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Leeds CITY COUNCIL

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

Meeting to be held in Civic Hall, Leeds on Monday, 19th December, 2011 at 9.30 am

MEMBERSHIP

Councillors

S Ali	-	Rotherham MBC
J Bromby	-	North Lincolnshire CC
D Brown	-	Hull City Council
J Clark	-	North Yorkshire CC
M Gibbons	-	Bradford MDC
R Goldthorpe	-	Calderdale MDC
B Hall	-	East Riding of Yorkshire CC
L Mulherin (Chair)	-	Leeds City Council
T Revill	-	Doncaster MBC
B Rhodes	-	Wakefield MDC
I Saunders	-	Sheffield City Council
L Smaje	-	Kirklees MDC
K Wilson	-	NE Lincolnshire CC
Vacancy	-	York City Council
J Worton	-	Barnsley MBC

Please note: Certain or all items on this agenda may be recorded.

Agenda compiled by:
Andrew Booth
Governance Services
Civic Hall
LEEDS LS1 1UR
Tel: 24 74325

Principal Scrutiny Advisor:
Steven Courtney
Tel: 24 74707

A G E N D A

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

3			**LATE ITEMS** To identify items which have been admitted to the agenda by the Chair for consideration. (The special circumstances shall be specified in the minutes.)	
4			**DECLARATIONS OF INTEREST** To declare any personal/prejudicial interests for the purpose of Section 81 (3) of the Local Government Act 2000	
5			**APOLOGIES FOR ABSENCE AND NOTIFICATION OF SUBSTITUTES** To receive any apologies for absence and notification of substitutes.	
6			**MINUTES OF PREVIOUS MEETINGS** To receive the minutes of the meetings held on 22 September, 29 September and 4 October 2011 (Minutes to follow)	
7			**REVIEW OF CONGENITAL HEART SERVICES IN ENGLAND: PROPOSED CHANGE IN MEMBERSHIP** To consider the report of the Head of Scrutiny and Member Development seeking to agree a change in the membership of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber).	1 - 2

8			**REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: SCRUTINY REFERRAL TO THE SECRETARY OF STATE FOR HEALTH - UPDATE** To consider the report of the Head of Scrutiny and Member Development regarding the referral to the Secretary of State in respect of matters relating to the proposed reconfiguration of Children's Congenital Heart Services in England.	3 - 6
9			**REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: JOINT COMMITTEE OF PRIMARY CARE TRUSTS (JCPCT) - UPDATE** To consider the report of the Head of Scrutiny and Member Development providing an update on the Joint Committee of Primary Care Trusts (JCPCT).	7 - 50
10			**REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: ADDITIONAL INFORMATION** To consider the report of the Head of Scrutiny and Member Development presenting additional information in respect of matters relating to the Review of Children's Congenital Heart Services in England.	51 - 240
11			**REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: CHILDREN'S HEART SURGERY FUND (CHSF) - UPDATE** To consider the report of the Head of Scrutiny and Member Development providing an update in respect of the Children's Heart Surgery Fund (CHSF).	241 - 244

12			**REVIEW OF CHILDREN'S CONGENITAL HEART SERVICES IN ENGLAND: LEEDS TEACHING HOSPITALS NHS TRUST (LTHT) - UPDATE** To consider the report of the Head of Scrutiny and Member Development providing an update in respect of Leeds Teaching Hospitals NHS Trust (LTHT).	245 - 246

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Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 24 74707

Report of the Head of Scrutiny and Member Development

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

Date: 19 December 2011

Subject: Review of Children's Congenital Heart Services in England: Proposed change in Membership

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

Summary of main issues

1. The Joint HOSC (Yorkshire and the Humber) forms the statutory overview and scrutiny body to consider the proposed reconfiguration of Children's Congenital Heart Services in England and the potential impact on children and families across the and the potential impact on children and families across the Yorkshire and Humber region. As such, it is necessary for the Joint HOSC to keep its agreed terms of reference under review and, where necessary, make amendments to reflect any changing circumstances. This includes any changes to the membership of the Joint HOSC.

2. In September 2011, the Joint HOSC agreed its revised Terms of Reference which included a number of changes to the membership of the Committee, which reflected changes following the local elections in May 2011 and subsequent appointments within Council's across the region.

3. Since the Joint HOSCs last meeting in October 2011, notification has been received from City of York Council of a further change to its nominated representative following changes agreed at the Full Council meeting held on 8 December 2011. Formal nomination is likely to take place at a meeting of York Council's Health Overview and Scrutiny Committee scheduled for 14 December 2011. This nomination will be report to the Joint HOSC meeting for formal approval.

Recommendations

4. Members are asked to agree the change in its membership as reported at the meeting.

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Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 24 74707

Report of the Head of Scrutiny and Member Development

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

Date: 19 December 2011

Subject: Review of Children's Congenital Heart Services in England: Scrutiny Referral to the Secretary of State for Health - update

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

Summary of main issues

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

2. The Joint HOSC submitted its formal consultation response to the Joint Committee of Primary Care Trusts (JCPCT) on 5 October 2011. A formal report was subsequently submitted to the JCPCT on 10 October 2011. In line with the *Overview and Scrutiny of Health – Guidance (Department of Health (DH) (July 2003))* a formal written response to the report and its recommendations within 28 days of receipt was requested.

3. On 14 October 2011, two copies of the Joint HOSC's report were sent to the Secretary of State for Health and the matter was formally referred for consideration on the basis of inadequate consultation with the Joint HOSC by the Joint Committee of Primary Care Trusts (JCPCT), as the appropriate NHS body.

4. The referral was made on behalf of the Joint HOSC and in accordance with the provisions set out in the Health and Social Care Act (2001) (as amended) and the associated regulations[1].

[1] The Local Authority (Overview and Scrutiny Committees Health Scrutiny Functions) Regulations 2002

5. On 8 December 2011, a formal response was received and is attached at Appendix 1 for information. This confirms that the Secretary of State for Health has referred this matter to the Independent Reconfiguration Panel for an initial review. The outcome of this initial review should be known by mid January 2012.

Recommendations

6. Members are asked to note the updated position.

Background documents

- Overview and Scrutiny of Health – Guidance (Department of Health (DH) (July 2003)
- A new vision for Children's Congenital Heart Services in England (March 2011)
- Scrutiny Inquiry Report: Review of Children's Congenital Cardiac Services (October 2011)

From the Rt Hon Andrew Lansley CBE MP
Secretary of State for Health

DH Department of Health

POC1_65199/

Richmond House
79 Whitehall
London
SW1A 2NS

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

Councillor Lisa Mulherin
Chair
Joint Health Overview and Scrutiny Committee
Leeds City Council
3rd Floor (East)
Civic Hall
Leeds
LS1 1UR

- 8 DEC 2011

Dear Councillor Mulherin,

REFERRAL FROM YORKSHIRE AND THE HUMBER JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE "REVIEW OF CHILDREN'S CONGENITAL CARDIAC SERVICES"

Thank you for your letter of 14 October 2011 referring proposals regarding the review of children's congenital cardiac services.

I am today writing to the Independent Reconfiguration Panel (IRP) asking them to undertake an initial review on your referral. Should the IRP advise that a full review is necessary, you will have the chance to present your case to them in full.

I have asked the IRP to report to me no later than 13 January 2012.

I am copying this letter to Dr Peter Barrett, Chair of the IRP and to Ian Dalton, Chief Executive, NHS North of England.

Yours sincerely,

ANDREW LANSLEY CBE

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Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 24 74707

Report of the Head of Scrutiny and Member Development

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

Date: 19 December 2011

Subject: Review of Children's Congenital Heart Services in England: Joint Committee of Primary Care Trusts (JCPCT) - update

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

Summary of main issues

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

2. The Joint HOSC submitted its formal consultation response to the Joint Committee of Primary Care Trusts (JCPCT) on 5 October 2011. A formal report was subsequently submitted to the JCPCT on 10 October 2011. In line with the *Overview and Scrutiny of Health – Guidance (Department of Health (DH) (July 2003))* a formal written response to the report and its recommendations within 28 days of receipt was requested.

3. Members of the Joint HOSC will already be aware that during the period of public consultation, the Royal Brompton and Harefield NHS Foundation Trust had sought a Judicial Review in an attempt to quash as flawed and unlawful the consultation by the JCPCT) concerning the reconfiguration of children's congenital cardiac services.

4. The ruling from the High Court was published on 7 November 2011 and found '*the consultation exercise was unlawful, and must therefore be quashed'*. A full copy of the judgement and its findings is attached at Appendix 1.

5. On 24 November 2011, the JCPCT lodged the application to appeal the above ruling, following a unanimously agreement at its meeting on 17 November 2011.

6. While a hearing date for the appeal is expected to be in early 2012, the full impact on the review process and timetable is not yet known. The Yorkshire and Humber representative on the JCPCT will be attending the meeting to provide an up-to-date position and address any questions raised by the Joint HOSC. The Director of Yorkshire and Humber Specialised Commissioning Group will also be in attendance.

Recommendations

7. Members of the Joint HOSC are asked to note the update provided and determine what, if any, additional scrutiny action should follow.

Background documents

- Overview and Scrutiny of Health – Guidance (Department of Health (DH) (July 2003)
- A new vision for Children's Congenital Heart Services in England (March 2011)
- Scrutiny Inquiry Report: Review of Children's Congenital Cardiac Services (October 2011)

Case No: CO/2440/2011

Neutral Citation Number: [2011] EWHC 2986 (Admin)
IN THE HIGH COURT OF JUSTICE
QUEEN'S BENCH DIVISION
ADMINISTRATIVE COURT

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 07/11/2011

Before :

THE HONOURABLE MR JUSTICE OWEN

- -

Between :

ROYAL BROMPTON & HAREFIELD NHS FOUNDATION TRUST	**Claimant**
- and -	
(1) JOINT COMMITTEE OF PRIMARY CARE TRUSTS	**Defendants**
(2) CROYDON PRIMARY CARE TRUST (on its own behalf and as representative of all Primary Care Trusts in England)	

- -
- -

Alan Maclean QC and **David Scannell** (instructed by **Hempsons Solicitors**) for the **Claimant**
Neil Garnham QC and **Marina Wheeler** (instructed by **Capsticks Solicitors LLP**) for the **Defendants**

- -

Judgment

The Honourable Mr Justice Owen:

1. The claimant, the Royal Brompton and Harefield NHS Foundation Trust (the RBH Trust) seeks to quash as flawed and unlawful a consultation by the first defendant, the Joint Committee of Primary Care Trusts (the JCPCT) concerning the reconfiguration of paediatric congenital cardiac services (PCCS) in England.

2. The RBH Trust is a specialist heart and lung centre based at the Royal Brompton Hospital London and Harefield Hospital, Middlesex. It is the largest specialist heart and lung centre in the UK and among the largest centres in Europe. Its hospitals have, for many decades, been at the forefront of specialised treatment for complex heart and lung disease. Its paediatric service provides a specialist service for children's heart and lung disease and comprehensive paediatric critical care services.

3. On 29 May 2008 the National Health Service Medical Director, Sir Bruce Keogh, acting on behalf of the National Health Service Management Board, requested the NHS National Specialised Commissioning Group (NSCG) to review the provision of paediatric congenital cardiac services, a review that came to be called the 'Safe and Sustainable Review' (the Review). In 2010 the JCPCT was established as the formal consulting body with responsibility for the conduct of the consultation on the Review and for taking decisions on issues the subject of the consultation.

4. On 1 March 2011, the JCPCT published a Consultation Document entitled "*Safe and Sustainable: A New Vision for Children's Congenital Heart Services in England"* (the Consultation Document).

5. The central proposal in the Consultation Document is that the number of centres providing paediatric cardiac surgical services be reduced from eleven to either six or seven, and that the paediatric congenital cardiac service be reconfigured into one of four national configuration options. Each of the four options includes two London surgical centres, namely Evelina Children's Hospital (Evelina) and Great Ormond Street Hospital for Children (GOSH).

6. The claimant challenges the consultation process on the basis that the decisions to exclude a three London centre option from the proposed options, and to exclude the RBH Trust from the preferred two London centre options are legally flawed. By its application for judicial review the RBH Trust seeks a declaration that the consultation is unlawful, and an order that it be quashed.

7. The application for judicial review was issued on 16 March 2011. Permission was granted at an oral hearing on 15 July 2011 by Burnett J, who also considered, but rejected, an application for interim relief, an assurance having been given on behalf of the defendant that the decision to be taken following the consultation process would not be taken pending judgment on the claim.

8. <u>The Legal Framework</u>

<u>The Decision Making Structures within the NHS</u>

It is necessary first to set the context within which the Review has been undertaken. Sections 1 and 3 of the National Health Service Act 2006 (the "Act"), oblige the

Secretary of State for Health to provide or secure certain medical services. By regulation 3 of the National Health Service (Functions of Strategic Health Authorities and Primary Care Trusts and Administration Arrangements) (England) Regulations 2002 (SI 2002/2375) (the "2002 Regulations"), as amended, that function has for the most part been delegated to Primary Care Trusts ("PCTs"), of which there are 152 in England.

9. PCTs commission services from 'providers', including NHS Foundation Trusts to meet the needs of the populations for which they are responsible.

10. Section 242 (2) (b) of the Act imposes a duty on each body to which it applies, which includes PCTs, to consult persons to whom services are being or may be provided on "*the development and consideration of proposals for changes in the way those services are provided".*

11. Paragraph 10.3.2 of the Department of Health's Overview and Scrutiny of Health Guidance provides that:

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

12. Specialised paediatric cardiology and cardiac surgery services are "specialised services", as defined in the National Specialised Services Definition Set. Specialised services are commissioned regionally by Specialised Commissioning Groups ("SCGs"), which are constituted as joint committees of the PCTs in their catchment area. There are ten SCGs in England corresponding to the ten Strategic Health Authorities.

13. The NSCG coordinates the work of the ten SCGs and oversees pan-regional commissioning where a specialised service has a catchment area or population greater than that of a single SCG.

14. <u>The Requirements of a Lawful Consultation</u>

The requirements of a lawful consultation were identified by the Court of Appeal in *R v North & East Devon HA Ex parte Coughlan* [2001] QB 213. The judgment of the court was given by Lord Woolf MR.

> *"108. It is common ground that, whether or not consultation of interested parties and the public is a legal requirement, if it is embarked upon it must be carried out properly. To be proper, consultation must be undertaken at a time when proposals are still at a formative stage; it must include sufficient reasons for particular proposals to allow those consulted to give intelligent consideration and an intelligent response;*

> *adequate time must be given for this purpose; and the product of consultation must be conscientiously taken into account when the ultimate decision is taken: R v Brent London Borough Council, Ex parte Gunning (1985) 84 LGR 168."*

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

15. The requirements of a lawful consultation identified by Lord Woolf reflect the underlying requirement of fairness to those who may be affected by the decision to which the consultation is directed.

16. The requirement that consultation must be at a time when proposals are at a formative stage can be expressed as a requirement that the decision maker has not pre-determined the issue upon which he goes out to consultation, i.e. that he has an open mind. That said, and as Mr Garnham QC submitted in the course of argument, to have an open mind does not mean an empty mind.

17. As Lord Woolf observed at paragraph 112 of *Coughlan*, the obligation on the consulting authority is to let those with a potential interest in the subject matter know in clear terms what the proposal is, and why it is under consideration. Where a number of options are under consideration by the decision maker, it is properly open to him to identify the option or options that he favours, provided that his mind is open to the possibility that further information or argument may lead to a different conclusion.

18. Thus in *Sardar & Others and Watford Borough Council* [2006] EWHC 1590 (Admin), Wilkie J observed at paragraph 29:

> *"29. ... the description "a formative stage" may be apt to describe a number of different situations. A Council may only have reached the stage by identifying a number of options when it decides to consult. On the other hand it may have gone beyond that and have identified a preferred option upon which it may wish to consult. In other circumstances it may have formed a provisional view as to the course to be adopted or may "be minded" to take a particular course subject to the outcome of consultations. In each of these cases what the Council is doing is consulting in advance of the decision being consulted about being made. It is, no*

> *doubt, right that, if the Council has a preferred option, or has formed a provisional view, those being consulted should be informed of this so as better to focus their responses. The fact that a Council may have come to a provisional view or has a preferred option does not prevent a consultation exercise being conducted in good faith at a stage when the policy is still formative in the sense that no final decision has yet been made ... "*

19. Similarly in *R (Medway Council & Others) v Secretary of State for Transport* [2002] EWHC 2516 (Admin), Maurice Kay J held that:

> *"26. In my judgment, subject to other issues such as those raised by the other grounds of challenge in this case, the Secretary of State was entitled to proceed in that way. Other things being equal, it was permissible for him to narrow the range of options within which he would consult and eventually decide. Consultation is not negotiation. It is a process within which a decision-maker, at a formative stage in the decision-making process, invites representations on one or more possible courses of action ..."*

20. The above passage was cited by Bean J in *R (on the application of Tinn) v Secretary of State for Transport & Another* [2006] EWHC 193 (Admin), who went on to observe that:

> "*32. But in public law context is everything. The defendants' decision announcing a preferred route has yet to be made. There is no dispute that in the context of major highway schemes single route consultation is not unusual; and it has not been suggested to be ipso facto unlawful. The requirement to consult while the proposals are at a formative stage cannot mean that there must be first round of consultation on whether to reduce the options consulted upon to one, and then a second round of consultation on that one ...* "

21. In the context of the NHS the Court of Appeal held in *R v Worcestershire Health Council* [1999] EWCA (Civ) 1525, per Simon Brown LJ that:

> "*If, as is clearly established (and is, in any event, only plain common sense) an authority can go out to consultation upon its preferred option, per O'Connor LJ* ["in Nichol v Gateshead Metropolitan Council (1988) 87 LGR 435 at 456 where in effect, he found it permissible for an authority to have a preferred option] *or with regard to a "course it would seek to adopt if after consultation it had decided that that is the proper course to adopt" per Woolf J (*R v Hillingdon Heath Authority Ex parte Goodwin [1984] ICR 800 at page 809), "*then it seems*

> *to me plain that it can choose not to consult upon the less preferred options. It does not, in other words, have to consult on all possible options merely because at some point they were developed, crystallised, canvassed and considered.*"

22. In this context Mr Maclean QC sought to rely upon the decision of Munby J in *R (Montpeliers & Trevors Association) v City of Westminster* [2005] EWHC 16 (Admin) as authority for the proposition that fairness may require consultation on every viable option. At paragraph 29 of his judgment Munby J observed that:

> *"... fairness required a consultation process in which all those interested, whether pro or con, were invited to express their views on all the various options."*

23. But it is important to have in mind the context in which that observation was made. When addressing the first issue to which the claim gave rise, the question of whether there had been a failure properly to consult, Munby J was satisfied on the evidence that:

> *"25... the statutory process was not a process of consultation meeting the Partingdale Lane criteria; and the subsequent process, although a process of consultation, was vitiated by the fact that one of the options – and an option which on any view was of central significance – had already been excluded from further consideration."*

The reference to Partingdale Lane criteria was a reference to *R (Partingdale Lane Residents Association) v Barnet London Borough Council* [2003] EWHC 947 (Admin), [2003] All ER (D) 29, a decision of Mr Rabinder Singh QC, sitting as a Deputy High Court Judge, in which he observed at paragraph 47 that:

> "*… consultation must take place at a stage when a policy is still at a formative stage ... a proposal cannot be at a formative stage if a decision maker does not have an open mind on the issue of principle involved.*"

Thus *Montpeliers* is an example of a case in which a consultation was flawed by predetermination of a central issue.

24. The second requirement of a fair consultation identified in *Coughlan* is that:

> "*... it must include sufficient reasons for particular proposals to allow those consulted to give intelligent consideration and an intelligent response".*

25. The corollary is that the information contained in a consultation document should not be so inaccurate or incomplete as to mislead potential consultees in their responses. Inaccurate or incomplete information may preclude an informed and intelligent response, which may in turn operate to the disadvantage of a party that may be

affected by the decision to which the consultation is directed, and in consequence render the consultation process so unfair as to be unlawful. The point is of particular importance where the information contained in a document that is put out to consultation is outside the knowledge of those consulted, and upon which they are therefore obliged to rely in formulating their response.

26. The Review – The Factual Background

The 2001 Report of the Public Inquiry into deaths at Bristol Royal Infirmary chaired by Professor Sir Ian Kennedy, noted that "*the healthcare needs of children are different from those of adults",* and described healthcare services for children as "*fragmented and uncoordinated*". Relevant recommendations included:

> *"192. National standards should be developed as a matter of priority for all aspects of the care and treatment of children with congenital heart disease.*
>
> *193. With regard to paediatric cardiac surgery, the standards should stipulate the minimum number of procedures which must be performed in a hospital over a given period of time in order to have the best opportunity of achieving good outcomes for children*;
>
> *194. With regard to those surgeons who undertake paediatric cardiac surgery... it may be that four sessions a week should be the minimum number required. Agreement on this should be reached as a matter of urgency after appropriate consultation;*
>
> *198. An investigation should be conducted as a matter of urgency to ensure that PCS (*paediatric cardiac surgery*) is not currently being carried out where the low volume of patients or other factors make it unsafe to perform such surgery".*

27. In response to the Kennedy report, the Department of Health convened a group, the Paediatric and Congenital Cardiac Services Review Group, jointly chaired by James Monro and David Hewlett, to make recommendations for the safe organisation of such services. The Monro report, published in December 2003, reached conclusions similar to those of the Kennedy report, recognising that there was a case for some re-organisation of the centres providing paediatric cardiac surgery services.

28. In 2006 a meeting was convened of children's heart surgeons and cardiologists from the surgical centres providing paediatric cardiac surgery services and other interested parties. The meeting, which was chaired by Professor Sir Roger Boyle CBE, National Director for Heart Disease and Stroke and Dr Sheila Shribman CBE, National Clinical Director for Children, Young People and Maternity Services, concluded that children's heart surgery services as currently configured in England were not sustainable.

29. In 2007 a report by the Children's Surgical Forum of the Royal College of Surgeons of England, … "*Surgery for Children – Delivering a First Class Service*", recommended inter alia fewer and larger paediatric cardiac surgical centres.

30. It was in response to such concerns that on 29 May 2008 Sir Bruce Keogh wrote to the NSCG on behalf of the NHS Management Board asking it to undertake a review of the provision of paediatric cardiac surgical services in England with a view to their reconfiguration.

31. At that point there were eleven hospital centres of varying size in England with 31 surgeons performing approximately 3,600 paediatric heart surgery procedures per year. The eleven surgical centres were:

i) Newcastle Upon Tyne Hospitals NHS Foundation Trust

ii) Leeds Teaching Hospitals and NHS Trust

iii) Alder Hey Children's Foundation Trust

iv) University Hospitals of Leicester NHS Trust

v) Birmingham Children's Hospital NHS Foundation Trust

vi) Great Ormond Street Hospital for Children NHS Trust (GOSH)

vii) University Hospitals Bristol NHS Foundation Trust

viii) Royal Brompton & Harefield NHS Foundation Trust (RBH Trust)

ix) Guys & St. Thomas' NHS Foundation Trust (Evelina)

x) Southampton University Hospitals NHS Trust

xi) John Radcliffe Hospital Oxford.

32. The aim of the Review was to develop a national service that has:

"(i) Better results in surgical centres with fewer deaths and complications following surgery;

(ii) Better, more accessible assessment services and follow up treatment delivered within regional and local networks;

(iii) Reduced waiting times and fewer cancelled operations;

(iv) Improved communication between parents and all of the services in the network that see their child;

(v) Better training for surgeons and their teams to ensure the service is sustainable for the future;

(vi) A trained workforce of experts in the care and treatment of children and young people with congenital heart disease;

(vii) Surgical centres in the forefront of modern working practices and new technologies that are leaders in research and development; and

(viii) A network of specialist centres collaborating in research and clinical development, encouraging the sharing of knowledge across the network."

33. The Review was guided by the five principles set out in the pre-consultation business case (the Business Case), and in very similar terms in the Consultation Document, namely:

"(i) The welfare of the child is paramount in all considerations;
(ii) Quality: all children in England and Wales with congenital heart disease must receive the very highest standard of care;
(iii) Equity: the same high quality of service must be available to each child regardless of where they live;
(iv) The NHS must plan and deliver care that is based around the needs of the child (children are not just little adults);
(v) Local where possible".

34. The Administrative Structure for the Review

The administrative machinery for managing the Review has evolved as the Review has progressed.

35. Day to day management of the Review has been led by a project team of the NSCG (the "NSCG Team"), assisted by a number of specialist working groups, in particular:

1. a Steering Group;

2. a Standards Working Group (a sub-group of the Steering Group) and

3. an Independent Assessment Panel (the "Independent Panel")

36. The Steering Group

The Steering Group was chaired by Dr. Patricia Hamilton, past President of the Royal College of Paediatrics and Child Health and Director of Medical Education in England. It comprised about 25 – 30 members drawn from professional and lay associations and commissioners representing a broad geographical spread. The original membership included Dr (now Professor) Shakeel Qureshi, a consultant paediatric cardiologist at the Evelina and then President elect of the British Congenital Cardiac Association (BCCA). It was subsequently expanded to include Professor Martin Elliott, a consultant paediatric cardiothoracic surgeon at GOSH, and a senior member of the BCCA.

37. The role of the Steering Group was originally to steer the development of proposals, reporting to the NSCG on, inter alia, the appropriate model of care, standards, and criteria for the designation of services.

38. Proposals for reconfiguration were initially to be developed by the SCGs organised into four regional zonal teams (" The SCG Collaboratives") reporting to the Steering Group. London was included within the South Eastern Zone which also comprised the East of England and SE Coast SCGs. The SCGs Collaboratives were charged with identifying reconfiguration options within their zones.

39. The Standards Working Group

The Standards Working Group was a multi-disciplinary panel of experts, set up as a sub-group of the Steering Group, to research and develop a framework of clinical and service standards. Draft Standards were to be presented to the Steering Group, then to the NSCG for endorsement. Once agreed, they were to be used to assess the existing 11 centres and their ability to provide a high quality service in the future.

40. The Independent Panel

The Independent Panel, chaired by Professor Sir Ian Kennedy, was tasked with reviewing each of the existing 11 providers of PCCS services and evaluating their compliance with the proposed service standards. Panel membership comprised experts in paediatric cardiac surgery, paediatric cardiology, paediatric anaesthesia/paediatric intensive care, paediatric nursing, paediatrics and child health, together with lay representatives and NHS commissioners. It was a requirement that members should have no existing or direct relationship with any of the 11 current providers.

41. In the Spring of 2009 concerns emerged as to how the arrangements for the Review would work in practice. It was considered that the process by which SCG Collaboratives would recommend centres within their zones might not result in an appropriate distribution of services. Secondly there was a question as to whether there was a body with authority to take decisions as to implementation of the Review.

42. At the end of 2009, and in the light of such concerns, the governance structure of the Review was revised. The SCG Collaboratives were disbanded. Secondly the NSCG recommended the establishment of a Joint Committee of Primary Care Trusts to act as a single body with delegated powers of consultation and decision making. In April 2010 the NHS Operations Board endorsed the proposed JCPCT subject to ministerial approval which was obtained in July 2010. Although the JCPCT was not formally constituted until it received ministerial approval, I shall refer to it throughout as the JCPCT.

43. With the creation of the JCPCT, the Steering Group's mandate was no longer to "steer" the Review, but to advise the JCPCT, the sole decision maker acting on behalf of all English PCTs, on clinical matters, including the design of the proposed congenital heart networks. The change was reflected in the Steering Group's revised Terms of Reference published in June 2010.

44. The progress of the Review

In January 2010, the 11 provider centres were asked to provide "baseline" information to the NSC Team setting out their current service provision. In March - April 2010, the Standards Working Group published and circulated their proposed national quality standards (Service Standards). The report endorsed the concentration of specialist

expertise, including surgery, cardiology, anesthesia and nursing, into larger teams at Specialist Surgical Centres, recommending inter alia that each such centre:

> *"C4 ...must be staffed by a minimum of four full time consultant congenital cardiac surgeons;*
>
> *C6 ...must undertake a minimum of 400 paediatric surgical procedures per year to avoid 'occasional practice';*
>
> *C7 ...should perform a minimum of 500 paediatric surgical procedures each year."*

45. The Service Standards also set out a 'vision' for the development of a new model of care, Children's Congenital Heart Networks, identifying the constituent parts of such networks: Specialist Surgical Centres designated to perform surgical and other interventionist procedures; Children's Cardiology Centres staffed by experienced paediatric cardiologists performing in-patient and out-patient non-invasive procedures and providing care for children with coronary heart disease; and District Children's Cardiology Centres based in local hospitals with a team led by a consultant paediatrician with expertise in cardiology able to receive referrals from other hospitals, GPs and others involved in primary care. The Service Standards acknowledged that networks would develop according to local circumstances; but the national model was directed at developing formal relationships between the three main elements of the service.

46. <u>The stages of the Review</u>

There were three distinct stages to the Review:

1. self-assessment;
2. an assessment by the Independent Panel;
3. a 'configuration options assessment' to establish a shortlist of options.

47. <u>Self-assessment</u>

Following publication of the draft Service Standards in March 2010, each centre wishing to be designated as a Specialist Surgical Centre was required to complete a self-assessment template directed at their compliance with criteria derived from the Service Standards. The template addressed the criteria in relation to which evidence was sought, including "*excellence of care*", and "*deliverability and achievability"*. The former was particularized in "*Core Requirement 7"*, which included the following:

> *"Each Tertiary Centre must have, and regularly update, a research strategy and programme that documents current and planned research activity, the resource needs to support the activity and objectives for development. The research strategy must include a commitment to working in partnership with other centres in research activity which aims to address research issues that are important for the further development*

> *and improvement of clinical practice, for the benefit of children and their families".*

48. The RBH Trust submitted its self-assessment in May 2010. It included over 100 supporting documents grouped into 20 appendices. In response to Core Requirement 7 it said, inter alia,

> *"The Trust has recently restructured its research and development arrangements including the recruitment of a new Associate Director of Research. A key aim of these changes is to improve the alignment of the Trust research activity with the objectives of the NHS at large."*

Appendix 20 to the response contained "*The Trust Research Strategy"*.

49. The centres were later sent a second template concerning the specialised nationally commissioned services that rely on cardiac surgery: paediatric heart and lung transplantation, complex tracheal surgery and respiratory extracorporeal membrane oxygenation ("ECMO"). Centres which did not currently provide such services were asked whether they wished to seek designation to do so following reconfiguration. The RBH Trust does not provide such services and did not seek designation to do so in future.

50. Under a section of the second template headed "*Other implications for reconfiguration*", information was requested about "*the likely impact on PICU* (Paediatric Intensive Care Unit) *if your centre was not designated*".

51. <u>The assessment by the Independent Panel</u>

On receipt of the self-assessments, the Independent Panel agreed initial scores for each centre. It then undertook a round of visits to the centres in May/June 2010, visiting the Royal Brompton on 9 June. Following the visits the self-assessments and scoring were reviewed, and each centre was given a score measuring its current and future compliance against the criteria.

52. On 20 August 2010, Teresa Moss, Director of National Specialised Commissioning, wrote to inform the RBH Trust that compliance with the designated standards had been scored. Similar letters were sent to the other centres. The letter explained that:

> *"The assessment visits constitute one element of the process for delivering recommendations for reconfiguration. The joint committee of NHS commissioners responsible for delivering recommendations (the JCPCT) will also take account of other criteria to ensure that eventual recommendations may lead to a safe, sustainable and accessible national service."*

53. The letter informed the Trust that each of the centres had been scored; but the covering email said that the JCPCT had decided not to divulge the scores at that stage. After making a number of observations as to the degree to which the RBH Trust had satisfied the criteria, the letter continued:

"The panel did not assess the deliverability and achievability section at any centre due to the difficulty in making this judgement given the information available to them. These criteria will be considered by the Joint Committee of PCTs in developing recommendations for configuration."

54. The scores at which the Panel arrived at that stage were subsequently made public in the Business Case and in the Consultation Document. They were as follows:

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

55. <u>The configuration options assessment</u>

The configuration options assessment was the process by which the JCPCT identified options for inclusion in the consultation process. There were two phases to the assessment:

i) the establishment of a shortlist of viable options;

ii) the scoring of shortlisted options against evaluation criteria to determine which options to put out to formal consultation.

56. Management consultants, KPMG, were engaged to assist in the configuration options assessment. The KPMG team was led by an associate partner, Professor Hilary Thomas.

57. <u>Phase 1 – the shortlisting of viable options</u>

At the first meeting of the proposed JCPCT on 7 July 2010, Professor Thomas was asked to reduce the large number of theoretical options for reconfiguration. It was agreed by the JCPCT that the following criteria should be applied to shortlist potential options:

"*(i) Each centre should perform a minimum of 400 paediatric procedures per year, but ideally 500 paediatric procedures.*

(ii) Centres will be included in the reconfiguration options in order of preference relating to their panel ranking.

(iii) 'Best fit': equitable access."

The steps in the process by which such criteria were applied to the theoretical options are set out in detail in the witness statement of Professor Thomas. But for present purposes it is sufficient to summarise the result, namely the identification of 13 options presented to the JCPCT at its meeting on 28 July 2010.

58. At its meeting on 28 July 2010, the JCPCT agreed inter alia that there should be at least two centres in London, but further narrowed the options to eight in number, deciding at that point that only those with two centres in London should be subjected to further analysis, a decision that was subsequently reversed. The draft minutes of the meeting record that:

> "*Members discussed the recommendation that two centres was the optimum number of centres for London. Members were of the opinion that it was likely that the Royal Brompton Hospital would be excluded from the potential options given the findings and outcome of the assessment panel of visits, the absence of any advantages of access and the advantages possessed by the other London centres. Members agreed that at this stage the Royal Brompton Hospital would be excluded from further analysis around travel and access. Though Members were in agreement that all three London centres would be included in the process for evaluating the London centres against the evaluation criteria on 1 September. Sir Neil said that this was a legitimate approach in order to keep the number of potential viable options manageable.* "

59. At the following meeting on 1 September, Professor Thomas presented five short-listed options chosen from the eight options agreed at the JCPCT meeting on 28 July 2010.

60. It was originally intended that the JCPCT would score the options at its meeting on 1 September 2010; but instead the method for scoring and analysis was discussed at length and a further meeting scheduled for 28 September.

61. Between the meeting of the JCPCT on 1 September and its next meeting on 28 September, KPMG were asked to reconsider the six two London centre options and four three London centre options that had been previously discounted by them in arriving at the five options presented at the meeting of 1 September. As a result twelve options were presented to the JCPCT for discussion on 28 September, namely:

    i) Four seven site options with two centres in London (as at the previous meeting).

    ii) Four six site options with two centres in London (one of which had been presented at the last meeting).

    iii) Four three London centre options.

The minutes of the meeting do not record any concluded view by the JCPCT as to options to be put out to consultation.

Phase 2 – the scoring of the options.

62. The options were scored against weighted criteria. In June/July 2010 the NSC team, acting on the advice of the Steering Group, consulted stake holder groups both as to the proposed criteria and as to the weightings to apply to such criteria for the purpose of the Configuration Evaluation. The stakeholders included SCG directors, parents who had registered for one of the 2010 engagement events and five clinicians nominated by the current surgical centres. They were notified that it would be for the JCPCT to agree the evaluation criteria and the weightings to be applied to them.

63. The criteria ranked in order of importance addressed:

(1) Quality: (a) centres will deliver a high quality service; (b) innovation and research are present; (c) clinical networks are manageable;

(2) Deliverability: (a) high quality NCSs will be provided; (b) the negative impact on other interdependent services will be kept to a minimum, as will negative impacts on the workforce;

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

(4) Access and travel times: negative impact of travel times for elective admissions are kept to a minimum; retrieval standards are complied with.

64. Innovation and research had originally been factors taken into account by the Independent Panel when assessing "*Leadership and Strategic Vision*" and "*Ensuring Excellent Care*", but had not been given a discrete score. The Independent Panel was therefore asked to reconvene, and separately to assess the capacity for research and innovation of each of the centres. The panel met for this purpose on 14 December 2010 and arrived at the following scoring:

PCSS Research and innovation

Evelina	5
GOSH	5
Birmingham	4
Bristol	4
Southampton	4
Newcastle	3
Leeds	2
Leicester	2
Liverpool	2
Royal Brompton	2
Oxford	1

65. At the meeting of the JCPCT on 11 January 2011, fourteen options and supporting analysis were presented to the JCPCT and were examined in detail, two further options to the twelve before the committee on 28 September having been added by the NSC team at the request of the JCPCT.

66. The JCPCT determined that the consultation should proceed on the basis that proposals incorporating two sites in London were preferred. Having formed that view, the JCPCT went on to determine that the consultation should proceed on the basis of an expressed preference for GOSH and the Evelina over the Royal Brompton as the London centres.

67. That decision was arrived at by applying the scoring of the London centres by the Independent Panel against the 4 weighted evaluation criteria: Quality, Deliverability, Sustainability and Access and Travel times, the weighted criteria and the scoring having received the approval of the JCPCT.

68. The centres received different scores only in "Quality" and "Deliverability". The difference in "Quality" was attributable to Evelina's higher overall score by the Independent Panel (ranked first amongst the 11 centres). In "research and innovation" both Evelina and GOSH had been scored the maximum 5 by the Independent Panel, whereas the Royal Brompton had scored 2.

69. Under deliverability, the difference in scores was attributable to two elements; first the benefit to the country of maintaining the provision of three Nationally Commissioned Services at GOSH, GOSH being one of three centres providing ECMO, one of two providing transplantation services and the sole provider of complex tracheal surgery. The second element was the assessment that the loss of the Royal Brompton's paediatric intensive care unit (PICU), supporting predominantly cardiac patients, would present a limited risk to local and national PICU provision.

70. The overall result of the scoring against the weighted criteria was:

(i)	Evelina	364
(ii)	GOSH	347
(iii)	Royal Brompton	264

71. Thus by the conclusion of the meeting of 11 January, there was provisional agreement as to the consultation options, four in number each with two London centres, namely GOSH and the Evelina.

72. On 16 February 2011, the JCPCT met in public to discuss and finally to agree the preferred options to be put out to consultation, the Consultation Document, and the form the consultation was to take. Before inviting questions, Sir Neil McKay concluded the formal session by saying:

> *"let me say categorically, the consultation exercise is what it says on the tin. We are open minded about the outcome, we are prepared to listen to alternative views, as we said on three occasions during the course of the afternoon, and we will move forward with further discussions in the autumn..."*

73. <u>The consultation</u>

The four month period for consultation began on 1 March 2011. By letter dated 3 March 2011, the RBH Trust sought the suspension of the consultation, and on 16

March issued its claim for judicial review, alleging that the consultation was unlawful and vitiated by unfairness.

74. Mid-way through the consultation period, the JCPCT published a further paper "*Safe and Sustainable – Improving children's congenital heart services in London"*. The introduction contained the following paragraph:

> "*At this half way stage in the public consultation on the future of children's congential cardiac services, now is an appropriate time to look at the issues that have been raised so far and focus on the unique situation in London. Every other surgical centre is the sole centre in its city or region; London has three centres close together."*

The paper went on to set out the case for two children's heart surgical centres in London.

75. The consultation formally concluded on 1 July 2011. During the 4 month consultation period, about 50 public events were held and approximately 55,000 written responses were received.

76. <u>The Issues</u>

The claimant's case as developed in argument is that the consultation process was flawed in two respects. The first and principal contention is that the critical issues so far as the claimant was concerned, namely whether the reconfiguration of paediatric cardiac surgery services in London should result in two rather than three London centres, and secondly that the two London centres should not include the Royal Brompton, had been pre-determined. It is accepted on behalf of the defendant that if that was the case, then the claim will succeed. Accordingly the first question is whether, on the facts, those issues had been determined by the JCPCT prior to the consultation exercise.

77. Secondly, and if such issues have not been pre-determined, then it is the claimant's case that the process of consultation was nevertheless flawed as unfair in a number of respects. There were four strands to the submissions. First it was submitted that the process by which the JCPCT arrived at its four preferred options, options that excluded three London centres, and secondly excluded the Royal Brompton as one of the London centres, was irrational. The second, and related argument, is that the Consultation Document was so misleading as to preclude '*intelligent consideration and an intelligent response'*. Thirdly it is submitted that the process was tainted by an appearance of bias. Fourthly the claimant contends that the process by which the JCPCT arrived at its preferred options involved a breach of legitimate expectation.

78. The defendant's case is firstly that on the premise that there was no pre-determination of the critical issues, the consultation process cannot as a matter of law be vulnerable to challenge on grounds of irrationality, and secondly that in any event on the facts the process was not irrational. It is further submitted that there is no factual basis for the contentions that the process was flawed either by misinformation in the Consultation Document, or by bias or breach of a legitimate expectation.

79. Accordingly the issues as refined in the course of argument are:

i) Was there pre-determination of the issues of whether the configuration of paediatric cardiac surgery would incorporate two rather than three London centres, and secondly whether the two London centres would exclude the Royal Brompton?

ii) If such issues were not pre-determined?

(a) is the consultation process amenable to challenge on grounds of irrationality, and if so, was it vitiated by irrationality?

(b) was the consultation process vitiated by procedural unfairness in one or more of the following respects:

(i) misinformation?

(ii) bias?

(iii) breach of legitimate expectation?

80. The Pre-determination Issue

It is submitted on behalf of the claimant that before embarking on the consultation process the JCPCT had decided that there will be only two London centres providing paediatric congenital cardiac services, that the evidence shows that that position had been reached as far back as July 2010, that the determination to have only two London centres was probably influenced by a 'perception' that London had to 'lose' a centre in order to make the process as a whole more palatable nationally, and that the two London centres would be GOSH and the Evelina. At paragraph 115 of the amended Statement of Facts and Grounds, it is asserted that the *"... quasi-scientific approach of the early stages of the Review*" was "*replaced by what appears to have been a classic backroom stitch-up ...".*

81. Mr Garnham accepted that if the issue of two as against three London centres had been determined prior to the consultation exercise, then the claimant will succeed. But he submitted that the claimant's submission is groundless, and that the evidence, whether documentary or contained in the witness statements filed on behalf of the JCPCT, clearly demonstrates that the issue had not been pre-determined.

82. The Consultation Document and the Response Form

The Consultation Document and the response form are the obvious starting point for consideration of the pre-determination issue. There are a number of passages in the Consultation Document that are of direct relevance. Section 1 contains an introduction by Professor Sir Bruce Keogh which concludes with the following paragraph:

> *"I want you to consider whether you think the proposed changes outlined in this document will deliver better care. Are there better solutions? We need an objective debate. In your deliberations refer to your own experiences but please assess*

> *the options impartially, without regard to personal or emotional influences – it is more important we give children the very best chance in life."*

83. Section 2 contains a summary headed "*The options for the number and location of hospitals that provide children's heart services in the future are:"* It then sets out the four preferred options each of which contains two London centres. Under the heading '*LONDON'* it states that "*the preferred two London surgical centres"* are the Evelina and GOSH. Section 5 addresses "*The process behind the proposed changes*", and at page 76 says:

> "*In this section we describe how we have taken advice from stakeholders and the way in which Safe and Sustainable has carried out all the necessary work to evaluate the existing surgical centres. We also explain the process of delivering four viable options for public consultation.*"

84. At page 93 there is a section headed '*LONDON'* which is in the following terms:

> "*It was recommended to the Joint Committee of Primary Care Trusts that options 10 and 12 (which included three centres in London) should not form part of the public consultation for the following reasons:*
>
> - *the joint committee of Primary Care Trusts recommends that two designated centres is the ideal configuration for the population of London, East of England and South East England. The question of whether two centres in London is the right number will be asked during consultation.*
>
> - *the forecast activity levels for London and its catchment area (currently around 1250 paediatric procedures per year) mean that two centres will be well placed to meet the proposed ideal number of procedures a year. This could only happen with three London centres if patients were diverted from neighbouring catchment areas into London. Our analysis shows this would significantly, and unjustifiably, increase travel times and impact on access for patients outside of London, South East and East of England.*
>
> - *the advice of the Safe and Sustainable Steering Group is two centres, rather than three, are better placed to develop and lead a congenital heart network for London, South East England and East of England according to the Safe and Sustainable model of care*.

