Public Document Pack

Health Overview and Scrutiny Panel

Thursday, 15th September, 2011
at 5.00 pm

PLEASE NOTE TIME OF MEETING

Committee Rooms 1 and 2 - Civic Centre

This meeting is open to the public

Members

Councillor Capozzoli (Chair)
Councillor Daunt
Councillor Fitzgerald
Councillor Parnell (Vice-Chair)
Councillor Payne
Councillor Thorpe
Councillor Turner

Contacts

Sharon Pearson/Karen Wardle
Democratic Support Officer
Tel: 023 8083 4597/2302
Email: sharon.pearson@southampton.gov.uk
Email: karen.wardle@southampton.gov.uk

Caronwen Rees
Policy & Performance Analyst
Tel: 023 8083 2524
Email: Caronwen.rees@southampton.gov.uk

PUBLIC INFORMATION

Southampton City Council's Seven Priorities

- More jobs for local people
- More local people who are well educated and skilled
- A better and safer place in which to live and invest
- Better protection for children and young people
- Support for the most vulnerable people and families
- Reducing health inequalities
- Reshaping the Council for the future

Fire Procedure – in the event of a fire or other emergency a continuous alarm will sound and you will be advised by Council officers what action to take.

Access – access is available for the disabled. Please contact the Democratic Support Officer who will help to make any necessary arrangements.

Public Representations

At the discretion of the Chair, members of the public may address the meeting about any report on the agenda for the meeting in which they have a relevant interest.

Smoking policy – the Council operates a no-smoking policy in all civic buildings.

Mobile Telephones – please turn off your mobile telephone whilst in the meeting.

Dates of Meetings: Municipal Year 2011/12

2011	2012
Weds 22 June	Thurs 19 January
Tues 26 July	Thurs 29 March
Thurs 15 September	
Thurs 10 November	

CONDUCT OF MEETING

Terms of Reference

The terms of reference of the Audit Committee are contained in Article 8 and Part 3 (Schedule 2) of the Council's Constitution.

Business to be discussed

Only those items listed on the attached agenda may be considered at this meeting.

Rules of Procedure

The meeting is governed by the Council Procedure Rules as set out in Part 4 of the Constitution.

Quorum

The minimum number of appointed Members required to be in attendance to hold the meeting is 3.

Disclosure of Interests

Members are required to disclose, in accordance with the Members' Code of Conduct, ***both*** the existence ***and*** nature of any "personal" or "prejudicial" interests they may have in relation to matters for consideration on this Agenda.

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Personal Interests

A Member must regard himself or herself as having a personal interest in any matter

(i) if the matter relates to an interest in the Member's register of interests; or

(ii) if a decision upon a matter might reasonably be regarded as affecting to a greater extent than other Council Tax payers, ratepayers and inhabitants of the District, the wellbeing or financial position of himself or herself, a relative or a friend or:-

  (a) any employment or business carried on by such person;

  (b) any person who employs or has appointed such a person, any firm in which such a person is a partner, or any company of which such a person is a director;

  (c) any corporate body in which such a person has a beneficial interest in a class of securities exceeding the nominal value of £5,000; or

  (d) any body listed in Article 14(a) to (e) in which such a person holds a position of general control or management.

A Member must disclose a personal interest.

Continued/……

Prejudicial Interests

Having identified a personal interest, a Member must consider whether a member of the public with knowledge of the relevant facts would reasonably think that the interest was so significant and particular that it could prejudice that Member's judgement of the public interest. If that is the case, the interest must be regarded as "prejudicial" and the Member must disclose the interest and withdraw from the meeting room during discussion on the item.

It should be noted that a prejudicial interest may apply to part or the whole of an item.

Where there are a series of inter-related financial or resource matters, with a limited resource available, under consideration a prejudicial interest in one matter relating to that resource may lead to a member being excluded from considering the other matters relating to that same limited resource.

There are some limited exceptions.

Note: Members are encouraged to seek advice from the Monitoring Officer or his staff in Democratic Services if they have any problems or concerns in relation to the above.

Principles of Decision Making

All decisions of the Council will be made in accordance with the following principles:-

- proportionality (i.e. the action must be proportionate to the desired outcome);
- due consultation and the taking of professional advice from officers;
- respect for human rights;
- a presumption in favour of openness, accountability and transparency;
- setting out what options have been considered;
- setting out reasons for the decision; and
- clarity of aims and desired outcomes.

In exercising discretion, the decision maker must:

- understand the law that regulates the decision making power and gives effect to it. The decision-maker must direct itself properly in law;
- take into account all relevant matters (those matters which the law requires the authority as a matter of legal obligation to take into account);
- leave out of account irrelevant considerations;
- act for a proper purpose, exercising its powers for the public good;
- not reach a decision which no authority acting reasonably could reach, (also known as the "rationality" or "taking leave of your senses" principle);
- comply with the rule that local government finance is to be conducted on an annual basis. Save to the extent authorised by Parliament, 'live now, pay later' and forward funding are unlawful; and
- act with procedural propriety in accordance with the rules of fairness.

AGENDA

Agendas and papers are now available via the City Council's website

1 APOLOGIES AND CHANGES IN MEMBERSHIP (IF ANY)

To note any changes in membership of the Panel made in accordance with Council Procedure Rule 4.3.

2 DISCLOSURE OF PERSONAL AND PREJUDICIAL INTERESTS

In accordance with the Local Government Act, 2000, and the Council's Code of Conduct adopted on 16th May, 2007, Members to disclose any personal or prejudicial interests in any matter included on the agenda for this meeting.

NOTE: Members are reminded that, where applicable, they must complete the appropriate form recording details of any such interests and hand it to the Democratic Support Officer prior to the commencement of this meeting.

3 DECLARATIONS OF SCRUTINY INTEREST

Members are invited to declare any prior participation in any decision taken by a Committee, Sub-Committee, or Panel of the Council on the agenda and being scrutinised at this meeting.

4 DECLARATION OF PARTY POLITICAL WHIP

Members are invited to declare the application of any party political whip on any matter on the agenda and being scrutinised at this meeting.

5 STATEMENT FROM THE CHAIR

6 MINUTES OF THE PREVIOUS MEETING (INCLUDING MATTERS ARISING)

To approve and sign as a correct record the minutes of the meeting held on 26th July 2011 and to deal with any matters arising, attached.

7 SAFE AND SUSTAINABLE - REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND, REPORT OF THE PUBLIC CONSULTATION

Report of the Executive Director of Health and Adult Social Care, providing a review of children's congenital heart services in England and a report of the public consultation for the Panel to note and to consider whether to submit a further response to the review, attached.

8 UPDATE ON ADULT SOCIAL CARE PROVIDER MARKET ISSUES

Report of the Executive Director of Health and Adult Social Care providing an update on Adult Social Care Provider Market Issues, attached.

Wednesday, 7 September 2011 HEAD OF LEGAL AND DEMOCRATIC SERVICES

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HEALTH OVERVIEW AND SCRUTINY PANEL

MINUTES OF THE MEETING HELD ON 26 JULY 2011

Present: Councillors Capozzoli (Chair), Daunt, Fitzgerald, Parnell (Items 8, 9, 10 and 11), Payne (Items 8, 9, 10 and 11), Thorpe and Turner (Items 7 and 8)

7. **ELECTION OF VICE-CHAIR**

The Panel appointed Councillor Parnell as Vice-Chair for the Municipal Year.

8. **MINUTES OF THE PREVIOUS MEETING (INCLUDING MATTERS ARISING)**

RESOLVED that the Minutes of the meeting held on 22nd June 2011 be approved and signed as a correct record, subject to an amendment on page 2, to change final paragraph under "Establishing the SHIP PCT Cluster" to read: "The mechanism for dealing with disputes and problems that might arise and decisions made by the cluster board was discussed in detail. The panel agreed they would write formally to the Cluster Board to seek re-assurance on dispute resolution between the Cluster and Local Authorities, specifically regarding the mechanism to be applied for resolving disputes regarding the eligibility of a service user for continuing care."
(Copy of the minutes circulated with the agenda and appended to the signed minutes).

9. **JOINT STRATEGIC NEEDS ASSESSMENT (JSNA)**

The Panel received, noted and commented on the report of the Executive Director of Health and Adult Social Care and Director of Public Health, on the findings of the Joint Strategic Needs Assessment (JSNA) and the arrangements for the publication of the JSNA covering the period 2011-2014. (Copy of the report circulated with the agenda and appended to the signed minutes).

The Panel received a presentation from Graham Watkinson, Public Health Consultant for NHS Southampton City and Martin Day, Strategic Business Manager, which highlighted the comments and key themes arising out of the consultation process which had taken place since September 2010. It was acknowledged that there was a legal requirement to produce the Joint Strategic Needs Assessment.

Main points from the presentation included:

- Feedback had been received from many different consultees and many data sets had been identified during the development and consultation process, some of which had highlighted areas of concern where performance in Southampton was below other towns and cities;
- Southampton has little data in some areas and there is a need to improve data collection, working with commissioning services to do so;
- It was considered important for there to be a clear mechanism for measuring outcomes of commissioning decisions taken and policies implemented;
- There was a requirement to be mindful of new and changing legislation and the changing NHS infrastructure;

- Substantial changes were expected in Southampton in the demography of the age of the population at the lower and upper end of the spectrum in the next seven years;
- The JSNA has a role to play in joining the emerging Clinical Commissioning Group and Local Authority via the Health and Wellbeing Board;
- Poverty was considered to encourage ill health and therefore it was thought important to address this issue;
- The Executive Summary needed to be reviewed regarding the language used and should be simplified to enable all to understand;
- The JSNA should signpost health assets which would enhance health and well-being of individuals;
- The integration of Public Health into the Authority will provide an opportunity to improve communication around the role other directorates can play in creating a healthier environment;
- Nine key themes had emerged from the consultation process and these themes had dovetailed with the six Marmot 2010 main policy recommendations. The following points were highlighted under the themes:
    - Improve Economic Wellbeing – the average gross weekly wage in Southampton was £54 less than other areas in England with many young people living in relative poverty;
    - Take Responsibility for Health – it was considered important to educate and empower people to take responsibility for their own health. Alcohol-specific hospital admissions for the under 18s in Southampton were high when compared with the rest of the UK. Alcohol in the UK was also relatively cheap when compared with the past and consideration about how to address this issue should be taken into account;
    - Improve Long Term Conditions – the percentage of people living in Southampton with long term medical conditions was increasing and it was considered important to try and prevent these diseases and offer more support to carers;
    - Responding to an Ageing Population - The ageing profile of Southampton was likely to increase the number of people living with disabilities, health conditions and requiring intensive support. It was considered that extending mobility and independence could be improving by encouraged access to additional enjoyable activities and helping people to stay fitter for longer. More activities to discourage social isolation were considered to be a good thing;
    - Creating a Healthy Environment – Ensuring the physical environment helped to promote walking, cycling and safe local recreation and play was considered important. As was the role of related services, for example, by encouraging warm homes, the risk of illness decreased, thereby saving NHS money.

10. **SOUTHAMPTON UNIVERSITY HOSPITALS TRUST - FOUNDATION TRUST APPLICATION**

The Panel considered and commented on the report of the Director of Communications and Public Engagement - Southampton University Hospitals Trust (SUHT), on the progress with SUHT's Foundation Trust Application (Copy of the report circulated with the agenda and appended to the signed minutes).

The Panel received a presentation from Judy Gillow (Director of Nursing) and Alison Ayers (Director of Communications), SUHT, setting out the process which had taken place from 2007 to date, including a detailed consultation which had involved key stakeholders. It was highlighted that in 2010 the process had been paused due to the national economic crisis which had caused difficulty with financial stability within the Trust. However in the spring of 2011 the Department of Health had been content to continue the process to the final stage and there had been satisfactory progress since that time. The success or otherwise of the application would be known at the end of September 2011.

Main points from the presentation included:

- By becoming a Foundation Trust, the local responsibility and accountability for managing budgets increased, and statistics from other Trusts had shown that many areas demonstrated great improvement;
- Foundation Trusts have tight frameworks in which to operate and therefore any expansion or contraction of service cannot be changed easily and required a consultation process;
- Members of the Council of the Foundation Trust represented the whole city and not wards and a view was expressed stating that the phrase used on the NHS website “Council Members” could be misleading as the public may consider them to be Members of Southampton City Council;
- It was considered to be useful for Members to establish a method of engagement with Members of the Council from SUHT;
- Good customer service was considered to be vital in maintaining the reputation of the Trust with patients and commissioners;
- There was a five year strategy report on becoming a Foundation Trust and the Panel asked for this to be circulated to their Members;
- An imminent meeting was scheduled to explore how LINK and the SUHT Council membership can work better together.

RESOLVED that the report and presentation be noted and supported by the Panel with the exception of Councillors Payne and Thorpe who abstained.

11. **TRANSFORMING OLDER PEOPLE'S MENTAL HEALTH SERVICES : PUBLIC CONSULTATION - FINAL REPORT AND RECOMMENDATIONS**

The Panel considered and commented on the report of the Head of Consumer Experience and Engagement Southern Health NHS Foundation Trust (SHFT), on the proposed closure of the Linden and Willow Wards at the Tom Rudd Unit, Moorgreen Hospital. (Copy of the report circulated with the agenda and appended to the signed minutes).

The Panel received a presentation from Pam Sorenson, Southern Health NHS Foundation Trust, updating the panel on the outcome of the public consultation and the process required to enable the closure of Linden and Willow Wards at Moorgreen hospital, which would release capacity of staff and finance. Although some redundancies would be required as a result of the changes clinical staff were not included in this aspect. Hampshire County Council and Eastleigh Borough Council had been consulted and confirmed that there was capacity for patients, if the closure took place. The Panel noted that there was a feeling that many medical services were migrating to the west of the city and that this situation needed to be monitored,

especially in connection with available transport for patients. The closed wards would be used for other purposes, in due course after consultation has taken place. It was confirmed that the impact of the changes would be the subject of a review in the future and the panel would be provided with copies of any reports of the review group.

RESOLVED to note the report with a request that there would be provision of a sustainable travel plan for residents on the east side of the city.

DECISION-MAKER:	HEALTH OVERVIEW AND SCRUTINY PANEL
SUBJECT:	SAFE AND SUSTAINABLE – REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND, REPORT OF THE PUBLIC CONSULTATION
DATE OF DECISION:	15 SEPTEMBER 2011
REPORT OF:	EXECUTIVE DIRECTOR OF HEALTH AND ADULT SOCIAL CARE
STATEMENT OF CONFIDENTIALITY	
None.	

BRIEF SUMMARY

The Health Overview and Scrutiny Panel discussed the Safe and Sustainable Review on 17 March 2011 and provided a response to the consultation (Appendix 1). Following the publication of the report of the Public Consultation on 24 August 2011 (Appendix 2), Health Overview and Scrutiny Committees (HOSCs) have an opportunity to add to their earlier submissions, should they wish to, until 5 October 2011. The Joint Committee of PCTs will consider the formal responses to the consultation proposals from the HOSCs in its decision-making process, along with an independent report to the consultation, full health impact assessment and other evidence.

RECOMMENDATIONS:

(i) To note the Report of the Public Consultation on the review of children's congenital heart services in England;

(ii) To note the publication of the Paper from Southampton University Hospitals NHS Trust to members of the JCPCT on the retrieval of critically ill children from the Isle of Wight and associated letter from Jeremy Glyde, Safe and Sustainable Programme Director, to Sir Neil McKay CB, Chair of the JCPCT, regarding the retrieval of critically ill children from the Isle of Wight

(iii) Consider if the Panel want to submit a further response to the review and the content of any such response.

REASONS FOR REPORT RECOMMENDATIONS

1. To update members on the Safe and Sustainable Review and to provide the Panel with an opportunity to submit additional feedback.

ALTERNATIVE OPTIONS CONSIDERED AND REJECTED

2. The consultation document details the full range of options that have are being considered. The Report of the Public Consultation provides details of the public's response to the consultation document.

DETAIL (Including consultation carried out)

3 **Independent Report on Public Consultation**

The 'Safe and Sustainable' review of paediatric cardiac surgical services in England consultation document setting out the options for change was published on 1 March 2011. The consultation ran until 1 July 2011. Both the HOSP and Southampton City Council provided a response to the consultation setting out a clear preference for option B, the only option which retains SUHT as a specialist surgical paediatric cardiac centre.

4. Ipsos Mori published their independent report on the public consultation on 24 August 2011. The report provides an analysis of more than 75,000 responses to the consultation. The report is comprehensive and is accompanied by a technical annexe which explains the methodology they have used to code the responses.

Key findings from the report include:

- Strong support amongst respondents for the Key Principles.
- Strong support for the need for 24/7 care in each of the Specialist Surgical Centres.
- Strong agreement that systems should be implemented to improve the collection, reporting and analysis of mortality and morbidity data.
- Option A received the highest level of support from personal respondents (58%) followed by Option B (34%), although more organisations supported Option B (41%) compared to Option A(18%).
- There were high levels of responses from people in the East Midlands and South Central regions. Option B was the most widely supported option across the country as a whole, excluding these regions.
- There were lower levels of support for Options C and D, with Option D receiving most support from respondents in the Yorkshire and Humber region.
- Three-quarters of respondents supported the proposal for two Specialist Surgical Centres in London (75% of personal respondents and 74% of organisations responding), with the majority supporting the proposed choice of Great Ormond Street Hospital for Children NHS Trust and Evelina Children's Hospital (65% of personal Respondents and 56% of organisations responding).

5. As highlighted above, although Option A was selected by more individuals than any other, more organisations supported Option B. Support for configuration options was strongly influenced by where people live. There were high levels of responses from people in the East Midlands and South Central regions. However, Option B was the most widely supported option across the country as a whole, excluding these regions. There was also a strong belief among many respondents that quality should be the deciding factor when planning future services.

6. **Retrieval of critically ill children from the Isle of Wight**

At the request of the *Safe and Sustainable* decision-making body, the Joint Committee of Primary Care Trusts (JCPCT), Southampton University Hospital NHS Trust (SUHT) has produced a report (Appendix C) on the safe retrieval of critically ill children from the Isle of Wight to provides JCPCT members with a more detailed understanding of the unique factors involved in retrieving a critically ill child by ferry. On 1 September 2011 Jeremy Glyde, *Safe and Sustainable* Programme Director, wrote to the JCPCT (Appendix D) around the emergency retrieval of children from the Isle of Wight. The letter advises that there is no available evidence that could reasonably suggest that a retrieval team from London or Bristol could reach the Isle of Wight in compliance with the time limits stipulated by the PICS standards, even if the Isle of Wight is considered to be a 'remote area' and measured by the higher time threshold of 4 hours. This advice is concordant with that provided to the JCPCT by the Paediatric Intensive Care Society in its formal response to consultation dated 23 June 2011. The secretariat will further advise the JCPCT to take these conclusions about retrievals from the Isle of Wight into account when considering the outcome of public consultation as part of the committee's deliberations to agree an eventual configuration option, and in any necessary re-

scoring of options.

7. **Health Impact Assessment: Interim Report**

In October 2010 Mott MacDonald were commissioned to carry out a Health Impact Assessment of the reconfiguration Options for children's heart surgery, to consider the positive and negative impacts that each proposed Option could have on:

_ health outcomes and existing health inequalities;
_ equality groups and deprived populations;
_ travel and access to the services; and
_ the resulting carbon dioxide emissions.

The purpose of the interim report (Members Room Document) is to provide a comprehensive overview of emerging findings based on the assessment tasks undertaken to date.

8. The interim report states that concentrating surgical expertise onto fewer sites and bringing non-surgical care closer to home will benefit patients. The development of strong congenital cardiac networks is acknowledged to be one of the benefits to vulnerable groups as they will increase equity of access and improve the delivery of care. The report also suggests issues for the JCPCT to consider during implementation.

9. The document shows that there are positives and negatives for all options and that the number of people significantly affected in all cases will be low.

10. **Next Steps**

11. The JCPCT is expected to make a final decision by the end of 2011. Implementation of any changes to children's congenital heart services is expected to start in 2013. A detailed implementation plan will be developed once a decision has been made.

Health Overview and Scrutiny Committees have the opportunity to add to their original consultation responses by 5 October 2011. Should the panel decided to submit further comments members may want to consider including the following points:

- Welcome the publication of the thorough report on the public consultation. Keen that appropriate weighting is given to professional opinions and results that are skewed as a result of local campaigns are acknowledged and considered appropriately. Pleased that quality and excellent care were recognised as the most important principle and standard for the future configuration of services.
- Recognise that the independent report on the public consultation could not include all detailed points provided in the written responses, rather than the questionnaires. However it is important that the detailed responses are considered along side the report. In relation to the Panel's previous response the point concerning patient numbers and flows, PICU, interdependences, GUCHD and complex procedures are considered by the JCPCT in their decision making.
- Welcome the report Retrieval of critically ill children from the Isle of Wight and the associated letter from Jeremy Glyde. Seek assurance that Southampton will be treated with the same status as Bristol – i.e. must be considered mandatory in any option chosen in order for the review to be fair and the IoW to be given equal access to services.

RESOURCE IMPLICATIONS

Capital/Revenue

None.

Property/Other

None.

LEGAL IMPLICATIONS

Statutory power to undertake proposals in the report:

The duty to undertake overview and scrutiny is set out in Section 21 of the Local Government Act 2000 and the Local Government and Public Involvement in Health Act 2007.

Other Legal Implications:

None.

POLICY FRAMEWORK IMPLICATIONS

AUTHOR:	Name:	Caronwen Rees	Tel:	023 802524
	E-mail:	Caronwen.rees@southampton.gov.uk		

KEY DECISION? Yes/No

WARDS/COMMUNITIES AFFECTED:	all

SUPPORTING DOCUMENTATION

Non-confidential appendices are in the Members' Rooms and can be accessed on-line

Appendices

1	Panel Response to the Safe and Sustainable Review
2	Ipsos Mori's Report on the Public Consultation
3	Southampton University Hospital NHS Trust Report on the Safe Retrieval of Critically Ill Children from the Isle of Wight
4	Letter from Jeremy Glyde, Safe and Sustainable Programme Director, to Sir Neil McKay CB, Chair of the JCPCT, regarding the retrieval of critically ill children from the Isle of Wight

Documents In Members' Rooms

1 Health Impact Assessment: Interim Report

Integrated Impact Assessment

Do the implications/subject of the report require an Integrated Impact Assessment (IIA) to be carried out. **No**

Other Background Documents

Integrated Impact Assessment and Other Background documents available for inspection at:

Title of Background Paper(s)	Relevant Paragraph of the Access to Information Procedure Rules / Schedule 12A allowing document to be Exempt/Confidential (if applicable)

Safe and Sustainable Review Response from Southampton Health Overview and Scrutiny Panel

Members of the Southampton Health Overview and Scrutiny Panel have considered the proposals for changes to Children's Congenital Cardiac Services in England. Below is our response to the initial consultation. Once the independent report on the outcome of the consultation is published in August 2011 the HOSP would wish to add to this submission.

The HOSP has chosen to respond in narrative form rather than use the response form provided. This is because it was considered that the form did not provide sufficient flexibility for our comments and concerns about the consultation form itself (see below).

Quality

The purpose of the Safe and Sustainable (SS) review is to ensure the services provided for children with congenital hearth disease are excellent. The Paediatric Cardiac Unit at Southampton University Hospitals Trust provides amongst the highest quality care in the world. It is the second best in the country, only Evelina Children's Hospital in London is rated higher. The 2010 Kennedy assessment highlighted Southampton as an exemplar of best practice in three different areas: Management of paediatric intensive care; Supporting parents with information and choice; Training and innovation.

The unit does not suffer the problems associated with smaller units indentified in the SS document. For example:

- the mortality rates in Southampton are low.
- there is established dual operating and mentoring of surgeons and a fourth surgeon will join the team in July.
- the Trust has no problem in attracting or retaining the best staff and has surgeons who are pioneers in certain surgical techniques.
- cancellation of planned surgery is not an issue.

Southampton University Hospitals NHS Trust has four children's heart surgeons (the fourth surgeon is a new appointment and starts with the Trust in July 2011). There are seven paediatric cardiologists in the service which involves more than 400 staff in total.

Additionally the unit is already part of an established Congenital Heart Network with Oxford and the system has worked well for patients. This has demonstrated that developing networks with centres that are de-designated as cardiology centres can work and this success should be built on and used as an example of best practice.

Southampton have had patients referred from other centres with complex needs e.g. from as far away as Liverpool and Ireland. The Southampton team

have pioneered work on teenagers where previous operations haven't been successful.

However the Unit only appears in one of the four proposed options for reconfiguration.

The Panel support the notion that the level of quality should be consistent across the country with all units meeting the highest standards. However, it must be acknowledged that it takes time to attract high quality staff, create leadership, build teams and meet the highest standards and will take a number of years for this to be achieved across networks. However SUHT can already evidence this and has the potential to roll this out across the network established with Oxford. This should be retained, built upon on, and learned from rather than dismantled.

Patient numbers

The SS document states that there should be a minimum volume of 400 paediatric surgical procedures for each Specialist Surgical Centre. This figure has had a huge impact on the options presented. However, there is a statement in the consultation document that; *"the scientific papers reviewed do not provide sufficient evidence to make firm recommendations regarding the cut-off point for minimum volume of activity for paediatric cardiac procedures"*. The document refers to, *"available evidence"* but does not show what that evidence is or the flexibility around the 400 figure.

There is however evidence that hospitals in Scotland for example are able to provide a high quality service with smaller volumes than 400 but that evidence is not referred to. Based on the figures in the document there are currently 3 centres with 3 or 4 surgeons that undertake 400+ operations per year and each of them rate lower that Southampton in the independent assessment of the centres led by Sir Ian Kennedy.

