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Leeds CITY COUNCIL

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

Meeting to be held in Civic Hall, Leeds, LS1 1UR on Friday, 12th January, 2018 at 10.30 am

(A pre-meeting will take place for all Members of the Committee at 10:00 a.m.)

MEMBERSHIP

Councillors

D Brown	-	Hull City Council
J Clark	-	North Yorkshire County Council
M Dickerson	-	North East Lincolnshire Council
H Douglas	-	City if York Council
M Greenwood	-	Calderdale Council
V Greenwood	-	Bradford MDC
B Hall	-	East Riding of Yorkshire Council
H Hayden (Chair)	-	Leeds City Council
W Johnson	-	Barnsley Council
P Midgley	-	Sheffield City Council
H Mumby-Croft	-	North East Lincolnshire Council
B Rhodes	-	Wakefield Council
A Robinson	-	Doncaster MBC
S Sansome	-	Rotherham MBC
E Smaje	-	Kirklees Council

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

Agenda compiled by:
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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: **No exempt items have been identified on this agenda.**	

Item No	Ward/Equal Opportunities	Item Not Open		Page No
3			**LATE ITEMS** To identify items which have been admitted to the agenda by the Chair for consideration. (The special circumstances shall be specified in the minutes.)	
4			**DECLARATION OF DISCLOSABLE PECUNIARY INTERESTS** To disclose or draw attention to any disclosable pecuniary interests for the purposes of Section 31 of the Localism Act 2011 and paragraphs 13-18 of the Members' Code of Conduct.	
5			**APOLOGIES FOR ABSENCE AND NOTIFICATION OF SUBSTITUTES** To receive any apologies for absence and notification of substitutes.	
6			**MINUTES OF THE PREVIOUS MEETING - 5 JULY 2017** To approve as a correct record minutes of the previous meeting held on 5 July 2017.	1 - 4
7			**CONGENITAL HEART DISEASE SERVICES FOR ADULTS AND CHILDREN: FUTURE COMMISSIONING ARRANGEMENTS** To consider a report from Leeds City Council's Head of Governance and Scrutiny Support setting out details of NHS England's final decisions on the commissioning of congenital heart disease services for adults and children across England; alongside submissions from Leeds Teaching Hospitals NHS Trust and Children's Heart Surgery Fund.	5 - 136

Item No	Ward/Equal Opportunities	Item Not Open		Page No
8			**THE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE (YORKSHIRE AND THE HUMBER): SUMMARY OF ACTIVITY AND THE FUTURE ROLE** To consider a report from Leeds City Council's Head of Governance and Scrutiny Support presenting an activity summary of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), alongside other key events, from January 2011; and providing an opportunity for the Joint Committee to consider its future role. **THIRD PARTY RECORDING** Recording of this meeting is allowed to enable those not present to see or hear the proceedings either as they take place (or later) and to enable the reporting of those proceedings. A copy of the recording protocol is available from the contacts named on the front of this agenda. Use of Recordings by Third Parties– code of practice a) Any published recording should be accompanied by a statement of when and where the recording was made, the context of the discussion that took place, and a clear identification of the main speakers and their role or title. b) Those making recordings must not edit the recording in a way that could lead to misinterpretation or misrepresentation of the proceedings or comments made by attendees. In particular there should be no internal editing of published extracts; recordings may start at any point and end at any point but the material between those points must be complete.	137 - 174

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

WEDNESDAY, 5TH JULY, 2017

PRESENT: Councillor H Hayden in the Chair

Councillors Douglas, Marilyn Greenwood, Vanda Greenwood, Johnson, Betty Rhodes, Robinson and Liz Smaje

Apologies Councillors D Brown, J Clark, Dickerson, B Hall, Midgley, Mumby-Croft and Sansome

35 Opening remarks

In the first meeting as Chair of the Joint Committee, the Chair opened the meeting and welcomed all those in attendance.

Prior to commencing the formal business, the Chair invited those members of the Joint Committee in attendance to give a briefing introduction.

36 Late Items

A submission from Leeds Teaching Hospitals NHS Trust was submitted in relation to Item 7 – Proposals to Implement Standards for Congenital Heart Disease for Children and Adults in England – Consultation (Minute 40 refers).

The details had been made available to members of the Joint Committee and were available on Leeds City Council's website.

37 Declaration of Disclosable Pecuniary Interests

There were no declarations of disclosable pecuniary interests made at the meeting.

38 Apologies for Absence and Notification of Substitutes

Apologies for absence had been received and were recorded as follows:

- Councillor D Brown – Hull City Council
- Councillor J Clark – North Yorkshire County Council
- Councillor M Dickerson – North East Lincolnshire Council
- Councillor B Hall – East Riding of Yorkshire Council
- Councillor P Midgley – Sheffield City Council

- Councillor H Mumby-Croft – North Lincolnshire Council
- Councillor S Sansome – Rotherham Metropolitan Borough Council

There were no substitute members in attendance.

39 Minutes of previous meetings - 25 November 2014 and 28 November 2014

The draft minutes of the meetings held on 25 November 2014 and 28 November 2014 were presented and agreed as accurate records.

There were no matters arising from the minutes identified at the meeting.

RESOLVED – That the draft minutes from the meetings held on 25 November 2014 and 28 November 2014 be agreed as a correct record.

40 Proposals to implement standards for congenital heart disease for children and adults in England - consultation

The Head of Governance and Scrutiny Support (Leeds City Council) submitted a report that introduced details of NHS England's consultation on its proposals to implement standards for congenital heart disease (CHD) services for children and adults in England.

The following details were appended to the report:

- The new review of Congenital Heart Disease in England – the Joint Committee's consultation response (December 2014);
- Proposals to implement standards for congenital heart disease services for children and adults in England – an NHS England consultation document (February 2017);
- Draft response to consultation on Congenital Heart Disease Services – Children's Heart Surgery Fund (July 2017)

A consultation response from Leeds Teaching Hospitals NHS Trust was also submitted to the meeting (Minute 36 refers).

The following representatives were in attendance for consideration of the item:

- Robert Cornall – Regional Director Specialised Commissioning (North), NHS England
- Ben Parker – Project Development Manager, CHD Programme, NHS England
- Debra Wheeler – General Manager, Yorkshire and Humber Congenital Heart Disease Network
- Dr Elspeth Brown – Consultant Cardiologist, Leeds Teaching Hospitals NHS Trust
- Dr John Thompson – Consultant Cardiologist, Leeds Teaching Hospitals NHS Trust

The Principal Scrutiny Adviser gave a briefing introduction and highlighted the information presented to the Joint Committee for consideration.

Representatives from NHS England were then invited to introduce the proposals in more detail, and proceeded to deliver a presentation covering the following areas:

- Aims of the discussion;
- Background to congenital heart disease and the agreed model of care;
- The rationale and case for change;
- An outline of the agreed service standards and associated implications;
- The process of assessment of current providers against the agreed service standards, and associated outcomes;
- Applying the agreed standards, the current proposals and associated impacts; and,
- Details of the consultation process, including confirmation that the deadline for consultation responses was midnight, Monday 17 July 2017.

The Joint Committee welcomed the range of information provided as part of the agenda papers and presented at the meeting.

The Joint Committee also confirmed its primary focus was on the potential impacts and implications of any proposals on the children, adults and their families across Yorkshire and the Humber; particularly in relation to the main questions being posed by NHS England around the proposed decommissioning of (level 1) surgical services from:

- Central Manchester University Hospitals NHS Foundation Trust (adult service);
- Royal Brompton and Harefield NHS Foundation Trust (services for adults and children); and,
- University Hospitals of Leicester NHS Trust (services for adults and children)

In considering these specific proposals, the Joint Committee did not feel it appropriate to comment on the impact of the proposals for the children, adults and their families from those areas most directly impacted by the proposed decommissioning of services.

In considering all the remaining information presented to the meeting, members of the Joint Committee raised and discussed a number of areas, including:

- Assurance about Leeds Teaching Hospitals NHS Trust progress towards meeting the agreed standards.
- Assurance about the implications of NHS England's proposals for children, adults and their families across Yorkshire and the Humber.
- Concerns around the current '…fragility of the Adult Congenital Heart Disease (ACHD) service in Manchester' and the specific implications for Leeds Teaching Hospitals NHS Trust and its patient population.
- Support the call from Leeds Teaching Hospitals NHS Trust for a 'rapid co-ordinated response' to ensure contingency plans can be put in place ahead of the planned transition of services to Liverpool.

- NHS England's position around services delivered in Newcastle not currently meeting the agreed service standards in terms of activity levels or co-location of specific services – with no robust plans to do so within the required timeframe.
- Newcastle's unique position in relation to delivering services and caring for patients with advanced heart failure (including heart transplantation and bridge to transplant).
- Concern that the future delivery of the highly specialised services currently delivered at Newcastle continued to be unresolved some 4 years after the original Safe and Sustainable review was halted.

Members of the Joint Committee also expressed a desire to be kept informed of the outcome of the consultation; its conclusions and NHSE's future decision-making arrangements and timescales regarding the future delivery of congenital heart disease services in England.

RESOLVED –

(a) That a response on behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) be drafted, setting out the main observations made at the meeting and reflecting the comments previously submitted during the development of the standards and subsequent consultation in 2014.

(b) That the response on behalf of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) be submitted to NHS England by the revised consultation deadline of midnight on 17 July 2017.

41 Date and Time of Next Meeting

The date and time of the next meeting of the Joint Committee was to be determined.

Following conclusion of all the discussion, the Chair thanked all those present for their attendance and contribution to the meeting.

The meeting closed at 3:25pm.

Leeds CITY COUNCIL

Report author: Steven Courtney
Tel: 0113 3788666

Report of Head of Governance and Scrutiny Support

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

Date: 12 January 2018

Subject: Congenital Heart Disease Services for Adults and Children: Future Commissioning Arrangements

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: Appendix number:	☐ Yes	☒ No

1 Purpose of this report

1.1 The purpose of this report is to introduce NHS England's decision around the future commissioning arrangements for Congenital Heart Disease Services for Adults and Children in England.

2 Background

2.1 In June 2013, the Secretary of State for Health accepted a report and recommendations (in full) from the Independent Reconfiguration Panel (IRP) and called a halt to the former Safe and Sustainable Review of Children's Congenital Heart Surgery Services in England.

2.2 A new CHD review, covering the whole lifetime pathway of care, commenced in July 2013 and public consultation on proposed CHD service specifications and draft standards took place between September 2014 and December 2014.

2.3 In mid-2015 NHS England agreed and published the new set of quality standards for all hospitals providing congenital heart disease.

2.4 In February 2017, launched a public consultation on how the agreed quality standards should be implemented. The proposals were considered by the Joint Health Overview and Scrutiny Committee (Yorkshire and Humber) at its meeting on 5 July 2017. The JHOSC's submission to the consultation is attached at Appendix 1.

3 Main issues

3.1 At its meeting on 30 November 2017, the NHS England Board considered and agreed the future commissioning arrangements for Congenital Heart Disease Services for Adults and Children in England. The report considered and agreed by the NHS England Board is attached at Appendix 2. The consultation analysis report is attached at Appendix 3.

3.2 Please note, for reasons of efficiency, details of the full business case considered by NHS England (totalling in excess of 370 pages) is not attached to this report but it is available using the following link: Congenital Heart Disease Services Full Business Case - NHSE Board 30 November 2017.

3.3 In addition, details of all the other papers considered by the NHS England Board at its meeting on 30 November 2017 are available using the following link: NHS England Board Meeting Papers - 30 November 2017

3.4 To help the Joint Committee consider NHS England's decision and address any questions members of the JHOSC may have, representatives from NHS England have been invited to attend the meeting.

3.5 In addition, representatives from Leeds Teaching Hospitals NHS Trust (LTHT) and Children's Heart Surgery Fund (CHSF) have also been invited to attend the meeting to assist the Joint Committee's consideration of associated matters. Written submissions provided by LTHT and CHSF are appended to this report at Appendix 4 and Appendix 5, respectively.

4 Recommendations

4.1 The Joint Committee is asked to consider the details set out this report and agree any appropriate response and /or actions.

5 Background papers[1]

5.1 None used

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

Appendix 1

Proposals to Implement Standards for Congenital Heart Disease for Children and Adults in England

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

Consultation response

Introduction

The purpose of this statement is to set out the views of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the NHS England's proposals to implement standards for Congenital Heart Disease (CHD) for children and adults in England. The consultation was launched on 9 February 2017 and due to conclude at midnight on 17 July 2017[1].

This response sets out the main observations of the joint committee following its meeting held on 5 July 2017 and the comments previously submitted during the development of the standards and subsequent consultation in 2014.

Background

The Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – the JHOSC – is a single representative body for the 15 top-tier local authorities across Yorkshire and the Humber. The JHOSC was initially established (in March 2011) to consider the Safe and Sustainable Review of Children's Congenital Cardiac Services in England, the associated proposals and respond to the options presented for public consultation.

Since being established, the JHOSC has some considerable experience considering the services, and proposed changes to those services, for children and adults affected by Congenital Heart Disease (CHD). The meeting held on 5 July 2017 represented the 20th meeting of the JHOSC considering the proposals and implications of the various reviews of services for children and adults affected by CHD.

The JHOSC's previous work, reports and findings were fundamental to the Secretary of State's decision to halt the Safe and Sustainable Review in 2013. Subsequently, the JHOSC was actively engaged in NHS England's new review of CHD services and the development of the service standards, which concluded with a formal consultation response in December 2014.

Throughout its work, the JHOSC has always been focused on the potential impacts and implications of any proposals on the children, adults and their families across Yorkshire and the Humber; keen to ensure any negative impacts would not disproportionately affect Yorkshire and the Humber. Nonetheless, in making previous recommendations the JHOSC has recognised the national nature of the reviews and has been equally mindful not to 'passport' any disproportionate impacts to other areas of England.

[1] This represents an extended period of consultation in recognition of the restrictions placed on public bodies (including the NHS) during the pre-election period immediately prior to the General Election held on 8 June 2017.

Main Observations

At its meeting on 5 July 2017, the JHOSC considered the main questions being posed by NHSE related to the proposed decommissioning of surgical services (level 1) from:

- Central Manchester University Hospitals NHS Foundation Trust (adult service);
- Royal Brompton and Harefield NHS Foundation Trust (services for adults and children); and,
- University Hospitals of Leicester NHS Trust (services for adults and children)

At its meeting, the JHOSC confirmed its focus was on the potential impacts and implications of any proposals on the children, adults and their families across Yorkshire and the Humber. In this, the JHOSC noted the comments from Leeds Teaching Hospitals NHS Trust (LTHT) that:

> '…*the changes in Manchester and Leicester will impact on Leeds Teaching Hospitals NHS Trust (LTHT). The Impact Assessment exercise suggests that these changes would result in the transfer of approximately 50 cases to LTHT, and we are confident that we can increase capacity across children's and adult services to accommodate these additional cases, and provide the full range of CHD services for our patient population.'*

In addition to the assurances provided about LTHT's progress in meeting the agreed standards, the JHOSC was also assured about the implications of NHSE's proposals for children, adults and their families across Yorkshire and the Humber. However, **the JHOSC did not feel it appropriate to comment on the impact of the proposals for the children, adults and their families from those areas most directly impacted by the proposed decommissioning of services**.

However, the JHOSC noted the concerns expressed by LTHT around the current '…fragility of the Adult Congenital Heart Disease (ACHD) service in Manchester'. The JHOSC would support LTHT's call for a 'rapid co-ordinated response' to ensure contingency plans can be put in place ahead of the planned transition of services to Liverpool.

The JHOSC noted NHSE's position in relation to the service current delivered in Newcastle not currently meeting the agreed service standards in terms of activity levels or co-location of specific services – with no robust plans to do so within the required timeframe. The JHOSC also noted Newcastle's unique position in relation to delivering services and caring for patients with advanced heart failure (including heart transplantation and bridge to transplant).

However, the JHOSC remained concerned that the issues regarding these highly specialised services – which featured significantly as part of the original Safe and Sustainable review and proposals – continued to be unresolved some 4 years after the that review was halted; with NHSE seemingly having little in the way of a contingency plan, or at least a contingency plan that it had shared publically.

It should be noted that in its previous reports and the referral to the Secretary of State for Health, the JHOSC advocated the retention of Newcastle in a reconfiguration of services and the JHOSC remained sceptical about the impact of a standards based approach (particularly in relation to activity levels) was likely to have on Newcastle's long-term future due to its geographical location and population density.

Nonetheless, the JHOSC was also concerned about the risk or potential risk of further legal challenge due to NHSE's perceived 'special treatment' of Newcastle and the impact this could have on services across England, with the potential for yet more delays and uncertainty.

The JHOSC would urge NHSE to carefully consider it proposals in relation to Newcastle, taking into account the longer-term national capacity needs for congenital heart disease services, setting out a well-defined action plan with associated timescales and a clear summary of the consequences of the desired outcomes being achieved or otherwise.

Issues previous raised by the JHOSC

As part of NHSE's previous consultation on the standards, the JHOSC highlighted a number of specific issues or concerns, including:

- Derogation[2]
- Stakeholder involvement
- Implications of the proposed standards
- Finance and affordability
- Networks

The following comments reflect the previous concerns highlighted in relation to the current proposals and consultation process.

Derogation

Previously, when NHSE described the derogation process the JHOSC was concerned about the transparency of the process and was keen to ensure it was not used as a mechanism to circumnavigate consultation about potential service reconfiguration in the future. By the very nature of the current consultation, the JHOSC was assured this had not been the case.

Stakeholder involvement

Previously, the JHOSC believed NHSE had fallen short on some aspects of the Independent Reconfiguration Panel (IRP) recommendations around stakeholder involvement – particularly in relation to the involvement, engagement and consultation with Black and Minority Ethnic (BME) communities. This view had predominantly been based on NHS England's decision not to translate its consultation documents into other languages (other than Welsh). Despite a rapid re-think and some translation of the consultation booklet taking place the JHOSC believed the new CHD review had repeated some of the well documented failings of the previous Safe and Sustainable review.

However, at its meeting on 5 July 2017, the JHOSC was assured that the most recent consultation had included the translation of the consultation materials into the 'seven most commonly spoken languages across England, in addition to Welsh. The JHOSC was also assured on the use of plain English across the consultation material, to help encourage participation.

[2] A process whereby there would be an agreed temporary delay in meeting key service requirements in full; supported by full implementation over a time limited period according to provider capacity and capability.

Implications of the proposed standards

Previously, the JHOSC highlighted that when considering the proposed standards, it was equally important to consider the likely impact and implications of implementing and achieving those standards. The JHOSC stated that it was difficult to whole-heartedly support proposals when the potential impact remained unclear and uncertain. The current proposals more clearly explain some of the likely impacts – but with some notable exceptions, particularly in relation to services currently provided by Newcastle (highlighted elsewhere).

The completed health impact assessments demonstrate NHSE's attempts to articulate it's assessment of the implications of the proposals. However, aside from the assurances provided around the impact on capacity at LTHT, **the JHOSC believes it is more appropriate for those areas more directly affected by the proposals to comment on the accuracy or completeness of those health impact assessments**.

However, the JHOSC would repeat its previous comments in relation to patient transport; in that a re-assessment against the standards will be required should there be any further proposed changes likely to impact on the current configuration or provision of services across Yorkshire and the Humber.

Previously, while accepting the aspiration to stop occasional practice, there was significant debate around what constituted occasional practice; with the JHOSC supporting the view there is insufficient evidence that outcomes would improve with surgical centres undertaking 400 – 500 procedures per annum. The JHOSC was not presented with any additional or supplementary evidence in this regard and therefore did not reconsider its position.

The JHOSC's previous concerns that standards relating to minimum levels of procedures and/or surgeons would lead to the closure of some existing centres sometime in the relatively near future have proven to be well founded – given the basis of the current consultation. However, the current and projected rate of increase in the population of adult patients with congenital heart disease (due to better survival rates etc.) was not reconsidered; therefore the JHOSC would urge NHSE to carefully consider and be reassured regarding the longer-term national capacity needs when considering the proposed decommissioning of surgical centres in the short-term. This position is also supported by the submission provided by Children's Heart Surgery Fund.

Finance and affordability

The JHOSC was previously concerned at the level of available detail and the robustness of financial modelling undertaken prior to consultation. These concerns were based on information previously provided by the Chief Executive of LTHT[3]; the ability of individual providers to generate (or borrow) capital for investment[4]; and the relatively low level of historical levels of funding/ investment for specialised services across Yorkshire and the Humber in comparison to most other areas of the country[5].

[3] It had previously been stated that discussions with commissioners would be needed about any necessary additional investment.

[4] Previously stated that the ability to borrow for capital investments could be directly influenced by the 'Foundation Trust (FT) status' of individual providers.

[5] It was previously stated that the legacy of historical spending patterns is likely to have led to a lower level of investment in specific areas across service providers.

The JHOSC did not consider any additional information regarding these matters; however it again noted and would support the specific comments from the Chief Executive of LTHT, calling for financial support for the provider networks (required as part of the standards for Level 1 surgical centres) to be specifically funded by NHSE – similarly to Operational Delivery Networks (ODNs) across other commissioned services.

Networks

Despite the importance and strength of network arrangements being a key feature of the agreed standards; the JHOSC previously expressed its disappointment that since NHS England formed in April 2013, the dedicated managerial support for the network had ceased to exist. Despite this, at its most recent meeting, the JHOSC was pleased to have in attendance the recently appointed General Manager of the Yorkshire and Humber Congenital Heart Disease Network. However, the comments from the Chief Executive of LTHT (detailed above) are particularly pertinent and supported by the JHOSC.

In addition, the current uncertainty around the long-term future of services provided by Newcastle may impact on future network arrangements and any future and/or ongoing financial support for the network will need to consider both the physical geography and size of the network; alongside the size of population served.

Summary

In general, the JHOSC once again recognises and welcomes NHS England's more open and transparent approach in relation to decisions regarding the future commissioning of congenital heart disease services (for children and adults). However, **the JHOSC did not feel it appropriate to comment on the impact of the proposals for the children, adults and their families from those areas most directly impacted by the proposed decommissioning of services**.

Nonetheless, the JHOSC would urge NHSE to carefully consider the current and projected rate of increase in service users and be reassured regarding the longer-term national capacity needs when considering the proposed decommissioning of surgical centres in the short-term.

The JHOSC has also included some specific comments in relation to the following areas that it would wish NHSE to take into account:

- Derogation
- Stakeholder involvement
- Implications of the proposed standards
- Finance and affordability
- Networks

However, concerns regarding the long-term future of services currently delivered in Newcastle remain – including the potential challenges from other areas regarding any perceived 'special treatment' around the implementation and achievement of the agreed congenital heart disease service standards.

As such, the JHOSC would urge NHSE to carefully consider its proposals in relation to Newcastle, taking into account the longer-term national capacity needs for congenital heart disease services, setting out a well-defined action plan with associated timescales and a clear summary of the consequences of the desired outcomes being achieved or otherwise.

The JHOSC will consider whether it wishes NHS England to provide a specific response to the issues identified in this response.

The JHOSC also wishes to be kept informed of the outcome of the consultation; its conclusions and NHSE's future decision-making arrangements and timescales regarding these and future proposals in relation to congenital heart disease services.

Cllr Helen Hayden (Chair)
Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

July 2017

NHS ENGLAND – BOARD PAPER

Paper: PB.30.11.2017/06

Title:

Congenital Heart Disease Services for Adults and Children: Future Commissioning Arrangements

Lead Directors:

Paul Baumann - Chief Financial Officer

John Stewart - Acting Director of Specialised Commissioning

Purpose of Paper:

To take final decisions on the commissioning of congenital heart disease services for adults and children across England following full public consultation on proposals.

