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Leeds
CITY COUNCIL

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

Meeting to be held in Civic Hall, Leeds, LS1 1UR on
Friday, 13th September, 2013 at 10.30 am

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

MEMBERSHIP

Councillors

J Worton – Barnsley Council

M Gibbons – Bradford Metropolitan Council

A McAllister – Calderdale Council

C Funnell – City of York Council

T Revill – Doncaster Metropolitan District Council

B Hall – East Riding of Yorkshire Council

D Brown – Hull City Council

L Smaje – Kirklees County Council

J Illingworth (Chair) – Leeds City Council

J Hyldon-King – North East Lincolnshire Council

J Bromby – North Lincolnshire Council

J Clark – North Yorkshire County Council

B Steele – Rotherham Metropolitan Borough Council

M Rooney – Sheffield City Council

B Rhodes – Wakefield Council

Item 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.**	

Item No	Ward/Equal Opportunities	Item 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			**DECLARATION 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 13-18 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 - 3 DECEMBER 2012 AND 10 APRIL 2013** To confirm as a correct record, the minutes of the meetings held 3 December 2012 and 10 April 2013. **(Copies to follow)**	
7			**SAFE AND SUSTAINABLE PROPOSALS FOR CHILDREN'S CONGENITAL CARDIAC SERVICES IN ENGLAND: ADVICE FROM THE INDEPENDENT RECONFIGURATION PANEL (IRP)** To receive and consider a report from the Head of Scrutiny and Member Development presenting the advice of the Independent Reconfiguration Panel (IRP) reported to the Secretary of State for Health on 30 April 2013.	1 - 242

Item No	Ward/Equal Opportunities	Item Not Open		Page No
8			**THE NEW REVIEW OF CONGENITAL HEART SERVICES IN ENGLAND** To receive and consider a report from the Head of Scrutiny and Member Development presenting details associated with the new review of congenital heart services in England.	243 - 276
9			**CHILDREN'S CONGENITAL CARDIAC SURGERY: SERVICE PROVISION AT LEEDS TEACHING HOSPITALS NHS TRUST** To receive and consider a report from the Head of Scrutiny and Member Development providing an update on; a) The current provision of children's heart surgery at Leeds Teaching Hospitals NHS Trust (LTHT); and, b) Progress of the subsequent phases of the review of quality of children's heart surgery services at LTHT.	277 - 342
10			**FUTURE OF THE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (YORKSHIRE AND THE HUMBER)** To receive and consider a report from the Head of Scrutiny and Member Development to consider the future role of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), as currently constituted.	343 - 346

Agenda Item 7

Leeds
CITY COUNCIL

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: 13 September 2013

Subject: Safe and Sustainable Proposals for Children's Congenital Cardiac Services in England: Advice from the Independent Reconfiguration Panel (IRP)

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

Purpose

1. The purpose of this report is to formally present the advice of the Independent Reconfiguration Panel (IRP) reported to the Secretary of State for Health on 30 April 2013.

Background

2. In November 2012, the Joint HOSC formally referred proposals for Children's Congenital Cardiac Services in England, agreed by the Joint Committee of Primary Care Trusts (JCPCT) following the Safe and Sustainable Review, to the Secretary of State for Health. The referral was subsequently passed to the IRP for consideration, review and advice.

3. The IRP concluded its review of the Safe and Sustainable proposals (and the associated referrals by Health Overview and Scrutiny bodies) and reported its findings and recommendations to the Secretary of State for Health on 30 April 2013.

Main issues and considerations

4. On 12 June 2013, an announcement from the Secretary of State for Health called a halt to the previous Safe and Sustainable review of Children's Congenital Cardiac Services in England. The IRP's full report and appendices, alongside a covering letter form the Secretary of State for Health, are attached to this report for consideration.

5. Details associated with the new review of congenital heart services in England are presented elsewhere on the agenda.

6. It should be noted that representatives from the IRP were invited to attend the meeting to present its report. However, this invitation to attend was declined as this would not '…*fit comfortably with our terms of reference as set out by the Secretary of State for Health. Our advice on Safe and Sustainable was commissioned by SofS and that is who we reported to. Advice was submitted on 30 April 2013 and that is the end of our involvement.*'

Recommendations

7. That the Joint HOSC:
    a. Notes the IRP's report and recommendations, as presented.
    b. Considers and comments on the IRP's report and recommendations (as appropriate) and identifies any specific action points in terms of the new review of congenital heart services in England and/or any scrutiny activity necessary at this stage.

Background documents[1]

8. None used

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[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.

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

DH Department of Health

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

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Councillor John Illingworth
Chair
Joint Health Overview and Scrutiny Committee
Yorkshire and the Humber
Leeds City Council
Health and Wellbeing and Adult Social Care
3rd Floor (East)
Civic Hall
Leeds
LS1 1UR

12 JUN 2013

Dear Cllr Illingworth,

"SAFE AND SUSTAINABLE REVIEW" OF CHILDREN'S CONGENITAL HEART SERVICES – INDEPENDENT RECONFIGURATION PANEL REPORT

Further to your letter of 27 November 2012 in which you referred proposals regarding the Safe and Sustainable review of children's heart surgery, I asked the Independent Reconfiguration Panel (IRP) for its advice on the matter.

At the same time, given the Panel had already commenced a full review of the proposals following referrals from Lincolnshire Council's Health Scrutiny Committee and Leicester, Leicestershire and Rutland's Joint Health Overview and Scrutiny Committee, I asked the IRP whether your referral could be incorporated as part of that full review.

The Panel has now completed its full review and shared its report with me.

A copy of their report, including its fifteen recommendations is appended to this letter and will be published today on the Panel's website at www.irpanel.org.uk

In order to make my decision on this important matter, I have considered in detail the IRP's report with regard to the specific concerns raised by your Committee.

It is clear the IRP has undertaken a very detailed review of all the evidence relating to this importance case. The IRP has considered a significant amount of material before formulating its final report, including that from the local NHS, your Committee and other groups with an interest in this case for change.

The report shows that the proposals of the Safe & Sustainable review clearly cannot go ahead in their current form. NHS England now needs to move forward on the basis of the IRP's recommendations, and the judgement of the court in the 'Safe and Sustainable' case - I understand that NHSE are withdrawing their appeal.

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The challenge for NHS England is to determine how to take this forward as quickly and effectively as possible. It will be working with all interested parties to ensure that real progress is made as quickly as possible, always focused on the best outcomes for patients. I have asked NHS England to report back to me by the end of July on how they intend to proceed.

I am sure you will join me in thanking the Panel for all their hard work.

Yours sincerely

Jeremy

JEREMY HUNT

IRP

Independent Reconfiguration Panel

ADVICE ON
SAFE AND SUSTAINABLE *PROPOSALS*
FOR CHILDREN'S CONGENITAL HEART SERVICES

Submitted to the Secretary of State for Health

30 April 2013

IRP

Independent Reconfiguration Panel

6th Floor
157 – 197 Buckingham Palace Road
London *SW1W 9SP*

Tel: 020 7389 8045/8046
Email: info@irpanel.org.uk
Website: www.irpanel.org.uk

Press Office
Tel: 020 7025 7530
Email: press@irpanel.org.uk

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Appendices

1 Independent Reconfiguration Panel general terms of reference

2 Letter of referral to Jeremy Hunt, the Secretary of State for Health from:

- Cllr Christine Talbot, Chair of the Health Scrutiny Committee for Lincolnshire Health
- Michael Cooke and Ruth Camamile, Chairman and Vice Chair of the Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee
- Cllr John Illingworth, Chair, Yorkshire and the Humber Joint Health Overview and Scrutiny Committee

3 Letters to the Secretary of State for Health from Lord Ribeiro, IRP Chairman, providing initial assessment advice, 21 September 2012 and 7 December 2012

4 Letters to Lord Ribeiro from Secretary of State for Health 22 October 2012, 10 December 2012 (with revised terms of reference) and 15 March 2013

5 IRP press release and media statements, 6 November 2012 and 11 December 2012

6 Site visits, meetings and conversations held

7 Information made available to the Panel

8 Panel membership

9 About the Independent Reconfiguration Panel

10 List of locations of cardiology outreach clinics

11 Profile of children's congenital cardiac centres

SUMMARY AND RECOMMENDATIONS

The Secretary of State for Health asked the IRP to advise whether it is of the opinion that the proposals for change under the *"Safe and Sustainable* Review of Children's Heart Services*"* will enable the provision of safe, sustainable and accessible services and if not why not. Overall, the Panel is of the opinion that the proposals for change, as presented, fall short of achieving this aim.

The Panel's view is that people - children and adults - with congenital heart disease in England and Wales will benefit from services commissioned to national standards for the whole pathway of their care.

The Panel agree that congenital cardiac surgery and interventional cardiology should only be provided by specialist teams large enough to sustain a comprehensive range of interventions, round the clock care, training and research.

However, the Panel has concluded the JCPCT's decision to implement option B (DMBC – Recommendation 17) was based on flawed analysis of incomplete proposals and their health impact, leaving too many questions about sustainability unanswered and to be dealt with as implementation risks.

SUMMARY AND RECOMMENDATIONS

Throughout our review, people told us that being listened to was something they valued. The opportunity to change and improve services is widely recognised and, in taking forward our recommendations, those responsible must continue to listen to legitimate criticisms and respond openly.

We set out below recommendations to enable sustainable improvements for these services and learning for future national commissioning of health services.

- **The proposals for children's services are undermined by the lack of co-ordination with the review of adult services. The opportunity must be taken to address the criticism of separate reviews by bringing them together to ensure the best possible services for patients.**

- **Patients should receive congenital heart surgery and interventional cardiology from teams with at least four full-time consultant congenital heart surgeons and appropriate numbers of other specialist staff to sustain a comprehensive range of interventions, round the clock care, training and research.**

SUMMARY AND RECOMMENDATIONS

- **Before further considering options for change, the detailed work on the clinical model and associated service standards for the whole pathway of care must be completed to demonstrate the benefits for patients and how services will be delivered across each network**

- **For the current service and any proposed options for change, the function, form, activities and location of specialist surgical centres, children's cardiology centres, district children's cardiology services, outreach clinics and retrieval services must be modelled and affordability retested.**

- **NHS England should ensure that a clear programme of action is implemented to improve antenatal detection rates to the highest possible standard across England.**

- **Further capacity analysis, including for paediatric intensive care units, should consider recent and predicted increases in activity, and patient flows.**

SUMMARY AND RECOMMENDATIONS

- **NHS England must establish a systematic, transparent, authoritative and continuous stream of data and information about the performance of congenital heart services. These data and information should be available to the public and include performance on service standards, mortality and morbidity.**

- **NHS England and the relevant professional associations should put in place the means to continuously review the pattern of activity and optimize outcomes for the more rare, innovative and complex procedures.**

- **NHS England should reflect on the criticisms of the JCPCT's assessment of quality and learn the lessons to avoid similar situations in its future commissioning of specialist services.**

- **More detailed and accurate models of how patients will use services under options for change are required to inform a robust assessment of accessibility and the health impact of options so that potential mitigation can be properly considered.**

- **Decisions about the future of cardiothoracic transplant and respiratory ECMO should be contingent on the final proposals for congenital heart services.**

SUMMARY AND RECOMMENDATIONS

- **NHS England should assure itself that any wider implications for other services of final proposals are fully assessed and considered within a strategic framework for the provision of specialised services.**

- **NHS England should develop a strategic framework for commissioning that reflects both the complex interdependencies between specialised services provision and population needs.**

- **NHS England must ensure that any process leading to the final decision on these services properly involves all stakeholders throughout in the necessary work, reflecting their priorities and feedback in designing a comprehensive model of care to be implemented and the consequent service changes required.**

- **NHS England should use the lessons from this review and create with its partners a more resource and time effective process for achieving genuine involvement and engagement in its commissioning of specialist services.**

SUMMARY AND RECOMMENDATIONS

The Panel's advice has been produced in the context of changing and peculiar circumstances. Since 1 April 2013, responsibility for commissioning congenital heart services rests with NHS England, which has inherited the original proposals, a judicial review, responsibility for the quality of current services and the potential consequences of the IRP's advice, subject to the Secretary of State's decision.

The Panel's advice sets out what needs to be done to bring about the desired improvements in services in a way that addresses gaps and weaknesses in the original proposals. The Panel's recommendations stand on their own irrespective of any future decision by NHS England regarding the judicial review proceedings. We note that the court's judgment of 27 March 2013 appears congruent to our own advice and that a successful appeal on legal grounds will not, of itself, address the recommendations in this report.

The Panel's advice addresses the weaknesses in the original proposals but it is not a mandate for either the status quo or going back over all the ground in the last five years. There is a case for change that commands wide understanding and support, and there are opportunities to create better services for patients. The challenge for NHS England is to determine how to move forward as quickly and effectively as possible.

SUMMARY AND RECOMMENDATIONS

Work to address gaps in the clinical model and associated service standards (Recommendation Three above) is underway and should be brought to a rapid conclusion. In parallel, there are different potential approaches to effect positive change that might be considered. These include whether to bring forward proposals for reconfiguration again or adopt a more standards-driven process that engages providers more directly in the managed evolution of services to be delivered. The critical factor to consider, in the Panel's view, is that engagement of all interested parties is the key to achieving improvements for patients and families without unnecessary delay.

List of abbreviations

ACHD	Adult congenital heart disease
AGNSS	Advisory Group for National Specialised Services
BAME	Black Asian and Minority Ethnic
BCCA	British Congenital Cardiac Association
CCAD	Central Cardiac Audit Database
CCC	Children's cardiology centre
CHD	Congenital heart disease
CHF	Children's Heart Federation
CIAG	Clinical Implementation Advisory Group
CQC	Care Quality Commission
DCCS	District children's cardiology services
DGH	District general hospital
DH	Department of Health
DMBC	Decision-making business case
EACTS	European Association for Cardio-Thoracic Surgery
ECMO	Extracorporeal membrane oxygenation
EP	Electrophysiology
GP	General practitioner
HDU	High dependency unit
HEHASC	Health Environmental Health and Adult Social Care
HES	Hospital Episode Statistics
HIA	Health impact assessment
HOSC	Health Overview and Scrutiny Committee
HSC	Health Scrutiny Committee
IRP	Independent Reconfiguration Panel
ITU	Intensive therapy unit
JCPCT	Joint Committee of Primary Care Trusts
Joint HOSC	Joint Health Overview and Scrutiny Committee
KPMG	Klynveld Peat Marwick Goerdeler – accountancy firm
LINks	Local involvement networks
LLR	Leicester, Leicestershire and Rutland
MDT	Multi-disciplinary team

MP	Member of parliament
NHS	National Health Service
NICOR	National Institute for Cardiovascular Outcomes Research
NICU	Neonatal intensive care unit
NSCT	National Specialist Commissioning Team
NSF	National service framework
ONS	Office for National Statistics
PBR	Payment by results
PCBC	Pre-consultation business case
PCT	Primary care trust
PDA	Patent ductus arteriosus
PEC	Paediatrician with expertise in cardiology
PICU	Paediatric intensive care unit
PwC	Price Waterhouse Cooper – accountancy firm
SCG	Specialist Commissioning Group
SHA	Strategic health authority
SMR	Standard mortality ratio
SRO	Senior responsible officer
VLAD	Variable life adjusted displays
Y&H	Yorkshire and the Humber

OUR REMIT

What was asked of us

1.1 The Independent Reconfiguration Panel's (IRP) general terms of reference are included in Appendix One.

1.2 On 27 July 2012, Cllr Christine Talbot, Chair of the Health Scrutiny Committee for Lincolnshire Health (Lincolnshire HSC) wrote to the Secretary of State for Health to refer for his consideration proposals for children's congenital cardiac (heart) services developed by NHS Specialised Services. Decisions on the proposals- known as *Safe and Sustainable* - had been made by a Joint Committee of Primary Care Trusts (JCPCT) at a meeting on 4 July 2012. A further referral of the proposals was made on 7 September 2012 by Michael Cooke and Ruth Camamile, Chairman and Vice Chair of the Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee (LLR Joint HOSC) (Appendix Two).

1.3 The Secretary of State wrote to Lord Ribeiro, IRP Chairman, on 8 August 2012 and 13 September 2012 requesting that the IRP undertake an initial assessment in accordance with the agreed protocol for handling contested proposals for reconfiguration of NHS services. The National Specialised Commissioning Team (NSCT) provided initial assessment information. The IRP set out its initial assessment of both referrals in a letter to the Secretary of State of 21 September 2012 (Appendix Three).

1.4 The Secretary of State wrote to Lord Ribeiro on 22 October 2012 asking the IRP to undertake a full review of the *Safe and Sustainable* proposals and attaching terms of reference (Appendix Four). The Panel was asked to submit its advice by 28 February 2013.

1.5 A further referral was made on 27 November 2012 by Cllr John Illingworth, Chair, Yorkshire and the Humber Joint Health Overview and Scrutiny Committee (Y&H Joint HOSC) (Appendix Two). The Secretary of State wrote to Lord Ribeiro on 29 November 2012 requesting an initial assessment and asking the Panel to consider the suitability of incorporating the referral into the full review already underway.

1.6 The IRP responded to the Secretary of State on 7 December 2012 concluding that the Y&H Joint HOSC's referral was suitable for inclusion within its review of the *Safe and Sustainable* proposals.

1.7 Revised terms of reference were issued with the Secretary of State's letter of 10 December 2012 to Lord Ribeiro together with an amended date for submission of advice (Appendix Four). The Panel was asked to advise by 28 March 2013:

a. *Whether it is of the opinion that the proposals for change under the "Safe and Sustainable Review of Children's Congenital Heart Services" will enable the provision of safe, sustainable and accessible services and if not, why not;*

b. *On any other observations the panel may wish to make in relation to the changes*

c. *On how to proceed in light of a. and b. above and taking account of the issues raised by the Health Scrutiny Committee for Lincolnshire, the Leicester, Leicestershire and Rutland Joint Health Overview and Scrutiny Committee and the Yorkshire and the Humber Joint Health Overview and Scrutiny Committee, subject to the proviso at d. below*

d. *The decision of the secretary of State taken regarding the designation of Birmingham Children's Hospital as a nationally commissioned provided of the Extra Corporeal Membrane Oxygenation service for children with respiratory failure should not form part of this review as this decision was not taken by the Joint Committee of Primary Care Trusts.*

The deadline for this review is subject to any further instructions the Secretary of State may need to issue in relation to timing in light of the judicial review challenge brought against the Joint Committee of Primary Care Trusts[1].

1.8 The Secretary of State issued further instructions to the IRP on 15 March 2013 extending the deadline for submission of the Panel's advice to 30 April 2013 so that account could be taken of the decision on redress in the light of the judicial review finding against the JCPCT[2] (Appendix Four).

1.9 Changes to the structure of the NHS came into effect on 1 April 2013 - notably, in this instance, the abolition of primary care trusts and as a consequence the abolition of the JCPCT whose decisions are the subject of this referral. Commissioning of NHS specialised services is now the responsibility of NHS England.

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[1] In October 2012, Save Our Surgery Ltd, an independent charity in Leeds, applied for a judicial review of the JCPCT's decision of 4 July 2012.

[2] On 7 March 2013, the Judge ruled against the JCPCT. The redress hearing took place on 27 March 2013 and the final written judgment was released on 24 April 2013.

OUR PROCESS

How we approached the task

2.1 The NSCT was asked to provide the Panel with relevant documentation and to help with arrangements for site visits, meetings and interviews with interested parties.

2.2 The Lincolnshire HSC, LLR Joint HOSC and Y&H Joint HOSC were also invited to submit documentation and suggest other parties to be included in meetings and interviews.

2.3 An IRP press release, advising that the Panel would be undertaking a review, was issued on 6 November 2012 and a media statement, confirming the inclusion of the Y&H Joint HOSC referral within the review, was issued on 11 December 2012 (Appendix Five).

2.4 All members of the IRP took part in the review. All ten sites currently providing children's congenital cardiac surgery and the cardiology centres in Manchester, Cardiff and Oxford were visited and evidence taken. The Panel undertook more than 25 days of oral evidence, meeting a wide cross section of individuals and organisations. Members were accompanied on visits and at evidence sessions by the IRP Secretariat. Details of the people seen during these sessions are included in Appendix Six.

2.5 All members of parliament in England and Wales were invited to submit views to the Panel. Panel members met Liz Kendall (Leicester West), Nicky Morgan (Loughborough), Jon Ashworth (Leicester South), Lilian Greenwood (Nottingham South), Keith Vaz (Leicester East), Heather Wheeler (South Derbyshire), the Bishop of Leicester and Lord Bach of Butterworth on 13 December 2012. Members met Greg Hands (Chelsea and Fulham) on 6 February 2013 and on 13 February 2013 met Stuart Andrew (Pudsey), Kevin Barron (Rother Valley), Hilary Benn (Leeds Central), Nic Dakin (Scunthorpe), Philip Davies (Shipley), Fabian Hamilton (Leeds North East), Kris Hopkins

(Keighley), John Healey (Wentworth and Dearne), Jason McCartney (Colne Valley), Austin Mitchell (Grimsby), Greg Mulholland (Leeds North West), Meg Munn (Sheffield Heeley), Barry Sheerman (Huddersfield), Angela Smith (Penistone and Stocksbridge), Julian Smith (Ripon and Skipton), Julian Sturdy (York Outer), Martin Vickers (Cleethorpes), Rosie Winterton (Doncaster Central) and Lady Masham. Other MPs were represented by parliamentary researchers.

2.6 A list of all the written evidence received – from the NSCT, NHS trusts, scrutiny committees, MPs and all other interested parties – is contained in Appendix Seven. The Panel considers that the documentation received, together with the information obtained in meetings, provides a fair representation of the views from all perspectives.

2.7 Throughout our consideration of these proposals, and in addressing our terms of reference, the Panel's focus has been the needs of patients, their families, the public and staff.

2.8 The Panel wishes to record its thanks to all those who contributed to this process. We also wish to thank all those who gave up their valuable time to present evidence to the Panel and to everyone who contacted us offering views.

2.9 The advice contained in this report represents the unanimous views of the Chairman and members of the IRP.

THE CONTEXT

A brief overview

3.1 Following a higher than expected number of deaths of children receiving heart surgery between 1984 and 1995, the Bristol Royal Infirmary Inquiry Report[3] (the Kennedy report) was published in 2001 recommending that specialist expertise be concentrated in fewer surgical units in England. A report by the Paediatric and Congenital Cardiac Services Review Group (the Munro report) was published in 2003. Further consideration by the Department of Health (DH) and relevant medical bodies followed until, in May 2008, the National Specialised Commissioning Team (NSCT) was asked to undertake a review with a view to reconfiguring surgical services for children with congenital heart disease[4]. Taking into consideration concerns that surgeons and resources may be spread too thinly across the centres, the review considered whether expertise would be better concentrated on fewer sites than the current eleven in England.

3.2 The *Safe and Sustainable* team was established to manage the review process on behalf of the ten Specialised Commissioning Groups (SCG) and their local primary care trusts (PCT). In December 2008, an expert clinical Steering Group was formed to direct the process of developing a report to the NHS Management Board and DH Ministers.

3.3 Draft quality standards, against which surgical centres would be assessed, were published in September 2009 and sent directly to all health overview and scrutiny committees and other organisations for comment. A revised version of the standards was published in March 2010. Also in March 2010, following a number of post-surgical deaths, surgery at the paediatric cardiac unit at the John Radcliffe Hospital, Oxford, was suspended.

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[3] Bristol Royal Infirmary Inquiry, Learning from Bristol: The report of the public enquiry into children's heart surgery at the Bristol Royal infirmary 1984 to 1995 (the Kennedy report) July 2001

[4] A working group to consider services for adults was also established in 2008. The working group published draft standards in 2009 *(Designation of Specialist Service providers for Adults with Congenital Heart Disease).* An Adults Congenital Heart disease group was re-convened in July 2011 to refine the standards and model of care in light of emerging *Safe and Sustainable* recommendations.

3.4 A process of self-assessment by surgical centres commenced in April 2010. In the same month, the *Safe and Sustainable* team published *Children's Heart Surgery – the Need for Change.* Later in April 2010, the NHS Operations Board recommended to DH Ministers that PCTs delegate their consultation responsibilities and decision-making powers to a joint committee of PCTs (JCPCT). The Secretary of State for Health approved the establishment of the JCPCT in June 2010. The revised NHS Operating Framework confirmed that the *Safe and Sustainable* review was expected to deliver recommendations for consultation in the autumn of 2010.

3.5 Between May and June 2010, an expert panel, chaired by Professor Sir Ian Kennedy, visited each surgical centre to meet staff and families and to assess each centre's ability to comply with the standards. Pre-consultation engagement events commenced in June 2010. In September 2010, the case for change was supported by the National Clinical Advisory Team and proposed processes for consultation were endorsed by OGC Gateway review. The JCPCT met for the first time as a formally constituted body in October 2010. Briefings for HOSCs by SCG representatives began the following month.

3.6 In August 2010, a review conducted by South Central Strategic Health Authority (SHA) recommended that the paediatric cardiac surgical service at the John Radcliffe Hospital, Oxford, should remain suspended pending the outcome of the *Safe and Sustainable* review.

3.7 In November 2010, on behalf of the JCPCT, a panel of experts chaired by Mr James Pollock, consultant congenital cardiac surgeon, investigated historical deaths at three surgical units in Leeds, Leicester and London (the Evelina Children's Hospital). The outcome of this investigation was presented to the Kennedy panel to consider whether it was necessary to revise its assessment of any of the three centres. The Kennedy panel found no cause to revise its assessment and the panel's report was published in December 2010.

3.8 Options for consultation were agreed by the JCPCT in February 2011 and a four-month public consultation began in March 2011. The consultation proposed concentrating clinical expertise on fewer sites by reducing the number of surgical centres from eleven to either six or seven.

3.9 A briefing for scrutiny committees, informing them of the forthcoming launch of the consultation, was issued in February 2011. Earlier communications to HOSCs, notably a Centre for Public Scrutiny briefing in April 2010, had alerted them to the intention to conduct a formal consultation and encouraged them to consider the need for a joint committee. In recognition of changes to membership resulting from local elections in May 2011, the deadline for receipt of consultation responses from HOSCs was extended to 5 October 2011. In the event, no national joint committee was formed and arrangements for scrutiny varied around the country with a mixture of individual and area and regional joint committees ultimately responding to the consultation.

3.10 Representatives of East Midlands SCG provided a presentation on the *Safe and Sustainable* review to a meeting of the LLR Joint HOSC in March 2011 and Lincolnshire HSC in April 2011 and to two Deliberative Stakeholder Events in Lincoln and Sleaford in May 2011. Between March and September 2011, representatives of the Yorkshire and the Humber SCG attended several meetings of the Y&H Joint HOSC to answer questions on the review. Engagement activities were held with focus groups in Yorkshire locations during the same period.

3.11 On 22 June 2011, it was announced that an independent panel of national and international experts, chaired by Adrian Pollitt, a former director of national specialised commissioning, had been appointed to advise the JCPCT on the potential impact of the children's congenital heart proposals on other services at the Royal Brompton Hospital.

3.12 The formal public consultation closed on 1 July 2011 (except for HOSCs). An independent analysis of the consultation, commissioned from Ipsos MORI, was published in August 2011. That analysis acknowledged that the impact of the proposed changes on other services had been raised as an issue during consultation.

3.13 A judicial review of the proposal to reduce the number of surgical centres in London from three to two centres was initiated by the Royal Brompton & Harefield NHS Foundation Trust in July 2011.

3.14 During August 2011, representatives of East Midlands SCG provided briefings for East Midlands HOSCs about responses to the public consultation and on a draft final Health Impact Assessment. Representatives of the Yorkshire and the Humber SCG provided briefings for the Y&H Joint HOSC in October and December 2011.

3.15 In September 2011, the *Safe and Sustainable* Steering Group considered clinical issues raised during the consultation and advised the JCPCT to agree the quality standards and model of care as set out in the consultation document. A supplementary report in response to issues raised during the consultation was published by the Kennedy panel in October 2011.

3.16 The Report of the Independent Panel on the Relationship of Interdependencies at the Royal Brompton Hospital (the*"Pollitt Report"*) was published on 15 September 2011. It stated that *"... although there would be an impact on the range of activity at the RBH the panel has concluded that paediatric respiratory services would remain viable at the RBH site in the absence of an on-site PICU".*

3.17 The formal consultation with HOSCs concluded on 5 October 2011. Also in that month, at the JCPCT's request, the Kennedy panel published a supplementary report in response to issues raised during consultation. The panel clarified that University Hospital of Leicester NHS Trust did not meet the requirement for the co-location of core paediatric services.

3.18 The Y&H Joint HOSC referred the *Safe and Sustainable* review of children's congenital cardiac services to the Secretary of State on 14 October 2011. The referral was particularly concerned with services currently provided at Leeds

General Infirmary and the potential effects of the proposals on patients and residents in Yorkshire and the Humber.

3.19 On 7 November 2011, the judgment was delivered in the judicial review brought by the Royal Brompton & Harefield NHS Foundation Trust. The judge, whilst rejecting a number of the arguments put forward, found against the JCPCT on a matter of process. An appeal against the judgment was lodged.

3.20 Later in November 2011, the JCPCT invited the 11 centres providing children's congenital heart services to submit new evidence demonstrating their compliance with the national quality standards relating to innovation and research.

3.21 The IRP submitted its initial assessment advice on the referral by the Y&H Joint HOSC on 13 January 2012. As well as commenting on the consultation process, and on communication and relationships between the Y&H Joint HOSC and the JCPCT, the Panel offered advice in relation to a number of outstanding requests for information sought by the Committee. The Secretary of State announced on 23 February 2012 that he had accepted the Panel's advice in full.

3.22 The Royal Borough of Kensington and Chelsea Health Environmental Health and Adult Social Care (HEHASC) Scrutiny Committee referred the *Safe and Sustainable* review of children's congenital cardiac services to the Secretary of State on 27 March 2011. The referral was particularly concerned with services currently provided at the Royal Brompton Hospital and the potential effects of the proposals on patients and residents in west London and south east England.

3.23 On 19 April 2012, the Court of Appeal announced its decision, dismissing the grounds raised by the Royal Brompton & Harefield NHS Foundation Trust and finding the public consultation to be lawful and proper.

3.24 The IRP submitted its initial assessment advice on the referral by the Kensington and Chelsea HEHASC Scrutiny Committee 23 May 2012. The

Panel offered comments on the JCPCT's efforts to address concerns raised by respondents to the consultation process that would inform the JCPCT ahead of its forthcoming decision-making meeting. The Secretary of State announced on 15 June 2012 that he had accepted the Panel's advice in full.

3.25 In line with the IRP's initial assessment advice on the referrals by Y&H Joint HOSC and by Kensington and Chelsea HEHASC Scrutiny Committee, some further work was undertaken to inform the JCPCT before its decision-making meeting.

3.26 The JCPCT held its decision-making meeting on 4 July 2012 and agreed that seven managed clinical networks should be established across England (and serving Wales). Each network would be led by a surgical centre - based in the Freeman Hospital Newcastle (north), Alder Hey Children's Hospital Liverpool (north west and north Wales), Birmingham Children's Hospital (midlands), Bristol Royal Hospital for Children (south west and south Wales), Southampton General Hospital (south central) and Great Ormond Street Hospital for Children and Evelina Children's Hospital (London, East Anglia and the south east).

3.27 On 13 July 2012, the Secretary of State for Health, having accepted the advice of the Advisory Group for National Specialised Services, designated Birmingham Children's Hospital as a nationally commissioned provider of Extra Corporeal Membrane Oxygenation (ECMO) services for children with respiratory failure – in place of the existing unit at Glenfield Hospital, Leicester.

3.28 The Lincolnshire HSC referred the *Safe and Sustainable* proposals to the Secretary of State on 27 July 2012. The referral was particularly concerned with services currently provided at Glenfield Hospital, Leicester and the potential impact of the proposals on patients and residents in Lincolnshire.

3.29 The LLR Scrutiny Committee referred the *Safe and Sustainable* proposals to the Secretary of State on 7 September 2012. The referral was particularly concerned with services currently provided at Glenfield Hospital, Leicester and the potential impact of the proposals on patients and residents in Leicester, Leicestershire and Rutland.

3.30 Following an initial assessment of both referrals by the IRP, the Secretary of State wrote to Lord Ribeiro on 22 October 2012 commissioning a full review of the *Safe and Sustainable* proposals from the Panel.

3.31 In October 2012, Save Our Surgery Ltd, an independent charity in Leeds, applied for a judicial review of the JCPCT's decision not to release scoring information related to the Kennedy panel assessment during the consultation period.

3.32 A further referral of the *Safe and Sustainable* proposals was made on 27 November 2012 by the Y&H Joint HOSC. The referral was particularly concerned about services currently provided at Leeds Children's Hospital (Leeds General Infirmary) and the potential impact of the proposals on patients and residents across Yorkshire and the Humber. In responding to the Secretary of State's request for initial assessment advice, the Panel confirmed the suitability of the Y&H Joint HOSC referral for inclusion within the full review already underway.

3.33 Revised terms of reference were issued with the Secretary of State's letter of 10 December 2012 to Lord Ribeiro together with an amended date for submission of the Panel's advice – 28 March 2013.

3.34 On 7 March 2013, the Judge ruled against the JCPCT in the judicial review brought by Save our Surgery Ltd and confirmed that a further hearing would be held on 27 March 2013 to consider redress.

3.35 On 15 March 2013, the Secretary of State issued further instructions to the IRP extending the deadline for submission of the Panel's advice to 30 April 2013 to enable the Panel to take account of the Judge's decision on redress.

3.36 On 18 April 2013, NHS England, the body that inherited responsibility for the *Safe and Sustainable* review from the JCPCT, started the process of appealing the judicial review.

3.37 The final written judgment was released on 24 April 2013. The order of the court was to quash the acceptance by the JCPCT, dated 4 July 2012, of Recommendation 17 contained in the Decision-Making Business Case of the *Safe and Sustainable* Review of Children's Congenital Cardiac Services in England, July 2012.

INFORMATION

What we found

4.1 A vast amount of written and oral evidence was submitted to the Panel. We are grateful to all those who took the time to offer their views and information. The evidence put to us is summarised below – firstly general background information followed by an outline of the proposals, the reasons for referral by the Lincolnshire HSC, LLR Joint HOSC, and Y&H Joint HOSC, issues raised by others and finally, the evidence gathered.

4.2 What is congenital heart disease?

4.2.1 Congenital heart disease (CHD) refers to defects in a child's heart that develop in the womb and are present at birth. CHD is a life-long condition that can be life threatening. It affects one in 133 children, such that around eight out of every 1,000 babies will have some form of congenital heart disease. To put this in context, there were 723,913 live births in England and Wales in 2011[5]. This means that approximately 5,800 babies with CHD were born that year. The number of children born with CHD is set to rise with projections of higher numbers of births in the period to 2025[6].

4.2.2 There are two main types of CHD:

- Cyanotic heart disease – where the patient appears blue, is a heart defect which results in low blood oxygen levels
- Acyanotic heart disease – is a heart defect with normal levels of oxygen in the blood but abnormal blood flow may cause high blood pressures in vessels supplying the lung

4.3 Who has CHD?

4.3.1 In the majority of instances when a baby is born with CHD, there is no known reason for the heart to have formed improperly. Some types of congenital heart

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[5] Office for National Statistics October 2011

[6] Office for National Statistics October 2011

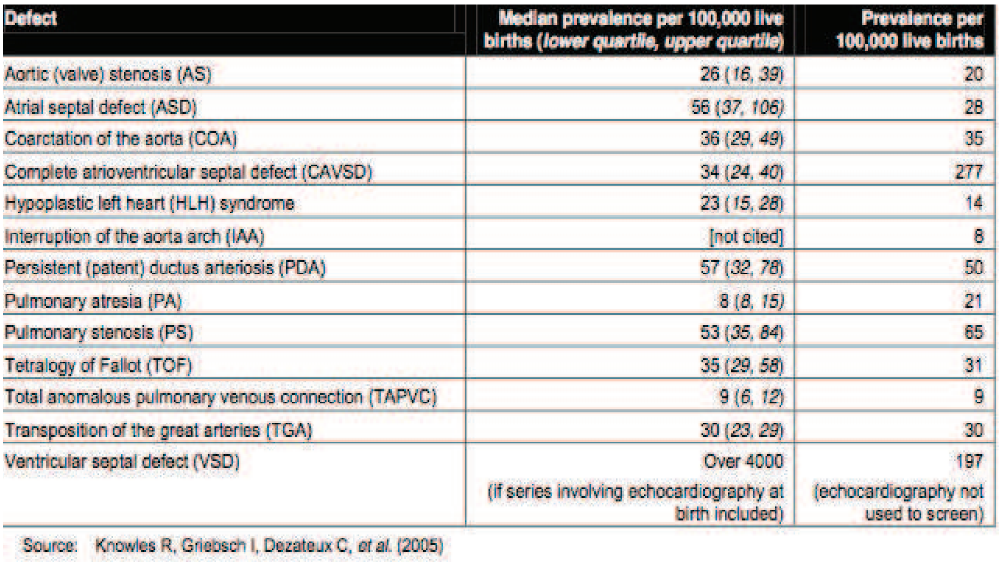
defects can be related to an abnormality of an infant's chromosomes, for example, children with Down Syndrome have a high incidence of CHD.

4.3.2 The Health Impact Assessment Scoping Report[7] identified that there are several 'at risk' groups which are, proportionally, more likely to be affected by CHD than the wider population. These are:

- Women who smoke and/or are obese during pregnancy
- Those in socio-economically deprived groups
- People living in areas with poor air quality
- Black, Asian and Minority Ethnic (BAME) Groups particularly those related to Indian, Pakistani, Bangladeshi and other Indian sub-continent populations

4.3.3 There are 35 medically recognised heart defects and prevalence by defect varies significantly as illustrated in Table 1.

Table 1: Congenital heart defect prevalence by defect



Defect	Median prevalence per 100,000 live births (*lower quartile, upper quartile*)	Prevalence per 100,000 live births
Aortic (valve) stenosis (AS)	26 (*16, 39*)	20
Atrial septal defect (ASD)	56 (*37, 106*)	28
Coarctation of the aorta (COA)	36 (*29, 49*)	35
Complete atrioventricular septal defect (CAVSD)	34 (*24, 40*)	277
Hypoplastic left heart (HLH) syndrome	23 (*15, 28*)	14
Interruption of the aorta arch (IAA)	[not cited]	8
Persistent (patent) ductus arteriosis (PDA)	57 (*32, 78*)	50
Pulmonary atresia (PA)	8 (*8, 15*)	21
Pulmonary stenosis (PS)	53 (*35, 84*)	65
Tetralogy of Fallot (TOF)	35 (*29, 58*)	31
Total anomalous pulmonary venous connection (TAPVC)	9 (*6, 12*)	9
Transposition of the great arteries (TGA)	30 (*23, 29*)	30
Ventricular septal defect (VSD)	Over 4000 (if series involving echocardiography at birth included)	197 (echocardiography not used to screen)

Source: Knowles R, Griebsch I, Dezateux C, *et al.* (2005)

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[7] Safe and Sustainable: Review of Children's Congenital Heart Surgery Services in England Health Impact Assessment: Final Scoping Report February 2011

4.4 Caring for children with CHD

4.4.1 CHD can, in some cases, be diagnosed in the womb. For other babies it is not identified until after birth or may even remain undetected until adulthood.

4.4.2 If, during a routine antenatal scan, the obstetrician or sonographer considers that a baby might have a heart problem, the mother would be referred to a fetal cardiologist for a specialist fetal cardiology assessment.

4.4.3 Prenatal diagnosis of major CHD improves results for children and can help to prevent serious complications such as brain damage. It also enables parents to consider whether to terminate the pregnancy. There has been a reduction in the percentage of pregnancies terminated in recent years due to improvements in diagnosis, the range of available interventions and outcomes.

4.4.4 If there is a diagnosis prior to birth, a plan of care would be set in place for mother and baby including, where clinically indicated, for the birth to take place in or near a cardiac surgical centre.

4.4.5 Those children diagnosed at a later stage of life might be seen initially by a GP or a paediatrician at a local hospital before being referred to a paediatric cardiologist.

4.4.6 Most children with CHD require monitoring and advice about their condition and its impact on daily life. Up to half of children with CHD will not need surgery. They will, however, require long-term expert cardiology support and a few children will require medication to treat their condition. Around 25-30 per cent of children with CHD have other significant healthcare needs.

4.4.7 Many children with CHD have problems eating and gaining weight and have to follow a special diet. Children with CHD are more susceptible to illnesses such as chest infections.

4.4.8 There is a wide range of different interventional cardiology procedures and over 150 different surgical procedures that are used to treat children with CHD. Sometimes surgeons and cardiologists will operate together or two surgeons may operate on a child together. Procedures range in complexity from day cases to surgery for highly complex conditions that require multiple operations at stages throughout life. The majority of operations are planned, but some emergency procedures are undertaken. Some children stay in hospital for many weeks or even months and this can have a significant impact on children and their families.

4.4.9 Children with CHD are supported by a range of specialists such as paediatricians with expertise in cardiology, cardiac liaison nurses, psychologists, paediatric cardiologists and congenital cardiac surgeons. To support the surgical and interventional cardiology procedures, a team of specialists is required including cardiac anaesthetists, perfusionists, intensivists and specialist nurses.

4.5 Caring for young people and adults with CHD

4.5.1 Until relatively recently, fewer than 20 per cent of children born with CHD used to reach the age of 16. However, by the 1980s - due to advances in heart surgery and more recently interventional cardiology - 85 per cent of children reached adulthood. There are now more adults than children with CHD in the UK and the number of adults living with CHD is increasing rapidly. CHD has become a lifelong condition. However, major heart surgery for CHD is commonly carried out during childhood and currently children still account for the majority of all congenital heart operations.

4.5.2 An important stage in the care of CHD patients is ‘transition’. This is when children move from being under the care of children’s services to under the care of adult services. This can be a crucial time in ensuring that young people feel supported to address the implications of their condition as they move into adult life. Teenagers with CHD are often at more risk of emergency hospital admissions and deteriorations in their health, as well as psychological problems.

4.5.3 For some females born with CHD it is safe to have children but for others the risks of complications associated with getting pregnant and giving birth are significant and unplanned pregnancy can be extremely serious. More women with CHD are giving birth as the number of adults with CHD increases.

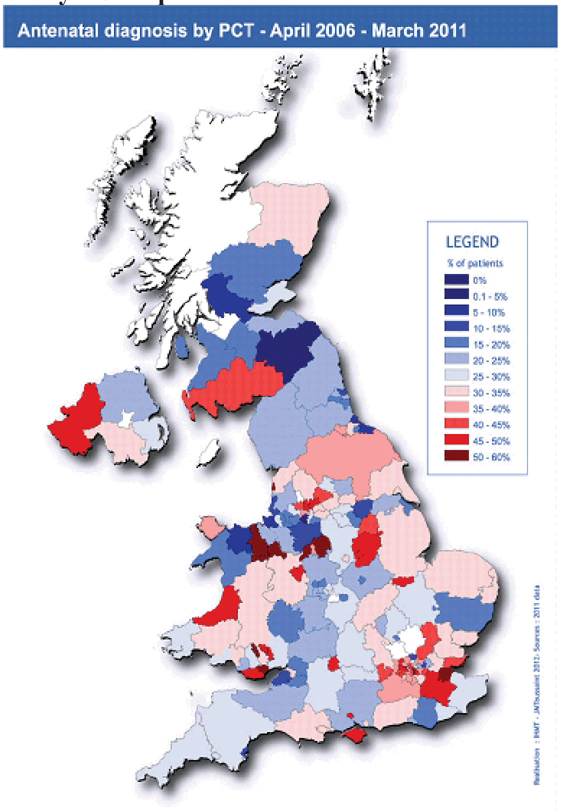
4.5.4 People with CHD face a range of issues in adulthood. For some, due to hereditary factors, the whole family is affected and need to be supported as a family unit. As more people with CHD get older, acquired heart problems become more common. Most adults with CHD will need lifelong monitoring and some will need surgery.

4.6 Current service provision

4.6.1 The start of the pathway of care for children with CHD may begin in the prenatal stage with a routine obstetric scan at their local maternity unit.

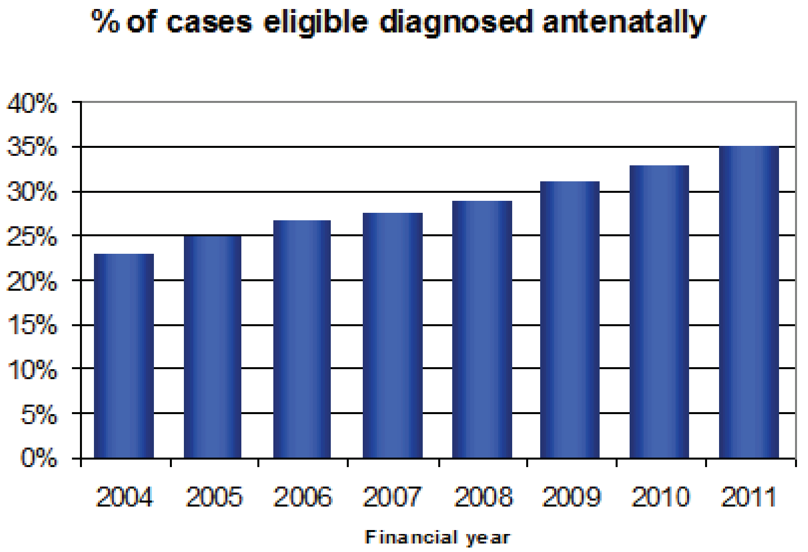
4.6.2 There is wide variation in the antenatal detection rates around the country as shown by the map below.

Map 1 Antenatal diagnosis by PCT April 2006 to March 2011



4.6.3 However, the percentage of cases of CHD that are being diagnosed antenatally is improving. The graph below shows the increase in detection rates between 2004 and 2011 for the UK.

Figure 1 [8]



4.6.4 Following the antenatal scan, or initial assessment by a GP or paediatrician, children with suspected CHD are referred to the specialist children's congenital heart service.

4.6.5 NHS specialist services for children with congenital heart disease are currently provided principally at ten hospitals in England at the following NHS trusts:

- Freeman Hospital at Newcastle-Upon-Tyne Hospitals NHS Foundation Trust
- Leeds General Infirmary at Leeds Teaching Hospitals NHS Trust
- Alder Hey Children's NHS Foundation Trust
- Glenfield Hospital at University Hospitals of Leicester NHS Trust
- Birmingham Children's Hospital NHS Foundation Trust
- Great Ormond Street Hospital For Children NHS Foundation Trust
- Bristol Royal Hospital for Children at University Hospitals Bristol NHS Foundation Trust
- Royal Brompton Hospital at Royal Brompton & Harefield NHS Foundation Trust

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[8] Source NICOR:
https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/Antenatal%20Diagnosis?Opendocument

- Evelina Children’s Hospital at Guy’s and St Thomas’ NHS Foundation Trust
- Southampton General Hospital at Southampton University Hospitals NHS Foundation Trust

4.6.6 John Radcliffe Hospital in Oxford ceased to undertake paediatric congenital heart surgery in March 2010 and formed a joint network with Southampton University Hospitals NHS Foundation Trust. John Radcliffe Hospital continues to provide a paediatric congenital cardiology service.

4.6.7 The location of the hospitals is shown in Map 2 below.

Map 2: Location of specialist paediatric congenital cardiac centres in England

4.6.8 Manchester Children’s Hospital at the University of Manchester Teaching Hospitals NHS Foundation Trust provides a paediatric congenital cardiology service in partnership with Alder Hey Children’s Hospital NHS Foundation Trust.

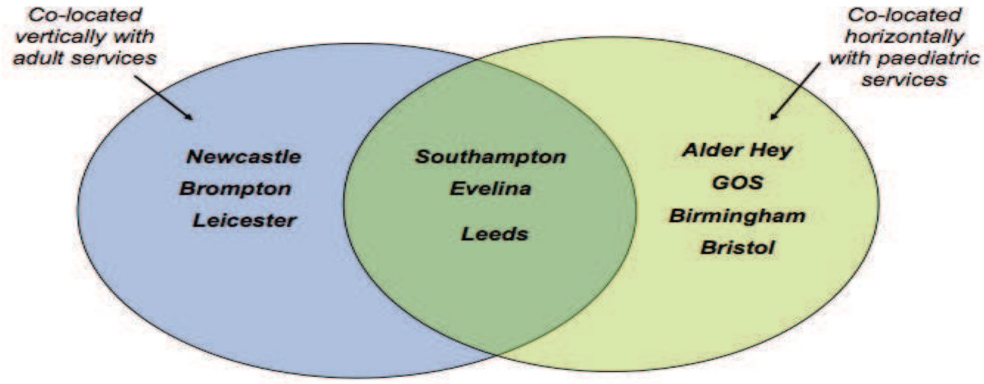
4.6.9 University Hospital of Wales in Cardiff ceased to undertake congenital heart surgery in 1998 and since 2001 has worked principally with the surgical unit in Bristol Royal Hospital for Children. University Hospital of Wales continues to provide a paediatric congenital cardiology service.

4.6.10 Paediatric cardiologists from each of the ten surgical centres provide outreach clinics in a number of district general hospitals in their network area. Outreach clinics are held in 157 locations. The location of these clinics is shown in the table in Appendix 10.

4.6.11 Children's congenital heart services are currently delivered in hospitals that fall into one of three categories:

- Specialist hospitals – Freeman Hospital, Royal Brompton Hospital and Glenfield Hospitals providing services for children and adults
- Specialist children's hospitals– Great Ormond Street Hospital, Alder Hey, Birmingham Children's Hospital, Bristol Royal Hospital for Children
- Specialist children's units within a large acute teaching hospitals – Leeds General Infirmary, Evelina Children's Hospital and Southampton General Hospital

Figure 2: pattern of co-location of children's congenital cardiac services



4.6.12 Table 2 sets out the number of surgical procedures in 2009/10, 20010/11 and 2011/12 by centre and the number of surgeons at each centre in June 2010 (as set out in the *Safe and Sustainable* consultation document) and in October 2012. Table 3 sets out the number of interventional cardiology procedures over the years 2009/10 to 2011/12.

Table 2: numbers of paediatric congenital heart surgery procedures and surgeons 2009/10 - 2011/12[9]

Children's Congenital Cardiac Centre	Paediatric surgical procedures			No. surgeons	
	2009/10	2010/11	2011/12[10]	Jun 2010	Oct 2012
Alder Hey Liverpool	398	434	393	3	3
Birmingham	553	478	499	3	4
Bristol	281	326	304	3	3
Evelina	350	387	401	3	3
Freeman Newcastle	241	265	252	2	3
Great Ormond Street	586	634	657	4	4
Glenfield Leicester	222	195	198	3	3
Leeds General Infirmary	300	335	316	3	4
Oxford Radcliffe	101	12	6	1	n/a
Royal Brompton	413	427	397	4	4
Southampton	231	333	341	2	3
Total	3,676	3,826	3,764		

Table 3: numbers of paediatric interventional cardiology procedures 2009/10 -2011/12[11]

Children's Congenital Cardiac Centre	Paediatric interventional cardiology procedures		
	2009/10	2010/11	2011/12[12]
Alder Hey Liverpool	202	170	201
Birmingham	346	367	360
Bristol	173	211	221
Evelina	181	172	196
Freeman Newcastle	103	92	104
Great Ormond Street	261	287	307
Glenfield Leicester	136	123	122
Leeds General Infirmary	162	182	149
Oxford Radcliffe	86	40	3
Royal Brompton	207	218	297
Southampton	105	147	192
Total	1,962	2,009	2,152

4.6.13 Appendix 11 provides a profile of each of the ten centres covering:

- Surgical and interventional cardiology activity in 2011/12
- Numbers of key medical and nursing staff as at 31st Oct 2012
- Other associated clinical specialties located on the hospital site
- Accommodation for parents and families

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[9] Source CCAD - figures include foreign private patient activity (this activity was excluded from the figures used by the Safe and Sustainable Review)

[10] Data for 2011/12 is provisional as it has not yet been validated

[11] Source CCAD - figures include foreign private patient activity (this activity was excluded from the figures used by the Safe and Sustainable Review)

[12] Data for 2011/12 is provisional as it has not yet been validated

4.6.14 The number of surgical and interventional procedures undertaken in England has increased by around nine per cent over the past six years as shown in Table 4 below.

Table 4: number of paediatric surgical and interventional cardiology procedures undertaken in England during 2006/07 to 2011/12[13]

Year	**2006/07**	**2007/08**	**2008/09**	**2009/10**	**2010/11**	**2011/12**[14]	**% change**
Surgical procedures	3,447	3,390	3,413	3,676	3,826	3,764	+9
Interventional cardiology	1,970	1,788	2,015	1,962	2,009	2,152	+9
Total	5,417	5,178	5,428	5,638	5,835	5,916	+9

4.7 Demography and at risk populations

4.7.1 The ten surgical centres in England serve the population of England and Wales for paediatric congenital heart surgery. In 2010, the population of 0-14 year olds in England and Wales was 9,661,000.

4.7.2 The latest population projections indicate that the population of 0-14 year olds will grow to 11,178,000 by 2025[15], an increase of 16 per cent on the 2010 population. As shown in Table 5, population growth in the 0-14 age group is projected to be most pronounced in London (26 per cent), the East Midlands (19 per cent), East (17 per cent) and West Midlands (16 per cent). Within London, the growth is projected to be particularly focused on northeast London.

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[13] Figures include foreign private patient activity (this activity was excluded from the figures used by the Safe and Sustainable Review)

[14] Data for 2011/12 is provisional as it has not yet been validated

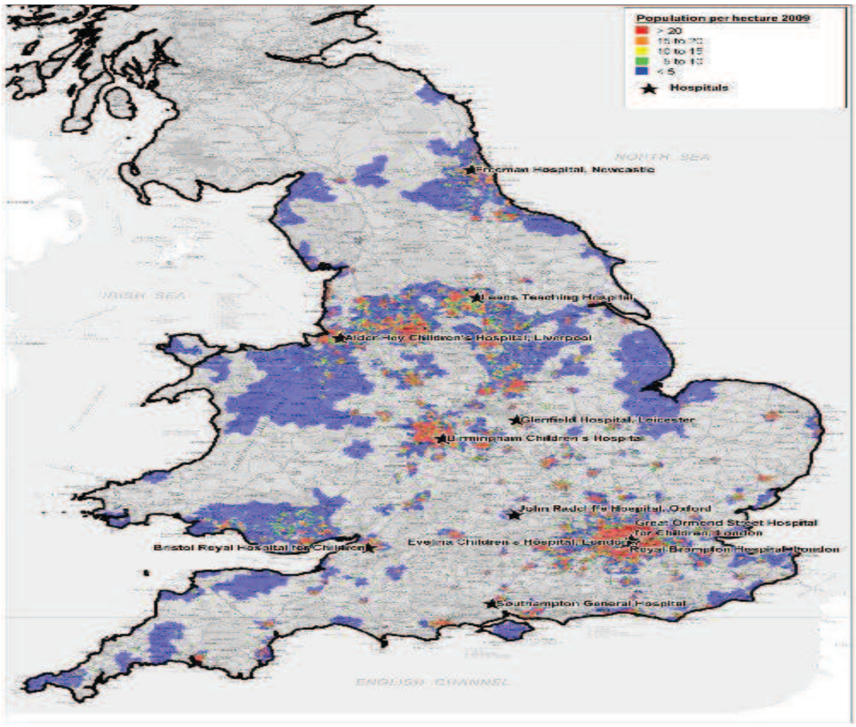
[15] UK national statistics website. available at: www.statistics.gov.uk/ hub/index.html

Table 5: projected population growth for 0-14 year olds in England and Wales 2010 to 2025[16]

Region	0-14 population 2010	0-14 population projection 2025	% change
England	9,150	10,610	16
Wales	511	568	
NE	427	465	9
NW	1,239	1,372	11
Y&H	908	1,031	13
WM	990	1,152	16
EM	765	912	19
East	1,026	1,199	17
London	1,455	1,829	26
SE	1,504	1,672	11
SW	861	959	11

4.7.3 Some populations have an increased risk of CHD. Map 3 below shows the postcode districts with high densities of two of more at risk groups.

Map 3: Postcode districts with high densities of two or more at risk groups[17]



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[16] UK national statistics website. available at: www.statistics.gov.uk/ hub/index.html

[17] Safe and Sustainable: Review of Children's Congenital Heart Surgery Services in England Health Impact Assessment: Final Scoping Report February 2011. Contains Ordnance Survey data (c) Crown copyright and database right 2011

4.8 Service Quality

4.8.1 The Care Quality Commission (CQC) has inspected each of the hospitals providing services during the last year. The inspections do not, however, necessarily include the paediatric cardiac wards and services. The date of the latest inspection and the outcome is set out in Table 6 below.

Table 6: Date and outcome of most recent CQC inspections at the ten hospitals providing paediatric congenital heart services

Hospital	Date of CQC inspection	Outcome
Alder Hey	January 2013	Compliant
Birmingham Children's Hospital	December 2012	Improvements required for standards of staffing.
Bristol Royal Hospital for Children	September 2012	Formal warning issued to University Hospitals Bristol NHS Foundation Trust in relation to staffing levels on the cardiac ward. Trust judged by CQC to be compliant November 2012.
Evelina Children's Hospital	March 2013	Compliant
Freeman Hospital	July 2012	Compliant
Glenfield Hospital	December 2012	Compliant
Great Ormond Street Hospital	January 2013	Compliant
Leeds General Infirmary	October 2012	Compliant
Royal Brompton	February 2013	Compliant
Southampton General Hospital	December 2012	Findings of non-compliance in relation to 4 of 5 standards; care and welfare, staffing, management of medicines and records

4.8.2 The areas of non-compliance raised by CQC for Birmingham Children's Hospital related to support for staff and staffing levels in operating theatres. There had recently been a change in staff's job roles as theatre staff were moved to work as a single team. The Trust has advised CQC it has taken action to address the issues.

4.8.3 CQC issued a warning notice to Bristol Royal Hospital for Children due to concerns about staffing levels on the paediatric cardiac ward, particularly in relation to high dependency beds. CQC has since confirmed that the Trust has taken the necessary action and is now compliant.

4.8.4 CQC found evidence of non-compliance at Southampton General Hospital in December 2012. The concerns related to quality of care, staffing levels, management of medication and record keeping. As at 26 April 2013, CQC had not published any statement about the outcome of checks on action in response to non-compliance.

4.8.5 On 28 March 2013, a meeting took place between CQC, NHS England and Leeds Teaching Hospitals NHS Trust regarding preliminary data suggesting high mortality, concerns about staffing levels, whistle blowing information from clinicians, and complaints from patients. In response to the concerns raised, the Trust took the decision to suspend children's congenital cardiac surgery at Leeds General Infirmary while an independent review was undertaken. Operations resumed on 10 April 2013 with agreement from NHS England following completion of the first stage of a review by a multi-disciplinary independent clinical team. A second stage of the review is being undertaken by NHS England looking at other areas where improvement may be necessary. This will comprise:

- A review of the way complaints from patients are handled, including issues raised by the Children's Heart Federation and
- Completion of a review of patients' case notes over the last three years.

4.8.6 In addition, NHS England will further explore issues that have been raised about referral practices to ensure they are clinically appropriate.

4.8.7 CQC has told the IRP that it supports this review and will consider the findings once available in the context of its own regulatory processes.

4.9 The proposals

4.9.1 For purposes of brevity, the *Safe and Sustainable* Review Team, the National Specialist Commissioning Team and secretariat are hereafter referred to as 'the NHS'. The *Safe and Sustainable* Review was initiated in 2008 to undertake a review of the provision of paediatric cardiac services in England. In summary, the reasons for the review were stated as:

- The different NHS services that care for children with congenital heart disease could work together better
- Clinical expertise is spread too thinly over 11 surgical centres
- Small teams cannot deliver a safe 24-hour emergency service
- Smaller centres are vulnerable to sudden and unplanned closure
- There is too much variation in the expertise available from centres
- Fewer surgical centres are needed to ensure that surgical and medical teams are treating the ‘critical mass’ of children necessary to maintain and develop their specialist skills
- Available research evidence identifies a relationship between higher volume surgical centres and better clinical outcomes
- Having a larger and varied caseload means larger centres are best placed to recruit and retain new surgeons and plan for the future
- The delivery of non-surgical cardiology care for children in local hospitals is inconsistent; strong leadership is required from surgical centres to develop expertise through regional and local networks

4.9.2 The aims of the review were to:

- Establish a network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network
- Achieve better results in the surgical centres with fewer deaths and complications following surgery
- Achieve better, more accessible diagnostic services and follow up treatment delivered within regional and local networks
- Reduce waiting times and ensure fewer cancelled operations

- Improve communication for parents between all of the services in the network that support their child
- Secure better training for surgeons and their teams to ensure the sustainability of the service
- Develop a trained workforce, expert in the care and treatment of children and young people with congenital heart disease
- Establish centres at the forefront of modern working practices and innovative technologies that are leaders in research and development

4.9.3 The review was based on the following principles:

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

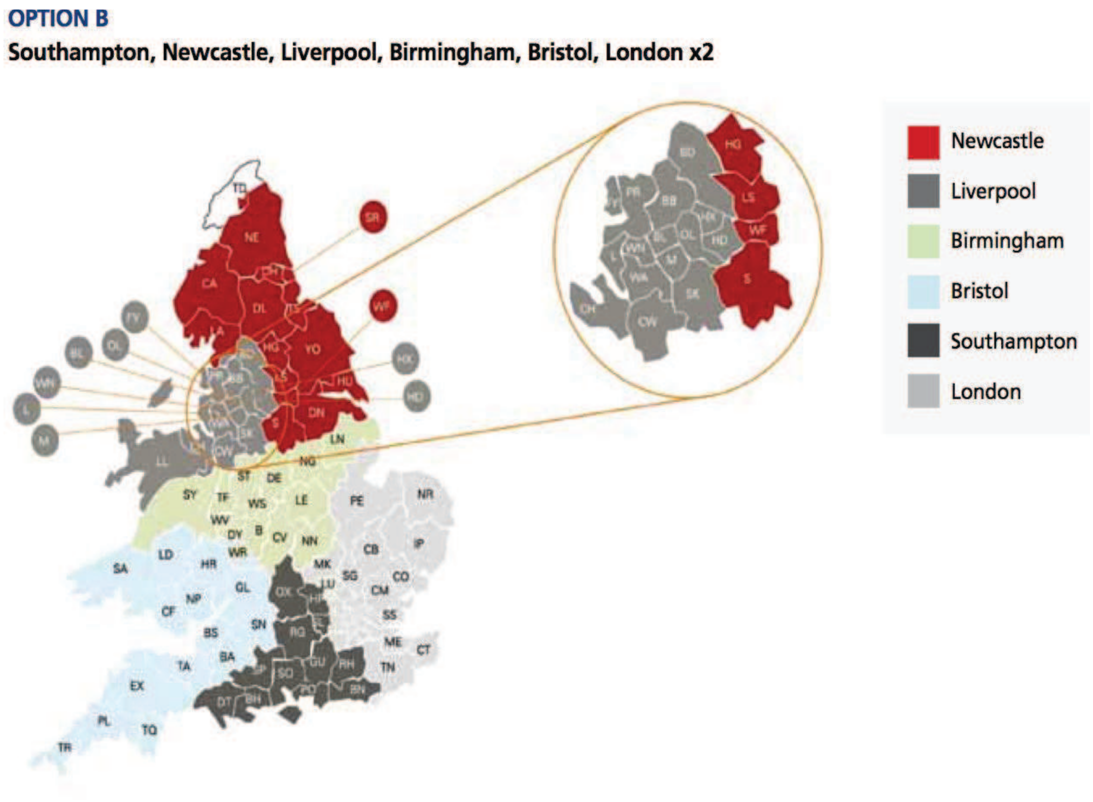
4.9.4 The proposals are to:

- Adopt new national quality standards covering seven key themes:
    - Congenital heart networks
    - Prenatal screening and services
    - Age appropriate care
    - Specialist surgical centres
    - Information and making choices
    - Family experiences
    - Ensuring excellent care
- Implement new systems for the analysis and reporting of mortality and morbidity data relating to treatments for children with CHD

- Develop congenital heart networks and reduce the number of children's heart surgery centres in England from ten to seven with 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
    - Evelina Children's Hospital at Guy's And St Thomas' NHS Foundation Trust
    - Great Ormond Street Hospital for Children NHS Foundation Trust
- De-commission the children's surgical services at Leeds General Infirmary, Glenfield Hospital Leicester and the Royal Brompton Hospital

4.9.5 The aim of the network model of care is to ensure that specialist tertiary centres, regional specialist centres, local hospitals, primary care and NHS commissioners plan, deliver and manage an entire pathway of care that delivers the best possible care for patients at every stage of treatment, including assessment, treatment and follow-up.