The data relating to the number of operations undertaken at Southampton is out of date. During 2010, Southampton performed 404 congenital heart surgery procedures, 338 of them were in children aged 16 or under. In February 2010 when surgery was suspended in Oxford, the majority of operations for its patients were performed in Southampton. This makes Southampton larger than the other centres being considered for closure.

The SS document states that around 100/125 procedures a year per surgeon is optimum. However, this makes a distinction between operating on children and adults – the same surgeons often operate on both. Also many operations require more than 1 surgeon e.g. for complex procedures. This is not taken into account in the assessment of the number of procedures performed. The other omission relates to the training of surgeons: approximately 40% of procedures will have a junior surgeon being mentored by a senior colleague. The Panel understand this is not reflected in the assessment of the number of procedures performed.

Patient Flows

The assumption that patients will travel to their nearest centre, and a consideration of existing clinical networks, has been used to deem that Bristol and Southampton are not both viable in the same configuration with the exception of the option that has been based solely on quality (which the Panel argue should be the prevailing factor). The Panel believe that the assumptions on which this is based are flawed. The analysis is based on a theoretical model of patient flows and doesn't take account of actual patient flows as they take place now, and the model does not allow for patient choice.

The majority of Oxford patients have been going to Southampton since the Oxford unit closed not just because it is nearer than Bristol or London but because they recognise the quality of service provided. The consultation document does not recognise that Southampton has replaced Oxford Radcliff as the centre for patients in the Oxford region and has not calculated potential patient numbers on that assumption.

Patients travel to the Southampton unit from both the south west and south east (e.g. Plymouth and Guildford) as well as from the north (e.g. Northampton). Ease of travel does not seem to have been considered. For example although some parts of Dorset may be theoretically closer to Bristol, in practice it is easier to travel to Southampton.

Patient choice has not been considered. It is not in line with the principles of the review that children should have to travel further for poorer quality care. Feedback from the consultation event that took place near Gatwick, who are counted as part of the London catchment, indicated that they prefer to come to Southampton. The SS review itself had rated the centres in terms of quality and this information is, rightly, widely available to parents and patients. This has the potential to impact on the centres parents choose for their child's treatment – particularly where the distance between two centres is not significant for them but one has ranked higher on quality.

The Panel believe there is enough work across the South of England and London to sustain 4 centres. Taking the activity across London, South East Coast, the South West and South Central there would be sufficient activity at Southampton if it was distributed differently to support the 4 best centres across the South. We understand that South West SHA also support option B and that the chief executive at Southampton University Hospitals NHS Foundation Trust will be receiving a letter from Sir Neil McKay (chair of the JCPCT) supporting the testing of redistributing the Brompton activity to support Option B.

Additionally population growth has not been projected at postcode level, but nationally. This fails to take into account projected regional differences in population growth. While the Panel understand that the projected population growth to 2025 will not require additional surgeons to deal with increased caseload, the distribution of the additional patients is unlikely to be evenly

distributed. According to the ONS 2008 based population projections for England published in May 2010:

"The East is projected to be the fastest growing English region over this period. The population of this region is projected to increase by 10 per cent over the decade to 2018, rising by over 0.5 million to 6.3 million. Over the same period, the population of five other regions (London, Yorkshire and The Humber, South West, East Midlands and South East) are also projected to increase by 8 per cent or more. In contrast, the North West and North East are projected to have the smallest percentage increases in population between 2008 and 2018."

This clearly shows that the greatest increase will be in those areas which are placed in the catchment of the London and southern centres. This would potential affect the patient numbers in these centres to a greater extent than those in the north.

Access and Travel Times

There are some clear errors in relation to the assumptions around access travel times on which the options have been assessed.

As has been highlighted by the review team previously, there have been significant errors in relation to retrieval times from the Isle of Wight (IOW) which is relevant to both Paediatric cardiology and surgery and PICU services. The retrieval times from the IOW have been calculated based on air travel when the reality is that Southampton's policy is to retrieve children from the Isle of Wight by road and ferry. The Panel are pleased that this issue is being reconsidered by the JCPCT and expect a full and fair review of how this will effect the options to ensure that patients from all parts of the Isle of Wight are not unfairly disadvantaged. The Panel also seek assurance that the details of this issue will be published in due course.

The Panel are also concerned that while distance to hospital was least important for parents, distance to hospital and access and retrieve times have been given such a high priority when evaluating the options. We are also concerned that travel times have not been based on actual patient flows rather than being assessed by road times from the centre of postcode areas.

Paediatric Intensive Care Unit

Option B has the least impact on the national provision of PICU services. Southampton has the 9th largest PICU in the country and has the lowest standardised PICU mortality of all the centres being considered in this process.

In the independent assessment, Southampton PICU was identified as being managed in an exemplary way (only 1 patient reported as turned away) and the throughput through PICU as excellent.

SUHT are concerned that their PICU will be adversely affected if cardiac surgery is taken away. We have heard from medical staff at SUHT that there PICU admissions will drop by 39% without cardiac patients and cardiac patients account for 44% of PICU bed days.

The South East Trauma Board have identified the importance of the Southampton Paediatric Care Unit for the care of the paediatric population in NHS South East Coast and voiced concerns about how this would be effected if paediatric cardiac surgery was removed from SUHT as have the Wessex Paediatric Intensive Care Forum (which covers the 9 hospitals that refer to SUHT PICU).

The Panel are concerned that the issues regarding the sustainability of PICUs have not been given enough consideration in the SS review.

Interdependencies

The Panel are concerned that not enough consideration has been given to the importance of having interdependent services on site.

The SUHT centre is able to offer the full range of maternity, paediatric and GUCH services co-located on a single site. The Panel have heard from both patients and doctors of the importance of this for congenital heart patients as they often have other needs and conditions, particularly those with the most complex conditions.

The framework for critical inter-dependencies report for specialised paediatric services identifies five services that require absolute co-location with cardiac surgery (paediatric cardiology, paediatric critical care, specialist paediatric anaesthesia, specialist paediatric surgery and specialised paediatric ENT). Professor Baker, the author of the framework, raised concerns at a public consultation event that the critical interdependencies had been ignored in developing the options and he had not been asked to assist in applying the framework to the options. The Panel are concerned that a full assessment of interdependencies has not been made and would like further information to be provided on how the four options proposed meet these requirements.

Grown Ups with Congenital Heart Disease

The Safe and Sustainable standards require that clear transition arrangements are in place between Specialist Surgical Centres and specialist adult units. This is already in place at SUHT as they currently treat and perform surgery on both children and adults with CHD.

Paediatric cardiac surgeons at the Southampton Centre also perform surgery for ‘grown up’ congenital heart patients however this surgery has not been included in the number of procedures performed per surgeon considered in the consultation document. Separating the two specialities would reduce the number of procedures performed and may impact on the ability to retain highly skilled staff, as well as removing the consistency appreciated by patients.

Given the importance place on transition arrangements and the feedback received from the medical profession and parents on this issue, the Panel find it difficult to understand why the children's and adults reviews are taking place separately rather than as one. No consideration seems to have been given to the benefits of having an integrated, cradle to grave, service. It is also difficult to understand how the outcome of the SS review will not have a significant impact on the GUCH review. The Panel would like this issue considered in more detail.

Complex Procedures

With the exception of the three highly specialist nationally commissioned services, no consideration appears to have been given to the most complex procedures which are not carried out at all centres.

Not every centre is currently doing the most complex surgeries, currently some centres specialise in certain procedures and publish their results as part of their CCAD return. Our understanding is that only one complex procedure - hypoplastic left heart - is audited on CCAD, with other complex procedures grouped under 'miscellaneous'. Not all centres undertake hypoplastic left heart and we assume this is the case for other complex procedures that are not audited on an individual procedure basis. We are concerned that this has been taken into account, particularly as existing expertise could be lost in the designation process. While we appreciate that new designated centres could develop specialism in complex procedures this will take time and the Panel feel there needs to be greater consideration and understanding of the current situation in order to ensure that patients do not suffer.

Consultation

Finally the Panel would like to highlight our concerns regarding the consultation itself. Members are concerned that the consultation response form was excessively long, leading and biased. There has not been any formal communication on the website, nor has it been publicised, that feedback could also be provided in written format rather than via the complicated consultation form.

The consultation document is very long and technical – although well written. The young person's summary version was not made available until the consultation was well underway.

The JCPCT have been absent from all consultation events and meetings that we have attended or been aware of. Those fielded from the regional arms of NHS SS have often struggled to answer questions and are not the decision makers. The Panel are also concerned that a third party organisation have been contracted to run the consultation and evaluate the feedback rather than those with specialist knowledge.

There has been significant interest in the SS review in Southampton. When the planned formal consultation meeting reached capacity, following several requests a further meeting was held. However, this meeting was also very popular and we were assured that further meeting would take place but as far as we are aware this did not in fact happen.

Conclusion

In conclusion the Panel feel strongly that they can only support option B. This is the only option which able to satisfy the quality criterion as five of the six centres judged to be providing the highest quality services are included as future surgical centres. Option B has centres with the best survival rates for surgery, centres which already undertake complex surgery and the option provides excellent access to patients from all parts of the country. The loss of the unit would be detrimental to the safe and sustainable delivery of a range of other paediatric services provided for the region. We believe that the given the quality, geographical distribution and patient flows the Southampton centre meets the aims of the review, and it has the strong support of the local community, patients and families.

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Ipsos MORI

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

Report of the public consultation

24 August 2011

Legal notice

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Executive summary

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

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

There were also consultation events and supplementary qualitative research, both of which are reported on separately.

It is important to remember that the results contained in this report are not representative of the population – they only refer to the people and organisations that responded to the consultation.

The suggested new approach

Five Key Principles

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

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

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

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

Among those responding, 70% of personal respondents and of 86% organisations agreed with this principle. Written comments suggested that many of those *disagreeing* were particularly concerned that surgery and interventional procedures have been excluded – they would like to see these also being provided close to home. Some highlighted the impact of increased travel times and the problems this can cause for the patient and their families. Other respondents though suggested that high quality care should always take precedence over ease of access.

Views on different aspects of the new approach

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

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

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

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

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

National Quality Standards

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

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

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

Only a minority of respondents chose to provide further comments on the National Quality Standards; the majority of these related to the **Specialist Surgical Centre** theme. Again, some respondents discussed the relationship between higher volumes of cases and better outcomes and put forward their view that the interpretation was incorrect.

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

Proposals for Specialist Surgical Centres in London

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

On the other hand, some respondents who disagreed with the proposal (particularly those living outside London) suggested that there should only be one centre in London, so that another centre could be situated elsewhere in the country.

If there were to be two centres in London, the majority of those responding supported the proposed choice of **Great Ormond Street Hospital for Children NHS Trust (GOSH)** and **Evelina Children's Hospital – Guy's and St Thomas' NHS Foundation Trust** (65% of personal respondents and 56% of organisations). Just under one in ten personal respondents preferred **Royal Brompton and Harefield NHS Foundation Trust and GOSH** (8%) and 16% preferred **Royal Brompton and Evelina**. The pattern for the two alternative options is reversed amongst organisations though, where 11% preferred **Royal Brompton and GOSH** and just 5% preferred **Royal Brompton and Evelina**.

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

Proposals for Specialist Surgical Centres outside London

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

Views on options

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

As might be expected, there were substantial differences in support for each option in different parts of the country. A large proportion of respondents to the consultation came from the East Midlands and the South Central regions, and their responses have influenced the overall results. Outside these two regions, there was greater support for **Option B** – 43%

compared to 35% for Option A), though **Option A** was supported by more respondents in six of the ten regions.

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

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

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

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

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

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

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

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

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

However, some respondents did comment further on the options proposed. **Option A** was considered by some respondents to offer the least disruption to patients as it would mean no relocation of specialised services. Others thought that it offered a good geographic spread. Some were concerned though that it would require Leeds to be involved in four networks.

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

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

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

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

The importance of quality

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

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

Preferred configuration

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

Text message responses

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

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

Petitions and campaign responses

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

- Almost half a million people (445,945) signed a petition to save heart surgery services in **Leeds**.
- Almost a quarter of a million people (240,094) signed a petition in support of **Southampton**.
- Around fifty thousand people (47,258) signed a petition in support of **Glenfield**.

Other petitions and campaigns also supported these three hospitals and Newcastle, Royal Brompton, Alder Hey and Oxford Radcliffe.

Key findings

- There were over 75,000 responses to the consultation via the various methods of response, with most using the response form[1].
- Over 20% of the responses received via the response form were from individuals from minority ethnic backgrounds.
- There was strong support amongst these respondents for the Key Principles.
- There was strong support for the need for 24/7 care in each of the Specialist Surgical Centres.
- There was strong agreement that systems should be implemented to improve the collection, reporting and analysis of mortality and morbidity data.
- Three-quarters of respondents supported the proposal for two Specialist Surgical Centres in London (75% of personal respondents and 74% of organisations responding).
- Almost half of respondents from London supported the proposal for two Specialist Surgical Centres in London (47% of those responding).
- The majority supported the proposed choice of Great Ormond Street Hospital for Children NHS Trust and Evelina Children's Hospital (65% of personal respondents and 56% of organisations responding).
- Option A received the highest level of support from personal respondents (58%) followed by Option B (34%). The majority of respondents to the consultation were from the East Midlands and South Central regions. Outside these two regions, more respondents supported Option B, as did organisations.
- There were lower levels of support for Options C and D, with Option D receiving most support from respondents in the Yorkshire and Humber region.

[1] It is important to remember that the results contained in this report are not representative of the population – they only refer to the people and organisations that responded to the consultation.

1. Overview of the consultation process

1.1 Background

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

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

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

1.2 Structure of this document

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

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

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

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

1.3 Structure of the consultation

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

Online response form – responses to specific questions on the proposals, available in 11 languages[2] 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 languages[3].

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

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

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

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

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

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

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

1.4 Responses to the public consultation

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

Table 1 – Responses to the public consultation

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

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

Table 2 – Responses by audience group

Response method	Audience	Total
Response forms	**Personal responses**[4]	**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 group[5]	**1,121**
	Hospital	196
	Charity/voluntary group	63
	Local patient group	27
	Local Authority	22
	Professional body	20
	Local parent group	15
	National patient group	10
	Academic organisation	9
	Strategic Health Authority	7
	Commissioner	7
	National parent group	6
	GP consortium	5
	Political party/group	4
	Trade body	1
	Other	62
	Not stated (including 'prefer not to say')	754
	Not stated as personal or organisation	**210**
Written comments	**Individual**	**167**
	Health professional	36
	Stakeholder	**204**
	MPs & politicians	67
	Health bodies	24
	Overview and Scrutiny Committees (OSC) and Local Involvement Networks (LINks)	23
	International	21
	Local groups	13
	Hospitals providing children's heart surgery	12
	Groups of NHS staff	12

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

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

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

Response forms

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

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

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

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

Text responses

A total of 25,157 text messages were received to the *Safe and Sustainable* number; this included 3,038 blank messages. There were also multiple responses received from some mobile phone numbers, though the majority sent just one message (19,852[6]).

[6] Having removed all blank messages

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

Chapter 6 contains analysis of the text message responses.

Open written responses

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

Campaigns/petitions

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

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

1.5 Interpreting the consultation responses

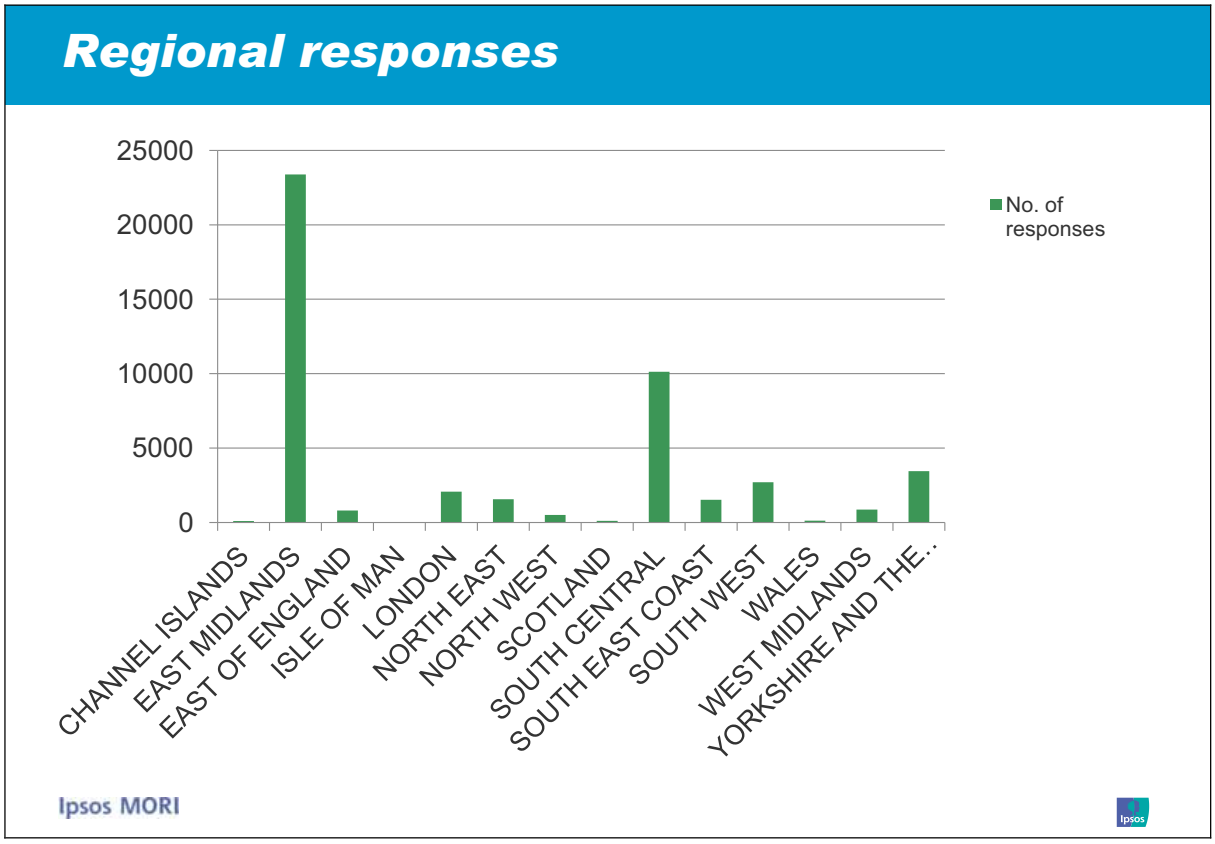
Understanding who has responded

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

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

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

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



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

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

Understanding the different audiences

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

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

Free text responses

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

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

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

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

2. The suggested new approach

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

2.1 Five Key Principles

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

- **Children**: the need of the child comes first in all considerations.
- **Quality**: all children in England and Wales who need heart surgery must receive the very highest standards of NHS care.
- **Equity**: the same high quality of service must be available to each child regardless of where they live or which hospital provides their care.
- **Personal service**: the care that every congenital heart service plans and delivers must be based around the needs of each child and family.
- **Close to families' homes where possible**: other than surgery and interventional procedures, all relevant cardiac treatment should be provided by competent experts as close as possible to the child's home.

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

Agreement with the principles overall

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

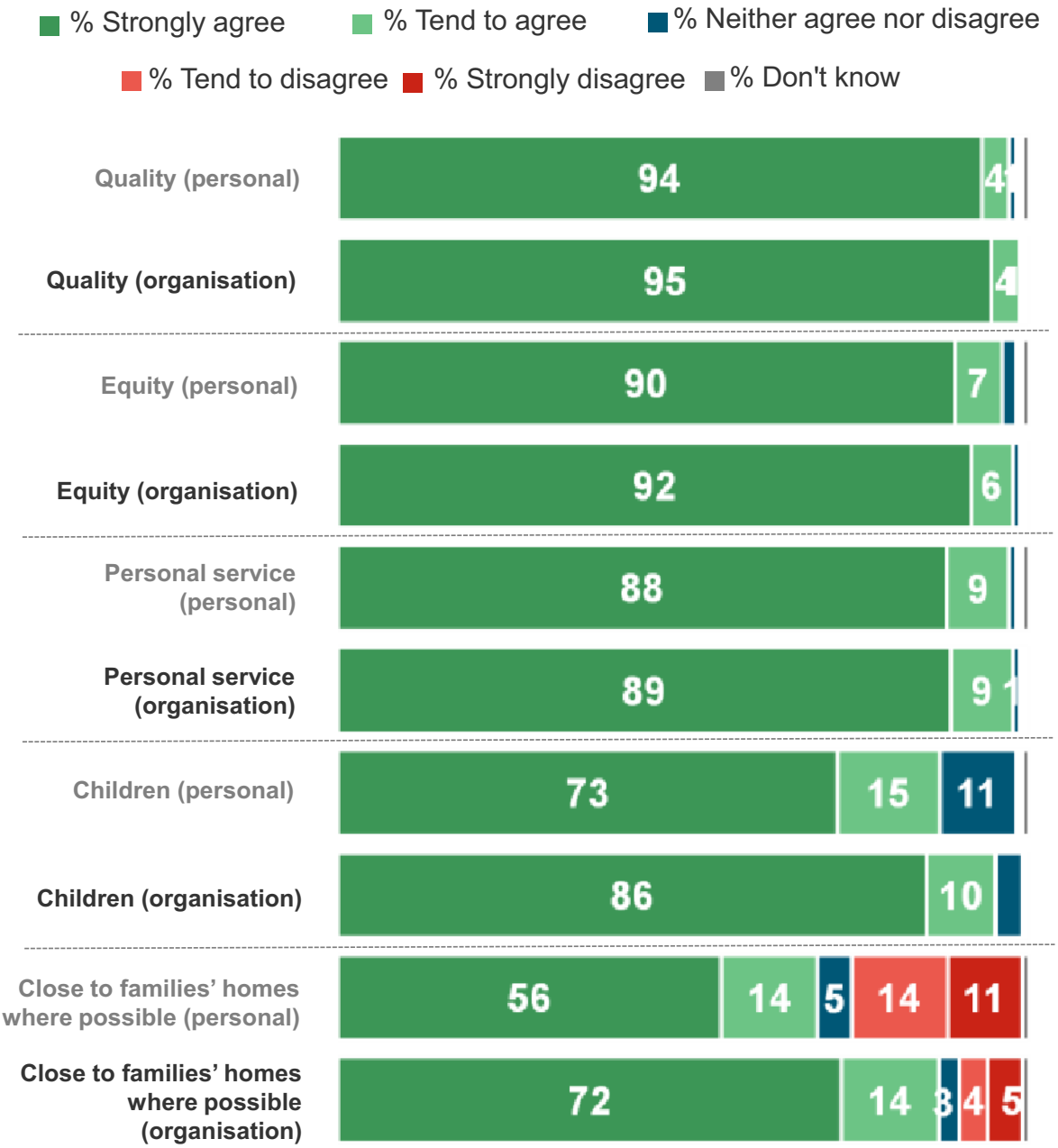
Views towards the fifth principle, that treatment should be *close to families' homes where possible*, were less positive than for the other four principles, though a majority still agreed.

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

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

The Five Key Principles

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



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

Ipsos MORI

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

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

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

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

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

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

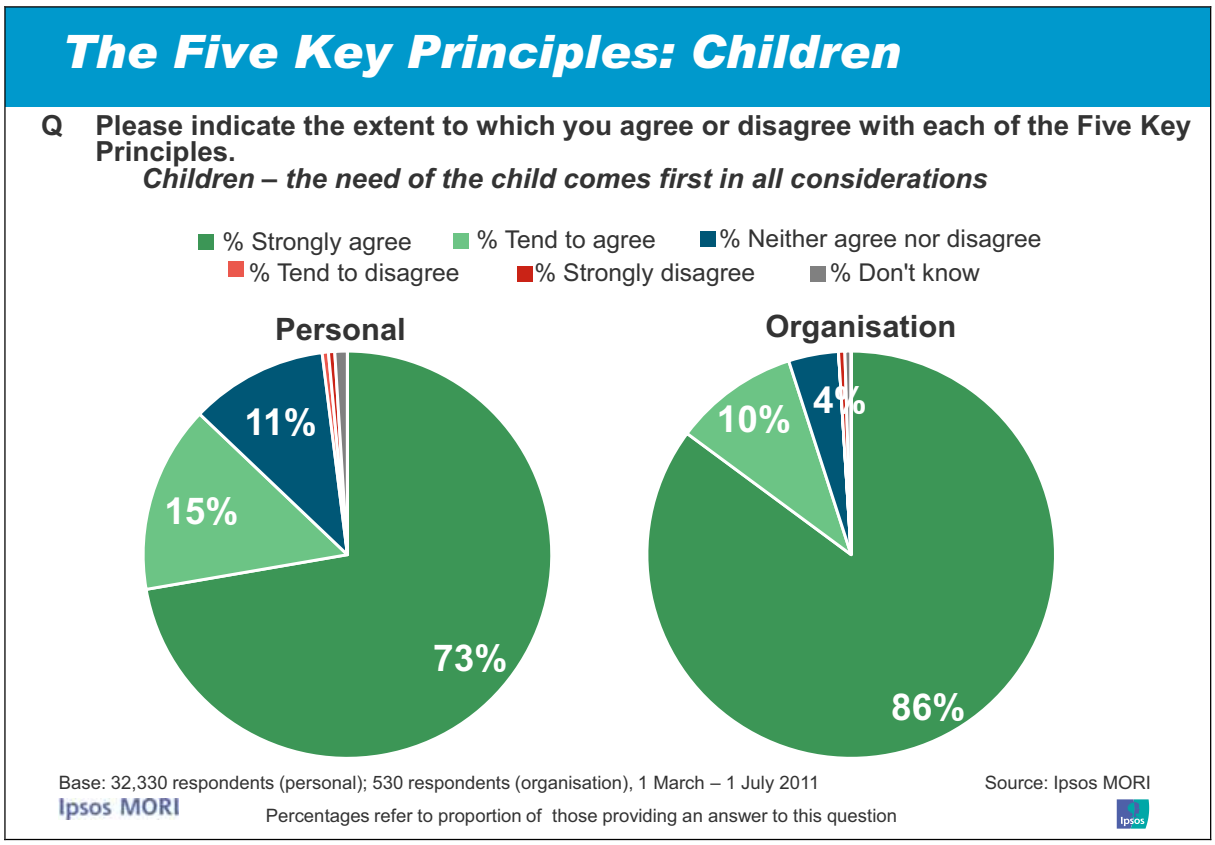
"Quality of specialist care is more important than local access."