Summary:

The introduction of a standards-based approach to commissioning congenital heart disease services for adults and children responds to calls from patients, patient groups, clinicians and professional bodies, and will ensure the highest quality of care is provided to patients within resilient and sustainable services. Already, this approach has driven significant improvements across the country to out of hours and seven day cover, the number of specialist nurses and rates of antenatal diagnosis. Occasional and isolated practice has now almost entirely been eliminated.

However, in line with the standards, there is both scope to secure further improvements and, crucially, the opportunity to make some further adjustments that will ensure services are able to respond rapidly to future clinical, technological and scientific advances and, in doing so, maintain their world leading status. The recommendations in this paper, if agreed, will further support us in moving towards full national compliance with the standards through:

- Commissioning Liverpool Heart and Chest Hospital NHS Foundation Trust to provide level 1 adult CHD services in the North West, with Manchester University Hospitals NHS Foundation Trust providing the full range of level 2 adult CHD services as an integral part of a North-West CHD Network;
- Continuing to commission University Hospitals of Leicester NHS Trust to provide level 1 CHD services, *conditional* on achieving full compliance with the standards in line with their own plan to do so and demonstrating convincing progress along the way;
- Backing the Royal Brompton and Harefield NHS Foundation Trust's ambitious

new outline proposal for achieving full compliance with the standards and continuing to commission level 1 services from them in the meantime, *conditional* on demonstrating convincing progress along the way;

- Continuing to commission Newcastle upon Tyne Hospitals NHS Foundation Trust to provide level 1 CHD services until at least March 2021, with further consideration to be given, by NHS England, to the future commissioning of both the Trust's advanced heart failure and transplant service and its level 1 CHD service;
- Ceasing to commission level 2 CHD services, including cardiology interventions in adults with CHD, from Blackpool Teaching Hospitals NHS Foundation Trust, Imperial College Healthcare NHS Trust, Nottingham University Hospitals NHS Trust, and University Hospital of South Manchester NHS Foundation Trust[1].

The Board is invited to:

- Note the results of the consultation;
- Note the assurances that due process has been followed and that it may appropriately proceed to take decisions;
- Agree the recommendations for changes to the provision of level 1 and level 2 adult and paediatric CHD services and the associated implementation schedules; and,
- Agree the proposals for full implementation of all the standards, and in particular confirm its support for the recommendations relating to better information, formal CHD networks and peer review.

[1] University Hospital of South Manchester has now merged with Central Manchester University Hospitals to form Manchester University Foundation Trust. Under the recommendations the newly merged Trust would provide level 2 services from its Royal Manchester Infirmary site.

Congenital Heart Disease Services for Adults and Children: Future Commissioning Arrangements

Purpose

1. In February 2017, a full public consultation was launched on proposals for the future commissioning of congenital heart disease services for adults and children in England. The purpose of this paper is to provide feedback to the Board on the responses received during consultation and, in light of this, present a set of recommendations on future commissioning arrangements for final decision by the Board.

2. This paper should be read in conjunction with the supporting materials set out in **Table 1.**

Table 1	Title	Description
Annex A	Congenital Heart Disease Consultation Report.	Independent analysis of consultation responses provided by Participate Ltd.
Annex B	Decision Making Business Case.	A detailed consideration and analysis of the impact of consultation proposals and alternative proposals presented during consultation.
Annex C	Notes of a meeting of the Liverpool and Manchester Trusts, chaired by Professor Huon Gray, National Clinical Director, Heart Disease.	Record of discussions and agreements reached between the Trusts at the meeting on 23 October 2017.
Annex D	Letter from the Liverpool Trusts.	Letter supporting the delivery of level 2 services in Manchester.
Annex E	Leicester Growth Plan.	Growth Plan materials supplied by the Trust.
Annex F	Letters from referring hospitals in response to Leicester's Growth Plan.	Compendium of letters supplied by the Trust.
Annex G	Joint consultation response from the Royal Brompton & Harefield NHS Foundation Trust and King's Health Partners.	Proposals for a collaborative approach that would meet the requirement for RBH paediatric care to be delivered in a holistic children's environment.

Background

3. Congenital heart disease (CHD) is the most common birth anomaly, and affects between 5 and 9 in every 1,000 babies born in the UK, meaning 3,500 to 6,300 babies are born with CHD in England and Wales each year. Not every baby will need surgery, but when it is needed, it is both life-saving and life changing. As such, a great deal of focus is often placed on the surgical episode. However, although surgery can represent a critical and life-saving intervention, for most, this will not be

a final cure. Congenital heart disease is a lifelong condition, and patients and their families will need monitoring, support and care throughout their lives.

4. Services for CHD in England are very good, and survival after surgery is as good as, if not better than, anywhere in the world[1]. A recent review has shown that UK mortality rates are low, compare favourably internationally[2], fell over the 10 years between 2000 and 2010, and more recently we have seen a continuing trend to improved survival[3]. About 80% of children with congenital heart disease will now survive into adulthood, with the result that for the first time, the number of adults living with CHD is thought to exceed the number of children and young people.

5. Despite these improvements, the origins of this review, which stem from the publication in 2001 of the public inquiry into concerns about the care of children receiving complex cardiac surgery at Bristol Royal Infirmary, remind us of the importance of not being complacent. We believe there is both scope to secure further improvements and, crucially, the opportunity to make some further adjustments that will ensure services are able to respond rapidly to future clinical, technological and scientific advances and, in doing so, maintain their world leading status. In doing so we are also seeking to ensure that services are more resilient, and will be sustainable for years to come.

6. When NHS England launched its review into congenital heart disease services, following previous failed attempts to put in place a coordinated programme of change, we listened to patients, their families and the clinicians who provide these services to understand what needed to be done.

7. They asked us to do two things. Firstly, they wanted to see national standards that set out what excellent care looks like and which every hospital would be expected to follow. Secondly, they asked us to deal with the uncertainty that had been allowed to develop about the future of individual centres providing these services, because it was affecting patient confidence and staff morale. So working with doctors, nurses, psychologists and patient representatives from across the country we developed a comprehensive set of service standards which, if implemented, would mean that hospitals providing this care were brought up to the level of the very best in every aspect of care.

8. In July 2015, the NHS England Board agreed the standards - almost 200 in total that covered the entire patient pathway, from diagnosis through to treatment and then on into care at home. The standards describe three levels of CHD service provision:

[1] See Annex B, Decision Making Business Case, Table 1: Survival Rates (paediatric surgery 2012-2015) before risk adjustment.

[2] Brown KL, Crowe S, Franklin R, et al. Trends in 30-day mortality rate and case mix for paediatric cardiac surgery in the UK between 2000 and 2010. Open Heart 2015;2:e000157.doi:10.1136/openhrt-2014-000157

[3] See Annex B, Decision Making Business Case, Figure 2: Variable Life Adjusted Display (VLAD) Chart for all 14 centres undertaking procedures in patients under 16 years of age, 2012-15.

- **Level 1 Specialist Surgical and Interventional CHD Centres**: manage all patients with highly complex CHD and provide the most highly specialised diagnostics and care, including all surgery and interventional cardiology.
- **Level 2 Specialist Medical Cardiology Centres:** provide the same level of specialist medical care as a level 1 centre, but not surgery or interventional cardiology (except for one specific minor procedure at selected adult centres). They focus on diagnosis and ongoing care and management. Not every network will include a level 2 centre: this will depend on local requirements for access and capacity.
- **Level 3 Local Cardiology Services :** accredited services in local hospitals run by general paediatricians / cardiologists with a special interest in CHD. They provide initial diagnosis, ongoing monitoring and care, including joint clinics with specialists from the level 1 or 2 centres, so allowing more care to be given nearer to home.

Using the standards to ensure services improve for patients

9. NHS England does not consider there to be a 'right number' of CHD surgery centres, nor that a certain number of centres should close. Rather, our aim is to ensure that every centre that offers CHD services meets the standards and, in doing so, provides the highest quality of care to patients on a sustainable basis. By setting standards that make clear what is required for an excellent service we have already seen improvements. For example, when NHS England completed its initial assessments, only seven centres had full out of hours cover for adults undergoing cardiology interventions (1 in 3 rota, specialist adult CHD interventionists); now all centres providing this service have full cover. Similarly, all now have full specialist adult cardiologist out of hours cover (1 in 4 rota). In addition, every centre now has consultant-led ward rounds seven days a week. These are important improvements that make a difference to the quality of care for patients. We have also seen increases in the number of specialist nurses and steady improvements in antenatal diagnosis of CHD; with targeted action becoming possible we expect to see more improvements.
10. The standards do not permit occasional and isolated practice (small volumes of surgery and interventional cardiology being undertaken in institutions that do not offer sufficient specialist expertise in this field). This has been of particular concern to patients and their representatives. We have worked with the hospitals involved and we are well on the way to completely eliminating occasional practice.
11. Patients and their families told us that while it was a good thing to have standards, they only really mattered if we ensured that they were met. Otherwise, they were a waste of time.
12. We therefore set out proposals to implement the standards, and asked for views in a full, formal, public consultation that ran between 9 February 2017 and 17 July 2017.

13. At the heart of our proposals was our aim that every patient should be confident that their care is being delivered by a hospital that meets the required standards. To achieve this, we proposed that in future, NHS England would only commission CHD services from hospitals that are able to meet the standards. The recommendations that the Board is now being asked to consider will, over time, ensure we achieve that aim and, more specifically, that:

    - **Every operation or cardiology intervention for CHD patients will be carried out by specialist doctors** with a volume of practice sufficient to develop and maintain their skills;
    - **All children with heart disease will receive their inpatient care in a holistic children's environment** so that they can receive optimum care for any non-cardiac clinical problems without either the child or the specialist having to travel to another hospital with the potential compromises involved;
    - **Daily interaction between teams will be facilitated,** which is particularly important for children with complex conditions and multiple medical needs;
    - **Resilience will be enhanced** through larger level 1 centres, with bigger teams, providing an assurance of full 24 hour seven day specialist care and the ability to cope with challenging clinical events or fluctuations in specialist staffing;
    - **Care will be delivered as close to home as possible**, through networked specialist level 2 centres, level 3 services and outreach clinics, all co-ordinated by a network team;
    - **Occasional and isolated practice will no longer be permitted**, so low volume surgery or interventional cardiology in institutions without sufficient specialist CHD expertise will cease.

14. **The recommendations set out in this paper modify NHS England's original consultation proposals, because we have listened to the views expressed and considered new proposals and information that has emerged as part of the process**.

Assurance of readiness for decision making

15. In taking final decisions as to whether to implement the consultation proposals or whether to take an alternative course of action the Board must:

    - give conscientious consideration to the results of the consultation;
    - ensure that NHS England has met the requirements of the Secretary of State's Four Tests for reconfiguration (and the fifth test set by the Chief Executive of NHS England) and has followed NHS England's Service Change Guidance;
    - ensure that NHS England has met its legal duties including those set out in sections 13C - Q of the NHS Act 2006 and in the Equality Act 2010, the Human Rights Act 1998 and the Children Act 2004;

- take into account all the relevant factors and no irrelevant factors; and,
- satisfy itself that due process has been followed.

The results of consultation

16. We received 7673 online consultation responses (survey) and 78 'other responses' in the form of letters/emailed documents. These were independently analysed by Participate Ltd and a report of their analysis accompanies this paper at **Annex A**. Further detail from the responses and the way they have influenced our thinking can be found in the relevant sections of the Decision Making Business Case (DMBC), also accompanying this paper at **Annex B**.

The five reconfiguration tests

17. NHS England has ensured that it has met the requirements of the five tests. This is described in Part 3 of the Decision Making Business Case (DMBC) accompanying this paper. In reviewing and accepting the DMBC, both the Oversight Group for Service Change and Reconfiguration and the Investment Committee have provided assurance that this requirement has been met.

Meeting our legal duties

18. Our external legal advisers have reviewed our compliance with sections 13C to 13Q of the NHS Act 2006 and the public sector equality duty. This is described in Part 3 of the DMBC accompanying this paper. We have completed a full Integrated Equalities Impact Assessment. This is described in the DMBC accompanying this document. In reviewing and accepting the DMBC, the Oversight Group for Service Change and Reconfiguration and the Investment Committee also provided assurance that this requirement has been met.

Taking account of the relevant factors

19. NHS England has received advice on the current (as at August 2017) assessment of each hospital providing level 1 and 2 CHD services against the standards, the impacts of implementing NHS England's proposals and appropriate mitigations of any potential adverse impacts. These assessments were undertaken by a specially convened National Panel including national and regional commissioners, clinical and patient representatives and chaired by Dr Vaughan Lewis. The panel met in August 2017. The report of its work is included at **Annex 6 of the DMBC** accompanying this paper. Its advice is reflected throughout the accompanying DMBC. The National Panel confirmed that there have been no changes in the assessment of any of the centres where change has been proposed which could imply that the original proposals would no longer be appropriate. It has also confirmed that the original proposals could, in principle, be implemented by the NHS England Board and that the impacts of doing so could be appropriately managed. The National Panel also considered alternative proposals that emerged during consultation.

20. NHS England has also received advice on a range of clinical issues in the light of consultation, including issues raised by respondents from a specially convened Clinical Advisory Panel chaired by Professor Sir Michael Rawlins. The panel met in August 2017. The report of its work is included at **Annex 5 of the DMBC** accompanying this paper. Its advice is reflected throughout the accompanying DMBC.

21. A full assessment of the financial impact, both revenue and capital, of NHS England's proposals is included in the DMBC accompanying this paper. In developing and agreeing the CHD standards, NHS England has been clear throughout that no additional funding will be provided to meet compliance costs for those providers wishing to offer these services and that no specific central funds are available for capital investment. The Investment Committee has confirmed that implementing the standards is affordable for NHS England under tariff and that risks around the capital funding requirement are minimal. The Investment Committee has also endorsed pump priming the development of CHD networks for a limited period in a similar way to other Operational Delivery Networks and using similar funding mechanisms from within the Specialised Commissioning budget.

Consideration and Recommendations

22. Having confirmed that NHS England has in its work on CHD followed due process, this paper now considers the proposals for change and whether the Board should decide to implement the proposals on which it has consulted, or, in light of the consultation response and all the other relevant factors, take a different course of action.

23. It is worth noting that the majority of standards can be met at every hospital currently providing level 1 services with the right focus, attention and in some cases some extra investment. However, there are two very important areas covered by the standards that have proved more challenging for certain hospitals, as follows:

    - **Surgical activity standards** require that each level 1 centre has a team of three surgeons from April 2016, increasing to four surgeons from April 2021. Each surgeon must undertake at least 125 operations per year. CHD surgeons work across paediatric and adult practice, and all these operations count. Only a small number of centres already undertake more than 500 operations a year. Requiring each surgeon to undertake 125 operations per year (equivalent to about three operations a week) will enable them to maintain and develop their skills and will ensure the best possible outcomes for patients. Bigger teams, more effectively networked with other centres will be more resilient, providing an assurance of full 24 hour seven day care and the ability to cope with challenging events, for example the loss of a surgeon. They will be better for training, and because less onerous for

surgeons, better for patient care. There is good evidence, from a large number of studies, for a link between centre size and outcomes.

Professor David Anderson, Consultant Heart Surgeon and Professor of Children's Heart Surgery, Guy's and St Thomas', past President of the British Congenital Cardiac Association (BCCA) and member of the Clinical Advisory Panel has said: *'125 really is a minimum number. It equates to three operations a week, per surgeon. Practice makes perfect … Some of the operations we do only come up once or twice a year…we must set a minimum standard in order to ensure that a surgeon has an acceptable level of skill refined and maintained through regular practice.'*

- **Paediatric co-location standards** require that level 1 centres delivering paediatric cardiac care must have a range of other paediatric specialties on site from April 2019. This means that specialist children's cardiac services will only be delivered in settings where a wider range of other specialist children's services are also present on the same hospital site. This determines what medical care is available by the bedside for a child in a critical condition, which is important because many children with CHD have multiple medical needs. It also facilitates daily interaction with the wider paediatric multidisciplinary team which is of significant benefit to patients. This approach brings paediatric cardiac services into line with expectations in other specialist children's services and with paediatric cardiac services in other countries. Having all tertiary specialties on one site means neither the child nor the specialist has to travel, and it avoids the potential compromises involved - in the care environment, access to the full team and equipment, and timeliness of advice and intervention. This works in both directions in that similar advantages are also gained by children under the care of other specialists who need access to the advice or care of a paediatric cardiologist.

  The Clinical Advisory Panel has said: *'care for children should be provided in a holistic children's environment with on-site access to the full range of paediatric specialties and services'.* And the Royal College of Paediatrics and Child Health has told us that *'Isolated children's services are unacceptable; specialist children's cardiac services must be delivered within a hospital providing a broad range of other specialist children's services."*

24. Having assessed all existing providers of level 1 services against the standards, four Trusts were identified as being unlikely to meet the standards and were the focus of our proposals for change and our formal consultation. These are now considered in turn. In each case we describe the original proposal and the reasons for that proposal, we then go on to discuss what we are now recommending, and if that differs from the original proposal we say why.

Level 1 and 2 Services: North-West England

25. In North-West England, specialist inpatient services for people with CHD (level 1) have, to date, been divided between two cities: Liverpool where children received their care at Alder Hey Children's Hospital; and Manchester where adults received their care at Manchester Royal Infirmary.

26. Running the service in this way inevitably required compromises, because it meant the adult service depending on a single surgeon. He could not be there all the time, and the distance between the cities was such that cover could not be provided from Liverpool. There also wasn't enough surgical work to allow him to meet minimum volume expectations – just 92 operations in 2016/17. On 19 June 2017 the service in Manchester was suspended by the Trust, when their surgeon moved to a new post at a different hospital. As a result, patients who previously received their care from the Manchester team currently receive much of that care from the clinical teams at Leeds, Newcastle and Birmingham under interim arrangements.

27. As such, NHS England's proposal was to bring the level 1 service together so that care for adults and children could be delivered in one city, by teams of surgeons, cardiologists and interventionists big enough to give full, consultant led, 24 hour, seven day care. Choosing which city should be the level 1 centre was always going to mean some people would be dissatisfied. We proposed that level 1 services should be centred in Liverpool, because around 80% of the operations are done in children and so moving the much larger children's service from Liverpool (Alder Hey Children's Hospital carried out 415 operations in 2015/16) to Manchester would be more difficult and potentially a greater risk than moving the smaller adult service to Liverpool. An important part of our proposal was that adults with CHD should still be able to get much of their care in Manchester if that is better for them. Inpatient care related to surgery and cardiology interventions is important, but it's something that happens only occasionally - sometimes just once in a lifetime - but outpatient appointments and investigations are a regular part of life for a person with CHD. So we wanted to make sure that people could still get that care in Manchester, without having to travel to Liverpool all the time if that's not convenient for them.

28. We've listened to concerns raised during the consultation and can confirm that Manchester can and should provide level 2 care for adults with CHD as part of a North-West England CHD Network (NWCHDN). That will mean they will still be able to provide maternity care to most women with congenital heart disease. It will also be possible to have some of the more straightforward interventional procedures conducted there. As such, Manchester will continue to play a pivotal role in the network of care for adults with CHD, and when a patient does need an operation or more complex intervention, the new service at Liverpool Heart and Chest Hospital will be able to provide it. Critically, all these services will meet the national standards, giving patients an assurance of the best care.

Recommendation for consideration by the Board:

After careful consideration of consultation responses and other supporting materials, the Board is asked to confirm that it is content to proceed with implementing its 'minded to' decision to commission adult level 1 CHD services from Liverpool Heart and Chest Hospital NHS Foundation Trust, with the full range of level 2 services to be commissioned from Manchester University Hospitals NHS Foundation Trust, as part of a North-West England CHD Network.

Under these network arrangements, we would expect Manchester University Hospitals to continue to play a leading role in providing maternity care for women with CHD, including the development of care pathways and the coordination of multidisciplinary discussions of maternity care. We would expect that care for women with complex needs would be discussed at the NW CHD Network multidisciplinary team meeting to determine the best place for delivery.

The Board's decision to support these network arrangements should be conditional on the Liverpool Trusts providing robust and adequate support for level 2 services in Manchester.

Assurance:

- Professor Huon Gray, National Clinical Director for Heart Disease, met with clinical and managerial leads from the Liverpool and Manchester Trusts on 23 October 2017. At this meeting there was agreement on the provision of maternity care for women with CHD, with services continuing in both Manchester and Liverpool: place of birth for women with complex needs would be discussed and determined at the NW CHD Network MDT. This could mean a bespoke arrangement to ensure that all aspects of care were 'wrapped around' the patient, including the relevant adult CHD support being provided at St Mary's Hospital if that was the most appropriate place for the woman to deliver. There was also agreement for continuing adult CHD interventions in Manchester, within the level 2 standards, subject to NW CHD Network MDT oversight. Professor Gray has confirmed that in the north-west, providers will work together to establish a robust network with strong level 1 and 2 centres providing ACHD and paediatric cardiac care to patients in the north-west (**Annex C**).
- We have received written confirmation from the Liverpool Trusts that they are committed to ensuring that Manchester University Hospitals NHS Foundation Trust (MFT) will be able to provide the full range of level 2 adult CHD services as described in the National Standards, including facilitating the delivery of obstetric care for women with CHD and adult CHD interventions at a level two centre in Manchester as part of the North West CHD Network (**Annex D**).
- The impacts of implementing this recommendation have been assessed. The full assessment is reported in the Decision Making Business Case accompanying this paper. This confirms that the recommendation could be implemented by the

NHS England Board and the impacts of doing so could be appropriately managed.

Implementation

NHS England will monitor progress in the North-West towards meeting the standards and take commissioning action, if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trusts' own plans and the original timetable set out in the standards.

Alder Hey Children's Hospital Trust, Liverpool Heart and Chest Hospital, The Royal Liverpool and Broadgreen Hospitals, Liverpool Women's Hospital and Manchester University Hospitals will be required to re-provide all level 1 and level 2 services for adults with CHD within the NW CHD Network by January 2019. A detailed implementation schedule can be found at **Appendix 1 to this paper**.

Level 1 Services: University Hospitals of Leicester NHS Trust

29. In the East Midlands, specialist inpatient services for people with CHD (level 1) have been provided by University Hospitals of Leicester NHS Trust (UHL) from its Glenfield Hospital site in Leicester. This is one of the two smallest level 1 CHD services in the country, and this has meant that, to date, the Trust has cared for too few patients for its surgeons to be able to fully develop and maintain their skills. In recent years the service has grown, but it still is not big enough to allow each of its three surgeons to do at least 125 operations per year, a minimum requirement that came into effect on 1 April 2016. In addition, Glenfield is a mainly adult hospital, so the other specialists whose care and advice are sometimes needed for children with congenital heart disease were not all immediately at hand. When their help was needed they were usually at one of the Trust's other hospitals, the Leicester Royal Infirmary (LRI), and that meant either the doctor or the child would need to travel to a different hospital. It also meant that the specialist heart doctors at Glenfield were not so easily available to the children with other conditions, who were at the LRI.

30. UHL has produced plans to address these concerns, so that the standards could be met. Although we were happy with their plan to move children's services all under one roof at the LRI, we did not think, at the time, that we could be sure that their plan to increase the number of patients they care for would be enough for them to be able to meet the surgical activity standards. As a result, NHS England proposed that UHL should not provide level 1 CHD services in future, and patients needing surgery, cardiology interventions and specialist inpatient care or investigations would go to another hospital, generally in either Birmingham or Leeds. Under those proposals, it would still have been possible for patients with CHD to have most of their care - most outpatient appointments and investigations and some inpatient admissions and cardiology interventions - in Leicester because it would still have provide level 2 services.