4.9.6 The proposed network areas to be served by the seven surgical centres can be seen in Map 4 below.



Map4: the seven proposed congenital heart networks[18]

4.9.7 The proposed model of care is based on:

- **District Children's Cardiology Services (DCCS)** providing non-interventional assessment and ongoing care led by consultant paediatricians with expertise in cardiology in district general hospitals (DGH) with a maternity unit with over 3,000 deliveries per year and;
- **Specialist Surgical Centres:** which would be a quaternary service comprising consultant congenital cardiac surgeons, consultant paediatric cardiologists and a specialist medical team providing surgery, interventional cardiology and diagnostic catheterisation as well as assessment and routine care
- The consultation documents also proposed the possibility of establishing **Children's Cardiology Centres** (CCC) at the centres that cease to provide surgical services. If established, these would provide a tertiary specialist service led by consultant paediatric cardiologists providing

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[18] Source: Review of Children's Congenital Cardiac Services in England: July 2012 Decision Making Business Case

more complex non-interventional care, including diagnostic catheterization.

4.9.8 The JCPCT told the Panel that decisions on the number and locations of DCCS and CCCs would not be resolved until standards for these units have been developed and potential DCCS and CCCs have undergone an assessment process.

4.10 Issues raised by scrutiny committees

4.10.1 In its referral letter of 27 July 2012, the Lincolnshire HSC stated that it was not satisfied that the proposals were in the best interests of the health service in Lincolnshire and in particular they raised concerns regarding the following:

- The impact of the closure of the Glenfield Hospital children's heart surgery unit on Lincolnshire families, in terms of clinical safety and accessibility
- The impact of the removal of the extra corporeal membrane oxygenation equipment from Glenfield Hospital to Birmingham Children's Hospital
- The decision-making process of the JCPCT

4.10.2 In its referral letter of 7 September 2012, the LLR Joint HOSC stated that it supports the principles of the *Safe and Sustainable* Review but is concerned at the outcome, believing that the decision of the JCPCT is not in the best interest of the local health service and the population it serves. Particular concerns were raised regarding:

- The JCPCT prediction of demand and capacity at Birmingham Children’s Hospital
- The impact of moving ECMO services and increased mortality
- Impact on paediatric intensive care capacity in the Midlands
- Impact on medical research at University Hospitals of Leicester NHS Trust (UHL) and Leicester University
- Accessibility of services
- The decision-making process of the JCPCT

4.10.3 In its referral letter of 27 November 2012, the Y&H Joint HOSC raised concerns that the overall patient experience for children and families across Yorkshire and the Humber will be significantly worse as a result of the proposals. Specific concerns were:

- The range of interdependent surgical, maternity and neonatal services are not co-located at proposed alternative surgical centres available to Yorkshire and the Humber children and their families
- The dismantling of the already well established and very strong cardiac network across Yorkshire and the Humber – and the implications for patients with the proposed Cardiology Centre at Leeds essentially working across multiple networks
- The current seamless transition between cardiac services for children and adults across Yorkshire and the Humber
- Considerable additional journey times and travel costs – alongside associated increased accommodation, childcare and living expense costs and increased stress and strain on family life at an already stressful and difficult time
- The implications of patient choice and the subsequent patient flows – resulting in too onerous caseloads (that is, overloading) in some surgical centres, with other centres unable to achieve the stated minimum number of 400 surgical procedures
- The validity of the Kennedy Panel 'Quality Assessments' in light of recent and/or forthcoming Care Quality Commission reports and/or compliance notices issued to current providers previously assessed by the Kennedy Panel
- The extent to which the JCPCT took account of the IRP's previous advice (endorsed by the Secretary of State for Health) that the JCPCT should give due consideration to comments from the Y&H Joint HOSC in relation to the PwC report on assumed patient flows and manageable clinical networks
- The implications of an unpopular solution imposed by the JCPCT for patient choice within the NHS

- The JCPCT's use of population projections/estimates to determine potential future demand for services, both in terms of using the most up-to-date information and the lack of consideration of regional variations that may impact on the long-term sustainability of specific/individual surgical centres
- The appropriateness, or otherwise, of the JCPCT and its supporting secretariat refusing legitimate requests from the Y&H Joint HOSC for access to non-confidential information during its scrutiny inquiry
- The adequacy of the public consultation conducted by the JCPCT
- Decision-making by the JCPCT

4.10.4 In later correspondence, following the initial referral, the Y&H Joint HOSC raised concerns regarding membership of the various *Safe and Sustainable* subgroups and the pattern of investment in nationally commissioned services.

4.11 **Issues raised by others**

4.11.1 Evidence from other parties opposed to the change broadly mirrored these concerns. There were, however, some additional concerns raised with the IRP by patients, charities, MPs and NHS organisations. These were:

- The evidence that a minimum of 400 operations is associated with better outcomes
- The impact of the proposals on adults with CHD and the services they use
- The robustness/validity of the health impact assessment
- The viability and sustainability of children's cardiology centres and the lack of certainty about what they will do and where they will be
- The wider impact of the proposals on the workforce
- The implications of a lack of alignment with associated neonatal networks
- Impact on children with CHD who have a range of significant other healthcare needs
- The contention that the vast majority of children will only travel to the surgical centre once
- Whether in fact care would be delivered closer to home under the proposals

- The impact of the removal of children's congenital cardiac surgery from the Royal Brompton Hospital
- The impact of the proposals on electrophysiology services and the accessibility of these services to the local populations
- That there were alternative options that would result in better accessibility
- The range of issues which have been left to the implementation stage leaving uncertainties, risks and anxieties about key aspects of the service

4.11.2 The following sections of the report outline what we heard in relation to each of these issues.

4.12 The clinical case and service quality

4.12.1 *Background and policy context*

The *Safe and Sustainable* Review was initiated primarily due to concerns that some surgical and medical teams were not operating on sufficient numbers of children to maintain and develop their specialist skills and that, due to the small number of surgeons in some surgical centres, there were risks to the resilience of the service and the maintenance of 24/7 cover. There were also concerns that clinical networks were fragmented and that the various services that treat children with congenital heart disease could do better in working together.

4.12.2 In terms of the context for the review, the Pre-Consultation Business Case (PCBC) Consultation Document and the Decision Making Business Case (DMBC) refer to the following reports and statements that had called for a reduction in the number of surgical centres, minimum activity thresholds for cardiac surgeons and the development of clinical networks:

- Bristol Royal Infirmary Inquiry, Learning from Bristol: The report of the public enquiry into children's heart surgery at the Bristol Royal Infirmary 1984 to 1995 (the Kennedy report) July 2001
- The report of the Paediatric and Congenital Cardiac Services Review Group, (the Munro report) 2003

- Congenital cardiac services; report of workshop, Department of Health June 2006
- Surgery for children: delivering a 1st class service, The Royal College of Surgeons of England July 2007
- Commissioning safe and sustainable specialised paediatric services: a framework of critical inter-dependencies, Department of Health September 2008

4.12.3 The proposals for change also reflect policy set out in the NSF for Children[19], the *Children's Plan*[20] and *Getting it right for children and young people*[21]. Reference is also made to the experience of centralisation in other clinical specialties such as stroke and vascular services as background to the review.

4.12.4 The *Safe and Sustainable* Review also draws on evidence of the benefits of developing managed network models of care in cancer services and highlights that the establishment of formal networks was one of the recommendations of the Framework of Critical Interdependencies report.

4.12.5 The evidence for the clinical case falls into three headings – the evidence of a relationship between volume and outcomes, the benefits of larger surgical teams and the benefits of clinical networks. The evidence relating to these issues formed the background to the proposed clinical model.

4.12.6 *The relationship between volume and outcomes*

The *Children's congenital cardiac services in England service standards* set a minimum number of surgeons and critical mass of surgical activity for children's congenital cardiac surgical centres. Standard C4 requires each surgical centre to be staffed by a minimum of four full-time consultant

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[19] National service framework for children, young people and maternity services 2004 Department of Health and Department for Education and Skills

[20] The Children's Plan: Building brighter futures 2007 Department of Education

[21] *Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs 2010 Sir Ian Kennedy Department of Health*

congenital cardiac surgeons. Standard C6 requires surgical centres to perform a minimum of 400 paediatric cardiac surgical procedures each year. Standard C7 sets the optimum minimum activity level at 500 such paediatric procedures. The standards state that these 400-500 paediatric procedures must be "*sensibly distributed*" between all four of the surgeons.

4.12.7 The evidence supporting the adoption of these standards refers to:

- The Kennedy Report
- The Munro report
- Evidence from other surgical specialties
- The report on optimal structure of a congenital heart surgery department in Europe, European Association for Cardio-Thoracic Surgery 2002
- International experience of a move to create larger centres in several European countries and in Canada.

4.12.8 The NHS also relied on an independent review of the available literature around the relationship between volume and outcome in paediatric cardiac surgery undertaken by the Public Health Resource Unit. It is from this literature review that the NHS draws the conclusion in the Consultation Document that "*available research evidence identifies a relationship between higher-volume surgical centres and better clinical outcomes*". Using the same source, the DMBC states that "*there is an inverse relationship between volume and inpatient hospital mortality which increased with the complexity of the operation*" and that there is evidence of a "*cumulative phenomena within institutions, in that higher-volume surgical units have increasingly better outcomes over time*".

4.12.9 Reference is also made to precedents in the UK for the centralisation of congenital cardiac services for children - with the closure of paediatric cardiac surgical services in Cardiff and Edinburgh - because the centres recognised that the surgical volumes were too low to remain sustainable.

4.12.10 The Panel heard from a number of people who questioned the evidence base that a minimum volume of 400 to 500 operations in a surgical centre is associated with better outcomes. They also felt that the evidence that exists had been used in a misleading way in the PCBC, consultation document and DMBC.

4.12.11 The Panel reviewed the evidence sources referenced by the NHS and tested these assertions with a variety of clinicians.

4.12.12 From the documentary evidence submitted, the Panel found that the thresholds for minimum critical mass recommended by the Kennedy Report, Munro Report and the European Association for Cardio-Thoracic Surgery[22] were substantially lower than 400-500 cases per surgical centre. The Kennedy Report suggested that paediatric congenital heart surgeons should perform a minimum of between 40 and 50 open–heart operations a year. The Munro report recommended that "*surgical centres should have a minimum of three paediatric cardiac surgeons performing a minimum of 300 paediatric surgical procedures per annum, on average, sensibly distributed between the surgeons to avoid occasional practice*". The EACTS report concluded that "*there are no data in the scientific literature of an exact cut-off point between what is a too small, adequate or optimal case load and indeed it seems impossible to ensure such points as so much of medical service is dependent on the local culture and circumstances*". The Report went on to recommend the optimal overall activity should be over 250 patients operated per year and each surgeon should perform 126 cardiac surgical procedures on adults or children.

4.12.13 Many people raised concerns regarding the way the conclusions that had been reached from the literature review undertaken by the Public Health Resource Unit[23] had been presented by the NHS.

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[22] Optimal structure of a congenital heart surgery department in Europe: European Association for Cardio-Thoracic Surgery 2002

[23] Ewart, H. The Relation between Volume and Outcome in Paediatric Cardiac Surgery; Public Health Research Unit - A Literature Review for the National Specialised Commissioning Group, 2009.

4.12.14 The Panel noted that the final report from the Public Health Resource Unit, in response to the question set in the brief: “*Do the findings of the review allow the generation of evidence based recommendations for the minimum volume of paediatric surgical activity for individual procedures, individual surgeons and/or individual surgical units, stratified by the age of the patient?”* stated: “*Whilst confirming the association between volume and outcome in paediatric cardiac surgery, the papers reviewed do not provide sufficient evidence to make firm recommendations regarding the cut off point for minimum volume of activity for paediatric cardiac procedures overall or for specific high complexity procedures at either institutional or surgeon level. Neither is it possible to stratify optimal volume by age of the patient. It is important to remember that volume is, in effect, a surrogate marker which subsumes a wide range of process and system characteristics which have yet to be identified or analysed for their association to outcome.”*

4.12.15 The Panel also noted that the report stated that “*in those studies expressing volume as a continuous variable no statistically significant inflection points were identified. This makes it difficult to make categorical recommendations on volume. The Bazzani study used a volume of 75 cases as the cut off between low and high volume and showed an association with outcome that may not have been statistically significant. Two Welke studies (2008, 2009) taken together suggest that a volume of over 250 cases per annum may be optimal”.’*[24]

Figure 3 : Data from the Welke study

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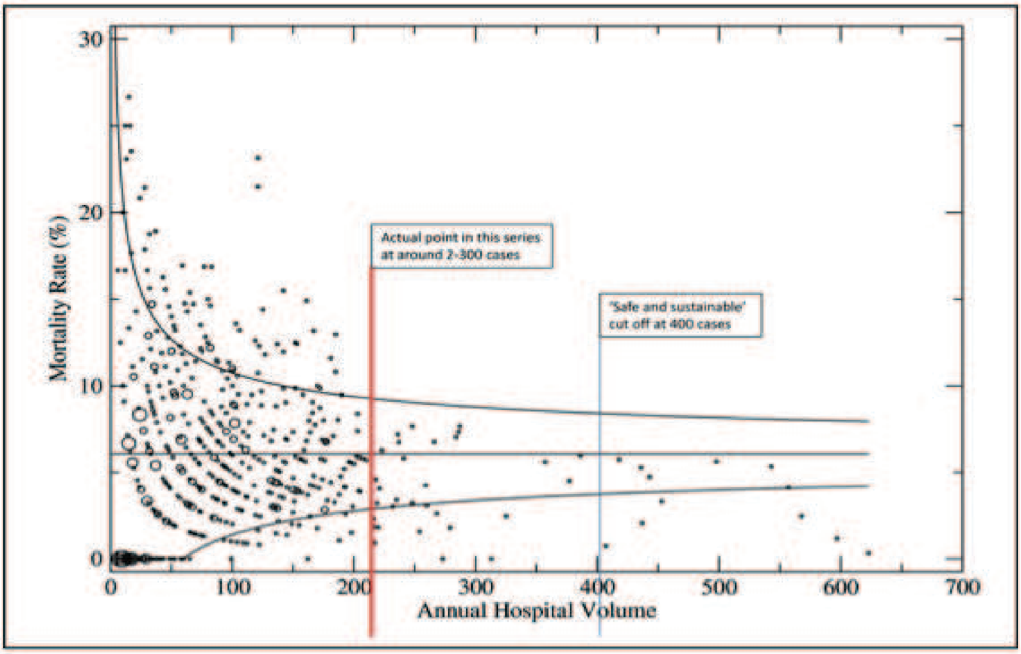
[24] Page 14 of the above publication



4.12.16 The Panel noted that the PCBC, consultation document and decision-making business case were silent on the facts that the Kennedy, Munro and EACT reports had recommended substantially lower thresholds than were being suggested by the NHS.

4.12.17 The Panel noted that the consultation document and DMBC do not indicate the lower thresholds suggested by the literature review. They do however acknowledge that "*Whilst confirming an association between volume and outcome in paediatric cardiac surgery the JCPCT has acknowledged that the scientific papers reviewed do not provide sufficient evidence to make firm recommendations regarding the cut-off point for minimum volume of activity for paediatric cardiac procedures overall, or for specific procedures at an institutional level. The standards are therefore based on the consensus of the professional societies, which in turn are based on the available evidence*".[25]

4.12.18 Many parents told the Panel that they did not believe the clinical case to reduce the number of surgical centres could be made based on the evidence of

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[25] Review of Children's Congenital Cardiac Services in England: July 2012 Decision Making Business Case – page 55

the link between volume and outcomes given the level of activity undertaken in the current surgical centres.

4.12.19 Parents, clinicians and HOSC members also raised similar concerns that it was not made clear that the international experience of centralization of cardiac surgical services referenced in the PCBC, consultation document and DMBC was based on units with much lower activity levels than the current centres in the UK and in many cases related to units with identified concerns regarding mortality.

4.12.20 It was also highlighted to the Panel that comparisons with the re-organisation of stroke units in London were not felt to be justified given that in London there were a large number of units each undertaking relatively small caseloads.

4.12.21 The Panel heard a variety of concerns from parents and clinicians regarding centres undertaking small volumes of complex procedures such as the Norwood Procedure. The Panel was told by clinicians from a number of the centres around the country that, prior to the *Safe and Sustainable* Review, it had been usual clinical practice to refer certain complex cases to centres such as Birmingham Children's and Great Ormond Street hospitals as they had a recognised level of expertise in such procedures. Some clinicians told the Panel that one of the consequences of the review had been to reduce the level of clinical cooperation between surgical centres and to create pressures on centres to demonstrate that they undertook the full range of cardiac surgical procedures.

4.12.22 The Panel heard from other clinicians whose view was that the surgical centres should be sufficiently large to undertake the full range of procedures. The Panel received information from one of the largest congenital paediatric cardiac surgery centre in the USA, in Boston Massachusetts, that they had introduced sub-specialisation within the team as a means of further improving outcomes.

4.12.23 The Panel noted that the NHS had observed in the DMBC that the literature review indicated "*an inverse relationship between volume and inpatient hospital mortality which increased with the complexity of the operation*".

4.12.24 The Panel sought the views of the Steering Group and the clinical adviser to the JCPCT who told the Panel that, in their view, complex and rare cases should not be restricted to a small number of surgical centres and that all centres should be large enough to have the competence to undertake the full range.

4.12.25 The Panel heard from a number of people who felt that it was misleading for the PCBC, Consultation Document and DMBC not to acknowledge the scale of change that had taken place since the Kennedy and Munro reports had been produced. At the time of the Kennedy Report, the surgical centre in Bristol had been undertaking around 47 paediatric operations per year. At the time of the Munro report, six centres in England and Wales were doing fewer than 200 cases a year and two were doing fewer than 100.

4.12.26 The Panel heard that the proposed standard for each cardiac surgeon of undertaking 100 -125 paediatric operations per year had not been endorsed by the professions as a whole. The Panel noted the PCBC acknowledged that the professional consensus was around 125 procedures taking into account operations on adults.

4.12.27 The Panel heard from the NHS that the final standards do not specify the number of paediatric procedures per surgeon but require the 400-500 paediatric procedures to be *"sensibly distributed between all four of the surgeons"*.

4.12.28 The Panel asked the National Institute for Cardiovascular Outcomes Research (NICOR) whether it was possible to identify the number of procedures undertaken by each surgeon to audit performance against the proposed standards. NICOR provided data that showed this is possible. Taking account of changes in personnel in year, the current data provided suggest each surgeon in England undertakes between 75 and 190 paediatric operations per year.

4.12.29 *Benefits of larger teams*

A number of the standards proposed by the NHS relate to the numbers of staff required in a specialist surgical centre. Standard C4 requires that the surgical centres are staffed by a minimum of four full-time consultant congenital cardiac surgeons. Standard C8 requires a minimum of one consultant paediatric cardiologist per 0.5 million population. Standard C9 requires each surgical centre to provide sufficient appropriately trained and experienced medical and nursing staff for a full 24-hour emergency service, seven days a week within legally compliant rotas.

4.12.30 The Panel heard that these standards were based on the advice of the Steering Group. The Panel also heard that the Steering Group was mindful that their proposed clinical standards went beyond the recommendations of the Munro Report - a minimum of three surgeons in each surgical centre, based on professional consensus at the time - but were consistent with the Royal College of Surgeons of England report in 2007. The latter had recommended four or five surgeons in each centre based on the need to concentrate expertise in the interests of quality.

4.12.31 The Panel heard from the NHS and Steering Group that the minimum of four full-time surgeons per team is based on an assessment of the job plans and available sessions of the surgeons. A minimum of four full-time surgeons is needed to ensure that at all times there should be a surgeon available to be in theatre; a surgeon on-call for emergencies; a surgeon available for outpatient clinics; and a surgeon available to undertake a combination of ward rounds, management duties, audit and governance, study leave and research.

4.12.32 The JCPCT told the Panel that a critical mass of four full-time surgeons was also considered necessary to address the implications of surgical specialisation and succession planning in each centre and to support training. It was highlighted to the Panel that less experienced surgeons often operate with a mentor, a more experienced surgeon, while they develop their competence. The JCPCT set out the benefits of larger surgical teams in providing a platform to train the next generation of surgeons.

4.12.33 The Panel heard from the clinical advisor to the JCPCT that congenital cardiac surgeons operate on all age groups, including adults with congenital problems. This emphasises the need for teamwork and the need to embed these children's services in established cardiac surgical centres, with the bigger team being able to cover all aspects of the service.

4.12.34 There was general support for the requirement of four surgeons, although some clinicians, including in centres that are to be retained under the proposals, felt that three surgeons was an acceptable number. The Panel noted that currently four of the ten surgical centres have four surgeons and six have three surgeons.

4.12.35 Clinicians in the existing centres told the Panel that having four surgeons and a large team of cardiologist, intensivists, cardiac anaesthetists, perfusionists, nurses and technicians was what made the difference to the environment for training, retention and recruitment and delivering a high quality service. The Panel heard support for the benefits of larger teams to support further sub-specialisation, training and a high level of consultant presence in the surgical centre.

4.12.36 The Panel heard from a number of clinical staff that the *Safe and Sustainable* Review had had been too narrowly focused on surgery and surgeons. They felt the review had not taken account of the contribution to achieving good outcomes of the wider teams who provide the seamless transitions from foetus to adulthood as well as the link to other specialist services. The Panel heard from many clinical teams that the improvements in outcomes over the years owe as much, if not more, to improvements in the quality of pre-surgical work up, new diagnostic imaging techniques, development of interventional cardiology and improvements in post surgical care, particularly in PICU, as they do to improvements in the quality of surgery.

4.12.37 *Benefits of networks*

The proposals are for the establishment of seven children's congenital heart networks in England. The DMBC sets out that these managed clinical networks are intended to deliver an integrated and co-ordinated approach to the care of children with congenital heart disease and their families, from antenatal screening and maternity services through to the transition to services for adults with congenital heart disease. This would be achieved by the implementation of common protocols within defined patient pathways, with clear accountability and governance structures.

4.12.38 These networks would be led by the specialist surgical centre who would hold the responsibility to provide clear and effective leadership of the network. A board of clinicians from across the network and lay people would oversee the running of each congenital heart network and ensure that other relevant services such as antenatal screening, child health services, psychology services and GP services are encompassed.

4.12.39 The benefits of the network were stated to be:

- Addressing the current inconsistent stage of development of the existing networks around the country
- Addressing the fragmented and inconsistent pattern of current services through the establishment of standards and clinical protocols
- Better coordination of the pathway of care
- Better collaboration in the provision of care and undertaking research
- Better communication amongst clinicians and with parents
- More accessible services for children and their families
- The ability of effective regional networks to facilitate a national network of designated surgical units, working together to share learning, best practice and innovation.

4.12.40 In its referral, the Y&H Joint HOSC raised concerns regarding the dismantling of the already well-established and very strong cardiac network across

Yorkshire and the Humber. The Committee also had concerns about the implications for patients if the proposed cardiology centre at Leeds had to work across multiple networks.

4.12.41 The Panel heard from the JCPCT that the strength of the current network in Yorkshire and Humber was acknowledged. The JCPCT also acknowledged to the Panel that there had been numerous responses to the consultation that had made reference to the strength of the existing network in Yorkshire and Humber. The JCPCT stated that they concur with the Y&H Joint HOSC's recommendation that the strengths of the Yorkshire and Humber network should be retained and built upon as part of the future service model. The JCPCT told the Panel that the establishment of a formal network board would be the driver for developing the congenital heart network in the north of England and that clinical colleagues from the existing Yorkshire and Humber network would be key to its development.

4.12.42 The Panel sought clarification regarding the pattern of services that the JCPCT envisaged for children in the Bradford, Halifax and Huddersfield areas. The Panel were told that subject to the outcome of the future designation process for CCCs, children in these areas would be aligned with the CCC in Manchester and not Leeds as they reside in the proposed Liverpool network. The JCPCT acknowledged that this would involve a longer journey for these children but felt strengthening specialist inpatient and outpatient paediatric cardiac services at local hospitals in Bradford, Calderdale and Huddersfield would mitigate this impact. The JCPCT stated that if a CCC was created in Leeds it would only have a clinical relationship with the Newcastle surgical centre and would not work across multiple networks.

4.12.43 Parents and clinicians from a number of areas around the country, including from centres proposed to be designated as surgical centres, raised concerns about the lack of alignment and cogent geography between the proposed children's congenital cardiac networks and fetal, paediatric and adult cardiac networks. A particular concern was the implication for children who were not diagnosed antenatally and for the 25 to 30 per cent of children with CHD who have multiple morbidities. The Panel was given examples of clinical scenarios where, given the proposed network boundaries, children could potentially be seen in up to four tertiary centres within the London networks resulting in a complicated set of relationships with different organisations and a high burden of travel to access services.

4.12.44 The Panel also heard concerns about the implications of a lack of alignment between paediatric and adult congenital cardiac networks and the particular challenges that would create for teenagers during transition to adult services. Clinicians advised the Panel that some patients do get lost to the service at the point of transition and that the scale of the loss increases with the geographic disconnection between paediatric and adult services. There are long-term implications for the health of patients who are lost to follow-up.

4.12.45 The Panel was told of the work underway by NHS London on the development of north/south hubs for specialist paediatric services and that this is not aligned with the network boundaries and patient flows assumed under the *Safe and Sustainable* proposals.

4.12.46 In a written response, the NHS told the Panel that NHS England *"will define the London networks with precision, taking account of the outcome of the separate on-going review of tertiary paediatric services in London. The development of formal paediatric networks in London provide an excellent framework for increased collaboration across Great Ormond Street and the Evelina Children's Hospital"*.

4.12.47 The Panel asked the JCPCT how Standard A6, which states congenital heart networks should be aligned to the networks for fetal and adult congenital services would be achieved. In a written response, the JCPCT stated that "*this is a network issue for implementation and alignment does not necessarily mean coterminous, reflecting the advice offered to the JCPCT by Prof Roger Boyle that coterminous was desirable but probably not achievable in all cases"*. In relation to fetal services, the Panel was told that this would be addressed by the Clinical Implementation Advisory Group (CIAG) and NHS

England during the implementation stage, as would the precise boundaries of the networks.

4.12.48 In relation to adult congenital services, the JCPCT told the Panel that the scope of the adult networks is not yet known, as the process for designating ACHD services will not conclude until 2014. The JCPCT stated that it would be for NHS England to determine how the ACHD networks align with paediatric networks. The Panel heard that there is broad consensus on the CIAG and the adult congenital heart disease advisory group that alignment should be achieved as far as possible, bearing in mind that not all surgical units provide both paediatric and adult congenital cardiac surgical services. The JCPCT stated that it has already reflected in the standards and model of care the importance of a seamless transfer of care from children to adult congenital services.

4.12.49 The Panel asked the JCPCT for further information about how they would make networks work effectively where they were not aligned. The Panel was told that where alignment cannot be achieved, the issues would be addressed by ensuring clarity about the relationships between different networks and establishing clear pathways for referral, clear structures, systems and processes. The JCPCT said that they believed that the issues around transition could be effectively managed even where transition was into a different network, through effective cardiac liaison nurse and transition nurse support.

4.12.50 The Panel heard proposals for alternative network options. The Y&H Joint HOSC had proposed an eight-centre model that retained Leeds as a surgical centre in addition to the seven proposed centres. Committee members told the Panel they felt this option would better support the population of Yorkshire and the Humber and that the Committee had put forward this proposal in its response to the consultation.

4.12.51 University Hospitals of Leicester NHS Trust told the Panel they had proposed a *Heart of England network* that would involve Birmingham Children's Hospital and Glenfield Hospitals in a joint venture providing surgery at both sites. The

Trust told the Panel that they considered this option would eliminate the concerns about lack of capacity, the risks to respiratory ECMO and the provision of paediatric intensive care in the Midlands area, as well as improving accessibility.

4.12.52 The Panel heard a similar proposal from Young Hearts, a charity in Oxfordshire, who proposed a model where surgery would take place in Oxford and Southampton with a joint group of 6-7 surgeons operating on both sites. Young Hearts told the Panel the proposals failed to give sufficient consideration to the risks associated with patients with CHD who require treatment in an emergency. They pointed out that John Radcliffe Hospital was a major trauma centre and a centre taking high-risk maternity patients. They highlighted to the Panel a range of implications of the proposals on other services at the John Radcliffe Hospital that they felt would be addressed under their alternative proposal.

4.12.53 The Royal Brompton & Harefield NHS Trust told the Panel they had proposed a three-centre network option for London.

4.12.54 The JCPCT told the Panel that they had considered all the responses put forward during the consultation. They had rejected these proposals on the basis that they did not comply with the standards in respect of the minimum number of surgical procedures per centre and minimum of four surgeons per centre who must be based permanently on a single site.

4.12.55 The Panel asked the NHS and the JCPCT what the arrangements for commissioning the services within the network would be and how CCCs and DCCS would receive their funding. The Panel was told that the commissioning arrangements have not yet being worked through. In response to further enquiries from the Panel, NHS England confirmed that, whilst it will commission all paediatric cardiac services from specialist surgical centres and CCCs, as well as paediatric and neonatal retrieval services, the responsibility for commissioning services provided directly by district cardiology services sits with clinical commissioning groups (CCG). NHS England also confirmed that commissioning would not at this stage be through a lead provider arrangement although this model is in general development within NHS England and may be adopted in the future for specialised services.

4.12.56 *The model of care – children's cardiology centres and district children's cardiology services*

The DMBC sets out the model of care for the paediatric congenital cardiac network. In addition to the specialist surgical centres, it is proposed the networks would comprise DCCS and possibly, in some areas, CCCs as well.

4.12.57 CCCs are described as a tertiary specialist service, which would be led by consultant paediatric cardiologists and would provide more complex non-interventional care than the DCCS. It is envisaged they would act as tertiary referral units for a designated surgical centre working to the same standards and would provide a link to the DCCS in their network.

4.12.58 DCCS would provide non-interventional assessment and ongoing care and would be led by consultant paediatricians with expertise in cardiology (PEC). The intention set out in the PCBC is that PECs would have two sessions per week for this activity. The DCCS are proposed to be located at hospitals with maternity units delivering over 3,000 births per annum. At the time of preparing the consultation document, there were 94 trusts with such units in England.

4.12.59 The Panel noted that in the PCBC it was proposed that centres that are not designated as surgical units in the future *would* become children's cardiology centres, while in the consultation document it is stated that centres that are currently providing heart surgery that ceased to do so *may* become children's cardiology centres.

4.12.60 The DMBC records that a number of concerns regarding CCCs were raised during the consultation. These can be summarised as follows:

- The proposals are not well developed and it is not clear whether these centres would be sustainable

- More senior and experienced paediatric cardiologists would gravitate to specialist surgical units and CCCs would be unable to recruit and retain high quality staff
- Clinicians would not value the service provided by an intermediate tier
- In practice there would be no difference between a CCC and a DCCS
- Parents would not have confidence in the quality of services and safety at CCCs

4.12.61 The DMBC records that although CCCs are considered to be viable, the Steering Group considered there were potential risks to the sustainability of CCCs and highlighted to the JCPCT that mitigation of these risks would be a key issue for implementation. The JCPCT approved the recommendation in the DMBC that the proposed model of care, including CCCs is viable and should be implemented in England.

4.12.62 The Panel heard a range of concerns from clinicians (in surgical centres that are proposed to be retained and those proposed to be de-designated), representatives of professional associations and from parents regarding the viability of CCCs. The concerns mostly echoed the issues raised during consultation but there were some new issues.

4.12.63 Many people told the Panel that they could not see how a CCC at the Royal Brompton Hospital would be viable or add value given the proximity of the proposed surgical centres at Great Ormond Street and Evelina Children's hospitals.

4.12.64 The Panel heard from clinicians and professional associations that paediatric cardiologists are a scarce resource and there are concerns that the proposals for CCCs would be unattractive to existing consultants and to future trainees. A number of clinicians told the Panel of their concerns about the implications of failure of the CCC model for patients in large geographic areas of the country which will be relying on the success of CCCs for access to specialist support for the day-to-day care of children with heart problems.

4.12.65 Issues were raised about the financial viability of CCCs as Trusts were not confident that the level of activity CCCs would undertake would attract sufficient payment under PBR to cover costs. The question of how attractive it would be to Trusts to provide these services was also raised.

4.12.66 The Panel was told by the NHS and the JCPCT that decisions on the number and locations of DCCS and CCCs would not be resolved until standards for these units have been developed and potential DCCS and CCCs have undergone an assessment process. The SRO for implementation told the Panel that work was underway to develop the standards for the CCCs and, on the basis of the standards, to work through the networks to identify where the cardiology centres should be. Potential CCCs would have to go through a self-assessment process and an external panel assessment in order to achieve designation. In terms of the funding for CCCs, the NHS told the Panel that the commissioning process is part of the implementation plan and would be picked up by NHS England but that the majority of funding would be via the payment by results tariff. The Panel was told that the financial viability of CCCs had not been assessed to date as the volume of activity these centres would undertake is not yet clear and would vary depending on network arrangements.

4.12.67 In relation to a CCC in London the JCPCT confirmed that there was a question over the value of a CCC given the proposed full range of services provided at the Evelina and Great Ormond Street hospitals.

4.12.68 The NHS and the JCPCT told the Panel that there was evidence that CCCs are a viable model as there are current centres in Edinburgh, Manchester and Cardiff. In addition, the former surgical centre at Oxford Radcliffe has begun to develop a relationship with Southampton, operating as a CCC.

4.12.69 The Panel visited Manchester, Cardiff and Oxford and spoke to commissioners from the National Services Division of the NHS in Scotland about the service in Edinburgh.

4.12.70 There were some common themes in the evidence the Panel received from the visits to Manchester, Cardiff and Oxford:

- All three centres cited the importance and benefits of retaining paediatric cardiology on site to support the needs of other specialist services, including non cardiac care of children with CHD, foetal and perinatal care
- Due to clinical governance considerations, Manchester and Cardiff no longer undertake diagnostic or interventional catheterisations nor electrophysiology (EP) except on older and larger children in Manchester who are treated by the adult EP service
- The number of post-procedural transfers from the surgical centres to the cardiology centres is small
- Mutual respect, communication and clear governance and accountability were essential to make the CHD pathway work effectively. However the Panel found different approaches to these issues had emerged in each centre
- Expectations about the demands of travelling for peripheral clinics, MDTs, emergencies and training need to be realistic – an hour's drive is considered at the outer limit of practice in Manchester and Cardiff
- Recruitment and retention of paediatric cardiologists has been an on-going issue

4.12.71 The Panel heard that there was a range of issues that would need attention if CCCs were to be established elsewhere:

- Enhancing the availability and capacity of retrieval and transfer teams
- Ensuring communication with the clinicians in the CCC is maintained when children are discharged from the surgical centre to home or to DCCS
- Testing capacity assumptions as distance has an impact on length of stay at the surgical centre and the level of day case activity tends to decline.

- Assessing and addressing the potential knock on effect of cessation of congenital cardiac surgery on referral patterns for other tertiary services provided by the de-designated surgical centres
- Developing contractual funding mechanisms that ensure the service is viable.

4.12.72 The Panel heard that the service in Cardiff is directly funded by commissioners and the clinicians in Cardiff control the onward referral of cases to surgical centres in England, most of which are to Bristol.

4.12.73 The Panel heard from the team at John Radcliffe Hospital Oxford regarding their experience of making the transition from a surgical centre to a cardiology centre. The team told the Panel that they have a very positive, constructive and mutually supportive relationship with their colleagues in Southampton.

4.12.74 They told the Panel about the challenges presented by relating to a surgical centre that is 60 miles away. In their view, the distance between the CCC and surgical centre would make a real difference to what it is possible to do at the CCC and to its viability and sustainability. Consequently, different solutions would be needed in different parts of the country. The team highlighted the importance of two issues - the clinical teams meeting face-to-face regularly and opportunities for staff in Oxford to work in Southampton to enable them to maintain confidence in caring for cardiac patients in the cardiology centre. Their experience is that this applies particularly to nursing (ward, high dependency and ITU) but also to anaesthetic and HDU/ITU physicians.

4.12.75 The Panel heard from Commissioners from the National Services Division of the NHS in Scotland that there are two cardiologists at Edinburgh, one of whom will shortly retire and it is unlikely that a replacement will be recruited as the volume of cases is not sufficient. They told the Panel that the service in Edinburgh is purely a medical cardiology service and diagnostic catheterisations and all interventions are undertaken in the surgical centre in Glasgow.

4.12.76 The Panel heard from a number of parents and clinicians who were concerned that the full impact on patients of the proposals had not been fully appreciated, particularly as 25-30 per cent of children with CHD have significant other healthcare conditions. They told the Panel that the range of services that could be retained in CCCs had been overstated and consequently the impact on patients had been understated. They highlighted the experience of Cardiff and Manchester in relation to EP and diagnostic catheterisations. In addition, they told the Panel CCCs would not have specialist paediatric cardiac anaesthetists and as a result, particularly over time, clinical skills and confidence in the remaining team would decline. As a result, children with congenital heart conditions who need an anaesthetic for any reason - from a diagnostic test to surgery un-related to their heart condition - would have to travel to the specialist surgical centre for treatment due to the clinical risks.

4.12.77 The Panel heard concerns from a number of parents and charities around the country about the implications for EP services. The Panel was told that children with rhythm abnormalities may require an implanted device as part of their management. Such devices are much more commonly used in adult patients and therefore a joint adult and paediatric service is better placed to provide optimum management of the children as they can use the extensive experience gained from adult patients.

4.12.78 The DMBC states that EP services would be provided in the CCCs working to protocols devised by the Network, which set size and weight parameters. The Panel heard from a number of clinicians around the country that they had significant doubts about the viability and clinical safety of providing EP services in centres that did not have on-site cardiac congenital surgical support. The evidence presented to the Panel included the results of a survey of paediatric electrophysiology clinicians.

4.12.79 The Panel heard that the experience of the Royal Brompton Hospital is that 30 per cent of children who have congenital cardiac surgery require EP or pacing (either as a child or as an adult) and for those that receive a cardiac catheter procedure as a child, 16 per cent will require electrophysiology or pacing (either as a child or as an adult).

4.12.80 The Panel spoke to a wide range of clinicians and professional associations about their views on district children's cardiology services and the role of the PEC. There was strong support for the role of the PEC, and the Panel was told there are a substantial number of PECs already in post. The Panel heard that historically the reason for the emergence of the role of the PEC was the volume of less complex cardiology problems was swamping the small number of paediatric cardiologists nationally. The concept of the PEC was to underpin the work of the paediatric cardiologist. Some clinicians explained that one of the unintended consequences of having a good PEC is that there is some deskilling of other paediatric colleagues who may then rely on the PEC who cannot provide 24/7 cover and is not sufficiently trained to deal with the complex and acute cases. Some concerns were raised about the support or priority the proposal for PECs would receive from trusts whose pressing concerns are 24/7 consultant rotas, weekend working and acute paediatrics.

4.12.81 A number of clinicians raised a general concern with the Panel regarding the risk to patient care if there is insufficient development of CCCs and DCCS before changes are made to the existing surgical centres.

4.12.82 *The model of care – co-located maternity and children’s services*

One of the major concerns raised with Panel by the Y&H Joint HOSC was the fact that currently Leeds General Infirmary provides a full range of interdependent surgical services, maternity and neonatal services on one site and in addition provides seamless transition between cardiac services for children and adults also on that site. This is in contrast to the proposed surgical centres that would be used by the Yorkshire and Humber population under the proposals, the Freeman Hospital in Newcastle, which is a specialist hospital, and the children’s hospitals in Birmingham and Alder Hey which are stand alone children’s hospitals and do not have fetal medicine and maternity services on the same site.

4.12.83 The Y&H Joint HOSC told the Panel that they believe that co-location of services in the way they are provided in Leeds can significantly reduce the potential negative impacts associated with the separation of the mother and baby immediately after birth. The Committee felt that these issues had not received sufficient consideration during the review and specifically when defining co-location.

4.12.84 The Y&H Joint HOSC referred to a statement issued in February 2011 by the BCCA referring to the numerous interdependencies between key clinical services from '*fetus to adult*' and setting out the BCCA's opinion that '*for these services at each centre to remain sustainable in the long term, co-location of key clinical services on one site is essential*'.

4.12.85 Committee members and local parents told the Panel that they could not understand a decision that would result in children from Yorkshire and the Humber being treated in hospitals that were not able to offer the level of co-location currently available. The Y&H Joint HOSC was critical of the definition of co-location used by the JCPCT which it felt did not reflect the definition that would be applied by the general public.

4.12.86 A number of parents from around the country told the Panel about stress on mothers and families of having their child being treated in a different place to where the mother had given birth. The Panel heard from families in other parts of the country how much they valued this integrated pattern of service delivery and the difference it had made them in terms of their experience. The Panel also heard from parents whose children had been treated in hospitals that did not have full co-location on one site who reported very positive experiences of the care that they had received.

4.12.87 A number of clinicians told the panel that given that 25-30 per cent of CHD children have co-morbidities they felt that co-location with specialist children's services was as significant to the quality of service as the size of the team and scale of the activity of the specialist surgical centre.

4.12.88 The Panel noted that the DMBC records that a variety of views were expressed during the consultation regarding the interpretation of co-location and that some respondents did argue that the range of services that should be incorporated in the definition of critical inter-dependencies should be broadened to include fetal, obstetrics, maternity, neonatal and general paediatric services.

4.12.89 The JCPCT told the Panel that they had accepted expert advice in respect of their definitions and interpretations in relation to critical interdependencies and co-location. In the view of the JCPCT while the Y&H Joint HOSC may be correct in stating that the public would generally consider co-location to mean services located on a single hospital site, in their view this is a complex issue that requires expert interpretation and on which they had taken expert advice. The JCPCT highlighted that in response to the respondents from Yorkshire and the Humber who suggested that the wrong definition of co-location had been used in the Kennedy Panel assessment, in August 2011 the JCPCT asked Prof Kennedy's Panel to reconsider its advice in the light of the evidence submitted during consultation. They told the Panel that the Kennedy Panel concluded, and they had accepted, that whilst the optimal arrangement was co-location of service on the same hospital site the assessments had been undertaken correctly.

4.12.90 The JCPCT highlighted that only two centres currently offer the full range of maternity and children’s services on one site, Leeds Teaching Hospital and Southampton General Hospital and they therefore felt this demonstrated that the model is an exception rather than the rule. They told the Panel that they had undertaken sensitivity tests as part of the appraisal process in which the various criteria used in the Kennedy assessment process were re-weighted so co-location of services was the highest scoring criterion and when this was done Newcastle still scored higher than Leeds.

4.12.91 The Y&H Joint HOSC raised issues associated with potential obstetric referral patterns, the impact these may have on patient numbers at the proposed designated surgical centres and to what extent such matters were taken into account within the JCPCT's decision-making processes.

4.12.92 The JCPCT told the Panel that there is no evidence to suggest that the obstetric services in Newcastle would have insufficient capacity to meet the needs of mothers who wished to be delivered, or whose clinical condition required delivery, close to the surgical centre in future. They also highlighted that standard F8 requires that that there must be facilities in the surgical centres, including access to maternity staff, that allow the mothers of newborn babies who are admitted as emergency to stay with their baby for reasons of bonding, establishing breastfeeding and emotional health of mother and baby.

4.12.93 *The model of care - adult services*

All of the overview and scrutiny committees who have referred the proposals raised concerns about why the review had not taken account of the impact on adults with CHD or, been undertaken as a single review of the service required to treat people with this life-long condition. They told the Panel that doing so would have enabled better solutions to be found that had a higher level of support and reduced the impact on accessibility.

4.12.94 The Panel was told by some professional associations that the professions had suggested four surgeons each undertaking 125 cases per centre but that they had not said that these should all be paediatric and that they had made their views known that the review of paediatric services should not be undertaken in isolation. The Panel was shown a letter co-signed by 35 ACHD professionals to Dr Pat Hamilton (Chair of the paediatric *Safe and Sustainable* Steering Group) urging her to include adult services in the review in May 2010.

4.12.95 The Panel heard similar concerns from clinicians in a number of trusts, including those designated under the proposals, and from parents.

4.12.96 The Panel heard from some professional associations and clinicians that adult congenital heart disease patients are by far the larger proportion of the total congenital heart disease patient population and the numbers of adult patients is set to increase substantially. They had concerns that the proposals would lead to a shortfall in capacity for ACHD patients. They also drew the Panel's attention to the fact that a substantial proportion of the workload of the 'paediatric' surgeons is ACHD patients. They told the Panel that the number of procedures on ACHD patients recorded on CCAD is only a partial dataset as many surgical procedures are carried out on ACHD patients by non-specialist surgeons. Their projections were that there are likely to be in excess of 3,000 adult congenital surgical procedures per year by 2025, plus a substantial volume of interventional procedures, the number of which is also increasing rapidly. They told the Panel that ACHD and paediatric surgical workload is likely to exceed 8,000 cases comfortably by 2025.

4.12.97 People told the Panel that the impact of the drive to move to larger centres was exaggerated by the decision to separate the review of paediatric and adult services. They did not feel it was right or appropriate that the future of adult congenital cardiac services should be determined by a review of children's services in which the needs of adult congenital heart disease patients had not been considered. People told the Panel they were concerned about the impact on patients if they had to move centres or networks when they transitioned to adult services. They told the Panel they were very concerned about the impact on vulnerable patients such as those with Down Syndrome who have a high incidence of congenital heart disease and patients who have a degree of neuro-disability.

4.12.98 Some clinicians told the Panel that in their view it will only be possible to be a designated ACHD surgical centre with an affiliated and closely geographically linked paediatric surgical centre.

4.12.99 The Panel heard from the JCPCT that Sir Bruce Keogh's letter of May 2008 asked the National Specialised Commissioning Group to establish a process of the reconfiguration of paediatric congenital cardiac services, and that the Secretary of State for Health's letter to Dame Ruth Carnall of August 2008 also refers to review of paediatric congenital cardiac services. They told the Panel that the process of two separate review processes across ACHD and paediatric congenital heart services was endorsed by the professional associations on the *Safe and Sustainable* Steering Group in December 2008. They told the Panel that the minutes of that meeting record that the issue was discussed and members agreed that ACHD services would be taken into account only insofar as the transition from paediatric to ACHD services was concerned.

4.12.100 The Panel heard from the JCPCT that their view was that the total workload would be below 5,000 procedures per annum for adults and children. The JCPCT confirmed that the outcome of the paediatric review would have a major influence in terms of the configuration of adult services. They told the Panel that the draft standards that have been developed by the ACHD group stipulate that, in the future, adult congenital surgical services need to be co-located with paediatric congenital cardiac services. They highlighted to the Panel that this recommendation was made after the JCPCT had made its decision, so in their view there was no predetermination.

4.12.101 The Panel asked the JCPCT whether, in the light of two separate reviews that had inevitable inter-dependencies, it had assessed the impact of their proposals for children's congenital heart services on ACHD services, for similar reasons as it had assessed the impact on PICU, respiratory ECMO, transplant services and on specialist respiratory services at the Royal Brompton Hospital. The JCPCT told the Panel that they had not.

4.12.102 *The model of care – retrieval services*

The Panel heard from paediatric transport specialists and clinicians in surgical centres that retrieval services are an integral part of the paediatric congenital cardiac service and there is a pressing need to develop a comprehensive, consistent, high-quality retrieval service across the country. This requirement was all the more urgent due to the increased demands that would be placed on retrieval services as a result of the proposals. In their view, there was no reason for retrieval services to be a constraint on the location of delivery of children's congenital cardiac services provided the retrieval service is planned and resourced accordingly.

4.12.103 The Panel raised this issue with the JCPCT who told the Panel that retrieval is a *mission–critical* issue and they saw an important opportunity to address the issue of retrieval generally, which it was agreed was too patchy currently. They told the Panel that irrespective of the Safe and Sustainable Review, this work is being taken forward nationally as part of implementation.

4.12.104 *Service quality*

The Y&H Joint HOSC raised questions with the Panel regarding the validity of the Kennedy Panel *Quality Assessments* in light of recent Care Quality Commission reports and enforcement action against University Hospitals Bristol NHS Foundation Trust.

4.12.105 The Panel asked Sir Ian Kennedy and the JCPCT about these issues. Sir Ian told the Panel that the assessments were a statement of what the assessment panel thought, in the light of the evidence they were presented with, about the level of safety and sustainability by reference to the Safe and Sustainable standards. Both he and the JCPCT highlighted that the standards applied by CQC are different and a significant period had elapsed between the *Safe and Sustainable* assessment process and the issues raised by CQC.

4.12.106 The NHS told the Panel that no concerns had been put to the Kennedy Panel by staff or parents at the time of the Kennedy Panel assessment that gave the Kennedy Panel any cause for concern in respect of matters highlighted by CQC.

4.12.107 The Panel noted that CQC has judged that Bristol Royal Hospital for Children has now complied with the CQC standards.

4.12.108 The Panel met with parents who had serious concerns regarding the quality of the services that they had received at some of the surgical centres. These concerns related to four of the surgical centres, three of which are proposed to be retained. Some of these families had experienced the death of their child and felt that there had been failings in the service that had contributed.

4.12.109 The Panel was troubled to hear some people assert that there were known and significant differences in the outcomes achieved by existing centres. The Panel sought the evidence behind these assertions. Data presented to the Panel, and in the public domain, about potential variation in outcomes in some cases suggested contradictory findings. The Panel asked the JCPCT, as commissioners, whether there existed any further information about the safety or performance of the current centres that would help inform the Panel's advice to the Secretary of State. The JCPCT confirmed that there did not.

4.12.110 The Panel heard a variety of views about the ability to use current data to identify variations in outcomes and in performance, as a means of driving up service quality. The key issues that constrain the ability to use data in this way are the small numbers of cases involved and the ability to stratify accurately the data to take account of the inherent risk of the procedure.

4.12.111 The Panel heard from the Medical Advisor to the JCPCT that NICOR had secured funding to roll out across all congenital cardiac providers in England a programme that allows individual providers to monitor their own performance using Variable Life Adjusted Displays (VLAD plots). In addition, further research is underway to obtain risk-adjusted standardized mortality ratios (SMRs) for each centre.

4.12.112 Having been informed on 18 March 2013 that the NICOR programme of research would likely lead to publication of SMRs for each centre in June 2013, the Panel notes that some results were used in the events surrounding the temporary closure of the Leeds surgical centre at the end of March. NHS England subsequently published, on 12 April 2013, comparative results for all ten current surgical centres using the new partial risk adjusted methodology.

4.13 Development of the proposals and assessment of the options

4.13.1 A substantial proportion of the concerns that were raised with the Panel related to the analysis that supported the development and assessment of the options and the way in which information was used to reach the final decision. The concerns raised fall under a number of headings.

4.13.2 *Population projections*

The Panel heard from HOSCs, Trusts, clinicians and parents that the assumptions for the future surgical workload were flawed because they failed to take account of the latest ONS population projections. The Y&H Joint HOSC also raised concerns that the JCPCT had not taken into account any regional differences in population growth, which they felt, were material to judgements about the accessibility and sustainability of the proposals.

4.13.3 The Panel heard from some people that they could not see why two centres were justified in London to serve a population that was not much greater and more geographically compact than the Midlands.

4.13.4 People told the Panel that future population growth and within that, regional variation in population growth, might result in excessive demands being placed on some centres and others failing to meet the minimum activity thresholds.

4.13.5 There were also concerns expressed to the Panel about the impact of the significant population growth in northeast London and the impact this might have on Great Ormond Street Hospital.

4.13.6 The Panel heard from a number of parents that they could see no justification for the changes when projected population growth meant that the existing ten surgical centres could reach the threshold of 400-500 cases.

4.13.7 The NHS told the Panel that their capacity analysis was concluded by February 2012, before the latest ONS statistics were published in March 2012. In their view any differences as a result of the updated population projections will be marginal, given the low incidence of congenital heart disease overall. They stated that they had used projected growth in population as a proxy for projecting the future surgical caseload because the cumulative impact of various factors, such as improved antenatal diagnosis, more sophisticated cardiology interventions or new drugs means that the number of operations required cannot be quantified with certainty. They told the Panel that if further capacity was required this could be accommodated in the proposed seven centres.

4.13.8 *Health impact assessment*

The Y&H Joint HOSC made a number of detailed criticisms of the health impact assessment (HIA) and identified some numerical inaccuracies in the document and errors in network maps. The Committee was also critical of the JCPCT's refusal to disclose information related to the HIA. Of particular concern was the fact that the health impact assessment did not consider impacts on a regional basis, that is, was the impact on the Yorkshire and the Humber population greater than the impact on other regions. Committee members told the Panel that they believe the 8–centre option recommended in their response to the consultation would have demonstrated this option had a lesser impact. The Panel was also told that the Committee believes that the proposals result in severe impacts on particular localised areas and vulnerable groups that are effectively masked by averaging them into a national picture. The Y&H Joint HOSC presented the Panel with data on the socio-demographic characteristics of the population in Kirklees and Leeds that demonstrated high levels of social deprivation. The Panel also received a regional impact assessment report that had been undertaken by Yorkshire and the Humber Specialised Commissioning Group that showed high levels of congenital cardiac health needs in the Bradford, Kirklees and Leeds areas.

4.13.9 Other HOSCs and local Trusts presented the Panel with detailed information on the demographic characteristics and health needs of vulnerable groups in other areas of the country whom they felt were adversely affected by the proposals. The Panel heard that the HIA demonstrated that option G had fewer negative impacts than option B.

4.13.10 The NHS told the Panel that their response to requests for information had been reasonable and that the HIA does not support the Y&H Joint HOSC view that there would be severe impacts on particular localised areas. Contrary to the Committee’s view, the NHS highlighted that the advice they received from the independent authors of the HIA was that the numbers of patients in vulnerable groups likely to experience impacts is very small under all the options and key vulnerable groups are expected to benefit disproportionately from the positive impact of improved health outcomes and care delivered closer to home.

4.13.11 Mott MacDonald, the authors of the HIA, acknowledged the errors identified by the Y&H Joint HOSC but stated that although regrettable, they made no material difference to the findings. They told the Panel that their analysis was based solely on the number of patients undergoing surgery and that they had not taken account of the impact on the patients and families who would have to travel to the specialist centre for interventional cardiology. The Panel asked if Mott MacDonald had been aware, at the time, that the standards that were consulted upon unequivocally stated that all interventional cardiology work would be undertaken in the surgical centres. Mott MacDonald confirmed that they were aware of this. They told the Panel that there were two reasons they did not take account of this. The first was for reasons of consistency, as the data used by KPMG in the access mapping, activity distribution mapping and development, assessment and scoring of the access criteria of the options was only for surgery. The second was that differing views were being expressed during the consultation about whether interventional cardiology would take place in the CCCs and, therefore, there were no reliable data on which to base an assessment. They also told the Panel that they had not attempted to assess the impact of the changes to district services for the same reason, that is, the absence of a reliable dataset.

4.13.12 The Panel asked Mott MacDonald what evidence they relied upon to conclude that the proposals would have significant benefits for particular vulnerable populations. The Panel heard that Mott MacDonald relied on the statements in the consultation document that the quality of care would be improved in the surgical centres and networks would be developed so as to bring more services closer to home. The Panel asked if any assessment had been undertaken to test this. The Panel was told that there had not.

4.13.13 The Panel noted that the HIA states that children who have CHD but also have significant other healthcare needs, referred to as children with "multiple morbidity" or "co-morbidity", and children with Down Syndrome were acknowledged to be more likely to experience disproportionate effects and asked if the HIA had been able to identify impacts on these patients. The Panel was told this had not been included due to a lack of data.

4.13.14 The Panel asked Mott MacDonald how they had calculated the average length of stay used in their carbon assessment of 3.9 days for surgical patients. The Panel were told that this was based on 2008/09 HES data and the length of stay for a defined range of procedures. The Panel noted that the list of procedures was not consistent with the list of procedures in the rest of the HIA analysis and the average length of stay was significantly shorter than the length of stay reported to the Panel when it visited the ten surgical centres.

4.13.15 Almost without exception, the parents who met the Panel told them that they had multiple trips to the surgical centre for admissions and procedures. They did not understand how the figure used in the consultation document and the HIA that 88.4 per cent of patients would visit the surgical centre once could be true. Trusts presented data to the Panel that suggested that the number of patients who would visit the surgical centre once for surgery or interventional cardiology would be less than 70 per cent. Clinicians told the Panel of the importance of pre-surgical visits to familiarize children and families with the facilities and staff before the operation, to reduce anxiety and how this was particularly important for children with learning difficulties who make up a significant proportion of the patient group. The Panel heard that for these patients, arriving in a new unit for surgery without familiarization would be extremely difficult. The Panel also heard that around 25-30 per cent of patients have co-morbidities and, of these, a proportion will require any surgery for any condition, or any diagnostic test that requires anaesthetic, to be undertaken at the cardiac surgical centre due to clinical risk associated with their conditions and the need for specialist paediatric congenital anaesthetic support.

4.13.16 The Panel asked the NHS for the data that they had relied upon to produce the 88.4 per cent figure. The Panel was told that the data used was an analysis from HES data of the frequency of spells in hospital for children undergoing certain cardiac procedures over the period 2000 to 2010. The NHS explained that the Central Cardiac Audit Database (CCAD) has three broad groupings of procedures:

- **Excluded procedures** – which are not judged to be major procedures
- **Qualifying procedures** – everything except the above
- **Specific procedures** – a sub-set of the 'qualifying procedures'

4.13.17 The Panel was told that the HES analysis covered the specific procedures but the NHS felt this was a reasonable sample as the specific procedures account for around 80 per cent of the qualifying procedures.

4.13.18 In response to further questions an analysis was provided which showed that the percentage of specific procedures that had actually been captured in the analysis was 62 per cent of qualifying surgical procedures and 36 per cent of qualifying interventional cardiology procedures, amounting to 52 per cent of all qualifying procedures.

4.13.19 *The report on testing patient flows*

The Y&H Joint HOSC told the Panel that they had welcomed the findings of the PwC report that had further tested assumptions about patient flows. They believed this report supported their view that children and families from across Yorkshire and Humber would not travel to the surgical centres assumed by the JCPCT. The Committee told the Panel that they did not believe that the JCPCT had taken account of their comments on this report and did not understand the rationale applied by the JCPCT of assuming that 25 per cent of patients from Doncaster Leeds, Sheffield and Wakefield would flow to Newcastle despite the findings from the PwC report. They stated that it would only take a further shift of less than two per cent from these postcode areas to render the Newcastle Centre unable to achieve the minimum number 400 procedures. They told the Panel that in their view it was likely a proportion of patients from Hull and

Halifax postcodes would also choose an alternative surgical centre to Newcastle. The Panel heard that, as a result of these issues, the Y&H Joint HOSC believed that option B, the proposed option, should have had a lower score for ‘sustainability’.

4.13.20 The Panel received a letter from 170 clinicians from all the hospitals in the Yorkshire and the Humber network stating that they did not support the proposals and wished to dispel any misconceptions about widespread clinician support for the proposals in the Yorkshire and the Humber area or the suggestion they would be happy to recommend that their patients travel to Newcastle.

4.13.21 The Panel heard from parents in Yorkshire and the Humber, and other areas affected by the proposals, who stated that they did not wish to travel to the centres in the network their postcode had been allocated to under the proposals and they would prefer to attend alternative centres. Parents told the Panel they felt the proposals ignored patient choice and the numbers of surgical cases that had been attributed to Newcastle, Bristol and Southampton relied on some people having to go to a centre that was not their nearest.

4.13.22 The Panel heard from PwC that their brief was to test the patient flows assumed under the four options in the consultation document in the options in 22 postcode areas with:

- The referring clinicians
- Parents or carers of children with CHD
- The general public

4.13.23 The methodology had involved surveys and focus groups. They told the Panel that the objective of the work was not a post-code analysis per se but to triangulate the views of these three groups.

4.13.24 The Panel asked PwC how they had engaged with parents and the public on the issues that would encourage them to travel to a centre that was not their nearest under the proposals, given that one of the three key findings from their work as set out in the DMBC was that "*parents have said, notwithstanding a preference for travelling closer to home where possible that a significant factor for where they send their child is 'where their cardiologist tells them to go"*. The Panel wished to understand what factors would lead people to travel further than they needed to for the same quality of service (to the second nearest centre to their home for example). PwC told the Panel that, during the sessions, people were sensitised to the fact that quality would not necessarily be the same and therefore quality was the most important driving factor, and they would travel further to get the best for their child.

4.13.25 PwC told the Panel that in order to gain views from referring clinicians they sent surveys to the clinical directors and medical directors in a number of trusts and asked them to identify their referring clinicians. The Panel asked PwC if they had used the catchments of the obstetric and neonatal units and population flows associated with those as part of their methodology, given these would be the clinicians who would identify and refer the children with CHD. PwC commented that they had raised with the NHS that methodology as a possible approach, but it was not the approach they had adopted. They told the Panel they felt the methodology used was appropriate.

4.13.26 PwC told the Panel that, based on their findings, their view was that the proposals could work if clinicians advised patients to have treatment at the designated surgical centre and the networks were actively managed and developed.

4.13.27 The NHS told the Panel that their interpretation of the advice from PwC was that the Newcastle network could be made to work if it was properly managed and referrals were made in the right way. The JCPCT told the Panel that some patients from Yorkshire and the Humber already travel to Newcastle (61 in 2008/09). In making their decision, they told the Panel that option B was consistently the highest scoring option and the JCPCT acknowledged the risks to the viability of the proposed Newcastle network and that mitigation of these risks would take place during the implementation phase.

4.13.28 *Capacity*

All three HOSCs raised with the Panel their concerns that as a consequence of patient flows not following the assumptions made in the proposals, and as a result of population growth, in future some centres might have insufficient capacity to meet demand or would be so large that this had a negative impact on quality. Some parents and a number of clinical teams raised similar concerns. The Panel was told that using the latest national census data and CCAD data that the 13 postcodes allocated to Birmingham Children's Hospital would generate 719 cases per year by 2025. This compares with the activity projected in the DMBC of 611. The Panel was told that the impact of moving ECMO to Birmingham would be equivalent to a further 250 operations in terms of the demand on PICU.

4.13.29 The LLR Joint HOSC, some parents, professional associations and a number of clinical teams, including in units designated under the proposals told the Panel they were concerned about the impact on PICU capacity in the Midlands and nationally.

4.13.30 The Panel heard from the NHS that they had undertaken detailed capacity assessments as part of the planning process. The JCPCT told the Panel that they are satisfied that there is sufficient capacity to accommodate any increase in workload associated with population growth and the impact of any patient flows which are contrary to the network proposals, which they believe would be small in number.