"In all these considerations the child's physical, social and emotional welfare must come first".

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

The Five Key Principles – Children

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



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

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

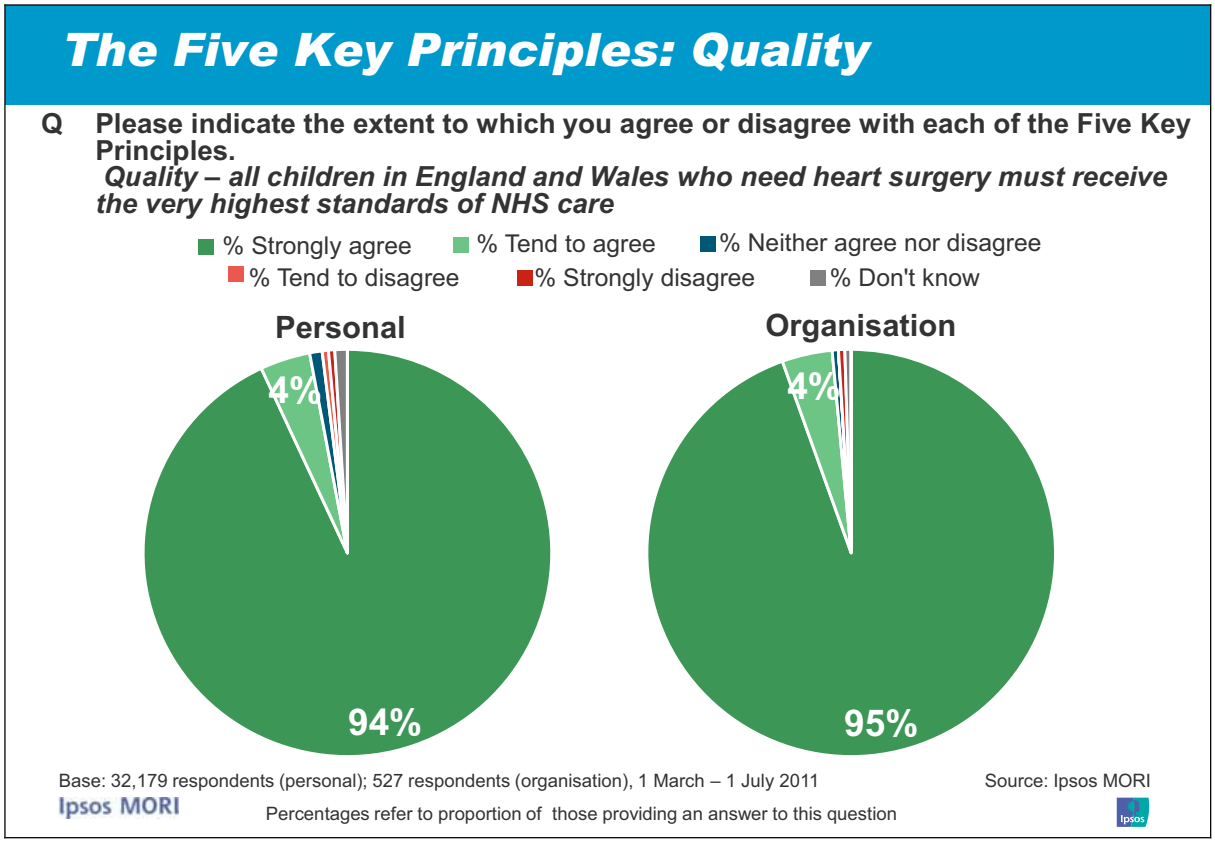
Of the 745 respondents who went on to comment on this principle in their own words, many reiterated that the child's needs have to come before anything else, with some saying that this was the most important of the five principles. Many respondents focused on the needs of the family, often adding a caveat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

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

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

The Five Key Principles – Quality

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



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

"Quality should be the utmost concern to us all."

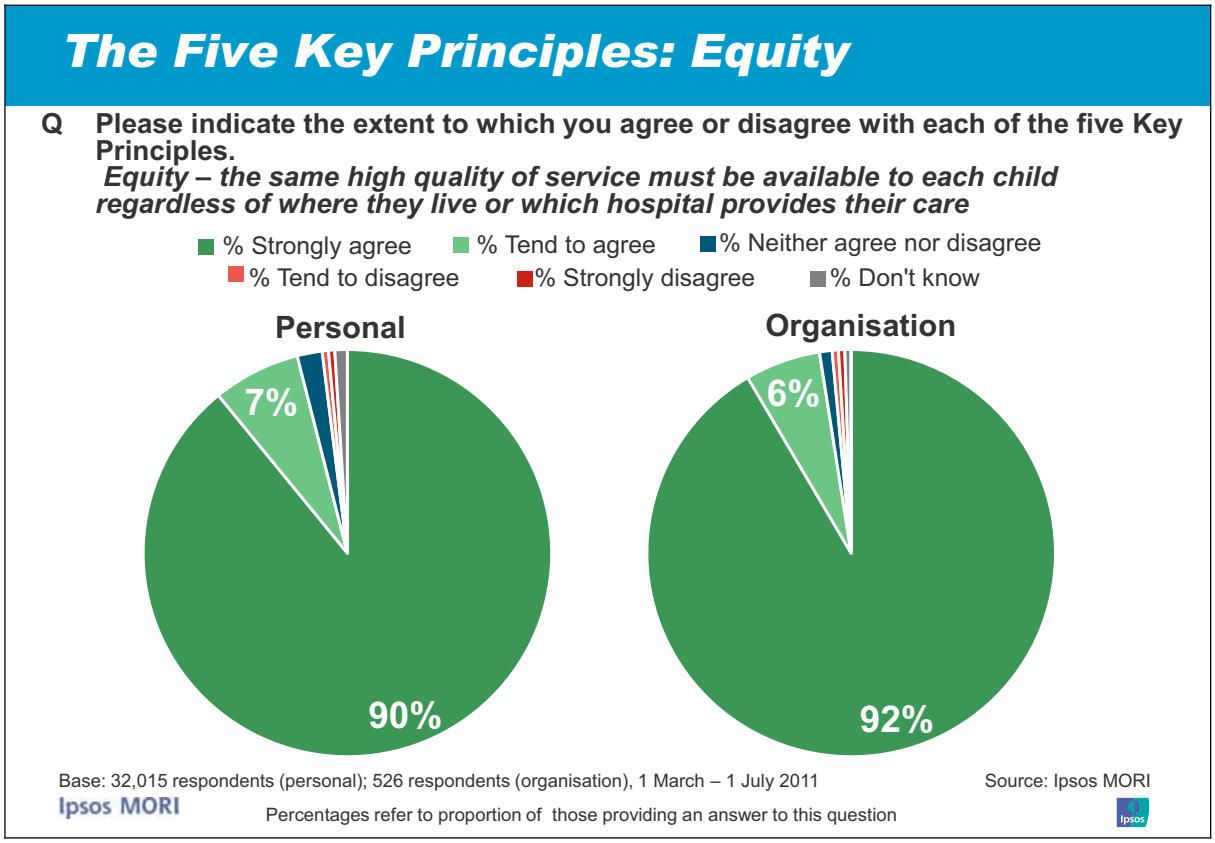
"Providing the highest possible standard of treatment is the most crucial requirement because cardiac care can so easily go wrong in the very young."

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

The Five Key Principles – Equity

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

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



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

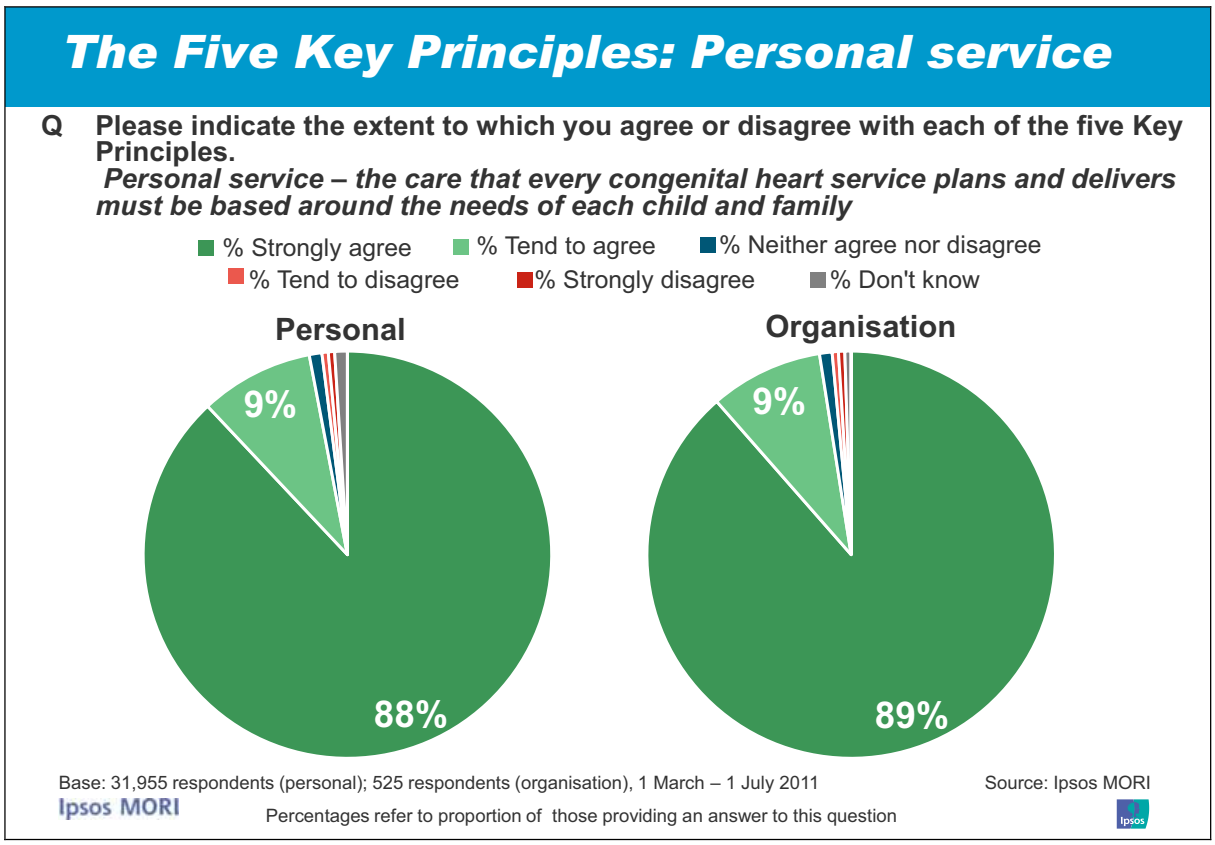
"The same high quality of service must be available to each child in a hospital that is close to where they live."

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

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

The Five Key Principles – Personal service

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



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

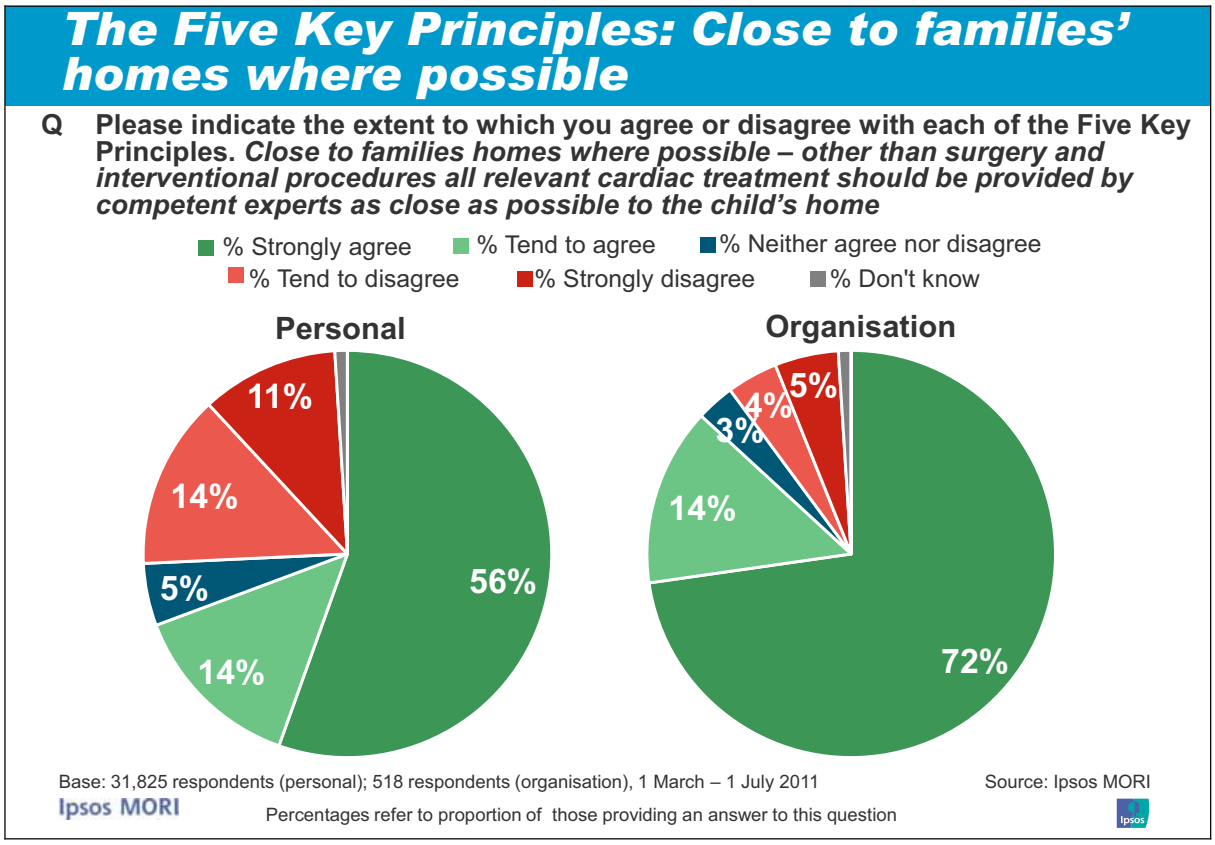
"The child's needs also involve the whole family"

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

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

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

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



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

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

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

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

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

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

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

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

2.2 Views on aspects of the new approach

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

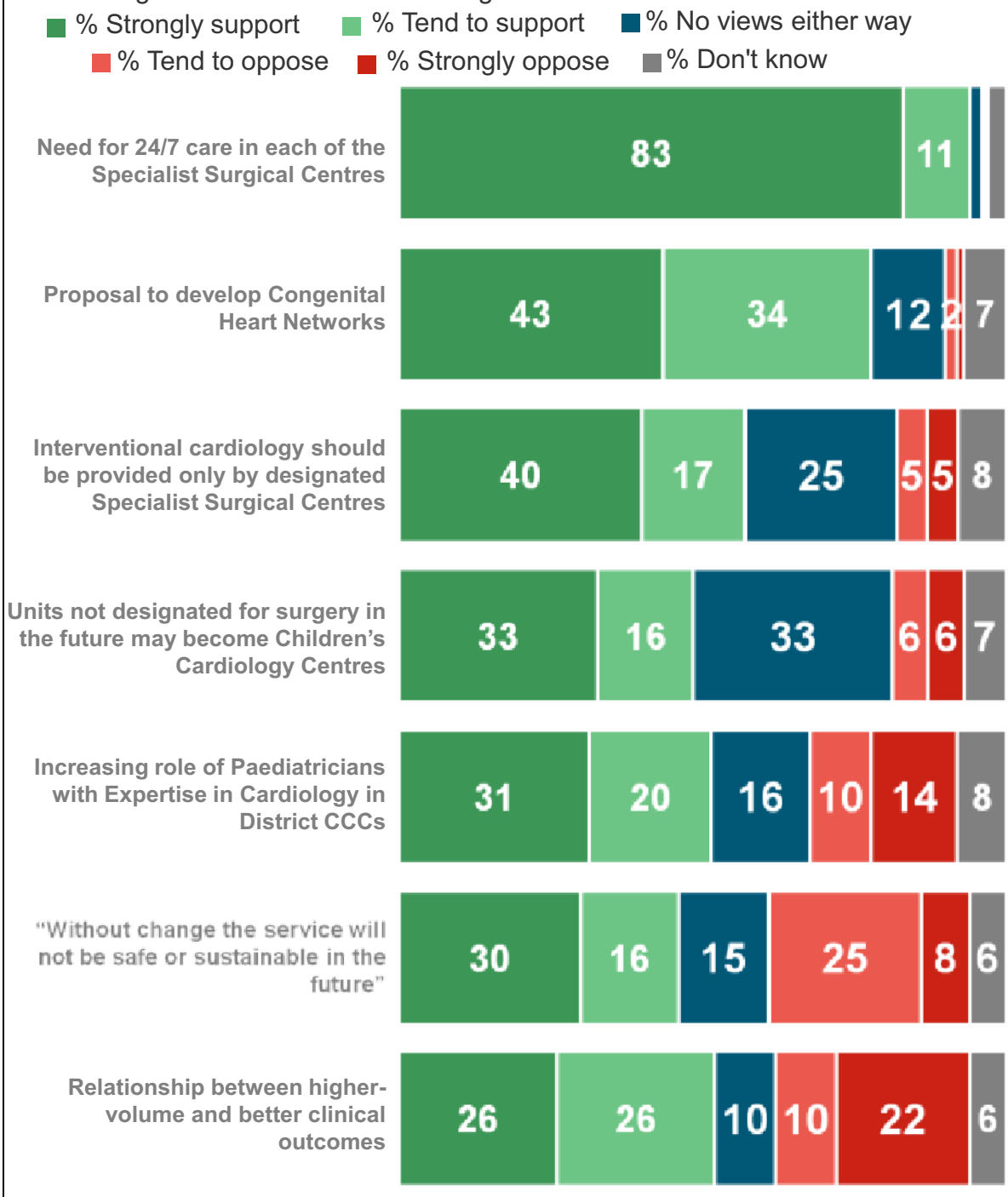
Support for, or opposition to, aspects of the new approach

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

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

Support for the new approach (personal responses)

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

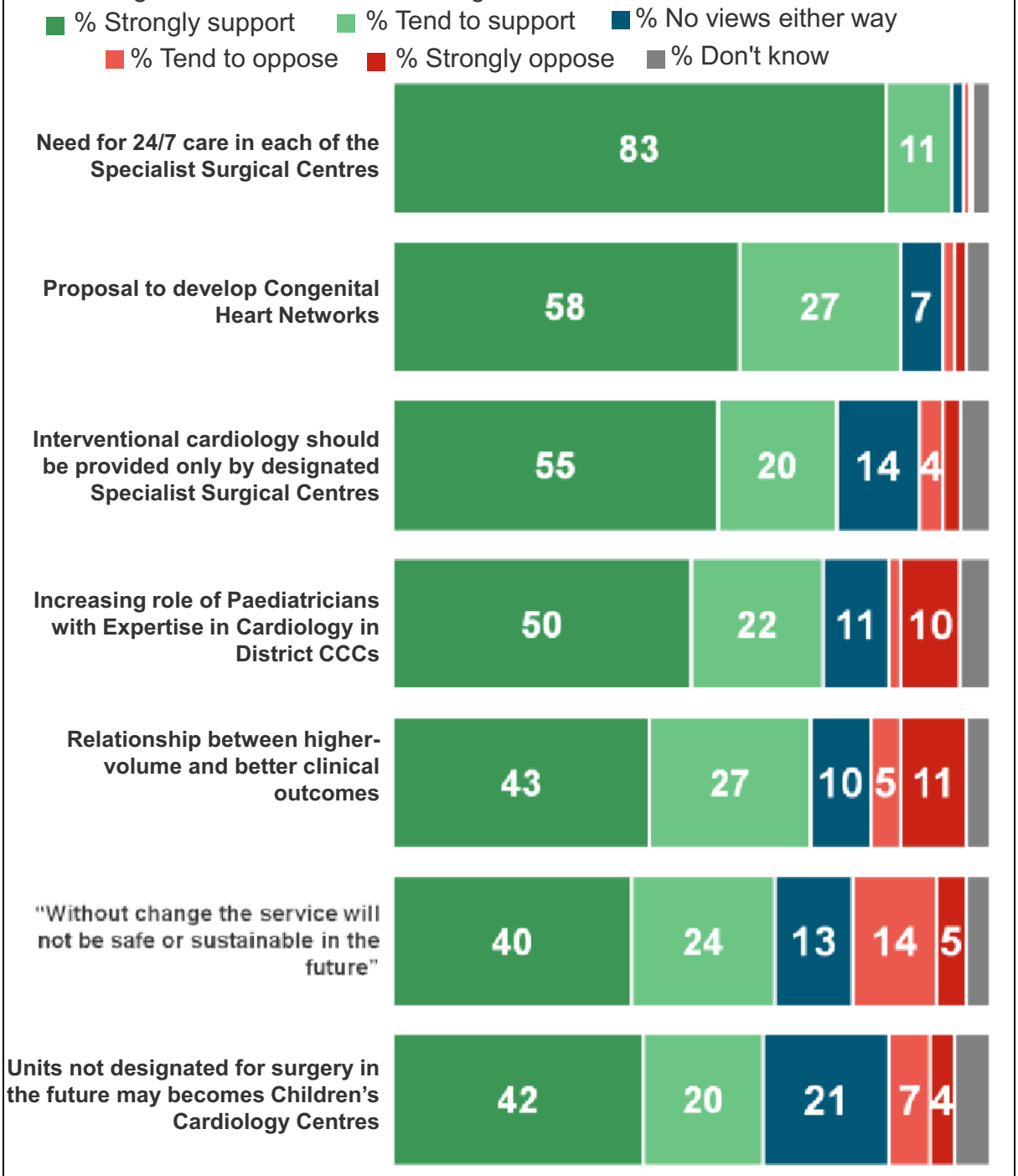


Ipsos MORI Base: All personal respondents providing an answer to each question (approx 27,000 respondents)1 March – 1 July 2011

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

Support for the new approach (organisation responses)

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



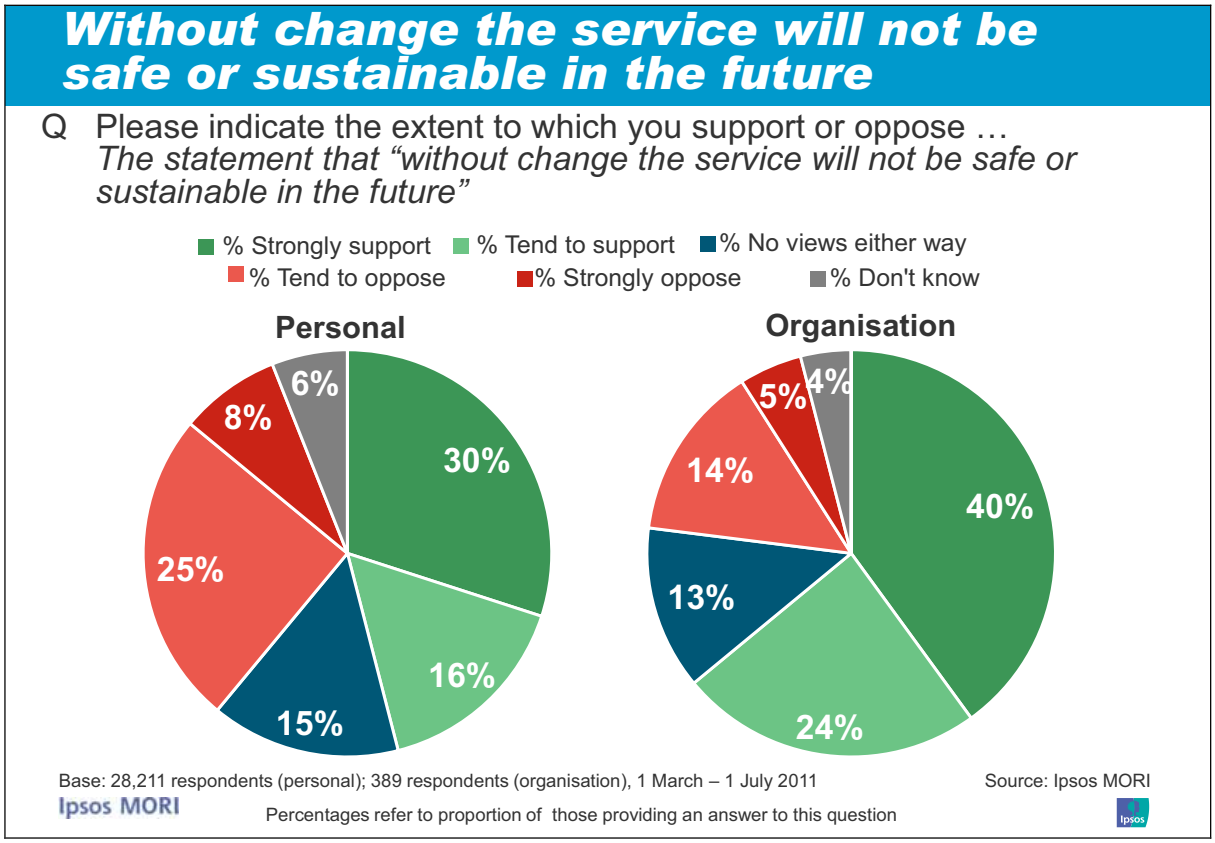
Ipsos MORI Base: All organisation respondents providing an answer to each question (approx. 380 respondents)1 March – 1 July 2011