31. Since that time, and in response to that prompt, UHL has further developed its plans to attract more patients to its service (**see Annex E**), and gained support from many of the surrounding hospitals (**see Annex F**). We also know from the consultation that, assuming UHL is meeting the standards, people want to see them continue to provide a level 1 CHD service.

32. Taking these developments into account we think it is now reasonable to give the Trust the opportunity to prove that it can implement its plans to meet the standards. To succeed, it will need to change the choices made by referring doctors and their patients, so neither we nor the UHL leadership can be absolutely certain what will happen. We plan, therefore, to monitor UHL's progress against their plan closely, and should it become clear that it is not going to be able to deliver its commitments and so meet the requirements, we will take the necessary action.

33. If UHL succeeds in attracting additional patients as planned, it will, of necessity, mean that activity levels at other hospitals will fall. Our analysis shows that the greatest impact is likely to be on Great Ormond Street and the Birmingham hospitals. The scale of the likely impact should not materially affect any other hospital's ability to meet the standards.

Recommendation for consideration by the Board

After careful consideration of consultation responses, other supporting materials and the additional evidence supplied by University Hospitals of Leicester NHS Trust around plans for achieving the co-location standard and meeting the surgical volumes standards, the Board is asked to confirm if it is content to continue to commission level 1 services from Leicester, conditional on the Trust achieving full compliance with the standards within the required timeframes, as described in its new plan to do so, and the Trust demonstrating convincing progress in line with the implementation milestones and key performance indicators (KPIs) set out in the implementation schedule at Appendix 1. Should this not be achieved, referral to the Specialised Services Commissioning Committee will be made to confirm that the process of decommissioning level 1 services should begin, with alternative arrangements put in place to ensure patients are able to benefit from receiving care from centres compliant with the required standards.

Assurance

- University Hospitals Leicester has provided a detailed plan for increasing the number of operations to be undertaken by its surgeons to allow it to meet the requirement of having a team of four surgeons, each undertaking 125 operations per year, from 1 April 2021 (**Annex E**). It has also provided statements of support from many of the hospitals that would be required to increase referrals (**Annex F**).
- The impacts of implementing this recommendation have been assessed. The

full assessment is reported in the Decision Making Business Case. This confirms that the recommendation could be implemented by the NHS England Board and the impacts of doing so could be appropriately managed.

Implementation

NHS England will monitor UHL's progress towards meeting the standards and take commissioning action if it becomes clear that the standards will not be met according to the agreed timescale and KPIs. These timescales and KPIs are informed by the Trust's own plans and the original timetable set out in the standards.

University Hospitals of Leicester NHS Trust will be required to achieve full compliance with the standards within the timeframes set out in the detailed implementation schedule which can be found at Appendix 1 to this paper. This includes achieving full co-location for all inpatient paediatric CHD care by April 2020 and increasing surgical activity so that it has a team of at least four surgeons, each undertaking at least 125 operations per year, from April 2021.

Level 1 Services: Royal Brompton and Harefield NHS Foundation Trust

34. The Royal Brompton and Harefield NHS Foundation Trust has provided specialist inpatient services for both adults and children with CHD (level 1) from its Royal Brompton Hospital (RBH) site in Chelsea. RBH is a mainly an adult hospital, so the other specialists whose care and advice are sometimes needed for children with congenital heart disease are not all immediately at hand. When their help was needed they were usually at another hospital, often Chelsea and Westminster Hospital, and that meant that either the doctor or the child would need to travel to a different hospital. RBH did not, at the time, produce any plans to address these concerns, so that the standards could be met. As such, NHS England proposed that RBH should not provide level 1 CHD services in future, and patients needing level 1 CHD care, including surgery, cardiology interventions and specialist inpatient care or investigations, would go to another hospital, generally still in London.

35. Since that time, and in response to our 'minded to' decision, RBH has begun to develop a proposal to work closely with another of the hospitals that provides level 1 CHD services in London, Guy's and St Thomas', part of King's Health Partners (**see Annex G**). They propose bringing together the CHD services offered by the two hospitals. Cardiac services for children would be provided from new buildings to be developed as part of the Evelina Children's Hospital and CHD services for adults from a newly created specialist heart and lung centre (both developments forming part of St Thomas' Westminster Bridge Campus).

36. We also know from the consultation that many aspects of RBH's service are held in high regard, with a special emphasis placed on the way their teams work together, and people want to see those teams kept together if possible.

37. Taking all that into account, we think it is reasonable now to allow the Trust to develop its plans further to the stage where they can be properly evaluated. The advantages of the proposed model (or one like it, involving another partner), if it could be delivered, would be very significant. Amongst these advantages is that this solution also addresses the parallel challenge relating to paediatric respiratory services, and that it facilitates keeping together the Royal Brompton's clinical and research teams. Although the proposal submitted involved Guy's and St Thomas', other partnerships might also be possible, so we will not make our decision specific to this one partnership arrangement. In any case, developing plans of this sort will mean RBH considering and fully evaluating a range of options, in terms of strategic fit, clinical quality, value for money and affordability (capital and revenue), and deliverability, to make sure that it is pursuing the best one.

38. It is important to note that the specific proposal presented in response to the consultation is ambitious and would require a great deal of money to fund the necessary new buildings and equipment, much, if not all, of which would probably need to be found by the Trusts themselves, including from surplus land disposals. So, if this option is pursued it would need to go through the exacting scrutiny that the Government requires of such projects. We plan, therefore, to monitor progress closely and provide appropriate support to the evaluation of options. However, if it becomes clear that RBH is not going to be able to meet the requirements through such an initiative, or that the solution cannot be put in place within a reasonable timescale, we would begin the process of decommissioning level 1 CHD services for children from the Royal Brompton site at this point.

Recommendation for consideration by the Board

After careful consideration of consultation responses and other supporting evidence, the Board is invited to note the outline alternative solution presented by the Royal Brompton and Harefield NHS Foundation Trust, for how full compliance against the standards might be achieved and, in light of this, confirm that NHS England should work with RBH and other potential partners on the full range of options for delivering a solution that could deliver full compliance with the standards and ensure the sustainability of other connected services. Progress should be reviewed by the NHS England Board over the next two years. Should a credible solution not have been presented by the end of November 2019 in the form of a submitted Outline Business Case, supported by NHS England, referral to the Specialised Services Commissioning Committee will be made to confirm that the process of decommissioning level 1 services for children should begin, with alternative arrangements put in place to ensure patients are able to benefit from receiving care from centres compliant with the required standards.

Assurance

- Royal Brompton & Harefield NHS Foundation Trust in collaboration with

King's Health Partners has submitted a proposal to develop a model for CHD services that brings together the existing Royal Brompton Hospital and Guy's & St Thomas' Hospital services to deliver a joint service that would meet the paediatric co-location standards (**Annex G**).

- The impacts of implementing this recommendation have been assessed at a level commensurate with the level of detail in the plans. The assessment is reported in the Decision Making Business Case. Further assessment of the plan, its impacts and appropriate alternatives will be undertaken as the plan passes through the public sector business case development process through to potential Outline Business Case approval.

Implementation

NHS England will monitor RBH's progress towards meeting the standards, and take commissioning action, if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and a realistic planning schedule.

RBH will be required to develop and deliver a credible solution for meeting the co-location requirements for its paediatric services. RBH should develop its plans (working with potential partners as appropriate) following Treasury guidance for preparing a Public Sector Business Case and using the five case model.

RBH will be required, as part of its planning process, to develop and deliver a detailed plan with clear milestones, that will achieve full co-location for all RBH paediatric specialist services by April 2022 at the latest.

A detailed implementation schedule can be found at **Appendix 1** to this paper.

Level 1 Services: Newcastle upon Tyne Hospitals NHS Foundation Trust

39. In the North-East of England, specialist inpatient services for adults and children with CHD (level 1) have been provided by Newcastle upon Tyne Hospitals NHS Foundation Trust (NUTH) from its Freeman Hospital site in Newcastle. This is one of the two smallest level 1 CHD services in the country, and this has meant, to date, that the Trust has cared for too few patients for its surgeons to be able to fully develop and maintain their skills, as it is not big enough to allow each of its three surgeons to do at least 125 operations per year, a minimum requirement that came into effect on 1 April 2016. In addition, the Freeman Hospital is a mainly adult hospital, so the other specialists whose care and advice are sometimes needed for children with congenital heart disease were not all immediately at hand. When their help was needed they were usually at one of the Trust's other hospitals, the Great North Children's Hospital (GNCH), and that meant either the doctor or the child would need to travel to a different hospital. It also means that the specialist heart doctors at the Freeman Hospital were not so easily available to the children with other conditions, who were at the GNCH.

40. The Trust has told us that it is confident it will reach the minimum 375 operations needed to meet the current requirement, but it does not consider it likely that it will have enough activity to be able to support a team of four surgeons each undertaking at least 125 operations a year as required by the standards from April 2021. In addition, while the Trust had looked at options for moving its paediatric cardiac services to the GNCH, they had not identified funding, or made definite plans, partly because of the uncertainty about the service's future. Under these circumstances NHS England would normally have proposed that NUTH should not provide level 1 CHD services in future. However, it was clear that if it did not provide level 1 CHD care, NUTH would also have to stop providing its advanced heart failure and heart transplant service for children and for adults with CHD. There are only two hospitals that do heart transplants for children and NUTH is also the main hospital for transplanting hearts for adults with CHD. These services could not be replaced in the short term without a negative effect on patients. Because of the way these services are intertwined, we cannot make a decision on one without also making a decision on the other, and heart transplants were outside the brief of our work on CHD services. Taking this into account we originally proposed that surgery and interventional cardiology for adults and children should continue to be provided by NUTH for the time being, with further consideration given to the commissioning position beyond 2021.

41. We are now recommending that NUTH should continue to provide a level 1 CHD service, until at least March 2021, which will allow us time to further consider our commissioning approach for both the CHD and the advanced heart failure and transplant service at the Trust from April 2021 onwards.

42. Whilst this consideration should assess the potential for moving the advanced heart failure and transplant service to another provider, it is possible that we could conclude that it is in the overall interest of patients to maintain current arrangements with permanent derogation against the 2021 surgical activity standard. If this were to be the case NUTH would still be required to meet the other standards, including having a team of at least three surgeons, each carrying out at least 125 operations a year, and to achieve full paediatric co-location.

43. Although NUTH has considered how it would achieve co-location of children's services, we think it would be premature to move to implementation of this until the commissioning position beyond 2021 is confirmed. As such, derogation against the co-location standard, for a time limited period, will be needed from April 2019.

Recommendation for consideration by the Board

After careful consideration of consultation responses and other supporting materials, the Board is asked to confirm that the commissioning of level 1 CHD services at Newcastle upon Tyne Hospitals NHS Foundation Trust should continue until at least March 2021.

Recognising the importance of the quality and sustainability of both the CHD service

and the interdependent advanced heart failure and transplant service, the Board is invited to agree that further consideration should be given to the future commissioning of both. This will inform our commissioning approach from 2021 to ensure services meet the required standards. Until the outcome of this work is known, derogation against the 2019 co-location standard should be assumed.

Assurance

- The impacts of implementing this recommendation have been assessed. The full assessment is reported in the Decision Making Business Case. This confirms that the recommendation could be implemented by the NHS England Board and the impacts of doing so could be appropriately managed.

Implementation

NHS England will further consider its commissioning approach for both the CHD and the transplant service at NUTH from April 2021 onwards. It will confirm its plans by no later than April 2019.

NHS England will monitor NUTH's progress towards meeting the standards, and take commissioning action, if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule, and subject to the relevant derogations. These timescales are informed by the Trust's own plans and the original timetable set out in the standards.

NUTH will be required to develop and deliver a plan to increase surgical activity so that it has a team of at least three surgeons, each undertaking at least 125 operations per year from 2019/20, in line with the detailed implementation schedule which can be found at **Appendix 1** to this paper.

NUTH will not be required to meet the 2019 deadline for full co-location for paediatric cardiac services, but will be required to meet these standards if NHS England confirms a plan to commission level 1 CHD services beyond March 2021.

44. If implemented, these revised proposals will mean that in future level 1 CHD services in England will be provided by the following hospitals:

- Alder Hey Children's Hospital NHS Foundation Trust (children's services) and Liverpool Heart and Chest Hospital NHS Foundation Trust (adult service) – subject to the conditions described above;
- Birmingham Women's and Children's Hospital NHS Foundation Trust (children's services) and University Hospitals Birmingham NHS Foundation Trust (adult service);
- Great Ormond Street Hospital for Children NHS Foundation Trust (children's services) and Barts Health NHS Trust (adult service);
- Guy's and St Thomas' NHS Foundation Trust (children's and adult services);

- Royal Brompton & Harefield NHS Foundation Trust (children's and adult services) – subject to the conditions described above;
- Leeds Teaching Hospitals NHS Trust (children's and adult services);
- Newcastle upon Tyne Hospitals NHS Foundation Trust (children's and adult services) – subject to the conditions described above;
- University Hospitals Bristol NHS Foundation Trust (children's and adult services);
- University Hospitals of Leicester NHS Trust (children's and adult services) – subject to the conditions described above; and
- University Hospital Southampton NHS Foundation Trust (children's and adult services).

Level 2 Services

45. Changes were also proposed to the provision of level 2 CHD services. These follow the same principle of only commissioning from hospitals that are able to meet the standards. We found a number of hospitals had been providing aspects of level 2 services, particularly cardiology interventions in adults with CHD, which were not able to meet the full level 2 standards. Common findings were that there were not enough doctors with specialist expertise in caring for CHD patients and that the doctors doing the interventions were not doing enough in CHD patients to develop and maintain their skills as required by the standards.
46. Since we made these proposals the situation has not really changed, except in one case, that of Papworth. Papworth Hospital has taken action in response to our assessment and as a result it now either meets or has good plans to be able to meet all the requirements.
47. With that in mind we consider that four hospitals, listed below, should no longer provide level 2 services for adults with CHD, including interventional cardiology.

Recommendation for consideration by the Board

After careful consideration of consultation responses and other supporting materials, the Board is asked to confirm that the commissioning of level 2 CHD services, including cardiology interventions in adults with CHD, should no longer continue at the following hospitals:

- *Blackpool Teaching Hospitals NHS Foundation Trust*
- *Imperial College Healthcare NHS Trust*
- *Nottingham University Hospitals NHS Trust*

- *University Hospital of South Manchester NHS Foundation Trust*[4]

Assurance

- The impacts of implementing this recommendation have been assessed by the National Panel which has confirmed that the recommendation could be implemented by the NHS England Board and the impacts of doing so could be appropriately managed.

Implementation

NHS England's regional teams will give notice on any contracts for the provision of level 2 services, and will no longer reimburse such services from the providers named above.

48. If implemented, these proposals will mean that in future level 2 CHD services in England will be provided by the following hospitals:

- Brighton and Sussex University Hospitals NHS Trust (adult service)
- Manchester University NHS Foundation Trust (adult service)
- Norfolk & Norwich University Hospitals NHS Foundation Trust (adult service)
- Oxford University Hospitals NHS Foundation Trust (children's and adult services)
- Papworth Hospital NHS Foundation Trust (adult service)

Further action to support full implementation of the standards

49. We are clear that all of the standards are important in ensuring excellent patient care and we are committed to ensuring that the NHS in England continues to work to see them all implemented in practice. A lot of the work we have done so far has concentrated on the challenge of meeting those standards that could not be met at every hospital working as they were. However, most of the standards are not of this type, and they can be met at every hospital with the right focus, attention and in some cases some extra investment. We are therefore putting in place a range of mechanisms to support the full implementation of all the standards.

Better information

50. Surviving surgery (or a cardiology intervention) is clearly vital for patients, but that is not the whole story when considering how good services are or the quality of life they achieve for patients and their families. Unfortunately, to date, few other reliable measures have been available. To address that shortfall we have:

- Developed a measure of patients' experience of their own care.

[4] University Hospital of South Manchester has now merged with Central Manchester University Hospitals to form Manchester University Foundation Trust. Under the recommendations the newly merged Trust would provide level 2 services from its Royal Manchester Infirmary site.

- Worked with the Congenital Heart Services Clinical Reference Group to introduce a dashboard that makes available a much wider range of measures of the quality of care than has ever been available before.
- Worked with the National CHD Audit to encourage reporting on a wider range of procedures and with a wider range of measures.
- Developed a research proposal to investigate longer term outcomes by diagnosis, which will now be commissioned by the Department of Health. This will use linked data from the national CHD audit and paediatric intensive care network databases, and other sources.

Networks

51. While most level 1 CHD surgical centres already have informal networks, the extent to which these networks have been developed varies. The standards place great emphasis on networks, and we believe they have a vital role to play in ensuring standards are met across the board. That's why we have agreed to provide funding to support their development.

Peer review

52. Peer review provides a mechanism by which centres are required to provide evidence to show that they meet the standards. The emphasis is on improvement and learning from other centres. NHS England's Specialised Commissioning Quality Surveillance Team (QST) will support the development and delivery of a rolling peer review programme that will cover all of the standards at all hospitals.

Conclusion

53. We have made a series of recommendations for changes to services for people with CHD. Ultimately, the aim of all our work has been to improve the care that patients receive. We believe that if these recommendations are implemented they will mean that, in time, every hospital will be brought up to the level of the very best in every aspect of care. It will mean that every child with CHD receives their care in a hospital that offers a holistic children's environment, with all the facilities and other specialists on site and readily able to contribute to their care. It will mean that all CHD surgeons and interventional cardiologists are doing enough procedures to develop and maintain their skills, and they will be part of teams large enough to provide full 24 hour / seven day care, resilient enough to continue to do so, even if one of the team leaves or is away for some reason. Occasional practice by non-specialists will be a thing of the past. Over time the full range of standards will be implemented with the help of more formal networked working, and including better information, communication and support which patients told us is so important. Commissioners, hospitals and patients alike will have access to a wider range of measures that can tell us all how well services are doing and help inform further improvements.

54. The Board is invited to:

- **Note** the results of the consultation;

- **Note** the assurances that due process has been followed and that it may appropriately proceed to take decisions;

- **Agree** the recommendations for changes to the provision of level 1 and level 2 adult and paediatric CHD services and the associated implementation schedules; and
- **Agree** the proposals for full implementation of all the standards, and in particular confirm its support for the recommendations relating to better information, formal CHD networks and peer review.

Appendix 1: Implementation Schedules

North West of England

- NHS England will monitor progress in the north-west towards meeting the standards and take commissioning action if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and the original timetable set out in the standards.
- Alder Hey Children's Hospital Trust, Liverpool Heart and Chest Hospital (LHCH), The Royal Liverpool and Broadgreen Hospital, Liverpool Women's Hospital and Manchester University Hospitals (MFT) will be required to re-provide all level 1 and level 2 services for adults with CHD within the North-West England CHD Network (NWCHDN) by January 2019.

Milestone- no later than	**Deliverable**	**Commissioner action if not delivered**
		Trust required to produce, and agree with NHS England, a recovery plan.
January 2018	NWCHDN Network MDT meets at least weekly.	If milestone missed.
April 2018	NWCHDN Network Board established.	If milestone missed.
September 2018	All outpatient appointments for adults with CHD delivered within the NWCHDN at both LHCH and MFT (and outreach), excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% outpatient appointments for adults with CHD delivered within the NWCHDN at both LHCH and MFT, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.
November 2018	All cardiology interventional procedures for adults with CHD delivered within the NWCHDN at both LHCH and MFT, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% interventional procedures for adults with CHD delivered within the NWCHDN at both LHCH and MFT, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.
January 2019	All cardiac surgery for adults with CHD delivered within the NWCHDN at LHCH, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% cardiac surgery for adults with CHD delivered within the NWCHDN at LHCH, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.

January 2019	All non-cardiac surgery for adults with CHD delivered within the NWCHDN at the appropriate centre, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% non-cardiac surgery for adults with CHD delivered within the NWCHDN at the appropriate centre, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.
January 2019	All inpatient admissions for adults with CHD delivered within the NWCHDN at the appropriate centre, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.	Less than 85% inpatient admissions for adults with CHD delivered within the NWCHDN at the appropriate centre, excluding patients whose care is delivered elsewhere because of patient choice or for clinical reasons.

University Hospitals of Leicester NHS Trust

- University Hospitals of Leicester NHS Trust will be required to achieve full compliance with the standards within the required timeframes and specified milestones. This includes achieving full co-location for all inpatient paediatric CHD care by April 2020 and increasing surgical activity so that it has a team of at least four surgeons, each undertaking at least 125 operations per year from April 2021.
- NHS England will monitor UHL's progress towards meeting the standards and take commissioning action if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and the original timetable set out in the standards.

Milestone- no later than	**Deliverable**	**Commissioner action if not delivered**	
		Trust required to produce, and agree with NHS England, a recovery plan.	**Referral to Specialised Services Commissioning Committee for decision whether to terminate the contract to provide level 1 CHD services.**
April 2018	Surgical activity for the year 2017/18 at least 375 operations.	Surgical activity less than 356.	Surgical activity is less than 337.
	Surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2018/19.	Fewer than three surgeons in post; no appointment made for replacement(s).
April 2019	Surgical activity for the year 2018/19 at least 403 operations.	Surgical activity less than 382.	Surgical activity is less than 362.
	Three surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2018/19.	Fewer than three surgeons in post; no appointment made for replacement(s).
April 2020	Surgical activity for the year 2019/20 at least 435 operations.	Surgical activity less than 418.	Surgical activity is less than 402.

	Three surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2019/20.	Fewer than three surgeons in post; no appointment made for replacement(s). One or more surgeons undertook fewer than 125 operations a year averaged across 2018/19 or 2019/20.
	Full co-location achieved for all inpatient paediatric CHD care.		Full co-location not achieved for all inpatient paediatric CHD care.
April 2021	Surgical activity for the year 2020/21 at least 471 operations.	Surgical activity less than 453.	Surgical activity is less than 435.
	Three surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2020/21.	Fewer than three surgeons in post. One or more surgeons undertook fewer than 125 operations a year, on average across the years 2018/19, 2019/20 and 2020/21.
	Fourth surgeon appointed and in post.		No appointment made for fourth surgeon.
April 2022	Surgical activity for the year 2021/22 at least 500 operations.	Surgical activity less than 487.	Surgical activity is less than 475.
	Four surgeons undertaking at least 125 operations per year.	Fewer than four surgeons in post. One or more surgeons undertook fewer than 125 operations in 2021/22.	Fewer than three surgeons in post.

Royal Brompton and Harefield NHS Foundation Trust

- The Royal Brompton and Harefield NHS Foundation Trust will be required to develop and deliver a credible solution for meeting the co-location requirements for its paediatric services. RBH should develop its plans (working with potential partners as appropriate) following Treasury guidance for preparing a Public Sector Business Case and using the five case model.
- The Royal Brompton and Harefield NHS Foundation Trust will be required, as part of its planning process, to develop and deliver a detailed plan with clear milestones, that will achieve full co-location for all RBH paediatric specialist services by April 2022.