4.13.31 The JCPCT told the Panel that the provision of adequate PICU capacity and effective arrangements for retrieval of patients is a requirement of the Safe and Sustainable Standards (C15, C60, C68). The Panel heard that the Capacity Working Group risk assessed the individual centres' plans for expansion of PICU to meet the needs of increased surgical cases. The JCPCT told the Panel that the CIAG terms of reference include the impact of reconfiguration on PICU and retrieval services and nationally a number of actions are underway to improve the effective operation of PICU and retrieval services. This includes the establishment of a PICU clinical reference group, whose terms of reference are to assist NHS England in the strategic planning of PICU services and develop new service specifications for both PICU and retrieval services. These specifications will be used by NHS England as a tool for achieving consistent standards across the country from 2013/14.

4.13.32 *Financial planning*

The Y&H Joint HOSC told the Panel that they believe that under option B families across Yorkshire and Humber would not only endure a significantly worse patient experience but that this would also be at a considerable greater expense. The Panel heard concerns that the overall financial implications are likely to be very significant, in terms of establishing the new arrangements, developing the proposed network model of care and meeting very significant increases in transportation and retrieval costs. They told the Panel that they believed there had been insufficient consideration given to the financial implications of the proposals. The Committee was concerned that the DMBC suggested that there would be a reduced level of spending in future and that this did not reflect the increased investment that was suggested during public consultation.

4.13.33 The Y&H Joint HOSC was also concerned about the impact on Leeds Teaching Hospitals NHS Trust, which it understood, would have to find savings to cover circa £14 million of legacy costs. Committee members told the Panel that they felt costs should have been part of the options assessment process.

4.13.34 The Panel heard concerns from trusts, clinicians and professional associations about whether the necessary funding would be available to develop and sustain the wider network of services and staff, particularly in DCCS. Some trusts told the Panel that they felt that the threshold for economic viability of a surgical centre was nearer 500 procedures per annum than the proposed minimum of 400.

4.13.35 A number of clinicians, professional associations and parents were concerned that the costs of the necessary expansion of retrieval service had not been taken into account. Some Committee members and parents were also concerned about funding for additional ambulance services for post-operative, non-urgent transfers to CCCs and DCCS.

4.13.36 The JCPCT told the Panel they had not included in their financial plans the additional costs of retrieval and ambulance services. They had followed the advice of the professional associations on the Steering Group that the precise ramifications for retrieval services could not be known until the JCPCT made a decision on the future configuration of congenital heart services. They told the Panel it was not the aim of the review to make savings and therefore the point of the financial analysis was to answer the question, whether the reconfiguration options were affordable to commissioners and the financial impact manageable by providers. This was why the financial criterion was not weighted and compared with other non-financial criteria. The JCPCT told the Panel that under option B, the NHS has circa £31million of commissioning funds available from those providers no longer supplying paediatric cardiac surgery and the estimated cost of revenue investment under option B was approximately £12.6 million, and hence option B was considered affordable. The JCPCT told the Panel that they recognised that further work would be necessary during implementation to firm up the costs, including the impact on retrieval services, but the view of the JCPCT was that there was sufficient headroom between the resources available and the investment required to give a high degree of confidence that option B was affordable. The JCPCT told the Panel that in their view it is likely that even after investment in a safe and sustainable service, in the medium term the cost of the service would reduce, due to economies of scale. The JCPCT told the Panel that the Y&H Joint HOSC had misinterpreted the figures in relation to the impact on Leeds Teaching Hospital NHS Trust. They told the Panel that, after taking account of savings in variable costs, the Trust may have to find savings of approximately £4.3 million to cover the indirect and fixed costs and that this figure compared to an average of £4.9 million for other trusts. The JCPCT further informed the

Panel that this is a small proportion of the Trust's total income, representing around 0.4 per cent of its turnover.

4.13.37 *Scoring of the options*

The Y&H Joint HOSC told the Panel they considered there had been an over-reliance on the Kennedy Panel assessments to measure 'quality'. The Panel heard that in their view the assessment of quality should have utilised the NHS framework for quality based on the domains of clinical effectiveness, safety and patient experience first highlighted by Lord Darzi's NHS Review in 2008[26]. In addition, in their view it was a particular flaw in the methodology not to include the impact of additional travel times and costs as part of the quality assessment, given its significance to patient experience. Committee members told the Panel they were also concerned that the Kennedy Panel assessment framework was based on only 35 per cent of the *Safe and Sustainable* Standards.

4.13.38 The Panel heard concerns from a significant number of parents that they did not understand how the Kennedy Panel scores could be described as a measure of 'quality' as the measures on which they were constructed were not those that they could relate to as a rounded assessment of quality. They told the Panel they did not think that these would be the measures of quality that parents had in mind when they were asked to score the relative importance of the appraisal criteria.

4.13.39 Some people told the Panel that outcome measures should have been used as part of the assessment and that a wider range of indicators of quality could have been used to triangulate the findings. They told the Panel they were concerned how few of the domains in the Kennedy Panel assessment were clinical measures.

4.13.40 The Panel heard from a number of people who were concerned that the Kennedy assessments were never intended to be used for comparative purpose

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[26] High quality care for all, Department of Health 2008

and yet subsequently, had been used in that way. Some trusts told the Panel they were concerned that they did not have an opportunity to correct any factual inaccuracies in the Kennedy Panel assessments and did not have access to the sub-scores. The Panel heard a number of challenges to the Kennedy Panel assessment process, scope, scores and the weighting that was used in these scores. A number of people told the Panel that they believed the scores had been manipulated and the outcome had been pre-determined as there had been suggestions circulating for some years that the service at Leicester and Leeds should be closed.

4.13.41 The JCPCT told the Panel that the Kennedy assessments were based on the quality standards that were endorsed by the professional bodies and aligned to other professional standards and are consistent with the NHS definition of quality. The Panel heard that no challenges to this methodology had been received during consultation and the JCPCT considered that it had taken account of patient experience through membership of the Children's Heart Federation on the Steering Group and in the consultation process through interviews, workshops and focus groups with parents and children.

4.13.42 The Panel was presented with several detailed critiques of the scoring process used by the JCPCT to select the preferred option. The JCPCT presented counter arguments to the Panel.

4.13.43 Key concerns in relation to the scoring of options were:

- Failure to consider Oxford as a surgical centre
- How the weightings were decided
- The relative weightings given to criteria, particularly the weighting given to accessibility
- Small differences in the Kennedy Panel assessment scores translated into large differences in the quality scores for options
- Inconsistencies in scoring in relation to access, co-location, research, risks and nationally commissioned services
- The robustness of sensitivity testing

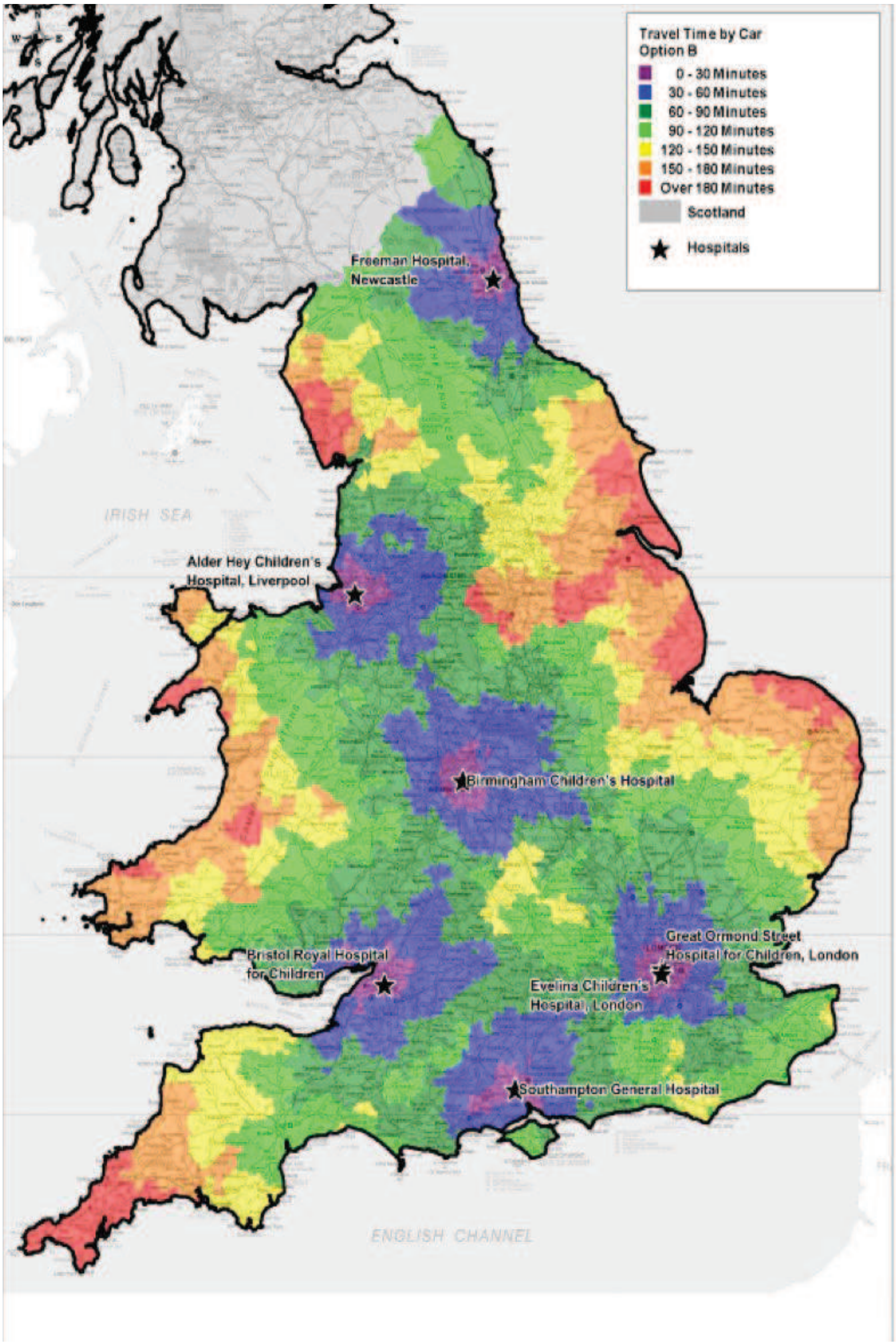
- Errors in attributing patient numbers to networks
- The inevitable outcome of weighting positively the options which included the "top three" scoring centres as two of these centres were in all options

4.14 **Accessibility**

4.14.1 All three referring scrutiny committees raised concerns regarding accessibility. The concerns focused on three issues - the planning methodology, the impact on local populations and the way in which the access component of the options assessment had been undertaken.

4.14.2 Access and transport links to the hospitals vary considerably around the country. Map 5 below shows the travel time to each of the proposed seven centres from within the proposed network areas. As can be seen, significant areas of the country (shown in yellow, orange and red) would have journey times in excess of over 120 minutes under the proposals. The direct impact of the changes on access for population is shown in Map 6, which shows the change in travel time under the proposals for different locations.

Map 5: travel time to surgical centres under the Safe and Sustainable proposals[27]



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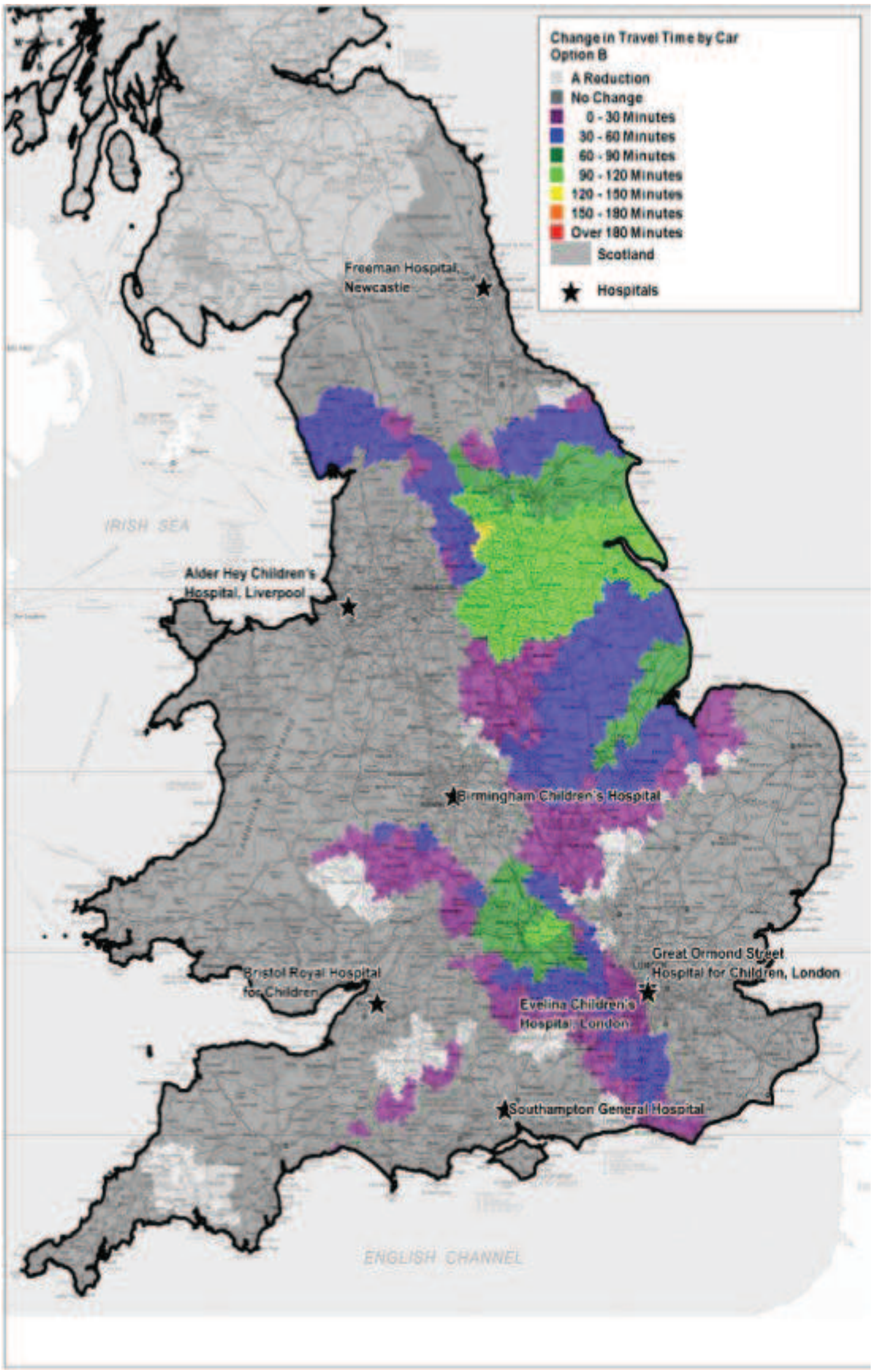
[27] Safe and Sustainable: Review of Children's Congenital Heart Surgery Services in England Health Impact Assessment: Final Report June 2012. Contains Ordnance Survey data © Crown copyright and database right

Map 6 Change in travel time under the Safe and Sustainable proposals[28]



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[28] Safe and Sustainable: Review of Children's Congenital Heart Surgery Services in England Health Impact Assessment: Final Report June 2012 Contains Ordnance Survey data © Crown copyright and database right

4.14.3 *Methodology*

The Lincolnshire HSC told the Panel they were not satisfied that the use of postcodes was an appropriate method to plan the network boundaries and assess the impact on accessibility. They considered that an alternative approach based on isochrones or the catchment areas of maternity and paediatric units would have been more appropriate.

4.14.4 The Y&H Joint HOSC highlighted to the Panel that the centre in Leeds currently undertakes a far higher volume of activity than the centre in Newcastle. They told the Panel that the population of Yorkshire and the Humber is in the region of 5.2 million people compared to 2.6 million in the NE and around 14 million people are within a two-hour drive of the current surgical centre at Leeds. They highlighted that the latest population projections show a higher rate of growth in the Yorkshire and the Humber area than in the north east of England. They questioned a planning methodology that did not take account of population and population density and stated they did not believe that the JCPCT had taken sufficient account of this when making its decision. They made reference to a statement from the BCCA in February 2011, which highlighted the need to reflect the distribution of the population in the planning of the location of the units in order to minimise disruption and strain on families.

4.14.5 The NHS told the Panel that they considered postcodes were a more accurate method than using isochrones and using the 2,292 postcode districts for the activity and journey time analysis had enabled them to gather a highly accurate picture of journey times and activity numbers.

4.14.6 The JCPCT told the Panel that the established aims of specialized commissioning are to commission from hospitals that can demonstrate that they have the necessary expertise. The Panel heard that other factors such as the availability of specific skills, management ability and interdependencies with other services are more important than population density. The JCPCT made reference to the 16 very rare and specialist treatments that are commissioned from the Newcastle upon Tyne Hospitals NHS Foundation

Trust. They told the Panel that to plan services on the basis of population density would go against the "*accepted logic*" for the commissioning of specialised services. However, they stated this did not mean that travel and population were irrelevant considerations as these issues were taken into account, but were not determinative.

4.14.7 *Impact on local populations*

The Panel heard concerns from all three referring HOSCs regarding the impact of the proposals on access for certain sections of their population. The issues of concern were:

- Travel times
- Poor transport links
- Low levels of car ownership
- Costs of travel, accommodation and childcare
- Adequacy of accommodation for parents and families at the proposed centres
- The impact on families including the social and personal burden of travel
- The impact on the availability of a wider support network for parents

4.14.8 The Panel heard from the Lincolnshire HSC and local parents that Lincolnshire is the largest rural county in England with very poor road and rail transport infrastructure and high levels of deprivation, particularly in the most remote parts of the county. Parents told the Panel that based on their own analysis they considered the assessments of the increases in travel time and the impact of travel had been substantially understated by the NHS. In particular, they consider the population of the north Lincolnshire coast is seriously disadvantaged by inclusion in the London network at a distance of 140 miles.

4.14.9 The Y&H Joint HOSC told the Panel that, under option B, 73 per cent of Yorkshire and the Humber patients would experience an increase in travel time of more than 1.5 hours compared to the national figure of 6.2 per cent and this demonstrates the disproportionate impact on those in Yorkshire and the

Humber. They told the Panel that they believe this analysis strengthens the case for a north of England solution that recognises and reflects the demographics and geography of that part of England. The eight centre solution put forward by the Y&H Joint HOSC would include Alder Hey, the Freeman and Leeds General Infirmary.

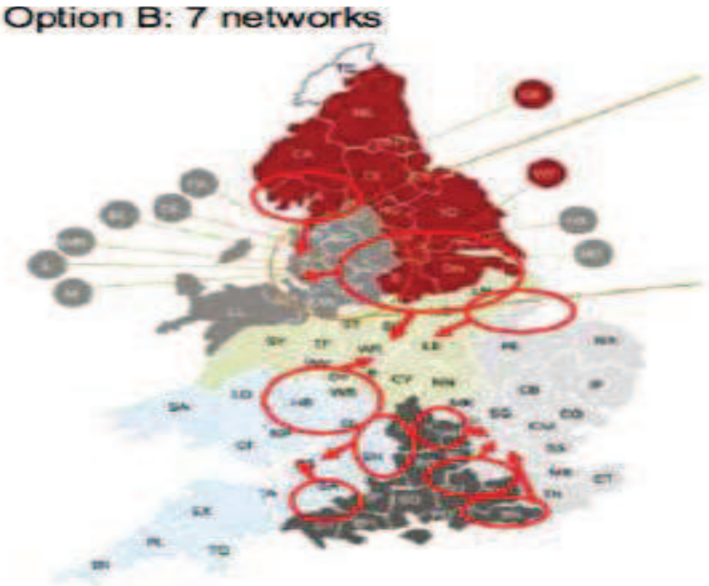
4.14.10 The Y&H Joint HOSC highlighted the impact on families in the Bradford, Halifax and Huddersfield area, who under the proposals would have to travel to the CCC in Manchester to receive services rather than the CCC in Leeds, which is much closer and a place with which they were familiar. This was felt to be particularly challenging for some of these populations due to low incomes, lack of access to cars and cultural issues for some sections of the population who rarely travel outside of their local community.

4.14.11 Leeds Teaching Hospitals NHS Trust presented an analysis of the impact on travel times for the population of Yorkshire and the Humber. This showed that under option B there was a more than five-fold increase in travel impact for the population of Bradford and a four-fold impact for other parts of Yorkshire and the Humber. The analysis also showed that with the exception of patients travelling from Grimsby and Scarborough all patients are currently within 70 minutes travel time of Leeds General Infirmary.

4.14.12 The Panel heard from parents in Yorkshire and the Humber, Lincolnshire and Leicestershire about their experiences of current travel times and how substantial the impact had been upon them and their wider family. The challenges of caring for siblings, the costs of travel, accommodation and difficulties of maintaining employment were highlighted by many, including LINks and local charities. Many parents told the Panel that their child had stayed in hospital for many weeks and in some cases months. Parents told the Panel they found it hard to contemplate the journeys that they would experience in future should their child need further treatment at the surgical centres and they were concerned about the impact this would have on them. The Panel was told the thought of having to travel to an unfamiliar place that does not feature in a family's life in any other way for work or shopping or days out is very unsettling to patients and families. The Panel heard concerns about the availability of accommodation in the proposed surgical centres. Parents were also concerned about whether there would be the retrieval and ambulance services in place to support transfers to the surgical centre and back to the CCC to limit the impact of distance on them. Parents told the Panel of their concerns about the impact on the families of those children diagnosed in future.

4.14.13 The Panel was told that people in nine areas of England would have to travel to a surgical centre that was not their nearest under the proposals. This includes patients from Surrey, Hertfordshire and Sussex - who would be required to travel to Southampton rather than London; patients from Oxford, Reading and Dorchester postcodes - who would be required to travel to Southampton rather than Bristol; patients from Hereford and Worcester - who would be required to travel to Bristol rather than Birmingham and a large section of the population in Yorkshire and Lincolnshire - who would be required to travel to Newcastle rather than Liverpool or Birmingham. These areas are highlighted in the map below with red arrows indicating the direction of the affected populations nearest surgical, as opposed to their designated, surgical centre.

Map 7



4.14.14 The Panel heard from a number of clinicians around the country about some of the challenges when children reach transition. They commented that young people and adults become very resistant to travelling because they can make up their own minds and have other pressures such as school, college, money, work or family commitments. Clinicians highlighted the importance of access as a key issue in minimising the number of patients who become lost to follow-up with potentially serious implications for patients long-term health. The Panel heard that people were concerned that they did not know what the implications for access to adult services would be.

4.14.15 *Assessment of accessibility in the options appraisal*

The Panel heard from many parents that they did not agree with the weighting that had been given to accessibility in the options scoring process. They told the Panel that they believed that the results of the survey undertaken by Ipsos MORI on behalf of the Children's Heart Federation had been misinterpreted to suggest that access was not important. While they agreed that quality was the primary concern of all parents, they stressed that accessibility was a key component of a quality service and did not understand why some of the networks that were being proposed resulted in people having to travel to the second or third nearest centre to their home to receive what should be an equal quality service.

4.14.16 Some trusts also raised concerns about the weighting for access and travel. They told the Panel that the weightings given by parents reported in the consultation document showed that they placed greater weight on access and travel and this should have informed the weighting used by the JCPCT, which instead was based on the Steering Group and SCG's views on weighting.

4.14.17 The Panel was told that options that did not include Southampton received a lower score than those that did, due to consideration of retrieval times from the Isle of Wight. The Panel heard that the scores erroneously presumed a relationship between retrieval standards and the travel times from congenital cardiac centres to the furthest parts of the proposed new networks. The Panel was told that this was reflected in the scoring, such that if removal of a congenital cardiac surgical centre would result in a travel time from the nearest retained surgical centre that was in breach of the Paediatric Intensive Care Society's retrieval time standards of three hours - or four hours in remote areas - that option would receive a lower score. The Panel heard that people did not understand why this criterion had been used as the standard since the time taken for the retrieval team to reach the bedside, and the presence or absence of a congenital cardiac surgical centre, had no impact on the availability of, or the speed of response to, retrieval - be that on the Isle of Wight or anywhere else as they are two separate groups of staff and two separate services. The Panel heard that a retrieval services supporting the Isle of Wight or any other areas would be in place irrespective of the presence or absence of a congenital cardiac surgical centre.

4.14.18 The JCPCT told the Panel that the standards state that treatment would be provided closer to home 'wherever possible' although the primary objective was to reduce the number of surgical units in the interests of safety and resilience. While the JCPCT considered that increased journey times was relevant, they told the Panel that all stakeholders agreed that this was the least important factor in the decision making process.

4.14.19 The JCPCT told the Panel they considered their analysis of retrieval times was sound.

4.14.20 The JCPCT told the Panel that the assessment of journey times, activity and numbers of patients affected, which were used in the development of options and assessment of the access score in the option appraisal, was based on cardiac surgical procedures and it did not include patients undergoing cardiac catheterisation procedures or the impact on patients with co-morbidities.

4.14.21 *Safety and travel times*

The Panel heard from some clinicians and parents that there were concerns that distance would in some cases result in an adverse impact on outcomes for babies and children. The Panel was told that there were two clinical conditions in particular where time to reach the surgical centre could have an impact on outcomes, these were:

- Patent ductus arteriosus (PDA)
- Septostomy

4.14.22 The Panel heard from a number of clinicians that PDA is a condition that affects very small, premature babies and the number of babies with this condition annually is small. Standard A29 states that neonates with PDA may receive surgical ligation in the referring neonatal intensive care unit (level 3) providing that the surgical team is dispatched from a designated specialist surgical centre and the unit is suitably equipped in terms of staff and equipment.

4.14.23 There were concerns that these patients would be harmed as a result of waiting to have their condition treated and that patients might wait longer than necessary to be treated if the surgical centre in their network was not the closest geographically.

4.14.24 Other clinicians told the Panel that PDA ligation is not a complex procedure nor is it time critical. The primary method of treatment is usually medication in the local hospital (NICU or Special Care Baby Unit); if medication fails to close the PDA, arrangements may be made for a surgical intervention on a planned basis. In many cases, correction of the PDA is not critical in the neonatal period. In such cases, children may be treated electively later in childhood. The Panel were told that issues of prematurity mean children with this condition have a high mortality rate.

4.14.25 The Panel asked the NHS if such patients would always have to be visited by the surgical team from the relevant network or if the team could be dispatched from another surgical centre if it was nearer, given the concerns that the child would have a longer wait than necessary.

4.14.26 The NHS told the Panel that the benefits of an integrated network approach (in particular, the benefits to clinical care and outcomes of the same medical and nursing teams in the NICUs and surgical unit developing a good working relationship) outweigh the perceived benefits of a model in which the NICU team would 'shop around' a number of potential 'first available' surgical units on a case by case basis. However, as an alternative to the above model, the baby could be transported as a day case to the surgical unit. As this would be on a planned basis, the NHS considered that the difference in transport time between the various surgical units would not be material. They highlighted that the standards stipulate that it would be for each Congenital Heart Network to determine local arrangements according to local circumstances for the management of PDA.

4.14.27 The Panel heard that some children require an urgent keyhole procedure called a septostomy. If the condition is not treated, the patient will die or be brain damaged due to acid in the blood. The Panel was told that the risk to these children is a function of how far/long they need to travel for a septostomy. The Panel heard that over the last four years, three babies in the Yorkshire and the Humber region have died because they did not get to Leeds quickly enough. A number of parents raised concern that deaths of these babies are not counted in the mortality statistics because they have not had an operation. People told the Panel they were concerned there would be more deaths due to greater distances for a significant proportion of the population in Yorkshire and the Humber, Leicestershire and Lincolnshire.

4.14.28 The Panel heard from Steering Group members that urgent septostomy is an important clinical issue. The Panel were told that most children requiring septostomy remain well in the early postnatal period but in a small percentage of cases there is an urgent need for this procedure and time is critical. Around 10 – 20 neonates per year require urgent septostomies in England. If the condition is identified antenatally, plans would be made for the delivery in or near the surgical centre. For those not diagnosed antenatally the critical issue is the time between birth and diagnosis and finally the transfer to a unit that can undertake the procedure (or in some cases the transfer of the team to the baby).

The availability of echocardiography (and a PEC/paediatric cardiologist) reduces the delay in diagnosis. The Panel were told that as most babies requiring septostomies are currently born outside a surgical centre there is an imperative to improve the ability to diagnose the condition antenatally, and improve the speed of post natal diagnosis and retrieval.

4.14.29 The NHS told the Panel that, as part of the implementation process, the professional associations had been asked to explore alternative models that would deliver the cardiology team to the neonate and Great Ormond Street Hospital is in the early stages of developing an outreach septostomy model in which the intervention would be performed in the outside neonatal unit. In addition, the resilience of surgical units to be able to respond to emergency situations would be strengthened in the future as an outcome of the concentration of medical expertise into larger teams.

4.14.30 *Care closer to home*

The Panel heard from parents who were unconvinced that, overall, care would be provided closer to home than it is now.

4.14.31 The Panel heard from trusts providing paediatric congenital cardiac services about the range of out-reach clinics that they currently undertake and the hospitals where there are PECs in place. The Panel heard from paediatric cardiologists at LGI that they had excellent PECs in 13 of the 17 locations where they undertake outreach clinics. They told the Panel that these PECs demonstrate how good their skills in echocardiography are by the fact that the paediatric cardiologists see no ‘innocent murmurs’ (that is, cases that do not need their expertise) in their clinics.

4.14.32 The NHS provided the Panel with a list of the locations where outreach clinics are held. The list can be found in Appendix 10. At the time of undertaking the review, there were 157 locations in England where outreach clinics were being held. The Panel heard from a number of Trusts that these services were well developed in a significant number of locations. The Panel noted that, under the proposals, DCCS would be located in hospitals with over 3,000 births per annum (94 such units at the time of the consultation).

4.14.33 The NHS told the Panel that the 157 outreach clinics involve a cardiologist from the surgical unit visiting a local setting for routine management of patients. The NHS described a situation where:

- Often there are no formal protocols in place as the local hospital is not expected to be an integral part of the network;
- Often it merely provides a setting for the visiting cardiologist.
- The frequency of attendances by the cardiologist varies, but as often as once-weekly is rare.

4.14.34 They told the Panel that the development of DCCS does not preclude the continued presence of a paediatric cardiologist in outreach settings if this is considered appropriate by the network. By contrast, the DCCS would be integrated within the Congenital Heart Network; staffed by one or more dedicated Consultant Paediatricians with Expertise in Cardiology and a specialist support team including nursing, dietetics and clinical psychology, and linked to the surgical unit and CCC via telemedicine facilities.

4.14.35 The Panel heard that the range of services offered by the DCCS would be much broader than that available in outreach clinics as they would be equipped to provide a range of diagnostic tests including: electrocardiography, chest radiography, 24-hour ambulatory electrocardiography and blood pressure, monitoring, treadmill exercise testing and high quality echocardiography facilities. The Panel heard that children seen at the DCCS would generally be seen for the following reasons:

- Prenatal diagnosis
- Follow up of previously diagnosed congenital heart defects
- Follow up management of arrhythmias
- Follow up of post-operative cardiac surgical or intervention patients
- Referrals from GPs, paediatricians, community paediatricians, nurse specialists

4.14.36 As with the decisions on CCCs, the NHS told the Panel that decisions on which units are designated as DCCS would depend on the development of standards and an assessment of which hospitals meet the standards.

4.14.37 The JCPCT told the Panel that they had not undertaken any formal assessment of the impact of DCCS and CCCs on the delivery of care closer to home. However, they told the Panel that they were assured that the model would result in children and their families getting much better and more accessible local services than currently and, for the overwhelming majority of patients, the overwhelming majority of the care would be more local than currently. The JCPCT told the Panel that the decision to reduce the number of surgical centres would have been fully justified, and supported by the professional associations even if the JCPCT had not developed a mode of care that sought to bring non-interventional care into local settings.

4.14.38 The Panel asked the JCPCT if any assessment had been made of the impact on accessibility for children with co-morbidities. The JCPCT told the Panel this assessment had not been done and it was anticipated that these patients would be able to be treated in the CCCs because there would be cardiologists, anaesthetists and specialist nurses, working across the network, not just in the surgical centre.

4.15 Sustainability

4.15.1 *Networks*

The Panel heard consistent concerns from HOSCs, local charities, trusts and parents in areas affected by the proposals about the risks that a number of centres would not achieve the 400 surgical procedures threshold due to patient choice. For the proposed option B, the Panel heard that the viability and sustainability of Newcastle, Southampton and Bristol all depended on patients using a surgical centre that was not their closest. The Panel heard similar concerns from some trusts that are designated to remain surgical centres under the proposals.

4.15.2 The JCPCT acknowledged that some of the proposed surgical centres have been openly critical of the network boundaries proposed in the selected option, option B, in that it gives them a much lower surgical caseload than they would otherwise wish.

4.15.3 *Children's Cardiology Centres*

Other concerns that the Panel heard which relate to the sustainability of the proposals are all the issues raised about CCCs described above. They focused on:

- CCCs being unable to attract and retain staff
- CCCs being unable to sustain a viable range of activity due to deskilling of staff
- The sustainability of CCCs when there is a significant distance between the CCC and surgical centre
- The financial viability of CCCs
- Insufficient funding to develop the model of DCCC as planned
- As is noted elsewhere in this report, the JCPCT told the Panel:
- They consider the proposed networks are viable to deliver the 400 minimum surgical procedures
- That while the model of CCCs carries some risks these would be addressed during implementation.
- The commissioning frameworks for CCCs would be addressed by NHS England
- The financial analysis demonstrates there would be sufficient funding to implement the proposals

4.15.4 *Workforce*

The Panel heard from professional associations that they were concerned that paediatric cardiologists were in short supply and that there had not been adequate workforce planning to test the viability and sustainability of the proposals. The Panel heard some similar concerns about other professional groups.

4.15.5 The Panel heard from the JCPCT that KPMG undertook a workforce review on behalf of the JCPCT in early 2011. KPMG told the Panel that they looked at the implications of the options on different workforce groups, including surgeons perfusionists, cardiologists, nurses, anaesthetists and intensivists. They had looked at various issues such as the numbers of each workforce group in post at the time, the number of each of these professionals required under the proposals and the gaps in terms of workforce requirements under the proposals. Whilst they had undertaken this exercise, it had not fed through into the decision-making process due to the fact that it was not possible to second-guess how people would respond to the implementation of the proposals in terms of those staff who would be willing to transfer, those that would leave the service etc.

4.15.6 A number of people told the Panel that they were not convinced that the proposals would deliver the intended benefits, particularly taking account of the risks and disruption associated with the change process and potential loss of skilled and scarce staff.

4.15.7 *The Royal Brompton Hospital*

The Royal Brompton & Harefield NHS Foundation Trust presented the Panel with a detailed assessment of the implications of the proposals on the Trust. The Trust is a tertiary and quaternary centre specialising in the treatment of heart and lung disease.

4.15.8 Key issues were:

- The acknowledged impact that, as a result of the proposals (particularly the loss of PICU), other specialist respiratory services currently provided by the Trust would have to be delivered elsewhere
- Implications for PICU capacity in London due to the non-viability of the Brompton PICU if paediatric cardiac surgery is removed
- The clinical infrastructure supporting other services would be put at risk
- The impact on:
    - Fetal medicine services

    - Adult congenital cardiac services
    - Pulmonary hypertension services
    - Electrophysiology services
    - The inherited cardiac disease service that is only available in the UK at the Brompton
- The impact on research and clinical and research partnerships
- The impact on training
- Impact on the Trust's business model and financial sustainability
- The impact of population growth in London on demand for paediatric congenital heart services

4.15.9 The Panel heard that the proposals would result in the Trust losing £11m of income after the deduction of direct costs and facing redundancy costs of c£3 million if paediatric cardiology services were lost and c£8.7 million if all paediatric services were lost. The Panel heard the financial impact would put at risk the rest of the Trust's services and put back its capital investment programme for some years. The Trust was concerned the proposals bring into question the Trust's long-term financial viability and as a result they could be found in breach of their terms of authorization by Monitor.

4.15.10 The Trust told the Panel that, in their view, the best option for London would be delivered through a three-centre network model and they had put this option forward during consultation.

4.15.11 The Panel received many submissions from senior clinicians from abroad highlighting the international reputation of the services provide at the Royal Brompton Hospital and raising concerns regarding the impact of the proposals. A significant number of charities and parents also raised concerns about the impact of the proposals on children who are treated at the Royal Brompton Hospital for congenital heart disease or receive other specialist paediatric services. Particular concerns were the destabilizing effect of the closure of the PICU on the service to cystic fibrosis patients, which the Panel was told, is the largest paediatric cystic fibrosis service in Europe and about potential fragmentation of services for children with respiratory conditions who currently receive a comprehensive service from the Royal Brompton Hospital. They were critical that the Pollitt report[29] had not considered issues of the longer-term sustainability of the services at the hospital.

4.15.12 The JCPCT told the Panel that the Pollitt report concluded that the services at the Royal Brompton Hospital would still be viable. They told the Panel that they had been criticized by the Trust for not incorporating respiratory services and adult services in the review but, the JCPCT believed it had to draw a line somewhere as there was a need to do something as quickly as possible about children's congenital heart services.

4.15.13 The NHS told the Panel that the Trust had argued strongly that adult services could continue in the absence of paediatric services but that the commissioners position is that they probably would not be able to because the standards developed by the ACHD review state services need to be co-located with paediatric services.

4.15.14 *Extracorporeal Membrane Oxygenation (ECMO)*

The referrals from LLR and Lincolnshire scrutiny committees raised concerns regarding the transfer of respiratory ECMO from Glenfield Hospital to Birmingham Children's Hospital. They highlighted that the ECMO service at Glenfield Hospital is the longest established ECMO service in the country and provides the majority (80 per cent) of the ECMO capacity nationally including mobile ECMO. They told the Panel that ECMO practitioners in the UK and overseas have voiced their concerns over the transfer of the service to Birmingham. The LLR Scrutiny Committee told the Panel that they accepted that ECMO can be moved in principle. However, they had been advised by recognised ECMO experts that the clinical outcomes would suffer for a number of years as a result of the transfer due to the disruption to established

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[29] Report of the independent panel on the relationship of interdependencies at the Royal Brompton Hospital Sept 2011 The Pollitt report

teams and the learning curve any new team must undergo to maximise clinical performance.

4.15.15 The Panel was told that the mortality rate for respiratory ECMO in Leicester is 20 per cent, while the national mortality rate (that is, that of the other nationally commissioned centres) is 50 per cent higher. The concern is that Glenfield Hospital's low mortality rate would not transfer with the service. In terms of the impact on outcomes, if over the last 10 years Glenfield Hospital's ECMO mortality had been at the national average, 62 more children would have died.

4.15.16 There were also concerns about the ability to recruit staff to the new respiratory ECMO service. A survey of ECMO staff at Glenfield Hospital demonstrated that many of the skilled nursing staff involved in delivering the ECMO services had indicated that they would be unable to relocate their lives and families to Birmingham.

4.15.17 The LLR Scrutiny Committee told the Panel the JCPCT had not addressed this issue in sufficient detail and did not take into account the views of national and international experts. It also believes that the decision did not properly assess the evidence of the impact of such a move given that the Glenfield Unit is the largest such unit in the country.

4.15.18 The Panel heard from others who disputed the figures on the relative outcomes from the different respiratory ECMO centres.

4.15.19 The JCPCT and experts on the Advisory Group for National Specialised Services (AGNSS) told the Panel there were risks in moving respiratory ECMO services. However, the JCPCT told the panel that in their view those risks had been assessed in detail and could be mitigated to an acceptable level.

4.15.20 *Impact on medical research at University Hospitals of Leicester NHS Trust and Leicester University*

The LLR Joint HOSC raised concerns regarding the impact of the proposals on research at University Hospitals Leicester NHS Trust. They told the Panel that the University of Leicester has recently secured significant funding from the National Institute of Health Research. They told the Panel that the loss of children's congenital heart services and ECMO would impact adversely on the ability of the University and the Trust to continue to attract sponsorship and also to recruit the high-calibre staff needed to ensure that the existing high-quality research is maintained and further developed. The Panel heard that the University and the Trust employ some 30 academics, 150 researchers plus a considerable number of support staff in the Cardiovascular Biomedical Research and this could be put at risk in the future as a result of the decision to move services.

4.16 Engagement, Consultation and Decision-making

4.16.1 The Y&H Joint HOSC told the Panel they believed that a public consultation exercise should aim to encourage participation, make information accessible and allow people to contribute in a way, which is convenient and meaningful to them. The Panel heard concerns about the accessibility of the consultation document as it was 230 pages long and that local people had told the Committee that that they found the consultation document and response form complex and not user-friendly. The Y&H Joint HOSC was concerned that the only means of responding for the first few weeks of the consultation was via an on-line questionnaire. They told the Panel this had disadvantaged some people and they did not feel that the communications plan had paid sufficient attention to the need to engage with BAME communities, particularly given these groups have an identified higher risk of congenital heart disease. The Panel heard that the consultation document was not translated into other languages until five weeks before the consultation closed.

4.16.2 The Panel heard similar concerns from other HOSCs, LINks, parents, charities and local groups. These groups also raised concerns that the methods used to support engagement were not based on best practice nor sufficiently innovative to elicit a good response from all communities. In addition, people told the Panel there had been restrictions on the number of people able to attend consultation events and they had to press hard in order to get numbers increased.

4.16.3 Some parents who met the Panel were very upset that in their view, rather than in engaging in a proper debate about their genuine concerns, those connected to the NHS had portrayed them as selfish, emotional parents unable or unwilling to see the bigger picture. They told the Panel they had been portrayed as people acting out of 'blind loyalty to a local unit'. Although they had a loyalty to the unit that had, in many cases, saved their children's lives they highlighted that their loyalty to their children was greater than their loyalty to an institution and therefore their intentions were to support what they felt would deliver the best quality services. They told the Panel that the issue was that they did not feel the clinical case had been made and that the decision was based on flawed information in the HIA, in the planning assumptions and in the scoring. They did not feel the process had been transparent. The Panel heard from one parent who said that he felt that those leading the review had lost sight of the NHS constitution guiding principle that 'the NHS belongs to the people' and the requirement that NHS services must reflect the needs and preferences of patients, their families and their carers.

4.16.4 A number of parents and some charities raised concerns about the role played in the process by the Children's Heart Federation (CHF) in undertaking surveys that influenced the weighting given to the access criterion and the fact that this organisation was the sole voice for children and parents inside the process. For many parents who spoke to the Panel this arrangement become more problematic after the CHF itself issued public statements critical of those challenging the proposals.

4.16.5 The Panel found some of the media statements issued by the CHF and the NHS were seen to be combative in style, serving to polarise the debate and unnecessarily antagonize those raising their concerns.

4.16.6 The Y&H Joint HOSC told the Panel they were particularly concerned that insufficient weight had been given to the petition from Yorkshire and Humber residents, which over 600,000 people had signed. The LLR Joint HOSC and a number of charities and parents told the Panel they were concerned about how the consultation responses had been interpreted and the weighting that was given to petitions, individual and organisational responses, particularly when a number of the organisations appeared to have no relationship to health services, such as banks and commercial retail organisations.

4.16.7 A number of people raised with the Panel a concern regarding bias. They highlighted that the membership of the Steering Group, although ostensibly based on representatives from professional associations, included people with a connection to all of the surgical centres included in the review with the exception of the three that were subsequently selected for de-designation at the end of the process. Their concern was heightened by individuals closely involved with the Steering Group and process both privately and publicly expressing views about which centres should close in advance of the options assessment. This included a statement issued by the CHF in 2010 about future services being provided at the seven centres that were finally selected.

4.16.8 The issue on which the Panel heard the greatest level of concern regarding the engagement and consultation process surrounded the decision-making at the JCPCT meeting on 4 July 2012. People told the Panel they felt it was completely unacceptable that there was no information circulated in advance of the meeting and this concern was much heightened by discovering the DMBC included eight new options that had not been subject to consultation nor had been communicated in advance. People told the Panel that they felt that ‘the goalposts had been changed’ due to the changes to the working assumptions and the rescoring methodologies that were applied. This issue was exemplified by the change in fortunes for option A, which appeared to emerge from the consultation as a strong option but in the DMBC was presented as relatively weak. They told the Panel there had been a lack of communication since the end of the consultation period.

4.16.9 The Panel heard concerns that the network boundaries of option B as set out for consultation were not the same as the network boundaries for option B as presented in the DMBC. The Panel was told that several postcode areas had been moved into different networks under the new option B and therefore it was misleading to suggest that support for option B in the consultation was necessarily support for option B in the DMBC. The changes related to Hereford and Worcester who move from the Birmingham to the Bristol network and Dorchester, west Oxford and Reading who move from the Bristol to the Southampton network.

4.16.10 The Panel heard from many people who felt they had been denied the opportunity to consider the new proposals and give their views. Many people were concerned that the decision has been made in advance of the meeting and it was not a genuine decision-making meeting.

4.16.11 A number of parents and HOSCs told the Panel they had submitted Freedom of Information Act requests to obtain basic information such as agendas, minutes and terms of reference and they had found the NHS to be unresponsive and defensive, particularly in response to challenge to the proposals. The Y&H Joint HOSC told the Panel that they felt very strongly that that such information should have been made available for public scrutiny. The Y&H Joint HOSC told the Panel that they felt the JCPCT and NHS had displayed contempt towards legitimate public scrutiny of the review and its proposals and they had been denied the ability to discharge their scrutiny function as fully as they would have liked. However, they also told the Panel that they welcome the suggestion that the Centre for Public Scrutiny would be involved as part of the ‘lessons learned’ activity associated with the review and they wished to be actively involved in contributing to this process.

4.16.12 The Panel heard from Ipsos MORI, who reported the results of the consultation, that it was usual practice with consultations to treat petitions as one response. However, it is made clear in the report how many people signed the petition and petitions have their own chapter in the report on the consultation. They told the Panel that they reported clearly and accurately the findings from the consultation including the different volume of responses from different regions to enable the JCPCT to consider this information. In relation to responses from organisations, Ipsos MORI told the Panel that they list all responses from organisations so that people can see the range of bodies who have responded. The Panel heard that the organizational response form encourages respondents to consider if they are genuinely responding on behalf of an organisation by asking questions about how they assembled members' views and how many people they were representing but the role of those reporting the results is not to make a judgment on how valid their view was.

4.16.13 The Panel heard from the NHS and the JCPCT that they considered that the engagement and consultation process had been thorough, robust and transparent and that the findings from engagement and consultation had been used to shape the standards, the options for consultation and the final proposals. The JCPCT told the Panel that the Y&H Joint HOSC was not a properly constituted joint HOSC because the Y&H Joint HOSC and all other joint HOSCs in England had failed to comply with the requirements of the legislation by not convening a single national joint scrutiny committee. Notwithstanding this issue, the JCPCT was of the view that the requests of the Y&H Joint HOSC had been dealt with reasonably up to the point of decision-making. In their view, their duty to provide information ended on 24 July 2012 when the Y&H Joint HOSC decided to refer the JCPCT's decision to the Secretary of State for Health.

4.16.14 The NHS told the Panel that before going to consultation they considered the number of different languages spoken across the country and followed what they considered to be standard best practice within the NHS which was to let people know that materials would be translated on request. They had responded promptly to requests for translation, but this took a month due to the scale of the task. They also redesigned the consultation workshops when the level of interest became apparent, which included changing the methodology to accommodate town-hall style debates.

4.16.15 The NHS told the Panel that the judicial review process had increased the time between consultation and decision and had limited their ability to engage and communicate with stakeholders. However, during this period Ipsos MORI published three reports on the outcome of consultation. The outcome of the Pollitt report on the impact on respiratory services at the Royal Brompton Hospital and the outcome of the PwC work on assumptions around patient flows and manageable networks were also published along with a number of newsletters.

4.16.16 The JCPCT told the Panel that feedback from the consultation was reflected in the DMBC and had a significant influence, as evidenced in particular by the consideration of new options. The Panel heard that the DMBC made reference to the significant support for LGI and the JCPCT was mindful of the strength of feeling in Yorkshire and the Humber. However, this had to be balanced with the soundness of the arguments being put forward.

4.16.17 The NHS told the Panel that the secretariat and KPMG developed the additional options set out in the DMBC and the JCPCT asked them to undertake further analysis to test various assumptions as well as the viability of the original and new options. The JCPCT told the Panel they held several meetings over the period 30 June 2011 to 12 June 2012 to consider the options. The Panel heard that the draft DMBC was written by the secretariat, was finalised between 13 and 29 June 2012 and was signed off by the Chair of the JCPCT to be submitted to the JCPCT in advance of the public meeting on 4 July 2012. The JCPCT told the Panel that the DMBC included a list of recommendations that the JCPCT considered at the meeting on 4 July 2012, and on which it reached its conclusions at that meeting.

OUR ADVICE

Adding value

5.1 Introduction

5.1.1 The proposals for changing children's congenital heart services, the subject of this review, are set out in the *Safe and Sustainable: Review of Children's Congenital Cardiac Services in England; Decision Making Business Case* of July 2012. The DMBC set out 20 recommendations, all of which were approved by the JCPCT on 4 July 2012.

5.1.2 The review of children's congenital heart services originates from a request in May 2008, from the NHS Medical Director, Sir Bruce Keogh on behalf of the NHS Management Board that *"the National Specialist Commissioning Group undertake a review of the provision of paediatric cardiac surgical services in England with a view to reconfiguration".*

5.1.3 The intervening four years comprised three main phases:-

- The development of service standards
- The assessment of current providers against service standards
- The development of service change proposals to enable service standards to be achieved in the future

5.1.4 The proposals have faced a number of challenges since the consultation period in 2011:

- Previous referrals to the Secretary of State for Health by the Y&H Joint HOSC and Kensington and Chelsea HEHASC Scrutiny Committee in 2011 on which the IRP provided initial advice
- A judicial review brought by the Royal Brompton & Harefield NHS Foundation Trust in 2011 which found in the Trust's favour but was overturned by the Court of Appeal
- A judicial review brought by Save our Surgery Ltd, a Leeds based charity, which found in favour of Save our Surgery Ltd in March 2013

5.1.5 This review is unique in the IRP's experience, being on a national footprint and about a set of specialised services that serve about eight in a thousand newborns - many of whom, with their families, live with the consequences of their condition for the rest of their lives. The JCPCT's proposals and, therefore, the review have been dominated by the arguments for and against concentrating the specialist surgery component of care in the fewer, larger centres identified in the DMBC. The rest of the care pathway, from antenatal screening through to provision of services for adults with congenital heart disease, has by comparison been largely ignored. This is illustrated by the paucity of evidence received during the review about the number of patients who are receiving NHS treatment for their CHD and prevalence of the condition in 0-16 year olds.

5.1.6 Much of the evidence that the Panel heard reflected the issues raised in the referrals from the three HOSCs, being focussed primarily on the NHS's analysis of, and the JCPCT's decision about, which of the ten surgical centres should continue. Significant other issues included the case for larger surgical centres, the sustainability of the proposed model of managed networks and the impact of the proposals on adults with congenital heart disease.

5.1.7 The Panel took evidence from the HOSCs, JCPCT, the Steering Group, Sir Ian Kennedy, expert advisors to the JCPCT, national specialised services' commissioners, professional associations and national charities. The Panel also took evidence in all ten surgical centres, the three cardiology centres and a number of retrieval services in England and Wales, giving the opportunity to meet and hear from many frontline staff, volunteers, local charities, parents and children involved with these services.

5.1.8 In common with the large quantity of correspondence received, those using the services described eloquently the skilled care they receive from highly motivated and committed staff, often over many months and years. The Panel also heard from some parents and others about poor quality of care and loss of confidence in services relating to a number of the surgical centres around the country - some that are proposed to be retained, and others that are not. Whilst it is not the remit of the Panel to take up individual cases, all the evidence from parents and relatives is hugely valuable and we are grateful for their time and effort in sharing their experiences. Individuals using the services with concerns were advised to take them up with relevant organisations.

5.1.9 The phrase *"waiting for the next Bristol"* captures the almost morbid sense of spectatorship and foreboding that hangs over these services. The review and closure of the Oxford surgical centre in 2010 had served to bring history back into sharp relief. The nature of the service and the high level of public interest over a long period means that centres will, from time to time, find themselves under close scrutiny irrespective of the presence of any underlying causes for concern. It is also the case that services will give real cause for concern at times for patients, commissioners and regulators. The Panel understands the burden of both history and the responsibility for the current safety and quality of services. However, the focus of this review and the Panel's advice is fundamentally about the longer-term future, mindful of the interests of both current patients and their families and those yet to be born.

5.1.10 Despite the uncertainty created by a succession of reviews since the Kennedy Report on the Bristol Inquiry in 2001, there have been many improvements in these services including most recently those stimulated by the process of assessment against national standards in 2010. Nevertheless, the current situation remains uncertain, holding back further decisions about investment in new facilities and permanent additional staff. The Panel also heard that the *Safe and Sustainable* process had been divisive, particularly for the professional staff involved. There is clearly a need to consider these issues when deciding how best to move forward in the interests of patients as quickly as possible.

5.1.11 Taking account of the current context, the Panel has considered in detail each of the issues raised before reaching its conclusions. In doing so, the Panel's primary focus is the best interests of children with congenital heart disease, now and in the future.

5.1.12 **The Secretary of State for Health asked the IRP to advise as to whether it is of the opinion the proposals for change under the "*Safe and Sustainable* Review of Children's Heart Services" will enable the provision of safe, sustainable and accessible services and if not why not. Overall, the Panel is of the opinion that the proposals for change, as presented, fall short of achieving this aim.**

5.1.13 **The Panel's view is that people - children and adults - with congenital heart disease in England and Wales will benefit from services commissioned to national standards for the whole pathway of their care.**

5.1.14 **The Panel agree that congenital cardiac surgery and interventional cardiology should only be provided by specialist teams large enough to sustain a comprehensive range of interventions, round the clock care, training and research.**

5.1.15 **However, the Panel has concluded the JCPCT's decision to implement option B (DMBC – Recommendation 17) was based on flawed analysis of incomplete proposals and their health impact, leaving too many questions about sustainability unanswered and to be dealt with as implementation risks.**

5.1.16 **Throughout our review, people told us that being listened to was something they valued. The opportunity to change and improve services is widely recognised and, in taking forward our recommendations, those responsible must continue to listen to legitimate criticisms and respond openly. We set out below recommendations to enable sustainable improvements for these services and learning for future national commissioning of health services.**

5.2 The proposals for change

5.2.1 The proposals for service change are driven by the adoption of national service standards covering seven key themes:

- Congenital heart networks

- Prenatal screening and services
- Specialist surgical centres
- Age appropriate care
- Information and making choices
- Family experience
- Ensuring excellent care

5.2.2 In particular, the JCPCT's decision to adopt the mandatory standards of a minimum of four full-time surgeons and 400 paediatric surgical procedures per surgical centre creates the need to reconfigure current centres, and an assessment of those centres against some of the service standards was a key component in the JCPCT's decision about which surgical centres should be closed.

5.2.3 The proposal for change that is the subject of this review is the implementation of seven congenital heart networks led by the following surgical centres:

- Freeman Hospital, Newcastle upon Tyne Hospitals NHS Foundation Trust
- Alder Hey Children's Hospital NHS Foundation Trust
- Birmingham Children's Hospital NHS Foundation Trust
- Bristol Children's Hospital, University Hospitals of Bristol NHS Foundation Trust
- Southampton University Hospitals NHS Foundation Trust
- Evelina Children's Hospital, Guy's and St Thomas' NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust

and de-commissioning of the children's congenital cardiac surgical services at Leeds General Infirmary, Glenfield Hospital Leicester and the Royal Brompton Hospital, London.

5.2.4 As the Panel quickly discovered, the proposals will have inevitable consequences for services for adults with congenital heart disease – who by definition are mainly the same group as the children, only older. Indeed, the Panel noted that in the course of the *Safe and Sustainable* review, approximately one quarter of the children using services will have become adults. The separate consideration of services for children and adults was raised as an issue throughout the review, not least because a parallel review of ACHD services has been underway for some time. In the Panel's opinion, this issue needs to be considered upfront to address our terms of reference in the most comprehensive and useful way.

5.3 Services for adults with CHD

5.3.1 Due to improved rates of survival, there are now more adults living with CHD than there are children and the adult CHD population is projected to grow rapidly in the coming years. The Panel heard that adults with congenital heart disease will be directly affected by the proposals and this was not considered as part of the JCPCT's decision. The JCPCT said that adult services were not within their remit and the decision to undertake two separate reviews had been endorsed by the professional associations on the Steering Group. The JCPCT told the Panel that a line had to be drawn somewhere and that the alternative was to delay progress.

5.3.2 Given that it is the same surgeons and, in some cases, cardiologists providing the care, and the majority of current specialist centres provide both paediatric and adult congenital heart services, the impact of a decision about children's services cannot be separated from the future of adult services. The JCPCT told the Panel that the draft standards developed by the adult review stipulate that, in future, adult congenital cardiac services need to be co-located with paediatric congenital cardiac services. Consequently, the proposals for children's services threaten the future of the adult congenital heart services at Leeds and Manchester in the north, Leicester in the east Midlands and the largest service in London and the UK at the Royal Brompton Hospital - the Brompton also being the largest research centre in the UK for adult disease.

5.3.3 The practical implications of making the decision about children's services separately from consideration of adult services were brought to the Panel's attention. The Panel agrees that there are risks to continuity of service for adolescents as they transition to adult services and that the need to co-ordinate implementation of changes to children's services with changes to adult services is unavoidable.

5.3.4 Representations on the logic of looking at congenital heart services for children and adults together had been made by many parties, including professional associations, at various points during the four years of deliberation. The IRP heard likewise throughout its review. The Panel agrees with the view commonly expressed to it that a single review would have enabled better solutions to be found that commanded a higher level of support.

5.3.5 **Recommendation One**

The proposals for children's services are undermined by the lack of co-ordination with the review of adult services. The opportunity must be taken to address the criticism of separate reviews by bringing them together to ensure the best possible services for patients.

5.4 The JCPCT's case for "*larger surgical centres*"

5.4.1 The Panel reviewed the JCPCT's case for change and sought views from all parties. The case for "larger surgical centres" for children's heart surgery is presented by its proponents as incontrovertible – a principle that *"everyone has signed up to"*. What the Panel heard was less straightforward. The case for larger centres relies on two key arguments:

- The relationship between volume of cases per centre and per surgeon and better outcomes for patients
- Larger teams are more sustainable and hence provide higher quality services

5.4.2 *The relationship between volume and outcome*

In clinical medicine, it is observed that there is generally a positive association between doing more of something and getting better results for patients. For some specialty services, there is clear evidence for a strong positive relationship between volume of procedures and outcomes achieved. The Panel reviewed the relevant published literature for congenital heart disease and took evidence from clinicians on this issue. Whilst there is some evidence of a positive relationship between volume of procedures and outcome at lower numbers per centre, for the current surgical centres in England and the proposed minimum of 400 procedures per centre, the evidence is that there is no significant positive relationship between increases in volume and expected outcomes.

5.4.3 The Panel found that the proposed standard of a minimum number of procedures per surgeon was initially set at 100 paediatric procedures, in addition to any adult caseload. However, the final standard moved away from setting the number of procedures per surgeon, to requiring each surgical centre to undertake a minimum of 400 and preferably 500 paediatric surgical procedures "*sensibly distributed between all four cardiac surgeons*". This was in recognition that most surgeons undertake adult practice and the balance of adult and paediatric work tends to change over the surgeon's career with the proportion of adult work increasing over time.

5.4.4 Some evidence suggests a more positive impact of volume on outcomes for relatively rare and complex procedures to treat, for example, hypoplastic left heart syndrome. This suggests either larger centres as proposed or concentrating such procedures in fewer centres. The Panel noted that much larger centres such as in Boston, USA were implementing surgical sub-specialisation to improve outcomes further.

5.4.5 The Panel was concerned that in presenting the case for change in the consultation document and the DMBC, the NHS failed to indicate that the evidence of a link between volume and outcome, and experience of rationalisation of services internationally, related to a much lower threshold of activity per centre than the standard of 400 cases per centre proposed. There was also a failure to explain that the Kennedy and Munro reports had suggested significantly lower thresholds per surgeon and per centre. The Panel met many well-informed parents as well as clinicians and HOSC members who had diligently read all the referenced material in the consultation document and DMBC. This failure to set information in context was at the heart of feelings reported to the Panel by some parents, HOSCs and clinicians that the process lacked transparency and used information selectively.

5.4.6 *Larger teams*

The Panel found widespread support for the standard of at least four full-time surgeons per team. This has a range of benefits such as aiding recruitment and retention of staff, supporting sub-specialisation, mentoring, collaborative working on complex cases, cover for planned and unplanned absence, training, research and audit. A number of clinicians also highlighted the relationship between stable teams and high quality services. The importance of the wider team of specialists who are involved in the care of children with CHD, was also highlighted to the Panel by many who felt that the implications for these professions had not been sufficiently addressed by the proposals.

5.4.7 Patients relying on a specialist service expect experienced, skilled staff to be available round the clock to provide all the care that may be required. The Panel agrees that achieving this in a sustainable way requires a minimum of four full-time consultant surgeons in each team and a volume of procedures sufficient to develop and maintain the skills of surgeons, cardiologists and other personnel in providing a high quality, comprehensive service.

5.4.8 **Recommendation Two**

Patients should receive congenital heart surgery and interventional cardiology from teams with at least four full-time consultant congenital heart surgeons and appropriate numbers of other specialist staff to sustain a comprehensive range of interventions, round the clock care, training and research.

5.5 The clinical model and managed clinical networks

5.5.1 *The clinical model*

The successful implementation of the proposed clinical model and managed clinical networks is critical to the future quality, sustainability and accessibility of services. The model underpinning the proposals is described in terms of service standards and three broad components - district children's cardiology services (DCCS), children's cardiology centres (CCC) and specialist surgical centres – working together as a managed network.

5.5.2 Whilst many people expressed support for the general concept of the proposed clinical model, those using the services were keen to know the detail – how it would work for patients and what services would be where. The necessary clarity and detail about the clinical model of services was not developed before consultation commenced and so the proposals appeared incomplete and uncertain. The JCPCT told the Panel that the number and location of CCCs and DCCS would not be known until standards had been developed for these services and potential centres had undergone an assessment process.

5.5.3 The Panel found some evidence of the proposed clinical model in working examples of paediatricians with an expertise in cardiology linked to a specialist centre. Despite the absence of clear standards and therefore consistency across the country, it was clear to the Panel that DCCS have real potential as part of a managed network providing suitably qualified paediatricians can be recruited and necessary facilities and activity funded.

5.5.4 The Pre-Consultation Business Case (PCBC), consultation document and DMBC all present the same confusion about why CCCs should be developed. It is unclear whether the intention was to provide a sop to de-designated surgical centres or that CCCs are an essential element of the model of care. The JCPCT told the Panel that, contrary to the proposal in the consultation document that the centres that cease to provide surgery may become CCCs, it was unlikely that a CCC at the Royal Brompton Hospital would be viable given the close proximity of the Evelina Children's Hospital and Great Ormond Street Hospital. Likewise, a CCC in Leicester could not be on the Glenfield Hospital site as on-site PICU is required and the PICU at Glenfield Hospital ceases to be viable with the loss of the surgical activity.

5.5.5 The lack of clarity is reinforced by references, as evidence of a viable model, to the existing CCCs in Manchester, Cardiff and Oxford. The Panel was not persuaded that any of these provide 'proof of concept' for the CCC element of the proposed clinical model. The Panel found evidence that the scope of clinical services in these centres was reducing due to valid clinical governance issues. This was illustrated by the on-going debate about the ability to undertake all electrophysiology outside of the surgical centre. The Panel also found that cross-site working between the cardiology centre and the surgical centre was a critical factor for creating sustainable roles and sustaining specialist skills and confidence across the whole clinical team. The impact of distance and travel time for clinical staff is therefore a key consideration in developing a viable model of a CCC working in association with its surgical centre.

5.5.6 If non-interventional cardiology centres are an essential element of the clinical model, their unique functions should be described and the form matched to the population need. Until such time as a clear and credible description can be provided of the scope of the clinical services that will be provided, the staff and facilities that they will comprise and the clinical staff inter-relationship with the surgical centre, there will remain valid doubts about the ability of CCCs to attract and retain scarce specialist staff and provide a broad and sustainable range of services to their catchment population.

5.5.7 A particular concern raised by many people with the Panel were the needs of children with CHD who have significant other health conditions and rely on specialist cardiac anaesthetists for any intervention where anaesthetic is required. Around 25-30 per cent of children with CHD fall into this category. The Panel heard grave doubts from clinicians that these skills could be sustained in the proposed CCCs. The Panel did not find sufficient evidence that the impact on these patients had been properly assessed.

5.5.8 **Recommendation Three**

Before further considering options for change, the detailed work on the clinical model and associated service standards for the whole pathway of care must be completed to demonstrate the benefits for patients and how services will be delivered across each network

5.5.9 *Managed clinical networks*

The *Children's congenital cardiac services in England service standards* acknowledge that the "*precise shape of each Congenital Heart Network should be determined by local needs and local circumstances including geography and transport"* so that as much care as possible is delivered closer to home.

5.5.10 The lack of evidence of consideration of the issues of local needs, geography and transport, and the lack of detail about where and how the rest of the non-surgical care pathway would be delivered, was at the heart of much of the criticism of the proposals. Given that the vast majority of care for this lifelong condition is provided by cardiologists, liaison nurses and their teams locally, the absence of a clear and compelling description of the totality of the care pathway is a substantial deficiency in the proposals. Patients expect proposals for major service change to describe services for the whole pathway in equal detail. This has been a consistent point of learning from previous IRP reviews of contested proposals for service change.

5.5.11 The case for a standalone CCC will likely depend on the benefits for other on-site services from access to paediatric cardiology advice, the opportunity to reduce negative accessibility impacts for patients and ensuring workable distances from surgical centres to associated district cardiology services for outreach and in-reach activity. In this context, the Panel consider that it is unclear how the proposed Northeast and Midlands networks, for example, could function effectively because of the populations and distances involved within catchment areas.

5.5.12 For those areas potentially losing a specialist surgical centre, the proposed mitigation of bringing services closer to home is questionable given that people cannot as yet be told where these services would be delivered and what they would comprise. As a result, there is lack of confidence that the proposals will deliver the claimed benefits for patients and for many in the areas most affected there is genuine fear that the service will be substantially worse, particularly in terms of accessibility and its impact on families.

5.5.13 The Panel heard a range of concerns regarding the lack of alignment between the proposed Congenital Cardiac Networks and fetal, neonatal, paediatric and adult congenital cardiac networks. The Panel noted that the standards set out that these networks should be aligned and agrees this is in the best interests of patients. The Panel was not convinced that the implications for patients of the lack of alignment of networks had been assessed or that clear plans existed for how it would be addressed.

5.5.14 The Panel found that the proposals would impose substantial additional demands on retrieval services and that the current service was considered to be inconsistent across the country. The Panel was advised that retrieval is not a constraint on configuration of services provided the service is planned and resourced appropriately. The JCPCT confirmed that this had not been assessed as part of the DMBC.

5.5.15 Overall, the Panel found a paucity of basic information about the clinical needs of patients with this long-term morbidity and their profile of service utilisation to support effective commissioning, compared to other long-term conditions. Information on prevalence and the numbers of patients in England and Wales with CHD under active monitoring and treatment by the NHS does not routinely exist.

5.5.16 Given the absence of critical detail regarding the number of CCCs and DCCS and the scope of their clinical activity, the Panel was not assured that the affordability of the proposals had been sufficiently assessed, or that CCCs would be a financially viable proposition for providers. With regard to DCCS, the nature, number, location and commissioner commitment from CCGs are all unknowns leaving huge doubts about the ability of the proposals to deliver care closer to home. There was insufficient clarity regarding the commissioning arrangements for the Panel to have confidence that the whole pathway would be effectively commissioned and underpinned by a sustainable contractual regime for providers.

5.5.17 **Recommendation Four**

For the current service and any proposed options for change, the function, form, activities and location of specialist surgical centres, children's cardiology centres, district children's cardiology services, outreach clinics and retrieval services must be described and financial viability and affordability retested.

5.5.18 *Antenatal detection*

The Panel was concerned about the lack of focus on addressing the stark variation in antenatal detection rates for CHD, across England. Given the evidence that antenatal detection has a beneficial impact on outcomes, and the variation in detection rates is not explained by the need to reduce the number of surgical centres, this is not acceptable and the NHS should be aiming to achieve consistently the highest possible rate.

5.5.19 **Recommendation Five**

NHS England should ensure that a clear programme of action is implemented to improve antenatal detection rates to the highest possible standard across England.

5.5.20 *Population, activity and capacity*

The Panel heard concerns from HOSCs, clinicians and parents that the planning assumptions for proposed change are flawed in the light of the latest activity data and population projections. There are risks that some centres, particularly Birmingham Children's and Great Ormond Street hospitals, may see excessive demands placed upon them given the pattern of regional population growth.

5.5.21 The Panel noted the nine per cent increase in activity in the period 2006/07 to 20011/12 (excluding foreign private patients) and the latest population projections that suggest a 16 per cent increase in the 0-14 population in England and Wales between 2011 and 2025. This is compared to the planning assumption of a 13.7 per cent increase on 2006/07 activity by 2025 (excluding foreign private patients) used in the DMBC.

5.5.22 The Panel also noted that the viability of the proposed networks centred on Newcastle, Bristol, Southampton and Evelina are all vulnerable to modest changes in assumptions about patient flows.

5.5.23 The Panel heard general concerns about PICU capacity given that the proposals for change render the PICUs at the Royal Brompton and Glenfield hospitals unviable. Doubts were expressed about whether sufficient capacity would exist to avoid disruption to the delivery of planned cardiac interventions. This view was overlaid with concerns about the impact of rising birth rates, particularly in the Midlands and London.

5.5.24 The Panel was concerned about the substantial difference in the assessment of the future number of adult patients with CHD and their future healthcare needs predicted by commissioners on the one hand and clinicians and professional associations on the other.

5.5.25 **Recommendation Six**

Further capacity analysis, including for PICUs, should consider recent and predicted increases in activity, the latest population projections and patient flows.

5.6 The safety and quality of services

5.6.1 The proposals for change have not been argued on the grounds that current services are unsafe. For several years, standard data have been collected about each intervention and summary comparative analysis is publicly available on the NICOR website. The Panel were consistently told that the quality of the outcome data and the range of robust, publicly available data on paediatric cardiac surgery in the UK is the envy of the rest of the world. Published mortality rates are uniformly around two percent or less for primary surgical procedures in all the current surgical centres, and as such comparable with the best equivalent services internationally.

5.6.2 In this context, the Panel were troubled to hear some people assert that there were known and significant differences between the outcomes achieved by the existing centres. The Panel sought the evidence behind these assertions without receiving anything conclusive. At the end of the review, the Panel asked the JCPCT, as commissioners, whether there existed any further information about the safety or performance of the current centres that would help inform the Panel's advice to the Secretary of State. The JCPCT confirmed that there did not.

5.6.3 The use or not, of outcome data to assess and compare the safety and quality of the children's cardiac surgery centres has been the subject of some debate since the Bristol enquiry. The Panel shares the view expressed by others that the absence of evidence of underperformance should not be a source of comfort. Equally, the Panel found no suggestion that there exists or is likely to exist a convenient single bullet solution to answer questions about the relative quality of services and outcomes achieved by different centres.

5.6.4 In its visits to the ten surgical centres, the Panel observed the positive impact of adopting both the agreed service standards and the continuous review of clinical performance and outcomes in multidisciplinary teams. The Panel heard widespread support for the development of a wider range of indicators of outcomes such as, for example, neurological function, which can give a measure of long-term outcomes.

5.6.5 The use of relevant data as indicators of the need to investigate the quality of services and the availability of standardised analysis of comparative clinical performance are critical elements in securing and demonstrating the overall quality of services.

5.6.6 The Panel were pleased to hear that funding has been secured to roll out across all congenital cardiac providers in England a programme that allows individual providers to monitor their own performance using Variable Life Adjusted Displays (VLAD plots). In addition, further work is underway to obtain risk-adjusted standardized mortality ratios (SMRs) for each centre. While challenges will remain to comparing centres reliably, the Panel considers that this will be an additional drive to help improve quality.

5.6.7 Overall, the Panel shares the impatience expressed by many that more progress has not been made to develop and adopt a common approach to clinical governance, including a comprehensive range of quality and clinical outcome measures.

5.6.8 **Recommendation Seven**

NHS England must establish a systematic, transparent, authoritative and continuous stream of data and information about the performance of congenital heart services. These data and information should be available to the public and include performance on service standards, mortality and morbidity.

5.6.9 The Panel heard a variety of views about the potential benefits of reducing even further the number of surgical centres that undertake relatively rare and complex procedures. Some clinicians were in favour while some felt that all surgical centres in future should deal with all patients. The Panel saw evidence of a shift away from the historical pattern of certain rare and complex procedures being undertaken in only a few centres. The Panel is mindful of the fact that the definition of what is a ‘complex’ procedure changes over time as clinical practice develops.

5.6.10 Rather than expecting every centre to be undertaking every type of procedure, the more likely pattern to be observed over time is a cycle of innovation, dissemination and some sub-specialisation. The Panel considers that this is desirable and should be encouraged. To ensure safe services of the highest possible quality for patients, this issue requires on-going and active monitoring, collaboration and management at a national level.

5.6.11 **Recommendation Eight**

NHS England and the relevant professional associations should put in place the means to continuously review the pattern of activity and optimize outcomes for the more rare, innovative and complex procedures.

5.6.12 The assessment of the current surgical centres against some of the service standards and subsequent use of that assessment to inform the scoring of options for quality has been the subject of enormous scrutiny and dispute. The Panel received a number of detailed critiques of both the assessment and scoring processes.

5.6.13 Whilst the proposed service standards were developed over a long period and were the subject of their own consultation, they remain the source of debate and some differences in interpretation. Co-location of services has been a particular source of dispute because of the differences between current surgical centres and the perceived benefits of more relevant services being on one site. The Panel recognises that there are real differences between the current surgical centres and considers that it was appropriate to adopt a method for scoring options on quality that reflected these differences.

5.6.14 Although incomplete and heavily dominated by input measures, the standards do describe professional consensus about the characteristics of a high quality service and, through the assessment process, focussed centres on maintaining good standards and identifying areas for improvement. The Panel found evidence of the beneficial impact of the standards and the assessment process on quality improvement.

5.6.15 The JCPCT's decision to rely on the Kennedy scores as predictors of material differences in the capability of centres in the future, and the way in which the Kennedy scores were then translated into differences in the quality of service scores for options, opened the floodgate of criticism. This criticism was exacerbated by the lack of information about changes to the scoring regime and new options before the DMBC was made public at the meeting of the JCPCT on 4 July 2012.

5.6.16 The Panel along with many others, were clear that the Kennedy process and scores were not originally intended to be a basis for comparing existing surgical centres. This was the basis on which the Panel provided its initial advice on the referral from the Y&H Joint HOSC and its request for the detail of the Kennedy scores to be released to it. However, even if one accepted that it was sound for the JCPCT to use the Kennedy scores in the way they eventually did, the Panel found no logic or evidence to explain the relationship between the Kennedy scores and differences in scores for quality of services between options in the DMBC. The Panel agrees that these issues undermined the credibility of the JCPCT's decision, contributing to the view that there was a degree of pre-determination of the outcome.

5.6.17 **Recommendation Nine**

NHS England should reflect on the criticisms of the JCPCT's assessment of quality and learn the lessons to avoid similar situations in its future commissioning of specialist services.

5.7 Impact on patients and their families

5.7.1 The potential impact of reducing the number of centres was recognized from the outset. The consultation sought views on the issue, based on the proposition that the vast majority of patients needing intervention only go to a surgical centre once and the networks of district services and children's cardiology centres will provide care closer to home. The subsequent analysis of accessibility and health impact assessment proceeded on the basis of these assumptions with no further scrutiny or analysis.

5.7.2 The Panel found that the assessment that 88 per cent of patients will travel to the surgical centre once was flawed. It was based on incomplete data regarding the number of stays in hospital per child over the period 2000-2010. Almost half of the procedures were missed from the analysis. In addition, the analysis did not assess the experience of the cohort of children who had their first intervention in 2000 by tracking the pattern of treatment over a ten-year period. As a result, the figure understated the number of interventions children have. Finally, no adjustment was made, or caveat stated to account for the fact that a ten-year data set cannot legitimately be used to represent the 16-year childhood experience of patients with CHD. The statement also gave no consideration to the need for patients and families to visit the surgical centre in advance to familiarise themselves with the centre and meet the team.

5.7.3 The Panel found that the Health Impact Assessment (HIA) used only data on the number of patients undergoing surgery and did not consider the impact on children undergoing interventional cardiology, who similarly would have to travel to the surgical centre under the proposals. This was despite equally robust, validated and detailed data being available for interventional cardiology as there is for cardiac surgery. Around 35 per cent of the patients receiving services at the surgical centre will be attending for interventional cardiology. The assessment, therefore, not only lacks important detail but is also based on flawed analysis of key data. Consequently, the downside impacts are systematically understated and the suggested mitigating impacts have no evidence to underpin them.

5.7.4 The Panel found that the assessment and scoring of the options on the access criterion was flawed for the same reason and systematically understated the impact and numbers of patients and families affected. The DMBC states categorically that it identifies the numbers of patients and families affected and yet the findings are based on an analysis that does not account for a significant proportion of patients.

5.7.5 The Panel heard from parents and others the same concerns that had been expressed in response to the consultation – that whilst securing the best possible care is paramount, the impact of accessibility in terms of time, costs, and stress is their greatest concern about the proposals. The Panel found a significant mismatch between parents' experiences and concerns and the JCPCT's presentation of accessibility. The JCPCT told the Panel that the primary objective was to reduce the number of surgical centres and access was the least important factor. The statement that 88 per cent will travel only once was a frequently quoted justification for weighting access as the least important criterion in the options scoring process.

5.7.6 The absence of detail in the proposals about what services would be provided where outside the seven designated surgical centres exacerbated the concerns of parents. The fact is that the accessibility of the service, and consequently the impact, for large sections of the population of England under the proposals is unknown and the pledge that the proposals will result in care closer to home is unproven. This issue is of particular relevance to the populations most affected in Yorkshire and the Humber and in the east Midlands.

5.7.7 In the case of the former, this was one element of a previous referral by the Y&H Joint HOSC. The IRP's advice of 13 January 2012 on this issue was that a suitably comprehensive health impact assessment was required to address the concerns raised. The JCPCT appears not to have noted this advice.

5.7.8 The Panel found that the proposals would have a disproportionate impact on people in Yorkshire and the Humber in terms of increase in travel times and potentially negative impacts on health inequalities due to the areas most affected having high concentrations of vulnerable groups. The Panel also had concerns about the impact on the population in some areas of the Lincolnshire coast for similar reasons.

5.7.9 The Panel was concerned that the network areas as proposed require some children and their families to travel to the CCC and/or surgical centre that is not the nearest, and in some cases not the second nearest to where they live. In effect the proposed network catchment areas place an excess social cost and burden on some children and families in order to achieve patient flows that generate 400 or more surgical procedures per centre per year. The statement that parents will 'travel to the moon' to access the best care for their children was stated frequently by those supporting the proposals, that is, people are willing to travel further to access a better quality service. However, the Panel found that for some patients and families the proposition is rather different, and they are being asked to travel further in future to a service that offers equal quality to one closer to them. The appropriateness and sustainability of designing a service on this assumption is clearly debatable and the legitimate concerns raised as a result were not addressed in a meaningful way.

5.7.10 A number of the surgical centres had themselves raised concerns about the sustainability of their proposed networks and the Panel agrees with them. Taking account of population density, geography and transport links there are clear challenges to sustainability for some of the proposed networks.

5.7.11 The Panel found that the standard of a minimum of 400 paediatric procedures per centre was based on professional opinion of the Steering Group, referencing the research evidence, and was devised before the implications for network boundaries and accessibility had been assessed. And yet the Panel found a complete unwillingness to debate the inevitable trade-offs that are inherent in the proposals between the potential benefits for outcomes of a threshold of 400 paediatric operations and the accessibility of the service to the population it serves.

5.7.12 The Panel concludes that the JCPCT's decision used a flawed and incomplete analysis of accessibility based on an inadequate health impact assessment. Consequently, the real impacts of the proposals and their potential mitigations were missed.

5.7.13 **Recommendation Ten**

More detailed and accurate models of how patients will use services under options for change are required to inform a robust assessment of accessibility and the health impact of options so that potential mitigation can be properly considered.

5.8 Impact on other services

5.8.1 The impact of the proposals on PICU capacity, respiratory ECMO and paediatric heart transplantation were looked at in some detail for the options appraisal under the deliverability criterion. Specific advice was sought about the national specialised services and, in addition, a bespoke review was commissioned about the impact on specialist respiratory services at the Royal Brompton Hospital.

5.8.2 In considering the impact of the options for change, both respiratory ECMO and transplant services were presented as variables – that is capable of being relocated if required, though not without some downside risks and costs. Whilst this position held up in evidence for respiratory ECMO, doubt exists about the ability to relocate transplant services because only one possible alternative to Newcastle was identified (Birmingham) and a parallel national review of cardiothoracic transplantation centres put the future of existing centres in doubt. There was a mismatch between the DMBC and what the Panel heard about the impact of transplant services on the decision of the JCPCT.

5.8.3 The Panel heard different clinical opinions about the current performance of respiratory ECMO services, the impact of relocation on outcomes and their relationship with cardiac ECMO. Whilst cardiac ECMO is now regarded as an essential element of a high quality paediatric cardiac surgery service, its presence does not indicate capability to deliver high quality respiratory ECMO. Consequently, everyone agreed that relocation of respiratory ECMO is not entirely risk free and, therefore, weighing those risks against the benefits of concentrating congenital heart services is a legitimate and necessary part of the decision.

5.8.4 In view of the relative impact on affected populations, the Panel agree that the transplantation and respiratory ECMO *"tail"* should not wag the CHD *"dog"*.

5.8.5 **Recommendation Eleven**

Decisions about the future of cardiothoracic transplant and respiratory ECMO should be contingent on the final proposals for congenital heart services.

5.8.6 The Panel heard concerns from a number of parents and the Royal Brompton & Harefield NHS Foundation Trust that the implications of the proposals on the wider range of services provided at the Royal Brompton Hospital and its future financial viability had not been assessed.

5.8.7 The Panel found that there are complex and sometimes subtle inter-relationships between tertiary services such that a change, like the loss of surgery for CHD, can trigger shifts in referral behaviour for other services. The Panel considers that these wider implications need to be understood fully to ensure the continued provision of safe, accessible and sustainable services across the whole tertiary services portfolio as well as the impact of change on research.

5.8.8 **Recommendation Twelve**

NHS England should assure itself that any wider implications for other services of final proposals are fully assessed and considered within a strategic framework for the provision of specialised services.

5.8.9 The focus on a single-issue mission of reducing the number of surgical centres undertaking children's congenital heart surgery, which has dominated the *Safe and Sustainable* review, in the absence of a clear strategic view of specialised services as a whole has created some of the difficulties which these proposals have encountered. This is exemplified by the review of the impact of the proposals on respiratory services at the Royal Brompton Hospital whilst ignoring the impact on adult services. The Panel is clear that this approach to commissioning specialised services is very unlikely to achieve the optimal pattern of services for the future.

5.8.10 The *Safe and Sustainable* Review has highlighted the tensions between the pattern of historic provision of specialised services and commissioning services based on population need, access and provider capability.

5.8.11 **Recommendation Thirteen**

NHS England should develop a strategic framework for commissioning that better reflects the complex interdependencies between existing specialised services provision and population needs.

5.9 Engagement, consultation and decision-making

5.9.1 The Panel accepts that undertaking the first national consultation of proposed changes to a complex, high profile service was not an easy task and it is clear that the NHS expended considerable effort to support engagement and consultation. The need to engage with HOSCs was identified early in the process and was a particular challenge given the absence of a national representative body. However, the approaches by a number of HOSCs around the country, such as those in Yorkshire and the Humber, to form a regional joint HOSC was a helpful and pragmatic response.

5.9.2 The Panel understands the concerns expressed by parents and others that the consultation document and response form was lengthy and complex. The Panel accepts that the ability to participate was hindered initially by limiting the response mechanism to an on-line system and not having translated materials available until five weeks before the end of the consultation.

5.9.3 It was also clear that the NHS was somewhat caught off guard by the substantial public response to consultation events in some parts of the country which left people feeling that there was an intention to limit debate.

5.9.4 The Panel found a climate of distrust had developed during the review. This emerged primarily due to two issues – concerns about a lack of transparency and the composition of the Steering Group.

5.9.5 As the IRP noted in its initial advice to the Secretary of State on the first referral from the Y&H Joint HOSC, the Committee has scrutinised the subject with considerable commitment and passion. There has been a clear mismatch in expectation between the three HOSCs who initiated this review and the NHS and JCPCT in relation to the interpretation of the NHS obligation to provide HOSCs with *"such information as the committee may reasonably require"* under the regulations. In addition, the NHS and JCPCT appeared to take an overly legalistic approach to the validity of the Y&H Joint HOSC rather than working with the spirit of scrutiny and their duty to involve. In the view of the Panel, the NHS was insufficiently responsive to legitimate requests for meetings and feedback from HOSCs. It is disappointing to observe, notwithstanding the difficult circumstances, that the relationship between the NHS and the Y&H Joint HOSC has broken down to the extent that it has.

5.9.6 A number of parents told the Panel they found it difficult to gain access to information they felt should be in the public domain and had to resort to Freedom of Information Act requests to obtain information such as minutes of meetings, membership of sub groups and data underpinning the NHS's analysis.

5.9.7 The Panel heard concerns about the lack of weight given to public petitions in considering the findings from consultation. The Panel were satisfied that the results of the consultation were reported accurately and these issues had been dealt with appropriately in the independent report on the consultation.

5.9.8 The issue that generated the greatest level of concern was the lack of engagement and information sharing with interested parties between the end of consultation and 4 July 2012 when the JCPCT met to make its decision. The concerns arose due to a lack of information about work undertaken in response to the consultation findings, such as the development and assessment of new options, and unexplained changes to the options scoring framework. This was compounded by the fact that the DMBC was not released until after the 4 July 2012 decision-making meeting. Confronted with eight new options and a changed scoring framework, people inevitably were left feeling denied access to information and the opportunity to comment and that the decision had been made in advance of the meeting with a significant degree of predetermination. More should have been done to provide information and engage with the interests of HOSCs and others in the period between the end of consultation and the JCPCT's decision on 4 July 2012. In this regard, both good practice and NHS guidance were not followed.

5.9.9 The Panel understands the reasons for selecting representatives from the professional associations to sit on the Steering Group and that they were there to represent their professional body and not their NHS organisation. However, the fact that this selection excluded anyone with a link to three of the ten centres was always going to be an issue that would attract attention. This sense of unease was subsequently given greater focus when the selected option excluded the centres that had no link to the Steering Group members. Given the inevitability of the concerns, this issue should have received greater consideration in constructing the governance arrangements for the review and in developing the stakeholder engagement plan for the review.

5.9.10 The Panel noted that there was a tendency for the NHS and JCPCT to present the views of the Steering Group, which were not always unanimous, as formal endorsement by the 'professional associations', which was not always the case.

5.9.11 The Panel heard from many parents in the areas most affected by the proposals that they felt that their legitimate concerns had not been listened to and they had found it very difficult to deal with being publicly accused in media statements issued by the NHS of 'putting lives at risk'.

5.9.12 The Panel found that there had been a strong emphasis on a communications strategy and the key messages to be transmitted but inadequate attention to developing a genuine engagement strategy from pre-consultation to decision, underpinned by a rigorous stakeholder analysis. The engagement process was over-reliant on the Children's Heart Federation (CHF) as the mechanism of engagement with children and parents and this placed CHF in the difficult position of being asked to deliver part of the process of pre-consultation activities as well as act as a representative body. The reality is that CHF and its role became a source of unhelpful divisiveness that undermined achieving the necessary engagement rather than delivering it. Other voices and organisations need to be more directly involved and engaged.

5.9.13 Much of the opposition to, and flaws in, the proposals originate in the lack of engagement of a wide range of stakeholders in the co-production of network models of care at the pre-consultation stage. This work should have been done at a level of detail to demonstrate how it subsequently informed options for change, revisions to those options and a final configuration of services at a level sensitive to local need, geography and transport as the service standards intended.

5.9.14 There is now a real opportunity to involve patients, public and other stakeholders in taking work forward as set out in the Panel's recommendations. This must be done in a way that shows there has been learning from the mistakes made, demonstrating a clear link between stakeholders' priorities and feedback in the development of the network model of care and the final configuration of services.

5.9.15 **Recommendation Fourteen**

NHS England must ensure that any process leading to a final decision on these services properly involves all stakeholders throughout in the necessary work, reflecting their priorities and feedback in a comprehensive model of care to be implemented and the consequent service changes required.

5.9.16 The Panel has reflected on the implications of the resources and time taken to review this one nationally commissioned service in the context of likely drivers for change in other nationally commissioned services. The Panel considers that it would be unsustainable to adopt a similar approach for each potential service. The IRP suggests that NHS England needs to consider the lessons that can be learned from this process and develop a different approach for other services.

5.9.17 However, the Panel is of the view that, irrespective of the footprint on which a service is provided, the basic principles of good practice in engagement and consultation should be adhered to and the work led by specialists with a depth of experience in community and patient engagement and consultation. The lessons learned from other IRP reviews of contested service changes provide a good framework to support the design of an effective process.

5.9.18 **Recommendation Fifteen**

NHS England should use the lessons from this review and create with its partners a more resource and time effective process for achieving genuine involvement and engagement in its commissioning of specialist services.

5.10 Next steps

5.10.1 The Panel has produced its advice in the context of changing and peculiar circumstances. Since 1 April 2013, responsibility for commissioning congenital heart services rests with NHS England, which has inherited the original proposals, a judicial review, responsibility for the quality of current services and the potential consequences of the IRP's advice, subject to the Secretary of State's decision.

5.10.2 The Panel's advice sets out what needs to be done to bring about the desired improvements in services in a way that addresses gaps and weaknesses in the original proposals. The Panel's recommendations stand on their own irrespective of any future decision by NHS England regarding the judicial review proceedings. We note that the court's judgment of 27 March 2013 appears congruent to our own advice and that a successful appeal on legal grounds will not, of itself, address the recommendations in this report.

5.10.3 The Panel's advice addresses the weaknesses in the original proposals but it is not a mandate for either the status quo or going back over all the ground of the last five years. There is a case for change that commands wide understanding and support, and there are opportunities to create better services for patients. The challenge for NHS England is to determine how to move forward as quickly and effectively as possible.

5.10.4 Work to address gaps in the clinical model and associated service standards (Recommendation Three above) is underway and should be brought to a rapid conclusion. In parallel, there are different potential approaches to effect positive change that might be considered. These include whether to bring forward proposals for reconfiguration again or adopt a more standards-driven process that engages providers more directly in the managed evolution of services to be delivered. The critical factor to consider, in the Panel's view, is that engagement of all interested parties is the key to achieving improvements for patients and families without unnecessary delay.

IRP

Independent Reconfiguration Panel

ADVICE ON SAFE AND SUSTAINABLE *PROPOSALS FOR CHILDREN'S CONGENITAL HEART SERVICES*

APPENDICES 1 - 9

Submitted to the Secretary of State for Health

30 April 2013

IRP

Independent Reconfiguration Panel

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

Tel: 020 7389 8045/8046
Email: info@irpanel.org.uk
Website: www.irpanel.org.uk

Press Office
Tel: 020 7025 7530
Email: press@irpanel.org.uk

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3 Letters to the Secretary of State for Health from Lord Ribeiro, IRP Chairman, providing initial assessment advice, 21 September 2012 and 7 December 2012

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Appendix One

Independent Reconfiguration Panel general terms of reference

The Independent Reconfiguration Panel is an advisory non-departmental public body. Its terms of reference are:

A1 To provide expert advice on:

- Proposed NHS reconfigurations or significant service change;
- Options for NHS reconfigurations or significant service change;

referred to the Panel by Ministers.

A2 In providing advice, the Panel will consider whether the proposals will provide safe, sustainable and accessible services for the local population, taking account of:

i. clinical and service quality

ii. the current or likely impact of patients' choices and the rigour of public involvement and consultation processes

iii. the views and future referral needs of local GPs who commission services, the wider configuration of the NHS and other services locally, including likely future plans

iv. other national policies, including guidance on NHS service change

v. any other issues Ministers direct in relation to service reconfigurations generally or specific reconfigurations in particular

A3 The advice will normally be developed by groups of experts not personally involved in the proposed reconfiguration or service change, the membership of which will be agreed formally with the Panel beforehand.

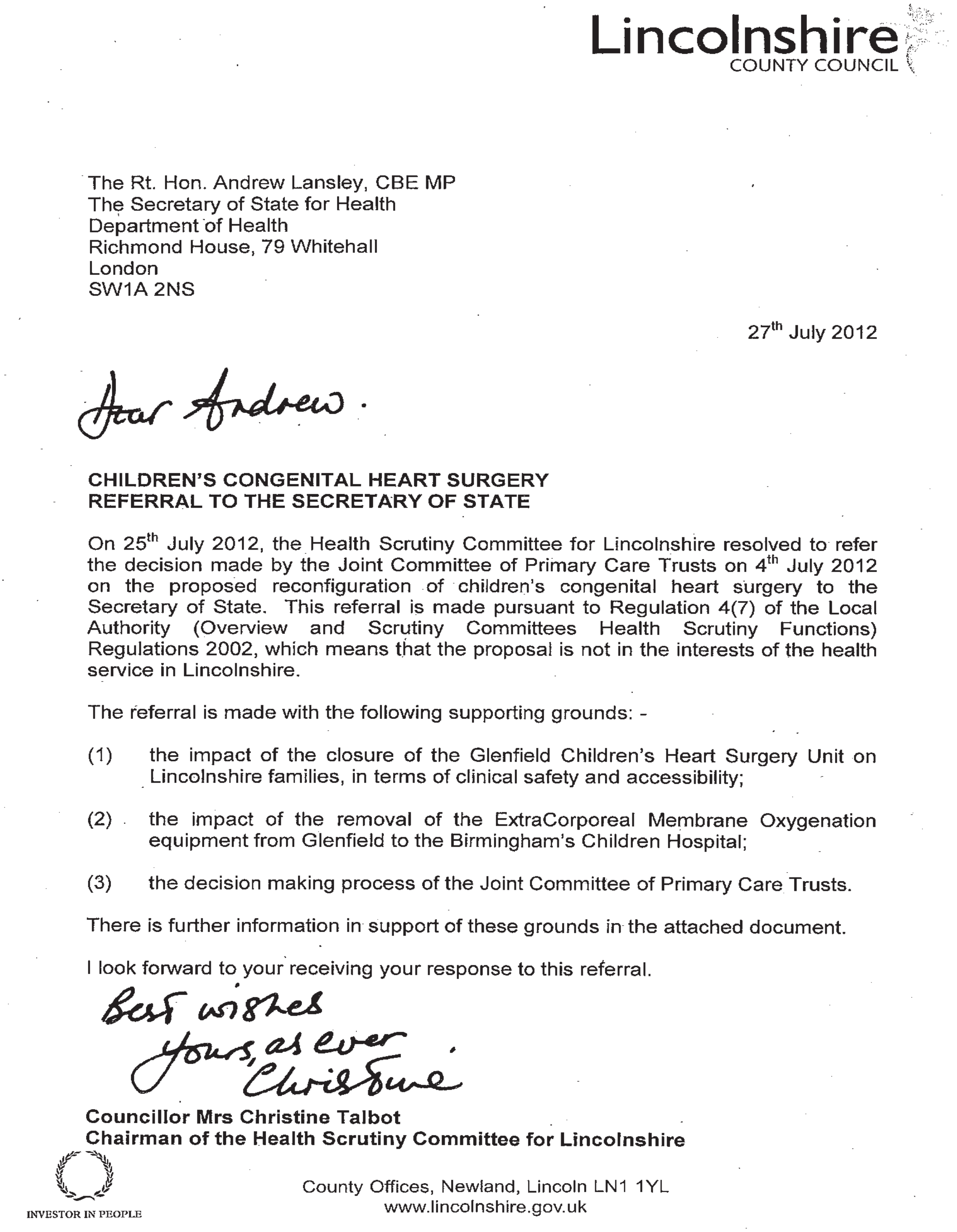
A4 The advice will be delivered within timescales agreed with the Panel by Ministers with a view to minimising delay and preventing disruption to services at local level.

B1 To offer pre-formal consultation generic advice and support to NHS and other interested bodies on the development of local proposals for reconfiguration or significant service change - including advice and support on methods for public engagement and formal public consultation.

C1 The effectiveness and operation of the Panel will be reviewed annually.

Appendix Two

Letters to Secretary of State for Health from HOSCs
27 July, 7 September and 27 November 2012



Lincolnshire
COUNTY COUNCIL

The Rt. Hon. Andrew Lansley, CBE MP
The Secretary of State for Health
Department of Health
Richmond House, 79 Whitehall
London
SW1A 2NS

27th July 2012

Dear Andrew.

CHILDREN'S CONGENITAL HEART SURGERY
REFERRAL TO THE SECRETARY OF STATE

On 25th July 2012, the Health Scrutiny Committee for Lincolnshire resolved to refer the decision made by the Joint Committee of Primary Care Trusts on 4th July 2012 on the proposed reconfiguration of children's congenital heart surgery to the Secretary of State. This referral is made pursuant to Regulation 4(7) of the Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002, which means that the proposal is not in the interests of the health service in Lincolnshire.

The referral is made with the following supporting grounds: -

(1) the impact of the closure of the Glenfield Children's Heart Surgery Unit on Lincolnshire families, in terms of clinical safety and accessibility;

(2) the impact of the removal of the ExtraCorporeal Membrane Oxygenation equipment from Glenfield to the Birmingham's Children Hospital;

(3) the decision making process of the Joint Committee of Primary Care Trusts.

There is further information in support of these grounds in the attached document.

I look forward to your receiving your response to this referral.

Best wishes
Yours, as ever
Christine

Councillor Mrs Christine Talbot
Chairman of the Health Scrutiny Committee for Lincolnshire

INVESTOR IN PEOPLE

County Offices, Newland, Lincoln LN1 1YL
www.lincolnshire.gov.uk

Leicester City Council
Rutland County Council
Leicestershire County Council

7th September 2012

The Right Hon Jeremy Hunt MP
The Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London
SW1A 2NS

Dear Secretary of State for Health

Glenfield Hospital – Children's Congenital Heart Surgery and Children's Extracorporeal Membrane Oxygenation (ECMO) Services

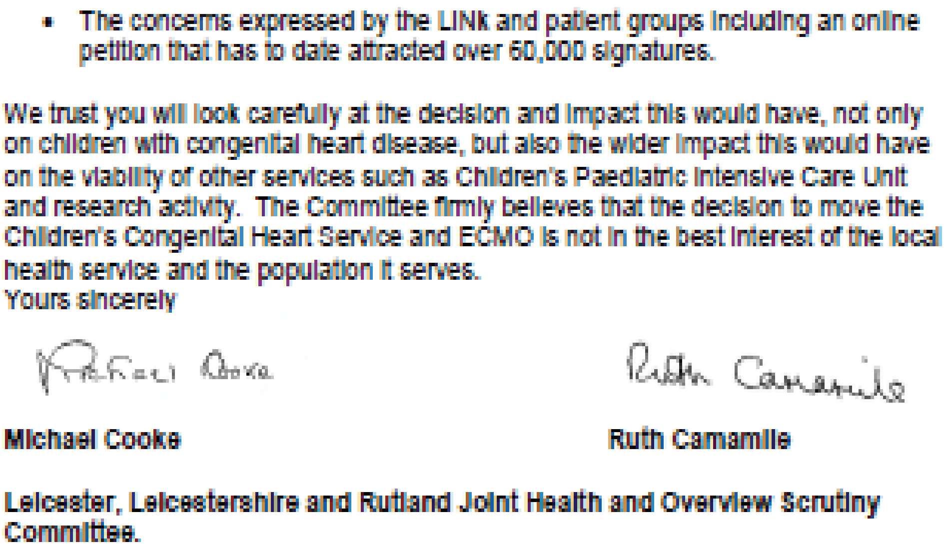
We wrote to your predecessor, Andrew Lansley, on 23rd August 2012 indicating that the Leicester, Leicestershire and Rutland Health Overview and Scrutiny Committee was extremely concerned about the decision to move Children's Congenital Heart Surgery and Children's ECMO Services from the Glenfield Hospital in Leicester to Birmingham Children's Hospital.

In the letter of 23rd August, we advised that it was our intention to test our evidence with the Joint Committee of Primary Care Trusts (JCPCT) prior to making a formal referral. We have since been advised that the referral made by Lincolnshire Health Scrutiny Committee is now with the Independent Reconfiguration Panel (IRP) and that the IRP is likely to be providing you with an interim view by 21st September. In view of this and the fact that the only date the JCPCT has offered is 29th October, the Joint Committee has decided to make a formal referral now, so that the evidence it has gathered can be referred to and assessed by the IRP alongside the referral from Lincolnshire. The formal referral document is attached.

The Committee was also made aware that the JCPCT is meeting on 4th October and has agreed to send a copy of this letter and the formal referral to it.

The decision to move Children's Congenital Heart Surgical and ECMO Services has not been well received and you should also be aware of the depth of feeling as evidenced by:

- The support of Leicester and Leicestershire MPs of all parties;
- The support from councillors of all parties in Leicester, Leicestershire and Rutland and from the wider representative body of East Midlands Councils;



- The concerns expressed by the LINk and patient groups including an online petition that has to date attracted over 60,000 signatures.

We trust you will look carefully at the decision and impact this would have, not only on children with congenital heart disease, but also the wider impact this would have on the viability of other services such as Children's Paediatric Intensive Care Unit and research activity. The Committee firmly believes that the decision to move the Children's Congenital Heart Service and ECMO is not in the best interest of the local health service and the population it serves.
Yours sincerely

Michael Cooke Ruth Camamile

Michael Cooke **Ruth Camamile**

Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee.

Leeds
CITY COUNCIL

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 50456
Civic Fax 0113 24 78889
Your ref
Our ref JI/SMC
Date 27 November 2012

Rt Hon Jeremy Hunt MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London SW1A 2NS

Sent by e-mail and post

Dear Secretary of State,

Re: Review of Children's Congenital Cardiac Services in England

Further to my previous letters dated 15 August 2012, 7 September 2012 and 31 October 2012, I can confirm that the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (Joint HOSC) met on 16 November 2012 and considered a draft report in support of its referral of the decision of the Joint Committee of Primary Care Trusts (JCPCT) concerning the future configuration and delivery of children's congenital cardiac services in England.

At its meeting on 16 November 2012, the Joint HOSC identified and agreed a number of amendments to the draft report. These amendments have now been completed and I am pleased to enclose the Joint HOSC's final report in this regard (the 2nd report) alongside a further copy on the Joint HOSC's first report (October 2011).

I can also confirm that the Joint HOSC reinforced its previous decision (made on 24 July 2012) to refer the JCPCT's decision for your consideration on the basis of that decision not being in the best interest of local health services across Yorkshire and the Humber, nor the children and families they serve. This referral is made in accordance with the provisions set out in the Health and Social Care Act (2001) (as amended) and the associated regulations[1] (specifically regulation 4(7)) and current Department of Health guidance[2].

There are a number of significant issues highlighted in both of the Joint HOSC's reports (October 2011 and November 2012). Nonetheless, the general view of the Joint HOSC is that, as a result of the JCPCT's decision and without the retention of the surgical centre at Leeds Children's Hospital, the overall patient experience for children and families across Yorkshire and the Humber will be significantly worse.

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[1] *The Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002 – Statutory Instrument 2002/ 3048*

[2] *Overview and Scrutiny of Health – Guidance (Department of Health (July 2003))*

After careful consideration of a range of evidence and the views of stakeholders, the conclusions reached by the Joint HOSC are based on number of reasons, in particular:

- The range of interdependent surgical services, maternity and neonatal services are not co-located at proposed alternative surgical centres available to Yorkshire and the Humber children and their families;
- The dismantling of the already well established and very strong cardiac network across Yorkshire and the Humber – and the implications for patients with the proposed Cardiology Centre at Leeds essentially working across multiple networks;
- The current seamless transition between cardiac services for children and adults across Yorkshire and the Humber;
- Considerable additional journey times and travel costs – alongside associated increased accommodation, childcare and living expense costs and increased stress and strain on family life at an already stressful and difficult time;
- The implications of patient choice and the subsequent patient flows – resulting in too onerous caseloads (i.e. overloading) in some surgical centres, with other centres unable to achieve the stated minimum number of 400 surgical procedures.

At the time of publishing its first report in October 2011, the Joint HOSC reported it had not been able to consider all the information identified as being necessary to conclude its review at that time. Regrettably – even though the JCPCT's decision was made in July 2012 – members of the Joint HOSC still feel they have been unreasonably denied access to information believed to be relevant to the review and the associated decision-making processes. This information falls within categories that would have been routinely published by any local authority in the country. The Secretary of State is already aware that, despite the assurances published in the Pre-Consultation Business Case, the JCPCT has released no information whatsoever about the work of the Health Impact Assessment Steering Group. This information was particularly relevant to the Joint HOSC in the discharge of its statutory duties.

As Chair of the Joint HOSC, I feel very strongly that such non-confidential information should have automatically been available for general public scrutiny at every stage of the decision making process. It should certainly have been published once it had been identified by a legitimate statutory body established to review decisions and decision-making within the NHS. A complaint has been lodged with the Information Commissioner's Office regarding the lack of disclosure and I look forward to the independent assessment of the case put forward. As such, please be aware that once again, on behalf of the Joint HOSC I reserve the right to add further comment and/or recommendations, as and when any additional information requested, or any other relevant details, become available.

As mentioned in my previous letter (31 October 2012), the Joint HOSC is aware that you have already invited the Independent Reconfiguration Panel (IRP) to undertake a full review of the JCPCT's decision[3]. I can confirm that at its meeting on 16 November 2012, the Joint HOSC also considered the current terms of reference you have set for the IRP in this regard. In formalising its referral, the Joint HOSC recommended the following areas be drawn to your

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[3] *Based on the referrals received from Lincolnshire County Council and the Leicester, Leicestershire and Rutland Joint Heath Overview and Scrutiny Committee.*

attention and incorporated into revised terms of reference for the IRP's review of the Safe and Sustainable review of children's congenital cardiac services in England:

- The validity of the Kennedy Panel 'Quality Assessments' in light of recent and/or forthcoming Care Quality Commission reports and/or compliance notices issued to current providers previously assessed by the Kennedy Panel.
- The extent to which the JCPCT took account of the IRP's previous advice (endorsed by the Secretary of State for Health) that the JCPCT should give due consideration to comments from the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the PwC report on assumed patient flows and manageable clinical networks.
- The implications of an unpopular solution imposed by the JCPCT for patient choice within the NHS.
- Issues associated with potential obstetric referral patterns, the impact these may have on patient numbers at the proposed designated surgical centres and to what extent such matters were taken into account within the JCPCT's decision-making processes.
- The JCPCT's use of population projections/ estimates to determine potential future demand for services, both in terms of using the most up-to-date information and the lack of consideration of regional variations that may impact on the long term sustainability of specific/ individual surgical centres.
- The appropriateness, or otherwise, of the JCPCT' and its supporting secretariat refusing legitimate requests from the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) for access to non-confidential information during its scrutiny inquiry.

The Joint HOSC also remains unconvinced by the adequacy of the Public Consultation conducted by the JCPCT – bearing in mind that the public were supplied with potentially misleading and unreliable information from Professor Kennedy's assessment panel, and unreasonably denied access to other information necessary to make an informed response. The enclosed report highlights this issue and also raises concerns around a number of other areas – including the Health Impact Assessments and the sensitivity testing undertaken by the JCPCT. The Joint HOSC believes these aspects also warrant specific and more detailed consideration by the IRP. On behalf of the Joint HOSC, I would urge you to specifically incorporate all of the above matters into revised terms of reference for the IRP's review.

I trust this information is helpful and I look forward to hearing from you in due course. Meanwhile, should need any additional information and/or any further clarification, please do not hesitate to contact me.

Yours sincerely

Councillor John Illingworth

Chair, Joint Health Overview and Scrutiny Committee (HOSC), Yorkshire and the Humber

cc All Members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)
All Members of Parliament representing Yorkshire and the Humber
All Yorkshire and the Humber Local Authority Leaders
Cllr. Lisa Mulherin, Leeds City Council

Appendix Three

Letters to Secretary of State for Health from Lord Ribeiro with initial assessment advice, 21 September and 7 December 2012

6th Floor

157 – 197 Buckingham Palace Road
London
SW1W 9SP

The Rt Hon Jeremy Hunt MP
Secretary of State for Health
Richmond House
79 Whitehall
London SW1A 2NS

21 September 2012

Dear Secretary of State

REFERRAL TO SECRETARY OF STATE FOR HEALTH
The *Safe and Sustainable* review of children's congenital heart services
Health Scrutiny Committee for Lincolnshire
Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee

Thank you for forwarding copies of the referral letters from Cllr Christine Talbot, Chair of the Health Scrutiny Committee for Lincolnshire (HSC), and from Michael Cooke, Chairman and Ruth Camomile, Vice Chairman of the Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee (LLR Scrutiny Committee) The National Specialised Commissioning Team (NSCT) provided initial assessment information. A list of all the documents received is at Appendix One.

The IRP has undertaken an initial assessment, in accordance with our agreed protocol for handling contested proposals for the reconfiguration of NHS services. The IRP considers each referral on its merits and its advice in this case is set out below. **The Panel concludes that these referrals are suitable for full review.**

Background
Following a higher than expected number of deaths of children receiving heart surgery between 1984 and 1995, the Bristol Royal Infirmary Inquiry report (the Kennedy report) was published in 2001 recommending that specialist expertise be concentrated in fewer surgical units in England. Further consideration by the Department of Health (DH) and relevant medical bodies followed until, in May 2008, the NSCT was asked to undertake a review with a view to reconfiguring surgical services for children with congenital heart disease. Taking into consideration concerns that surgeons and resources may be spread too thinly across the centres, the review considered whether expertise would be better concentrated on fewer sites than the current eleven in England.

The *Safe and Sustainable* team was established to manage the review process on behalf of the ten Specialised Commissioning Groups (SCG) and their local primary care trusts (PCT). In December 2008, an expert clinical Steering Group was formed to direct the process of developing a report to the NHS Management Board and DH Ministers.

Draft quality standards, against which surgical centres would be assessed, were published in September 2009 and sent directly to all health overview and scrutiny committees (HOSC) and other organisations for comment. The final version of the standards was published in March 2010. Also in March 2010, following a number of post- surgical deaths, surgery at the paediatric cardiac unit at the John Radcliffe Hospital, Oxford, was suspended.

A process of self-assessment by surgical centres commenced in April 2010. In the same month, the *Safe and Sustainable* team published *Children's Heart Surgery – the Need for Change.* Later in April 2010, the NHS Operations Board recommended to DH Ministers that PCTs delegate their consultation responsibilities and decision-making powers to a joint committee of PCTs (JCPCT). The Secretary of State for Health approved the establishment of the JCPCT in June 2010. The revised NHS Operating Framework confirmed that the *Safe and Sustainable* review was expected to deliver recommendations for consultation in the autumn of 2010.

Between May and June 2010, an expert panel, chaired by Professor Sir Ian Kennedy, visited each surgical centre to meet staff and families and to assess each centre's ability to comply with the standards. Pre-consultation engagement events commenced in June 2010. In September 2010, the case for change was supported by the National Clinical Advisory Team and proposed processes for consultation were endorsed by OGC Gateway review. The JCPCT met for the first time as a formally constituted body in October 2010. Briefings for HOSCs by SCG representatives began the following month.

In August 2010, a review conducted by South Central strategic health authority (SHA) recommended that the paediatric cardiac surgical service at the John Radcliffe Hospital, Oxford, should remain suspended pending the outcome of the *Safe and Sustainable* review.

In November 2010, on behalf of the JCPCT, a panel of experts chaired by Mr James Pollock, consultant congenital cardiac surgeon, investigated historical deaths at three surgical units in Leeds, Leicester and London (the Evelina Children's Hospital). The outcome of this investigation was presented to the Kennedy panel to consider whether it was necessary to revise its assessment of any of the three centres. The Kennedy panel found no cause to revise its assessment and the panel's report was published in December 2010.

Options for consultation were agreed by the JCPCT in February 2011 and a four-month public consultation began in March 2011. The consultation proposed concentrating clinical expertise on fewer sites by reducing the number of surgical centres from eleven to either six or seven. A judicial review of the proposal to reduce the number of surgical centres in London from three to two centres was initiated by the Royal Brompton & Harefield NHS Foundation Trust.

A briefing for HOSCs, informing them of the forthcoming launch of the consultation, had been issued in February 2011. Earlier communications to HOSCs, notably a Centre for Public Scrutiny briefing in April 2010, had alerted them to the intention to conduct a formal consultation and encouraged them to consider the need for a joint committee. In recognition of changes to membership resulting from local elections in May 2011, the deadline for receipt of consultation responses from HOSCs was extended to 5 October 2011. In the event, no national joint committee was formed and arrangements for scrutiny varied around the country with a mixture of individual and area and regional joint committees ultimately responding to the consultation.

Representatives of East Midlands SCG provided a presentation on the *Safe and Sustainable* review to a meeting of the LLR Scrutiny Committee on 21 March 2011 and Lincolnshire HSC in April 2011 and to two Deliberative Stakeholder Events in Lincoln and Sleaford in May 2011.

On 22 June 2011, it was announced that an independent panel of national and international experts, chaired by Adrian Pollitt, had been appointed to advise the JCPCT on the potential impact of the children's congenital heart proposals on other services at the Royal Brompton Hospital.

The formal public consultation closed on 1 July 2011 (except for HOSCs). An independent analysis of the consultation, commissioned from Ipsos MORI, was published in August 2011. That analysis acknowledged that the impact of the proposed changes on other services had been raised as an issue during consultation.

During August 2011, representatives of East Midlands SCG provided briefings for East Midlands HOSCs about responses to the public consultation and on a draft final Health Impact Assessment. Further briefings were held in the run-up to the JCPCT decision-making meeting in July 2012.

In September 2011, the *Safe and Sustainable* Steering Group considered clinical issues raised during the consultation and advised the JCPCT to agree the quality standards and model of care as set out in the consultation document. A supplementary report in response to issues raised during the consultation was published by the Kennedy panel in October 2011.

The Report of the Independent Panel on the Relationship of Interdependencies at the Royal Brompton Hospital (the *"Pollitt Report"*) was published on 15 September 2011. It stated that *"... although there would be an impact on the range of activity at the RBH the panel has concluded that paediatric respiratory services would remain viable at the RBH site in the absence of an on-site PICU"*.

The formal consultation with HOSCs concluded on 5 October 2011. Also in that month, at the JCPCT's request, the Kennedy panel published a supplementary report in response to issues raised during consultation. The panel clarified that University Hospital of Leicester NHS Trust did not meet the requirement for the co-location of core paediatric services.

The Yorkshire and Humber Joint Health Overview and Scrutiny Committee (Joint HOSC) referred the *Safe and Sustainable* review of children's congenital cardiac services to the Secretary of State on 14 October 2011. The referral was particularly concerned with services currently provided at Leeds General Infirmary and the potential effects of the proposals on patients and residents in Yorkshire and the Humber.

On 7 November 2011, the judgement was delivered in the judicial review brought by the Royal Brompton & Harefield NHS Foundation Trust. The judge, whilst rejecting a number of the arguments put forward, found against the JCPCT on a matter of process. An appeal against the judgement was lodged.

Later in November 2011, the JCPCT invited the 11 centres providing children's congenital heart services to submit new evidence demonstrating their compliance with the national quality standards relating to innovation and research.

The IRP submitted its initial assessment advice on the referral by the Yorkshire and Humber Joint HOSC on 13 January 2012. As well as commenting on the consultation process and on communication and relationships between the Joint HOSC and the JCPCT, the Panel offered advice in relation to a number of outstanding requests for information sought by the Joint HOSC. The Secretary of State announced on 23 February 2012 that he had accepted the Panel's advice in full.

The Royal Borough of Kensington and Chelsea Health Environmental Health and Adult Social Care (HEHASC) Scrutiny Committee referred the *Safe and Sustainable* review of children's congenital cardiac services to the Secretary of State on 27 March 2011. The referral was particularly concerned with services currently provided at the Royal Brompton Hospital and the potential effects of the proposals on patients and residents in west London and south east England.

On 19 April 2012, the Court of Appeal announced its decision, dismissing the grounds raised by the Royal Brompton & Harefield NHS Foundation Trust and finding the public consultation to be lawful and proper.

The IRP submitted its initial assessment advice on the referral by the Kensington and Chelsea HEHASC Scrutiny Committee 23 May 2012. The Panel offered comments on the JCPCT's efforts to address concerns raised by respondents to the consultation process that would inform the JCPCT ahead of its forthcoming decision-making meeting. The Secretary of State announced on 15 June 2012 that he had accepted the Panel's advice in full.

In line with the IRP's initial assessment advice on the referrals by Yorkshire and Humber Joint HOSC and by Kensington and Chelsea HEHASC Scrutiny Committee, further work was undertaken and completed to inform the JCPCT before its decision-making meeting.

The JCPCT held its decision-making meeting on 4 July 2012 and agreed that seven managed clinical networks should be established across England (and serving Wales). Each network would be led by a surgical centre - based in the Freeman Hospital Newcastle (north), Alder Hey Children's Hospital Liverpool (north west and north Wales), Birmingham Children's Hospital (midlands), Bristol Royal Hospital for Children (south west and south Wales), Southampton General Hospital (south central) and Great Ormond Street Hospital for Children and Evelina Children's Hospital (London, East Anglia and the south east).

On 13 July 2012, the Secretary of State for Health, having accepted the advice of the Advisory Group for National Specialised Services, designated Birmingham Children's Hospital as a nationally commissioned provider of ExtraCorporeal Membrane Oxygenation (ECMO) services for children with respiratory failure – in place of the existing unit at Glenfield Hospital, Leicester.

The Lincolnshire HSC referred the *Safe and Sustainable* review of children's congenital cardiac services to the Secretary of State on 27 July 2012. The referral was particularly concerned with services currently provided at Glenfield Hospital, Leicester and the potential effects of the proposals on patients and residents in Lincolnshire.

The LLR Scrutiny Committee referred the *Safe and Sustainable* review of children's congenital cardiac services to the Secretary of State on 7 September 2012. The referral was particularly concerned with services currently provided at Glenfield Hospital, Leicester and the potential effects of the proposals on patients and residents in Leicester, Leicestershire and Rutland.

Basis for referral
The referral letter of 27 July 2012 from Cllr Talbot, Chair of the Lincolnshire HSC states that:

"This referral is made pursuant to Regulation 4(7) of the Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002, which means that the proposal is not in the interests of the health service in Lincolnshire.

The referral is made with the following supporting grounds:-

(1) the impact of the closure of the Glenfield Children's Heart Surgery Unit on Lincolnshire families, in terms of clinical safety and accessibility;
(2) the impact of the removal of the ExtraCorporeal Membrane Oxygenation equipment from Glenfield to the Birmingham Children's Hospital;
(3) the decision making process of the Joint Committee of Primary Care Trusts."

The documentation supplied with the referral letter of 7 September 2012 from Michael Cooke, Chairman and Ruth Camomile, Vice Chairman of the LLR Scrutiny Committee states that:

"This referral is made pursuant to regulation 4(7) of the Local Authority (Overview and Scrutiny Health Scrutiny Functions) Regulations 2002.

The LLR Scrutiny Committee supports the principles of the Safe and Sustainable Review but is concerned at the outcome, believing that the decision of the JCPCT is not in the best interest of the local health service and the population it serves. The grounds for challenge are summarised below.

(a) The JCPCT prediction of demand and capacity at Birmingham Children's Hospital;
(b) The impact of moving ECMO services and increased mortality;
(c) Impact on paediatric intensive care capacity in the Midlands
(d) Impact on medical research at University Hospitals of Leicester NHS Trust and Leicester University;
(e) Accessibility of services;
(f) The decision-making process of the JCPCT."

IRP view

With regard to the referrals by the Lincolnshire HSC and LLR Scrutiny Committee, the Panel notes that:

- The proposals have aroused considerable national interest
- These are the third and fourth referrals to date relating to the *Safe and Sustainable* proposals for children's congenital cardiac services
- It is understood that further referrals are anticipated
- Common themes have been raised in the referrals so far received, including
    - the impact on patients and residents in the localities concerned, notably travel times and use of post code analysis to assess the likely impact
    - the impact on other services provided by the hospitals affected in those localities, including possible impact on staff retention
    - the consultation and decision-making process adopted by the JCPCT
    - the impact on medical research

Conclusion

The IRP offers its advice on a case-by-case basis taking account of the specific circumstances and issues of each referral.

The *Safe and Sustainable* proposals for children's congenital heart services have already been the subject of two referrals to the Secretary of State for Health. The IRP provided initial assessment advice on referrals from the Yorkshire and Humber Joint HOSC on 13 January 2012 and from the Kensington and Chelsea Health HEHASC Scrutiny Committee on 23 May 2012. Both referrals were made prior to final decisions being made by the JCPCT. In both cases, the Panel offered advice designed to enable the consultation process to be completed prior to the JCPCT's decision-making meeting to be held on 4 July 2012.

In addition to the referrals referenced above, and these referrals from the Lincolnshire HSC and the LLR Scrutiny Committee, the Panel is aware that the Yorkshire and Humber Joint HOSC has written to the Secretary of State advising of its intention to refer the proposals again following the JCPCT's decision of 4 July 2012. The Panel has been advised that referrals from other HOSCs are also expected.

Further, the Panel understands that a letter before action has been issued to the JCPCT on behalf of a Leeds based charity prior to making an application for a judicial review of the JCPCT's decision of 4 July 2012. The JCPCT's concern, that further legal proceedings may lead to delay in making changes to services, is noted.

Clearly, these developments mean that there is a high risk of uncertainty for the services concerned. Alongside the considerable public interest in this, the first national consultation to have been conducted since the introduction of health scrutiny by local authorities, the IRP considers that the issues raised merit further consideration. The Panel believes that a full review would be appropriate and stands ready to undertake such a review if requested.

Yours sincerely

Lord Ribeiro CBE
IRP Chairman

APPENDIX ONE

LIST OF DOCUMENTS RECEIVED

Health Scrutiny Committee for Lincolnshire

1 Letter of referral from Cllr Talbot, Chair, Health Scrutiny Committee for Lincolnshire to Secretary of State for Health, 27 July 2012

Attachment:

2 Document in support of submission produced by Health Scrutiny Committee for Lincolnshire

Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee

1 Letter of referral from Cllr Cooke, Chairman, and Cllr Camomile, Vice-Chairman, Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee to Secretary of State for Health, 7 September 2012

Attachment:

2 Document setting out evidence gathered by LLR Scrutiny Committee in support of referral to the Secretary of State for Health, with supporting appendices:
3 Projected demand
4 Capacity at Birmingham Children's Hospital
5 Effect of the Review on ECMO Provision
6 Impact on Paediatric Care Services
7 Evidence provided by the University of Leicester
8 purpose and Scope of the Review
9 Initial letter to the Secretary of State for Health
10 Minutes of Leicester City Council's Health and Community Involvement Scrutiny Commission, 26 July 2012
11 Minutes of Leicester City Council meeting, 28 June 2012
12 Minutes of Leicestershire County Council Cabinet meeting, 23 July 2012
13 Report to the University Hospitals of Leicester Trust Board, 26 July 2012
14 Leicester LINk email to east Midlands MPs and LINk briefing paper
15 Report of Dr Nichani, Consultant paediatric Intensivist, University Hospitals of Leicester
16 Report to the University Hospitals of Leicester Trust Board, 30 August 2012
17 Responses of east midlands health and overview scrutiny committees
18 Minutes of the Leicester, Leicestershire and Rutland Health Overview Scrutiny Committee, 4 September 2012

National Specialised Commissioning Team

1 Lincolnshire HSC specific IRP template for providing initial assessment information

Links and attachments:

2 Referral from the Lincolnshire OSC to the Secretary of State for Health, 27 July 2012
3 Response to the consultation from the Lincolnshire OSC (via response form)
Response form (for reference)
4 Letter from Cllr Mrs Christine Talbot, Chair of the Health Scrutiny Committee for Lincolnshire, 24 May 2012
5 Letter from Dr Kevin Harris, Medical Director, University Hospitals of Leicester NHS Trust to Jo Sheehan, Deputy Director, NSCT, 26 October 2012
6 Letter from Mr Giles Peek, Director, Paediatric and Adult ECMO programme, Glenfield Hospital, to Teresa Moss, Director, NSCT, 11 June 2012
7 Ipsos MORI report of the public consultation, August 2011

8 *Safe and Sustainable* Steering Group – membership, 2010
9 Decision Making Business Case, Appendix LL – *Safe and Sustainable* Capacity Review, May 2012
10 NSCT's statement on children's respiratory ECMO
11 Statement: ECMO and children's congenital heart services, 10 July 2012

12 *Safe and Sustainable* general IRP template for providing initial assessment information

Links and attachments:

13 Report of the Public Inquiry into children's heart surgery at the Bristol Royal infirmary 1984-1995: Learning from Bristol, July 2001
14 The relation between Volume and Outcome in Paediatric Cardiac Surgery. A Literature Review for the National Specialised Commissioning Group. Henrietta Ewart, Consultant in Public Health Medicine, PHRU, Oxford, September 2009
15 Children's Heart Surgery Centres in England: Comments on Draft Service Specification Standards (Comments received up to 17 February 2010), February 2010
16 Letter from Cllr Christopher Buckmaster, Chair, Health Scrutiny Committee, the Royal Borough of Kensington and Chelsea, to Jeremy Glyde, Programme Director, *Safe and Sustainable*, 8 September 2010
17 Children's Heart Surgery in England – A Need for Change, April 2011
18 Papers from the JCPCT meeting in public (launch of the consultation), 16 February 2011
19 Pre-consultation Business Case, February 2011
20 Consultation document, February 2011
21 Better care for your heart – a summary (consultation document for young people), March-July 2011
22 Consultation document and questionnaire in Welsh, March-July 2011
23 Consultation document and questionnaire in minority languages
24 Consultation document – improving children's congenital heart services in London, March-July 2011
25 National Clinical Advisory Team (NCAT) report, September 2010
26 OGC Gateway Report, September 2010
27 NHS London's approval to launch consultation, 8 February 2011
28 NHS London's assurance report, 8 February 2011
29 Health Impact Assessment – Key Emerging Findings, 21 June 2011
30 Health Impact Assessment – draft final report (interim report), 5 August 2011
31 Ipsos MORI – *Safe and Sustainable* Review of Children's Congenital Heart Services in England: Report of the public consultation, 24 August 2011
32 Report of the Independent Panel on the relationship of interdependencies at the Royal Brompton Hospital ("Pollitt Report"), 15 September 2011
33 Report from Sir Ian Kennedy's independent expert panel to the JCPCT, 17 October 2011
34 Testing assumptions for future patient flows and manageable clinical networks for *Safe and Sustainable* (PWC), October 2011
35 Report to the JCPCT by Dr Patricia Hamilton CBE, Chair of the *Safe and Sustainable* Steering Group, on behalf of Steering Group members, 17 October 2011
36 Judgement – High Court, 7 November 2011
37 Report of Sir Ian Kennedy's Panel in response to the additional evidence submitted in relation to "innovation and research", 14 February 2012
38 Judgement – Court of Appeal, 19 April 2012
39 Responses from organisations to an independent report on family travel analysis, 24 April 2012

40 Safe and Sustainable: Implementation Plan during 2012/13 and Transfer into the NHS Commissioning Board for April 2013, August 2012
41 Papers presented at the JCPCT meeting in public, 4 July 2012
42 Transcript from the JCPCT's decision-making meeting in public, 4 July 2012
43 Letter from professional associations regarding the JCPCT's decision on the future configuration of children's congenital heart services

Other information received

Information forwarded by Dr Peter Barry, Department of Child Health, Leicester Royal Infirmary:

1 Document: Congenital Heart Surgery Review – The clinical case for keeping surgery at Glenfield Hospital, Leicester
2 Letter to Sir Neil McKay CB, Chair Joint Committee of Primary Care Trusts, from Dr Peter Carter, Chief executive and General Secretary, Royal College of Nursing, 7 September 2012
3 Email from Dr W Lynch, Chairman Extracorporeal Life Support Organisation, 17 September 2012
4 Email from Mrs Nicky Morgan, MP for Loughborough, 18 September 2012

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

The Rt Hon Jeremy Hunt MP
Secretary of State for Health
Richmond House
79 Whitehall
London SW1A 2NS

7 December 2012

Dear Secretary of State

REFERRAL TO SECRETARY OF STATE FOR HEALTH
The *Safe and Sustainable* review of children's congenital heart services
Yorkshire and the Humber Joint Health Overview and Scrutiny Committee

Thank you for your letter of 29 November 2012 attaching the referral letter and supporting evidence from the Yorkshire and the Humber Joint Health Overview and Scrutiny Committee (HOSC).

The IRP has undertaken an initial assessment of the referral from the Joint HOSC in accordance with our agreed protocol for handling contested proposals for the reconfiguration of NHS services. The referral has been assessed with reference to the documentation previously received from the Lincolnshire County Council Health Scrutiny Committee and from the Leicester, Leicestershire and Rutland Joint HOSC.

The Panel concludes that the referral is suitable for inclusion within its review of the *Safe and Sustainable* proposals. However, the depth and range of the issues raised and the extensive number of individuals and groups from whom oral evidence will need to be taken, will require further time to complete the review.

With your agreement, we would propose to submit our report on the revised date of Thursday 28 March 2013 and look forward to receiving terms of reference amended accordingly.

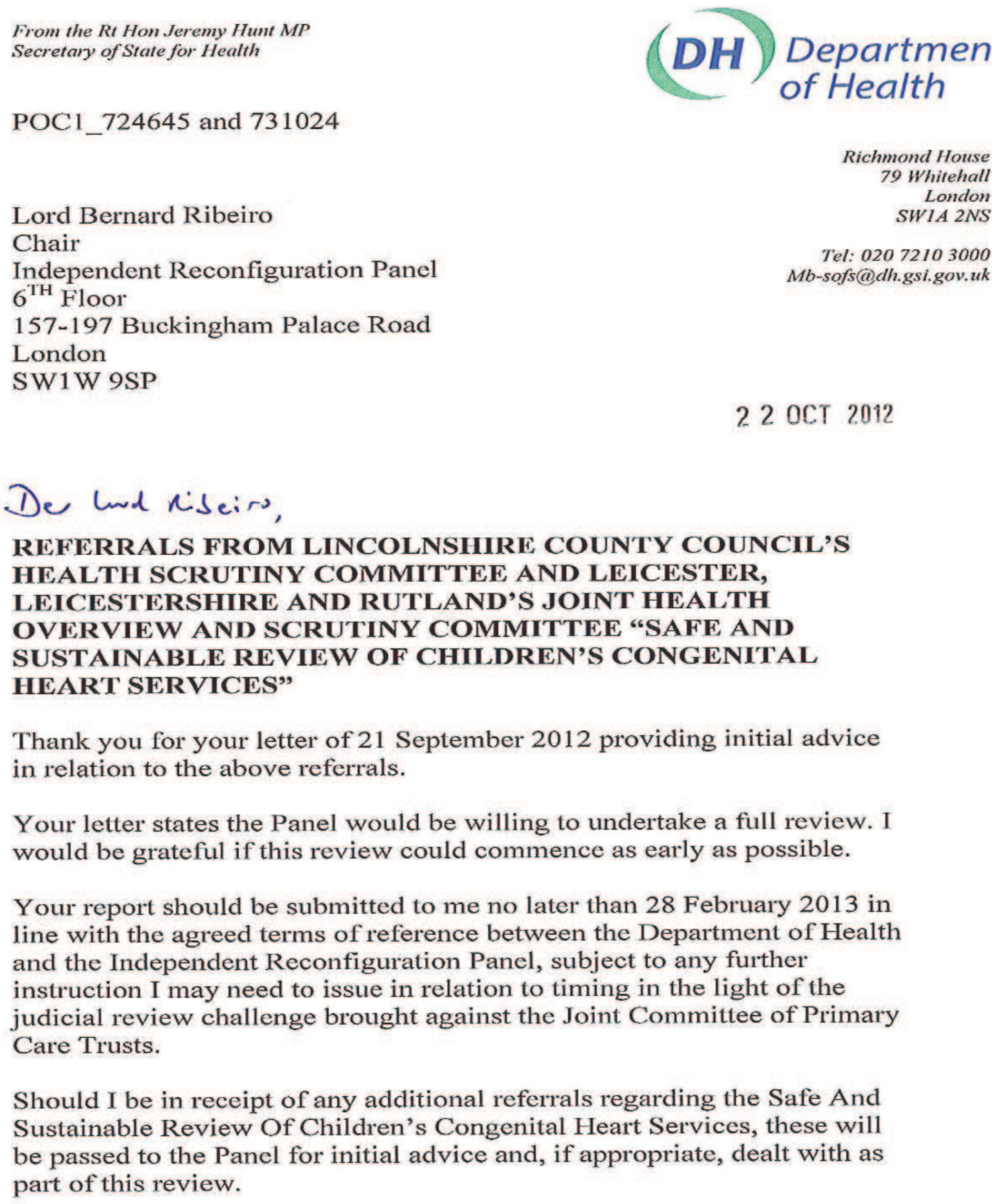
Yours sincerely

T Ribeiro

Lord Ribeiro CBE
IRP Chairman

Appendix Four

Letters to Lord Ribeiro, IRP Chair from Secretary of State for Health 22 October 2012, 10 December 2012 (containing revised terms of reference for full review) and 15 March 2013



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

POC1_724645 and 731024

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

Lord Bernard Ribeiro
Chair
Independent Reconfiguration Panel
6TH Floor
157-197 Buckingham Palace Road
London
SW1W 9SP

22 OCT 2012

Dear Lord Ribeiro,

REFERRALS FROM LINCOLNSHIRE COUNTY COUNCIL'S HEALTH SCRUTINY COMMITTEE AND LEICESTER, LEICESTERSHIRE AND RUTLAND'S JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE "SAFE AND SUSTAINABLE REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES"

Thank you for your letter of 21 September 2012 providing initial advice in relation to the above referrals.

Your letter states the Panel would be willing to undertake a full review. I would be grateful if this review could commence as early as possible.

Your report should be submitted to me no later than 28 February 2013 in line with the agreed terms of reference between the Department of Health and the Independent Reconfiguration Panel, subject to any further instruction I may need to issue in relation to timing in the light of the judicial review challenge brought against the Joint Committee of Primary Care Trusts.

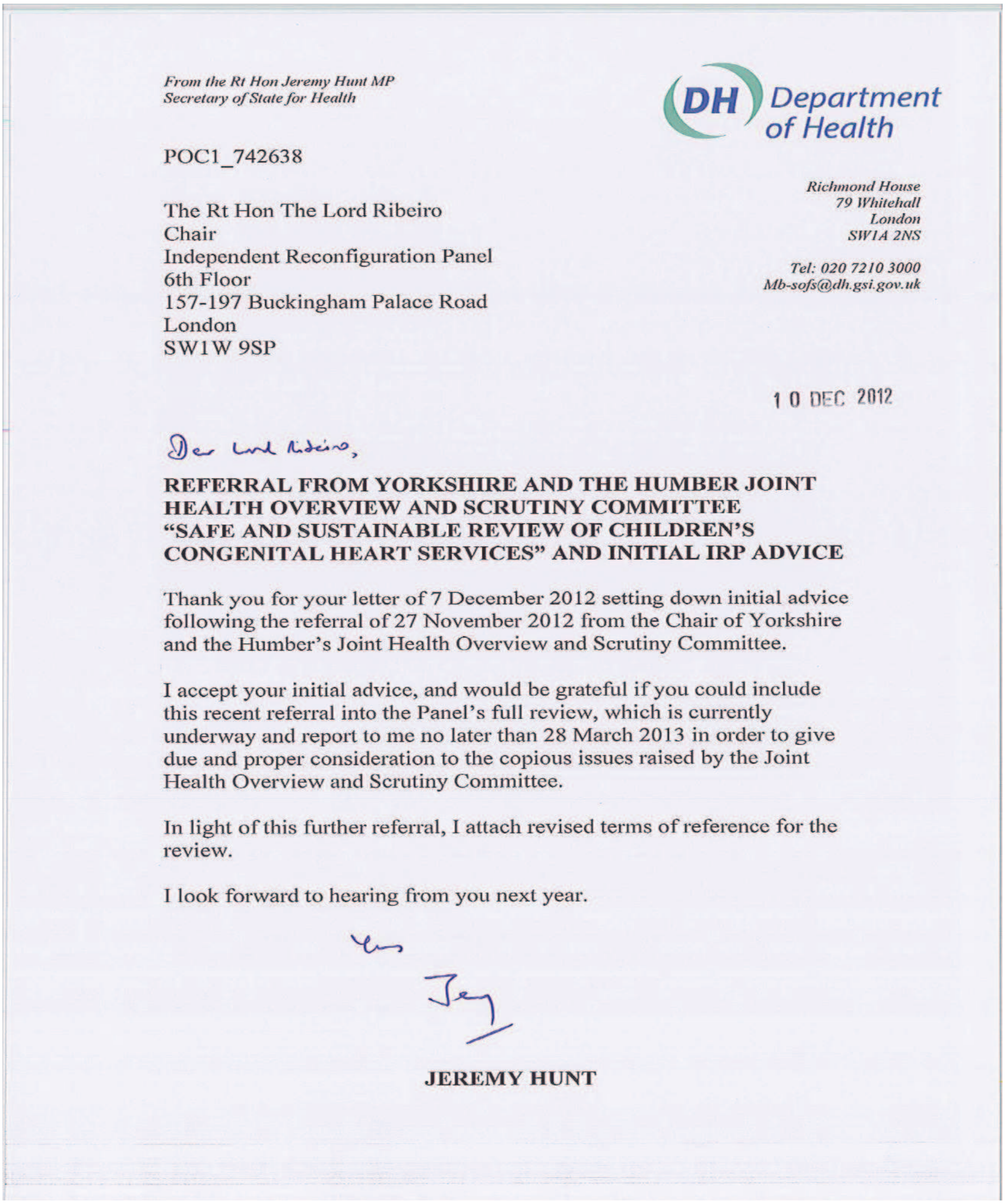
Should I be in receipt of any additional referrals regarding the Safe And Sustainable Review Of Children's Congenital Heart Services, these will be passed to the Panel for initial advice and, if appropriate, dealt with as part of this review.

The decision of the Secretary of State taken regarding the removal of the Extracorporeal Membrane Oxygenation equipment from Glenfield to Birmingham should not form part of the review as this decision was not taken by the Joint Committee of Primary Care Trusts.

I will write to you again regarding this review should the court grant permission to bring the judicial review proceedings.

Yours sincerely

JEREMY HUNT



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

Department of Health

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

POC1_742638

The Rt Hon The Lord Ribeiro
Chair
Independent Reconfiguration Panel
6th Floor
157-197 Buckingham Palace Road
London
SW1W 9SP

1 0 DEC 2012

Dear Lord Ribeiro,

REFERRAL FROM YORKSHIRE AND THE HUMBER JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE "SAFE AND SUSTAINABLE REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES" AND INITIAL IRP ADVICE

Thank you for your letter of 7 December 2012 setting down initial advice following the referral of 27 November 2012 from the Chair of Yorkshire and the Humber's Joint Health Overview and Scrutiny Committee.

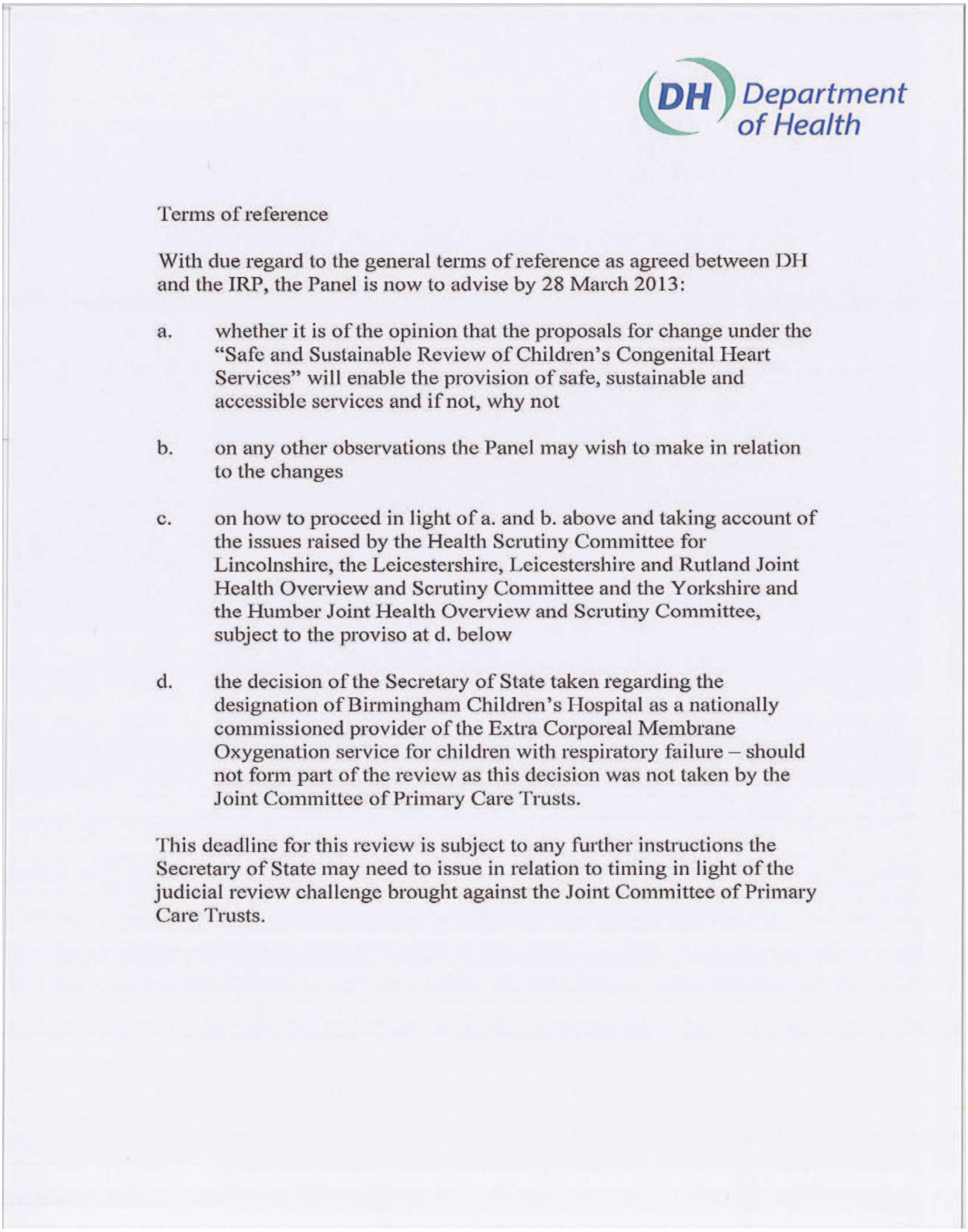
I accept your initial advice, and would be grateful if you could include this recent referral into the Panel's full review, which is currently underway and report to me no later than 28 March 2013 in order to give due and proper consideration to the copious issues raised by the Joint Health Overview and Scrutiny Committee.

In light of this further referral, I attach revised terms of reference for the review.

I look forward to hearing from you next year.

Yours

JEREMY HUNT



Department of Health

Terms of reference

With due regard to the general terms of reference as agreed between DH and the IRP, the Panel is now to advise by 28 March 2013:

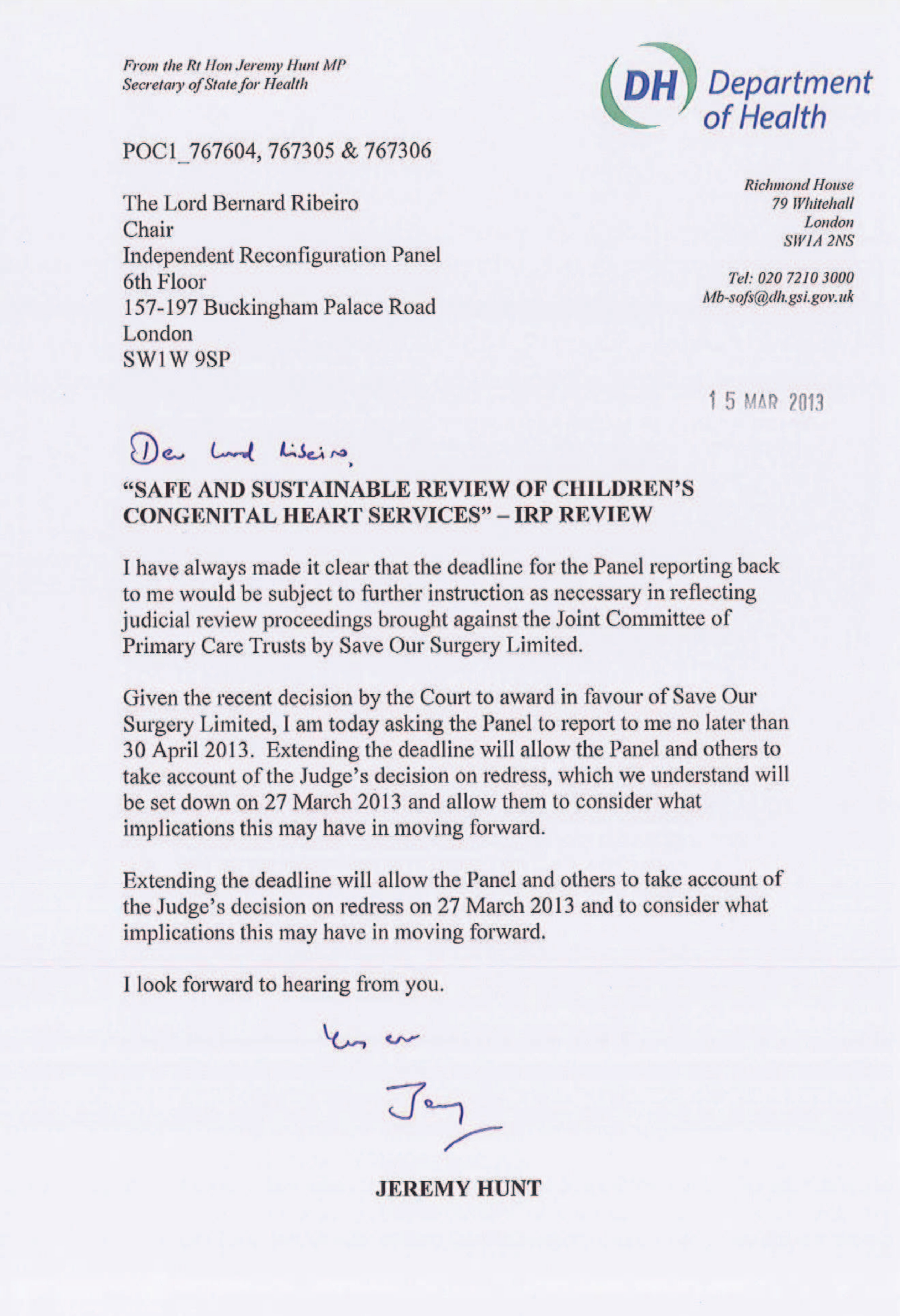
a. whether it is of the opinion that the proposals for change under the "Safe and Sustainable Review of Children's Congenital Heart Services" will enable the provision of safe, sustainable and accessible services and if not, why not

b. on any other observations the Panel may wish to make in relation to the changes

c. on how to proceed in light of a. and b. above and taking account of the issues raised by the Health Scrutiny Committee for Lincolnshire, the Leicestershire, Leicestershire and Rutland Joint Health Overview and Scrutiny Committee and the Yorkshire and the Humber Joint Health Overview and Scrutiny Committee, subject to the proviso at d. below

d. the decision of the Secretary of State taken regarding the designation of Birmingham Children's Hospital as a nationally commissioned provider of the Extra Corporeal Membrane Oxygenation service for children with respiratory failure – should not form part of the review as this decision was not taken by the Joint Committee of Primary Care Trusts.

This deadline for this review is subject to any further instructions the Secretary of State may need to issue in relation to timing in light of the judicial review challenge brought against the Joint Committee of Primary Care Trusts.



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

Department of Health

Richmond House
79 Whitehall
London
SW1A 2NS

Tel: 020 7210 3000
Mb-sofs@dh.gsi.gov.uk

POC1_767604, 767305 & 767306

The Lord Bernard Ribeiro
Chair
Independent Reconfiguration Panel
6th Floor
157-197 Buckingham Palace Road
London
SW1W 9SP

15 MAR 2013

Dear Lord Ribeiro,

"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.

Yours ever

Jeremy

JEREMY HUNT

Appendix Five

IRP press release and media statement, 6 November and 11 December 2012

IRP

www.irpanel.org.uk

Press release
6th November 2012

IRP undertaking independent health review

The Independent Reconfiguration Panel (IRP), the independent expert on NHS service change, has started a full review to consider whether the *Safe and Sustainable* proposals for children's congenital heart services will enable the provision of safe, sustainable and accessible services.

The IRP provided initial assessment advice in September 2012 following two referrals from the Health Scrutiny Committee for Lincolnshire, and from the Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee. The Health Secretary, Rt Hon Jeremy Hunt MP, accepted the IRP's advice that a full review should be undertaken.

Lord Ribeiro, Chairman of the IRP, said: "The Panel's key focus throughout the review will be children with congenital heart disease and the quality of care they need to receive. During the course of the review we will gather evidence from a range of people and listen to all interested parties to ensure that the recommendations we make are in the best interests of the children - and their families - across England that need to access these services."

As part of the review process the IRP will visit the hospitals currently providing children's congenital heart surgery to see the facilities and meet patients, clinicians and other staff. Over the coming weeks, Health and Overview Scrutiny Committees and MPs in England and Wales will be invited to share their views and any new evidence they may have with the IRP. IRP panel members will also hold a series of meetings to hear directly from a range of interested parties, including local authority representatives and interest groups.

The IRP strives to ensure that its reviews are open and accountable to the people using the services that are affected by this review. Anyone wishing to share their views or provide new evidence as part of this review can contact the IRP in the following ways:

- By email: info@irpanel.org.uk
- In writing: IRP, 6th Floor, 157-197 Buckingham Palace Road, London SW1W 9SP

- By leaving a voice message on: 020 7389 8046

The IRP is not able to respond to individual emails, letters or phone calls, however all information and views will be taken into account by the IRP and contributors will be acknowledged in the final report.

The IRP will make recommendations to the Health Secretary by 28 February 2013 in relation to the changes (subject to any changes of date that may be made). The final decision on changes to services will be made by the Health Secretary.

ENDS

For further information, contact the IRP press office on 020 7478 7835 or email press@irpanel.org.uk

Notes to editors:

1. The IRP will publish the findings of this review on the website - www.irpanel.org.uk - once they have been considered by the Health Secretary
2. The IRP was set up in 2003 to provide advice to the Secretary of State for Health on contested proposals for health service change in England
3. The Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002 require NHS organisations to consult their Health Overview and Scrutiny Committees (OSCs) on any proposals for substantial changes to local health services. If a Health Overview and Scrutiny Committee is not satisfied that either a thorough consultation process has taken place or that the proposal meets the needs of the local community, it may refer the proposals to the Secretary of State for Health under regulation 4(7) of the Local Authority (Overview and Scrutiny Committee Health Scrutiny Functions) Regulations 2002
4. IRP panel members have wide ranging expertise in clinical healthcare, NHS management, public and patient involvement and handling and delivering successful changes in the NHS
5. Further information, including details of all panel members, is available from www.irpanel.org.uk

IRP
www.irpanel.org.uk

MEDIA STATEMENT: 11 December 2012

IRP asked to consider Yorkshire and Humber referral as part of review

The Independent Reconfiguration Panel (IRP), the independent expert on NHS service change, has a full review underway to consider whether the *Safe and Sustainable* proposals for children's congenital heart services will enable the provision of safe, sustainable and accessible services.

Following a referral from Leeds City Council on behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and Humber) dated 27 November 2012, the IRP provided initial advice to the Health Secretary on 7 December.

On 10 December 2012, the Rt Hon Jeremy Hunt MP, Secretary of State for Health, confirmed that he agrees with the IRP's initial advice and would like the referral considered as part of the IRP's ongoing review into children's congenital heart services.

Given the need for the IRP to incorporate the latest referral into its review, the Health Secretary has updated the terms of reference. The IRP will now make recommendations to the Health Secretary one month later - by 28 March 2013 - in relation to the changes. The final decision on changes to services will be made by the Health Secretary.

Anyone wishing to share their views or provide new evidence as part of this review can contact the IRP in the following ways:

- By email: info@irpanel.org.uk
- In writing: IRP, 6th Floor, 157-197 Buckingham Palace Road, London SW1W 9SP
- By leaving a voice message on: 020 7389 8046

The IRP is not able to respond to individual emails, letters or phone calls, however all information and views will be taken into account by the IRP and contributors will be acknowledged in the final report.

ENDS

For further information, contact the IRP press office on 020 7478 7835 or email press@irpanel.org.uk

Appendix Six

Site visits, meetings and conversations held

13 November 2012

IRP **Lord Ribeiro, Cath Broderick, Fiona Campbell, Sanjay Chadha, Nick Coleman, Glenn Douglas, Jane Hawdon, Nicky Hayes, Brenda Howard, Nick Naftalin, John Parkes, Linda Pepper, Ray Powles, Hugh Ross, Gina Tiller, Richard Jeavons, Martin Houghton, Fiona Wood**

Clinical Seminar

Mr W Brawn, Dr T Salmon, Dr I Jenkins, Ms A Johnson, Dr D Mabin, Dr G Sharland

21 November 2012

IRP **Lord Ribeiro, Fiona Campbell, Sanjay Chadha, Nick Coleman, Glenn Douglas, Nick Naftalin, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood**

Evidence gathering session

Sir Neil McKay, Chair of the Joint Committee of PCTs
Ms Rosalind Banks, Advisor to the JCPCT, KPMG
Prof Sir Roger Boyle, Medical Adviser to the JCPCT
Mr Andy Buck, JCPCT Member, Yorkshire and the Humber, and Chief Executive, South Yorkshire and Bassetlaw PCTs
Prof Martin Elliott, *Safe and Sustainable* Steering Group Member, and Co-Medical Director, Great Ormond Street Hospital for Children NHS Foundation Trust
Mr James Ford, Communications Support to the JCPCT
Mr Jeremy Glyde, Programme Director, *Safe and Sustainable*
Ms Catherine Griffiths, JCPCT Member, East Midlands
Dr Kate Haire, Medical Adviser, National Specialised Commissioning Team
Mr Leslie Hamilton, Medical Adviser to the JCPCT and Vice Chair of the Steering Group, and Consultant Cardiac Surgeon, Freeman Hospital, Newcastle
Ms Suzie Hutchinson, Chief Executive, Little Hearts Matter
Mr Eamonn Kelly, JCPCT Member, West Midlands
Prof Sir Ian Kennedy, Chair, *Safe and Sustainable* Assessment Panel, and Chair, Bristol Public Inquiry
Ms Sue McLellen, Chief Operating Officer, London SCG, and JCPCT Member
Ms Teresa Moss, JCPCT Member, National Specialised Commissioning
Mr Brian Niven, Health Service Improvement Team, Mott MacDonald
Ms Catherine O'Connell, JCPCT Member, East of England, Director of Commissioning, Midlands and East Region, and Chief Operating Officer, Midlands and East Specialised Commissioning Group
Ms Kerry Schofield, Principal Consultant, Mott MacDonald
Dr Sheila Shribman, Medical Advisor to the JCPCT, and National Clinical Director for Children, Young People and Maternity, Department of Health
Ms Fiona Smith, *Safe and Sustainable* Steering Group Member (represented the Royal College of Nursing)
Ms Ann Sutton, JCPCT Member, South East Coast, and Director of Commissioning, NHS Commissioning Board

Ms Maria von Hildebrand, Member of the Safe and Sustainable Steering Group, and member of Professor Kennedy's Assessment Panel
Dr Tim Wilson, Partner, Health Advisory, PwC
Ms Julie Wootton, Chair, Children's Heart Federation

26 November 2012

IRP **Lord Ribeiro, Cath Broderick, Sanjay Chadha, Nick Coleman, Glenn Douglas, Nicky Hayes, Nick Naftalin, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood Sarah Skinner**

Evidence gathering session

Cllr Michael Cooke, Leicester City Council, Chair of Joint LL&R HOSC and Chair of Health and Community Involvement Scrutiny Commission
Cllr Ruth Camamile, Leicestershire County Council, Vice Chair of Joint LL&R HOSC and Chair of Adults and Communities and Health Scrutiny and Overview Committee
Cllr Deborah Sangster, Leicester City Council, Elected Member on Joint Health and Health and Community Involvement Scrutiny Commission
Cllr Lucy Stephenson, Rutland County Council Elected Member on Joint Health and Health and Social Care Scrutiny Council
Cllr Alan Bailey, Leicestershire County Council, Elected Member on Joint Health and Adults and Communities and Health Scrutiny and Overview Committee
Dr Aidan Bolger, Consultant Adult Congenital Heart Disease, Glenfield Hospital

27 November 2012

IRP **Lord Ribeiro, Cath Broderick, Fiona Campbell, Glenn Douglas, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood, Sarah Skinner**

Site visit – Glenfield Hospital, Leicester

Evidence gathering session

Mr Jim Birrell, Interim Chief Executive, University Hospitals of Leicester NHS Trust
Dr Kelvin Harris, Medical Director
Dr Giles Peek, Head of the East Midlands Congenital Heart Centre & ECMO Director
Dr Aidan Bolger, Clinical Lead for Congenital Cardiology
Mr Mark Wightman, Director of Communications and External Relations
Dr Elizabeth Lee, Clinical Psychologist in Paediatric Cardiology
Dr Marianne Elloy, Paediatric ENT Consultant,
Dr Demetris Taliotis, Consultant Paediatric Cardiologist,
Dr Peter Barry, Consultant, Paediatric Intensive Care,
Ms Carmel Hunt, Matron
Ms Elizabeth Aryeetey, Lead Nurse

27 November 2012

IRP **Lord Ribeiro, Cath Broderick, Fiona Campbell, Glenn Douglas, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood, Sarah Skinner**

Evidence gathering session

Cllr Christine Talbot, Chairman, Health Scrutiny Committee for Lincolnshire
Dr Frances Bu'lock, Paediatric Cardiologist, East Midlands Congenital Heart Centre
Mr Simon Evans, Scrutiny Officer, Health Scrutiny Committee for Lincolnshire
Cllr Howard Johnson, Health Scrutiny Committee for Lincolnshire
Mr Preston Keeling, LINk representative, Health Scrutiny Committee for Lincolnshire, Chairman, HealthWatch Transition Board and Chief Executive, The Respite Association.
Ms Christer Larsson, Parent Representative
Ms Samantha Norton, Parent Representative
Dr Alastair Scammell, Consultant Paediatrician, United Lincolnshire Hospitals, Lincolnshire NHS Trust

27 November 2012

IRP **Lord Ribeiro, Cath Broderick, Fiona Campbell, Glenn Douglas, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood, Sarah Skinner**

Evidence gathering session

Mr Mick Whiteley, Lincolnshire Parent Representative
Ms Francesca Larsson, Parent Representative
Ms Debbie Walden. Parent Representative
Ms Julie McLaughlin, Parent Representative

28 November 2012

IRP **Lord Ribeiro, Fiona Campbell, Brenda Howard, Linda Pepper, Richard Jeavons, Fiona Wood, Zoe Dubber**

Evidence gathering session

Mr Eric Charlesworth, Chair, Leicester LINk
Mr Martin
Mr Wayne Matts, Parent Representative
Ms Marie Middleton, Heart Link
Ms Gill Smart, Treasurer, Heart Link
Mr Geoff Smart, Heart Link
Mr Dam Tansey, Founder, Keep the Beat

28 November 2012

IRP **Lord Ribeiro, Fiona Campbell, Brenda Howard, Richard Jeavons, Linda Pepper, Fiona Wood, Zoe Dubber**

Evidence gathering session

Mr Ballu Pater, Chair, Mercury Patients' Panel
Mr David Gorrod, Member
Mr Zuffar Haq, Member

4 December 2012

IRP **Lord Ribeiro, Brenda Howard, , Nick Naftalin, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood**

Site visit – Bristol Children's Hospital

Evidence gathering session

Mr Robert Woolley, Chief Executive, University Hospitals Bristol NHS Foundation Trust
Mr Ian Barrington, Division Manager, Women's and Children's Services,
Mr William Booth, Matron and Lead Nurse, Paediatric, Cardiac and Critical Care Services
Mr James Fraser, Consultant, Paediatric Intensive Care; Lead Doctor, Children's Hospital
Ms Judith Hernandez, Deputy Divisional Manager, Cardiac and Critical Care Centre
Ms Deborah Lee, Director, Strategic Development
Dr Robin Martin, Consultant, Paediatric and Adult Congenital Cardiology
Dr Andrew Parry, Lead Consultant Paediatric Cardiac Surgeon
Dr Dirk Wilson, Paediatric Cardiologist, Cardiff Hospital

5 December 2012

IRP **Lord Ribeiro, Cath Broderick, Fiona Campbell, Sanjay Chadha, Glenn Douglas, Brenda Howard, Linda Pepper, Ray Powles, Hugh Ross, Richard Jeavons, Fiona Wood, Sarah Skinner**

Site visit – Birmingham Children's Hospital

Evidence gathering session

Mr David Melbourne, Interim Chief Executive, Birmingham Children's Hospital
Dr Vinod Diwakar, Consultant General Paediatrician and Chief Medical Officer,
Dr Fiona Reynolds, Consultant Paediatric Intensivist and Deputy Chief Medical Officer
Dr David Barron, Consultant Paediatric Cardiac Surgeon
Dr Ashish Chikermane, Cardiac Services Clinical Lead
Ms Helen Watson, Head of Nursing, Specialised Services
Dr Oliver Stumper, Cardiology Lead
Dr Rishi Hazarika, Associate Medical Director for Strategy
Ms Amanda Baugh, Associate Service Director, Specialised Services,
Ms Margaret Farley, Lead Nurse Extracorporeal Life Support
Dr Linda Edwards, Consultant Paediatric Intensivist and Medical Lead Extra Corporeal Life Support

6 December 2012

IRP **Lord Ribeiro, Fiona Campbell, Glenn Douglas, Richard Jeavons, Fiona Wood**

Site visit – Alder Hey Children's Hospital

Evidence gathering session

Ms Louise Shepherd, Chief Executive, Alder Hey Children's NHS Foundation Trust
Dr Ian Lewis, Medical Director, National Co-Chair Children and Young People's Health Outcomes Forum
Dr James Bruce, Clinical Head of Division, Royal Manchester Children's Hospital
Dr Prem Venugopal, Consultant Cardiac surgeon
Dr Gordon Gladman, Consultant Cardiologist, Clinical Director North West, Wales & Isle Of Man, Paediatric Congenital Cardiac Network
Dr Sameer Misra, Paediatrician with Expertise in Cardiology, Royal Bolton Hospital NHS Foundation Trust
Dr Steve Kerr, Clinical Director, Clinical Care
Mr Ian Atkinson, General Manager, Surgery, Cardiac, Anaesthesia and Clinical Care
Ms Jen Riley, Cardiac Service and Network Manager
Mr Simon Kenny, Clinical Director, surgery, Cardiac, Anaesthesia and Critical Care
Ms Pauline Brown, Lead Nurse, surgery, Cardiac, Anaesthesia and Critical Care
Ms Mary Murray, Cardiac Liaison Nurse
Ms Emma Callaghan, Parent Representative

12 December 2012

IRP **Lord Ribeiro, Sanjay Chadha, Nick Coleman, Glenn Douglas, Linda Pepper, Ray Powles, Brenda Howard, Hugh Ross, Fiona Wood, Richard Jeavons, Zoe Dubber**

Site visit – Leeds General Infirmary

Evidence gathering session

Ms Maggie Boyle, Chief Executive, Leeds Teaching Hospitals NHS Trust
Dr John Thompson, Congenital Cardiologist
Ms Stacey Hunter, Divisional General Manager
Dr Mark Darowski, Paediatric Intensivist
Dr Helen Jepps, Paediatrician with Expertise in Paediatric Cardiology
Dr Kate English, Congenital Cardiologist
Dr Simon Newell, Neonatal Consultant
Dr Dominic Hares, Paediatric Congenital Cardiologist
Mr Jon Arnold, Parent,
Mike Collier, Chairman of Leeds Teaching Hospitals
Dr Osama Jaber, Congenital Cardiac Surgeon

13 December 2012

IRP **Lord Ribeiro, Ray Powles, Richard Jeavons, Martin Houghton**

Meeting with MPs and other representatives

Ms Liz Kendall (Leicester West), **Ms Nicky Morgan** (Loughborough), **Mr Jon Ashworth** (Leicester South), **Ms Lilian Greenwood** (Nottingham South), **Mr Keith Vaz** (Leicester East), **Ms Heather Wheeler** (South Derbyshire), **the Bishop of Leicester** and **Lord Bach of Butterworth**

18 December 2012

IRP **Lord Ribeiro, Fiona Campbell, Brenda Howard, Nick Naftalin, Ray Powles, Fiona Wood, Sarah Skinner**

Site visit – Southampton General Hospital

Evidence gathering session

Mr Mark Hackett, Chief Executive, University Hospital Southampton NHS Foundation Trust
Ms Alison Ayres, Director of Communications
Mr Matt Ayres, Divisional Director
Ms Anne Banning, Cardiac Physiologist, Oxford
Dr Tara Bharucha, Paediatric Cardiologist
Dr Aisling Carroll, Adult Congenital Cardiologist
Dr Richard Cope, Cardiac Anaesthetist
Ms Maria Crocker, Patient Representative, Oxford
Ms Louise George, Patient Representative, Oxford
Mr Michael George, Patient Representative, Oxford
Dr James Gnanapragasam, Clinical Lead, Paediatric Cardiac Service
Ms Gill Harte, Paediatric Cardiac Nurse Specialist
Dr David Howe, Foetal Medicine Consultant
Dr Michael Lavrsen, Paediatric Cardiac Surgeon
Dr Zek Lim, Paediatric Cardiologist
Dr Iain Macintosh, Director, PICU
Ms Sam Prior, Patient Representative, Southampton
Ms Carol Purcell, Matron, Child Health
Dr Trevor Richens, Paediatric Cardiologist
Dr Kevin Roman, Paediatric Cardiologist
Dr Tony Salmon, Adult Congenital Cardiologist
Ms Alison Sims, Manager, Southampton – Oxford Paediatric Cardiac Network
Dr Nicola Viola, Paediatric Cardiac Surgeon
Dr David Wilson, Professor of Genetics
Dr Peter Wilson, Clinical Director, Child Health

20 December 2012

IRP **Lord Ribeiro, Sanjay Chadha, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood, Zoe Dubber**

Site visit – Freeman Hospital

Evidence gathering session

Sir Leonard Fenwick, Chief Executive, Newcastle upon Tyne Hospitals NHS Foundation Trust
Dr John O'Sullivan, Consultant Paediatric Cardiologist
Dr Thasee Pillay, Clinical Director Cardiothoracic Services
Ms Helen Byworth, Head of Contracting
Dr Simon Haynes, Consultant in Paediatric Cardiac Anaesthesia and Intensive Care
Dr David Spencer, Consultant Paediatric Respiratory Physician

Dr Andrew Cant, Clinical Director for Children's Services
Mr Peter Baylis, Non-Executive Director
Mr Ivan Hollingsworth, Parent
Ms Angie Johnson, Matron Paediatric Congenital Services
Dr Yam Thiru, Consultant Cardiac Intensivist
Dr Asif Hasan, Consultant Cardiothoracic Surgeon
Dr Lee Ferguson, Consultant Cardiac Intensivist
Dr Majd Abuharb, Consultant Paediatric Cardiologist from the Network
Mr Paddy Walsh, Paediatric Cardiac Liaison Nurse
Ms Liz Bailey, Directorate Manager Cardiothoracic Services
Ms Angela Dragoné, Director of Finance
Mr Jonathan Forty, Assistant Medical Director
Ms Louise Robson, Executive Director of Business and Development
Mr Ian Purcell, Clinical Director of Cardiothoracic Services

8 January 2013
IRP **Lord Ribeiro, Cath Broderick, Nick Coleman, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Hugh Ross, Richard Jeavons Fiona Wood**

Site visit – Great Ormond Street Hospital for Children

Evidence gathering session
Ms Fiona Dalton, Deputy Chief Executive, Great Ormond Street Hospital for Children NHS Foundation Trust
Dr Allan Goldman, Cardiac Intensivist and Clinical Unit Chair for Critical
Dr Martin Elliott, Co-Medical Director & Cardiothoracic Surgeon
Dr Victor Tsang, Head of Paediatric Cardiothoracic Surgery
Mr Robert Burns, Deputy Chief Operating Officer
Prof Andrew Taylor, Clinical Unit Chair of Cardio-respiratory
Ms Eithne Polke, Service Co-ordinator – CATS
Dr Shankar Sridharan, Paediatric Cardiology Consultant and Cardiac Network Lead for GOSH
Ms Suzanne Cullen, Head of Nursing for cardiac and respiratory services
Ms Anne Layther, General Manager for Critical Care and Cardiorespiratory services
Dr Sachin Khambadkone, Consultant Cardiologist and Clinical Lead for Transition Services from Paediatrics
Dr Jan Marek, Cardiology Consultant and ECHO Cardiography & Fetal Lead
Ms Sara O'Curry, Clinical Psychologist and Lead for Psychology, Social work, Family and Play for Cardiology
Dr Nick Barnes, Paediatrician with expertise in Cardiology, Northampton General, part of GOSH network.
Ms Miranda Bertram, Mother of a child who came to the Cardiac Unit

9 January 2013

IRP **Nicky Hayes, Cath Broderick, Fiona Campbell, Sanjay Chadha, Jane Hawdon, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Hugh Ross, Richard Jeavons, Fiona Wood**

Evidence gathering session
Ms Anne Keatley-Clarke, Chief Executive, Children's Heart Federation
Ms Penny Green, Director, Down's Heart Group
Ms Julie Wootton, Chair of Trustees, Children's Heart Federation, and Chair of Trustees, Max Appeal
Ms Suzie Hutchinson, Chief Executive, Little Hearts Matter
Ms Hazel Greig-Midlane, HeartLine Association

9 January 2013
IRP **Lord Ribeiro, Cath Broderick, Fiona Campbell, Sanjay Chadha, Jane Hawdon Nicky Hayes, Brenda Howard, Linda Pepper, Nick Naftalin, Ray Powles, Hugh Ross, Richard Jeavons, Fiona Wood**

Evidence gathering session
Dr Leslie Hamilton, Cardiac Surgeon, Freeman Hospital, Newcastle
Dr James Roxburgh, President of the Society for Cardiothoracic Surgery and Consultant Surgeon, Guy's and St Thomas's Hospital, London
Prof Norman Williams, President of the Royal College of Surgeons of England; Professor of Surgery and Director of Surgical Innovation, Barts and the London Hospital

10 January 2013
IRP **Lord Ribeiro, Cath Broderick, Fiona Campbell Sanjay Chadha, Nick Coleman, Glenn Douglas, Jane Hawdon Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Hugh Ross, Richard Jeavons**

Site visit – Evelina Children's Hospital

Evidence gathering session
Dr Ian Abbs, Medical Director, Guy's & St Thomas' NHS Foundation Trust
Prof Dave Anderson, Congenital Cardiothoracic Surgeon, Consultant Lead Surgery
Ms Jo Wilson, Chief Executive, Evelina Children's Heart Organisation (ECHO)
Ms Miranda Jenkins, General Manager- Strategy, Children's Services
Dr Grenville Fox, Joint Clinical Director, Children's Services
Dr Sara Hanna, Joint Clinical Director, Children's Services
Dr Owen Miller, Head of Service, Clinical Lead, Paediatric and Fetal Cardiology
Dr Adam Carter, Paediatrician with Expertise in Cardiology (PEC), Epsom & St Helier

24 January 2013
IRP **Lord Ribeiro, Cath Broderick, Fiona Campbell, Sanjay Chadha, Nick Coleman, Glenn Douglas, Ray Powles, Brenda Howard, Nick Naftalin, Richard Jeavons, Fiona Wood, Zoe Dubber**

Site visit – The Royal Brompton Hospital

Evidence gathering session

Mr Bob Bell, Chief Executive, Royal Brompton & Harefield NHS Foundation Trust
Dr Duncan Macrae, Consultant Paediatric Intensivist, Director of the Paediatrics Division
Mr Olivier Ghez, Consultant Congenital Cardiac Surgeon
Dr Lorna Swan, Consultant Adult Congenital Heart Disease
Dr Gillian Halley, Consultant Paediatric Intensivist
Dr Ian Balfour-Lynn, Consultant in Paediatric Respiratory Medicine
Dr Julene Carvalho, Consultant in Foetal and Paediatric Cardiology
Dr Rodney Franklin, Consultant Paediatric Cardiologist
Dr Jan Till, Consultant Paediatric Electrophysiology Cardiologist
Carolyn Webster, Operational Senior Nurse, PICU and Rose Ward
Mr Lawrence Mack, General Manager, Paediatrics Division and the Heart Division
Prof Michael Gatzoulis, Consultant, Adult Congenital Heart Disease & Professor of Cardiology
Dr Darryl Shore, Consultant Congenital Cardiac Surgeon & Director of the Heart Division (Royal Brompton Hospital)
Ms Lynda Shaughnessy, Clinical Nurse Specialist in Adult Congenital Heart Disease (Transition clinics)
Dr B Sethia, Consultant Congenital Cardiac Surgeon
Prof Stuart Cook, Professor of Clinical and Molecular Cardiology, National Heart and Lung Institute
Dr Sabine Ernst, Consultant Electrophysiologist
Prof S Yen Ho, Consultant Cardiac Morphologist
Ms Margaret Jiggins, Clinical Nurse Specialist in Children's Cardiac Care
Prof Andy Bush, Consultant in Paediatric Respiratory Medicine and Professor of Paediatric Respirology
Dr Margarita Burmester, Consultant Paediatric Intensivist and Director, PICU
Dr Simon Jordan, Consultant Thoracic Surgeon
Dr Andrea Kelleher, Consultant Paediatric Anaesthetist
Ms Julie Combes, Nurse Lead for Practice Education
Dr Michael Rigby, Consultant Paediatric Cardiologist
Mr Simon Clarke, Consultant Paediatric Surgeon, Chelsea and Westminster Hospital
Dr Claire Hogg, Consultant in Paediatric Respiratory Medicine
Ms Jane Docker, Family Liaison Manager

25 January 2013
IRP **Lord Ribeiro, Nicky Hayes, Brenda Howard, Richard Jeavons**

Evidence gathering session

Dr Ravi Gill, Association of Cardiothoracic Anaesthetists
Dr Kate Grebenik, Association of Cardiothoracic Anaesthetists

25 January 2013
IRP **Lord Ribeiro, Nicky Hayes, Brenda Howard, Richard Jeavons**

Evidence gathering session

Prof Brian Jarman, Emeritus Professor Faculty of Medicine, Imperial College, London

29 January 2013

IRP **Lord Ribeiro, Fiona Campbell, Nick Coleman, Glenn Douglas, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Gina Tiller, Richard Jeavons, Fiona Wood, Sarah Skinner**

Evidence gathering session

Cllr John Illingworth, Leeds City Council, Chair Y&H Joint HOSC
Cllr Jim Clark, North Yorkshire County Council
Mr Steven Courtney, Scrutiny Officer
Cllr Mark Dobson, Former Chair, Y&H Joint HOSC
Cllr Peggy Elliott, North East Lincolnshire Council
Cllr Michael Gibbons, City of Bradford MDC
Cllr Ruth Goldthorpe, Calderdale Council
Cllr Barbara Hall, East Riding Council
Cllr Lisa Mulherin, Former Chair, Y&H Joint HOSC
Cllr Anthony Revill, Doncaster MBC
Cllr Elizabeth Smaje, Kirklees Council

29 January 2013

IRP **Lord Ribeiro, Fiona Campbell, Nick Coleman, Glenn Douglas, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Gina Tiller, Richard Jeavons, Fiona Wood, Sarah Skinner**

Evidence gathering session

Dr Phil Batin, Mid Yorkshire Hospital
Dr Steven Lindsay, Bradford Royal Infirmary
Dr Maurice Pye, York Teaching Hospital

29 January 2013

IRP **Lord Ribeiro, Fiona Campbell, Nick Coleman, Glenn Douglas, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Gina Tiller, Richard Jeavons, Fiona Wood, Sarah Skinner**

Evidence gathering session

Dr Mark Darowski, Leeds General Infirmary
Dr Chris Day, Bradford Hospitals
Dr Heather Durward, Chesterfield Royal Hospital
Dr Sandeep Kapoor, Scunthorpe and Grimsby Hospitals
Dr Vijay Kumar, Calderdale Royal Hospital
Dr Murray Wheeler, York District Hospital

30 January 2013

IRP **Lord Ribeiro, Fiona Campbell, Sanjay Chadha, Linda Pepper, Ray Powles, Brenda Howard, Nick Naftalin, Nicky Hayes, Gina Tiller, Richard Jeavons, Fiona Wood, Sarah Skinner**

Evidence gathering session

Ms Lois Brown, Director of SOS Ltd
Dr Kevin Watterson, Cardiac Surgeon, Director of SOS Ltd and Chairman of CHSF
Ms Sara Matley, Consultant Clinical Psychologist, Trustee of CHSF and Director of SOS Ltd
Ms Sharon Cheng, Director of CHSF and Company Secretary of SOS Ltd

30 January 2013
IRP **Lord Ribeiro, Fiona Campbell, Sanjay Chadha, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Gina Tiller, Richard Jeavons, Fiona Wood, Sarah Skinner**

Evidence gathering session

Cllr Keith Wakefield, Leader, Leeds City Council
Mr Tom Riordan, Chief Executive
Ms Joanne Lancaster, Parent
Ms Gareth Lancaster, Parent
Ms Sarah Lowi Jones, Parent

30 January 2013
IRP **Lord Ribeiro, Fiona Campbell, Sanjay Chadha, Nicky Hayes, Brenda Howard, Nick Naftalin, Linda Pepper, Ray Powles, Gina Tiller, Richard Jeavons, Fiona Wood, Sarah Skinner**

Evidence gathering session

Ms Maggie Boyle, Chief Executive, Leeds Teaching Hospitals NHS Trust
Ms Stacey Hunter, Divisional Manager
Dr John Thompson, Paediatric Cardiologist
Dr Kevin Watterson, Surgeon

30 January 2013
IRP **Lord Ribeiro, Fiona Campbell, Sanjay Chadha, Nicky Hayes, Brenda Howard, Linda Pepper, Gina Tiller, Richard Jeavons, Fiona Wood, Sarah Skinner**

Evidence gathering session

Leeds parents

31 January 2013
IRP **Lord Ribeiro, Nick Coleman, Glenn Douglas, Nick Naftalin, , Brenda Howard, Ray Powles, Fiona Campbell, Cath Broderick, Richard Jeavons, Fiona Wood**

Evidence gathering session

Mr John Adler, Chief Executive, University Hospitals of Leicester NHS Trust
Dr Kevin Harris, Medical Director
Dr Aidan Bolger, Consultant in Adult Congenital Heart Disease
Mr Giles Peek, Consultant Congenital Surgeon
Dr Peter Barry, Consultant in Paediatric Intensive Care
Ms Elizabeth Aryeetey, Lead Nurse

Ms Carmel Hunt, Matron
Dr Frances Bu'lock, Consultant Paediatric Cardiologist
Ms Gail Faulkner, ECMO Specialist
Dr Hillary Killer, ECMO Coordinator
Dr Chris Harvey, Consultant ECMO Specialist
Dr Michael Green, Children's CDU

1 February 2013
IRP **Richard Jeavons, Fiona Wood**

Teleconference
Dr John Gibbs, Central Cardiac Audit Database

6 February 2013
IRP **Brenda Howard, Richard Jeavons, Fiona Wood**

Evidence gathering session
Ms Gail Fortes-Mayer, Assistant Director, Specialised Children's Services, West Midlands Specialised Commissioning Team
Ms Jo Sheehan, Acting Director, National Specialised Commissioning Team
Mr Paul Larsen, Finance Lead, National Specialised Commissioning Team
Ms Teresa Moss, Former Director, National Specialised Commissioning Team
Dr Marilena Korkodilos, Public Health Director, London Specialised Commissioning Group
Mr Simon Williams, Divisional Director, London Specialised Commissioning Group
Ms Jo Pope, Senior Project Manager, Tertiary Paediatrics, London Specialised Commissioning Group
Ms Zuzanna Bates, Project Liaison Manager, Specialised Services, Safe and Sustainable Team

6 February 2013
IRP **Brenda Howard, Richard Jeavons, Fiona Wood**

Evidence gathering session
Dr Dirk Wilson, NHS Wales, Consultant Paediatric Cardiologist, Cardiff and Vale University Health Board
Dan Phillips (by phone), Director of Planning, Welsh Health Specialised Services Committee

6 February 2013
IRP **Brenda Howard, Richard Jeavons, Fiona Wood**

Evidence gathering session
Mr Ian Biggs, Care Quality Commission

6 February 2013
IRP **Brenda Howard, Fiona Wood**

Teleconference

Ms Kathy Collins, Programme Director/Nursing and Quality Advisor, National Services Division, NHS in Scotland

6 February 2013
IRP **Brenda Howard, Fiona Wood**

Teleconference
Mr Dean Sullivan, Director of Commissioning, Health and Social Care Board, Northern Ireland
Ms Miriam McCarthy, Consultant in Public Health Medicine

6 February 2013
IRP **Lord Ribeiro, Ray Powles, Richard Jeavons, Martin Houghton**

Meeting with MP
Mr Greg Hands (Chelsea and Fulham)

7 February 2013
IRP **Lord Ribeiro, Fiona Campbell, Nick Coleman, Glenn Douglas, Nicky Hayes, Brenda Howard, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood**

Evidence gathering session
Prof Sir Roger Boyle, Adviser to the National Specialised Commissioning Team; and Chair, ACHD Advisory Group
Prof John Deanfield, Professor of Cardiology, UCL; and Chair, ACHD Advisory Group
Mr Jeremy Glyde, ACHD Programme Director, National Specialised Commissioning Team
Ms Christy Rowley, Assistant Programme Manager, National Specialised Commissioning Team

7 February 2013
IRP **Lord Ribeiro, Fiona Campbell, Nick Coleman, Glenn Douglas, Jane Hawdon, Brenda Howard, Linda Pepper, Richard Jeavons, Fiona Wood**

Evidence gathering session
Ms Anna Quigley, Ipsos MORI
Ms Caroline Callahan, Ipsos MORI

7 February 2013
IRP **Lord Ribeiro Fiona Campbell, Nick Coleman, Glenn Douglas, Jane Hawdon, Brenda Howard, Linda Pepper, Ray Powles Richard Jeavons, Fiona Wood**

Evidence gathering session
Ms Jo Sheehan, Acting Director, National Specialised Commissioning Team,
Mr Jeremy Glyde, Programme Director, *Safe and Sustainable*
Ms Teresa Moss, Former Director, NSCT
Dr Kate Hair, Medical Adviser to the NSCT
Ms Caroline Taylor, Senior Responsible Owner for Implementation, *Safe and Sustainable*

Ms Michael Wilson, Interim Implementation Programme Director, *Safe and Sustainable*
Mr Paul Larsen, *Safe and Sustainable*
Ms Zuzana Bates, *Safe and Sustainable*
Mr James Ford, Grayling

7 February 2013
IRP **Lord Ribeiro, Fiona Campbell, Nick Coleman, Glenn Douglas, Jane Hawdon, Brenda Howard, Linda Pepper, Richard Jeavons, Fiona Wood**

Evidence gathering session
Prof Terence Stephenson, Chair, Academy of Medical Royal Colleges
Dr Hilary Cass, President, Royal College of Paediatrics and Child Health

8 February 2013
IRP **Lord Ribeiro, Nicky Hayes, Brenda Howard, Ray Powles, Richard Jeavons**

Site visit – Manchester Cardiology Centre

Evidence gathering session
Mr Mike Deegan, Chief Executive, Central Manchester University Hospitals NHS Foundation Trust
Mr Darren Banks, Director of Strategic Development
Mr Phil Bullen, Consultant Obstetrician
Dr Ngozi Edi-Osagie, Consultant Neonatologist
Dr Peter-Marc Fortune, Associate Clinical Head of Division Director, RMCH
Dr Gordon Gladman, Consultant Paediatric Cardiologist, Alder Hey
Dr Andreas Hoschtitzky, Consultant Congenital Cardiac Surgeon
Dr Danny Keenan, Consultant Cardiac Surgeon/Associate Medical Director
Dr Vaikom Mahadevan, Consultant ACHD Cardiologist
Dr Nilima Malaiya, Paediatric Cardiologist
Ms Jen Riley, Network Manager
Mr John Wareing, Associate Director, Strategic Development

11 February 2013
IRP **Lord Ribeiro, Fiona Campbell, Jane Hawdon, Brenda Howard, Ray Powles, Richard Jeavons, Fiona Wood**

Site visit – Oxford Cardiology Centre

Evidence gathering session
Prof Edward Baker, Medical Director, Oxford Radcliffe Hospitals NHS Trust
Dr Nick Archer, Consultant Paediatric Cardiologist
Ms Cathy Lurcock, Children's Cardiac Liaison Nurse
Dr Elizabeth Orchard, Cardiology Registrar
Mr Tony McDonald, Divisional General Manager, Children's and Women's Division
Ms Alison Sims, Network Manager for Southampton

11 February 2013

IRP **Lord Ribeiro, Fiona Campbell, Brenda Howard, Richard Jeavons, Fiona Wood**

Evidence gathering session

Ms Caroline Langridge, Chairman Young Hearts Charity
Dr Fiona Spensley, Vice Chair and parent
Ms Kim Homewood, Secretary and parent
Ms Yvonne Thomas, Fundraising and parent
Mr Vincent Kehoe, Step-parent
Ms Maureen Brill, Media and communications

12 February 2013

IRP **Lord Ribeiro, Fiona Campbell, Nick Coleman, Glenn Douglas, Nicky Hayes, Brenda Howard, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood**

Evidence gathering session

Prof Sir Ian Kennedy, Former Chairman, Healthcare Commission and BRI Inquiry

12 February 2013

IRP **Brenda Howard, Fiona Campbell, Nick Coleman, Glenn Douglas, Nicky Hayes, Linda Pepper, Ray Powles, Fiona Wood**

Evidence gathering session

Mr Neil Hurst, Team Member, Health Impact Assessment, Mott MacDonald
Mr Brian Niven, Project Director, Health Impact Assessment
Ms Kerry Schofield, Project Manager, Health Impact Assessment
Dr Carol Singleton, Clinical Consultant, Health Impact Assessment

12 February 2013

IRP **Brenda Howard, Fiona Campbell, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood**

Evidence gathering session

Dr Peter-Marc Fortune, Paediatric Intensive Care Society, Consultant Paediatric Intensivist, Central Manchester University Hospitals NHS Foundation Trust
Mr Steve Hancock, Embrace
Mr David Rowney, Consultant Anaesthesia and Intensive care, Retrieval, Scotland

12 February 2013

IRP **Brenda Howard, Fiona Campbell, Nick Coleman, Glenn Douglas, Nicky Hayes, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood**

Evidence gathering session

Ms Joanna Devlin, Senior Manager, PwC
Dr Tim Wilson, Partner, PwC

12 February 2013

IRP **Lord Ribeiro, Fiona Campbell, Nick Coleman, Glenn Douglas, Nicky Hayes, Brenda Howard, Linda Pepper, Ray Powles, Richard Jeavons, Fiona Wood**

Evidence gathering session

Dr Pat Hamilton, Chair, *Safe and Sustainable* Steering Group; Immediate Past President, Royal College of Paediatrics and Child Health
Mr Bill Brawn, Steering Group; Consultant Cardiac Surgeon, Birmingham Children's Hospital NHS Foundation Trust; Chair, European Association for Cardio-Thoracic Surgery, congenital domain
Dr Leslie Hamilton, Steering Group; Consultant Cardiac Surgeon, Newcastle upon Tyne Hospitals NHS Foundation Trust; Society for Cardiothoracic Surgery in Great Britain and Ireland
Dr Shakeel Qureshi, Steering Group; Immediate Past President, BCCA
Dr Tony Salmon, Steering Group; President, BCC; Consultant Paediatric Cardiologist, Southampton University Hospitals NHS Trust
Dr Graham Stuart, Steering Group; Chair, Clinical Reference Group for Congenital Heart Services
Dr Dirk Wilson, Steering Group; Consultant Paediatric Cardiologist, Cardiff and Vale UHB

13 February 2013
IRP **Richard Jeavons, Fiona Wood**

Evidence gathering session

Ms Miller Owen, Evelina Children's Hospital
Ms Miranda Jenkins, Evelina Children's Hospital
Mr Thomas Witter, Evelina Children's Hospital
Ms Marion Ridley, Evelina Children's Hospital

13 February 2013
IRP **Lord Ribeiro, Ray Powles, Richard Jeavons, Fiona Wood**

Evidence gathering session

Dr Tony Salmon, President British Congenital Cardiac Association
Dr John Thomson, Honorary Secretary
Prof David Anderson, Council Member

13 February 2013
IRP **Lord Ribeiro, Ray Powles, Richard Jeavons, Martin Houghton**

Meeting with MPs and other representatives

Mr Stuart Andrew (Pudsey), **Mr Kevin Barron** (Rother Valley), **Mr Hilary Benn** (Leeds Central), **Mr Nic Dakin** (Scunthorpe), **Mr Philip Davies** (Shipley), **Mr Fabian Hamilton** (Leeds North East), **Mr Kris Hopkins** (Keighley), **Mr John Healey** (Wentworth and Dearne), **Mr Jason McCartney** (Colne Valley), **Mr Austin Mitchell** (Grimsby), **Mr Greg Mulholland** (Leeds North West), **Ms Meg Munn** (Sheffield Heeley), **Mr Barry Sheerman** (Huddersfield), **Ms Angela Smith** (Penistone and Stocksbridge), **Mr Julian Smith** (Ripon and Skipton), **Mr Julian Sturdy** (York Outer), **Mr Martin Vickers** (Cleethorpes), **Ms Rosie**

Winterton (Doncaster Central) and **Lady Masham**. Other MPs were represented by parliamentary researchers.

14 February 2013
IRP **Nicky Hayes, Richard Jeavons**

Evidence gathering session
Ms Fiona Smith, Royal College of Nursing

14 February 2013
IRP **Nicky Hayes, Richard Jeavons, Fiona Wood**

Teleconference
Prof Kenneth Palmer, Karolinska ECMO Centre, Stockholm

20 February 2013
IRP **Gina Tiller, Cath Broderick, Fiona Campbell, Sanjay Chadha, Glenn Douglas, Nicky Hayes, Brenda Howard, Linda Pepper, Ray Powles, Hugh Ross, Richard Jeavons, Martin Houghton, Fiona Wood**

Evidence gathering session
Sir Neil McKay, Chair, Joint Committee of PCTs
Prof Sir Roger Boyle, Medical Adviser to the JCPCT
Mr Jeremy Glyde, Programme Director, Safe and Sustainable
Dr Kate Hare, Medical Adviser to the JCPCT
Ms Teresa Moss, National Specialised Commissioning Team
Ms Ann Sutton, Director of Commissioning, NHS Commissioning Board
Ms Caroline Taylor, SRO for Implementation, Safe and Sustainable
Ms Ros Banks, KPMG

25 February 2013
IRP **Jane Hawdon, Nick Naftalin, Richard Jeavons, Fiona Wood**

Teleconference
Dr Alan Fenton, British Association of Perinatal Medicine
Dr Bryan Gill, British Association of Perinatal Medicine

28 February 2013
IRP **Lord Ribeiro, Fiona Campbell, Jane Hawdon, Brenda Howard, Ray Powles, Richard Jeavons Fiona Wood**

Site visit – Cardiff Cardiology Centre

Evidence gathering session
Dr Dirk Wilson, Consultant, Cardiff and Vale University Health Board
Dr Victor Ofoe, Consultant
Ms Clare Logan, Cardiac Nurse Specialist
Mr Tony Bradley, Cardiac Social Worker
Mrs Sarah Lloyd, Child Health Service Manager
Mrs Bernie Steer, Divisional Nurse

Miss Lisa Davies, Specialised Planner – WHSSC
Dr Poonamallee Govindaraj, Network representative from Royal Glamorgan Hospital
Dr Maha Mansour, Network representative from Singleton Hospital
Dr Geraint Morris, Network representative from Singleton Hospital

5 March 2013
IRP **Richard Jeavons, Martin Houghton**

Evidence gathering session
Ms Ann Sutton, Director of Commissioning, NHS England

16 April 2013
IRP **Richard Jeavons**

Teleconference
Mr Ian Dalton, NHS England

22 April 2013
IRP **Lord Ribeiro, Nick Naftalin, Ray Powles, Richard Jeavons, Martin Houghton**

Evidence gathering session
Prof Sir Roger Boyle, NICOR

Appendix Seven

Information made available to the Panel

Supporting papers

No.	Document Title
1	Secretary of State for Health letter to Lord Bernard Ribeiro, IRP Chairman, 22.10.12
2	Terms of reference for review of Safe and Sustainable proposals for children's congenital heart services, 10 December 2012
3	IRP initial assessment advice, 21 September 2012 and 7 December 2012
4	a. Referral letter from Cllr Christine Talbot, Chair, Health Scrutiny Committee for Lincolnshire, 27 July 2012 and follow-up letter 6 December 2012 b. Presentation to IRP, 27 November 2012 c. Statement from acute paediatricians of Lincoln and Boston hospitals
5	Lincolnshire Parents presentation to IRP, 27 November 2012
6	Personal Impact Statements from parents a. J McLaughlin b. K Cartledge c. S Dowson d. P Jowett e. S Norton f. D Walden
7	Referral letter from Cllr Michael Cooke, Chair, and Cllr Ruth Camamile, Vice-Chair, Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee, 7 September 2012
8	Supporting evidence to referral: a. The JCPCT prediction of demand and capacity at Birmingham Children's Hospital b. The impact of moving ECMO services and increased mortality c. Impact on Paediatric Intensive Care capacity in the Midlands d. Impact on medical research at University Hospitals of Leicester NHS Trust and Leicester University e. Accessibility of services f. The decision-making process of the JCPCT Appendices: 1. Projected demand 2. Capacity at Birmingham Children's Hospital 3. Effect of the Review on ECMO Provision 4. Impact on Paediatric Care Services 5. Evidence provided by the University of Leicester 6-1. Purpose and Scope of the Review 6-2. Initial letter to the Secretary of State 6-3. Minutes of Leicester City Council's Health and Community Involvement Scrutiny Commission, 26 July 2012 6-4. Minutes of Leicester City Council meeting on 28 June 2012 6-5. Minute of Leicestershire County Council's Cabinet, 23 July 2012 6-6. Report to the University Hospitals of Leicester Trust Board, 26 July 212 6-7. Leicester LINk's email to east midlands MPs and LINk's briefing paper to them 6-8. Report of Dr Nichani, Consultant Paediatric Intensivist, University Hospitals of Leicester 6-9. Report to the University Hospitals of Leicester Trust Board, 30 August 2012 6-10. Responses of east midland Health and Overview Scrutiny Committees

	6-11. Minutes of the Leicester, Leicestershire and Rutland Health Overview Scrutiny Committee, 4 September 2012
9	LLR Joint HOSC: Submission to IRP regarding Safe and Sustainable Review of Children's Congenital Heart Surgery
10	Leicestershire LINk: Paediatric cardiac care Responses Interim Report
11	Correspondence to National Specialised Commissioning Team, provided by Heart Link Children's Charity, 18 and 22 January 2010
12	Leicestershire County Council draft response from HOSC to the independent report on the outcome of the consultation
13	Leicester City Council Health and Community Involvement Scrutiny Commission, cover paper, 20 September 2011
14	Leicestershire LINk briefing, 13 July 2012
15	Specialised Services briefing on quality, 24 August 2011
16	Leicester LINks email to local MPs, 16 July 2012
17	Leicester LINks letter to Safe and Sustainable Programme Director, 5 July 2012
18	Safe and Sustainable Programme Director letter to Leicester LINks, 20 July 2012
19	Response to Safe and Sustainable from paediatric consultants, Coventry & Warwickshire Hospital, 25 June 2011
20	Leicestershire County Council HOSC committee papers, Correspondence with Safe and Sustainable Team, 26 September 2011
21	Leicestershire County Council HOSC correspondence with Safe and Sustainable Team, 20 and 22 September 2011
22	University Hospitals of Leicester NHS Trust email correspondence with Leicestershire County Council HOSC re consultation responses, 5 August 2011
23	Safe and Sustainable: Health and Equality Impact Assessment, Leicester Summary, April 2011
24	Leicestershire LINk letter to Safe and Sustainable Programme Director, 17 January 2011
25	Description of Safe and Sustainable Parents Meeting at Glenfield Hospital, 26 May 2010
26	Presentation to IRP by Wayne Matts, parent
27	LLR LINk presentation to IRP
28	Referral letter from Cllr John Illingworth, Chair Yorkshire and Humber Joint Health Overview and Scrutiny Committee, 27 November 2012
29	Supporting evidence to referral: a. Scrutiny Inquiry Report: Review of Children's Congenital Cardiac Services in England (Yorkshire and Humber Joint HOSC), 2nd report, November 2012 b. report appendices c. Scrutiny Inquiry Report: Review of Children's Congenital Cardiac services (Yorkshire and Humber Joint HOSC), October 2011
30	Letter from Cllr John Illingworth, Chair Yorkshire and Humber Joint HOSC to Secretary of State for Health, 20 December 2012 with attachments: a. The transport impact of proposed models of paediatric cardiac centralsisation in north-east England b. Analysis of national specialised commissioning spend by programme, service and trust (2004/05-2011/12) c. Analysis of national sepcialised commissioning spend by programme, service and trust (2004/05-2011/12 methodology. Appendix 1 d. National specialised commissioning spend by trust (2011-12): proportionate spend per person

	by SHA. Appendix 2 e. National specialised commissioning spend by trust (2011-12): proportionate spend per person by government office region. Appendix 3 f. Venn diagram outlining membership/attendance crossover. Appendix 1 g. Summary of Board/meeting crossovers. Appendix 2
31	a. Correspondence between National Specialised Commissioning Team and Leeds City Council legal Services, 8, 13 and 18 March 2013 b. Letter to IRP, 29 April 2013 and copy of letter to Secretary of State for Health, 25 April 2013
32	Safe and Sustainable website link: http://www.specialisedservices.nhs.uk/safe_sustainable/childrens-congenital-cardiac-services
33	Consultation Document - A new vision for children's congenital heart services in England, March 2011
34	Review of Children's Congenital Cardiac Services in England, Decision Making Business Case, July 2012
35	Information Template for IRP: Safe and Sustainable – general 1. Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol, July 2001 2. The Relation Between Volume and Outcome in paediatric Cardiac Surgery. A Literature Review for the National Specialised Commissioning Group, September 2009 3. Children's Heart Surgery Centres in England: Comments on Draft Service Specification Standards, February 2010 4. Letter from Cllr C Buckmaster, Chair, Health Scrutiny Committee for the Royal Borough of Kensington and Chelsea, 8 September 2012 5. Children's Heart Surgery in England - a need for change, April 2011 6. Papers from the JCPCT meeting in public (launch of consultation), 16 February 2011 7. Pre-consultation business case, February 2011 8. Consultation document, February 2011 9. Better care for your heart - a summary, March 2011 10. Consultation document and questionnaire in Welsh, March 2011 11.Consultation document and questionnaire in minority languages 12. Consultation document - improving children's congenital heart services in London, March 2011 13. National Clinical Advisory Team report, September 2010 14. OGC Gateway Report, September 2010 15. NHS London approval to launch consultation, 8 February 2011 16. NHS London assurance report, 8 February 2011 17. Health Impact Assessment - Key Emerging Findings, 21 June 2011 18. Health Impact Assessment - draft final report, 5 August 2011 19. Ipsos MORI - Safe and Sustainable Review of Children's Congenital Heart Services in England: Report of the Public Consultation, 24 August 2011 20. Report of the Independent Panel on the relationship of interdependencies at the Royal Brompton Hospital (Pollit Report), 15 September 2011 21. Report from Sir Ian Kennedy's independent expert panel to the JCPCT, 17 October 2011 22. Testing assumptions for future patient flows and manageable clinical networks for *Safe and Sustainable* (PWC), October 2011 23. Report to the JCPCT by Dr P Hamilton CBE, Chair of the *Safe and Sustainable* Steering Group, 17 October 2011 24. Judgement - High Court, 7 November 2011 25. Report of Sir Ian Kennedy's Panel in response to the additional evidence submitted in relation to "innovation and research", 14 February 2012 26. Judgement - Court of Appeal, 19 April 2012 27. Responses from organisations to an independent report on family travel analysis, 24 April

	2012 28. Safe and Sustainable: Implementation Plan during 2012/13 and transfer into the NHS Commissioning Board for April 2013, August 2012 29. Papers presented at the JCPCT meeting in public, 4 July 2012 30. Transcript from the JCPCT’s decision-making meeting, 4 July 2012 31. Letter from professional associations regarding the JCPCT's decision on the future configuration of children's congenital heart services
36	Information template for IRP - LINCOLNSHIRE HOSC 1. Response to the consultation from the HSC for Lincolnshire (via response form) and response form (for reference) 2. Letter to JCPCT from Cllr C Talbot, Chair HSC for Lincolnshire, 24 May 2012 3. Letter to National Specialised Commissioning Team from Dr Kevin Harris, Medical Director, University Hospitals of Leicester NHS Trust, 26 October 2011 4. Letter to Ms Teresa Moss, Director, National Specialised Commissioning Team from Mr Giles Peek, Director, Paediatric and Adult ECMO programme, Glenfield Hospital, Leicester, 11 June 2012 5. Safe and Sustainable Steering Group membership 6. Advisory Group for National Specialised Commissioning (AGNSS) membership 7. JCPCT Decision making business case Appendix LL - Safe and Sustainable Capacity Review, May 2012 8. National Specialised Commissioning Team statement on children's respiratory ECMO 9. Safe and Sustainable Steering Group statement: ECMO and children's congenital heart services, 10 July 2012
37	Information template for IRP - LEI, LEICS, RUT JHOSC 1. University Hospitals of Leicester NHS Trust Board paper: Safe and Sustainable Update, 30 August 2012 2. Letter to Ms Teresa Moss, Director, National Specialised Commissioning Team from Mr Giles Peek, Director, Paediatric and Adult ECMO programme, Glenfield Hospital, Leicester, 11 June 2012 3. Letter to National Clinical Services Expert Panel from Jeremy Glyde, Safe and Sustainable Programme Director, 28 February 2012 4. JCPCT Decision making business case, Annex KK, July 2012 5. JCPCT Transcript from the JCPCT decision-making meeting, 4 July 2012 6. JCPCT presentation on finance and capacity at decision-making meeting, 4 July 2012 7. Responses to the consultation by a. Leicestershire County Council HOSC, Leicester City Council Health and Community Involvement Scrutiny Commission, LLR Joint HOSC 8. Response to consultation from Great Ormond Street Hospital, London 9. Response to consultation from University Hospitals of Leicester NHS Trust 10. Response to consultation from Leicestershire LINk 11.Response to consultation from Leicester City HOSC 12. Response to consultation from Heartlink 13. Response to consultation from Evelina Children's Heart Organisation 14. Response to consultation from North East Regional Joint HOSC 15. Ipsos MORI - Safe and Sustainable Review of Children's Congenital Heart Services in England: Report of the Public Consultation, 24 August 2011 16. Report to the JCPCT by Dr Patricia Hamilton, Chair Safe and Sustainable Steering Group, 17 October 2011 17. Report of the Advisory Group for national Specialised Commissioning (AGNSS), March 2012 18. Advice from the Nationally Commissioned Services Expert Panel 19. A new vision for children's congenital heart services in England: Capacity review, May 2012 20. Letter to National Specialised Commissioning Team from Dr Kevin Harris, Medical Director, University Hospitals of Leicester NHS Trust, 26 October 2011

	21. Safe and Sustainable, Health Impact Assessment: Final Report, June 2012 22. Safe and Sustainable, Option AB proposal, October 2012 23. Report of Sir Ian Kennedy's panel in response to additional evidence submitted in relation to innovation and research, 24 February 2012 24. Letter from JCPCT Chair to Chief Executive, University Hospitals of Leicester NHS Trust, 19 October 2012
38	Presentations to IRP at clinical seminar on paediatric congenital cardiac services, 13 November 2012 1. Introduction and Overview - Dr Tony Salmon, President, British Congenital Cardiac Association 2. Paediatricians with expertise in Cardiology - Dr David Mabin, Consultant Paediatrician, Royal Devon & Exeter Hospital 3. The role of paediatric intensive care and retrieval teams, Dr Ian Jenkins, Consultant Intensivist, University Hospitals Bristol NHS Foundation Trust 4. Specialist paediatric cardiac nursing, Angie Johnson, Lead Nurse, Congenital Cardiac Services, The Newcastle upon Tyne Hospitals NHS Foundation Trust 5. Fetal cardiology (antenatal diagnosis and care), Dr Gurleen Sharland, Consultant Fetal Cardiologist, Guy's and St Thomas' NHS Foundation Trust
39	JCPCT slides for powerpoint presentation to IRP, 21.11.12
40	a. Safe and Sustainable: Adult Congenital Heart Disease Advisory Group paper - Co-location b. Draft minutes of Advisory Group meeting, 19 November 2012
41	Safe and Sustainable: stakeholder engagement and public consultation activity: a breakdown of events
42	Safe and Sustainable: a. Response form and b. Online response form
43	Safe and Sustainable: Implementation Plan during 2012/13 and transfer into the NHS Commissioning Board for April 2013
44	Documents submitted by Safe and Sustainable team in response to referral from YORKSHIRE AND HUMBER JOINT HOSC (Doc a substitutes for the normal information template. Doc b lists appendices to Doc a which are documents previously provided plus docs c-h: a. Response to the issues raised by the Yorkshire and the Humber JHOSC in the referral submitted in November 2012, 18 January 2013 b. List of appendices to the Safe and Sustainable response c. Letter to Director of National Specialist Commissioning Group from NHS Medical Director, 29 May 2008 d. Letter to Chair, National Specialised Commissioning Group from Secretary of State for Health, 1 August 2008 e. Yorkshire and the Humber Regional Impact Assessment f. News Cutting from Yorkshire Evening Post, 15 November 2012 g. Statement by the National Congenital Heart Patient Charities Co-location of Surgical/Specialist Centres, January 2010 h. Engagement with the Yorkshire and the Humber JHOSC, July 2009 onwards
45	a. Capacity review template, 29 June 2011 b. Frequency spells paediatric cardiac surgery summary 2000-2010 c. NatCanSat spells 10 years d. Response to IRP requests for information on governance e. Children's congenital cardiac services in England - Service Standards, agreed 4 July 2012 f. Comments on decision to hold separate review of services for adults with congenital heart disease g. Engagement with young people h. Response to IRP questions about children's cardiology centres and What types of urgent care may be provided at Children's Cardiology Centres?

	i. Response to IRP questions about children's cardiology centres - minutes of Steering Group / British Congenital Cardiac Association meeting, 12 July 2011 j. Response to IRP questions about activity projections k. Response to IRP questions about activity projections - paper by Dr Martin Aston-Key, Medical Advisor to Safe and Sustainable, 10 August 2009 l. Response to IRP questions on communications strategy, including communications plans and media plan m. Engagement and communications paper, 15 March 2010 n. Paper on local engagement o. Clinical Implementation Advisory Group Draft Terms of Reference p. Ipsos MORI consultation analysis ethnicity by region q. Ipsos MORI consultation analysis health professionals responding r. Topic guide for one-to-one family consultation 1 s. Topic guide for one-to-one family consultation 2 t. Health and equality impact forums - facilitator guide for break out sessions u. Capacity Review covering letter, 27 May 2011 v. Capacity Review - Briefing note for SCG Directors w. Capacity Review - Master Template x. Capacity Review - Birmingham Children's Hospital NHS Foundation Trust, Expansion in PICU Capacity, Outline Business Case, OBC Appendices, OBC Executive Summary, Staffing of theatres capital expansion project, Cardiac Services business case proforma, powerpoint presentation on replacement of cardiac catheter & provision of hybrid cardiac theatre y. Children's congenital heart services draft programme plans z. Summary of capacity returns to IRP aa. Additional briefing for IRP, 13 February and related papers bb. Various correspondence between Safe and Sustainable Team and Yorkshire and Humber Joint HOSC, 2011 - 2013 cc. Supplementary response on extent of focus groups with BAME groups in Leicester dd. Supplementary response on evidence for critical mass of 400 paediatric procedures ee. Supplementary response on consideration of latest population projections ff. Supplementary response on data analysis of activity levels gg. Supplementary response on methodology issues hh. Letter to IRP from Chair of Safe and Sustainable Steering Group, 22 February 2013 plus appendices ii. Children's congenital heart services, Phase 2, Implementation, programme initiation document jj. Opening risk register kk. Letter to Y&H Joint HOSC, 18 July 2012 ll. Letter to Chief Executive, Leeds Teaching Hospitals NHS Trust, 20 August 2010 mm. Report of Sir Ian Kennedy's panel in response to questions made by the JCPCT, 17 October 2011 nn. Briefing note, Extra-corporeal membrane oxygenation service for neonates and children oo. National standards for nationally designated centres providing ECMO for neonates and children with severe potentially reversible respiratory failure, November 2012 pp. List of workshop participants, 13 February 2013 qq. Agenda for paediatric respiratory ECMO model of care workshops, 23 January 2013 rr. Yorkshire and the Humber Regional Impact Assessment ss. British Congenital Cardiac Association: Recommendations for therapeutic catheterisation in paediatric heart disease, December 2012 tt. Report of the independent panel on the relationship of interdependencies at the Royal Brompton Hospital, 15 September 2011
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	b. Presentation to IRP by Trust during visit to Freeman Hospital, 20 December 2012 c. Presentation to IRP by Dr S Haynes, consultant children's anaesthetist and intensivist, Freeman Hospital, 20 December 2012 d. Presentation to IRP on Implications of selection as a surgical centre, 20 December 2012 e. Presentation to IRP by Dr Ferguson on *Governance*, 20 December 2012 f. Presentation to IRP by Mr Hasan on *Transplantation*, 20 December 2012 g. Presentation to IRP, *If not a surgical centre*, 20 December 2012 h. Development for the Children's Heart Unit
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77	Note of conversation between Prof K Palmer, Karolinska Institute, Sweden and Dr N Coleman, IRP, 14 February 2013
78	Statement by Mrs B Pearson
79	Documentation provided by parents: a. article, email and blogs b. Ms F Woollard statement c. Ms S Ward witness statement d. Ms S Dring statement

	e. Anon statement f. Ms S White statement g. Ms M Reeve statement h. Anon statement i. Mr G Hall statement j. Ms J Chambers statement k. Anon statement l. Mr & Mrs G Lancaster m. Mrs S Lloyd
80	Congenital heart services - analysis of surgical workforce
81	Documentation provided by The Paediatric Intensive Care Society: a. Standards for the care of critically ill children, June 2010 b. Presentation to IRP *Current PIC retrieval arrangements*
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84	Documentation provided by Cardiff and Vale University Health Board: a. Children's Heart Unit for Wales: Clinical Guidelines, Feb 2012 to Jan 2013 b. Sample job plan c. Evolution of the Children's Heart Unit for Wales, 1991-2013
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88	Draft paper: Quality assurance and technical performance in the operating room, Karmichalis and del Nido plus other information provided by Dr P del Nido and Prof E Ladd, Department of Cardiac Surgery, Boston Children's Hospital, Massachusetts, USA
89	No. of procedures by no. of spells paediatric cardiac surgery summary by trust 2000-2010, NatCanSat
90	Documentation supplied by Mr & Mrs S Turner
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92	Letter to IRP from Royal College of Surgeons, Royal College of Paediatrics and Child Health and Society for Cardiothoracic Surgery in Great Britain and Ireland, 13 November 2012
93	Documentation relating to judicial review - Save our Surgery Ltd (Claimant) and Joint Committee of Primary care Trusts (Defendant) and Newcastle upon Tyne Hospitals NHS Foundation Trust (Interested Party) a. Approved Judgement, 7 March 2013 b. Transcript of relief hearing, 27 March 2013

Members of the public who contacted the IRP (emails, letters and phone calls)

1	Dr W Lynch	40	Ms L Mitchell
2	Mstr D Callaghan	41	Mr& Mrs G Burkill
3	Mr D Mcbride	42	Ms G Crowson
4	Ms L Evans	43	Mr A Mehra
5	Mr & Mrs S &Y Turner	44	Dr H Klonin
6	Ms K Watkins	45	Prof C Gutierrez
7	Ms S Barnes	46	Ms ? Nacka
8	Dr J Cordingley	47	Anon
9	Ms R Puaca	48	Mrs K Ashberry
10	Mr & Mrs S&E Berry	49	Ms C Rose
11	Mrs C Johnson	50	Ms C Karlsen
12	Anon	51	Mrs S Puri
13	Dr J Barker	52	Dr S Milo
14	Ms K Watkins	53	Mr A Hargreaves
15	Mrs M Mair	54	Mr R Chenery & Miss H Ladigus
16	Mr R Leinster	55	Ms ? Delanry
17	Mrs M Hoult	56	Prof MH Wu
18	Mrs L Waites	57	Mr J Marler-Hausen
19	Ms C Wilkins	58	Mr K Hamilton
20	Mrs D Walden	59	Mrs S Saverton
21	Ms C Steel	60	Dr U Neudorf & Dr C Muntjes
22	Ms S Smith	61	Prof M Vogel
23	Ms C Hibbard	62	Dr I Adachi
24	Ms E Hooley	63	Mr P Mbengi
25	Anon	64	Ms S Coucher
26	Mr A Bandyopadhyay	65	Ms J Burton
27	Ms K Vickers	66	Dr S Yen Ho
28	Ms D Popplewell	67	Mr J Refroy
29	Mr J Woollard	68	Dr T Ju Le
30	Mr A Birkett	69	Dr S Huat Seong
31	Mr R Hobson	70	Mr K Appel
32	Mr S Nicholson	71	Prof M Bonvicini
33	Anon	72	Mr& Mrs J&F Findlay
34	Dr J Parsons	73	Ms M McGuire
35	Mr T Watson	74	Prof B Mulder
36	Mr A Scher	75	Ms T Mundee
37	V Zyko	76	Mr D Berryman
38	Dr M Babu	76	Mrs N Lyster
39	Prof M Mellander	77	Prof C Cottrill

78	Mrs J Martin	118	Mr T Hawkins
79	Mr K & Mrs H Cornmell	119	Dr C Unter
80	Mr & Mrs R Ridgewell	120	Dr P Moceri
81	Mr P Williams	121	Prof B Stiller
82	Mr R Worrall	122	Profs I Muhll & D Taylor
83	Ms L Tromans	123	Prof C Broberg
84	Ms M Cornmell	124	Ms L Simpson
85	Mrs R Martin	125	Dr A Garg
86	Dr G Murphy	126	Mr C & Mrs S Nicholls
87	Dr W Promphan	127	Mr R Puddifoot
88	Mr P Mehta	128	Dr P Chetaile
89	Mr & Mrs L Worrall	129	Dr P Chow
90	Mr E Waite	130	Dr A Tillett
91	Mr P Martin	131	Mrs E Lambert
92	Prof G Thiene	132	Miss E Morrison
93	Dr T Hornung	133	Ms J Jones
94	Dr H Matsui	134	Ms J Hughes
95	Anon	135	Mrs C Pridmore
96	Prof W Yip	136	Ms E Galley
97	Ms J Griffin	137	Mr T Hobbs
98	Mr P Robinson	138	Ms J Sanders & Mr M Lewis
99	Mr J Trussell	139	Ms J Griffin
100	Mr A Tompkins	140	Mr T Hargreaves
101	Ms D Steed	141	Ms M Cliff
102	Ms Y Edwards	142	Mr S Davies
102	Dr J Cyriac	143	Ms S Lloyd
103	Ms M Elliott	144	Dr H Kafka
104	Ms N Garbutt	145	Mr S & Mrs A Brook
105	Mr & Mrs T Ellis	146	Mr M Blackburn
106	Ms V Laing	147	Mr A & Mrs M Wallis
107	Mr K Choi	148	Mr S & Mrs G Knutton
108	Mr M Arnold	149	Dr R Ramanan
109	Ms S Lloyd	150	Prof P Hutton
110	Ms C Hargreaves	151	Dr F Lacour-Gavet
111	Mrs R Veale	152	Dr M Rahman
112	Ms G Annis-Potter	153	Ms F Larrson
113	Dr M Tunstall	154	Mrs R Vale
114	Mr P Dodd	155	Mr P Holliday
115	Ms D Havercroft	156	Ms F Copeland & N Tran
116	Ms C Baldwin	157	Mr M Wilkinson
117	Dr D Lindo	158	Mr R Fullerton

159	Mr E Stevenson	200	Cllr J Clark
160	Mr B & Mrs C Beevers	201	Mr C Thornborough
161	Ms D Irons	202	Ms E Barrett
162	Mr T Ashton	203	Mrs M Dennison
163	Mr J Owen	204	Mr J Sauve
164	Ms S Caines	205	Ms H Burton
165	Mr P & Mrs J Hogg	206	Ms S Casey
166	Mrs S Nickels	207	Mrs B Pearson
167	Dr J Tweddell	208	Ms C Ruane
168	Mr T Paradise	209	Ms S Milner
169	Mr R Aitken	210	
170	Mrs M Lloyd		
171	Anon		
172	Ms H Smith		
173	Mr S Hawkes		
174	Mr A Filarowski		
175	Ms Lyn Jeffrey		
176	Dr A Crucean		
177	Mr R & Mrs D Ward		
178	Mr M Collier		
179	Ms C Wheatley		
180	Mr H Cunningham		
181	Mrs A Butler-Smith		
182	Ms M Hellawell		
183	Mr D Turner		
184	Ms A Harris		
185	Mr S Whitehorn		
186	Mr A & Mrs K Harmer		
187	Mr S & Mrs L Booth		
188	Dr J Jacobs		
189	Prof J Weil		
190	Mr J & Mrs I Baugh		
191	Mrs M Paneth		
192	Dr K Butler		
193	Prof R Bartlett		
194	Mrs J Fawkes		
195	Ms R Wood		
196	Prof S Colan		
197	Dr R Bini		
198	Dr D Kumar		
199	Ms P Wardle		

Appendix Eight

Panel membership

Chair:

Bernard Ribeiro	Former consultant surgeon, Basildon Hospital Past president of the Royal College of Surgeons

Membership:

Cath Broderick (lay member)	Independent consultant on involvement and engagement
Fiona Campbell (lay member)	Independent consultant specialising in health and social policy
Sanjay Chadha (lay member)	Justice of the Peace Committee Member, Multiple Sclerosis (MS) Society
Nick Coleman (clinical member)	Consultant in Intensive Care Medicine and Associate Medical Director, University Hospitals of North Staffordshire
Glenn Douglas (managerial member)	Chief Executive Maidstone and Tunbridge Wells NHS Trust
Jane Hawdon (clinical member)	Consultant Neonatologist and Clinical Academic Group Director Children's Health, Barts Health NHS Trust
Nicky Hayes (clinical member)	Consultant Nurse for Older People King's College Hospital NHS Trust
Brenda Howard (managerial member)	Interim Director, Derby Royal Hospital Project advisor to West Leicestershire CCG
Nick Naftalin (clinical member)	Emeritus Consultant Obstetrician and Gynaecologist Leicester Royal Infirmary
John Parkes (managerial member)	Chief Executive Greater East Midlands Commissioning Support Organisation
Linda Pepper (lay member)	Independent consultant on involvement and engagement
Ray Powles (clinical member)	Head of Haemato-oncology, Cancer Centre London Former Head of Haemato-oncology, the Royal Marsden Hospital
Hugh Ross (managerial member)	Independent consultant Former NHS chief executive
Gina Tiller (lay member)	Chair NHS North of Tyne

Appendix Nine

About the Independent Reconfiguration Panel

The Independent Reconfiguration Panel (IRP) offers advice to the Secretary of State for Health on contested proposals for NHS reconfigurations and service changes in England. It also offers informal support and generic advice to the NHS, local authorities and other interested bodies in the consideration of issues around NHS service reconfiguration.

The Panel consists of a Chairman, Lord Ribeiro and members providing an equal balance of clinical, managerial and patient and citizen representation.

Further information about the Panel and its work can be found on the IRP Website:

www.irpanel.org.uk

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IRP

Independent Reconfiguration Panel

ADVICE ON SAFE AND SUSTAINABLE *PROPOSALS FOR CHILDREN'S CONGENITAL HEART SERVICES*

APPENDIX 10

Submitted to the Secretary of State for Health

30 April 2013

IRP

Independent Reconfiguration Panel

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

Tel: 020 7389 8045/8046
Email: *info@irpanel.org.uk*
Website: *www.irpanel.org.uk*

Press Office
Tel: 020 7025 7530
Email: *press@irpanel.org.uk*

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[1] Source: Data supplied by each Hospital Trust. Information as at 31st October 2012

ALDER HEY CHILDREN'S HOSPITAL

Activity 2011-12

Paediatric surgical procedures:393

Paediatric interventional cardiology: 201

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice	3	2	1
Consultants with paediatric plus adult congenital cardiac practice			
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	6	6	1
Consultants with paediatric and congenital cardiac plus adult cardiac practice			
Cardiac liason nursing			
Children's nurses	6.2		

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	2.5
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	7
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	

ALDER HEY CHILDREN'S HOSPITAL

CORE CLINICAL SERVICES						
Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	Off-site	On-site	On-site	On-site	On-site	Off-site
Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	Off-site	Off-site	On-site	Off-site	Off-site	Off-site
Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	Off-site	On-site	On-site	On-site	On-site	On-site
Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Dietician	Paediatric Ear, Nose Throat (Airway)				
Location	On-site	On-site				

Support for parents and families as at 31 October 2012

- 69 rooms and 15 self-contained apartments on hospital site within 3 min walk of ward and PICU
- 1 bedside place on ward, with hot drink facilities, bathroom and parent's room
- 2-4 rooms on PICU with hot drink facilities, bathroom

BIRMINGHAM CHILDREN’S HOSPITAL

Activity 2011-12

Paediatric surgical procedures:499

Paediatric interventional cardiology: 360

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice			
Consultants with paediatric plus adult congenital cardiac practice	4	4	
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	8	8	2
Consultants with paediatric and congenital cardiac plus adult cardiac practice	2	2	
Cardiac liason nursing			
Children’s nurses	5.8		

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	11
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	17.5
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	

BIRMINGHAM CHILDREN'S HOSPITAL

CORE CLINICAL SERVICES						
Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	Off-site	On-site	On-site	On-site	On-site	Off-site
Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	Off-site	Off-site	On-site	Off-site	Off-site	Off-site
Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	Off-site	On-site	On-site	On-site	On-site	On-site
Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	Off-site	On-site	On-site	On-site	On-site	On-site
Service	Dietician	Paediatric Ear, Nose Throat (Airway)				
Location	On-site	On-site				

Support for parents and families as at 31 October 2012

- 13 rooms on cardiac ward floor, plus 60 additional rooms on hospital site
- 1 bedside place on each ward, and shared family room with hot drink facilities, microwave and fridge
- 1 room on PICU corridoor and a family room with hot drink facilities, microwave and fridge
- Other on-site facilities: sensory play room, quiet room, milk expressing room

BRISTOL CHILDREN'S HOSPITAL

Activity 2011-12

Paediatric surgical procedures: 304

Paediatric interventional cardiology: 221

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice			
Consultants with paediatric plus adult congenital cardiac practice	3	3	
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	4	4	
Consultants with paediatric and congenital cardiac plus adult cardiac practice	4	4	
Cardiac liason nursing			
Children's nurses	3.3		

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	5
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	6
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	

BRISTOL CHILDREN'S HOSPITAL

CORE CLINICAL SERVICES						
Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	On-site	On-site	On-site	On-site	On-site	Off-site
Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	On-site	Off-site	On-site	On-site	On-site	On-site
Service	Dietician	Paediatric Ear, Nose Throat (Airway)				
Location	On-site	On-site				

Support for parents and families as at 31 October 2012

- 1 room on ward, plus unspecified additional rooms in Ronald MacDonald House a short walk away
- Several rooms for PICU

EVELINA CHILDREN'S HOSPITAL

Activity 2011-12

Paediatric surgical procedures: 401

Paediatric interventional cardiology: 196

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice			
Consultants with paediatric plus adult congenital cardiac practice	3	3	
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	10.2	11	2
Consultants with paediatric and congenital cardiac plus adult cardiac practice			
Cardiac liason nursing			
Children's nurses	3.9		

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	6
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	9.6
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	

EVELINA CHILDREN'S HOSPITAL

CORE CLINICAL SERVICES						
Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	On-site	On and off-site	On-site	On and off-site	On-site	On-site
Service	Dietician	Paediatric Ear, Nose Throat (Airway)				
Location	On-site	On-site				

Support for parents and families as at 31 October 2012

- 1 pull down bed beside every bed on paediatric cardiology ward, plus rooms provided 5 minutes walk away and 20 rooms at Ronald McDonald House at Guy's, a free shuttle bus ride away.
- Parents room on ward with kitchen facilities, TV and recreation facilities, laundry, bathing and showers available
- 8 ensuite rooms, kitchen, sitting and bath rooms for PICU-attending parents
- 2 family rooms for neonatal unit

FREEMAN CHILDREN'S HOSPITAL

Activity 2011-12

Paediatric surgical procedures:252

Paediatric interventional cardiology: 104

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice			
Consultants with paediatric plus adult congenital cardiac practice	3	3	
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	1.5	1.5 (0.5 retired and returned on annual contract)	
Consultants with paediatric and congenital cardiac plus adult cardiac practice	3	3	
Cardiac liason nursing			
Children's nurses	5		

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	4
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	5
Consultants with paediatric and congenital cardiac plus other paediatric practice	
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	

FREEMAN CHILDREN'S HOSPITAL

CORE CLINICAL SERVICES						
Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	Off-site	On-site	On-site	On-site	On-site	On-site
Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	On-site	Off-site	On-site	On-site	Off-site	Off-site
Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	Off-site	Off-site	Off-site	Off-site	Off-site	On-site
Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	Off-site	Off-site	Off-site	On-site	On-site	On-site
Service	Dietician	Paediatric Ear, Nose Throat (Airway)				
Location	On-site	On-site				

Support for parents and families as at 31 October 2012

- 4 cubicles on the ward for parent and child plus roll out beds available for bedside parents
- Unspecified number of flats available 5 minute walk away with kitchen and bathroom

GLENFIELD CHILDREN'S HOSPITAL

Activity 2011-12

Paediatric surgical procedures:198

Paediatric interventional cardiology: 122

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice			
Consultants with paediatric plus adult congenital cardiac practice	3	2	1
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	5.6	5.6	
Consultants with paediatric and congenital cardiac plus adult cardiac practice			
Cardiac liason nursing			
Children's nurses	3.8	3.8	

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	
Consultants with paediatric and congenital cardiac plus adult cardiac practice	5
Consultants with other mixed practice	
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	10
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	

GLENFIELD CHILDREN'S HOSPITAL

CORE CLINICAL SERVICES						
Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	On and off-site	On-site	On and off-site	On-site	On and off-site	On-site
Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	On-site	On and off-site	On and off-site	On and off-site	Off-site	Off-site
Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	Off-site	Off-site	Off-site	Off-site	Off-site	Off-site
Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	Off-site	Off-site	On-site	Off-site	On-site	On-site
Service	Dietician	Paediatric Ear, Nose Throat (Airway)				
Location	On-site	On-site				

Support for parents and families as at 31 October 2012

- 7 rooms in children's ward and 6 adjacent to PICU. Family rooms available on site. Wet room, toilets, kitchen, laundry facilities available

GREAT ORMOND STREET CHILDREN'S HOSPITAL

Activity 2011-12

Paediatric surgical procedures: 657

Paediatric interventional cardiology: 307

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice	2.3	2	1
Consultants with paediatric plus adult congenital cardiac practice	2	2	
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	19.2	22	
Consultants with paediatric and congenital cardiac plus adult cardiac practice			
Cardiac liason nursing			
Children's nurses	8		

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	12.5
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	6.5
Consultants with paediatric and congenital cardiac plus other paediatric practice	
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	1

GREAT ORMOND STREET CHILDREN'S HOSPITAL

CORE CLINICAL SERVICES

Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	On-site	On-site	On-site	On-site	On-site	On-site

Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	On-site	On-site	On-site	Off-site	On-site	Off-site

Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	Off-site	On-site	On-site	On-site	On-site	On-site

Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	On-site	On-site	On-site	On-site	On-site	On-site

Service	Dietician	Paediatric Ear, Nose Throat (Airway)
Location	On-site	On-site

Support for parents and families as at 31 October 2012

- All children on the wards can have one parent stay with them with beds available
- 30 rooms and 8 self-contained flats available in patient hotel, plus further rooms and family accommodation nearby
- Female only accommodation available

LEEDS TEACHING HOSPITAL

Activity 2011-12

Paediatric surgical procedures:316

Paediatric interventional cardiology: 149

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice			
Consultants with paediatric plus adult congenital cardiac practice	4	2	2
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	10	8	2
Consultants with paediatric and congenital cardiac plus adult cardiac practice			
Cardiac liason nursing			
Children's nurses	4.2	4.2	

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	1
Consultants with paediatric and congenital cardiac plus other paediatric practice	3
Consultants with paediatric and congenital cardiac plus adult cardiac practice	1
Consultants with other mixed practice	
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	7
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	

LEEDS TEACHING HOSPITAL

CORE CLINICAL SERVICES						
Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Dietician	Paediatric Ear, Nose Throat (Airway)				
Location	On-site	On-site				

Support for parents and families as at 31 October 2012

- single ensuite rooms available on the ward; kitchen, breast feeding facilities
- ensuite rooms on-site near PICU
- Shared access to 70 beds, playrooms, kitchens, laundry outside the hospital for families

ROYAL BROMPTON HOSPITAL

Activity 2011-12

Paediatric surgical procedures: 397

Paediatric interventional cardiology: 297

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice	1	1	
Consultants with paediatric plus adult congenital cardiac practice	3	3	
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	7	6	1
Consultants with paediatric and congenital cardiac plus adult cardiac practice			
Cardiac liason nursing			
Children's nurses	8.5		

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	1
Consultants with paediatric and congenital cardiac plus adult cardiac practice	5
Consultants with other mixed practice	
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	6.6
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	

ROYAL BROMPTON HOSPITAL

CORE CLINICAL SERVICES						
Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	On-site	On-site	On-site	On-site	On-site	On-site

Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	On-site	Off-site	On-site	On-site	Off-site	Off-site

Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	Off-site	Off-site	On-site	Off-site	Off-site	On-site

Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	On-site	Off-site	On-site	Off-site	On-site	On-site

Service	Dietician	Paediatric Ear, Nose Throat (Airway)
Location	On-site	On-site

Support for parents and families as at 31 October 2012

- 7 double rooms on site with kitchen and sitting room plus 16 rooms 5 minutes walk away. 3 family flats 10 minutes walk away.
- 1 bedside place on ward, plus unspecified additional rooms in Ronald MacDonald House a short walk away

SOUTHAMPTON HOSPITAL

Activity 2011-12

Paediatric surgical procedures:341

Paediatric interventional cardiology: 192

STAFFING

Specialty	Whole time equivalents	Number of staff in post	
		Permanent	Locum
Paediatric and congenital cardiac surgeons			
Consultants with pure paediatric cardiac practice			
Consultants with paediatric plus adult congenital cardiac practice	3	2	1
Consultants with adult congenital cardiac practice			
Paediatric congenital cardiologists			
Consultants with pure paediatric and congenital cardiac practice	6	6	
Consultants with paediatric and congenital cardiac plus adult cardiac practice	1	1	
Cardiac liason nursing			
Children's nurses	2		

Specialty	Whole time equivalents
Anaesthetists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	5
Consultants with paediatric and congenital cardiac plus adult cardiac practice	6.6
Consultants with other mixed practice	1
Consultant intensivists involved with paediatric and congenital cardiac services	
Consultants with pure paediatric and congenital cardiac practice	
Consultants with paediatric and congenital cardiac plus other paediatric practice	8.25
Consultants with paediatric and congenital cardiac plus adult cardiac practice	
Consultants with other mixed practice	

SOUTHAMPTON HOSPITAL

CORE CLINICAL SERVICES						
Service	Fetal diagnostic cardiology	Paediatric cardiac surgery	Paediatric cardiology	Adolescent congenital cardiac surgery	Adolescent congenital cardiology	Adult congenital cardiac surgery
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Adult congenital cardiology	Neonatal intensive care	Paediatric intensive care	Adult intensive care	Neonatology	Obstetrics
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Maternity	General paediatrics	General paediatric surgery	Paediatric nephrology	Paediatric neurology	Paediatric respiratory medicine
Location	On-site	On-site	On-site	On-site	On-site	On-site
Service	Genetics	Child psychiatry	Counselling	Dental	Clinical psychology	Physiotherapy
Location	On-site	On-site	On-site	On-site	On-site	On-site

Service	Dietician	Paediatric Ear, Nose Throat (Airway)
Location	On-site	On-site

Support for parents and families as at 31 October 2012

- Ocean ward has parent beds at each space, plus quiet room, TV room, adolescent area, kitchen, bathroom and laundry facilities available on the ward
- 6 ensuite rooms opposite PICU, with kitchen, sitting room, quiet room and play room, plus 2 flexible use rooms. Further on-site rooms available
- Dormitory beds available on-site, and free cardiac accommodation available within 5 minute walk
- Reduced price parking and meals

IRP

Independent Reconfiguration Panel

ADVICE ON SAFE AND SUSTAINABLE *PROPOSALS FOR CHILDREN'S CONGENITAL HEART SERVICES*

APPENDIX 11

Submitted to the Secretary of State for Health

30 April 2013

IRP

Independent Reconfiguration Panel

6th Floor

157 – 197 Buckingham Palace Road

London

SW1W 9SP

Tel: 020 7389 8045/8046

Email: info@irpanel.org.uk
Website: www.irpanel.org.uk

Press Office

Tel: 020 7025 7530

Email: press@irpanel.org.uk

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7. Queen Elizabeth the Queen Mother Hospital, Margate
8. Kent & Canterbury Hospital, Canterbury
9. Princess Royal University Hospital, Farnborough (Kent)
10. William Harvey Hospital, Ashford (Kent)
11. Conquest Hospital, Hastings
12. Eastbourne District General Hospital, Eastbourne
13. Royal Alexandra Hospital for Sick Children, Brighton
14. East Surrey Hospital, Redhill
15. Epsom General Hospital, Epsom
16. West Suffolk Hospital, Bury St Edmunds
17. The Ipswich Hospital, Ipswich
18. Watford General Hospital, Watford
19. Kingston Hospital, Kingston-Upon-Thames
20. Queen Mary’s Hospital, Roehampton
21. Queen Mary’s Hospital, Carshalton
22. St Mary’s Hospital, Paddington
23. Hammersmith Hospital, Shepherd’s Bush
24. Northwick Park Hospital, Harrow
25. Lister Hospital, Stevenage
26. Queen Elizabeth II Hospital, Welwyn Garden City
27. Medway Maritime Hospital, Gillingham
28. Colchester Hospital, Colchester
29. Chelsea & Westminster Hospital, Chelsea
30. St Peter’s Hospital, Chertsey
31. Maidstone Hospital, Maidstone
32. Southend Hospital, Southend
33. Mayday Hospital, Croydon
34. Worthing Hospital, Worthing
35. Crawley Hospital, Crawley
36. West Middlesex University Hospital, Twickenham
37. Princess Alexandra Hospital, Harlow
38. St John’s Hospital, Chelmsford
39. Hillingdon Hospital, Hillingdon
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64. Heatherwood Hospital, Ascot
65. St Mary’s Hospital, Isle of Wight
66. Queen Alexandra Hospital, Portsmouth
67. Royal Hampshire Hospital, Winchester
68. North Hampshire Hospital, Basingstoke
69. Salisbury District Hospital, Salisbury
70. Poole Hospital, Poole
71. Bournemouth Hospital, Bournemouth
72. West Dorset Hospital, Dorchester
73. Yeovil Hospital, Yeovil
74. Derriford Hospital, Plymouth
75. St Richard’s Hospital, Chichester
76. Horton General Hospital, Banbury
77. Kettering General Hospital, Kettering
78. Milton Keynes District Hospital, Milton Keynes
79. Great Western Hospital, Swindon
80. Royal Berkshire Hospital, Reading
81. Stoke Mandeville Hospital, Aylesbury
82. Wycombe General Hospital, High Wycombe
83. Queen’s Medical Centre, Nottingham
84. Royal Derby Hospital, Derby
85. Pilgrim Hospital, Boston
86. Grantham Hospital, Grantham
87. Lincoln County Hospital, Lincoln
88. Kingsmill Hospital, Mansfield
89. Birmingham Women’s Hospital, Birmingham
90. Birmingham Heartlands Hospital, Birmingham

91. Birmingham City Hospital, Birmingham
92. North Staffordshire University Hospital, Stoke on Trent
93. New Cross Hospital, Wolverhampton
94. Russell’s Hall Hospital, Dudley
95. Walsgrave University Hospital, Coventry
96. Warwick General Hospital, Warwick
97. Royal Shrewsbury Hospital, Shrewsbury
98. Hereford County Hospital, Hereford
99. Princess Royal Hospital, Telford
100. Worcester Royal Infirmary, Worcester
101. Kidderminster Hospital, Kidderminster
102.Alexandra Hospital, Redditch
103. Queen’s Hospital, Burton
104. Good Hope Hospital, Sutton Coldfield
105. North Devon District Hospital, Barnstaple
106. Royal United Hospital, Bath
107. Cheltenham General Hospital, Chelthenham
108. Royal Devon and Exeter Hospital, Exeter
109. Gloucestershire Royal Hospital, Gloucester
110. Musgrove Park Hospital, Taunton
111. Torbay Hospital, Torbay
112. Royal Cornwall Hospital, Truro
113. Leighton Hospital, Crewe
114. Royal Albert Edward Infirmary, Wigan
115. Royal Bolton Hospital, Bolton
116. Burnley General Hospital, Burnley
117. St Mary’s Hospital, Manchester
118. The Cardiothoracic Centre, Liverpool
119. Wrexham Maelor Hospital
120. Macclesfield General Hospital
121. Blackpool Victoria Hospital, Blackpool
122. Warrington Hospital, Warrington
123. Queen’s Park Hospital, Blackburn
124. Countess of Chester Hospital, Chester
125. Whiston Hospital, Prescot
126. Arrowe Park, Wirrall
127. Liverpool Women’s Hospital, Liverpool
128. Royal Lancaster Infirmary, Lancaster
129. Furness General Hospital, Barrow In Furness
130. Fairfield General Hospital, Bury
131. Rochdale Infirmary, Rochdale
132. Stepping Hill Hospital, Stockport
133. Salford Royal Hospital, Salford
134. Tameside General Hospital, Ashton-under-Lyme
135. Trafford General Hospital, Manchester
136. Wythenshawe Hospital, Manchester
137. Airedale District General Hospital, Airedale
138. Barnsley District General Hospital, Barnsley
139. Bradford Royal Infirmary, Bradford
140. Chesterfield Royal Infirmary, Chesterfield
141. Dewsbury District General Hospital
142. Doncaster Royal Infirmary, Doncaster
143. Diana Princess of Wales Hospital, Grimsby
144. Calderdale Royal Infirmary, Halifax
145. Huddersfield Royal Infirmary, Huddersfield
146. Hull Royal Infirmary, Hull
147. Friarage Hospital, Northallerton
148. Rotherham District General Hospital, Rotherham
149. Scarborough District General Hospital, Scarborough
150. Scunthorpe District General Hospital, Scunthorpe
151. Sheffield Children’s Hospital, Sheffield
152. Bassetlaw Hospital, Worksop
153. York District General Hospital, York
154. Bishop Auckland Hospital, Bishop Auckland
155. Darlington Memorial Hospital, Darlington
156. West Cumberland Hospital, Whitehaven
157. James Cook University Hospital, Middlesbrough

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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: 13 September 2013

Subject: The new review of congenital heart services in England

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

Purpose

1. The purpose of this report is to present details associated with the new review of congenital heart services in England.

Background

2. Following the restructuring arrangements across the NHS that came into force from 1 April 2013, NHS England became the body responsible for commissioning specialised services. This includes congenital heart services.

3. On 12 June 2013, an announcement from the Secretary of State for Health called a halt to the previous Safe and Sustainable review of Children’s Congenital Cardiac Services in England. This followed the advice provided by the Independent Reconfiguration Panel (IRP) – the detail of which is presented elsewhere on the agenda. In making that announcement, the Secretary of State invited NHS England to provide details of its proposed approach for undertaking a new review by 31 July 2013.

Main issues and considerations

4. NHS England is now responsible for undertaking a national review of congenital heart services for children and adults, which will consider the whole lifetime pathway of care for people with congenital heart disease (CHD) and aim to:
    - Achieve the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
    - Tackle variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care

- Achieve great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home.

5. At its Board meeting on 18 July 2013, NHS England considered a report setting out board proposals for undertaking the review. The report is attached at Appendix 1.

6. The details provided to the Secretary of State for Health – via a letter from the Chair of NHS England – is attached at Appendix 2

7. It should be noted that NHS England Board has established a committee (or sub-group) that will provide formal governance for the review work going forward. The membership of that committee is as follows:
   - Sir Malcolm Grant (NHS England's Board Chairman) – Chair
   - Margaret Casely-Hayford (Non-Executive Director)
   - Ed Smith (Non-Executive Director)
   - Sir Bruce Keogh (Medical Director)
   - Bill McCarthy (National Director for Policy)

8. The committee held its first meeting on 29 July 2013, the notes of which are attached at Appendix 3.

9. To date, NHS England has convened a series of different stakeholder meetings. The notes from these meetings are attached to this report for information, as follows:
   - National charities and patient groups – 16 July 2013 (Appendix 4);
   - National clinical organisations – 16 July 2013 (Appendix 5);
   - Clinicians from surgical centres – 22 July 2013 (Appendix 6); and,
   - Local charities and patient groups – 7 August 2013 (Appendix 7).

10. A senior representative from NHS England will be in attendance at the meeting to outline the process for the new review and address questions from the Joint HOSC.

11. The local charity, Children's Heart Surgery Fund (CHSF) has also been invited to the meeting to inform the Joint HOSC's discussion and consideration of the information presented.

Recommendations

12. That the Joint HOSC:
    a. Considers and comments on the details presented in this report, and outlined at the meeting
    b. Identifies any additional scrutiny activity necessary at this stage.

Background documents[1]

13. None used

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[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.

NHSE180713

BOARD PAPER - NHS ENGLAND

Title: New review of congenital heart services

Clearance: Bill McCarthy, National Director: Policy

Purpose of paper:

- To describe the challenge facing NHS England in improving congenital heart disease services
- To outline early thinking on the way forward

Key issues and recommendations:

On 12 June 2013 the Secretary of State announced in Parliament that the safe and sustainable proposals for children's congenital heart services could not go ahead in their current form. He went on to say that "it is right we continue with this process, albeit in a different way".

NHS England is the body responsible for commissioning specialised congenital heart services and for taking forward the process.

A new review is being established to consider the whole lifetime pathway of care for people with congenital heart disease (CHD), to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources.

Actions required by Board Members:

- To note the proposals for conducting a review of congenital heart disease services

New review of congenital heart services

Summary

Following the outcome of judicial review, the report by the Independent Reconfiguration Panel (IRP) and the Secretary of State's announcements relating to the safe and sustainable review of children's congenital heart services, NHS England is now the responsible body for taking forward the process. A new review is now being established to consider the whole lifetime pathway of care for people with congenital heart disease (CHD).

The ambition of this review is to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources:

- the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
- tackling variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care
- great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home

We recognise that continued uncertainty is a risk to the service and unsettling for patients. We must therefore set ourselves the target of delivering the new review at pace. But we know that speed cannot be an excuse for imposing a top down solution or for running a process where people feel excluded from the real discussions, so we will be setting ourselves the additional challenge of achieving new levels of transparency and the highest levels of genuine participation. We know that this will need a new approach. We want to make sure that as well as mobilising NHS England's resources from right across the organisation, that we also work closely with partners and stakeholders to design the way forward.

By the end of September we will have established the new programme, co-designed a process for the work going forward and undertaken initial work on how to secure high quality resilient services.

By June 2014 working closely with stakeholders, we will have developed, tested and revised a proposition, undertaken work to identify a preferred approach to implementation, and completed the necessary preparatory work.

Background

1. Around eight out of every 1,000 babies have some form of congenital heart disease (CHD) – around 5,800 babies in 2011. The number of children born with CHD is expected to rise, as the birth rate rises. As technology and expertise continue to develop, it is possible to do more than ever before to improve their lives, so that more children with CHD are surviving to adulthood.
2. NHS cardiac surgery for children is currently provided by 10 hospitals in England. Specialist paediatric cardiology is also provided by a further three centres. Around 3,700 paediatric surgical procedures and 2,000 paediatric interventional cardiology procedures are carried out each year.

3. A recommendation for the concentration of medical and nursing expertise in a smaller number of centres of excellence was made as far back as 2001, in the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary. Since that time, there have been major improvements in outcomes, so that analysis of risk adjusted mortality for 2009-12, published this year by the National Institute for Cardiovascular Outcomes Research (NICOR), shows that no surgical unit has a mortality rate significantly above the "expected" rate, and on this evidence (for example, mortality rates alone) services are currently "safe".

4. For adults, around 850 surgical procedures and 1,600 interventional cardiology procedures are carried out each year and reported to NICOR by 25 hospitals in England, however a further 10 hospitals have undertaken procedures in recent years but not provided data to NICOR.

The safe and sustainable review

5. The safe and sustainable review was established in 2008, with a view to reconfiguring surgical services for children with CHD. Taking into consideration concerns that surgeons and resources may be spread too thinly across the centres, the review considered whether expertise would be better concentrated in fewer sites.

6. At the end of the four year programme, in July 2012, a joint committee of Primary Care Trusts (JCPCT) made a series of decisions on the future of children's congenital heart services in England, covering:
   - the development of congenital heart networks,
   - service standards,
   - improving the collection, reporting and analysis of outcome data, and
   - the configuration of surgical services, which would have reduced the number of centres providing children's heart surgery from ten to seven, with surgery ceasing at Leeds, Leicester and the Royal Brompton.

7. The decision regarding configuration resulted in two separate challenges: a judicial review (JR), and referrals to the Secretary of State, who in turn asked the Independent Reconfiguration Panel (IRP) to consider the JCPCT findings.

8. The JR was decided on 7 March 2013, when the High Court declared that both the consultation process and the decision making process of the JCPCT were unlawful and quashed the decision to reconfigure surgical services. The judgement was based on a narrow point of process and the Court recognised "the compelling and urgent clinical case for the reform of existing paediatric congenital cardiac services" stating that the judgment should not be "construed as advocating a need to return to the start of the consultation process". Following legal advice, NHS England initially sought leave to appeal this decision but - in the light of the IRP's report and the Secretary of State's response (see below) - has since withdrawn this request.

9. The IRP were of the view that children and adults with CHD in England and Wales would benefit from services commissioned to national standards for the whole pathway of their care. They agreed that congenital cardiac surgery and interventional cardiology should only be provided by specialist teams large

enough to sustain a comprehensive range of interventions, round the clock care, training and research. However, the IRP concluded that the JCPCT's decisions were based on "flawed analysis of incomplete proposals and their health impact, leaving too many questions about sustainability unanswered and to be dealt with as implementation risks".

Addressing the IRP findings

10. On 12 June 2013 the Secretary of State announced in Parliament that he accepted the IRP's advice, and that "the [Safe and Sustainable] proposals cannot go ahead in their current form". He went on to say that "it is right we continue with this process, albeit in a different way" and that "NHS England now must move forward on the basis of these clear recommendations".

11. The IRP's report highlighted the need to align the review of children's CHD services with ongoing work to consider the provision of adults' CHD services. Since the same surgeons operate on the same patients at different times in their lives, there are considerable dependencies between adults' and children's services, especially in the availability of surgical teams to provide 24/7 cover.

12. The IRP were also concerned that the while the Safe and Sustainable process received 75,000 responses to its public consultation, some stakeholders were nonetheless left feeling that their views were not fully heard or understood, or that they were not given all the information they needed to contribute fully. This in turn created, for some, the perception of a pre-determined outcome.

13. The IRP's report called for NHS England to develop a strategic framework for commissioning that reflects the complex interdependencies between specialised services provision and population need as a context within which any decisions about congenital heart services should be taken.

14. Importantly, neither the Courts, nor SofS nor IRP have questioned the need for change to ensure the resilience, sustainability and excellence of these services.

The challenge for NHS England

15. The challenge for NHS England is how to ensure that services for people with congenital heart disease are provided in a way that achieves the highest possible quality, within the available resources, now and for future generations:

    - Securing the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
    - Tackling variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care
    - Delivering great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home

16. To do this, we need to develop a process which is as transparent and inclusive as it can be, particularly in the use of evidence and data. Almost as important as the thoroughness of our work will be the need to be seen to be engaging as widely as possible, bringing patients, clinicians and their representatives together

in the joint pursuit of an effective and equitable solution, in the interests of all service users now and in the future. What we do for CHD services will in some ways be seen as a template for whether and how NHS England undertakes other major service change in future.

17. It is widely acknowledged that the uncertainty which has been caused by recent developments is one of the greatest risks to the current delivery of the service. Patients and families are now unsure about precisely where and how they will receive treatment. Surgical centres are hamstrung in their planning, and recruitment and retention is made more difficult by the lack of a clear service model. This in turn creates a risk that the safety and quality of services may not be able to be maintained, that service levels could reduce or there could be unplanned closure(s). Charities, clinicians and other stakeholders gave a huge commitment to support change; many say they are demoralised, frustrated, exhausted and angry. Some doubt that there is the will to make the necessary changes happen.

18. These concerns need to be addressed as part of the new process. To support this measures designed to give commissioners early warning of any emerging concerns at units providing children's congenital heart services will be rolled out across the country, (and to adapt it to include adult services) accepting that it is still a developmental approach, and used as the basis of regular conversations between area teams and providers. A system will be established to ensure that aggregated information is regularly provided to the board committee.

19. In the light of all this, NHS England must bring forward an implementable solution within a year, ie by the end of June 2014. Given the complexity of the issues, the enlarged scope (children AND adults), the legitimate but differing views of stakeholders, and the need to build as much consensus wherever possible (in circumstances where some of the relationships have been badly bruised) this is a demanding but important ambition. We simply cannot re-run the previous process and hope to achieve a different outcome in a quarter of the time.

20. Instead, we must find ways to do this differently. As the sole national commissioner of specialised services NHS England has an opportunity not open to our predecessors. This creates a significant opportunity to drive service improvement including reduced variation in access and quality. We can focus on national standards for a national service, commissioned through a single model which enables us to drive change in the interests of patients.

Principles / Approach

21. We propose the following principles and approach:

- **Patients come first**: the new review must have patients and their families at its heart, with a relentless focus on the best outcomes now and for the future. That aim over-rides organisational boundaries.
- **Retaining what was good from earlier work**: although the JCPCT's decision on configuration of children's congenital heart services has been overturned, much else was developed as part of that process and the subsequent implementation programme including a model of care, service standards, and well-developed thinking about network working. Similarly standards for adult services have also been developed and are ready for

formal consultation. This work has had extensive clinical and patient input and has the potential to be applicable to whatever service configuration is decided. Therefore NHS England must work with stakeholders to determine how much of this work can be retained.

- **Transparency and participation**: NHS England is committed to openness, transparency and participation. We should work with user, clinical and organisational stakeholders to ensure that we develop an approach to take the work forward that is true to those values. Our work should be grounded in standards, rigour, honesty and transparency.
- **Evidence**: the IRP reflected criticism of the way in which Safe and Sustainable used evidence to support its conclusions. The new review will need to be clear about the nature and limitations of the available evidence, and about any intention to rely on expert opinion in the absence of evidence. Notwithstanding the comment above about "retaining what was good", we must have no preconceived notions about the outcome. Wherever there is an assumption it must be made explicit, and justified.

22. We have not attempted to develop a full plan describing how the work will be taken forward, because we want to take time to understand from stakeholders what was good and should be retained from the previous process and what did not work well. We believe however that it is likely that a standards driven process – developing, testing, adopting and applying best practice standards for every part of the pathway – has much to commend it, and we will be testing this with stakeholders.

Governance

23. The Board has established a committee which will provide formal governance of this work. The committee is chaired by Sir Malcolm Grant, Board Chairman, and includes Margaret Casely-Hayford and Ed Smith (non-executive directors), Sir Bruce Keogh (Medical Director), and Bill McCarthy (National Director for Policy). To support the committee, arrangements will be put in place for clinical, organisational and service user representation.

24. Bill McCarthy is the senior responsible officer for this work. John Holden (Director of System Policy) will co-ordinate the work within NHS England and ensure the full involvement of the many different stakeholders.

Stakeholder engagement and communications

25. We are drawing up a stakeholder engagement plan, based on how these stakeholders tell us they wish to be involved, and identifying the different groups, their preferred channels of communication and the key messages throughout the process. For example we know that some of the existing surgical centres have well established patient groups and using these channels may be one way to reach the majority of those most directly affected. For patients, families and their representatives we have sought expert external help from three charities - National Voices, Involve and Centre for Public Scrutiny (CFPS) – to help us design and implement effective and appropriate engagement. They can also

help us manage our risks (eg CFPS are experienced in working with oversight and scrutiny committees and can help us better understand the local government dimension). Due to their limited size these bodies are unable to be directly involved in the work but all have agreed to act in a mentoring capacity. For clinicians, Sir Bruce is convening a clinical advisory panel which will guide him throughout the process and will help design broader clinical engagement and address specific issues which may arise. He has identified the need for some international perspective on this work and will take some soundings from his international peers to determine how best international advice is provided.

