D: The interpretation of the evidence for higher volumes is incorrect if defined at over 400 cases per year/no evidence to support this/outcomes plateau at 250	129
D : No/not enough research/data to support this statement/research is inconclusive/should not form rigid future policies	111
D: Size of facility does not necessarily mean better standards/higher volumes does not mean better outcomes/quantity does not equal quality/lower volume units do excellent work	98
D: Is not correct/is inaccurate/is not a valid statement/disproved by latest research/from America/mentions of Guildhall/unsure of impartiality of research	48
D: There is a limit to the number of procedures a centre/surgeon can do before it becomes too big /becomes remote and bureaucratic	27
D: D/statement D is important/essential	21
D: No evidence for upper limits/over 200/250 producing better outcomes	19
D: Bigger centres are not better centres/do not have better outcomes/smaller hospitals have good outcomes	16
D: Southampton is not the biggest but has high success rate/ranked 2nd in country	14
D: Complexity of surgery/severity of condition is a factor/centres doing more complex surgery may have worse outcomes	14
D: The more practice a surgeon/medical staff has the more expertise is gained/evidence shows that skills used consistently ensure better clinical outcomes	13
D: Hospitals with high ranking/standard of care/expertise should be safeguarded/retained/should not be based on geography/postcode/each hospital should be judged on its own merit	8
D: Concerns that large centres may dilute the services/may mean lack of personal attention/loss of continuity in staff	6
D: Team work/co-operation has been shown to be the key to good outcomes	5
D: Evidence shows that outcomes improve if the number of operations carried out is over 200/smaller units should close	5
D: Data would suggest that quality is maintained with 2/3 surgeons performing less than 500 operations	2
D: Need to see evidence for each hospital/unit/surgeon	2

D: Higher volume could lead to less diversity/loss of skills on some areas	1
D: Other D mentions	23
D: Other D positive mentions	8
D: Other D negative mentions	17
Proposal G - proposal to increase the role of paediatricians with expertise in cardiology in district Children's Cardiology Services across England (NET)	459
G: A paediatrician with cardiac knowledge/increase of paediatricians with cardiac knowledge is no replacement for a cardiologist	282
G: Will the paediatricians have sufficient cardiac knowledge/may not be able to gain sufficient practical experience/will need formal training/monitoring	38
G: Need more paediatric cardiac specialists/good to increase knowledge of cardiology/often frontline for diagnosis	34
G: Care will be put at risk if the paediatrician is off sick/on holiday	20
G: G/proposal G is important/essential	20
G: Should not happen as it will affect care/put children at risk/may lead to poor diagnosis and treatment/emergency cover	17
G: This will not work/question feasibility/will take too long to achieve/will not receive investment needed/only feasible if resources earmarked	16
G: Cardiologists/expert medical staff will gravitate to specialist centres/leave other areas without adequately trained cardiologists/quality will be affected	15
G: Local link is vital to ensure early referral to specialists/adequate local and accessible provision/expertise would need to be provided	10
G: Essential that this happens/support this	10
G: Cardiologists(and relevant facilities) and surgeons (and relevant facilities) need to be close/located together/co-location of specialist surgery units and cardiology centres	7
G: Without specialist medical staff the system will not be sustainable/concern as to whether there are sufficient health professionals to staff centres/problems with staff moving around	5
G: These paediatricians must be given meaningful access to specialist surgical centres and not treated as second class clinicians	5
G: I would rather go to a single centre where everything can be done/all services should be on one site	3
G: There will be no difference between a cardiology centre and a local hospital/district general hospital (DGH)	3
G: Earlier diagnosis/timely surgical intervention could avoid further damage	2
G: High quality/excellent care is important/necessary/paramount	2
G: Other G mentions	32
G: Other negative G mentions	21
G: Other G positive mentions	3
Misc (NET)	433
Negative comments about the consultation/review process/document	77
No change for change sake/political/financial reasons/changes must benefit patients/medical field	73
All 11 centres should stay open/no centres should close/should remain fully operational/should improve existing centres/should be opening more centres	66
Decisions need to be evidence based/where is the evidence/this is asserted but there is no evidence/empirical research is required	39
Agree with all of it/all proposals/sounds good - general agreement/positive comments	38
Have no access to document/reference pages not available/do not have enough information	25

Questionnaire is confusing/poorly constructed/biased/leading	19
Change is needed/necessary/important	18
Child's needs come first	15
These proposals/some of these proposals will put lives at risk/have a detrimental effect on cardiac care	15
This is up to the experts to decide/medical profession not politicians who decide	12
Keep units with the best results/the high quality centres/close those with poor outcomes	12
Changes proposed will take time/training of doctors takes years/concern about what will happen in the transition/has there been an impact assessment	10
The network model will benefit from newer technology in future years eg telemedicine/this happens in adult care	8
Statistics/figures/information for Southampton are out of date/Southampton has 3 surgeons/is gaining a fourth surgeon	7
Mentions of Yorkshire/West Yorks	6
Other services may suffer as a result	5
Children's cardiac service must be planned in context of wider services	5
Evidence is from America/based on American hospitals	3
Do not understand statements F and G/are not easy to understand	3
Joined up, co-located care more likely to improve safety than fewer, larger centres	1
Proposal F - proposal that current surgical units that are not designated for surgery in the future may become Children's Cardiology Centres (NET)	384
F: Cardiologists/most experienced/knowledgeable staff will gravitate to specialist centres/leave other areas without adequately trained cardiologists/quality will be affected	126
F: There will be no difference between a cardiology centre and a local hospital/district general hospital (DGH)	64
F: It will be difficult to maintain excellent cardiology services without a surgical service/children's cardiology inevitably involves surgery	23
F: Current surgical centres that are performing to very high standards/performing well should be retained/kept/have the required investment/gives greater choice	21
F: This will not work/question feasibility/do not understand their role	19
F: Cardiologists (and relevant facilities) and surgeons (and relevant facilities) need to be close/located together/co-location of specialist surgery units and cardiology centres	16
F: They may collapse/will have to close/will become uneconomic to maintain/will not generate income/will not be sustainable	15
F: F/statement F is important/essential	13
F: A paediatrician with cardiac knowledge/increase of paediatricians with cardiac knowledge is no replacement for a cardiologist	12
F: Adequate local and accessible provision/expertise would need to be provided	7
F: Parents would not want to take their children to a Children's Cardiology Centre if their surgeon/medical staff are not there/need continuity of care	7
F: Children's Cardiology Centres provide substandard care/will be second rate	4
F: Without access to emergency/interventional services, the cardiology centre will be no more than a clinic/will become de-skilled	4
F: Need more information/about skills and expertise within these surgical areas	3
F: Surgical teams should be able to travel if necessary/have tertiary visiting specialists/outreach clinics	3
F: Concerns that large centres/multiple points of contact/may dilute the services/may mean lack of personal attention/loss of continuity in staff	3

F: Children's cardiology centres must be planned and equipped with the support services essential for 21st century cardiology	1
F: The proposal should identify a schedule for the development of these centres	1
F: A dedicated multi disciplinary imaging team with access to cardiac MR & CT is essential in each of these centres	1
F: Other F mentions	122
F: Other F negative mentions	25
F: Other F positive mentions	3
Statement E 'In the future interventional cardiology should be provided only by designated Specialist Surgical Centres' (NET)	278
E: Neither agree or disagree/should read 'neither agree nor disagree'	100
E: What will happen to the non surgical centres?	44
E: E/statement E is important/essential	30
E: Distance is a problem/might not make it to the hospital in time/what happens in an emergency	20
E: Future interventional cardiology/procedures should be provided by designated specialists whether in a surgical centre or current centres/need to provide for emergency care	17
E: Hospitals with high standard of care should be safeguarded/retained/should not be based on geography/each hospital should be judged on its own merit/close those with poor outcomes	13
E: Cardiologists (and relevant facilities) and surgeons (and relevant facilities) need to be close/located together/co-location of specialist surgery units and cardiology centres	8
E: Without access to emergency/interventional services, the cardiology centre will be no more than a clinic/will become de-skilled	8
E: A paediatrician with cardiac knowledge/increase of paediatricians with cardiac knowledge is no replacement for a cardiologist	7
E: Problems for specialist staff having to commute to specialist centres/strong teams will be lost/leaving the NHS/going to surgical centres	5
E: Important as procedures become more complex/more practice increases skills	4
E: No rationale or evidence for stopping interventional catheterisation in centres NOT doing surgery/this is not done in adult cardiological interventions	4
E: Southampton Hospital is ranked second but only in one of the options	3
E: Good practice is measurable in existing hospitals	2
E: This up to the experts to decide/not qualified to comment	1
E: Other E mentions	19
E: Other E negative mentions	17
E: Other E positive mentions	3
Statement C 'The need for 24/7 care in each of the Specialist Surgical Units' (NET)	274
C: Glenfield provides this now/but has been omitted by the S&S team	209
C: 24/7 care is necessary/vital	24
C: C/statement C is important/essential	12
C: 24/7 care is already provided by NHS/in my local unit	9
C: Other C negative mentions	6
C: Southampton provides this now	5
C: 24/7 care must be available to treat cardiac conditions	5
C: Other C positive mentions	4
C: Other C mentions	4
C: Existing units that currently supply 24/7 care should not be closed	3

