Leeds CITY COUNCIL

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Report of the Head of Scrutiny and Member Development

Report to the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

Date: 22 September 2011

Subject: Proposed Reconfiguration of Children's Congenital Heart Services in England: Questions to the Joint Committee of Primary Care Trusts (JCPCT)

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	☐ Yes	☒ No
Are there implications for equality and diversity and cohesion and integration?	☐ Yes	☒ No
Is the decision eligible for Call-In?	☐ Yes	☒ No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Not applicable Appendix number: Not applicable	☐ Yes	☒ No

Summary of main issues

1. The Joint Health Overview and Scrutiny Committee HOSC (Yorkshire and the Humber) forms the statutory overview and scrutiny body to consider and respond to the proposed reconfiguration of Children's Congenital Heart Services in England – taking into account the potential impact on children and families across the region.

2. In considering the proposals set out in the *Safe and Sustainable Consultation Document: A new vision for Children's Congenital Heart Services in England (March 2011),* Members of the Joint HOSC have sought to consider a wide range of evidence and engage with a range of key stakeholders.

3. As part of the public consultation on the future of Children's Congenital Heart Services in England, HOSCs have been given until 5 October 2011 to respond to the proposals.

4. In preparation for the previous meeting (2 Septmeber 2011), direct input was sought from the Joint Committee of Primary Care Trusts (JCPCT), as the appropriate decision-making body. However, the invitation to attend the meeting was declined.

5. At the meeting on 19 September 2011, the Joint HOSC considered a series of questions aimed at the JCPCT and the associated responses. However, representatives from the JCPCT were unable to attend that meeting.

6. The questions aimed at the JCPCT and the associated responses (referred to above) are presented at Appendix 1. This includes some supplementary questions/ responses to the original questions posed. Supplementary responses were received on 16 September 2011.

7. Furthermore, additional information on a number of points identified in the original response has been sought by a member of the Joint HOSC (Cllr. Smaje). Details of the request and the response provided are attached at Appendix 2.

8. A representative from the JCPCT will be in attendance at the meeting to discuss the responses and address any further questions identified by the Joint HOSC.

Recommendations

9. Members are asked to consider the details associated with this report and identify/ agree any specific matters for inclusion in the Committee's report to be presented to JCPCT later in the year

Background documents

- A new vision for Children's Congenital Heart Services in England (March 2011)

APPENDIX 1

Questions posed to the Joint Committee of Primary Care Trusts (JCPCT)

1	**Why was the Leeds unit not included in all four options on the grounds of population density in the Yorkshire and the Humber region, on the same basis that the units at Birmingham, Bristol, Liverpool and the 2 London centres, which feature in all four options?**
	No centres have been included in options solely on the grounds of 'population' but rather on the grounds of high caseloads and the ability of other surgical centres to assume these caseloads were surgical centres with high caseloads to be removed from potential configuration options (population levels are of course a good indicator of a caseload in any individual centre but are not in themselves sufficiently informative to evaluate potential configuration options). For example, Birmingham Children's Hospital has been included in all options because the JCPCT concluded that its very high caseload (555 surgical procedures) could not reasonably be met by other surgical centres taking into account existing caseloads at other centres and reasonable travel times. Similarly, the JCPCT concluded that the combined caseload for the London centres (around 1,250 surgical procedures covering London, South East and Eastern England) could not be reasonably met by one surgical centre in London, or by other surgical centres outside of London were there to be no surgical centre in London. NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance. By contrast, Leeds Teaching Hospitals NHS Trust has a relatively low caseload (316 surgical procedures in 2009/10, and 336 in 2010/11). The JCPCT□s analysis did not suggest that other surgical centres in potential configuration options would struggle to assume the Leeds caseload were the Leeds centre removed from potential configuration options. In your letter you refer to Alder Hey Children□s Hospital. This centre was not included in all options on the grounds solely of its own caseload (400 surgical procedures) but because the retention of Alder Hey was a reasonable recommendation after applying the following two working principles: i. The population and caseload suggests a need for two surgical centres in the North of England, as there is insufficient forecast activity to reasonably suggest the retention of three centres ii. A potential option that comprised the Freeman Hospital and Leeds Teaching Hospital NHS Trust (at the exclusion of Alder Hey Children□s Hospital) would not be viable as for both centres to achieve a minimum of 400 surgical procedures (as required by the Safe and Sustainable standards) would require significantly unreasonable changes to patient flows and clinical networks. Because of this, only options which included Liverpool and Leeds or Liverpool and Newcastle were considered. You also refer in your letter to the surgical centre in Bristol, but this centre has not been included in configuration options on the grounds of population or caseload.