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

The need for change[7]

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

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



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

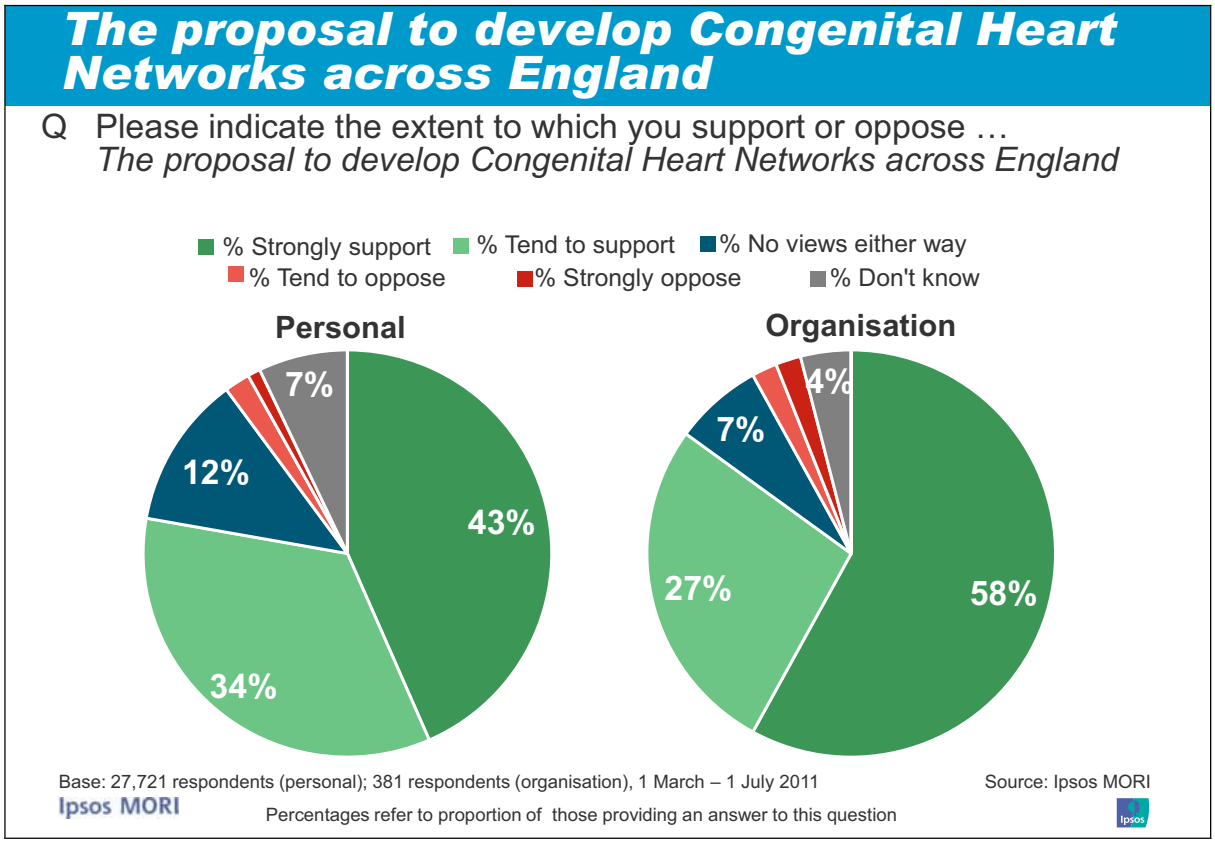
Of those who provided comments about the elements, statements and proposals presented, 715 respondents commented specifically on the statement that "*without change the service will not be safe or sustainable in the future*". In particular, some respondents asked whether the service was not safe now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

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

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

Congenital Heart Networks[8]

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



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

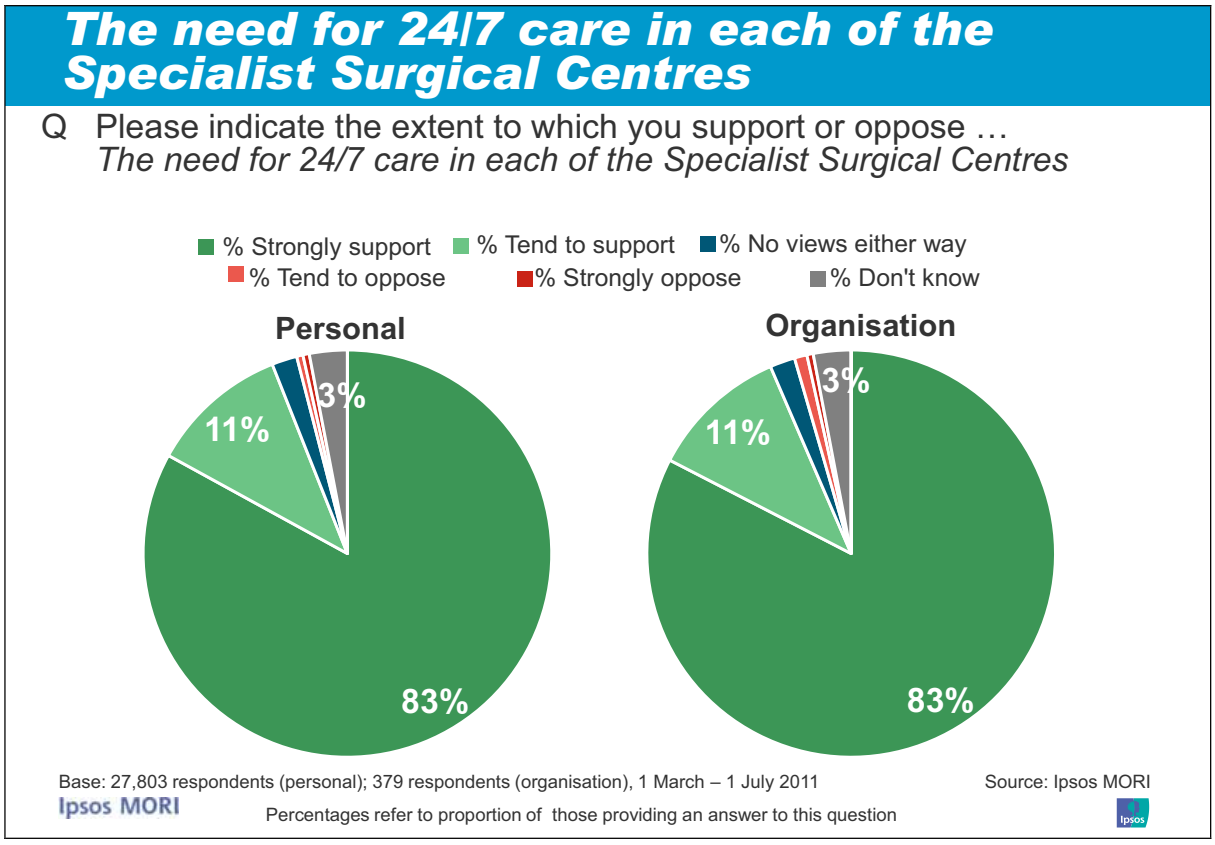
Fewer respondents commented specifically on this proposal than for others (250). Of those commenting, there was a concern that some areas may be left without adequately trained cardiologists. There was also a concern about the networks in terms of quality, how autonomous they might be, and how continuity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

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

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

The need for 24/7 care[9]

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



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

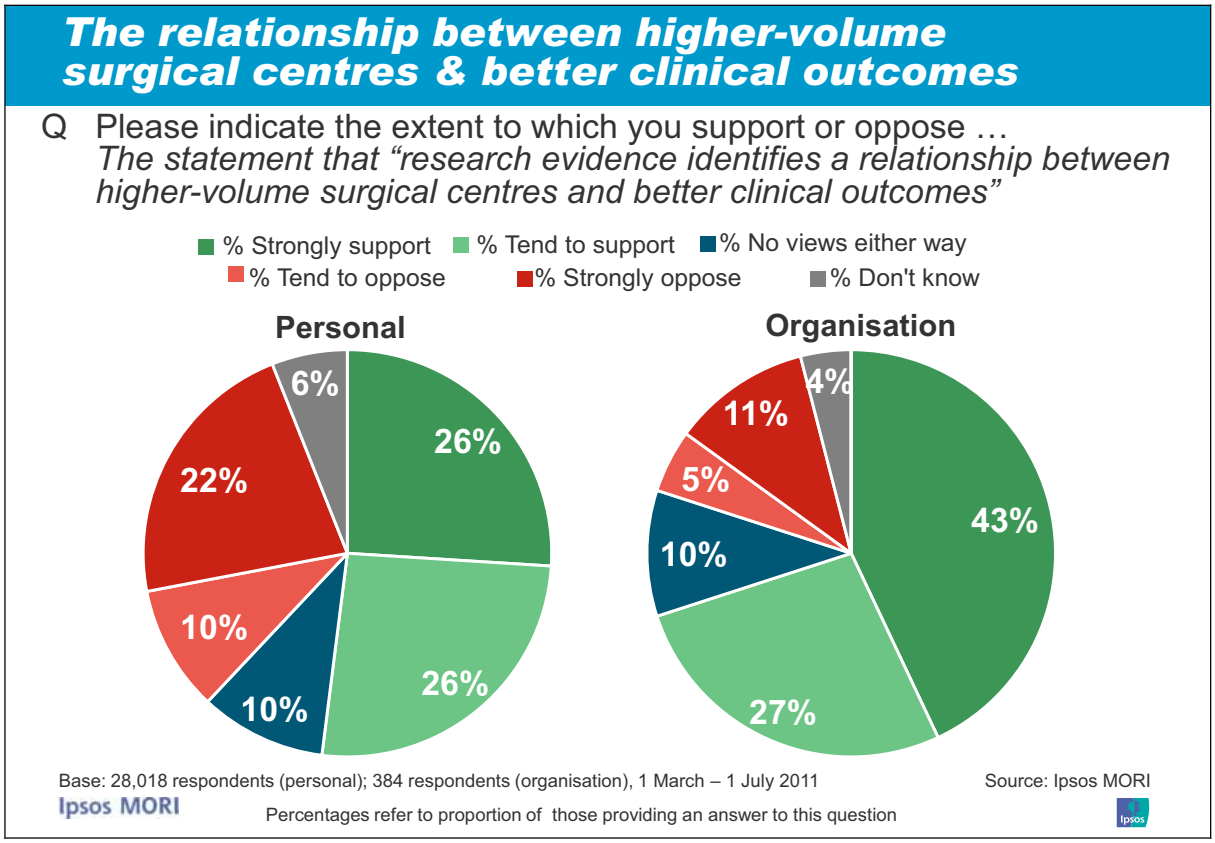
"Glenfield already provides 24/7 care. The S/S appear to have ignored this"

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

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

The relationship between higher-volume centres and clinical outcomes[10]

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



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

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

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

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

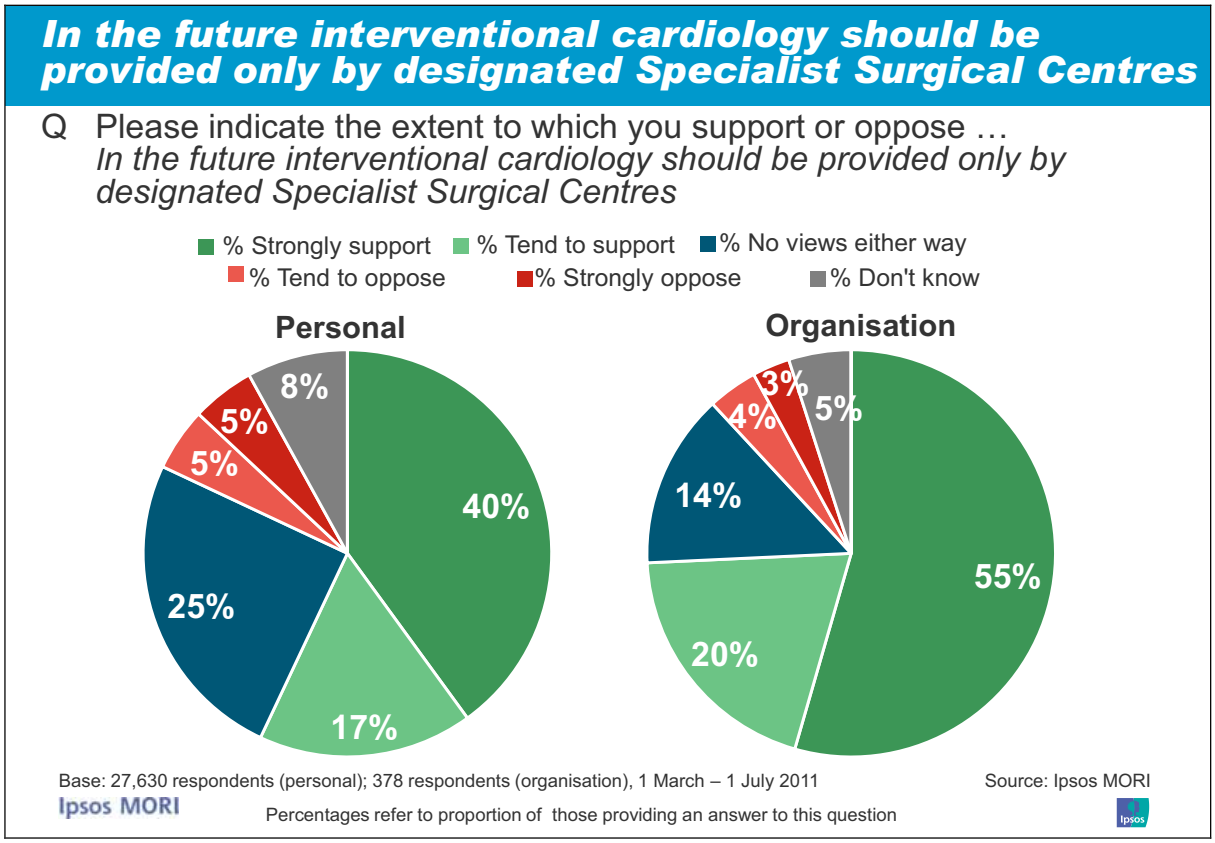
"There is no evidence to show that outcomes improve when the number of operations performed goes above 200, or that the centres performing more than 400 operations are better."

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

Specialist Surgical Centres[11]

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

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



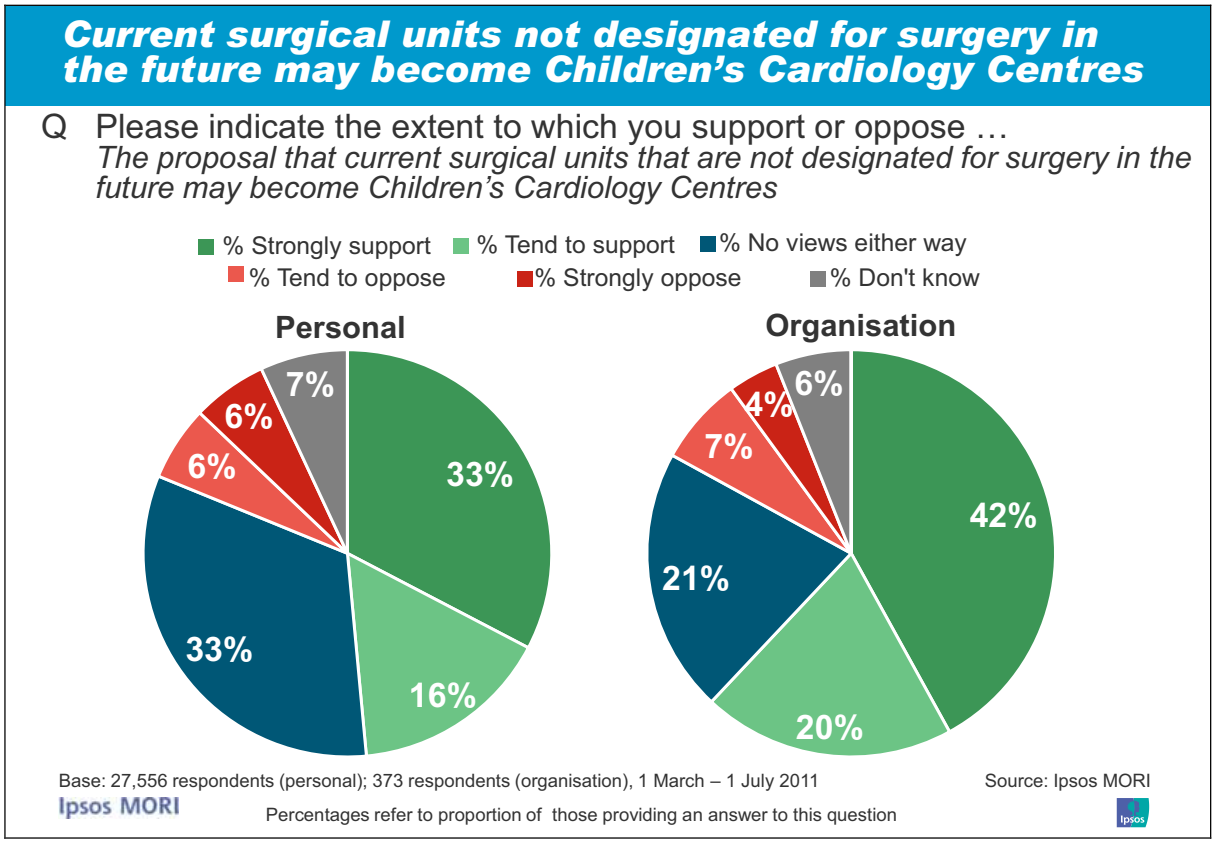
The respondents commenting spontaneously on the proposal tended to query what would happen to the non-surgical centres.

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

Children's Cardiology Centres[12]

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

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



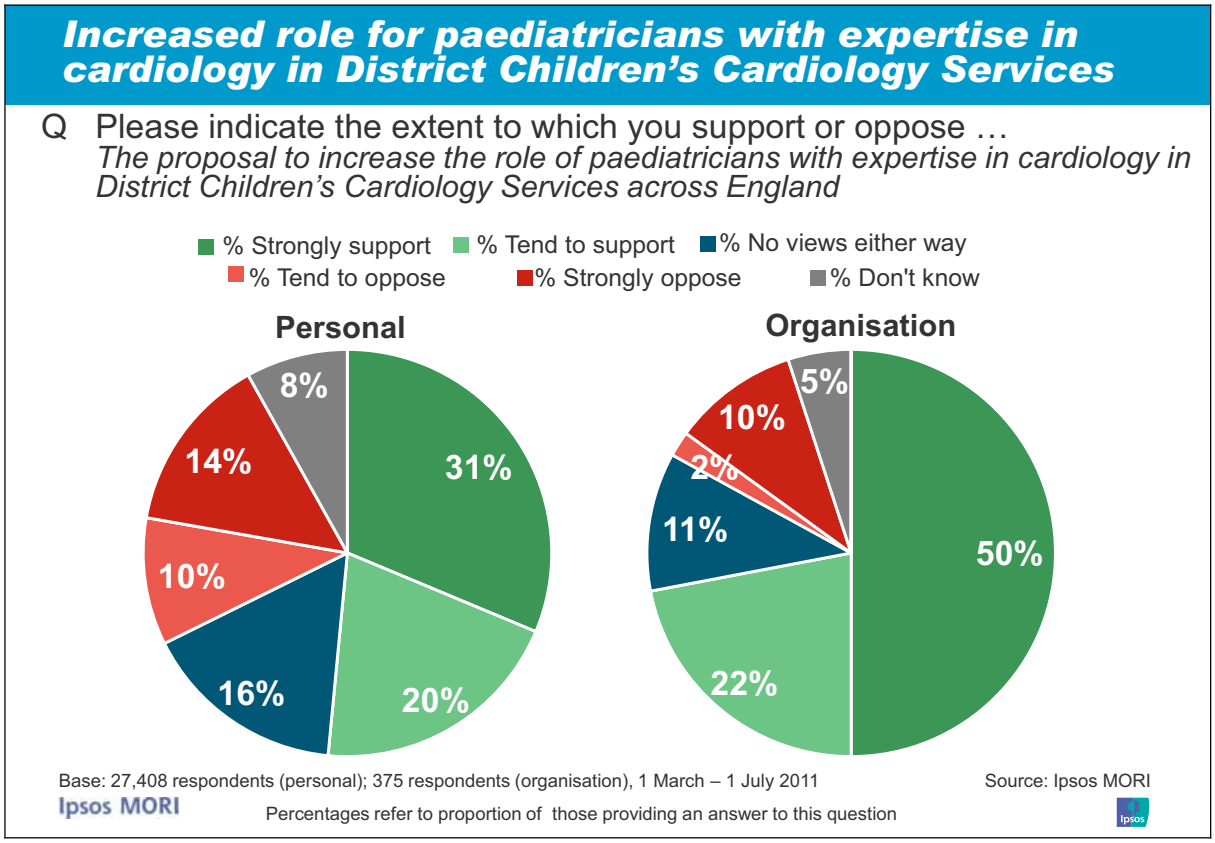
Levels of opposition for the proposal were higher in certain regions – the North East (12%) and London (11%). Opposition was also higher among those with prior experience of Royal Brompton and Harefield NHS Foundation Trust (18%) and Oxford Radcliffe Hospitals NHS Trust (14%).

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

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

Developing the role of paediatricians with expertise in cardiology[13]

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



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

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

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

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

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

2.3 Mortality and morbidity data

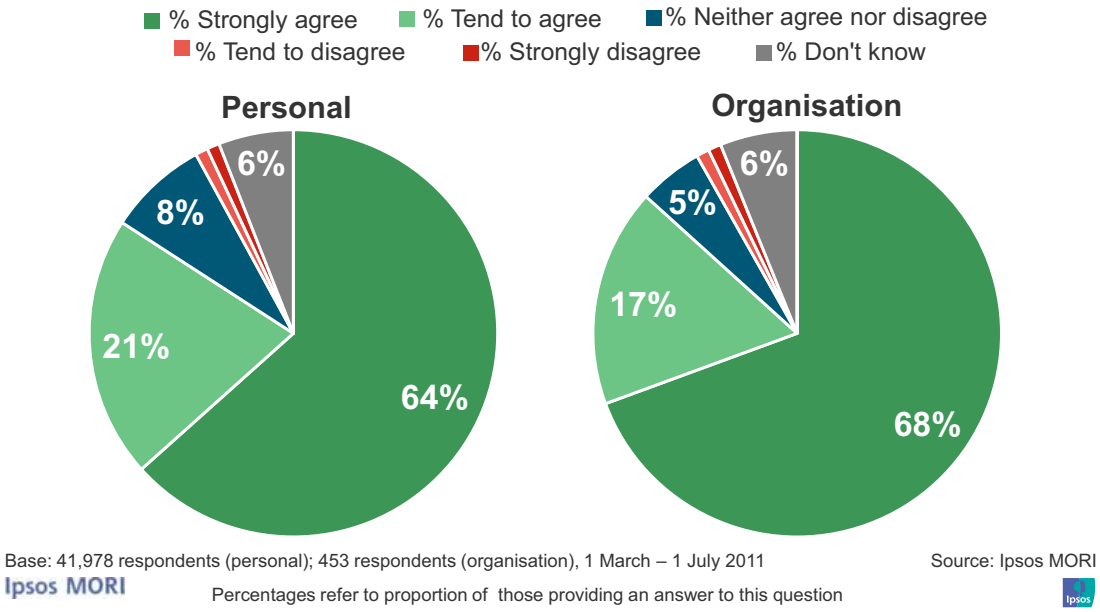
Improving the collection, reporting and analysis of data[14]

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

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

Mortality and morbidity data

Q 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?