C: 24/7 care must be available in non surgical units as well	1
Statement B - proposal to develop Congenital Heart Networks across England (NET)	250
B: Cardiologists/health professionals may/will gravitate to specialist centres/leave other areas without adequately trained cardiologists/quality will be affected	117
B: Paediatricians with an interest in cardiology are no substitute for specialist cardiologists	62
B: Concern over quality of networks/provision left/too autonomous/not integrated/loss of continuity	56
B: B/statement B is important/essential	30
B: Why develop when perfectly good hospitals already exist/general hospitals will lose their current expertise	10
B: Remaining centres will not be as effective after the proposed changes/will atrophy	7
B: Should ensure sharing of best practice/protocols for co-operation/requires good communication	6
B: Southampton has formed a network with Oxford which is effective and sustainable	5
B: Congenital heart networks are already in place in some areas of the country	5
B: Do not support this concept if it increases the distance travelled by patients/families to their hospital/need to ensure that care is as close to home as possible	3
B: Leeds Heart Unit already has a well-established network that is the gold standard and is being rolled out to the rest of the UK	3
B: Issues over funding of networks/will not create income	3
B: B is too vague/evidence is not good	3
B: Has account been taken of the Welsh Assembly's decision to establish a children's hospital for Wales/needs to include Wales	2
B: Research shows that big units do not work	1
B: Leicester has strong networks already	1
B: Cardiologists (and relevant facilities) and surgeons (and relevant facilities) need to be close/located together/co-location of specialist surgery units and cardiology centres	1
B: Other B negative mentions	19
B: Other B positive mentions	3
B: Other B mentions	13
OPTIONS (NET)	45
Other option mentions	14
I choose Option A/Option A covers all these statement/proposals	13
I choose Option B/Option B covers all these statement/proposals	11
Disagree with all options/changes/is disastrous	5
I choose Option C/Option C covers all these statement/proposals	2
A seven centre model offers more choice/is preferable	2
I choose Option D/Option D covers all these statement/proposals	1
A nine centre model would be better	1
Q.8 What, if any, comments do you have on the number of Specialist Surgical Centres in London?	
	Total

Total	51663
Centre numbers (NET)	1575
Support two centres (NET)	1079
Two centres are needed in London because of the population/volume of patients/potential patients/demand	349
Two centres is a good idea/support having two in London - not specified further	321
Two centres in London would adequately cater for estimate of approx 800 cases	145
Other mentions of two centres	125
Two centres will allow development of adjacent centres in the South West and Midlands(elsewhere in the country)	77
Two centres will concentrate the expertise/three centres would dilute it/provide specialist care	73
More than 2 centres in London mean that other areas of the country will be disadvantaged	25
Support one centre (NET)	505
One should be sufficient in London/one large facility with a full range of facilities/services/London doesn't need two	299
One in London and one or more elsewhere in the country	203
Other mentions of one centre	11
Support three centres (or more) (NET)	1500
No London centres need to close	1122
All London centres should collaborate/working together creates better outcomes	763
Two centres would not be able to cope with the demand if one of the three London centres closed	190
All three centres should be kept and developed	112
All three London units are busy/see high numbers of patients	75
Closing this/these services will have knock-on effects to other services/will make other services unsustainable.	34
Population will increase so need 3 or more centres/Number of cases will increase so need 3 or more centres	28
Other mentions of three centres	23
Closing a centre will increase waiting list/times	20
Will lose staffing expertise	13
Closing and re-building a centre is a waste of money/don't close and centres to save money	11
General comments about London (NET)	1082
Negative (NET)	714
Don't like London/government is London centric/just because it's the capital it is favoured/London doesn't concern me	341
London is too far away/don't close local services/too far for people to travel from other regions	177
Travel to London is expensive/inconvenient	111
London has poor access/difficult to get into	91
London is too expensive (families to stay and visit children/patients)	78
Travelling to London will add stress to families Stress related content in travelling to London.	41
Difficult to find accommodation in London Difficult to find parent accommodation	24
It will benefit people living in London, not people living outside London	13
London is a small area	7
London should not have any specialist services	5
Other London negative	57
Positive (NET)	396
London has a large/dense population/biggest city in the country/supports a large area	270
London is easily accessible/has good transport links	76

Other London positive	75
I support the facilities proposed in London	7
Royal Brompton & Harefield NHS Foundation Trust (NET)	681
Positive (NET)	681
Royal Brompton and GOSH have a strong/close working relationship.	346
Royal Brompton provides high quality/excellent cardiac care/surgery/specialist procedures/experience	193
Service at Royal Brompton should remain open/Royal Brompton should be included as one of the hospitals	185
Royal Brompton: have personal experience of the services (I/family/friend was/is being treated there)	62
Closure of Royal Brompton will leave children at risk (Including cystic fibrosis patients)	47
Royal Brompton is able to provide childhood to adulthood care	39
Royal Brompton has excellent/the highest scores/ranking/best results	24
The recommended options will be destructive of other services rather than providing a platform	24
Closure of paediatric cardiac care at Royal Brompton would make other inpatient paediatric service unsustainable	23
Royal Brompton has a good reputation/locally/nationally/internationally	17
Royal Brompton has ground breaking research which would suffer should the unit close down	13
Royal Brompton has four children's heart surgeons who undertake over 400 operations each year.	11
Royal Brompton can already/has the capacity to provide a full range of services/see/take more patients	8
Royal Brompton is excellently located/covers a wide region	4
Other Royal Brompton & Harefield positive	77
Location/geographical spread (NET)	632
Centres should give as even spread as possible across the country/the North/South/East/West is not well served	437
Care/facilities should be close to the patient's home/be more local/easy to access	123
Children will be at risk/jeopardises child safety making them travel further	47
Other locational negative comments	47
Other locational positive comments	24
Need one North of the Thames/river and one facility South of the river	14
Other hospitals (NET)	557
Support the service of non-London based hospital (all mentions of other hospitals outside London)	399
The introduction of any specialist centres in London should not detract the importance of other centres across the UK	190
Other London hospitals - Hammersmith hospital should be an option	7
Standard of care (NET)	263
High quality care is paramount/ retain high quality services	167
Other mentions of care	37
Children/patients need all the services/appropriate treatment in one location/Co-location of services is necessary/important/paramount/access to all procedures at one location	34
Patients in familiar surroundings feel more comfortable	20
Children need to be seen in specialist paediatric hospitals/facilities/services	10
Services should be retained where they see the most patients/save the most lives/perform the most surgery etc	4
Stand alone Cardiac/children's centre is inappropriate/old fashioned model for 21st century care	2
Services should be retained wherever the facilities are in place	2
Great Ormond Street Hospital for Children NHS trust (NET)	215

Positive (NET)	184
Service at GOSH should remain open/GOSH should be included as one of the hospitals	91
GOSH provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	54
GOSH: have personal experience of the services (I/family/friend was/is being treated there)	22
GOSH has a good reputation/locally/nationally/internationally	15
GOSH has excellent/the highest scores/ranking/best results	7
GOSH can already/has the capacity to provide a full range of services/see/take more patients	6
GOSH is excellently located/covers a wide region	4
GOSH is a dedicated children's hospital/has key paediatric facilities/integrated children's services	4
GOSH is able to provide childhood to adulthood care	2
GOSH has an ECMO facility	1
Other GOSH positive	30
Negative (NET)	40
GOSH does not treat adults/GUCH patients	4
GOSH provides poor/poorer quality cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	3
GOSH should not be one of the two facilities	2
Support closure of service at GOSH	2
Not sure of the service GOSH provides/no experience/knowledge of the facilities/standards	2
Other GOSH negative	29
Other facility numbers (NET)	213
More centres the better/need more centres/not enough centres - unspecified number	72
Need the correct number of centres for the need/Appropriate for population size	58
London has at least 2 centres with its population then elsewhere with a similar population should have at least 2	29
Other (unspecified) facility number mentions	26
London has enough/too many centres/units/facilities	21
London has more centres per head of population/not equitable	10
Miscellaneous (NET)	199
Dislike/Disagree with the assessment/reports/data in the 'Safe & Sustainable' review	65
Agree with the assessment/reports/data/'Safe & Sustainable'	42
Don't know/don't have enough information/don't know them well enough	34
Unable to view/download document/reference page not available	12
This is up to experts to decide/Local population to decide	12
Need more information/consultation doesn't provide enough information	11
Disagree with the way the question is being asked/questionnaire is biased	11
Keep centres/centre as it increases competition/Increases patient choice	11
I support option B	6
The process has not been fair	2
Other negative comments	177
Other neutral comments	148
Evelina Children's Hospital - Guys & St Thomas's NHS Foundation Trust (NET)	145
Positive (NET)	129
Service at Evelina should remain open/Evelina should be included as one of the hospitals	68
Evelina provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	46
Evelina: have personal experience of the services (I/family/friend was/is being treated there)	17