The following page, page 94, poses the following questions*:*

> *"Do you support the proposal for two Specialist Surgical Centres in London?*
>
> *Do you support this choice? (i.e. Great Ormond Street Hospital for Children and the Evelina Children's Hospital) or do you think the Royal Brompton & Harefield NHS Foundation Trust should replace one of these other two London Hospitals?*"

85. At page 118 under the heading '*We Would Like Your Views'*, the following question is posed:

> "*To what extent do you support or oppose EACH of the FOUR alternative proposed options for the location of the Specialist Surgical Centres?*"

86. The Response Form by which consultees were invited to respond to the Consultation Document contained six questions of direct relevance, Q7 – Q10 inclusive, and Q15 and Q16. The section containing Q7 – Q10 had an introductory heading in the following terms:

> "*The following section asks about the proposals for specialist surgical centres in London. It is proposed that two London hospitals will be chosen as specialist surgical centres.*"

Q7 asked "*Do you support the proposal for two Specialist Surgical Centres in London?"*and provided for a 'tick box' response 'yes', 'no', or 'don't know'. Beside the 'No' box there is the explanatory note:

> "*DO NOT SUPPORT THE PROPOSAL FOR TWO SPECIALIST SURGICAL CENTRES IN LONDON.*"

Q8 invited comments on the number of London centres. Q9 set out the proposal that the two centres in London will be GOSH and Evelina, and posed the question:

> "*If there were to be only two Specialist Surgical Centres in London, please indicate whether you support this choice (*i.e. GOSH and Evelina *…), or whether you think the Royal Brompton & Harefield NHS Trust should replace one of these other two London Hospitals?*"

Q10 invited comments on the proposals for Specialist Surgical Centres in London.

87. Q15 posed the question:

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

and provided a box for each of the eleven existing centres plus a 'don't know' box. Q16 provided the consultee with the opportunity to give reasons for their preferred configuration of centres.

88. It is submitted on behalf of the claimant that the whole structure of the Consultation Document is such that an option with two as opposed to three London centres is realistically the only likely outcome of the exercise. Mr Maclean sought to place emphasis upon the summary at section 2 in which the four options for the future are identified, each of which has two London centres, the preferred centres being GOSH and Evelina. He also relies upon section 5 in which views are sought as to whether the consultee supports the proposal for two centres in London, and as to whether the RBH Trust should replace GOSH or the Evelina, and upon the fact that there is no express question as to whether a three London centre is to be preferred.

89. But in my judgment it is clear from Q7 and Q8 of the response form, that it is open to a consultee to take issue with the proposal for two London centres, and from Q9 to take issue with the exclusion of the RBH Trust. A fair reading of both documents does not lead to the conclusion that either issue had been pre-determined. Neither the Consultation Document nor the Response Form indicate that the JCPCT will not contemplate any options other than those that they have preferred or a variation of the preferred options. On the contrary as Professor Sir Bruce Keogh says in the first section of the Consultation Document:

> *"I want you to consider whether you think the proposed changes outlined in this document will deliver better care. Are there better solutions? We need an objective debate."*

90. <u>The documentary material</u>

It is then necessary to consider the documentary material upon which Mr Maclean relies in support of his contention that the irresistible inference to be drawn is that the option of a three London centre had been excluded as early as July 2010.

91. He invited my attention to a paper presented to the JCPCT by the NSCG Team at the meeting of the JCPCT on 1 September 2010, which at page 2 under the heading "*Unresolved issues to date"* said "*Before we score each option we will tidy up the following unresolved issues",* including the question "*Which 2 London sites should be designated?*" He submitted that the phrase '*tidy up'* was illuminating, and secondly that the inference inevitably to be drawn from the question as to which of two London sites should be designated, is that a decision had already been taken that there were to be only two London sites. He further submitted that the latter point was also borne out by the minutes of the meeting of 1 September in which it is recorded that:

> *"It was proposed that the matrix would be used to score each of the London sites to decide which two should be designated."* (page 8)

and furthermore that there had been pre-scoring by the NSCG Team.

92. But the passages upon which Mr Maclean sought to rely have to be considered in context. The exercise upon which the JCPCT was then engaged, with the assistance of the NSCG Team and KPMG, was in producing preferred options upon which to go out to consultation. Minutes of the meeting of the JCPCT of 28 July 2010 record that after hearing an account of the process by which the options identified by KPMG and the NSCG team had been arrived at:

> *Members discussed the recommendation that two centres was the optimum number of centres for London, Members were of the opinion that it was likely that the Royal Brompton would be excluded from the potential options given the findings and outcomes of the assessment panel visits, the absence of advantages around access and the advantages possessed by the other London centres. Members agreed that at this stage the Royal Brompton Hospital would be excluded from further analysis around travel and access though Members were in agreement that all three London centres would be included in the process for evaluating the London centres against the evaluation criteria on 1 September. Sir Neil (Sir Neil McKay, chairman of JCPCT) said that this was a legitimate approach in order to keep the number of potential viable options manageable."* (page 10)

93. As to the meeting of 1 September, it concluded with a decision to hold a further meeting on 28 September "*for a detailed review of the issues and scoring exercise"*; and in response to a question as to which options needed to be remodelled, Sir Neil is recorded as saying that *"a review of some of the existing options*" might be required to make the meeting of 28 September worthwhile (page 18).

94. The minutes of the meeting of 28 September (before the court in draft form) record that the JCPCT "*had also asked why no options with three London centres had been presented",* and do not contain a record of a concluded view as to preferred options. The minutes of a meeting of the Steering Group on 14 October contain a record of an extensive discussion as to "*Potential options for consultation"*, including reference to 12 potential options of which "*Some were for three sites in London"*. The minutes of the next meeting of the Steering Group on 7 January 2011 note further discussion of a three as against two London centre model, before recording that the JCPCT's preference was for 2 centres (page 17).

95. It was then at the meeting of 11 January 2011 that a decision was made by the JCPCT that

> *"…three-London site options would be excluded from consultation and the choice as to which of the three closed would be offered" It would be stated that based on intelligence, the Committee's preference for closure was Brompton".*

96. It is therefore clear that whilst in July 2010 the NSCG Team had been recommending options based on the analysis undertaken by KPMG that excluded three London sites, the JCPCT, the decision maker, did not arrive at a final decision as to its preferred options until 11 January 2011. The minutes of its meetings prior to that date demonstrate that it had been involved in the process of narrowing the options so as to identify, for the purpose of the consultation exercise, those that it favoured.

97. Secondly Mr Maclean placed reliance on the following passage in the draft Business Case dated 5 January 2011 and considered by the JCPCT at its meeting on 11 January:

> *"... it was agreed that there should be two centres in London.*
>
> *The decision regarding which of the two London sites should be designated was not made until the JCPCT meeting on the 1st September 2010. Therefore the decisions made to get to the 5 viable options to be scored against the evaluation criteria stand alone and can include, at this point, any two London sites."*

98. There are two points to be made. First the document was a draft prepared for consideration by the JCPCT. The passage relied upon by Mr Maclean is to be found in Appendix 8 under the heading "*Evidence supporting the options assessment"*. In the Business Case as adopted by the JCPCT, it appears as Appendix AC, but in a different form. The passages relied upon by Mr Maclean do not appear. Appendix AC contains a summary of the analytical process by which the preferred options were identified, including a section headed "*London requires at least 2 centres",* which contains the following paragraph:

> *"Therefore it is recommended that there should be at least two centres for London".*

99. The draft Business Case was considered by the JCPCT on 11 January. The relevant minute records that *"Gaps in the document were to be fleshed out following today's meeting once the options were identified"*. Unless that minute is duplicitous, the options to be put to consultation had not been decided upon by the JCPCT prior to that meeting.

100. Mr Maclean also sought to rely on a passage at page 6 of the minutes of the meeting of 11 January as revealing as to the reality of the situation, namely:

> *"Ms McLellan recommended the note under Table 1 on page 59 'All options including GOSH and Evelina' be rephrased to read 'Two London Centres'"*

Ms McLellan was the Chief Operating Officer of the London Specialised Commissioning Group. The passage in question is contained in a footnote to a table in Appendix 2 "*Travel time analysis"*. In the Business Case as approved by the JCPCT, the relevant note was amended in the matching appendix, Appendix S, to read "*All options include a minimum of two sites in London."* The original draft reflected the conclusions at which the NSCG had arrived; but the JCPCT corrected the draft to reflect the true position, namely that the preferred options to be put out to consultation all included two London sites. I do not consider that it can properly be inferred from the form of the original note that the two discrete issues, namely the number of London sites and secondly their identity, had been predetermined.

101. Mr Maclean made a similar point in relation to the Consultation Document, inviting comparison of the draft and the final versions. The relevant passage in the draft is in the following terms:

> *"Option B is the best option for retaining centres ranked highest for quality in terms of their ability to meet the proposed new standards of care. Although the Royal Brompton Hospital*

> *in London was rated highly it does not feature in this Option or any of the others because of the decision to propose just two centres in London."*

The final version reads:

> *"Option B is the best option for retaining centres ranked highest for quality in terms of their ability to meet the proposed new standards of care. Although the Royal Brompton Hospital in London was rated highly it does not feature in this Option or any of the others because of the proposal for just two centres in London."*

102. I do not consider the change from '*decision to propose'* to '*proposal for'* has the significance that Mr Maclean seeks to attach to it. It does not in my judgment indicate a closed mind on the part of the JCPCT.

103. The fourth passage upon which Mr Maclean sought to rely in this context appears in a report to the GOSH board by Professor Elliot, a member of the Steering Group on 18 February 2010.

> *"The cardiac review had recommended that the three hospitals currently undertaking cardiac surgery in London be reduced to 2 centres working together. The preferred view seemed to be Guys and St Thomas' [i.e. Evelina] and GOSH would be the two with the Brompton patients spilt (sic.) between the two sites. The Trusts had been asked to work up joint proposals by 31 March 2010."*

104. The identity of the 'cardiac review' to which Professor Elliot is recorded as referring is not specified in the minute. But his reference to the Trusts having been asked to work up joint proposals plainly relates to steps being taken by the London SCG group chaired by Dr Pinto-Duschinsky (formerly Crowther). She says in her witness statement that notwithstanding the change in the governance arrangements for the Review, the group, which included representatives of the RBH Trust, continued to meet as "*...it was a useful mechanism to bring together the SCG representatives and to facilitate discussion on proposed solutions between the providers"*. Paragraphs 13 and 14 of her witness statement are of particular relevance:

> *"13. Through the work of the zonal group, the three Trusts agreed that they were happy to work on a proposal for a single network, and try to put together a joint proposal by the end of March (2010) so that a joint proposal could be put forward to the national review. This approach was endorsed by the three Trust Chief Executives, including Robert Bell (of the Royal Brompton). My letter to the three Chief Executives on the 26th Ocotber 2009 sets out the position.*
>
> *14. I had a meeting with the three Chief Executives on the 17th February 2010. Whilst that meeting was not*

> *minuted, the meeting was followed immediately by the zonal group meeting. The outcome of my meeting with the Chief Executives is accurately described in section 5 of the minutes of the zonal meeting, which highlighted "PCCS collaborative meeting". As recorded the three Chief Execs agreed that further work needed to be done in modelling 2 options:*
>
> *(1) a single network of clinicians with surgery and interventional procedures carried out on two sites: Evelina and GOSH.*
>
> *(2) a second option also based on a single team of clinicians which would take account of potential changes in the Oxford and Southampton services by addressing the volume of surgery which could be undertaken within the three current sites.*
>
> *In other words there was an acceptance in principle that a London solution with the Evelina and GOSH as the surgical centres was the preferred option, subject to the possibility that increased patient flows as a result of national changes might mean it would be better to have surgery maintained on all three sites. It is fair to say that all three Chief Executives had various concerns and Robert Bell said that his Board would have some concerns about the proposed reconfiguration. However, all three agreed to progress to work on a single network. The view to base Option 1 around GOSH and the Evelina was because work in London at the time on specialist children's services was proposing 2 networks across the north and south of London based around these 2 children's hospitals."*

105. Professor Elliott was a member of the zonal group and attended the meeting on 17 February 2010. His report to the GOSH board upon which Mr Maclean seeks to place reliance, was made on the following day. It is therefore reasonable to assume that it was the work of the zonal group to which he was referring. If so then the reference does not afford any support for the contention that there had been a predetermination of the critical issues by the JCPCT.

106. It follows that I do not consider that the documentary material upon which Mr Maclean relies, support his argument. Viewed in isolation the passages in question might give rise to suspicion that there had been a predetermination, but viewed in context such suspicion is dispelled.

107. <u>The Defendant's Witness Statements</u>

Thirdly it is necessary in this context to consider the witness statements filed on behalf of the defendant. The chairman of the JCPCT, Sir Neil McKay, emphatically

rejected any suggestion that the JCPCT or any of its members had in any way made any decision about the final outcome of the Review. He concluded his witness statement by setting out the statement that he made at the public meeting on 16 February 2011:

> "*We want to know what you think. We want you to challenge us. We want you to really put us on the spot about the figures that we have emerged with ... that is the whole purpose of the consultation, and let me say categorically, the consultation is what it says on the tin. We are open-minded about the outcome, we are prepared to listen to alternative views, as we said on two or three occasions during the course of this afternoon.*"

adding in his witness statement that "*I meant what I said. I am not a liar*".

108. Jeremy Glyde, the NSCG Director of the Review, gave similar evidence. So too did Professor Hilary Thomas of KPMG who was responsible for the analysis of options for reconfiguration of paediatric cardiac services. She concluded her witness statement by stating that:

> "*174. Nothing I saw or heard during the whole of my involvement in this process led me to suspect that the JCPCT were entering this consultation with their minds made up. There was nothing to suggest that they were simply going through the motions.*"

109. No application was made for cross-examination of such witnesses; but if there had been pre-determination of the issues in question, then each has given false evidence. In the course of submissions Mr Maclean drew back from asserting that that was the case. But in my judgment he cannot escape the conclusion that if there was pre-determination of the issues, then the consultation exercise was conducted in bad faith in that regard; and the witnesses to whom I have referred have not told the truth in their witness statements.

110. That is a conclusion that I emphatically reject. There is simply no basis upon which I can properly conclude that their evidence on this central issue should be rejected.

111. It follows that in my judgment the argument that there was pre-determination of either issue by the decision maker, the JCPCT, is unsustainable. The JCPCT was entitled to identify and to consult upon its preferred options which did not include a three London centre model and which excluded the RBH Trust. But such pre-disposition did not amount to pre-determination.

112. <u>The Irrationality Challenge</u>

It is submitted on behalf of the RBH Trust that the JCPCT acted irrationally in excluding three London centres from the preferred options identified in the Consultation Document and in excluding the Royal Brompton from the two London centre options, and that in consequence the consultation process was fundamentally flawed.

113. The first question that arises is whether the decision by the JCPCT to identify its preferred options is justiciable.

114. Judicial Review is available to challenge decisions with legal consequences. In *Shrewsbury and Atcham Borough Council & Another v Secretary of State for Communities and Local Government & Another* [2008] EWCA Civ 148 a challenge was made to proposals made by the Secretary of State for Communities and Local Government to replace two-tier local government in some parts of the country with unitary authorities. In his judgment Carnwath LJ addressed the issue of whether the relevant decisions were within the scope of the proceedings, and advanced the following propositions:

> "*32. Judicial Review, generally, is concerned with actions or other events which have, or will have, substantive legal consequences: for example, by conferring new legal rights or powers, or by restricting existing legal rights or interests. Typically there is a process of initiation, consultation, and review; culminating in the form of action or event ("the substantive event") which creates a new legal right or restriction. For example, the substantive event may be the grant of a planning permission, following a formal process of application, consultation and resolution by the determining authority. Although each step in the process may be subject to specific legal requirements, it is only at the stage of the formal grant of planning permission that a new legal right is created.*
>
> *33. Judicial Review proceedings may come after the "substantive event", with a view to having it set aside or "quashed"; or in advance, when it is threatened or in preparation, with a view to having it stayed or "prohibited". In the latter case, the immediate challenge may be directed at decisions or actions which are no more than steps on the way to the substantive event".*

115. Carnwath LJ therefore recognised that a challenge by way of judicial review may be made in advance of the substantive event, where that event is threatened or in preparation. But that is not this case. At this stage a reconfiguration of paediatric cardiac surgical services with two London centres is a proposal the subject of consultation. There has as yet been no decision with legal consequences for the RBH Trust or for GOSH or the Evelina. The proposals are still at the formative stage.

116. It follows that I do not consider that the decisions made by the JCPCT as to its preferred options are justiciable.

117. There is a further reason for arriving at that conclusion. The claimant's argument is advanced on the premise that the defendant was under an obligation specifically to put the options that included three London centres out to consultation on the basis that they had been found to be viable. Mr Maclean sought to derive support for that proposition from the decision of Munby J in *Montpeliers*. But it is in my judgment a misreading of the decision in *Montpeliers* to assert that it is authority for the proposition that there is a duty to consult on all viable options. The process of

consultation in *Montpeliers* was flawed because one of the options had been excluded from further consideration (see paragraph 22 above). In other words the process of consultation was vitiated by the predetermination of a central issue. In the instant case, and for the reasons set out above, I am satisfied that the issue of two against three London centres had not been predetermined.

118. It was open to the JCPCT to identify its preferred options see Lord Woolf in *Coughlan* (paragraph 14 above) and Simon Brown LJ in *Worcestershire Health Council* (paragraph 21 above). The Consultation Document set out the reasoning by which it had arrived at its preferences. The purpose of the consultation was to elicit responses to the proposals that it contained in the form of the preferred options. It was open to those responding to the consultation paper to argue that the reasoning was unsound, and to advance the case for a three London centre deploying the arguments that have been forcefully advanced in support of the submission that the decision to exclude the three London centre options from the preferred option was irrational. The weight objectively to be attached to the arguments now advanced on behalf of the RBH Trust as to the selection of the preferred options, and as to the preference for GOSH and Evelina over the Royal Brompton is not a matter for this court, but they will no doubt be carefully considered by the JCPCT when considering the responses to the consultation.

119. It follows that I reject the argument that the consultation process is flawed by irrationality. But in any event, and if wrong as to that, I do not consider that the decisions in issue can be characterised as irrational. The process by which the JCPCT arrived at its four preferred options are set out in the Consultation Document and the Business Case. Whilst there may be powerful arguments in support of a three London centre option, it cannot be said that to prefer two London centre options is irrational.

120. I am reinforced in that conclusion by the evidence from Dr Crowther, who after marriage is known as Dr Pinto-Duschinsky, who chaired the SCG Collaborative Group for the South Eastern Zone which included London. Although the SCG Collaborative Groups had been disbanded (see paragraph 42 above), Dr Crowther continued to work with GOSH, the Evelina and the RBH Trust to develop proposals to be submitted to the Review, offering a single network of care in London. To this end further meetings were held with participants from the three Trusts on 20 January 2010, 17 February 2010, 18 March 2010, 4 June 2010, 7 July 2010 and 24 November 2010.

121. At the meeting on 17 February 2010, the Chief Executives from the three Trusts agreed that further work needed to be done on modeling two options, the first of which was "*a single network of clinicians with surgery and interventional procedures carried out on two sites: Evelina and GOSH*". That is confirmed by a '*Provider collaborative - feasibility study'*, produced by the three Trusts and dated 31 March 2010 which set out the two options under consideration:

> *"Option 1 – two sites (GOSH and Evelina)" and "Option 2 – three sites (RB&H, GOSH and Evelina), in the event of changes in surgical capacity at Southampton and Oxford".*

The report summary records that:

> *"Guidance from the commissioners present at the initial and workstream meetings has indicated that the two site model should constitute the primary focus of this report. This has been corroborated by Sarah Crowther, the Executive Chair of Commissioning in meetings with various representatives from the three hospitals".*

122. In the light of such evidence it is difficult to see how it can be suggested that the decisions by which the JCPCT arrived at its preferred options were irrational.

123. The Misinformation Issue

The RBH Trust contends that the Consultation Document was so flawed as fatally to undermine the integrity of the consultation process. It is submitted that the passages relied upon so distorted the consultation process as to preclude a properly informed response from consultees, and accordingly to render the process procedurally unfair.

124. The submission was based upon an analysis of two elements of the Consultation Document, first the manner in which information as to the activity level for paediatric congenital cardiac procedures in London was presented, and secondly the scoring of deliverability in the Configuration Assessment.

125. As to the first, section 5 of the Consultation Document, which sets out the process by which the JCPCT arrived at its four preferred options for reconfiguration, has a section at page 93 headed '*LONDON*' which contains the following paragraph:

> "*The forecast activity level for London and its catchment area (currently around 1,250 paediatric procedures per year) mean that two centres would be well placed to meet the proposed ideal number of 500 procedures a year. This could only happen with three London centres if patients were diverted from neighbouring catchment areas into London. Our analysis shows this would significantly, and unjustifiably, increase travel times and impact on access for patients outside of London, South East and East of England."*

The section concluded with a summary of the advice given by the Steering Group, namely: *" ... two centres, rather than three, are better placed to develop and lead a congenital heart network for London, South East England and East of England ...".*

126. In essence it was submitted that the paragraph set out above was grossly misleading, and would inevitably have distorted the responses of consultees, who would have assumed that to implement a three London centre model would adversely effect the service in question as numbers would fall short of the proposed optimal number of 500 procedures per annum per centre. In fact the projected London case load in each of the preferred options was 1,482. If the increase was to be divided equally between the three London centres, then GOSH would be doing 625 procedures, the Evelina 425 and the Royal Brompton 437. As Mr Glyde explained at paragraph 261 of his second witness statement, if the additional case load was to be split in proportion to

the existing share of cases, i.e. if existing referral patterns continue, GOSH would be doing 651 procedures, Evelina 406 and the Royal Brompton 425.

127. Mr Maclean argued that in either case the Royal Brompton would be doing more than 400 procedures per annum, the figure identified by the standards working group as the minimum number to avoid '*occasional practice'* (see paragraph 43 above). He therefore argued that it was misleading, and grossly unfair for the relevant section of the consultation document, to have referred to the current activity level for London and its catchment area of around 1,250 procedures per annum, but to have omitted reference to the projected case load of almost 1,500. He further argued that the projected caseload, if shared equally between the three London centres would result in each undertaking of the order of 500 procedures per annum.

128. He also made the point that in calculating the Royal Brompton's current caseload, referrals from outside England were left out of consideration, arguing that such omission was a further respect in which the analysis presented in the Consultation Document was unfair to the Royal Brompton, in that when considering the quality of service, it is the number of procedures carried out that is of significance, the source of referrals being irrelevant.

129. In his witness statement Mr Glyde sought to justify the paragraph in question, arguing that it was factually correct in that it accurately stated the current number of relevant paediatric procedures, and that two centres would be well placed to meet the optimum identified by the Standards Working Group of '*a minimum of 500 paediatric surgical procedures each year*'. He acknowledged that in retrospect it might have been clearer to have left out the reference to 1,250 procedures per annum, or alternatively to have noted the projected number of procedures in the bracketed section of the paragraph in question.

130. Mr Glyde also advanced the reason why overseas private patients were not included in the projected figures, namely that such referrals are subject to unpredictable fluctuations. That may be the case; and the total number of procedures carried out by a centre may be of relevance to an assessment of the service that it provides. But the failure to refer to the procedures carried out privately at the Royal Brompton does not appear to me to be misleading given that in the inter-London scoring exercise, the results of which were set out in tabular form at pages 95/96 of the Consultation Document, each of the centres was scored equally under the criterion 'Sustainability', the criterion that included:

> "*All designated centres are likely to perform at least 400 procedures each year, ideally 500 paediatric procedures each year."*

131. Furthermore this section of the Consultation Document was addressing the configuration of congenital cardiac surgical services to meet the demand for such services in the resident population, and in particular the number, rather than the identity, of London centres. I do not therefore consider that the absence of a reference to private patient numbers was materially misleading with regard to the latter issue.

132. I accept that it would have been preferable for reference to have been made to the projected caseload, either in place of or in addition to the reference to the current figure. But the question is whether the failure to do so of itself had the effect of

rendering the consultation process unfair in the sense that it was likely to affect the response of consultees on the issue of whether a two London centre option was to be preferred to a three London centre option.

133. In my judgment it did not. At page 93 of the Consultation Document under the heading 'LONDON' the JCPCT is recorded as recommending that:

> "*... two designated centres is the ideal configuration for the population of London, East of England and South East England.*"

The next paragraph, asserts that two centres would be well placed to meet the proposed ideal number of 500 procedures per annum. Thus it is clear that it is not being suggested that a three London centre option is not viable, rather that a two London centre configuration is ideal.

134. Secondly the proposition that a two London centre option was the ideal configuration was as valid on a caseload of 1500 as of 1250, bearing in mind that whichever apportionment of the difference between the two figures is assumed, the projected figures for two of the existing London centres, the Evelina and the RBH Trust, would have fallen well short of the figure of 500 procedures per annum.

135. I do not therefore consider that the failure to refer to the projected caseload would have so distorted the consultation process as to render it unfair to the RBH Trust.

136. The second aspect of the Consultation Document that it is submitted is misleading, is in relation to the scoring of deliverability. In the table set out at page 95/96 '*Scoring the London Sites'*, the RBH Trust received the lowest score of 2, as against scores of 4 for GOSH and 3 for the Evelina. An explanation is advanced in the text:

> "*Because the PICU at the Royal Brompton Hospital exists predominantly to support cardiac surgery, we propose it is scored lower than the Evelina Children's Hospital on the sub-criterion involving 'the negative impact for the provision of paediatric intensive care and other interdependent services is kept to a minimum.'"*

137. Mr Maclean submitted that it was common ground that should paediatric congenital cardiac surgery no longer be carried out at the Royal Brompton, its PICU would no longer be viable. Accordingly he sought to argue that the negative impact should be assessed as greater than at the Evelina rather than lesser.

138. But in my judgment his argument was misconceived. As Mr Glyde says in his second witness statement (paragraph 267) the Royal Brompton received a lower score for deliverability than the Evelina because the Royal Brompton's PICU predominantly supports cardiac patients, and if it is to be de-designated, the impact on non-cardiac patients would be more manageable than for a centre whose PICU had a large number of non-cardiac patients, the position in relation both to GOSH and the Evelina.

139. In July 2011, and as a result of the RBH Trust's representation that decommissioning of its PICU would destabilise and render unviable a number of its other paediatric

services (notably respiratory services, including cystic fibrosis), the JCPCT commissioned a review by an international independent panel of experts, chaired by Adrian Pollitt.

140. Following consideration of written material and a visit to the Royal Brompton on 6 September, the Pollitt panel reported on 16 September. It found that de-designation would render the Royal Brompton's PICU unviable (as anticipated), but that admissions as a result of interventions associated with respiratory services were rare. The panel concluded that all respiratory services would remain viable; that the great majority of paediatric respiratory activity would continue to take place at the Royal Brompton; but that arrangements would need to be put in place for some rare and complex cases.

141. Mr Maclean sought to rely upon the decision of the JCPCT to instruct the Pollitt panel as amounting to an explicit recognition by the JCPCT that "*something had gone wrong*" with the consultation process, arguing that it demonstrated that the JCPCT had failed to take any or any proper account of the consequential effect of the termination of the relevant services at the Royal Brompton in arriving at its preferred options. I do not agree. In my judgment the decision to constitute the Pollitt panel was an appropriate response to representations made by the RBH Trust, and serves to demonstrate the manner in which the process of consultation can and should work.

142. <u>The Bias Issue</u>

It is submitted on behalf of the RBH Trust that the consultation process was vitiated by bias, or by the appearance of bias. The argument was based upon the fact that Professor Qureshi and Professor Elliot were members of the Steering Group, Professor Qureshi being a consultant paediatric cardiologist at the Evelina, and Professor Elliott, a consultant paediatric thoracic surgeon at GOSH. Mr Maclean contends that the usual principles by which a decision may be impugned on grounds of actual or apparent bias apply, i.e. would a fair-minded and informed observer, having considered the facts, conclude that there was a real possibility that the process was biased, see e.g. *Magill v Porter* [2002] 2AC 357. He therefore invited me to undertake the well established two stage process, first to ascertain all the relevant circumstances, and secondly to consider whether such circumstances would lead a fair minded and informed observer to conclude that there was a real possibility of bias, see *Re Medicaments (No. 2)* [2001] 1WLR 700, and *Flaherty v National Greyhound Racing Club Ltd.* [2005] EWCA Civ 117.

143. But it is necessary first to consider whether the decision by the JCPCT to reduce the six viable options to four preferred options, and the exclusion of the RBH Trust from the preferred options, is amenable to challenge on grounds of bias.

144. There is in my judgment an insurmountable obstacle facing the RBH Trust in relation to this limb of its challenge. Its argument is based upon the membership of the Steering Group of Professor Qureshi and Professor Elliott. But I am satisfied on the evidence that the Steering Group was not the decision maker. Whilst it is clear from the minutes of the Group, see in particular the minutes of the meeting of 6 January 2011, that it had formed the view that options limited to two London centres were to be preferred, and that that would have the consequence that the Royal Brompton would be excluded, its role was to make recommendations to the JCPCT. The JCPCT

took account of the recommendations, as it was fully entitled to do, but it and not the Steering Group made the decisions in question.

145. It is of note in this context that at the meeting of the steering group on 6 January 2007 Deborah Evans, representing the South West and South Central specialised commissioning groups, "*... queried whether it might be a risk that some centres had staff members sitting on the steering group representing their associations, while others were not and co-incidentally those centres might be among those de-designated"*. The minutes go on to record that "*the group highlighted that it was not its role to make a decision"*. Thus whilst the minutes recorded sensitivity as to the perception of the role of the Steering Group, there can in my judgment be no doubt that the steering group understood that its role was limited to giving advice from the clinical perspective.

146. In this context Mr Maclean sought to rely upon the decision in *R (Goldsmith) v Wandsworth LBC* [2004] EWCA Civ 1170, (2004) 7 CCL Rep 472 as support for the proposition that where a decision maker adopts recommendations of a subordinate body, whose recommendations are vitiated by unfairness, a decision adopting the recommendations is likewise vitiated. He therefore submits that if the recommendations made to the JCPCT were tainted by bias, actual or apparent, in the Steering Group "*that vitiating flaw will necessarily pollute the JCPCT in turn, unless the JCPCT has taken remedial steps which function to sever the nexus between the decisions taken and the infected upstream process"*.

147. *Goldsmith* concerned the discharge by the Wandsworth Borough Council of its duty to provide community care services. It had taken the decision under challenge on the advice of its Local Continuing Care Panel (LCCP). The Court of Appeal came to the conclusion that the LCCP had given Wandsworth defective advice based on inadequate information, and in consequence Wandsworth's decision was flawed. But that is not this case. It is not contended, nor in my judgment could it be, that the recommendation made by the Steering Group to the JCPCT was defective. It was based upon the analysis carried out by the NSC Team with the assistance of KPMG. Secondly and in any event it is clear from the minutes of the meetings of the JCPCT and from the witness statement of Sir Neil McKay that it arrived at its decision as to its preferred options after a full and proper consideration of the material before it, and was not simply rubber stamping the recommendations of the Steering Group.

148. I therefore reject the contention that the consultation was tainted by bias, whether actual or apparent.

149. Legitimate Expectation

In the weighted scoring exercise summarised at paragraph 71 above, GOSH, Evelina and The Royal Brompton scored respectively, 347, 364 and 264. The Royal Brompton was scored the lowest on two criteria, quality and deliverability. As to quality, the RBH Trust scored lowest on research and innovation as a result of the assessment carried out by the Independent Panel in December 2010 (see paragraph 64 above).

150. The contention that the process of assessment of 'research and innovation' was unfair to the RBH Trust is based upon the argument that there was a failure on the part of the

JCPCT to meet a legitimate expectation that the criteria and scoring in the Assessment Evaluation undertaken by the Independent Panel, would be "*separate*" from the Configuration Evaluation, and would have no "*direct bearing*" on its scoring.

151. There is no issue between the parties as to the relevant legal principles: first per Laws LJ at paragraph 68 of *R (Nadarajah and Abdi) v Secretary of State for the Home Department* [2005] EWCA Civ 1363

> "*Where a public authority has issued a promise or adopted a practice which represents how it proposes to act in a given area, the law will require the promise or practice to be honoured unless there is good reason not to do so".*

152. Secondly a legitimate expectation requires a clear and unequivocal representation, see Lord Hoffman in *R (Bancoult) v Secretary of State for Foreign and Commonwealth Affairs (No. 2)* [2009] 1 AC 453, citing Bingham LJ in *R v Inland Revenue Commissioners*, *Ex parte MFK Underwriting Agents* [1990] 1 WLR 1545, 1569.

153. The issue is whether there was a clear and unequivocal representation by the JCPCT giving rise to a legitimate expectation.

154. It is submitted on behalf of the claimant that the representation is to be found in the self-assessment template form, which drew the distinction between the two stages of the evaluation process, the "*Assessment Evaluation*" and "*Configuration Evaluation.*" The form said:

> *"The evidence you supply in this exercise will be assessed as part of the evaluation process we will undertake, and therefore will ultimately inform the final recommendation.*
>
> *The entire evaluation process has 2 discrete stages – Assessment Evaluation and Configuration Evaluation. This process will fulfil the first stage of the assessment evaluation.*
>
> *...*
>
> *It should be noted that the criteria and scoring process for the Configuration Evaluation have not yet been determined. This will be communicated to all stakeholders in due course. However, the criteria and scoring for the Configuration Evaluation is separate from the Assessment Evaluation. The information supplied in the assessment stage of the process will not have any direct bearing on the scoring of the configuration evaluation process.*
>
> *...*
>
> *Scores will be allocated against each criterion, which will come together as a final score for each centre.*
>
> *Individual scores for each centre will help identify the configuration options, which will then be tested against criteria such as ease of access, affordability and deliverability, and the*

> *risks of reconfiguration. The exact scoring mechanism for this stage has yet to be determined."*

155. The claimant contends that such statements amounted to a clear and unequivocal representation, but that contrary to that representation, the scoring from the Assessment Evaluation was used in the Configuration Evaluation.

156. Mr Garnham sought to argue that the statements did not amount to a clear and unequivocal representation with the effect for which the claimant contends, relying in particular on the statement that "*Individual scores for each centre will help identify the configuration options"*. The scores produced by the evaluation assessment would obviously affect the identification of configuration options; but that does not undermine or qualify the clear and unequivocal representation that the information supplied in the assessment stage would not have a direct bearing on the scoring of the configuration evaluation process.

157. As to the question of whether the information provided by the RBH Trust had a direct bearing on the scoring of the Configuration Evaluation, the evidence is clear. As Professor Thomas explained in her witness statement:

> "*86. For the second sub criterion "innovation and research" the JCPCT used the Independent Panel's scores for centres which the panel scored in a meeting held in December 2010 using information from the completed submissions from their assessment, including self assessment forms which had been sent to the centres in March 2010.*"

158. Her evidence reflected that given by Professor Sir Ian Kennedy who said in terms that the assessment of each centre's research and innovation capacity and outlook was based both on the centre's submissions in the self-assessment form and on the site visits carried out by the independent panel. His explanation of the scoring is in the following terms:

> "*41. The Panel gave the Royal Brompton a consensus score of two out of five. This score was based on the written evidence given to the panel by the Royal Brompton. It was the Royal Brompton's responsibility (as with every other centre) to provide us with all the relevant information with regard to research into paediatric cardiac surgical services, and any plans that they had for development. The reason why some of the centres had higher scores than others was because, on the basis of their submission, they provided evidence which better demonstrated that they met the Standards. Based on the Royal Brompton's written submissions, the panel felt that not all of the research undertaken and referred to by the Royal Brompton during the assessment visit applied to paediatric cardiac surgery and was not, therefore, as relevant in meeting Standards. The Royal Brompton's responses did not contain sufficient reference to or contain sufficient*

> *plans to develop research in the area of paediatric cardiac surgery. RBHT's Research Strategy made insufficient reference to research into paediatric cardiac surgical services.*
>
> *42. The Independent Panel appreciated that the Royal Brompton has a good record in clinical research; however, the panel felt that the research undertaken by the two Bio Medical Research Units ("BRUs ") at the Royal Brompton was not specifically relevant to paediatric cardiac surgical services.*
>
> *43. The independent panel's score in December 2010 reflected its previous findings from the assessment in June 2010, as published in the independent panel report published in January 2011: this recorded that RBHT has a good track record with clinical research, however, the panel felt that this standing has recently slipped, and the research undertaken by the two BRU's was not relevant to paediatric cardiac surgery. This was because the panel did not feel that there were explicit plans for research undertaken by the BRU's to include research relevant to paediatric cardiac surgical services."*

159. I therefore reject the submission that the information supplied in the assessment stage did not have any direct bearing on the scoring of the configuration evaluation process.

160. Secondly Mr Garnham submitted that if the process adopted deviated from that communicated by the template, the RBH Trust did not suffer any unfairness in consequence. There were two strands to the argument, first that had the RBH Trust been given the opportunity further to respond on the issue of research and innovation, its case would not have been any stronger.

161. To assess the validity of that submission it is necessary to consider the relevant parts of the self-assessment form submitted by the RBH Trust. At section 1.11 the form invited a response to the following:

> "*Please describe the way the Paediatric Team works to learn, develop and grow, taking into account learning from practice, national and international research evidence, best practice and multi-disciplinary working. Please include any example of innovative working that you have undertaken and how these have proven benefit to clinical care.*"

162. Section two of the self-assessment form was directed to '*Achievement of Core Requirements'*. The third bullet point under core requirement 7, '*Ensuring Excellent Care,'* was:

> "*Each Tertiary Centre must have, and regularly update, a research strategy and programme that documents current and*

> *planned research activity, the resource needs to support the activity and objectives for development. The research strategy must include a commitment to working in partnership with other centres in research activity which aims to address research issues that are important for the further development and improvement of clinical practice, for the benefit of children and their families.*"

The form also asked those responding to attach their '*Research Strategy and Programme'*.

163. In its response the Trust said:

> "*Research strategy: The Trust has a clear and accountable research strategy and infrastructure (Appendix 20e). Our willingness to work with other centres is evidenced by several of our recent studies including several national epidemiological studies in congenital heart disease and the national multi-centre NIHR-funded 'CHiP' trial, which is run from the Royal Brompton.*
>
> *…*
>
> *The Trust has recently restructured it's research and development arrangements including the recruitment of a new Associate Director of Research. A key aim of these changes is to improve the alignment of the Trust research activity with the objects of the NHS at large.*"

164. The Independent Panel's assessment of the information provided by the RBH Trust is set out in the evidence given by Professor Sir Ian Kennedy (see paragraph 158 above). His evidence is addressed in witness statements from Dr Duncan Macrae, a consultant paediatric intensivist and Director of Paediatric Intensive Care at the Royal Brompton, and by Professor Timothy Evans, who was the medical director and director of research and development at the RBH Trust.

165. In addition to his role within the RBH Trust, Dr Macrae is currently the President of the International Paediatric Cardiac Intensive Care Society, the paediatric editor for the European Journal 'Intensive Care Medicine' and an associate editor of 'Paediatric Critical Care Medicine' based in the United States. In his second witness statement he addresses the assessment of 'research and innovation' by the Independent Panel. The following paragraphs are of particular relevance:

> *"6. Professor Kennedy says at paragraph 41 that the consensus score of 2 out of 5 was reached at a meeting held the following day, on 14 December 2010, based on our written material supplied to his Assessment Panel. He makes a series of assertions with which I disagree. He says that it was our responsibility to provide he and his colleagues with the written information with regard to surgical services, and that they thought that not all research undertaken and referred to by us applied to paediatric cardiac surgery and was therefore not relevant in meeting the Standards. He says that our*

responses did not contain specific plans to develop research in paediatric cardiac surgery and contained insufficient reference to research into paediatric cardiac surgical services. The short answer is that we never thought that any of these were relevant to the process that Prof Kennedy and his Panel had been represented to us as undertaking. We thought that we were being asked not about the content of our research, but about the application and the governance of research.

7. Research is not described as a component of excellence in the Template questions we were sent in advance of the visit of Professor Kennedy's Panel. The Template invited us (at section 10 ...) to describe the opportunities for innovative working and new ways of working across the network with improvements in screening diagnostics and telemedicine. That is what we did in our response, when we dealt with how we utilise new discoveries to improve the way in which we treat patients.

8. Similarly, at section 11 ..., we are asked to describe how the cardiac team works to learn, develop and grow, taking into account learning from national and international research. Once again, this was a question about how we were able to exploit and apply research advances (made here and elsewhere alike), and we answered it accordingly. The question is simply not about the very different matter of how we were going to contribute to the advancement of knowledge through research by clinicians and others from the Royal Brompton.

9. The governance questions arose ... in Excellent Care, where we were told that we must have and regularly update a research strategy and a program that documents current and planned research. We were asked to explain how we supported the activity and objectives for development and it was stressed that we must have a commitment to working in partnership with other activities in research activities that seeks to address research issues that are important for the further development and improvement of clinical practice. All this is about the governance of research and the shaping of research on how we support our researchers. That is why we provided the research strategy of the Trust in our response. Nothing in the questions put to us indicated that we were to be assessed on the content of our research, still less that the (illfounded) conclusions reached as to the nature and quality of our research were to prove to have such an important role in the process.

...

11. Anyone interested in this sort of issue would have looked at the results of the spadework in this field done by the professionals. I would have expected them to ask how we had fared in the Higher Education Funding Council for England (HEFCE) Research Assessment Exercise (RAE). I would understand if they did not want to rely on this Exercise unquestioningly, for the reasons given by Prof Kennedy, but anyone interested in the issue would have sought to probe how many of the highest scoring people submitted by Imperial College worked in the relevant fields. No one asked us any questions about that at any stage of the process.

> *12. The Rand Analysis referred to by Professor Evans was an assessment produced for the NHS. It did not look at grants, but it did look at the citation of individual papers. It collected all the papers together and look at the institutes from which they came. Again it was a careful, ambitious piece of work which is highly respected. Anyone interested in the research output of this hospital would have been fascinated by this because it shows that this hospital eclipses every university in the country except our own partner, Imperial, and that we do so handsomely. Again, we were never asked about this and it is plain that it was not considered by Professor Kennedy or the Safe & Sustainable process more generally.*
>
> *13. Prof Kennedy and his colleagues could have asked to see the papers and we would have produced a list. Looking at Professor Kennedy's statement I see that there is some suggestion that a lot of our research may have nothing to do with children. With respect to Prof Kennedy, who is an academic lawyer, any such suggestion is entirely misplaced. I have caused an analysis to be prepared ... listing all of the cardiological publications emanating from this hospital from 2008 to the end of 2010. Not only does it indicate the volume of work (498 discrete publication plainly supports the inference to be drawn from the Rand Analysis) but 227 or 44% of them deal with paediatric cardiac disease."*

166. Dr Macrae goes on to say that when Professor Kennedy and his team visited the Royal Brompton on 9 June 2010, he cannot remember anyone asking significant questions about research, nor suggesting that their research was not relevant to paediatric cardiac surgery.

167. Dr Macrae's understanding of the issues at which the Template was directed appears to me to be fully justified. Secondly his evidence clearly demonstrates that the assessment of 'research and innovation' based on the RBH Trust's response to the Template did not reflect the true position.

168. Professor Evans is a consultant in Intensive Care and Thoracic medicine at the RBH Trust, and Professor of intensive care medicine at Imperial College London within the National Heart and Lung Institute. He pointed out that it is a feature of the RBH Trust that its hospitals are specialist heart and lung hospitals treating patients of all ages, the only such hospitals in the UK. Thus, the research conducted by the RBH Trust is *"... on an enormously wide spectrum",* and *"it may be that paediatric services will actually benefit most from techniques being pioneered more aggressively in adults."* He argued that that illustrates the value of a speciality-based hospital as opposed to a multi-speciality children's hospital. Whilst research undertaken in a children's hospital will obviously be focussed on paediatric services, it does not follow from the fact that research undertaken at the RBH Trust, or by the Trust in conjunction with Imperial College, is not limited in that manner, that such research may not be of direct relevance to the paediatric services that it provides.

169. It is not for this court to make an assessment of the research undertaken at the RBH Trust, either alone, or in conjunction with Imperial College, nor is it necessary to undertake a detailed analysis of the different measures of research activity to which Dr Macrae and Professor Evans referred in their evidence. But in the light of their evidence I reject the argument that to have informed the RBH Trust that its capacity

for research and innovation was being assessed by reference to the self-assessment form, and to have invited further submissions, would not have made any difference to the assessment made by the Independent Panel.