NHS England will monitor RBH's progress towards meeting the standards, and take commissioning action if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and the original timetable set out in the standards. NHS England will expect the following:

- Strategic Outline Case prepared by the Trust, supported by NHS England and submitted for approval by 30 June 2018
- Outline Business Case prepared by the Trust, supported by NHS England and submitted for approval by 30 November 2019
- Full Business Case approved by 30 August 2021

Milestone- no later than	**Deliverable**	**Commissioner action if not delivered**	
		Trust required to produce, and agree with NHS England, a recovery plan.	**Referral to Specialised Services Commissioning Committee for decision whether to terminate the contract to provide level 1 CHD services.**
June 2018	Strategic Outline Case (SOC) prepared by the Trust, supported by NHS England, and submitted for approval.		SOC not submitted.
April 2019	Early priorities for joint working implemented.		

	Detailed plan to achieve full co-location for all inpatient paediatric specialist services.	Co-location plan not delivered.	Further slippage to delivery of co-location plan vs recovery plan.
November 2019	Outline Business Case (OBC) prepared by the Trust, supported by NHS England, and submitted for approval.		OBC not submitted.
August 2021	Full Business Case.		Approved FBC not delivered.
April 2022	Full co-location achieved for all inpatient paediatric specialist services.	Full co-location not achieved for all RBH paediatric specialist services.	Full co-location not achieved for all inpatient paediatric CHD care.

Newcastle Upon Tyne Hospitals NHS Foundation Trust

NHS England will further consider its commissioning approach for both the CHD and the heart transplant service at NUTH from March 2021 onwards, and will confirm its plans by no later than April 2019.

- NUTH will be required to develop and deliver a plan to increase surgical activity so that it has a team of at least three surgeons, each undertaking at least 125 operations per year, within the required timeframes, and specified milestones.
- NUTH will not be required to meet the 2019 deadline for full co-location for paediatric cardiac services but will be required to meet these standards, if NHS England confirms a plan to commission level CHD services beyond April 2021.

NHS England will monitor NUTH's progress towards meeting the standards, and take commissioning action if it becomes clear that the standards will not be met according to the timescale set out in the implementation schedule. These timescales are informed by the Trust's own plans and the original timetable set out in the standards.

Milestone- no later than	**Deliverable**	**Commissioner action if not delivered**	
		Trust required to produce, and agree with NHS England, a recovery plan.	**Referral to Specialised Services Commissioning Committee for decision whether to terminate the contract to provide level 1 CHD services.**
February 2018	Growth plan to increase surgical activity to at least 375 operations a year by 2019/20.	Plan not delivered.	Further slippage to delivery of plan vs recovery plan.
April 2019	NHS England to produce a commissioning plan for CHD services including advanced heart failure and heart transplant for children and adults with CHD.	n/a	n/a
April 2020	Surgical activity for the year 2019/20 at	Surgical activity less than 365.	Surgical activity is less than 356.

	least 375 operations.		
	Three surgeons undertaking at least 125 operations per year.	One or more surgeons undertook fewer than 125 operations in 2019/20.	Fewer than three surgeons in post.
To be confirmed if long term commissioning of level 1 CHD confirmed.	Full co-location achieved for paediatric cardiac services.		Full co-location not achieved for all inpatient paediatric CHD care.

NHS England
Congenital Heart Disease
Public Consultation
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05	7th September	Participate	Glossary added
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Contents

Introduction

Participate Ltd has been commissioned by NHS England to independently analyse and report upon the data from the **'Congenital Heart Disease Programme Consultation'**. The following summary report sets out the analysed and thematic data from the consultation that concluded in July 2017.

Context

Congenital Heart Disease (CHD) services have been the subject of a number of public inquiries and reviews, starting with Bristol in 2001. This level of scrutiny, over a 16-year period, has resulted in a national service which has had to contend with significant uncertainty, leading to difficulties in recruiting and retaining expert staff in some areas and causing concern for patients and their families.

In 2015, NHS England published new standards for CHD services. These standards – almost 200 for each of the paediatric and adult providers operating at level, 1, 2 and 3[1] – were collaboratively developed over a two-year period by: patients and their families/carers; clinicians; commissioners, and other experts. They were the subject of extensive public consultation, and all the views put forward about them were considered before the standards were finalized and agreed by the NHS England Board.

At the end of 2015, NHS England asked providers to assess themselves against a core set of standards – considered to be most closely and directly linked to measurable outcomes and to effective systems for monitoring and improving quality and safety – in order to assess where each provider was currently at, in terms of achieving the standards, and what plans they had in place to meet them within set time-frames. These were then considered by two independent panels - regional and national - made up of a wide range of experts, including clinicians, commissioners, quality leads and patient representatives.

[1] **Level 1**: Specialist surgical centres deliver the most highly complex diagnostics and care, including all surgery and interventional cardiology.
Level 2: Specialist cardiology centres provide the same level of medical care as Level 1 hospitals, but do not provide surgery or complex interventional cardiology.
Level 3: Local cardiology services are involved in diagnosis of CHD and provide routine and follow up care for patients with CHD particularly those with less complex problems.

The outcome of that exercise resulted in the findings in the national report, published by NHS England in July 2016.

No commissioning decisions have been taken about the future of any CHD services in England. NHS England has set proposals which it is 'minded' to take forward, based on the findings of the self-assessment exercise. These formed the basis of the public consultation.

Consultation Methodology

The consultation was hosted through the NHS England consultation hub and elicited a mix of qualitative data as well as quantitative data collected via an online survey.

The vast majority of responses were received electronically via the online survey and other responses were received via hard copy response forms, letter or email. All of the responses were processed i.e. reviewed and analysed.

Consultation activity included: two public question time style events in the two geographies where greatest service change was proposed and there was a high demand for places at events; three webinar meetings to allow potential respondents to seek clarification on the proposals – one of which focused on patients, families and carers of patients with learning difficulties; meetings were held in either hospitals or areas with CHD services – the audience being with patients, families, clinicians and interested members of the public and with staff directly impacted by the proposed changes; attendance at Local Authority Health Overview and Scrutiny Committees. Participants of all of these activities were asked to submit their views via the online survey, though notes were kept of the key themes that arose at meetings (see page 52).

During consultation there were targeted materials or events created for groups identified through equality analysis as potentially being differently impacted by the proposed changes:

- an online youth portal with animation was created for children and young people with CHD to enable them to contribute thoughts and opinions – in addition youth workers were at children and family events and used the online and other materials to work with children and young people (see page 56).
- consultation materials were provided in 5 languages (Urdu, Tamil, Gujarati, Hindi and Punjabi) for CHD patients and families from South Asian backgrounds, additionally all CHD clinicians were written to, to encourage patients of South Asian descent to contribute to the consultation and NHS England made the offer of translators where needed.
- an Easyread version of the consultation material was created for CHD patients and

families to enable those who did not wish or were unable to read full consultation materials. Advice from CHD specific learning disability charities was taken to ensure the Easyread version enabled as many people to interact with the consultation as possible; an online webinar meeting was held rather than a physical meeting for families of those with CHD and learning difficulties.

Approach to Analysis

The body of this report contains the detailed analysis and feedback from all responses received. The raw coded data and the full set of responses have been passed to NHS England for consideration within the decision-making process.

PLEASE NOTE: Some respondents may have answered the formal consultation survey and emailed a document/sent in letters, which mirror their response in some aspects. Therefore, we have analysed the emailed documents/letters using the same process, but have separated the data findings within this report to ensure that responses are not double counted.

Individual comments from letters/emails and to the open ended questions within the survey have been coded into key themes, which have been broken down in terms of frequency with which a comment is made in the analysis. This enables the most frequent themes to emerge. Please note that comments can be multi-coded for themes, which is why the frequencies add up to more than the number of responses i.e. one response may be coded more than once due to the number of themes it contains. It should also be noted that:

- Through cross tabulation of the data by region we have aimed to extract the findings by area
- Themes have also been extracted by specific stakeholder groups and these are outlined within the body of this report.

Standardised Responses

- It is apparent within the survey responses and within the letters/emails received that regional groups have formulated 'stock or standardised' responses in some instances, which contain very similar feedback about their local trust
- In fact both UHL and Royal Brompton encouraged respondents (via their website / members magazine) to complete the consultation survey in a specific manner in order to put forward the particular concerns held in regards to those trusts
- Therefore, where standardised responses have been identified we have coded the themes from these separately to ensure they do not overwhelm the feedback from other groups/respondents

- A total of 6 standardised response templates were received:
  - Question 4 - 25 responses relating to none of the units meeting all the standards but some will stay open – 71% Midlands and East, 8% London
  - Question 4 - 156 responses stating that the standards don't improve patient care and supporting Royal Brompton – 61% London, 21% South East and 8% East of England
  - Question 4 - 1,964 responses concerning inconsistency of application of standards for Newcastle and Southampton – 92% Midlands and East, 2% North West, 2% South East and 2% West Midlands
  - Question 13 - 151 responses stating that Royal Brompton is an internationally renowned centre for CHD research and highlighting the importance of the PICU for other conditions – 64% London, 17% South East England and 7% East of England
  - Question 14 - 19 responses relating to Professor Huon Gray's concerns about adequacy of the service and highlighting Glenfield's ECMO importance and the unfair retention of Newcastle – 89% Midlands and East and 11% East of England
  - Question 14 – 35 responses about the previous safe and sustainable review highlighting the excellent services at Royal Brompton with adult and children's services providing continuity and positive outcomes – 74% London, 11% South East and 9% South West.

A glossary of terms used within the feedback and analysis can be found at the end of this report.

Summary of Findings

The data sections within this report set out the analysis and feedback from each dialogue method including the: survey data; meeting notes; young person's survey and; the letters/emails received.

- The analysis from 7673 surveys
- Coding of 79 letters/emails
- Themes to have emerged from the consultation meetings
- Overall feedback from the 'Young People with CHD' survey report.

The overall themes which have emerged throughout these dialogue methods are outlined within the summary of findings section below. The themes have been placed under the relevant headings of the consultation questions/proposals.

PROPOSAL TO ONLY COMMISSION FROM PROVIDERS ABLE TO MEET THE STANDARDS

- The majority of survey respondents (86%) oppose the proposal that CHD services will only be commissioned from hospitals that are able to meet the full set of standards within set timeframes
- Clinicians and national organisations showed higher levels of agreement with the proposal, but point out that the implementation will require investment in additional resources which is extremely challenging in terms of recruitment and funding
- Impacts on other services such as dentistry, radiology and anaesthetics were highlighted by Royal Colleges who also questioned the effect on super regional services
- Most hospital Trusts that responded to the consultation disputed that the standards would lead to better outcomes
- The issue of co-location was also raised by all stakeholder categories, with some asserting that the benefits could be achieved through networks and partnership working and others emphasising the benefits of co-location
- In terms of feedback from the Midlands and East region, the main themes from the 70.6% of respondents were:
    - It is felt that Glenfield (UHL) is not being treated fairly or consistently in comparison to other sites
    - That the standards do not 'make sense' clinically or for patients

  - In the long term Glenfield (UHL) is set to 'meet the standards' in the future
- In terms of feedback for the London region, the main themes from the 7.8% of respondents were:
  - Patient outcomes should be the main focus
  - The Royal Brompton is well respected and meets all standards in partnership with Chelsea and Westminster
- In terms of feedback for the North East region, the main themes from the 1.7% of respondents were:
  - Newcastle has cutting edge facilities and should be kept
  - Standards should set out sensible guidelines and make patient sense
  - Standards are a good idea
- In terms of feedback for the North West region, the main themes from the 3.0% of respondents were:
  - Facilities need to be local to avoid risk to patients including death
  - Think about the effect on families having to travel and quality of life
  - Retain the excellent services at Manchester
- In terms of feedback for Northern Ireland, the main themes from the 0.0% (only 2 responses) of respondents were:
  - Northern Ireland patients are having to travel to England for treatment
  - Timeframes for referrals are important along with bed availability
- In terms of feedback for Scotland, the main themes from the 0.2% of respondents were:
  - Standards are being used to make the case for closure
- In terms of feedback for the South East and South West regions, the main themes from the 6.0% of respondents were:
  - Royal Brompton provides excellent service and should be retained
  - Insisting on co-location would not lead to improvement
- In terms of feedback for Wales, the main themes from the 5.2% of respondents were:
  - Newcastle does not meet the standards and is unlikely to do so in future
  - More consideration should be given to diverting cases to Glenfield
- Overall the impact on children and families was asked to be considered in terms of travel times and there needs to be specific consideration of services for children and babies.

VIABLE ACTIONS TO HELP MANCHESTER, ROYAL BROMPTON AND LEICESTER TO MEET LEVEL 1 STANDARDS

- The following sets out the main themes to have emerged from responses in relation to the request for viable actions which could help the trusts meet the standards
- In relation to UHL (University Hospitals of Leicester NHS Trust) these include:
    - Support UHL in relationships with network referring hospitals
    - All patients should be given the choice of Glenfield (UHL)
    - Analyse the referral process and procedures
    - Support care close to home
    - Include patient feedback in Key Performance Indicators and Care Quality Commission (CQC) inspection reports
    - Assess effect of Extra Corporeal Membrane Oxygenation (ECMO) on Paediatric Intensive Care Unit (PICU) viability (perception that the units are unsustainable without CHD services)
    - Increase PICU beds for ECMO
    - Delay decision until the results of the PICU review
    - Assess patient numbers independently (not based on the closure of other units).
    - University Hospitals of Leicester also provided a detailed response which suggested:
        - UHL provides excellent standards of care and support the overall NHSE standards approach
        - The only outstanding standard is case numbers and UHL submitted a more comprehensive growth plan to demonstrate how these numbers can be achieved which NHSE should accept
        - UHL growth plan does not rely on any other centre to close
        - NHSE should support UHL to further develop their regional network and remove uncertainty which affects referrals
        - NHSE should acknowledge that decommissioning would substantially reduce patient choice and increase risk
        - UHL demonstrates good outcomes (CQC, mortality rate, patient satisfaction) with higher caseloads than historical Bristol level
        - Standards are aspirational and were not developed to decide closures
        - There is a shortage of specialist staff which uncertainty has made worse, particularly with funding issues and the impact of Brexit

        - Co-located adult and children's CHD services leads to better transition and better patient outcomes
        - Where does the finance come from to replace this capacity
        - There is insufficient evidence to support the 125 cases per surgeon standard and all the units would be considered large or very large by international standards
        - Leicester should be given the same opportunity as Newcastle as the ECMO service is as important as their transplant service
        - Meeting the volume standard over 3 years should not be measured retrospectively
- In relation to the Royal Brompton & Harefield NHS Foundation Trust, these include:
    - Challenge the co-location standard and instead encourage collaborative working
    - Re-assess the validity of standards against clinical outcomes
    - Closure would lead to extra pressure on the system and clinical shortcomings especially for children with CHD
    - Royal Brompton also provided a detailed response which suggested:
        - Without CHD Level 1, PICU services could not be sustained at RBH reducing capacity by 16 beds and 687 admissions
        - Without PICU, no paediatric congenital procedures could take place, all cardiac intensive care support for children including ECMO support would cease
        - The Trust would not be able to operate as a level 2 cardiac centre
        - The Trust's 8 bedded Level 2 paediatric high dependency service would be discontinued
        - Without a surgical facility, interventional cardiology or immediate access to intensive care, other services would become untenable
        - Retention of the outpatient or diagnostic service would be unrealistic for patients and their families
        - RBH has the largest fetal service in the country and high early CHD detection rates
        - A range of paediatric and adult respiratory services would be lost. E.g. Cystic Fibrosis, difficult asthma
        - Many staff work across both adult and paediatrics and are highly trained in the management of CHD and respiratory disease. It is likely they

would seek to leave adding to the impact of Brexit. Estimation of 90% of staff currently employed transferring to other units is optimistic. Many will leave or move abroad. This will impact patient care elsewhere

- World leading research supported by Imperial College would be severely impacted together with medical training and education
- RBH has amongst the best patient outcomes in the country with a 30 day survival rate of 99%and patient satisfaction ratings of 98%. There is no evidence as to how these proposals will improve the excellent service currently provided
- No evidence to suggest that any detailed plan has been considered to transfer services and patients. Where are all the thousands of patients at RBH going to be treated and can receiving institutions provide enough staff and beds
- RBH has been recommissioned to provide ECMO as part of the National ECMO Network
- Only reason for closure is non-compliance with co-location standard:
  - Just 1 of 470 new CHD standards
  - NHSE state every unit failed at least 1 standard – why is this the most important?
  - NHSE changed the standard from "within 30 minutes"
  - Standard is achieved in partnership with Chelsea and Westminster Hospital which is closer than many same site co-located hospitals
  - Fewer than 1% of emergency paediatric CHD patients at RBH need other specialist paediatric services.
- RBH provides a seamless transition from children to adult CHD – more important than the link between paediatric CHD and other paediatric services

- Royal Brompton also presented an alternative high level proposal in partnership with Kings Health Partners for how meeting the standards might be achieved. The key points were:
  - Work together as a single service in partnership with other leading centres in regional networks across fetal, neonatal, children's and adult services in a nationally sustainable service for CHD with over 9,000 outpatient visits at 30 locations in London, home counties and south east

- A new joint Guys and St Thomas's and Royal Brompton CHD service, training and developing a multi-disciplinary workforce for CHD. This will support new models of care, new technologies and personalised medical care. A major contribution to workforce strategy for a post Brexit UK including the intention to join with other KHP partners in South London Genomic Medical Centre bid.
- Intention to develop state of the art facilities for patients of all ages requiring specialist heart and lung treatments on the Westminster Bridge campus.
- Bringing together various teams to provide an ideal platform to deliver high quality paediatric and adult sub specialised surgery consolidating expertise through critical mass and scale. Numerous sub specialist areas of ACHD care have the potential to be significantly strengthened and the co-location of services for inherited and acquired cardiac disease will allow CHD patients to benefit for advances in other areas. Co-location of paediatric services on the same site as adult and other related services (maternity, fetal) provides for the best of all linkages and equality of access to services
- Training and education benefits from the combined scale including the development of national practitioner curriculum and benefits of scales for training programmes and rotations in a resource limited environment. The relationship between the Evelina/Guys and St Thomas's (national training programmes) and Royal Brompton (international training) provides for a joint team with the ability to be leaders in this field
- These services would be combined into a single CHD service enabling benefits of standardisation of protocols for both the specialist centre and the wider networks served. Developing standard protocols, pathways, joint leadership and governance processes would be a priority for implementation before April 2019
- Royal Brompton's CHD service in collaboration with Imperial College has the largest ACHD research output in the world. Bringing together the whole spectrum of CHD care in an environment including a wide range of non-cardiac specialists provides the optimal setting and academic support to deliver a comprehensive research strategy. In addition Kings Health Partners (KHP) in partnership with the Kings College London (KCL) has just established the new KCL Academic Institute for Children. This scale would attract the best talent and allow for sub specialities and be attractive to commercial and research partners providing sustainable models of funding

  - A commitment to work in partnership with patients and families to co-design services in order to ensure that their needs are central to provision
  - There is an established transition programme in place between the teams and the nurse-led model at clinics is highly successful. Transition services would be strengthened through increase in scale together with the established high quality psychological services.
  - For ACHD, the coming together of two successful high risk pregnancy services would raise the delivery of care to a higher level, creating a potentially world leading service. London does not have a service combining a designated pulmonary hypertension centre, a high risk cardiac obstetric team, on onsite neonatal unit and onsite maternity care.
  - The proposed model provides continuity of care from ante-natal through to adulthood on an acute campus with all the interdependent services. Working through care pathways for patients referred by local centres will continue together with partnership working with broader, world leading services in Kings Health Partners.
  - The model will provide strengths of existing services for palliative, bereavement care and dental care
  - Non CHD specialist heart and lung patients, including PICU, will benefit from the development of a world leading cardiovascular and respiratory health system.
- Central Manchester University Hospitals NHS Foundation Trust provided a detailed response which included:
  - Supporting evidence based standards to drive quality and safety of patient care
  - Concerns about the limitations of the proposed compliance based approach and possible failure to optimise configuration of future services in North West England
  - Need to adopt a more strategic approach for services like CHD with gap analysis of the proposed model against existing services, especially geographical locations
  - Options for service change should have been presented to the public for consultation
  - Development of transition and implementation plans
  - The focus on a few surgical standards has missed the opportunity to deliver networks that provide care across the full spectrum of CHD

  - Delivery of Level 2 services in Manchester cannot be achieved in isolation from the network and must have a formal link and active support from a Level 1 centre and commissioners
  - Keen to ensure that patient pathways are optimised
  - Although not in favour of the proposed approach, the Trust will as far as possible ensure that unintended consequences are mitigated
  - Would like to agree the clinical model for the North West in order to provide certainty for patients and staff
- Other suggestions to improve CHD services in Manchester included
  - Cross location working in Liverpool and Manchester will deliver better results
  - Increase the surgical rota
  - Train more medical staff locally
  - Share best practice and regional facilities

VIEWS AND SUPPORT FOR CENTRAL MANCHESTER AND LEICESTER PROVIDING LEVEL 2 SERVICES

- In terms of the survey, respondents mainly neither supported nor opposed the proposal to seek Level 2 services from Manchester and Leicester if they do not provide Level 1
- The findings from the qualitative data infer that most respondents feel that Level 1 services should be retained at the two sites, with outreach clinics at Level 2 and 3 being provided
- Devolved NHS administrations felt that it was important to take into account the views of their residents who are treated in England
- There were also comments that Manchester and Leicester should not be linked within this question as they are in two different regions, with Leicester's situation being different as they are without any other local unit.

VIEWS AND SUPPORT FOR ROYAL BROMPTON PROVIDING ADULT ONLY LEVEL 1 SERVICE

- There were strong levels of disagreement from respondents from the London region that the Royal Brompton should provide an adult only Level 1 service
- Concerns were raised that best practice learning from co-location of child and adult services should be considered along with the potential impact upon pregnant women.
- Most hospital Trusts that responded to the consultation felt that the co-location standard should be within 30 minutes and Royal Brompton achieves this in partnership with Chelsea and Westminster Hospital.

VIEWS AND SUPPORT FOR ALLOWING NEWCASTLE MORE TIME TO MEET THE LEVEL 1 STANDARDS

- There were strong levels of opposition with the proposal that Newcastle continues to provide a Level 1 service within different timeframes
- However, the majority of these were from the Midlands & East region which aligns with the qualitative comments from those respondents that Newcastle is perceived to be given 'special treatment,' when all standards should be applied 'fairly'
- There was however, stronger clinical support that Newcastle should continue working in a different timeframe as it provides the full range of paediatric cardiology services and is a transplant centre
- Concerns were raised by Children's Heart Charities that the future retirement of a leading surgeon and discontinuing the service for Ireland would adversely affect Newcastle.

VIEWS & SUPPORT FOR THE ASSESSMENT OF THE IMPACT ON TRAVEL OF THE PROPOSALS

- The assessment of the impact upon travel was seen as inaccurate overall within the responses received. This was a particularly prevalent view in relation to current patients at University Hospitals of Leicester travelling to Birmingham.
- Clinicians and respondents from the London area demonstrated higher levels of agreement that the assessment was accurate
- Respondents from Wales asked that consideration be given to the fact that they travel into England to use CHD services
- It was felt that travel data should be published to allow external analysis

- It was stated that travel times seemed to be based upon car journeys only and there is a need to consider public transport times
- A risk assessment was requested on the potential impact of extended travel times
- A lack of public transport and especially from rural locations was asked to be considered
- The cost of additional transport was questioned and whether patients/carers would be compensated for longer journeys
- It was felt that there is the need to consider the likely stress of increased travel times for families
- Commissioning more Level 2 and 3 services closer to home was suggested
- Grouping appointments and holding more remote/digital appointments were also suggested as ways in which to avoid longer travel times
- Public representatives felt a more detailed model of the potential impacts is required to mitigate risks and ensure continuity of patient care
- A small minority felt that health benefits would outweigh any travel difficulties and that CHD patients are already travelling long distances.