Evelina has excellent/the highest scores/ranking/best results	16
Evelina can already/has the capacity to provide a full range of services/see/take more patients	7
Evelina is a dedicated children's hospital/has key paediatric facilities/integrated children's services	5
Evelina is excellently located/covers a wide region	4
Evelina has a good reputation/locally/nationally/internationally	4
Evelina is able to provide childhood to adulthood care	3
Other Evelina positive	11
Negative (NET)	19
Evelina provides poor/poorer quality cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	4
Evelina should not be one of the two facilities	3
Not sure of the service Evelina provides/no experience/knowledge of the facilities/standards	2
Other Evelina negative	12
No answer/no comment	135
Unspecified hospital positive (NET)	91
Unspec hospital - positive	91
Don't support two centres (NET)	88
Disagree with two centres/Do not want two centres	88
Other positive comments	51
Negative (NET)	32
Royal Brompton does not have a dedicated children's hospital/have key paediatric facilities	16
Support closure of service at Royal Brompton	9
Other Royal Brompton & Harefield negative	6
Royal Brompton provides poor/poorer quality cardiac care/surgery/specialist procedures/experience/	3
Not sure of the service Royal Brompton provides/no experience/knowledge of the facilities/standards	1
Concerned about Adult care at Royal Brompton/need to ensure transitional care from childhood to adulthood	1
Royal Brompton closing will have no effect on care of children	1
Don't support three centres (NET)	18
Three is too many	18
Unspecified hospital negative (NET)	10
Unspecified hospital - negative	10

Q.10 What, if any, comments do you have on the proposals for Specialist Surgical Centres in London?	
	Total
Total	51663
Royal Brompton & Harefield NHS Foundation Trust (NET)	1813
Positive (NET)	1744
Service at Royal Brompton should remain open/Royal Brompton should be included as one of the hospitals	1159
Royal Brompton provides high quality/excellent cardiac care/surgery/specialist procedures/experience	557
Closure of Royal Brompton will leave children at risk (Including cystic fibrosis patients)	554

Royal Brompton has ground breaking research which would suffer should the unit close down	409
The recommended options will be destructive of other services rather than providing a platform	374
Royal Brompton has excellent/the highest scores/ranking/best results	367
Royal Brompton has four children's heart surgeons who undertake over 400 operations each year.	364
Closure of paediatric cardiac care at Royal Brompton would make other inpatient paediatric service unsustainable	254
Other Royal Brompton & Harefield positive	127
Royal Brompton is able to provide childhood to adulthood care	109
Royal Brompton: have personal experience of the services (I/family/friend was/is being treated there)	99
Royal Brompton has a good reputation/locally/nationally/internationally	62
Royal Brompton can already/has the capacity to provide a full range of services/see/take more patients	50
Royal Brompton and GOSH have a strong/close working relationship.	26
Royal Brompton is excellently located/covers a wide region	3
Negative (NET)	83
Royal Brompton does not have a dedicated children's hospital/have key paediatric facilities	37
Other Royal Brompton & Harefield negative	27
Support closure of service at Royal Brompton	10
Royal Brompton provides poor/poorer quality cardiac care/surgery/specialist procedures/experience	8
Not sure of the service Royal Brompton provides/no experience/knowledge of the facilities/standards	5
Concerned about Adult care at Royal Brompton/need to ensure transitional care from childhood to adulthood	3
Royal Brompton closing will have no effect on care of children	1
Facility numbers (NET)	1268
Support three centres (or more) (NET)	948
No London centres need to close	775
All London centres should collaborate/working together creates better outcomes	466
Two centres would not be able to cope with the demand if one of the three London centres closed	48
Closing this/these services will have knock-on effects to other services/will make other services unsustainable.	42
Closing and re-building a centre is a waste of money/don't close and centres to save money	17
All three London units are busy/see high numbers of patients	17
Population will increase so need 3 or more centres/Number of cases will increase so need 3 or more centres	10
All three centres should be kept and developed	10
Closing a centre will increase waiting list/times	7
Will lose staffing expertise	6
Other mentions of three centres	4
Support one facility (NET)	151
One should be sufficient in London/one large facility with a full range of facilities/services	114
One in London and one or more elsewhere in the country	38
Other mentions of one centre	1
Support two centres (NET)	124
Two centres is a good idea/support having two in London - not specified further	57
Other mentions of two centres	38

Two centres are needed in London because of the population/volume of patients/potential patients/demand	11
Two centres will allow development of adjacent centres in the South West and Midlands(elsewhere in the country)	9
Two centres will concentrate the expertise/three centres would dilute it	8
Two centres in London would adequately cater for estimate of approx 800 cases	3
More than 2 centres in London mean that other areas of the country will be disadvantaged	1
Other facility numbers (NET)	37
More centres the better/need more centres/not enough centres - unspecified number	21
Other (unspecified) facility number mentions	6
Need the correct number of centres for the need/Appropriate for population size	4
London has at least two centres with its population than elsewhere with a similar population should have at least 2	4
London has enough/too many centres/units/facilities	2
London has more centres per head of population/not equitable	1
Don't support two centres (NET)	32
Disagree with two centres/Do not want two centres	32
Don't support three centres (NET)	1
Three is too many	1
Great Ormond Street Hospital for Children NHS trust (NET)	472
Positive (NET)	414
Service at GOSH should remain open/GOSH should be included as one of the hospitals	195
GOSH provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	152
GOSH has a good reputation/locally/nationally/internationally	45
GOSH: have personal experience of the services (I/family/friend was/is being treated there)	41
GOSH is a dedicated children's hospital/has key paediatric facilities/integrated children's services	37
GOSH has excellent/the highest scores/ranking/best results	36
GOSH can already/has the capacity to provide a full range of services/see/take more patients	19
GOSH is excellently located/covers a wide region	16
GOSH has an ECMO facility	14
GOSH is able to provide childhood to adulthood care	1
Other GOSH positive	32
Negative (NET)	70
GOSH does not treat adults/GUCH patients	15
GOSH provides poor/poorer quality cardiac care/surgery/specialist procedures/experience/expertise	11
Support closure of service at GOSH	6
Not sure of the service GOSH provides/no experience/knowledge of the facilities/standards	6
GOSH should not be one of the two facilities	1
Other GOSH negative	37
Standard of care (NET)	458
High quality care is paramount/ retain high quality services	309
Other mentions of care	48
Children/patients need all the services/appropriate treatment in one location/Co-location of services is necessary	45
Stand alone Cardiac/children's centre is inappropriate/old fashioned model for 21st century care	33
Children need to be seen in specialist paediatric hospitals/facilities/services	20

Services should be retained where they see the most patients/save the most lives/perform the most surgery etc	12
Patients in familiar surroundings feel more comfortable	12
Services should be retained wherever the facilities are in place	8
Miscellaneous (NET)	402
Dislike/Disagree with the assessment/reports/data in the the 'Safe & Sustainable' review	115
Don't know/don't have enough information/don't know them well enough	109
The process has not been fair	49
This is up to experts to decide/Local population to decide	47
Agree with the assessment/reports/data/'Safe & Sustainable'	40
Disagree with the way the question is being asked/questionnaire is biased	17
I support option B	12
Need more information/consultation doesn't provide enough information	9
Keep centres/centre as it increases competition/Increases patient choice	5
Unable to view/download document/reference page not available	4
Evelina Children's Hospital - Guys & St Thomas's NHS Foundation Trust (NET)	300
Positive (NET)	265
Evelina provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise	115
Service at Evelina should remain open/Evelina should be included as one of the hospitals	96
Evelina has excellent/the highest scores/ranking/best results	56
Evelina: have personal experience of the services (I/family/friend was/is being treated there)	44
Evelina is a dedicated children's hospital/has key paediatric facilities/integrated children's services	22
Evelina is excellently located/covers a wide region	16
Evelina is able to provide childhood to adulthood care	12
Evelina can already/has the capacity to provide a full range of services/see/take more patients	10
Evelina has a good reputation/locally/nationally/internationally	8
Other Evelina positive	26
Negative (NET)	40
Other Evelina negative	21
Evelina provides poor/poorer quality cardiac care/surgery/specialist procedures/experience/expertise	10
Not sure of the service Evelina provides/no experience/knowledge of the facilities/standards	8
Evelina should not be one of the two facilities	4
General comments about London (NET)	296
Negative (NET)	247
Don't like London/government is London centric/just because its the capital it is favoured/London doesn't concern me	117
London is too far away/don't close local services/too far for people to travel from other regions	59
London is too expensive (families to stay and visit children/patients)	33
Travel to London is expensive/inconvenient	33
London has poor access/difficult to get into	28
Difficult to find accommodation in London Difficult to find parent accommodation	12
Travelling to London will add stress to families Stress related content in travelling to London.	11
It will benefit people living in London, not people living outside London	3
London should not have any specialist services	2
Other London negative	16
Positive (NET)	58