170. But the second strand to the argument advanced by Mr Garnham is directed to the scoring of the London centres, see paragraphs 68 – 70 above. He submitted that a different assessment of 'research and innovation' would not have made any difference to the preference for GOSH and the Evelina at which the JCPCT arrived. He substantiated the argument by reference to the table at pages 95/96 of the Consultation Document, from which it can be seen that the RBH Trust scored lower than GOSH and the Evelina on two criteria, 'Quality' and 'Deliverability'.

171. GOSH scored highest on 'Deliverability' because it provides three highly specialised nationally commissioned services, children's heart transplantation, ECMO services and complex tracheal surgery. The Evelina scored higher than the RBH Trust by virtue of the assessment of the negative impact for the provision of paediatric intensive care.

172. As to 'Quality' the weighted scoring for GOSH, the Evelina and the RBH Trust was 117, 156 and 78 respectively. The Evelina was given a higher score than GOSH under 'quality' by reference to the original assessment by the independent panel, see paragraph 54 above. As for the difference in scoring between GOSH and the RBH Trust, the explanatory note above the table says under the heading 'Quality':

> "*Similarly Great Ormond Street Hospital and the Royal Brompton Hospital were ranked equally by the panel, but the higher score for Great Ormond Street is due to its capacity for 'research and innovation'.*"

They had been ranked equal in the assessment made by the Independent panel, see paragraph 54 above. But if at this stage the RBH Trust had been scored the same as GOSH for 'research and innovation', its total score on the inter London centre scoring would have been 303, as against 347 for GOSH and 364 for the Evelina.

173. Mr Garnham therefore argued that had the RBH Trust been given an opportunity to make further submissions as to its capacity for 'research and innovation', and had such submissions persuaded the JCPCT that it should be scored equally with GOSH in that regard, it would still have been ranked third in the comparative assessment, and that in consequence there was no unfairness to the RBH Trust.

174. I do not agree. It was of course open to the RBH Trust to respond to the Consultation Document advancing the arguments as to its capacity for research and innovation summarised by Dr Macrae and Professor Evans in their witness statements, arguments that the JCPCT would be obliged to take fully into account in arriving at its final decision as to the reconfiguration of PCCS services. But in my judgement the consequence of the failure to meet the RBH Trust's legitimate expectation was seriously to distort the consultation process. Those responding to the Consultation Document would inevitably have proceeded on the premise that the RBH Trust's capacity for research and innovation was poor, a point made graphically in the colour coding on the diagram at page 102.

175. I recognise that when addressing the issue of which the London centres are to be preferred, the Consultation Document identified reasons for preferring GOSH and the Evelina. But from the viewpoint of a consultee, the question of which two London centres should be included in the proposed reconfiguration cannot be viewed in isolation from the question of whether there should be two or three London centres. Bearing in mind that each of the centres scored equally under 'Sustainability', had the RBH Trust been scored equally with GOSH in relation to research and innovation, it would have been a legitimate line of thought for a consultee, weighing the relevant considerations, to have arrived at the conclusion that notwithstanding the analysis of the projected case load (see paragraph 126 above), a three London centre configuration was to be preferred, a configuration that would have the advantage of preserving the unique features of a specialist heart and lung hospital. But such a conclusion was in effect precluded by the assessment of research and innovation at the RBH Trust as 'poor'.

176. As Sullivan J observed in *R(Greenpeace Ltd) v Secretary of State for Trade and Industry* [2007] EWHC 311 (Admin),

> "*63. In reality, a conclusion that a consultation exercise was unlawful on the ground of unfairness will be based upon a finding by the court, not merely that something went wrong, but that something went "clearly and radically" wrong".*

But I have come to the conclusion that that is the case. The assessment of the quality of the service provided by the RBH Trust would plainly be regarded as of central importance by a consultee when considering the options for reconfiguration of PCCS; and it seems to me that the low scoring of the RBH Trust on 'quality' in the weighted scoring of the London centres, must inevitably have affected the responses to the Consultation Document in a manner seriously adverse to the Trust.

177. I therefore consider that the failure to meet the RBH Trust's legitimate expectation as to the use to which the information provided in response to the self-assessment Template, and the likely consequential effect upon the assessment of 'Quality' in the inter London centre scoring, rendered the consultation process unfair to the Trust, the unfairness being of such a magnitude as to lead to the conclusion that the process went radically wrong.

178. <u>Conclusion</u>

It follows that in my judgment the consultation exercise was unlawful, and must therefore be quashed.

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Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 24 74707

Report of the Head of Scrutiny and Member Development

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

Date: 19 December 2011

Subject: Review of Children's Congenital Heart Services in England: Additional Information

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

Summary of main issues

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

2. The Joint HOSC submitted its formal consultation response to the Joint Committee of Primary Care Trusts (JCPCT) on 5 October 2011. A formal report was subsequently submitted to the JCPCT on 10 October 2011. In line with the *Overview and Scrutiny of Health – Guidance (Department of Health (DH) (July 2003))* a formal written response to the report and its recommendations within 28 days of receipt was requested.

3. During its inquiry, the Joint HOSC identified some specific concerns in relation to the consultation process and the availability of a range of information it considered necessary in order to fully consider the proposals and the implications for children and families across Yorkshire and the Humber.

4. On a number of occasions during the inquiry, the Joint HOSC requested that a range of information be made available prior to the 5 October 2011 consultation deadline, which can be summarised as:

    - The detailed breakdown of assessment scores for surgical centres produced by the Independent Expert Panel (chaired by Sir Ian Kennedy);
    - A finalised Health Impact Assessment report;

- A detailed breakdown of information on the likely impacts on identified vulnerable groups across Yorkshire and the Humber referred to in the Health Impact Assessment (interim report);
- The Price Waterhouse Coopers (PwC)report that tested the assumed patient travel flows under each of the four options presented for public consultation;

5. With its report, *Scrutiny Inquiry Report: Review of Children's Congenital Cardiac Services (October 2011)*, the Joint HOSC reserved the right to make further comment if/ when additional information became available.

6. Since 5 October 2011, the following additional information has been considered by the JCPCT and made publicly available.

    - Testing assumptions for future patient flows and manageable clinical networks (PwC final report – October 2011)
    - Report (and associated letter) of Sir Ian Kennedy's panel in response to questions made by the JCPCT (17 October 2011)
    - Report of Dr Patricia Hamilton CBE, Chair of the Safe and Sustainable Steering Group, on behalf of Steering Group members (17 October 2011)

7. These detail are appended to this report for consideration by the Joint HOSC

Recommendations

8. Members of the Joint HOSC are asked to consider the additional information presented and determine what, if any, additional scrutiny action should follow.

Background documents

- Overview and Scrutiny of Health – Guidance (Department of Health (DH) (July 2003)
- A new vision for Children's Congenital Heart Services in England (March 2011)
- Scrutiny Inquiry Report: Review of Children's Congenital Cardiac Services (October 2011)

Testing assumptions for future patient flows and manageable clinical networks for Safe and Sustainable

In March 2011 the NHS *Safe and Sustainable* review published for consultation four options for reconfiguring children's congenital cardiac services in England. Public consultation ends on 1 July 2011.

The four alternative options make a number of assumptions about future patient flows and manageable clinical networks. These assumptions have been informed by detailed analysis of travel times and a consideration of current clinical networks. As part of the consultation process the review will test these assumptions around a small number of postcodes with parents of children with congenital heart disease, the general public and clinicians.

The postcodes for further testing have been agreed by the 10 Specialised Commissioning Groups in England applying the following criteria:

- Where assumptions have been made about travel to a particular surgical centre but where another surgical centre is closer or roughly equal in distance, such that it is reasonable to question alternative locations; and
- Where local intelligence suggests that new referral patterns / patient flows have already emerged as a result of a collaborative approach across current centres and which may have the effect of replacing the 'closest to home' principle

Postcodes for further testing are:

BD (Bradford and district)

BN (Brighton and district)

CV (Coventry and district)

DN (Doncaster and district)

DT (Dorchester and District)

GU (Guildford and district)

HD (Huddersfield and district)

HP (Hemel Hempstead and district)

HR (Hereford and district)

HU (Hull)

HX (Halifax and district)

LN (Lincoln and district)

LS (Leeds and district)

NG (Nottingham and district)

OX (Oxford and district)

PE (Peterborough and district)

RG (Reading and district)

RH (Redhill and district)

S (Sheffield and district)

SL (Slough and district)

WF (Wakefield and district)

WR (Worcester and district)

The National Specialised Commissioning Team, as secretariat to the review, has commissioned PwC to provide an independent analysis of three separate work streams:
1. Undertake interviews and focus groups with clinicians in relevant areas around future potential referral flows and the strength of existing relationships and current clinical networks
2. Undertake interviews and a survey with parents of children with congenital heart disease (a sample of parents across the determined postcode areas) around assumptions about patient flows and clinical networks, taking account of distance, transport links and the strength of existing relationships
3. Conduct focus groups with the general public (a sample of the general public from across the determined postcode areas) around assumptions on patient flows

PwC are presently working with the NSCT to agree the scheduling and content of discussions for these interviews and focus groups.
This work will be co-ordinated so that final reporting can occur for autumn 2011 and feed into the deliberations of the Joint Committee of Primary Care Trusts, who will be considering the outcome of the current public consultation during the autumn, before making a final decision on the future configuration of services.
Although this is an important part of consultation, this 'testing of assumptions' exercise should not be seen as usurping or substituting the public consultation process. This exercise is limited in scope and does not seek to canvass views on other elements of the matters consulted upon.
In addition to the limited exercise described, the consultation response form specifically asks all consultees whether they have any comments on the assumptions that have been made about patient flows. Consultees are also free to express their views in other forms of communication.
25 May 2011

www.pwc.com

National Specialised Commissioning Team (NSCT)

Testing assumptions for future patient flows and manageable clinical networks

Final report
October 2011

Workstreams 2, 3, & 4: Clinical, Parent & General Public

Executive Summary – Workstreams 2, 3 & 4

pwc

Table of contents

Executive summary:
Clinical, Parent and General Public

Evidence base:

- *Workstream 2*: Interviews with two nominated clinicians from each of the 11 surgical centres that were the focus of Safe & Sustainable (S&S). 153 responses to a postal survey (37% - 40+% response rate range) of referring paediatricians. Three clinician focus groups (42 clinicians) to 'sense check' Workstream 2 findings and agree issues.
- *Workstream 3*: 172 responses to a postal survey (25% response rate) by parents from the 22* postcode areas identified by the NSCT for testing and 21 telephone interviews with parents.
- *Workstream 4*: Focus groups with 102 members of the general public recruited from across the 22 postcodes identified for further exploration by NSCT.

**22 postcode areas*:
Bradford, Brighton, Coventry, Doncaster, Dorchester, Guildford, Hemel Hempstead, Hereford, Huddersfield, Halifax, Hull, Leeds, Lincoln, Nottingham, Oxford, Peterborough, Reading, Redhill, Sheffield, Slough, Wakefield and Worcester

Clinical, parent & public feedback

Referrals/patient flows

- Although clinician interviews on the whole identified the view that patient volumes would increase under *Safe & Sustainable* (S&S) options, they considered a degree of patient flows may not be as assumed on the basis of a number of specific postcode areas.
- In particular there were some postcode areas identified by clinicians and also the majority of parents and the public, where the indication would be that the S&S assumed surgical centre would not be the preferred choice.
- If patient flows for these postcode areas were factored into assumptions and projected levels of activity, they may have implications in particular for the Newcastle centre under Options A, B and C – ***see table overleaf.***
- That said, the majority of parents and the public also indicated if told/advised to go to an alternative centre compared to their preferred centre, they would consider the alternative. However there was more reluctance amongst members of the public to consider travelling to Newcastle as a centre.
- As per the table overleaf, there are also implications for the Leicester centre under Option A, the Bristol and Southampton centres under Option B and Leeds under Option D. *For note: in discussing options with parents and the public, the surgical centres referred to were as per those specific centres named for Options A – D in S&S (see Appendix).*
- Centres all indicated having plans to accommodate the increased patient flows under S&S options. However, clinicians expressed concern that the projected flows were worked out on children's procedures only, but practically grown up children's (GUCH) services would also be undertaken and these could stretch units beyond their capacity.
- When a number of referring paediatricians were surveyed about their referral patterns under the four options identified by S&S, they indicated that on the whole they would refer to the cardiac surgical centres assumed, even where this required a change in current referral behaviour – ***see table overleaf.***
- For example, 94% of referrers indicated complying with S&S assumptions under Option A and 44% suggested this would require a change in their referral pattern, while 97% of referrer under Option C would refer to the assumed centres and 59% of them would require a change in their referral pattern to do so for this option.
- The key factors identified by referring clinicians as determining their referral preference were: *Existing joint working relationships; Proximity of surgical cardiac centre; and Clinical outcomes.*
- When parents were asked to prioritise factors influencing choice of cardiac surgical centre, travel time was prioritised below factors such as: *Reputation of the centre; Recommendation from a GP or other healthcare professional; Availability of the surgical team and Previous experience of using the centre.*

Overview of clinician, parent & general public feedback

Referral behaviours and patient flows

✓ = *majority parents/public agree with S&S assumptions*	Postcode areas highlighted where parents & public prefer not to flow to S&S assumed centres			
	Option A	**Option B**	**Option C**	**Option D**
Freeman, Newcastle	Leeds, Wakefield	Leeds, Wakefield, Doncaster & Sheffield	Leeds, Wakefield, Doncaster & Sheffield	*N/A*
Alder Hey, Liverpool	✓	✓	✓	✓
Glenfield, Leicester	Coventry	*N/A*	*N/A*	*N/A*
Birmingham	✓	✓	✓	✓
Bristol	✓	Reading	✓	✓
London x 2	✓	✓	✓	✓
S/hampton	*N/A*	Brighton	*N/A*	*N/A*
Leeds	*N/A*	*N/A*	*N/A*	Nottingham

	% of Referring clinicians who would refer to surgical centre assumed by S&S	% of Referring clinicians who will need to change referral patterns to align with options	Key factors identified by the referring clinicians as determining their referral preference
Option A	118 (94%)	Yes (44%)	• Existing joint working relationships (34%) • Proximity of centre (28%) • Clinical outcomes (15%) • Personal professional relationship with the centre (14%) • Historical (7%) • Patient choice (1%)
Option B	114 (96%)	Yes (50%)	
Option C	114 (97%)	Yes (59%)	
Option D	112 (93%)	Yes (49%)	

Less disruptive → **More disruptive**

Key factors identified by parents influencing choice of cardiac surgical centre	Key factors identified by the general public as influencing choice of cardiac surgical centre
1. Reputation of centre 2. Recommendation from a GP or other healthcare professional 3. The surgical team available 4. Previous experience of using centre *These factors were the ones most commonly identified as influencing their current centre and preferred centre under the different S&S options.*	1. Ability to see the same team of doctors and nurses each time 2. The hospital has a good reputation 3. Availability and price of car parking facilities 4. Ability to spend enough time with doctors and nurses 5. The hospital has good facilities 6. Part of a network, where you could go to a local hospital for outpatient appointments and a specialist centre for surgery

- 153 referring clinicians responded to a survey; of these 105 out of 122 (86%) who reported their role identified that they were *not* a paediatrician with expertise in cardiology.
- 46% of respondents (70) indicated that their average number of referrals per annum to paediatric cardiac surgical services was in the range of 0 – 5.
- In terms of mode of travel, 142 parents (83%) indicated that they had access to their own car for either all or part of their journey.
- Most general public focus group participants indicated that they would travel by car; with less than 10% indicated that they would use public transport to access one of the current centres if travelling for surgery.

Source: PwC survey of referrers & parents, clinician interviews and focus groups with clinicians & general public

Clinical, parent & public feedback

Referrals/patient flows cont'd

- The general public highlighted: *Ability to see the same team of doctors and nurses; Hospital having a good reputation and Availability and price of car parking facilities,* as the factors that mattered to them.
- When a number of these findings were discussed at the three clinician focus groups that were held to 'sense check' primarily the clinical workstream findings, but also feedback from parents and the public, there were helpful comments from participants. In particular there were some views around the referrer survey results and factors to consider in interpreting the findings (table opposite).
- Overall the findings on referrals/patient flows generated good discussion in the clinical focus groups and led onto specific dialogue around issues identified by participants as important for debate, such as: managed clinical networks, the role of outreach clinics, cardiology centres (learning from the experiences of Manchester and Cardiff), retrieval and impact of S&S options on other services.

Clinical focus group questions/comments to consider in interpreting findings:
• The response rate for the referrer survey was queried and that too much reliance may be placed upon it. The response rate was in the range of 37% to 40%. In our experience this is positive for a postal survey where no reminders have been sent and it provides a good 'snap shot' of referral behaviours.
• The focus on referring paediatricians for this survey was also discussed; and whilst it was understood, there was a view that input from referring obstetricians would have been helpful, as increasingly cardiac problems are being detected at the antenatal stage.
• It was indicated that referral behaviours may vary dependent on the type of referrer and the nature of case presenting e.g. co-morbidities. Also the impact of patient choice and clinical outcomes on referral behaviour and commissioning behaviours was highlighted.
• It was highlighted that experiences/feedback can vary by what stage of the patient journey individuals/families are at.
• There was some surprise that travel did not feature as more of an issue with parents. The majority of parents surveyed indicated that they travelled to centres by their own private transport. Most members of the public (representing a range of socio economic backgrounds) who participated in focus groups also indicated that they would plan to travel to centres by car. Feedback suggested that when travelling with a child or children for a hospital appointment it was preferable (where possible) to use private transport.

Clinical, parent & public feedback

Travel times

- Given the smaller number of centres proposed under the four S&S options, as expected a lower proportion of parents estimated that they would be within one hour of a paediatric cardiac surgical centre under Options A – D when compared to current travel arrangements.
- The majority of parents indicated travelling to centres by their own private transport. Most members of the public who participated in focus groups also indicated that ideally they would travel to centres by car.
- Less than 10% of focus group participants indicated that they would use public transport if accessing surgery, although nearly 20% stated that they might use public transport when travelling for an outpatient appointment – ***see table on slide 5.***
- In addition, members of the general public identified some ideas on how S&S options could be made more amenable and accessible, and these are summarised in the table opposite.

Members of the general public identified how S&S options could be made more amenable and accessible under two themes of travel and information issues:

Travel Issues:

- Financial assistance with additional travel costs over and above distance to nearest hospital and help with car parking (e.g. no charge, reduced rates or vouchers).
- Affordable overnight accommodation; and an ambulance or personal transport for those in very remote areas.

Information Issues:

- More information on travel times, distances and routes to centres; as well as in terms of specialists available, waiting times and facilities to enable decision making.
- Flexible visiting times, ideally to fit with off-peak public transport; and accessible information and better co-ordination of public transport options.

Clinical, parent & public feedback

Managed clinical networks

- Clinicians at the centres mainly stated that currently 'informal' networks were in existence or elements of networks as envisaged by S&S.
- Referrers, as well as clinicians at the cardiac centres were supportive of the concept of clinical networks. They however identified varying levels of existing network development and suggested that the most well developed current networks were those related to centres that were more likely not to continue to be cardiac surgical units under S&S options - ***see table overleaf.***
- Clinical discussions did identify challenges with networks but also helpfully a range of enabling actions such as alignment with other networks, protocols being in place and communication channels being supported - ***see table overleaf.***
- In terms of managed clinical networks, while both parents and the general public were positive about the concept of these, there was more of a preference from parents to access all care at a specialist centre. This was somewhat in contrast to members of the general public who indicated it was more desirable to have care managed locally rather than travelling to a specialist centre all the time for all aspects of care.

Managed clinical networks - *see table overleaf*	
Views from parents	• Parents were asked whether they would prefer to have outpatient appointments and ongoing management of care at their preferred centre under each of the options or at a more local centre. A slightly higher proportion wished to access all care at a specialist centre. • 48 – 53% of parents across the four options indicated they would prefer to have all care at a specialist centre whereas 39 – 46% stated they would prefer to have outpatient appointments and ongoing management of care at a local hospital.
"It would depend if you would be seeing the same surgeon, if you could see the same surgeon or cardiologist as at the specialist centre then I would go to a local hospital, otherwise I would probably just travel." (Quote from parent) *"I would worry a lot about continuity of care and transfer of patient notes." (Quote from parent)*	
Views from members of the general public	• Overall networks were considered a good idea and members of the public felt that it was more desirable to have care managed locally rather than travelling to a specialist centre on several occasions.
Factors to consider to help support networks	• Members of the general public identified three key themes to help support the successful functioning of clinical networks, as follows: 1. Continuity of care within the team of health professionals. 2. Continuous and strong communication between the specialist centre and local care provider, supported by technology (e.g. email, video-conferencing). 3. Ability to meet the surgeon prior to an inpatient admission and ideally for one follow-up.

Overview of clinician, parent & general public feedback

Managed clinical networks

Under each of Options A - D, referring paediatricians indicated the most well developed network feature and the least well developed feature

	Option A	Option B	Option C	Option D
Most developed network feature	Development of the role of PECs (60%)	Development of the role of PECs (61%)	The delivery of non-interventional care in local care settings (51%)	The delivery of non-interventional care in local care settings (67%)
Least developed network feature	Formal protocols agreed by the surgical centre and local services (39%)	Formal protocols agreed by the surgical centre and local services (40%)	Formal protocols agreed by the surgical centre and local services (32%) and strengthened cardiac liaison teams (32%)	Strengthened cardiac liaison teams (39%)

Option A	Option B	Option C	Option D
Parents indicating preferring to have outpatient appointments &/or ongoing management of care at a local hospital by Options A – D:			
56 (44%)	51 (43%)	52 (46%)	52 (39%)
Parents indicating preferring to have all care at the specialist centre by Options A – D:			
67 (53%)	59 (50%)	54 (48%)	70 (53%)

- Respondents to the referrer survey, indicated that of the existing 11 centres which S&S identified, Leicester, Southampton, Bristol and Leeds appeared to have the most well developed network features, as envisaged by S&S.

Key challenges	Enabling factors - referrer survey/ focus groups
Links/alignment to other services	• Closer links between ante-natal, neonatal and adult cardiac services. • Improve transport arrangements through development/use of a critical care transport service.
Capacity for increased workload	• Increased capacity and space at future centres under selected option for medical and surgical cases and critical care. • Formal service level agreements in place.
Level of outreach clinics	• Increased capacity at outreach clinics and greater number of clinics. • Greater consistency in equipment and staff availability at clinics.

Key challenges	Enabling factors - referrer survey/ focus groups
Shared protocols and pathways	• Shared cardiac protocols. • Cross-network protocols/working arrangements.
Role of local paediatricians	• Increasing the number of PECs in local hospitals and appropriate support for nursing staff, with training and funding in place.
Commissioning and funding	• Robust commissioning arrangements in place and funding to support effective networks.
Communications	• Telemedicine with real time video imaging • Systems to support confidential sharing of patient notes across networks, as required.
Transition planning	• To support effective network operation and give all key stakeholders confidence that their views were being considered, a desire for transition planning was highlighted and sooner than later.

Source: PwC survey of referrers & parents, clinician interviews and focus groups with clinicians & general public

Clinical, parent & public feedback

Managed clinical networks cont'd

- Discussion of these findings in the clinician focus groups flagged that parents view's on networks were likely influenced by the fact that a number of children requiring cardiac surgery have several co-morbidities requiring specialist input and so the preference for parents would be to visit a centre that could address all their children's needs.
- Participants at the focus groups suggested that clarity was needed on how networks would be set up, and how they would function. Specifically they discussed the following, which overlaps with some of the feedback from the clinician interviews:
  - The need for transition plans to be developed and quickly operationalised once a preferred S&S option has been chosen. It was also highlighted that these should cover a range of factors including training at paediatrician and nursing level as well as 'step down' care.
  - Aligning the cardiac networks to other existing networks, such as those for foetal/obstetric services, neonatal services and grown up children in order that a holistic, child centred approach is taken to ensure that children with co-morbidities receive all services in a single centre or a small number of hospitals working together.
  - Clarity on how the network models would deal with cross-over between, for example London and the Midlands and specific postcode areas where clinicians indicated that there were issues or uncertainties.
  - The need for IT systems to support network functioning, particularly to promote good communication within and between centres and also to allow the confidential sharing of patient notes by professionals working across each network.
  - Clear guidance for referrers on how the system should operate in their area, supported by robust commissioning arrangements. Also clinical protocols developed by networks to reduce variation.
  - Funding arrangements for patient care to incentivise network functioning by being attractive to both the centres and peripheral units.
- Other themes that were highlighted by clinicians as needing further consideration in the spirit of supporting the principles of S&S were: *The role of the cardiology centre; Retrieval; Promoting positive clinical outcomes; Impact of S&S options on other services and Consistency in outreach clinics as well as support for community paediatricians and nursing staff.*

Clinical, parent & public feedback

Summary

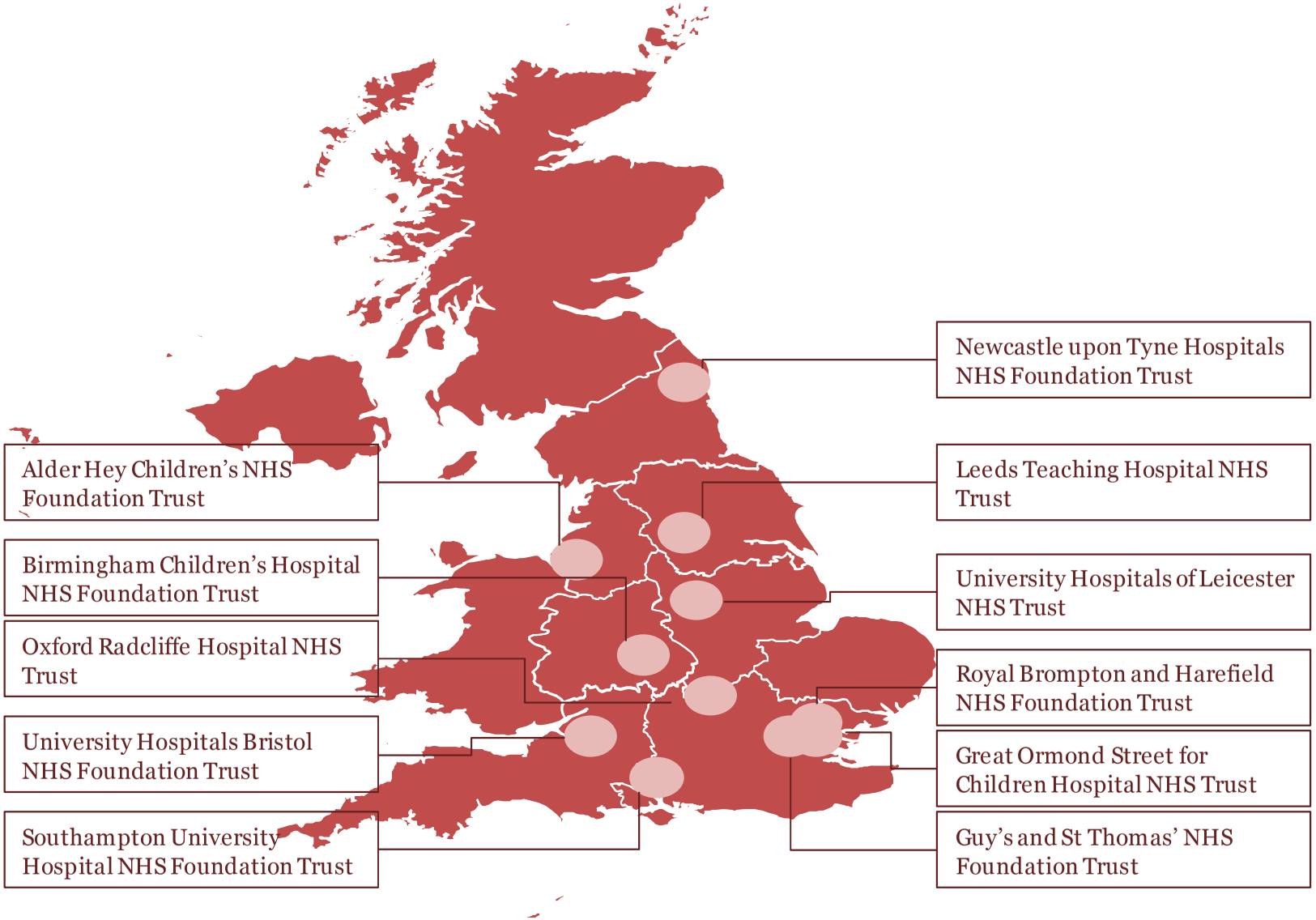
- Overall, the clinical, parent and public workstreams brought together a range of viewpoints but all were united in wanting to promote high quality services for children's heart surgery as well as providing constructive feedback on patients flows/referrals and managed clinical networks.
- On the whole the feedback was provided in the spirit of wanting the decision making process on S&S options to be appropriately informed of key facts and issues; and also for thought and consideration to be given to any associated transition and implementation plans.

Acknowledgements

- The PwC team is grateful to all those who have contributed to this project. In particular, we appreciate the contributions from parents of service users of paediatric cardiac surgical services, the general public and clinicians who have given up their valuable time in order to participate in surveys, interviews and focus groups.

Appendix

Safe and Sustainable Review - 11 centres focused upon...



Safe and Sustainable Review - Options A, B, C & D and associated centres...

Option A:	Option C:
Seven surgical centres at:	***Six surgical centres at:***
1. Freeman Hospital, Newcastle (NUTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Glenfield Hospital, Leicester (UHL) 4. Birmingham Children's Hospital (BCH) 5. Bristol Royal Hospital for Children (UHB) 6. Evelina Children's Hospital, London (GSTT) 7. Great Ormond Street Hospital for Children, London (GOSH)	1. Freeman Hospital, Newcastle (NUTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Birmingham Children's Hospital (BCH) 4. Bristol Royal Hospital for Children (UHB) 5. Evelina Children's Hospital, London (GSTT) 6. Great Ormond Street Hospital for Children, London (GOSH)
Option B:	**Option D:**
Seven surgical centres at:	***Six surgical centres at:***
1. Freeman Hospital, Newcastle (NUTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Birmingham Children's Hospital (BCH) 4. Bristol Royal Hospital for Children (UHB) 5. Southampton General Hospital (SUH) 6. Evelina Children's Hospital, London (GSTT) 7. Great Ormond Street Hospital for Children, London (GOSH)	1. Leeds General Infirmary (LTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Birmingham Children's Hospital (BCH) 4. Bristol Royal Hospital for Children (UHB) 5. Evelina Children's Hospital, London (GSTT) 6. Great Ormond Street Hospital for Children, London (GOSH)

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National Specialised Commissioning Team

Testing assumptions for future patient flows and manageable clinical networks

Workstream 2

Final report
October 2011

Workstream 2: Clinical – clinician interviews, referrer survey & focus groups

pwc

Table of contents

Executive summary:
Clinician interviews, referrer survey & focus groups

Evidence base:

- Interviews with two nominated clinicians (mix of cardiac surgeons, cardiologists and cardiac intensivists) from each of the 11 surgical centres which were the focus of S&S.

- 153 responses to a postal survey (37% - 40+% response rate range) of referring paediatricians.

- Three clinician focus groups to 'sense check' Workstream 2 findings and agree and discuss issues. These involved 42 individuals representing clinicians from the 11 centres, including liaison nurses, as well as referring paediatricians and network clinical leads, where in place.

Clinician feedback - Referrals/patient flows

- The clinicians interviewed from the 11 cardiac surgical centres were nominated by their Chief Executive and they were a mix of cardiac surgeons, cardiologists and cardiac intensivists. Although on the whole they identified patient volumes would increase under S&S options, they considered some patient flows may not be as per S&S assumptions on the basis of a number of specific postcode areas.
- In particular there were some postcode areas identified by clinicians and also parents and the public (via the parallel workstreams being undertaken) where the indication would be that the S&S assumed surgical centre would not be the preferred choice.
- If patient flows for these postcode areas were factored into assumptions and projected levels of activity, they may have implications in particular for the Newcastle centre under Options A, B and C – ***see table overleaf.***
- Centres all indicated having plans to accommodate the increased patient flows under S&S options. However, clinicians expressed concern that the projected flows were worked out on children's procedures only, but practically grown up children's (GUCH) services would also be undertaken and these could stretch units beyond their capacity.
- Alongside clinician interviews at the centres, referring paediatricians were contacted and requested to partake in a postal survey on the S&S options.
- The referring clinician survey found that 83% of referrers indicated having the same referral behaviour as other paediatricians in their Trust. Also the key factors they identified as determining their referral preference were: *Existing joint working relationships; Proximity of surgical cardiac centre; and Clinical outcomes.*
- When asked about their referral patterns under the four options identified by S&S, referring paediatricians indicated that on the whole they would refer to the cardiac surgical centres assumed – ***see table overleaf.***
- For example, 94% of referrers indicated complying with S&S assumptions under Option A and 44% suggested this would require a change in their referral pattern, while 97% of referrer under Option C would refer to the assumed centres and 59% of them would require a change in their referral pattern to do so for this option.
- When some of these findings were discussed at the three clinician focus groups which were held to 'sense check' the clinical workstream findings, there were helpful comments from participants in particular around the referrer survey results and factors to consider in interpreting the findings.

Overview of clinician feedback

Referral behaviours/patient flows

- Clinicians at the 11 centres identified in S&S highlighted a number of postcode areas where they considered that patients may not flow to centres assumed. When cross referenced to the postcode areas where parents of service users and the general public suggested S&S assumed centres were not their preferred centre of choice (8 postcodes identified by them), there were certain postcode areas consistently identified with potential implications for three of the four S&S options as follows:
  - **Option A** – patients *preferring to flow to Liverpool than Newcastle*
  - **Option B** – patients *preferring to flow to Birmingham or Liverpool than Newcastle*
  - **Option C** – as above, patients *preferring to flow to Birmingham or Liverpool than Newcastle*

- 153 referring clinicians responded to a survey; of these 105 out of 122 (86%) who reported their role identified that they were *not* a paediatrician with expertise in cardiology.
- Key factors identified by the referring clinicians as determining their referral preference were:
  - Existing joint working relationships;
  - Proximity of centre; and
  - Clinical outcomes.

Referral behaviours under S&S options

	% of Referring clinicians who would refer to surgical centre assumed by S&S	% of Referring clinicians who indicated their referral pattern would need to change to align with Options A-D
Option A	118 (94%)	Yes (44%)
Option B	114 (96%)	Yes (50%)
Option C	114 (97%)	Yes (59%)
Option D	112 (93%)	Yes (49%)

Less disruptive — **More disruptive**

Managed Clinical Networks

Under each of Options A - D, referring paediatricians indicated the most well developed network feature and the least well developed feature

	Option A	Option B	Option C	Option D
Most developed network feature	Development of the role of PECs (60%)	Development of the role of PECs (61%)	The delivery of non-interventional care in local care settings (51%)	The delivery of non-interventional care in local care settings (67%)
Least developed network feature	Formal protocols agreed by the surgical centre and local services (39%)	Formal protocols agreed by the surgical centre and local services (40%)	Formal protocols agreed by the surgical centre and local services (32%) and strengthened cardiac liaison teams (32%)	Strengthened cardiac liaison teams (39%)

Challenges for Future Networks

- Lack of alignment with other networks e.g. PICU, maternity and neonatal
- Reliance on paediatricians with expertise in cardiology (PECs) and funding required to have them in place
- IT channels/mechanisms to support networks, notes transfer and video imaging
- Referral guidance and clinical protocols in place to support consistency and quality

Source: PwC survey of referrers, clinician interviews and focus groups with clinicians

Clinical feedback

Referrals/patient flows cont'd

- There were comments relating to the response rate for the survey which was 37% to 40% and placing too much emphasis on this. In our experience this is positive for a postal survey with no reminders having been sent; and provided a good 'snap shot' of referral behaviours.
- The focus on referring paediatricians for this survey was also discussed; and whilst it was understood, there was a view that input from referring obstetricians would have been helpful, as increasingly cardiac problems are being detected at the antenatal stage.
- It was also indicated that referral behaviours may vary dependent on the type of referrer and the nature of case presenting e.g. co-morbidities.
- That said, overall the findings on referrals/patient flows generated good discussion and led onto specific dialogue around managed clinical networks, the role of outreach clinics, cardiology centres, retrieval and impact of S&S options on other services. In summary, there was acknowledgement and discussion of the patient flows in the focus groups and then an emphasis on discussing if S&S were implemented, what were some of the areas which would benefit from further planning and input.

Managed clinical networks

- Clinicians at the centres mainly stated that currently 'informal' networks were in existence or elements of networks as envisaged by S&S. Clinicians agreed with the S&S identified features of regional paediatric cardiac networks and had suggestions for ways of supporting/strengthening these, such as:
  - Robust network funding.
  - Communication assisted by telemedicine with real time video imaging.
  - National guideline/template for a network to promote consistency.

They also indicated challenges to networks such as:

  - Lack of alignment with other networks e.g. PICU, foetal and neonatal.
  - Reliance on paediatricians with expertise in cardiology (PECs).

- Referrers, as well as clinicians at the cardiac centres were supportive of the concept of clinical networks. They however identified varying levels of existing network development - ***see table on previous page.***
- Generally the feedback suggested that the most well developed current networks were those related to centres that were less likely to continue to be cardiac surgical units under S&S options.

Clinical feedback

Managed clinical networks cont'd

- Participants at the focus groups were likewise supportive of networks. However, they suggested that clarity was needed on how networks would be set up, and how they would function. Specifically they discussed the following, which overlaps with some of the feedback from the clinician interviews:
  - The need for transition plans to be developed and quickly operationalised once a preferred S&S option has been chosen. It was also highlighted that these should cover a range of factors including training at paediatrician and nursing level as well as 'step down' care.
  - Aligning the cardiac networks to other existing networks, such as those for foetal/obstetric services, neonatal services and grown up children in order that a holistic, child centred approach is taken to ensure that children with co-morbidities receive all services in a single centre or a small number of hospitals working together.
  - Clarity on how the network models would deal with cross-over between, for example London and the Midlands and specific postcode areas where clinicians indicated that there were issues or uncertainties.
  - The need for IT systems to support network functioning, particularly to promote good communication within and between centres and also to allow the confidential sharing of patient notes by professionals working across each network.
  - Clear guidance for referrers on how the system should operate in their area, supported by robust commissioning arrangements. Also clinical protocols developed by networks to reduce variation.
  - Funding arrangements for patient care to incentivise network functioning by being attractive to both the centres and peripheral units.
- Overall, the clinical workstream brought together a range of viewpoints from across surgical centres and referring clinicians. It captured a strong desire to promote high quality services for children's heart surgery as well as feedback on patients flows/referrals and managed clinical networks.
- Other themes that were highlighted by clinicians as needing further consideration in the spirit of supporting the principles of S&S were: *The role of the cardiology centre; Retrieval; Promoting positive clinical outcomes; Impact of S&S options on other services and Consistency in outreach clinics as well as support for community paediatricians and nursing staff.*

Executive summary:
Clinician interviews (Workstream 2)

Evidence base:

- Interviews with two nominated clinicians from each of the 11 surgical centres which were the focus of S&S.

- The clinicians were nominated by their Trust Chief Executive and were most commonly cardiac surgeons, cardiologists and cardiac intensivists.

- The interview format was designed to explore the S&S review options around patient flows and clinical networks.

Options A – D: Clinician's views on impact on patient volumes and patient flows

Option A	• Under this option, clinicians indicated that patient volumes would increase for six of the seven centres as anticipated. However, the Birmingham centre indicated that there would be a decrease, potentially below the 400 threshold and that it was due to the exclusion of 'out of area' referrals in the activity figures. • Clinicians also suggested some patient flows may not be as per S&S assumptions, such as for patients from Coventry, Northampton, Leeds, Sheffield and Hull.
Option B	• All centres under this option identified an increase in patient volumes. However, the Bristol centre highlighted as per S&S, the risk that the number of procedures per year would be below the 400 threshold and GOSH that it would be a 'net loser'. • Clinicians also suggested some patient flows may not be as per S&S assumptions, such as for patients from Hemel Hempstead, Guildford, Leeds, Sheffield, Doncaster, Northampton, Hereford, Worcester, Oxford and Reading.
Option C	• The six centres under this option identified an increase in patient volumes. • However, clinicians suggested some patient flows may not be as per S&S assumptions, such as for patients from Northampton, Leeds, Sheffield and Doncaster.
Option D	• The six centres under this option identified an increase in patient volumes. • Clinicians also suggested some patient flows may not be as per S&S assumptions, such as for patients from Northampton, Doncaster, Lincoln, Nottingham and Peterborough.

Clinical networks: Clinician's views on managed clinical networks

Current network arrangements	• Clinicians at the centres mainly stated that currently 'informal' networks were in existence or elements of networks as envisaged by S&S were in place.
Views on managed clinical networks as per S&S	• Clinicians agreed with the S&S features of regional paediatric cardiac networks and had suggestions for ways of supporting/strengthening these.
Challenges for clinical networks as per S&S	**Clinicians indicated challenges to networks such as:** • Lack of alignment with other networks e.g. PICU, maternity and neonatal. • Reliance on paediatricians with expertise in cardiology (PECs).
Factors to help support networks	**Factors to support network development identified by clinicians included:** • Robust network funding. • Communication assisted by telemedicine with real time video imaging. • National guideline/template for a network to assist with consistency.
General comments	• Clinicians participating in the interviews, appeared well informed and had been working with their Trusts to explore the implications of the different S&S options. • From their experience, clinicians recognised where clinical flows would be different from S&S, however indicated that these variations could generally be managed and altered over time. • There was strong engagement with robust managed clinical networks. • There was a general desire to see S&S finally concluded such that services could be developed accordingly.

Executive summary:
Referrer survey (Workstream 2)

Evidence base:

- 410 surveys were sent via 82 Clinical Directors of paediatrics (or their equivalent) in Trusts referring to one of the 11 centres. They were requested to self complete a survey, if appropriate and to circulate the survey to up to another 4 referring colleagues.

- The 153 responses received represents a response rate in the range of 37% to 40+% - dependent on whether all 82 Directors forwarded surveys to their colleagues.

Options A – D: where referrers would send patients and referrers priorities in determining referral preference.....

Option A	• 94% of referrers indicated that they would refer to surgical centre assumed by S&S under this option. • Referrers indicated that proximity to centre (67%) was the first priority under this option, with existing joint working relationships (55%) the second priority. • Patient choice (11%) was the lowest priority in determining preference under Option A.
Option B	• 96% of referrers indicated that they would refer to surgical centre assumed by S&S under this option. • Proximity to centre (62%) was the first priority for referrers, but under this option clinical outcomes (53%) was the second priority, followed by existing joint working relationships as the third priority (50%). • Historical (9%) was the lowest priority under this option.
Option C	• 97% of referrers indicated that they would refer to surgical centre assumed by S&S under this option. • Proximity to centre (68%) was once again the first priority under this option, with existing joint working relationships (48%) the second priority. • Historical (13%) and patient choice (12%) were the lowest priorities in determining referral preference.
Option D	• 93% of referrers indicated that they would refer to surgical centre assumed by S&S under this option. • Proximity to centre (69%) and existing joint working relationships (54%) were again the first and second priority under this option. • Historical (12%) and patient choice (12%) remained the lowest priorities in determining referral preference.

Clinical networks: would referrers be supportive of these ?

Views of clinical networks	• The survey results indicated that in terms of the key features of networks as identified by S&S, Birmingham and Newcastle had the least well developed networks. • Formal protocols and cardiac liaison teams were features of proposed Safe and Sustainable networks that showed the scope for most future development being required. • The majority (90%) of paediatricians indicated that they would agree or strongly agree with the principle of sending most referrals to the same centre in order to build relationships in local networks.
Factors to consider to help support networks	• Referring paediatricians most commonly identified five potential challenges associated with networks: 1) Transport and proximity 2) Capacity to handle increased workload 3) Need to increase level of outreach 4) Developing and agreeing shared pathways and protocols 5) Developing the role of local paediatricians

Executive summary:
Clinician focus groups (Workstream 2)

Evidence base:

- Three clinician focus groups to 'sense check' Workstream 2 findings and agree and discuss issues.

- A mix of 42 professionals attended these groups including clinicians from the 11 centres, referring paediatricians, clinical network leads and cardiac liaison nurses.