VIEWS ON AND SUPPORT FOR THE ASSESSMENT OF THE IMPACT ON EQUALITIES AND HEALTH INEQUALITIES OF THE PROPOSALS

- The assessment of equality and health inequality impacts was perceived to be inaccurate overall throughout the responses
- In terms of the impact upon the South Asian communities, it should be noted that 88% of those responding within the survey with this ethnic background were from the Midlands & East region. Therefore, most comments mainly reflected the regional feedback for the Leicester area and the feeling that the potential loss of CHD services would unfairly impact upon the large South Asian community in that area. It was also stated that a greater understanding of CHD within the Black, Asian and Minority Ethnic (BAME) community is required
- It was felt that there is a need to consider language barriers, where English is not the first language for patients and where there may be the potential loss of support staff that can speak other languages (especially in the Leicester area)
- In terms of religious beliefs it was felt that patients need help to heal emotionally and spiritually, which can be achieved with good, local medical care and linking into families

- It was stated that non-British families would suffer inequality as they are less likely to have a family support network to support parents and siblings
- Younger people were mainly concerned about losing their local services and the impact this could potentially have on their families/parents in terms of travel. They were also concerned about losing their established relationships with clinicians and the transition from child to adult services
- It was felt that as CHD is a life-long condition it requires regular check-ups and interventions, meaning that longer journey times have a big impact upon families/carers and that a network of local outreach clinics are needed
- Social deprivation was also asked to be considered and the health inequalities between communities
- There was a call to consider the impact upon patients with other medical problems/disabilities, including those with learning difficulties
- A full Equality Impact Analysis (EQIA) was also requested (although it was provided with the consultation document).

VIEWS AND SUPPORT FOR THE DESCRIPTION OF THE IMPACTS OF THE PROPOSALS ON OTHER SERVICES

- Overall it was felt by the respondents that the description of other known impacts is not accurate
- It was reaffirmed that there are concerns regarding the potential loss of ECMO in Leicester and that it is seen as a centre of excellence. The potential impact on an already short supply of PICU beds is also a concern
- Respondents also stated that the Royal Brompton is recognised as a world leading centre for research into adult CHD and if it were to close, the UK would potentially lose its recognition in this field and it would have a detrimental impact on patients. It was also stated that there would be perceived impacts on an already short supply of PICU beds and on children's respiratory care and research
- Other considerations not already mentioned included: how will it be possible to achieve outreach clinics across large regions; would cardiac liaison nurses be able to offer a local approach and; what would be the potential impact on fetal medicine.
- There were concerns raised about the impact on the national PICU capacity as a knock-on-effect of the closure of CHD services at Royal Brompton and Leicester. This

concern related to the potential closure of these PICUs as they are heavily CHD dependent

- It was stated that last winter the severe shortage of PICU beds led to some elective surgery being cancelled
- Comments were made that for two weeks there was no spare PICU capacity
- It was also inferred that PICU beds are constantly full with the only empty beds available to transfer patients being in Scotland or France

The analysis of feedback per dialogue method, which has enabled the extrapolation of the summarised themes, now follows within the body of this report.

Survey Data Feedback

The following section sets out the analysis of the survey data collated from the Congenital Heart Disease consultation survey. In total there were 7673 responses to the survey. The full responses have been shared with NHS England, to inform the decision-making process.

Q1 In what capacity are you responding?

Table 1 – In what capacity are you responding?		
Response	**Total %**	**Number of Responses**
Member of the public	**44%**	**3381**
Other	**35 %**	**2695**
Other - Advocate / on behalf of	32%	2472
Other – Family	1%	67
Other - NHS staff	1%	62
Other – Patient	0%	30
Other - Not stated	0%	30
Other - Stakeholder (MP, Patient Groups, Councils etc)	0%	17
Other – Public	0%	10
Other – Volunteer	0%	3
Other - Retired NHS Staff	0%	2
Other – Academic	0%	2
Parent, family member or carer of current CHD patient	**11%**	**872**
Clinician	**4%**	**324**
Current CHD patient	**4%**	**297**
NHS provider organisation	**1%**	**54**
Voluntary organisation / charity	**0%**	**28**
Other Public Body	**0%**	**7**
NHS Commissioner	**0%**	**6**
CHD Patient Representative	**0%**	**5**
Industry	**0%**	**4**
Total (base 7673 responses)	**100%**	**7673**

It should be noted that the percentages have been rounded, which is why there are a number of respondent categories at 0% when in fact there were responses from these stakeholder types. All responses have been analysed and coded for themes from every stakeholder type.

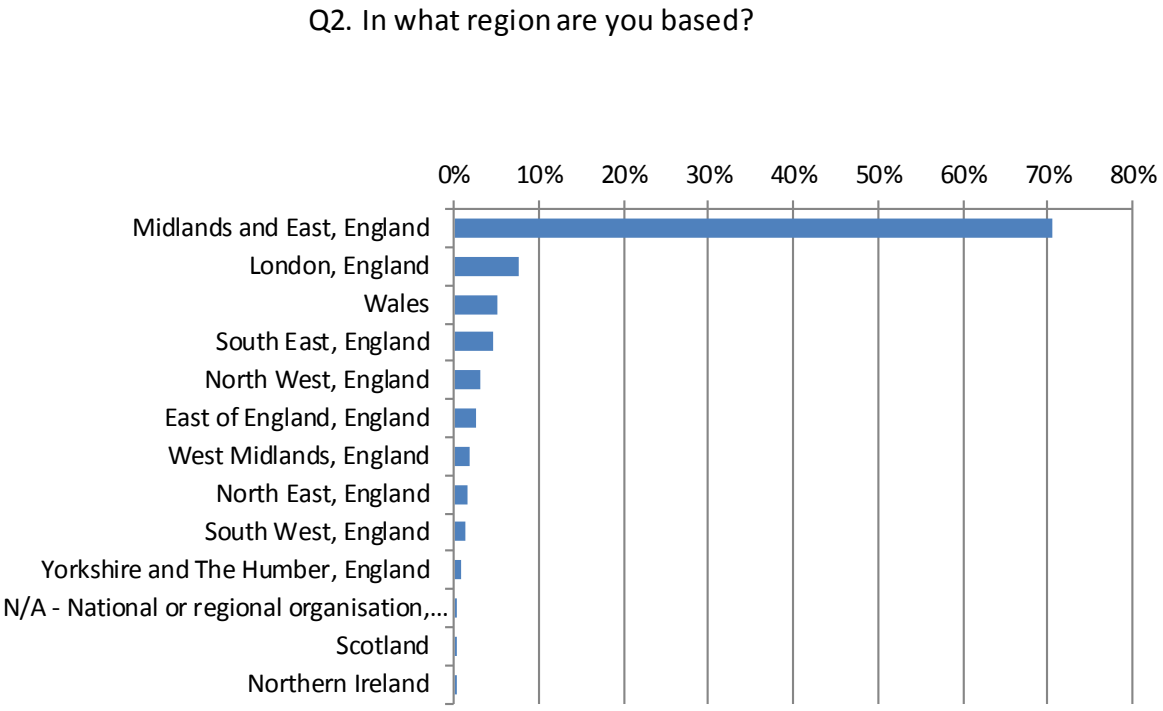
It is apparent that the majority of the responses are from members of the public and those categorised as 'other'. Data has been analysed according to how respondents self-categorised, although some respondents categorising as "other" would fit into different specified categories.

The 'other' category can be broken down as follows:

- Advocate or on behalf of another (2,472 = 92% of other, 32% of all respondents);
- Family of CHD Patient (67 = 2% of other, less than 1% of all respondents);
- NHS Staff (62 = 2% of other, less than 1% of all respondents);
- Patient (30 = 1% of other, less than 1% of all respondents);
- Not stated (30 = 1% of other, less than 1% of all respondents);
- Stakeholder - MP, Patient Groups, Councils etc (17 = less than 1% of other and all respondents);
- Public (10 = less than 1% of other and all respondents);
- Volunteer (3 = less than 1% of other and all respondents);
- Retired NHS Staff (2 = less than 1% of other and all respondents) and
- Academic (2 = less than 1% of other and all respondents).

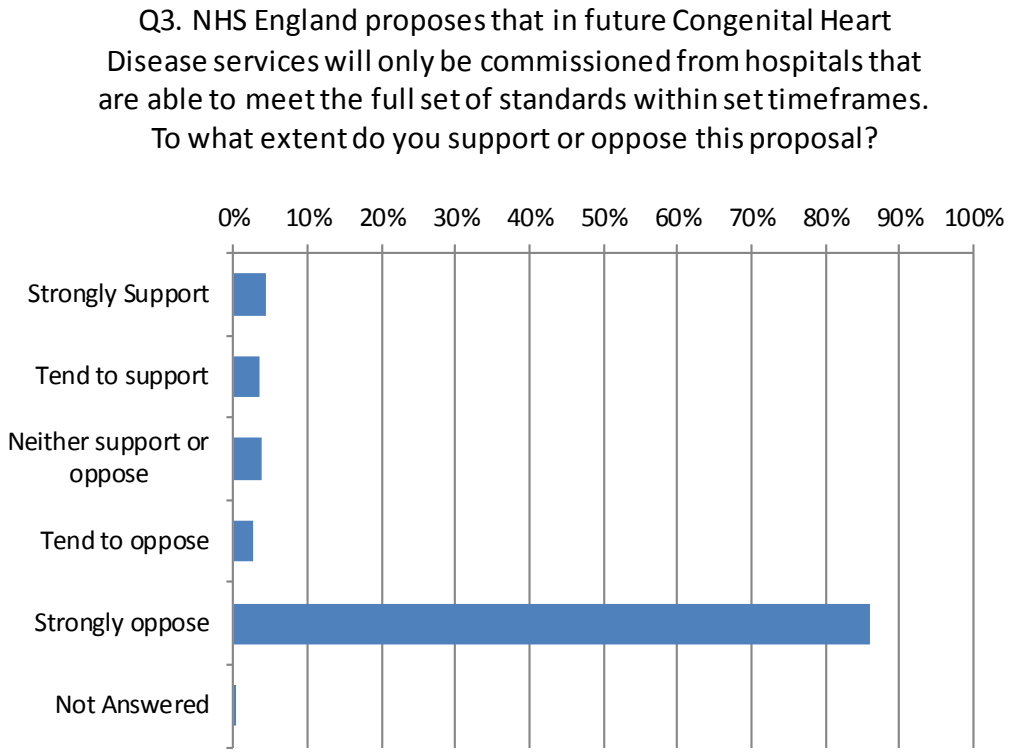
It should also be noted that the responses categorised as 'NHS Provider' are not necessarily the response that represents the views of that organisation, as they are mixed with personal/individual responses from staff who work for that particular provider.

Q2 – In what region are you based?



Q2 chart above demonstrates that the majority of the responses (71% of 7673 responses) are from the Midlands and East region. This finding means that the themes, which have emerged from the open-ended questions, have a strong regional slant towards the perceived impact on services in the Midlands and East region. However, by cross tabulating the themes by region we have drawn out specific differences by area.

Q3 - NHS England proposes that in future Congenital Heart Disease services will only be commissioned from hospitals that are able to meet the full set of standards within set timeframes. To what extent do you support or oppose this proposal?



The majority (86%) of survey respondents strongly oppose the proposal that CHD services will only be commissioned from hospitals that are able to meet the full set of standards within set timeframes. This analysis has been cross tabulated against the regional profiling and it infers that the strength of opposition runs across all regions. Those responses that represent national organisations demonstrate higher levels of support (although it should be noted that they count for less than 1% of the responses). Clinicians also showed higher levels of support (19% strongly support / 10% tend to support of all clinician responses).

Q4. Please explain your response to question 3

Table 6 – Q4 comments coded for themes	
Response	**Total**
Treat all centres fairly / consistently	**34%**
Inconsistency in applying standards	**29%**
Standard Response C: I have signed a document to authorise the submission of the following statements electronically on my behalf and my postcode is xxxx • NHS England is not only commissioning from hospitals that meet the standards • No Hospital meets all the standards • Inconsistency – Newcastle is being allowed more time to achieve the standards and is unlikely to ever do so • Southampton cannot meet the standards without cases from London being diverted due to the proposals being implemented	**26%**
Newcastle does not / will not meet the standards / given more time	**18%**
Standards must make clinical and patient sense	**14%**
No hospital meets all the standards / None would be commissioned	**14%**
None	**11%**
More consideration should be given to Glenfield (UHL) / divert cases here / world class ECMO / set to meet standards in 2018	**11%**
All hospitals should be given the same time to achieve standards	**10%**
Patient outcomes should be the ultimate goal and this is being ignored in the current plans	**10%**
Standards are being used to make the case for closure	**10%**
Needs to be local / risk of death in emergency	**7%**
The Royal Brompton provides excellent service and should be retained	**6%**
Consider the effect on quality of life for family having to travel	**4%**
Southampton cannot meet the standards without diverted cases	**4%**
ECMO / PICU and transplant centres should not be unfairly penalised	**4%**
A good idea	**4%**
Insisting on physical co-location would not improve things for patients / worse outcomes	**3%**
Physical co-location should not be the decisive factor in closing a CHD unit	**3%**
The standards set out sensible guidelines	**3%**
Need more finance / support for current services	**3%**
Patients are being diverted to other hospitals to make the case for closure	**3%**
Royal Brompton does meet all the standards in partnership with Chelsea and Westminster Hospital	**2%**
Standard Response B: I disagree with this proposal because it puts the focus on the standards themselves, instead of the impact they have on patient care. The standards only mention the resources available at each hospital, they ignore the outcome achieved. • For example, NHS England says that the 'co-location' standard is needed to make sure that: 1) Different services involved in CHD care work well together 2) All services can be at the patient's bedside within 30 minutes • In the case of Royal Brompton the CHD service already achieves both of these outcomes.	**2%**

Table 6 – Q4 comments coded for themes	
Response	**Total**
• There is no evidence showing that other trusts that are rated as meeting the co-location standard have better response times, teamwork, care quality or patient outcomes than the Royal Brompton. • NHS England has not explained specifically what is better at so-called 'co-located trusts' that isn't already happening at the Royal Brompton. • There is no reason to believe that meeting this "standard" would make things any better for patients. The deciding factor should always be the impact on patients. • The entire proposal is misleading/unattainable. For example, Newcastle will never be able to meet the full set of standards as they currently stand.	
Where is the evidence base that more operations make surgeons better / why the volume standard	**2%**
Timeframes for referrals are important / bed availability	**2%**
All hospitals should provide CHD services	**1%**
Need access to a facility that is safe and successful	**1%**
Should create centres of excellence	**1%**
Leicester provides specialist services for babies and children / excellent services	**1%**
Outcomes are better in specialist units	**1%**
Specialist staff Issues / would not move and would be lost	**1%**
A patient should have access to full treatment	**1%**
Strong evidence base for the proposals	**1%**
Excellent service should be retained at Manchester Royal Infirmary	**1%**
Newcastle has cutting edge facilities and should be kept	**0%**
There is a strong and established service available in Leicester	**0%**
Standard Response A: Completing for another person Postcode Strongly oppose as none of the units are meeting all the standards but some will stay open despite not meeting all the standards	**0%**
Insufficient knowledge of the standards	**0%**
Lack of a detailed implementation plan	**0%**
Poor service and advice given	**0%**
Will lead to privatisation of the service	**0%**
Too much money spent on reviews	**0%**
Keep Leeds hospital open	**0%**
Northern Ireland patients are having to travel to England for treatment	**0%**
Total	**100%**

Table 6 outlines the range of themes to have emerged from the survey comments relating to Q4, whether or not respondents support or oppose the proposal set out by NHS England. Please note that themes which state 0% refer to those themes that emerged less than 1% out of all responses, but were still apparent. It should be noted that the most common themes emerge from responses from the Midlands and East region as 71% of all responses are from that area. Cross tabulation of the themes by region enables the analysis to draw out conclusions by area.

The themes relating to Midlands and East are as follows: it is felt that Glenfield (UHL) is not being treated fairly or consistently in terms of the standards being applied in comparison to other sites; the site in Newcastle has been referred to in terms of a perception that it is being given additional time to meet the standards as it is a transplant centre; Southampton has been referenced as only being sustainable because cases are diverted to it; that the standards do not make sense clinically or for patients and; that Glenfield (UHL) is set to meet the standards in 2018.

There are also strong themes relating to services at the Royal Brompton and the London area which are as follows: patient outcomes should be the focus rather than the resources available; a perception that insisting on physical co-location of services would not improve outcomes for patients and should not be the decisive factor on closing a CHD unit; the Royal Brompton is seen to deliver an excellent service and; the Royal Brompton does meet all standards in partnership with Chelsea and Westminster hospital.

In terms of the Manchester area, the key themes to emerge were: a local service is required; Manchester Infirmary is seen to provide an excellent service and; there are issues in retaining specialist staff.

Overall, other themes to have emerged include: there is a need to consider the quality of life for families and travel times; more financial support is required for services; ECMO/PICU and transplant centres should not be unfairly penalised and; there needs to be consideration of services specifically for children and babies.

Q5 - Three hospital trusts have been assessed as not able to fully meet the standards within set timeframes. NHS England proposes that surgical (level 1) services are no longer commissioned from these trusts: - Can you think of any viable actions that could be taken to support one or more of these trusts to meet the standards within the set timeframes?

Table 7 – can you think of any viable actions that could be taken to support one or more of these trusts to meet the standards within the set timeframes?	
Response	**Total**
Apply the standards fairly / treat centres equally	**45%**
SUPPORT UHL in relationships with Network Referring Hospitals	**23%**
Work with local provider to support growth plan and network referrals	**17%**
None	**15%**
All hospitals should be given the same time / support to achieve standards	**15%**
Analyse referral process and procedures	**13%**
All patients in East Midlands / England should be offered the choice of Glenfield (UHL)	**11%**
See what EMCH does for yourself - Talk to patients, family and staff	**8%**
It is suggested that Royal Brompton does meet the standards. The one standard that is challenged is the co-location standard	**8%**
Re-assess the validity of the standards / clinical outcomes	**7%**
Provide more funding / employ more staff	**6%**
Support care close to home	**5%**
Newcastle does not / will not meet the standards / given more time	**4%**
Include patient feedback in KPI's / CQC	**3%**
Assess effect of ECMO on PICU and increase PICU beds for both ECMO and surgical / delay until results of PICU review	**3%**
Recognise areas of expertise	**3%**
Remove the cloud of uncertainty over planned closures	**2%**
Assess patient numbers independently - not based on closure of other units	**2%**
Share best practice and regional facilities	**2%**
Encourage collaborative working with hospitals	**2%**
Provide a detailed action plan	**2%**
Better communication about success / rationale	**1%**
Standards should not be applied retrospectively	**1%**
Investigate why the system is failing	**1%**
Closure of Brompton would add extra pressure and lead to clinical shortcomings especially for children CHD	**1%**
Train more medical staff locally to allow more developed specialisms	**1%**
Don’t know	**1%**
Some retained centres meet fewer standards than those set to close	**1%**
A team of experienced CHD staff from hospitals which do meet the criteria could help those failing to reach the acceptable levels	**1%**
Don't close Manchester	**0%**
Cross location working in Liverpool and Manchester will deliver better results	**0%**
Don't see how Newcastle can meet the standards	**0%**

Table 7 – can you think of any viable actions that could be taken to support one or more of these trusts to meet the standards within the set timeframes?	
Response	**Total**
In the consultation document, NHS England states that none of the centres currently meet all of the standards.	**0%**
Don't see how Leicester can meet the standards	**0%**
Limit the number to 500 and spread additional cases	**0%**
Move children's surgery from Liverpool to Manchester	**0%**
Increase surgical rota in Manchester	**0%**
Poor clinical care at Manchester	**0%**
There is no defined pathway to support the care of ACHD patients who require non-cardiac surgery	**0%**
Extension to ward 30 will help Leicester meet standards	**0%**
Encourage healthy lifestyle	**0%**
Each trust should appoint a local celebrity champion	**0%**
Total	**100%**

Table 7 outlines the range of themes to have emerged from survey comments relating to Q5, asking for viable actions which could help one or more of the Trusts to meet the standards. Please note that themes which state 0% refer to those themes that emerged less than 1% out of all responses, but were still apparent. Cross tabulation of the themes by region enables the analysis to draw out conclusions by area.

In terms of comments relating to UHL (University Hospitals of Leicester NHS Trust) the most common themes were: apply the standards fairly and with consistency; support UHL in relationships with network of referring hospitals; work with the local provider to support growth plans and network referrals; all patients in that area should be given the choice of Glenfield (UHL); analyse the referral process and procedures; talk to the patients, family and staff at EMCHC/Glenfield (UHL) (East Midlands Congenital Heart Centre) about what they do; support care close to home; include patient feedback in KPIs and CQC; assess effect of ECMO on PICU and increase PICU beds for both ECMO and surgical / delay until results of PICU review and; assess patient numbers independently not based on the closure of other units.

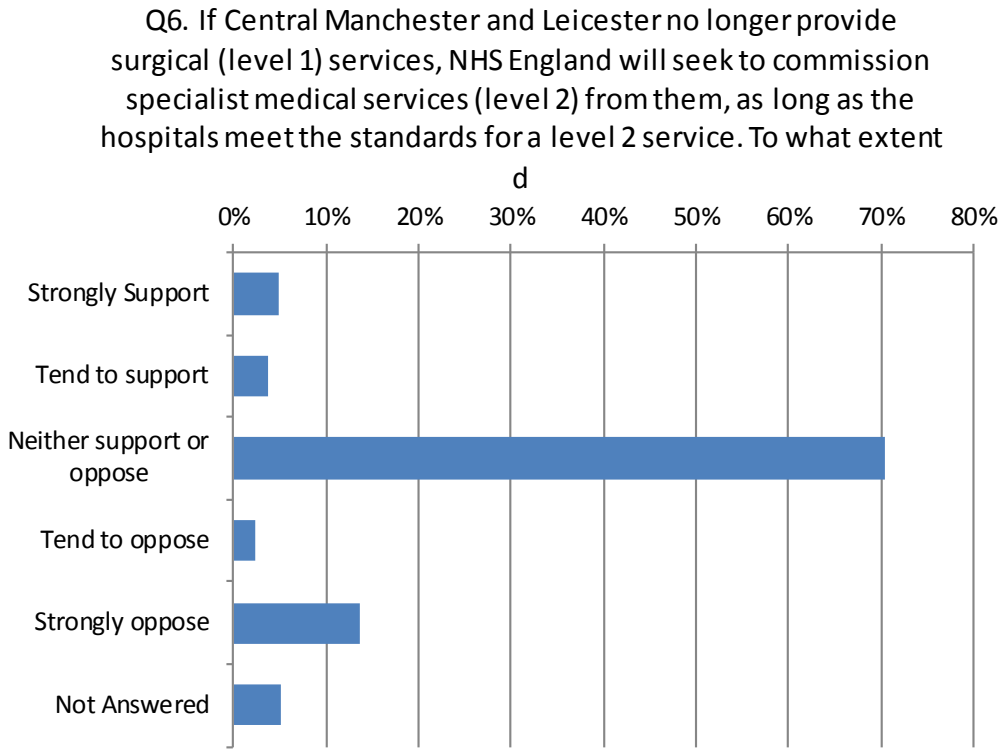
In terms of feedback from the London area in relation to Royal Brompton & Harefield NHS Foundation Trust, the most common themes include: the co-location standard is challenged as by working in partnership it meets all standards; there is a call to re-assess the validity of the standards against clinical outcomes; encourage collaborative working between hospitals

and; closure of the Brompton would add extra pressure and lead to clinical shortcomings especially for children with CHD.