Base: 41,978 respondents (personal); 453 respondents (organisation), 1 March – 1 July 2011

Source: Ipsos MORI

Ipsos MORI

Percentages refer to proportion of those providing an answer to this question

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

3. National Quality Standards

A set of proposed National Quality Standards, falling under seven key themes, have been developed as part of the *Safe and Sustainable* Review. It is proposed that all hospitals that are designated as Specialist Surgical Centres should meet each of these standards. Respondents were asked to indicate the extent to which they supported or opposed the National Quality Standards within the key themes:

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

3.1 National Quality Standards – key themes

Views on the new quality standards

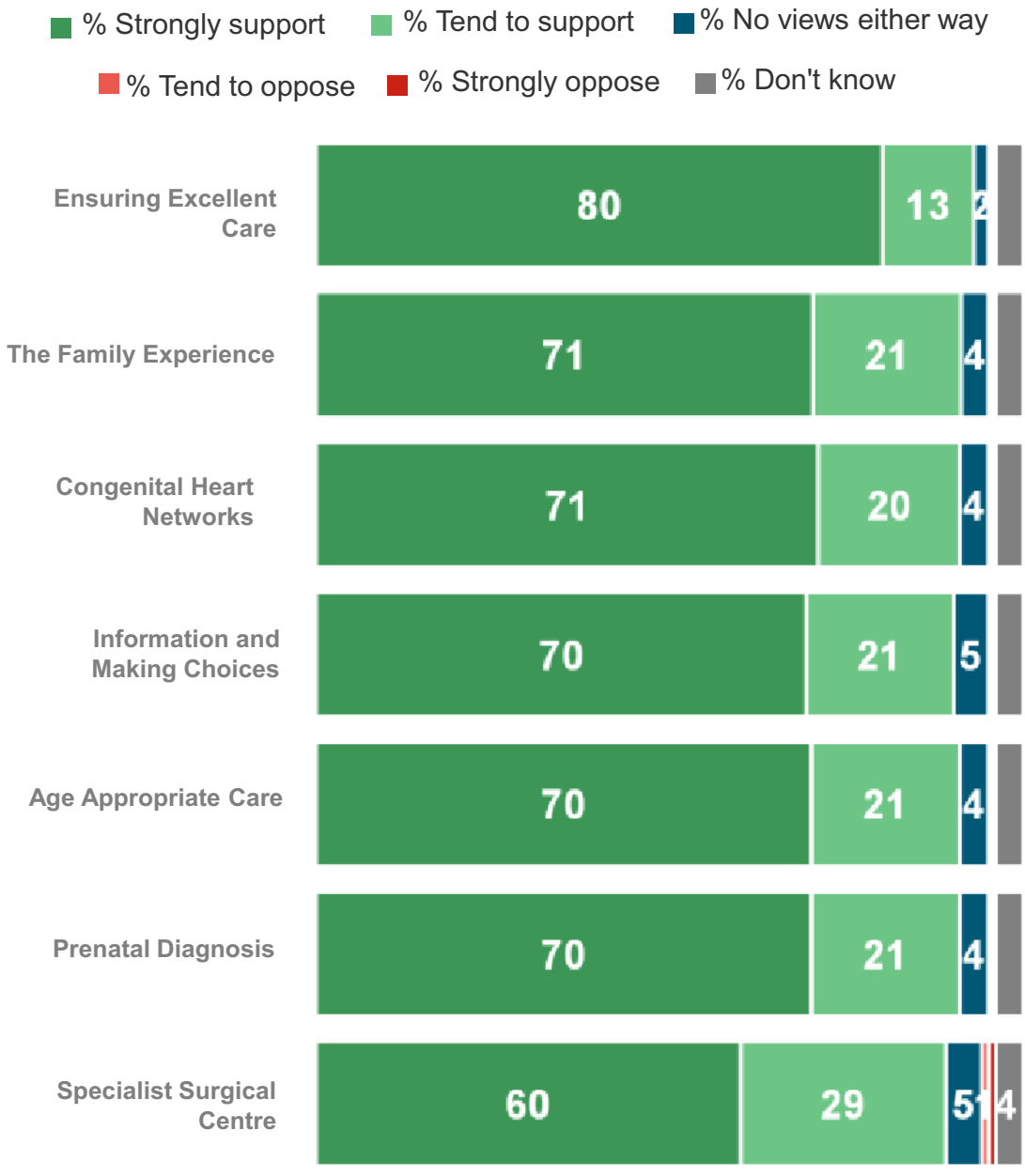
The following charts provide an overview of respondents' support for, or opposition to, the proposed National Quality Standards across each of the key themes, broken down by personal and organisation responses. Later sections discuss each of these in more detail.

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

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

National Quality Standards (personal responses)

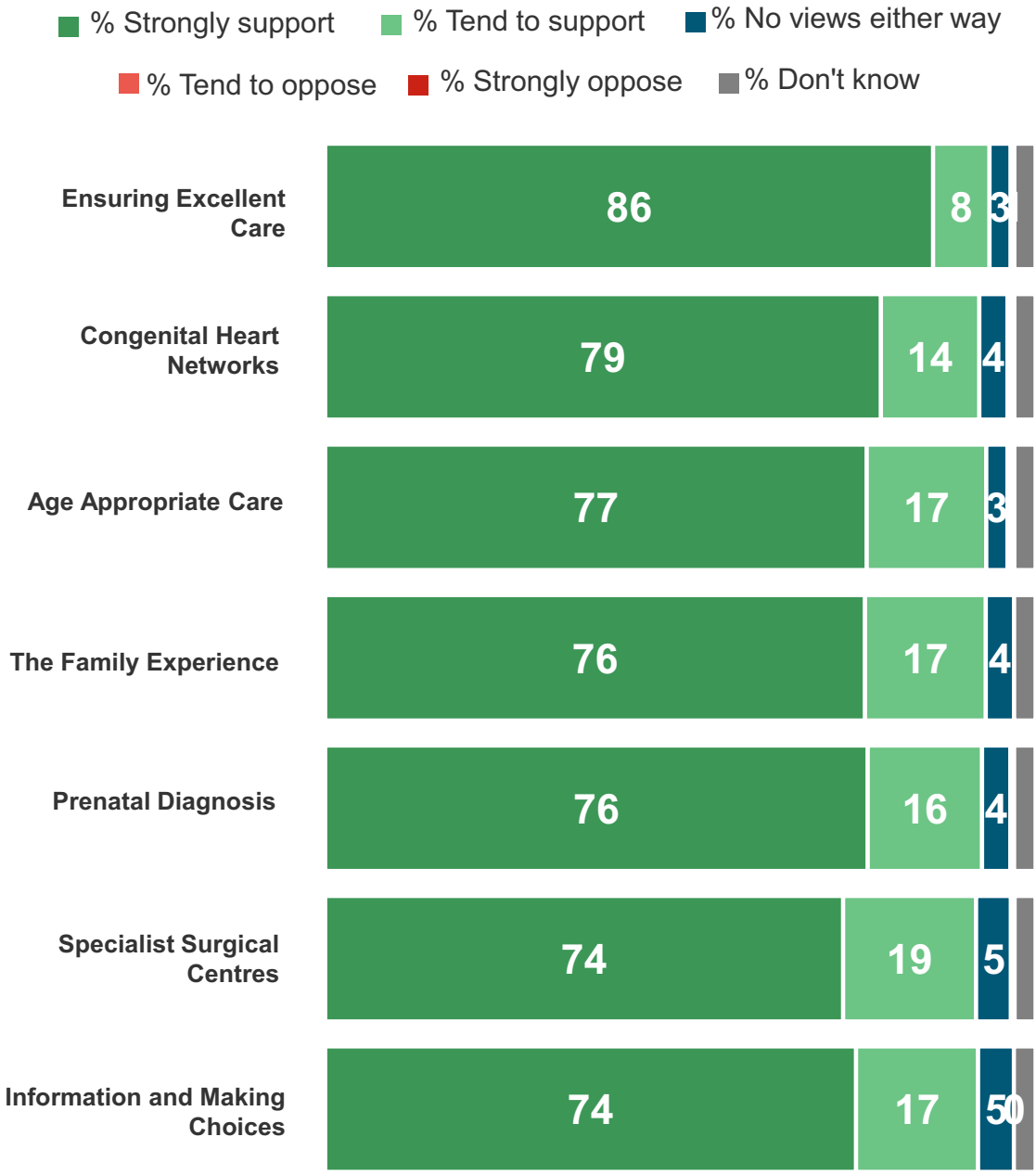
Q Please indicate the extent to which you support or oppose the national quality standards within each of these seven key themes.



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

National Quality Standards (organisation responses)

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



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

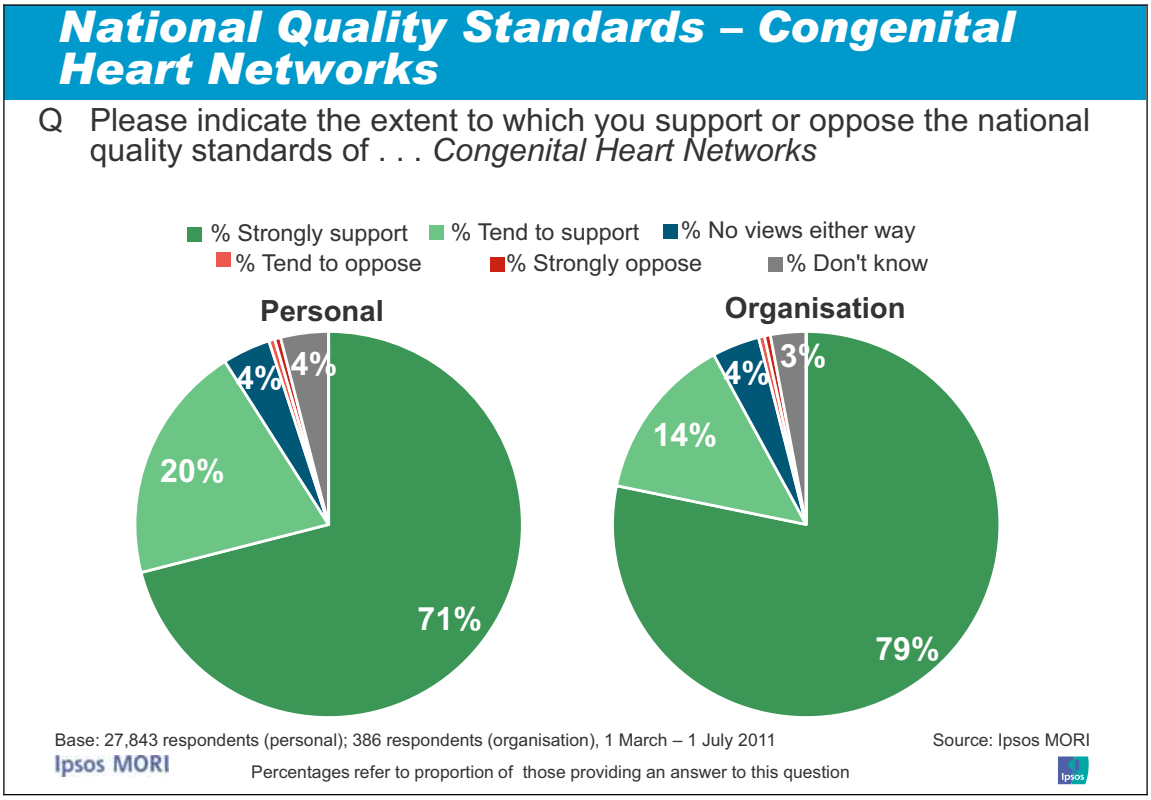
Ipsos MORI

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

National Quality Standards – Congenital Heart Networks[15]

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

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



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

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

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

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

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

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

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

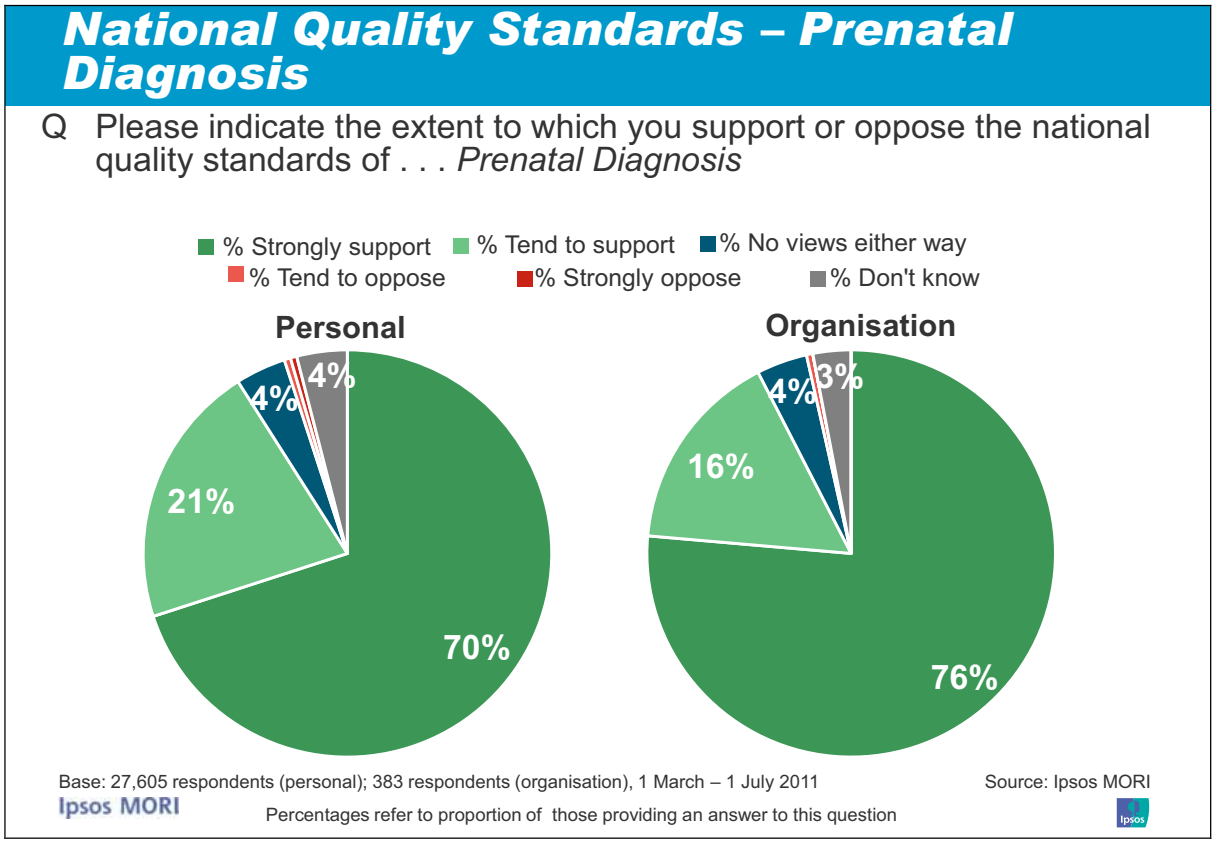
Other comments restated the importance of such networks (and standards relating to these), while a small number referred to existing examples of networks.

National Quality Standards – Prenatal Diagnosis[16]

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

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

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



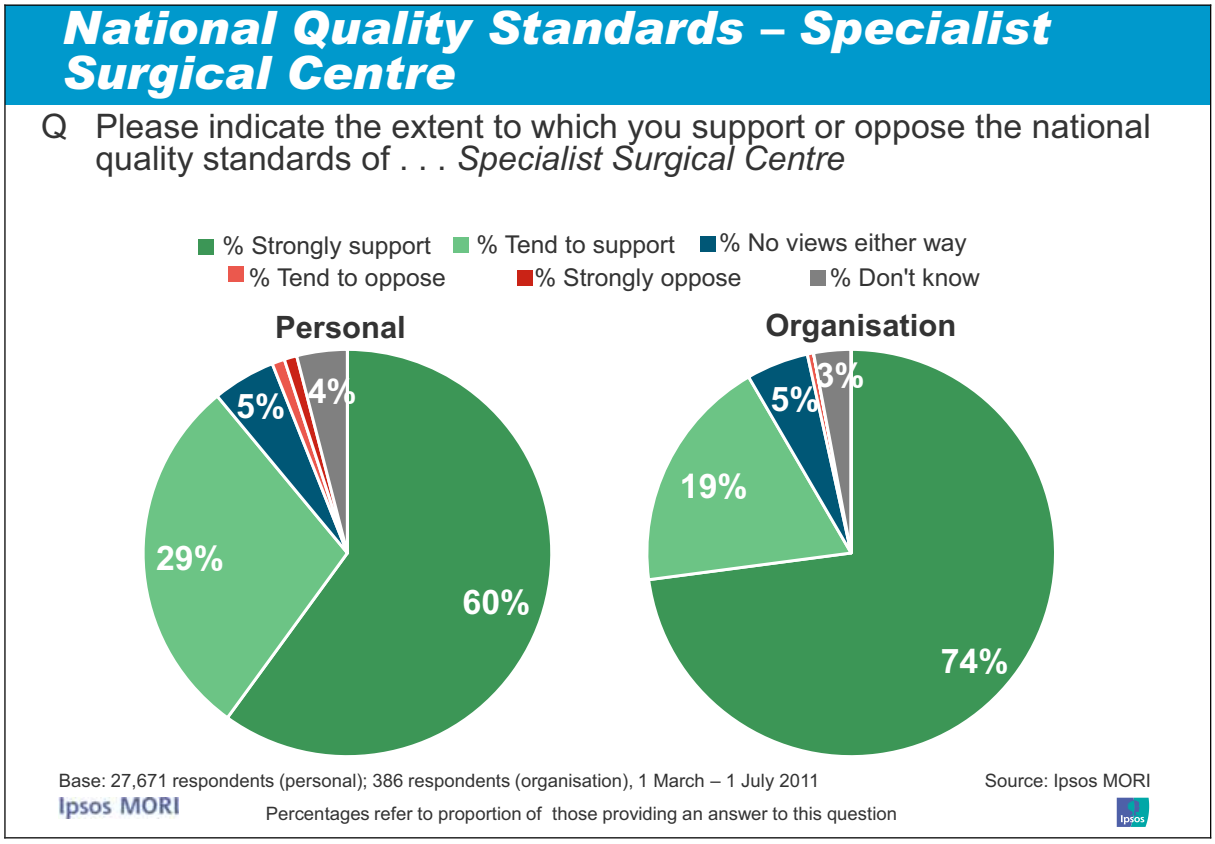
Slightly fewer respondents made comments on the standards relating to *Prenatal Diagnosis* (201), but among those that did, their responses generally stated a belief that prenatal diagnosis was extremely important and would help prepare expectant parents. Other respondents commented that this would allow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

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

"Prenatal diagnosis is imperative so that babies can be born in a hospital with the specialist care required…"

National Quality Standards – Specialist Surgical Centre[17]

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



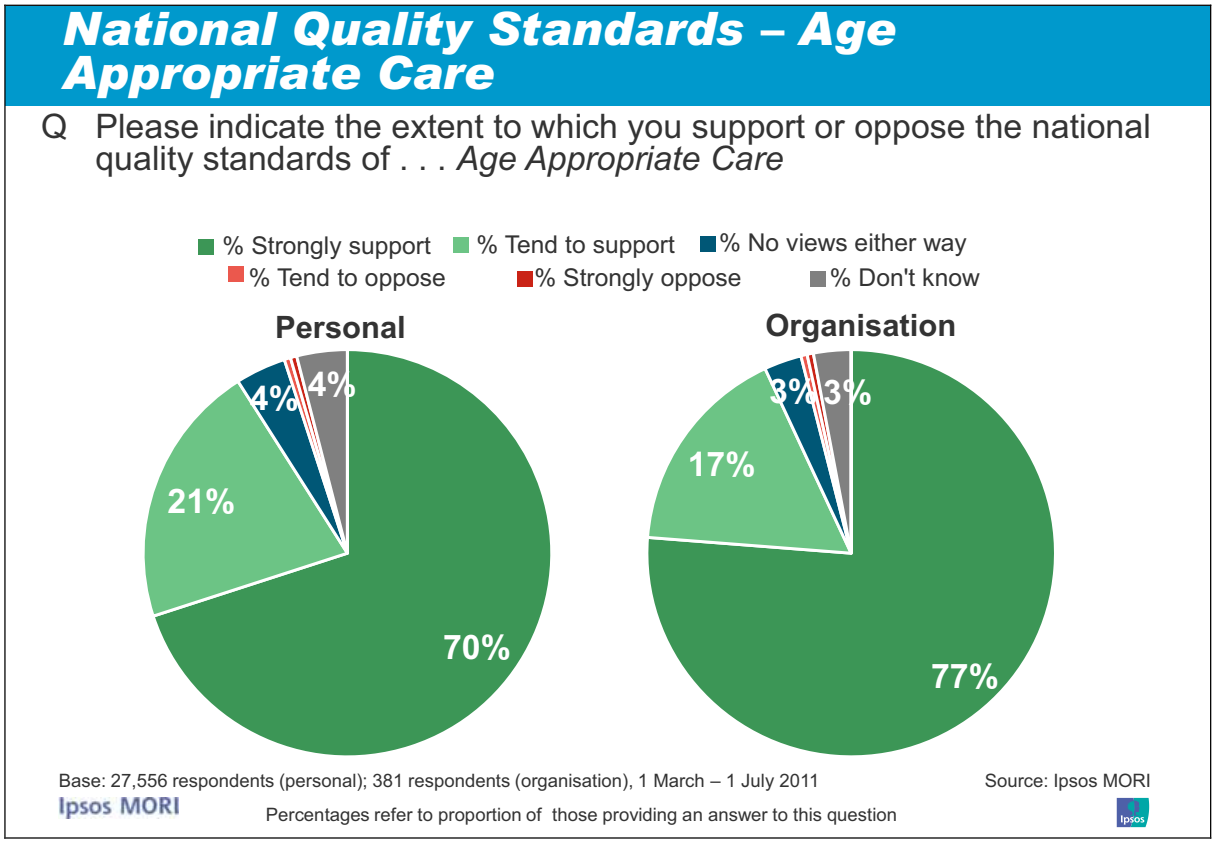
The *Specialist Surgical Centre* theme was the one on which most people commented. Of the 338 respondents who provided comments, around half of these argued that there is insufficient evidence to show that outcomes are better as a result of performing significantly more cases (400+) / with four surgeons.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

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

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

National Quality Standards – Age Appropriate Care[18]

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

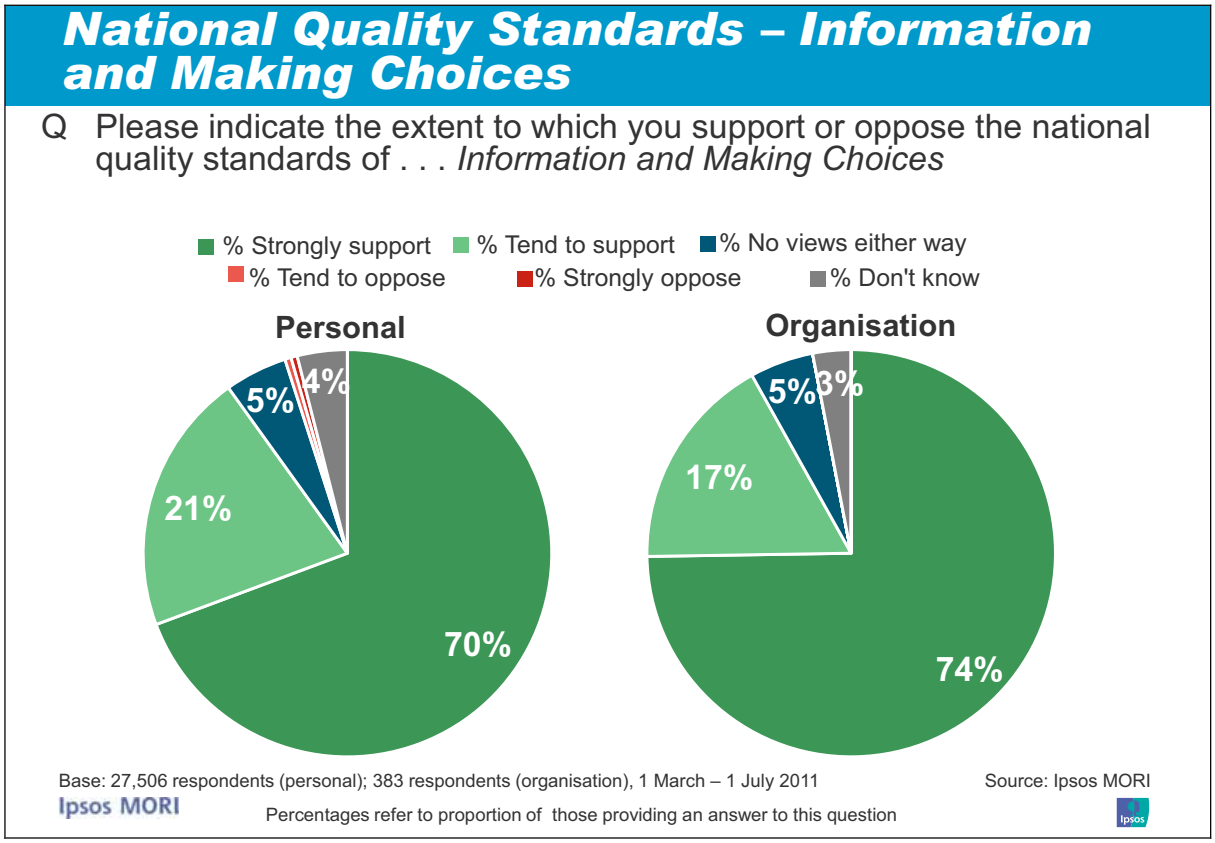


Just 141 respondents provided comments related to *Age Appropriate Care*, the most common being that this was well provided by Glenfield Hospital. Other responses stated the importance of age appropriate care and a small number stressed the value of continuity of care and/or seeing the same doctors from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

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

National Quality Standards – Information and Making Choices[19]

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

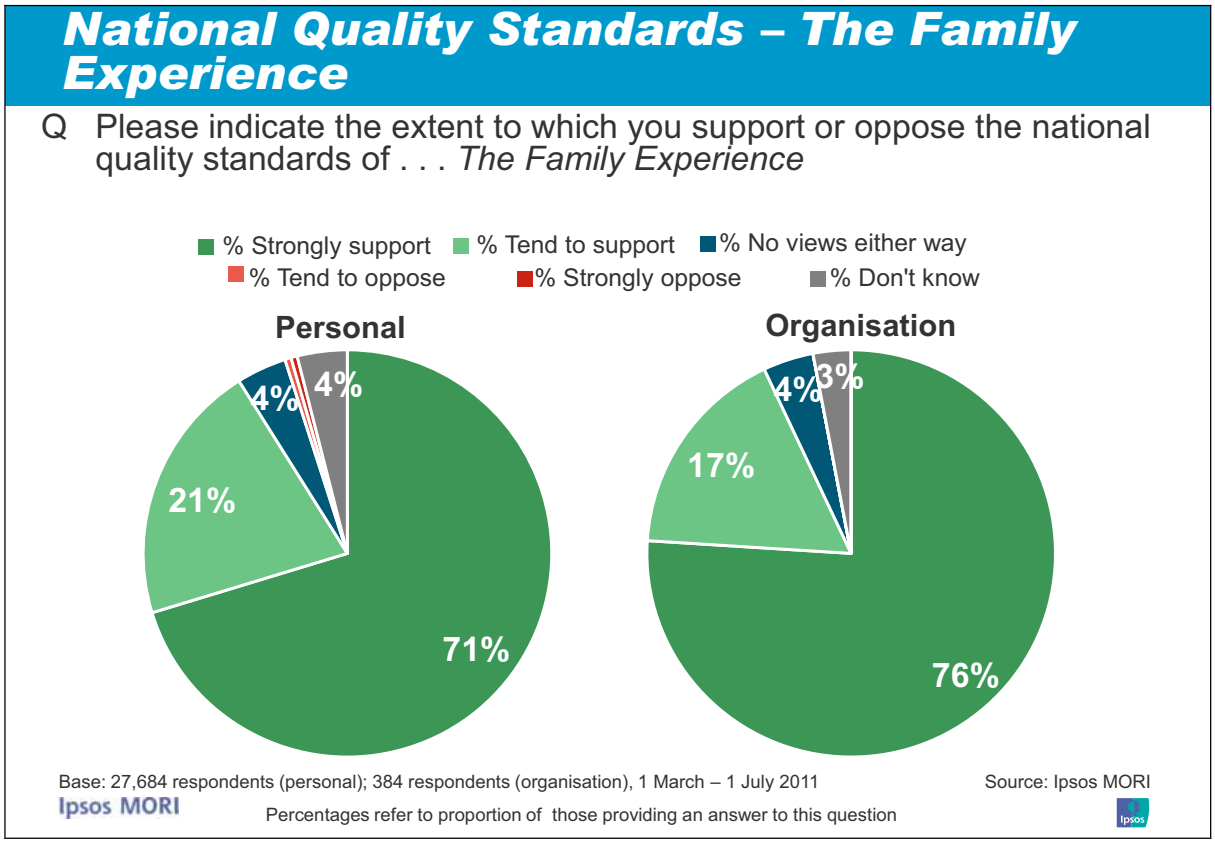


This theme received the lowest number of verbatim comments (71). Those that did provide a response tended to refer to the importance of these standards and noted how important information was for parents and children to point them in the right direction and help them make decisions.