Summary of clinical focus group feedback

Overview of focus group discussions

- Three focus groups were undertaken on completion of analysis of a referring paediatrician survey, interviews at the 11 centres (that were the focus of S&S) and contact with parents and the public (via parallel workstreams). The purpose of the focus groups were to 'sense check' findings and discuss agreed areas for debate/of issue.
- The focus groups involved input from relevant stakeholders (42 individuals who were a mix of clinicians from the 11 centres, referring paediatricians, clinical network leads and cardiac liaison nurses) and on hearing feedback from the referrer survey and parent and public contact, there were a range of questions around methodology and points flagged for consideration such as:
  - How referral behaviours may vary dependent on the type of referrer and nature of the case presenting e.g. obstetric referrals, children with co-morbidities.
  - Variation in experience across outreach clinics could influence responses.
  - The impact of patient choice and clinical outcomes on referral behaviour and commissioning behaviours.
  - Experiences/feedback can vary by what stage of the patient journey individuals/families are at.
- Overall feedback from participants recognised that there were constraints around the scale and level of the work undertaken in the timeline and information available. However, the findings presented and answers provided to questions were found to be helpful and there was a general view that focus now needed to be given to how would the actual operation of a chosen S&S option be supported.
- As a result, the format of the groups was to then explore further areas of particular interest and/or concern to participants and to have an opportunity for their views to be heard and fed into the clinical workstream findings.
- The key areas that were repeatedly discussed across the groups were:
  - ***The role of the cardiology centre*** – would they add another layer but no value? Were referral routes via them clear?

    Participants did suggest that lessons could be learnt from Cardiff and Manchester where there are similar configurations. Shared appointments (staff from cardiology centres and surgical centres undertaking joint appointments) were also proposed as a helpful link for cardiology and surgical centres.

Summary of clinical focus group feedback

- *Functionality of networks* - the need to align the cardiac networks to other existing networks, such as those for foetal/obstetric services, neonatal services and GUCH was highlighted, in order that a holistic, child centred approach is taken.

  Also the need for IT systems to support network functioning, particularly to promote good communication within and between centres and to facilitate the sharing of patient notes by professionals working across each network .

- *Audit of staff skills* - to support the operation of networks and staff , it was felt that an audit across proposed surgical centres, cardiology centres and outreach clinics should be undertaken in order to identify any gaps in knowledge, skills or experience, so that training could be planned and put in place to address these gaps.

- *Retrieval protocols* - it was indicated that consideration needed to be given to the development of protocols covering whether patients are retrieved to a cardiology centre or a surgical centre, and recognising the challenge of retrieving patients within existing networks and beds availability.

- *Commissioning processes* - to support the provision of high quality care there was a call for robust commissioning and a review of funding arrangements to remove disincentives to operating managed clinical networking. This was particularly highlighted in relation to outreach clinics, which also was an area where it was felt greater consistency needed to be promoted.

- Overall, the clinical focus groups brought together a range of viewpoints from across surgical centres and referring clinicians. They captured a strong desire to highlight areas for further consideration and associated planning with regard to S&S options and all on the basis of promoting high quality services for children's heart surgery

Introduction and approach

Introduction to the study

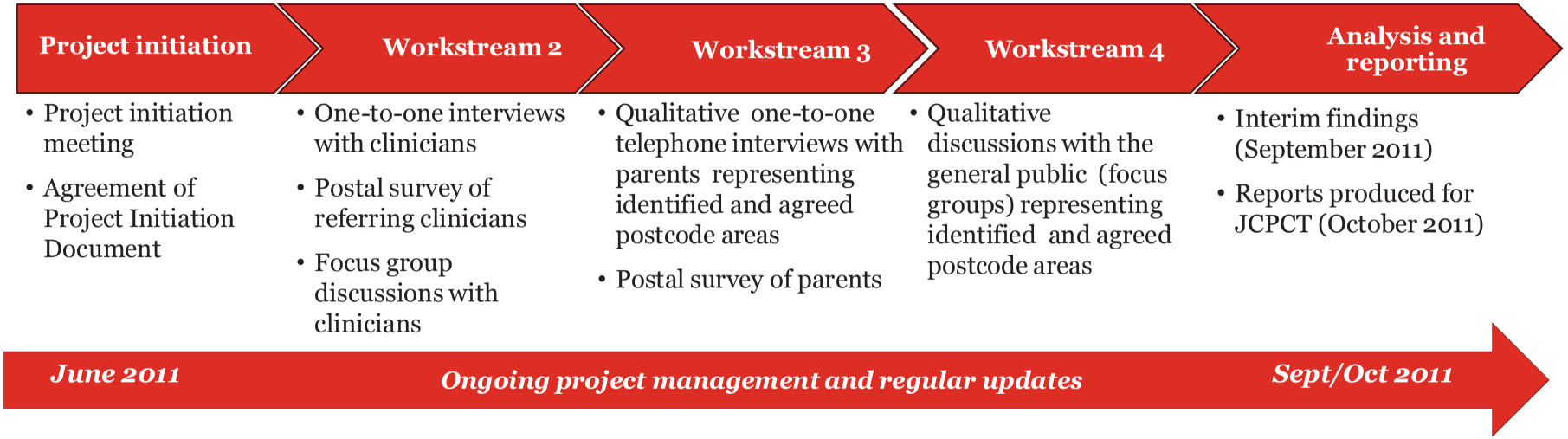
- PricewaterhouseCoopers LLP (PwC) was appointed by the National Specialised Commissioning Team (NSCT) to undertake a study on future patient flows and manageable clinical networks, as part of the *Safe and Sustainable* (S&S) review of children's congenital cardiac surgery in England.

- The study sought to examine the assumptions on patient flows that have been made across 22 postcode areas (diagram opposite) in England, under the four service reconfiguration options (Options A – D) which have been identified as part of this review (see Appendix). These assumptions have been informed by analysis of travel times (patients travelling to their nearest centre) and a consideration of current clinical networks.

- Key stakeholders involved in the project have been clinicians (Workstream 2), parents of services users (Workstream 3) and members of the general public (Workstream 4).

Methodology across Workstreams

- This final report presents the findings from Workstream 2 (clinical) and has three sections:
  - Feedback from clinician interviews at the 11 centres.
  - Findings from the referring clinician survey.
  - Clinician focus groups.
- The sections of the report relating to the clinician interviews and the referrer survey are broadly structured around the following themes:
  - Options A – D and centres where patients may flow/be referred to i.e. patient flows/referrals
  - Views on managed clinical networks.
- ***For note:*** in discussing options with parents and the public, the surgical centres referred to were as per those specific centres named for Options A – D in S&S (see Appendix).



Findings: Surgical Centre Clinician Interviews

- Approach to interviews

- Findings by interview theme:

  Patient patterns and impact on patient volumes;
  Managed clinical networks;
  Capacity & capability to deliver by the units under each option;
  Patient quality; and
  Summary of other issues raised.

Approach : Surgical Centre Clinician Interviews

- Most commonly two clinicians (Paediatric Intensive Care specialist and either a Paediatric Cardiac Surgeon or a Paediatric Cardiologist) at each centre were interviewed.
- These clinicians were nominated for interview after initial requests to their Trust Chief Executive.
- The interview format was designed to explore the S&S review options around patient flows and clinical networks. Interview themes explored the areas detailed in the following figure.
- The responses/findings recorded in the following slides are from the discussions with the clinicians in the centres. Validation checks have not been undertaken on these findings, they have been collated and presented in terms of the four options (A – D) identified by S&S.

Findings: Surgical Centre Clinician Interviews

Patient patterns and impact on patient volumes

Feedback on the surgical procedure number assumptions

The table describes the change in numbers of procedures for each centre per option as reported by the clinicians interviewed at the eleven centres. Clinicians at Birmingham Hospital identified that under Option A there would be a decrease, they indicated that S&S was based on data that included 'out of area' referrals which would not occur in this option. For the Bristol centre and Option B, the clinicians agreed with the concern in S&S that this would be below the 400 threshold. Also GOSH, identified a 'net loss' in activity terms under Option B.

	Option A	Option B	Option C	Option D
Birmingham Hospital	Down , below 400 threshold	Increase	Increase	Increase
Bristol Royal Hospital	Increase	Increase, but below 400 threshold	Increase	Increase
Great Ormond Street Hospital	Increase	Increase, but overall a 'net loss'	Increase	Increase
Evelina Hospital, London	Increase	Slight / marginal increase	Increase	Increase
Glenfield Hospital, Leicester	Increase	Surgical unit close		
Alder Hey Hospital, Liverpool	Increase	Increase	Increase	Increase
Freeman Hospital, Newcastle	Increase	Increase	Increase	Surgical unit close
Southampton General Hospital	Surgical unit close	Increase	Surgical unit close	
Oxford Radcliffe Hospital	Surgical unit close			
Royal Brompton Hospital, London	Surgical unit close			
Leeds General Infirmary	Surgical unit close			Increase

Feedback on patient flows for each Option

On the basis of their experience, the surgical centre clinicians provided feedback on patient flow patterns under the four options. These are summarised below, with variance from S&S assumptions shown in red font.

	Option A	Option B	Option C	Option D
Birmingham Hospital	Fewer out of area referrals			
Bristol Royal Hospital	Oxford, Reading and Southampton likely to go to London Yeovil, Dorchester and Bournemouth may not come to Bristol	Parts of Plymouth may continue to go to Southampton Dorchester may not come to Bristol	Oxford, Reading and Southampton likely to go to London Yeovil and Dorchester may not come to Bristol	
Great Ormond Street Hospital	Northampton lost from GOSH in all options			
		Doubt that current patients from Hemel Hempstead would go to Southampton. Guildford patients may not go to Southampton.		
Evelina Hospital, London	Currently see some Brighton and Hove patients	Overlaps and existing patient flows between Southampton, Evelina & Brompton		
Glenfield Hospital, Leicester	Gain Sheffield and Doncaster Coventry and Warwick patients may still choose Birmingham	Surgical unit would close •Patients would go to Birmingham or London •Northampton patients likely to go to London •North Peterborough and South Lincolnshire will be a problem especially around retrieval		
Alder Hey Hospital, Liverpool	If Leeds closes, Liverpool will receive patients from Leeds/Sheffield			
		Doubt Doncaster and Sheffield would go to Newcastle		

Continued - Feedback on patient flows for each Option

	Option A	Option B	Option C	Option D
Freeman Hospital, Newcastle	Calculating numbers on assumption of taking circa 1/3 of Leeds patients	Calculating numbers on assumption of taking circa 2/3 of Leeds patients		Surgical unit would close
Southampton General Hospital	Surgical unit would close Patients to Bristol or more likely to go to Evelina Reading and Oxford likely to go to Bristol	Hereford & Worcester likely to go to Bristol, while Brompton cases to Southampton Patients are expected to go to Bristol but query if this would happen, Dorchester patients likely still to come to Southampton.	Surgical unit would close Patients to Bristol or more likely to go Evelina Reading and Oxford likely to go to Bristol	
Oxford Radcliffe Hospital	Surgical unit would close North of Oxford would go to Leicester	Surgical unit would close South of Oxford in particular, and Reading likely not to go to Bristol unless it is the only unit with capacity. It is more probable that they will go to London or some to Southampton	Surgical unit would close	
Royal Brompton Hospital, London	Surgical unit would close Oxford patients and those displaced from other centres are likely to come to London	Surgical unit would close As Option 'A', but with Southampton, there may be fewer patients coming to London and without Leeds/Leicester, there may be more for London	Surgical unit would close As Option 'A' without Southampton/Leeds/ Leicester may be more patients for London	Surgical unit would close As Option 'A' without Southampton/Leicester there may be more patients for London
Leeds General Infirmary	Surgical unit would close Bradford patients to Liverpool Leeds and Hull patients more likely to go to Liverpool, or even London, rather than Newcastle	Surgical unit would close Sheffield and Doncaster patients more likely to go to Birmingham (or Liverpool) than Newcastle		Some Newcastle patients would go to Glasgow. Cumbria patients to Liverpool or a few to Glasgow Leicester patients would go to Leeds, Birmingham or even Southampton

Other issues raised around patient volumes and flows

During the interviews, clinicians reported other issues for consideration around patient volumes and flows, as summarised below.

	Option A	Option B	Option C	Option D
Birmingham Hospital	Similar footprint to existing	Would have to absorb Leicester's catheter work circa extra 250 per year. Increase to circa 750 surgical cases per year - still manageable as a single team Relative reduction in complexity of cases as doing more "routine" work, though absolute numbers of complicated cases remains as at present		
Bristol Royal Hospital	Who will mandate the patient flows? It is possible that referral behaviour may not shift? Ultimate referral decision will depend upon bed availability Where complex patients have co existing non cardiac condition they will go to where both conditions can be treated			
		Will be the smallest unit in the country in this option and not appealing		
Great Ormond Street Hospital	Likely to be a "net" gain Business plan to have 3-5% gain on current 650 cases	GOSH likely to be a net "loser" of patients Reduction in numbers would limit development potential and impact upon GOSH ambition to be amongst the best in the world as the only UK hospital capable of achieving this	Likely to be a "net" gain Business plan to have 3-5% gain on current 650 cases	
Evelina Hospital, London		Leicester and ECMO is removed – other centres would have to do respiratory ECMO		
Glenfield Hospital, Leicester	Would need to expand PICU, at capacity already	Surgical unit would close Gap in ECMO capability and capacity – take minimum of five years to develop ECMO service		
Alder Hey Hospital, Liverpool	As it is likely that Leeds and Sheffield (and possibly Doncaster) patients would come to Liverpool rather than Newcastle, numbers would increase to c irca 550/600 cases in each of these options			

Continued - Other issues raised around patient volumes and flows

	Option A	Option B	Option C	Option D
Freeman Hospital, Newcastle	Volume of procedures increase by circa 100 per year Would have to absorb circa 70 extra catheter studies per year	Volume of procedures increase by circa 200 per year Would have to absorb circa 140 extra catheter studies per year		Surgical unit would close
	Relative reduction in complexity of cases as doing more "routine" work as Leeds do not do the same level of complex work			
Southampton General Hospital	Surgical unit would close	Changing existing referral patterns would be very difficult	Surgical unit would close	
Oxford Radcliffe Hospital	Surgical unit would close			
Royal Brompton Hospital, London	Surgical unit would close 85% of PICU cases are cardiac (not all surgical), this is circa 400 annually that would be displaced, hence PICU would become unsustainable. 400 catheters per year would also stop.			
Leeds General Infirmary	Surgical unit would close Leeds has 14 million population within two hours drive, Newcastle has just 2 million Leeds could be part of three or four networks, difficult to know where to send a sick baby especially in the middle of the night			Infrastructure would need to grow, Trust board in support of this

Findings: Surgical Centre Clinician Interviews

Managed Clinical Networks

Existing relationships, challenges and enablers to S&S network options

Clinicians were asked to indicate their current networking arrangements and how these would be impacted by the four options.
All clinicians agreed with the principals/features of a managed clinical network as identified by S&S.

	Option A	Option B	Option C	Option D
Birmingham Hospital	• Informal learning network exists but needs better management and more strategically operated • Have good working relationships with existing referring hospitals			
	• Would lose existing cardiology outreach service in Burton, Derby and Coventry	• Willing and able to extend network across these options • Leicester would become children's cardiology centre and use their existing network across the East Midlands		
Bristol Royal Hospital	Elements of the network exist			
		Will be smallest unit in country under this option which could affect networking ability		
Great Ormond Street Hospital	• Currently a model exists and is working very well and an intermediate layer between GOSH and the local centre is not therefore welcomed • Network areas currently patchy, S&S would help to define geographical areas • Current good links with Oxford including telemedicine link			
		• The reduction of numbers in this option is a block to effective networking		

Continued - Existing relationships, challenges and enablers to S&S network options

	Option A	Option B	Option C	Option D
Evelina Hospital, London	Currently networks are haphazard			
	Stronger links need to be developed in the absence of Brompton and Southampton. Challenges around Southampton doing things differently to Evelina	Need to reduce any ambiguity between Southampton and Evelina pathways, as they overlap	Paediatricians would abide by managed clinical networks especially for Option C	Risky option as loss of transplant centre in Newcastle
Glenfield Hospital, Leicester	Current network is gearing to look like Option A	Surgical unit would close This would affect current outreach service in Derby, Nottingham, Mansfield, Lincoln, Boston, Grantham, Peterborough,Kettering and new service in Nuneaton Could use these outreach services in new networks Question the value of a cardiac centre if left with non-interventional work		
		London going to South Lincolnshire would be difficult, would need air ambulance retrieval		Nottingham may not wish to alter its network to look North
Alder Hey Hospital, Liverpool	• Current networks exist but are informal. A formal network will need to be created and managed as well as being backed by the surgical centre • Formalising the network will be a challenge • Cardiac surgeons from Evelina come to Liverpool a few times a year. Also have relationships with Manchester and GOSH but no managed clinical networks exist here			
		Manchester and Leeds could act as surgical recovery centres		

Continued - Existing relationships, challenges and enablers to S&S network options

	Option A	Option B	Option C	Option D
Freeman Hospital, Newcastle	• Would need to take on a further 14 outreach sites, though Leeds could serve these • Currently have informal networks within the region • Willing to build new network, however forming functional relationships could be an issue • Need to develop protocols, standards and scale outreach			Unit would close Risk of reduced transplant expertise, links and protocols
Southampton General Hospital	Surgical unit would close • Blue babies would not go to Southampton as it will not be a cardiac surgical centre	• Existing clinical networks with West Sussex and Dorchester but would need to build relationships with Guildford, Redhill and Brighton	Surgical unit would close • Blue babies would not go to Southampton as it would not be a cardiac surgical centre	
Oxford Radcliffe Hospital	Surgical unit would close Networking is possible but who would be working in Oxford? Difficult to work on split sites Neonatal units will have to be centralised also			
Royal Brompton Hospital, London	Unit would close • Elements of a network in place with Cardiac Liaison Nurses, and a partnership model with 30 years of relationship history, which will be difficult to replace/reconfigure • All London hospitals need to work together			
Leeds General Infirmary	• Clinical risk from confusion caused by dealing with multiple networks • Ill feeling has developed by the S&S process which could hinder network development			
	• Unit would close			Leeds has a good existing network

Cross cutting network themes

Interviewees discussed a range of issues in the interview process and the following are the key themes relevant to networking that were highlighted.

Alignment:

- Other networks such as PICU, maternity and neonatal are not aligned with the proposed S&S options

Co-location:

- Co-location of other services, general surgery, maternity etc. should have more importance
- Cardiologist and Surgeon are best co-located in the same unit

Referrers and referral processes:

- Over reliance upon Paediatricians with Expertise in Cardiology (PECs) which may be neither possible nor reliable
- Must not have too many referring layers within the network

Communication is Key:

- Telemedicine with real time video imaging is essential

Robust and adequate network funding is required:

- This requires local investment in equipment, which has not been forthcoming

A national guideline/template for a network needed for consistency:

- Currently 'informal' networks in existence or elements of networks as envisaged by S&S were in place, a national guideline would help support consistency

Over emphasis of surgical rather than medical care:

- The Safe and Sustainable review focussed on the surgical side of things and not the same consideration give to the medical aspect

Findings:
Surgical Centre Clinician Interviews

Capacity and capability to deliver by the units under each option

Capacity and capability

Clinicians reported the impact of the options on their unit's capacity and capability to deliver , as summarised below.

	Option A	Option B	Option C	Option D
Birmingham Hospital	This is more or less "as is" current service delivery	• Capability and capacity to deliver the service especially with new theatre and ICU beds • Relative drop in complexity of cases, however already scaled to cope with large increase in numbers • ICU is a potential issue but this has been considered and scaled • Ward capacity would be stretched but there are plans to build an extra ward to meet demand • Increased catheter numbers but can absorb these. • Loss of ECMO service from Leicester which should be diffused to other centres and Birmingham have capacity also		
Bristol Royal Hospital	Capacity to increase work across all options			
		Total numbers may not reach 400 threshold Do not need two units in South in the same option that makes Birmingham too big	Prefer six centre options as per 'C' & 'D'	
Great Ormond Street Hospital	• Not likely to be much impact, but not as sustainable (clinically or financially) as 'C' or 'D'. • Aiming for 740 cases p.a. (increase of 90) and moving to a new building		Six unit options are more sustainable financially and clinically	
Evelina Hospital, London	• Can cope with demand but would have implications for MRI, cath lab and patient accommodation	• Can cope with demand but would have implications for MRI, cath lab and patient accommodation • Can do respiratory ECMO and develop this service		

Continued - Capacity and capability

	Option A	Option B	Option C	Option D
Glenfield Hospital, Leicester	• Have capacity and the Trust has a funded business plan to develop the cardiac services over the next few years if the option is chosen • Very little capital cost involved due to good facilities on site and capacity for expansion	Surgical unit would close • This would make Leicester an out-patient only service and it would become increasingly difficult to recruit and retain cardiology and ICU expertise • If Leicester closes there is a big gap in ECMO capability and capacity rendering it unsafe for children who require ECMO • 100 trained ECMO nurses would not move from one centre to another therefore there would be a loss in capability • Leicester has training, capability and capacity which would have to be developed elsewhere • It would not just be cardiac surgery that moves but intensive care and ECMO also. Birmingham can take additional load of paediatric cardiac surgery but would not be able to take up the additional load of intensive care patients		
Alder Hey Hospital, Liverpool	• An addition of 100 patients means two extra beds and two extra surgeries a week which is possible • Medical centres would not have great skills and would have to focus on taking medical cardiology to a new level • Training and accreditation would be an issue in the new cardiology centres • Better planning of in-patient cases and better step down bed management and co-ordination with new cardiology centres in Leeds and Manchester. • There would be no impact on capacity to deliver			

Continued - Capacity and capability

	Option A	Option B	Option C	Option D
Freeman Hospital, Newcastle	• Considering children only there is capacity to cope but in reality there is a need to consider GUCH (grown up children heart services) which would require a new build and plans have been drawn up which estimate a required investment of £6m • Biggest staff issue is a national one of not enough Echo technicians or perfusionists. • For PICU there is a threshold that will be crossed requiring increased staff for option A which would be able to manage B and C. The need for space is a linear relationship with increased numbers			Surgical Unit would close
Southampton General Hospital	Surgical unit would close *(See further explanation as per Options C and D)*	• Plans to build another block (PICU) to add another 150 patients • Confident that would be able to handle additional workload	Surgical unit would close • Capacity would have to be reduced and cardiac surgeons relocate or move to adult cardiac surgery • Since the capacity and capability would get affected, level in clinics would diminish • There would be no / less liaison service / nurses • Possibility of destabilising PICU and due to it being downgraded recruitment and retention of paediatric anaesthetists would be difficult. • Retrieval service would have to move to London or Bristol	
Oxford Radcliffe Hospital	Surgical unit would close Issue with ability to deliver cardiac medical service and PICU			

Continued - Capacity and capability

	Option A	Option B	Option C	Option D
Royal Brompton Hospital, London	Surgical unit would close • If paediatric cardiac goes, adult congenital services would be adversely effected too, due to loss of a natural source of new patients. This would be a loss of about 10% of Trust turnover. ENT, dental and other services to those with heart and lung problems would be lost. • Adverse impact on quality in the remaining services, due to loss of co-location/adjacency of (back up and support) services • Sessional/ad hoc staff could be engaged, but they would not be 24/7, and the bringing in of extra problems: e.g. decreased quality, increased travel times, and decreased safety. • All potential mitigation, e.g. for respiratory bronchoscopy support, would be a negative compromise compared with the status quo – cardiac might be made a little better at the expense of making respiratory services worse			
Leeds General Infirmary	Surgical unit would close • Investment would be required in transport, and cardiology services. • Would become an outpatient department and all other paediatric surgical services would stop • The reconfiguration would be a move backwards to fragmented services • Loose Leeds as a fully integrated service , general surgery, maternity etc all on same site. Other units are stand alone cardiac centres			• More cardiologists required • No slack in current system, an increase of 10% workload would destabilise • There would be an increase to 600 cases per year which would mean change in infrastructure would be required

Findings:
Surgical Centre Clinician Interviews

Patient Quality

Key patient quality GAINS

Clinicians reported the following potential gains to patient quality, in terms of safety, experience and clinical outcomes, under each option

	Option A	Option B	Option C	Option D
Birmingham Hospital	"As Is"	• Move towards "one stop" outpatient system of ECGs and Echos to avoid multiple visits. Can fit 24 hour ECG for return next day • Patient experience in terms of delays and cancellations mitigated by doubling theatre space and increasing ICU capacity		
Bristol Royal Hospital	Quality depends upon resources, increasing activity would increase quality – important to have a number of patients annually to maintain staff resource level and for adequate training and development			
Great Ormond Street Hospital	• With GOSH's 650 (or more) cases, the volume of activity to support good patient experience, outcomes and the volume of activity for academic work			
Evelina Hospital, London	• Key gain is to have a minimum number of surgeons in each centre. • Neuro, ENT, etc in the same location which is important for safe delivery			
Glenfield Hospital, Leicester	• Retains nationally recognised respiratory ECMO centre that would not easily transfer to another site • Travel times reduced as 11m population of Midlands compared with 7m in London, makes sense to have two Midlands centres re travel aspect	Surgical unit would close		
Alder Hey Hospital, Liverpool	• If well planned, patient safety would not be affected – managed clinical networks would be crucial to supporting patient safety			

Continued - Key patient quality GAINS

	Option A	Option B	Option C	Option D
Freeman Hospital, Newcastle	• Increased numbers allows for more skilled staff and more procedures to take place therefore improving outcomes			Surgical unit would close • Population density is greater around Leeds so travelling times reduced in this option
Southampton General Hospital	Surgical unit would close	• Correcting findings in S&S regarding travelling times would promote this option in terms of access and support patient experience in that regard	Surgical unit would close	
Oxford Radcliffe Hospital	Surgical unit would close			
Royal Brompton Hospital, London	Surgical unit would close			
Leeds General Infirmary	Surgical unit would close			• All services are located in one place in Leeds with the interdependencies, this is not the same for other centres, therefore there is likely to be gain from this option in that patient experience of 'one stop' shop for services

Key patient quality RISKS

As well as reporting on patient quality gains, clinicians also fed back views on quality risks in terms of safety, experience and clinical outcomes for each option.

	Option A	Option B	Option C	Option D
Birmingham Hospital	• Reduced numbers, possibly below 400 hence skills would be reduced	• Transport from Lincoln would be an issue • If numbers increase above 800 the evidence suggests that it would have to fragment to function and this could be counter effective		
		• Closing ECMO in Leicester and thus this function would have to be dispersed		
Bristol Royal Hospital	In the absence of a 'driver' of patient flows, would centres like Bristol get the patient flows – activity may not be as projected and could have impact on quality			
Great Ormond Street Hospital	Little impact	• As a 'net loser' reduced numbers would lead to reduced quality • Possible that reduced numbers could also reduce charitable donations	Little impact	
Evelina Hospital, London	• Over emphasis on time to travel - ICU starts when patient first seen not when they arrive at centre • However, still need to mitigate risk, retrieval service on Isle of Wight (IoW), mitigated by Southampton continuing to do this, directing to either Southampton (medical) or Evelina (surgical)			
Glenfield Hospital, Leicester		Surgical unit would close • It will take five years to develop an ECMO service therefore this will lead to unsafe ECMO provision in make shift arrangements. There are 150 respiratory cases in one year, these cases may get treated by ventilators and could lead to a higher mortality rate making these options unsafe. • Have other centres the appropriate configuration i.e. space for parking, air ambulance or expansion.		

Continued - Key patient quality RISKS

	Option A	Option B	Option C	Option D
Alder Hey Hospital, Liverpool	• Managed clinical safety is crucial to ensure patient safety, formalising it will be difficult and is a key risk. • It is not completely safe for medical cardiac centres to do diagnostic catheterisation.			
Freeman Hospital, Newcastle		Too large a scale could risk quality, continuity and team working		Surgical centre would close • National Transplant Centre would have to move to Birmingham
Southampton General Hospital	Surgical centre would close *(See further explanation as per Options C and D)*		Surgical centre would close • From IoW would take more time to go to Bristol or London • Southampton is one of the quality centres across the country, removing it would affect clinical outcomes negatively • Fragmentation of a good team is not good for outcomes and there would be lower staff calibre due to issues with recruitment and retention - affecting clinical service quality	
Oxford Radcliffe Hospital	Surgical centre would close • Potential for pre op mortality to increase with increasing travelling times			

Continued - Key patient quality RISKS

	Option A	Option B	Option C	Option D
Royal Brompton Hospital, London	Surgical centre would close • Disruption to existing team therefore performance would not be at the same level and things would get worse before improvements are realised. Mitigated by having a phased change with clinical ownership • Staff may not comply with the changes			
Leeds General Infirmary	Surgical unit would close			• East Coast patients would be particularly at risk because of travel, even under this configuration, but with Option 'D' the service should be better than other options
	• Model is reliant on PECs which are new posts and hundred's would be required. They are not paediatric cardiologists, and they have limited skills and would need support • Increased risk to a large numbers of patients who would have to travel • Finite numbers of ambulances, they could be in use when required by the next patient			

Summary of other key issues raised during the centre interviews

Centre specific comments

Other centre specific comments

	Other centre specific comments comments
Birmingham Hospital	• Future capacity would have to cope with increased antenatal detection which has not been well developed in the Midlands
Bristol Royal Hospital	• Not enough importance given by S&S to co-location • Clarity of the role of cardiology centres and nature of cases they will treat especially in relation to individuals with co-morbidities
Great Ormond Street Hospital	• 400 cases a year, a modest number, with a greater number (650 or more) patient experience and outcomes supported
Evelina Hospital, London	• Managed clinical networks and no ambiguity – referral networks and pathways
Glenfield Hospital, Leicester	• Need to ensure units do not become too big. London could serve just inside M25 so patient flows from elsewhere are more local • "We cannot transplant Leicester ECMO service to another place, we would have to start it all over again"
Alder Hey Hospital, Liverpool	• Availability of beds in the lead centre would impact on referrals – effective capacity planning very important
Freeman Hospital, Newcastle	• GUCH is a significant issue and it is highly likely that GUCH would follow paediatrics and it is the Leeds GUCH that would require the biggest reconfiguration at Newcastle as it provides both services • Managing the transition is critical; this must be at a national level and by an external body
Southampton General Hospital	• No meaningful analysis of patient journey times for the IoW was made in the analysis. Inclusion of ferry times could mean that option A, C and D could impact the 90 minute patient travel times
Oxford Radcliffe Hospital	• Assess what is going to happen to the medical cardiology centres - become office based cardiology units with depleting skills. They may initially do diagnostic interventions but that in the long term retaining this is questionable. An impact on overall neonatology service in those centres , as a number of neonates have problems related to the heart

Other centre specific comments

	Other centre specific comments comments
Royal Brompton Hospital, London	• S & S did not really look at 'quality' e.g. for RBH it was research based, and was it properly assessed? • Do Evelina and GOSH actually have the capacity (particularly the estate) to cope with increased numbers? • Services could be rationalised around London as a whole. Distribution is unlikely to be based on the Thames (i.e. North/South), as that is not how transport works
Leeds General Infirmary	• Surgical mortality is maybe 3-4% (in many cases 1%); the reconfiguration might improve this a little, but there is evidence that the pre and post surgery care (including transport) can influence the overall mortality by 2.5 times .Therefore the reconfiguration may have implications regarding mortality overall

General issues raised by clinicians in the interview process

Managing the transition is key to success:

- This would be best done centrally and with an emphasis on people factors being critical and clinical ownership of the transition essential

Future for the decommissioned units:

- Downgrading to a cardiology centre impacts upon many other surgically dependant services including PICU expertise. There was an apprehension that these units would not manage medically sick cardiac patients. These are children with complex needs and hence other specialist services may also decline. Units would find recruitment and retention difficult, further compounding the problem

London dynamic:

- It remains unclear how London would divide up its patients. North of the river/South of the river has been assumed but has this been worked through especially in terms of transport links

Travel times:

- There are mixed messages, some say that it is the time that the patient is first seen that matters (i.e. before travel) others say that the longer the travel time the higher the surgical mortality. Concerns exist around the calculation of journey times in the S&S consultation document

ECMO services:

- There is broad interest in providing these but a recognition that they would take years to become fully effective when building from an inexperienced unit

GUCH (grown up children's heart services):

- Concern that in reality the location of these services would have a significant impact upon capacity of children's services that has not been adequately addressed

Retrieval services:

- National consideration for retrieval services required - perhaps delivered through networks

Service funding:

- Appropriateness of the current tariff system for this long term condition - tariff payments to referral centres acting as a disincentive to networks

Findings: referring clinician survey

- Approach to referrer survey
- Findings from referrer survey

Overview of questionnaire used for surveying referring paediatricians

- Based on national HES referral data from the 11 paediatric cardiac surgical centres that were a feature of S&S, the PCTs and corresponding hospital Trusts which refer/have referred to these centres were identified and a sample of 82 Trusts referring less than 85% of patients to the centres were determined – this was on the basis that their referral patterns were not clear cut and therefore could influence the success or otherwise of the future service configuration and network arrangements proposed by S&S.
- An internet search and telephone calls were undertaken to identify the Clinical Director for Paediatrics or an equivalent at these 82 Trusts. This Director was then sent a survey, along with four additional surveys for distribution to referring colleagues in that Trust. A four week response period was given and this was extended where requested for people who had been on leave/out of the office.
- The table below provides a summary of the key questions which were covered in the survey.

Section	Description
Current referral patterns	Clinicians were asked to indicate the centre to which they currently refer most of their patients, whether their referral patterns were in line with other colleagues in their Trust and the factors which influence their current referral decisions. Data was also gathered on the average number of referrals made per year.
Exploring the four options	Each of the options were explored in turn by asking clinicians where they would refer patients in terms of cardiac surgical centres under each of the options and the main factors which influenced their decision. This section also explored whether this would require a change from current referral patterns, and how many patients they would refer to each of the centres under the four options per year.
New network arrangements	Clinicians were asked whether the six features of the proposed managed clinical networks under S&S were currently in existence for the centre which they had selected under each of the options. They were also asked to identify the challenges which exist with taking part in such a network, and what might need to be developed to make it viable.
Other comments	Clinicians were also asked to note any other comments specific to this work around testing patient flows as part of the S&S review.

Source: PwC survey of referring paediatricians

Overall 153 responses to the survey were received, with paediatricians currently referring to all eleven surgical centres…

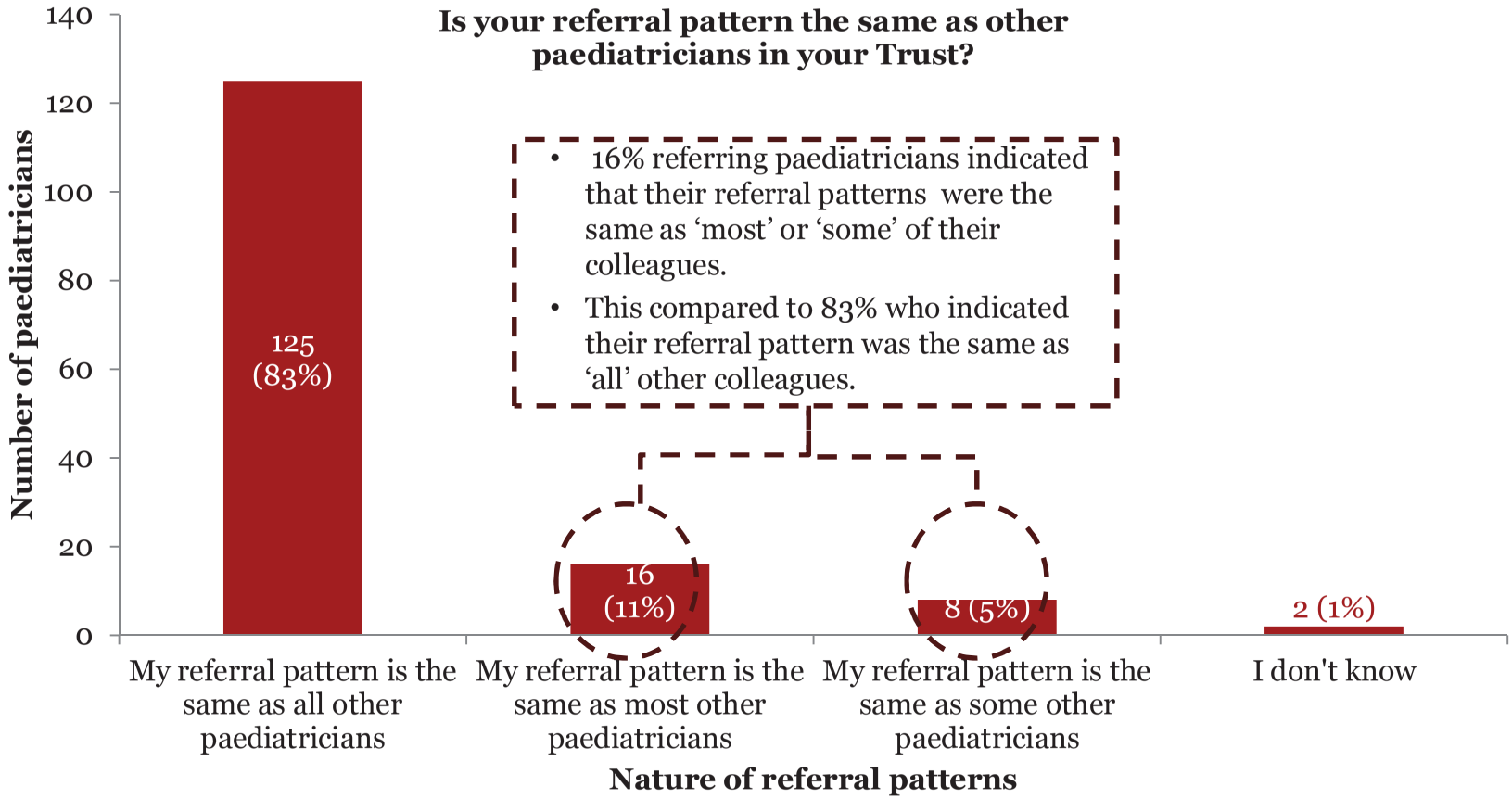
- Some 410 surveys were sent via 82 Clinical Directors of paediatrics (or their equivalent) in Trusts (for self completion, if appropriate and forwarding on to up to 4 referrer colleagues). The 153 responses received represents a response rate in the range of 37% to 40+% (dependent on whether all 82 Directors forwarded all surveys to their colleagues).
- Most responses were received from paediatricians who currently refer to Royal Brompton Hospital, London (17%) and Glenfield Hospital, Leicester (14%). Fewer responses were received from those currently referring to Freeman Hospital, Newcastle (3%), Birmingham Hospital (3%) and Oxford Radcliffe Hospital (4%).
- It should be noted that not all 153 paediatricians who responded to this survey answered all of the questions within the survey. Therefore the value of 'n' varies throughout the report.

Centre to which majority of patients are referred	% of respondents who refer to this centre	Centre to which majority of patients are referred	% of respondents who refer to this centre
Alder Hey Hospital, Liverpool	15 (10%)	Oxford Radcliffe Hospital	6 (4%)
Birmingham Hospital	4 (3%)	Royal Brompton Hospital, London	25 (17%)
Great Ormond Street Hospital	19 (13%)	Southampton General Hospital	14 (9%)
Evelina Hospital, London	8 (5%)	Bristol Royal Hospital	17 (11%)
Leeds General Infirmary	18 (12%)	Glenfield Hospital, Leicester	21 (14%)
Freeman Hospital, Newcastle	4 (3%)		

Source: PwC survey of referring paediatricians *n = 151*

Referring clinician survey – key findings

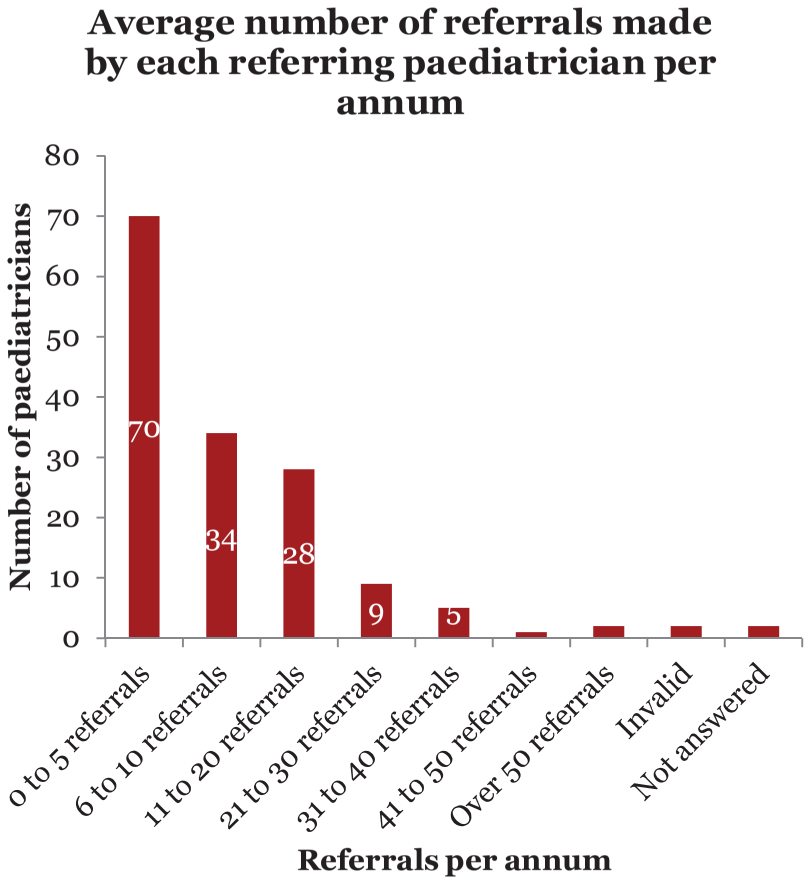
The majority (83%) of referring paediatricians indicated that their referral pattern was the same as all other paediatricians in their Trust…



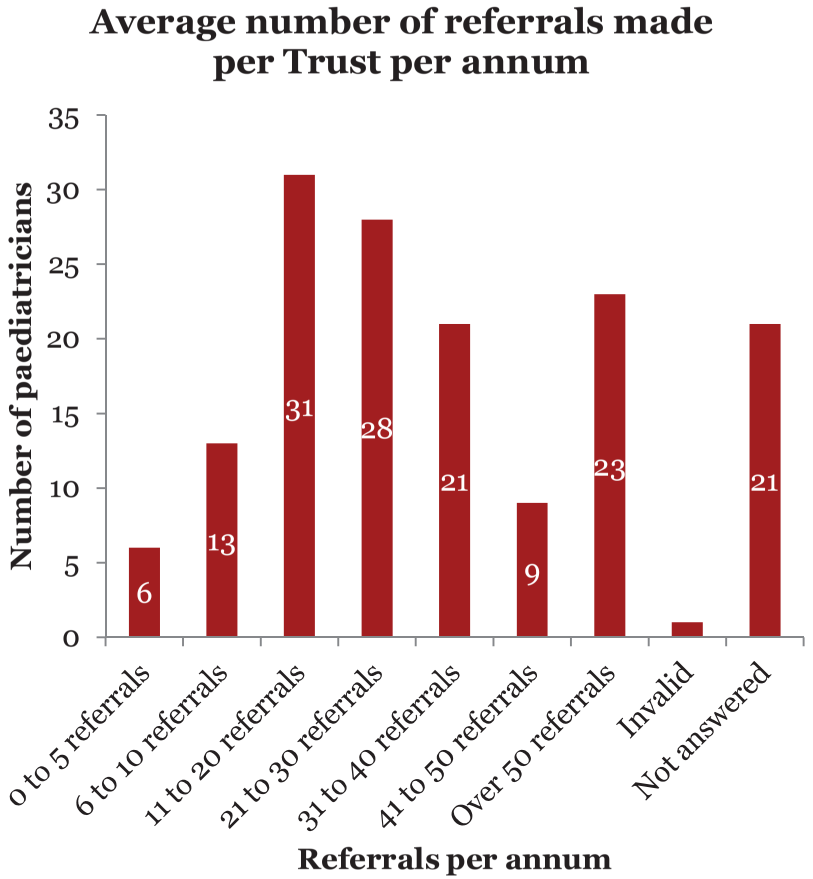
Source: PwC survey of referring paediatricians

n=151

Most paediatricians indicated that they refer five or less children for paediatric cardiac surgery per year, although the number of referrals per Trust varied…



Source: PwC survey of referring paediatricians *n=153*



Source: PwC survey of referring paediatricians *n=153*

Over a quarter of paediatricians indicated that existing joint working arrangements was the key factor in determining their referral preference…

Existing joint working arrangements	• This was identified as the 1st priority of 42 referring clinicians
Proximity of centre	• This was identified as the 1st priority of 33 referring clinicians
Clinical outcomes	• This was identified as the 1st priority of 19 referring clinicians
Personal professional relationship with the centre	• This was identified as the 1st priority of 17 referring clinicians
Historical	• This was identified as the 1st priority of 9 referring clinicians
Patient choice	• This was identified as the 1st priority of 1 referring clinician

Source: PwC survey of referring paediatricians *n = 123*

- Two paediatricians stated that other factors are key in determining preference, citing cot availability and the number of joint clinics held at a centre as the rationale for this.
- Thirty paediatricians gave invalid answers.