2	**Why isn't the genuine co-location of paediatric services provided at the Leeds Children's Hospital, alongside maternity services and other co-located services and specialisms on the same site at Leeds General Infirmary given greater weighting? Such service configurations have been described as the 'gold standard' for future service provision, yet it appears not to have been given sufficient weighting in the case for Leeds.**
	I am advised that Leeds Teaching Hospitals NHS Trust received the maximum score of 'excellent' for current co-location of services, and a very high score for how those services could continue to be delivered in the event of an increased caseload. These high scores reflect the provision of on-site services that you describe in your letter. However, the Trust was also assessed against its ability to meet other quality standards and when considered in the round, the Trust received the second lowest score of all eleven surgical centres.
3	**Why isn't the "exemplar" cardiac network which has operated in the Yorkshire and Humber region since 2005 given greater weighting in the drawing up of the four options? The future network model proposed in the consultation document is again described as the 'gold standard' for the future service delivery model, yet three of the four options put forward would see the fragmentation of this unique and exemplary cardiac network.**
	Professor Sir Ian Kennedy's panel advised that none of the current surgical units have developed networks that fully comply with the Safe and Sustainable standards, but the panel acknowledged the strength of the current network in Yorkshire and Humber by assessing it as 'strong'. However, the panel also identified a number of gaps in compliance and as such the network was not described as „exemplary□. As I describe above, the Trust was assessed NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance. against a number of different standards and the cumulative conclusions of the panel led to Leeds Teaching Hospital being awarded the second lowest score
4	**Why doesn't the Leeds unit feature in more of the four options put forward given that all surgical centres are theoretically capable of delivering the nationally commissioned Extra Corporeal Membrane Oxygenation (ECMO) service?**
	It is not correct that „all surgical centres are theoretically capable of delivering the nationally commissioned Extra Corporeal Membrane Oxygenation (ECMO) service□. During the assessment process, all centres were asked whether they would be able to provide nationally commissioned services, including ECMO for children with severe respiratory failure. Leeds Teaching Hospitals NHS Trust submitted an application to deliver ECMO services but the application was declined as the panel was not confident that the Trust had demonstrated that it had the appropriate skills and infrastructure to deliver respiratory ECMO for children.

5	**Why isn't travel and access to the Leeds unit given a higher weighting given the excellent transport links to the city by motorway and road network (including access to the M1, M62 and A1(M)), the rail network (including direct access to the high speed East Coast mainline and the Transpennine rail route) and access by air via the Leeds-Bradford airport? Almost 14 million people are within a two hour travelling distance of the Leeds unit.**
	Travel and access was considered as part of the options appraisal process, although the parents and clinicians with whom we consulted on the matter recommended that it receive the lowest of the criteria used for arriving at the final options for consultation. The model of care that we describe in the consultation document proposes to reduce travel times for the many families who currently travel long distances to receive treatment by bringing non-interventional assessment and follow-on care closer to the homes of children with congenital heart disease by establishing these services in local hospitals. All of the options for consultation also ensure that the children in Yorkshire and the Humber can be reached by a specialist retrieval time in compliance with the standards around emergency retrieval times set by the Paediatric Intensive Care Society (PICS).
6	**We are keen to understand in more detail the relative strengths and weaknesses of each surgical centre. We therefore request the detailed breakdown of the assessment scores determined by the Independent Assessment Panel, Chaired by Sir Ian Kennedy (referred to on page 82 of the consultation documents).**
	The detailed breakdown of scores will be made available once the JCPCT has concluded its deliberations. This is because the JCPCT members agreed last year that they did not wish to see the detailed breakdown of scores while they continued their work. Scrutiny committee members and other stakeholders have therefore received the same level of detail that has been shared with the JCPCT members themselves.
	Supplementary question: The original question asked for a detailed breakdown of the Kennedy scores. Please clarify: ***(a) What information about the scores has been made available to the Trusts.*** ***(b) What opportunity have Trusts had to challenge or correct inaccuracies in respect of the narrative feeding into the scores?*** ***(c) Is the intention to revisit the scores at any time to update or amend the values in the light of any challenges or concerns?*** *The Trusts were provided with the weightings for each element of the assessment when the self-assessment template was shared with them in March 2010. At the conclusion of the assessment an interim report on the panel's findings was shared with the centres in August 2010. The Trusts received Professor Kennedy's full report, with the cumulative weighted scores for each centre, in January 2011.* *In response to the interim report, Leeds Teaching Hospitals NHS Trust wrote to the secretariat to ask that alleged inaccuracies in the report be corrected. Professor Kennedy's panel met in December 2010 - before the panel's report was finalised - to consider the Trust's concerns. The panel concluded that it had not made any errors of fact and that its findings remained valid, though the panel agreed to change some wording in the final version of the report to clarify certain points in response to the Trust's concerns.* *The JCPCT has asked Professor Kennedy's panel to consider responses to consultation that allege that the panel's report includes factual inaccuracies and to advise the JCPCT as to whether, as a result of the panel's further deliberations, the panel wishes to advise the JCPCT of the need to re-visit the previous scores. The panel will present its report to the JCPCT in October 2011. The JCPCT will also consider the responses to consultation that have suggested that there is a need to reconsider the weightings attached the scoring process.*

7	**How has the potential impact of the proposed reconfiguration of surgical centres on families, including the additional stress, costs and travelling times, been taken into account within the review process to date?**
	Despite the potential impacts to families to which you refer, it is important to note that the outcome of the recent public consultation was overwhelming support for the need for reconfiguration of services. The issues that you have described have been explored during options-appraisal process, as well as during the consultation. Patients, their families and carers, clinicians and the public have told us about this during engagement events, undertaken while the options were developed, as well as at the consultation events, and responses to the consultation. Focus groups with young people and their families were run to explore these issues in depth. A Health Impact Assessment has been undertaken by an independent expert third party to explore, assess and analyse the positive and negative NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance. impacts resulting from the proposed changes , and the measures to enhance and mitigate these, on patients and the public with particular emphasis on the vulnerable groups. Locally, workshops were run by an independent third party in Leeds, Bradford and Kirklees to assess impacts of the proposed changes on vulnerable groups. The HIA Scoping Report, Key Emerging Findings from Phases 1&2, and the HIA Interim Report have been published and shared with HOSCs and LINKs. The JCPCT will consider the independent final HIA Report, as well as the independent qualitative report from Ipsos Mori. Additionally, the Safe and Sustainable standards provide for improved facilities for families in the designated surgical centres, including family accommodation.
	Supplementary question: The original question asked how the potential impact on families has been taken into account within the review process to date. The supplementary question is how has the potential impact on families (not the patient) fed into the short listing of the options for consultation. *The standards and model of care – the proposed standards and model of care were informed by the outcome of a comprehensive public engagement held between September and December 2009; comments received during the exercise have been published so that stakeholders can see how their comments have informed the final proposals.* *Family accommodation - parents have raised as a concern the provision of appropriate family accommodation at surgical centres in the future; the standards seek to address this issue and Sir Ian Kennedy's panel was asked to specifically assess the applicant centres against this standard; on the day of the assessment visits to each centre the panel met with a delegation of parents to hear their views.* *Journey times – parents and professionals have also raised as a concern the possibility of increased journey times, for both elective appointments and emergency retrievals; the criteria for the evaluation of potential options applied by the JCPCT has included a detailed analysis of travel times for elective appointments and an analysis of potential retrieval times against the current standards set out in the Paediatric Intensive Care Society standards.* *Financial costs – where the Safe and Sustainable review has not been able to respond to the concerns of parents because those concerns fall outside of the scope of the review – for example around the reimbursement of travel costs for families not entitled to financial assistance under the Healthcare Travel Cost Scheme - the Safe and Sustainable Team has brought those concerns to the attention of the relevant government department (in this case the Department of Health).*

	Supplementary question: Please can reassurance be given that patients and families in Yorkshire & the Humber are not being disproportionally disadvantaged in the options not including Leeds, compared to other areas of the country. *The Joint Committee of Primary Care Trusts has sought to deliver a number of options that provide the best "fit" of services taking into account the need for equitable access to high quality services. Indeed one of the key principles driving the review is that 'the same high quality of service must be available to each child regardless of where they live or which hospital provides their care'. The JCPCT has set out the potential 'risks and benefits' of each option on p115 – 166 of the consultation document and HOSC members are invited to advise the JCPCT on the extent to which, in their opinion, the options favour or disadvantage the population of Yorkshire and Humber.*
8	**Why have congenital cardiac services for adults been excluded from the review when, in some cases, the same surgeons undertake the surgical procedures?**
	The NHS is reviewing the provision of congenital cardiac services via two separate but related reviews. The view of experts, endorsed by the Steering Group in December 2008 and by the SCG Directors Group in 2009, was that the immediate concerns around safety and sustainability related to the paediatric element of the service. The process for the designation of adult congenital services will proceed in 2011 with reference to the separate standards that have been developed by a separate expert group and which were published in 2009.
	Supplementary question: The original questions relate to adult congenital heart services. Please can reassurance be provided that any decision taken relating to paediatric heart surgery will not, by default, impact detrimentally on the adult congenital heart services in Leeds. *The remit of the JCPCT is children's congenital heart services in England. A separate review of adult services is underway and the first stage of this review is to seek opinion from the public, NHS staff and scrutiny committees on draft quality standards. This exercise will be underway in the coming months. The final version of the standards will then be used to designate providers of adult congenital heart services in 2012. The aim of the NHS in both reviews is to improve congenital heart services, not impair them. If significant changes are recommended to adult services the NHS will hold a full and proper public consultation and it will be for stakeholders, including the scrutiny committee, to advise the NHS on the extent to which, in their opinion, the proposed changes impact positively or detrimentally.*

9	**We have heard that more children with congenital cardiac conditions are surviving into adulthood, which suggests an overall increase in surgical procedures (for children and adults), which is likely to be beyond the 3600 surgical procedures quoted in the consultation document:** **(a) As such, what would be the overall impact of combining the number of adult congenital heart surgery procedures with those performed on children, i.e. how many procedures are currently undertaken by the same surgeons and what are the future projections?** **(b) How would this impact on the overall number of designated surgical centres needed to ensure a safe and sustainable service for the future?** **(c) What would be the affect on the current and projected level of procedures for each of the existing designated centres?**
	Any adult congenital heart surgery is over and above the 3600 procedures for children (u16s). The current number of operations on adults is less than 870 p.a. (CCAD), so approximately 20% of the national caseload on congenital heart surgery is adult. This is likely to grow at a faster rate than children□s surgery given that more children are surviving into adulthood. Nevertheless the analysis that has been undertaken to date suggests that no centre will be overwhelmed by this additional activity. The HOSC should be aware that as a separate exercise a review of adult congenital heart surgery is being undertaken which will conclude where this surgery will take place and will have the benefit of the conclusions of the paediatric heart surgery review to support it.
	Supplementary question: Please can the 870 adult procedures quoted be provided broken down by region and parts (b) and (c) of original question 9 be answered. *The actual number of adult (>15 years old) surgical procedures was 859, excluding private patients, Scottish and NI centres. The breakdown is provided at Annex 2.* *In response to 9b and 9c, as I mentioned in my previous response the analysis to date (see p. 126 of the pre-consultation business case) implies that no centre will be overwhelmed by the adult congenital work (although until the GUCH review is completed it is not possible to know where the GUCH work will take place). It is reasonable to assume that the GUCH review would need to consider growth in this service in detail. The Safe and Sustainable assumed that every 5% increase in GUCH caseload is equivalent to a 1% increase in the paediatric caseload.*
	Supplementary question: Please can you explain why the number of adult congenital heart procedures can't be added into the number of procedures per centre? *The remit of this review is to reconfigure paediatric congenital heart surgery, and the adult procedures cannot be therefore added, as they are a subject of a separate review which has not yet reported.*
10	**How has the impact on other interdependent hospital services and their potential future sustainability been taken into account within the review process to date?**
	The review has assessed the impact of inter-dependent services and their sustainability. This is outlined in both the pre-consultation business case and the consultation document. The JCPCT will now consider evidence around inter-dependent services (including paediatric intensive care services) that has been submitted during consultation before making a final decision.

11	**The Government's Code of Practice on Consultation (published July 2008) sets out seven consultation criteria: Please outline how the recent public consultation process meets each criterion?**
	Please see Annex A.
12	**What specific arrangements have been put in place to consult with families in Northern Ireland?**
	The remit of the review is services in England and Wales. Responsibility for the NHS in Northern Ireland rests with the devolved administration in Northern Ireland. However, the NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance. Secretariat publicised the consultation and encouraged the population of Northern Ireland to take part in the consultation via advertisements in local newspapers in Northern Ireland.
13	**How have ambulance services (relevant to the affected patient populations) been engaged with in the review process – particularly in relation to drawing up the projected patient flows and associated travel times?**
	I understand that EMBRACE has presented to the JCPCT and to the OSC an analysis of potential retrieval times relevant to Yorkshire and the Humber. Furthermore, ambulance services were invited to sit on the Safe and Sustainable Steering Group and the separate group that developed the quality standards. They are also represented on the Health Impact Assessment Steering Group. The Health Impact Assessment has taken into account the impact of the proposed changes on the provision of ambulance services. Retrieval times have been considered and analysed. The proposed times for retrieval comply with the Paediatric Intensive Care Society (PICS) guidelines. The proposed Safe and Sustainable clinical standards include a mandatory requirement that there must be „an appropriate mechanism for arranging retrieval and timely repatriation of patients.
14	**How has the impact on training future surgeons, cardiologists and other medical/ nursing staff been factored into the review?**
	The JCPCT recognises that improved training processes will need to be put in place for clinical staff and the independent expert panel, chaired by Professor Sir Ian Kennedy, has also concluded that „the succession planning for surgeons must be a key consideration for the future delivery of paediatric cardiac service.□ The professional associations representing surgical, medical and nursing staff who sit on the steering group (which is chaired by the Director for Medical Education for England) and other experts with whom we have consulted (for example in the Deaneries) have advised that this is an issue for the implementation phase of the review rather than the assessment phase.
15	**What are the training records of each of the current surgical centres and how have these been taken into account in drawing up the proposals?**
	I am unsure as to what you mean by „training records and I would be grateful if you were to clarify your question so that I may provide an answer.

	Supplementary question: Please could you provide information on the number of new cardiologists and cardiothoracic surgeons who have been trained by each centre over the last 5-10 years. How has the "track record" for training new doctors fed into the assessment of each of the current surgical centres. The „track record for training new doctors' has not fed into the assessment of the current centres. We do not hold the data to which you refer.
16	**Why have services provided in Scotland been excluded from the scope of the review, when the availability and access to such services may have a specific impact for children and families across the North of England and potentially Northern Ireland?**
	As I have explained previously, the scope of the review is services in England and Wales. The small number of cases that flow from Scotland and Northern Ireland to English surgical centres have been taken into account by this review. However, the catchment area for Newcastle does not include Scotland as the children's heart surgical unit in Glasgow is part of the Scottish devolved administration's responsibility and therefore outside the scope of the Safe and Sustainable review.
	Supplementary question: Please can you clarify the position with regard to Scotland? Have Scotland been invited to take part in the consultation in the same way that Northern Ireland has? If they haven't, please can you explain why a different approach has been taken. *The approach was consistent. Responsibility for the NHS in Scotland rests with the devolved administration in Scotland but the secretariat publicised the consultation in Scotland via advertisements in local newspapers.*
17	**Please confirm whether or not a similar review around the provision of congenital heart services for children, is currently being undertaken in Scotland. Please also confirm any associated timescales and outline how the outcomes from each review will inform service delivery for the future.**
	A review of the surgical centre in Glasgow is not within the remit of the JCPCT and I believe that NHS Scotland is best placed to answer your question.

ANNEX 1

Compliance of the *Safe and Sustainable* consultation with the *Code of Practice for Consultations*

Criterion 1: Formal consultation should take place at a stage when there is scope to influence the policy outcome.

The formal public consultation on the proposals to improve children"s congenital heart services was launched at the time when no decisions have been made on the number or location of the surgical centres, nor on the proposed standards and model of care, and the consultation has provided an opportunity to shape the proposals, bring forward relevant evidence and to submit alternative options for the JCPCT s consideration.

Additionally, informal consultation took place in the early stages of the Safe and Sustainable Review.

Patients and the public were invited to give their comments on the proposed clinical standards via an extensive public engagement exercise in the autumn of 2009, which included a national stakeholder event in October 2009.

Nine public engagement events were held in major cities across England between June and July 2010. The events were widely publicised in collaboration with local NHS commissioners, surgical centres and local interest groups. All events were well attended by parents, children, NHS staff, local scrutiny representatives and the media. At these events participants had the opportunity to put questions to a panel of experts. Written reports on the events were provided to the JCPCT so that the issues raised could be taken into account when developing criteria for the evaluation of options and in further development of the proposed clinical model of care.

From summer 2009 *Safe and Sustainable* has published a quarterly newsletter setting out background information, progress to date and future steps in the review process. A website provides background information and documents relating to the review, including detailed minutes of Steering Group meetings and Standards Working Group meetings and relevant reports. This enables the public to keep up to date with the process for the development of the draft standards and the review process. NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance.

In September 2010 the Office of Government Commerce undertook an independent review of the way in which the NSC Team had managed the *Safe and Sustainable* Review. The report was positive and the Review was particularly commended for "excellent clinician, patient and key stakeholder engagement". Similarly in September 2010 the National Clinical Advisory Team undertook an independent review of the clinical case for change driving the Review and the review was commended for the level of engagement with NHS staff and the public.

A number of briefings tailored to specific interest groups were published before and during the formal consultation. For example, in August and October 2010 every Health and Overview Scrutiny Committee in England and every Local Involvement Network in England were briefed about the Review. A briefing for every Member of Parliament was published in September 2010 which encouraged them and their constituents to take part in consultation events. In November 2010, a briefing was published for the Chief Executive of every local authority in England and in March 2011, for every General Practitioner in England.

Criterion 2: Consultation should normally last at least 12 weeks with consideration given to longer timescales where feasible and sensible

The consultation was launched on 1 March 2011 and ended on 1 July 2011. It lasted four months, one more month than the 12 weeks as recommended above. The consultation has been extended to over 7 months for Health and Overview and Scrutiny Committees (up to 5 October 2011).

Criterion 3: Consultation documents should be clear about the consultation process, what is being proposed, the scope to influence and the expected costs and benefits of the proposals.

Consultation literature has clearly explained the background for the need for change, the process followed to deliver options for consultation, and the process of consultation itself. The outcome of the financial assessment is set out in the Pre-Consultation Business Case and Consultation Document. The benefits, as well as risks and proposed mitigation of risks associated with the proposed changes are outlined in the consultation documentation. NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance.

The outcome of the Health Impact Assessment was published in all key stages – in February 2011, the HIA Scoping Report was published, with Key emerging findings from Phases 1 and 2 published in June 2011 (during consultation, as set out in the guidance), and the Interim HIA Report was published in August 2011.

The response form included a mixture of open and closed questions, thus giving consultees an opportunity to express their views on issues not specifically addressed in the questions.

Criterion 4: Consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is intended to reach.

The consultation was targeted at different audiences. As many as 2,086 people attended 16 consultation events. These included three workshops specifically for young people, as well as a consultation document written for young people specifically. There were around 40 focus groups and workshops with parents, children, vulnerable groups, including BAME communities, supplemented by additional phone interviews and family interviews. The *Safe and Sustainable* review team has worked with clinicians, commissioners and voluntary sector to raise awareness of the consultation, in England, Wales, Scotland and Northern Ireland. During the consultation, the documentation was available in 12 languages: English, Welsh, Chinese, Polish, Hindi, Urdu, Gujarati, Punjabi, Bengali, Somali, Farsi and Arabic. This resulted in more than 75,000 responses, making it one of the biggest consultations in the NHS. Around 20% of responses came from Black and Ethnic Minority (BAME) groups, and 10% from young people, a reflection of the high degree of awareness raised among these groups.

Criterion 5: Keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees' buy-in to the process is to be obtained.

Safe and Sustainable has kept the burden of the consultation to a minimum by consulting at the formative stage. The consultation response form was available online and was user-friendly (for example, username or password was not required to respond to the questions).

Criterion 6: Consultation responses should be analysed carefully and clear feedback should be provided to participants following the consultation.

NHS Specialised Services supports the work of the National Specialised Commissioning Group (NSCG). The NSCG oversees and co-ordinates the work of regional Specialised Commissioning Groups, providing support and guidance.

The consultation responses were analysed by Ipsos MORI, the independent expert third party, to ensure the analysis is independent and objective. The feedback was provided by publicising the outcome of the consultation in the national and local media, and on the *Safe and Sustainable* website. The responses that were received from organisations via letters or emails were published in full on the *Safe and Sustainable* website. The consultation documentation includes a high-level implementation plan. The response form includes the name of the Consultation Coordinator, to whom the consultees could submit comments about the consultation process.

Criterion 7: Officials running consultations should seek guidance in how to run an effective consultation exercise and share what they have learned from the experience.

A Consultation Coordinator was appointed and named in the consultation documentation as the person to contact with any queries or complaints regarding consultation process. Lessons learned are being shared within the organisation with those who are planning to consult.

Actual number of adult (>15 years old) surgical procedures (excluding private patients, Scottish and NI centres)

HOSPITAL	NUMBER
Alder Hey Hospital	7
Basildon Hospital	0
Birmingham Children's Hospital	19
Bristol Children's Hospital	65
Evelina Children's Hospital.	42
Freeman Hospital	88
Glenfield Hospital	41
Great Ormond Street Hospital	13
Hammersmith Hospital	1
Harley Street Clinic	*9*
Hull Royal Infirmary	0
John Radcliffe Hospital	16
King's College Hospital	10
Leeds General Infirmary	56
Liverpool Heart And Chest Hospital	27
Manchester Royal Infirmary	35
Northern General Hospital	0
Nottingham City Hospital	5
Queen Elizabeth Hospital	63
Royal Brompton Hospital	168
Royal Hospital For Sick C....	*2*
Royal Sussex County Hospital	9
Royal Victoria Hospital	*11*
Southampton General Hospital	66
St George's Hospital	20
St Marys Hospital, Paddington	8
St Thomas Hospital	0
University College Hospital	82
University Hospital Of No....	0
University Hospital Of Wales	18
Victoria Hospital	0
Sub-total	**881**
less private and non England and Wales hospitals	***22***
Total	**859**

APPENDIX 2

Additional points of clarification

(1) Response to original question 2: '…*However, the Trust was also assessed against its ability to meet other quality standards and when considered in the round, the Trust received the second lowest score of all eleven surgical centres.'*

Point of clarification*: What is mean by other quality standards, can we have a list of quality standards from the trust that it has to comply to together with information on their compliance?*

Response: The quality (service) standards referred to are available using the following link:
http://www.specialisedservices.nhs.uk/library/30/Paediatric_Cardiac_Surgery_Standards_1.pdf

The report of the independent expert panel (Chaired by Sir Ian Kennedy) presented to the JCPCT is available using the following link:
http://www.specialisedservices.nhs.uk/library/30/Appendix_K1___Reports_of_the_Independent_Expert_Panel_Chaired_by_Professor_Sir_Ian_Kennedy_1.pdf

There has been an ongoing debate/ discussion around the availability of the breakdown in scores for each centre, and any assurance/ validation process with individual centres before these were published. The Joint HOSC has had varying opinions on the process, with LTHT stating that the Trust had not received a detailed breakdown of the scores, despite several requests. The breakdown in scores has been requested on behalf of the Joint HOSC. However, these have not been provided. It has been stated that the JCPCT has not considered the breakdown in the assessment scores.

(2) Response to original question 3: *'Professor Sir Ian Kennedy's panel advised that none of the current surgical units have developed networks that fully comply with the Safe and Sustainable standards, but the panel acknowledged the strength of the current network in Yorkshire and Humber by assessing it as 'strong'. However, the panel also identified a number of gaps in compliance and as such the network was not described as 'exemplary'.*

Point of clarification: *Can we find out from Safe and Sustainable what the safe and sustainable standards are for networks? Can we get a copy of Sir Ian Kennedy's report to see what it said in relation to this? Can Leeds tell us where the gaps are in relation to the standards referred to?*

Response: The network standards and the associated assessments are detailed in the above links. However, at this point the associated scores have not been made available.

(3) Response to original question 4: '…*Leeds Teaching Hospitals NHS Trust submitted an application to deliver ECMO services but the application was declined as the panel was not confident that the Trust had demonstrated that it had the appropriate skills and infrastructure to deliver respiratory ECMO for children.'*

Point of clarification: *Can Leeds Trust answer why this may be the case?*

Response: Leeds Teaching Hospitals NHS Trust have been invited to comment on the response received, including this specific point.

(4) Response to original question 5: '…t*hat the children in Yorkshire and the Humber can be reached by a specialist retrieval time in compliance with the standards around emergency retrieval times set by the Paediatric Intensive Care Society (PICS).'*

Point of clarification: Can we find out from the PICS what the standards are?

Response: The retrieval standard referred to is 3hrs from the decision to retrieve a child (or 4hrs in the case remote area, where the Retrieval Service has considerable distance to travel).

This standard is set out in Standard 123 (page 39) of the overall Standards for the Care of Critically Ill Children which is available here: http://www.rcoa.ac.uk/docs/sccic_2010.pdf Section D refers to retrieval and transfer times and is covered by standards 98-131.