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

National Quality Standards – The Family Experience[20]

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



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

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

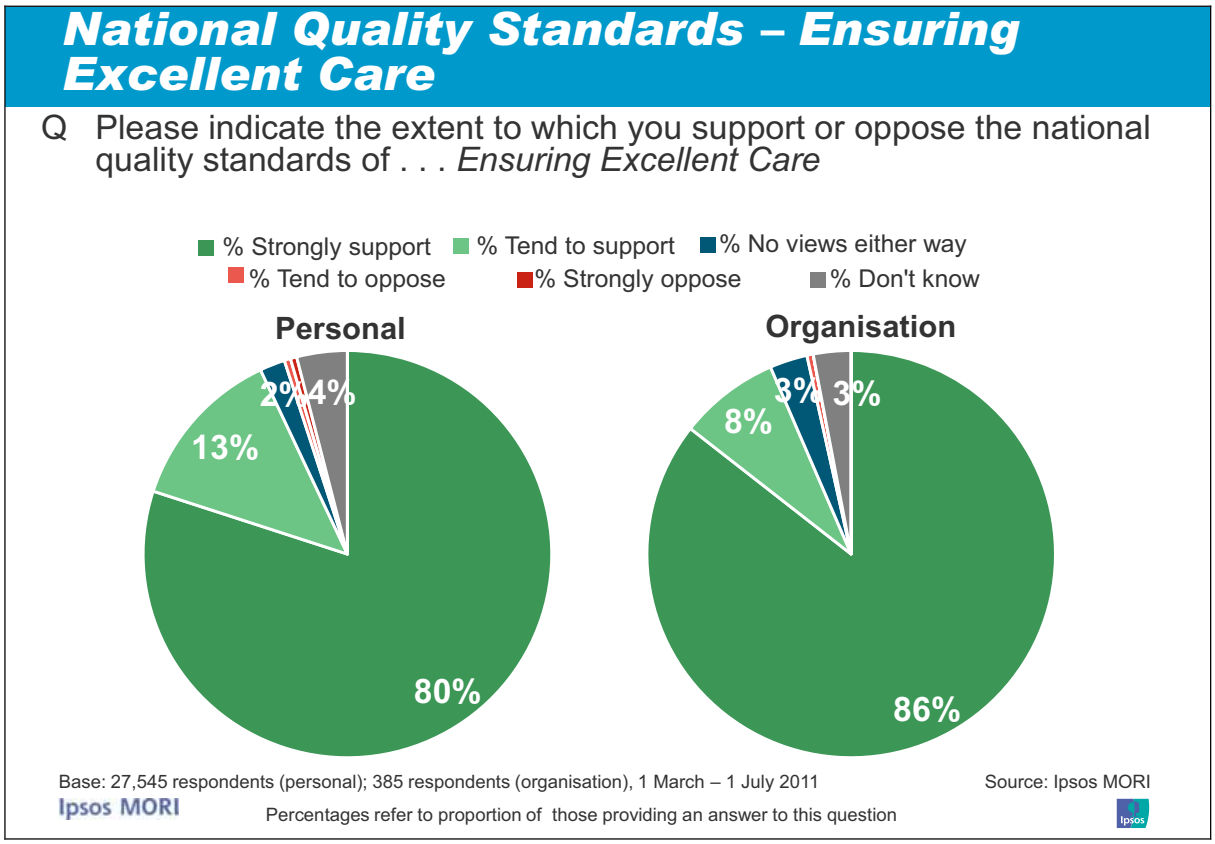
A smaller number of responses made similar comments about other specific hospitals, while others restated the importance of this issue for families.

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

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

National Quality Standards – Ensuring Excellent Care[21]

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



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

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

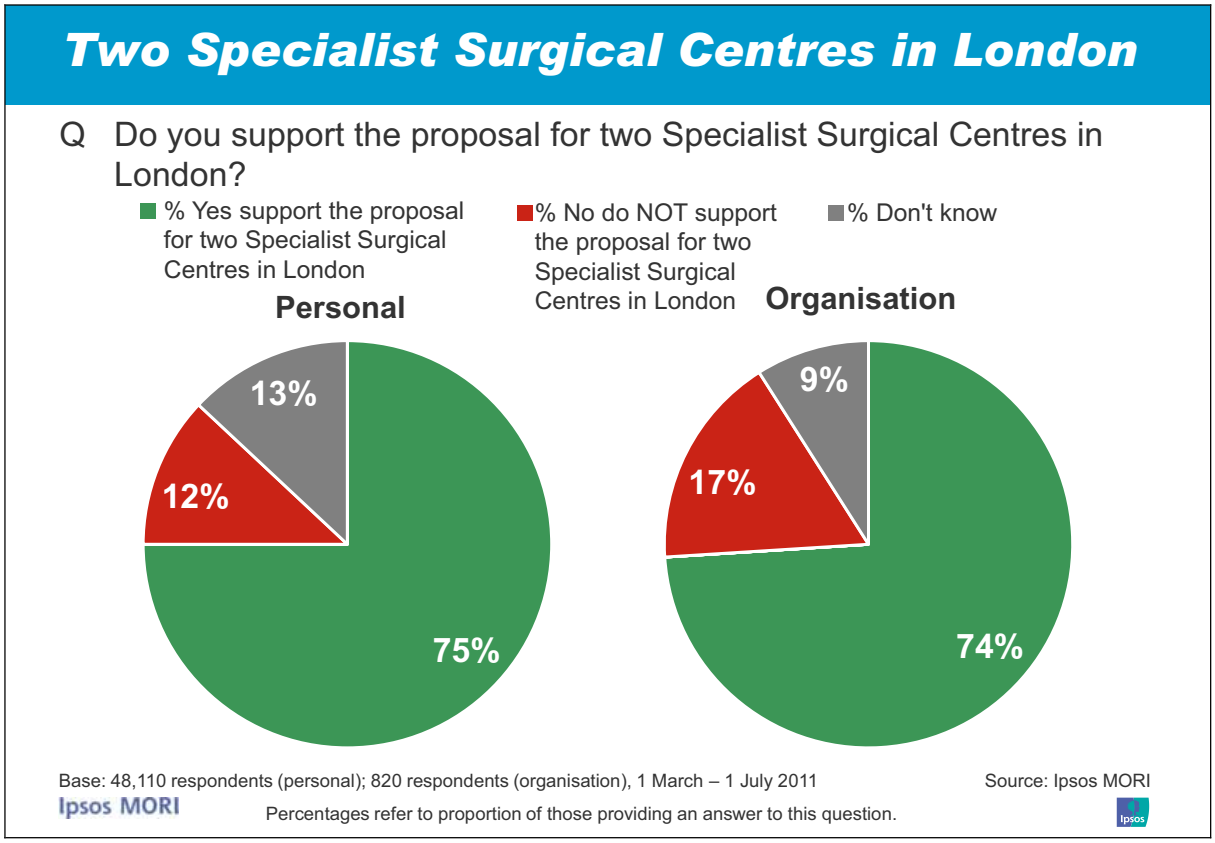
4. Proposals for Specialist Surgical Centres in London

The *Safe and Sustainable Review of Children's Congenital Heart Services* proposes that two Specialist Surgical Centres will be located in London and that these should be Great Ormond Street Hospital and Evelina Children's Hospital. This chapter considers responses on these proposals[22].

4.1 Two Specialist Surgical Centres in London

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

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



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

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

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

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

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

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

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

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

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

4.2 Proposals for Specialist Centres in London

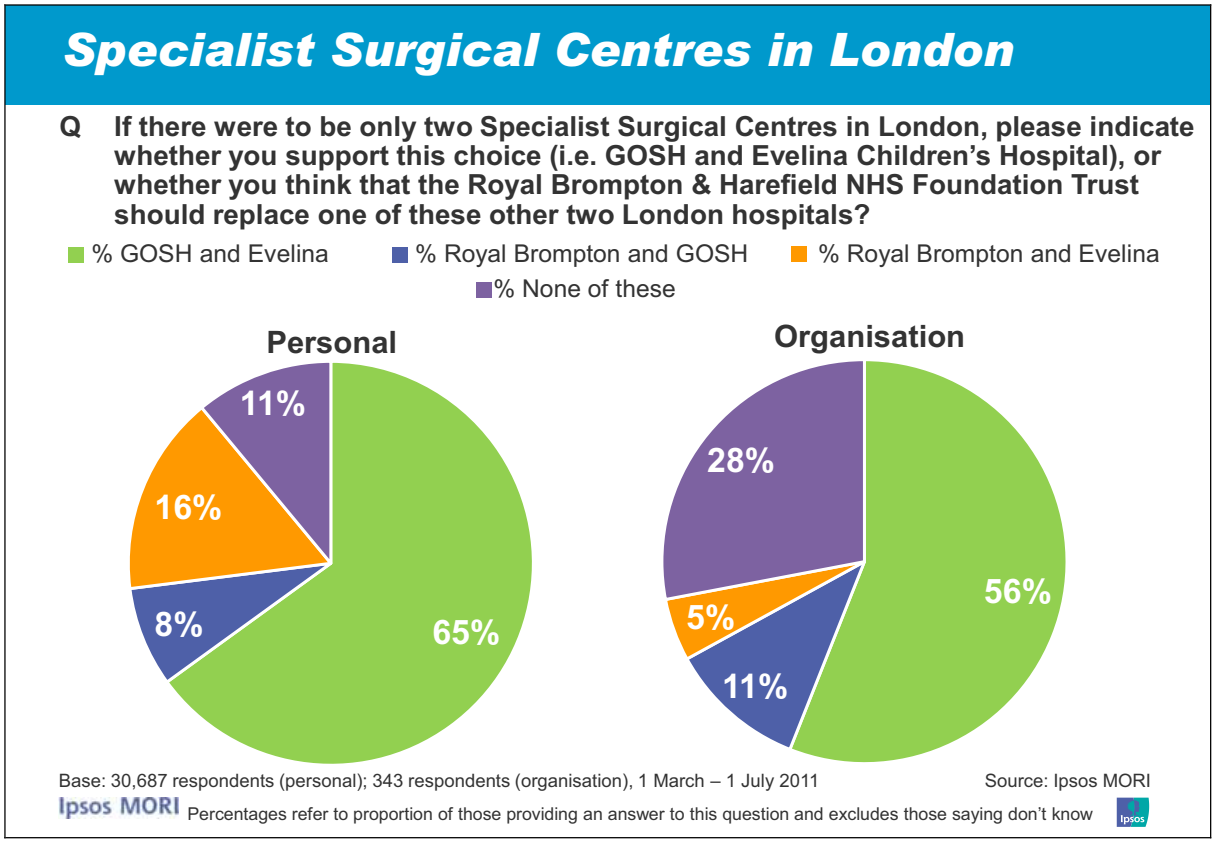
Respondents were also asked, if there were to be only two Specialist Surgical Centres in London, whether they supported the proposal that these should be GOSH and Evelina Children's Hospital or whether they preferred a different combination.

In the case of personal respondents, two in five (39%) supported GOSH and Evelina, one in twenty (5%) preferred Royal Brompton and GOSH, and one in ten (10%) preferred Royal Brompton and Evelina. Around two in five (39%) however, did not know or did not provide an answer. **Of those responding[23], two thirds supported the proposal (65%)**, 8% preferred Royal Brompton and GOSH, 16% preferred Royal Brompton and Evelina while 11% said none of these.

The vast majority of organisations (70%) did not know or did not provide an answer. Again, however, GOSH and Evelina was the most popular combination of the three (17% of organisation respondents in total supported this choice). **Of those responding[24], 56% supported the proposal,** 11% preferred Royal Brompton and GOSH, 5% preferred Royal Brompton and Evelina, while 28% said none of these.

[23] This excludes those not stating an answer or saying 'don't know'

[24] This excludes those not stating an answer or saying 'don't know'



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

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

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

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

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

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

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

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

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

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

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

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

"*Care should be concentrated at the two best performing units and therefore would support Great Ormond Street and Evelina Children's Hospital"*

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

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

5. Proposals for Specialist Surgical Centres outside London

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

5.1 Views on options for centres outside London

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

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

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

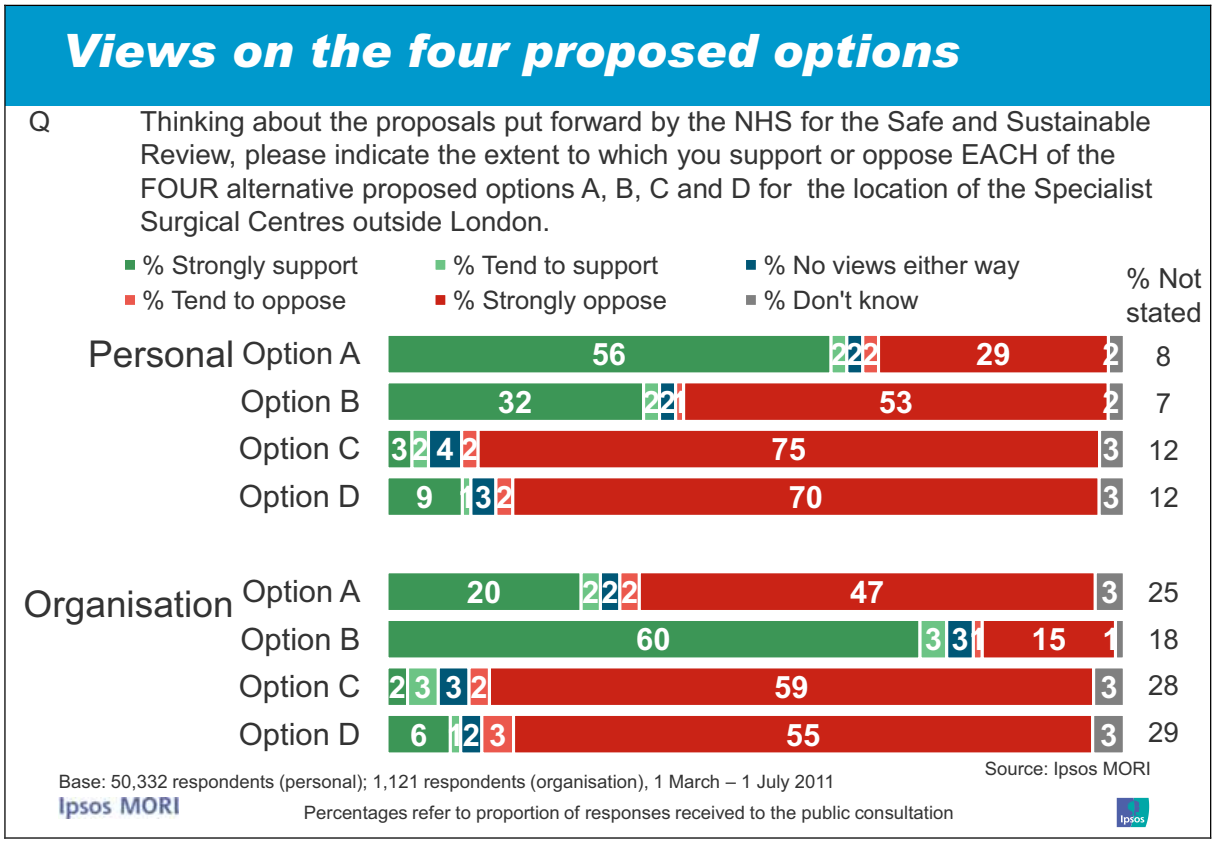
Option C	**Option D**
Alder Hey Children's NHS Foundation Trust (Liverpool)	Alder Hey Children's NHS Foundation Trust (Liverpool)
Birmingham Children's Hospital NHS Foundation Trust	Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS	University Hospitals Bristol NHS

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

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

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

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



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

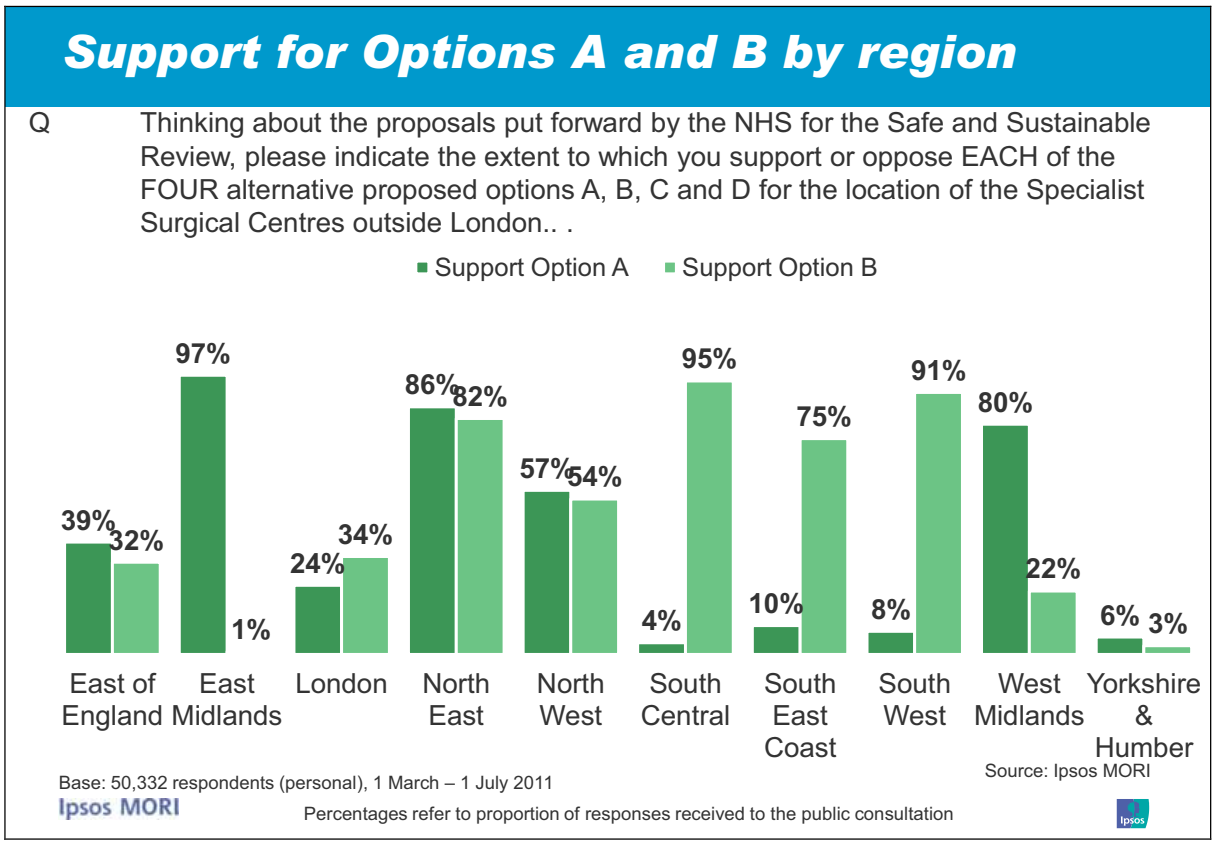
As might be expected, personal responses differ markedly by region. Just under half of the response forms that were received from individuals were from the East Midlands region, and respondents in this region were overwhelmingly likely to support Option A (97%), which is the

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

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

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

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



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

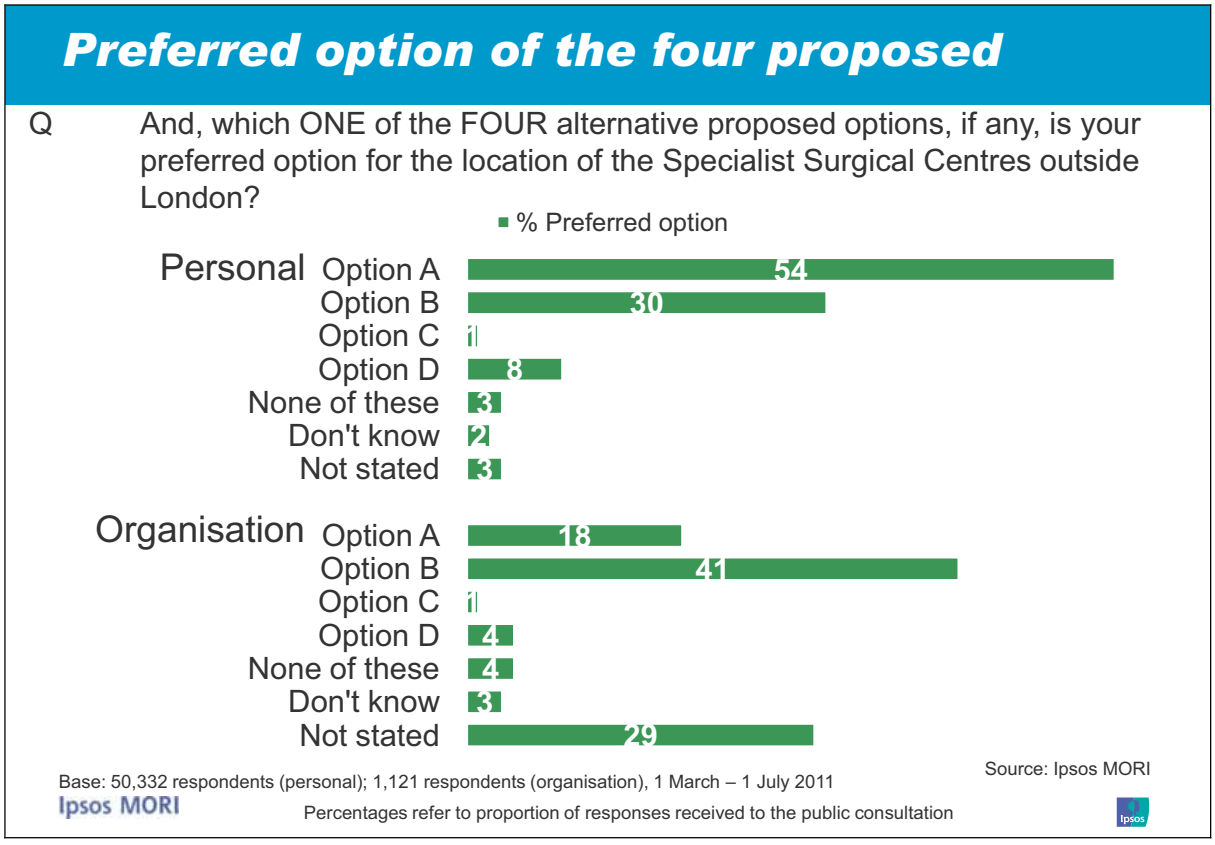
Option C received the lowest level of support – around one in twenty responses from personal respondents and organisations supported this option. Support of Option D was slightly higher, and was highly concentrated among individuals based in Yorkshire and

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

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

5.2 Preferred options

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

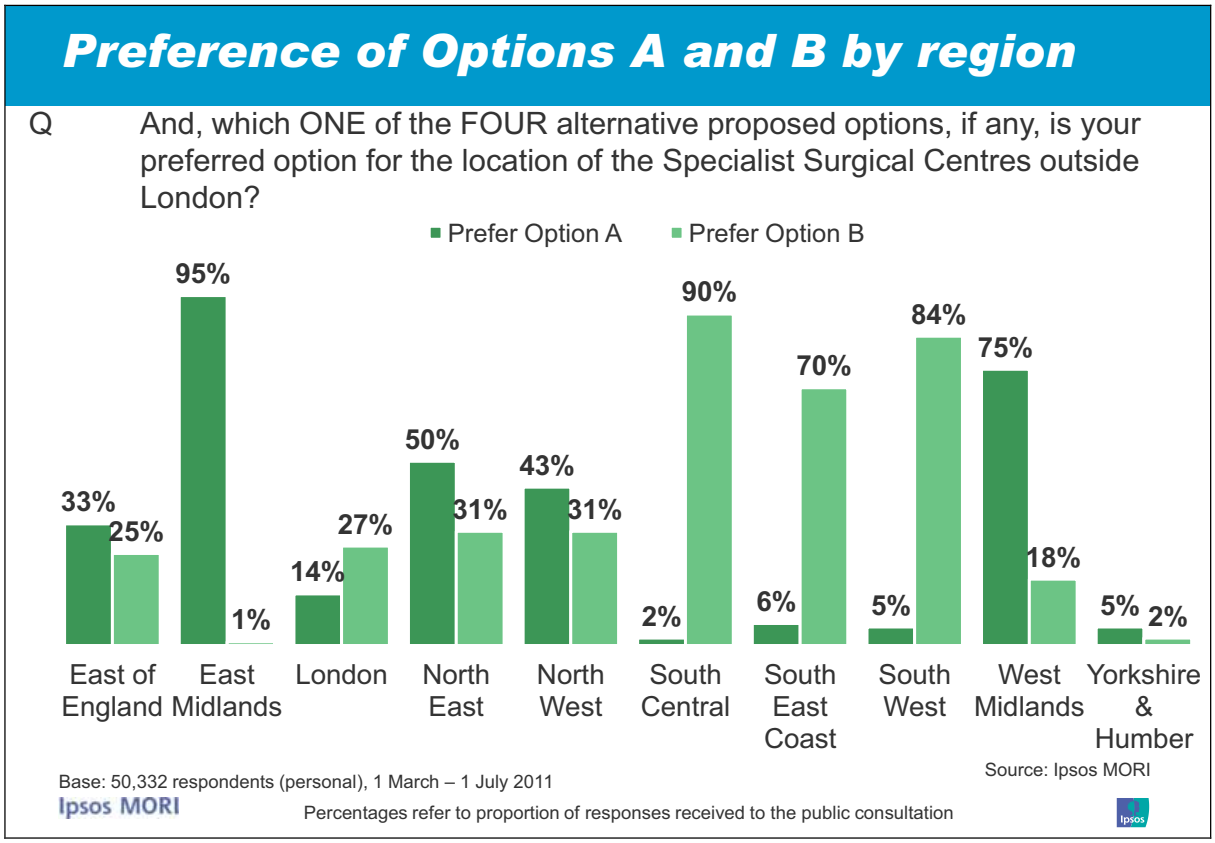


As with support, region was key. Those who responded from the East Midlands and the West Midlands were overwhelmingly likely to prefer Option A (with preference levels of 95% and 75% respectively), and those in the south of the country were especially likely to support Option B (with preference in South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