Note: *The list above orders the referral preferences based on the frequency at which referring clinicians ranked each of the preferences as their first choice. Adopting an approach of weighting each preference (so that the first choice gets multiplied by a factor of 7, the second choice gets multiplied by a factor of 6, and so on) results in a similar outcome in that the first, second, fifth and sixth preferences indicated in the list above remain the same. However, adopting a weighting approach results in personal professional relationship with the centre being prioritised third and clinical outcomes being prioritised fourth.*

Under each of the options, research showed that most paediatricians would refer to the centres which would be expected based on their current referral patterns…

- In each instance, over 90% of referring clinicians were in agreement with sending their patients to the centre which would be expected (based on the centre to which they currently refer) under the S&S review assumptions.
- Most referring paediatricians (97%) indicated that they would refer patients to the centre which had been assumed by the S&S review under Option C, whilst fewest paediatricians indicated that this would be the case under Option D (93%).

Option	% of referring paediatricians who would refer to centre assumed under S&S
Option A *(n=125)*	118 (94%)
Option B *(n=119)*	114 (96%)
Option C *(n=117)*	114 (97%)
Option D *(n=121)*	112 (93%)

Source: PwC survey of referring paediatricians

n varies by option – see table above

Existing joint relationships the most common factor in referral decisions under the current configuration, whilst proximity most common under each of the proposed options…

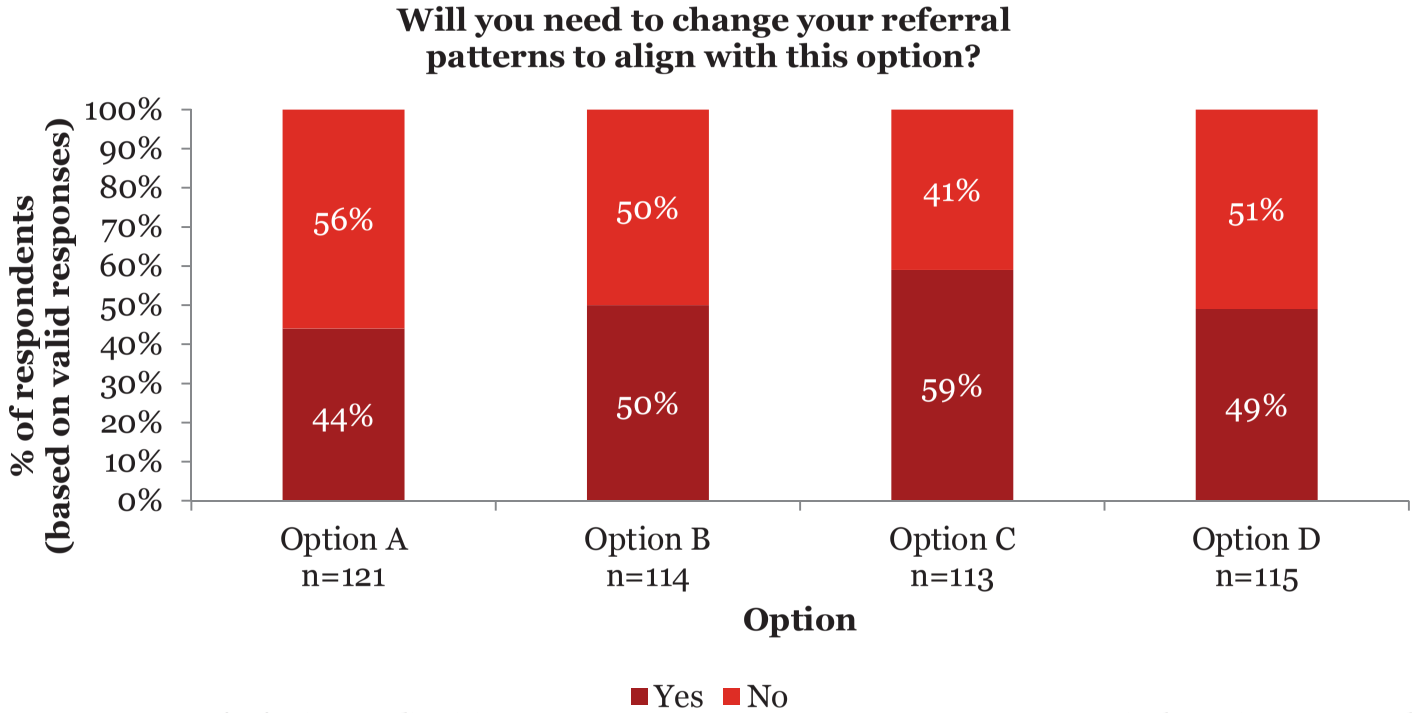
- Paediatricians were asked to state their "top three" factors which would influence their referral decisions under the four proposed options. The table below shows the percentage of paediatricians who selected each factor within their "top three".
- In Options A, C and D, existing joint working relationships was the second most commonly cited factor in influencing referral decisions, in line with views on referrals under the current service configuration. However in Option B, more paediatricians (53%) indicated that clinical outcomes would influence their referral decision than existing joint working relationships (50%).

	Option A n = 125	Option B n = 119	Option C n = 117	Option D n = 121
Proximity	84 (67%)	74 (62%)	79 (68%)	84 (69%)
Existing joint working relationships	69 (55%)	59 (50%)	56 (48%)	65 (54%)
Clinical outcomes	53 (42%)	63 (53%)	52 (44%)	55 (46%)
Personal professional relationship	45 (36%)	46 (39%)	43 (37%)	49 (41%)
Historical	20 (16%)	11 (9%)	15 (13%)	15 (12%)
Patient choice	14 (11%)	16 (13%)	14 (12%)	14 (12%)
Other	2 (2%)	2 (2%)	2 (2%)	2 (2%)

Source: PwC survey of referring paediatricians *n varies by option – see table above*

Referring paediatricians indicated that most change to referral patterns would be required under Option C…

- 59% indicated under Option C that they would need to change their referral pattern to align with this option. For Option B as many referring paediatricians (50%) indicated that they would have to alter referral patterns as those who indicated that referral patterns would stay the same.
- In contrast, 44% of referring paediatricians indicated that they would be required to alter existing referral patterns under Option A and 49% indicated that this would be the case under Option D.



Source: PwC survey of referring paediatricians

n varies by option – see graph above

Under Options A and B, referring paediatricians indicated that the development of the role of paediatricians with expertise in cardiology was the most well developed network feature…

	Centre	Formal pathways	Formal protocols	Local care settings	Paediatricians role	Liaison teams	Average
Option A	Freeman Hospital, Newcastle (8)	43% [1]	14%[1]	0%[1]	14%[1]	29%[1]	20%
	Alder Hey Hospital, Liverpool(13)	64%[2]	45%[2]	73%[2]	64%[2]	18%[2]	53%
	Glenfield Hospital, Leicester (22)	81%[1]	50%[2]	86%[1]	81%[1]	75%[2]	75%
	Birmingham Hospital (9)	38%[1]	25%[1]	50%[1]	50%[1]	38%[1]	40%
	Bristol Royal Hospital (23)	68%[4]	45%[3]	90%[3]	85%[3]	45%[3]	67%
	Evelina Hospital, London (21)	42%[2]	44%[1]	55%[1]	67%[3]	32%[2]	48%
	Great Ormond Street Hospital(31)	33%[1]	46%[3]	57%[1]	60%[1]	43%[1]	48%
	Average	53%	39%	59%	60%	40%	
Option B	Freeman Hospital, Newcastle (8)	43%[1]	14%[1]	0%[1]	14%[1]	29%[1]	20%
	Alder Hey Hospital, Liverpool (13)	70%[3]	50%[3]	70%[3]	70%[3]	20%[3]	56%
	Birmingham Hospital (21)	25%[5]	7%[6]	25%[5]	25%[5]	25%[5]	21%
	Bristol Royal Hospital (17)	80%[2]	50%[1]	94%[1]	88%[1]	50%[1]	72%
	Southampton General Hospital (16)	50%	63%	88%	94%	75%	74%
	Evelina Hospital, London(15)	43%[1]	50%[1]	67%	73%	43%[1]	55%
	Great Ormond Street Hospital (29)	42%[3]	48%[6]	69%[3]	65%[3]	42%[3]	53%
	Average	50%	40%	59%	61%	41%	

Note: [1] – *One less valid answer than from Q8,* [2] *- Two less valid answers than from Q8, and so on.* *n varies by option – see table above*
Source: PwC survey of referring paediatricians

Under Options C and D, referring paediatricians indicated that non-interventional care delivered in local settings was the most well developed network feature…

	Centre	Formal pathways	Formal protocols	Local care settings	Paediatricians role	Liaison teams	Average
Option C	Freeman Hospital, Newcastle (8)	43%[1]	14%[1]	0%[1]	14%[1]	29%[1]	20%
	Alder Hey Hospital, Liverpool (13)	70%[3]	50%[3]	80%[3]	60%[3]	30%[3]	58%
	Birmingham Hospital (23)	24%[6]	6%[7]	24%[6]	24%[6]	24%[6]	20%
	Bristol Royal Hospital (21)	63%[2]	40%[1]	85%[1]	80%[1]	40%[1]	62%
	Evelina Hospital, London (20)	44%[2]	41%[3]	56%[2]	61%[2]	33%[2]	47%
	Great Ormond Street Hospital (32)	33%[2]	41%[5]	60%[2]	57%[2]	37%[2]	45%
	Average	46%	32%	51%	49%	32%	
Option D	Leeds General Infirmary (20)	85%	68%[1]	85%	75%	70%	77%
	Alder Hey Hospital, Liverpool (11)	78%[2]	56%[2]	78%[2]	78%[2]	22%[2]	62%
	Birmingham Hospital (17)	31%[4]	8%[5]	31%[4]	31%[4]	31%[4]	26%
	Bristol Royal Hospital (21)	63%[2]	42%[2]	85%[1]	80%[1]	40%[1]	62%
	Evelina Hospital, London (20)	41%[3]	41%[3]	56%[2]	61%[2]	33%[2]	46%
	Great Ormond Street Hospital (31)	34%[2]	42%[5]	66%[2]	62%[2]	38%[2]	48%
	Average	55%	43%	67%	64%	39%	

Note: [1] *– One less valid answer than from Q8,* [2] *- Two less valid answers than from Q8, and so on.*
Source: PwC survey of referring paediatricians

n varies by option – see table above

Referring paediatrician views on the proposed S&S network features and how developed they currently are at centre level…

Option	Most developed network feature	Least developed network feature	Centre with most well developed network features	Centre with least well developed network features
Option A n= 127	Development of the role of paediatricians with expertise in cardiology (60%)	Formal protocols agreed by the surgical centre and local services (39%)	Glenfield Hospital, Leicester (75%)	Freeman Hospital, Newcastle (20%)
Option B n= 119	Development of the role of paediatricians with expertise in cardiology (61%)	Formal protocols agreed by the surgical centre and local services (40%)	Southampton General Hospital (74%)	Freeman Hospital, Newcastle (20%)
Option C n= 117	The delivery of non-interventional care in local care settings (51%)	Formal protocols agreed by the surgical centre and local services (32%) and strengthened cardiac liaison teams (32%)	Bristol Royal Hospital (62%)	Freeman Hospital, Newcastle (20%) and Birmingham Hospital (20%)
Option D n= 120	The delivery of non-interventional care in local care settings (67%)	Strengthened cardiac liaison teams (39%)	Leeds General Infirmary (77%)	Birmingham Hospital (26%)

Source: PwC survey of referring paediatricians

n varies by option – see table above

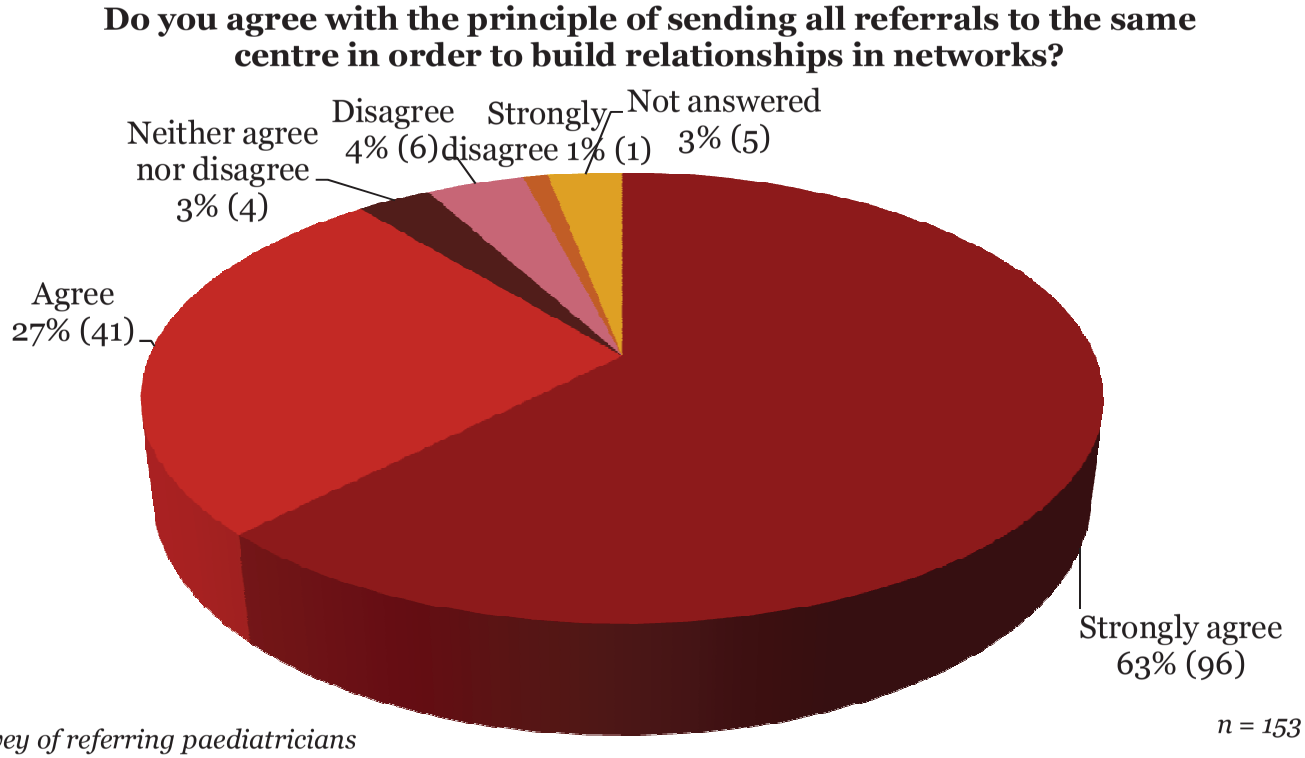
Referring paediatricians identified a number of key challenges and enabling factors associated with networks…

- Referring paediatricians most commonly cited the following challenges (grouped under themes) associated with taking part in a network with the features proposed by Safe and Sustainable and their view on enabling factors to assist in overcoming these challenges. These are highlighted in the following table.

Key challenges	Enabling factors
1) Links to other services	• Closer links between ante-natal, child and adult cardiac services. • Improve transport arrangements through development/use of a critical care transport service.
2) Capacity to handle increased workload	• Increased capacity and space at future centres under selected option for medical and surgical cases and critical care. • Enhanced capacity at outreach clinics in support of the above. • Formal service level agreements in place .
3) Need to increase level of outreach	• Ensure continuation of existing outreach clinics. • Increased capacity at outreach clinics. • Greater number of clinics.
4) Developing and agreeing shared protocols and pathways	• Shared cardiac protocols. • Cross-network protocols/working arrangements.
5) Developing the role of local paediatricians	• Increasing the number of paediatricians with expertise/interest in cardiology in local hospitals.

Source: PwC survey of referring paediatricians

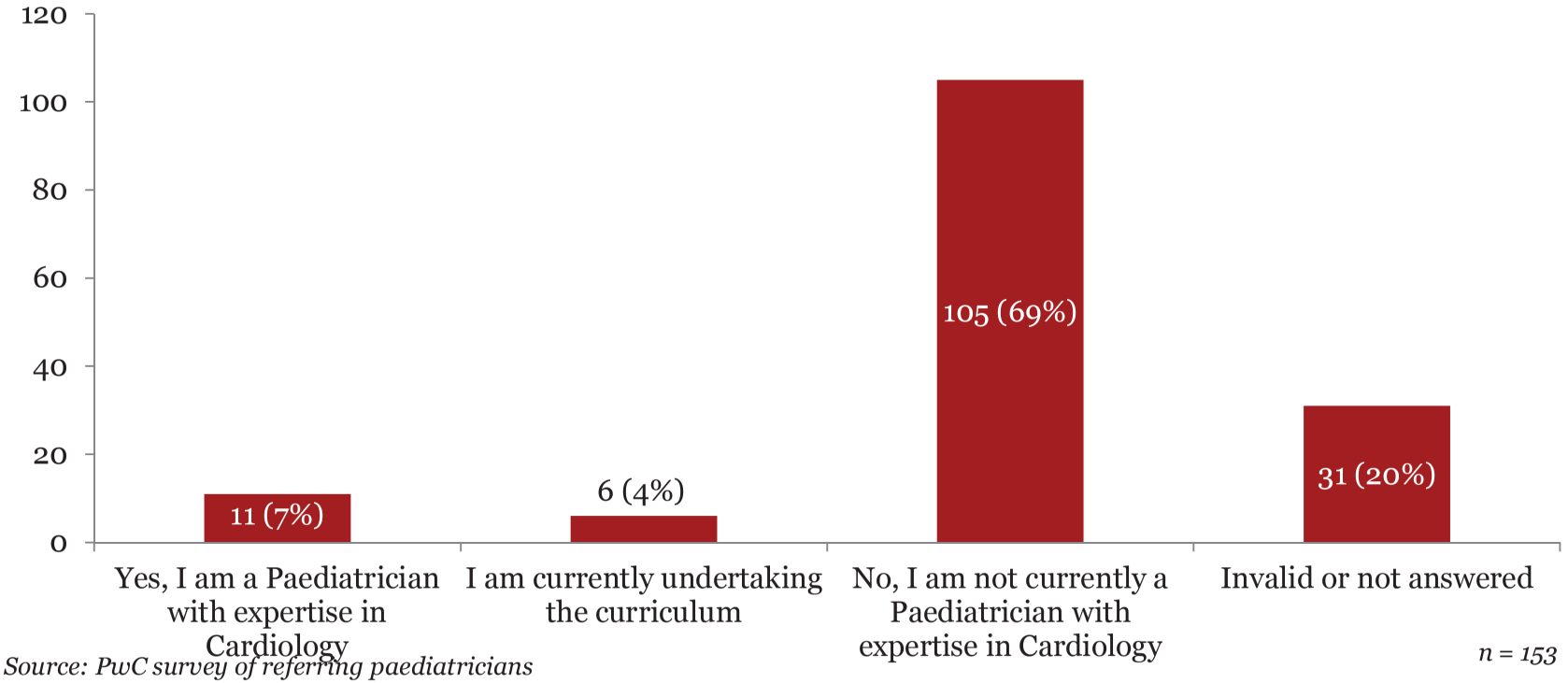
The vast majority (90%) of paediatricians indicated that they strongly agreed or agreed with the principle of sending the majority of referrals to the same centre, in order to build good relationships in local networks…



Source: PwC survey of referring paediatricians

Most respondents to the survey were general paediatricians without expertise in cardiology…

Are you a paediatrician with expertise in cardiology who has undertaken the joint curriculum of the Royal College of Physicians and the Royal College of Paediatrics and holds the relevant certificate?



n = 153

Source: PwC survey of referring paediatricians

Completed questionnaires were received from a number of referrers across Strategic Health Authorities in England.....

Strategic Health Authority (SHA):	Number (and %) of referring paediatricians who returned surveys:
East Midlands SHA	22 (14%)
East of England SHA	14 (9%)
London SHA	22 (14%)
North East SHA	0 (0%)
North West SHA	17 (11%)
South Central SHA	9 (6%)
South East Coast SHA	7 (5%)
South West SHA	23 (15%)
West Midlands SHA	2 (1%)
Yorkshire and The Humber SHA	15 (10%)
Other or SHA/hospital not specified	22 (14%)
Total:	**153 (100%)**

Source: PwC survey of referring paediatricians *n = 153*

Findings: clinician focus groups

- Approach to focus groups

- Key themes emerging from discussion:
  - *Network set-up, alignment and geography;*
  - *The role and function of outreach clinics and cardiology centres;*
  - *Potential for destabilisation of other services;*
  - *Retrieval; and*
  - *Supporting positive clinical outcomes.*

Approach to clinician focus groups

Introduction

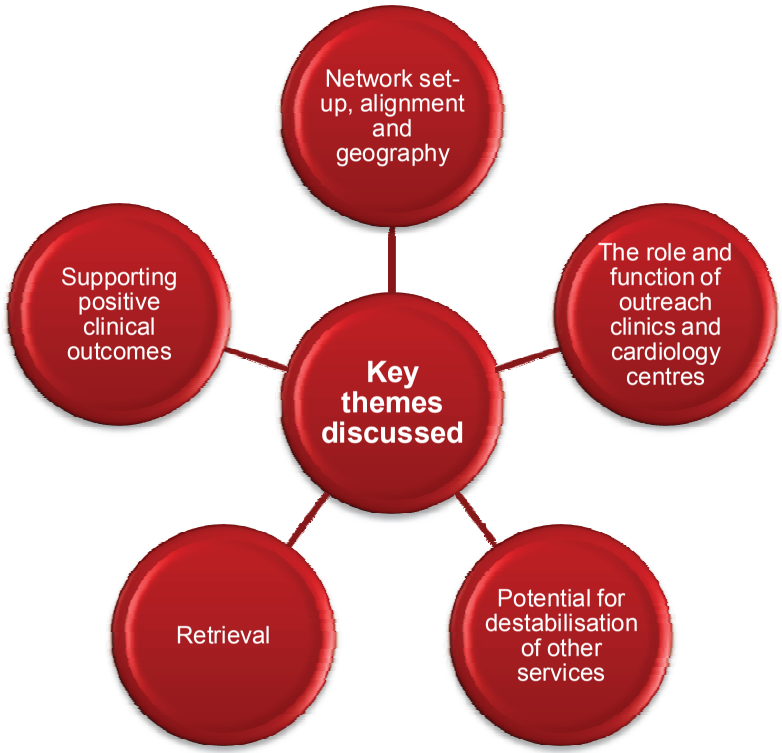
This report summarises the discussion, ideas and suggestions captured at the three focus groups held across England in September 2011 in relation to Workstream 2 (Clinical). The focus groups were designed and facilitated by PwC as part of their work for the National Specialised Commissioning Team to test assumptions for future patient flows and manageable clinical networks.

Objectives of focus groups

The purpose of the groups were to share and "sense check" findings gathered through the survey of referring paediatricians and interviews with clinicians (supported by data from the survey of parents and focus groups with members of the general public). The format of each focus group was as follows:

- Initial session on key findings on referral behaviours and clinical networks from referring clinician survey and feedback from parents and the public; and
- Subsequent discussion session on agreed themes emerging from the presentations of key findings.

The remainder of this report provides an overview of the comments received from across focus group participants and also sets out the key themes which were discussed (see diagram below).



Approach to composition of Workstream 2 clinician focus groups

Three focus groups were organised as follows:

- Midlands group (M) on 20 September 2011.
- South group (S) on 21 September 2011.
- North group (N) on 22 September 2011.

A mix of professionals attended these groups as shown in the table below, along with details as to how each group of professionals were identified and invited to attend. Each of the 11 centres referred to in S&S were represented by participants from one or more of these professional groups within each focus group.

Professional group	Method of identifying participants
Clinicians from the 11 centres	• The two clinicians who were interviewed as part of the centre interviews within Workstream 2 were re-contacted and invited to attend, or to nominate an alternative clinical colleague, to participate in the focus group.
Referring paediatricians	• HES data on referring hospitals was used to identify a number of referrers and a number of respondents to the referrer survey (where they indicated interest in being involved in further aspects of the project) were contacted and invited to the focus groups.
Clinical network leads	• Clinical network leads (where they are in place) were identified via the centre interviews or through discussions with the NSCT. These individuals were then contacted via email to invite them to the group.
Cardiac liaison nurses	• Liaison nurses were identified via contact with the Royal College of Nursing (RCN) and from discussions as part of the centre interviews. Each nurse identified was contacted, inviting them to attend the group or nominate an alternative in their area.

Summary of discussion and points raised – referral behaviours and manageable clinical networks

Each focus group commenced with a summary presentation of findings from the survey of referring paediatricians and interviews with clinicians, supported by data from the survey of parents and focus groups with members of the general public where relevant. The table below summarises the findings which were discussed and the key elements of feedback received and which group raised the question, for example, the Midlands group (M) asked for clarification around the postcode areas.

Topic area	Summary of areas/findings presented to groups	Questions raised and feedback from participants
Project methodology	• High level overview of the three workstreams, qualitative and quantitative approaches used and the 22 postcode areas being examined.	• Clarification on postcode areas considered, and areas within these (M) • Clarification on specific questions asked of referrers and parents, and on how each option was examined (M) • Approach to recruiting parents and members of the public from a range of backgrounds and socio-economic groups (M)
Referral behaviours	• Referrer and parent views on key factors determining referral preferences. • Changes required to referral patterns under each option. • Level of agreement /compliance with assumptions made within the S&S options i.e. feedback from referrers and parents and public as to whether they would refer to /or attend surgical centres as assumed by S&S.	• Surprise that cost and car parking was not more of an issue for parents, and queries over how parents judge reputation (M, N, S) • How referral behaviours may vary dependent on the type of referral and the nature of case presenting e.g. co-morbidities (M, S) • Criteria for identifying referring clinicians and parents and the public – comments on referrer survey response rate (M, S) • Impact of patient choice and clinical outcomes on referral behaviour and commissioning behaviours (S, N)
Clinical networks	• Current level of development of network features on the basis of referring clinician survey. • Challenges and enabling factors associated with networks. • Views on the principle of networks and model of care involving outreach clinics.	• Variation in experience across outreach clinics and could influence responses (M, N) • Why some referrers and parents are not supportive of networks and cardiology centres (N) • Experiences/feedback can vary by what stage of the patient journey individuals/families are at (M)

Summary of responses to question raised – referral behaviours and manageable clinical networks

A number of the questions detailed in the previous table related to the methodological approach adopted to contacting referrer, parents and the public – a summary of responses to these questions are detailed below.

Questions raised from participants	Response to questions/queries on methodology applied

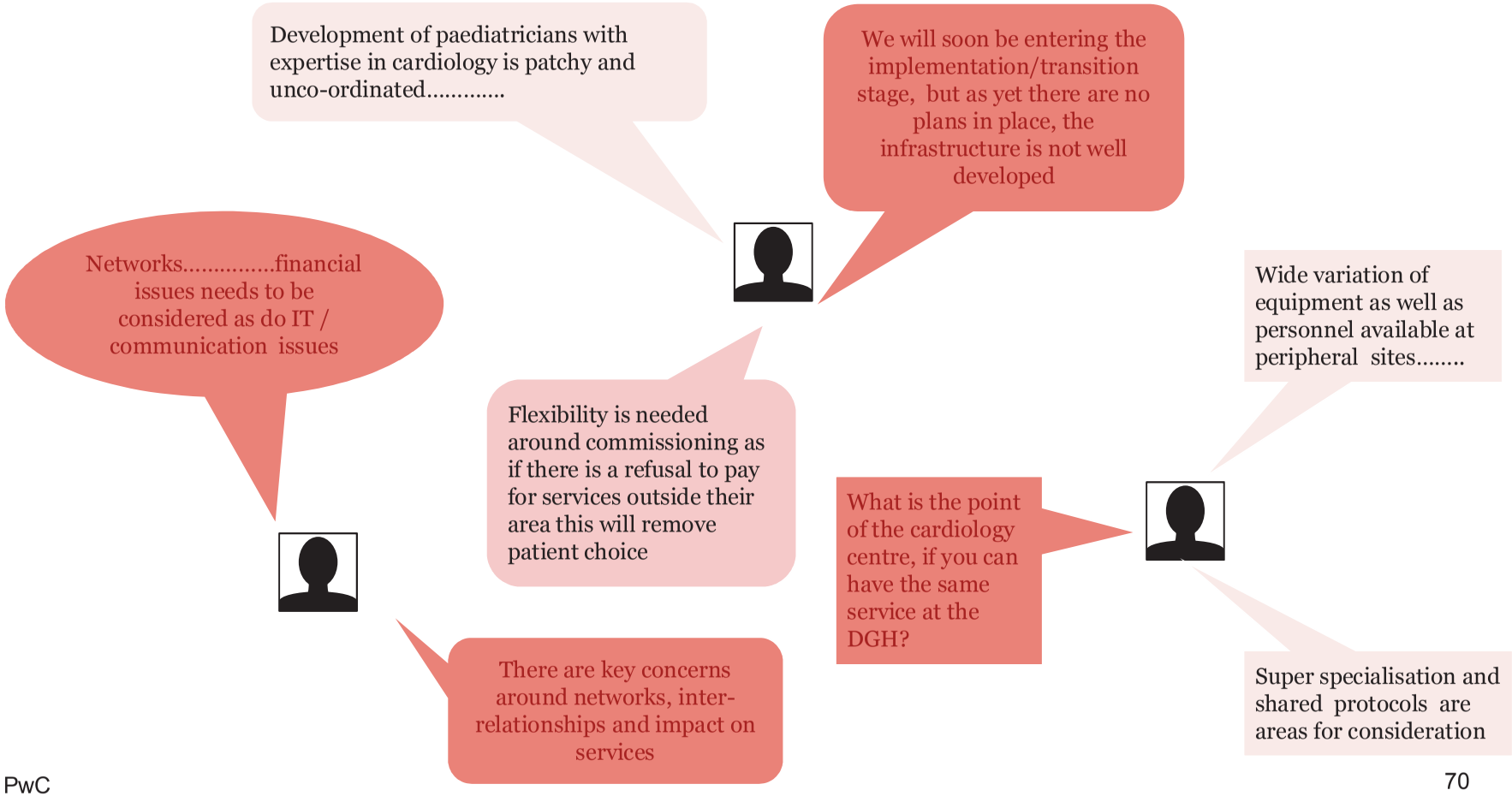
Clarification on postcode areas considered, and areas within these	• The 22 postcodes that were the focus of the parent and public workstreams were identified by the National Specialised Commissioning Team (NSCT) and Specialised Commissioning Group (SCG) Directors. They were chosen on the basis that they were:
	  • Postcodes where an assumption had been made to travel to a particular surgical centre but where another surgical centre is closer or roughly equal in distance to them such that it is reasonable to question alternative locations
	  • Where local intelligence has suggested that new referral patterns / patient flows are already emerging as a result of a collaborative approach across current centres and which may have the effect of replacing the 'closest to home' principle
	• In addition in recruiting parents and the public for involvement in this work, we sought to get coverage of postcode districts within each of the 22 postcode areas.

Clarification on specific questions asked of referrers & parents & how each option was examined	• In the slides in the clinical and parent and public reports where we present the findings of the research, we have documented the exact questions that were asked.
Approach to recruiting parents and members of the public from a range of backgrounds and socio-economic groups	• In recruiting the general public, we worked to get involvement from a spectrum of the public in terms of age, gender, socio-economic background and postcode area. Our ability to be as prescriptive for parent recruitment was lessened due to confidentiality issues – our key focus was to recruit parents across the 22 postcode areas and who had children that were both relatively new and longer term users of services.
Criteria for identifying referring clinicians and parents and the public – comments on referral survey response rate	• In the absence of a comprehensive and robust list of referring clinicians to the 11 centres, HES data was reviewed to identify referring Trusts. A sample of 82 Trusts which currently refer less than 85% of patients to one of the existing centres was identified – this was on the basis that their referral patterns were not clear cut and therefore could influence the success or otherwise of the future service configuration and network arrangements under S&S. • An internet search was undertaken to identify the clinical director for Paediatrics at these Trusts or their equivalent. This director was then sent a survey, along with four additional surveys for distribution to referring paediatricians colleagues in that Trust.

Summary of discussion and points raised – examples of recurring comments from focus group attendees

A number of recurring comments and themes were highlighted by participants at the focus groups, some examples of these are provided below.

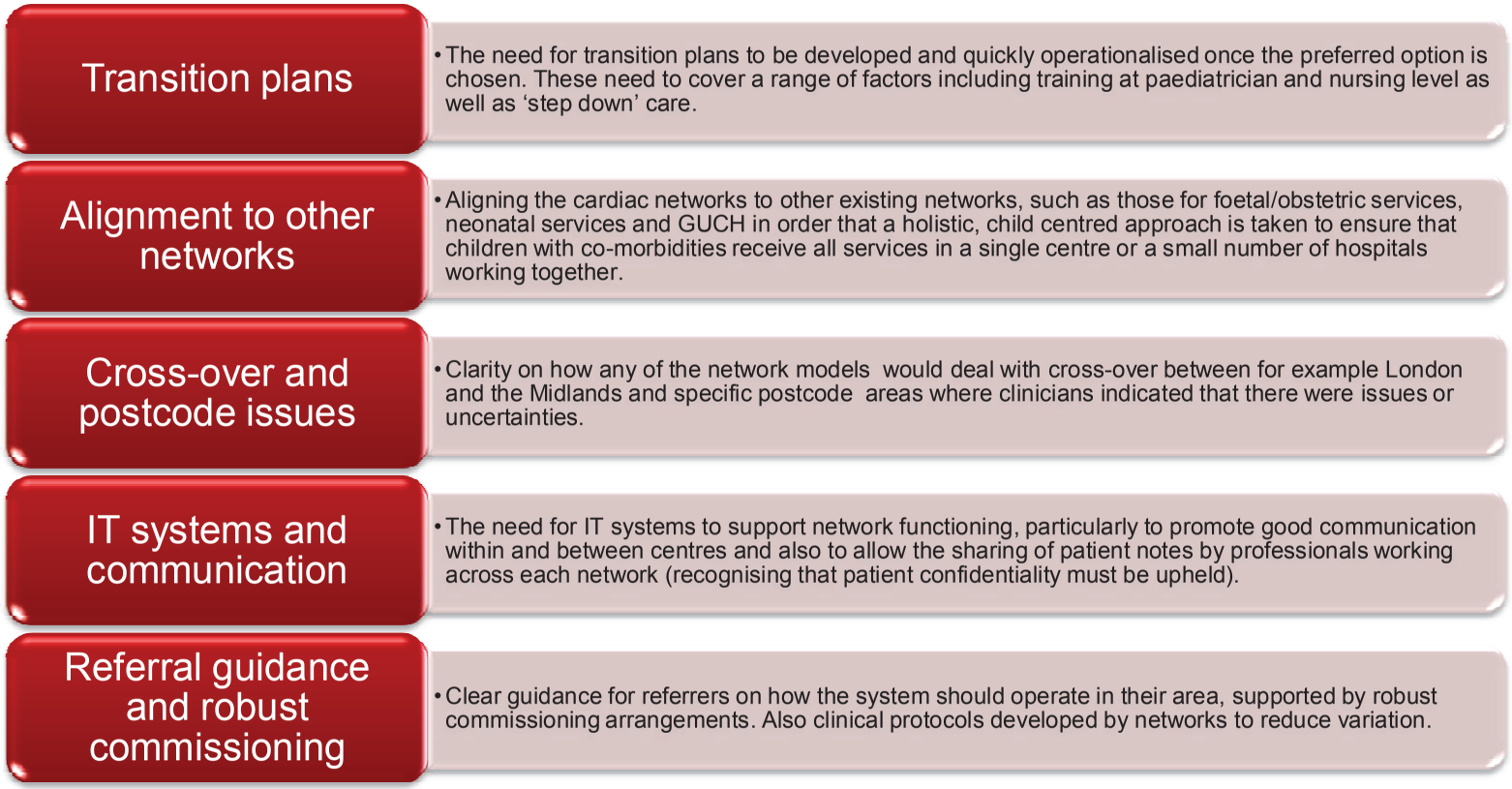
The rest of this report provides further detail on the themes which most commonly were discussed across the groups and the views and ideas that were generated.



Key themes from clinician focus groups

Theme 1: Network set-up, alignment and geography

Three groups all agreed that clarity was needed on how networks would be set up, and how they would function. There were a number of areas in which participants requested such clarity, or put forward suggestions as to how networks could operate more effectively – these are shown in the diagram below.



Theme 2: The role and function of outreach clinics and cardiology centres

Participants discussed promoting consistency in outreach clinics and debated whether the role of cardiology centres would work within the proposed network models under S&S, although they indicated that the S&S process had tended to focus on the surgical aspects of care so far. An overarching concern for both of these concepts was that both outreach services and cardiology centres would require the support of *Paediatricians with Expertise in Cardiology (PECs)*, however their availability was considered to be patchy, and this could be costly and time-consuming to overcome. Participants identified a range of areas in which further clarity was required, or suggestions as to how these concepts could operate more effectively – these are shown in the table below.

Outreach clinics – how to support these?	Cardiology centres - areas to be considered/clarified
• ***Inequity in provision –*** availability of the equipment and cardiac liaison nursing support within each clinic on a consistent basis, however, commissioning arrangements can be a disincentive.	• ***Co-location with surgical centres –*** there was discussion that this was thought to be advantageous particularly for urgent patients where referrers may be reluctant to refer to a stand-alone cardiology centre. However the definition of co-location was debated. In general there was also a view that there needed to be more clarity around the referral route for cardiac patients between referrer, cardiology centre and cardiac surgical centre.
• ***Service standards –*** clinics should be supported by agreed standards to ensure that patients receive a consistently high level of service regardless of location.	• ***Staffing and skills –*** there were views that these centres should be staffed by cardiologists and the availability and capacity of PECs was questioned . Participants also highlighted the need for ECHO expertise. Overall there was a view that likely to be difficulties in recruiting skilled staff to these centres.
• ***Children with co-morbidities –*** often children and parents in this group are keen to receive all care at a specialist centre to promote continuity of care and prevent duplication.	• ***Impact on other services –*** other specialties were often thought to be dependent on the existence of in-house cardiology expertise, although there was concern that paediatric anaesthetists with skills in cardiac care would only be based in surgical centres.
• ***Operating model -*** a preferred , cost-effective operating model would need to be identified in terms of who is responsible for the clinics (i.e. the surgical centre or the host Trust), supported by technology for sharing patient notes and to promote efficient use of staff time.	• ***Sustainability –*** these centres were viewed as less attractive places to work and would need careful consideration in terms of job planning and training. Shared appointments between cardiology centres and surgical centres was put forward as a potential solution where this would be geographically viable (i.e. relatively short distances between the two types of centre).

Theme 3: Potential for destabilisation of other services

In each of the groups, a number of participants indicated concerns that the implementation of any one of the four options under S&S could potentially destabilise services beyond those in the surgical centres during the transition period and the longer term. Broadly these destabilising effects could be grouped into two core areas – effect on service provision and effects on staff – as shown below.

Effects on services

- Changes implemented as a result of S&S were thought to most likely impact upon **PICU, cardiac wards, retrieval, outreach and other tertiary services**, with some further concerns over the ability to provide more general surgical and respiratory services in the absence of access to cardiology surgical support. Such assumptions could be tested using data from existing sources.
- Learning from the **experience of previous reconfigurations** of paediatric cardiac surgery (e.g. In Cardiff, Glasgow/ Edinburgh and the North West) should be considered.
- A mechanism for **supporting decommissioned units in the transition period** was desired. It was thought that patients may be reluctant to use these units.

Effects on staff

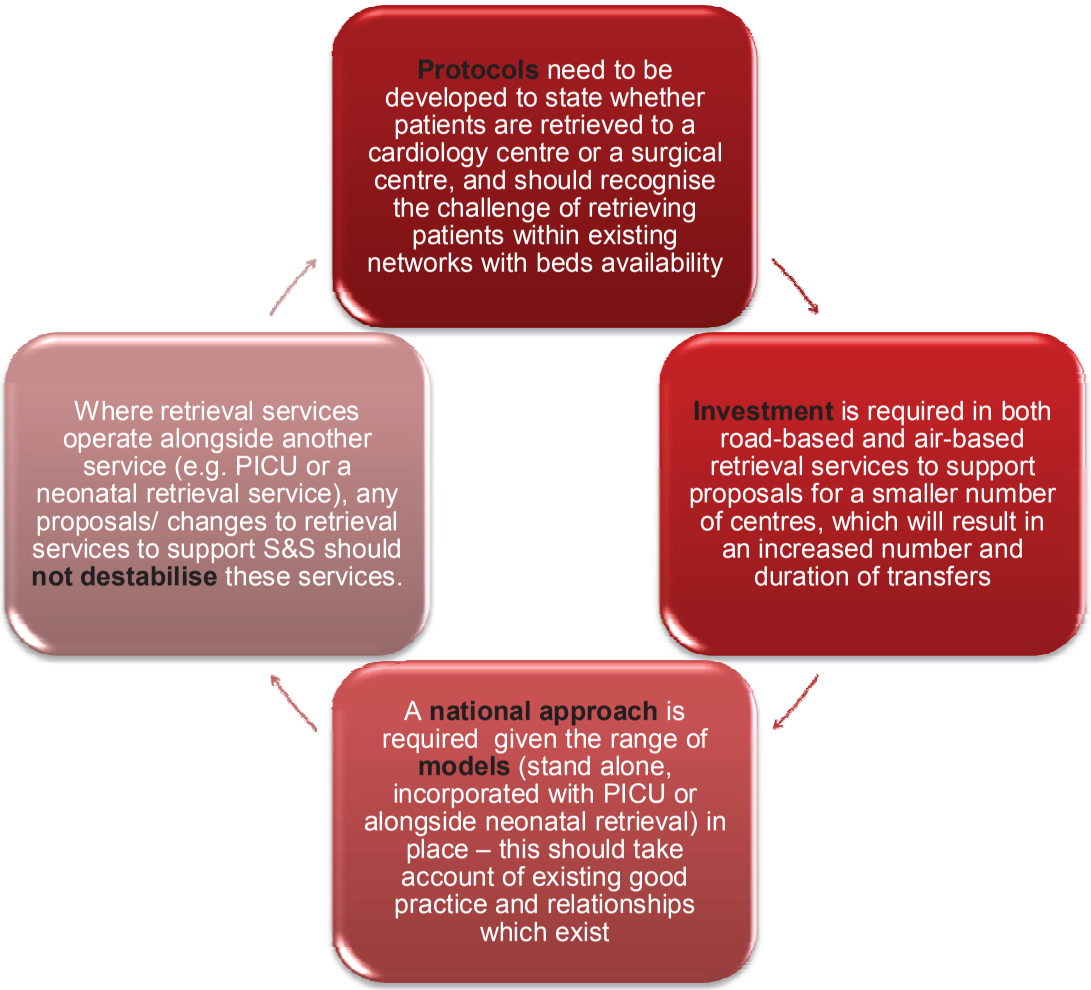
- The people aspects of the transition process need to be considered, particularly as any **staff moves** (planned or unplanned) could decrease levels of experience and skills in decommissioned units, and thus impact upon the quality of service provided.
- However this could also impact on centres within the chosen option, if **experienced staff** from the decommissioned units are not willing to work elsewhere, and new staff with the requisite skills cannot be found.
- Therefore there is a need to thoroughly **test** the extent to which staff in units to be decommissioned would be willing to move to other centres across **each of the options** and across **each of the professional groups** (clinical, nursing and more widely).

Theme 4: Retrieval

Two of the three groups specifically discussed issues around retrieval services, and how they would function to support the provision of paediatric cardiac surgery.

Concerns as to how well supported current retrieval services could operate in the future network model were expressed.

There were a number of linked areas in which participants requested clarity, or put forward suggestions as to how retrieval services could operate more effectively – these are shown in the diagram opposite.



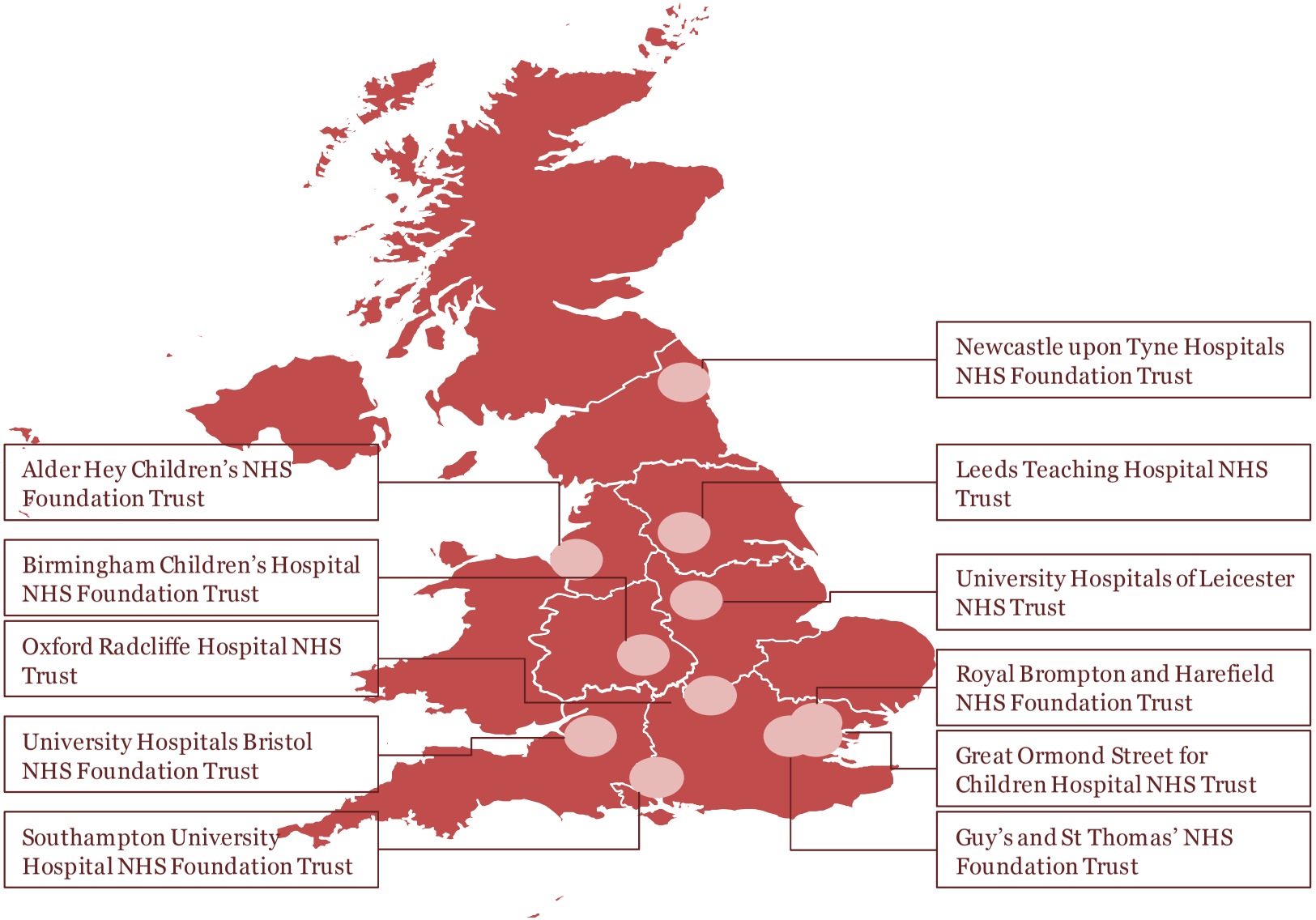
Theme 5: Supporting positive clinical outcomes

During the discussion, each of the three groups highlighted the need to promote that any changes optimise the quality of clinical outcomes achieved by paediatric cardiac surgical services, and agreed that as a core principle, the experience of good quality care should be the same whether in a surgical centre or outreach clinic. Suggestions on how these positive outcomes could be promoted were put forward as follows:

- The need to ensure that **commissioning processes** support the provision of high quality care, recognising that all centres cannot and do not currently provide the full range of cardiac surgical procedures, or to the same standard. There are datasets (such as CCAD and PICA.net) which can be used to compare procedures undertaken and outcomes achieved between the different centres, and there was a view that this needs to be understood and shared more widely.
- **Funding arrangements** to remove disincentives to networking. For example, where tariff payment is paid to an outreach hospital, the surgical centre clinician time is funded at cost, creating a disincentive for the surgical centre to provide expertise to outreach clinics. In addition, there is variation in the funding arrangements to support the provision of liaison nurses across different networks, potentially resulting in differential experiences of care.
- Shared **clinical protocols** should be developed within and across the cardiac networks in order to reduce variation in care standards and outcomes. Variation currently exists in terms of personnel available, equipment and prescribing habits, and this needs to be addressed for the future.
- An **audit of skills** across proposed surgical centres, cardiology centres and outreach clinics should be undertaken in order to identify any gaps in knowledge, skills or experience, so that **training** can be put in place to address these gaps.
- Participants questioned the **three-tier model** proposed by S&S but suggested that it may be workable as long as the system **eradicates any undue delays** in terms of referral of patients between the different tiers and there is clarity and appropriate support for the role of individual clinicians and NHS organisations.

Appendix

Safe and Sustainable Review - 11 centres focused upon...



Safe and Sustainable Review - Options A, B, C & D and associated centres...

Option A:	Option C:
Seven surgical centres at:	***Six surgical centres at:***
1. Freeman Hospital, Newcastle (NUTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Glenfield Hospital, Leicester (UHL) 4. Birmingham Children's Hospital (BCH) 5. Bristol Royal Hospital for Children (UHB) 6. Evelina Children's Hospital, London (GSTT) 7. Great Ormond Street Hospital for Children, London (GOSH)	1. Freeman Hospital, Newcastle (NUTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Birmingham Children's Hospital (BCH) 4. Bristol Royal Hospital for Children (UHB) 5. Evelina Children's Hospital, London (GSTT) 6. Great Ormond Street Hospital for Children, London (GOSH)
Option B:	**Option D:**
Seven surgical centres at:	***Six surgical centres at:***
1. Freeman Hospital, Newcastle (NUTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Birmingham Children's Hospital (BCH) 4. Bristol Royal Hospital for Children (UHB) 5. Southampton General Hospital (SUH) 6. Evelina Children's Hospital, London (GSTT) 7. Great Ormond Street Hospital for Children, London (GOSH)	1. Leeds General Infirmary (LTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Birmingham Children's Hospital (BCH) 4. Bristol Royal Hospital for Children (UHB) 5. Evelina Children's Hospital, London (GSTT) 6. Great Ormond Street Hospital for Children, London (GOSH)

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National Specialised Commissioning Team (NSCT)

Testing assumptions for future patient flows and manageable clinical networks

Final report
October 2011

Workstreams 3 & 4: Parents and the general public

Workstreams 3&4

pwc

Table of contents

Executive summary:
Parent survey & interviews and general public focus groups

Evidence base:

- 172 responses to a postal survey (response rate of 25%) by parents from the 22* postcode areas identified by NSCT for testing and 21 telephone interviews with parents *(Workstream 3);* and

- Focus groups with 102 members of the general public recruited from across the 22 postcodes identified for further exploration by NSCT *(Workstream 4)*.

**22 postcode areas*:
Bradford, Brighton, Coventry, Doncaster, Dorchester, Guildford, Hemel Hempstead, Hereford, Huddersfield, Halifax, Hull, Leeds, Lincoln, Nottingham, Oxford, Peterborough, Reading, Redhill, Sheffield, Slough, Wakefield and Worcester

Parent and general public feedback

Referral/patient flows

- Across the parents surveyed and the general public who participated in focus groups, the majority of individuals identified paediatric cardiac centres as preferred centres to travel to, in line with assumptions made by the Safe and Sustainable (S&S) review for Options A – D. That said, there were a common set of postcode areas for specific options where the paediatric cardiac centres identified as preferred centres to travel to by the majority of parents and the public, did not match assumptions made by S&S. In total there were eight such postcode areas: *Coventry, Leeds, Wakefield, Brighton, Doncaster, Reading, Sheffield & Nottingham.*
- These postcode areas were ones where the majority of parents and the consensus from members of the general public (from said postcode areas) was that their preferred centre was not in line with S&S assumptions. However, that is not to say that many also indicated if told/advised to go to an alternative centre they would not do so, although there was more reluctance amongst members of the public to consider travelling to Newcastle as a centre.
- If the preference of the parents and the public were factored into assumptions of patient flows, they may have implications for projected levels of activity at in particular the Newcastle centre under Options A, B and C – ***see table overleaf.***
- As per the table overleaf, there are also implications for the Leicester centre under Option A, Bristol and Southampton centres under Option B and Leeds under Option D.

Travel times

- When parents were asked to prioritise factors influencing choice of cardiac surgical centre, travel time was prioritised below factors such as: *Reputation of the centre; Recommendation from a GP or other healthcare professional; Availability of the surgical team and Previous experience of using the centre.*
- While the general public highlighted: A*bility to see the same team of doctors and nurses; Hospital having a good reputation and Availability and price of car parking facilities*, as the factors that mattered to them.
- Given the smaller number of centres proposed under the four S&S options, as expected a lower proportion of parents estimated that they would be within one hour of a paediatric cardiac surgical centre under Options A – D when compared to current travel arrangements.
- The majority of parents indicated travelling to centres by their own private transport. Most members of the public who participated in focus groups also indicated that they would travel to centres by car.
- Less than 10% of focus group participants indicated that they would use public transport if accessing surgery, although nearly 20% stated that they might use public transport when travelling for an outpatient appointment – ***see table overleaf.***

Overview of parent and general public feedback

Referrals/patient flows

✓ = *majority parents/public agree with S&S assumptions*	Postcode areas highlighted where parents & public prefer not to flow to S&S assumed centres				Key factors identified by parents influencing choice of cardiac surgical centre	Key factors identified by the general public as influencing choice of cardiac surgical centre
	Option A	**Option B**	**Option C**	**Option D**		
Freeman, Newcastle	Leeds Wakefield	Leeds Wakefield Doncaster Sheffield	Leeds Wakefield Doncaster Sheffield	*N/A*	1. Reputation of centre 2. Recommendation from a GP or other healthcare professional 3. The surgical team available 4. Previous experience of using centre *These factors were the ones most commonly identified as influencing their current centre and preferred centre under the different S&S options.*	1.Ability to see the same team of doctors and nurses each time 2.The hospital has a good reputation 3.Availability and price of car parking facilities 4.Ability to spend enough time with doctors and nurses 5.The hospital has good facilities 6.Part of a network, where you could go to a local hospital for outpatient appointments and a specialist centre for surgery
Alder Hey, Liverpool	✓	✓	✓	✓		
Glenfield, Leicester	Coventry	*N/A*	*N/A*	*N/A*		
Birmingham	✓	✓	✓	✓		
Bristol	✓	Reading	✓	✓		
London x 2	✓	✓	✓	✓		
S/hampton	*N/A*	Brighton	*N/A*	*N/A*		
Leeds	*N/A*	*N/A*	*N/A*	Nottingham		

Managed clinical networks

	Option A	**Option B**	**Option C**	**Option D**
Parents who stated that they would prefer to have outpatient appointments and ongoing management of care at a local hospital	56 (44%)	51 (43%)	52 (46%)	52 (39%)
Parents who stated that they would prefer to have all care at the specialist centre	67 (53%)	59 (50%)	54 (48%)	70 (53%)
Parents who did not indicate where they would prefer their child to receive care	4 (3%)	8 (7%)	7 (6%)	11 (8%)
Parents who indicated that the existence of a managed clinical network would change their choice of preferred main centre under this option	6 (5%)	7 (6%)	7 (6%)	6 (5%)

Travel times

- In terms of mode of travel, 142 parents (83%) indicated that they had access to their own car for either all or part of their journey.
- 104 parents (61%) travelled to their current centre solely using their own car whilst a further 38 parents (22%) indicated that they used their own car, plus one or two other modes of transport.
- Most focus group participants indicated that they would travel by car. Less than 10% of participants indicated that they would use public transport to access one of the current centres if travelling for surgery.

Source: PwC survey of parents and focus groups with the public

Parent and general public feedback

- Members of the general public identified how S&S options could be made more amenable and accessible, as follows.

  Travel Issues:

  – Financial assistance with additional travel costs over and above distance to nearest hospital and help with car parking (no charge, reduced rates or vouchers);

  – Affordable overnight accommodation; and an ambulance or personal transport for those in very remote areas.

  Information Issues:

  – More information on travel times, distances and routes to centres; as well as in terms of specialists available, waiting times and facilities to enable decision making;

  – Flexible visiting times, ideally to fit with off-peak public transport; and accessible information and better co-ordination of public transport options.

Managed clinical networks

- In terms of managed clinical networks, while both parents and the general public were positive about the concept of these, there was more of a preference from parents to access all care at a specialist centre.

Managed clinical networks	
Views from parents	• Parents were asked whether they would prefer to have outpatient appointments and ongoing management of care at their preferred centre under each of the options or at a more local centre. A slightly higher proportion wished to access all care at a specialist centre. • 48 – 53% of parents across the four options indicated they would prefer to have all care at a specialist centre whereas 39 – 46% stated they would prefer to have outpatient appointments and ongoing management of care at a local hospital.
"It would depend if you would be seeing the same surgeon, if you could see the same surgeon or cardiologist as at the specialist centre then I would go to a local hospital, otherwise I would probably just travel." (Quote from parent) *"I would worry a lot about continuity of care and transfer of patient notes." (Quote from parent)*	
Views from members of the general public	• Overall networks were considered a good idea and members of the public felt that it was more desirable to have care managed locally rather than travelling to a specialist centre on several occasions for all aspects of care.
Factors to consider to help support networks	• Members of the general public identified three key themes to help support the successful functioning of clinical networks, as follows: 1. Continuity of care within the team of health professionals. 2. Continuous and strong communication between the specialist centre and local care provider, supported by technology (e.g. email, video-conferencing). 3. Ability to meet the surgeon prior to an inpatient admission and ideally for one follow-up.

Executive summary:
Parent survey & interviews (Workstream 3)

Evidence base:

- 688 questionnaires were sent to parents of service users across the 22 postcodes areas identified by NSCT.

- These 688 were determined with the assistance of the paediatric cardiac centres and sought to identify parents who had children receiving a range of services and over varying time periods.

- 172 responses were received representing a response rate of 25%.

- 21 depth interviews were also undertaken with parents of current service users across the 22 postcode areas to obtain qualitative information on service use and the potential options.

Options A – D: where parents would choose (analysed on the basis of parent's current postcode)

Option A	• All parents from 11 of the 22 postcode areas selected the centres which would be expected under S&S. • Some parents from the remaining 11 postcode areas did not identify centres assumed by S&S. Of these 11, there were six (*Coventry, Doncaster, Dorchester, Leeds, Sheffield and Wakefield*), where the majority of responding parents did not identify the S&S assumed centres. Further details on the preferred centres of parents in these postcode areas can be found on slide 26.
Option B	• All parents from six of the 22 postcode areas selected the centres as per S&S. • Some parents from the remaining 16 postcode areas did not identify centres assumed by S&S. Of these 16, there were 11 (*Brighton, Doncaster, Dorchester, Guildford, Hemel Hempstead, Leeds, Reading, Redhill, Sheffield, Slough and Wakefield*) where the majority of responding parents did not identify the S&S assumed centres. Further details on the preferred centres of parents in these postcode areas can be found on slide 27.
Option C	• All parents from 12 of the 22 postcode areas selected the centres which would be expected under S&S. • Some parents from the remaining 10 postcode areas did not identify centres assumed by S&S. Of these 10, there were five (*Doncaster, Dorchester, Leeds, Sheffield and Wakefield*) where the majority of responding parents did not identify the S&S assumed centres. Further details on the preferred centres of parents in these postcode areas can be found on slide 28.
Option D	• All parents from 16 of the 22 postcode areas selected the centres which would be expected under S&S. • Some parents from the remaining six postcode areas did not identify centres assumed by S&S. Of these six, there were two (*Dorchester and Nottingham*) where the majority of responding parents did not identify the S&S assumed centres. Further details on the preferred centres of parents in these postcode areas can be found on slide 29.

Options and clinical networks: parents feedback on changes in travel times under Options A – D and views on managed clinical networks

Options A – D and travel times	• Travel time was less important to parents in choosing a surgical centre, with factors such as reputation of the centre, recommendation from a GP or other healthcare professional and the surgical team available chosen as the most important factor by a greater number of parents. • Given the smaller number of surgical centres which would be available in the four options in the future, as expected a lower proportion of parents estimated that they would be within one hour of a paediatric cardiac surgical centre under Options A – D when compared to current arrangements. • 51% of parents indicated that currently they were within one hour travel distance to their current centre, while for the four options, this would change to 26% (Option A), 19% (Option B), 15% (Option C) and 37% (Option D).
"You don't expect everything to be on your doorstep so the fact it's only an hour away is great for us, but I wouldn't really want to go much further, especially in the case of an emergency." (Quote from parent)	
Views of clinical networks	• Parents were asked whether they would prefer to have outpatient appointments and ongoing management of care at their preferred centre under each of the options or at a more local centre. A slightly higher proportion wished to access all care at a specialist centre. • 48 – 53% of parents across the four options indicated they would prefer to have all care at a specialist centre whereas 39 – 46% stated they would prefer to have outpatient appointments and ongoing management of care at a local hospital.
"It would depend if you would be seeing the same surgeon, if you could see the same surgeon or cardiologist as at the specialist centre then I would go to a local hospital, otherwise I would probably just travel." (Quote from parent)	

Executive summary:
General public focus groups (Workstream 4)

Evidence base:

- Participants were recruited from across the 22 postcodes identified for further exploration by NSCT.

- In total 102 individuals took part in the focus groups.

- Recruitment criteria sought to get a range of participants from the general public in terms of age, gender and socio-economic background.

Options A – D: where the public would choose as a preferred centre

Option A	• Focus group participants from 17 of the 22 postcode areas did identify centres assumed by S&S as their preferred centres. However, this was not the case in five postcode areas (*Coventry, Lincoln, Peterborough, Leeds and Wakefield*), with the public not having centres assumed by S&S (*Leicester and Newcastle*) as their preferred choice.
Option B	• Participants did identify centres assumed by S&S in 13 postcode areas. Focus group participants from nine of the 22 postcode areas *(Lincoln, Hull, Wakefield, Leeds, Sheffield, Doncaster, Reading, Oxford and Brighton)* did not identify centres *(Birmingham, Newcastle and Southampton)* assumed by S&S to be their chosen centre to travel to.
Option C	• Focus group participants from 16 of the 22 postcode areas did identify centres assumed by S&S as their preferred centres. However, this was not the case in six postcode areas (*Lincoln, Doncaster, Hull, Wakefield, Leeds and Sheffield),* with the public not having centres assumed by S&S (*Birmingham and Newcastle*) as their preferred choice.
Option D	• Generally focus group participants agreed with the assumptions being made in this option with only one of the 22 postcode areas (*Nottingham)* not identifying the centres*(Leeds)* assumed by S&S to be their chosen one to travel to. • There was some concern expressed about the national geographical spread of centres in this option, particularly taking into consideration the absence of the centre in Newcastle.

Clinical networks: would the public be supportive of these?

Views on clinical networks	• Overall networks were considered a good idea and participants felt that it was more desirable to have care managed locally rather than travelling to a specialist centre on several occasions for all aspects of care. • However focus group participants from three of the 22 postcode areas (*Nottingham, Huddersfield and Worcester)* indicated that they would prefer to travel to the specialist centres under one or more of the options.
Factors to consider to help support networks	• Focus group participants identified three key themes to help support the successful functioning of clinical networks, as follows: – Continuity of care within the team of health professionals. – Continuous and strong communication between the specialist centre and local care provider, supported by technology (e.g. email, video-conferencing). – Ability to meet the surgeon prior to an inpatient admission and ideally for one follow-up.

Introduction and approach

Introduction to the study

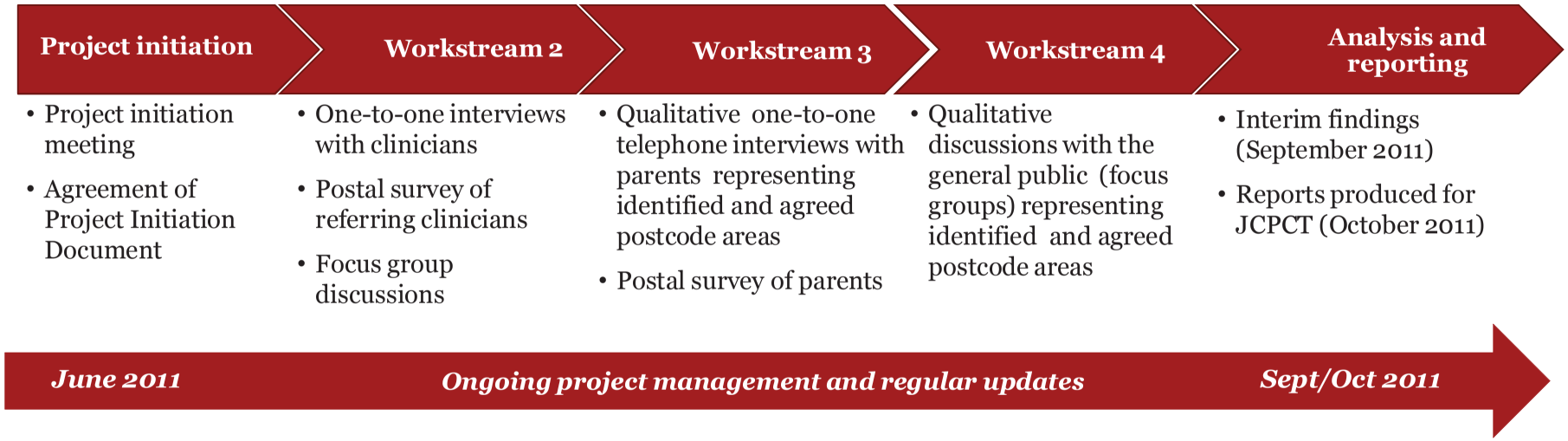
- PricewaterhouseCoopers LLP (PwC) was appointed by the National Specialised Commissioning Team (NSCT) to undertake a study on future patient flows and manageable clinical networks, as part of the *Safe and Sustainable* (S&S) review of children's congenital cardiac surgery in England.

- The study sought to examine the assumptions on patient flows that have been made across 22 postcode areas (diagram opposite) in England, under the four service reconfiguration options (Options A – D) which have been identified as part of this review (see Appendix). These assumptions have been informed by analysis of travel times (patients travelling to their nearest centre) and a consideration of current clinical networks.

- Key stakeholders involved in the project have been clinicians (Workstream 2), parents of services users (Workstream 3) and members of the general public (Workstream 4).

Methodology across Workstreams

- This final report presents the findings from Workstreams 3 (parents) and 4 (general public) from the perspective of:
  - Parents of current service users (based on findings from a postal survey and quotes from parents who participated in telephone interviews).
  - Members of the general public (based on findings from focus groups).
- Reporting is structured around the following themes:
  - Options A – D and centres where patients and public may go to i.e. patient flows/referrals
  - Views on managed clinical networks.
- In discussing options with parents and the public, the surgical centres referred to were as per those specific centres named for Options A – D in S&S (see Appendix).



Findings: survey and telephone interviews with parents

- Approach to parent survey & interviews
- Findings from parent survey & interviews

An approach involving Trust Information Managers in the distribution of questionnaires was adopted to protect the anonymity and confidentiality of patients…

- In order to comply with data protection legislation and to protect the confidentiality and anonymity of patients and their parents, a multi-stage approach to distributing questionnaires was undertaken in order to help ensure that confidential patient details were not shared outside of the NHS.
- This process involved:
  - PwC distributing information on the sampling criteria of patients to Trust Information Managers in a number of the existing paediatric cardiac surgical centres * which have treated patients from at least one of the 22 postcode areas being examined. At this stage, the sample included all patients who lived in one of the 22 postcode areas, had an inpatient admission and/or outpatient appointment in the last two years and was not deceased).
  - Trust managers returning a list of all patients meeting the sampling criteria on an anonymised basis to PwC.
  - PwC selecting a sample from each centre, seeking coverage across the key sampling criteria (including postcode districts within postcode areas) and on a proportionate basis across the 22 postcode areas – details of the final sample was then returned to each Trust Information Manager so that patient details (name and address) could be matched back into the data file.
  - Trust Information Managers organised for identified parents to be sent a pack containing either a questionnaire for return by post or a letter requesting their participation in a telephone interview. Due to confidentiality issues and to minimise the burden placed on Trust staff, no reminders for participation were issued to parents.

** Eight centres participated in providing details as the identified 22 postcode areas, mapped most directly to these centres.*

Overview of questions used for surveys and telephone discussions with parents of current service users

- The table below provides a summary of the key questions which were covered in both the postal survey and the topic guide used for the depth telephone interviews with parents.

Section	Description
Background information	Parents were asked to provide some background information including their postcode, the gender and age of their child, along with the age at which the child was referred.
Views on current centre	Parents were asked to indicate the centre(s) which they were currently accessing (including any outreach clinics), the types of services which they have used, the mode(s) of transport which they usually use to access the paediatric cardiac surgical centre and the time which this takes.
Exploring the four options	Each of the options were explored in turn, asking parents where they would choose to go in each scenario and the main factors which influenced their decision. This section also explored the mode of transport which parents would use to reach the selected centre under each option and the estimated time taken to reach the chosen centre.
Managed clinical networks	Parents were asked whether they would prefer to access outpatient appointments and ongoing management of care locally or at the specialist centre under each option, and whether the existence of network arrangements would change their choice of centre under any of the options.
Other comments	Parents were also asked to note any other comments specific to this work around testing assumptions on patient flows and managed clinical networks under the four options, or any suggestions as to how the centres or options could be improved.

- For note, in discussing options with parents (and the public), the surgical centres talked about were as per those specific centres named for Options A – D in S&S (see Appendix).
- The remainder of this section sets out in detail the findings from the survey of parents, supported by quotes from those parents who participated in telephone interviews.

Further detail on telephone discussions with parents of current service users

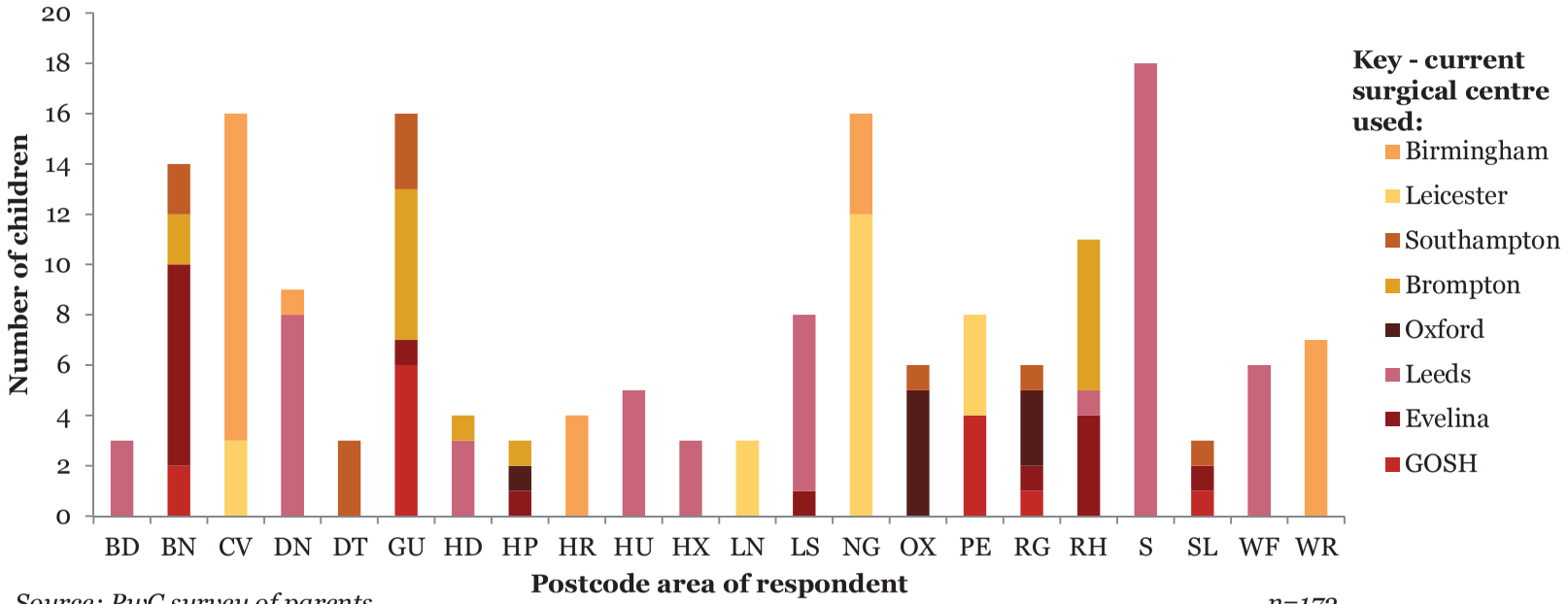
- In total, 21 parents participated in a depth telephone interview aimed at exploring in further detail their experience of their current centre, views on the four options and to explore the concept of managed clinical networks. The purpose of these telephone interviews was to supplement the data gathered via the survey of parents and also to provide a qualitative understanding of the issues which were identified via the survey.
- Quotes from parents have been used to illustrate some of the key findings in the remaining section of this report, however in addition to this, the table below provides a further summary of views expressed by parents during these telephone interviews.

Section	Quotes from parents
Views on current centre	• *"Anything I have to say about [Hospital A] would be very positive. We were so worried about the whole thing, the staff were so very good and I only have good things to say. Under the circumstances it was the best experience it could have been."* • *"The staff were phenomenal, I couldn't say enough about them."*
Views on the four options	• *"We agree in principal that there should be a reduced number of centres for better care. The location is an issue for some people, it's OK for us as we have good family networks but for others it would be more difficult to travel."* • *"I am unhappy with the options that have been proposed, but I agree in principal with the review."*
Managed clinical networks	• *"A local centre is imperative."* • *"I would worry a lot about continuity of care and transfer of patient notes."* • *"I really would want to see the experts from the surgical centre, but it's so much easier when it is closer to home."*
Other comments	• *"We have no qualms with treatment or outpatient checks but it just seems a big thing to go to [City A]. It would seem more 'normal' to go to [Town A] as other children from school go to [Hospital in Town A] for appointments, so it's more normal for the child. It's a psychological thing I suppose."* • *"It is so hard for parents already without the added stress of additional travel time."* • *"Most parents would travel anywhere for the health of their children but there needs to be a balance between the distance travelled and the care of the child as it affects them being far from home."*

688 questionnaires were sent to parents of service users across the 22 postcodes areas…

- 688 questionnaires were sent to parents and in total, 172 responses were received – this represents a response rate of 25%.
- The chart below shows the 22 postcode areas (see overleaf for detail of postcodes and abbreviations) and analyses the 172 parent responses by the paediatric cardiac centres currently being attended. For example, of the 15 parents contacted from Guildford (GU), six were currently attending GOSH, a further five the Brompton, three Southampton and one Evelina.

Current surgical centre used by respondents by postcode area



Source: PwC survey of parents

n=172

Most parents who responded were from the Coventry, Guildford Nottingham and Sheffield postcode areas, in line with the profile of referrals from the 22 postcode areas being considered…

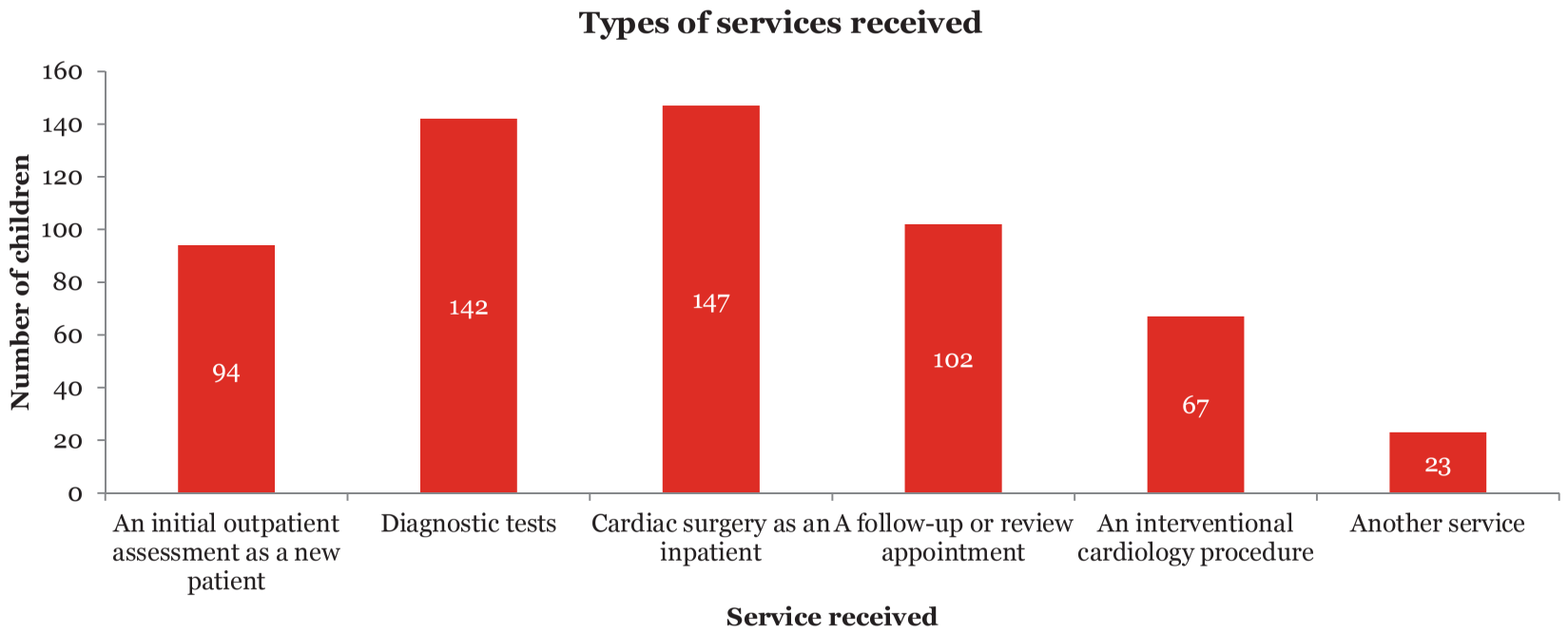
- The 172 parents who responded to the survey came from across the range of 22 postcodes being examined, as shown in the table.
- Of the 172 respondents to the survey, 100 (58.1%) parents had a son who had used paediatric cardiac surgical services whilst 71 (41.3%) had a daughter who had used these services.
- Most (107 of 172, or 62.2%) of these children were referred to the service more than two years ago.
- 40 children (23.3%) had been referred between one and two years ago.
- 16 children (9.8%) had been referred between six months and one year ago.
- Eight children (4.9%) had been referred less than six months ago.
- **Please note: not all of the 172 respondents answered all of the questions within the survey. Therefore the value of 'n' varies for some of the findings.**

Postcode area	% of responses	Postcode area	% of responses
Bradford (BD)	3 (1.7%)	Lincoln (LN)	3 (1.7%)
Brighton (BN)	14 (8.1%)	Leeds (LS)	8 (4.7%)
Coventry (CV)	16 (9.3%)	Nottingham (NG)	16 (9.3%)
Doncaster (DN)	9 (5.2%)	Oxford (OX)	6 (3.5%)
Dorchester (DT)	3 (1.7%)	Peterborough (PE)	8 (4.7%)
Guildford (GU)	16 (9.3%)	Reading (RG)	6 (3.5%)
Huddersfield (HD)	4 (2.3%)	Redhill (RH)	11 (6.4%)
Hemel Hempstead (HP)	3 (1.7%)	Sheffield (S)	18 (10.5%)
Hereford (HR)	4 (2.3%)	Slough (SL)	3 (1.7%)
Hull (HU)	5 (2.9%)	Wakefield (WF)	6 (3.5%)
Halifax (HX)	3 (1.7%)	Worcester (WR)	7 (4.1%)

Source: PwC survey of parents
n=172

Children had accessed a range of services as part of their treatment, from appointments and diagnostic tests through to cardiac surgery…

- Respondents indicated that their children had received a range of services in relation to paediatric cardiac surgery since the time of their referral, as shown in the chart below.
- Most (147 or 85.5%) indicated that their child had received cardiac surgery as an inpatient and/or diagnostic tests (142 or 82.6%).



Source: PwC survey of parents
n=172

Reputation was the factor which influenced the choice of current cardiac surgical centre amongst parents…

- Parents were asked to indicate up to three factors which most influenced their decision to use the current centre where their child is receiving paediatric cardiac surgical services. The figure below shows the five most commonly cited factors.
- It should be noted that 33 parents (19.2%) also cited other reasons in response to this question.
- Fewer than 15 parents (9.1%) selected the following factors within their "top three": ease of access to the motorway network, availability of car parking, availability of public transport and cost of travel.

Reputation of the centre	• This was identified as one of the top three factors selected by 86 parents (50.0%)
Recommendation from a GP or other healthcare professional	• This was identified as one of the top three factors selected by 79 parents (45.9%)
The surgical team available	• This was identified as one of the top three factors selected by 74 parents (43.0%)
Travel time	• This was identified as one of the top three factors selected by 49 parents (28.5%)
Previous experience of using this centre	• This was identified as one of the top three factors selected by 24 parents (14.0%)

"This would give me some comfort to know that it's a good centre."

"I would prefer to have the same surgeon for all operations and also be familiar with the people and the area."

"It's a stressful time and we had a good experience before and knew the centre so this puts you at ease."

Source: PwC survey of parents
n=172

Over 90% of parents could access their current centre in under two hours, and over 80% of parents used their own car for all or part of this journey…

- Most parents (87 or 51.5%) indicated that travel times to their current centre were under one hour *(n=169)*.
  - A further 69 parents (40.8%) indicated that their travel time was between one and two hours.
  - Only 13 parents (7.7%) indicated that their current travel time was two hours or longer.
- 121 parents (70.8%) used a single mode of transport to reach the current centre whilst the remaining 50 parents (29.2%) used multiple modes of transport *(n=171)*.
  - In terms of mode of travel, 142 parents (82.6%) indicated that they have access to their own car to reach the current centre, either for all or part of this journey.
  - 104 parents (60.5%) travelled to the current centre solely using their own car whilst a further 38 parents (22.1%) indicated that they used their own car, plus one or two other modes of transport.
  - Six parents (3.5%) travelled to the current centre solely via a car belonging to a friend or family member whilst a further eight parents (4.7%) used this mode of transport for part of their journey.
  - Nine parents (5.2%) travelled to the centre solely using public transport (bus or train) whilst a further 51 parents (29.7%) used public transport for part of their journey.

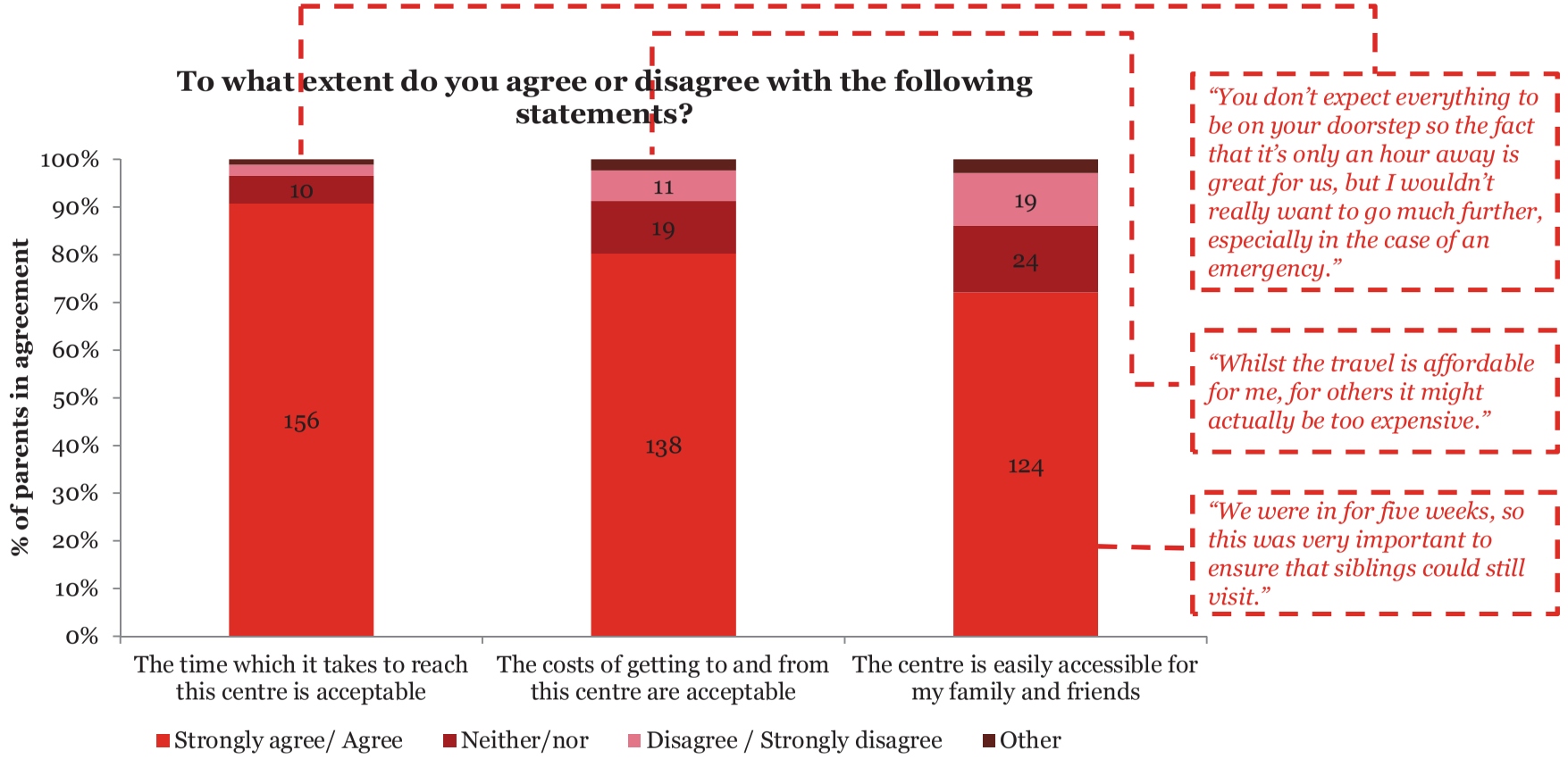
"It's just easier to drive, it doesn't take as long."

"We live in a rural location so it would take three hours by public transport and I wouldn't do it with a sick child."

"We don't drive to the hospital due to car parking and also we only have one car – if it's an early appointment my husband needs the car to take the other children to school."