London has a large/dense population/biggest city in the country/supports a large area	19
London is easily accessible/has good transport links	17
I support the facilities proposed in London	5
Other London positive	21
Other hospitals (NET)	230
Support the service of non-London based hospital	206
The introduction of any specialist centres in London should not detract the importance of other centres across the UK	24
Other London hospitals - Hammersmith hospital should be an option	7
Location/geographical spread (NET)	178
Centres should give as even spread as possible across the country/the North/South/East/West is not well served	95
Care/facilities should be close to the patient's home/be more local/easy to access	32
Need one North of the Thames/river and one facility South of the river	18
Children will be at risk/jeopardises child safety making them travel further	15
Other locational positive comments	18
Other locational negative comments	9
Unspecified hospital positive (NET)	128
Unspecified hospital - positive	128
Unspecified hospital negative (NET)	11
Unspecified hospital - negative	11

Q.14 What, if any, comments do you have on the proposals for Specialist Surgical Centres outside London?	
	Total
Total	51663
OTHER (NET)	10529
Standard of care (NET)	7324
Quality/expertise/reputation (include high scoring facilities) should be the key	7065
Should be based on what is best for children and families	130
Quality of service takes precedence over location/length of travel	111
Care will suffer for those not near services/long distance travel will put lives at risk	41
The review should take account of congenital heart surgery service for teenagers and adults	7
Number of interventional catheter procedures carried out should be taken into account/sites may be lost after S&S	1
Three highest scoring quality hospitals in the South of England	1
Other care related comments	105
Geographical spread (NET)	4618
Needs to/should be should be based on geographical spread/locations/fair spread across the country	3372
Reduces extra travel for patients in the North	738
Poor options for people living in the South of England (including Channel Islands/IOW)	242
Centres should be close to motorway/good transport links/these have the best links/easy parking/transport	161
Poor options for people living in the North of England/UK/Scotland/the North needs to be covered/covers the North	77
Need to be located close to centres of high population/closest to the most amount of people/near to large cities	74
Midlands needs two centres/Midlands has a bigger population than London/should have 2 centres also	58

Poor options for people living in the East/East Midlands of England/the East/East Midlands needs to be covered	32
Needs to be closest to my home as possible/this is closest to my house/nearest to me	30
All of the options are too far away from me/us (any location/not London)	12
Spread/options/facilities/centres should be regional, not national	6
Midlands - support 1 centre	4
Well developed networks/co-location of other service (Foetal medicine network, neonatal network)	4
Provides a workable model for Northern units	2
Other location/facility numbers in areas type comments	162
Facilities (NET)	2854
Allows retrieval of patients from anywhere in the UK (incl IOW) within the stipulated time (campaign 5)	1123
This would mean the least impact on PICU (Paediatric intensive care unit) services	793
Makes sure all centres reach the minimum 400 operations/target caseload/volumes	558
Centres than can already/have the capacity to provide a full range of services in one location most important factor	300
This option/these facilities are able to provide cradle (childhood) to old age care (adulthood)	208
Keep(s) ECMO and Transplantation (specialist) services in their current location(s) (merge 210/211 and Option A relocation of services)	205
Don't close any/keep all hospitals/facilities open/stay as they are/all are important	117
Accommodation facilities/parent services must be available/these centres have accommodations/parent facilities	86
This option would mean least disruption to families/important for the services to be least disruptive to families	72
Two transplant facilities is important/needed/necessary/do not agree with 1 transplant centre	52
More facilities the better/need as many services as possible	39
ECMO facilities/these have ECMO capability/services with ECMO facilities are paramount	28
Ensures equity of provision/equality for patients/should be equity for all patients	7
This option would mean fewer centres closing	5
Centres should be appropriately funded	5
Centres should be appropriately managed	2
Three ECMO facilities are needed	1
Other Comments (NET)	369
Facilities outside of London are important/surgery outside of London is crucial for all	157
Other personal costs comments (travel costs/accommodation costs etc)	95
Support configuration with 5/6/7 - more centres outside London	40
This is the option that retains centres without having to waste money on developing further services	38
Patient choice is a fundamental principle of NHS	27
We must not allow political decisions to be made/politics must not play a part in the options/Govt should rethink	13
Alder Hey/Liverpool and Birmingham are included in all the options	10
Support 3 London centres/all three London Centres should be retained	9
Support 1 London centre/configuration with 1 London facility/centre	3
Alternative option suggestions	3
London has good transport links/easy to access from anywhere in the country	2
Support 2 London centres/configuration with 2 London facilities/centre	2
Other London related comments	1
London has/serves a large population	1
Misc (NET)	316
Comments solely about London based services (GOSH/Evelina/Royal Brompton/other London services)	120

Disagree with proposals/lacks common sense/joined up thinking/don't agree with any options	93
Options are based on inaccurate data/false choices/inappropriate weighting	46
Agree with proposals/make sense/sound good/they are vital etc - general positive comments	20
Would have been more sensible to look at existing centres/development centres and map these to cardiac centres	11
Disagree - This is just a cost cutting exercise/disgraceful when the government wastes money elsewhere	10
Consultation document does not provide enough/appropriate information	8
Disagree - This will cost lives/impact negatively children's health	6
Most appropriate configuration /best option/I know these ones (unspecified) no mention of quality/travel/location	5
Would like to see 6 centres across England, all of which could provide both cardiac and respiratory ECMO	4
Questionnaire is confusing/poorly constructed	3
All centres considered in the review, with the exception of Oxford, were shown to be safe	1
S&S plan will cause disinvestment/fall of morale/standards/difficulties with recruitment/staff shortages	1
Support other hospital or other location	3
Preferred option (NET)	6990
Option B (NET)	5718
Positive (NET)	5674
Support Option B/Option B is the best one	5541
Support Option B - other	133
Option B offers the least disruption/no relocation of services required	6
Negative (NET)	46
Option B is the worst one/oppose B	25
Option B is unsustainable/should not be an option/don't understand the logic/it's too southern biased (coexistence of Southampton and Bristol)	23
Option A (NET)	694
Positive (NET)	674
Support Option A/Option A is the best one	575
Support A - other	74
Option A offers the least disruption/no relocation of services required	34
Support A - recommended by the consultation	2
Negative (NET)	20
Option A is the worst one/oppose A	20
Option D (NET)	671
Positive (NET)	609
Support Option D/Option D is the best one	606
Option D offers the least disruption	4
Negative (NET)	62
Option D is the worst one/oppose D	32
Option D has too few centres	19
Option D not viable as they would have to move transplant and ECMO from the specialised team	18
Option C (NET)	46
Negative (NET)	31
Option C has too few centres	21
Option C is the worst one/oppose C	12
Positive (NET)	15
Support Option C/Option C is the best one	15
Subnet: Southampton University Hospitals NHS Trust (NET)	2347
Positive (NET)	2335
Options/possible closure (NET)	1923

Service at Southampton should remain open/should be included as one of the options/I support Southampton	1152
Southampton is ranked 2nd in the country/in the performance review/has excellent results	1026
Service at Southampton closing would increase travel times for families in the area	130
Southampton is in only one of the options/do not agree with this	125
Southampton: have personal experience of the services (I/family/friend was/is being treated there)	109
Closing Southampton would leave numbers of patients/children at risk	107
Service at Southampton closing would impact on expertise/training/research	53
Services closing in Southampton would put a strain on London services	12
Service at Southampton closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	10
Southampton - other positive	46
Southampton - other negative	16
Southampton - other neutral	13
Standard of care (NET)	1075
Southampton provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	999
Southampton has a good reputation locally/nationally/internationally	207
Southampton works in partnership with Oxford/has a network model with Oxford	46
Southampton is able to provide cradle (childhood) to old age care (adulthood)	16
Location/population (NET)	531
Southampton is centrally located/covers a wide region/geographically well placed	463
Southampton has easy access/close to motorway/good transport links/good parking	65
Southampton is in a densely populated area/large city/surrounding areas heavily populated	35
Southampton is my nearest centre/closest to my home	19
Facilities (NET)	249
Southampton treats large numbers of patients	129
Southampton is a training/teaching hospital	42
Southampton has well developed networks (Foetal medicine network, neonatal network, cardiac network etc)	42
Southampton can already/has the capacity to provide a full range of services in one location	38
Southampton provides accommodation/facilities for families (for families)	11
Negative (NET)	13
Southampton should not be one of the options/support the closure of services at Southampton	12
Southampton has easy access to London/close to London centres	5
Subnet: Leeds Teaching Hospitals NHS Trust (NET)	1050
Options/possible closure (NET)	944
Service at Leeds should remain open/Leeds should be included as one of the options/I support Leeds	893
Service at Leeds closing would increase travel times for families in the area	36
Leeds: have personal experience of the services (I/family/friend was/is being treated there)	26
Leeds: closing Leeds would leave numbers of patients/children at risk	16
Leeds is in only one of the options/do not agree with this	9
Service at Leeds closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	3
Leeds - retaining Leeds offers least disruption to families	1
Leeds - other positive	17
Leeds - other negative	13
Leeds - Other neutral	4
Positive (NET)	257
Location/population (NET)	190