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

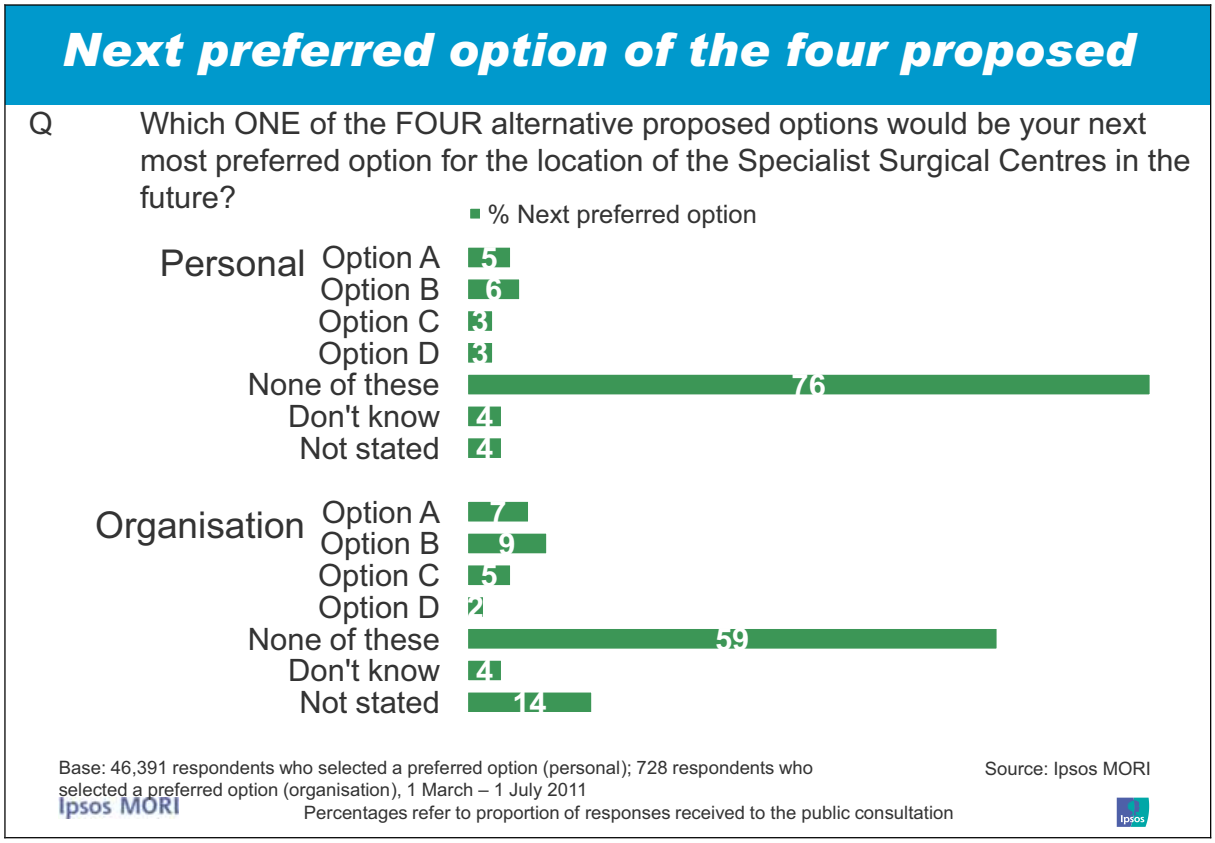
Preference for Option D was overwhelmingly concentrated among those who responded from Yorkshire and Humber: 90% of those from this region supported Option D.

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



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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

"Leeds covers 14 million people within a two hour travel time, it's central."

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

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

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

"Leicester's Glenfield hospital is a fantastic hospital. Dedicated staff and excellent treatment."

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

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

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

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

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

"Quality outcomes should be the deciding factor."

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

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

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

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

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

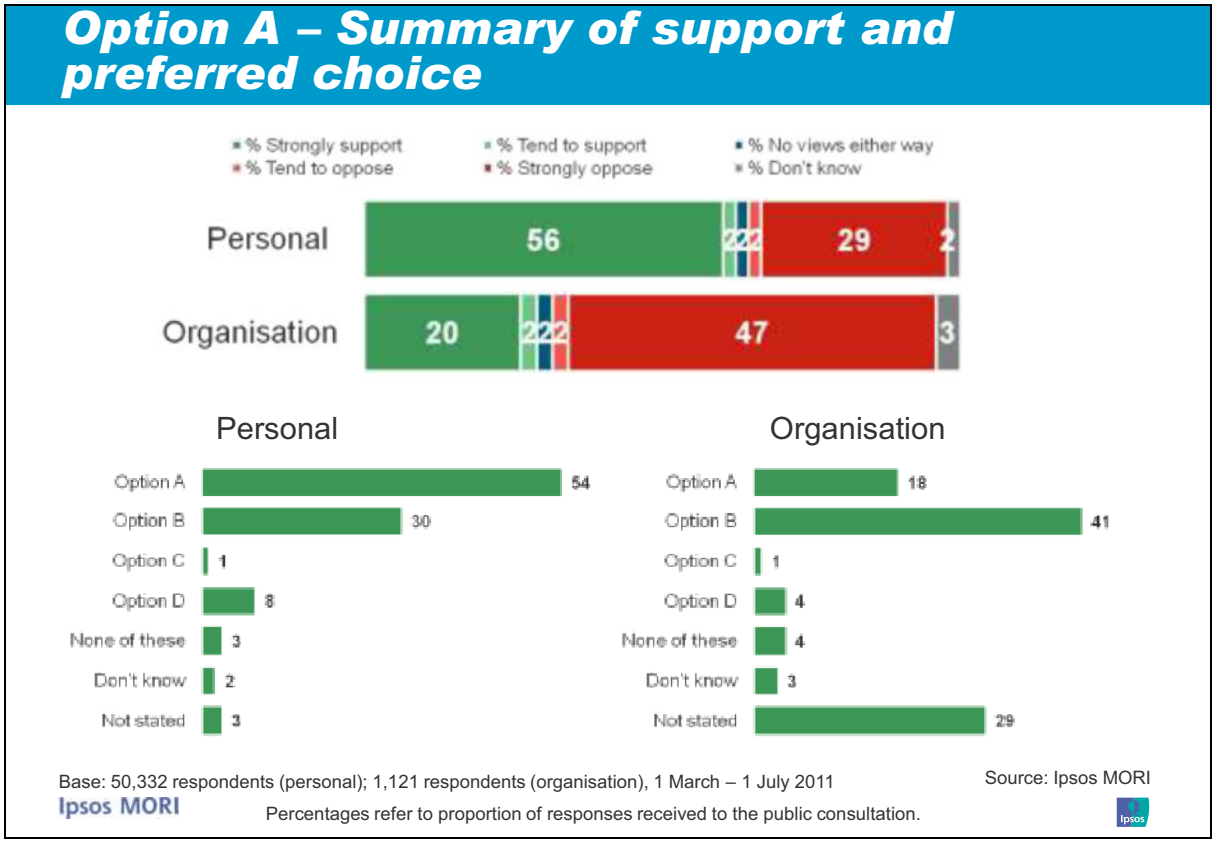
Some respondents also discussed the facilities and services available at proposed centres (4,102 in total), such as retrieval of patients within the stipulated time, reaching the minimum 400 operations (this includes a group of responses using identical wording (or very similar) supporting Option D)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

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

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

5.3 Views on Option A

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



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

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

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

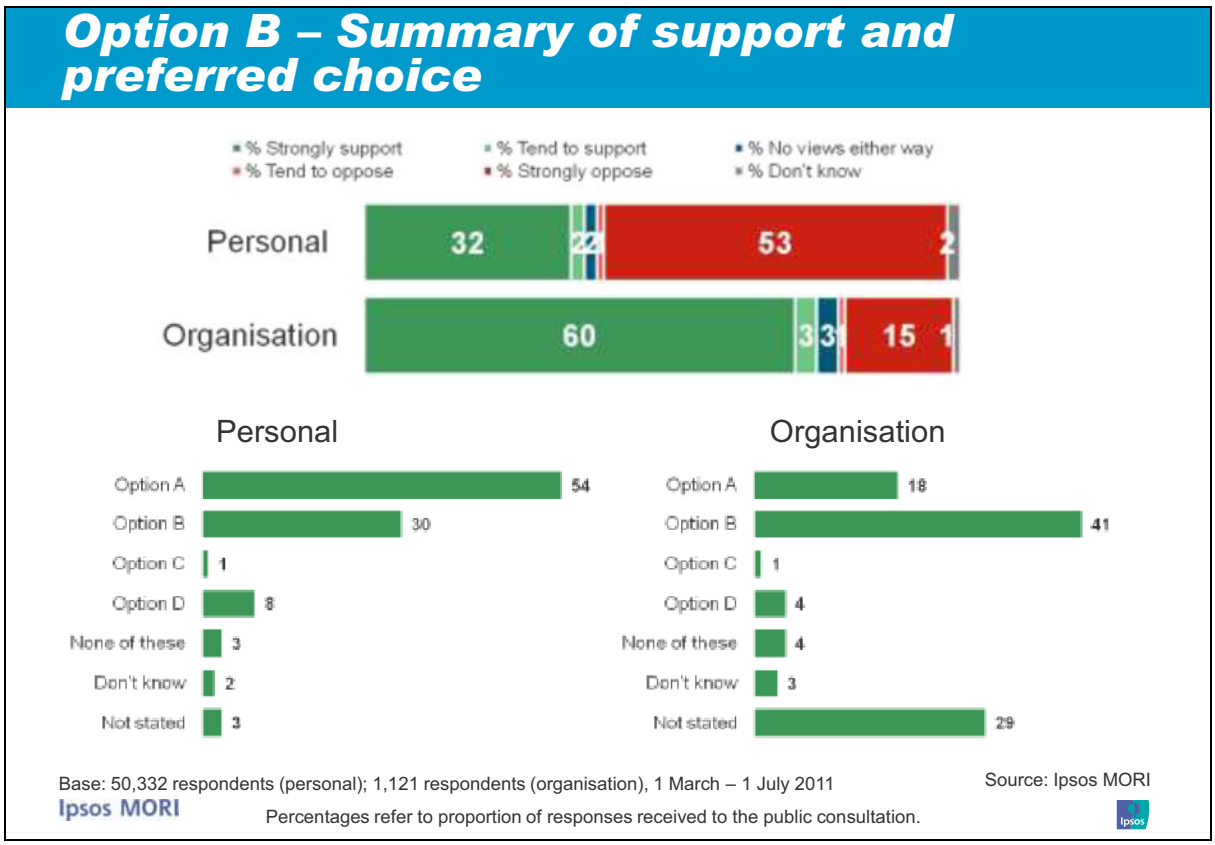
"Option A is the only choice. Specialised services should stay where they currently are. It takes years to build the expertise in these services."

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

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

5.4 Views on Option B

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



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

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

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

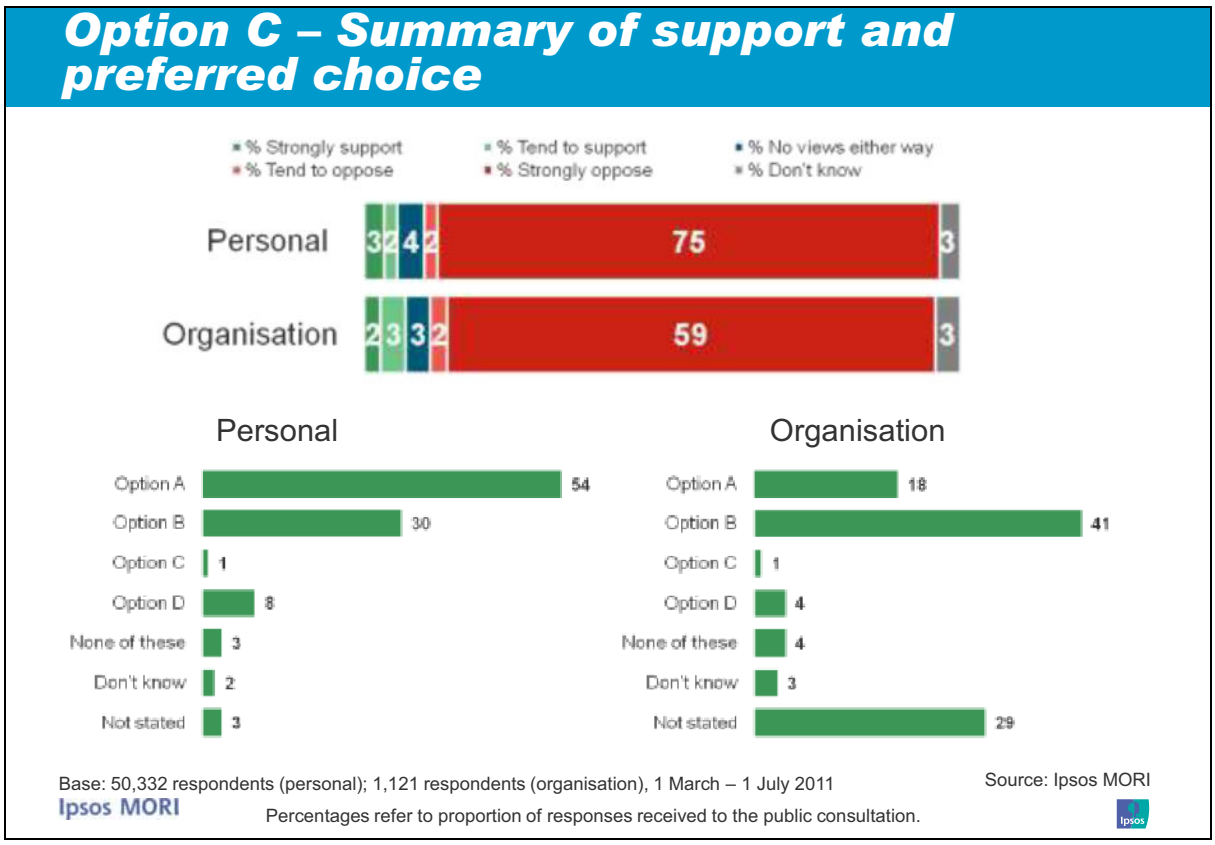
"Option B has centres scoring highest for quality; centres with best surgery survival rates; has centres which already undertake complex surgery; and provide excellent access to patients from all parts of the country."

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

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

5.5 Views on Option C

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

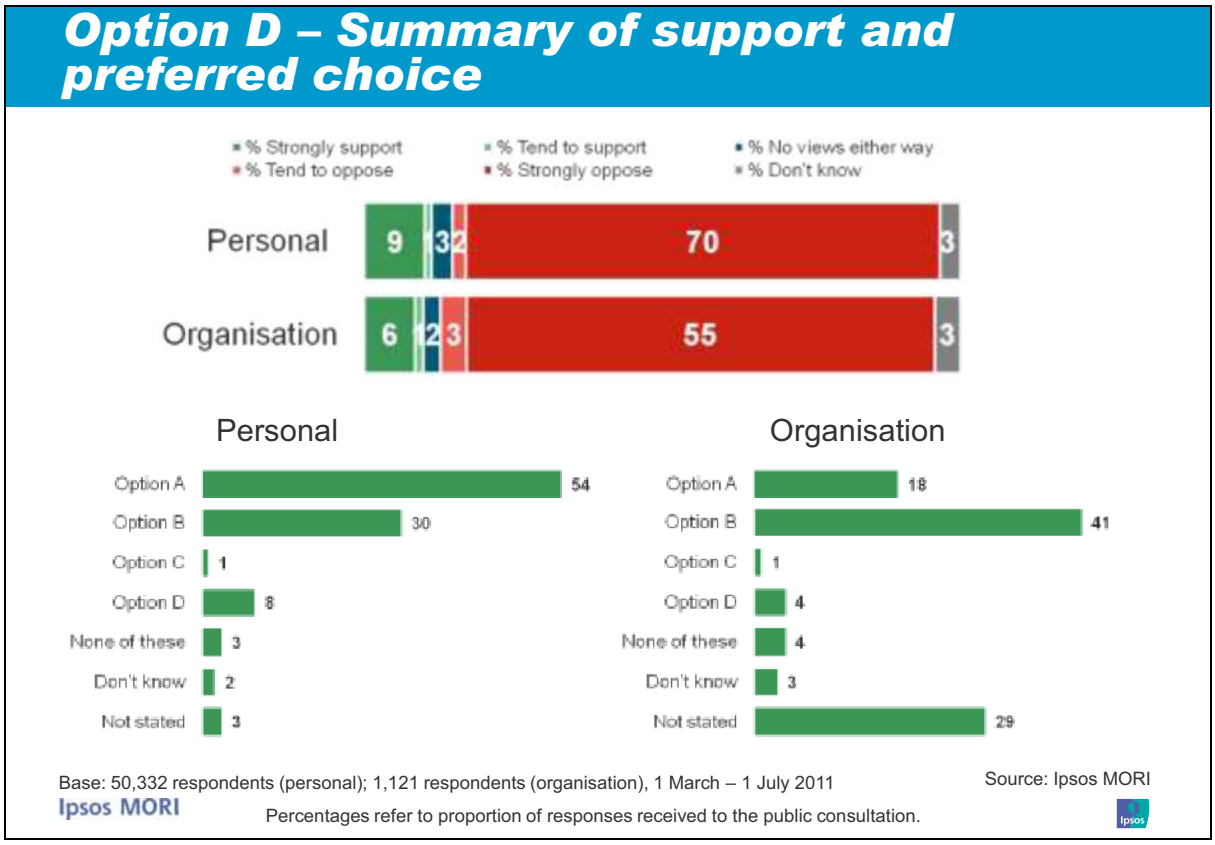


Relatively few respondents spontaneously commented on Option C – just 48 comments were made in total. Of these, there were more negative than positive and most referred to there being too few centres in Option C in the respondents' view.

"Option C has only 6 centres nationally."

5.6 Views on Option D

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



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

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

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

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

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

5.7 Preferred configuration

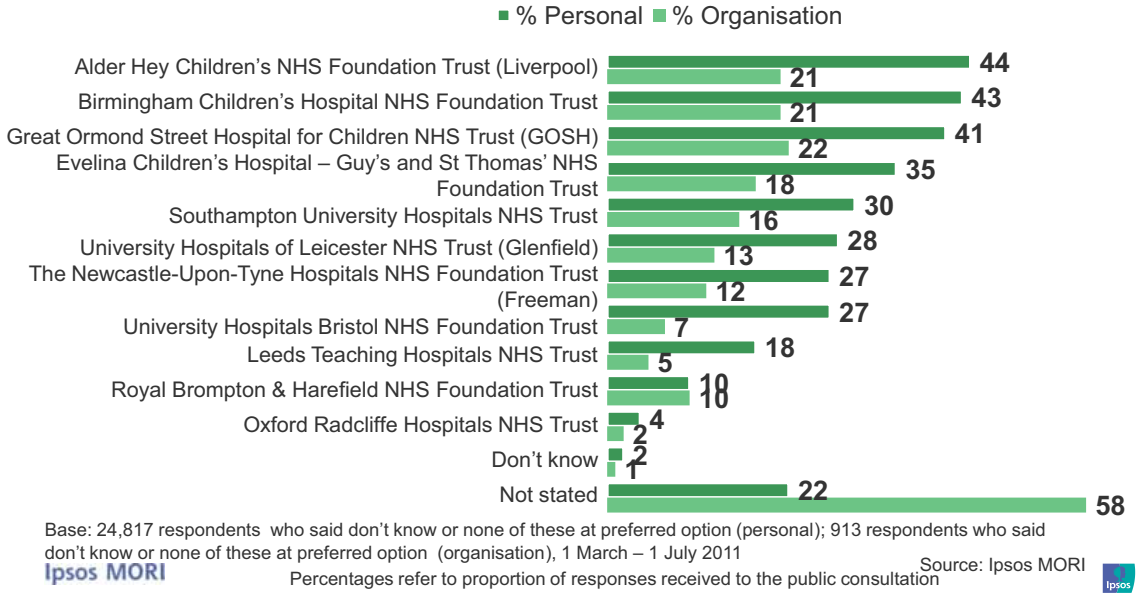
Those who did not express a preference for the location of centres inside and outside of London were asked an additional question wherein they selected their preferred configuration of locations of centres across England.

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

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

Preferred configuration

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



Base: 24,817 respondents who said don't know or none of these at preferred option (personal); 913 respondents who said don't know or none of these at preferred option (organisation), 1 March – 1 July 2011

Ipsos MORI

Source: Ipsos MORI

Percentages refer to proportion of responses received to the public consultation

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

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

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

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

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

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

Table 4 – Most commonly selected configurations of Specialist Surgical Centres

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

Source: Ipsos MORI

5.8 Assumptions on how postcodes have been assigned

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

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

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

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

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

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

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

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

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

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

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

6. Text message responses

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

6.1 Numbers of text messages received

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

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

6.2 Discussion of response themes

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

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

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

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

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

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

Support for, or opposition to, each of the hospitals

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

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

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

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

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

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

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

Priorities

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

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

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

General opinions of the proposals

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

7. Stakeholder responses

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

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

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

8. Petitions and campaign responses

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

Table 6 – Petitions and campaigns

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

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

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

[29] Approximate figure – counted but not verified by Ipsos MORI (may contain duplicates)
[30] Stated number of responses received with petition (not verified by Ipsos MORI – may contain duplicates)
[31] Stated number of responses received with petition (not verified by Ipsos MORI – may contain duplicates)
[32] Stated number of responses received with petition (not verified by Ipsos MORI – may contain duplicates)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Petition S – Southampton University Hospitals NHS Trust website comments

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

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

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

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

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

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

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

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

Appendices

The appendices to this report are:

Appendix A: Responses from organisations

Appendix B: Petitions/campaigns

Appendix C: Demographics

Appendix A: Responses from organisations

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Proposed centres for the location of Specialist Surgical Centres
Alder Hey Children's NHS Foundation Trust
Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
Great Ormond Street Hospital for Children NHS Trust
Guy's & St Thomas' NHS Foundation Trust (Evelina Children's Hospital)
The Leeds Teaching Hospitals NHS Trust

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

Responses using the response form

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

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

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

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

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

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

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

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

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

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

Appendix B: Petitions and campaigns

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

Petition A

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

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

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

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

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

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

Petition B

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

Option A is

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

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

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

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

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

Petition C

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

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

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

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

Petition D

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

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

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

Petition E

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

Petition F

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

Petition G

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

Petition H

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

Petition I

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

Petition J

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

Petition K

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

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

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

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

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

Petition L

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

Petition M

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

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

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

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

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

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

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

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

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

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

IF AFTER READING THIS YOU AGREE, PLEASE SIGN THE PETITION

Petition N

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

Petition O

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

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

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

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

Petition P

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

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

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

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

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

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

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

Petition Q

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

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

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

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

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

Petition R

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

Petition S

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

Petition T

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

Petition U

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

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

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

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

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

Petition V

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

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

Petition W

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

Petition X

Dear Mr Cameron

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

Please can you stop this?

Thank you

Petition Y

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

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

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

Appendix C: Demographic information

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

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

Table A1

Consultation responses by gender

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

Source: Ipsos MORI

[34] Source: Census 2001, mid-year estimates 2010

Table A2

Consultation responses by age

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

Source: Ipsos MORI

Table A3

Consultation responses by experience

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

Source: Ipsos MORI

Table A4

Consultation responses by region

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

North West	510	1	13
Yorkshire and Humber	3,446	7	10
Wales	122	*	
Scotland	115	*	
Isle of Man	2	*	
Stating region	47,360		
Not stated (where question asked)	2,972		
Total	***50,332***		

Source: Ipsos MORI

Table A5

Consultation responses by ethnicity

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

Source: Ipsos MORI

[35] This data is taken from the 2001 census.

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Southampton NHS
University Hospitals NHS Trust

The safe retrieval of critically ill children from St Mary's hospital on the Isle of Wight

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PICS Standard 123. The retrieval team should arrive at the referring unit within three hours of the decision to retrieve the child.

Note: In remote areas, where the Retrieval Service has considerable distance to travel, retrieval team should arrive within four hours of the decision to retrieve the child.