In relation to Central Manchester University Hospitals NHS Foundation Trust, the most common themes to emerge were: cross location working in Liverpool and Manchester will deliver better results; need to employ more staff and increase funding; move children's services from Liverpool to Manchester; increase the surgical rota; train more medical staff locally to allow more developed specialisms and; share best practice and regional facilities.

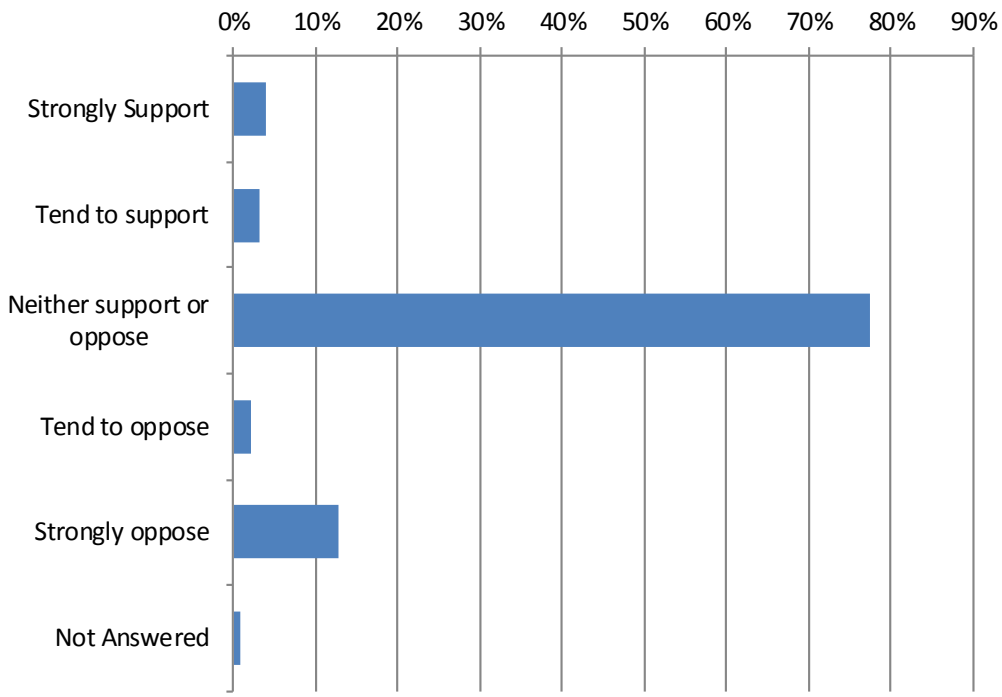
It should be noted that there is commonality of themes across all regions in terms of focusing upon patient outcomes, sharing resources and training local staff.

Q6 - If Central Manchester and Leicester no longer provide surgical (level 1) services, NHS England will seek to commission specialist medical services (level 2) from them, as long as the hospitals meet the standards for a level 2 service. To what extent do you support or oppose this proposal?



Q6 chart demonstrates that the majority (71%) of respondents neither support nor oppose the proposal to seek level 2 services from Manchester and Leicester if they do not provide level 1, with 14% strongly opposing. It should be noted that there was not a regional slant to the responses in this section, other than a larger proportion (36% of 596) of London area responses did not answer this question.

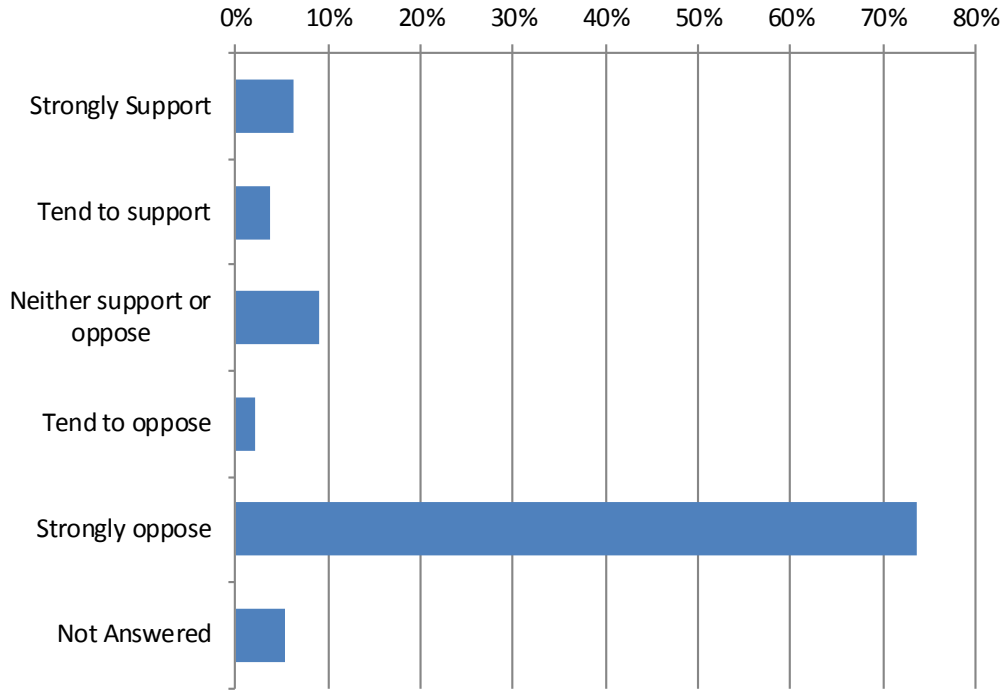
Q7 - The Royal Brompton could meet the standards for providing surgical (level 1) services for adults by working in partnership with another hospital that provides surgical (level 1) services for children. As an alternative to decommissioning the adult services, NHS England would like to support this way of working. To what extent do you support or oppose the proposal that the Royal Brompton provide an adult only (level 1) service?



Although Q7 Chart demonstrates that 77% of responses neither support nor oppose proposals that the Royal Brompton provide an adult only (level 1) service, it should be noted that most of those responses are from outside of the London region. The findings show that 13% of all responses strongly oppose this proposal, however, this accounts for 70% (420 out of 596) of all responses from the London area. This infers that there are strong levels of disagreement with this proposal in the London region near to the Royal Brompton.

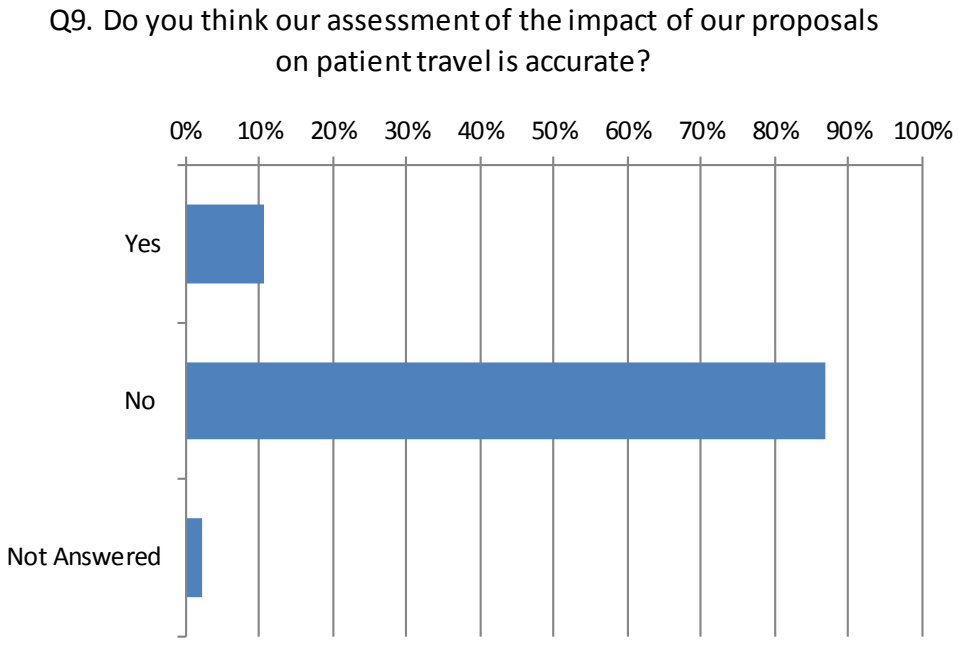
Q8 - NHS England is proposing to continue to commission surgical (level 1) services from Newcastle Upon Tyne Hospitals NHS Foundation Trust, whilst working with them to deliver the standards within a different timeframe. To what extent do you support or oppose this proposal?

Q8. NHS England is proposing to continue to commission surgical (level 1) services from Newcastle Upon Tyne Hospitals NHS Foundation Trust, whilst working with them to deliver the standards within a different timeframe.



Q8 Chart demonstrates that the majority (74%) of all responses oppose the proposal to continue level 1 services at Newcastle whilst working with them to deliver standards within a different timeframe. Most of those responses which oppose this proposal represent the East or Midlands regions (87% of 5657 responses which strongly oppose), which aligns with the qualitative comments that Newcastle is perceived to be given 'special treatment' and that all standards/timeframes should be applied consistently. The 10% of responses which either strongly support or tend to support, are spread across all regions but with a stronger emphasis towards the North East (109 out of 133 North East responses).

Q9 - Do you think our assessment of the impact of our proposals on patient travel is accurate?



Q9 Chart demonstrates that the majority (87%) of respondents feel that the assessment of the impact of the proposals on patient travel is not accurate. In terms of the respondents that felt the impact on patient travel is accurate, these were more strongly from the London area and the South East. Interestingly a higher percentage of clinicians and CHD patients (in comparison to other stakeholder types) felt that the assessment of the impact is accurate (44% of clinicians and 43% of CHD patients that responded).

Q10 - What more might be done to avoid, reduce or compensate for longer journeys where these occur?

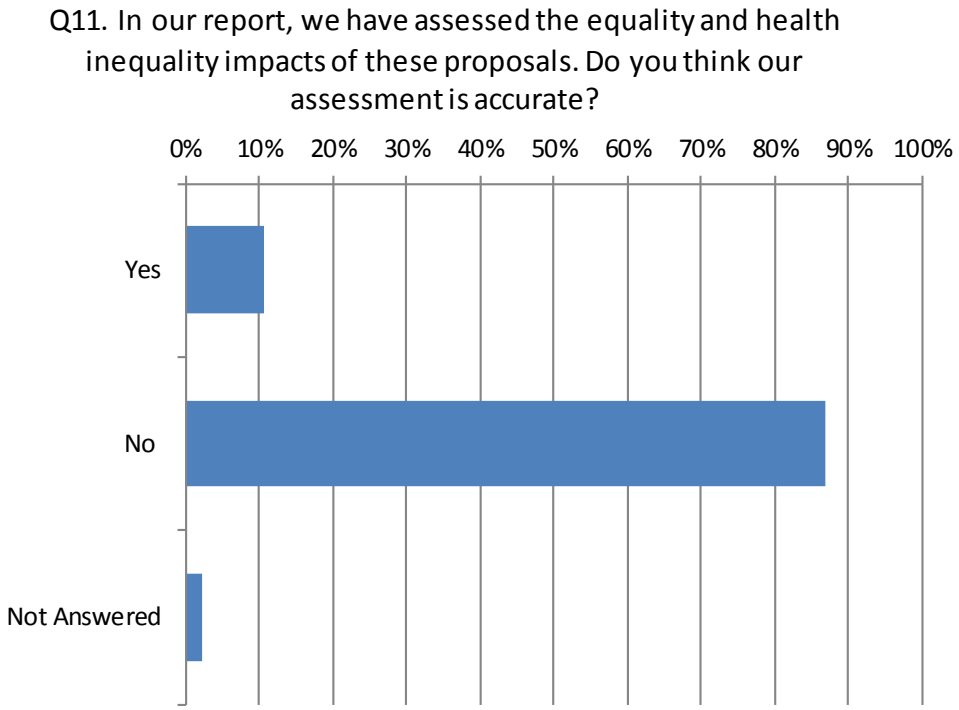
Table 8 - What more might be done to avoid, reduce or compensate for longer journeys where these occur?	
Response	**Total**
Publish travel data to allow all to analyse / look at different times	**37%**
Travel times based on car - what about public transport.	**29%**
Keep existing units open and save costs (redundancies / reconfiguration)	**18%**
None	**18%**
Provide a risk assessment of public transport / additional transport times	**17%**
What about cost of transport / compensation / Taxi / hospital transport	**12%**
Impact of additional travel times on patients and families	**12%**
Explain how they came to the conclusion that moving the heart centre to Birmingham will increase travel times by only 14 minutes / ridiculous estimates	**11%**
Consider impact of additional stress on the patient	**6%**
Provide care as close to patients home as possible by commissioning of more L2 and L3 services	**5%**
Increased travel times could cause death (including children)	**4%**
Any increase in travel is unacceptable	**4%**
Adequate provision of patient/carer/family accommodation at low cost / Ronald McDonald house	**3%**
Will cause a reduction in family support	**2%**
Disruptive if you have a disabled child.	**2%**
Better co-ordination between centres co-location	**2%**
Consider cultural / rural / medical barriers to public transport	**2%**
More staff and resources for remaining sites	**2%**
Health benefits outweigh travel issues / Promote this	**1%**
What about increased ambulance journeys (L1 and L2)	**1%**
Loss of patient / relative earnings needs to be considered	**1%**
Need low cost / free parking	**1%**
Keep to appointment times to save wasted time / group appointments	**1%**
Appointments on evenings and weekends when travel is easier	**1%**
Consider effect on children's education	**1%**
Air ambulance for critical cases	**0%**
SUPPORT UHL in relationships with Network Referring Hospitals	**0%**
Treat all centres equally	**0%**
Remote appointments by Skype etc	**0%**
All appointments on one day	**0%**
Ask patients and families for feedback	**0%**
How many people are affected?	**0%**
Choose hospitals in the south with a high density of provision	**0%**
Total	**100%**

Table 8 outlines the range of themes to have emerged from the survey comments relating to Q10, seeking what might be done to avoid, reduce or compensate for longer journeys where these occur. Please note that themes which state 0% refer to those themes that emerged less than 1% out of all responses, but were still apparent. Cross tabulation of the themes by region enables the analysis to draw out conclusions by area. However, there was not a stronger emphasis of themes by any particular region other than the Midlands and East respondents who felt that any increase in travel time is unacceptable.

The most common themes overall were that: travel data should be published to allow external analysis; travel times seem to be based on a car and it is felt that public transport times need to be considered; keep centres open to avoid other costs of redundancy or reconfiguration; a risk assessment should be provided of the impact of additional travel times (especially taking into account public transport); the cost of transport was questioned and whether compensation or hospital transport would be offered to patients/carers for longer journeys (especially for disabled children); it was felt that the conclusion of moving the [Leicester] heart centre to Birmingham would increase travel times by 14 minutes is incorrect (under estimated); consideration of the potential stress on patients and families was asked to be taken into account; providing care closer to home by commissioning more Level 2 and Level 3 services was suggested and; the loss of patient/carer earnings if they need to travel further was also asked to be considered.

In terms of suggestions to reduce/avoid longer travel times, the most common themes were: ensure appointments are kept so that resources aren't wasted and group appointments where possible; hold evening and weekend appointments when travel is sometimes easier and; consider including remote appointments by Skype where possible.

Q11 - In our report, we have assessed the equality and health inequality impacts of these proposals. Do you think our assessment is accurate?



Q11 Chart demonstrates that the majority (91%) of respondents feel that the assessment of equality and health inequality impacts is not accurate. Cross tabulation of this data shows that there is not a strong regional emphasis towards these responses nor any particular bias towards respondent type (although more clinicians tended to agree that the assessment is accurate).

Q12 - Please describe any other equality or health inequality impacts which you think we should consider, and what more might be done to avoid, reduce or compensate for the impacts we have identified and any others?

Table 9 – Please describe the equality or health inequality impacts that should be considered.	
Response	**Total**
A local and integrated network of care is essential	**40%**
CHD is lifelong and requires regular medical checkup	**33%**
None	**23%**
Lack of public transport - rural location	**21%**
A greater understanding is needed on the impact of increased incidence of CHD in the BME community.	**20%**
Social deprivation / financial impacts	**20%**
Care needed for close to home for family support	**18%**
Children would be adversely affected	**13%**
Re-think and don't close these centres	**13%**
Other medical problems / disabilities in addition to CHD	**10%**
Ability to access local treatment	**9%**
Best practice learning from co-location of child and adult / other services	**8%**
Effect on other family members (e.g. school / work)	**6%**
Adverse health effects of travel	**5%**
Impact on pregnant women	**5%**
All regions should have a centre / maximum journey times	**3%**
A full and complete EQIA is still outstanding	**1%**
Older patients may have travel difficulties	**1%**
Consider language barriers / asylum seekers	**1%**
There is an increasing incidence of CHD	**1%**
An issue in transition from child to adult service	**0%**
Survey is discriminatory to those without online access	**0%**
Being honest about mistakes	**0%**
People will understand if its explained to them	**0%**
Impact on the ambulance service	**0%**
Increase in air pollution	**0%**
CHD patients need to make healthy choices (smoking / exercise)	**0%**
Religious beliefs	**0%**
Can telemedicine and or remote monitoring be used more?	**0%**
Support for parents travelling from Northern Ireland	**0%**
Total	**100%**

Table 9 outlines the range of themes to have emerged from the survey comments relating to Q12, which asks respondents to describe the equality or health inequality impacts that should be considered. Cross tabulation of the themes by region enables the analysis to draw out conclusions by area.

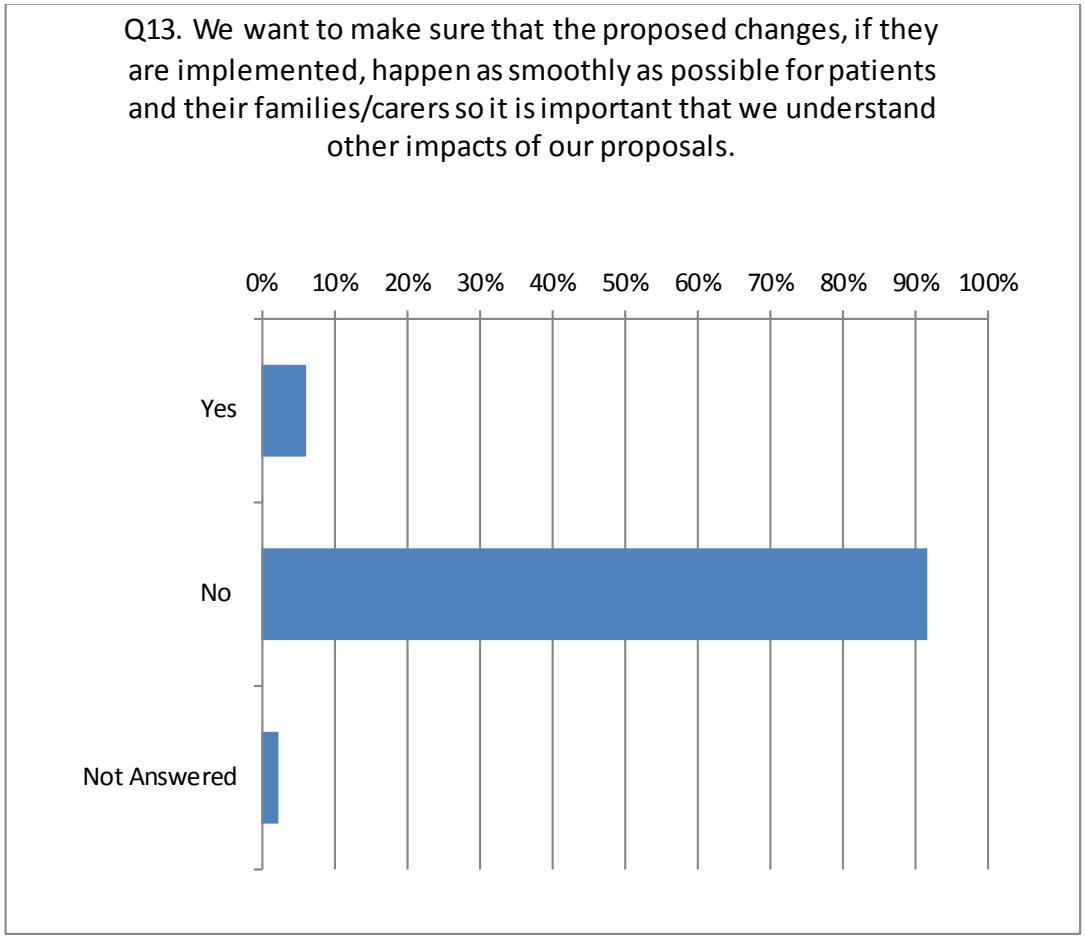
A lack of public transport and the impact of rural locations were particularly asked to be considered by respondents from the Midlands/East region and from Wales, this was not a strong theme for the London region.

Respondents from the London region also requested that best practice learning from co-location of child and adult/other services should be considered along with the potential impact upon pregnant women.

All other themes were common across all regions and included:

- A local and integrated network of care is essential so that services are available to all patients/carers;
- CHD is a lifelong issue and therefore requires regular medical check-ups (meaning longer journey times have a strong impact on patients/carers);
- The need to consider social deprivation and the financial impacts of increased travel times;
- A greater understanding is required of the impact of increased incidences of CHD in the BAME communities;
- Consider patients with other medical problems/disabilities in addition to CHD;
- It is also felt that a full EQIA (Equalities Impact Assessment or Analysis) is needed;
- Consider language barriers; religious beliefs and; the transition from child to adult services.

Q13 - We want to make sure that the proposed changes, if they are implemented, happen as smoothly as possible for patients and their families/carers so it is important that we understand other impacts of our proposals. Do you think our description of the other known impacts is accurate?



Q13 Chart demonstrates that the majority of respondents (92%) feel that the description of other known impacts is not accurate. Cross tabulation of this data shows that no conclusions can be drawn in terms of respondent type or region, as there is commonality throughout. However, it should be noted that more clinicians tended to agree that the assessment was accurate.

Q14 - Please describe any other impacts which you think we should consider, and what more might be done to avoid, reduce or compensate for the impacts we have identified and any others?

