

JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (YORKSHIRE & THE HUMBER)

Meeting to be held in Civic Hall, Leeds, LS1 1UR on Wednesday, 10th April, 2013 at 11.00 am

(A pre-meeting will take place for all Committee Members at 10.00am)

MEMBERSHIP

Councillors

S Ali – Rotherham Metropolitan Borough Council J Bromby – North East Lincolnshire Council D Brown – Hull City Council J Clark – North Yorkshire County Council P Elliott – North Lincolnshire Council C Funnell – City of York Council M Gibbons – Bradford Metropolitan Council R Goldthorpe – Calderdale Council B Hall – East Riding of Yorkshire Council J Illingworth (Chair) – Leeds City Council T Revill – Doncaster Metropolitan District Council B Rhodes – Wakefield Council M Rooney – Sheffield City Council L Smaje – Kirklees County Council J Worton – Barnsley Council

Agenda compiled by: Guy Close Governance Services Tel: 39 50878 Principal Scrutiny Advisor: Steven Courtney Tel: 24 74707

ltem No	Ward/Equal Opportunities	Item Not Open		Page No
1			APPEALS AGAINST REFUSAL OF INSPECTION OF DOCUMENTS	
			To consider any appeals in accordance with Procedure Rule 25* of the Access to Information Procedure Rules (in the event of an Appeal the press and public will be excluded).	
			(*In accordance with Procedure Rule 25, notice of an appeal must be received in writing by the Chief Democratic Services Officer at least 24 hours before the meeting.)	
2			EXEMPT INFORMATION - POSSIBLE EXCLUSION OF THE PRESS AND PUBLIC	
			1 To highlight reports or appendices which officers have identified as containing exempt information, and where officers consider that the public interest in maintaining the exemption outweighs the public interest in disclosing the information, for the reasons outlined in the report.	
			2 To consider whether or not to accept the officers recommendation in respect of the above information.	
			3 If so, to formally pass the following resolution:-	
			RESOLVED – That the press and public be excluded from the meeting during consideration of the following parts of the agenda designated as containing exempt information on the grounds that it is likely, in view of the nature of the business to be transacted or the nature of the proceedings, that if members of the press and public were present there would be disclosure to them of exempt information, as follows:	
			No exempt items have been identified on this agenda.	

ltem No	Ward/Equal Opportunities	ltem Not Open		Page No
3			LATE ITEMS	
			To identify items which have been admitted to the agenda by the Chair for consideration.	
			(The special circumstances shall be specified in the minutes.)	
4			DECLARATIONS OF DISCLOSABLE PECUNIARY INTERESTS	
			To disclose or draw attention to any disclosable pecuniary interests for the purposes of Section 31 of the Localism Act 2011 and paragraphs 13-16 of the Members' Code of Conduct.	
5			APOLOGIES FOR ABSENCE AND NOTIFICATION OF SUBSTITUTES	
			To receive any apologies for absence and notification of substitutes.	
6			MINUTES - 3RD DECEMBER 2012	
			To confirm as a correct record, the minutes of the meeting held on 3 rd December 2012.	
			(Copy to follow)	
7			CHILDREN'S CONGENITAL HEART SERVICES: SERVICE PROVISION AT LEEDS TEACHING HOSPITALS NHS TRUST	1 - 10
			To receive and consider a report from the Head of Scrutiny and Member Development providing an update on service provision at Leeds Teaching Hospitals NHS Trust, specifically in relation to children's congenital heart services.	

ltem No	Ward/Equal Opportunities	ltem Not Open		Page No
8			REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: JUDICIAL REVIEW OUTCOME AND IMPLICATIONS	11 - 64
			To receive and consider a report from the Head of Scrutiny and Member Development providing an update on the judicial review outcome and implications in relation to the review of children's congenital heart services in England.	
9			REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: IMPLEMENTATION UPDATE	65 - 98
			To receive and consider a report from the Head of Scrutiny and Member Development providing an update associated with the implementation phase of the review.	



Report author: Steven Courtney Tel: 24 74707

Report of the Head of Scrutiny and Member Development

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

Date: 10 April 2013

Subject: Children's Congenital Heart Services: Service Provision at Leeds Teaching Hospitals NHS Trust

Are specific electoral Wards affected?	🗌 Yes	🖂 No		
If relevant, name(s) of Ward(s):				
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?	🗌 Yes	🖂 No		
If relevant, Access to Information Procedure Rule number: Not applicable				
Appendix number: Not applicable				

Summary of main issues

- Following recent media reports, highlighting concerns raised by the Children's Heart Federation (CHF) regarding clinical practices and services on the children's cardiac surgery unit at Leeds Children's Hospital, the Chair of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (JHOSC) wrote to the Chief Executive of CHF, inviting her to attend the meeting. A copy of this letter is attached at Appendix 1.
- The CHF concerns highlighted in the media had been reported to the Care Quality Commission (CQC). Consequently, the regional office of the CQC was contacted in order to understand and seek assurance around the CQC's processes and outcome of its deliberations around the matters raised. The CQC was invited to provide this assurance to members of the JHOSC at the meeting.
- 3. Quite separate to the arrangements in hand for the JHOSC to consider current clinical practice at Leeds Teaching Hospitals Trust (LTHT), on 28 March 2013 LTHT issued a statement outlining its decision to temporarily pause children's cardiac surgery and associated interventions, following discussions with senior representatives from NHS England and the CQC earlier that day. The statement (attached at Appendix 2) also outlined that the Trust had agreed to carry out an internal review independently validated and supported by external experts, to look at all aspects of congenital cardiac surgery for children undertaken at the unit in Leeds.
- 4. Representatives from LTHT have been invited to attend the meeting to outline its decision and associated matters in more detail.

- 5. Notwithstanding the statement issued by LTHT, further information has come to light around the Trust's decision to temporarily pause children's cardiac surgery and associated interventions. Information includes the following:
 - Copy of an email from the Chair of the Central Cardiac Audit Database (CCAD) Steering Committee to the Chair of the National Institute for Clinical Outcomes Research (NICOR) Executive Committee (Appendix 3); and,
 - Statement from the British Congenital Cardiac Association (BCCA) (Appendix 4)
- 6. To help the JHOSC consider the attached information and the developing situation, a range of organisations/ contributors are being invited to attend the meeting. These include:
 - The NHS Commissioning Board (NHS England)
 - The Central Cardiac Audit Database (CCAD) Steering Committee
 - The National Institute for Clinical Outcomes Research (NICOR) Executive Committee
 - The British Congenital Cardiac Association (BCCA)
 - The Care Quality Commission (CQC) national office
 - The NHS Trust Development Authority (NHS TDA)
- 7. It should be noted that due to the changing nature of the circumstances, those attending cannot be confirmed at this time. Further details will be provided at the meeting.

Recommendations

8. That the JHOSC considers the information presented and determines any appropriate actions and/or scrutiny activity at this stage.

Background documents¹

9. None

The background documents listed in this section are available to download from the Council's website, unless they contain confidential or exempt information. The list of background documents does not include published works.



Anne Keatley-Clarke, Chief Executive Children's Heart Federation Level One 2-4 Great Eastern Street London EC2A 3 NW **Councillor John Illingworth**

Chair, Scrutiny Board (Health and Wellbeing and Adult Social Care) 3rd Floor (East) Civic Hall LEEDS LS1 1UR

E-Mail address john.illingworth@leeds.gov.uk Civic Hall Tel. 0113 39 51411 Civic Fax 0113 24 78889 Your ref Our ref JI/SMC Date 21 March 2013

Dear Ms. Keatley-Clarke,

Re: Concerns associated with the children's cardiac surgery unit at Leeds General Infirmary

As you may be aware, for some time the Joint Health Overview and Scrutiny Committee (JHOSC) for Yorkshire and the Humber has been considering the proposed service model and reconfiguration of children's cardiac surgical centres across England, and the implications for children and families in this region. Underpinning the JHOSC's consideration has been the quality of service available to children and families.

Through recent media reports I have become aware that the Children's Heart Federation has recently raised concerns regarding clinical practices and services on the children's cardiac surgery unit with the Care Quality Commission (CQC). Clearly, the concerns reported are relevant to the JHOSC's recent work and will no doubt be of particular interest to members on the JHOSC.

I shall contact the CQC separately to seek assurance of its processes and the outcome of its deliberation. Nonetheless, in the context of its on-going work, I think it is appropriate for the JHOSC to formally consider the concerns raised by CHF.

Arrangements for the next meeting of the JHOSC are currently being put in place. The meeting will take place on **10 April 2013 at Leeds Civic Hall, commencing at 11:00am**, and I wish to invite you to attend this meeting to discuss the concerns raised.

Given recent developments associated with the legal challenge brought against the JCPCT and the subsequent announcement that the Independent Reconfiguration Panel (IRP) will now report to the Secretary of State for Heath by 30 April 2013, the JHOSC will be considering if any further submission to the IRP is necessary and/or warranted.

I should be grateful if you could confirm your availability for 10 April 2013 and, for the purpose of inclusion on the agenda, it would be helpful if you could share a copy of letter (and any associated attachments) sent by CHF to the CQC. Please forward any details to Steven Courtney (Principal Scrutiny Adviser) at steven.courtney@leeds.gov.uk.

Should you wish to discuss arrangements for the meeting in more detail, please contact Steven on 0113 247 4707.

I look forward to hearing from you in the near future.

Yours sincerely

Councillor John Illingworth Chair, Scrutiny Board (Health and Wellbeing and Adult Social Care)

cc All members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

The Leeds Teaching Hospitals

Statement

27 March 2013

Re: Children's heart surgery at Leeds

Maggie Boyle, Chief Executive of Leeds Teaching Hospitals NHS Trust, said today:

"Following discussions earlier today with senior representatives from NHS England and the Care Quality Commission the Trust has agreed to carry out an internal review independently validated and supported by external experts. This will look at all aspects of congenital cardiac surgery for children undertaken at the unit in Leeds.

"We have taken the decision to temporarily pause children's cardiac surgery and associated interventions while this review is conducted, a process we would aim to complete in around three weeks. We apologise to parents and families who will be affected during this time, and can assure them we always put the safety of our patients first.

"It is really important to us that the review is done as speedily and comprehensively as possible, which, of course, we hope will show the services in Leeds to be safe. We are confident in the quality of the care provided by our staff and hope they will bear with us during this difficult time.

"Families whose surgery may be affected during this time are being contacted directly by the Trust."

Ends

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From: John Gibbs
Sent: 28 March 2013 12:40
To: Roger Boyle
cc: Bruce Keogh; Steering Committee for CCAD
Subject: SMRs for Paediatric Cardiac Surgery

Roger - I am truly appalled that this has happened in this way with no consultation with the congenital steering committee. As you well know, this is work in progress and we have not even got the data statistically analysed yet. It is not fair to the public or the centres for Nicor to leak provisional data which hasn't even reached the stages of p values or confidence limits.

We had, as you also know, carefully planned the processs leading up to public release of centre specific SMRs, with the hard won support of the SCTS, the BCCA, our data contributors and of our parent support groups. It has to be in everyone's interest for national audit to be based on solid statistics and clinicians' trust that due process has been followed. I think the way this has been handled will destroy years of hard work by the congenital cardiac audit team to earn that trust.

The future work of the congenital CCAD steering committee and its research group will be impossible if data is to be leaked before it has been properly statistically analysed and signed off as sound. If our planned work on reintervention shows any sign of outliers prior to complete statistical analysis do you plan to engineer those centres to be immediately shut without warning too?

In the first instance, will you please allow Emmanouil to divert his attention urgently to calculating the confidence intervals for this data so that we can at least let Leeds know if they are at the green or the red line. If that cannot be done Nicor will need to find an NIGB acceptable way and funds to allow David Spiegelhalter to step in.

I sense a conflict of interest here. I cannot see that Nicor would release incompletely analysed data from SCTS or BCIS or any of the other national audits and I see no fair reason why that should be the case for congenital heart disease just because of the S&S process. It rings of politics rather than proper process.

John

John Gibbs

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Statement issued by the British Congenital Cardiac Association

1st April 2013

It is a matter of urgency that the events in Leeds that resulted in the temporary suspension of paediatric cardiac surgery and intervention are understood and resolved. The clinical fallout of ceasing surgical and catheter interventions, even for a short period, could lead to acute under provision of services in the North of England. This event is occurring in the context of the National Safe and Sustainable Paediatric Cardiac Services Review, the recent Judicial Review of this process, and also the findings of the Independent Reconfiguration Panel, due to report shortly.

Our professional bodies, with the total support of all the current hospitals providing these services, have assisted in the development of the Central Cardiac Audit Database (under the auspices of the National Institute for Cardiovascular Outcomes Research, hosted by University College London). This has been running for over 10 years and provides a unique, audited dataset of outcomes in our centres, publicly available on the CCAD website. This is a public and open resource, of which our professionals are extremely proud.

To provide even more sophisticated data to the professionals and public, the CCAD steering group have recently been working on collecting more information which takes into account outcomes in relation to the severity of the different conditions. It is anticipated that this partial risk stratification will provide additional information about the outcomes of interventions in children and will help us to improve the care for all children in the UK.

We are very concerned that some of this preliminary 'raw' data, which has not been verified, has entered the public domain before CCAD or any of the hospitals have had an opportunity to assess or ratify the information. As a result of the fact that the data has not undergone stringent checks, the suggestion that there is a higher than expected mortality rate in Leeds or any other centre, is premature. For the clinicians who have worked tirelessly to support CCAD and the patients who depend on it, it is essential that information is released only after the standard safeguards have been applied. Failure to do so will severely undermine the confidence that the clinicians and public have invested in this important process.

Currently, the British Congenital Cardiac Association is not aware of any centres having a higher than expected mortality. CCAD must be given the opportunity to examine, audit and correct the data before any conclusions can be drawn about mortality, including risk stratified outcomes, in Leeds or indeed any of the UK centres.

Meanwhile, we must ask that any review of Leeds is rapid and effective so that services are disrupted for as short a period as possible and, if appropriate, reinstated rapidly. Furthermore, due process following the outcome of the Judicial Review is awaited, and the publication of the report of the Independent Reconfiguration Panel chaired by Lord Bernard Ribeiro must be considered. Leeds and the other UK centres urgently require a clear decision about the future configuration of services so that cardiac care for children remains at the highest standard. Resolution of the current crisis in Leeds is now critical.

Dr Tony Salmon President British Congenital Cardiac Association



Report author: Steven Courtney Tel: 24 74707

Report of the Head of Scrutiny and Member Development

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

Date: 10 April 2013

Subject: Review of Children's Congenital Heart Services in England: Judicial Review outcome and implications

Are specific electoral Wards affected?	🗌 Yes	🖂 No		
If relevant, name(s) of Ward(s):				
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?	🗌 Yes	🖂 No		
If relevant, Access to Information Procedure Rule number: Not applicable				
Appendix number: Not applicable				

Summary of main issues

- Following the review of Children's Congenital Cardiac Services in England, at its meeting on 4 July 2012, the Joint Committee of Primary Care Trusts (JCPCT) agreed consultation Option B for implementation. The JCPCT also agreed the designation of congenital heart networks led by the following surgical centres:
 - Newcastle upon Tyne Hospitals NHS Foundation Trust
 - Alder Hey Children's Hospital NHS Foundation Trust
 - Birmingham Children's Hospital NHS Foundation Trust
 - University Hospitals of Bristol NHS Foundation Trust
 - Southampton University Hospitals NHS Foundation Trust
 - Great Ormond Street Hospital for Children NHS Foundation Trust
 - Guy's and St. Thomas' NHS Foundation Trust
- 2. At its meeting on 24 July 2012, the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (the JHOSC) agreed to refer the matter to the Secretary of State for Health and submitted its final report in this regard in November 2012 (having provided an earlier report in October 2011).
- 3. At that time, the Secretary of State for Health had asked the Independent Reconfiguration Panel (IRP) to undertaken a review of the JCPCT's decision and provide its advice by 28 March 2013.
- 4. Quite separate to the work of the JHOSC, the Leeds based organisation, Save Our Surgery Ltd. (SOS Ltd.), sought to bring forward a Judicial Review of the JCPCT's

decision. In summary, SOS Ltd. challenged the JCPCT's decision on the following grounds:

- That the scores produced by Sir Ian Kennedy's Independent Expert Panel should have been made available during the public consultation (March 2011 July 2011) to allow consultees to provide full informed responses.
- Given the significance attached to the scores produced by Sir Ian Kennedy's Independent Expert Panel, by the JCPCT meeting, the JHOSC agreed to consider regular updates and issues associated with the implementation phase of the review.
- 5. The High Court hearing took place over the course of three days (11, 12 and 18 February 2013). The full judgement was passed down on 7 March 2013 and found in favour of SOS Ltd. on both claims. The full judgement is attached at Appendix 1 for information.
- 6. On 15 March 2013, the Secretary of State for Health wrote to the Chair of the IRP, extending the deadline for its report to 30 April 2013. A copy of that letter is attached at Appendix 2. In that letter, the Secretary of State outlined that:

'Extending the deadline will allow the Panel and other to take account of the Judge's decision on redress on 27 March 2013 and to consider what implications this may have in moving forward.'

7. On 27 March 2013, a further 'remedy hearing' took place to consider the redress in response to the previous judgement. At the time of compiling this report, the outcome redress outcome had not been published. However, it is understood that on the basis of fundamental unfairness on the quality scoring, decisions 15-17 (as outlined in recommendations 15-17 of the decision making business case) were quashed. These are detailed below:

Recommendation 15:

Agree the proposed scoring of options against the weighted criteria.

Recommendation 16:

Option B is consistently the highest scored option when sensitivity tests are applied

Recommendation 17:

Agree option B for implementation and the designation of congenital heart networks led by the following surgical centres:

- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Alder Hey Children's Hospital NHS Foundation Trust
- Birmingham Children's Hospital NHS Foundation Trust
- University Hospitals of Bristol NHS Foundation Trust
- Southampton University Hospitals NHS Foundation Trust
- Two surgical units in London
- 8. It is understood that it was also held that any future decision would need review and/or reflect any new evidence.
- 9. The full implications/ ramifications of this redress are not yet known, however it is intended that appropriate representatives attend the meeting to allow the JHOSC to

consider such matter in more detail. Representatives from the following bodies have been invited to attend the meet:

- The NHS National Commissioning Board (NHS England)
- Save Our Surgery Ltd.
- Leeds Teaching Hospitals NHS Trust

Recommendations

10. That the JHOSC considers the information presented and determines any appropriate actions and/or scrutiny activity at this stage including, but not limited to, any further submission it may wish to make to the Independent Reconfiguration Panel.

Background documents¹

11. None

¹ The background documents listed in this section are available to download from the Council's website, unless they contain confidential or exempt information. The list of background documents does not include published works.

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Neutral Citation Number: [2013] EWHC 439 (Admin)

Case No: CO/10505/2012

IN THE HIGH COURT OF JUSTICE **QUEEN'S BENCH DIVISION ADMINISTRATIVE COURT**

Royal Courts of Justice Strand, London, WC2A 2LL

Date: 07/03/2013

Party

Before :

THE HON. MRS JUSTICE NICOLA DAVIES DBE

Between :

R on the application of Save our Surgery Limited Claimant

- and -

Joint Committee of Primary Care Trusts **Defendant**

Newcastle Upon Tyne Hospitals NHS Foundation Interested Trust

Philip Havers QC and Jeremy Hyam (instructed by Hempsons Solicitors) for the Claimant Dinah Rose QC and Marina Wheeler (instructed by Capsticks Solicitors) for the Defendant Fenella Morris QC (instructed by Samuel Phillips Solicitors) for the Interested Party

Hearing dates: 11th, 12th, 18th February 2013

. **Approved Judgment**

Mrs Justice Nicola Davies :

1. The claimant seeks to quash the decision of the defendant, the Joint Committee of Primary Care Trusts (the JCPCT) made on 4 July 2012 which identified seven specialist centres in England for the future performance of paediatric cardiac surgery. Those centres are to be located in Bristol, Birmingham, Liverpool, Newcastle, Southampton and London (two centres) ("the Decision"). Of twelve options considered in a consultation process the JCPCT decided that Option B, an option excluding Leeds General Infirmary (Leeds) but including the Freeman Hospital (Newcastle) would provide the best quality care.

Factual Background

- 2. The 2001 Report of the Public Inquiry into deaths at Bristol Royal Infirmary chaired by Professor Sir Ian Kennedy noted that healthcare services for children were "fragmented and uncoordinated" and made a series of recommendations. Reports by groups of experts in 2003, 2006 and 2007 recommended re-organisation of the centres providing paediatric cardiac surgery services. The consensus was, that in order to achieve better and safer results, surgical expertise needed to be concentrated in fewer, larger centres. A minimum number of surgeons were needed in each centre to ensure adequate cover. Each needed to perform a minimum number of procedures per year to ensure sufficient expertise. In order to achieve the stated aims of a high quality sustainable service with equitable access the number of surgical centres in England would have to be reduced and local arrangements for non-surgical centres would have to be strengthened.
- 3. In response to such concerns in 2008 the NHS Medical Director, Sir Bruce Keogh, acting on behalf of the NHS Management Board requested the NHS National Specialised Commissioning Group (NSCG) to review the provision of paediatric congenital cardiac services. The review became known as the "Safe and Sustainable Review" (the Review). The Review was led by a project team (the NSC team) and was assisted by specialist groups which included:
 - The Steering Group: this primarily provided clinical advice. It was chaired by Dr Patricia Hamilton and comprised 25-30 members of professional and lay associations and commissioners from around the country;
 - The Standards Working Group: a sub group of the Steering Committee led by clinicians whose role was to research and develop a framework of clinical and service standards;
 - An Independent Assessment Panel (the "Kennedy Panel") chaired by Professor Sir Ian Kennedy whose role was to review the existing providers of paediatric congenital cardiac services ("PCCS") and evaluate their compliance with the proposed service standards currently and in the future. The panel was comprised of experts in paediatric cardiac surgery, paediatric cardiology, paediatric

anaesthesia/paediatric intensive care, paediatric nursing together with lay representatives and NHS commissioners.

4. In 2010 the JCPCT was established as the formal consulting body with responsibility for the conduct of the consultation of the Review and for taking decisions on issues the subject of the consultation. On 1 March 2011, the JCPCT published a Consultation Document entitled "Safe and Sustainable: A New Vision for Children's Congenital Heart Services in England" (the Consultation Document). The essence of the proposal was that the number of centres providing paediatric cardiac surgical services be reduced from eleven to seven and that the paediatric congenital cardiac service be reconfigured into one of a number of national configuration options.

The Legal Challenge

- 5. The claimant is a shell company created solely for the purpose of this litigation. Its funds are raised from public contributions and it draws upon the support of many local people, a petition signed by 600,000, together with local MPs and clinicians. The preliminary work in respect of this challenge was carried out by the Children's Heart Surgery Fund (CHSF) but following advice from the Charity Commissioners the CHSF had no further involvement in the proposed litigation. The defendant challenges the standing of the claimant to act in these proceedings.
- 6. The claimant does not challenge the merits of the Decision. The challenge is to the consultation process which preceded the Decision and its product, namely the Decision. The claimant's contention is that the same were flawed by:
 - a) procedural unfairness a failure to disclose sub-scores awarded by the Kennedy Panel which were the key to understanding the "material differences" in "Quality" between the centres considered in the configuration assessment. This failure deprived the consultees of the opportunity to make intelligent and informed responses, which, had they been taken into account by the JCPCT, at the very least may and probably would have had a significant influence on the outcome of the configuration assessment;
 - b) a failure to take into account material considerations: a failure by the JCPCT itself sufficiently to inquire into and then take into account the supposed "material differences" in "Quality" between the centres which were being considered in the configuration assessment by failing to have regard to the Kennedy Panel sub-scores and by relying on mistaken and erroneous advice/assurance from Professor Sir Ian Kennedy.
- 7. For the purposes of these proceedings the claimant does not challenge the decision that it is Leeds **or** Newcastle as the one northern centre. In the event that the decision is quashed the claimant would contend that both could continue to provide these services.

- 8. The defendant contends that the consultation process was fair, all relevant considerations were properly taken into account by the JCPCT when the decision was made. The overall scores awarded by the Kennedy Panel were disclosed to consultees and were considered by the defendant as was a detailed report prepared by the Kennedy Panel. The report identified the areas of strength and weakness in compliance with identified criteria which it had assessed on the evidence provided to it by the centres. The report provided sufficient information to enable consultees to comment intelligently on the proposals for reconfiguration of the service.
- 9. Fairness does not oblige a decision maker to disclose all underlying materials which have informed advice provided to the decision maker. Such a requirement is particularly inappropriate where the advice itself, and the reasons for it, have been disclosed; where the advice consists of an exercise of individual and collective expert judgment, rather than an objectively verifiable analysis of data; where the information being assessed has been provided by the consultees themselves; and where the decision maker has not had access to, or relied upon, the material in question. There is no principle of fairness that requires the disclosure to consultees of material which has not been considered or relied upon by the decision maker. The logic of the claimant's case is that not only the sub-scores but also the working notes and individual scores of members of the Kennedy Panel together with all the evidence considered by them ought to have been disclosed to consultees.
- 10. The application for judicial review was issued on 2 October 2012. On 21 November 2012 HHJ Mackie QC sitting as a Deputy High Court Judge made an order which included the following:
 - i) Newcastle Upon Tyne Hospitals NHS Foundation Trust be joined as an interested party;
 - ii) A rolled up hearing to determine the application for permission and the substantive claim be heard.
- 11. Having considered the submissions I grant permission to the claimant to apply for judicial review.

Legal Framework

12. Sections 1 and 3 of the National Health Service Act 2006 require the Secretary of State for Health to provide or secure certain medical services. By regulation 3 of the National Health Service (Functions of Strategic Health Authorities and Primary Care Trust and Administration Arrangements) (England) Regulations 2002 (SI 2002 / 2375), as amended, that function has been substantially delegated to Primary Care Trusts ("PCTs"). Section 242 (2) (b) of the 2006 Act imposes a duty on each body to which it applies which includes PCTs, to consult persons to whom services are being or may be provided on "*the development and consideration of proposals for changes in the way those services are provided*".

13. Paragraph 10.3.2 of the Department for Health Overview Scrutiny of Health Guidance provides that :

"...where a proposed service change spans more than one PCT, they will need to agree a process of joint consultation. The Board of each will need to formally delegate responsibility to a Joint Committee, which would act as a single entity. Following consultation the Joint PCT Committee will be responsible for making the final decision on behalf of the PCTs for which it is acting."

14. Specialised paediatric cardiology and cardiac surgery services are "specialised services", commissioned regionally by Specialised Commissioning Groups ("SCGs"), which are constituted as joint committees of PCTs in their catchment area. The NSCG coordinates the work of the SCGs and oversees, when necessary, pan-regional commissioning.

Lawful Consultation

15. The law imposes obligations of fairness upon any consultation exercise, the requirements of a lawful consultation were identified by the Court of Appeal in *R v North and East Devon Health Authority, ex parte Coughlan [2001] 1QB 213*:

"108 It is common ground that, whether or not consultation of interested parties and the public is a legal requirement, if it is embarked upon it must be carried out properly. To be proper, consultation must be undertaken at a time when proposals are still at a formative stage; it must include sufficient reasons for particular proposals to allow those consulted to give intelligent consideration and an intelligent response; adequate time must be given for this purpose; and the product of consultation must be conscientiously taken into account when the ultimate decision is taken (R v Brent London Borough Council ex parte Gunning (1985) 84 LGR 168)...

112...It has to be remembered that consultation is not litigation: the consulting authority is not required to publicise every submission it receives or (absence and statutory obligation) to disclose all its advice. Its obligation is to let those who have a potential interest in the subject matter know in clear terms what the proposal is and exactly why it is under positive consideration, telling them enough (which may be a good deal) to enable them to make an intelligent response. The obligation although it might by quite onerous, goes no further than this."

16. In Devon County Council v Secretary of State for Communities and Local Government [2010] EWHC 1456 (Admin) Ouseley J. stated:

"68. What needs to be published about the proposal is very much a matter for the judgment of the person carrying out the consultation to whose decision the courts will accord a very broad discretion...But, in my judgment, sufficient information to enable an intelligible response requires the consultee to know not just what the proposal is in whatever detail is necessary, but also the factors likely to be of substantial importance to the decision, or the basis on which the decision is likely to be taken...

70...: a flawed consultation exercise is not always so procedurally unfair as to be unlawful; R (Greenpeace) v Secretary of State for Trade and Industry [2007]Env LR 29, Sullivan J...the true test is whether the consultation process was so unfair that it was unlawful..."

- 17. Within the context of this case the claimant identified the "factors" (paragraph 68) as representing the Kennedy sub-scores. The defendant contends that they represent the factors developed in the Consultation Document namely accessibility, deliverability, sustainability and quality; the sub-scores are the underlying assessment of these factors.
- 18. In *R v Secretary of State for the Home Department ex parte Doody [1994] 1.A.C 53.* the challenge was to decisions of the Secretary of State by serving prisoners as to the minimum terms of imprisonment which they would have to serve prior to their cases being reviewed. Lord Mustill dealt with the issue of what fairness required in the context of the case and stated at p.560 (e):

"....(2) The standards of fairness are not immutable. They may change with the passage of time, both in the general and in their application to decisions of a particular type. (3) The principles of fairness are not to be applied by rote identically in every situation. What fairness demands is dependent on the context of the decision and this is to be taken into account in all its aspects...(5) Fairness will very often require that a person who may be adversely be affected by the decision will have an opportunity to make representations on his own behalf either before the decision has taken with a view to producing a favourable result; or after it is taken, with a view to procuring its modification; or both. (6) Since the person affected usually cannot make worthwhile representations without knowing what factors may weight against his interest fairness will very often require that he is informed of the gist of the case which he has to answer...

The respondents acknowledge that it is not enough for them to persuade the court that some procedure other than the one adopted by the decision maker would be better or more fair. Rather, they must show that the procedure is actually unfair. The court must constantly bear in mind that it is to the decision maker, not the court, that Parliament has entrusted not only the making of the decision but also the choice as to how the decision is made..."

- 19. The defendant relies upon the above passage in support of its contention that it is the gist of the case of which consultees have to be informed. The claimant does not accept that the 'gist of the case' is sufficient for the purpose of a consultation exercise, *Doody* was not a consultation case it was a challenge to a decision.
- 20. The defendant also relies upon the authority of *Bushell and Another v Secretary of State for the Environment [1980] AC 75* Lord Diplock p.95:

"What is fair procedure is to be judged not in the light of constitutional fiction...but in the light of the practical realities as to the way in which administrative decisions involving forming judgments based on technical considerations are reached..."

Bushell did not involve a consultation process, the issue was one of fairness at an inquiry.

21. In *R* (*Eisai*) *v* National Institute for Health and Clinical Excellence and Others [2008] *EWCA CIV 438* the claimant pharmaceutical company held the UK marketing authorisation for a drug used in the treatment of Alzheimer's disease. NICE decided that it was not cost efficient and published guidance to that effect. The claimant challenged the procedure by which NICE had reached its decision contending that as a consultee of NICE, it should have had access to a fully executable version of the economic model that NICE had used to determine the cost effectiveness of the drug, rather than the only partly executable version which NICE had made available to all consultees. It was an important feature of *Eisai* that throughout the consultation process, the claimant had asked for a copy of the fully executable version of the model. Richards LJ cited the above passages in *ex-parte Coughlan* and continued:

"26. The mere fact that information is "significant" does not mean that fairness necessarily requires its disclosure to consultees...nevertheless the degree of significance of the undisclosed material is obviously a highly material factor.

27. What fairness requires depends on the context and the particular circumstances; see for example, R v Secretary of State for Education, ex-parte M [1996] ELR 162, at pp. 2006-2007, where Simon Brown LJ emphasised the need to avoid a mechanistic approach to the requirements of consultation...

30. ... The fact that the material in question comes from independent experts is plainly relevant to the overall assessment, but it was a combination of factors – including the

requirement of a high degree of fairness...the crucial nature of the advice, the lack of good reason for non-disclosure, and the impact on the applicants- which led to what was on the facts a fairly obvious conclusion...

65...even if one accepts the possibility that release of the fully executable version would add two to three months to the appraisal process, that has to be viewed in the context of an already lengthy process...I do not think that either the additional time or the additional cost to NICE should weigh heavily in the balance in deciding whether fairness requires release of the fully executable version. If fairness otherwise requires release of the fully executable version, the court should in my view be very slow to allow administrative consideration of this kind to stand in the way of its release.

66...procedural fairness does require release of the fully executable version of the model. It is true that there is already a remarkable degree of disclosure and of transparency in the consultation process; but that cuts both ways, because it also serves to underline the nature and importance of the exercise being carried out. The refusal to release the fully executable version of the model stands out as one exception to the principle of openness and transparency that NICE has acknowledged as appropriate in this context. It does place consultees...at a significant disadvantage in challenging the reliability of the model. In that respect it limits their ability to make an intelligent response in something that is central to the appraisal process..."

- 22. The request by the claimants in *Eisai* for disclosure of the relevant model was contrasted with the position of the claimant in *R* (*Easyjet*) v *Civil Aviation Authority and Others [2009] EWCA CIV 1361* in which the claimant's challenge was based upon the fact that the defendant had acted unfairly in failing to consult the airlines. After its own stated deadline for accepting representations from any party had passed, the defendant obtained and took into account material evidence from BAA explaining their underlying calculations for additional security costs. The defendant did not inform the airlines about this material, nor was there any opportunity to scrutinize or comment upon it. The essential factual difference between *Eisai* and *Easyjet* was that in *Eisai* the claimant had made clear that it wanted to see and comment on the fully executable version of the model whereas in *Easyjet* the airlines were content to leave the completion of the process of scrutinising and assessing the security costs to the defendant without any further input from them.
- 23. The court recognised that the airlines had played a full part in the consultation process prior to the identified deadline. It found that the process was not unfair and relied upon the fact that the airlines were content for the defendant to complete the final stage of the process without any further input during which period further submissions

were received upon which they did not comment. Of note is the following identified by Maurice Kay LJ [74]:

"...what fairness demands is dependent on the context of the decision.

The decision in the present case does not impact on personal liberty, a person's home, the use which a property owner may make of his property or the right to conduct a business. Its context is the regulation by a statutory body of one aspect of the process charged by a private monopoly supplier to its customers...the ultimate issue is not the provision or non provision of a service. It is simply the charge that may be levied by the airports per passenger

[73] This puts the decision of the CAA at the "soft" end of the spectrum...fairness should reflect the context as I have described it. It is for this reason that I reject Mr Béar's submission that the present case is on all fours with Eisai where the regulatory decision was effectively as to whether or not the company should be enabled to market their drug within the NHS. I see that as a significantly more intrusive decision which is more likely to attract a higher level of procedural fairness..."

24. As to the refusal of the JCPCT to consider the sub-scores the claimant relies upon the authority of *Kaioa & Others v West & Another [1985] 159 C.L.R 550* Brennan J stated at 628:

"a person whose interests are likely to be affected by an exercise of power must be given an opportunity to deal with relevant matters adverse to his interests which the repository of the power proposes to take into account in deciding upon its exercise;... the person whose interests are likely to be affected does not have to given an opportunity to comment on every adverse piece of information, irrespective of its credibility, relevance or significance...nevertheless in the ordinary case where no problem of confidentiality arises an opportunity should be given to deal with adverse information that is credible, relevant and significant to the decision to be made. It is not sufficient for the repository of the power to endeavour to shut information of that kind out of his mind and to reach a decision without reference to it. Information of that kind creates a real risk of prejudice, albeit unconscious, and it is unfair to deny a person whose interests are likely to be affected by the decision an opportunity to deal with the information..."

25. In Lambeth London Borough Council v Ireneschild [2007] EWCA CIV 234 an issue of procedural unfairness arose based upon the fact that the respondent was not

provided with an opportunity to address the provisional views of the author of an assessment of her care and accommodation needs. Hallett LJ relied upon the fact that the material in the assessment was essentially derived from the respondent herself as one of the factors in deciding that there had been no unfairness. The defendant submits that the process identified is similar to the facts of the present challenge: the claimant was told what the issues were; was asked relevant questions and given an opportunity to put forward its best answers. The claimant contends that this was not a consultation case, the document was an internal report by one of the authority's own officers. Hallett LJ regarded as significant the fact that the process allowed for representations to be made after the assessment had been completed, it was not a final determination of an entitlement.

26. As to what has to be demonstrated: in *R* (*Smith*) *v* North Eastern Derbyshire NHS *Trust* [2006] *EWCA CIV* 1291 May LJ stated that in such a challenge

> "The defendants would have to show that the decision would inevitably have been the same and the court must not unconsciously stray from its proper province of reviewing the propriety of the decision making process into the forbidden territory of evaluating the substantial merits of the decision..."

- 27. In considering the authorities cited by the parties I have paid particular attention to and given weight to those which consider a challenge to the consultation process. From the authorities the following principles can be identified:
 - i) The issue for the court is whether the consultation process was "so unfair it was unlawful" *Devon County Council*;
 - Lawful consultation requires that: i) it is undertaken at a time when proposals are still at a formative stage; ii) it must include sufficient reasons for particular proposals to allow those consulted to give intelligent consideration and an intelligent response; iii) adequate time must be given for this purpose; iv) the product of the consultation must be conscientiously taken into account when the ultimate decision is taken;
 - Disclosure of every submission or all of the advice received is not required. Save for the need for confidentiality, those who have a potential interest in the subject matter should be given an opportunity to deal with adverse information that is credible, relevant and significant to the decision to be made. The degree of significance of the information is a material factor;
 - iv) The fact that the information in question comes from an independent expert or from the consultee is relevant but it is a combination of factors including fairness, the crucial nature of the advice, the lack of good reason for non disclosure and the impact upon consultees which are to be considered upon the issue of fairness;

- v) What fairness requires is dependent on the context of the decision; within that the court will accord weight and respect to the view of the decision-maker;
- vi) If the person making the decision has access to information but chooses not to consider it, that of itself, does not justify non-disclosure; it will be for the court to consider the reason for non-disclosure;
- vii) A consultation process which demonstrates a high degree of disclosure and transparency serves to underline the nature and importance of the exercise being carried out; thus, non-disclosure, even in the context of such a process, can limit the ability of a consultee to make an intelligent response to something that is central to the appraisal process;
- viii) The more intrusive the decision the more likely it is to attract a higher level of procedural fairness;
- ix) If fairness requires the release of information the court should be slow to allow administrative considerations to stand in the way of its release.

The Assessment and Consultation Process

28. In March 2010 the draft service Standards were published following which each of the existing surgical centres was sent a Self-Assessment Template. The purpose of the exercise was to enable each centre to supply information and evidence to demonstrate that it met specified core criteria derived from the Standards or would be able to meet them in the future.

Self Assessment Template

29. The template contained an explanation of the evaluation process and the method of scoring, including the weightings to be applied to the scores. The text included the following:

"2. Evaluation process and scoring

Evaluation process

The evidence you supply in this exercise will be assessed as part of the evaluation process we will undertake, and will therefore ultimately inform the final recommendation. The entire evaluation process has 2 discrete stages – Assessment Evaluation and Configuration Evaluation. This process will fulfil the first stage of the Assessment Evaluation.

The second stage of the Assessment Evaluation will be visits by the Assessment Panel to each centre... for one day in order to review the current service against the criteria specified in the self-assessment. The visit will give the Panel the opportunity to meet all members of the team, to see the service in operation, and to gain assurance against all reported development opportunities in the self-assessment document...

It should be noted that the criteria and scoring process for the Configuration Evaluation have not yet been determined. This will be communicated to all stakeholders in due course. However, the criteria and scoring for the Configuration Evaluation is separate from the Assessment Evaluation. The information supplied in the assessment stage of the process will not have any direct bearing on the scoring of the configuration evaluation process."

....Scoring

Scores will be allocated against each criterion, which will come together as a final score for each centre. The scoring process will take place as follows:

Before the assessment visit, each member of the Panel will score these self assessment submissions using the criteria detailed below.

An assessment of the financial viability of the proposals will be conducted by the NSC Team and supplied to the Panel for their consideration, alongside the completed self assessments.

Subsequently, during the assessment visits, the first stage scores will be validated by each member of the assessment panel, as a result of what they see, hear and observe during the day.

The scores will then be cross checked between all panel members at the end of each visit, to ensure consistency and rationality.

Feedback will be given to each individual centre by letter to the Chief Executive when all assessment visits to all centres have concluded (July 2010).

Individual scores for each centre will help identify the configuration options, which will then be tested against criteria such as ease of access, affordability and deliverability, and risks of reconfiguration. The exact scoring mechanism for this stage has yet to be determined.

For the Self Assessment Evaluation Stage, each question within the 9 self assessment criteria will be scored individually, as indicated below:

- 1. Inadequate (no evidence to assure panel members)
- 2. Poor (limited evidence supplied)
- 3. Acceptable (evidence supplied is adequate but some questions remain unanswered or incomplete)
- 4. Good (evidence supplied is good, and the panel are assured that the centre has a good grasp of the issues)
- 5. Excellent (evidence is exemplary)

Each question within that criterion will then be weighted according to the stated multiplier, in order to reach a final score for each question. The sum of these final scores will be the total score for that criteria.

The total scores for each criterion will come together as a final score for each centre...

3. How the Criteria for Self Assessment were derived

The criteria that this template asks for evidence against are as follows:

- 1. Leadership and Strategic Vision
- 2. Strength of Network
- 3. Staffing and Activity
- 4. Independent Services
- 5. Facilities and Capacity
- 6. Age Appropriate Are
- 7. Information and Choice
- 8. Excellence of Care
- 9. Deliverability and Achievability

Criteria 1 and 9 are derived from the need to review the strength of the organisation, in terms of its future sustainability and ability to ensure continuous improvement.

Criteria 2-8 as derived from the full designation standards document, which is detailed at Appendix 1. The designation standards document describes the proposed future model of care for Paediatric Cardiac Surgery Services. The standards will, in effect, be used for two purposes:

As a tool for assessment

A number of the standards are "core requirements" in order to pass the assessment evaluation stage of the process, and to be able to move forward to the configuration evaluation. These are represented by criteria 2 to 8.

As a commissioning service specification

Once the reconfiguration is complete, and centres are designated, they will be expected not only to have the core requirements in place, but also to demonstrate to commissioners how they will achieve the standards, within timescales specified. The standards document will therefore be used as an ongoing commissioning service specification which will be managed through local performance management processes."

- 30. Criteria 1-8 contained sub-criteria. 'Leadership and Strategic Visions' contained 11, the remaining criteria contained 3 identical sub-criteria briefly described as:
 - a) Current achievements against standards
 - b) Development plans
 - c) Meet the minimum of 400 procedures.
- 31. Leeds and Newcastle submitted their Self-Assessment Templates in March-May 2011. SCG commissioners were asked to provide commentary on the assessments as a form of validation. Centres were sent two subsequent Templates: a Financial Template, and a Template relating to Nationally Commissioned Services (NCS). The NCS template asked centres if they wished to be considered as providers for paediatric cardiothoracic transplantation (provided at the time by Great Ormond Street Hospital "GOSH" and Newcastle), extra-corporeal membrane oxygenation (ECMO) (provided by GOSH, Newcastle and Leicester) and complex tracheal surgery (only provided at GOSH).

Kennedy Panel assessment

32. On receipt of the Self-Assessments, Kennedy Panel members individually allocated initial scores to each centre's submissions. They visited the centres: "We interrogated the centres on the information they had provided to us, to see what the story was behind the figures and data provided". (Witness Statement, Professor Sir Ian Kennedy). The statement continues:

"...Using the evidence that we had been given and had gathered, the Independent Panel members assessed the centres current performance in meeting the Standards and the robustness and achievability of the centres' development plans for meeting the Standards, if they were not currently met...We were as interested in the centres' ability to meet them in the future, and the realism and feasibility of their ambitions in this respect...Each sub-score constituted a judgment on a number of factors, and the views of the different experts on the Independent Panel – drawing from their own experience - on those factors. The scores were composite of these factors..."

Each centre was said to be scored independently of the others. The final consensus score was the result of discussion.

33. Weightings (identified in the template) were applied to the scores by the NSC team. Sensitivity analyses were applied to test the robustness of the process.

Criteria	Newcastle		Leeds	
	consensus	weighted	consensus	weighted
1.	45	99	36	78
2.	10	45	11	48
3.	8	73	8	73
4.	11	48	14	62
5.	12	56	9	42
6.	10	29	11	31
7.	9	27	11	31
8.	12	48	9	36
9.	0	0	0	0
	117	425	109	401

34. The sub-scoring for Newcastle and Leeds was as follows:

- 35. The Steering Group convened to consider the applications to provide Nationally Commissioned Services (NCS). It reported in July 2010 that the three current providers of services, (GOSH, Leicester and Newcastle) were delivering good outcomes, NCS should be maintained in these locations if possible. At that time it was considered that Birmingham could develop a transplant and ECMO service if required.
- 36. In August 2010, each centre received initial feedback on the Kennedy Panel assessments by letter from the Director of National Specialised Commissioning which stated that compliance with the standards had been scored, and a summary of findings specific to the centre was provided. Centres were informed that the ninth criterion, "deliverability and achievability", which focused on the financial affordability of

proposals submitted by the centres, had not been scored by the Kennedy Panel, and would instead form part of the consideration by the JCPCT in developing proposals for reconfiguration.

37. On 28 September 2010 the Kennedy Panel attended the meeting of the JCPCT to report on the outcome of the assessments. The JCPCT were given the final consensus scores (but not the sub-scores). The centres were ranked as follows:

Evelina	535
Southampton	513
Birmingham	495
Great Ormond Street	464
Royal Brompton	464
Bristol	449
Newcastle	425
Liverpool	420
Leicester	402
Leeds	401
Oxford	237

38. The minutes of the JCPCT meeting record discussion relating to disclosure of the subscores:

> "Dr Carroll requested the Committee be given access to the subcomponents of the panel's original scorings. Mr Glyde said a summary report had been offered to members at a previous meeting but not taken up by members. Ms Claire stated that she did not wish to see the detail: she believed that the expert's interpretation was authoritative. Sir Ian Kennedy highlighted the risk of judicial review; the process was undermined if data was provided when experts had been appointed to make a judgment. Ms Llewellyn shared Sir Ian Kennedy's concerns. Asked if the detail was disclosable under the Freedom of Information Act, Mr Glyde said he believed that it would be once the process was concluded.

> Ms Christie suggested that the summary report of key findings from each centre be provided by the panel Sir McKay endorsed Ms Christie's suggestion and advised the Committee to be disciplined in resisting requesting further detail once the summary was provided."

39. Professor Sir Ian Kennedy's evidence as to the advice which he gave at the meeting was that the JCPCT should limit their judgment to the context in which they had the opportunity to test the evidence. The JCPCT was free to use the conclusions and report as they wished but "questioning the scores themselves would take them into an area in which they were not expert." Sir Ian's recollection of the reference he made to the risk of judicial review in the minutes was "…this was a caution that the process as

a whole needed to be conducted fairly, and with considerable care, and of the dangers of JCPCT acting beyond its expertise."

- 40. In December 2010, the Kennedy Panel produced the "Report of the Independent Expert Panel" ('the Kennedy Report'). It set out the total scores and a narrative assessment of each centre's compliance with the specified criteria. For each centre, there was an overview followed by an assessment of compliance and gaps in compliance in relation to each of the individual template questions. This was shared with the centres and made public in January 2011.
- 41. Professor Sir Ian Kennedy described his report as "a very substantial piece of qualitative analysis of each centre against these standards. It analysed whether the centres could meet the standards now or in the future. The full report provides an explanation for the scores, and would enable an informed challenge to our findings of fact as mounted by Leeds Teaching Hospitals NHS Trust in its response to the consultation..."
- 42. The summary for Leeds noted the following:

"Areas of compliance

The Network is currently very strong and the trust has good relationships with all key stakeholders

All critically interdependent services are currently co-located

The PICU currently meets core PICU standards and there are two separate rotas for anaesthetists

The Trust has good facilities that can sustain an increase in activity to 400 procedures per year

The Trust had implemented best practice from Ohio

Areas of weaker compliance

The Trust did not demonstrate innovative working practices

The Trust has no plans to use telemedicine for paediatric cardiac surgery

Waiting lists at the trust are long

There are concerns about future staffing capacity in PICU and theatres

The trust has no transition nurse

The Trust did not sufficiently describe an academic research portfolio"

- 43. The main body of the report described areas in which Leeds complied with the standards, including co-location of relevant paediatric services on one hospital site, compliance with the paediatric intensive care standards, a strong network, and a stand-alone paediatric retrieval service. Areas of non-compliance identified for Leeds included an unsustainable model of paediatric intensive care, inefficient working practices, limited confidence in the leadership within the service, limited evidence of the strategic importance of paediatric cardiology services to the Trust, limited evidence of relevant academic research and clinical innovation, limited confidence in the Trust's ability to develop a larger congenital heart network and limited confidence in this regard.
- 44. The summary for Newcastle noted:

"Areas of compliance

The Trust has a strong record of delivering high quality services and had a strong clinical governance structure

The Trust demonstrated highly innovative work, especially with regard to the use of Berlin Hearts. It was the first centre to set up a cardiac genetics database. The estates strategy was strong

All services are co-located as per the standards

Areas of weaker compliance

Because of the small and specialist nature of the PICU it has insufficient staffing levels to maintain a consultant led service

There was limited information about how the trust would work with other hospitals in the network, including hos the IT strategy and transition would be applied within the network, and how it would resolve the concerns working with Carlisle.

There is no clinical psychologist or Children's Cardiac Specialist Nurse"

Configuration options assessment

- 45. Between July 2010 and February 2011 the JCPCT, under the chairmanship of Sir Neil McKay, considered the options for the national configuration of the service. In July 2010, the JCPCT agreed that the following principles should apply:
 - i) Each option (cluster of centres) should ensure that all centres included within in it are able to carry out a minimum of 400 procedures per year, ideally 500 and options should contain six or seven centres;

- ii) Due to the size of its catchment population, London requires at least two centres;
- iii) Oxford should be discounted due to sub-optimal quality and lack of contribution to access times;
- iv) Birmingham to remain in all options due to high referrals from a large catchment population;
- v) Bristol and Southampton are mutually exclusive but one required in all options to serve local populations;
- vi) Two sites are required in the "North" but patient numbers are insufficient to sustain three: for demographic and geographic reasons, options to include Liverpool and *either* Newcastle or Leeds.
- 46. At a JCPCT meeting on 11 January 2011 two additional criteria were applied which required, *inter alia*, that options must include a minimum of three centres capable of providing ECMO services, two centres providing transplant services and one providing complex tracheal surgery. The JCPCT then considered which of the viable options should be put forward for consultation. The options were scored against weighted evaluation criteria which were the product of consultation undertaken by the NSC team. The following evaluation criteria (in order of importance) were agreed for assessing the options:
 - i) Quality:
 - (a) centres will deliver a high quality service;(b) innovation and research are present;(c) clinical networks are manageable;
 - ii) Deliverability:
 - (a) high quality NCSs will be provided;
 - (b) the negative impact on other interdependent services will be kept to a minimum, as will negative impacts on the workforce;
 - iii) Sustainability:

centres are likely to perform at least 400-500 procedures; will not be overburdened and will be able to recruit and retain newly qualified staff.

iv) Access and travel times:

negative impact of travel times for elective admissions are kept to a minimum; retrieval standards are complied with.

- 47. "Quality" contained three elements. The Kennedy Panel consensus scores for each centre were used by the JCPCT to score the "high quality service" element within the option ranked first of the four. Options were scored on the basis of the extent to which they met the criteria: ranging from: 1 (some elements met) to 4 (criteria exceeded). Weightings were applied to the scores for each of the four criteria to reach a total score for each option. Options were then ranked.
- 48. On 16 February 2011, the JCPCT met in public to discuss and agree the Pre Consultation Business Case (PCBC) and the Consultation Document. The four reconfiguration options proposed were:

<u>Option A</u>: Newcastle, Liverpool, Leicester, Birmingham, Bristol, London x 2 <u>Option B</u>: Newcastle, Liverpool, Birmingham, Bristol, Southampton, London x 2 <u>Option C</u>: Newcastle, Liverpool, Birmingham, Bristol, London x 2 <u>Option D</u>: Leeds, Liverpool, Birmingham, Bristol, London x 2

Consultation Evaluation

49. The Consultation Document "Safe and Sustainable: A New Vision for Congenital Heart Services in England" issued on 1 March 2011, set out the process by which these options had been identified, and the evidence which had informed the proposals. The analysis was supported by the PCBC. The consultation took place between 1 March to 1 July 2011. During the four month consultation period about 50 public events were held, 77,000 responses were received. Events held in Leeds attracted many participants, including representatives of CHSF. Issues such as transport infrastructure, travel times and the co-location of paediatric and adult services on one site at Leeds were raised at the events in Leeds. No query or issue arose in respect of the Kennedy Panel's sub-scores. Consultation responses were analysed by Ipsos MORI and presented in a written report.

Consultation responses

- 50. Leeds submitted a detailed response to the consultation, arguing its case for retention of Leeds as a centre for paediatric cardiac surgery whilst raising concerns about the review process. It identified advantages in retaining Leeds, and where it had the edge over Newcastle. In a section headed "Issues and concerns in relation to the Safe and Sustainable process" the following was stated:
 - "In broad terms our concerns relate to

Matters of factual accuracy and consistency.

Matters of scope, context and approach in the review and with the options appraisal.

3.1 Matters of factual accuracy and consistency

The final report received from Professor Ian Kennedy's Review in January 2011 was different from the draft letter about the report that the Trust had commented on in 2010 and contained a number of inaccuracies around the PICU configuration and specialist nurse posts. Although the Trust had responded to the inaccuracies in the draft letter, a number of them were not corrected in the final report from Sir Ian Kennedy. There was not an opportunity to correct the final report before this information was placed in the public domain, and indeed members of the Safe and Sustainable team have repeated this information in the media.

Despite requests, the details of Sir Ian Kennedy's expert panel's scores for Leeds have not been shared with us nor have the errors been rectified. The Pre Consultation Business Case (PCBC) and the final consultation document attempt to describe the process and assumptions that the JCPCT used to shortlist the final four options that had been put to the public..."

It should be noted that there had been no previous request by Leeds for disclosure of the details of the Kennedy Panel's scores.

- 51. Within the same part of the response complaint was made that the ratings given to access and travel times were not consistent with Leeds own polling; challenge was made to the inclusion of Newcastle in three of the four options when it was said that it could only just reach 400 procedures whereas Leeds could easily deliver over 500 and it was noted that the Kennedy Panel had scored current networks in a differential way based on current practice and track records, whereas the scoring of the options had not adopted this approach but had given all potential options the same score.
- 52. Comments on matters of "scope" included challenge to the definition of co-location used by the Kennedy Panel; the failure to take adequate account of the population density of Leeds; and assumptions about patient flows. The response also questioned how, if the Kennedy Panel had decided not to score centres on deliverability or achievability, matters such as impact on the workforce, recruitment etc. would be considered.
- 53. Leeds proposed an alternative configuration option which replaced Newcastle with Leeds. It did not challenge the principle that Leeds and Newcastle were mutually exclusive as stated in the Consultation Document. Finally, Leeds set out in detail its proposals for future network arrangements, the Kennedy Panel having identified that as a gap in compliance.
- 54. Sharon Cheng, Director of CHSF submitted a response to the consultation which expressed strong support for the Leeds centre. The response echoed points made by Leeds, drawing attention to the "gold-standard" co-location of children's services at Leeds and its extensive cardiac network. The view was also expressed that the

provision of NCS had been allowed to dominate. The CHSF response did not challenge the assessments of the Kennedy Panel nor did it ask for the Kennedy subscores.

- 55. On 29 June 2011, the JHOSC submitted an initial response to the consultation which questioned the definition of co-location and predicted patient flows from the region. It noted the high level of surgical activity at Leeds, and suggested that too great an emphasis was being placed on NCSs. After the end of the public consultation, the JHOSC made a number of requests for further information which included a request for the sub-scores from the Kennedy Panel. The JHOSC's full response to the consultation, submitted on 5 October 2011, noted its concern that requests for information, such as the sub-scores agreed by the Kennedy Panel, had not been met.
- 56. Thereafter, the JHOSC complained to the Secretary of State pursuant to Regulation 5 of the Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002 that the JCPCT's consultation with the JHOSC had been inadequate and that information requested, including the sub-scores, had not been provided in advance of the consultation deadline. The IRP, considered the complaint, and advised the Secretary of State that it did not recommend a full review into the matters raised. The IRP noted that the detailed breakdown of the Kennedy Panel sub-scores had not been seen by the JCPCT: "...it was not material to the production of the consultation document, nor will it be material to the decision making process. The JCPCT's commitment to release this information once it has made its final decision is, in our view, reasonable." The Secretary of State accepted the IRP's advice and informed the JHOSC on 23 February 2012. No challenge has been brought to the decision of the Secretary of State.

Further Kennedy Panel Assessment

- 57. In August 2011, following submissions from consultees, the JCPCT requested that the Kennedy Panel consider and advise further in relation to three specific matters: (i) alleged factual inaccuracies in the assessments of the Leeds and Leicester centres, (ii) the definition of co-location used by the Panel and (iii) its application in relation to 3 provider centres: the Royal Brompton in London, the Glenfield Hospital in Leicester and the Freeman Hospital in Newcastle. The Panel was asked to consider if any statements of fact required revision and whether there be revision to the previous scoring.
- 58. The Kennedy Panel met to consider these matters. Its Report ("Report of Sir Ian Kennedy's Panel in Response to Questions by the Joint Committee of Primary Care Trusts" dated 17 October 2011) rejected the suggestion of factual inaccuracy. It noted that questions had been raised previously about its assessment of PICU reconfiguration at the Leeds centre and its specialist nurse posts but it had rejected these.

The Price Waterhouse Cooper (PwC) Report

59. In May 2011, PwC were commissioned to review assumptions about patient flows and clinical networks in the four configuration options being consulted upon. The work focused on 22 postcodes which were broadly equidistant to two or more surgical units. The Newcastle network was of particular concern, because some users of the Leeds unit expressed a preference during the consultation to travel to centres other than Newcastle, should Leeds close. The report found that all networks could be delivered with different degrees of risk. It recognised more reluctance to consider travelling to Newcastle than to other centres. It also found 96% of clinicians stated that they would refer in line with the networks envisaged, and that parents would follow the advice of referring clinicians. Accordingly PwC concluded that, if managed, all the networks in the four options could work.

KPMG work: sensitivity testing and option appraisal

60. KPMG carried out sensitivity testing and in-depth analysis following the consultation process taking into account the issues raised by consultees and the alternative options being considered. The scoring of "Quality" was altered to take account of the concern of consultees that it had not received adequate prominence. The principle that Newcastle and Leeds were mutually exclusive remained. New assumptions and options were considered. Option G (including Leeds rather than Newcastle) was one of the new options introduced and scored. Option B received the highest overall score as it scored highest for quality and deliverability. Option G scored well for quality and highest for travel and access and came second in the overall scoring.

The Advisory Group for National Specialised Services ('AGNSS') Report

61. The cessation of paediatric cardiac surgery at three of the providers would necessitate the re-location of one or more of three NCS that require on-site back-up from a consultant congenital cardiac surgeon. AGNSS advised the JCPCT that whereas ECMO services could be developed at Birmingham, there were significant risks in a proposal to move Paediatric Cardiothoracic Transplant and 'Bridge to Transplant' services from Newcastle. AGNSS noted the conclusion reached by Birmingham Children's Hospital, the only other potential provider of transplant services in England, that it was not able to sufficiently address these complex risks. AGNSS also advised the JCPCT that Newcastle provided excellent clinical outcomes for transplant services and had developed expertise in aspects of paediatric cardiothoracic transplantation that were unique to the United Kingdom.

The Decision Making Business Case ('DMBC')

62. In June 2012 the Safe and Sustainable Review of Children's Congenital Cardiac Services in England was completed in the form of a decision making business case. It included the core recommendation that Option B should be implemented and the designation of congenital heart networks led by the centres contained within it. It was not made public until after the Decision in July 2012. Its purpose was to summarise the key evidence and issues from the consultation and assist the JCPCT in its decision-making. Six new options were considered viable, formally scored and put forward for consideration. These included Option G which contained the same centres as Option B, save that Newcastle was substituted by Leeds. When scored, Option B

remained the highest scoring option followed by Option G. Nine sensitivities were tested, and the options rescored. In each of these exercises, Option B remained the highest scoring option.

63. Section 12, headed "Testing the evidence for option B", advised:

"[A]lthough the scoring process has consistently highlighted option B as the highest scoring option the JCPCT should not regard the scoring process as determinative. Rather the JCPCT's decision should be based on a consideration of all of the available evidence in the round, including the evidence for and against alternative options".

Relevant matters considered in this section included the importance placed by consultees on quality, the definition of co-location, ways to mitigate increased travel times, population density and projections, the "validity of the Newcastle network" and advice relating to the NCSs.

64. The DMBC identified the importance of high quality care as being one of the most frequently mentioned issues for respondents discussing either specific hospitals or the options more generally. Its importance was reflected in the following at page 154:

"Some respondents suggested that the outcome of the Kennedy's Panel Report was that there was no material difference across the centres, such as the suggestion that "all centres are within 95% of the top scoring centre"...

Such was the concern of how the JCPCT should reflect the findings of the panel around the scoring of "quality" that the chair of the Panel, Professor Sir Ian Kennedy wrote to the JCPCT in October 2011:

"the panel is of the view that it's report has identified important differences in the extent to which the centres can meet the quality standards in the future: panel members have reflected these differences in their scores and in the report. It is our view that the outcome of the panel's work would be rendered redundant were the JCPCT to interpret the report's conclusions thus finding that there are no material differences across the centres and their ability to meet the quality standards in the future. This interpretation would not be justified. To repeat, there are important differences.

It is therefore proposed that the sub-criteria "high quality service" has the greatest influence on the total score for quality based on a strong theme from respondents during consultation – that "quality" of service should be the most important of the JCPCT's considerations...".

65. In relation to NCS, the DMBC noted that under Option B transplant services would remain in their current locations. It recalled previous advice from the Steering Group that changes to NCS could be managed but noted that this assumed an alternative safe provider. Whilst Birmingham had been considered a possible alternative, recent capacity testing by the NCS team questioned this, and Birmingham itself doubted that it could develop a Transplant and "Bridge to Transplant" service to replace the Newcastle service within a three year time-frame.

The Decision

66. On 4 July 2012 the JCPCT met in public to consider and agree the recommendations of the Review, including which option to adopt for the reconfiguration of paediatric cardiac surgical services. In his witness evidence, Sir Neil McKay, Chair of the JCPCT, identified the key issues considered at the meeting and why the JCPCT chose option B:

"There were two key reasons for the JCPCT favouring option B over option G. The issues were quite finely balanced, but the JCPCT was satisfied that the differences were conclusive. Firstly, and as demonstrated by the scoring, option B was the higher scoring option for quality. The second reason related to nationally commissioned services (NCS) and in particular the risks around relocating cardiothoracic transplant services, which would be needed if cardiac surgery services at Newcastle ceased"

Of that risk Sir Neil McKay stated:

"the importance of retaining a safe transplant service was such that the scoring process carried out by the JCPCT (and the earlier quality assessment) would have needed to show a material difference in favour of option G, or there would have had to be another significant countervailing argument in favour of option G in order to counterbalance the risk. Again the issue of transplant was not itself determinative (that is, we did not decide on the basis of the issues relating to Birmingham's ability to undertake transplants) but it was a significant consideration".

Claimant's Case Ground 1

- 67. In summary the claimant's position is:
 - (i). Without the scores the consultees could not sensibly, intelligently, or meaningfully respond to all that they had to in respect of the total scores and the Kennedy Report;
 - (ii). The scores were being used comparatively. It is not the claimant's case that the JCPCT were not entitled to rely on comparative scorings but if so it is a further

reason to disclose the sub-scores so as to enable centres to see how they compare and comment upon their comparisons;

- (iii). The more information that is given the more intelligible and meaningful the response. The more productive and more transparent the consultation exercise the more information will be generated and thus improve the quality of the decision making;
- (iv). During the consultation exercise Leeds requested the sub-scores as did the JHOSC and CHSF subsequently. If Leeds thought the scores were relevant what good reason was there to refuse disclosure. If disclosure were deemed appropriate after the consultation it makes no sense to have withheld the sub-scores prior to the decision making when disclosure could have been meaningful.
- 68. The Kennedy Panel's scores were important. They were relied upon by the JCPCT as a proxy for "quality", high quality service was given the highest weighting to reflect its importance. The scores fed directly into the final decision and were ultimately determinative of it.
- 69. In October 2011 Professor Sir Ian Kennedy wrote to the JCPCT indicating that there were important differences between the centres which were reflected in the scores. No consultee, in possession of the Kennedy narrative and only the total scores, could properly understand the "material differences" still less make informed and intelligent consultation responses in respect of the accuracy, or validity of the ranking process, as the absence of the sub-scores rendered it impossible for any centre to know how it had scored upon individual criterion. As to the defendant's argument that the information used by the Panel emanated from Leeds; the provision of the information cannot and does not provide any indication of the scoring subsequently attached by independent assessors.
- 70. Leeds were the most affected centre because they came bottom in the ranking, Oxford having been excluded. As the scores were relevant to the assessment, the breakdown of the scoring should have been disclosed to the centres whether or not the JCPCT proposed to look at it. If there is a public law duty to make information available to a consultee disclosure cannot be denied simply because one party does not wish to look at that information.
- 71. The claimant relies on the importance of the scoring against a background in which the chair of the JCPCT at a meeting in November 2011 is noted as having said:

"Members had heard that financially there was little to discriminate between options G and B and that they were the best value for money. While there were many issues to be addressed in implementation, there was no showstopper to suggest that either option B and G could not work..."

Further, on 23 April 2012 the JCPCT met, by this time the advice from AGNSS had been received. It is noted that:

"the Secretariat's advice to the Committee was that the relocation of the paediatric transplant service was not "a showstopper"; i.e. the issue of relocation of NCS should not dictate the final list of options for consideration on 4 July. However, AGNSS's advice was very strong evidence which should be fed into the scoring process around deliverability and into a consideration of the options generally".

- 72. As there was no 'showstopper' and Professor Sir Ian Kennedy had identified 'material differences' Leeds required proper disclosure in order to respond to an aspect of the process which had become central to the appraisal. Following disclosure and consideration of the sub-scores the claimant contends that it has concerns and doubts as to a) the accuracy of the scoring, b) the fairness of using the Kennedy scores as a comparative ranking tool and c) on the evidence then available to the JCPCT a fair comparative assessment of quality as between Leeds and Newcastle should not have ranked Leeds lower than Newcastle.
- 73. During the course of the hearing Leading Counsel on behalf of the defendant, the interested party and the Court pressed the claimant as to precisely what the case was as to concerns which could or would have been raised had the sub-scores been disclosed. As a result a schedule was prepared by the parties which represents, in summary, the claimant's case as to the points which would have been raised following disclosure of the sub-scores. The schedule is attached to this judgement as Annexe1.

Reason for non-disclosure of scores

74. The reason for non disclosure given by Professor Sir Ian Kennedy is noted in the JCPCT minutes of 28 September 2010. The subsequent refusal of disclosure by the IRP and the Secretary of State relies upon the fact that as the detailed breakdown of the scores had not been seen by the JCPCT it would or could not be material to the decision making process and thus did not need to be disclosed. It is the claimant's case these are plainly bad reasons.

Was it inevitable that the outcome would have been the same

75. The short answer is no, nor does the defendant contend that it was. In his statement Sir Neil McKay stated "even if the quality assessment (based in part on the findings of the Independent Panel) or the scoring more generally had favoured Option G in my view this may not have been enough to draw the JCPCT into choosing Option G". The claimant relies upon the use of the word "may", it being said that that is sufficient to justify a quashing of the decision for unfairness. The issues of ECMO, transplantation and the advice of AGNSS could never have been the 'trump cards' as was acknowledged in the advice that was given to the JCPCT to the effect that there were no "showstoppers".

Appendix One

- 76. During the course of these proceedings Newcastle's Self Assessment Template was disclosed. In respect of each of the core requirements: e.g. strength of network, staffing and activity, etc. the final question in each section was "Would your ability to meet this core requirement be affected by meeting the minimum stated volume of 400 paediatric cardiac surgical procedures a year? In identical form, in response to each such question are these words: "See appendix one outlining the Director of Finance's initial estimate of resources required to meet the quality standards and to increase activity."
- 77. In his written evidence Professor Sir Ian Kennedy identified the task of the Panel as including future compliance and the feasibility of proposals for such compliance. Appendix One represented the financial background to any future proposal. The Court was informed that the Kennedy Panel had not seen, and it follows, had not considered the content of Appendix One. No reason was advanced as to why this was.
- 78. The claimant's contention is that Appendix One indicated whether or not future compliance could be achieved, thus proper consideration of its content was of critical importance. Further, this part of the assessment of the core requirements was worth, after weighting, more than 47.5 % of the total available for "Quality". Shorn of the financial information provided by each centre Newcastle's answers to this question are simply statements of good intention which cannot properly reflect upon the comparative quality of the centres given the direct and important link of available funding. Thus, how can the scores fairly be relied upon as the determinative criteria in the configuration assessment? This is another cogent submission which an informed consultee such as Leeds is likely to have wished to make to the JCPCT having seen the sub-scores and the disparity in scoring.

Ground (2) Failure by the JCPCT itself to scrutinise or properly take into account the Kennedy sub-scores.

- 79. There was a duty on the JCPCT to carry out sufficient inquiry into the matter that was under consideration in *Secretary of State for Education and Science v. Tameside Metropolitan Borough Council* [1977] AC 1014. A material failure to take into account relevant considerations will justify the quashing of a decision see *R(Alconbury) v. Secretary of State for the Environment Transport and the Regions* [2010] UKHL 23.
- 80. Where advice is proffered to a decision-maker (here, by Professor Sir Ian Kennedy in 2011), an improper reason given by that adviser which exerts influence on the decision-maker may vitiate the consultation process or cause the decision-maker to fail to take into account relevant and material information which will vitiate the decision– *R(Evans) v. Lord Chancellor* [2011] EWHC 146 (Admin); *Goldsmith v. Wandsworth Borough Council* [2004] EWCA Civ 1170.
- 81. The claimant relies upon the following:

- (i) Initially, at least, the JCPCT, or some members of it, thought that there was an expectation that the Kennedy sub-scores and underlying methodology would be disclosed;
- (ii) To the JCPCT's knowledge, interested consultees had requested disclosure of the Kennedy sub-scores and this request had been refused;
- (iii) Sir Ian Kennedy had expressly advised the JCPCT that there were *important differences* between the centres but had also advised them not to seek to look at the underlying data for fear of judicial review. That advice was bad. The JCPCT had an obligation to scrutinise and assess the information which underlay the Kennedy scoring, particularly as it then sought to compare and rank centres when Professor Sir Ian Kennedy had explained that the centres had not been scored one against the other;
- (iv) As the JCPCT had only the Kennedy Report (or a digested summary of it) there was no way of ascertaining what the '*important differences*' between the centres were. The 'key' to understanding the weight which the Panel had allocated to aspects of 'compliance' or 'gaps in compliance' were the Kennedy sub-scores;
- (v) The reliance on the advice of Professor Sir Ian Kennedy, meant that the JCPCT did not scrutinise the use of the Kennedy scores and the ranking table when they should have done so, in view of the fact that:
 - (a) The Self-Assessment Template had stated that the scores would not be used directly in the configuration assessment, when in fact that is precisely how those scores were being used;
 - (b) The Kennedy Panel itself had made clear that the Panel had not scored the centres against each other but in isolation and on their own merits;
 - (c) The Kennedy scores were now being used as the proxy for 'high quality service' in the configuration assessment which necessarily ranked Options against each other, and by necessary implication, would depend on a comparative ranking between centres. Thus the only relevant difference between Option B and Option G, the two highest scoring configuration options, was that Option B included Newcastle in substitution for Leeds. In short the configuration assessment quickly turned into a Leeds vs. Newcastle 'play-off', a fact recognised by the JCPCT itself (April 2012).
- 82. The JCPCT had a duty properly to scrutinise the use of the scores in the configuration process and to understand what were the '*material differences*' between the centres which the Kennedy Panel insisted were so important. They failed to discharge their duty to take into account a plainly material consideration, the sub-scores, which were the key to their understanding (a) how the respective scores had been arrived at and (b) whether those scores could properly be used for a comparative assessment in the way they were.

Defendant's Case Grounds One and Two

- 83. Disclosure of the Kennedy Panel's sub-scores was not necessary to render the consultation process fair. In particular:
 - (i) Fairness does not oblige a decision-maker to disclose to consultees the underlying material which has informed judgments or assessments made by those who have advised the decision-maker, it does not even require the disclosure of the advice itself. In any event, disclosure of the advice, and a summary of the reasons for it, was done in this case, and is sufficient. Fairness does not require the disclosure of material which has not been considered or relied upon by the decision-maker;
 - (ii) Consultees were provided with sufficient information to make informed and intelligent responses to the consultation; they did in fact make such representations;
 - (iii) The information analysed by the Kennedy Panel was derived from the centres themselves: they were aware of the detail of such information; consultees had all the information concerning the assessments of the Kennedy Panel which was available to and relied on by the defendant;
 - (iv) Disclosure of the sub-scores would not have promoted sound or efficient decisionmaking, and would have been disproportionate.
- 84. The sub-scores did not add in any material way to the information placed before consultees. They were not "the key" to understanding the supposed "material differences" in quality between the centres or the Kennedy Report. Consultees were provided with sufficient information to enable them to understand the areas of strength and weakness identified by the Kennedy Panel in relation to each centre, and the differences between them. Most of the points now advanced by the claimant could have been, and in some instances were, advanced on the basis of the information provided to consultees. The history of the consultation shows that consultees were not prevented from probing the qualitative assessment made by the Kennedy Panel. Leeds, CHSF and other supporters of the centre made detailed representations as to why they felt the quality of Leeds had been underestimated, including by comparison with Newcastle. Challenges to the process were pursued. The Kennedy Panel reconsidered matters put to it and the defendant sought further advice from others, including PwC.
- 85. The configuration assessment depended on a number of criteria, of which quality was only one. The scores for "high quality service" depended on the number of the high or lowest ranking centres which were included in each option. Reliance is placed upon Sir Neil McKay's evidence that when the Decision was made, scores were only one mechanism used to inform the defendant's thinking:

"Although the Independent panel's work was a major part of the assessment of "quality" it had no bearing on the JCPCT's assessment of deliverability, as set out below. I want to make it clear again that it was not just the scores themselves that informed the JCPCT's conclusions. The final decision was the product of two years of analysis and evaluation by the JCPCT, in the largest single service reconfiguration analysis that the NHS has undertaken to date".

- 86. The Kennedy scores were not determinative of the configuration assessment. If this were correct, it would be expected that the Brompton Hospital would appear in the reconfigured option, having been ranked fourth equal with GOSH. Equally there would be no place for Liverpool ranked fourth from the bottom below Newcastle.
- 87. In the configuration assessment, a very significant factor in preferring Option B to Option G was that Newcastle was one of only two centres to provide the nationally-commissioned transplant and bridge to transplant service. It was essential to retain two centres for this service, and the evidence before the JCPCT showed that transferring the service to another centre would carry significant safety risks. Thus, even if disclosure of the Kennedy Panel sub-scores might have permitted additional representations on the relative quality of Leeds and Newcastle to be made, it is very unlikely that such submissions would have affected the Decision.
- 88. Disclosure of the sub-scores was not necessary to render the process fair, it was unlikely to improve the quality of the decision-making. The sub-scores were not material which the JCPCT was obliged to take into account when making its decision.
- 89. Further, the decision not to disclose the sub-scores has already been the subject of independent scrutiny by the IRP and thereafter the Secretary of State. No challenge has been brought to the decision of the Secretary of State, although Councillor Illingworth, the Chair of the JHOSC, seeks to make the same complaint in his evidence in these proceedings.

Reason for non disclosure

- 90. As Sir Ian Kennedy explained, the aim was to safeguard the integrity of the process. The reference to judicial review was "a caution that the process as a whole needed to be conducted fairly, and with considerable care, and of the dangers of the JCPCT acting beyond its expertise". Sir Neil McKay's view was that the narrative in the Kennedy Report was sufficient; it was this which informed its decision-making. As Professor Sir Ian Kennedy had pointed out to "check" their work would have required the JCPCT to have access to all the evidence to which the Kennedy Panel had access. This was impossible and disproportionate. The JCPCT was entitled to entrust the task of assessment to an expert Panel, and to consider the Panel's report of the outcome of that work, and its final judgments (the overall scores) on each centre. The material considerations, to which the JCPCT was obliged to and did have regard were the views of the Panel and the reasons why it had formed those views.
- 91. The receipt of a "flood" of such material from consultees would have greatly increased the complexity, length and cost of the consultation process, to no public benefit. Not only was the decision not to consider or disclose the sub-scores one which the defendant was entitled to make: it was a sensible and proportionate decision, conducive to efficient decision-making.

Disclosure would have made no difference

- 92. On the facts, it cannot sensibly be argued that disclosure of the sub-scores would have altered the Decision of the JCPCT to chose Option B:
 - (a) Sensitivity testing undertaken to address the complaint that the merits of Leeds as a centre had been underestimated, still resulted in Option B scoring higher than Option G;
 - (b) The Kennedy Panel assessment and scores were only one element in the decision to select Option B. A vital element in evaluating the configuration options was that Newcastle provided NCS; in particular a transplant and bridge to transplant service, which the JCPCT was advised could not safely be developed at an alternative centre within acceptable time scales. The JCPCT was entitled to give this factor considerable weight.
- 93. In the circumstances, there is no realistic prospect that disclosure of the sub-scores would have affected the decision of the JCPCT.

Appendix One

94. The assumption that Appendix One was relevant material which the Kennedy Panel had to assess in order to evaluate Newcastle's response to the identified question (c) is incorrect. What the question required was an explanation from each centre of the way in which its services and facilities would have to be extended and how they would implement such expansion including the risks attendant upon it in order to meet the minimum number of 400 procedures per year. It did not require the centres to state how the expansion would be funded. The fact that Newcastle referred to Appendix One, a financial appendix, in respect of its answer to question (c) does not make the document relevant to the Kennedy Panel's assessment of those answers. The Kennedy Panel did assess question (c) as demonstrated by the witness statement of Professor Sir Ian Kennedy and the analysis in the Kennedy Report which contains judgments of the centre's development plans. The financial appraisal of the centres was carried out by the Secretariat/ NSC Team in conjunction with the centres and local commissioners and the conclusion was that all potential configuration options were affordable.

Ground Two

95. The following additional points, were made in response to Ground Two. The defendant relied on the judgment of the independent experts it had appointed but also had available to it the full explanation of their judgment and reasoning. It challenged and scrutinised the advice received to the extent that it was both necessary and proportionate to do so. The JCPCT was entitled to entrust the task of assessment to the Panel and to consider the Report of the outcome of that work and its final judgment. The material considerations to which the JCPCT was obliged to have regard and did; were the view of the Panel and the reasons why it had formed those views. It is not accepted that the advice given by Professor Sir Ian Kennedy was bad

advice, in any event, it is irrelevant. The question for the court under Ground Two is whether the sub-scores were or were not a material consideration to which the defendant was obliged to have regard.

The Interested Party

- 96. The Newcastle Upon Tyne NHS Foundation Trust comprises a cluster of hospitals in Newcastle which include the Freeman Hospital and within it the site of the Cardiothoracic Centre, the Children's Heart Unit and the Institute of Transplantation; other specialist units include the Northern Centre for Cancer Care, the Liver Unit and the Great Northern Children's Hospital. The interested party had not intended to become involved in these proceedings but following service of a number of witness statements by the claimant which were said to contain inaccurate and professionally derogatory information the Trust felt an obligation to set the record straight. The interested party filed a number of statements properly identifying the facilities and the care provided at Newcastle. It is the only Trust in the country to provide all cardiac care from conception, through birth, childhood and adulthood. The Freeman Hospital is one of only two children's cardiac pulmonary transplant units in the UK, it is among the top 5 centres in the world, within this field and has an international reputation.
- 97. In skilful and succinct submissions Miss Morris QC on behalf of the interested party sought to identify its strengths as a centre and in general terms supported the case for the defendant. During the course of these proceedings there appear to be a retraction, of sorts, of part of the evidence given by one of the claimant's witnesses in respect of Newcastle. Mr Havers QC made clear that it was no part of the claimant's case to cast aspersions on the quality of the care or the facilities provided by Newcastle. The Court was grateful for the claimfication. In view of this clarification and the interested party's support for the case of the defendant, I hope I do no disservice to the quality of its submissions if I specifically consider the submissions made on behalf of the defendant.

The claimant's standing within these proceedings

- 98. The defendant submits that the claim should be dismissed because the claimant does not have a sufficient interest in the matter to which it relates contrary to Section 31 (3) of the Senior Courts Act 1981 which provides that the court should not grant [permission] unless it considers that the applicant has a sufficient interest in the matter to which the application relates. The defendant submits that the claimant is a shell company, founded solely for the purpose of this litigation. It has taken no part in the consultation process. As a corporate entity it has no involvement in the provision of paediatric cardiac services, it is not affected by the decision which it seeks to challenge.
- 99. It is unclear who the claimant is or whose interests it represents. The claimant is supported by representatives of the Leeds' centre of the CHSF and the Chairman of the JHOSC. CHSF's response to the Consultation Document made no reference to nor request for the Kennedy Panel's sub-scores. The JHOSC's request and subsequent

complaint in respect of the sub-scores was dealt with by the Secretary of State in respect of whose decision no challenge has been raised.

- 100. As to the Petition on which the claimant relies it is the defendant's contention that the Petition was organised and submitted by CHSF. The financial contribution came largely from CHSF which is unable to bring this claim because of advice received from the Charity Commission in September 2012 namely that bringing the claim might be incompatible with the aims of the charity whose object is the "advancement of the relief of sick children, and adults with congenital heart conditions, within the Area of Benefit"; the point being that Newcastle came within the same area. Further the Petition states its support for the Leeds centre but there is nothing to suggest that the signatories support the de-designation of Newcastle.
- 101. The claimant contends that it has sufficient interest. Sufficient interest is the remedy afforded by judicial review; in this case the quashing of the reconfiguration decision on the grounds that the consultation process was unfair and flawed. The claimant plainly has an interest in that remedy. The majority, if not all of the individuals who have contributed to the fighting fund, together with the Directors of the claimant, would have a direct sufficient interest in their own right had they brought the claim as individuals. Some of those individuals are clinicians, others are members of the public. The adverse costs in litigation are such that no citizen of ordinary means would prudently contemplate bringing this litigation as an individual. Incorporation was and is the proper means of allowing the interests of a substantial number of persons who consider the defendant's decision to be unfair and unlawful to be jointly represented. There is no obvious better placed challenger, in fact there is no other challenger.
- 102. I am satisfied that the claimant has sufficient interest in these proceedings. The claimant represents many individuals who have contributed financially in order to bring these proceedings. It includes individuals who have been or could be directly affected by the closure of the Leeds Unit and clinicians who work within the unit. Incorporation, following the intervention of the Charity Commission, was a proper means of allowing the interests of a substantial number of such persons to pursue this litigation.

Conclusion

- 103. This was a comprehensive consultation, lasting a matter of months and prompting 77,000 responses. Thought and care was given to the consultation process both as to its content and implementation. When considered necessary, independent work or advice was commissioned; professional groupings provided advice when requested. Those responsible for, and involved in, the setting up and implementation of this process aimed to provide one which was informed, detailed and transparent.
- 104. One aspect of the process were the assessments of the relevant centres provided in the form of scores by the Kennedy Panel. As an independent panel, primarily comprised

of experts in the relevant field, it is accepted that their scoring would involve the exercise of professional judgment. As the process of evaluation developed, the importance of the criteria of quality increased and within it the sub-criterion of high quality service for which the Kennedy scores were a proxy.

- 105. The minutes of the JCPCT meeting 1 September 2010 note that Oxford was to be excluded from all options because it scored so significantly lower than its nearest comparator. Sir Neil McKay was asked whether any other centres should be excluded, given that quality became more important amongst closely ranked centres. It is recorded that he "summarised that quality would have to be the distinguishing factor...".
- 106. In the DMBC, Ipsos Mori reported of the public consultation that:

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

- 107. To reflect the importance to be attached to this criteria "Quality" was given a weighting of 39/ 100 whereas Sustainability was given 25, Deliverability 22 and Access and Travel 14. Of the Quality criterion the DMBC records that the subcriterion for "high quality service has the greatest influence on the total score for quality based on the strong theme from respondents during the consultation – that "quality" of service should be the most important of the JCPCT's considerations…"
- 108. The DMBC identified the total scores for 'Quality' as being:
- 1. Option B 3 Option G 2

2.	High quality service Innovation and research Clinical networks	Option B 3 3 2	Option G 2 3 3
		8	8

The totals of the sub-criteria scores were identical. It was the weighting given to 'high quality service' which resulted in an additional point for the overall score for 'Quality' for Option B. Immediately below the table it was stated that the proposed scores for the sub-criterion of high quality service were based on the scores applied by Professor Kennedy's Panel.

- 109. In my view these figures demonstrate:
 - a) the comparative closeness of the scoring;
 - b) the weighting attached to 'high quality service' reflective of its importance in the context of the overall scoring;
 - c) the significance attached to the Kennedy Panel's scores in the scoring of 'Quality', itself an important factor.

I do not accept the defence description of the sub-scores as being no more than 'underlying workings'. They provided the basis for the consensus score which was ultimately used as one of the most valuable and thus significant tools in the assessment of 'Quality' of the respective centres.

- 110. The DMBC advised the JCPCT to consider the extent to which each option included the three highest scoring centres (which would increase an option score) and the three lowest scoring centres in any option (which would lower an option score). Liverpool, Leicester and Leeds, in that order, were the lowest scoring. Newcastle was immediately above Liverpool, fourth from bottom. The point made on behalf of the defendant was that in order for there to be any real change not only would Newcastle have to come down the rankings, Leeds would have to move up. It is, however, of note that although Leeds was at the bottom of the rankings Newcastle was just outside the last three, some five points ahead of Liverpool.
- 111. The closeness of the scoring and the relationship of those scores to Leeds was noted at the public meeting of the JCPCT on 4 July 2012. The note of the meeting includes the following:

"Mr Buck noted that the proposed scores for B and G were three and two respectively and the only difference was the presence of Leeds. Miss Banks confirmed this; Leeds had scored less well than Newcastle in the Kennedy Assessment which was the reason for this result. Mr Glyde explained that the report was in the public domain but the Committee had decided not to consider the sub-scores so it could not respond as to the specific strengths and weaknesses in each trust. For that reason, KPMG had focused on the overall score, which had placed Newcastle higher than Leeds in terms of overall compliance with standards. However, the next agenda item would explore the submissions put to the Committee of the relevant strengths of its service compared to Newcastle."

The claimant relies on this entry as demonstrating the point at the core of its challenge. The scoring is close, the only difference between B and G being the presence of Leeds which scored less well by reason of the Kennedy assessment. Crucially, the JCPCT acknowledged that it could not respond to the specific strengths and weaknesses in Leeds and Newcastle because it had decided not to consider the sub-scores. Mr Havers QC summarised the position thus: QED.

- 112. The question for this Court is: did the duty of fairness require disclosure of the Kennedy Panel's sub-scores? The sub-scores represented an expert evaluation which translated into a score which was the purpose of the assessment exercise. In my view the following matters are relevant to this question:
 - i) The score assumed increasing importance and thus significance in the evaluation process and was ultimately determinative of the difference in the 'Quality' score as between Leeds and Newcastle;
 - ii) The importance of 'Quality' has to be considered against a background in which a) it was identified as an important component by the many respondents to the consultation process; and b) 'important' and 'material differences' between the centres were said to have been identified by the Kennedy Panel, hence the advice given in October 2011 and recorded in the DMBC;
 - iii) The DMBC advised the JCPCT that 'high quality service' had the greatest influence on the total score for 'Quality' and that 'quality of service' should be the most important of the JCPCT's considerations;
 - iv) The Chair of the JCPCT identified 'two key reasons' for favouring Option B, the first being B's higher scoring for 'Quality';
 - v) This was a consultation process relating to the provision of paediatric cardiac surgical services; a matter of the highest importance to any child requiring such care and his or her family.
- 113. Leeds, together with the other centres, was given a Self-Assessment Template which provided considerable detail as to the process. It completed the Template, received feedback and, subsequently, the total score and the narrative contained in the Kennedy Report. Was this sufficient? Leeds did not consider it to be so because in its response to the Consultation Document it requested the sub-scores, the JCPCT refused the request. I do not regard Leeds' request as unreasonable. I accept the claimant's contention that 'Quality' was not well differentiated in the Kennedy Panel scoring. The narrative in the Kennedy Report identified areas of compliance and non-compliance, but, this was not an audit, it was scoring.
- 114. As to the submission that as the information emanated from Leeds it would know what it was providing; this, in my view, misses the fundamental point namely that Leeds did not know how such information was being evaluated and scored. On any view the information was of relevance. For the reasons identified it became significant in the context of the process.
- 115. The sub-scores provided the clearest indication of the Panel's judgment upon separate sub-criteria. The fact that such scoring contained an exercise of professional judgment

does not preclude it from being a useful guide to the assessment still less prevent any request for reassessment or reappraisal. As evidence of the JCPCT's willingness to revert to the Kennedy Panel when queries arose relevant to their assessment are the instances when the JCPCT referred questions from Leeds and Leicester for further consideration. A similar process could have been carried out in respect of any queries upon sub-scores. Had this been done Leeds would have been better informed as to how to direct its response upon specific issues which became central to the appraisal process.

- 116. The submission that, in any event, the importance of the transplantation work at Newcastle would have 'trumped' the Leeds bid is at odds with the comment of Sir Neil McKay that following the AGNSS Report there were no 'showstoppers' and by his concession identified in paragraph 75 above. Further, the argument that disclosure of the sub-scores would have made no difference to the final result given that Option B maintained its highest score during sensitivity testing ignores the point that within such testing the same scores based upon the same sub-scores were being used.
- 117. For the reasons identified in paragraphs 112-116 above I am satisfied that fairness did require disclosure of the sub-scores to enable Leeds to provide a properly focussed and meaningful response. The refusal of the JCPCT to a specific request by Leeds for disclosure was, in my view, ill judged. The JCPCT was on notice of the importance of the criteria of 'Quality' and within it the use being made of the Kennedy Panel scores. With these considerations in mind, even if the JCPCT chose not to look at the sub-scores, consultees should have been given such an opportunity.

Scores used as comparators

118. In essence the claimant's case is that as the scores were being used by the JCPCT as comparators as between the centres this adds weight to the argument for disclosure of the sub-scores. There is no good evidence as to the thinking or practice of the JCPCT upon this point. A Secretariat briefing paper was relied upon but that goes only so far and is not direct evidence of what the JCPCT thought. In any event, the claimant, having succeeded upon the substance of Ground One, this submission takes the case little further.

Appendix One

119. The inclusion of Appendix One in the claimant's case arose following disclosure of Newcastle's Self Assessment Template. It was not identified at the outset of these proceedings. It has not been directly commented upon in witness statements provided by the defendant, that is an observation not a criticism. In the absence of specific evidence I proceed with a considerable degree of caution. In my view there is force in the defence submission that reference to the financial appendix was not relevant to question (c). If that is correct, why did Newcastle include the reference in its identical answers to the same specific question? As the evidence stands there is no satisfactory, or indeed, any answer. The defendant contends that this issue has nothing to do with

the non-disclosure of the Kennedy Panel's sub-scores, it is the claimant's case that it would have further added to the need to disclose those sub-scores. Given the unsatisfactory evidential position relating to this late point I do not believe the Court is in a position to make a determination.

Ground 2

120. The sub-scores provided the basis for the consensus score which was ultimately one of the most significant tools in the assessment of 'Quality' of the respective centres. The JCPCT knew that one of its observers (Dr Carroll) had raised the issue of scrutiny of the sub-scores, as had consultees. The JCPCT also knew that 'Quality' was becoming more significant as the process developed. In my view, and commensurate with their duty to properly scrutinise and assess all relevant evidence, the JCPCT should have considered the sub-scores. The JCPCT's stance, to the effect: 'it is appropriate to leave this to the experts', failed to reflect the significance of the sub-scores in that they provided the basis of what ultimately was the difference of one point in the critical 'Quality' scoring as between Leeds and Newcastle. If the JCPCT wished for clarification it could have sought the assistance of the Kennedy Panel. It follows, and I so find, that the sub-scores were a material consideration. Accordingly I find that the claimant succeeds upon its challenge upon Ground Two.

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A. Witness complaint about KP assessment	B. Communication of KP assessment	C. Was the issue addressed during the	D. Claimant's response to D's
of Leeds Leadership and Strategic Vision KP was wrong to criticise the Trust's strategy as not giving sufficient emphasis to paediatric cardiac surgery: Hunter §21 [5/13/213]	during the Review Feedback letter [8/9/79] Kennedy Panel Report December 2010 [1/8/201]	Review? Not raised by Trust (see Hunter w/s §21 [5/13/214]	submission C scored 3/5. 'Acceptable' C. did not know this. It appeared from the KP narrative 'compliance' that 'The Trust's overall strategy is clear, and demonstrates a clear direction of Travel for the Trust as a whole' One might have thought a score of '4' or '5' was appropriate. One couldn't guess that the matter mentioned in narrative would result in a score of '3' acceptable. Had Leeds known the scores they could have made submissions on this point as said in
Strength of Network KP was wrong to criticise the Trust's lack of plans to provide an effective Network in the north: Hunter §40.1-40.3 [5/13/223-225	Feedback letter [8/9/79] KP Dec 2010 Report "no robust development plans" [1/8/204]	Response to consultation includes section on "future network arrangements" [3/1/12]	Hunter's statement. Having identified that the existing network was 'strong' Leeds only scored, 4, 4, 3 for the respective questions. 4 when they might reasonably have thought they would score 5, and 3, on the most weighted question, when they might reasonably have scored at least 4. Had they had the scores, Leeds could have focussed on these issues in their consultation response and sought a re- marking of these aspects of the assessment based on further evidence.

Annexe One

A. Witness complaint about KP assessment of Leeds	B. Communication of KP assessment during the Review	C. Was the issue addressed during the Review?	D. Claimant's response to D's submission
			Without the scores they did not know to what extent, if at all, the identified 'gaps in compliance' weighed with the Panel. They were have been shooting in the dark.
Staffing and Activity KP was wrong to criticise staffing capacity in PICU Hunter §41-43 [226-227]	Feedback letter [8/9/79] KP Dec 2010 Report – does not meet minimum activity thresholds and concerns about consultant cover for PICU [1/8/206]	Correspondence about PICU configuration alleged to be "factually inaccurate" [10/13/250- 251, 10/15/256-257, and 10/19/271], KP Report October 2011 [3/4/63-64]	Again it is the scores that explain what weight if any, is attached to particular issues. The 400+ staffing and activity question was worth a maximum of 80 points. Leeds scored 3 x 16 =48), and would been able cogently to argue for a 4. That alone would have resulted in Leeds obtaining 16 more points overall. Leeds would have argued that objectively they should have scored better than Newcastle, on the basis of the evidence given. Newcastle however also scored 3. No such argument could be made without the scores.
Staffing and Activity KP was wrong to criticise the division of the PICU: Blackburn §10 [5/14/229- 234]; Darowski §8-9, 11 [5/8/142-144]	Feedback letter [8/9/79] "concern about sustainability of current model for paediatric intensive care across two sites" KP Dec 2010 Report [1/8/206-207]	As above	Again, without the scores this is rather a meaningless item of 'non-compliance'. Based on the evidence it is able to provide Leeds would have been able to argue for a re-mark upwards. It seems that when KP agreed to recognise that the two PICUs were divided by a corridor

A. Witness complaint about KP assessment of Leeds	B. Communication of KP assessment during the Review	C. Was the issue addressed during the Review?	D. Claimant's response to D's submission	
Interdependent Services KP failed to appreciate the value of co-location: Darowski §§13-15 [5/8/145-147]	KP Dec 2010 Report [1/8/167, 207]	Responses to consultation: Leeds [3/1/1-3, 8]; Darowski (Paediatric Critical Care Network) [16/15/276a-c]; CHSF [3/2/34-35]; JHOSC [12/5/43-46]. KP Report October 2011 [3/4/65-68] DMBC [3/7/169]	and not located in different hospitals they did not concede that the thrust of the criticism should be withdrawn. Armed with the scores they could have pointed out that they provided consultant cover and Newcastle did not. The point here is that it was the scores that mattered in comparison to Newcastle. Leeds scored 5,5,4 to Newcastle's 4,4,3. Leeds would have been able to argue in a focussed way for a 5, re. the 400+ question, where the only relevant criticism was the panel did not feel assured that there were strong plans in place to achieve the move of patients to the network. Leeds would also have been able to point out that the differential between Leeds and Newcastle did not represent what it perceived as the gulf between the centres.	
Facilities and Capacity KP was wrong to mark Leeds down for having long waiting lists: Illingworth (2) §16(i) [5/10/166-167]	KP Dec 2010 Report "long-waiting lists not sufficiently identified as a risk [1/8/202] and "inefficiencies in current working practices" [1/8/209]	Not responded to by Leeds JHOSC response to consultation [12/5/47]	Again without the scores (Leeds in fact scored 3,3,3 to Newcastle's 4,4,4), Leeds could not mount a focussed attack on the supposed compliance deficiencies that resulted in a lower score. The issue (in the comparative	

A. Witness complaint	B. Communication of	C. Was the issue	D. Claimant's
about KP assessment	KP assessment	addressed during the	response to D's
of Leeds	during the Review	Review?	submission
			assessment between Newcastle and Leeds) was worth 14 points overall. One can see from the KP report that Newcastle had a key gap in compliance 'concerns over capacity in PICU'. Which does not appear to be reflected in its uniformly higher scores. Indeed one learns from Newcastle's self assessment template that an additional wing was required that could only be accommodated subject to funding [CB1/2/28]. As Leeds has now learnt, the KP did not assess the financial viability of these plans at all.
Leadership and Strategic Vision Score for Estates and IT was unfair: recently reconfigured services and creation of Children's Hospital showed great leadership and vision Hunter §22-26 [5/13/214]	Feedback letter [8/9/79], Dec 2010 report [1/8/201]	Leeds refer to estate reconfiguration and Children's Hospital in self-assessment Template [1/3/45] and in Response to consultation [3/1/2-3] Hunter did not submit document referred to in her w/s §21	The same point as already made above. Without the scores Leeds could not know the importance or weight attached by the Panel to the matters identified in its narrative report. The focussed comments Leeds would have been able to make are articulated by Ms Hunter. They would have allowed Leeds to submit that Leeds ought to have scored 4 rather than 3 on two or three separate aspects of the assessment.
Strength of Network	Submission	Submission made in	The points above are repeated. Without the
Differential in scores	(formulated in §7	Leeds' response to	

A. Witness complaint about KP assessment of Leeds	B. Communication of KP assessment during the Review	C. Was the issue addressed during the Review?	D. Claimant's response to D's submission
should be greater: Illingworth §§39-41 [5/10/176]; Hunter §§27- 40.3 [5/13/217-225]; Watterson (4) §§9-12 [5/9/154]	Counsel's written note 11.02.13) relies on KP Dec 2010 Report See also Note on PwC Report	consultation [3/1/7-8]; and JHOSC [17/1/17 §32]	scores, it is impossible to know what if any weight has been attached to what aspects of the identified 'compliance' or 'gaps in compliance' either in respect of Leeds in isolation, or in comparison with Newcastle. Leeds would have had a strong argument for a re-mark where Leeds only scored 4,4,3 to Newcastle's 3,4,3.
Staffing and Activity Scores not fair reflection of reality given Leeds had more staff and operating with waiting lists: Illingworth §42 [5/10/177], Hunter §42	Submission has no factual basis: centres have same staff patient ratio. See Kennedy w/s §35 [6/6/48] is a qualitative not numerical assessment KP Report Dec 2010 identified waiting lists as a risk [1/8/209]	Response to consultation compared L with N PICU [3/1/11]	Again, the point relates to the actual scores given under each heading. Armed with the scores a focussed criticism could be made that Leeds had been undervalued by the assessment panel on the basis of the objective evidence.
Facilities and Capacity Unclear why Newcastle scored so much higher than Leeds: Illingworth §42 [5/10/177]	No substantive submission is made. Sub-scores do not answer the question posed – why Newcastle scored higher		The sub-scores reveal that Leeds 3,3,3, scored lower than Newcastle 4,4,4, on each sub-question. Whether these are fair comparative scores knowing what Leeds knows about its own facilities and what it can read from the KP report about Newcastle's is precisely the sort of focussed submission Leeds would have been able to make.
Age Appropriate Care Scores do not reflect differences between the centres – Leeds children are	KP Dec 2010 report makes it clear Freeman is not an adult hospital. Hunter's repeated	Point made in Response to consultation [3/1/2-3]	Leeds scored 4,4,3, Newcastle 3,4,3. Yet Leeds children are treated in a dedicated

A. Witness complaint about KP assessment of Leeds	B. Communication of KP assessment during the Review	C. Was the issue addressed during the Review?	D. Claimant's response to D's submission
treated in a dedicated Children's hospital: Watterson §30-32 ; Hunter §44 [5/13/227]	assertion to contrary is incorrect. See Hasan (1) [5/16/249-253, 257] and (2)[5/17/297 - para 5.10: Watterson misunderstands relationship: Freeman unit operates as part of the Children's Hospital]		hospital and Newcastle is not. How Newcastle managed to score 4, to Leeds 3, on development plans is unexplained by the Kennedy narrative which says 'the panel did not deem all development plans complete as they did not demonstrate a grasp of the risks associated with sustaining the provision of age appropriate care' [CB1/8/169] Leeds would have been able to make a focussed submission for a re- mrk, and an increase from 3 to 4.
Interdependent services Score did not properly reflect the differences: notably that Leeds is a single-site hospital Illingworth (2) §41(c) [5/10/177], failed appreciate value of co- location Darowski §§14, 16, 17 [5/8/146]	KP approach to assessment of co- location in Dec 2010 report [1/8/167, 207]	Point made by many respondents to consultation eg Leeds Response [3/1/1-3, 8]; JHOSC [12/5/43-46] Darowski [16/15/276a-c] Revisited in KP Report Oct 2011 [3/44/65-68]	The points above are repeated.
Information and choices Leeds should have got a higher score on "choices" to show respect for review's patient choice agenda; Watterson §47 [5/1/20]	The PwC work on patient flow is irrelevant to this criterion. This criterion is about ensuring patients and their families have access to good information and support	CHSF made the submission in consultation that indicated networks went against principle of patient choice [3/2/37] Considered and rejected by D (decided that was consistent with principle): DMBC [3/7/110] and 4/7 meeting [3/9/281-282]	PwC is not irrelevant. It is objective evidence that undermines the assumption that the Kennedy Panel truly assessed quality. The points above apply as to focussed submissions on issues by reference to the scores. On Information and Choices Leeds scored 4,4,3, to Newcastle's 3,3,3. The real focus would have been on

A. Witness complaint	B. Communication of	C. Was the issue	D. Claimant's	
about KP assessment	KP assessment	addressed during the	response to D's	
of Leeds	during the Review	Review?	submission	
			Leeds' score of 3 on the 400+ question, particularly in the light of the very positive KP 'compliance' narrative at [CB1/8/211] and the limited area of non- compliance identified on the same page. This alone would have been worth 5 points.	

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From the Rt Hon Jeremy Hunt MP Secretary of State for Health



POC1_767604, 767305 & 767306

The Lord Bernard Ribeiro Chair Independent Reconfiguration Panel 6th Floor 157-197 Buckingham Palace Road London SW1W 9SP Richmond House 79 Whitehall London SW1A 2NS

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1 5 MAR 2013

Der Lond Liseins

"SAFE AND SUSTAINABLE REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES" – IRP REVIEW

I have always made it clear that the deadline for the Panel reporting back to me would be subject to further instruction as necessary in reflecting judicial review proceedings brought against the Joint Committee of Primary Care Trusts by Save Our Surgery Limited.

Given the recent decision by the Court to award in favour of Save Our Surgery Limited, I am today asking the Panel to report to me no later than 30 April 2013. Extending the deadline will allow the Panel and others to take account of the Judge's decision on redress, which we understand will be set down on 27 March 2013 and allow them to consider what implications this may have in moving forward.

Extending the deadline will allow the Panel and others to take account of the Judge's decision on redress on 27 March 2013 and to consider what implications this may have in moving forward.

I look forward to hearing from you.

Jen

JEREMY HUNT

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Report author: Steven Courtney Tel: 24 74707

Report of the Head of Scrutiny and Member Development

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

Date: 10 April 2013

Subject: Review of Children's Congenital Heart Services in England: Implementation Update

Are specific electoral Wards affected?	🗌 Yes	🖂 No		
If relevant, name(s) of Ward(s):				
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?	🗌 Yes	🖂 No		
If relevant, Access to Information Procedure Rule number: Not applicable				
Appendix number: Not applicable				

Summary of main issues

- Following the review of Children's Congenital Cardiac Services in England, at its meeting on 4 July 2012, the Joint Committee of Primary Care Trusts (JCPCT) agreed consultation Option B for implementation. The JCPCT also agreed the designation of congenital heart networks led by the following surgical centres:
 - Newcastle upon Tyne Hospitals NHS Foundation Trust
 - Alder Hey Children's Hospital NHS Foundation Trust
 - Birmingham Children's Hospital NHS Foundation Trust
 - University Hospitals of Bristol NHS Foundation Trust
 - Southampton University Hospitals NHS Foundation Trust
 - Great Ormond Street Hospital for Children NHS Foundation Trust
 - Guy's and St. Thomas' NHS Foundation Trust
- 2. At its meeting on 24 July 2012, the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (Joint HOSC) agreed to amend its Terms of Reference to cover the implementation stage of the review.
- 3. At its meeting on 16 November 2012, the JHOSC considered Safe and Sustainable Children's Congenital Heart Services: Implementation Plan during 2012/13 and Transfer into the NHS Commissioning Board for April 2013 (August 2012) and membership details of the Implementation Advisory Group (September 2012). At that meeting, the JHOSC agreed to consider regular updates and issues associated with the implementation phase of the review.

4. The purpose of this report is to provide an update associated with the implementation phase of the review.

Recommendations

5. That the JHOSC considers the information presented and determines any appropriate actions and/or scrutiny activity at this stage.

1.0 **Purpose of this report**

1.1 The purpose of this report is to provide an update associated with the implementation phase of the review of Children's Congenital Cardiac Services in England.

2.0 Background information

- 2.1 Following the review of Children's Congenital Cardiac Services in England, at its meeting on 4 July 2012, the Joint Committee of Primary Care Trusts (JCPCT) agreed consultation Option B for implementation. The JCPCT also agreed the designation of congenital heart networks led by the following surgical centres:
 - Newcastle upon Tyne Hospitals NHS Foundation Trust
 - Alder Hey Children's Hospital NHS Foundation Trust
 - Birmingham Children's Hospital NHS Foundation Trust
 - University Hospitals of Bristol NHS Foundation Trust
 - Southampton University Hospitals NHS Foundation Trust
 - Great Ormond Street Hospital for Children NHS Foundation Trust
 - Guy's and St. Thomas' NHS Foundation Trust

3.0 Main issues

- 3.1 At its meeting on 24 July 2012, the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (Joint HOSC) agreed to amend its Terms of Reference to cover the implementation phase of the Review of Children's Congenital Cardiac Services in England.
- 3.2 At its meeting on 16 November 2012, the JHOSC considered *Safe and Sustainable* Children's Congenital Heart Services: Implementation Plan during 2012/13 and Transfer into the NHS Commissioning Board for April 2013 (August 2012) and membership details of the Implementation Advisory Group (September 2012). At that meeting, the JHOSC agreed to consider regular updates and issues associated with the implementation phase of the review.
- 3.3 At its meeting in November 2012, the JHOSC also raised concerns regarding the membership of the Implementation Advisory Group (i.e. in particular, concern regarding the lack of representation from Yorkshire and the Humber on that body). The JHOSC agreed that such concerns be raised with the appropriate bodies and/or representatives.
- 3.4 Attached at Annex 1 is a report provided by the Programme Implementation Director that describes the arrangements that have been put in place to support the planning and preparation for implementation.
- 3.5 The report outlines that the work of the Programme Board has been solely focussed on planning and preparation: no changes to services have or will be made until the appropriate time.
- 3.6 In addition, the report also provides the following information:
 - An explanation of future governance and lead responsibilities under the new NHS structures. This may be found in section 2.

- Details on membership of the Clinical Implementation Advisory Group (CIAG). This may be found in section 3 and appendix 1. Information on CIAG's subgroups may be found in sections 3.1 and 3.2 and appendices 2 and 3.
- An outline of engagement activity, which may be found in section 4 and an update on progress, which may be found in section 5.
- 3.7 A copy of the most recent newsletter (Heartnews: February 2013) is attached at Annex 2.
- 3.8 Appropriate NHS representatives will be in attendance at the meeting.

4.0 Corporate Considerations

4.1 Consultation and Engagement

4.1.1 There are no specific considerations relevant to this report.

4.2 Equality and Diversity / Cohesion and Integration

- 4.2.1 When agreeing consultation Option B for implementation, the JCPCT had regard to the Health Impact Assessment (June 2012) report produced by Mott McDonald.
- 4.2.2 The Health Impact Assessment (HIA) report identified the following as vulnerable groups:
 - Children (under 16s)* who are the primary recipient of the services under review and, therefore, most sensitive to service changes;
 - People who experience socio-economic deprivation;
 - People from Asian ethnic groups, particularly those with an Indian, Pakistani, Bangladeshi and other Indian subcontinent heritage;
 - Mothers who smoke during pregnancy; and
 - Mothers who are obese during pregnancy;

These are defined as vulnerable groups because they are more likely to need the services under review and, are most likely to experience disproportionate impacts.

4.2.3 Prior to finalising its initial report in October 2011, and in order to have a better understanding of the extent (number) of vulnerable groups across Yorkshire and the Humber, the Joint HOSC requested a detailed breakdown of the information detailed in the interim HIA report. This information has not been provided.

4.3 Council Policies and City Priorities

4.3.1 There are no specific considerations relevant to this report.

4.4 Resources and Value for Money

4.4.1 There are no specific considerations relevant to this report.

4.5 Legal Implications, Access to Information and Call In

4.5.1 This report does not contain any exempt or confidential information.

4.6 Risk Management

4.6.1 There are no specific considerations relevant to this report.

5.0 Conclusions

5.1 The attached report provides members of the JHOSC with an update associated with the implementation phase of the Review of Children's Congenital Cardiac Services in England.

6.0 Recommendations

6.1 That the JHOSC considers the information presented and determines any appropriate actions and/or scrutiny activity at this stage.

7.0 Background documents¹

Children's Congenital Heart Services Programme Board – minutes from meetings:

- 7 November 2012
- 6 December 2012
- 23 January 2013

Safe and Sustainable Networks Group – minutes from meetings:

- 9 November 2012
- 11 December 2012
- 15 January 2013

Clinical Implementation Advisory Group – minutes from meetings:

- 18 September 2012
- 28 November 2012

¹ The background documents listed in this section are available to download from the Council's website, unless they contain confidential or exempt information. The list of background documents does not include published works.

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Yorkshire and Humber JHOSC Update on planning and preparation for implementation

1. Introduction

In July 2012, a joint committee of Primary Care Trusts (JCPCT), by virtue of delegated powers of decision making, made a decision on the future configuration of children's congenital heart services in England.

Since that decision, initial planning and preparation for implementation has been coordinated nationally by an implementation programme board supported by a clinical advisory group, on behalf of NHS specialised commissioners. From April 2013, responsibility for commissioning the services will transfer to the NHS Commissioning Board. The JCPCT decision has been subject to challenge by judicial review and referral to the Secretary of State (who has asked the Independent Reconfiguration Panel to advise). Pending those decisions the programme board has continued to prepare and plan for implementation. This is in line with the expectations of the courts and the Secretary of State which expect appropriate planning and preparation for implementation to proceed but that any changes made should be limited to those that are reversible.

This paper describes the arrangements that have been put in place to support the planning and preparation for implementation. It is important to note from the outset that the work of the programme board has been solely focussed on planning and preparation: no changes to services have or will be made until the appropriate time.

2. Programme organisation

On April 1st 2013, there will be significant changes to the NHS with the abolition of Strategic Health Authorities and Primary Care Trusts and the creation of many new organisations including the NHS Commissioning Board (NHSCB) and Clinical Commissioning Groups. From this date the children's congenital heart services implementation programme will transfer to the NHSCB. Although established under the old NHS arrangements the children's congenital heart services implementation programme already has a good level of integration with the new systems and structures, particularly with the NHS Commissioning Board.

The programme sponsor is Ann Sutton, Director of NHS Commissioning (Corporate), NHSCB.

The Senior Responsible Owner (SRO) is Caroline Taylor, currently Chief Executive, NHS North Central London. The SRO chairs the programme board and is accountable to the sponsor for delivery of the programme.

The clinical lead for the programme is Professor Deirdre Kelly, Professor of Paediatric Hepatology, Birmingham Children's Hospital NHS Foundation Trust. The



clinical lead chairs the Clinical Implementation Advisory Group. The role of the clinical lead is to:

Specialised Services

- Provide clinical leadership to the programme.
- Provide clinical advice and guidance to the programme manager and SRO.
- Represent the views of the CIAG at the Programme Board.
- Establish and maintain effective mechanisms for clinical engagement throughout the programme, in particular linking with Royal Colleges and other professional and expert bodies, national and regional NHS leaders and provider clinicians.
- Lead the development of quality standards and take an active role in developing other programme deliverables.

A programme board has been established, chaired by Caroline Taylor, to provide assurance to the NHSCB and DH regarding achievement of implementation milestones and sustainability of services during the implementation phase(s). The programme board meets monthly. Its role is to:

- Take overall responsibility for the programme
- Approve the:
 - Programme initiation document
 - Programme plan and milestones
 - o Communications and engagement plan
 - Benefits realisation plan
 - Plan for evaluation
- Agree significant variations to the programme plan
- Monitor and manage programme progress
- Own risks and issues and steers approach to mitigation / resolution
- Provide visible leadership, direction and commitment to the programme, promoting effective communication of the programme's goals and progress
- Ensure availability of essential programme resources
- Ensure resolution of any escalated issues
- Report to programme sponsor

The Programme Board will continue to steer the programme under the new NHS structures. Its reporting lines (as shown above) are already embedded in the new structures.

The terms of reference of the programme board are attached as appendix 4. As with all programme materials, these terms of reference reflect the original JCPCT decision and will be subject to full review and amendment following the conclusion of the challenge processes.

The board has met on five occasions. Confirmed minutes for the first three meetings have been made available with this briefing.



3. Clinical Implementation Advisory Group (CIAG)

Specialised Services

The role of the clinical implementation advisory group is to:

- Advise the programme board on the clinical aspects of the programme
- Ensure that the programme achieves the best clinical outcome for patients
- Lead and advise its sub-groups in the development of the programme deliverables
- Approve deliverables produced by the sub-groups
- Act as clinical advocates for the programme

Advice on constituent membership of the CIAG was initially sought from the professional associations via the former *Safe and Sustainable* Steering Group in February 2012. A draft proposal for constituent membership was worked up by the secretariat, taking advice from the Steering Group, for presentation to Professor Deirdre Kelly (Chair of CIAG) in July 2012. Professor Kelly asked the professional associations to nominate their own members to the group, being mindful that members on the group represent their associations, not their employing Trust. The implementation advisory group reviewed membership at its first meeting in September 2012.

The terms of reference of the CIAG are attached as appendix 1. As with all programme materials, these terms of reference reflect the original JCPCT decision and will be subject to full review and any necessary amendment following the conclusion of the challenge processes.

The group has met on three occasions. Confirmed minutes for the first two meetings have been made available with this briefing..

The Clinical Implementation Advisory Group has established two sub-groups. The focus of these groups is drawn from the summary of issues to be addressed during implementation presented to the JCPCT as part of the decision making business case.

3.1 The Networks Sub-Group

The purpose of the Networks Sub-Group is to describe what must be done by NHS commissioners and NHS Trusts to enable network boards to:

- provide clear leadership
- ensure a coordinated pathway from prenatal suspected diagnosis through infancy, childhood and transition into adult services
- be responsible for the performance of member organisations

The terms of reference of the Networks Sub-Group are attached as appendix 2. As with all programme materials, these terms of reference reflect the original JCPCT



decision and will be subject to full review and any necessary **Specialised Services** amendment following the conclusion of the challenge processes.

The group has met on four occasions. Confirmed minutes for the first three meetings have been made available with this briefing. Progress is described in section 5 below.

3.2 The Standards Sub-Group

The purpose of the Standards Sub-Group is:

- To describe generic referral pathways for children with suspected congenital heart disease
- To describe the core services offered by:
 - District Children's Cardiology Services (DCCS)
 - Children's Cardiology Centres (CCC)
- To develop standards for cardiology services, building on the Safe and Sustainable standards across all settings including Specialist Surgical Centres, Children's Cardiology Centres and District Children's Cardiology Services.
- To advise commissioners on the development of processes of selfassessment and peer review of services against the standards.

The draft terms of reference of the Standards Sub-Group are attached as appendix 3. Please note that these are draft and therefore may be subject to further change. As with all programme materials, these terms of reference reflect the original JCPCT decision and will be subject to full review and any necessary amendment following the conclusion of the challenge processes.

The group has met on two occasions.

4 Stakeholder Engagement

The programme board recently considered proposals for its communication and engagement strategy. It considered that while good levels of engagement were being achieved in the programme's work, more needed to be done to improve the flow of communications. Once implemented, the strategy will address this, ensuring that all stakeholders have access to information through a variety of channels.

So far workshops have been held with clinicians (September 2012), charities (September 2012), provider organisations (October 2012), nurses (January 2013), Commissioners (December 2012 and March 2013).

The NHS Commissioning Board has developed, with the support and input of lead clinicians and patient and public representatives, a new national specification for children's congenital heart disease. This incorporates the Safe and Sustainable standards. Following initial engagement, the NHS Commissioning Board consulted



on the specification in December 2012¹ to test it further with more stakeholders, to ensure all needs and considerations have been taken into account.

Specialised Services

The latest edition of the children's congenital heart services programme's newsletter was published in February 2013². A copy is provided with this briefing for ease of reference.

Representatives of service users are members of the programme board and CIAG and have been invited to join the standards sub-group.

The programme board has been mindful of respecting the processes underway that challenge the JCPCT's decision. Only limited information has therefore been placed in the public domain. As part of this measured approach, the programme board recently sought the views of clinicians and provider organisations on the emerging programme plan. The plan has not been published at this stage as it is still in development, but the programme board would be happy to share the draft plan with the JHOSC. In preparing the plan particular attention was paid to ensuring that there was clarity about what could and should appropriately be done before the challenges were resolved and what needed to wait for resolution. The plan will be subject to full review once the challenges are fully resolved to take account of whatever changes are necessary as a result.

5. Progress

Defining the networks: a sub-group working on behalf of the Clinical Implementation Advisory Group (CIAG) has developed a specification for children's congenital heart networks (CCHNs). The group's work took account of the Commissioning Board's recent guidance on developing operational delivery networks (ODNs) which refers to the need to develop children's congenital heart networks as ODNs. This specification, developed by clinicians from across the country, was used by the Commissioning Board as the basis for its network specification. This makes it possible for CCHNs to access CQUIN (Commissioning for Quality and Innovation) funding set aside for the development of ODNs.

Informal feedback on the new national specification for children's congenital heart disease suggests that the response was generally positive. The NHS Commissioning Board will publish a full response in spring 2013 after working through all the comments. The specification incorporates the Safe and Sustainable standards. Recognising that not all of the standards will be met straight away, the draft specification states that:

'In 2013/14 each centre will be expected to work with their area team to undertake a baseline assessment of that unit's position against the standards, and to develop an agreed, timetabled action plan for achieving the standards.

During 2013/14 each centre is expected to:

¹ https://www.engage.commissioningboard.nhs.uk/consultation/ssc-area-e

² Available from: <u>http://www.specialisedservices.nhs.uk/document/stakeholder-newsletters-cardiac</u>



- Support the development of a regional implementation plan, **Specialised Services** including joint monitoring mechanisms to give confidence that standards and safety are maintained throughout the period of transition;
- Ensure that other services for children and adults are not adversely affected by plans to reconfigure children's congenital heart services;
- Communicate consistently with families, staff and referrers, and actively seek their involvement as implementation plans are developed;
- Ensure that staff facing change and uncertainty feel valued and protected and understand that their skills and expertise will continue to be needed by the children's congenital heart networks;
- Work collaboratively with other centres to maintain a good outcome overall.'

CIAG's standards sub-group will further develop standards for cardiology services, particularly within Children's Cardiology Centres and District Children's Cardiology Centres.

Staffing remains a key issue. A baseline assessment is planned in the next few months to inform the programme's thinking about the scale and nature of the workforce challenge.

The national specialised commissioning team is undertaking a wider review of paediatric ECMO (Extra Corporeal Membrane Oxygenation) services, with the full support of the professional associations. The aim is to agree a common specification and standard for the national service. The review is considering both cardiac and respiratory ECMO as well as the current and future arrangements for ECMO retrieval. The aim is to reflect the revised service specification in contracts for 2013/14.

The programme has taken steps to ensure that it has good links with work underway within the Commissioning Board around paediatric intensive care (PIC) and paediatric transport and retrieval services. The service specifications for both PIC and retrieval have been published for consultation. Once implemented these will lead to consistent high quality services being commissioned across the country.

6. Conclusion

The work of the implementation programme described above has so far been focussed on planning and preparation, recognising the challenges to the JCPCT's decision. Despite the provisional nature of the work, important progress has been made in understanding how children's congenital heart networks would function. The work to develop additional cardiology standards is considered to be similarly important. The programme has placed high importance on clinical leadership and has enjoyed strong clinical support. Representatives of service users have been involved at the heart of the programme's decision making, and the programme is continuing to explore ways to improve user engagement.

The programme board recognises the need to take stock following the conclusion of the challenge processes. The NHS remains determined to improve services for children with congenital heart disease, and would welcome input from the JHOSC to help shape its thinking, especially in understanding what matters to patients and their families and in improving user engagement.



Appendix 1

Children's Congenital Heart Services, Phase 2, Implementation Clinical Implementation Advisory Group Terms of Reference

Note: As with all programme materials, these terms of reference reflect the original JCPCT decision and will be subject to full review and amendment following the conclusion of the challenge processes.

Introduction

A joint committee of Primary Care Trusts (JCPCT), by virtue of delegated powers of decision making, made a final decision on the future configuration of children's congenital heart services in England in July 2012. Implementation will be planned and coordinated nationally, initially on behalf of NHS specialised commissioners, and from April 2013, on behalf of the NHS Commissioning Board.

A Clinical Implementation Advisory Group has been established to advise NHS commissioners on relevant clinical issues during the period of implementation. This document sets out the Terms of Reference for this advisory group.

Programme Scope

- Improving the quality of care of children with suspected or diagnosed congenital heart disease, from the pre-natal period (including care of women whose unborn child has suspected or confirmed congenital heart disease), through infancy, childhood and through transition to transfer into adult services
- Establishing seven children's congenital heart networks that cover the whole population of England and Wales
- Developing standards for Children's Cardiology Centres and District Children's Cardiology Services and commissioning these services as required in each network
- Ensuring the application of quality standards covering network working and the whole care pathway from prenatal screening and services through transition to transfer to adult services
- Commissioning of heart surgical services for children, that meet the specified quality standards, from the seven designated providers
- Decommissioning of heart surgical services for children from the four providers that were not designated
- Implementing new systems to improve the collection, analysis and reporting of outcome data
- Designating Birmingham Children's Hospital NHS Foundation Trust as a nationally commissioned provider of extracorporeal membrane oxygenation (ECMO) services for children with respiratory failure in place of the unit at University Hospitals of Leicester NHS Trust



The programme initiation document (PID) gives full details of programme scope (including what is not in scope), dependencies and linkages.

Specialised Services

Programme Objectives

To ensure that:

- Excellent care with a focus on the child and their family will be achieved by developing standards of care for the whole patient pathway from the pre-natal period (including care of women whose unborn child has suspected or confirmed congenital heart disease) through infancy, childhood and through transition to transfer into adult services, implemented through commissioning and monitored and managed by the networks.
- 2. Seven managed children's congenital heart networks are established covering the whole population of England, each with a specialist surgical centre.
- 3. The new model of care including local and regional cardiology services for children with congenital heart disease and a reduced number of specialist surgical centres is established.
- Nationally commissioned ECMO services for children with respiratory failure are provided by Birmingham Children's Hospital NHS Foundation Trust in place of University Hospitals of Leicester NHS Trust.
- 5. Transition to the new system is managed safely and efficiently, and in such a way as to realise the benefits described in the PID, and clinical interdependencies and linkages are managed.

Purpose

The clinical implementation advisory group will:

- Advise the programme board on the clinical aspects of the programme
- Ensure that the programme achieves the best clinical outcome for patients
- Lead and advise its sub-groups in the development of the programme deliverables
- Approve deliverables produced by the sub-groups
- Act as clinical advocates for the programme

Deliverables

- Advice to NHS commissioners that will inform the updating of the implementation plans over the period of implementation, responding to the various challenges and opportunities of implementation and the management of risk
- Advice on the establishment of Children's Congenital Heart Networks including proposed role, governance arrangements including outline terms of reference,



membership and relationships and outline job descriptions and **Specialised Services** person specifications for key network roles

- Advice on implementing referral pathways that accord with the agreed model of care, and the alignment of the Children's Congenital Heart Networks with other clinical networks (including adult congenital heart networks)
- Guidance on the use of telemedicine
- Quality standards for Children's Cardiology Centres and District Children's Cardiology Services that are endorsed by key stakeholders
- Developing a commissioner led long-term peer review process for the Children's Congenital Heart Networks
- Advice on establishing precise network boundaries having regard for patient flows from referring hospitals and the operation of patient choice
- Advice on the clinical workforce and training implications of the changes
- Service specifications for relevant services in the congenital heart networks (that are not developed by a formal Clinical Reference Group)
- Advice on the impact of the changes on inter-dependent clinical services, including paediatric intensive care services, neonatal surgery, retrieval services and nationally commissioned services
- Advice on safe service planning for rare and complex congenital heart procedures
- Recommendations for improving the reporting of outcome data, taking account of the work of NICOR and the clinical reference group
- Recommendations on evaluation of the changes
- Advice on managing the impact of the changes on potentially vulnerable groups and mitigations
- Advice on communication and engagement with clinical and organisational stakeholders
- Exceptional reports, as required, to NHS commissioners and key stakeholders that provide advice on significant implementation issues

Membership

All members of the Clinical Implementation Advisory Group are required to declare any professional or personal interests which may affect their contributions. These interests should be declared to the Clinical Implementation Advisory Group Chair and reviewed as and when they occur.

The group will be chaired by Professor Deirdre Kelly, clinical lead for the programme.



Specialised Services

Member	Representing	Role
Professor Deirdre Kelly	Chair	Professor of Paediatric Hepatology, Birmingham Children's Hospital NHS Foundation Trust
Dr Alan McGee	British Congenital Cardiac Association	Consultant Paediatric Cardiologist, Royal Brompton & Harefield NHS Foundation Trust
Anne Keatley-Clarke	Children's Heart Federation	Chief Executive, Children's Heart Federation
Professor Basky Thilaganathan	Royal College of Obstetrics and Gynaecology	Professor of Fetal Medicine, St George's Healthcare NHS Trust
Mr Carl Davis	ECMO representative	Consultant Paediatric and Neonatology Surgeon, The Royal Hospital for Sick Children, Glasgow
Mr David Barron	Society for Cardiothoracic Surgery of Great Britain and Ireland	Consultant Congenital Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust
Dr David Mabin	Royal College of Paediatrics and Child Health	Consultant Paediatrician with Expertise in Cardiology, Royal Devon & Exeter NHS Foundation Trust
Dr Dirk Wilson	Wales	Consultant Paediatric Cardiologist, Cardiff and Vale University Health Board
Donna Kirwan	Fetal Anomaly Screening Programme	National Projects Officer, NHS FASP
Elizabeth Aryeetey	Royal College of Nursing	Lead Nurse, East Midlands Congenital Heart Centre, University Hospitals of Leicester NHS Trust
Fiona Smith	Royal College of Nursing	Adviser in Children and Young People's Nursing, Royal College of Nursing
Gail Fortes-Mayer	NHS specialised commissioning, Clinical Reference Group	Assistant Director, Specialised Commissioning, Midlands and East
Dr Graham Stuart	Chair, Congenital Heart Services Clinical Reference	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust



Specialised Services

		Specialised			
	Group				
Dr lan Jenkins	Paediatric Intensive Care Society	Consultant in Paediatric Intensive Care & Anaesthesia, University Hospitals of Bristol NHS Foundation Trust			
Jeremy Glyde	Safe and Sustainable	Programme Director, Safe and Sustainable, NHSCE			
Jo Sheehan	NHS specialised commissioning	Acting Director of National Specialised Commissioning Team			
Mr Leslie Hamilton	Society for Cardiothoracic Surgery of Great Britain and Ireland (Past President)	Consultant Cardiac Surgeon and former Deputy Chair of Safe and Sustainable Steering Group, Newcastle-upon-Tyne Hospitals NHS Foundation Trust			
Michael Cumper	Somerville Foundation	Chairman, Somerville Foundation			
Michael Wilson	NHS specialised commissioning	Interim Implementation Programme Director			
Dr Peter-Marc Fortune	Paediatric Intensive Care Society	Consultant Paediatric Intensivist and Associate Clinical Head, Royal Manchester Children's Hospi			
Dr Ravi Gill	Association of Cardiothoracic Anaesthetists	Consultant in Cardiac Anaesthesia and Intensive Care Medicine, Southampton University Hospitals NHS Foundation Trust			
Dr Rob Martin	British Congenital Cardiac Association (President Elect)	Consultant in Paediatric and Adult Congenital Cardiology, University Hospitals of Bristol NHS Foundation Trust			
Dr Sara O'Curry	British Psychological Society	Consultant Clinical Psychologist specialising in Paediatric Cardiology, Great Ormond Street Hospital for Children NHS Foundation Trust			
Dr Tony Salmon	British Congenital Cardiac Association (President)	Consultant in Paediatric and Adult Congenital Cardiology, Southampton University Hospitals NHS Foundation Trust			
Dr Venu Gopalan	Royal College of Paediatrics and Child Health	Hon Secretary of Paediatricians with Expertise in Cardiology Special Interest Group			





Specialised Services

Dr Vimal Tiwari	Royal College of General Practitioners	General Practitioner
Observers		
Kathy Collins	The NHS in Scotland	Nursing and Quality Adviser, NHS National Services Scotland
Dr Miriam McCarthy	The NHS in Northern Ireland	Deputy Secretary for Healthcare Policy, DHSSPS

Individuals may also be invited as members, or co-opted for specific meetings, at the discretion of the Chair if it is considered that they will contribute specific expertise.

Sub-Groups

Much of CIAG's work will be delivered by sub-groups. These will report into the CIAG. The chair of each sub-group will be a member of CIAG, but the membership of sub-groups may be drawn from beyond CIAG's membership by agreement with the CIAG chair. Initially four groups will be established:

- Children's Congenital Heart Networks sub-group
- Standards sub-group (inc. Children's Cardiology Centres & District Children's Cardiology Services)
- Clinical Outcomes sub-group
- Specialist Surgical Centres sub-group

Chairs of sub-groups are responsible for representing the opinions of that group to the clinical implementation advisory group.

Formal terms of reference will be developed for each of these groups.

Linkages

CIAG will also establish a relationship to other key clinical groups.

The linkage with the **Paediatric Transport Group** established under the auspices of the National Specialised Commissioning Team will be managed by shared membership between CIAG and the Transport Group.

The linkage with the separate **review of adults with congenital heart disease** will be managed through shared membership between CIAG and the Advisory Group on Adults with Congenital Heart Disease, including the President of the British Congenital Cardiac Association, the Director of National Specialised Commissioning,



the Chair of the Somerville Foundation and the Chief Executive of **Specialised Services** Children's Heart Federation.

The linkage with the **Clinical Reference Group for Congenital Heart Services** will be managed through Dr Graham Stuart who chairs the CRG and is a member of CIAG, in addition to other senior representatives of the relevant professional associations who are expected to sit on both groups (such as the President of the British Congenital Cardiac Association).

Executive Group

An executive group of CIAG will provide day to day oversight of the group's programme of work, including that of its sub-groups. This is an executive and not a decision making group, working to the agenda established by the programme board and CIAG. The group meets monthly, as well as maintaining more frequent contact as necessary by email and through conference calls. The membership of the group is:

Member	Role	Position
Professor Deirdre Kelly Chair	Chair of the Clinical Implementation Advisory Group	Professor of Paediatric Hepatology, Birmingham Children's Hospital NHS Foundation Trust
Dr Andy Mitchell	Special Adviser	Medical Director, NHSCB, London Region
Ann Jarvis	Chair, Children's Congenital Heart Networks sub-group	Acute Portfolio Director (Specialised Commissioning), Medical Directorate, NHSCB
Mr David Barron	Chair, Specialist Surgical Centres Sub-group	Consultant Congenital Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust
Dr Graham Stuart	Chair, Clinical Reference Group for Congenital Heart Services	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust
Dr lan Jenkins	Member of the Paediatric Transport Group (alternating with Dr Peter-Marc Fortune)	Consultant in Paediatric Intensive Care and Anaesthesia, University Hospitals of Bristol NHS Foundation Trust
Michael Wilson	Children's Congenital Heart Services Interim Implementation Programme Director	NHS Specialised Commissioning



Specialised Services

Dr Peter-Marc Fortune	Member of the Paediatric Transport Group (alternating with Dr Ian Jenkins)	Consultant Paediatric Intensivist and Clinical Director of Critical Care, Central Manchester University Hospitals NHS Foundation Trust
Dr Tony Salmon	Chair, Standards sub-group Member of review of adults with congenital heart disease	Consultant in Paediatric and Adult Congenital Cardiology, Southampton University Hospitals NHS Foundation Trust
TBC	Chair, Clinical Outcomes Sub- group	

Accountability

The Clinical Implementation Advisory Group is accountable to the Children's Congenital Heart Services Programme Board.

Conduct of Meetings

The group will meet quarterly. The frequency of meetings will depend on progress made in between meetings and some work may be carried out via email and correspondence.

Quorum is ten members including the Chair.

Support

Given the significant commitment required, sessional payments will be made available to the employing organisations of Chairs of CIAG subgroups to support backfill.

Both CIAG and its sub-groups will be supported by the programme team. This support will include support to chairs in preparing agendas, minute taking, venue booking and the development of working papers for groups.





Children's Congenital Heart Services, Phase 2, Implementation

Children's Congenital Heart Services Networks sub-group Terms of Reference

Note: As with all programme materials, these terms of reference reflect the original JCPCT decision and will be subject to full review and amendment following the conclusion of the challenge processes.

Introduction

A joint committee of Primary Care Trusts (JCPCT), by virtue of delegated powers of decision making, made a final decision on the future configuration of children's congenital heart services in England in July 2012. Implementation will be planned and coordinated nationally, initially on behalf of NHS specialised commissioners, and from April 2013, on behalf of the NHS Commissioning Board.

A Clinical Implementation Advisory Group has been established to advise NHS commissioners on relevant clinical issues during the period of implementation, a subgroup of which, the Networks sub-group has also been established.

This document sets out the Terms of Reference for the Networks sub-group.

Programme Scope

- Improving the quality of care of children with suspected or diagnosed congenital heart disease, from the pre-natal period (including care of women whose unborn child has suspected or confirmed congenital heart disease), through infancy, childhood and through transition to transfer into adult services
- Establishing seven children's congenital heart networks that cover the whole population of England and Wales
- Developing standards for Children's Cardiology Centres and District Children's Cardiology Services and commissioning these services as required in each network
- Ensuring the application of quality standards covering network working and the whole care pathway from prenatal screening and services through transition to transfer to adult services
- Commissioning of heart surgical services for children, that meet the specified quality standards, from the seven designated providers
- Decommissioning of heart surgical services for children from the four providers that were not designated
- Implementing new systems to improve the collection, analysis and reporting of outcome data
- Designating Birmingham Children's Hospital NHS Foundation Trust as a nationally commissioned provider of extracorporeal membrane



Specialised Services

oxygenation (ECMO) services for children with respiratory failure in place of the unit at University Hospitals of Leicester NHS Trust

fLeicester

The programme initiation document (PID) gives full details of programme scope (including what is not in scope), dependencies and linkages.

Programme Objectives

To ensure that:

- 1. Excellent care with a focus on the child and their family will be achieved by developing standards of care for the whole patient pathway from the pre-natal period (including care of women whose unborn child has suspected or confirmed congenital heart disease) through infancy, childhood and through transition to transfer into adult services, implemented through commissioning and monitored and managed by the networks.
- 2. Seven managed children's congenital heart networks are established covering the whole population of England, each with a specialist surgical centre.
- 3. The new model of care including local and regional cardiology services for children with congenital heart disease and a reduced number of specialist surgical centres is established.
- Nationally commissioned ECMO services for children with respiratory failure are provided by Birmingham Children's Hospital NHS Foundation Trust in place of University Hospitals of Leicester NHS Trust.
- 5. Transition to the new system is managed safely and efficiently, and in such a way as to realise the benefits described in the PID, and clinical interdependencies and linkages are managed.

Purpose

The Networks subgroup will describe what must be done by NHS commissioners and NHS Trusts to enable network boards to:

- provide clear leadership
- ensure a coordinated pathway from prenatal suspected diagnosis through infancy, childhood and transition into adult services
- be responsible for the performance of member organisations

The Networks sub-group will make reference to the following headings:

- Governance
- Accountability
- Critical leadership roles
- Patient pathway and clinical protocols



• Competencies and training requirements

Specialised Services

- Relationship with other paediatric and neonatal services, and other networks
- Stakeholder involvement in the networks

Deliverables

The Networks Subgroup will provide:

- A written report for consideration by the Clinical Implementation Advisory Group
- An illustrated description of the patient pathway from a child's / mother's perspective

Membership

All members of the Networks sub-group are required to declare any professional or personal interests which may affect their contributions. These interests should be declared to chair of the Networks sub-group and reviewed as and when they occur.

The group will be chaired by Ann Jarvis.

Member	Representing	Role
Ann Jarvis	Chair (From 15 th January 2013, previously Prof Deirdre Kelly)	Acute Portfolio Director (Specialised Commissioning),Medical Directorate, NHSCB
Alison Sims (From 25.02.13)	South of England Paediatric Strategic Partnership	Network Manager
Angie Johnson	RCN	Matron, Paediatric Cardiothoracic Services, Freeman Hospital, The Newcastle upon Tyne Hospitals NHS Foundation Trust
Anne Keatley-Clarke	Service users	Chief Executive, Children's Heart Federation
Dr Ari Kannivelu	Paediatricians with Expertise in Cardiology Special Interest Group	Consultant Paediatrician (Cardiology) at The Shrewsbury and Telford Hospital NHS Trust
Prof. Basky Thilaganathan	Royal College of Obstetrics and Gynaecology	Professor of Fetal Medicine, St George's Healthcare NHS Trust
Dr Graham Stuart	Chair, Congenital Heart Services Clinical Reference Group	Consultant Cardiologist, University Hospitals of Bristol NHS Foundation Trust



Specialised Services

Jeremy Glyde	Safe and Sustainable	Programme Director, Safe and Sustainable National Specialised Commissioning Team		
Mr Leslie Hamilton	Society for Cardiothoracic Surgery of Great Britain and Ireland (Past President)	Consultant Cardiac Surgeon and former Deputy Chair of Safe and Sustainable Steering Group, Newcastle-upon-Tyne Hospitals NHS Foundation Trust		
Michael Wilson	NHS specialised commissioning	Interim Implementation Programme Director		
Dr Peter-Marc Fortune	Paediatric Intensive Care Society	Consultant Paediatric Intensivist and Clinical Director of Critical Care, Central Manchester University Hospitals NHS Foundation Trust		
Dr Ravi Gill	Association of Cardiothoracic Anaesthetists	Consultant in Cardiac Anaesthesia and Intensive Care Medicine, Southampton University Hospitals NHS Foundation Trust		
Dr Rob Martin	British Congenital Cardiac Association (President Elect)	Consultant in Paediatric and Adult Congenital Cardiology, University Hospitals of Bristol NHS Foundation Trust		
Dr Sara O'Curry	British Psychological Society	Consultant Clinical Psychologist specialising in Paediatric Cardiology, Great Ormond Street Hospital for Children NHS Foundation Trust		
Dr Tony Salmon	British Congenital Cardiac Association (President)	Consultant in Paediatric and Adult Congenital Cardiology, Southampton University Hospitals NHS Foundation Trust		

Individuals may also be invited as members, or co-opted for specific meetings, at the discretion of the Chair if it is considered that they will contribute specific expertise.

Accountability

The group is established as a sub-group of the Clinical Implementation Advisory Group. The Clinical Implementation Advisory Group reports to the Programme Board.

Conduct of Meetings

The group will meet on a monthly basis.

Quorum is seven members including the Chair.

Support



The Networks sub-group will be supported by the programme **Specialised Services** team. This support will include support to chairs in preparing agendas, minute taking, venue booking and the development of working papers for groups.



Children's Congenital Heart Services, Phase 2, Implementation Clinical Implementation Advisory Group Standards Sub-group Draft Terms of Reference

Note: As with all programme materials, these terms of reference reflect the original JCPCT decision and will be subject to full review and amendment following the conclusion of the challenge processes.

Introduction

A joint committee of Primary Care Trusts (JCPCT), by virtue of delegated powers of decision making, made a final decision on the future configuration of children's congenital heart services in England in July 2012. Implementation will be planned and coordinated nationally, initially on behalf of NHS specialised commissioners, and from April 2013, on behalf of the NHS Commissioning Board. The JCPCT decision included establishing a number of congenital heart networks in England including the development of District Children's Cardiology Services and Children's Cardiology Centres *for which standards will need to be developed*'.

This document sets out the Terms of Reference for the Clinical Implementation Advisory Group Standards Sub-group.

Programme Scope

- Improving the quality of care of children with suspected or diagnosed congenital heart disease, from the pre-natal period (including care of women whose unborn child has suspected or confirmed congenital heart disease), through infancy, childhood and through transition to transfer into adult services
- Establishing seven children's congenital heart networks that cover the whole population of England and Wales
- Developing standards for Children's Cardiology Centres and District Children's Cardiology Services and commissioning these services as required in each network
- Ensuring the application of quality standards covering network working and the whole care pathway from prenatal screening and services through transition to transfer to adult services
- Commissioning of heart surgical services for children, that meet the specified quality standards, from the seven designated providers
- Decommissioning of heart surgical services for children from the four providers that were not designated
- Implementing new systems to improve the collection, analysis and reporting of outcome data



 Designating Birmingham Children's Hospital NHS Foundation Trust as a nationally commissioned provider of extracorporeal membrane oxygenation (ECMO) services for children with respiratory failure in place of the unit at University Hospitals of Leicester NHS Trust

The programme initiation document (PID) gives full details of programme scope (including what is not in scope), dependencies and linkages.

Programme Objectives

To ensure that:

- 1. Excellent care with a focus on the child and their family will be achieved by developing standards of care for the whole patient pathway from the pre-natal period (including care of women whose unborn child has suspected or confirmed congenital heart disease) through infancy, childhood and through transition to transfer into adult services, implemented through commissioning and monitored and managed by the networks.
- 2. Seven managed children's congenital heart networks are established covering the whole population of England, each with a specialist surgical centre.
- 3. The new model of care including local and regional cardiology services for children with congenital heart disease and a reduced number of specialist surgical centres is established.
- 4. Nationally commissioned ECMO services for children with respiratory failure are provided by Birmingham Children's Hospital NHS Foundation Trust in place of University Hospitals of Leicester NHS Trust.
- 5. Transition to the new system is managed safely and efficiently, and in such a way as to realise the benefits described in the PID, and clinical interdependencies and linkages are managed.

Sub-group purpose

To describe generic referral pathways for children with suspected congenital heart disease

To describe the core service offering for:

- District Children's Cardiology Services (DCCS)
- Children's Cardiology Centres (CCC)

To develop standards for cardiology services, building on the Safe and Sustainable standards across all settings including Specialist Surgical Centres, Children's Cardiology Centres and District Children's Cardiology Services.

To advise commissioners on the development of processes of self-assessment and peer review of services against the standards.



Specialised Services

Sub-group deliverables

A paper describing the minimum service offering for DCCSs and CCCs, and referral pathways into and onwards from these services.

A document setting out standards document for cardiology services, across all settings including SSCs, CCCs and DCCSs.

A paper setting out proposals for self-assessment and peer review processes for DCCSs and CCCs.

Membership

All members of the Clinical Implementation Advisory Group Standards Sub-group are required to declare any professional or personal interests which may affect their contributions. These interests should be declared to the Clinical Implementation Advisory Group Standards Sub-group Chair and reviewed as and when they occur.

The group will be chaired by Dr Tony Salmon.

Member	Role
Dr Tony Salmon Chair	Consultant in Paediatric and Adult Congenital Cardiology, Southampton University Hospitals NHS Foundation Trust
Colette Cochran	Paediatric Cardiac Nurse Specialist, Southampton University Hospitals NHS Foundation Trust
Dr Anjum Gandhi	Consultant Paediatrician, Heart of England NHS Foundation Trust
Dr David Mabin	Consultant Paediatrician with Expertise in Cardiology, Royal Devon & Exeter NHS Foundation Trust
Dr Dirk Wilson	Consultant Paediatric Cardiologist, Cardiff and Vale University Health Board
Dr Fiona Willcoxson	Consultant in Children's Cardiology, Leeds Teaching Hospitals NHS Trust
Dr Frances Bu'Lock	Consultant Paediatric Cardiologist, University Hospitals of Leicester NHS Trust
Mr James Bruce	Consultant Paediatric Surgeon and Clinical Head, Royal Manchester Children's Hospital
Dr Ian Peart	Consultant Paediatric Cardiologist, Alder Hey Children's NHS Foundation Trust





Specialised Services

Dr James Gnanapragasam	Consultant Paediatric Cardiologist, Southampton University Hospitals NHS Foundation Trust
Dr Janet Burns	Consultant Cardiologist, NHS Lothian
Dr Milind Chaudhari	Consultant Paediatric and Adult Congenital Cardiologist, The Newcastle upon Tyne Hospitals NHS Foundation Trust
Dr Nick Archer	Consultant in Paediatric Cardiology, Oxford University Hospitals NHS Foundation Trust
Dr Owen Miller	Consultant in Paediatric & Fetal Cardiology, Guys and St Thomas' NHS Foundation Trust
Dr Rodney Franklin	Consultant and Lead Paediatric Cardiologist, Royal Brompton & Harefield NHS Foundation Trust
Dr Wilf Kelsall	Consultant Paediatric Cardiologist & Neonatologist, Cambridge University Hospitals NHS Foundation Trust
Gail Fortes-Mayer	Assistant Director, Specialised Commissioning, Midlands and East
Dr Sara O'Curry	Consultant Clinical Psychologist specialising in Paediatric Cardiology, Great Ormond Street Hospital for Children NHS Foundation Trust
Suzie Hutchinson	Chief Executive, Little Hearts Matter
Michael Wilson	Interim Implementation Programme Director

Individuals may also be invited as members, or co-opted for specific meetings, at the discretion of the Chair if it is considered that they will contribute specific expertise.

Linkages

The links between the work of the standards sub-group and the work of the other CIAG sub-groups, and other associated groups are managed through the CIAG Executive Group.

Accountability

The Clinical Implementation Advisory Group Standards Sub-group is accountable to the Children's Congenital Heart Services, Phase 2, Clinical Implementation Advisory Group.



Specialised Services

Conduct of Meetings

The group will meet on a monthly basis as well as maintaining more frequent contacts as necessary by email and through conference calls.

Quorum is eight including the Chair.

Support

The Clinical Implementation Advisory Group Standards Sub-group will be supported by the programme team. This support will include support to chairs in preparing agendas, minute taking, venue booking and the development of working papers for groups.

Safe and Sustainable

Children's congenital heart services in England

ISSUE 8 FEBRUARY 2013



Welcome

You are probably all aware of the landmark decision the NHS made last year on the future of children's heart services. The Joint Committee of Primary Care Trusts (JCPCT), the decision-making body, announced the development of seven congenital heart networks – a decision which was welcomed by professional associations, royal colleges and parent groups. It announced that these networks would provide services through partnerships between local centres and seven Specialist Surgical Centres.

Why implementing change as soon as possible is vital

"Whilst I respect the need to scrutinise the JCPCT's decision, I think it's important that we all remember why these changes were called for in the first place. Put simply, the way that children's heart services are provided is not sustainable for the future. I am a heart surgeon and am only too aware of the immense pressures that surgeons currently face. Surgical expertise has been spread too thinly for far too long. Children's heart surgeons need to work in larger teams in fewer centres - not only will this allow us to see enough patients to maintain the highest level of surgical skills but it will also make it easier to innovate and develop new life-saving techniques. Larger surgical teams will mean care around the clock, fewer cancelled operations and enough cover for emergencies. Ultimately this will improve outcomes and will help save lives."

Mr William Brawn CBE, Past President of the British Congenital Cardiac Association, Chair of the *Safe and Sustainable* Standards Working Group and member of the *Safe and Sustainable* Steering Group

Of course implementing these changes is a complex job, requiring detailed and careful planning and that is what the NHS has turned its attention to since the decision was made. That is the right thing to do, so that once the challenges to the decision have been resolved, the NHS is in the best position possible to move quickly to deliver these long planned improvements. In this newsletter you will find an update on the planning for implementation that has taken place so far as well as news on the review being carried out by the Independent Reconfiguration Panel (IRP) and the current legal challenge.

Keep up to date with the latest information on the on the websit ecialisedserv ifeandsusta

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An update on legal proceedings

The workshops identified several key issues which participants highlighted must be addressed during implementation:	 Setting standards for regional and local paediatric cardiology services Defining the networks with precision Strong leadership of the networks Staff annagement and behinned talent within 	 Consistent approaches for commissioning, Consistent approaches for commissioning, investment and governance Managing risks during the transition phase 	 Maintaining momentum Clear messages about the progress of the review Integrated care and interdependent services Working together Consistent data collection 	For more information please go to the NHS Specialised Services website. Updates on the implementation programme and	the deliberations of the Clinical Implementation Advisory Group will be available in future newsletters. Alternatively, if you wish to contact the implementation team please refer to the contact details on page six.	On 1 April 2013 the new NHS Commissioning Board (NHS CB) will assume responsibility for planning for implementation of the decision to reconfigure children's congenital heart services in England. The current Clinical Implementation Advisory Group will continue to advise the NHS CB on relevant clinical issues. The main aim of the	NHS CB is to improve health outcomes for people in England. You can learn more about the NHS CB at http://www. commissioningboard.nhs.uk
Implementation planning The process of planning for implementation is well underway and several initial workshops and meetings	nave been need with national charities, clinicans and the hospitals currently providing surgery. Clinical Implementation Advisory Group Specialist doctors and nurses will continue to play	an extremely important advisory role during the implementation phase. A Clinical Implementation Advisory Group, which is made up of senior clinicians and patient and parent representatives, has been formed and has met three times. Its role is to	Programme Expert unincal advice to the implementation Programme Board. The Group is chaired by Professor Deirdre Kelly, Professor of Paediatric Hepatology at Birmingham Childrens Hospital. A list of its members is available on the NHS Specialised Services website.	wenubers are very possive and commuted to developing patient focused, high quality networks. I have established a number of reference groups covering important issues such as networks, standards and operdiatric transport. We are all	average of the need for good communication with aware of the need for good communication with our stakeholders, patients and their families and of the importance of ensuring patient safety and the continuity of services during the transition phase."	Professor Kelly, Chair of the Clinical Implementation Advisory Group Charity workshop A number of charities including the Children's Heart Federation, Little Hearts Matter, Down's Heart Group, ARC, Max Appeal and Tiny Tickers took part in a workshop to discuss implementation issues that were raised during and since the public consultation. Workshop with clinicians and NHS managers The aleven brostrial trusts involved in the review	where invited to attend a workshop where tokew were invited to attend a workshop where NHS colleagues could work together to identify the key priorities for implementation and how best they can work together to overcome challenges on a national, regional and local level. Clinicians, hospital chief executives, other senior leaders, commissioners and members of the national implementation team attended
lanning for implementation	task for the Implementation Programme Board implement the JCPCT's decision. Its objectives to ensure:	1. Excellent care with a focus on the child and their family will be achieved by developing standards of care for the whole patient pathway from the pre-natal period	chick has suspected or confirmed congenital heart disease) through infancy, childhood and through transition to transfer into adult services, implemented through commissioning and monitored and managed by the networks.	 Seven managed chlidrens congenital heart networks are established covering the whole population of England, each with a specialist surgical centre. 	 The new model of care including local and regional cardiology services for children with congenital heart disease and a reduced number of specialist surgical centres is established. 	 Nationally commissioned ECMO services for children with respiratory failure are provided by Birmingham Children's Hospital NHS Foundation Trust in place of University Hospitals of Leicester NHS Trust. Transition to the new system is managed safely and efficiently, and in such a way as to realise the desired benefits, and clinical interdependencies and linkages are managed. 	"I'm proud to have been asked to use my experience in shaping NHS services to lead the process of planning for implementation of improvements to children's heart services. The NHS' work on stroke care is now saving up to 400 lives a year in the capital and that is the kind of transformation we can bring to NHS services. It's dinckly important that we plan not that is the kind of transformation we can bring to NHS services. It's taken place. My approach is collaboration say that children's conservice and be established as taken place. My approach is collaboration be diver a significent amount of planning has already to commisciones and when a black of bodies diverse autorosticides, patients.
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Caroline Taylor, Implementation Lead

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Support for developing networks

St., This week marked an important turning point in the future care of childrag point in the future care of childrag point in the future care of childran fragatad. We strongly believe that the decision taken by the Joint Committee of Phinary Care Transk (JCPCT) will improve children is outcomes and help is aver more children's lives in the future. Treating CHD ncluded presidents of Paediatrics and Child mproving access to access specialist care and royal colleges of The Times to express heir support for the future. A number of decision. Signatories he Royal College of **College of Surgeons** chat children's heart Cardiac Association centres would work professional bodies of England and the in partnership with ensure families can medicine wrote to announced in July local clinicians and of specialist care commissioners to **British** Congenital surgery would be pooled into seven closer to home in Health, the Royal centres and that each of those The JCPCT Page 97

for children are t new national d deliver better mes, allowing for ped to

Birmingham Children's Hospital, Great Ormond surgical Centres at Bristol Royal Hospital for Street Hospital, Evelina Children's Hospital, Children, Southampton General Hospital, with Specialist

numbers of staff are increased. Families often need ong distances to surgical centres for ongoing care appointments. Ongoing care will now be provided available closer to home - not just in some areas expert nurses and paediatricians with expertise in eating difficulties, and more families will benefit The congenital heart networks will minimise the by having access to psychologists and dietitians. cardiology as these roles are expanded and the current problem of too many families travelling Alder Hev Children's Hospital in Liverpool and support with their child's sleeping pattern and such as assessment and ongoing care will be as is currently the case but consistently across the country. Families will have access to more the Freeman Hospital in Newcastle. Services closer to home for more families.

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leart surgery will be er larger centres with d volume of cases to

pert care close The decision v

coming financial year (April 2013 to March 2014) used by the NHS Commissioning Board to set out Heart Networks that will be rolled out during the a specification for the new Children's Congenital well as advice on key leadership positions within the role, scope and membership of networks as nurses and others) has made recommendations on the way networks should work. This covers networks. These recommendations have been A working group of senior clinicians (doctors,

at we now move forward re that the process of braced with no delays. ations will help to ensure as are implemented so

TERENCE STEPHENSON Medical Royal Colleges

the future

ecutive and General r, Royal College of Nursing

believe it will create a able service that is safe



Y SALMON ht, British Congenital Cardiac / for Cardiothoracic Britain and Ireland

nt, Society in Great B

local specialist care

-ocal clinicians and

commissioners will

work in partnership

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OR NORMAN WILLIAMS t, Royal College of Surgeons

t, Royal College of cs and Child Health

The chance to give your views

Independent Reconfiguration Panel

of State. The IRP is the independent expert on NHS service change and provides advice to the Secretary 4 July 2012, which was requested by the Secretary carrying out a full review of the decision made on of State for Health on proposals for health service The Independent Reconfiguration Panel (IRP) is change in England.

Overview and Scrutiny Committee. More information on these referrals are available at www.irpanel.org.uk Committee and Yorkshire and Humber Joint Health Secretary of State from Lincolnshire County Council Health Scrutiny Committee, Leicester, Leicestershire and Rutland Joint Health and Overview Scrutinv The review was prompted by referrals to the

the current surgical centres and is due to provide its advice to the Secretary of State by 28 March 2013. IRP to explain the rationale for the decision and to will assist the IRP in whatever way possible to help The JCPCT and several advisers have met with the answer members' questions. Safe and Sustainable The Secretary of State will make the final decision submit their views to them. The IRP has visited all to provide new evidence as part of the review to the panel's review. However, it is important that to change. The IRP encourages anyone wishing the IRP understands from patients and families the reasons why children's heart services need following his consideration of the IRP's advice.

Post: Independent Reconfiguration Panel, Heres how you can share your views with the IRP. E-mail: info@irpanel.org.uk

vebsite.

6th Floor, 157 - 197 Buckingham Palace Road, London, SW1W 9SP

By leaving a voice message on 020 7389 8046

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The IRP is keen to hear all views by 28 February 2013.

An update on legal proceedings

Last October Save Our Surgery Ltd, a group with close connections to the Leeds based campaign decision on the best way to improve children's heart services. They are seeking to guash the issued legal proceedings against the JCPCT's group Children's Heart Surgery Fund (CHSF), ICPCT's decision in its entirety.

and the public to analyse the sub scores to ensure unfair – an argument which relies on one ground: Kennedy's independent expert panel's sub-scores to a) the JCPCT and b) the general public during The campaign group argues that the decision is such as Leeds Teaching Hospitals NHS Trust and the CHSF the opportunity to challenge the the consultation process. Save Our Surgery Ltd claims that this would have enabled the JCPCT that they were correct and enabled consultees that the JCPCT should have disclosed Sir lan accuracy of the scores.

guess' the Kennedy Panel subscores and nor could The NHS mounted a strong defence of its decision and the review process during a three day hearing in February at the High Court. The NHS' case was that the campaign group's criticism of the process by the Kennedy Panel, nor its expertise. Therefore is misconceived and that the JCPCT's decision not to analyse the panel's 450 sub-scores was proper the NHS believes the JCPCT was entirely right to could have had – all the information relied upon conclude that it was not in a position to 'second can be reviewed on the NHS Specialised Services and appropriate. The JCPCT neither had – nor consultees for the same reason. These scores

Commenting on the legal proceedings, Sir Neil McKay CB, Chair of the Joint Committee of Primary Care Trusts, said:

"I believe that the NHS decision to expand access to local care and pool surgical expertise is right for children with congenital heart disease and their families. If we want to save more children's lives and reduce complications such as brain damage, we believe it's the right decision for the country. The UK's medical royal colleges which represent the doctors and nurses support the NHS decision.

"We believe that the consultation was transparent, fair and lawful however I do not deny citizens' right to challenge NHS decision makers when appropriate to do so and we have defended the very detailed process in the High Court.

"It is incumbent on all those in the NHS to strive to deliver excellent standards of care with the highest possible outcomes for patients and families. Save Our Surgery has argued that we should keep heart surgery in both Leeds and Newcastle. We considered this carefully but maintaining the status quo is not the answer as it would leave children in Yorkshire and Humberside with an inferior service than children in the rest of country would receive."

A decision is due to be made by the courts in the coming weeks.

Contact 💌

If you have any questions about the implementation programme, please contact the Implementation Programme Board by writing to:

CCHS.Implementation@london.nhs.uk