Leeds is centrally located/covers a wide region/geographically well placed (including Yorkshire is the biggest county)	97
Leeds is in a densely populated area/large city/surrounding areas heavily populated	91
Leeds has easy access/close to motorway/good transport links/good parking	40
Leeds is my nearest centre/closest to my home	6
Leeds population demographics are more prone to heart problems (high Asian %)	2
Facilities (NET)	111
Leeds can already/has the capacity to provide a full range of services in one location co location of services	87
Leeds has well developed networks/links (Foetal medicine network, neonatal network, cardiac network etc)	21
Leeds is able to provide cradle to old age care	20
Leeds treats large numbers of patients	19
Leeds is a training/teaching hospital	5
Leeds provides accommodation/facilities for families (for families)	1
Standard of care (NET)	87
Leeds provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise	84
Leeds has a good reputation locally/nationally/internationally	5
Negative (NET)	16
Leeds should not be one of the options/support the closure of services at Leeds	11
Leeds scored poorly in the review/lower than other services	7
Leeds has poor access/limited transport links/poor parking/confusing road infrastructure	1
Subnet: University Hospitals of Leicester NHS Trust (Glenfield) (NET)	873
Positive (NET)	622
Standard of care (NET)	368
Glenfield provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	338
Glenfield has a good reputation locally/nationally/internationally	56
Facilities (NET)	323
Glenfield has an ECMO facility	282
Glenfield provides accommodation/facilities for families (for families)	63
Glenfield is able to provide cradle to old age care	25
Glenfield can already/has the capacity to provide a full range of services in one location	22
Glenfield is a training/teaching hospital	13
Glenfield has well developed networks/links (Foetal medicine network, neonatal network, cardiac network etc)	12
Glenfield has Heartlink (children's charity)	10
Glenfield treats large numbers of patients (including from other hospitals/regions)	8
Location/population (NET)	273
Glenfield is centrally located/covers a wide region/geographically well placed	184
Glenfield has easy access/close to motorway/good transport links/good parking	116
Glenfield is my nearest centre/closest to my home	27
Glenfield is in a densely populated area/large city/surrounding areas heavily populated	20
Glenfield is accessible by helicopter/has a helipad	14
Other (NET)	46
Glenfield - other positive	39
Glenfield cuts down costs for families/parents visiting/taking children to hospital etc	5
Glenfield - other neutral	4
Options/possible closure (NET)	590
Service at Glenfield should remain open/Glenfield should be included as one of the options/I support Glenfield	511
Glenfield :have personal experience of the services (I/family/friend was/is being treated there)	94
Service at Glenfield closing would increase travel times for families in the area	50
Closing Glenfield would leave numbers of patients/children at risk	26

Glenfield - retaining Glenfield offers least disruption to families	16
Service at Glenfield closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	11
Service at Glenfield closing would impact on expertise/training/research	10
Glenfield is in only one of the options/do not agree with this	9
Negative (NET)	75
Glenfield scored poorly in the review/lower than other services	32
Glenfield should not be one of the options/support the closure of services at Glenfield	30
Glenfield is a split site/not a co-located site	11
Glenfield - other negative	22
Subnet: Alder Hey Children's NHS Foundation Trust (Liverpool) (NET)	784
Positive (NET)	744
Service at Liverpool should remain open/should be included as one of the options/I support Liverpool	724
Liverpool is centrally located/covers a wide region/geographically well placed (including Isle of Man and Wales)	21
Liverpool is in a densely populated area/large city/surrounding areas heavily populated	9
Liverpool provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	9
Liverpool : have personal experience of the services (I/family/friend was/is being treated there)	5
Liverpool has easy access/close to motorway/good transport links/good parking	4
Service at Liverpool closing would increase travel times for families in the area	4
Liverpool has a good reputation locally/nationally/internationally	2
Liverpool - other positive	8
Negative (NET)	42
Liverpool should not be in all of the options	11
Liverpool is not well placed/too far away from larger centres/poor location	9
Liverpool should not be one of the options/support the closure of services at Liverpool	8
Liverpool is a split site/not a co-located site	7
Liverpool has a poor reputation	4
Liverpool has poor access/limited transport links/poor parking/confusing road infrastructure	1
Liverpool - other neutral	2
Liverpool - other negative	4
Subnet: The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman) (NET)	570
Positive (NET)	508
Options/possible closure (NET)	444
Service at Newcastle should remain open/should be included as one of the options/I support Newcastle	388
Newcastle: have personal experience of the services (I/family/friend was/is being treated there)	35
Service at Newcastle closing would increase travel times for families in the area	29
Newcastle: closing Newcastle would leave numbers of patients/children at risk	19
Service at Newcastle closing would impact on expertise/training/research	10
Service at Newcastle closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	8
Newcastle - other positive	25
Newcastle - other negative	32
Newcastle - other neutral	6
Standard of care (NET)	258
Newcastle provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	251
Newcastle has a good reputation locally/nationally/internationally	29
Location/population (NET)	188
Newcastle is centrally located/covers a wide region/geographically well placed (including Scotland, Northern Ireland and Isle of Man)	127

Newcastle provides ECMO/transplant/specialist facilities	50
Newcastle is able to provide cradle to old age care	13
Newcastle treats large numbers of patients	9
Newcastle has easy access/close to motorway/good transport links/good parking	8
Newcastle can already/has the capacity to provide a full range of services in one location	6
Newcastle is in a densely populated area/large city/surrounding areas heavily populated	5
Facilities	3
Negative (NET)	82
Newcastle is a split site/not a co-located site	31
Newcastle is not well placed/too far away from larger centres/poor location	21
Newcastle (and surrounding areas) does not have a large population	18
Newcastle should not be one of the options/support the closure of services Newcastle	16
Newcastle does not treat large numbers of patients/not as much as other locations	11
Newcastle is a small facility/limited capacity for further services	1
Subnet: University Hospitals Bristol NHS Foundation Trust (NET)	127
Negative (NET)	73
Bristol should not be one of the options/support the closure of services at Bristol	22
Bristol should not be in all of the options	21
Bristol - other negative	15
Bristol has a poor reputation/history etc	12
Bristol scored poorly in the review/lower than other services	9
Bristol is not well placed/too far away from larger centres/poor location	7
Bristol has poor access/limited transport links/poor parking/confusing road infrastructure	2
Positive (NET)	56
Service at Bristol should remain open/should be included as one of the options/I support Bristol	36
Bristol is centrally located/covers a wide region/geographically well placed (Wales)	20
Bristol provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	6
Bristol : have personal experience of the services (I/family/friend was/is being treated there)	3
Bristol is in a densely populated area/large city/surrounding areas heavily populated	3
Service at Bristol closing would increase travel times for families in the area	2
Bristol has easy access/close to motorway/good transport links/good parking	1
Bristol has a good reputation locally/nationally/internationally	1
Bristol is my nearest centre/closest to my home	1
Bristol - other positive	8
Bristol - other neutral	7
Subnet: Unspecified hospitals (NET)	124
Location/population (NET)	76
Unspec hospital has easy access/close to motorway/good transport links/good parking	58
Unspec hospital is centrally located/covers a wide region/geographically well placed	47
Unspec hospital is accessible by helicopter/has a helipad	6
Unspec hospital is my nearest centre/closest to my home (least disruptive)	5
Unspecified hospital is in a densely populated area/large city/surrounding areas heavily populated	1
Facilities (NET)	60
Unspec hospital has an ECMO facility	48
Unspec hospital provides accommodation/facilities for families (Good parent facilities)	43
Unspec hospital can already/has the capacity to provide a full range of services in one location	2
Options/possible closure (NET)	59
Service at (unspecified) should remain open/should be included as one of the options/I support this hospital (unspec)	27
Unspecified Service - retaining service offers least disruption to families	17
Unspec hospital - Have personal experience of the services (I/family/friend was/is being treated there)	11

Unspecified service cuts down costs for families/parents visiting/taking children to hospital etc delete	6
Service at (unspecified hospital) closing would increase travel times for families in the area	3
Unspecified Service: cuts down costs for families/parents visiting/taking children to hospital etc	3
Unspec hospital - other positive	5
Unspec hospital - other negative	1
Standard of care (NET)	51
Unspec hospital provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	50
Unspec hospital has a good reputation locally/nationally/internationally	3
Subnet: Birmingham Children's Hospital NHS Foundation Trust net1 = (NET)	124
Positive (NET)	68
Service at Birmingham should remain open/should be included as one of the options/I support Birmingham	38
Birmingham provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	15
Birmingham is centrally located/covers a wide region/geographically well placed	14
Birmingham - other positive	8
Birmingham (or a central location) should take on ECMO/Transplant/ECMO and Transplant facilities	4
Birmingham: have personal experience of the services (I/family/friend was/is being treated there)	3
Birmingham is in a densely populated area/large city/surrounding areas heavily populated	2
Birmingham is my nearest centre/closest to my home	1
Birmingham has easy access/close to motorway/good transport links/good parking	1
Negative (NET)	58
Birmingham and Leicester/Leeds are close together	13
Birmingham should not be in all of the options	9
Birmingham should not be one of the options/support the closure of services at Birmingham	6
Birmingham has poor access/limited transport links/poor parking/confusing road infrastructure	6
Birmingham is not well placed/too far away from larger centres/poor location	5
Birmingham is a split site/not a co-located site	4
Birmingham - other negative	20
Birmingham - other neutral	4
Subnet: Great Ormond Street Hospital for Children NHS Trust (GOSH) (NET)	33
Service at GOSH should remain open/should be included as one of the options/I support GOSH	22
GOSH provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise	11
GOSH is centrally located/covers a wide region/geographically well placed	3
GOSH : have personal experience of the services (I/family/friend was/is being treated there)	2
GOSH - other positive	4
GOSH - other neutral	1
GOSH - other negative	3
Subnet: Oxford Radcliffe Hospitals NHS Trust (NET)	30
Positive (NET)	25
Oxford can already/has the capacity to provide a full range of services in one location	13
Service at Oxford should remain open/should be included as one of the options/should resume surgery	7
Oxford provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	2
Oxford - other positive	1
Oxford - other negative	3
Negative (NET)	5