We have been asked to submit a final paper to the JCPCT summarising the issues affecting the retrieval of acutely unwell patients from St Mary's Hospital on the Isle of Wight, to the paediatric intensive care service at Southampton General Hospital.

We will describe the background to this, its relevance to the decision making process and the reality on the ground in order to help the committee come to a true understanding of the real impact on patients.

Background and relevance to the decision making process

At the heart of this issue is the fair and accurate application of the Paediatric Intensive Care Society standard number 123 and the influence this has on the designation of surgical centres in the safe and sustainable review. The standard itself is endorsed by all the relevant professional organisations and the steering group has agreed that every designated surgical centre must meet this standard for all DGH's in its network in the future. The JCPCT separately has stated that it will consider only those configuration options in which the standard could be reached in every network..

It is made clear in the consultation document on page 87 (and was re-iterated at every consultation event) that the inability of any centre other than Bristol to meet the four hour element of the standard with regard to Truro hospital and the three hour standard for three other distant hospitals, notably Haverfordwest which nearly breaches four hours, led to the exclusion of any option in which this centre was not designated. In contrast, the inability of any centre other than Southampton to meet even the four hour remote element of the standard with regard to St Mary's Hospital in the Isle of Wight has had no impact on the options appraisal.

This error occurred because the standard mode of transport for retrieval of patients from the Isle of Wight (road and ferry) was not taken into account. It was wrongly assumed that these patients would usually be collected using air transport. In fact the Isle of Wight is so close to the mainland that air is only used on rare occasions. Transporting intensive care patients in an ambulance is a lot easier and safer than in an aircraft. This view is reflected by the fact that the Acute Transport Group of the Paediatric Intensive Care Society do not consider air transport to be safe or reliable enough to replace existing modes of transport. As our current model can meet the PICS standard for time, then it is the mode of transport

of choice. We understand that the Paediatric intensive Care Society, in a separate communication, has endorsed this position.

Assessing "worst case scenario" journey times for retrieval

Retrieval times were assessed using the DirectGov journey planner from potential surgical centre to referring hospital, with all journeys by car and starting at 1200hrs. This is described in Appendix T of the consultation document.

DirectGov is the official UK government website for citizens, its car journey planner is updated via the Highways Agency; it is the only journey planner that allows the user to put in a specific time of departure and the only journey planner that synchronises with the ferry times. Twelve mid-day was chosen because it generated the marginally longest times and the stated aim was to generate a 'worst case scenario' (see para 1, page 210 of the Pre-Consultation Business Case). Car journey times were used, as no standard times by blue light were available for all the journeys. In addition the use of blue lights is associated with increased accidents and the steering group did not wish to promote less safe modes of transport. All retrieval calculations in Appendix T of the Pre-Consultation Business Case (page 210) were made using this method and all of them exclude St Mary's. If St Mary's is restored and the methodology described in Appendix T applied, one can see that it is not possible for a centre other than Southampton to get there in less than 4 hours (4 hours and 4 minutes from Bristol and 4 hours and 5 minutes from London). If Bristol is not the retrieval centre then the time to Truro is 4 hours 15 minutes.

In our experience over many years, it is the case that during the night and at all times during the winter, the ferry service to the island is less frequent and this extends the retrieval times considerably. For example in the winter day times the ferries run every 90 minutes or less frequently. If the JCPCT continues to uphold the principle that "worst case scenario" times ought to be considered, then it must take note of the retrieval times when they are known to be the longest.

During times of reduced service, the worst case scenario is that it would take Bristol 5 hours and 3 minutes to retrieve a patient and 4 hours and 48 minutes for the Evelina to do so. This is based on a decision to retrieve at 2315hrs. The longest retrieval time from Southampton is 3 hours and 32 minutes.

Reality on the ground

SUHT has a published protocol that is followed for retrieving patients by ferry from the Isle of Wight.

When a referral is received, the first thing we do, while information is being acquired about the patient is to check the ferry timetable. Once we have assessed which ferry we are most likely to be able to catch, we ring the ferry company, book the slot for the ambulance and ask them to expect us. We do this so that they don't close the gate and so that their staff know to waive the normal pre-boarding time. We also liaise with them because even when the ferry is full, they have been prepared to bump an already booked but not loaded vehicle and let us take its place. Given the close proximity of Southampton General Hospital to the ferry ports it has not been necessary to delay departure and therefore there is no grounds for assuming that the operators would be prepared to do this for hospitals in Bristol or London. We do not expect them to alter their timetable and they have made no undertaking to us to do so. If the ferry is already loaded then we cannot go at the front, but

if we arrive in time, we get priority boarding and therefore priority disembarkation. We use both the Southampton and Portsmouth ferries, depending on times. If there is a delay in the ferry then we have to consider using a helicopter. We have done this twice in the last 6 years. On one further occasion the patient was stable on ICU at St Mary's so stayed there until we could retrieve the next day.

Having taken all of these steps, the average time from decision to arrival at St Mary's is 2 hours and 45 minutes (this average excludes the patient we left on the island overnight). This time includes retrievals that are done throughout the year and at any point during day or night and are therefore influenced by the variation in ferry timetables.

Assessing the real retrieval times from Southampton to St Marys shows that even if the London centre used blue lights and was able to arrive at either Portsmouth or Southampton in ninety minutes, the average time would therefore still exceed 4 hours (4hrs 15mins). It is likely that it would in fact be much longer as no other team would have the benefit of commencing their journey just ten minutes away from the terminal.

Materiality

We have been asked to consider the issue of materiality. In other words, does the number of patients that retrieval times apply to really warrant the application of the standard to the designation of surgical centres?

In fact this issue has already been considered by the review in its decision to exclude options that do not include Bristol. This is made clear on page 211 of the Pre-Consultation Business Case, where the statement is made that "It is recognised that the need for emergency retrieval is rare for children with congenital heart problems but time is of the essence when it is required". This test was applied as a safety measure for all, without any consideration of materiality. The assumption was that no child would be put at risk because of a failure to adhere to this safe and sustainable standard, and there is no assertion from PICS that they are prepared to waive it.

With that in mind the JCPCT may nevertheless find it informative to consider a comparison of the materiality of retrievals from both the Isle of Wight and Truro.

The South West Audit of Critically Ill Children (SWACIC) is published on the PICAnet web site. This shows that between 2004 and 2008, 14 children a year were collected from Truro by the Bristol PICU team. It is not recorded how many of these were cardiac surgical patients; however the overall percentage of patients with a cardiological diagnosis to explain their critical illness is 4%. In other words it can be assumed according to this data that on average one cardiac surgical patient a year is retrieved from Truro.

To compare this with retrievals from the Isle of Wight, we have complete annual data on our database for the last six calendar years and during this time 112 patients were referred to us from St Mary's, of which 72 were transferred. This means that an average of 12 patients per year were transferred and all patients were ventilated ICU patients. During the same period six acute cardiac surgical patients were transferred (one per year), of which two had potentially time sensitive lesions- a TAPVD and a prostin resistant critical coarctation. The latter patient was retrieved in the middle of the night and the time taken from decision to arrival at the referring hospital was 2 hrs and 55 minutes. She was immediately and continuously resuscitated by the retrieval team, transferred to Southampton and operated on later that same day. She is now fit and well and back home

in Scotland and her family are grateful that a children's cardiac intensive care was close enough to reach her.

In terms of the total patients affected the numbers are still small but almost exactly the same in Truro or on the Isle of Wight. This should be no surprise as the population of the Isle of Wight is 145,000, only marginally smaller than Western Cornwall (170,000), but it has the second highest incidence of congenital cardiac disease in the country (see appendix 1). In fact the main difference is that the patients of the Isle of Wight would experience a longer enforced delay in retrieval than those from Truro. If Southampton rather than Bristol had to go to Truro the enforced delay would be 1 hr and 10 minutes. If London had to come to the Isle of Wight the enforced delay is 1hr and 46minutes.

Conclusion

These factors lead us to conclude that the designation of Southampton as a surgical centre should be considered mandatory in the same way that Bristol is. We conclude that, based on the facts presented in this paper and the model proposed by S&S, Southampton should be included in all short-listed options. Option B appears to be the best solution given that it would not necessarily be beneficial to consult further on new options. We welcome the opportunity provided by the consultation process to highlight the oversight of retrieval from the Isle of Wight and would strongly assert that for the JCPCT not to correct the error would be to fatally flaw the review process.

Appendix 1

Section on retrieval times taken from the SUHT response to the public consultation

The continued maintenance of a safe retrieval service to all mainland district general hospitals (DGH) was given due consideration in the selection of cardiac centres.

This is well documented in appendix T of the pre-consultation business case (page230-231) produced by Safe and Sustainable (reproduced for the West & South England & South Wales below). The method of calculating retrieval journey times was chosen with a view to demonstrating worst-case scenarios. "Blue light" ambulance journey times were considered but it was felt that car journey times should be used with a view to giving a "worst-case" timing.

It was determined that in order to ensure a retrieval time from Truro that would be compliant with the Paediatric Intensive Care Society (PICS) standards[1], namely standard number 123, Bristol would need to remain as a cardiac centre. As a consequence of this, configuration options which did not include Bristol (options 1,7 and 11) were eliminated.

Unfortunately, the equally important need to provide a safe retrieval service for St Mary's Hospital on the Isle of Wight was overlooked at the time of selection of centres. This was brought to the attention of the review team in March 2011. St Mary's Hospital on the Isle of Wight serves a population of 145,000 people and it does not have a CAA approved airport suitable for landing of fixed-wing aircraft and PICS does not regard helicopter transport as a reliable means of retrieval because of the difficulties of flying at night or in bad weather. In other words the only reliable and safe way of retrieving critically ill children from the Isle of Wight is by means of road and ferry.

The retrieval times to St Mary's, Isle of Wight would breach the PICS standards if Southampton were no longer a surgical centre. The review calculated retrieval times using the website www.direct.gov.uk and using the same website for calculation, a retrieval team leaving Evelina Children's Hospital, London at 12 noon would require four hours and five minutes to reach St Mary's Hospital on the IOW and one leaving the Bristol Children's hospital would require four hours four minutes. This would be in breach of the PIC retrieval standards and Safe and Sustainable have acknowledged this in their response to the Trust of 3 June.

The focus now appears to have shifted to exploring times of departure where the travel time to St Mary's are the quickest and this is in direct contrast to the original methodology of calculating travel times for a 12 noon start in order to consider "worst-case" timings. The need to retrieve a critically ill child may occur at any time of the day or night. The PICS standard (no123) is a clinical safety recommendation based on the recognition that the critically ill child may deteriorate if specialist intensive care is not provided as soon as possible. It is because of this that the original methodology was chosen to highlight the worst case scenario and a 12 noon start (which gave a slightly longer travel time) was chosen and it was stipulated that blue light times would not be considered.

Unlike the mainland centres the most difficult time to reach the Isle of Wight is at night when the ferries are infrequent. Journey times can be significantly prolonged in winter and during periods of bad weather. In summary the 12 noon start time does not represent the

[1] Paediatric Intensive Care Society, *Standards for the care of critically ill children (4th Edition),* June 2010

worst case scenario for the Isle of Wight but even in this setting the PICS retrieval time standard is breached.

Having devised a methodology with a view to demonstrating the worst case times for mainland DGH's there can be no justification for exploring the best case times for St Mary's Hospital on the Isle of Wight. The methodology applied must be the same for all hospitals. Further, time is of the essence, and in practice retrieval teams will make every effort to reach their destination within the shortest possible time and this applies both to the mainland and the Isle of Wight in equal measure. Our position is that the real clinical need to retrieve critically ill children from the Isle of Wight, which has inherent transport difficulties, and which had been overlooked in the initial appraisal, must be given equitable consideration.

As you can see in the charts reproduced below, taking the safety of children on the Isle of Wight into account leads to a very different picture of the comparison between Options A and B in Appendix T of the Pre-consultation Business Case.

Appendix T
West & South England & South Wales – 12:00 travel time (current travel time)

Option A

	Bristol	Southampton	Oxford	London	Birmingham
Truro	**03:04**				
Barnstaple	**02:12**				
Plymouth	**02:16**				
Aberystwyth					**02:55**
Haverfordwest	**02:33**				
Carmarthen	**01:43**				
Swansea	**01:24**				
Bournemouth	**02:17**	**(00:41)**			
Dorchester	**01:52**	**(01:13)**			
Yeovil	**01:20**				
Portsmouth		**(00:29)**		**02:02**	
Brighton				**01:48**	
Margate				**02:00**	
Isle of Wight				**04:05**	

Key to shading:
Blue = No change in travel time
Green = Change in travel time, with new time less than 3 hours
Red = Change in travel time, with new time over four hours
() = current travel time

Option B

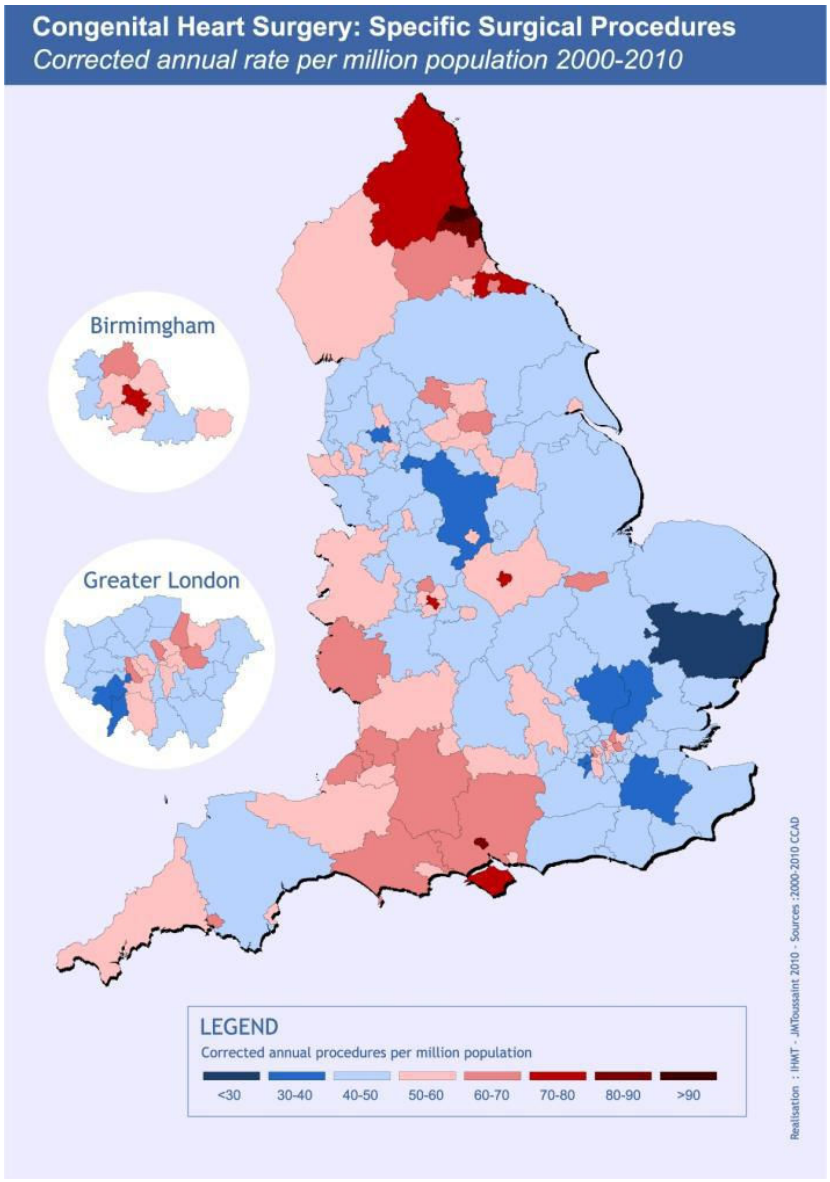
	Bristol	Southampton	Oxford	London	Birmingham
Truro	**03:04**				
Barnstaple	**02:12**				
Plymouth	**02:16**				
Aberystwyth					**02:55**
Haverfordwest	**02:33**				
Carmarthen	**01:43**				
Swansea	**01:24**				
Bournemouth		**00:41**			
Dorchester		**01:13**			
Yeovil	**01:20**				
Portsmouth		**00:29**			
Brighton		**01:42**			
Margate				**02:00**	
Isle of Wight		**02:19**			

Yellow = A decrease in travel times

Comparison of travel times to St Mary's, Isle of Wight at different times of day showing 12noon is not the worst-case journey time.

Hospital	12noon	2310
London	04:05	04:53
Bristol	04:04	04:52
Southampton	02:19	03:22

Data taken from the HIA scoping document showing that the Isle of Wight has high incidence of congenital cardiac defects requiring surgery



Safe and Sustainable

NHS
Specialised Services

2nd Floor, Southside
105 Victoria Street
London SW1E 6QT

Tel: 020 7932 3128

Sir Neil McKay CB
Chair, Joint Committee of PCTs
Victoria House
Capital Park
Fulbourn
Cambridge
CB21 5XB

1 September 2011

Dear Sir Neil

Retrieval of critically ill children from the Isle of Wight

I am writing to let you know of the advice that the secretariat will give to members of the Joint Committee of Primary Care Trusts (JCPCT) around the emergency retrieval of children from the Isle of Wight.

You will recall that in response to evidence submitted by Southampton University Hospitals NHS Trust (SUHT) in March 2011 the secretariat undertook a significant amount of work to explore the issues in depth and to advise the JCPCT on a potential response.

As an outcome of this work, in June 2011 you agreed with Mark Hackett, Chief Executive of SUHT, that you would ask the secretariat to work with the Trust to deliver a paper that provides JCPCT members with a more detailed understanding of the unique factors involved in retrieving a critically ill child by ferry and you asked the secretariat to provide further advice on the extent to which a retrieval team from London or Bristol could reach St Mary's Hospital on the Isle of Wight in compliance with the Paediatric Intensive Care Society standards for the retrieval of critically ill children (which themselves form part of the proposed *Safe and Sustainable* standards for designated providers of paediatric cardiac surgery).

In pursuance of this further work members of the secretariat attended SUHT on 27 June and 29 July and met with Mark Hackett, Dr Tony Salmon, Dr Iain Macintosh and Alison Ayres.

A paper prepared by SUHT is attached for consideration by JCPCT members. The opinions and recommendations set out therein are those of SUHT.

In October 2011, when the JCPCT next meets, the secretariat will advise the JCPCT that there is no available evidence that could reasonably suggest that a retrieval team from London or Bristol could reach the Isle of Wight in compliance with the time limits stipulated by the PICS standards, even if the Isle of Wight is considered to be a 'remote area' and measured by the higher time threshold of 4 hours. This advice is concordant with that provided to the JCPCT by the Paediatric Intensive Care Society in its formal response to consultation dated 23 June 2011.

The secretariat has reached this conclusion by exploring whether there are any reasonable grounds for suggesting that the road-journey times from the Evelina Children's Hospital or Bristol Children's Hospital to the Isle of Wight as calculated with reference to the methodology set out in the Pre-Consultation Business Case do not reflect the actual total journey time, including the ferry element. We have concluded that there are no existing protocols or informal arrangements between SUHT and the ferry companies that have the effect of a ferry being deliberately delayed to await an ambulance. There are therefore no reasonable grounds for suggesting that such a practice could be effectively implemented between the ferry companies and retrieval teams based in London or Bristol in the future.

The secretariat will further advise the JCPCT to take these conclusions about retrievals from the Isle of Wight into account when considering the outcome of public consultation as part of the committee's deliberations to agree an eventual configuration option, and in any necessary re-scoring of options.

Yours sincerely

Jeremy Glyde
Safe and Sustainable Programme Director

Cc Mr Mark Hackett, Chief Executive of SUHT
Members of the JCPCT

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DECISION-MAKER:	**HEALTH OVERVIEW AND SCRUTINY PANEL**
SUBJECT:	**UPDATE ON ADULT SOCIAL CARE PROVIDER MARKET ISSUES**
DATE OF DECISION:	15 SEPTEMBER 2011
REPORT OF:	EXECUTIVE DIRECTOR OF HEALTH AND ADULT SOCIAL CARE
STATEMENT OF CONFIDENTIALITY	
None.	

BRIEF SUMMARY

To provide Members of HOSC with an outline written summary of the current position regarding the provision of contracted care following notifications being received by the council from CQC and 3 established providers operating within Southampton who provide a combination of care and support to Southampton citizens. A more detailed verbal briefing will be given at the meeting.

RECOMMENDATIONS:

(i) To note the update from Adult Social care and the action being taken.

REASONS FOR REPORT RECOMMENDATIONS

1. To ensure members are fully informed regarding issues with contracted care which have received some media coverage, and the actions being taken to ensure Southampton residents continue to receive appropriate care.

ALTERNATIVE OPTIONS CONSIDERED AND REJECTED

2. None.

DETAIL (Including consultation carried out)

3. In the last 6 weeks the Care Quality Commission (CQC) have been actively reviewing and inspecting a number of local adult health and social care services. To summarise

- CQC have been on site with regard to the Southampton Care UK domiciliary care services and talking with the commissioners including social work staff.
- CQC have been on site at Oak Lodge, a BUPA nursing care home service specialising in services for very vulnerable older people with dementia and the provision of end of life care as well as being in dialogue with the Head of Personalisation and Safeguarding's staff and commissioners.
- CQC have been on site at Abbeycroft Residential Care Home where

there have been safeguarding concerns and talking with our Commissioning staff and Safeguarding teams.

- CQC have been on site at Tatchbury Manor Care Home which, although is a Hampshire based service, has some residents placed by us on site.
- CQC have been on site inspecting Mental Health services at Antelope House (an NHS service) and interviewing staff from Health and Social Care including the approved mental health practitioners.

4. A verbal update will be provided to Scrutiny Members of the early findings from this field work and what it means for Southampton City Council and what additional action has been taken to ensure Southampton citizens are receiving good enough care .

RESOURCE IMPLICATIONS

Capital/Revenue

5. None

Property/Other

6. None

LEGAL IMPLICATIONS

Statutory power to undertake proposals in the report:

7.

Other Legal Implications:

8. None.

POLICY FRAMEWORK IMPLICATIONS

AUTHOR:	Name:	Penny Furness-Smith	Tel:	023 80832548
	E-mail:	Penny.furness-smith@southampton.gov.uk		

KEY DECISION? No

WARDS/COMMUNITIES AFFECTED:	

SUPPORTING DOCUMENTATION

Non-confidential appendices are in the Members' Rooms and can be accessed

on-line

Appendices

1.	
2.	

Documents In Members' Rooms

1.	
2.	

Integrated Impact Assessment

Do the implications/subject of the report require an Integrated Impact Assessment (IIA) to be carried out.	Yes/No

Other Background Documents

Integrated Impact Assessment and Other Background documents available for inspection at:

	Title of Background Paper(s)	Relevant Paragraph of the Access to Information Procedure Rules / Schedule 12A allowing document to be Exempt/Confidential (if applicable)
1.		
2.		

TO BE DETACHED BY DEMOCRATIC SERVICES

REPORT MONITORING FORM	
THIS FORM MUST BE COMPLETED FOR ALL REPORTS!	
PLEASE ENSURE YOU COMPLETE THE SECTIONS HIGHLIGHTED IN YELLOW NEAR THE END OF THIS FORM.	
DATE OF DECISION:	
DECISION MAKER:	
SUBJECT/TITLE OF REPORT:	

KEY DECISION?		[TYPE YES, NO or N/A]
DATE PROPOSAL INCLUDED IN FORWARD PLAN:		
REGULATION 15 EXCEPTION?		[TYPE YES, NO or N/A]
Date notification given to Scrutiny:		
REGULATION 16 URGENCY?		[TYPE YES, NO or N/A]
Date agreement of Scrutiny obtained:		

OTHER LEGAL IMPLICATIONS:	Paragraph number/comment:
Human Rights Act 1998:	
Equalities Act 2010	
Crime & Disorder Act 1998(specifically s.17 duty):	
Proceeds of Crime Act 2002(Money Laundering):	
Freedom of Information Act 2000:	
European “State Aid” Guidance:	

POLICY FRAMEWORK PLANS:

Annual Library Plan		Adult Learning Plan	
Best Value Performance Plan		14-19 Strategy	
Community Strategy (Including Local Agenda 21 Strategy)		Economic Development Strategy	
Children & Young Peoples Plan (CYPP)		Health and Well-Being Strategy	
Plan & Strategies which together comprise the Development Plan		Crime & Disorder Reduction Strategy	
Youth Justice Plan		Local Transport Plan	
Medium Term Plan Economic Development			
Housing Strategy (inc HRA Business Plan)			

KEY AREAS TO BE ADDRESSED/CONSIDERED:

Organisational Development/Human Resources Issues	

Report Tracking

VERSION NUMBER:	
DATE LAST AMENDED:	
AMENDED BY:	

PEOPLE WHO HAVE BEEN CONSULTED IN THE PREPARATION OF THE REPORT

Authors who fail to carry out adequate consultation resulting in deferral will be required to provide reasons.

Name	**Departments that MUST be consulted**	Date consultation Issued	Date comments Received
	Legal Services		
	Democratic Services		
	Financial Services		
Andrew Elliot	**Property and Procurement Services**		
Sarah Dennis	**If the proposal within the report touch on any staffing or IT resource issues consultation will also include the Head of Organisational Development and IT**		

Others who have been consulted:			
Name	Division/Portfolio	Date consultation Issued	Date comments Received

Approval by Executive Member:

Name: | Date:

Approval by Level 1 Manager:

Name: | Date:

Approval by Executive Director/ Policy Coordinator:

Name: | Date:

FOR DEMOCRATIC SERVICES USE ONLY:

DATE AND TIME REPORT RECEIVED: Date | Time:

LEGAL CLEARANCE: [TYPE YES or NO]

Name:

FINANCIAL CLEARANCE: [TYPE YES or NO]

Name:

POLICY CLEARANCE: [TYPE YES or NO]

Name: