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
Independent Reconfiguration Panel

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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 HOSC

27 July, 7 September and 27 November 2012

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

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

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

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

Leicester, Leicestershire and Rutland Joint Health and Overview Scrutiny Committee.
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 regulations1 (specifically regulation 4(7)) and current Department of Health guidance2.

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.

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 a 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. 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 attention:

\[\text{Based on the referrals received from Lincolnshire County Council and the Leicester, Leicestershire and Rutland Joint Heath Overview and Scrutiny Committee.}\]
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
Safe and Sustainable Steering Group – membership, 2010


NSCT’s statement on children’s respiratory ECMO

Statement: ECMO and children’s congenital heart services, 10 July 2012

Safe and Sustainable general IRP template for providing initial assessment information

Links and attachments:


Children’s Heart Surgery Centres in England: Comments on Draft Service Specification Standards (Comments received up to 17 February 2010), February 2010

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

Children’s Heart Surgery in England – A Need for Change, April 2011

Papers from the JCPCT meeting in public (launch of the consultation), 16 February 2011

Pre-consultation Business Case, February 2011

Consultation document, February 2011

Better care for your heart – a summary (consultation document for young people), March-July 2011

Consultation document and questionnaire in Welsh, March-July 2011

Consultation document and questionnaire in minority languages

Consultation document – improving children’s congenital heart services in London, March-July 2011

National Clinical Advisory Team (NCAT) report, September 2010

OGC Gateway Report, September 2010

NHS London’s approval to launch consultation, 8 February 2011

NHS London’s assurance report, 8 February 2011

Health Impact Assessment – Key Emerging Findings, 21 June 2011

Health Impact Assessment – draft final report (interim report), 5 August 2011


Report from Sir Ian Kennedy’s independent expert panel to the JCPCT, 17 October 2011

Testing assumptions for future patient flows and manageable clinical networks for Safe and Sustainable (PWC), October 2011

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

Judgement – High Court, 7 November 2011

Report of Sir Ian Kennedy’s Panel in response to the additional evidence submitted in relation to “innovation and research”, 14 February 2012

Judgement – Court of Appeal, 19 April 2012

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
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

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

POCI_724645 and 731024

Lord Bernard Ribeiro
Chair
Independent Reconfiguration Panel
6TH Floor
157-197 Buckingham Palace Road
London
SW1 W 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

POC1_742638

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

10 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.

Jeremy Hunt
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.
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.

Jeremy Hunt
Appendix Five

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

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
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

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


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

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

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

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

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

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


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 Lavsen, 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
Evidence gathering session

9 January 2013

IRP
Lord Ribeiro, 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

Evidence gathering session

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

Evidence gathering session

24 January 2013

IRP

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 Gatzioulis, 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 Respiriology
Dr Margarita Burmester, Consultant Paediatric Intensivist and Director, PICU
Dr Simon Jordan, Consultant Thoracic Surgeon
Dr Andrea Kelleher, Consultant Paediatric Anaesthesitst
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

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

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
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 Shafeeq 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 Poonamalee 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

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    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 |
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| | Safe and Sustainable website link: http://www.specialisedservices.nhs.uk/safe_sustainable/childrens-congenital-cardiac-services  
| | Review of Children's Congenital Cardiac Services in England, Decision Making Business Case, July 2012  
| | Information Template for IRP: Safe and Sustainable – general  
| | 2. The Relation Between Volume and Outcome in paediatric Cardiac Surgery. A Literature Review for the National Specialised Commissioning Group, September 2009  
| | 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  
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| | 21. Report from Sir Ian Kennedy’s independent expert panel to the JCPCT, 17 October 2011  
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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
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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
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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-corpooreal 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

Documents provided by PWC on behalf of Safe and Sustainable Team:
a. Findings re: Testing assumptions for future patient flows and manageable clinical networks
b. Questionnaire for parents/guardians
c. Questionnaire for paediatric cardiac referring hospitals
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<td>g. Witness statement of Sir Neil McKay, Chief executive, Midlands and East Strategic Health Authority, 19 December 2012</td>
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h. Development for the Children's Heart Unit

Documents provided by the Royal Brompton & Harefield NHS Foundation Trust:

a. Submission to IRP, 17 January 2013

Appendices

b. A proposal for a London, South and East England Children's Cardiac Network

c. The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995 - Learning from Bristol

d. Report of the paediatric and congenital cardiac services review group, December 2003

e. Safe and Sustainable: Review of children's congenital cardiac services in England - Pre-consultation business case, 16 February 2011

f. Loss to specialist follow-up in congenital heart disease; out of sight, out of mind. Wray et al, heart.bmj.com, 11 January 2013

g. A commentary on the population and activity growth assumptions relied upon in the Safe and Sustainable Decisions Making Business Case

h. Optimal structure of a congenital heart surgery department in Europe. Daenen et al, 23 October 2002

i. Safe and Sustainable: Review of children's congenital cardiac services: July 2012 Decision Making Business case


l. Letter from Prof. Pascal R Vouhe, Universite Paris V Rene Descartes


o. London Specialised Commissioning Group: Update on national designation of paediatric congenital cardiac surgery centres with particular reference to London, 9 April 2010

p. A proposal to establish a national and international service for children with heart and lung disease, RB&H Trust/GOSH Trust, 3 April 2009

q. Witness statement of Dr Duncan Macrae, Royal Brompton Hospital to High Court of Justice, 2011

r. Witness statement of Prof. Timothy Evans, Royal Brompton Hospital to High Court of Justice, 2011

s. Accessory pathway ablation in a 6-year-old girl using remote magnetic navigation as an alternative to cryoablation. Mantziari et al, Images of Pediatric Cardiology, 21 October 2012

t. Remote-controlled magnetic navigation and ablation with 3D image integration as an alternative approach in patients with intra-atrial baffle anatomy. Ernst et al, Circ A and E, 24 October 2011


v. What I think is important, Gil Wernovsky MD, The Cardiac Centre, The Children's Hospital of Philadelphia

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### 57 Document provided by University Hospital Southampton NHS Foundation Trust:
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- d. Surgical reintervention analysis

### 58 Documents provided by Great Ormond Street Hospital for Children NHS Foundation Trust:
- a. Presentation to IRP by Trust - Children's Heart Surgery the Need for Change
- b. GOSH children's heart services activity levels
- c. Quality of care analysis, dr foster on behalf of Great Ormond Street Hospital for Children NHS Trust, November 2010
- d. Cardiorespiratory Unit Annual Report 2011/12, September 2012

### 59 Document provided by Oxford University Hospitals NHS Trust:
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### 60 a. Review of paediatric cardiac surgery services at Oxford Radcliffe Hospitals NHS Trust
b. Spiellehelter analysis

### 61 Documents provided by Prof. B Jarman, Faculty of Medicine, Imperial College, London
- a. Information provided by email
- b. Submission to IRP
- c. Summary of reasons for Imperial College request to analyse CCAD data

### 62 Documents provided by Young Hearts:
- a. Submission to IRP from the Rt Hon Andrew Smith MP and the Young Hearts, 6 December 2012
- b. Letter to Secretary of State for Health, 26 November 2012 (includes paper requesting that JCPCT decision be referred to IRP with alternative proposals for Oxford)
- c. Letter to IRP, 10 January 2013
- d. Response to Safe and Sustainable consultation
- e. Briefing paper for IRP meeting, 11 February 2013
- f. Oxford University Hospitals NHS Trust profile
- g. Association of Cardiothoracic Anaesthetists paper
- h. SCSCG briefing note for Oxfordshire HOSC, January 2013
- i. Letter to IRP, 7 March 2013

### 63 i. Letter to IRP from Little Hearts Matter, Children's Heart Federation, The Somerville Foundation, Heartline Association
ii. Documentation provided by The Children's Heart Surgery Fund:
- a. Submission to IRP, 4 December 2012
- b. List of public meetings 2011 and petition form
- c. BraveHearts, issue 3, spring 2013
- d. Letter to IRP, 12 April 2013
- iii. Letter to IRP from The Somerville Foundation, 13 January 2013

### 64 Documentation provided by the Heartline Association:
Submission to IRP, 29 January 2013

### 65 Documentation provided by Little Hearts Matter:
- a. Submission to IRP, 5 December 2012 Enclosures:
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  ii. Letter to JCPCT 25 September 2012
  iii. Briefing on consultation questionnaire 21 June 2011
  iv. Briefing on MORI consultation report 24 August 2011
  v. Email correspondence re Safe and Sustainable Guide, 3 March 2011
- b. Paper: Future shape of cardiology services, 7 February 2013

### 66 Documentation provided by the Cystic Fibrosis Trust:
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<td>d. Changing lesion demographics of the adult with congenital heart disease: an emerging population with complex needs, Alan Stuart, Future Cardiology, 2012</td>
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Submissions to IRP from Members of Parliament:

a. Yvette Cooper, MP for Normanton, Pontefract and Castleford, 26 October 2012
b. Liz Kendall, MP for Leicester West and Nicky Morgan, MP for Loughborough, 30 October 2012 and 4 December 2012 and 15 April 2013 on behalf of East Midland MPs and other representatives
c. Mike Wood, MP for Batley and Spen, 31 October 2012
d. Keith Vaz, MP for Leicester East, 26 November 2012
e. spare
f. The Rt Andrew Andrew Smith, MP for Oxford East, 6 December 2012 (see OTH15)
g. Julian Smith, MP for Skipton & Ripon, 12 December 2012
h. Lorely Burt, MP for Solihull, 13 December 2012
i. The Rt Hon Stephen Dorrell, MP for Charnwood, 18 December 2012
j. Jeremy Lefroy, MP for Stafford, 20 December 2012
k. Kevan Jones, MP for North Durham, 20 December 2012
l. Julian Sturdy, MP for York, 10 January 2012
m. The Rt Hon Hilary Benn, MP for Leeds Central, 28 January 2013
n. Fabian Hamilton, MP for Leeds North East, 29 January 2013
o. Rachel Reeves, MP for Leeds West, 31 January 2013
p. Stuart Andrew, MP for Pudsey, 6 February 2013 and 5 April 2013 and 26 March 2013 on behalf of Yorkshire MPs and other representatives
q. Greg Hands, MP for Chelsea & Fulham, 6 February 2013
r. Austin Mitchell, MP for Great Grimsby, 15 February 2013
s. Greg Mulholland, MP for Leeds North West, 20 February 2013
t. Michael Dugher, MP for Barnsley East, 12 March 2013
u. Meg Munn, MP for Sheffield Heeley, 14 and March 2013

Submissions to IRP from local authorities:

a. Oxfordshire County Council, 31 October 2012
b. Durham County Council Adults, Wellbeing and Health Overview and Scrutiny Committee, 28 November 2012
c. Rotherham Metropolitan Council, 7 December 2012
d. Devon County Council
e. Kensington & Chelsea Health, Environmental Health and adult Social care Scrutiny Committee, 4 December 2012
f. Northumberland County Council, 7 December 2012
g. North East Joint Health Scrutiny Committee, 10 December 2012
h. Hartlepool Borough Council Health Scrutiny Forum, 13 December 2012
i. Calderdale Adults Health and Social Care Scrutiny Panel (To Secretary of State for Health, 3 January 2013
j. Kirklees Council representative on Yorkshire and Humber Joint Health Scrutiny Committee, 8 January 2012
k. Calderdale Council Health and Wellbeing Board and Adults Health and Social Care Scrutiny Panel, 24 January 2013
l. West Midlands Regional Chairs and Officers' Forum
m. Leeds City Council, 15 February 2013
n. North Yorkshire County Council Scrutiny of Health Committee, 26 March 2013

Note of conversation between Prof K Palmer, Karolinska Institute, Sweden and Dr N Coleman, IRP, 14 February 2013

Statement by Mrs B Pearson

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
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<td>Letter to IRP from specialist in care of children in Yorkshire and the Humber, 11 December 2012</td>
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<td>a. Letter to Secretary of State for Health from Irwin Mitchell LLP, 14 December 2012</td>
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Members of the public who contacted the IRP (emails, letters and phone calls)

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Appendix Eight

Panel membership

Chair:
Bernard Ribeiro
Former consultant surgeon, Basildon Hospital
Past president of the Royal College of Surgeons

Membership:
Cath Broderick
Independent consultant on involvement and engagement
(lay member)

Fiona Campbell
Independent consultant specialising in health and social policy
(lay member)

Sanjay Chadha
Committee Member, Multiple Sclerosis (MS) Society
(lay member)

Nick Coleman
Consultant in Intensive Care Medicine and Associate Medical Director, University Hospitals of North Staffordshire
(clinical member)

Glenn Douglas
Chief Executive
Maidstone and Tunbridge Wells NHS Trust
(managerial member)

Jane Hawdon
Consultant Neonatologist and Clinical Academic Group Director Children’s Health, Barts Health NHS Trust
(clinical member)

Nicky Hayes
Consultant Nurse for Older People
King’s College Hospital NHS Trust
(clinical member)

Brenda Howard
Interim Director, Derby Royal Hospital
Project advisor to West Leicestershire CCG
(managerial member)

Nick Naftalin
Emeritus Consultant Obstetrician and Gynaecologist
Leicester Royal Infirmary
(clinical member)

John Parkes
Greater East Midlands Commissioning Support Organisation
Chief Executive
(managerial member)

Linda Pepper
Independent consultant on involvement and engagement
(lay member)

Ray Powles
Head of Haematology, Cancer Centre London
Former Head of Haematology, the Royal Marsden Hospital
(clinical member)

Hugh Ross
Independent consultant
Former NHS chief executive
(managerial member)

Gina Tiller
Chair
NHS North of Tyne
(lay member)
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