Oxford should not be one of the options/support the closure of Oxford	4
Oxford has a poor reputation	1
Subnet: Royal Brompton & Harefield (NET)	27
Service at Royal Brompton should remain open/should be included as one of the options/I support Royal Brompton	21
Royal Brompton provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	5
Closing Royal Brompton would leave numbers of patients/children at risk/adult care/other services may have to close	2
Royal Brompton is able to provide cradle (childhood) to old age care (adulthood)	1
Royal Brompton can already/has the capacity to provide a full range of services in one location	1
Royal Brompton has a good reputation locally/nationally/internationally	1
Royal Brompton - other positive	1
Royal Brompton - other neutral	1
Royal Brompton - other negative	4
Subnet: Evelina Children's Hospital - Guy's and St Thomas NHS Foundation Trust (NET)	22
Service at Evelina should remain open/should be included as one of the options/I support Evelina	16
Evelina is ranked highly in the country/in the performance review/has excellent results	4
Evelina provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise	1
Evelina - other negative	3
Evelina - other neutral	1
Other negative comments on the consultation/review process/document - narrow/oversimplistic	45
Other positive comments on the consultation/review process/document - potential for improvement etc	6
Don't know/know nothing about these hospitals	62
Other - Negative comments	228
Other - Neutral comments	158
Other - Positive comments	64

Q.16 Please give your reasons for your preferred configuration for the location of the Specialist Surgical Centres in the future.	
	Total
Total	51663
OTHER (NET)	6758
Geographical spread (NET)	3730
Needs to/should be based on geographical spread/locations/fair spread across the country	2525
Reduces extra travel for patients in the North	877
Provides a workable model for Northern units	288
Centres should be close to motorway/good transport links/these have the best links/easy parking/transport	148
Need to be located close to centres of high population/closest to the most amount of people/near to large cities	107
Poor options for people living in the South of England (including Channel Islands/IOW)	65
Midlands needs two centres/Midlands has a bigger population than London/should have 2 centres also	49

Needs to be closest to my home as possible/this is closest to my house/nearest to me	44
Poor options for people living in the North of England/UK/Scotland/the North needs to be covered/covers the North	40
Poor options for people living in the East/East Midlands of England/the East/East Midlands needs to be covered	17
Air ambulance retrieval needs to be utilised/utilised more	6
Spread/options/facilities/centres should be regional, not national	5
All of the options are too far away from me/us (any location/not London)	3
Midlands - support 1 centre	3
Well developed networks/co-location of other service (Foetal medicine network, neonatal network)	3
Other location/facility numbers in areas type comments	47
Standard of care (NET)	3543
Quality/expertise/reputation (include high scoring facilities) should be the key	3167
Three highest scoring quality hospitals in the South of England	274
Quality of service takes precedence over location/length of travel	73
Care will suffer for those not near services/long distance travel will put lives at risk	20
Should be based on what is best for children and families	2
Patient outcomes could be improved by better co-ordination/shared practice and integration of existing services	1
Number of interventional catheter procedures carried out should be taken into account/sites may be lost after S&S	1
Other care related comments	69
Facilities (NET)	1248
Makes sure all centres reach the minimum 400 operations/target caseload/volumes	615
Keep(s) ECMO and Transplantation (specialist) services in their current location(s) (merge 210/211 and Option A relocation of services)	192
This option would mean least disruption to families/important for the services to be least disruptive to families	117
Centres than can already/have the capacity to provide a full range of services in one location most important factor	105
Don't close any/keep all hospitals/facilities open/stay as they are/all are important	93
Accommodation facilities/parent services must be available/these centres have accommodations/parent facilities	93
Two transplant facilities is important/needed/necessary/do not agree with 1 transplant centre	64
Allows retrieval of patients from anywhere in the UK (incl IOW) within the stipulated time (campaign 5)	60
This would mean the least impact on PICU (Paediatric intensive care unit) services	41
ECMO facilities/these have ECMO capability/services with ECMO facilities are paramount	27
More facilities the better/need as many services as possible	25
This option/these facilities are able to provide cradle (childhood) to old age care (adulthood)	16
Ensures equity of provision/equality for patients/should be equity for all patients	9
This option would mean fewer centres closing	7
Centres should be appropriately funded	5
Centres should be appropriately managed	2
Three ECMO facilities are needed	1
Other Comments (NET)	1229
Support 3 London centres/all three London Centres should be retained	770
Alder Hey/Liverpool and Birmingham are included in all the options	351
Patient choice is a fundamental principle of NHS	262
Support configuration with 5/6/7 - more centres outside London	39

Other London related comments	38
Support 1 London centre/configuration with 1 London facility/centre	33
This is the option that retains centres without having to waste money on developing further services	33
Other personal costs comments (travel costs/accommodation costs etc)	32
Support 2 London centres/configuration with 2 London facilities/centre	20
London has/serves a large population	6
We must not allow political decisions to be made/politics must not play a part in the options/Govt should rethink	5
Alternative option suggestions	5
London has good transport links/easy to access from anywhere in the country	4
Facilities outside of London are important/surgery outside of London is crucial for all	3
Misc (NET)	97
Comments solely about London based services (GOSH/Evelina/Royal Brompton/other London services)	19
Most appropriate configuration /best option/I know these ones (unspecified) no mention of quality/travel/location	17
Options are based on inaccurate data/false choices/inappropriate weighting	16
Disagree with proposals/lacks common sense/joined up thinking/don't agree with any options	12
Disagree - This is just a cost cutting exercise/disgraceful when the government wastes money elsewhere	10
Agree with proposals/make sense/sound good/they are vital etc - general positive comments	5
Questionnaire is confusing/poorly constructed	4
Disagree - This will cost lives/impact negatively children's health	3
Consultation document does not provide enough/appropriate information	3
There is no evidence that carrying out 400 procedures per year leads to better outcomes	3
Would have been more sensible to look at existing centres/development centres and map these to cardiac centres	3
Where is the evidence for the number of procedures to be performed/are the target numbers appropriate	3
All centres considered in the review, with the exception of Oxford, were shown to be safe	1
Support other hospital or other location	4
Preferred option (NET)	835
Option A (NET)	416
Negative (NET)	268
Option A requires Leeds to be involved in 4 networks, which would cause communication difficulties	265
Option A is the worst one/oppose A	4
Positive (NET)	148
Support Option A/Option A is the best one	132
Option A offers the least disruption/no relocation of services required	16
Option B (NET)	362
Positive (NET)	356
Support Option B/Option B is the best one	356
Negative (NET)	6
Option B is the worst one/oppose B	5
Option B is unsustainable/should not be an option/don't understand the logic/it's too southern biased (coexistence of Southampton and Bristol)	1
Option D (NET)	76
Positive (NET)	72

Support Option D/Option D is the best one	72
Negative (NET)	4
Option D not viable as they would have to move transplant and ECMO from the specialised team	3
Option D has too few centres	1
Option D is the worst one/oppose D	1
Option C (NET)	2
Negative (NET)	2
Option C is the worst one/oppose C	1
Option C has too few centres	1
Subnet: Leeds Teaching Hospitals NHS Trust (NET)	769
Options/possible closure (NET)	698
Service at Leeds should remain open/Leeds should be included as one of the options/I support Leeds	671
Service at Leeds closing would increase travel times for families in the area	47
Leeds: have personal experience of the services (I/family/friend was/is being treated there)	15
Leeds: closing Leeds would leave numbers of patients/children at risk	4
Leeds is in only one of the options/do not agree with this	1
Leeds - other positive	11
Leeds - other negative	2
Leeds - Other neutral	3
Positive (NET)	694
Facilities (NET)	591
Leeds can already/has the capacity to provide a full range of services in one location co location of services	586
Leeds is able to provide cradle to old age care	9
Leeds has well developed networks/links (Foetal medicine network, neonatal network, cardiac network etc)	3
Leeds is a training/teaching hospital	2
Standard of care (NET)	548
Leeds provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise	548
Location/population (NET)	100
Leeds is centrally located/covers a wide region/geographically well placed (including Yorkshire is the biggest county)	63
Leeds is in a densely populated area/large city/surrounding areas heavily populated	38
Leeds has easy access/close to motorway/good transport links/good parking	16
Leeds is my nearest centre/closest to my home	10
Negative (NET)	9
Leeds scored poorly in the review/lower than other services	8
Leeds should not be one of the options/support the closure of services at Leeds	2
Other (NET)	1
Leeds cuts down costs for families/parents visiting/taking children to hospital etc	1
Subnet: Southampton University Hospitals NHS Trust (NET)	752
Positive (NET)	749
Options/possible closure (NET)	532
Southampton is ranked 2nd in the country/in the performance review/has excellent results	279
Service at Southampton should remain open/should be included as one of the options/I support Southampton	247
Southampton: have personal experience of the services (I/family/friend was/is being treated there)	60
Service at Southampton closing would increase travel times for families in the area	36

Closing Southampton would leave numbers of patients/children at risk	15
Southampton is in only one of the options/do not agree with this	11
Service at Southampton closing would impact on expertise/training/research	5
Southampton - other positive	9
Southampton - other negative	15
Southampton - other neutral	10
Standard of care (NET)	393
Southampton provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	329
Southampton has a good reputation locally/nationally/internationally	111
Southampton works in partnership with Oxford/has a network model with Oxford	43
Southampton is able to provide cradle (childhood) to old age care (adulthood)	1
Location/population (NET)	163
Southampton is centrally located/covers a wide region/geographically well placed	104
Southampton has easy access/close to motorway/good transport links/good parking	41
Southampton is my nearest centre/closest to my home	26
Southampton is in a densely populated area/large city/surrounding areas heavily populated	7
Facilities (NET)	120
Southampton treats large numbers of patients	92
Southampton can already/has the capacity to provide a full range of services in one location	19
Southampton is a training/teaching hospital	4
Southampton has well developed networks (Foetal medicine network, neonatal network, cardiac network etc)	3
Southampton provides accommodation/facilities for families (for families)	2
Negative (NET)	4
Southampton should not be one of the options/support the closure of services at Southampton	4
Subnet: Birmingham Children's Hospital NHS Foundation Trust net1 = (NET)	619
Positive (NET)	593
Birmingham (or a central location) should take on ECMO/Transplant/ECMO and Transplant facilities	498
Service at Birmingham should remain open/should be included as one of the options/I support Birmingham	66
Birmingham is centrally located/covers a wide region/geographically well placed	30
Birmingham provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	10
Birmingham has easy access/close to motorway/good transport links/good parking	6
Birmingham - other positive	6
Birmingham is in a densely populated area/large city/surrounding areas heavily populated	5
Birmingham is my nearest centre/closest to my home	5
Birmingham: have personal experience of the services (I/family/friend was/is being treated there)	3
Negative (NET)	21
Birmingham should not be one of the options/support the closure of services at Birmingham	8
Birmingham has poor access/limited transport links/poor parking/confusing road infrastructure	7
Birmingham and Leicester/Leeds are close together	2
Birmingham is not well placed/too far away from larger centres/poor location	1
Birmingham - other negative	9
Birmingham - other neutral	8
Subnet: University Hospitals of Leicester NHS Trust (Glenfield) (NET)	593

Positive (NET)	492
Location/population (NET)	327
Glenfield is centrally located/covers a wide region/geographically well placed	190
Glenfield has easy access/close to motorway/good transport links/good parking	177
Glenfield is my nearest centre/closest to my home	80
Glenfield is accessible by helicopter/has a helipad	20
Glenfield is in a densely populated area/large city/surrounding areas heavily populated	9
Standard of care (NET)	304
Glenfield provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	279
Glenfield has a good reputation locally/nationally/internationally	42
Facilities (NET)	285
Glenfield has an ECMO facility	228
Glenfield provides accommodation/facilities for families (for families)	126
Glenfield can already/has the capacity to provide a full range of services in one location	23
Glenfield has Heartlink (children's charity)	19
Glenfield is able to provide cradle to old age care	18
Glenfield is a training/teaching hospital	13
Glenfield treats large numbers of patients (including from other hospitals/regions)	4
Glenfield has well developed networks/links (Foetal medicine network, neonatal network, cardiac network etc)	3
Other (NET)	69
Glenfield - other positive	32
Glenfield cuts down costs for families/parents visiting/taking children to hospital etc	30
Glenfield - other neutral	7
Options/possible closure (NET)	301
Service at Glenfield should remain open/Glenfield should be included as one of the options/I support Glenfield	192
Glenfield :have personal experience of the services (I/family/friend was/is being treated there)	87
Glenfield - retaining Glenfield offers least disruption to families	38
Service at Glenfield closing would increase travel times for families in the area	36
Closing Glenfield would leave numbers of patients/children at risk	15
Service at Glenfield closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	10
Service at Glenfield closing would impact on expertise/training/research	10
Glenfield is in only one of the options/do not agree with this	1
Negative (NET)	25
Glenfield should not be one of the options/support the closure of services at Glenfield	11
Glenfield scored poorly in the review/lower than other services	8
Glenfield is a split site/not a co-located site	2
Glenfield - other negative	8
Subnet: Unspecified hospitals (NET)	446
Location/population (NET)	338
Unspec hospital is centrally located/covers a wide region/geographically well placed	199
Unspec hospital has easy access/close to motorway/good transport links/good parking	181
Unspec hospital is my nearest centre/closest to my home (least disruptive)	102
Unspec hospital is accessible by helicopter/has a helipad	15

Unspecified hospital is in a densely populated area/large city/surrounding areas heavily populated	7
Standard of care (NET)	239
Unspec hospital provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	233
Unspec hospital has a good reputation locally/nationally/internationally	18
Facilities (NET)	192
Unspec hospital has an ECMO facility	144
Unspec hospital provides accommodation/facilities for families (Good parent facilities)	122
Unspec hospital can already/has the capacity to provide a full range of services in one location	12
Options/possible closure (NET)	163
Unspec hospital - Have personal experience of the services (I/family/friend was/is being treated there)	52
Unspecified Service - retaining service offers least disruption to families	51
Unspecified Service: cuts down costs for families/parents visiting/taking children to hospital etc	31
Service at (unspecified) should remain open/should be included as one of the options/I support this hospital (unspec)	31
Service at (unspecified hospital) closing would increase travel times for families in the area	7
Unspecified service cuts down costs for families/parents visiting/taking children to hospital etc delete	1
Unspec hospital - other positive	11
Unspec hospital - other negative	4
Unspec hospital - other neutral	5
Subnet: The Newcastle-Upon-Tyne Hospitals NHS Foundation Trust (Freeman) (NET)	162
Positive (NET)	135
Options/possible closure (NET)	102
Service at Newcastle should remain open/should be included as one of the options/I support Newcastle	82
Newcastle: have personal experience of the services (I/family/friend was/is being treated there)	18
Service at Newcastle closing would increase travel times for families in the area	9
Service at Newcastle closing would impact on expertise/training/research	3
Newcastle: closing Newcastle would leave numbers of patients/children at risk	2
Service at Newcastle closing would be a waste of money/money has been spent on this facility recently and makes no sense to close it	1
Newcastle - other positive	5
Newcastle - other negative	4
Newcastle - other neutral	4
Standard of care (NET)	70
Newcastle provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	68
Newcastle has a good reputation locally/nationally/internationally	5
Location/population (NET)	46
Newcastle is centrally located/covers a wide region/geographically well placed (including Scotland, Northern Ireland and Isle of Man)	31
Facilities	6
Newcastle provides ECMO/transplant/specialist facilities	4
Newcastle can already/has the capacity to provide a full range of services in one location	3
Newcastle is in a densely populated area/large city/surrounding areas heavily populated	1
Newcastle has easy access/close to motorway/good transport links/good parking	1

Newcastle treats large numbers of patients	1
Negative (NET)	30
Newcastle is not well placed/too far away from larger centres/poor location	11
Newcastle should not be one of the options/support the closure of services Newcastle	9
Newcastle is a split site/not a co-located site	7
Newcastle (and surrounding areas) does not have a large population	7
Newcastle does not treat large numbers of patients/not as much as other locations	3
Subnet: Royal Brompton & Harefield (NET)	150
Service at Royal Brompton should remain open/should be included as one of the options/I support Royal Brompton	93
Royal Brompton provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	81
Royal Brompton: have personal experience of the services (I/family/friend was/is being treated there)	38
Royal Brompton has a good reputation locally/nationally/internationally	9
Closing Royal Brompton would leave numbers of patients/children at risk/adult care/other services may have to close	6
Royal Brompton treats large numbers of patients	3
Royal Brompton is able to provide cradle (childhood) to old age care (adulthood)	1
Royal Brompton - other positive	15
Royal Brompton - other neutral	12
Royal Brompton - other negative	7
Subnet: Alder Hey Children's NHS Foundation Trust (Liverpool) (NET)	87
Positive (NET)	85
Service at Liverpool should remain open/should be included as one of the options/I support Liverpool	60
Liverpool is centrally located/covers a wide region/geographically well placed (including Isle of Man and Wales)	13
Liverpool provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	9
Liverpool : have personal experience of the services (I/family/friend was/is being treated there)	4
Liverpool should take on ECMO/Transplant/ECMO and Transplant facilities	3
Liverpool has a good reputation locally/nationally/internationally	2
Liverpool is in a densely populated area/large city/surrounding areas heavily populated	2
Liverpool has easy access/close to motorway/good transport links/good parking	2
Service at Liverpool closing would increase travel times for families in the area	2
Liverpool can already/has the capacity to provide a full range of services in one location	1
Liverpool - other positive	4
Negative (NET)	7
Liverpool - other neutral	5
Liverpool - other negative	2
Subnet: University Hospitals Bristol NHS Foundation Trust (NET)	65
Positive (NET)	41
Bristol is centrally located/covers a wide region/geographically well placed (Wales)	20
Service at Bristol should remain open/should be included as one of the options/I support Bristol	20
Bristol has easy access/close to motorway/good transport links/good parking	3
Bristol : have personal experience of the services (I/family/friend was/is being treated there)	2
Bristol provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise/staff/service/facilities	1