26. Our communications will be as open and as often as possible – we have already initiated a fortnightly blog on the NHS England website where we will trail forthcoming meetings and provide a summary of recent progress and discussions. With the support of the NHS England Director of Communications and his team, we are also considering the potential for dedicated web pages, or other IT applications which allow documents and other information to be freely exchanged. We want to give anyone who is interested a simple and easy to use way to find out what is going on and to become involved. We will use social media as appropriate – and if our stakeholders find it helpful – to discuss and share information. We are also considering how we can address the needs of those who do not have access to the internet or do not use English as a first language.

Resources

27. We need to take this opportunity to review the resourcing of this work. It will be important to ensure that it is a priority for the whole organisation and that the resources of the whole organisation are appropriately mobilised to support the work. The cost of dedicated programme management and administrative support will be met from recycling funds previously reserved for the Safe and Sustainable process. The estimated annual cost of this support is £500k.

Conclusion

28. As the body responsible for commissioning specialised congenital heart services, NHS England is setting out ambitious plans to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources. To achieve this, a new Congenital Heart review is being established to consider the whole lifetime pathway of care for people with CHD. The Board is asked to consider and comment on the proposed approach.

Bill McCarthy

National Director: Policy

July 2013

Annex 1: Programme Plan

Our indicative timetable is follows:

Phase 1 – up to October 2013

Co-design a process for the work going forward

- Take advice from external experts to help shape listening exercise *[done]*
- Review previous stakeholder input in order not to lose what has already been achieved; and check its continuing relevance with stakeholders *[under way]*
- Begin communications as per stakeholders preferences, eg blog, shared resources on webpage/sharepoint *[under way]*
- Agree approaches to participation, identify preferred communications channels

Establish the programme

- Establish governance, advisory and stakeholder arrangements *[under way]*
- Develop programme plan, update Board, secure agreement, update Secretary of State *[under way]*
- Identify resources *[underway]*

Initial work on how to achieve programme aims of higher quality services

- Agree with stakeholders what should be taken forward from previous processes
- Complete work on proposed paediatric cardiology standards *[underway]*
- Bring together adult and children's standards and agree process for approval and adoption *[underway]*
- Develop proposals for testing/implementing formal network arrangements *[underway]*
- Work with stakeholders to identify any fixed points and how these would influence service design. This is likely to include (but not be limited to) discussion of the provision of transplant services, the need for children's heart surgery and other tertiary paediatrics to be provided on the same site, and the need for children's and adults' surgery (and interventional cardiology) to be provided in close proximity
- Develop a "proposition" – not a list of sites, but a straw man of what a high quality and sustainable service looks like for adults and children, unconstrained by current configuration – the optimal model
- Consider and weigh, with legal advice, possible approaches for a managed process to translate these fixed points into firm proposals for structuring services, test with stakeholders, outline agreed process
- Establish the required capacity of the service in future years
- Set an ambitious timeline to have completed the work and be ready to implement.

Phase 2 – up to February 2014

Develop, test and revise the proposition

- Using multiple channels, including local and national clinically led events, engage on the clinical appropriateness and user acceptability of the proposition

- Benchmark existing provision against the proposition – considering access as well as service quality
- Test any emerging alternative proposals
- Review dependencies – eg for children, neonatal and paediatric intensive care (PICU) and retrieval services, extracorporeal membrane oxygenation (ECMO). While the IRP recommended that decisions about the future of transplant services and respiratory ECMO should be contingent on final proposals for congenital heart services, in practice the level of interdependency may mean that they need to be considered together
- Weigh alternative implementation approaches: early thinking suggests that some fixed points could constitute 'hurdle criteria' for potential providers within a commissioner led standards driven approach, however alternative approaches need to be considered including option appraisal and designation and provider led regional solutions.
- Agree revised proposition with clinical and patient groups

Phase 3 – up to June 2014

Preparation for implementation

Work in this phase will of course be dependent on the nature of the proposition developed and the measure of agreement with that approach.

- If the solution is for a national plan in which current centres continue/cease to provide surgery, then – subject to legal advice - there may need to be further full formal consultation. This could take the timeline for implementation beyond one year.
- If the solution is a commissioning approach to enforce a set of national standards which invites providers to cooperate to provide the service, any consultation could be undertaken sub-nationally as part of the development of tenders. Assuming local resolution and provider cooperation, the focus of this period would be on developing the tender exercise.

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NHS
England

4W12
Quarry House
Quarry Hill
Leeds LS2 7UE
Tel: 0113 825 1104

Rt Hon Jeremy Hunt MP
Secretary of State for Health
Richmond House
79 Whitehall
London
SW1A 2NS

31 July 2013

Dear Secretary of State

New review of congenital heart disease (CHD) services

In your letter of 12 June about the “Safe and Sustainable” review, you asked NHS England to report back to you by the end of July setting out how we intend to take the process forwards.

I am pleased to enclose the paper which our Board considered at its meeting in public on 18 July, which sets out our thinking on the nature of the problem and the principles which must underpin our approach. In line with our commitment to transparency, a video recording of the Board’s discussion is also available, at http://www.england.nhs.uk/2013/07/22/boardvids-180713/. Annex 1 of the Board paper describes an outline timetable for the work.

We have set ourselves the hugely ambitious challenge of an implementable solution within a year. This does not mean we think the job is easy; on the contrary, it is exceedingly difficult. We have a duty to patients now and to future generations to ensure the best possible quality of care within the available resource. That means best outcomes, a positive patient experience, and consistently high levels of safety.

We do not see this as a competition between providers to find “winners” and “losers”. Instead, we want a single national service which sets high standards for the delivery of care, which are uniformly available to all NHS patients in England, wherever they live. Beyond this aspiration for a national service underpinned by national standards, we do not profess to know yet precisely what the answer is. We are very clear that the Independent Reconfiguration Panel’s (IRP) report requires us, amongst other things, to look at children’s and adults’ services together, to look afresh at the demographic and other relevant data, to describe the entire pathway, and to properly involve all stakeholders throughout the work. So, we need a new process. Although the *Safe and Sustainable* conclusions cannot be implemented, there has nonetheless been some very good work during the past five years, with extensive involvement from clinicians and patient groups, to develop standards and proposals for networks. As IRP suggests, this work needs to be completed. Once validated it will give us a platform for future work, but it does not in any way require us to reach the same conclusions as the previous process.

As we continue our initial discussions over the next few weeks, and begin to develop a proposition for debate in the autumn, there is bound to be speculation about the “answer” we have in mind. But having promised that we will listen before we act, I can assure you that we have no such prejudice. I welcome your support in reiterating this message.

We are still in an extended period of listening and we regularly publish the notes from our meetings to open the debate as widely as possible. I have established a committee of the Board to give this topic the focus it deserves, and Professor Sir Mike Rawlins will chair a clinical advisory panel to support our medical director Professor Sir Bruce Keogh in obtaining excellent clinical engagement and advice.

We are absolutely committed to achieve the service change required for these very vulnerable patients. We will exploit the full potential of NHS England as the sole national commissioner, and do so in a way that properly engages all interested parties, but at sufficient pace to mitigate the risks of further delay.
Yours sincerely

Professor Sir Malcolm Grant
Chair

Note of meeting of Board CHD sub group - 29 July 2013

The group discussed progress to date including the recent Board paper and outline timetable, and the discussion on 18 July.

In discussion the following points were made:

- in response to the Secretary of State's request for an update by the end of July, the Chair would write to Mr Hunt, with a short explanatory letter, enclosing the Board paper
- an initial series of meetings with stakeholders was underway, including a meeting with local charities and patient groups, scheduled for 7 August
- NHS England would need to be able to reconcile the work of the new CHD review with the "Call to Action" - and explain clearly how the two were related
- the process for the new CHD review would establish a precedent for similar exercises in future dealing with other specialties and should, as far as possible, use the specialised commissioning approach (clinical reference groups to advise on standards, development of networks etc).
- we must avoid well-intentioned but misguided pragmatism, ie the path of least resistance, or simply developing a solution to accommodate every existing provider. NHS England must determine the characteristics of the best possible service and commission with that in mind
- the number of units, and the link between volume of activity and patient outcomes, were recurrent themes in early discussions. IRP had criticised the way in which evidence regarding volume and outcomes had been presented in the previous review. So – if the new review relied on numbers of cases per surgeon/centre, it would need to differentiate clearly between evidence and judgement
- irrespective of any evidenced link between volume and outcome, there were intuitive grounds for having four surgeons in each unit, to ensure sustainability and to "future proof" the service. These included mutual support, better on-call arrangements, opportunities for training etc. Having enough surgeons meant removing some of the stress of what was intrinsically a very stressful job
- similarly, the intuitive arguments for larger units, with greater concentration of expertise, were that public expectations were rising, pressures on surgical teams was greater, babies were operated on earlier and operations were increasingly complex. These were potential reasons for performing some of the most difficult and complex operations in a very limited number of centres
- it will be important to think radically about what is best for patients in the long term, which requires a focus on principles and standards, and how best to future-proof the service – for example anticipating changes in technology and clinical practice. This requires a broader approach than simply reviewing the merits of the current providers – how, for example, to best align leading edge research and current practice?
- given the need to consider adults' services alongside children's, the questions about the precise meaning of "co-location", and the need to consider the latest data and best projections, NHS England was not required to work towards a set number of units (eg reducing from 10 to 7). It may be that the conclusion of the review will be to prescribe a

number of units, which could be the same or fewer, but this was not the starting point of the review

- some stakeholders had raised safety concerns and there were undoubtedly risks during transition – this was being discussed with NHS England's patient safety domain lead and we would agree a consistent process to be followed. CQC had legal responsibility for essential levels of safety & quality, and NHS England could address issues locally through its regional medical directors working with CQC (eg in Quality Surveillance Groups), with potential escalation to the Chief Inspector of Hospitals
- as the sole national commissioner NHS England wanted a single national service to a single set of national standards, consistently applied. This may require some sharing of accountability, potentially though the way that contracts are let and managed (it was a matter of concern that relationships between centres appeared to have broken down).
- whatever the outcome of this review it was clear that there were practical issues to overcome, for example in the relationships between centres to help ensure an appropriate degree of co-operation and collaboration. NHS England would also need to consider how to support those affected by change – for example patients and families who might potentially need to use different services, and clinicians and staff whose units might be affected
- summing up, the Chair reiterated the importance of openness, transparency, clinical leadership and service user engagement in the way NHS England conducted its business. The success of this new review would depend in part on early clarity about the fixed points around which the service must be built, the use of formal standards and networks, and consideration of the sustainability and "future proofing" of the service, including links to research. This in turn would require careful thought as to how to rebuild damaged relationships and the potential for some sharing of accountability in a national service of the future.
- NHS England would continue engagement and discussion with a view to developing an initial proposition for discussion in the autumn.

Note of meeting with national charities and patient groups, 16 July 2013

In his introduction Bill McCarthy emphasised that NHS England wanted to achieve a lasting solution for every family in England who needs these services. This review should not be seen as a competition to find winners and losers; the aim was to get the best quality of care within the available resource, now and in the future. Quality included outcomes, safety, and patient experience. John Holden outlined the board paper due to be considered on 18 July.

In discussion the following points were made:

- NHS England had the legal responsibility for commissioning specialised services including those for CHD. The government gave NHS England a mandate which set out a series of objectives. As an independent body, at arm's length from government, NHS England had a Board which approved its key decisions. Of course, these decisions could be challenged through normal processes, including judicial review and Oversight and Scrutiny Committees, so it was essential that NHS England engaged properly with all stakeholders, including local government, throughout the new process.
- concern was raised about the blog which had attracted comment – some of it "potentially libellous" - from those critical of CHF's involvement. Some attendees felt that the comments were given added weight because they appeared on an NHS blog. NHS England wanted to talk to all stakeholders, national and local, and would not rule out any group. This did not imply special access or influence for any organisation or individual. Every stakeholder had a right to expect to be heard and for their views to be taken into account – including those who sometimes had difficulty being heard. Some of those present felt that the "ease with which bullying and harassing comments could be posted on blogs" made it difficult for parents to express different views
- the process would be transparent and accountable. Assumptions would be made explicit – there would be no "back-room deals" or pre-determined outcomes
- good engagement meant being able to shape decisions before they were made, not comment on them afterwards. One source of concern was the knock-on effect of decisions regarding CHD which might affect the viability of other services. How was the work on CHD going to link in to the wider work on specialised service commissioning?
- patient groups (national and local) would want the opportunity to co-design both the process of engagement and the idea of what a really good service looks like – they were the experts on what it felt like to be on the receiving end of the service. Where people had legitimate concerns about some aspect of service change (for example the transport implications) this did not mean change was impossible, but any solution must explicitly address those concerns and come up with some practical and useful ways to address them if there was to be any chance of stakeholders accepting a solution which was not their first choice.
- national organisations felt they were able to provide a national perspective, which was different from the perspective of local groups linked to a particular unit

- attendees quoted Bruce Keogh who (on another topic) had previously described some NHS organisations as "trapped in mediocrity". What was NHS England's ambition for CHD services – was it excellence? Or are we happy with adequate? There should also be an ambition to "reduce injustice". As the single national commissioner, NHS England wanted a single national consistent service, not a patchwork of variable quality. People want an excellent, world class service, and NHS England shared this ambition – mediocre was not acceptable.
- delay was a problem in itself affecting service viability, recruitment, retention, training and so on. Major change would take time to implement even if an agreed plan could be delivered quickly. Where there were problems in quality of care, these needed to be addressed promptly through the appropriate interventions, without waiting for reconfiguration to be the vehicle for "managing out" problems.
- there were concerns about patient safety now, for example where there were instances of occasional practice. This was a serious issue of clinical governance for Trust boards to address, and of concern to the whole system, not just one or two organisations. CQC had a key role to regulate against essential levels of safety and quality. As commissioner, NHS England would not hesitate to act if there were concerns about patient safety.
- would NHS England re-work all the standards? Was everything "up for grabs"? It would be helpful for stakeholders to know exactly what was considered to be fixed. As far as possible NHS England would build on the platform of work already delivered on standards and networks, recognising that some issues needed further clarification (eg the meaning of "co-location") and that adults' and children's standards must be consistent if there is to be a single service for the whole patient pathway.
- attendees noted that co-location is very important for people with an underlying condition such as 22q11.2 deletion
- NHS England would not rule out "setting the bar even higher" if that were in the best interests of patients now and in the future.
- at the same time, it would be important to do as much as possible in the interim – before the completion of the new review – to help stabilise and support improvement in current provision (for example what work on networks and standards could be implemented sooner)? NHS England recognised the desirability of supporting immediate improvement where possible, and would be considering the options and would want to bring forward proposals, but would need to manage risks of legal and other challenge by ensuring wide engagement.
- as a new organisation, and the sole national commissioner of national services, NHS England had an opportunity not open to its predecessor bodies. JCPCT had not been given the option to look at children's and adults' CHD services together. NHS England had to consider not just the viability of services now but resilience for the future.
- attendees were interested in the most effective means of communicating and engaging with NHS England. The problem to be solved was big and complex. One suggestion was that as well as providing updates, the blog (or another medium) should address a series of different topics in more detail to stimulate debate
- who were the stakeholders and what were their interests? NHS England would draw up an engagement plan. One observation was that surgery must be seen as a

national issue – relatively small numbers, finite expert resource, of interest to the whole population wherever they lived; whereas ongoing support (which is the vast majority of clinical contact time for most patients) might be seen as more of a regional issue with more local solutions.

- there was a balance to be struck between getting to an optimal model as quickly as possible (to help stabilise a fragile service) versus a sufficiently thorough engagement exercise, which could not be rushed.
- the Board paper was welcomed for recognising (in para 15) that this was not just an issue about the location of surgical centres, but about delivering a whole service for the whole population, from ante natal testing though children and young people, transition to adults and end of life care. The Board paper was also welcomed because the new aim was to look at more than just surgical outcomes.
- it would be essential for NHS England to consider the whole pathway of care – for most patients there would be a small number of highly significant surgical interventions, compared with much more extensive and enduring contact with local cardiology services. This in turn meant that the focus on transport /retrieval was understandable but related principally to the surgical events, which were infrequent, rather than on-going care (“commuting” to cardiology appointments) which was regular. These are very different issues. So – put crudely – focusing on travel times as a main determinant of location of surgical centres could be a “red herring”
- however, there were examples where even short journeys proved problematic, for example where patients had to return home on the tube after heart surgery. A complete solution would need to recognise that whatever the journey time, patients and their families needed reassurance about the very practical difficulties which confronted families at a time of huge stress and worry. In the context of travel this included simple but significant issues like car parking.
- there were already examples which NHS England should consider where surgery had ceased at a centre but a new pattern had been established whereby patients travelled to the next nearest centre for their surgery - for example following the cessation of surgery at Cardiff patients now typically travelled to Bristol for surgery
- there was concern that the previous process had been derailed, and a plea for statements of commitment from NHS England that there would be strenuous efforts to see this process through for the benefit of all patients now and in the future – in the full realisation that this may be fraught with conflicting interests and opinions.
- NHS England were challenged for not being sufficiently “passionate about the issues”. But there had been no lack of passion in the previous process which had been unable, despite best endeavours, to deliver a lasting solution.
- NHS England was therefore totally committed to achieve a workable solution but would do so with rigour, honesty and transparency building on clinically relevant standards once these had been assured and it was clear that the adult/child alignment was correct.
- monitoring and evaluation of the implementation of the review would be improved if a congenital heart disease register can be established. It would also avoid ‘lost to follow-ups’ in transition and movement of adults.

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Note of meeting with national clinical organisations, 16 July 2013

John Holden outlined the board paper due to be considered on 18 July.

The main points made during the meeting were as follows:

- there was a general welcome for the NHS England board paper on CHD services and the principles and approach described, but concern that no matter how transparent the process, there would inevitably come a point where difficult decisions had to be made – how would disagreement be managed?
- decisions would always rely on judgement as well as evidence – for example to describe the optimal approach – and the new review must be honest about use of expert opinion and how it was presented.
- the new review should be seen in the broader NHS context – part of a bigger debate in public about the future of NHS services, and not simply a niche argument about local "closures" which inevitably divided opinion on geographical lines
- some issues which had been set out in the draft service standards needed to be further clarified – for example what exactly did "co-location" mean? This was clearly important but some felt that it had been "fudged" in the past. Similarly some aspects of the model of care needed to be better understood – eg the logic for and precise role of cardiology centres
- important relationships (for example between surgical centres, and between their respective clinicians), which were good at the start of the last review, had been damaged. Whilst it was right that the new review should proceed at pace (because services were currently vulnerable) there was an equal risk that if the process was too hurried there would be no opportunity to rebuild these relationships. There may be a need for NHS England to provide/arrange some "diplomacy"
- the other side of this argument (proceeding at pace) was a general concern that a lengthy review would run up against the general election timetable and there would be a failure of political will to support agreed change – this was precisely why many clinicians were now sceptical/wary of engaging again
- cardiac surgery, although a dramatic and very important part of the patient pathway, was potentially only a small component of the care a patient would receive over a lifetime. So it was important to think of cardiology and the whole network of care, and not just focus on the understandably high profile given to surgery
- how would this new review link in to the wider process of specialised commissioning?
- there was a risk of service deterioration even during the next 12 months – it would be essential to take steps where possible to stabilise the existing service, through better more formal networks, and adoption of those standards which were not contentious or likely to change. This ought to be a "bottom up" service-led approach, though networking arrangements might require some central support at first
- NHS England should work with the professions to consider how more comprehensive data collection/dissemination could help

- if the new review were to be built around “fixed points” – as the Board paper seemed to suggest – then the clinical validity of these fixed points was a key consideration. A significant number of centres could potentially fail to satisfy the “fixed points” – what would be the immediate/medium/longer term implications of that? Would there be an opportunity to address shortcomings?
- it was noted that there had been a review of transplantation services submitted to Sir Bruce Keogh in March 2013, and that this would be relevant to the work of the new CHD review
- the role of senates should not be overlooked, (especially in developing networks), nor the contribution of clinical reference groups (CRGs). There were key individuals who needed to be involved (including CRG chairs and regional medical directors). In considering his clinical advisory panel (and supporting arrangements) Bruce Keogh would need to reflect on this.
- there would be lessons to learn from the way in which other bodies had engaged with their stakeholders on Safe and Sustainable (for example, Royal College of Nursing had run workshops three times per year to hear from its members in surgical centres)
- NHS England should consider how to identify, hear from and reflect the views of “parent spokespeople” who could give balanced, authoritative accounts of their own experience, and the importance of designing services not just for today but for future generations
- there may be potential for a UK- or England– wide network of care with geographical subsets – possibly organised under a single contract, for the provision of a national service, to mirror the single national commissioner (NHS England).
- NHS England would need to properly understand and work continuously with local government and the health oversight and scrutiny committees, to mitigate the risk that any decision could be appealed by any local authority at the end of the process
- without seeking to deny the room for improvement, clinicians wanted the language of this review to recognise the huge strides that had been made in this specialty since the 1990s – the current quality of the service, how hard all professions had worked to make the necessary changes

Note of meeting with clinicians from surgical centres, 22 July 2013

In his introduction Bill McCarthy emphasised that NHS England wanted to achieve a lasting solution for every family in England who needs these services. This review should not be seen as a competition to find winners and losers; the aim was to get the best quality of care within the available resource, now and in the future. Quality included outcomes, safety, and patient experience. John Holden summarised the governance of the work.

The main points made during the meeting were as follows:

- professional relationships had been damaged, focus on "closures" has undermined network working (and communication between surgical centres) to the detriment of patient care. The last 5 years had been hugely disruptive - some could not face the prospect of "filling in yet another form" for the new review. There had been "hundreds of meetings". And yet at the same time there was much to commend the former process – a very large consultation exercise with a significant response rate. What could NHS England do differently to achieve a more lasting outcome, in less time? Would the prospect of "closure" be "taken off the table" – this would facilitate a different kind of debate (less confrontational, more honest about room for improvement).
- NHS England must not be complacent – instead must show it has listened, understood and will not repeat mistakes of previous approach. For example the Judicial Review was upheld not simply on a narrow technical point but a more fundamental rejection of JCPCT's decision. IRP had criticised the actions of CHF (national charity). There were fears that the new review would simply "repackage" Safe & Sustainable. NHS England's promise of transparency and use of evidence is nothing new, eg data on cardiac surgeons' mortality rates has been available for some time.
- some clinicians stated that there was a great danger in destabilising retrieval, PICU and other services by the cardiac review process and outcomes.
- the new review should be clear about "case for change" – needs to be current & relevant, eg reflective of latest mortality data, not the situation 25 years ago – a great deal has changed, survival rates are very good, and "natural selection" in the intervening period has meant that some UK centres already ceased to provide surgery – maybe those which remain provide the right balance? IRP recognised there is currently more than one model of provision – perhaps these best reflect different local circumstances?
- the new review needs to build up from standards; there has been extensive work on these with good clinical engagement (not just children's surgery but now cardiology centres and standards for adults services). But need to quality assure the standards; consider interface between adults' and children's standards; and be clear who signs them off.
- some of the new standards were "inclusive not aspirational" – ie set at a level which all current centres could meet. Was this sufficiently challenging and honest? Should the bar be raised? Co-location was "swept over" and not sufficiently specified. If very high aspirational standards were agreed, then this would have

clear consequences for current provision - eg what if a centre is not currently compliant?

- need to recognise that even if mortality has improved, questions remain about sustainability and resilience of surgical centres. This in turn links to debate about whether the "numbers" (eg 4 surgeons, minimum 400 cases per centre, etc) are right. The number is the "weakest [ie least evidenced] aspect" of the standards. Worldwide the best centres have grown out of small units, attracting more cases because of their reputation – so there is not necessarily a causal link which means big is always better. However some clinicians said they now looked overseas at the models which would predominate in the next decade and beyond, and this implied larger centres.
- clear differences of opinion about these numbers – eg IRP said relationship between volume of activity and outcomes was not sufficiently contextualised; some clinicians unconvinced about simple correlation given the high standards achieved in smaller units overseas. But others noted that sufficient volume per centre is essential, eg for training and research, and sufficient number of surgeons is essential to make the unit resilient to events.
- some clinicians stated that for surgeons to successfully attempt the most demanding and complex work on new born babies requires them to perform these most difficult procedures regularly – eg one per week (from which it is possible to extrapolate much larger numbers for the overall volume of activity required for each centre to be viable). This is "common sense". Arguably the "number should be 500 not 400".
- even if mortality rates across England have improved and are now uniformly good, there remain issues about morbidity (ie poor health of the patient after surgery) and patient experience. It is only the current lack of robust data on these issues which means they are not central to the debate about safety and optimal numbers of cases. In future they may be.
- others questioned whether all surgical centres would necessarily perform the full range of surgery in future, or whether the most complex cases should always be referred to fewer centres with particular expertise.
- recognising that some individuals would have "the best reputation", it was damaging that current data/discussion focused on the performance of the surgeon, when in fact it was the performance of the whole team which made the difference. Outcomes should be unit specific not surgeon specific. Key factors would include whether the antenatal service was poor? Was the transport and retrieval good? Was the PICU full?
- previous process did not listen closely enough to professional views; the review became a competition between centres for survival. Investment decisions were suspended due to uncertainty which in turn caused potential deterioration in service (or missed opportunity to improve) – vicious circle.
- undue focus on numbers could lead to potentially perverse consequences in terms of decisions to treat, and appropriate referrals between centres in the best interest of patient outcomes. As soon as a number (of cases required) is decided, it is bound to have an effect on behaviours – including whether or not patients are referred on to other centres. This could in some situations potentially compromise patient care.

- after two decades of improvement, of which we should be proud, services had effectively reached a plateau – to move up to the next level, over the next decade, it was argued the services would need to consolidate. This was not just about surgical capacity but also related services including PICU beds, and the highly skilled nursing staff who were in short supply. Further improvement required research, innovation and investment.
- effective antenatal diagnosis and adequate nurse staffing were at least as important to good outcomes as the precise number of surgical procedures undertaken.

Summing up Bill McCarthy noted that:

- there had evidently been a great deal of good work with extensive clinical involvement – for example the development of standards – and NHS England would seek to build on this
- engagement would be as wide as possible. We would not exclude any local or national stakeholder; nor would we give special access or influence to any group or individual
- alignment of children's and adults' standards would be an early priority for NHS England
- NHS England did not have a predetermined outcome in mind nor did we have an exact process (beyond the outline described in the Board paper). There was clearly a trade-off between the pace required to address concerns about "limbo", versus the necessary engagement to shape major change in the NHS
- there would inevitably be rumours but NHS England was committed to openness and transparency; there would be no side deals or unspoken agreements
- the aims of the project were to develop an appropriate programme of work in response to the findings of the IRP, and to commission high quality care not just for now but for the future.
- clinicians had emphasised the importance of considering morbidity as well as mortality; of looking at the whole patient pathway; and recognising that factors such as transport, PICU and nursing levels play a very significant part
- relationships had been damaged and NHS England must consider what it could do to help rebuild the trust which had been lost
- there was great value in regular discussion with a group of clinical representatives from every surgical centre
- some of the debate had touched on the risk of perverse behaviours, eg in the interests of preserving a unit's surgical status, linked to a breakdown in relationships between centres. Bill had heard elsewhere descriptions of "occasional practice". This felt like an extremely serious clinical governance issue for all Trusts – and in particular those attending today's meeting - to consider.

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Note of meeting with local charities and patient groups, 7 August 2013

In his introduction Bill McCarthy acknowledged the wealth of experience in the room and the importance of ensuring that all those present felt they had an opportunity to be heard – "everyone counts". Bruce Keogh was unavailable today but was closely involved in the process. John Holden summarised progress to date, including the meeting of NHS England's Board on 18 July, and the key points that the Board had endorsed.

Experience of the past few years

Attendees discussed their experience of the past few years. Many criticised the previous *Safe & Sustainable* process. These notes record the views expressed. Not all the participants necessarily agreed with everything said, and in presenting this honest record it should not be assumed that the views expressed are endorsed by NHS England. Views included:

- the process was "back to front", starting from an end point that three units must close
- decisions about which units would close had "already been made" from the outset
- there was an excessive focus on surgery; the rest of the lifetime of care was an "afterthought"
- it had been a process which pitted one surgical unit against another, damaging clinical relationships to the detriment of patient care
- the four year timescale had created uncertainty and sapped morale
- concern about misleading media headlines – this reinforced perceptions that it sometimes "suited NHS management" to allow stories to run which should be refuted
- some attendees queried whether there was any part of *Safe and Sustainable* that could be relied on – NHS England should be wary of importing the previous work into the new review. In the subsequent discussion, others suggested that as part of the previous process there had in fact been good work on development of networks, and national standards e.g. for surgical centres. And it was argued by some that *Safe and Sustainable* "forced units to move forward"
- some local groups felt patronised by the way they were treated; their concerns were dismissed as "localism" or it was implied that they "didn't have the foresight" or expertise to understand the issues
- sometimes the objective appeared to be to justify actions and to "fob off" legitimate concerns; engagement sometimes felt "tokenistic" or "hostile" (e.g. meetings that ended before everyone had been heard; heavy-handed security)
- the "bullying" nature of some communications "accused those who challenged the process of costing lives"
- the claimed number of consultation responses was a "distortion" of the true figure and did not accurately reflect the size of some local campaigns

Expectations of the new review

Attendees discussed their expectations and concerns about the way the new process would be conducted, and the factors that would be important for NHS England to consider. Again, not all the participants necessarily agreed with everything said, and it should not be assumed that the views expressed are endorsed by NHS England. Views included:

Scope

- the review should include the whole pathway from foetal diagnosis to end of life care
- attendees wanted to know who would decide which aspects of the previous review could be rolled forward and what should be discarded?
- would clinical reference groups (CRGs) help to decide these questions?
- there had to be a balance between a review that was too narrow to make sense, and a review that was too broad to ever be completed. But even so attendees wanted clarity about various components of the service – would they be covered in the review or elsewhere – for example electrophysiology/ arrhythmia services; foetal cardiology/screening; transplants
- there remained uncertainty about the significance of patient numbers – it was the "most divisive thing in review" - the logic of fewer larger centres depended in part on whether 400 patients was a decisive factor - yet few of the current surgical centres currently performed significantly more than 400 patients p.a.
- the definition of co-location would be a factor – would NHS England be using the earlier work of Ted Baker on this subject ?

Approach

- attendees welcomed the fact that this meeting with local groups was taking place and were reassured by the way the new review was being conducted so far, but "we are naturally sceptical"
- some felt the most important thing was to "take closure off the agenda" – if NHS England is unsure at this stage whether any centres will need to cease surgery then it should say so. Starting from the premise that "closure" was necessary would make it very difficult to build trust or have a constructive, inclusive process. "No-one wants another beauty contest"
- attendees wanted the best outcomes for patients which might – or might not - include reducing the number of surgical units. That had to be a decision based on a transparent process, up to date evidence, and an even-handed approach
- it was argued that the IRP projections had demonstrated the need for 10 surgical centres – and challenged the assumption that "bigger is better"
- around the world those centres which were large had grown organically – any movement of services had to be achieved in this way, not simply "cut and pasted" from one centre to another in order to rationalise units
- attendees liked the suggestion – set out in the Board paper - of a standards driven approach for the whole pathway of care.
- some felt "we're on same page" – ie there was a measure of agreement about the importance of national standards, measurable/accountable improvement, a broader

focus on the whole pathway from antenatal to end of life (at any age) – and that the service needs to be national, with all providers a part of it, not in competition, some will excel at different parts of pathway/different procedures, components may vary locally but standards should not.

- some felt that it "makes sense" for some clinicians/centres to specialise in certain procedures – others disagreed with this idea
- attendees asked whether NHS England was committed to follow all of the IRP and JR recommendations

<u>Resources (human and financial)</u>

- since the previous process started "10 consultants had left their posts" – there was some natural turnover but also evidence that the process and uncertainty had taken its toll – there were unfilled training posts and a number of consultants now aged in their 60s
- this risk (of further delay) had to be understood and addressed – in the commercial world no business would identify a major threat and say "we'll take a year to address it"
- £6m had been spent on the previous process – should there not instead be equivalent investment in new posts for congenital heart disease (CHD)?
- attendees noted that cancer services had been well resourced and had improved dramatically - that should be the aim for CHD

<u>Transparency/openness of review</u>

- if clinical reference groups were part of the decision making process, where would they draw their patient representation from ? is it only the national charities? Need to have a breadth of knowledge including some people with direct experience of being on the receiving end of services – transparency was required regarding CRG membership
- some attendees noted that "we too have the same responsibility – to be open and transparent – open minded – not everyone will be happy about the outcome [others said "maybe they will"] – because any change is hard to deal with".
- would NHS England be open about the names of people eg on its Board Committee which had oversight of this work?

<u>Communication and engagement</u>

- direct engagement with local charities and groups was welcomed and felt more like meaningful dialogue. Some felt that this approach made the role of national charities less significant
- attendees liked the regular blog but did not have time to see when updates were posted – could they receive an email or other reminder to alert them?
- attendees agreed there was no simple answer to the challenge of reaching seldom heard groups, including ethnic minority groups . Was translation of materials possible (but into what language?)
- attendees would welcome another opportunity to meet at a sensible interval (quarterly – ie 4 times per year - was suggested by some) – they did not want this to be a one off event

Patient safety, improving quality and ensuring viability of services

- attendees agreed the reason they were so passionate was that there were some really good things going on in every centre
- there were nonetheless some concerns about patient safety and consistency of care – until the review was complete how could this be assured – eg were appropriate referrals being made – was this because units were in competition?
- where parents had questions about referrals who could they turn to ? was there a need for a "parents' ambassador", someone you can contact who could ensure your voice was heard?
- attendees noted that deaths of children with CHD, and other very poor outcomes, were often not a direct consequence of the surgery, but due to a complex series of factors, which might include:
    - incorrect/non-referrals – "clinical governance is not in place, despite what we're told"– attendees cited mismanagement of rarer cases, where some centres "did not understand or accept the need to refer on", or where the patient was "passed around system" between "people with an interest, rather than the relevant expert teams"
    - antenatal diagnostics – eg the detection rate is too low which means families and hospitals are sometimes unprepared when a child is born with CHD and needs urgent help; attendees described their experience of serious congenital problems which had been missed on successive scans; sonographers "need better training" – attendees noted the work of Tiny Tickers eg in Wales
    - failure to listen to parents raising concerns – being told "you're a paranoid parent" – clinicians should not be so dismissive (especially those lacking expertise in CHD who "don't know what they're looking for")
- many attendees had concerns about data – eg figures published on NICOR website appeared to be out of date. No consistent register of ante natal detection – eg London has no register; West Midlands uses a different format, sent to Europe but not compatible with British data
- was there a need for standards and data requirements to be legislated – eg requirement to provide data within set deadlines etc – currently reliant on voluntary returns, self governance?
- comparisons with cancer services are not entirely valid - cancer services are very protocol-driven whereas in CHD the patient must be seen by a specialist team with the right expertise

Patient and family support

- attendees noted the lack of dedicated local patient groups for adults (by contrast with children's groups) – was there a need for more networks of patient support?
- it was important not to focus only on surgery, which is a small but very important part of patients' lives – the care pathway is much more than surgery and attendees/clinicians spent much of their time helping people to live with CHD

- teenagers and younger adults, may need particular consideration – they “fall between the cracks” of excellent children’s support and independent adults (some of whom achieved amazing things but that was not a realistic ambition for every patient)
- support for bereaved families was in some cases very inadequate – this was a major concern and a cultural (including communications) as well as a clinical problem – a whole pathway of care included the end of life, perhaps some very difficult decisions which would have to be made by family/carers, and then coping with the immediate and longer term impact of bereavement
- people dealing with bereavement needed immediate practical care and support and may want more than “just a booklet” – and on occasions the attitude of professionals felt obstructive when families wanted to understand what had happened
- it was suggested there was scope for a piece of work with eg British Heart Foundation and the National Centre for Palliative Care to include better bereavement care as part of the whole pathway approach – especially but not only concerning the death of a child
- attendees agreed - but also noted that clinicians grieve – not in the same way as a parent or family member, but were deeply affected nonetheless

NHS England response

Bill McCarthy summarised what NHS England would take away from the meeting, and responded to questions/clarifications. The key points he made were:

- the scope of services covered by the review had been a consistent theme of the discussion and NHS England had undertaken to come back with a clear position on scope – which needs to be relevant to the real experience of patients. Amongst other things attendees have highlighted ante-natal testing, electrophysiology, and transplant services
- at the end of this process NHS England would have to be able to explain how it had addressed the recommendations of the Judicial Review and the Independent Reconfiguration Panel. But some of their recommendations only made sense if NHS England followed exactly the same approach as *Safe and Sustainable* which of course we might not do, so it was not sensible or even possible at this stage to give a guarantee that we would comply with every recommendation
- NHS England is nonetheless absolutely committed to transparency and openness in our work and we expect to be held to account for the decisions we make, and to be able to differentiate between those which are based on evidence and those which rely on judgement
- Clinical Reference Groups (CRGs) are part of the new arrangements for developing and agreeing clinical standards and we expect to use them to support this work – as we would expect with any specialised service that NHS England commissions in future. Their job is to tell us what the “gold standard” looks like and we can then consider how best to achieve that
- all the CRGs bring the relevant experts together and include patient representatives. We will be transparent about membership and will seek assurance that the patient representation is broad enough to capture the full range of views
- we know that trust is fragile and if patient groups have concerns – an “uneasy” feeling – tell us. Give us a chance to address it.

- concerns about resourcing are well understood, but the reality is there no significant funding increase for the NHS in the foreseeable future
- concerns about the implementation of change are well made and this includes understanding the impact on all people involved, ie both the patients who may need to be treated elsewhere and should expect to receive at least as good a service, and the clinicians and staff in the units for whom any change of location will have major impact – we need to consider how can these concerns be addressed as part of any implementation planning
- we are aware that some people think a year is too long for the this work and that the commercial sector might act quicker to respond to a risk – but we also have to consider the potential for challenge (including judicial review and IRP referrals)
- regarding the question of "closure" and how many units should there be - there is no number. We do not have a target in mind. We want a national service delivered to high national standards in the interests of all patients now and in the future.
- we acknowledge the concerns which have been raised about which charities and representative groups NHS England should deal with but we have been clear – we will talk to everyone, although none has special influence
- we cannot control what the media will report or the language used, but despite the importance of the issue, NHS England will be restrained/understated in its approach. We welcome the comments from attendees who say that we all have a role to play in calming down understandable nervousness and anxiety. At the end of the process it may be we are in complete agreement, or we may not, but NHS England will conduct a transparent and professional process and if at any stage attendees have a concern that this is not the case, tell us first and give us a chance to put it right. It is more likely to be "cock up than conspiracy"
- our commitment to transparency includes the use of data, both in the process of the review and in the delivery of services. There is undoubtedly room for improvement in consistency, timeliness, and openness in what is published. Mortality data is very good, ante natal screening date is not, and so on. We are unlikely to need to legislate to drive improvements in this area because we can use our contracting power to achieve better compliance over time.
- we remain very concerned about damaged relationships and the potential impact on patient care. We want a single national service and we are even interested in exploring the idea of a single national contract. One of the attractions of this would be that it would entail mutual clinical responsibility and mutual dependency, helping to reinforce some of the cooperation we are told has been lost
- there are questions for us to consider around the experience of patients and families at the end of life, and the care and support which needs to be provided at that time – it is part of the whole pathway of care – there may be ways In which we can help, for example facilitating a discussion to identify practical improvements
- NHS England has already taken up with clinical representatives of surgical units (in our recent meeting with them), and with NHS England's own Patient Safety lead clinician (the "domain lead"), the question of referrals from one centre to another, and related clinical behaviour. Whatever else is taking place it is imperative that referral decisions continue to be made in the best interests of patients. Clinicians bear personal responsibility to make best possible judgements in interest of patients

- local safety investigations are not part of the national review, although headlines will sometimes confuse the two
- there are multiple ways in which the review process could be challenged (for example through Oversight and Scrutiny Committees) – obviously NHS England wants to avoid this risk materialising and so we have no interest in a process which feels to some like it is unrepresentative or "not listening". Attendees should feel free to flag any concerns at any stage of this review process. We will, undoubtedly, make some mistakes along the way, but we want an opportunity put them right and/or to explain our actions
- if there are some things we can begin to implement as we go along we will do so if this is clearly in the interest of patients, will help to improve/stabilise services, and does not prejudice the eventual outcome
- we will endeavour to always be clear when we are basing a decision on evidence, and when we are relying on judgement, and what the rationale is for that judgement
- if attendees would like a further meeting – perhaps at regular intervals, eg quarterly – we would be happy to organise that. That does not mean there should be no contact between meetings. We will use the blog, and in due course perhaps other means of keeping in touch, and we welcome suggestions.

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Agenda Item 9

Leeds
CITY COUNCIL

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: 13 September 2013

Subject: Children's Congenital Cardiac Surgery: Service provision at Leeds Teaching Hospitals NHS Trust

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

Purpose

1. The purpose of this report is to provide an update on:
   a. The current provision of children's heart surgery at Leeds Teaching Hospitals NHS Trust (LTHT); and,
   b. Progress of the subsequent phases of the review of quality of children's heart surgery services at LTHT.

Background

2. On 28 March 2013 LTHT was presented with new mortality data from the Congenital Cardiac Audit Database (CCAD) by NHS England's Medical Director. This data indicated higher mortality rates at LTHT for 2010-11 and 2011-12 compared to other children's cardiac units in England. LTHT was also informed that two senior clinicians had independently raised concerns – one related to medical staffing of the unit and the other related to the quality delivered within it. In addition, at the meeting, a representative of the Care Quality Commission (CQC) informed LTHT that the CQC had information from patient complaints, which raised the concern that patients were being refused timely referrals to other Units for either a second opinion or for further treatment such as transplant.

3. LTHT decided to pause children's cardiac surgery pending further investigation – a decision supported by NHS England and the CQC.

4. At its previous meeting, on 10 April 2013, the Joint HOSC heard from representatives from NHS England, the CQC and LTHT. At that meeting details were provided of an

urgent Quality Surveillance Group (QSG) meeting (convened by NHS England on 2 April 2013) and a subsequent Risk Summit (held on 4 April 2013), where it had been agreed by NHS England, CQC, the NHS Trust Development Authority and LTHT that a review would be carried out.

5. It was reported that the review would have distinct phases, where the first phase had consisted of an urgent review of LTHT Children's Cardiac Unit to ascertain if there were significant and readily identifiable safety concerns.

6. It was outlined that the first phase review had focused on clinical governance processes, staffing capacity and capability, and the patient experience which included referral management and patient pathways in and out of the Unit. It was reported that the first phase review had found no evidence of immediate significant safety concerns in these areas and that surgery would be recommenced on a phased basis.

7. It was further reported that subsequent phases of the review work would involve:
    a. A case note review of the deaths (mortality review) that have occurred and the complaints brought by a third Party.
    b. Understanding data handling, the application of data relevant to Unit mortality and inter-Unit comparison at a national level

8. At the time of the Joint HOSC's previous meeting, the finalised report from the first phase review was not available. Therefore, for completeness, a copy of the full report is now appended to this report for information. This was formally published by NHS England on 23 April 2013 and includes the report from the National Institute for Cardiovascular Outcomes Research (NICOR) – which, on the request of NHS England, had provided an independent analysis of paediatric cardiac surgical mortality in units within England and Wales for 2009-12. As outlined in the statement released by NHS England, it is important that the two reports are considered jointly.

Main issues and considerations

9. As previously outlined, it was always intended that the review of quality would be undertaken in different phases. As such, a representative from NHS England has been invited to the meeting to provide a verbal update on further progress in this regard.

10. It is intended to invite LTHT to provide a written update on current service provision and progress on the unit since the first phase review and the recommendations made. It is hoped that this information will be presented at the meeting.

Recommendations

11. That the Joint HOSC:
    a. Considers and comments on the details presented in this report, and outlined at the meeting
    b. Identifies any additional scrutiny activity necessary at this stage.

Background documents[1]

12. None used

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[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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Review of Children’s Congenital Cardiac Surgery Service at Leeds

23 April 2013 - 16:16

NHS England has released the Review of Children’s Congenital Cardiac Surgery Service at Leeds Teaching Hospitals NHS Trust report.

This report is the output of the independent review team that formed part of the first stage of the review into children’s heart surgery at Leeds. This report looked at systems within the unit and found that there were no immediate issues that would prevent a resumption of surgery.

This report should be read in conjunction with the NICOR Investigation of mortality from paediatric cardiac surgery in England 2009 – 12.

This report from the National Institute for Cardiovascular Outcomes Research, which is part of the University College London, was commissioned to inform the review. This report reviewed the data, based on further information provided by Leeds Teaching Hospital and found that the mortality rate was within the acceptable range. However, this report was also very critical of the hospital’s data collection, describing ‘major deficiencies’ in the data submitted, which it said could be a measure of ‘organisational culture’.

It is important that both reports are read and considered together.
NHS England welcomes these reports and the reassurance they offer that that the immediate safety concerns raised at the end of March have been addressed in order that the unit could recommence surgery on a phased basis.

This is not the end of the process, and a second stage of the review is underway in which we now need to explore some of the wider issues around how the unit operates as a whole. We hope we will soon be able to give the unit a full clean bill of health beyond this immediate reassurance of safety.

Throughout this process our sole concern has been the safety of patients

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Report of the External Review of Children's Congenital Cardiac Surgery Service at Leeds Teaching Hospitals NHS Trust

Contents:

Dr Damian Riley
Medical Director, West Yorkshire, NHS England
on behalf of the Review Team

9 April 2013

Executive Summary

Background

On 28th March 2013 Leeds Teaching Hospitals NHS Trust (LTHT) Chair, Chief Executive and Interim Medical Director were presented with new mortality data from the Congenital Cardiac Audit Database (CCAD) by Sir Bruce Keogh (NHS England Medical Director). This data indicated that LTHT's Children's Cardiac Surgery Unit had higher mortality rates for 2010-11 and 2011-12 compared to other children's cardiac units in England. Those present at the meeting were also informed that two senior clinicians had independently raised concerns, one over medical staffing of the unit the other on the quality delivered within it. In addition, at the meeting, a representative of the Care Quality Commission (CQC) informed LTHT that the CQC had information from patient complaints, which raised the concern that patients were being refused timely referrals to other Units for either a second opinion or for further treatment such as transplant.

LTHT confirmed that one of its surgeons was presently not operating pending a separate internal investigation.

At the meeting, LTHT decided to pause children's cardiac surgery pending further investigation. This decision was supported by NHS England and the CQC.

Following an urgent Quality Surveillance Group (QSG) convened by NHS England on 2nd April 2013 and the subsequent Risk Summit held on 4th April 2013, it was agreed by NHS England, CQC, the NHS Trust Development Authority and LTHT that a review would be carried out.

This review would have distinct phases.

The first phase would be an urgent review of LTHT Children's Cardiac Unit to ascertain if there were significant and readily identifiable safety concerns. The review would focus on clinical governance processes, staffing capacity and capability, and the patient experience which included referral management and patient pathways in and out of the Unit. This review will report its findings and conclusion back to the Chair of The Risk Summit for sign-off.

Subsequent phases of the review work will involve:

- A case note review of the deaths that have occurred and the complaints brought by a third Party.
- Understanding data handling, the application of data relevant to Unit mortality and inter-Unit comparison at a national level

This report presents the finding of Phase One of the review process, and the findings and recommendations should be interpreted together with any other evidence which subsequently becomes available.

Methodology

A multidisciplinary Review Team was convened with expert medical and nursing advisers from outside LTHT joining NHS England Area Team Medical Director and the LTHT Deputy Medical Director (Quality). The Review Team undertook a document review, direct interviewing of relevant staff groups and individuals, and direct observation of the Children's Unit. The Review did not observe surgery or out-patient clinics being undertaken. Case records were selected for those cases where specific concerns were known to have been raised.

Summary of Findings:

Within the context and remit of this review no evidence was found of immediate significant safety concerns in terms of clinical governance, staffing or in the management of the patient pathway for surgical care in the Unit, or for referral to other Units in the examples of the specific case files examined.

A number of very positive aspects of practice are present in the service provided by this Unit. The teamwork is strong, inter-professional working appears effective, surgical staffing levels are comparable to other Units, clinical supervision is in place and internal monitoring of morbidity and mortality is functional internally through audit and regular feedback systems.

The nursing workforce presented themselves as a highly committed and professional team with a strong child and family focus. Whilst some recommendations are made to support continuous improvement, no serious concerns were evident during the review regarding the nursing workforce or standard of nursing care, though it must be acknowledged that assurance is limited by the process of the review.

The report makes recommendations in a number of areas, which in the body of the report are identified as high, medium or low priority. The identification of a recommendation as high, medium or low priority should be considered by LTHT. It is noted that a number refer to overall policy and process in the hospital, whilst other refer to changes that may be specific to the Unit.

Each recommendation has been assessed as to its impact upon the decision to restart surgery, indicating the immediate risk posed to the safe recommencement of surgery by the Unit if the *status quo* was maintained. The matrix in Table 1 below summarises the impact assessment of these.

Conclusion

Data Management internally in the Unit and by LTHT for internal audit, routine care, routine morbidity and mortality audit processes was found to be adequate, but there were lapses in data uploading and export to national reporting databases, in particular to CCAD. The team has identified this as an area for improvement, in addition to recommending improvements in complaint handling, the format of multidisciplinary case discussions and the information conveyed in some clinic letters to patients. Whilst the issues identified represented low risk to the safe recommencement of surgery, members of the review team suggest that the amendments to complaints handling, and other methods of assessing patient feedback, should be attended to with some priority in order that the Unit may assure itself of delivering a good patient experience.

However the Review found no evidence that the Unit should not commence surgery again, and therefore recommends to the Risk Summit that this should be considered in a safe and structured way.

Dr Damian Riley
Medical Director, West Yorkshire, NHS England
on behalf of the Review Team

9 April 2013

Table 1: Impact Assessment of Recommendations

	High Impact/Risk	Medium Impact/Risk	Low Impact /Risk
Governance	No issues	No issues	• Pathologist attendance at MDT when relevant histology discussed is recommended • To modify gatekeeper role of Cardiologist in case selection and presentation to MDT • Complaint policy and response process to be modified. • Assessment of patient/family experience to be enhanced
Staffing	No issues	No issues	• External Mentor for more new consultant surgeons to be considered • Succession planning to be considered • Increasing PICU establishment to meet PICS standards
Patient Pathway and Referral Arrangements	No issues	No issues	• To introduce real-time monitoring and evaluation of referrals to other units for use as audit tool • Patient advice letter templates to be modified to reflect higher mortality of certain cardiac conditions
Data Management	No issues	No issues	• Coding accuracy and data management Resource to be clarified for data being assimilated for external validation and use in national programmes

Appendix 1.

Children’s Heart Surgery Review (Phase One)

Terms of Reference

April 2013

This is a jointly agreed and commissioned review on behalf of NHS England and Leeds Teaching Hospitals NHS Trust which will report to the next NHS England Risk Summit on Sunday 7th April 2013.

Remit:

- With regard to the safety of surgery performed in Leeds on children up to and including 16 years of age for congenital cardiac conditions to review and advise upon
    - the clinical governance systems and processes in place to deliver safe and effective care
    - the ability of the Unit to undertake proposed surgical procedures
    - the existing service and comment on overall safety, with reference to current best practice

Review team

- **Professor John Wallwork:** Former Cardiothoracic Surgeon, Papworth Hospital
- **Professor David Anderson:** Consultant paediatric cardiac surgeon, Guys and St Thomas’ NHS Foundation Trust
- **Dr Jo De-Giovanni:** Consultant Cardiologist, Birmingham Children’s Hospital
- **Sue Ward** Director of Nursing (Children) Central Manchester Foundation Trust
- **Dr Damian Riley:** Medical Director, West Yorkshire Area Team, NHS England
- **Dr A Bryan Gill:** Deputy Medical Director (Quality and Governance), Leeds Teaching Hospitals NHS Trust

Objectives:

With regard to Governance Process

- To investigate the management arrangements for the Unit to ensure they are robust and fit for purpose
- To investigate incident levels and reporting, and complaint handling
- To determine data handling record keeping and clinical audit process
- To determine effectiveness of policies for devices and therapies
- To determine the Clinical prioritisation processes
- To determine the MDT approach used in patient management and reviews
- To determine the risk management process including maintenance of the risk register
- To understand safeguarding arrangements
- To determine infection control governance arrangements

With regard to Staffing and Unit Capability

- To explore recruitment, professional development, and appraisal/revalidation systems
- To determine the staffing levels, both quantitatively and qualitatively, for all relevant disciplines of staff (surgical, nursing, anaesthetic and Intensivist and ancillary) for the service being provided

- To determine the range of surgical procedures undertaken including analysis of individual consultant contribution and comment on the appropriateness of such for the Unit relative to the population served and patient demand

With regard to patient management and patient experience

- To ensure appropriate patient care pathways are operational
- To determine patient flows and patient management through the service including referral patterns to other Children's Congenital Cardiac Surgery Units

Principles:

- The review is jointly commissioned by NHS England and Leeds Teaching Hospitals NHS Trust
- Patient identifiable information shall not be released
- Serious concerns and risks to patient safety are to be notified without delay to the Medical Director of NHS England & Leeds Teaching Hospitals NHS Trust
- Media relations and communications with stakeholders is conducted through the commissioners of this review

Appendix 2

Review Methodology*:*

The Review took place on 5th, 6th and 7th April 2013.

The Review Methodology included:

Document Review:

- Review of Trust Documents including Organisation Policies and Protocols
- Review of specified Audit data and outcomes
- Review of details from case records
- Review of (redacted) complaint responses for last 2 years
- Review of Incident data for last 2 years
- Review of Terms of Reference of Clinical Governance Groups
- Review of SOP for scheduling of operations
- Review of Waiting List and activity data
- Review of Workforce and staffing data

Structured interviews of all relevant staff groups including

- Surgeons (3)
- Consultant Cardiologists including Interventional Cardiologists (10)
- Junior doctors (training grade cardiology staff) (2)
- Anaesthetists (1),
- Theatre staff (1),
- Nursing staff (17),
- Intensivists (2)
- Liaison nurses (2),
- Counsellor (1),
- Psychologist (1),
- Matron (1),

Direct inspection of

- Ward 12
- ICU environments
- Trust HQ and Divisional HQ facilities

Staff were offered individual or group interview.
Surgeons were interviewed individually and as a group.
“Open interview slots” were allocated for any staff who wished to be seen individually.

Staff were asked if they considered any feature of the Unit to be unsafe, or if they knew of any reason why the Unit should not recommence surgery. Staff were asked all relevant questions pertaining to the Terms of Reference of the review (see above)

A total of 17 nursing staff were involved and interviewed

Direct observation of surgery or out-patient consultations was not part of this review.

Appendix 3

Grading of Evidence:

Evidence was interpreted with the following weighting:

Grade A evidence

Evidence of Implementation of Organisational Policies and Protocols
Patient Records
4D / Oscar database and PAS system
Professional assertions and Statements and corroborated answers
Minutes of Meetings
Facilities and Operation of Unit: Inspection by Review Team
Non-redacted complaint responses
Externally validated Audit data
Internal audit data from wards and dashboard.

Grade B evidence

Existence of Organisational Policies and Protocols
Opinions of staff groups without any other corroboration
Redacted complaints responses

Grade C evidence

Anecdote

Appendix 4

Review of Children's Congenital Cardiac Surgery Service at Leeds Teaching Hospital Trust.

Outline of Review programme for the 5th, 6th and 7th April 2013.

Friday 5th April 2013

Activity	Time	Staff Group/Individuals	Location	Comments
Review Team Assemble	09:00 - 10:30	N/A	LTHT Trust HQ	
Draft terms of reference	10:30- 12:00	Team (DR, BG, JW)	LTHT Trust HQ	
Meet Surgical Team	15:00	Team (DR, BG, JW) plus LTHT children's cardiac surgeons	Divisional HQ, LGI	
Meet Unit staff	16:00	Unit staff	Aire FM room, LTHT	
Inspection of Unit	17:00 …..		Unit	

Saturday 6th April 2013:

Operation Room – Radio Aire Seminar Room, E floor, Jubilee Wing, Leeds General Infirmary.

Activity	Time	Staff Group/Individuals	Location	Comments
Review Team Brief	10:00 - 10:30	N/A	Ops Room	
Staff Interviews	10:30- 12:00	Congenital Cardiologists	Ops Room	
Staff Interviews	12:00- 13:00	Theatre Team	Ops Room	
LUNCH	13:00 – 13:30			
Staff Interviews	13:30- 14:30	PICU Consultants	Ops Room	
Staff Interviews	14:30 – 15:30	Liaison Nurses	Ops Room	
Staff Interviews	15:30 – 16:30	Open Slot *	Ops Room	
Visit to Ward 12	16:30 – 17:30	Matron [redacted] [redacted] to support	Ward 12	
Visit to PICU	17:30 – 18:00	[redacted] to support	PICU	
Review Team	18:00 …..		Ops Room	

Sunday 7th April 2013:

Operation Room – Radio Aire Seminar Room, E floor, Jubilee Wing, Leeds General Infirmary.

Activity	Time	Staff Group/Individuals	Location	Comments
Review Team Brief	09:00 – 09:30	Team Update (Mike Bewick)	Ops Room	
Report	10:00 – 12:30	Team	Ops Room	
Staff Interviews	12:30 – 13:00	Interventional Cardiologist	Ops Room	
LUNCH	13:00 – 13:30	Lunch		
Review Team	13:30 - 17:00	Surgeon Interview / Team discussion regarding scheduling in future Consolidation /Evaluation	Ops Room	

***Any member of staff who wishes to see the review team please feel free.**

Appendix 5

Review Findings:

Section 1: With regard to Governance Process

- To investigate the management arrangements for the Unit to ensure they are robust and fit for purpose
- To investigate incident levels and reporting, and complaint handling
- To determine data handling record keeping and clinical audit process
- To determine effectiveness of policies for devices and therapies
- To determine the Clinical prioritisation processes
- To determine the MDT approach used in patient management and reviews
- To determine the risk management process including maintenance of the risk register
- To understand safeguarding arrangements
- To determine infection control governance arrangements

General Management Arrangements

Issue	Evidence Seen / Reference Documents	grade	Findings / Opinion	Recommendations	priority	impact
capacity	LTHT Divisional organisation structure provided Staffing chart and clinically led reporting lines of management for new service design (April 2013) provided List of Consultant staff in all relevant disciplines provided	A	Board / Divisional / Service management arrangements demonstrated, with clinical leads and management reporting lines noted. This was in process of change to newer clinically led teams, from 1/4/13	LTHT to continue with planned changes	H	L
Systems	Electronic Clinical	A	Standardised clinical guidelines are in place.	No change recommended		

including Clinical Guidelines being followed	Guideline documents seen		Some minor differences in practice between consultants were noted by the nursing staff but practice was generally considered to be consistent across the clinicians.			

Incident management

Issue	**Evidence Seen / Reference Documents**	**grade**	**Findings / Opinion**	**Recommendations**	priority	impact
SI	SI policy seen	A	No SI in Unit in 2 years	No change recommended		
Incidents Process	Policy Multiple staff groups interviewed and congruous with their response about process,	A	(see also risk section) IR1 forms completed regularly by staff on Unit IR1s completed by ward staff → screened by Matron →Clinical Leads then score the risk using 5x5 matrix → Higher risk incidents reported to Trust Quality group Matron covers Ward 12 and Paediatric Critical care (Cardiac PICU and General PICU) Matrons reviews and logs on DATIX Monthly report to Ward Dashboard and report reviewed at Monthly Performance Review meeting which is attended by DGM, Divisional Nurse, and Divisional Medical Manager.	No change recommended		
Incident reporting	Paediatric cardiac services incidents and	A	94 incidents were reported during a 12 month period. None were serious untoward incidents, 1	No change recommended in reporting culture		

	complaints 2011-2013 Level 2 investigation report 174405 Discussion with staff. Syringe pump errors improvement work display.		required a “level 2” investigation (risk score 9). 41% were recorded as medication errors. All staff described that errors primarily fell into two themes – discrepancies in the documented amount of oramorph syrup and syringe pump errors. Action was underway to address both issues. Oramorph discrepancies had been identified as being due to displacement. The use of red aprons is being introduced to identify staff undertaking medication administration to reduce interruption. Staff who make drug errors were reported to receive a package of support but are not automatically removed from medication practice or re-trained. Staff reported a proactive, fair blame risk reporting culture. LTHT medicines management team was aware and had investigated	Nursing teams are introducing “do not disturb” process to medication rounding – to implement	H	L
Incident Review	Staff reported getting feedback via Specialty Governance group. Minutes of monthly governance meetings	A	Incidents are reviewed at monthly governance meetings and action plans are developed. Consultants, the Matron and band 7 staff are core members of this group, in addition the Matron advised that any staff member can attend. Staff reported receiving personal feedback from their line manager if they submitted an incident report and that learning is communicated via	No change recommended		

			communication boards, books and staff meetings. At a Trust level an e-Bulletin is used to share learning. The Matron reported that she undertakes spot checks to ascertain whether information has reached front line staff.			

Risk Management

Issue	Evidence Seen / Reference Documents		Findings / Opinion	Recommendations	P	I
Risk assessment	Interview with Staff Risk management documentation.	B	(see also above) Following IR1 completion, Matron and lead cardiologist decide risk score, classifying these as green amber or red Red if >15 Reported incidents reviewed at Monthly Performance Meeting. Red are escalated Reviewed at Divisional Clinical Governance Meeting (attendance as for performance meeting but also includes clinical directors) Through the Division, all RED risks are reported to Board. Board secretary seeks clarification as needed from DGM Specialty Governance Meetings held monthly and driven by clinicians. Process updated monthly.	No change recommended		

			Since January 2013 Trust reviewing Risk register process			
Proactive risk assessment	The Medical Director reported that a Trust review of risk management is underway.	B	No evidence was presented to demonstrate that individual wards undertake active risk assessments and maintain local risk registers. Staff reported attending an annual risk study day.	Establish local risk assessment processes at ward level	M	L

Complaints management

Issue	**Evidence Seen / Reference Documents**		**Findings / Opinion**	**Recommendations**	P	I
No of Complaints	10 complaints presented to Team for 2 years period Redacted email trail between Service and Corporate team reviewed	B	No complaints gone to PHSO One complaints relating to care given to child in 2005 not formally responded to, complainant informed it was out of time. In light of likely extensive grief and lasting effect on family, it would seem more appropriate for a meeting to be offered an some form of explanation and response to be offered	A flexible approach to time-limit for complaining to be adopted	H	L
Complaints Policy	Complaints Policy Being Open Policy	A	Guidance issued to staff at the Trust by the complaints team in the Policy document, including ‘Tips and Sound bites’, ‘Checking and reviewing responses to complaints’ and			

	Electronic governance system.		‘Guide to letter writing’; all recommend the use of accessible language appropriate to the complainant. Several of the examples viewed appeared not to comply with this, nor the wider advice within the guidance to staff, for example, the low level of empathy shown or an acknowledgement that the events surrounding the complaint have been stressful and traumatic for the complainant and family members. The policy document is lengthy and does not refer to the potential value of using complaints and concerns as valuable sources of organisational learning and patient care until page 8. The supplementary information on complaints management would appear to be one approach to improve this position; however, its lack of inclusion within the policy and framing the importance of using feedback to improve patient care challenges the strength of the overall organisational governance concerning complaints management.	Policy Review advised	H	L
Complaints handling: process	Interviews with DGM, Service manager and Clinicians interviews Complaint response-time internal audit	A	All logged onto Datix-Web Complaints received by Corporate HQ team Sent to Divisional Manager. Divisional manager decides who to send complaint to For clinical complaints, they are sent to Children’s Service Manager who liaises with the relevant clinician who supplies factual response. This is formatted into a letter and sent for	To review process: recommend Board level designated accountable officer for complaints (Chief Nurse or Medical Director) sign off Continue to log using Datix-web Advise continue to improve response times	H	L

			checking to Divisional Manager, then to Divisional General Manager for sign-off. Then it is sent to Complainant, with copy to clinician and to DGM and to Corporate team			
			Service manager said they “*match the clinical or technical complexity of the response to that used in the complainant’s letter*.”	More understandable style to be considered	M	L
			Subsequent Specialty Clinical Governance and Divisional Meeting discuss overall themes and essence of complaint. No clear examples could be given as to learning or changes as a result of any complaint.	More emphasis needed on learning from complaints,	H	L
			Trust wide review of complaint handling is already underway, prompted by recent Trust patient survey			
Style of Response	All Redacted complaint responses	B	The responses list events and actions without any real explanation of why they did or did not take place at certain stages. Not all concerns raised were acknowledged or responded to within the correspondence seen. Overall, the tone of the correspondence could be interpreted as patronising and defensive. The correspondence contained limited or no acknowledgement of any organisational learning or acceptance of unintended distress or anxiety for the complainants or the patients.	As above	M	L

Timing of responses	Trust data for monitoring of complaint response times	A	Showing steady improvement	To continue improving	M	L
Specific Complaints refuted by Unit	Partially redacted complaint responses to 2 patients who had been transferred to [redacted] 4D database entries on case	A	Not able to substantiate allegation [redacted] Style of responses: Very factual. Significant use of technical language Limited evidence of empathy In these two cases, little evidence of description of “why” things were done, only ”what” things were done. No evidence of reflection by the Unit / management or any acceptance that any learning could be derived. No evidence in the complaint response that meeting with complainants offered	No immediate action by Trust in relation to response formally indicated, but Trust to be prepared to offer opportunity to meet families Future Responses to complaints to indicate empathy and all possible learning	M H	L L
Allegation raised at Risk Summit that a patient was advised to self-fund for treatment outside England	4D database entries on case	B	Not able to substantiate allegation [redacted]	No further action needed		

			[redacted]			
Patterns of Patient management and referral that were causing concern	Interviews with Liaison Nurses, with ward and ICU nursing staff and cardiologist	A	Not able to substantiate concerns Staff specifically asked, and without exception they informed review team that there had not been a large number of complaints, no increase seen in recent weeks, that they had never witnessed any hesitation to refer to any particular Unit at any time if requested to do so for a second opinion. Example quoted of 27 referred cases which were operated on at Evelina Unit in past 3 years	Implement real-time patient/family feedback	M	L
Complaints prevention	Discussion with Matron	B	The Matron described a daily walk-round to speak to families with a view to addressing any concerns.	To Consider intentional rounding	L	L

Data Management

Issue	Evidence Seen / Reference Documents	Gr	Findings / Opinion	Recommendations	Pr	Imp
“missing data”	Statements from cardiologists and intensivists and surgeons CCAD February 2013 draft Data Quality Audit report Fosters Alerts reviewed monthly PICANET data	A A	CAD draft report identified Overall DQI for the Unit (surgery and catheter) was 93.5% compared to 95% for previous year. Draft Report concludes “*On the whole, the NICOR/CCAD data where submitted were accurate, well documented, good quality and were appropriately recorded in Theatre and Congenital Cath lab books that were seen*. “ Comments made in report referring to database manager not ensuring records are available for visit. Draft Report states “*a less than adequate database management support has been available to the clinicians since the last validation visit”* Since then, LTHT and Unit have taken action and changed personnel, increasing the resource and staffing for uploading data to database. Surgeons state they personally enter an operation code. It is not clear to review if data completion or coding for some operations truly reflects the entire complexity of the operation particularly if the data manager did not	To continue implemented changes to data management and to address recommendations in the CCAD draft report.	H	L

			understand significance and some data fields not complete CCAD draft Report notes feedback monthly to clinicians of data and states *“Clinical Staff are therefore involved in the validation of diagnostic and procedure codes on a routine basis but the timeliness of this may have lapsed*” Review team considered Unit collected data adequately for day to day running, and for morbidity and mortality meetings. (see also Audit). Mortality data kept. PICANET (PICU) data reportedly more accurate. Dedicated data entry resource was adequate for this.			

Audit

Issue	**Evidence Seen / Reference Documents**		**Findings / Opinion**	**Recommendations**		
Unit clinical audit activities	MSSA audit presentation seen Feb 2012 Chylothorax audit presentation PAWS audit presentation Routine pre-op urinalysis	A	An audit programme is in place	No change recommended Audit programme to continue		

	audit Surgery to ICU Handover audit presentation Coronary anatomy in TOF / echo accuracy audit Surgical site infection surveillance programme					
Other	Hand hygiene audit	A	See infection control			
Mortality and morbidity	(see documents log in appendix) M+M meetings discuss relevant cases Dr Foster Alert Print Outs issued to Specialty Governance group	A	Trust uses Dr Foster alerts reactively All relevant staff groups attend M+M meetings with exception of pathologist	Consideration to be given to pathologist attending M+M meeting when relevant histology is discussed	M	L
ICU audit	PICANET data	A	PICANET shows Length of Stay in ICU in line with expected with other Units (this can be seen as one proxy measure for morbidity)	No Action		

Introduction of Device and therapies

Issue	**Evidence Seen / Reference Documents**	**Gr**	**Findings / Opinion**	**Recommendations**	P	I
Allegation that Staff may not follow	Policy seen Interviews with cardiology staff	A	No significant concern identified Relevant staff aware Policy present	Continue to follow existing processes		

protocol			Ethical approvals process for clinical and research			

Real-time monitoring of standards and clinical governance

Issue	Evidence	Gr	Findings	Recommendations	P	I
Safety Thermometer	Electronic ward dashboards	A	VTE, pressure ulcers and falls are reported on the monthly dashboard. No concerns were evident relating to these aspects of practice.	No change recommended		
Quality Assurance	Electronic ward dashboards	A	Ward Managers undertake a weekly quality assurance round, which includes review of hand hygiene, nutrition, documentation and cleanliness. Matrons undertake the same review on a monthly basis. Findings are fed-back to staff and displayed on communication boards. Staff reported that action plans were developed to address deficits. A range of improvement tools were being utilised to facilitate improvements.	Consider on-going refinement of systematic approach to quality improvement.	M	L
Infection prevention and control	MSSA audit Interview with Intensivists and Nursing staff on ward Hand hygiene audit results Electronic ward dashboards	A	No significant concern identified Relevant staff aware Policy present Except for January 2013, hand hygiene results satisfactory HCAIs are reported on the ward dashboard. There have been no MRSA bacteraemias in the past 12 months in the cardiology services.	No change recommended		

			Hand hygiene audits showed 100% compliance for ward L12. PICU had risen from 42% compliance to 90% in the past 3 months			
Ward rounds	Staff discussion	A	Nurses and consultants reported that the co-ordinating nurse always attends ward rounds. Releasing time to care work is being undertaken to improve ward round efficiency.	No change recommended		
Nursing handover	Staff discussion	A	Nursing hand over had been reviewed as part of the Releasing time to care programme. Staff reported a 15 minute reduction in handover time. SBAR has been introduced to improve communication. Board rounds are held twice daily to update staff on each patient's status.	No change recommended		
Documentation	Documentation review. Electronic ward dashboard	A	A risk-based nursing assessment is in place. Care plans were found to reflect the needs of the child and family. Documentation standards are audited by the Matron and Ward Managers. A patient held record has been introduced to support continuity.	No change recommended		
Access to medical/ surgical support	Discussion with staff	A	Staff reported improvements associated with implementation of a "Cardiologist of the week". All nursing staff reported feeling confident to escalate concerns about a patient to the relevant consultant. Nurses felt well supported by medical and	No change recommended		

			surgical staff 24/7.			
Team culture	Discussion with staff	A	Nursing and medical staff reported an excellent team culture in which professionals work effectively together. Communication and relationships between professionals were considered by all staff groups to be strong and effective. All staff cited a strong believe in the quality of the service. Nursing leadership is currently being reviewed. The substantive Ward Manager is currently acting up into the Matron role following retirement of the post holder. A band 6 sister is acting up into the Ward Manager role. Both staff appeared confident in their acting roles and staff from all professional groups describes strong and clear leadership.	No change recommended		
Patient feedback	Electronic ward dashboard Inpatient ward survey	A	Limited patient feedback is captured in a routine manner. Staff were aware of the Friends and Family Test but this did not appear to have been implemented. A standard Trust survey is given to 10 families per month but returns were reported to be poor and staff didn't appear to receive regular feedback on the findings. The Liaison Nurses reported that families are currently expressing support for the service with a small number requesting transfer to another service.	Consider reviewing the process to obtain family feedback. Develop a system to enable regular feedback that is reported to staff and acted upon. Consider developing a specific children's survey. Consider use of electronic patient feedback systems.	H	L

Section 2:
With regard to Staffing and Unit Capability

- To explore recruitment, professional development, and appraisal/revalidation systems
- To determine the staffing levels, both quantitatively and qualitatively, for all relevant disciplines of staff (surgical, nursing, anaesthetic and Intensivist and ancillary) for the service being provided
- To determine the range of surgical procedures undertaken including analysis of individual consultant contribution and comment on the appropriateness of such for the Unit relative to the population served and patient demand

Staffing

Issue	Evidence Seen / Reference Documents	Gr	Findings / Opinion	Recommendations	P	I
Surgical capacity and locum usage	Appointments process discussed w Trust and with locum consultant surgeons Discussion with Theatre,. Anaesthetist, cardiology and Surgical Team Staffing sheet from Trust	A	Locum consultants have considerable experience. Have trained initially in Europe. Have worked for many years in Leeds Unit in non-consultant Grade Appointed to Locum Consultant posts in 2012. External (College) representative on panel for locum consultant appointment – full AAC process followed Mentored and work allocated by senior surgeon. Close team-working arrangements described by surgeons and confirmed by theatre staff and anaesthetists. Anaesthetists were highly complementary about surgical competence of all surgeons. 3 WTE surgeons a present, 4th temporarily not operating	Staffing levels to continue		

			Surgical team augmented by 5th surgeon who comes once/month for 2 or 3 days operating This compares favourably to many other Units in England One has general Surgery CCT but does not have Cardiac specialty CCT, All surgeons when interviewed demonstrated insight into case complexity and the need to work within limits of competence. All gave evidence of referring to other colleagues or Units if they felt it was required. One surgeon, formerly a Consultant in England, comes once / month to do operations. Those cases are selected in advance by senior surgeon through scheduling meeting. All imaging and records are sent in advance to the surgeon for inspection. All surgeons (including the visiting surgeon) see the patient prior to operation – usually the day before. All surgeons personally take the consent from the family.	One surgeon is advised for future post applications to consider certification as cardiac surgeon CCT	L	L
Surgeon competence	Appoints process (RCS oversight-check) Discussion with surgeons about case allocation and log books	A B	External Surgeon (College) representative on panel No concerns found re surgical competence. All surgeons quoted significant numbers of relevant operations undertaken, maintained log books and had experience of complex cases.			

	Comments from other staff including nurses, anaesthetists	B	Surgeons will now be under scrutiny since this issue arose in March 2013. It may cause some level of stress.	External Mentor for surgeons to be considered	L	L
Induction of new nursing staff and skills development	Ward 12 orientation pack Interviews with staff	A	New staff are allocated to a preceptor and undergo an internal education programme supported by the Clinical Educators. Competency is assessed by the preceptor. Staff reported having good access to continuing education and those interviewed were able to offer examples of education programmes that they had undertaken. These included clinical training as well as leadership and management. A programme of rotation between the ward and PICU is in place. Staff described that this was a positive experience, which developed skills and provided insight into the patient journey.	Consider placing all new starters on an accredited critical care programme.	M	L
Junior doctors and training grades	Interview	B	Consultant cardiologist and surgeon access 24/7 Well supported Good training opportunities Very positive culture evident Positive comments from many staff regarding Teamwork which appears highly valued	No change recommended		
Establishments	Papers prepared by Divisional Nurse Manager: LTHT Paediatric Cardiology Ward L12- Nurse Staffing (April 2013) and LTHT	A	The current PICU establishment provides 5.6wte/bed compared to the Paediatric Intensive Care Society (PICS) Standard (2010) of 7.01wte/bed. A business case is reported to have been approved to increase the PICU establishment by19.8wte band 5 nurses to enable compliance	Recruitment to additional posts New Unit opening in April 2013 Consider a review of	M L	L L

	Intensive Care (PIC) Staffing Benchmarked against PIC Standards November 2010 – update December 2012 Discussion with Matron and Ward Staff		with current standards. Ward staffing is stated to be based on Defining Staffing Levels for Children and Young People's Services, RCN (2003) rather than the updated guidance published in April 2011. Ward managers were reported to be 40% supervisory and 60% clinical. Establishments contain a 20% uplift to cover annual leave, sickness and education and training. This is below that recommended by the RCN but compares fairly with other paediatric services in the North of England. Skill mix within Ward L12 is appropriate, with a high proportion of experienced band 5 staff nurses. 6 Cardiology Specialist (Liaison) Nurses are in post, which is slightly below the Safe & Sustainable recommended level of 7. One specialist nurse is designated as the Transition Nurse, which accords with Safe & Sustainable standards. 3 Clinical Educators support training and education across PICU and Ward L12. This complies with PICS standards.	establishments against the standards set out in Health care service standards in caring for neonates, children and young people. RCN (2011). Consider making Ward Managers 100% supervisory		
H.R Datasets	Divisional Performance Review Report January 2013	A	Turnover of nursing staff was reported to be low though no data was reviewed. However all staff involved in the discussions had been in post over 5 years and a summary of staff experience provided by the Divisional Nurse Manager demonstrated that the majority of cardiology ward nursing staff	No change recommended		

			had over 5 years' experience in cardiology nursing with 10 staff had over 10 years' experience. The PICU was considered to have a higher number of less experienced nurses. Sickness absence was reported as 4.41%, which compares with national averages. Sickness action plans are monitored via the divisional performance review. An electronic system is used to monitor sickness and highlight trigger points. The Matron and Ward Managers described a culture of proactive sickness management. Staff reported having an appraisal in the last 12 months and having PDPs in place. Compliance with mandatory training is monitored via Divisional performance reviews.			
Shift system	Discussion with nursing staff	A	An 11.5 hour shift system is worked by all staff.	Consider reviewing the impact of long shifts on incidents and sickness absence rates.	L	L

Professional Development

Issue	Evidence Seen / Reference Documents	gr	Findings / Opinion	Recommendations	p	I
Appraisal and revalidation systems and implementation	ORSA submission	A	No concerns			
	Consultant appraisal	B	All Consultants and locum consultants have had			

			annual appraisals by a different consultant outside Unit Surgeon 1: march 2012: date confirmed for 2013 Surgeon 2: Date confirmed for 2013 Surgeon 3: Date TBC Surgeon 4: Date TBC	Expedite Appraisals for 2013	M	L
Nursing Induction and Supervision	Ward 12 orientation pack	A	New staff are allocated to a preceptor and undergo an internal education programme supported by the Clinical Educators. Competency is assessed by the preceptor. Staff reported having good access to continuing education and those interviewed were able to offer examples of education programmes that they had undertaken. These included clinical training as well as leadership and management. A programme of rotation between the ward and PICU is in place. Staff described that this was a positive experience, which developed skills and provided insight into the patient journey.	Consider placing all new starters on an accredited critical care programme.		

Section 3:
With regard to patient management and patient experience

- To ensure appropriate patient care pathways are operational
- To determine patient flows and patient management through the service including referral patterns to other Children’s Congenital Cardiac Surgery Units

Procedures undertaken and Patient Pathways

Issue	Evidence Seen / Reference Documents		Findings / Opinion	Recommendations	P	I
Referrals in to Unit	Description of process from Cardiologists, Service manager, Theatre staff and anaesthetists	A	Satisfactory Process in MDT meetings Network consists of LTHT based paediatric cardiologists who visit DGH’s in Region. They support local Paediatricians with specialist interest Referrals come via DGH paediatricians, to LTHT cardiologists. LTHT cardiologists manage patients in out-patient clinic, and as required at their judgement bring case for discussion (by alerting the MDT coordinator) at the weekly surgical case conference meeting. Output of this goes to weekly surgical scheduling meeting Planning meeting weekly, Appropriate attendance including theatre lead nurse.	Consider joint medical/surgical review of all cases This will avoid situation of cardiologist becoming “gatekeeper” to surgery.	M	L

			Plans 3 weeks ahead. Space for emergencies left on schedule			
Referrals from Cardiologists or surgeons to other Units	Description from lead cardiologist Evidence of a patient record from case conference stating “if patient requests 2nd opinion we will support this” Evidence from patient complaint responses describing how at clinic appointments patients were offered referral to other Units for 2nd opinion. Liaison nurses interview	A	No concern identified about seeking second opinion from, or referral to, any other unit. Liaison nurses interview comment that no reticence to refer has ever been witnessed	Real-time recording of referrals made to other units, and why, useful for learning and governance	L	L
How patients / parents are guided to informed consent	Example templates for out-patient letters seen eg for LV hypoplastic Left heart.		Unit letter template quotes “up to 50% mortality” for complex high risk HLH [redacted] The mortality Is up to 70% in the opinion of the review team, in the subgroup with small/restrictive atrial septal defect	Revise family information sheets to reflect current national/centre results	M	L
Waiting List Delay in appointments and access to surgery	Waiting List data for interventional cardiology and cardiac Surgery		Activity increase in 2012 compared to 2011. Numbers on in-patient waiting list remaining stable.	No change recommended		

Procedures	Description from Lead cardiologist and liaison nurse and surgeons 2 patients 4D records	B A	Highly specialised work eg transplant and hypoplast surgery are transferred to other units, Effective and timely referral appears to be undertaken In-line with accepted practice In cases of Hypoplastic LV parents generally recommended to consider Evelina or Birmingham Unit since the Dr Foster Database shows these Units undertake the most. Transplant – preference unit is Newcastle unless family request for GOSH	No change recommended		
Transfer of Patients	Transfer of patients policy Staff discussion		Paediatric intensive care unit retrieval is included in the Trust-wide transfer policy. This policy doesn't appear to include other paediatric transfer scenarios. PICU staff described use of a specific safe transfer tool but this does not appear to be included in the transfer policy.	Consider developing a separate Paediatric Transfer Policy.		

MDT processes and activities

Issue	**Evidence Seen / Reference Documents**		**Findings / Opinion**	**Recommendations**	**p**	**I**
Liaison between cardiologists and	"4D" Oscar database system demonstrated.	A	Satisfactory process	Continue current practice See also comments above re all		

Surgeons Decision making process to list for surgery			Evidence seen of how it records out-patient attendances and DNA's, in-patient admissions, links to clinical record notes, and lists those clinicians present at case conference . Decision making process and discussions at Case Conference meetings recorded in these notes. Evidence seen of process for adding patients to Surgical List, and that the urgency or listing is decided at that point.	cases being presented See also comments regarding pathologist attendance		
Nursing input to MDT	Discussion with staff	A	Nursing and medical staff reported that a senior nurse from the cardiology ward and a Liaison Nurse always attend the weekly MDT meeting and actively participate in decision-making.	No change recommended		
Psychosocial meetings and input	Discussion with staff	A	The Liaison Nurses work closely with the psychologist, counsellors, play specialist, social worker and physiotherapist to address the holistic needs of the child and family. A weekly multi-professional meeting takes place to discuss cases, identify needs and plan support. Ward nurses attend this meeting if the patient being discussed is an inpatient. Consultants do not attend but are invited. Counsellor and/or psychologist generally present in Fetal diagnosis clinic and would be involved in counselling re termination and survival options.	No change recommended		

Unit Facilities and Capacity

Issue	Evidence Seen / Reference Documents	Gr	Findings / Opinion	Recommendations	P	I
Surgical scheduling and allocating waiting lists and priorities	Discussion w surgeons SOP	A	No concerns. Multidisciplinary input. SOP in place	No change recommended		
Clinical Environment (TBA- new PICU/ward and theatre)	Direct Inspection		“State of the art” purpose-built PICU due for occupation in 1 week	To undertake move without delay	H	L
Cleanliness	Electronic ward dashboards		The ward and PICU appeared clean. A new PICU has just been completed, which will amalgamate the existing PICU and PHDU. The service is expecting to move into the new facility in the next few weeks.	No change recommended other than To move as planned		
Child and family friendly	Observation		The clinical areas have family rooms, play facilities and appropriate family-friendly décor.	No change recommended		

Appendix 6

Evidence Log

Ref	Title	Summary of document content	Weighting
Miscellaneous – Independent review process			
M1.1	Terms of reference of review	Terms of reference for the review group	
M1.2	Information sharing agreement		
M1.3	Signature and disclosure of conflict of interest		
M1.4	Agenda		
M1.5	Notes of meeting 6.4.13		
M1.6	Notes of meeting 7.4.13		
XX	Data Report to risk summit 4.4.13 seen by Review Team		
Incidents & Complaints			
IC 1.1.1	Complaints	10 complaints from 2011 to date	
IC 1.1.2	Data demonstrating all fetal cases and outcome (Aug 2012 – April 2014	Outlines TOP; IUD; live birth outcomes	
IC 1.1.3	Example standard letter HLH restrictive Interarterial communication	Standard fetal counselling letter template	
IC 1.1.4	Selection of patient information leaflets	Also include support groups and unit information folder	
IC 1.1.5	Incidents and Complaints	Document showing volume and nature of complaints and incidents 2011 - 2013 (Including Level 2 Investigation Report 16.09.12)	
IC 1.2	Examples of Children's Directorate Performance Review	July 2012 - March 2013	
IC 1.2.1	July 2012	Children's performance Improvement plan – timeliness of IR1 inputting; Children's performance improvement plan – Admissions, discharges and transfers transacted on PAS within 30 minutes	

IC 1.2.2	August 2012	Patient safety report; patient experience; effectiveness of care; Productivity and efficiency; Information Governance; workforce; finance; Other directorate issues	
IC 1.2.3	November 2012	Patient Safety; Patient experience; Productivity and Efficiency; Finance; other directorate issue	
IC 1.2.4	December 2012	Patient safety; patient experience; productivity & efficiency; Finance; other directorate issues	
IC 1.2.5	January 2013	Patient safety; patient experience; effectiveness of care; information governance; productivity and efficiency; workforce; finance; other directorate issues	
IC 1.2.6	April 2013	Handover agenda; Bank, agency & overtime reductions; indicators dashboard	
IC 1.3	Examples of Divisional Clinical Governance Oct-12		
IC 1.3.1	Agenda		
IC 1.3.2	Minutes of meeting		
IC 1.3.3	Completion of mandatory audits table		
IC 1.3.4	Level 2 investigation report		
IC 1.3.5	Case 1 HC investigation		
IC 1.3.6	SI report 2012 /21438		
IC 1.3.7	NICE non-compliance statement		
IC 1.3.8	NICE guidance implementation plan		
IC 1.3.9	Divisional clinical governance arrangements		
IC 1.3.10	Oxford delivery plan – summary of residual risks and delivery plan		
IC 1.3.11	Risk profile		
IC 1.3.12	NHSLA maternity clinical risk management standards 2012 – 13. Sept 2012		
IC 1.3.13	CEMACH 2007 – 2009 – perinatal mortality review	Local plan December 2012	
IC 1.3.14	Failsafe task list for Antenatal & Newborn Screening Programmes		
IC 1.4	Examples of Divisional Clinical Governance Jan-13		

IC 1.4.1	Agenda		
IC 1.4.2	Minutes of meeting 15.10.12		
IC 1.4.3	Exceptional Agenda		
IC 1.4.4	Learning points to avoid harm from misplaced Nasogastric tube that are inserted for the purpose of feeding		
IC 1.4.5	Action plan Ward 36 – December 2012		
IC 1.4.6	Maternal Obesity action plan		
IC 1.4.7	Oxford Delivery plan – summary of residual risks and delivery plan (updated August 2012)		
IC 1.4.8	Women's directorate clinical governance report Q2	Report date Oct 2012. includes complaint response times; incidents themes; investigations; mandatory audits; NICE guidance implementation	
IC 1.4.9	Leeds children's Hospital clinical governance report Q2	Report date Oct 2012. includes complaint response times; incidents themes; investigations; mandatory audits; NICE guidance implementation	
IC 1.4.10	SI report 2012 / 9344		
IC 1.5	Quality assurance guidance - Current Version		
IC 2.1	E-Bulletin Apr-13	Demonstrating 1 process used for communicating results of incidents and sharing learning with staff	
IC.3.1	HCAI		
IC 3.1.1	WCHND HCAI Action Plan 2012 - 2013		
IC 3.1.2	Infection Prevention and Control Policy No. 14	Expiry date Oct 2013	
IC 3.1.3	Managing the Risks associated with infection Prevention and control policy	**was noted to be due review 3.9.12**	
IC 4.1	Safeguarding Children's Policy	Current Version. Review date June 2013	
IC 4.2	Policy for the implementation of new interventional procedures Apr-12		
IC 4.3	Policy for the reporting and management of Serious incidents Oct-12	Review date October 2015	
IC 4.4	Policy for the reporting and management of incidents Nov 2011	Review date November 2013	
IC 4.5	Complaints and concerns policy Oct-11	Review date October 2013	

IC 4.6	Risk Management Policy – Oct 2011	Review date October 2013	
IC 4.7	Risk management group papers		
IC 4.7.1	Risk Management - Terms of Reference - Current Version		
IC 4.7.2	Trust Board paper Feb 2013		
IC 4.7.3	Corporate risk register Feb 2013		
IC 4.8	Being open policy Oct 2011- Oct 2013	Review due Oct 2013	
IC 5.1	Audit presentations	Examples of audits undertaken	
IC 5.1.1	Safe Airway bundle audit presentation		
IC 5.1.2	Annual report of the Paediatric Intensive Care Audit Network (PICANET) Jan 2009 – Dec 2011		
IC 6.1	Specialty Clinical Governance Forum - Terms of Reference	Terms of Reference	
IC 7.1	Waiting Lists and Access	Inpatient waiting list and run rates for paediatric cardiac surgery and paediatric interventional cardiology	
organisational			
O 1.1	Operational structure LTHT	Organogram	
O1.2	Divisional operational structure	Organogram	
O 1.3	Children's Heart Surgery Designation30th August 2012	Risk profile for Children's Heart Surgery Designation	
O 2.1	Yorkshire Heart Centre Congenital & Structural Intervention process Jan 2013	Process draft author J Bentham & J Thompson	
O 2.2	Duct dependent Heart disease guidelines		
O 2.3.1	Pre-operative proforma		
O 2.3.2	Clinical psychology / Counselling referral form		
O 3.1	Workforce	Medical and nursing workforce data	
O 3.2	Workforce	MDT Co-ordinator job description for Congenital Cardiac Services	
mortality			

MO 1.1	Clinical Governance steering group paper 8.10.12	Paper on Dr Foster's relative risk mortality – speciality level reporting – Sept 2012	
MO 1.2	Performance summary Feb 12 – Jan 13	Demonstrates mortality, LOS, readmission rates, peer group comparison data.	
MO 1.3	LOS 2009 - 2011	Including readmission rates	
MO 2.1	Standards for completing the certificate of the cause of death. Dec 2009.		
MO 2.2	Process for the reporting and investigation of mortality outlier alerts. January 2012		
MO 2.3	Cause of death proforma & Mortality case review proforma		
MO 3.1	Examples of coding audits	Interventional radiotherapy coding audits sept 2012 Thoracic surgery clinical coding audit aug 2012	
MO 4.1	Article heart journal March 2013.	Real time monitoring of risk-adjusted paediatric cardiac surgery outcomes using variable life-adjusted display (VLAD)	
MO 5.1	PAWS scoring chart (Example)		
MO 6.1	CCAD - Data Quality Audit 28th February 2013	Full report from CCAD procedures for congenital heart disease	
professional			
P 1.1	ORSA revalidation questionnaire Sept 2012		
P 2.1	Leave procedure Sept 2009	**LTHT to consider if review due**	
P 3.1	Staffing FTE rates 2.4.13		
P 4.1	NHS (appointment of consultants) regulations. Good practice guide Jan 2005		
P 5.1	National & International meeting 2011 - 2013 local courses attended (incomplete)	Also includes papers published	

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NICOR statement - Paediatric cardiac surgery

12 April 2013

NICOR (the National Institute for Cardiovascular Outcomes Research) analyses data submitted by NHS clinicians about heart disease patients' quality of care and outcomes. NICOR is committed to providing appropriately analysed, accurate outcome data in a timely manner which is understandable by the public, healthcare providers and the medical profession. We work closely with the specialist Clinical Societies.

At the request of NHS England, NICOR recently provided an independent analysis of paediatric cardiac surgical mortality in units within England and Wales for 2009-12. The analysis benefits from the use of new sophisticated case mix-adjustment methodology (PRAiS – Partial Risk Adjustment in Surgery).

The analyses reveal no statistically significant outliers in terms of mortality at any of the units in England and Wales, including at Leeds General Infirmary. Mortality is only one of the measures used to determine quality of care, but is currently the most robust available.

NICOR has policies in place relating to analysis, communications and release of data. We will investigate whether any breach of these policies has occurred and act promptly to ensure that NICOR protocols are followed by all staff.

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Investigation of mortality from Paediatric Cardiac Surgery in England 2009-12

8 April 2013

Dr David Cunningham
Senior Strategist, NICOR

Dr Rodney Franklin
Clinical lead for Congenital Heart Disease, NICOR

Mr Ben Bridgewater
Chairman, SCTS adult cardiac surgery database committee

Professor John Deanfield
Director, NICOR

with statistical advice and support from

Professor David Spiegelhalter,
Winton Professor of the Public Understanding of Risk
Statistical Laboratory, University of Cambridge

NICOR is the National Institute for Cardiovascular Outcomes Research. It is part of University College London and is based at 170 Tottenham Court Road, London W1T 7HA

All comments should be sent to Professor Deanfield by email: j.deanfield@ucl.ac.uk.

1. Introduction

NICOR's mission is to provide accurate data on cardiovascular outcomes for the public, healthcare providers and the medical profession. It hosts the National Congenital Heart Disease (CHD) registry which has been reporting adjusted outcomes for procedures for over a decade. The current analysis for outcomes for congenital heart surgery in England and Wales has been requested by NHS England to assist in their deliberations on CHD service provision.

2. Methods

a) This report covers 2009-10, 2010-11 and 2011-12 as well as a composite 3 year performance for 2009-12. Comparison has been made between the 10 centres in England who undertake paediatric CHD surgery.

Description	Reference name
Alder Hey	ACH
Birmingham	BCH
Bristol	BRC
Freeman	FRE
Leicester	GRL
Great Ormond Street	GOS
Evelina	GUY
Leeds	LGI
Brompton	NHB
Southampton	SGH

Table A

b) Outcomes are partially risk adjusted using a new model (Partial Risk Adjustment in Surgery; PRAiS) that estimates the risk of death within 30 days of a primary surgical procedure, based on specific procedure, age, weight and the patient recorded diagnoses and comorbidities (Crowe et al, JTVCS 2012 doi: 10.1016/J.JTCVS.2012.06.23). Outcomes over time are displayed using a bespoke version of the Variable Life Adjusted Display (VLAD) technique previously described. (Lovegrove et al 1997, The Lancet 350:1128-1130).

c) Data include the total number of cases and the number of deaths within 30 days. Units vary widely in the complexity and risk of operations conducted, and so it is inappropriate to make comparisons based on crude mortality rates. The PRAiS system uses historical data to provide a PRAiS Expected number of deaths that allows for variation in case-mix – this is an important innovation from NICOR that, for the first time, allows proper risk-adjustment in this complex area.

d) The ratio of Observed to PRAiS-Expected deaths is the Standardised Mortality Ratio (SMR), but this is based on historical levels of overall risk. In order to make comparisons within each year, the PRAiS-Expected numbers of deaths are re-calibrated by dividing by the overall SMR for all cases in England for that time period to create an Expected Mortality – this is still the PRAiS system, but adjusted for the period.

e) The Relative Risk (RR) is the Observed number of deaths divided by the Expected deaths, and provides a comparison with national average risks during each period. The Average Risk is the Expected deaths divided by the number of cases, and is intended to give a reflection of caseload complexity. Only cases with a life status at 30 days validated by ONS tracking have been included.

f) Results are shown using 'funnel plots', which relate the relative risk to the total expected number of deaths. Units inside the funnel have a relative risk that is not 'significantly' different from average - a raised relative risk could be due to chance alone. Units outside the 'funnel' merit attention. The funnel shape arises because Units to the left of the plot are smaller and so we would expect more variability due to chance.

3. Data Extraction

a) There was a clear process for data submission to NICOR by individual Trusts with a CQC mandated deadline of 1 June 2012 for 2011/12 data. Following this deadline, a period of two months was allowed for units to ensure their data quality was optimised.

b) A patient-anonymised data extract was taken in August 2012 and used to generate the analyses for 2011-12. Previous years followed a similar pattern.

c) It was clear to the NICOR Steering Group that there were major deficiencies in the data submitted by Leeds (as exemplified by Table B). This has been addressed as actively as possible in the intervening period, as part of NICOR's process to optimize data quality.

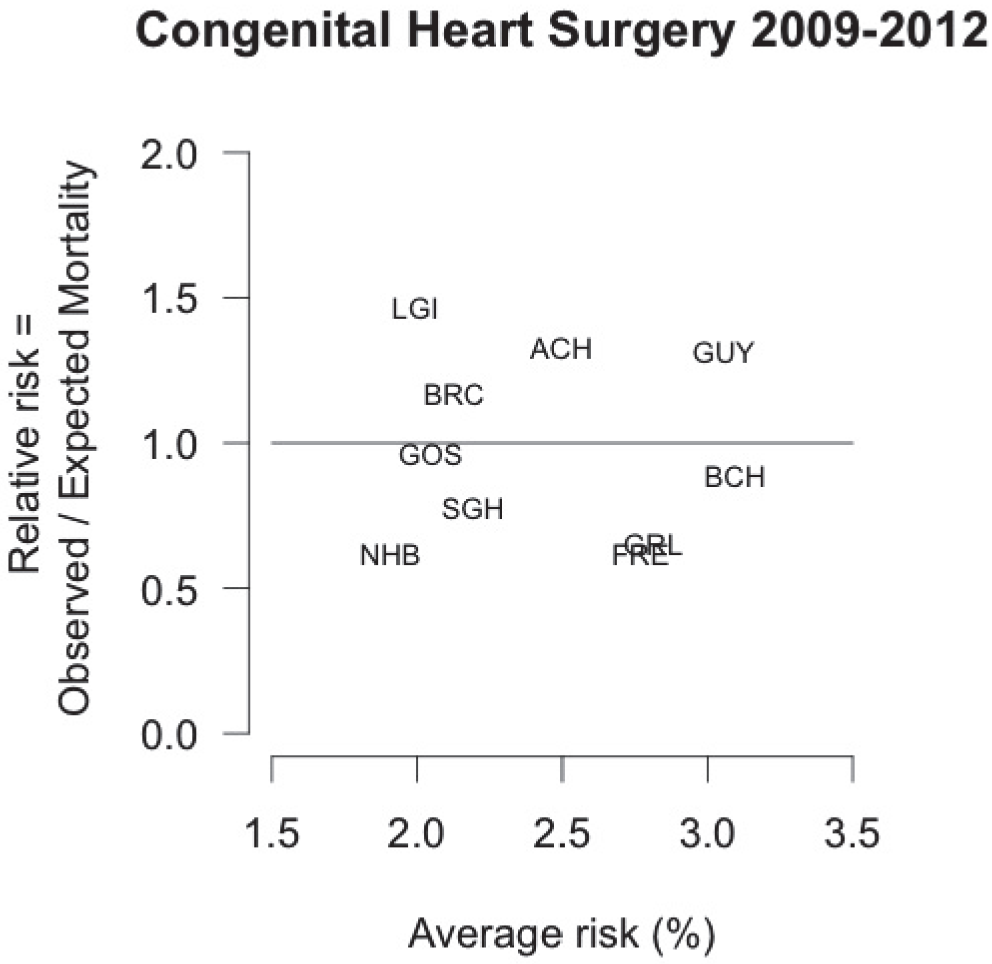
d) The new data included in the current analysis of 07/04/13 is the reason for the difference in the outcomes for individual Trusts from the preliminary data. The effectiveness of the data submission process could be considered as a measure of organizational culture and commitment to quality service delivery.

Unit	Missing weight in 2011-12 data
BRC	0%
GOS	0%
GUY	0%
NHB	0%
RAD	0%
SGH	0%
ACH	0.3%
GRL	0.5%
BCH	1.2%
FRE	1.4%
LGI	34.7%

Table B: data as submitted August 2012

4. Results

a) The figure below shows the Relative Risk plotted against the Average Risk (measuring the complexity of cases seen by each Unit). There is no evidence that the complexity of cases is related to the Relative Risk, suggesting the PRAiS risk-adjustment system is compensating for Units taking on more difficult cases.



b) Outcomes For 2009-10

England 2009-10

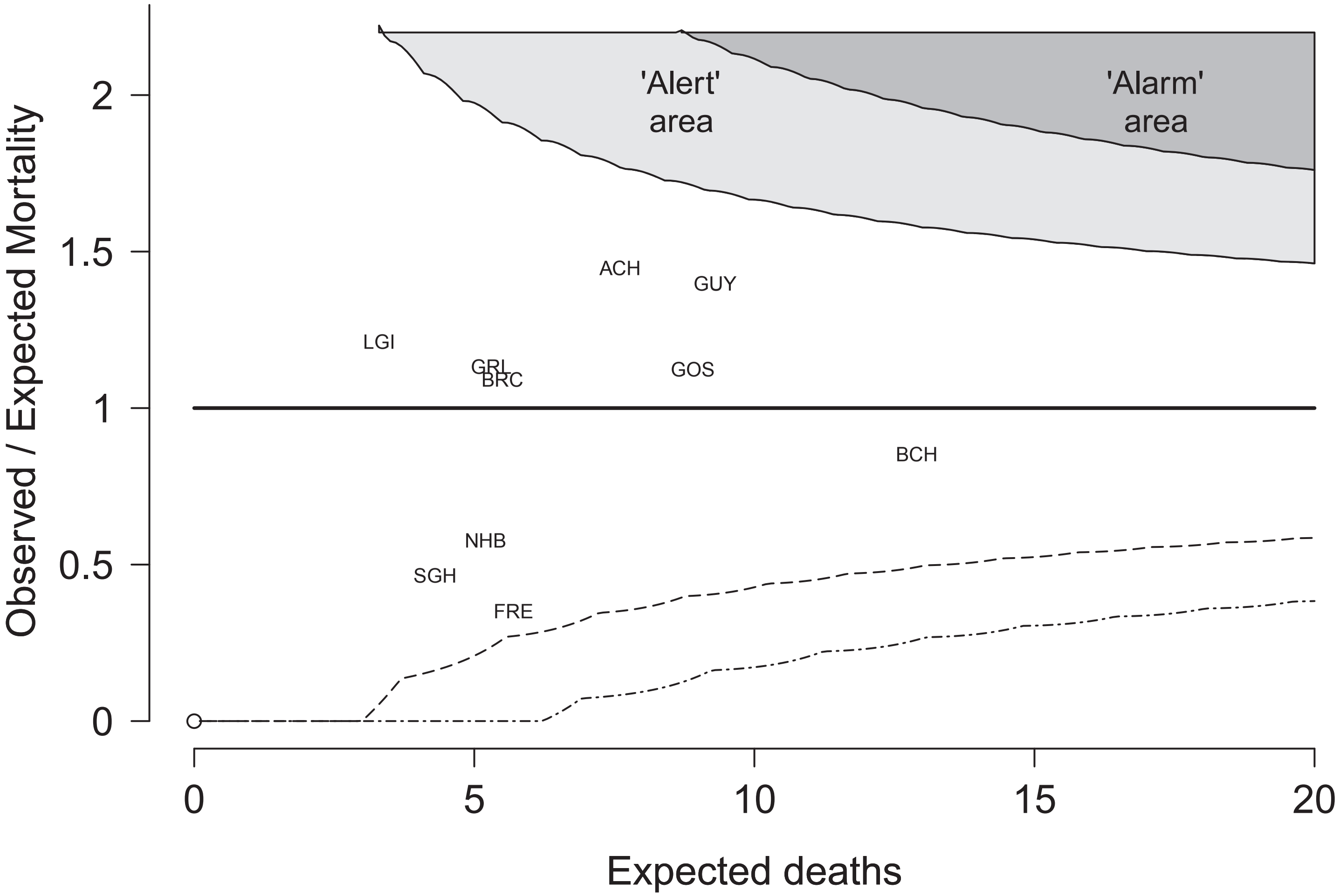
Cases	3178
Expected deaths	93.6
Observed deaths	68
SMR	72.6%

Unit	Cases	Observed Deaths	Crude Mortality Rate	PRAiS Expected Deaths	PRAiS-generated SMR	Expected (recalibrated) Deaths	Average Risk	Relative Risk	Poisson mid p-value
ACH	384	11	2.9%	10.4	105.8%	7.6	2.7%	1.46	0.112
BCH	504	11	2.2%	17.8	61.9%	12.9	3.5%	0.85	0.690
BRC	270	6	2.2%	7.6	78.6%	5.5	2.8%	1.08	0.399
FRE	224	2	0.9%	7.8	25.5%	5.7	3.5%	0.35	0.949
GRL	218	6	2.8%	7.3	82.5%	5.3	3.3%	1.14	0.360
GOS	483	10	2.1%	12.3	81.3%	8.9	2.5%	1.12	0.345
GUY	329	13	4.0%	12.8	101.3%	9.3	3.9%	1.40	0.118
LGI	221	4	1.8%	4.6	87.3%	3.3	2.1%	1.20	0.334
NHB	332	3	0.9%	7.1	42.0%	5.2	2.1%	0.58	0.822
SGH	213	2	0.9%	5.9	34.0%	4.3	2.8%	0.47	0.864

The **Poisson mid-p** value indicates the probability of observing such an extreme relative risk if the Unit was actually ‘average’ – values less than 0.025 have traditionally indicated an ‘alert’ and values less than 0.001 an ‘alarm’.

All data is risk adjusted using the PRAiS model.

Congenital Heart Surgery 2009−2010



An average Unit has a 1 in 40 chance of being in the 'Alert' area, and 1 in 1000 chance of 'Alarm' area

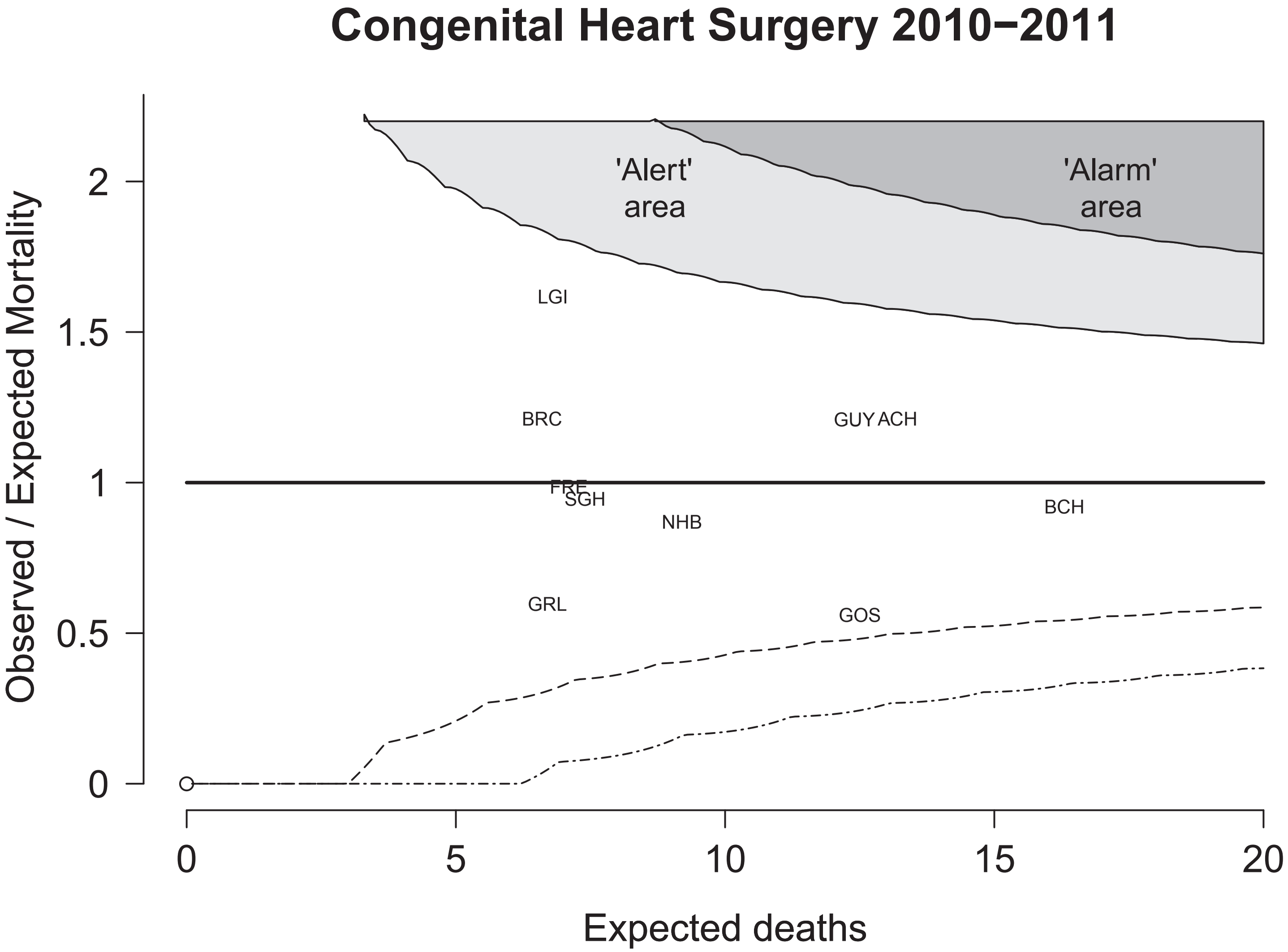
c) Outcomes for 2010-11

England 2010-11

Cases	3417
Expected deaths	100.7
Observed deaths	98
SMR	97.4%

Unit	Cases	Observed Deaths	Crude Mortality Rate	PRAiS Expected Deaths	PRAiS-generated SMR	Expected (recalibrated) Deaths	Average Risk	Relative Risk	Poisson mid p-value
ACH	420	16	3.8%	13.5	118.2%	13.2	3.2%	1.21	0.216
BCH	408	15	3.7%	16.7	90.0%	16.3	4.1%	0.92	0.608
BRC	304	8	2.6%	6.8	118.0%	6.6	2.2%	1.21	0.282
FRE	242	7	2.9%	7.3	96.2%	7.1	3.0%	0.99	0.489
GRL	205	4	2.0%	6.8	58.5%	6.7	3.3%	0.60	0.846
GOS	517	7	1.4%	12.8	54.5%	12.5	2.5%	0.56	0.948
GUY	356	15	4.2%	12.7	117.8%	12.4	3.6%	1.21	0.226
LGI	312	11	3.5%	6.9	158.4%	6.8	2.2%	1.63	0.063
NHB	357	8	2.2%	9.4	84.9%	9.2	2.6%	0.87	0.632
SGH	296	7	2.4%	7.6	92.0%	7.4	2.6%	0.94	0.536

The **Poisson mid-p** value indicates the probability of observing such an extreme relative risk if the Unit was actually 'average' – values less than 0.025 have traditionally indicated an 'alert' and values less than 0.001 an 'alarm'.
All data is risk adjusted using the PRAiS model.



An average Unit has a 1 in 40 chance of being in the 'Alert' area, and 1 in 1000 chance of 'Alarm' area

d) Outcomes for 2011-12

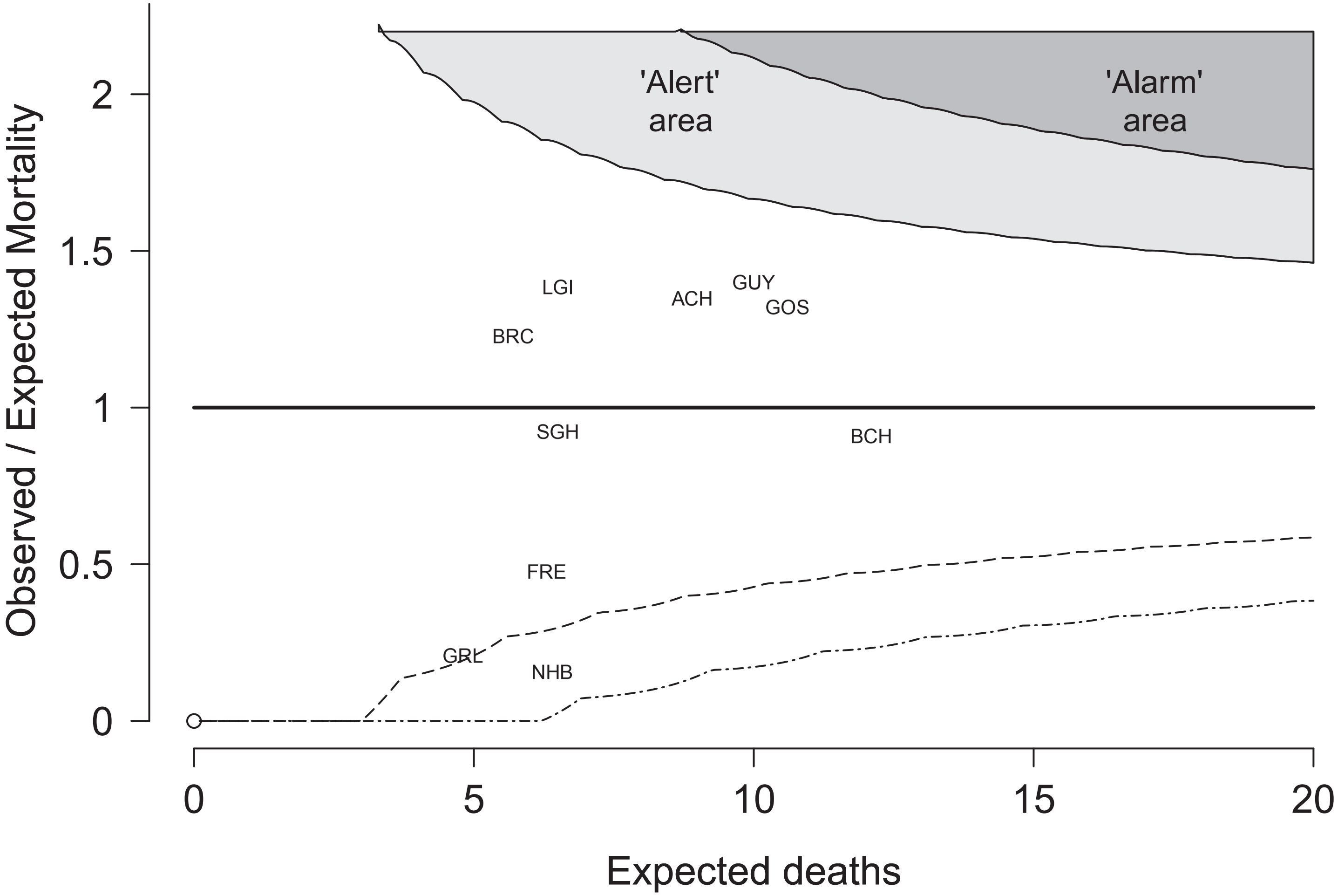
England 2011-12

Cases	3359
Expected deaths	98.8
Observed deaths	78
SMR	78.9%

Unit	Cases	Observed Deaths	Crude Mortality Rate	PRAiS Expected Deaths	PRAiS-generated SMR	Expected (recalibrated) Deaths	Average Risk	Relative Risk	Poisson mid p-value
ACH	375	12	3.2%	11.3	106.2%	8.9	3.0%	1.35	0.153
BCH	432	11	2.5%	15.4	71.4%	12.1	3.6%	0.91	0.611
BRC	273	7	2.6%	7.2	97.7%	5.7	2.6%	1.24	0.278
FRE	231	3	1.3%	8	37.7%	6.3	3.5%	0.48	0.912
GRL	179	1	0.6%	6.1	16.3%	4.8	3.4%	0.21	0.972
GOS	574	14	2.4%	13.5	103.4%	10.6	2.4%	1.31	0.154
GUY	359	14	3.9%	12.7	110.2%	10.0	3.5%	1.40	0.111
LGI	299	9	3.0%	8.2	109.8%	6.5	2.7%	1.39	0.162
NHB	322	1	0.3%	8.1	12.4%	6.4	2.5%	0.16	0.993
SGH	315	6	1.9%	8.3	72.7%	6.5	2.6%	0.92	0.559

The **Poisson mid-p** value indicates the probability of observing such an extreme relative risk if the Unit was actually 'average' – values less than 0.025 have traditionally indicated an 'alert' and values less than 0.001 an 'alarm'.
All data is risk adjusted using the PRAiS model.

Congenital Heart Surgery 2011−2012



An average Unit has a 1 in 40 chance of being in the 'Alert' area, and 1 in 1000 chance of 'Alarm' area

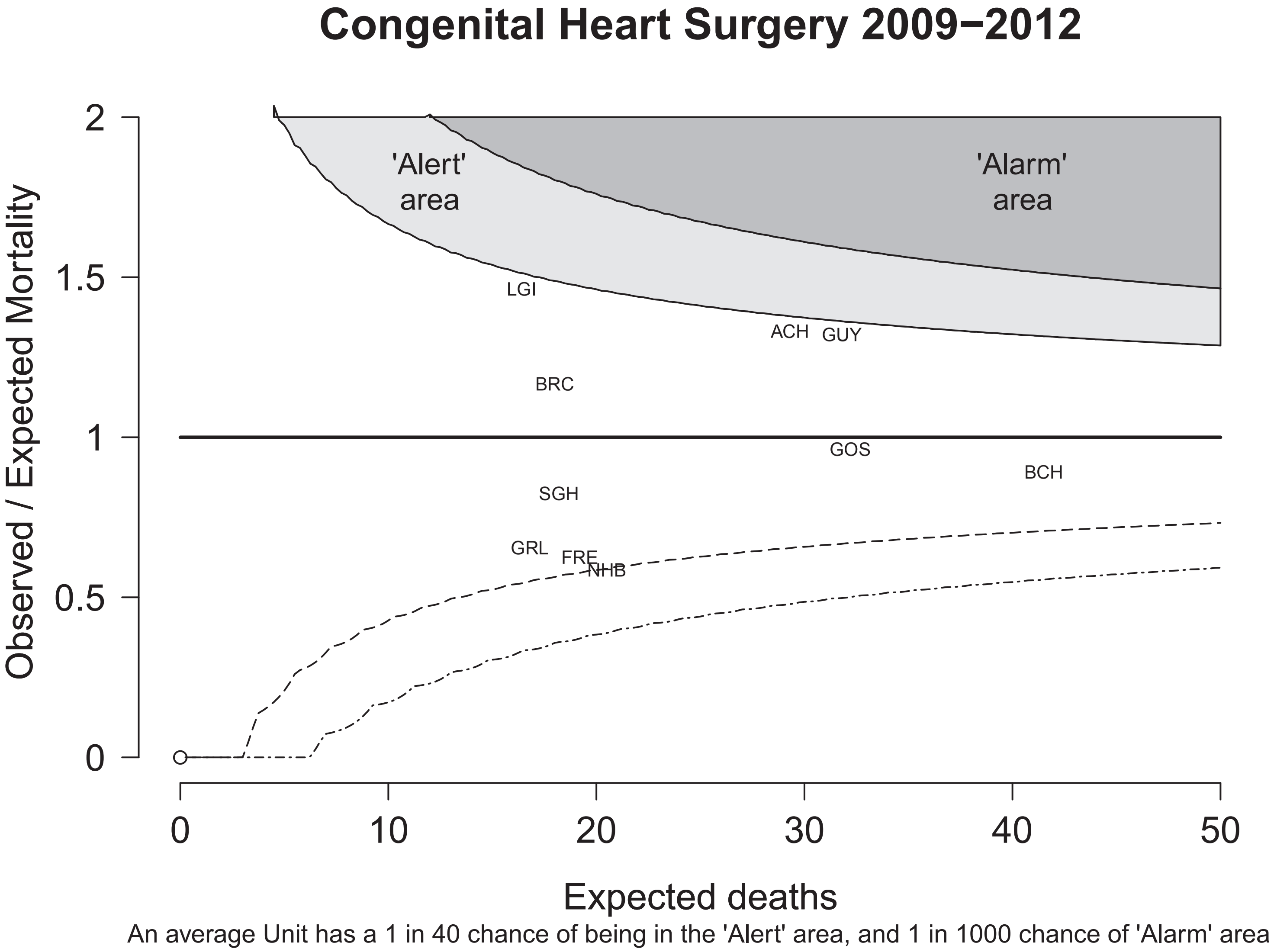
e) Outcomes 2009-12

England 2009-12

Cases	9954
Expected deaths	293.1
Observed deaths	244
SMR	83.3%

Unit	Cases	Observed Deaths	Crude Mortality Rate	PRAiS Expected Deaths	PRAiS-generated SMR	Expected (recalibrated) Deaths	Average Risk	Relative Risk	Poisson mid p-value
ACH	1179	39	3.3%	35.24	110.8%	29.3	3.0%	1.33	0.043
BCH	1344	37	2.8%	49.9	74.1%	41.5	3.7%	0.89	0.755
BRC	847	21	2.5%	21.61	97.7%	18.0	2.6%	1.17	0.234
FRE	697	12	1.7%	23.08	51.9%	19.2	3.3%	0.62	0.957
GRL	602	11	1.8%	20.24	54.5%	16.8	3.4%	0.65	0.929
GOS	1574	31	2.0%	38.64	80.3%	32.2	2.5%	0.96	0.570
GUY	1044	42	4.0%	38.23	109.9%	31.8	3.7%	1.32	0.041
LGI	832	24	2.9%	19.72	122.4%	16.4	2.4%	1.47	0.038
NHB	1011	12	1.2%	24.62	51.9%	20.5	2.4%	0.62	0.976
SGH	824	15	1.8%	21.81	64.8%	18.2	2.6%	0.78	0.764

The **Poisson mid-p** value indicates the probability of observing such an extreme relative risk if the Unit was actually ‘average’ – values less than 0.025 have traditionally indicated an ‘alert’ and values less than 0.001 an ‘alarm’.
All data is risk adjusted using the PRAiS model.


Congenital Heart Surgery 2009−2012
Observed / Expected Mortality
2
1.5
1
0.5
0
'Alert'
area
'Alarm'
area
LGI
ACH
GUY
BRC
GOS
BCH
SGH
GRL
FRE
NHB
0
10
20
30
40
50
Expected deaths
An average Unit has a 1 in 40 chance of being in the 'Alert' area, and 1 in 1000 chance of 'Alarm' area

5. Conclusions

- Using data available on 05/04/13, no centre crosses the standard criterion for an 'alert', neither in individual years nor for the pooled 3 year period.

- By definition, around half of all Units will have more deaths than 'expected'. It is therefore inappropriate to label centres as 'blameworthy' for these deaths, as the analysis does not show a significantly increased mortality rate.

- In 2011-12, LGI experienced nine 30-day deaths compared to 6.5 expected (recalibrated). This is compatible with chance variation.

- Over the pooled 3-year period 2009-2012, LGI experienced 24 deaths compared to 16.5 expected (recalibrated), a relative risk of 1.46. With this pooled data, they were very close to the 'alert' threshold, as were 2 other centres.

- These findings do not indicate a 'safety' problem in any centre.

- However, centres with 3-year outcomes approaching the alert threshold may deserve additional scrutiny and monitoring of current performance.

6. Comments

- Data submission by individual Trusts to NICOR has been very variable. Leeds have underperformed consistently in this regard. The data submission could be considered as a measure of the organisation and commitment to Quality Service delivery and excellence by Trusts. Additional data from all centres is being submitted, with a ‘window’ until 19 April 2013 to allow full PRAiS methodology to be used. We do not, however, expect this to change materially the output of the current analysis of 7 April 2013.

- PRAiS software represents an incremental advance in risk adjustment for CHD surgery. It has undergone prospective validation, but will be further refined and tested with use. It has been made available to all 10 Trusts and will be installed within the next month to facilitate local QC/QA.

- The data in this analysis provides a good guide to centre performance with respect to operative mortality. The data should, however, not be considered in isolation when judging unit overall performance.

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: 13 September 2013

Subject: Future of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

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

Purpose

1. The purpose of this report is to consider the future role of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), as currently constituted.

Background

2. In March 2011, a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) was established to consider the emerging proposals from the Safe and Sustainable Review of Children's Congenital Cardiac Services in England and the options for public consultation agreed by the Joint Committee of Primary Care Trusts (JCPCT).

3. At that time, the terms of reference identified that purpose of the Joint HOSC's work was to make an assessment of, and where appropriate, make recommendations on the potential options to reconfigure the delivery of Children's Congenital Heart Services in England. It was highlighted that this would specifically include consideration of the:
   - Review process and formulation of options presented for consultation;
   - Projected improvements in patient outcomes and experience;
   - Likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times;
   - Views of local service users and/or their representatives;
   - Potential implications and impact on the health economy and the economy in general, on a local and regional basis;
   - Any other pertinent matters that arise as part of the Committee's inquiry.

4. Consideration was also given to the adequacy of the arrangements for consulting on the proposals, which was the subject of an unsuccessful referral to the Secretary of State for Health in October 2011.

5. Following the JCPCT's decision on the proposed future model of care and designation of surgical centres on 4 July 2012, it became increasingly apparent that there would be significant issues associated implementation that the Joint HOSC wished to consider on an on-going basis. Revised terms of reference to reflect this position were agreed on 24 July 2012.

6. In November 2012, the Joint HOSC referred the JCPCT's decision to the Secretary of State for Health. This was subsequently passed to the Independent Reconfiguration Panel (IRP) for consideration and advice (as reported elsewhere on the agenda).

7. Prior to the outcome of the IRP's review and the decision of the Secretary of State for Health being announced, the Joint HOSC considered an update on implementation at its previous meeting in April 2013.

Main issues and considerations

8. On 12 June 2013, an announcement from the Secretary of State for Health called a halt to the previous Safe and Sustainable review of Children's Congenital Cardiac Services in England. The IRP's full report and appendices, alongside a covering letter form the Secretary of State for Health in this regard are presented elsewhere on the agenda.

9. In addition, details associated with the new review of congenital heart services in England are also presented elsewhere on the agenda. However, there are currently no proposals in terms of changes to services to consider and/or pass comment on.

10. As such, in the absence of any standing Joint HOSC arrangements in Yorkshire and the Humber, the Joint HOSC was established with a very clear and defined remit – i.e. considering and responding to proposals arising from the Safe and Sustainable review of Children's Congenital Cardiac Services in England. However, as the review and its proposals were halted by the Secretary of State for Health in June 2013 there is no legitimate scope of work for the Joint HOSC to continue in its current form.

11. With proposals for a new review in development, a new JHOSC (potentially involving the same membership) may become necessary and established sometime in the future. However, this would require further consideration (and agreement) by each of the constituent authorities and revised terms of reference.

12. Experience from establishing the current Joint HOSC would suggest that forming such arrangements can be a complex process, therefore work in this regard would need to be carefully considered and planned. It would also need to reflect and take into account the proposals for taking forward the new review (considered elsewhere on the agenda).

13. It is worth considering that there may be outstanding actions arising from other aspects of the meeting agenda – and these should be specifically highlighted and recorded. Nonetheless, it is recommended that consideration be given to dissolving the Joint HOSC in its current form.

Recommendations

14. That the Joint HOSC:
    a. Notes and comments on the content of this report;
    b. Identifies any specific outstanding actions, including those arising from this meeting;
    c. Resolves to formally dissolve the Joint HOSC in its current form; and,
    d. Asks that the regional network of health scrutiny officers works to establish any further Joint HOSC arrangements that may be necessary to reflect the new review of congenital heart services in England, including consideration (and agreement) by each of the constituent authorities.

Background documents[1]

15. None used

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[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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