Table 10 – Describe other impacts to consider.	
Response	**Total**
ECMO – International centre of excellence – should have same status as Heart transplants	**31%**
PICU – capacity – outcome of review not available for public to consult on	**31%**
Loss of CHD specialist skills – recruitment already challenged – where will staff come from?	**30%**
Cost – lack of capital available for receiving hospitals to build additional capacity	**27%**
Transition - risk of losing staff	**25%**
None	**20%**
Outreach clinics- how these will be possible across such a large region	**20%**
ECMO – ability to replicate like for like (Simon Stevens test on bed closures due to reconfiguration)	19%
Centres are performing well / centres of excellence - so keep them	**19%**
Fetal medicine – the need for seamless transition of care	**18%**
Cardiac Liaison Nurses- how will they be able to offer the local approach currently offered	**18%**
Level 2 centres - No proven plan for how these will actually work across 4 networks	**14%**
Staff having to work further away	**10%**
Additional stress / health impact of travel	**10%**
Travel for patients and parents	**10%**
Upgrades to other hospitals / reconfiguration of closed units	**7%**
Continuity of care - shared notes	**7%**
Increased demand on ambulance service	**4%**
Advanced warning of closures and new arrangements / Level 1 2 and 3 plan	**3%**
All areas need a heart centre	**3%**
Look after child at Different doctors / education affects	**3%**
Need for accommodation	**2%**
Standard Response A: CONGENITAL HEART RESEARCH • Royal Brompton is recognised as the world's leading centre for adult CHD research - this research is crucial for making the advances that will improve the care CHD patients receive in future. IMPACT ON CHILDREN'S INTENSIVE CARE • NHS England says that its plans for Royal Brompton will cut the number of 'paediatric intensive care units' (PICUs) that look after the sickest children. IMPACT ON CHILDRENS' SPECIALIST RESPIRATORY CARE AND RESEARCH • NHS England admits that its plan for Royal Brompton will impact on the Trust's children's specialist respiratory services, but says that it will only look at this in detail once plans CHD services were finalised.	**2%**

Table 10 – Describe other impacts to consider.	
Response	**Total**
Parking and costs.	**1%**
Cost cutting exercise	**1%**
Loss of parental income / work	**1%**
Judge based on clinical performance KPI's	**1%**
Equality impact assessment required	**1%**
Improve public transport network	**0%**
Adult congenital services	**0%**
Any change has risk	**0%**
All initial diagnosis at Level 3 - need good service	**0%**
Paediatrician with cardiac expertise at local level would help	**0%**
Cannot talk to elected representatives due to election	**0%**
Total	**100%**

Table 10 outlines the range of themes to have emerged from the survey comments relating to Q14, which asks respondents to describe any other impacts that should be considered. Cross tabulation of the themes by region enables the analysis to draw out conclusions by area.

There is commonality of the main themes throughout all regions with two exceptions:

- In the Midlands/East region there are particular concerns raised in regards to the potential loss of ECMO, which in Leicester is seen as an international centre of excellence and should be given the same status as the heart transplant centre in Newcastle. The potential impact on an already short supply of PICU beds is also a concern
- In the London area, a number of standardised responses have been received in regards to the Royal Brompton and these outline that the facility is recognised as a world leading centre for research into adult CHD and if it were to close, the UK could lose its recognition in this field along with patients suffering. They also state that any potential closure could have an impact on an already short supply of PICU beds and that there are potential impacts on children's respiratory care and research.

In terms of the most common themes throughout all comments, these include:

- The loss of specialist CHD staff needs to be considered (especially in line with any needed transition between units) where recruitment in these areas in already a challenge;

- The outcome of the PICU review is not available for the public to consult upon and PICU capacity needs to be considered;
- There is a lack of funding for the hospitals to build capacity;
- How will it be possible to achieve outreach clinics across large regions;
- How will cardiac liaison nurses be able to offer a local approach;
- There will be a potential impact upon fetal medicine;
- Need to consider how Level 2 centres will work across four networks;
- The potential impacts on patients/carers in terms of stress, travel and having to see different specialists; the potential for increased demand on ambulance services if people need to travel further;
- Being able to achieve continuity of care and share records across larger regions and; there needs to be a plan for new arrangements across Levels 1,2 and 3.

Q15 - Do you have any other comments about the proposals?

Table 11 – Do you have any other comments?	
Response	**Total**
Don't close the unit	**27%**
Decision is biased towards some hospitals - vested interest / Newcastle	**25%**
Insufficient PICU beds / unit / PICU review results?	**24%**
All regions should have a level 1 centre.	**23%**
None	**21%**
Consider detrimental financial and health effects on patients and families	**20%**
In current NHS crisis why are we wasting money on replicating services that are high quality already	**19%**
Glenfield (UHL) is excellent - only closed due to unrealistic target for number of operations	**18%**
'Quantity over quality' goes against NHS England commissioning strategy.	**17%**
Would create an inferior service	**17%**
Unrealistic waste of money / Cost of moving services	**16%**
Manchester and Leicester are separate cases and should not be linked in Q5.	**13%**
Centres meet CQC standards	**11%**
What problem are you trying to solve? / CHD surgery is best in the World	**11%**
Insufficient capacity to meet service demand	**9%**
Consider the ECMO impact of closing Glenfield (UHL) / only mobile ECMO / Funded by donation	**7%**
Royal Brompton excellent - only closed due to co-location	**6%**
Loss of skills when staff leave / move abroad	**5%**
Lack of patient / parental choice	**4%**
Support centres to achieve the target	**4%**
Would create additional costs in other areas	**3%**
Consider clinical research benefits of centres	**3%**
Just cost cutting	**2%**
Questions are biased / do not enable response	**2%**
Be open and transparent in communicating changes	**2%**
Principles behind the changes are sound	**1%**
Don't waste any more time / money on consultations	**1%**
Needed to improve efficiency and best practice	**1%**
Standard Response B - Below are some other comments that we would like to make. Please add the points you agree with in your own words, and make any other final points you'd like to make. - The last review of CHD services – Safe and Sustainable – was criticised for only looking at children's services. It is for this reason that this review looks at adult services too. - This review says it wants to cover "the entire patient pathway from diagnosis, through treatment and end of life care". For most CHD patients these days, diagnosis takes place before birth, and end-of-life care takes place in old age.	**0%**

Table 11 – Do you have any other comments?	
Response	**Total**
- It therefore doesn't make sense that this review should want to break up one of the largest and most successful joint child and adult services in the country at Royal Brompton, which cares for patients from before they are born right through to older age. Royal Brompton provides continuity for patients in a way that they value. - It seems irrational to say that children's gastroenterologists and general surgeons must be based on site, when they are needed as an emergency in less than 1% of cases. - Outcomes for congenital heart disease surgery in this country are among the best in the world. All the evidence shows that Royal Brompton has some of the best patient outcomes and satisfaction levels in the UK. I do not believe there is a problem and am unclear as to why NHS England appears intent on solving one.	
Need further clarity on outreach clinics	**0%**
Save money on admin / repeat prescriptions etc instead / foreign aid	**0%**
Standard Response A - Adequate – Prof Huon Gray fears that without action the service will be left to be 'adequate', since the events in Bristol in 1991 and the subsequent reviews, the CHD profession has transformed and in fact should be seen as a major success story for NHS England and is far from ' adequate '. o National Mortality rates have gone from 14% to 2% of UHL mortality rates have gone from 13% - 0.6% of The number of CHD centres has gone from 17 to 10 o Occasional practice has gone from 190 cases to 5 cases Crucial information needed to inform the consultation - The review into ECMO services is a crucial aspect of this consultation and it is inappropriate that the results of that review are not part of this consultation process. This was a recommendation from the previous Independent Review Panel following the Safe and Sustainable review. Caseload - Caseload has featured as the key standard in the CHD review. NHS England assumptions are that the current ECMO caseload for ECMO delivered by EMCHC can easily and safely be delivered dispersed across the remaining cardiac surgical centres, all of whom in theory can undertake ECMO as it may be required after cardiac surgery. It is a huge assumption that the ECMO currently provided by EMCHC (over 50% of the UK requirements) will be able to be delivered by the units spread across the country. They are proposing to dilute ECMO practice whilst using concentration of cardiac surgical practice as a rationale for service reconfiguration. This is in direct contrast to NHS England's own quote from Mr Martin Kostolony highlighted on page 12 of the consultation document and again shows an inconsistency of approach which is not acceptable or fair.	**0%**

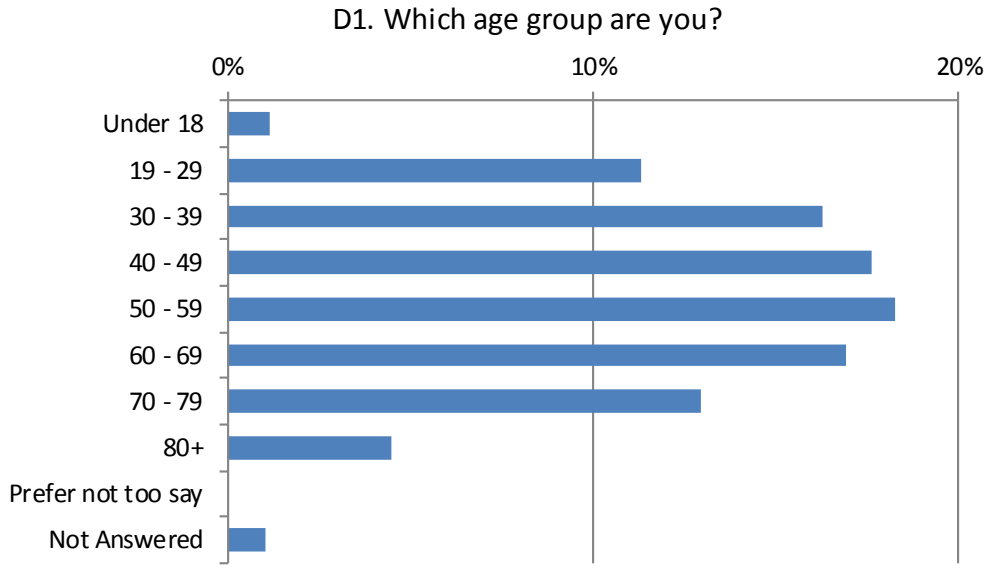
Table 11 – Do you have any other comments?	
Response	**Total**
Specialist knowledge - The assumption that there will be appropriately trained clinical and nursing staff available to deliver this specialist care across all of the units is severely challenged by the fact the majority of ECMO provided by EMCHC is provided for children with catastrophic respiratory and cardiac failure not related to cardiac surgery and in which other Level 1 centres have little or indeed no expertise (. This is currently evidenced by the fact the EMCHC ECMO team travel the country including to the current surgical centres to place patients in this situation on ECMO and bring them back to Glenfield (UHL) for optimal expert care) . Replicating this expertise will be as difficult as expecting all centres to deliver transplant surgery – the key rationale for the derogation being applied to Newcastle.	
Need to consider impact on ethnic minorities / disabilities	**0%**
As we are in purdah, is this a fair or lawful consultation - I cannot get access to my MP/councilors to discuss this and get a different view from that proposed by NHSE	**0%**
I don't have enough information to answer	**0%**
Inequality - Royal College of Physicians' census, in 2016, the East Midlands had the least number of cardiologists per head of population of any region in the UK	**0%**
Hope this isn't the road to privatization	**0%**
I agree with all the points made by my MP, Greg Hands, on his web site regarding the Royal Brompton hospital.	**0%**
Good that learning disabilities / autism have been considered	**0%**
Total	**100%**

Table 11 outlines the range of themes to have emerged when survey respondents were asked for any other comments relating to the proposals. The common themes to have emerged from this section reflect the responses throughout the survey:

- A call not to close units which are already seen as centres of excellence;
- Treat all units fairly and consistently by applying standards in the same timescale;
- All regions should have a Level 1 service; take into account networked approaches and do not focus on co-location;
- Cost elements in terms of a lack of funding and the perceived wasted cost of reconfiguration;
- Manchester and Leicester are different facilities and so should not be linked (as per Q6);
- Staff retention, loss of skills and insufficient specialist capacity and; that the evidence put forward is incorrect and that the reviews of services are unfair.

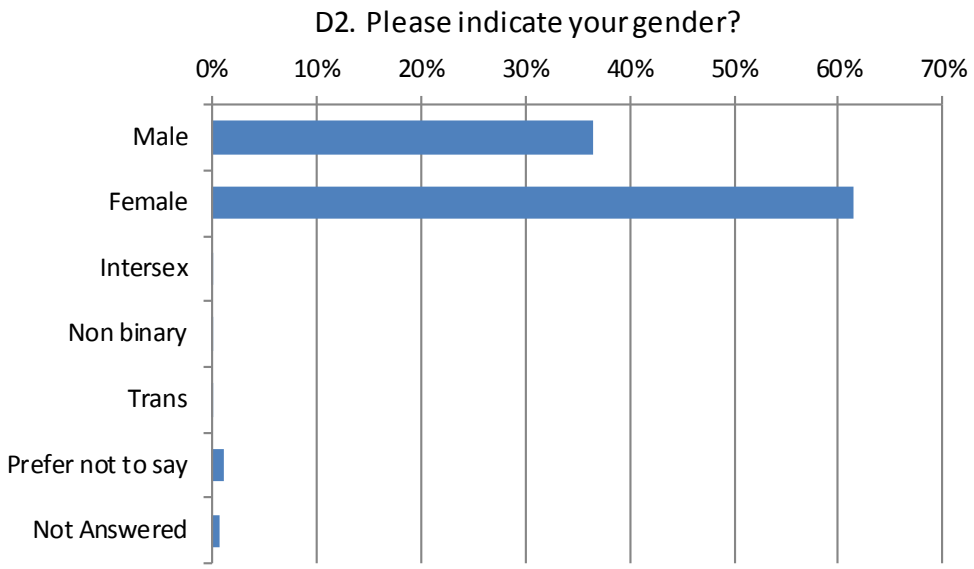
Respondent Profiling

The following sets out the responses in terms of the respondent profiling section of the survey.

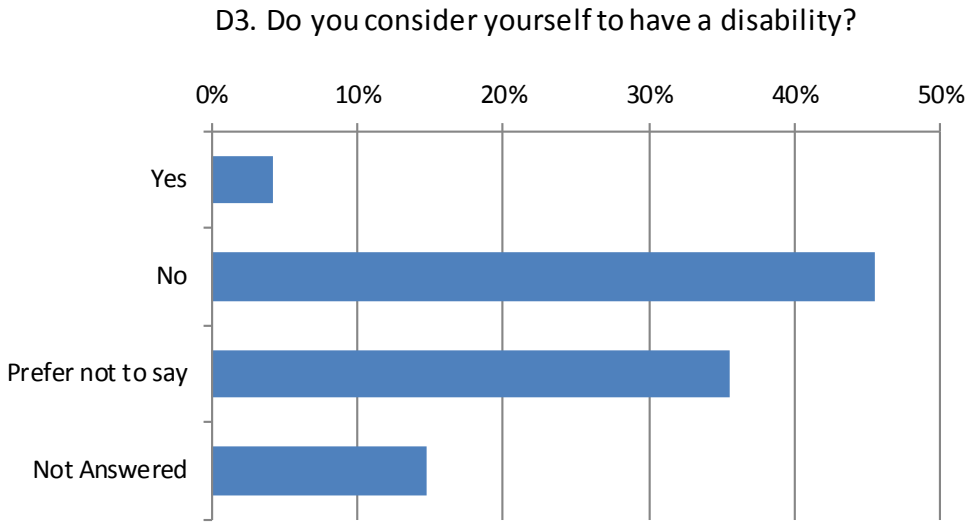


A wide range of age categories are represented in terms of the responses to the survey, including the traditionally harder to reach groups aged 19-29 years old (at 11% of all responses). When interrogating the data further it is apparent that in terms of CHD patients, the age ranges reflect the overall age spread of all responses as indicated in the Table 2 below. This again infers that there is a broadly representative balance of ages reflected in the responses from service users.

Table 2 – Ages of CHD patient responses		
Age Category	**Number of responses**	**Total %**
Under 18	4	1%
19 - 29	44	15%
30 - 39	78	26%
40 - 49	59	20%
50 - 59	57	19%
60 - 69	33	11%
70 - 79	15	5%
80+	1	0%
Prefer not to say	1	0%
Not Answered	5	2%
Total	297	



D2 above indicates that most of the responses (61%) are from female respondents, which is common in terms of survey completion.



D3 above indicates most of the respondents (45%) do not consider themselves to have a disability, with 36% preferring not to say.

Table 3 – What do you consider your ethnic origin to be?		
Response	**Total**	**Number of responses**
White: Welsh/English/Scottish/Northern Irish/British	**79%**	**6051**
White: Any other White background	**2%**	**164**
White: Irish	**1%**	**83**
White: Gypsy or Irish Traveller	**0%**	**1**
Asian/Asian British: Any other Asian background	**1%**	**46**
Asian/Asian British: Bangladeshi	**0%**	**5**
Asian/Asian British: Indian	**8%**	**578**
Asian/Asian British: Pakistani	**1%**	**71**
Black or Black British: Black - African	**1%**	**47**
Black or Black British: Black - Caribbean	**0%**	**14**
Black or Black British: Any other Black background	**0%**	**3**
Mixed: Any other mixed background	**0%**	**18**
Mixed: White and Asian	**0%**	**21**
Mixed: White and Black African	**0%**	**2**
Mixed: White and Black Caribbean	**0%**	**7**
Other ethnic background: Any other ethnic group	**1%**	**47**
Other ethnic background: Chinese	**0%**	**12**
Prefer not to say	**0%**	**4**
Not Answered	**7%**	**499**
Total	**100%**	**7673**

Table 3 demonstrates that the majority (79%) of survey respondents consider themselves to be White British in terms of ethnicity. Again as the percentages have been rounded those that show at 0% actually represent small numbers of responses (less than 1% of responses). In fact, all ethnicity types are represented within the responses if in small numbers (as shown in the total number of responses column).

Table 4 – Please indicate your religion or belief.	
Response	**Total**
Christian	**49%**
Atheist	**1%**
Buddhist	**0%**
Hindu	**4%**
Jewish	**0%**
Muslim	**3%**
No religion	**23%**
Sikh	**2%**
Any other religion	**1%**
Prefer not to say	**9%**
Not Answered	**7%**
Total	**100%**

Table 4 demonstrates most survey respondents (49%) consider themselves to be Christian, with 39% stating they have no religion/prefer not to say/have not answered.

Table 5 – What best describes your sexual orientation?	
Response	**Total**
Heterosexual	**39%**
Bisexual	**0%**
Gay	**0%**
Lesbian	**0%**
Prefer not to say	**43%**
Not Answered	**17%**
Total	**100%**

Table 5 demonstrates that most (39%) survey respondents consider themselves to be heterosexual, with 43% preferring not to say.

Meeting Notes Data

The following sets out the list of meetings that have been held during the consultation and themes to have emerged throughout all meetings.

Events – Notes from Meetings

- **28 February, 1.30pm– 4pm**: Norfolk & Norwich Patient, Public and Staff Event, Norfolk and Norwich University Hospital
- **1 March, 5–7pm** (open to all)
- **2 March 10am**: North East Health Scrutiny Committee, Hartlepool Borough Council
- **2 March, 2–4pm** (for CCGs)
- **2 March, 5–7pm** (for families and carers of those with CHD and Learning Disabilities)
- **3 March, 10.30am – 12.30pm**: Oxford Patient, Public and Staff Event, John Radcliffe Hospital
- **6 March, 10am**: Derbyshire Health Scrutiny Committee, Matlock County Council
- **7 March, 6pm - 8pm**: London Question Time
- **9 March, 2pm – 4pm**: Leicester Staff Briefing
- **9 March, 6pm - 8pm**: Leicester Question Time
- **11 March, 10am – 12pm**: Manchester Patient, Public and Staff event, Manchester Art Gallery
- **14 March, 10.15am**: Nottingham/Nottinghamshire OSC, Nottinghamshire County Council
- **14 March, 2pm**: Joint Leicester, Leicestershire and Rutland OSC, Leicester City Council
- **15 March, 10am**: Lincolnshire OSC, Lincolnshire County Council
- **15 March, 1.30pm – 4pm**: Cardiff Patient, Public and Staff event, University Hospital Wales
- **16 March, 1.30pm – 4pm**: Birmingham Patient, Public and Staff Event, Birmingham Children's Hospital
- **18 March**: Little Hearts Matter Patient and Families Event, Birmingham
- **20 March** : Northampton HOSC, Northampton
- **21 March, 5pm – 7pm**: Leeds Patient, Public and Staff event, Leeds General Infirmary
- **22 March, 1.30pm – 4pm**: Barts Patient, Public and Staff event, Barts Hospital
- **23 March, 4pm – 7pm**: Alder Hey Patient, Public and Staff event, Institute in the Park – Alder Hey
- **25 March, 10am – 12pm**: Papworth Patient Event, Papworth Hospital
- **27 March, 2.30pm – 4.30pm**: Great Ormond Street Patient, Public and Staff Event, Great Ormond Street Hospital
- **28 March, 2pm**: Rutland Health and Wellbeing Board, Rutland County Council
- **28 March, 5pm – 7pm**: Evelina/Guys Patient, Public and Staff event, Evelina Hospital
- **31 March, 3pm – 6pm**: Southampton Patient, Public and Staff event, Southampton General
- **14 June, 5pm – 7pm** : Wrexham Patient, Public and Staff event, Holt Lodge Hotel
- **15 June, 3pm – 6pm** : Blackpool Patient, Public and Staff event, Lancashire Cardiac Centre, Blackpool Hospital
- **19 June, 2pm – 5pm** : Bristol Patient, Public and Staff event, Education Centre, Bristol Royal Infirmary
- **22 June, 1.00pm – 3.00pm** : Lincolnshire Patient, Public and Staff event, New Life Centre Sleaford
- **24 June, 11am - 2pm** : Royal Brompton Patient and family event, Royal Brompton Hospital
- **27 June, 6pm – 8pm** : Newcastle Patient, Public and Staff event, Newcastle Civic Centre

- **27 June, 5pm**: Leicester, Leicestershire, Rutland Joint OSC, Leicester City Council
- **28 June, 6pm – 8.30pm**: Middlesbrough Patient, Public and Staff event, St Mary's Centre, Corporation Road, Middlesbrough
- **30 June, 1pm - 3pm**: Nottingham Patient, Public and Staff event, The Education & Conference Centre, Nottingham University Hospitals, City Hospital Campus
- **1 July, 1pm - 4pm**: Leicester Patient and Family event, Glenfield (UHL) Hospital 5 July, 2.00pm, Joint Yorkshire and the Humber OSC, Leeds City Council
- **11 July, 6.30pm**: Kensington & Chelsea OSC, Chelsea Old Town Hall.