Bristol should take on ECMO/Transplant/ECMO and Transplant facilities	1
Bristol is in a densely populated area/large city/surrounding areas heavily populated	1
Bristol has a good reputation locally/nationally/internationally	1
Service at Bristol closing would increase travel times for families in the area	1
Bristol - other positive	3
Bristol - other neutral	6
Negative (NET)	24
Bristol should not be one of the options/support the closure of services at Bristol	9
Bristol - other negative	7
Bristol should not be in all of the options	3
Bristol has poor access/limited transport links/poor parking/confusing road infrastructure	2
Bristol scored poorly in the review/lower than other services	2
Bristol is not well placed/too far away from larger centres/poor location	2
Bristol has a poor reputation/history etc	2
Subnet: Great Ormond Street Hospital for Children NHS Trust (GOSH) (NET)	62
Service at GOSH should remain open/should be included as one of the options/I support GOSH	32
GOSH provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise	26
GOSH : have personal experience of the services (I/family/friend was/is being treated there)	12
GOSH has a good reputation locally/nationally/internationally	8
GOSH is centrally located/covers a wide region/geographically well placed	4
GOSH is my nearest centre/closest to my home (causes least disruption)	2
GOSH - other positive	12
GOSH - other neutral	3
GOSH - other negative	2
Subnet: Oxford Radcliffe Hospitals NHS Trust (NET)	43
Positive (NET)	32
Oxford can already/has the capacity to provide a full range of services in one location	13
Service at Oxford should remain open/should be included as one of the options/should resume surgery	9
Oxford - other positive	12
Oxford - other neutral	4
Oxford - other negative	6
Negative (NET)	13
Oxford should not be one of the options/support the closure of Oxford	13
Oxford has a poor reputation	1
Subnet: Evelina Children's Hospital - Guy's and St Thomas NHS Foundation Trust (NET)	36
Service at Evelina should remain open/should be included as one of the options/I support Evelina	16
Evelina provides high quality/excellent cardiac care/surgery/specialist procedures/experience/expertise	10
Evelina: have personal experience of the services (I/family/friend was/is being treated there)	8
Evelina is ranked highly in the country/in the performance review/has excellent results	4
Evelina is my nearest centre/closest to my home	1
Evelina - other positive	7
Evelina - other negative	4
Other negative comments on the consultation/review process/document - narrow/oversimplistic	1
Don't know/know nothing about these hospitals	22

Other - Negative comments	22
Other - Neutral comments	107
Other - Positive comments	4

Q.18 What, if any, comments do you have about the assumptions we have made concerning how postcodes have been assigned in any of the four options for the Specialist Surgical Centres?	
	Total
Total	51663
Negative comments (NET)	7885
Data (NET)	7609
Ignores patient choice/parents/families should have a say in where their child is treated	5947
Don't agree with forcing families/patients/children to travel further away/to lower quality centres	1005
Will result in risk of greater harm/higher mortality rates if people have to travel further/risking lives/dangerous	692
Data is inaccurate/poorly researched/poor idea/don't agree/not well thought out/unfair on people	651
Will result in further inconvenience/family disruption/causing less family disruption needs consideration	535
Will increase travel costs for families/patients/consider families' finances	503
Disagree with assumptions concerning patient flow	493
Diagram in the consultation document (page 109) is wrong as Southampton takes patients from postcodes attributed to Bristol/other areas	490
Discrepancies in the document do not give credibility to this process	328
Work on travel times is incorrect/needs modifying/more research/road networks/air travel	220
Ignores the wishes of doctors/paediatricians/doctors views/opinions need to be included	198
Agree with assumptions concerning patient flow	195
Emerging local intelligence of Postcodes is not an accurate reflection of patient views	185
Ignores existing networks/other specialties (PICU, Adult cardiac, neonatal, neurosurgery etc)	67
Based on the differences of surgical procedures or patient treatment/referral requirements in hospitals	54
Other negative comments	123
Regions (NET)	471
South of England is not adequately covered (Southampton/Isle of Wight/Channel Islands etc)	384
North of England/UK/Scotland/Yorkshire is not adequately covered (Scotland incl)/covers the North	71
East of England is not adequately covered	13
West of England/UK/Wales is not adequately covered	5
West of England is favoured over East England	2
Other positive comments	47
Neutral comments (NET)	5675
Quality needs to be decisive factor/quality centres are what matters/more important than location	5201
Keep services local/minimise travel times/geographical locations	298
Accurate data is essential/important/good data can only improve services	97
Population density should be the decisive factor/is important	71
Centres should offer a full range of services on one site/co location of facilities is important	34
Need more centres/have as many centres as possible	24

Cost of setting up/not needing to spend money on new/upgrading facilities should be considered	24
Keep bureaucracy to a minimum	22
Data should be made public	19
System is already in place/its safe/works well	18
People/patients will travel - not specified further	10
Other (NET)	3881
The Oxford - Southampton partnership provides a model of joint working between centres	2898
Hospitals (NET)	1020
Service at Southampton should remain open/should be included as one of the options/I support Southampton	525
Service at Liverpool should remain open/should be included as one of the options/I support Liverpool	225
Service at Glenfield should remain open/Glenfield should be included as one of the options/I support Glenfield	116
Service at Leeds should remain open/Leeds should be included as one of the options/I support Leeds	93
Service at Newcastle should remain open/should be included as one of the options/I support Newcastle	32
Service at Royal Brompton should remain open/should be included as one of the options/I support Royal Brompton	28
Service at GOSH should remain open/should be included as one of the options/I support GOSH	17
Service at Birmingham should remain open/should be included as one of the options/I support Birmingham	16
Service in (unspecified London) should remain open/should be included as one of the options/I support unspecified London	11
Service at Evelina should remain open/should be included as one of the options/I support Evelina	7
Service at unspecified hospital should remain open/should be included as one of the options	4
Service at Bristol should remain open/should be included as one of the options/I support Bristol	4
Preferred option (NET)	1307
Option D (NET)	604
Support Option D/Option D is the best one	592
Option D offers the best geographical spread/less travel times	12
Option B (NET)	543
Option B is not viable as Southampton cannot generate enough work	304
Option B forces people to travel too far	213
Support Option B/Option B is the best one	97
Option B offers the best geographical spread (includes IOW/Channel Islands retrieval times)	78
Option B offers the best quality care best scores/survival rates/innovation/staff etc	71
Option A (NET)	198
Support Option A/Option A is the best one	112
Option A offers the best geographical spread/less travel times	69
Option A offers the best postcode allocation	18
Option A offers the best quality care	6
Option A offers the best catchment (population)	3
Option C (NET)	2
Option C offers the best geographical spread	1
Support Option C/Option C is the best one	1
Postcodes (NET)	615
This is a postcode lottery/do not agree with postcode lottery/postcodes should be irrelevant	385
Inappropriate postcode groupings/distributions	236

Positive comments (NET)	119
Good idea/support the proposal/seems fair/sensible	85
Offers a good geographical spread/easy travel for patients/minimises retrieval times	30
Offers best quality care/facilities	16
Misc (NET)	68
Unfavourable comments about consultation/not enough information in the consultation	53
Have not read the document/document not available/wouldn't download etc	15
Least preferred option (NET)	34
Option B is the worst one	16
Option D is the worst one	15
Option C is the worst one	8
Option A is the worst one	7

Appendix E: Numbers of text messages received

The following table illustrates the number of blank and non-blank text messages received to the public consultation.

		Number of messages sent not including blanks																												
		0	1	2	3	4	5	6	7	8	9	10	11	12	13	14	16	18	21	22	23	25	30	Total						
Number of messages sent including blanks	1	2895	19777																							22672				
	2	6	74	549																						629				
	3		1	9	79																						89			
	4				1	38																					39			
	5					3	18																				21			
	6							17																			17			
	7								7																		7			
	8									15																	15			
	9										7																7			
	10											7															7			
	11												2														2			
	12													1	2												3			
	13															1											1			
	14																1										1			
	16																	1									1			
	18																		1								1			
21																			1							1				
22																				1						1				
23																					1					1				
25																						1				1				
30																							1			1				
55																								1		1				
Total	2901	19852	558	80	41	18	17	7	15	7	7	3	2	1	1	1	1	1	1	1	1	1	1	2	23518					

- 0 Blank Messages
- 1 Blank Message
- 2 Blank Messages
- > 2 Blank Messages