(Quotes from parents)

Parents were most satisfied with the staff available at the current centres whilst they were less satisfied with the accessibility of the centre for their friends and family (i)…



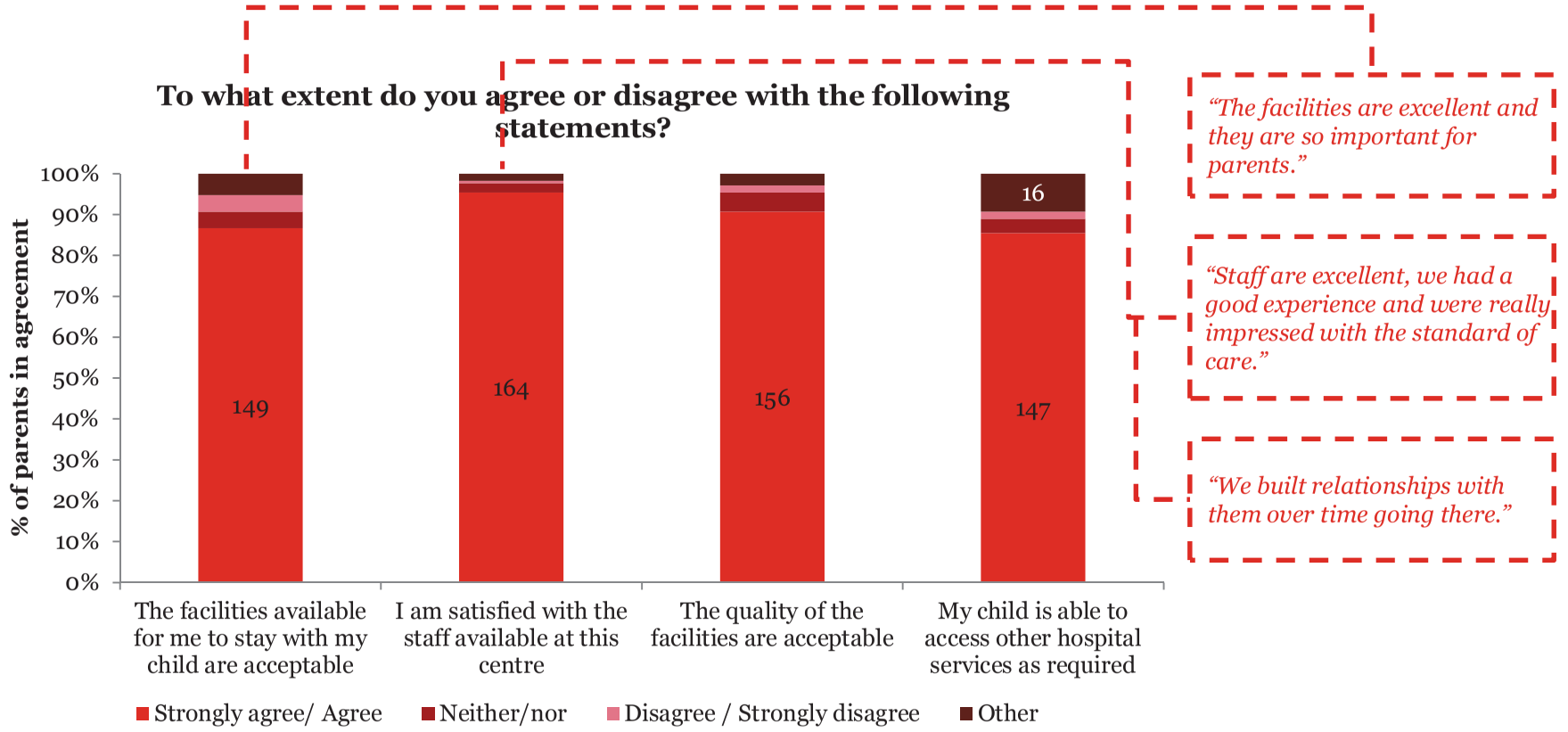
"You don't expect everything to be on your doorstep so the fact that it's only an hour away is great for us, but I wouldn't really want to go much further, especially in the case of an emergency."

"Whilst the travel is affordable for me, for others it might actually be too expensive."

"We were in for five weeks, so this was very important to ensure that siblings could still visit."

Source: PwC survey of parents
n=172

Parents were most satisfied with the staff available at the current centres whilst they were less satisfied with the accessibility of the centre for their friends and family (ii)…



"The facilities are excellent and they are so important for parents."

"Staff are excellent, we had a good experience and were really impressed with the standard of care."

"We built relationships with them over time going there."

Source: PwC survey of parents
n=172

Under Option A, the research showed that parents in 11 of the 22 postcode selected the centres which would be expected under S&S…

- In 11 of the 22 postcode areas (BD, BN, HP, HR, HX, LN, OX, RG, RH, SL and WR), parents selected the centres which would be expected under S&S. For the remaining 11 this was not the case and the exceptions to this are highlighted in red in the table below.
- For example, of the four respondents from Hull, three (75%) indicated that they would prefer to travel to Newcastle under Option A (assumed S&S centre), whilst one (25%) indicated that they would prefer to travel to Liverpool.

Paediatric cardiac surgical centre selected by parent under Option A

Postcode area	Liverpool	Birmingham	GOSH	Evelina	Newcastle	Bristol	Leicester	Total (%)
Coventry (CV)	-	13 (81%)	-	-	-	-	3 (19%)	16 (100%)
Doncaster (DN)	1 (14%)	3 (43%)	-	-	2 (29%)	-	1 (14%)	7 (100%)
Dorchester (DT)	-	-	1 (33%)	1 (33%)	-	1 (33%)	-	3 (100%)
Guildford (GU)	-	1 (8%)	9 (69%)	3 (23%)	-	-	-	13 (100%)
Huddersfield (HD)	-	-	-	-	-	-	1 (100%)	1 (100%)
Hull (HU)	1 (25%)	-	-	-	3 (75%)	-	-	4 (100%)
Leeds (LS)	3 (100%)	-	-	-	-	-	-	3 (100%)
Nottingham (NG)	-	3 (19%)	-	-	-	-	13 (81%)	16 (100%)
Peterborough (PE)	-	-	3 (43%)	-	-	-	4 (57%)	7 (100%)
Sheffield (S)	2 (25%)	2 (25%)	2 (25%)	-	1 (13%)	-	1 (13%)	8 (100%)
Wakefield (WF)	3 (100%)	-	-	-	-	-	-	3 (100%)

Source: PwC survey of parents

n=127

Under Option B, the research showed that parents in six of the 22 postcodes selected the centres which would be expected under S&S…

- In six of the 22 postcode areas (BD, HD, HR, HX, LN and WR), parents selected the centres which would be expected under S&S. For the remaining 16 this was not the case and the exceptions to this are highlighted in red in the table below. For example, of the seven respondents from Doncaster, two (29%) indicated that they would prefer to travel to Liverpool under Option B, whilst three (43%) would prefer Birmingham and two (29%) stated that they would travel to Newcastle.

Paediatric cardiac surgical centre selected by parent under Option B

Postcode area	Liverpool	Birmingham	GOSH	Evelina	Newcastle	Bristol	Southampton	Total
Brighton (BN)	-	-	2 (22%)	5 (56%)	-	-	2 (22%)	9 (100%)
Coventry (CV)	-	12 (86%)	1 (7%)	1 (7%)	-	-	-	14 (100%)
Doncaster (DN)	2 (29%)	3 (43%)	-	-	2 (29%)	-	-	7 (100%)
Dorchester (DT)	-	-	-	-	-	-	3 (100%)	3 (100%)
Guildford (GU)	-	-	9 (64%)	2 (14%)	-	-	3 (21%)	14 (100%)
Hemel Hempstead (HP)	-	-	1 (50%)	1 (50%)	-	-	-	2 (100%)
Hull (HU)	1 (25%)	-	-	-	3 (75%)	-	-	4 (100%)
Leeds (LS)	3 (100%)	-	-	-	-	-	-	3 (100%)
Nottingham (NG)	-	12 (92%)	-	-	1 (8%)	-	-	13 (100%)
Oxford (OX)	-	-	2 (50%)	-	-	-	2 (50%)	4 (100%)
Peterborough (PE)	-	2 (40%)	3 (60%)	-	-	-	-	5 (100%)
Reading (RG)	-	-	2 (40%)	1 (20%)	-	-	2 (40%)	5 (100%)
Redhill (RH)	-	-	2 (29%)	5 (71%)	-	-	-	7 (100%)
Sheffield (S)	3 (38%)	3 (38%)	1 (13%)	-	1 (13%)	-	-	8 (100%)
Slough (SL)	-	-	1 (33%)	1 (33%)	-	-	1 (33%)	3 (100%)
Wakefield (WF)	3 (100%)	-	-	-	-	-	-	3 (100%)

Source: PwC survey of parents

n=118

Under Option C, the research showed that parents in 12 of the 22 postcodes selected the centres which would be expected under S&S…

- In 12 of the 22 postcode areas (BD, BN, HD, HP, HR, HX, LN, OX, RG, RH, SL and WR), parents selected the centres which would be expected under S&S. For the remaining 10 this was not the case and the exceptions to this are highlighted in red in the table below.
- For example, of the 13 respondents from Nottingham, 12 (92%) indicated that they would prefer to travel to Birmingham under Option C, whilst one (8%) stated that they would prefer to travel to Newcastle.

Paediatric cardiac surgical centre selected by parent under Option C

Postcode area	Liverpool	Birmingham	GOSH	Evelina	Newcastle	Bristol	Total
Coventry (CV)	-	12 (86%)	-	2 (14%)	-	-	14 (100%)
Doncaster (DN)	2 (29%)	3 (43%)	-	-	2 (29%)	-	7 (100%)
Dorchester (DT)	-	-	1 (33%)	1 (33%)	-	1 (33%)	3 (100%)
Guildford (GU)	-	1 (8%)	9 (69%)	3 (23%)	-	-	13 (100%)
Hull (HU)	1 (25%)	-	-	-	3 (75%)	-	4 (100%)
Leeds (LS)	3 (100%)	-	-	-	-	-	3 (100%)
Nottingham (NG)	-	12 (92%)	-	-	1 (8%)	-	13 (100%)
Peterborough (PE)	-	2 (40%)	3 (60%)	-	-	-	5 (100%)
Sheffield (S)	3 (38%)	3 (38%)	1 (13%)	-	1 (13%)	-	8 (100%)
Wakefield (WF)	3 (100%)	-	-	-	-	-	3 (100%)

Source: PwC survey of parents *n=113*

Under Option D, the research showed that parents in 16 of the 22 postcodes selected the centres which would be expected under S&S…

- In 16 of the 22 postcode areas (BD, BN, HD, HP, HR, HU, HX, LN, LS, OX, RG, RH, S, SL, WF and WR), parents selected the centres which would be expected under S&S. For the remaining six this was not the case and the exceptions to this are highlighted in red in the table below.
- For example, of the five respondents from Peterborough, two (40%) indicated that they would prefer to travel to Birmingham under Option D, whilst three (60%) stated that they would prefer to travel to GOSH.

Paediatric cardiac surgical centre selected by parent under Option C

Postcode area	Liverpool	Birmingham	GOSH	Evelina	Leeds	Bristol	Total
Coventry (CV)	1 (7%)	12 (84%)	-	1 (7%)	-	-	14 (100%)
Doncaster (DN)	-	1 (13%)	-	-	7 (88%)	-	8 (100%)
Dorchester (DT)	-	-	1 (33%)	1 (33%)	-	1 (33%)	3 (100%)
Guildford (GU)	-	1 (8%)	9 (69%)	3 (23%)	-	-	13 (100%)
Nottingham (NG)	-	12 (92%)	-	-	1 (8%)	-	13 (100%)
Peterborough (PE)	-	2 (40%)	3 (60%)	-	-	-	5 (100%)

Source: PwC survey of parents

n=133

The factors influencing parental choice of centre under each of the four options were broadly similar to those which influenced choice of current centre…

- Reputation of the centre was the factor which influenced the greatest number of parents for both the current centre and under each of the four options.
- Beyond this, previous experience of using the centre, the surgical team available and travel time all featured in terms of influencing parental choice of the current centre and within each of the options.
- Whilst a recommendation from a GP or other healthcare professional featured in terms of choosing the current centre, this only featured under Option D in fifth place.

"I've been to [Hospital A] before and I know how to get there but I have never been to [Hospital B] so it would be a bit more daunting. It would be somewhere new so I would feel easier going to [Hospital A] rather than somewhere I don't know".

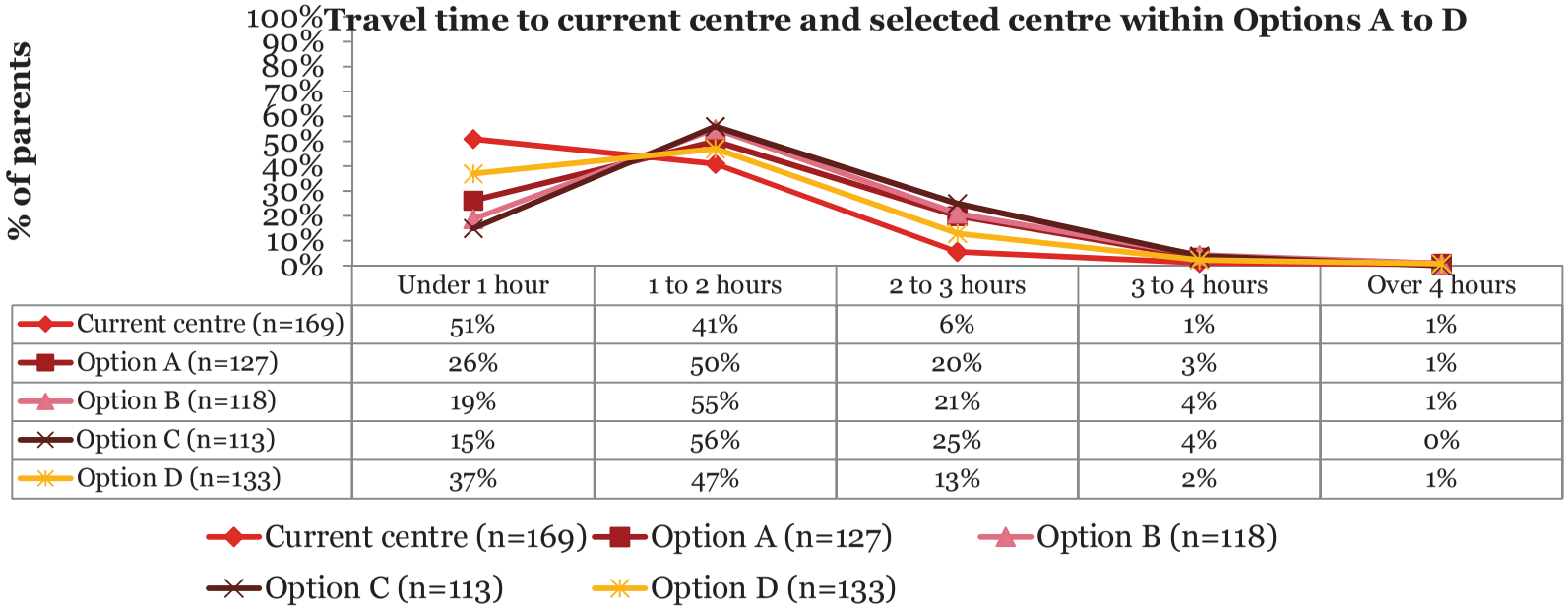
"Geography; it's the only one within two hours of us".

	Current centre n = 172	Option A n = 127	Option B n = 118	Option C n = 113	Option D n = 133
1	Reputation of the current centre - 86 (50.0%)	Reputation of the centre - 80 (63.0%)	Reputation of the centre - 70 (59.3%)	Reputation of the centre - 69 (61.1%)	Reputation of the centre - 77 (57.9%)
2	Recommendation from a GP or other healthcare professional - 79 (45.9%)	Previous experience of using this centre - 61 (48.0%)	The surgical team available - 54 (45.8%)	Travel time - 51 (45.1%)	Previous experience of using this centre - 68 (51.1%)
3	The surgical team available - 74 (43.0%)	The surgical team available - 61 (48.0%)	Previous experience of using this centre - 53 (44.9%)	The surgical team available - 50 (44.2%)	The surgical team available - 66 (49.6%)
4	Travel time - 49 (28.5%)	Travel time - 50 (39.4%)	Travel time - 52 (44.1%)	Previous experience of using this centre - 48 (42.5%)	Travel time - 57 (42.9%)
5	Previous experience of using this centre - 24 (14.0%)	Ease of access – motorway network - 16 (12.6%)	Ease of access – motorway network -18 (15.3%)	Ease of access – motorway network - 16 (14.2%)	Recommendation from a GP or other healthcare professional - 12 (9.0%)

Source: PwC survey of parents

A greater proportion of parents expected to be travelling for between one and four hours to the centres under the four options than under current arrangements…

- As shown in the graph below, a lower proportion of parents estimated that they would be within one hour of the cardiac centre under each of the options when compared to current arrangements, with the resultant impact that a greater proportion of parents would travel for between one and four hours to reach a centre.
- It should be noted that we did not seek to validate the estimates of travel time which were suggested by parents under each of the options.



	Under 1 hour	1 to 2 hours	2 to 3 hours	3 to 4 hours	Over 4 hours
Current centre (n=169)	51%	41%	6%	1%	1%
Option A (n=127)	26%	50%	20%	3%	1%
Option B (n=118)	19%	55%	21%	4%	1%
Option C (n=113)	15%	56%	25%	4%	0%
Option D (n=133)	37%	47%	13%	2%	1%

Source: PwC survey of parents

A slightly higher proportion of parents wished to access all care at a specialist centre, but few parents indicated that the existence of a network would change their choice of preferred centre…

- Parents were asked to indicate whether they would prefer to have outpatient appointments and ongoing management of care at their preferred centre under each of the four options, or whether they would prefer to receive this care at a more local hospital. The findings from this are detailed below.
- There was most support for local care amongst parents in response to Option C (46.0%) and least support under Option D (39.1%).

	Option A n= 127	Option B n= 118	Option C n= 113	Option D n= 133
Parents who stated that they would prefer to have outpatient appointments and ongoing management of care at a local hospital	56 (44.1%)	51 (43.2%)	52 (46.0%)	52 (39.1%)
Parents who stated that they would prefer to have all care at the specialist centre	67 (52.8%)	59 (50.0%)	54 (47.8%)	70 (52.6%)
Parents who did not indicate where they would prefer their child to receive care	4 (3.1%)	8 (6.8%)	7 (6.2%)	11 (8.3%)
Parents who indicated that the existence of a managed clinical network would change their choice of preferred main centre under this option	6 (4.7%)	7 (5.9%)	7 (6.2%)	6 (4.5%)

Source: PwC survey of parents Please note: not all of the respondents answered the question on managed clinical networks within the survey. Therefore the value of 'n' varies for some of the findings.

"It would depend if seeing the same surgeon, if you could see the same surgeon or cardiologist as at the specialist centre then I would go to a local hospital, otherwise I would probably just travel."

"I would definitely want to continue with the current network arrangement and have the appointments at [Town A] but there needs to be a continuity of care, especially with the consultants."

"I would choose to have all appointments at the same specialist centre as [child] had a complicated history and he felt comfortable there. He was not keen to change where he was going for appointments due to the quality of care he was being given."

Findings: general public focus groups

- Approach to general public focus groups
- Findings from general public focus groups

Recruitment for general public focus groups

Focus groups Held:	No. of participants
Coventry	9
Brighton	9
Guildford/ Redhill	11
Reading/ Slough	7
Oxford/ Hemel Hempstead	6
Huddersfield/ Halifax	6
Leeds/ Bradford/ Wakefield	11
Nottingham	6
Peterborough	6
Lincoln	5
Doncaster/ Sheffield	12
Hereford/ Worcester	9
Hull/Dorchester*	5
Total	**102**

** Note that discussions with members of the public in these areas were conducted by telephone.*

- Participants were recruited from across the 22 postcodes identified for further exploration by NSCT.
- In total 102 individuals took part in the focus groups. The numbers of the public recruited per postcode area, were broadly in proportion to the referral levels identified in S&S for the cohort of 22 postcode areas.
- Recruitment criteria sought to get a range of participants from the general public in terms of age, having and not having dependent children, gender and socio-economic background and also from across postcode districts within the overarching postcode areas*.
- The key exclusion criteria applied was personal or family related use of paediatric or adult cardiac surgery services or congenital cardiology or cardiology services.
- Overall, there was broad consensus of findings between those of different ages, genders and socio-economic groups – these findings are described in more detail in the sections that follow.

** Groups were undertaken largely by age band and socio economic group as our experience and that of other Market Research Society accredited organisations (e.g. Discovery Research) has found that if such groups are mixed, participants can be more reluctant to share and voice their true opinions.*

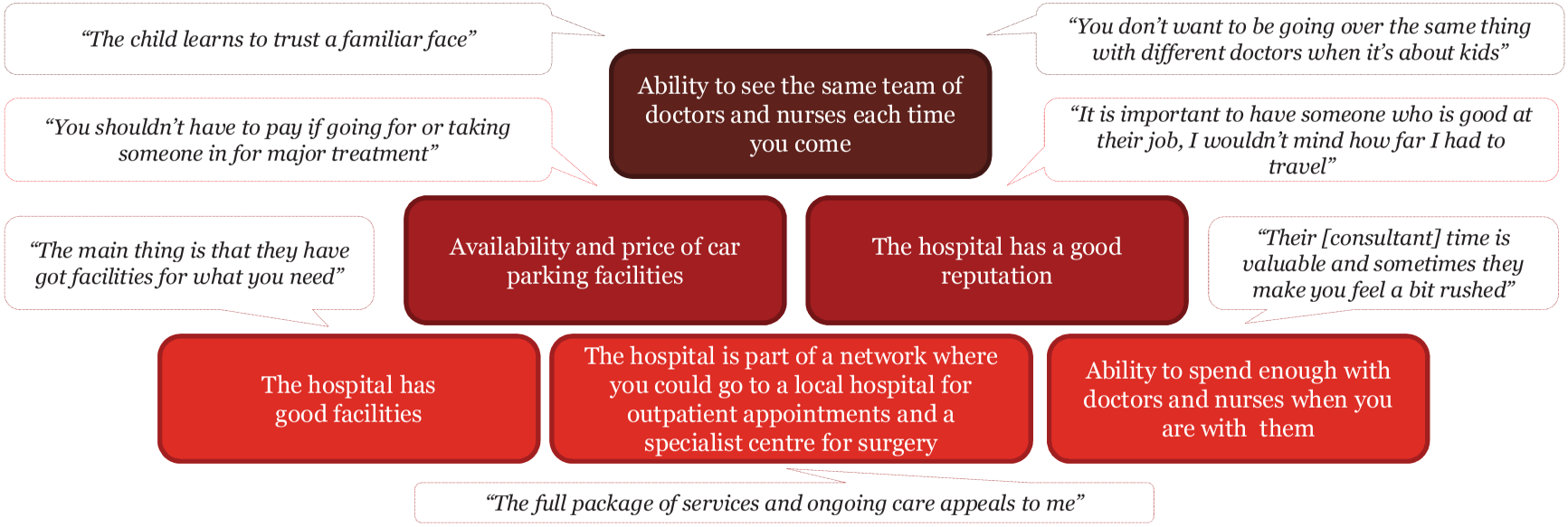
Overview of discussion guide used for focus groups with members of the general public

- The table below provides a summary of the areas discussed with members of the public across the 22 postcode areas considered as part of this study.
- For note, in discussing options with the public (and parents), the surgical centres talked about were as per those specific centres named for Options A – D in S&S (see Appendix).

Section	Description
Introduction and overview	The focus group facilitator provided an overview of the topic to be discussed including key principles of the Safe and Sustainable Review.
Warm-up discussion	Participants were asked to introduce themselves to the group and also indicate the distance they had travelled to the group and their mode of transport.
Existing centres	Views on where participants would travel under the existing arrangements were discussed, to enable comparison with the follow-on discussion of each option.
Options A, B, C and D	Each of the options were discussed in turn, firstly asking participants where they would choose to go, then moving on to discuss whether this was in line with the assumptions made by S&S. Where differences arose, the acceptability of the centres outlined for each postcode area were discussed. Their views on managed clinical networks was also sought.
Exercise - postcards	Participants were asked to note on a postcard any points which they had not mentioned already or the point(s) which they felt most strongly about over the course of the discussion. Participants were also asked to provide ideas on how options could be made more amenable/accessible.

Important factors in accessing specialised health services

- The diagram below shows the six factors (from a list of 13) which were most frequently selected by members of the public when asked to identify the factors which would be most important to them in accessing a specialised health service (such as paediatric cardiac surgery).



- In addition to this, most participants indicated that they would travel to the current centres by car. Less than 10% of participants indicated that they would use public transport to access one of the current centres if travelling for surgery, although nearly 20% stated that they might use public transport when travelling for an outpatient appointment.
- Across all of the postcode areas examined, participants were able to estimate their journey time to one of the current centres or a centre under each of the four options – in each case, the journey times indicated by participants appeared realistic.

Option A

- The table below shows the seven centres which feature in Option A, along with the assumptions that S&S have made for each of the 22 postcode areas, and where patients would potentially flow to. For postcode areas highlighted in **red**, the consensus amongst focus group members was that the S&S centre would not be their preferred choice.
- Focus group participants from five of the 22 postcode areas did not identify centres (Leicester and Newcastle) assumed by S&S to be their chosen centre.
- However, participants from the five postcodes did indicate that although they had preferred alternative centres, if their preferred alternative was not available they would travel to the S&S assumed centre.

Birmingham Hospital	Bristol Royal Hospital	GOSH or Evelina Hospital, London	Glenfield Hospital, Leicester	Alder Hey Hospital, Liverpool	Freeman Hospital, Newcastle
Hereford Worcester	Dorchester Oxford (part) Reading (part)	Brighton Guildford Hemel Hempstead Oxford (part) Reading (part) Redhill Slough	Coventry Doncaster Lincoln Nottingham Peterborough Sheffield	Bradford Halifax Huddersfield	Hull Wakefield Leeds

Option A – Feedback from postcode areas disagreeing with preferred centre NSCT assumptions

Coventry
Assumption: Leicester
Preferred choice: Birmingham

Lincoln
Assumption: Leicester
Preferred choice: Newcastle

Peterborough
Assumption: Leicester
Preferred choice: London

Wakefield
Assumption: Newcastle
Preferred choice: Liverpool

Leeds
Assumption: Newcastle
Preferred choice: Liverpool

Reasons for preferred choice:

- ***Felt to be a "natural flow"*** for example towards Birmingham and Liverpool - people travelling there for shopping or to use airports.
- ***Better transport links for certain centres*** - motorway over 'A' class road for Newcastle rather than Leicester.
- ***Reputation or awareness of certain centres*** over others – GOSH and Alder Hey recognised by focus group participants, not the case for Freeman Hospital in Newcastle.
- If considering ***public transport, London preferred*** – express trains to London, whereas less knowledge/ information on services to other areas (e.g. Leicester).

Option B

- The table below shows the seven centres which feature in Option B, along with the assumptions that S&S have made for each of the 22 postcode areas, and where patients would potentially flow to. For postcode areas highlighted in **red**, the consensus amongst focus group members was that the S&S centre would not be their preferred choice.
- Focus group participants from nine of the 22 postcode areas did not identify centres (Birmingham, Bristol, Newcastle and Southampton) assumed by S&S to be their chosen centre.
- However, participants from the postcodes mapped to the centres in Birmingham, Bristol and Southampton did indicate that although they had preferred alternative centres, if their preferred alternative was not available they would travel to the S&S assumed centre. There was more reluctance amongst those mapped to the Newcastle centre to travel there.

Birmingham Hospital	Bristol Royal Hospital	GOSH or Evelina Hospital, London	Alder Hey Hospital, Liverpool	Freeman Hospital, Newcastle	Southampton General Hospital
• Coventry • Hereford* • Lincoln • Nottingham • Worcester*	• Dorchester • Oxford (part) • Reading (part)	• Hemel Hempstead • Peterborough • Slough	• Bradford • Halifax • Huddersfield	• Doncaster • Hull • Leeds • Sheffield • Wakefield	• Brighton • Guildford • Oxford (part) • Reading (part) • Redhill

Option B – Feedback from postcode areas disagreeing with preferred centre NSCT assumptions

Brighton
Assumption: Southampton
Preferred choice: London

Lincoln
Assumption: Birmingham
Preferred choice: Newcastle

Doncaster
Assumption: Newcastle
Preferred choice: Birmingham

Oxford
Assumption: Bristol or Southampton
Preferred choice: London or Bristol

Hull
Assumption: Newcastle
Preferred choice: Liverpool or Newcastle

Reading
Assumption: Bristol or Southampton
Preferred choice: London or Bristol

Leeds
Assumption: Newcastle
Preferred choice: Liverpool

Sheffield
Assumption: Newcastle
Preferred choice: Birmingham

Wakefield
Assumption: Newcastle
Preferred choice: Liverpool

Reasons for preferred choice:

- ***Felt to be a "natural flow"*** for example towards Liverpool in the northern postcode areas and towards London for Brighton.
- ***Better transport links for certain centres*** - road network to Birmingham viewed as congested, and roads to London seen as superior than those to Southampton.
- ***Reputation or awareness of certain centres*** over others – GOSH and Alder Hey recognised by focus group participants, not the case for Southampton and Newcastle.
- If considering ***public transport, London preferred*** – for some travelling to Southampton, this meant changing trains in London anyway.

Option C

- The table below shows the six centres which feature in Option C, along with the assumptions that S&S have made for each of the 22 postcode areas, and where patients would potentially flow to. For postcode areas highlighted in **red**, the consensus amongst focus group members was that the S&S centre would not be their preferred choice.
- Focus group participants from six of the 22 postcode areas did not identify centres (Birmingham and Newcastle) assumed by S&S to be their chosen centre.
- However, participants from five of these six postcodes (excluding Lincoln) did indicate that although they had preferred alternative centres, if their preferred alternative was not available they would travel to the S&S assumed centre. There was more reluctance amongst those mapped to the Newcastle centre to travel there.

Birmingham Hospital	Bristol Royal Hospital	GOSH or Evelina Hospital, London	Alder Hey Hospital, Liverpool	Freeman Hospital, Newcastle
• Coventry • Hereford* • Lincoln • Nottingham • Worcester*	• Dorchester • Oxford (part) • Reading (part)	• Brighton • Guildford • Hemel Hempstead • Oxford (part) • Peterborough • Reading (part) • Redhill • Slough	• Bradford • Halifax • Huddersfield	• Doncaster • Hull • Leeds • Sheffield • Wakefield

Option C – Feedback from postcode areas disagreeing with preferred centre NSCT assumptions

Doncaster
Assumption: Newcastle
Preferred choice: Birmingham

Hull
Assumption: Newcastle
Preferred choice: Liverpool or Newcastle

Leeds
Assumption: Newcastle
Preferred choice: Liverpool

Lincoln
Assumption: Birmingham
Preferred choice: Newcastle

Sheffield
Assumption: Newcastle
Preferred choice: Birmingham

Wakefield
Assumption: Newcastle
Preferred choice: Liverpool

Reasons for preferred choice:

- ***Felt to be a "natural flow"*** for example few in the northern postcode areas were familiar with the journey to Newcastle.
- ***Better transport links for certain centres*** - road network to Birmingham viewed as congested.
- ***Reputation or awareness of certain centres*** over others – Alder Hey and London centres recognised by focus group participants, not the case for Newcastle.
- If considering ***public transport, Birmingham preferred*** – as transport to Newcastle was viewed as being more expensive.

Option D

- The table below shows the six centres which feature in Option D, along with the assumptions that S&S have made for each of the 22 postcode areas, and where patients would potentially flow to. In this instance, there is only one postcode area (highlighted in **red)** where the consensus amongst focus group members was that the S&S centre was not their preferred choice.
- Only those focus group participants from one of the 22 postcode areas (Nottingham) did not identify centres (Leeds) assumed by S&S to be their chosen centre.
- However, participants from this postcode area did indicate that although they a preferred alternative centre, if their preferred alternative was not available they would travel to the S&S assumed centre.

Birmingham Hospital	Bristol Royal Hospital	GOSH or Evelina Hospital, London	Alder Hey Hospital, Liverpool	Leeds General Infirmary
• Coventry • Hereford • Worcester	• Dorchester • Oxford (part) • Reading (part)	• Brighton • Hemel Hempstead • Peterborough • Redhill • Guildford • Oxford (part) • Reading (part) • Slough	• None	• Bradford • Halifax • Huddersfield • Nottingham • Sheffield • Doncaster • Hull • Leeds • Lincoln • Wakefield

Option D – Feedback from postcode areas disagreeing with preferred centre NSCT assumptions

Nottingham
Assumption: Leeds
Preferred choice: Birmingham

Reasons for preferred choice:

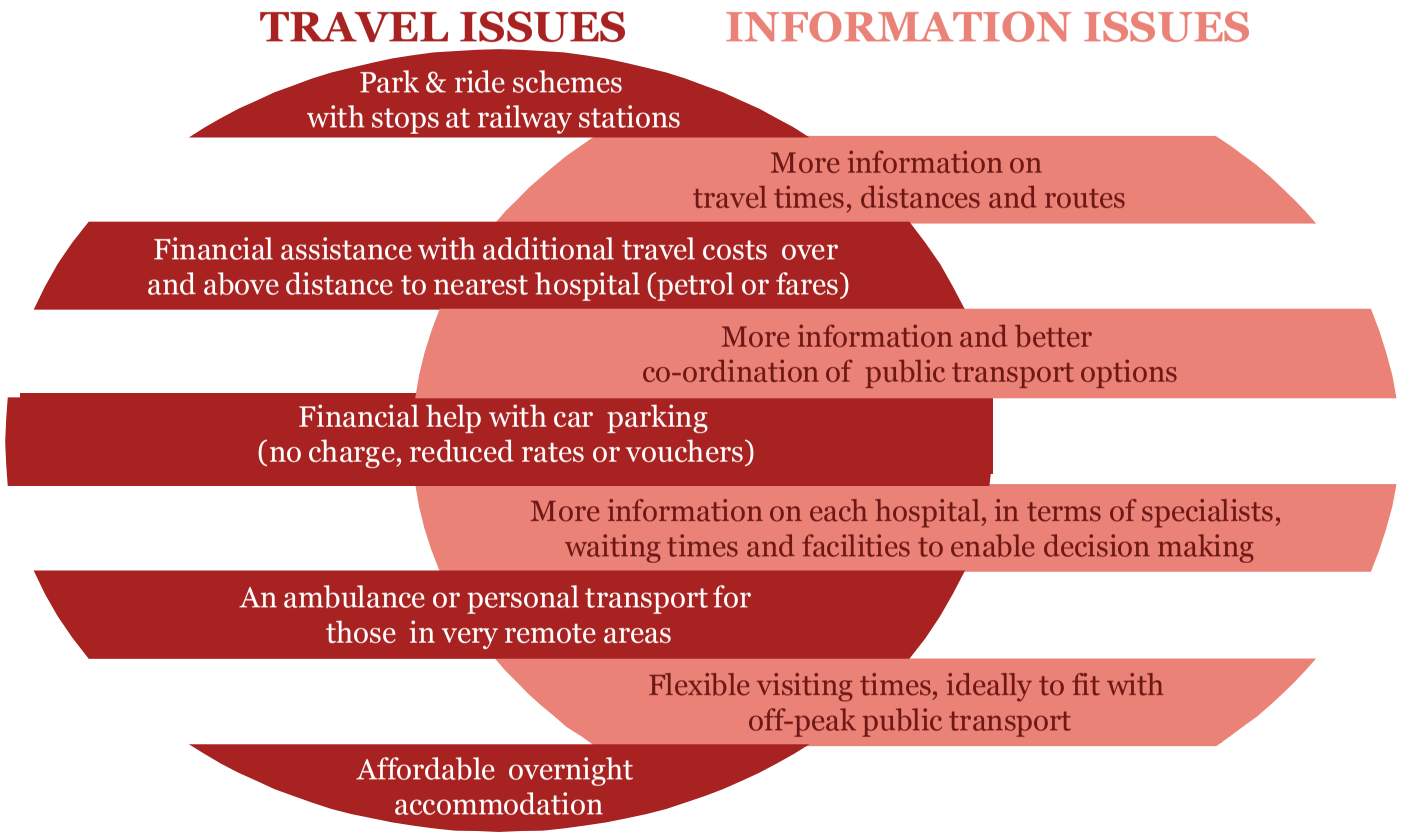
- ***Reputation of certain centres*** over others – Birmingham recognised by focus group participants as a dedicated children's hospital, not the case for Leeds.
- ***Focus and title of certain centres*** - Concerns that Leeds is known as a Teaching Hospital, and this may mean that service users may encounter a greater number of specialists in training, rather than solely fully qualified staff.

Views from members of the public on the proposed managed clinical network arrangements…

- Overall networks were considered a good idea and participants felt that it was more desirable to have care managed locally rather than travelling to a specialist centre. Participants suggested that these networks should be supported by:
  - Continuity of care, particularly with the team of health professionals that the patient and their family sees, whether at the specialist centre or across the network.
  - Continuous and strong communication between the specialist centre and any local care providers.
  - Technology (such as email and video conferencing) to stay in touch with the specialist centre.
  - The ability to meet the surgeon before surgery takes place, and in some cases for at least one follow-up appointment.
- However, in some instances where participants lived close to one of the current specialist centres, participants stated that they would rather travel to the specialist centre and have their care all in one place. This was due to the travel time being considered reasonable as well as the desire to see the specialist team. For example:
  - Those who lived in Nottingham indicated that they would rather travel to Leicester (under Option A) for all appointments.
  - Those who lived in Huddersfield would rather travel to Leeds (under Option D).
  - Those who lived in Worcester would rather travel to Birmingham (under each of the options).

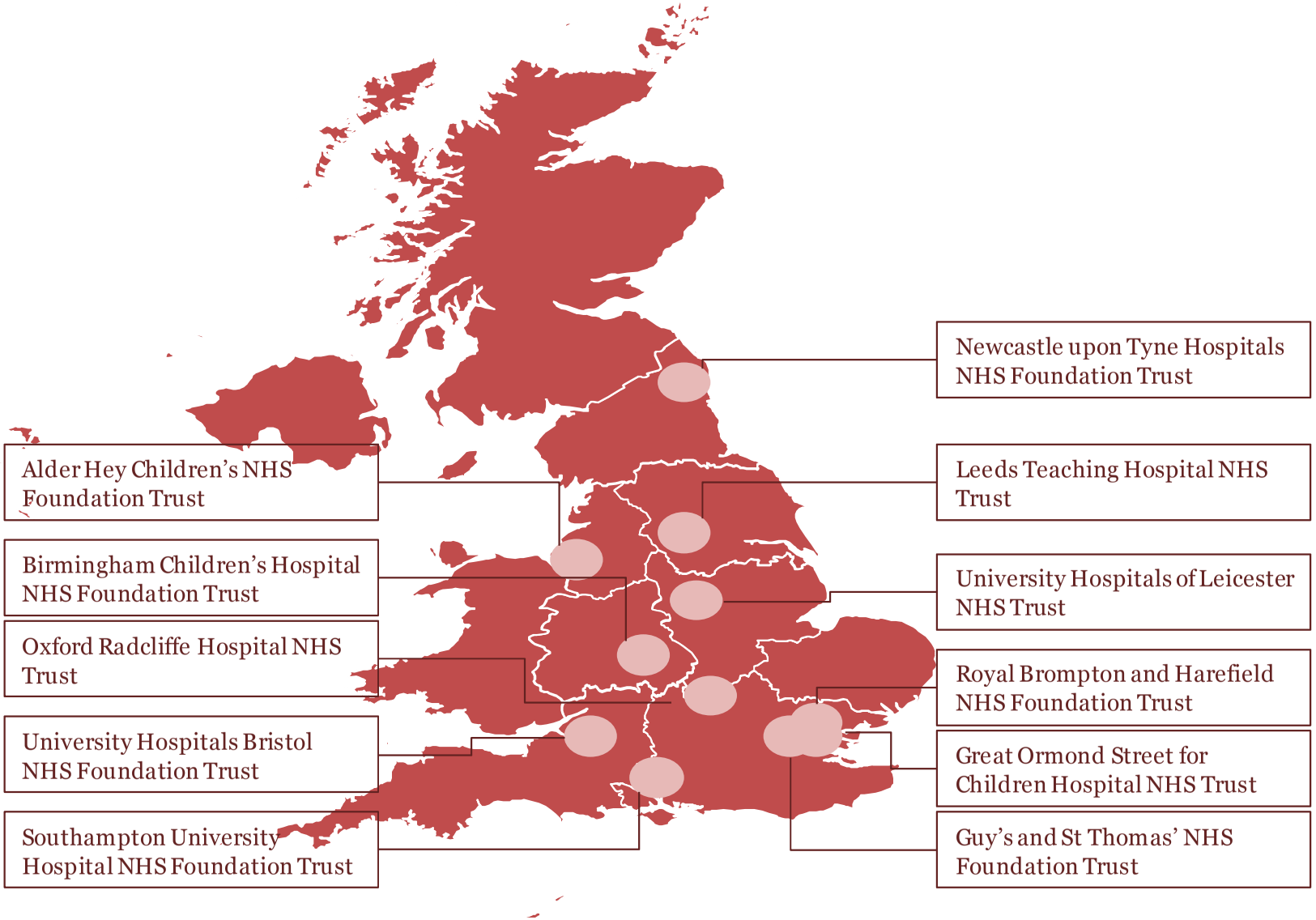
Ways of making the options more amenable and accessible

- Participants cited a variety of ways to make the options more amenable and accessible, although these could be broadly categorised into the themes of (i) travel issues and (ii) information issues, as shown in the diagram below. Overall, there were differing views on entitlements around accessing services, with a minority stating that they should be entitled to free travel, accommodation and personalised transport within the NHS.



Appendices

Safe and Sustainable Review - 11 centres focused upon...



Safe and Sustainable Review - Options A, B, C & D and associated centres...

Option A:	Option C:
Seven surgical centres at:	***Six surgical centres at:***
1. Freeman Hospital, Newcastle (NUTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Glenfield Hospital, Leicester (UHL) 4. Birmingham Children's Hospital (BCH) 5. Bristol Royal Hospital for Children (UHB) 6. Evelina Children's Hospital, London (GSTT) 7. Great Ormond Street Hospital for Children, London (GOSH)	1. Freeman Hospital, Newcastle (NUTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Birmingham Children's Hospital (BCH) 4. Bristol Royal Hospital for Children (UHB) 5. Evelina Children's Hospital, London (GSTT) 6. Great Ormond Street Hospital for Children, London (GOSH)
Option B:	**Option D:**
Seven surgical centres at:	***Six surgical centres at:***
1. Freeman Hospital, Newcastle (NUTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Birmingham Children's Hospital (BCH) 4. Bristol Royal Hospital for Children (UHB) 5. Southampton General Hospital (SUH) 6. Evelina Children's Hospital, London (GSTT) 7. Great Ormond Street Hospital for Children, London (GOSH)	1. Leeds General Infirmary (LTH) 2. Alder Hey Children's Hospital, Liverpool (AH) 3. Birmingham Children's Hospital (BCH) 4. Bristol Royal Hospital for Children (UHB) 5. Evelina Children's Hospital, London (GSTT) 6. Great Ormond Street Hospital for Children, London (GOSH)

Under Option A, the research showed that most parents selected the centres which would be expected under S&S based on the centre which they are currently using…(analysis by current centre attended, rather than parent's postcode area)

Current centre (below)	AH	BCH	GOSH	GSTT	NUTH	UHB	UHL
Alder Hey Hospital, Liverpool	-	-	-	-	-	-	-
Birmingham Hospital	-	26 (93%)	-	-	-	-	2 (7%)
Great Ormond Street Hospital	-	-	13 (100%)	-	-	-	-
Evelina Hospital, London	-	-	-	14 (100%)	-	-	-
Leeds General Infirmary	12 (43%)	4 (14%)	2 (7%)	1 (4%)	6 (21%)	-	3 (11%)
Freeman Hospital, Newcastle	-	-	-	-	-	-	-
Oxford Radcliffe Hospital	-	-	4 (100%)	-	-	-	-
Royal Brompton Hospital, London	-	-	6 (75%)	2 (25%)	-	-	-
Southampton General Hospital	-	1 (10%)	2 (20%)	5 (50%)	-	2 (20%)	-
Bristol Royal Hospital	-	-	-	-	-	-	-
Glenfield Hospital, Leicester	-	1 (5%)	-	-	-	-	21 (95%)

n = 127

Under Option B, the research showed that most parents selected the centres which would be expected under S&S based on the centre which they are currently using… (analysis by current centre attended, rather than parent's postcode area)

Current centre (below)	AH	BCH	GOSH	GSTT	NUTH	UHB	SUHT
Alder Hey Hospital, Liverpool	-	-	-	-	-	-	-
Birmingham Hospital	-	27 (100%)	-	-	-	-	-
Great Ormond Street Hospital	-	-	11 (100%)	-	-	-	-
Evelina Hospital, London	-	-	-	12 (100%)	-	-	-
Leeds General Infirmary	15 (54%)	5 (18%)	1 (4%)	1 (4%)	6 (21%)	-	-
Freeman Hospital, Newcastle	-	-	-	-	-	-	-
Oxford Radcliffe Hospital	-	-	4 (67%)	-	-	-	2 (33%)
Royal Brompton Hospital, London	-	-	6 (75%)	2 (25%)	-	-	-
Southampton General Hospital	-	-	-	-	-	-	11 (100%)
Bristol Royal Hospital	-	-	-	-	-	-	-
Glenfield Hospital, Leicester	-	11 (73%)	2 (13%)	1 (7%)	1 (7%)	-	-

n = 118

Under Option C, the research showed that most parents selected the centres which would be expected under S&S based on the centre which they are currently using… (analysis by current centre attended, rather than parent's postcode area)

Current centre (below)	AH	BCH	GOSH	GSTT	NUTH	UHB
Alder Hey Hospital, Liverpool	-	-	-	-	-	-
Birmingham Hospital	-	27 (100%)	-	-	-	-
Great Ormond Street Hospital	-	-	11 (100%)	-	-	-
Evelina Hospital, London	-	-	-	11 (100%)	-	-
Leeds General Infirmary	15 (54%)	5 (18%)	1 (4%)	1 (4%)	6 (21%)	-
Freeman Hospital, Newcastle	-	-	-	-	-	-
Oxford Radcliffe Hospital	-	-	4 (100%)	-	-	-
Royal Brompton Hospital, London	-	-	6 (75%)	2 (25%)	-	-
Southampton General Hospital	-	1 (11%)	2 (22%)	4 (44%)	-	2 (22%)
Bristol Royal Hospital	-	-	-	-	-	-
Glenfield Hospital, Leicester	-	11 (73%)	1 (7%)	2 (13%)	1 (7%)	-

n = 113

Under Option D, the research showed that most parents selected the centres which would be expected under S&S based on the centre which they are currently using… (analysis by current centre attended, rather than parent's postcode area)

Current centre (below)	AH	BCH	GOSH	GSTT	LTH	UHB
Alder Hey Hospital, Liverpool	-	-	-	-	-	-
Birmingham Hospital	-	27 (100%)	-	-	-	-
Great Ormond Street Hospital	-	-	11 (100%)	-	-	-
Evelina Hospital, London	-	-	-	11 (92%)	1 (8%)	-
Leeds General Infirmary	-	-	-	1 (2%)	46 (98%)	-
Freeman Hospital, Newcastle	-	-	-	-	-	-
Oxford Radcliffe Hospital	-	-	4 (100%)	-	-	-
Royal Brompton Hospital, London	-	-	6 (75%)	2 (25%)	-	-
Southampton General Hospital	-	1 (11%)	2 (22%)	4 (44%)	-	2 (22%)
Bristol Royal Hospital	-	-	-	-	-	-
Glenfield Hospital, Leicester	1 (7%)	11 (73%)	1 (7%)	1 (7%)	1 (7%)	-

n = 133

Sir Neil McKay
Chair, Joint Committee f Primary Care Trusts
105 Victoria Street
London
SW1E 6QT

17 October 2011

Dear Neil,

Safe and Sustainable: Response to Public Consultation

You will have received under separate cover the panel's responses to the further questions put to us by the Joint Committee of PCTs in August.

During the course of our most recent deliberations the panel members identified a statement, made by a number of respondents during the consultation, to which we would wish to respond by this letter.

The panel members have serious concern about the suggestion made by some respondents that as the panel has advised that all surgical centres currently operating are "safe" the JCPCT's main consideration should be related to matters of access, travel and convenience. There is thus a suggestion that matters of quality and sustainability are irrelevant given that centres have been judged, in the view of some respondents, to have passed the "bar" mark.

The panel members wish to reiterate that they did not assess the centres against any kind of bar. That was not their task. The panel members were asked to assess each centre against its particular ability to meet the *Safe and Sustainable* standards, which are comprehensive in nature and number.

The panel is of the view that its report has identified important differences in the extent to which the centres can meet the quality standards in the future; panel members have reflected these differences in their scores and in the report.

It is our view that the outcome of the panel's work would be rendered redundant were the JCPCT to interpret the report's conclusions as finding that there are no material differences across the centres in their ability to meet the quality standards in the future. This interpretation would not be justified. To repeat, there are important differences. We would remind the JCPCT of the advice that we gave in the introduction to our report, and which we note has been well received by a number of respondents, that "*mediocrity must not be our benchmark for the future*".

With best wishes.

Yours sincerely

Ian Kennedy

Professor Sir Ian Kennedy
on behalf of panel members

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REPORT OF SIR IAN KENNEDY'S PANEL IN RESPONSE TO QUESTIONS MADE BY THE JOINT COMMITTEE OF PRIMARY CARE TRUSTS

17 OCTOBER 2011

Introduction

1. The panel presents this report to the Joint Committee of Primary Care Trusts (JCPCT) in response to questions put to the panel by the JCPCT in August 2011 about the panel's previous report on the outcome of the assessment of all current providers of paediatric cardiac surgical services[1].

2. In August 2011 the panel was asked to respond to:

   i. Alleged factual inaccuracies in the panel's assessment of two centres (University Hospitals of Leicester NHS Trust and Leeds Teaching Hospital NHS Trust) including advice on whether the panel's previous scoring should be adjusted for these centres

   ii. Suggestions made by some respondents during public consultation that the panel had incorrectly applied the definition of 'co-location' as set out in the critical interdependencies framework[2]

   iii. The following questions in respect of three named centres (Newcastle-upon-Tyne Hospitals NHS Foundation Trust, University Hospitals of Leicester NHS Trust and Royal Brompton & Harefield NHS Foundation Trust):

      a. Considering each one separately, do these surgical centres meet the definition of co-location applied by the panel?
      b. If yes, what mitigating factors led the panel to make this conclusion despite the absence of co-location of services on one site?
      c. If no, what factors led the panel to make this conclusion?

[1] 'Report of the Independent Expert Panel Chaired by Professor Sir Ian Kennedy', Safe and Sustainable, December 2010

[2] 'Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Interdependencies', Department of Health, 2008

3. The panel's terms of reference state that the panel was not being asked to consider the merits or implications of statements made during public consultation that purport to demonstrate how the situation in individual centres has changed since the time of the assessment visits in 2010.

4. The panel met on 12 September 2011 and 17 October 2011 and this report sets out the unanimous conclusions and recommendations of panel members.

5. Panel members and declarations of interest are set out in Appendix A.

6. Evidence that was considered by the panel is described in Appendix B.

Summary of panel's report

Factual accuracy

7. The panel rejects suggestions that factual inaccuracies are present in its assessment of University Hospitals of Leicester NHS Trust; the panel does not advise the JCPCT to re-visit the scoring of this centre.

8. The panel reiterates that it has serious concerns about the viability of the paediatric intensive care unit at Glenfield Hospital (Leicester).

9. The panel rejects suggestions that factual inaccuracies are present in its assessment of Leeds Teaching Hospitals NHS Trust; the panel does not advise the JCPCT to re-visit the scoring of this centre.

Interpretation of the term 'co-location'

10. The panel is content that it has correctly applied the term 'co-location' as it appears in the framework of critical interdependencies.

Application of the requirements of co-location

11. The panel reiterates that the University Hospitals of Leicester NHS Trust does not meet the requirements of co-location of the *Safe and Sustainable* standards nor the requirements of the critical interdependencies framework on which the standards are based.

12. The panel considers that Newcastle-upon-Tyne Hospitals NHS Foundation Trust and the Royal Brompton & Harefield NHS Foundation Trust do meet the requirements of co-location.

Factual accuracy: University Hospitals of Leicester NHS Trust

13. The panel was provided with a full copy of the Trust's formal response to consultation, which was sent to the secretariat by the Trust's Chief Executive on 1 July 2011.

14. The panel noted that in this document the Trust had suggested that errors of fact had been made by the panel in its previous report and that the Trust had been 'under-scored' by the panel on some elements of the assessment, including on the standards relating to the co-location of interdependent services[3]. The panel considered the relevant sections of the consultation response including a summary of the Trust's concerns set out in Appendix 1 of the document, headed '*Detailed Responses to the Kennedy Panel Assessment'*.

15. The panel's response to each relevant concern is set out below. In accordance with the panel's terms of reference the panel did not consider statements made by the Trust which purport to demonstrate how the ability of the Trust to meet the *Safe and Sustainable* standards has changed since the panel's assessment on 26 May 2010.

Transition

16. The Trust wrote '*we were under-scored for our transitional arrangements which we hope can be corrected by recognition of the following:*

A designated cardiac liaison nurse dedicated to transition across the network

Protocols which were presented as evidence to the expert panel

Paediatric and adult cardiac liaison nurses who share office accommodation and work closely together both at the centre and in the network hospitals

[3] The panel noted that on page 2 of the document the Trust refers to concerns of alleged inaccuracies previously submitted to the secretariat; the panel members were not aware of these concerns when it met in December 2010 to finalise its report.

Paediatric and adult congenital cardiologists who share facilities, M&M meetings, MDT meetings and collaborate in the transition of individual patients / families'

17. The panel's report in December 2010 concluded that the Trust partly complied with the *Safe and Sustainable* standards in that it had '*a dedicated transition nurse'* but that '*there is no transition nurse within the network*[4]'.

18. In considering the Trust's concerns the panel referred to the Trust's original submission which referred to a '*nominated*' transition nurse who, it was said, '*works with her paediatric and adult liaison colleagues and the cardiology consultant to ensure individually appropriate transition arrangements'*[5]. The panel also noted that the Trust had not submitted a job description for a 'designated' transition nurse working in the 'network' as required by the standards.

19. The panel is mindful that it was not persuaded in 2010 that the 'East Midlands Congenital Heart Network' was sufficiently well established; the panel concluded in its report in 2010 that the Trust had adopted a top-down 'hub and spoke' model to networking instead of a collaborative approach[6]. It therefore follows that, in the opinion of the panel, the Trust had not sufficiently demonstrated that there was an appropriate level of cover by a dedicated transition nurse for the network as required by the standards.

20. Based on this evidence and on discussions on the day of the visit the panel remains of the view that the Trust is not fully compliant with the standards[7] which calls for a 'designated' transition nurse working in the 'network'.

[4] Page 46 of the panel's report

[5] Page 31 of the Trust's submission

[6] Page 41 of the panel's report

[7] Standard D3

Follow-up

21. The Trust wrote '*The Trust believes that there was a misunderstanding regarding patients being brought back to Glenfield for out-patient appointments. We run a substantial number of peripheral clinics in Nottingham, Derby, Mansfield, Kettering, Grantham, Peterborough and Lincoln'.*

22. In its previous report the panel concluded that '*patients are generally brought back to Glenfield Hospital instead of having outpatient appointments in the network*[8]*'*. On 12 September 2011 the panel had regard to the Trust's original submission and to evidence submitted on 26 May 2010, specifically a presentation slide titled 'Outreach Network' which reported 9,037 outpatient attendances at Glenfield Hospital and 2,199 outpatient attendances in outreach clinics.

23. This evidence did not persuade the panel at the time that patients are generally seen in the network and the panel, while acknowledging the location of peripheral clinics, is not persuaded that the Trust has demonstrated that the panel's previous conclusions are incorrect.

Clinical Psychology

24. The Trust wrote '*The review reported that there was no clinical psychology support. We would like to reassure the review that EMCHC has a long-standing arrangement with the clinical psychology consultants within the dedicated paediatric service based at the Leicester Royal Infirmary'.*

25. On 26 May 2010 the panel had noted that provision was made for access to a clinical psychologist but that the clinical psychologist was not based at Glenfield Hospital; the panel also noted that there was a long waiting list and that the service was provided on what appeared to be an 'ad hoc' basis.

[8] Page 41 of the panel's report

The panel also took account of the Trust's original submission which reads '*All patients / parents can access a clinical psychologist, but we do not currently have dedicated provision. However, we have funding for a dedicated post, and we are in the process of recruiting to this*[9]*'*.

26. In view of this evidence the panel has concluded that its previous findings were correct at the time.

Registrar cover for Paediatric Intensive Care Unit (PICU)

27. The Trust wrote '*The review reported that there was insufficient registrar cover for PICU. We would like to reassure the review that PICU has had an 8 person specialist registrar rota for several years, which rarely has any gaps'*.

28. In its previous report the panel had stated that '*it felt that PICU may not be sustainable because consultants had to cover both PICUs' and 'there is no sufficient throughput of SpRs'*. The panel members had '*serious concerns over the long-term sustainability of the PICU as there were no robust plans to recruit more PICU consultants*[10]*'*.

29. On 26 May 2010 Trust clinicians and managers had acknowledged to the panel that the split-site arrangement was not ideal and that running an emergency retrieval team from within the PICU added to pressures in the intensive care system. The panel had also noted that the PICU at Glenfield Hospital was not designated as a training unit and that this could create pressure if, for example, a registrar or consultant was on a retrieval or elsewhere.

30. The panel had not been persuaded in May 2010 that the PICU was sustainable given the split-site arrangement. There was not, in the panel's opinion, a sufficient number of consultants to provide an appropriate level

[9] Page 31 of the Trust's submission

[10] Page 42 of the panel's report

of cover, taking into account the need to cover the retrieval service. The panel had also expressed concerns that the Trust had not demonstrated sufficiently robust plans to recruit more consultants.

31. On 12 September 2011 the panel members reiterated their concerns that the PICU at Glenfield Hospital may not be sustainable.

Nursing staffing and recruitment

32. The Trust wrote '*There have been no nursing vacancies within the paediatric cardiac nursing establishments for more than 3 months in the last 5 years. There are a mix of full and part-time staff working in PICU; many of the latter chose to augment their hours when the unit is busy rather than commit to a full-time contract. We believe that this may have been mistaken as the Trust being reliant on over-time'.*

33. In May 2010 the panel had concluded that 'the Trust was over-confident in its ability to meet the challenge of recruiting the large numbers of nursing staff required to meet the current capacity requirements' and that the Trust 'appeared dependent on over-time to sustain an appropriate level of nursing cover'[11].

34. From the Trust's submission and evidence presented on the day of the visit the panel members were not persuaded that the level of nursing support in PICU was sufficient to provide a sustainable service, nor were they persuaded that the Trust had robust plans that would suggest an appropriate solution in the short-term. The panel had substantial concerns about the extent to which over-time was relied upon to provide nursing cover for the paediatric cardiac surgical service at Glenfield Hospital.

35. The panel members recall that in May 2010 Trust clinical and managerial staff accepted that there was a need for the paediatric cardiac surgical

[11] Page 42 of the panel's report

service to recruit more trained nurses; the panel were not persuaded at the time that the plans for recruitment were sufficiently realistic or achievable.

36. In considering the Trust's recent evidence the panel members are mindful that having no current vacancies merely speaks to the Trust's establishment; it does not suggest nor prove that the establishment itself is appropriate.

37. When considering the evidence on 12 September 2011 the panel members reiterated that they were not at the time – and are not currently – seeking to compare centres against each other. Each centre was separately assessed based on a consideration of its ability to comply with the *Safe and Sustainable* standards. However, in responding to the concerns set out by University Hospital of Leicester NHS Trust about the panel's approach to Newcastle-upon-Tyne Hospitals NHS Foundation Trust, the panel wish to record that they were persuaded at the time that Newcastle's analysis of what was required to meet the challenges of recruiting and retaining nurses – including efforts already made - was much more robust than that described by Leicester. Newcastle had sufficiently demonstrated a record of having successfully increased its nursing establishment in the past, including a description of how the Trust had worked innovatively with its university partner to forge links with potential recruits before they had graduated from training.

Stakeholder groups

38. The Trust wrote '*We were surprised by the impression [that the Trust did not demonstrate a strong relationship with its commissioners]. The Trust has received considerable support and has an excellent relationship with the East Midlands Specialist (sic) Commissioning Group'*.

39. The panel reiterate that their findings relate only to how the Trust has engaged with commissioners in respect of how the Trust can meet the *Safe and Sustainable* standards for paediatric cardiac surgical services.

40. Although there was good evidence of relationships with clinicians, the panel were not persuaded that the Trust had described coherent arrangements or plans to meet the challenge of achieving and maintaining - on a sustainable basis - an increased caseload nor that the Trust had demonstrated that it had effectively engaged with the Specialised Commissioning Group on this issue.

Summary of panel's response to University Hospitals Leicester NHS Trust

41. The panel advises the JCPCT that the suggestions of factual inaccuracies in the assessment of the Leicester centre are without merit; the panel does not advise the JCPCT that it wishes to re-visit the scoring of this centre.

Factual accuracy: Leeds Teaching Hospitals NHS Trust

42. The panel was provided with a copy of the Trust's formal response to consultation dated 1 July 2011, and with a copy of correspondence that had passed between the Chair of the JCPCT and the Chief Executive of the Trust in April 2011.

43. The panel noted that in its 'response to consultation' the Trust was suggesting that errors of fact had been made by the panel in its previous report; that the Trust had been 'under-scored' by the panel on some elements of the assessment; and that the Trust has not been afforded 'an opportunity to correct the final report' before its release to the JCPCT in December 2010.

44. The panel rejects the suggestion that the Trust had not been afforded an opportunity to correct alleged factual inaccuracies. The panel had met in December 2010 to consider the Trust's concerns. Panel members had concluded that the Trust's concerns about factual accuracy – including those relating to PICU configuration and specialist nurse posts - were without merit, though the panel agreed to change some wording in the final report to clarify the position with regard to PICU provision.

45. In summary, the panel advises the JCPCT that the suggestions of factual inaccuracies in the assessment of the Leeds centre are without merit; the panel does not advise the JCPCT that it wishes to re-visit the scoring of this centre.

46. The panel members have also expressed surprise that the Trust has continued to raise these concerns given that the Chair of the JCPCT had clearly and accurately described to the Chief Executive of the Trust in April 2011 how the panel had previously considered and responded to the Trust's concerns.

Co-Location of Interdependent Services

Meaning and application of co-location

47. The panel has taken account of representations put to the JCPCT during consultation about the meaning of 'co-location' as set out in the critical interdependencies framework, including those from the British Congenital Cardiac Association, the Paediatric Intensive Care Society, the Royal College of Paediatrics and Child Health and Professor Edward Baker, the chair of the working group responsible for the critical inter-dependencies framework.

48. The panel notes that the critical inter-dependencies framework[12] defines co-location as:

> *Co-location in this context was defined as meaning either location on the same hospital site or location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site. These would be reinforced through formal links such as consultant job plans and consultant on-call rotas.*

[12] Page 8

49. Although the panel members have previously advised the JCPCT that co-location on the same site is the optimal arrangement – and that the panel has reflected that advice in the scoring of individual centres - they did not see it as meaning that the relevant interdependent service was always required to be on the same site as the paediatric cardiac surgical service but, rather, sufficiently close by to be deemed to be '*within the same parameters*'.

50. In response to the representations made to the JCPCT during consultation to the effect that the intention of the critical inter-dependencies framework was to define 'co-location' as meaning 'immediately adjacent' (or such equivalent) the panel members note that the critical inter-dependencies framework does not state this either explicitly nor sufficiently through the context and by implication. In the panel's opinion the use of the words 'neighbouring' and 'within the same parameters' and references to 'job plans and on-call rotas' invites a subjective consideration of the meaning of 'co-location' that encourages an interpretation not limited to that which is 'immediately adjacent'.

51. As regards the application of the panel's interpretation of the definition of 'co-location' the panel has previously advised the JCPCT that it is open to JCPCT members – if they so wish - to adopt a different interpretation to that applied by the panel.

Application of the term 'co-location' to the three centres

52. In respect of the interpretation applied by the panel, members sought to apply the term consistently as regards the Newcastle, Leicester and Royal Brompton centres, at which the following services are not located on the same site as paediatric cardiac surgery:

Provider	Location of paediatric cardiac surgical services	Location of specialised paediatric surgical services	Location of Ear Nose Throat (Airway) services
Newcastle upon Tyne NHS Foundation Trust	Freeman Hospital	Royal Victoria Infirmary	Freeman Hospital
University Hospitals of Leicester NHS Trust	Glenfield Hospital	Leicester Royal Infirmary	Leicester Royal Infirmary
Royal Brompton & Harefield NHS Foundation Trust	Royal Brompton Hospital	Chelsea & Westminster Hospital	Chelsea & Westminster Hospital

53. The panel members considered the three questions put to them about these three centres:

Considering each one separately, do these surgical centres meet the definition of co-location as applied by the panel?

54. In the opinion of the panel, all relevant interdependent services at the Newcastle-upon-Tyne NHS Foundation Trust and the Royal Brompton & Harefield NHS Foundation Trust meet the co-location requirements of the critical inter-dependencies framework.

55. In respect of the University Hospitals of Leicester NHS Trust, while the panel is of the opinion that the specialised paediatric surgical service at the Leicester Royal Infirmary meets the co-location requirements, the panel advises that the ENT service cannot be regarded as being co-located with

the paediatric cardiac surgical service in compliance with either the *Safe and Sustainable* standards nor with the critical interdependencies framework on which the standards are based.

If yes, what mitigating factors led the panel to make this conclusion despite the absence of physical co-location of services on one-site?

56. The panel advises that it did not consider 'mitigating factors' as it did not apply an interpretation that required co-location of services on a single site. The 'test' applied by the panel was whether the services met the definition of co-location as set out in the critical inter-dependencies framework.

If no, what factors led the panel to make this conclusion?

57. The panel was not persuaded that the ENT service at the Leicester Royal Infirmary is sufficiently close to the paediatric cardiac surgical service at Glenfield Hospital to ensure that service delivery would not be impaired by being on a different site. The panel therefore reiterates that University Hospitals of Leicester NHS Trust does not meet the co-location requirements and notes with some concern that the Trust saw no reason to remedy this situation.

58. The interdependent services that serve the Freeman Hospital in Newcastle and the Royal Brompton Hospital do, in the panel's opinion, meet the co-location standards as they are sufficiently close to the paediatric cardiac surgical services to fall 'within the same parameters' required by the critical interdependencies framework.

59. The panel wishes to emphasise that their conclusions in this respect are not based solely on a consideration of distance and travel times. Where services were not on the same site the panel also took account of staff rotas and job plans and the extent to which there is a need for an immediate response from the relevant clinical service. In the panel's opinion a differentiating factor between the centres is that ENT services are considered by the panel to be more 'time critical' than other relevant interdependent services. Taking all of this evidence into account, the panel concluded that the ENT service in Leicester cannot be regarded as being 'co-located' despite the fact that the services which are not on the same site are roughly the same distance away in both Leicester and Newcastle. The Royal Brompton Hospital's ENT service is much closer to the paediatric cardiac surgical service than it is in Leicester, and as such it does, in the panel's opinion, meet the co-location requirements of the critical interdependencies framework.

60. The panel further advises the JCPCT that the scores awarded to individual centres under the heading 'Interdependent Services' also reflected an assessment of other elements of the services as set out in the *Safe and Sustainable* standards[13]. As such the panel's score for each centre under this heading was a cumulative judgment taking into account other clinical services, staffing establishments and theatre and bed capacity. The lower score for Glenfield Hospital therefore reflects a consideration of all of these issues by the panel in the round.

END

[13] Standards C12 – C21, C64 and C65

Appendix A

Panel members

Professor Sir Ian Kennedy (Chair)

Dr Michael Godman, Consultant Paediatric Cardiologist, Royal Hospital for Sick Children Edinburgh (retired) nominated by the British Congenital Cardiac Association

Maria von Hildebrand, lay representative

Dr David Mabin, Consultant Paediatrician with Expertise in Cardiology, Royal Devon & Exeter NHS Foundation Trust, nominated by the Royal College of Paediatrics and Child Health

Dr Neil Morton, Consultant in Paediatric Anaesthesia and Pain Management, Royal Hospital for Sick Children in Glasgow, nominated by the Paediatric Intensive Care Society

Sally Ramsay, independent adviser in children's nursing, nominated by the Royal College of Nursing.

Julia Stallibrass MBE, former Deputy Director of National Specialised Commissioning

Apologies and Declarations of Interests

Sir Ian Kennedy explained to panel members who were present on 12 September 2011 that he had advised Mr James Monro (nominated by the Society for Cardiothoracic Surgery of Great Britain and Ireland) to send apologies for this meeting in view of recent public statements that Mr Monro had made in support of one of the centres. While Sir Ian had no doubts that Mr Monro had discharged his responsibilities in this process with objectivity and without bias, he said that Mr Monro had accepted the need to avoid any risk of perceived bias at this stage of the process. Mr Monro also gave apologies for the meeting on 17 October.

Declarations of interest are as set out in the panel's report of December 2010. The only addition was that in September 2011 Julia Stallibrass was a member of the panel that was chaired by Adrian Pollitt and which had explored the relationship of paediatric interdependent services at the Royal Brompton & Harefield NHS Foundation Trust.

APPENDIX B

EVIDENCE CONSIDERED BY THE PANEL

1. Response to consultation by the Oxford Radcliffe Hospitals NHS Trust dated 28 June 2011
2. Response to consultation by University Hospitals of Leicester NHS Trust
3. Response to consultation by Leeds Teaching Hospitals NHS Trust
4. Correspondence between Sir Neil McKay and Leeds Teaching Hospitals NHS Trust in April 2011
5. Response to consultation by the Royal College of Paediatrics and Child Health dated June 2011
6. Statement by the British Congenital Cardiac Association dated 18 February 2011
7. Response to consultation by the Paediatric Intensive Care Society dated 23 June 2011 and attached letter from Professor Edward Baker dated 1 June 2011
8. The self assessment submissions of Leeds Teaching Hospitals NHS Trust and University Hospitals of Leicester NHS Trust and supporting documentation submitted by the centres
9. Presentations made, and materials submitted by the centres on the day of the assessment visits

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Report to the Joint Committee of PCTs by Dr Patricia Hamilton CBE, Chair of the *Safe and Sustainable* Steering Group, on behalf of Steering Group members

This paper sets out the Steering Group's further advice to the JCPCT having taken into account the evidence submitted by respondents during public consultation

17 October 2011

1. Introduction

17 October 2011

1.1 As an outcome of public consultation Steering Group members have received and considered the following evidence:

i. Report on the outcome of consultation published by Ipsos Mori on 23 August 2011
ii. Report on the outcome of focus groups held by Ipsos Mori, published on 25 August 2011
iii. Responses to consultation made by organisations by letter or email (and a summary of such responses prepared by the secretariat)
iv. Report on the consultation events dated August 2011
v. Notes of the meeting between the Steering Group and members of the British Congenital Cardiac Association held on 12 July 2011
vi. Health Impact Assessment interim report dated August 2011

1.2 Additionally, a number of Steering Group members were present at public consultation events as members of the panel (attendance details are provided in the summary report on the consultation events).

1.3 This paper sets out the Steering Group's further advice to the JCPCT having taken this evidence into account. The Steering Group's advice to JCPCT Members was agreed at a meeting of the Steering Group on 13 September 2011 and covers the:

i. Proposed *Safe and Sustainable* standards for Specialised Surgical Centres
ii. Proposed model of care that envisages the development of congenital heart networks across England comprising Children's Cardiology Centres and District Children's Cardiology Centres
iii. Recommendations made by the Steering Group for improving the monitoring and reporting of outcome data
iv. Implementation of the JCPCT's eventual decision
v. Responses to consultation on which the Steering Group's advice has been sought on relevant clinical issues

2. Proposed *Safe and Sustainable* standards for Specialised Surgical Centres

2.1 Having considered the evidence submitted during public consultation Steering Group members advise the JCPCT to agree the standards as set out in the consultation document.

2.2 Steering Group members further advise the JCPCT to accept the additional standards as set out in Appendix A subject to further advice that is being sought from the British Association of Perinatal Medicine around proposed standards A29 to A31 (the Steering Group's final advice will be reported at the meeting of the JCPCT in November 2011).

3. Proposed model of care

3.1 Having considered the evidence submitted during public consultation Steering Group members advise the JCPCT that the proposed model of care is viable. Specific elements of the model of care considered by the Steering Group are as follows:

Viability of the proposed Children's Cardiology Centres (CCCs)

3.2 Steering Group members were conscious that this issue has generated significant debate during consultation and that the medium to long-term viability of the CCCs has been questioned by some respondents; these concerns are based around the potential loss of specialist expertise at these centres given the JCPCT's proposal that they do not provide interventional cardiology services in the future.

3.3 Steering Group members advise the JCPCT that the CCCs are a viable proposition, and they are mindful of existing precedents such as the successful transition of the Cardiff centre from a surgical centre to a non-interventional cardiology centre in the past decade.

3.4 However, there are potential risks that need to be managed. When surgery is lost to a cardiology unit, a potential risk is that there may be insufficient motivated staff to make the CCC model work. Based on the Cardiff experience, staff turnover may be high. After an unsteady three years following the decision to cease surgery the service was made stable, due in part to the appointment of a cardiologist dedicated to making the model work. The inducements for retaining key staff could include favourable job plans, clear PAs for joint working and sufficient allowance in job plans for travel.

3.5 Steering Group members recommend that designation standards are developed for the CCCs and that potential risks are addressed during the phase of implementation.

Role of the proposed Children's Cardiology Centres / Interventional Cardiology / Diagnostic Catheterisation

3.6 Based on existing professional guidance the JCPCT's consultation document proposed that CCCs do not provide interventional cardiology services nor diagnostic catheterisation services given the (small) risk of an emergency requiring surgical support.

3.7 On 13 September Steering Group members received a briefing from the President of the British Congenital Cardiac Association (BCCA) which suggests that the revised professional guidance (due in October 2011) is likely to continue to recommend that interventional cardiology services should only be performed in designated surgical centres; but that diagnostic catheterisation may be performed in the proposed CCCs. On the understanding that this description is reflected in the impending BCCA guidance the Steering Group members advise the JCPCT to reflect this guidance in the model of care and the standards for the Specialised Surgical Centres and the CCCs.

3.8 Steering Group members further considered the delivery of Electrophysiology (EP) for children with congenital heart disease. As with interventional cardiology and diagnostic catheterisation there is a small risk of an emergency requiring surgical support. Steering Group members advise that that the provision of EP can be delivered outside of a designated surgical centre provided that the local congenital heart network has developed clear protocols, including a consideration of local governance arrangements, and that local network governance arrangements determine the size and weight parameters for undertaking interventional EP on children without paediatric surgical backup. Steering Group members emphasise that children requiring EP should be seen in dedicated children's services, not adult services as is current practice in some parts of the country. It is recommended that this advice is reflected in future standards for CCCs.

Role of the proposed District Children's Cardiology Services

3.9 Steering Group members advise that the proposed District Children's Cardiology Services – which envisage a local service delivered by Consultant Paediatricians with

Expertise in Cardiology - is a viable proposition. Further work will be required during the implementation phase to establish appropriate governance arrangements across the network and to develop standards against which the DCCS will be measured.

4. Recommendations made by the Steering Group for improving the monitoring and reporting of outcome data

4.1 Steering Group members advise the JCPCT to agree the proposals for improving the monitoring and reporting of outcome data as set out in the JCPCT's consultation document.

5. Implementation issues

5.1 Potential impact to Paediatric Intensive Care Units (PICU)

5.1.1 In de-designated centres, a decrease in caseload resulting from the loss of cardiac work will have effects on staff retention in the first place then, potentially, recruitment.

5.1.2 In de-designated centres, there will be an expectation that the PICU can still meet demands of its catchment, particularly seasonal winter surges. Discussions held within the Steering Group have highlighted that PICUs that lose cardiac surgery may then lose the ability to flex their bed numbers by decreasing cardiac surgical throughput on a seasonal basis. This extent to which this flexibility can be extended to the PICUs that retain cardiac surgery is uncertain as these units will then be under pressure to perform more cases overall and with lower rates of cancellations than tolerated previously (as per the proposed standards).

5.1.3 Consequently, there may need to be a continuing investment in non-cardiac PICUs to avoid winter crises.

5.1.4 Cardiology is an essential service to PICU patients to detect hitherto undetected underlying cardiac disease, be that congenital or acquired. It was accorded 'Amber 3' status in the *Critical Interdependencies Framework* (meaning that it does not 'necessarily' require co-location with PICU) but care must be taken to preserve cardiology services in de-designated centres.

5.1.5 Already there are difficulties associated with admitting children from areas that border the catchments of other tertiary centres, particularly when they suffer from multiple conditions. These families can then be subject to

disparate referral patterns where they may be seen in two or even three different tertiary centres. In creating new referral flows to support the new cardiac surgical options, the congenital heart networks will need to develop mitigation strategies to ensure that such fragmentation of care is not exacerbated.

5.2 Potential impact to retrieval services

5.2.1 Steering Group members advise the JCPCT that the precise ramifications for retrieval services cannot be known until the JCPCT has made a decision on the future configuration of congenital heart networks. However, some potential difficulties are self-evident.

5.2.2 In all of the options submitted for consultation larger numbers of critically ill children will move over greater distances. However, the Steering Group advises that this does not present increased risk to the child provided the options comply with the maximum journey time thresholds as set out in the Paediatric Intensive Care Society standards for the care of critically ill children. The evidence is that these distances have not been shown to be associated with increased risk.

5.2.3 As an outcome of reconfiguration there may be more District General Hospitals that are relatively remote to the surgical centre. Some experience of this already exists in England such as the South West Peninsula and its relationship with the Bristol centre, and Great Yarmouth and its relationship with London. The evidence is that these distances have not been shown to be associated with increased risk. However, there is consensus within the Paediatric Intensive Care Society that, in the context of sparse and hitherto unreliable air transport infrastructure in the UK, the current limits of transfer times as set out by PICS standards are realistically safe limits. In the Northeast and Yorkshire Regions, for example, if one of the two cardiac surgical units ceases cardiac surgery the remaining unit will need to reach all the populations at the other 'extremity' through a working partnership with the other retrieval team (and perhaps other surrounding teams) with clearly defined operating procedures and, almost certainly, significant investment. The same principles would potentially apply to the South Central England,

Southwest England, East Midlands and Wales depending on the JCPCT's eventual decision.

5.2.4 Consequently, consideration needs to be given to consolidating the remaining retrieval services that have not amalgamated. In the last eighteen months, three new amalgamated services have been commissioned with sustainability and economies of scale in mind: 'NEWTS' (Liverpool & Manchester), serving NW England & NW Wales; 'WMPRS' (Stoke & Birmingham) serving the W Midlands; and 'EMBRACE' (Leeds & Sheffield) serving Yorkshire & Humberside. London already has two large, amalgamated transport services, CATS & STRS. This leaves Newcastle, Leicester, Nottingham, Southampton, Oxford, Bristol & Cardiff as un-amalgamated unit-based services. The JCPCT's proposal for Congenital Heart Networks across England supports the case to form further acute transport groupings in the future. Experience of setting up the other amalgamated services shows that this needs to be financially supported.

5.2.5 The matter of transfer of children back from the surgical centre was discussed at the Steering Group. It was suggested that retrieval services should be commissioned in such a way that 'repatriating' children back to local services should be part of the contract with both the retrieval service and ambulance providers.

5.3 Potential impact on workforce

5.3.1 The Steering Group is aware that some respondents have suggested during consultation that potential impacts on the NHS workforce must be identified and assessed by the JCPCT as part of the process for agreeing a final configuration option. However, the Steering Group agrees with the JCPCT's position as set out in the consultation document, which is that the potential impact of reconfiguration on the workforce cannot be determined with confidence before the JCPCT has made a final decision and, as such, should not be a consideration in the JCPCT's process for agreeing a final decision. Rather, this is an issue for implementation, and it will be important for the Congenital Heart Networks and commissioners to identify and resource education and training requirements, particularly for nurses.

6 The following sections of this report provide the Steering Group's response to submissions made to the JCPCT during consultation and on which the JCPCT has sought clinical advice from the Steering Group.

6.1 Rare and complex procedures

6.1.1 A number of respondents have suggested that the delivery of 'rare and complex' surgical procedures should be restricted to a very small number of designated surgical units, reflecting a recommendation in the report of the Bristol Inquiry in 2001.

6.1.2 Steering Group members advise the JCPCT that 'rare and complex' procedures are not currently defined; in any event they would not advise that rare and complex procedures are restricted to a smaller number of centres. Steering Group members do not consider that reconfiguration poses particular risks for rare diagnoses and they advise that the impact of reconfiguration to the delivery of rare and complex procedures can be managed within appropriate clinical governance frameworks. This is because Steering Group members are reassured that the relevant concerns set out in the Bristol report in 2001 can be safely addressed by the larger, expert surgical centres proposed by the JCPCT; a rigorous clinical governance framework across the national congenital heart network (with the active participation of commissioners, providers, professional associations and lay organisations) will enable a safe service planning for rare and complex procedures across the network.

6.2 Nationally commissioned services

6.2.1 The JCPCT has received opposing evidence about the significance that the JCPCT should attach to the current location of the nationally commissioned services.

6.2.2 Steering Group members advise the JCPCT that the recommendations of the separate expert panel that reported on nationally commissioned services in 2010 remain valid. While the re-location of a nationally commissioned service presents some potential risks, these risks can, in the view of the Steering Group, be managed.

6.3 Analysis of mortality data

6.3.1 It has been put to the JCPCT during consultation that Professor Spiegelhalter's analysis of mortality data (which was published following the separate review of the paediatric cardiac surgical service at the John Radcliffe Hospital in 2010) should be applied by the JCPCT to differentiate between high quality and low quality surgical units.

6.3.2 The Steering Group's previous advice was that owing to a low national caseload and difficulties in adjusting for complexity, mortality outcomes should not be used to identify potential configuration options. As such, mortality outcomes have not been analysed by the JCPCT[1] or played any part in the development of configuration options.

6.3.3 The Steering Group does not advise the JCPCT to apply an analysis of mortality data in the future process for agreeing a configuration option for the reasons previously explained.

END

[1] Except for the limited purpose of receiving Mr Pollock's report in response to the publication of Professor Spiegelhalter's analysis in December 2010

Appendix A
Proposed additional standards

Background

In full term babies the *ductus arteriosus (arterial duct*) usually closes naturally within the first few days of life. In babies born prematurely it may remain open ('patent') resulting in extra blood flow through the lungs – this may delay / prevent weaning from the ventilator. It is the practice to refer these babies for surgical ligation of their patent *ductus arteriosus* (PDA). These babies are cared for in the Neonatal Intensive Care Unit / Special Care Baby Unit and the practice in some centres has been for the neonatal team to transfer the baby to the surgical centre for operation. With larger surgical teams in the Specialist Cardiac Surgical centres, alternative pathways may be developed.

	Designation Standard	Measures	Compatible Evidence Base	Status
A29	As the sole exception to the *Safe and Sustainable* standards which stipulate that heart surgery on children must be performed in a designated Specialist Surgical Centre it is permissible for neonates with *patent ductus arteriosus* (PDA) to receive surgical ligation in the referring neonatal intensive care unit (level 3) provided that the visiting surgical team is despatched from a designated Specialist Surgical Centre and is suitably equipped in terms of staff and equipment.	Written protocols	Gould D et al (2003) 'A comparison of on-site and off-site Patent Ductus Arteriosus ligation in premature infants', Pediatrics Vol 112, 6	**Mandatory**
A30	It will be for each Congenital Heart Network to determine whether this arrangement is optimal (rather than transferring the neonate to the Specialist Surgical Centre) according to local circumstances, including a consideration of clinical governance and local transport issues.	Written protocols		**Mandatory**
A31	All Congenital Heart Networks must have clear protocols that address the provision of surgical ligation for neonates with PDA.	Written protocols		**Mandatory**

Background

A number of participants at consultation events sought reassurance that surgical centres will continue to be audited against the standards once the designation process has concluded. This proposed standard does not stipulate a timetable for future audits (that is for the commissioning body to stipulate outside of the standards document) but it does ensure that the standards themselves and the outcome of future audits are widely publicised.

	Designation Standard	Measures	Compatible Evidence Base	Status
E14	Specialist Surgical Centres must make parents and carers aware of the *Safe and Sustainable* standards and the outcome of audits of compliance. As a minimum this will include publishing the *Safe and Sustainable* standards on the centre's website and informing parents of their existence in first appointment letters and other relevant literature.	Patient / parent literature Compliance audits	National Service Framework for Children, Young People and Maternity Services (2003 and as modified).	**Mandatory**

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Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 24 74707

Report of the Head of Scrutiny and Member Development

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

Date: 19 December 2011

Subject: Review of Children's Congenital Heart Services in England: Children's Heart Surgery Fund (CHSF) - update

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

Summary of main issues

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

2. The Joint HOSC submitted its formal consultation response to the Joint Committee of Primary Care Trusts (JCPCT) on 5 October 2011. A formal report was subsequently submitted to the JCPCT on 10 October 2011. In line with the *Overview and Scrutiny of Health – Guidance (Department of Health (DH) (July 2003))* a formal written response to the report and its recommendations within 28 days of receipt was requested.

3. During its inquiry, the Joint HOSC considered a wide range of evidence and heard from a variety of witnesses. This included the Leeds based charity, Children's Heart Surgery Fund (CHSF).

4. Since the submission of the Joint HOSC's inquiry report, a range of additional information has become available and is presented elsewhere on the agenda for consideration. To help maintain an overview of additional local activity, the CHSF has submitted a brief update (Appendix 1) for consideration by the Joint HOSC.

5. A representative from the CHSF will be in attendance to address any questions raised by the Joint HOSC.

Recommendations

6. Members of the Joint HOSC are asked to note the update provided and determine what, if any, additional scrutiny action should follow.

Background documents

- Overview and Scrutiny of Health – Guidance (Department of Health (DH) (July 2003)
- A new vision for Children's Congenital Heart Services in England (March 2011)
- Scrutiny Inquiry Report: Review of Children's Congenital Cardiac Services (October 2011)

APPENDIX 1

Children's Heart Surgery Fund – campaign update

Children's Heart Surgery Fund are continuing to campaign to retain Leeds Paediatric Heart Surgery Service, however, momentum has slowed down some what due to a judicial review of Safe and Sustainable brought against JCPCT by the Royal Brompton and Harefield NHS Foundation Trust which concluded on Monday 7th November that "*the consultation exercise was unlawful, and must therefore be quashed*

It now looks like the final outcome may not be known until spring/Summer 2012 which gives us more time to make the case for Leeds. Whilst we feel it is very frustrating that this decision will yet again be delayed, we know it is vital the correct decision should be made in the end.

On November 2nd we were given the opportunity to meet the Minister Simon Burns through Rachel Reeves MP, we were delighted we were given the chance to demonstrate the case for Leeds and the logic behind keeping the service in this city. The Minister was in listening mode, and explained on a number of occasions that he was happy to listen but couldn't at this stage interfere with the process. Jeremy Glyde, Programme Director of Safe and Sustainable was also at the meeting. I took the opportunity to ask if option E (LTHT's submission) was under consideration and he assured me further options were being considered, and some of them certainly had Leeds in them.

Our discussion points were based on the Adult service, Co-location of services- Population density, patient flows. I also had the opportunity to ask Mr Burns if the final decision was not in Leeds favour, could we come back and see him, he replied yes!

On November 8th we were informed that the publication of independent research conducted by Price Waterhouse Cooper into patient flows confirmed what CHSF and LTHT have been saying for the past few months: that the Review's predictions of patient flows did not match local knowledge and that most of Leeds's future and existing patients would travel to Liverpool or Leicester for treatment rather than Newcastle. This will have an impact on the projected number of 400 operations at Newcastle; the Newcastle unit will simply not make the required number.

CHSF Trustees attended an EGM on Weds 30th November, the subject was making a decision on a potential Judicial Review- it was thought and confirmed by all Trustees that CHSF have come so far in this campaign and we have to continue to fight for the Children of this region, it was unanimously decided that should the final decision (whenever that be) not be in Leeds favour then we would also be serving the JCPCT with a Judicial Review.

It was also agreed that CHSF should send a document as our submission to the Safe and Sustainable should we have a fresh consultation. This document is being created and will be submitted just before the festive break.

Sharon Cheng, Charity Director

December 2011

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Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 24 74707

Report of the Head of Scrutiny and Member Development

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

Date: 19 December 2011

Subject: Review of Children's Congenital Heart Services in England: Leeds Teaching Hospitals NHS Trust (LTHT) - update

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

Summary of main issues

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

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3. During its inquiry, the Joint HOSC considered a wide range of evidence and heard from a variety of witnesses. This included the Leeds Teaching Hospitals NHS Trust.

4. Since the submission of the Joint HOSC's inquiry report, a range of additional information has become available and is presented elsewhere on the agenda for consideration.

5. The recent High Court judgement (also presented elsewhere on the agenda) has led to a delay in the anticipated review timetable. To help maintain an overview of any impact on the current service provider (i.e. LTHT), representatives from the Trust have been invited to attend the meeting and update members of the Joint HOSC.

Recommendations

6. Members of the Joint HOSC are asked to note the update provided and determine what, if any, additional scrutiny action should follow.

Background documents

- Overview and Scrutiny of Health – Guidance (Department of Health (DH) (July 2003)
- A new vision for Children's Congenital Heart Services in England (March 2011)
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