Topic
Insufficient capacity to meet service demand / Growth
Loss of CHD specialist skills – recruitment already challenged – where will staff come from / move abroad / Brexit
Re-assess the validity of the standards / clinical outcomes (ref 125 cases)
Insufficient PICU beds / unit
Additional stress / health impact of travel
Closure of Brompton would add extra pressure and lead to clinical shortcomings especially for children CHD / Respiratory services (including Cystic Fibrosis)
Standards must make clinical and patient sense
All hospitals should be given the same time / support to achieve standards
Consider the effect on quality of life for family having to travel
Need further clarity on outreach clinics
Better communication about success / rationale / open and transparent / FOI requests
ECMO / PICU and transplant centres should not be unfairly penalised / difficult cases
Glenfield (UHL) is excellent - only closed due to unrealistic target for number of operations
Newcastle does not / will not meet the standards / given more time
Advanced warning of closures and new arrangements / Level 1 2 and 3 plan
Assess effect of ECMO on PICU and increase PICU beds for both ECMO and surgical / delay until results of PICU review
More consideration should be given to Glenfield (UHL) / divert cases here / world class ECMO / set to meet standards in 2018
The Royal Brompton provides excellent service and should be retained
Needs to be local / risk of death in emergency
When will closures be implemented
Level 2 centres - No proven plan for how these will actually work across 4 networks
Continuity of care - shared notes
Remove the cloud of uncertainty over planned closures
This is a repeat of "Safe and Sustainable" / decision to close already made
Cost – lack of capital available for receiving hospitals to build additional capacity
Support UHL in relationships with Network Referring Hospitals
Consider transition to adult - co-located adult and children's services
ECMO – International centre of excellence – should have same status as Heart transplants
Consider detrimental financial and health effects on patients and families
Decision by the Autumn
All patients in East Midlands / England should be offered the choice of Glenfield (UHL)

Topic
Include patient feedback in KPI's / CQC / outcomes
Royal Brompton DOEs meet all the standards in partnership with Chelsea and Westminster Hospital / co-location
Standards are being used to make the case for closure
All regions should have a level 1 centre.
Consider the ECMO impact of closing Glenfield (UHL) / only mobile ECMO / Funded by donation
Lack of a detailed implementation plan
Insisting on physical co-location would not improve things for patients / worse outcomes
Inaccurate travel data / publish your figures
Apply the standards fairly / treat centres equally
Equality impact assessment required / Risk analysis
How will meeting the standards be measured in future (NICOR) / decommissioning
Work with local provider to support growth plan and network referrals
Consider clinical research benefits of centres
None (few) of the centres currently meet all of the standards.
Standards should not be applied retrospectively
Timeframes for referrals are important / bed availability
Leicester provides specialist services for babies and children / excellent services
Glenfield (UHL) has submitted a plan to reach the target
There is a strong and established service available in Leicester
Standards were initially set to be aspirational goals not hard targets
Fetal medicine – the need for seamless transition of care
Would create additional costs in other areas
Improve public transport network
Increased demand on ambulance service
Lack of patient / parental choice
Parking and costs.
Share best practice and regional facilities
Decision is biased towards some hospitals - vested interest / Newcastle
Just cost cutting
Excellent service should be retained at Manchester Royal Infirmary
Will lead to cherry picking of cases / unnecessary surgery (operations undertaken to meet target)
Newcastle has cutting edge facilities and should be kept
A patient should have access to full treatment
Train more medical staff locally to allow more developed specialisms
Questions are biased / do not enable response / Not enough public meetings
Need to look at additional or updated data (ref 125 cases)
In current NHS crisis why are we wasting money on replicating services that are high quality already
Will face legal / judicial challenge
Analyse referral process and procedures
Would create an inferior service
Quantity over quality goes against NHS England commissioning strategy.
Staff having to work further away

Topic
What problem are you trying to solve? / CHD surgery is best in the World
Physical co-location should not be the decisive factor in closing a CHD unit
Closed due to uncertainty created by review
Southampton cannot meet the standards without diverted cases
Centres are performing well / centres of excellence - so keep them
Centres meet CQC standards
Outreach clinics - how these will be possible across such a large region
Cross location working in Liverpool and Manchester will deliver better results
Loss of parental income / work
Need for accommodation
Travel is secondary to best care
Support care close to home
Don't close the unit
Recognise areas of expertise
Need more finance / support for current services
Look after child at Different doctors / education affects
Outcomes are better in specialist units
Encourage collaborative working with hospitals
Strong evidence base for the proposals
Assess patient numbers independently - not based on closure of other units
Good that learning disabilities / autism have been considered
Provide more funding / employ more staff
Leicester covers a wide rural population
Increase surgical rota in Manchester
Set up services in Liverpool / move from Manchester
Newcastle now taking Manchester cases (since collapse)
Provide a detailed action plan
Need access to a facility that is safe and successful
Needed to improve efficiency and best practice
Will private / overseas patients be included in the case numbers
Simon Stevens Test on Beds / Bed closure
Patients are being diverted to other hospitals to make the case for closure
Need to consider impact on ethnic minorities / disabilities
See what EMCH does for yourself - Talk to patients, family and staff
Northern Ireland patients are having to travel to England for treatment
Hope this isn't the road to privatization
Cardiac Liaison Nurses- how will they be able to offer the local approach currently offered
Principles behind the changes are sound
Should create centres of excellence
Don't waste any more time / money on consultations
This unit is not under threat of closure / little interest

Young People Survey Data

NHS England established an online youth portal with an animation for children and young people with CHD to enable them to contribute thoughts and opinions. This approach included an online survey. The following sets out the themes to have emerged from the young people with CHD survey. A full report of these survey findings has been given to NHS England.

- Most were aware of potential closures of University Hospital of Leicester, Central Manchester Hospitals and Royal Brompton. Many were very worried with concerns about doctors being overworked, longer waiting times for surgery, travelling further and continuity of care. Those who were not worried considered that the provision of best care was more important than where it was provided
- More respondents were affected by Royal Brompton and University Hospital of Leicester stopping heart surgery and cardiac interventions than Central Manchester Hospitals. Concerns related to not being able to get to another hospital in time, time out of school and time off work for parents.
- Positive comments related to a larger hospital with more experience providing better care
- A large number of respondents were worried about getting further surgery or interventions at a different hospital that they had not previously used. Concerns related to being far away from home, not knowing the clinicians and not getting to the hospital in time. Additional worries of a new place and needing more help when their conditions worsened were also mentioned
- There were mixed views about having ongoing care and follow up appointments at their current hospital. Consultants moving and difficulties in recruiting for a non-surgical centre were raised as issues. It was also felt that having all their care at the same hospital would be safer as they would see the same doctor who is familiar with their care
- Key areas to help prepare for changes were:
    - Continuity of support
    - High quality care
    - Close to home
    - Knowing where they would be going

  - Clear communication
  - Pre visits to the new centre
- Where the patient's surgical hospital is retained, there was a mixed view on how worried patients were that the changes would affect them or their hospital. These concerns related to additional demand, less personal service, increased waiting times and bed shortages. Alternatively bigger and better care for all was highlighted
- High quality care across the country could lead to a personal decline in care. There is an expectation that high quality of care should be delivered. The personal relationships with cardiologists would potentially decline due to high workloads.

Other comments related to keeping the existing hospital open, better quality surgery, but offset against having further to travel for check-ups and the effect upon the support networks these hospitals provide for families.

Feedback by Stakeholder Category

The following sets out the themes to have emerged from key stakeholder groups, which has been identified from the survey responses, letters and emails received.

PROPOSAL TO ONLY COMMISSION FROM PROVIDERS ABLE TO MEET THE STANDARDS

Children's Heart Charities

- Support the need for standards and volume of operations per surgeon, but should be aspirational not hard targets. Outcomes have improved dramatically since the Bristol scandal.

Royal Colleges and Specialist Societies

- Support the implementation of the full set of standards, but requires significant additional resources in several regions especially in dental services. The impact on other services has not been fully considered, this includes radiology, anaesthetics, theatres and dental services. Specialist services are including transplant, cardiac electrophysiology and pulmonary hypertension services are super-regional services and not covered in this consultation.
- Standards are extensive / aspirational and no centre currently meets every standard. Aim is to achieve the full set of standards within 5 years, but many standards will have to be met earlier. Huge challenge when underfunded and resourced.

Hospital Trusts

- Comments relating specifically to the standards themselves were made
  Positive responses included comments that standards:
  - Provide enhanced patient safety
  - Ensure better patient outcomes
  - Deliver clinically agreed best practice
  - Promote sustainability of services and workforce
  - Are supported by relevant professional bodies.
  - Should be used to identify gaps and increase quality and need to be applied equally

Negative responses included comments that standards:
  - Have placed too much emphasis on compliance with a comparatively small number of the standards which are treated as more important.
  - Will not produce improvements in quality of care.
  - For co-location are not achievable within the original timeframes for Newcastle due to the complex nature of surgery undertaken.
  - Require NHSE support to achieve targets.
- The target numbers make sense in order to ensure staff cover and expertise, but there should be a sub-specialisation of more complex small volume cases. There is no clinical basis for the target numbers to provide better outcomes.

Public representatives (MPs, Councillors, Overview and Scrutiny Committees (OSCs))

- Standards are not being applied in a fair and equitable way by NHS England as Newcastle has been given additional time. NHSE are accepting that lower standards of care are acceptable for an indeterminate period of time. Catchment areas are not set to change and population growth is not evidenced, so Newcastle will fail to meet this target (volume standard) in future too.

The NHS in the Devolved Administrations

- Support robust and appropriate standards as long as they do not destabilise the service or create additional risks.
- Important to remove uncertainty and provide a period of stability for the benefit of staff and patients.
- Removal of occasional practice is welcomed as no longer acceptable.

VIABLE ACTIONS TO HELP MANCHESTER, ROYAL BROMPTON AND LEICESTER TO MEET LEVEL 1 STANDARDS

Children's Heart Charities

- Closer working relationship between Manchester and Liverpool to ensure stability. Manchester could be closed. There is concern as to the viability of Manchester as a Level 2 centre given the staffing issues and perceived deskilling. A clean break may be more desirable than a slow degradation of service leading to poor patient outcomes
- Leicester suffering from instability making recruitment difficult. No justification to close. Concern that babies with undetected heart conditions would not reach surgical centres in time

- Closure of units should only happen where there is a case backed by evidence to support the view that care standards and outcomes would be improved for patients by the closure and no adverse effects on other services

Respiratory Charities/Organisations

- Need to end this uncertainty.

Royal Colleges and Specialist Societies

- Brexit may add challenges to economics and recruitment and retention of personnel.

Hospital Trusts

- Leicester surgical activity below target and not likely to reach targets with current workloads too low for 4 surgeons. Services are not co-located. Too little activity across the UK to support current number of centres. Leicester can achieve the numerical target and has submitted a detailed plan which NHS England has failed to respond to. Retrospective data has been used to assess the standard when originally this was not going to be the case. Leicester is a centre of excellence (ECMO) and should be given the same time as Newcastle.
- Manchester: Paediatric and adult surgical teams should work across the Liverpool and Manchester axis to provide an effective way of meeting the standards without exacerbating the current instability within the service. It would also ensure care for pregnant women could be retained on a site that afforded the gold standard co-location of neonatal, paediatric, obstetric and adult services.
- Royal Brompton: Patients can easily travel across London with alternative good standard resources. Appointments can be enhanced using teleconferencing and outreach facilities. Transfer to Great Ormond Street Hospital is straightforward and will be well supported.

Public representatives (MPs, Councillors, OSCs)

- NHS England has arbitrarily rejected the growth plan put forward by UHL. No evidence that NHS England has undertaken any assessment of the growth plans of any of the other centres. The standard is also applied with immediate effect rather than the average in 3 years' time.
- Treat each centre equally and fairly and provide the same level of support to achieve the standards.

- What problem are you trying to solve - National Mortality rates have gone from 14% to 2%; UHL mortality rates have gone from 13% to 0.6%; the number of CHD centres has gone from 17 to 10; occasional practice has gone from 190 cases to 5 cases.

The NHS in the Devolved Administrations

- Is there any scope for sites to develop as a standalone adult or paediatric service rather than being an integrated provider.
- Patients in North Wales access services in Alder Hey (children) and Central Manchester (adults). The closure of Manchester requires Liverpool Heart and Chest Hospital (LHCH) to be in a position to safely introduce and deliver a new service. Concerns exist around establishing and staffing this service and current waiting list pressures.
- Patients in Mid Wales currently access services in Birmingham. Birmingham confirms their ability to handle additional Leicester activity. Essential that plans are fully implemented prior to service transfer to ensure sustainability.

VIEWS AND SUPPORT FOR CENTRAL MANCHESTER AND LEICESTER PROVIDING LEVEL 2 SERVICES

Public representatives (MPs, Councillors, OSCs)

- The impact of establishing a Level 2 centre in Manchester with a level 1 centre retained in the Network is far less than establishing one in Leicester, leaving the region with no Level 1 centre and where every patient will have to go out of the region for Level 1 care. How has the impact on the East Midlands region, patients here and expected population growth been assessed?

The NHS in the Devolved Administrations

- It is important that the voices of patients from Wales that are under the care of the other centres (England) are heard in this consultation and play an active part in any decisions made.

VIEWS AND SUPPORT FOR ROYAL BROMPTON PROVIDING ADULT ONLY LEVEL 1 SERVICE

Children's Heart Charities

- Consider other related health issues for children (complex conditions) and antenatal diagnosis of CHD

Respiratory Charities/Organisations

- It is inadequate and simplistic to state that 'there are alternative providers of specialist paediatric respiratory services in London'

Royal Colleges and Specialist Societies

- Closure of paediatric services at Royal Brompton would detrimentally impact Internationally recognised research

Hospital Trusts

- Royal Brompton only fails on 1 standard out of 470, co-location, which it meets in collaboration with Chelsea and Westminster, a few minutes away. Professor Huon Gray admits that there is no evidence to support physical co-location, a standard that was changed at the last minute from "within 30 minutes". Patients have already tried other London Hospitals and chosen RBH and transfer to them would cause chaos. RBH internationally recognised research function and fetal care would be lost. Co-location of child and adult is more important as it provides smooth transition.

Public representatives (MPs, Councillors, OSCs)

- The Royal Brompton Hospital: recognised as a national and international leader in the treatment of heart and lung disease. Expert staff carry out some of the most complicated heart and lung surgery. The only specialist heart and lung unit in the country that treats both children and adults. A large unit and home to Europe's largest centre for cystic fibrosis and other chronic lung conditions.

The NHS in the Devolved Administrations

- There will be limited impact on Scottish patients. Need clarity on electrophysiology at the Brompton if plans to close go ahead.

VIEWS AND SUPPORT FOR ALLOWING NEWCASTLE MORE TIME TO MEET THE LEVEL 1 STANDARDS

Children's Heart Charities

- Newcastle is unlikely to meet the standards due to retirement of a leading surgeon and ending of service for Ireland. Alternative transplant service needs to be developed.

Royal Colleges and Specialist Societies

- Support ongoing commissioning of CHD in Newcastle working to a different timeframe. Newcastle provides the full range of Paediatric cardiology services including transplant, ECMO, VAD and electrophysiology. It is one of only 2 units proving paediatric cardiac transplant.

Public representatives (MPs, Councillors, OSCs)

- Strongly support Newcastle being given more time to retain specialist Level 1 CHD services in the north east, outcomes are among the top 5 achieved internationally and Newcastle leads the way in the UK in providing treatment for infants and children with 'end-stage' heart failure.

VIEWS & SUPPORT FOR THE ASSMMENT OF THE IMPACT ON TRAVEL OF THE PROPOSALS

Children's Heart Charities

- Better planning for service changes and logistics to reduce travel impacts and address effects of travel on families – clear process of action. Concern that there is not enough family/parental accommodation capacity which will cause additional costs to patients travelling long distance for care. Reconfiguration of charity accommodation will take time and money.

Royal Colleges and Specialist Societies

- Additional support in the transition process would be essential for patients, parents and staff.
- Need to increase the number of outreach clinics for routine appointments. Inclusion of members from the wider team may allow a MDT approach for 'spoke' (hub and spoke approach) clinics. Members of the wider team should be used to deliver care and support locally.
- Need good communication and sharing of information between providers to reduce duplication of investigations. Could include secure videoconferencing methods to reduce the need for face to face consultations. Information should be available in a range of languages or use of interpreters.
- Access to accommodation would reduce costs for families travelling long distances to surgical centres.

Hospital Trusts

- Outreach centres at level 2 and 3 critical to success, with patients only attending Level 1 for surgery, pre and post operative appointments. Accommodation at level 1 centres key for family support. Concern that this approach underestimates the impact on patient travel for pre and post operative appointments for interventions, maternity or surgery unrelated to the patients' congenital condition.
- Assumptions in the travel times need to consider patient choice and the ability of other centres to cope with volumes

Public representatives (MPs, Councillors, OSCs)

- Most Lincolnshire patients would have to travel to Leeds which does not equate with stated additional journey times.
- Recommendation 10 of the Independent Reconfiguration Panel in 2013 [Advice of the Independent Reconfiguration Panel on Safe and Sustainable Proposals for Children's Congenital Heart Services - submitted to the Secretary of State for Health on 30 April 2013 and published on 12 June 2013] which states: "More detailed and accurate models of how patients will use services under options for change are required to inform a robust assessment of accessibility and the health impact of options so that potential mitigation can be properly considered"
- Many constituents are concerned with the continuity of their care and the additional burden of finding suitable alternative services and travel.

The NHS in the Devolved Administrations

- Patients and their families should have information on accommodation and travel options where they have to commute long distances. Appointments well in advance may help reduce costs for patients, family and carers.

VIEWS ON AND SUPPORT FOR THE ASSESSMENT OF THE IMPACT ON EQUALITIES AND HEALTH INEQUALITIES OF THE PROPOSALS

Children's Heart Charities

- Financial impact and cost of travel on deprived families

Respiratory Charities/Organisations

- The impact assessment excluded Paediatric respiratory services meaning the scale and impact of these proposals are unknown for this group.

- Proposals disadvantage one patient population whilst reconfiguring services for another and also breaches section 13H of the National Health Service Act 2006.

Hospital Trusts

- Need to take into account low income and disability issues. Key to reduce the number of appointments and need to travel. Concern that pregnant women haven't been properly considered.

Public representatives (MPs, Councillors, OSCs)

- Health inequality impacts affecting rural areas such as Lincolnshire. There are levels of rural deprivation in Lincolnshire where people are unable to access public services with ease, particularly reliable public transport. Also affects the East Midlands BAME population and patients with learning disabilities. There is a significant health inequalities gap between the North East and the rest of the country, both in terms of life expectancy and healthy life expectancy.

VIEWS AND SUPPORT FOR THE DESCRIPTION OF THE IMPACTS OF THE PROPOSALS ON OTHER SERVICES

Children's Heart Charities

- Concern around the slow speed of change causing uncertainty and service failure with a crisis of confidence in the need to change due to delays and recruitment and staffing issues.
- Joined up and better communication for regional services needed. PICU review will impact on CHD needs. Shared local and regional cardiology outpatient clinics would aid communication and confidence – invest in level 2 or the whole system will fail. A competent diagnostic and cardiology service must be maintained in the units where surgery is no longer offered. Capacity needs to reference the increased number of adult patients due to the success of paediatric cardiology
- Brompton needs to deliver a child focused hospital environment. Detrimental loss of research service if closed. Concerns that Evelina and Great Ormond Street Hospital would be able to cope with volume

Respiratory Charities/Organisations

- If surgery ceases at Royal Brompton then cystic fibrosis care and research will become unsustainable. Improved outcomes have resulted in a steadily growing cystic fibrosis population, whilst service provision has remained static.

- Steps to remedy the impact will only be considered after the decision has been taken. This will destabilize respiratory services at Royal Brompton.
- Frustration, upset, anger and fear of the cystic fibrosis community caused by the decision to enter full public consultation on the CHD proposals whilst the impact on respiratory services remains unquantified and out-of-scope.
- Proposals disregard the findings of the Independent Reconfiguration Panel's report dated 30 April 2013 on the "Safe and Sustainable" review's proposals (note also Pollitt Review, the respiratory 'consultation' exercise in 2012, and to the Independent Reconfiguration Panel in 2013)

Royal Colleges and Specialist Societies

- Children and adults with congenital heart disease should be able to access dental assessment, care and treatment by specialists and consultants in Paediatric dentistry and special care dentistry when required. There are a number of regions without the resources at present.
- There is a risk that units which are currently performing well may become too stretched when they take on the work of other units which are unable to meet the standards. The uncertainty created by recent events, the review and lack of a clear model could lead to difficulties in maintaining quality and safety of delivery or unplanned closures. Need to decide and act quickly.

Hospital Trusts

- The lengthy consultation process has caused instability and created problems like Manchester.
- Needs a capacity and demand evaluation to scope additional resources and identify capital requirements.
- Those Trusts who responded to the consultation were mainly those under the threat of closure or those likely to take additional CHD patients and be required to increase their resources if closures take place. This creates a contradictory synopsis for this group.

Public representatives (MPs, Councillors, OSCs)

- NHS England has failed to explain how mobile ECMO services will be provided in the future.
- Closure of the PICU at Glenfield (UHL) Hospital will impact the overall level of PICU bed availability in England.

- Will ECMO currently provided by East Midlands Congenital Heart Centre (EMCHC) (over 50% of the UK requirements) be delivered by the units spread across the country? It is proposed to dilute ECMO practice whilst using concentration of cardiac surgical practice as a rationale for service reconfiguration. This is in direct contrast to NHS England's own quote from Mr Martin Kostolony highlighted on page 12 of the consultation document.

The NHS in the Devolved Administrations

- It will be important to consider the review of ECMO services and paediatric intensive care which will affect CHD. For ECMO, will there be an expansion or revision of the network providers. Will the network be combined for respiratory and cardiac ECMO. Will there continue to be a respiratory ECMO network for adults and paediatrics. There would be merit in operating a combined respiratory and cardiac network, although it is acknowledged that there are currently differing commissioning arrangements for these services. Impact of Leicester closure on ECMO capacity needs to be established.
- Plans need to be developed to ensure that services are adequately provided, before implementing any changes, which may have an impact on other services (PICU, ECMO and respiratory services)

Other Responses

The following sets out the 'other responses' received to the consultation in terms of emails and documents. These responses have been coded for common themes (outlined within the frequency tables in this section). The themes have informed the previous section detailing the feedback by stakeholder category and have also informed the summary of findings at the start of this report.

Responses (outside of the survey) were received from 6 MPs, 7 Charities, 10 Councils, 7 NHS Trusts, 1 CCG, 1 Professional Association, 3 NHS members of staff, 6 patient groups (including 2 Healthwatchs), 1 Royal College, 1 University, 1 School, 1 Community Organisation, 1 Evaluation Organisation, 5 CHD Patients, 11 family members of CHD Patients and 13 members of the public. Some stakeholders provided more than one response from different respondents within their organisation. For this reason the number of stakeholder responses is greater than the number of stakeholders.

Letter and Email Response by Type of Respondent

Type of Respondent	Politicians & Stakeholders	Public	Total
Total Respondents	50	29	79
Effect on PICU (review needed) / bed capacity if centres close / network capacity / foetal / respiratory / ECMO	35	16	51
Would create substantial additional costs in other areas / funding for provider network and staffing	33	11	44
World renowned heart disease hospital / centre of excellence / Research / and should be retained	29	15	44
Unnecessary risk to patient safety	24	17	41
Adverse effect of travel on patient and family	20	19	39
Judge against excellent clinical outcomes and CQC results	22	13	35
Glenfield (UHL) is a world class centre of excellence / ECMO / mobile ECMO and should not be decommissioned	15	19	34
Could result in loss of specialist staff / resource	21	10	31
May affect the viability of providing other services	22	2	24
Every region should have a level 1 centre	12	10	22
Royal Brompton meets co-location with Chelsea and Westminster Hospital	17	3	20
Need to consider the increase in CHD and long term capacity needs when proposing closing surgical centres	16	4	20
Co-location is not clinically essential	14	4	18
Process is not transparent - not all documents have been made available / decisions to close taken before consultation	15	3	18
Poor evidence of cost savings and no cost benefit analysis undertaken	14	3	17
Consider the financial impact of travel and subsistence / deprived communities / reimburse	10	7	17
Need to remove uncertainty around Child and Adult CHD services as soon as possible	11	6	17
Brompton / Leeds / UHL / Manchester provides lifelong care and transition from child to adult	12	2	14
There is insufficient evidence that outcomes would improve with surgical centres undertaking 400 – 500 procedures per annum / could lead to unnecessary surgery	10	4	14
Develop networks of care and links between level 1 and 2 centres	14	0	14
Concern about special treatment of Newcastle - not meeting standards and unlikely to do so - legal challenge / inconsistency of approach	13	1	14
Standard should not be applied retrospectively (2016)	11	3	14

Type of Respondent	Politicians & Stakeholders	Public	Total
Total Respondents	50	29	79
Unfair rejection of UHL growth plan by NHSE	10	3	13
Unrealistic journey time quoted	9	3	12
Recognition that Newcastle provides specialist transplant services	10	1	11
Welcome a set of clinical standards developed from consultation	10	1	11
NHSE should develop a strategic model, gap analysis against existing structure then detailed implementation plan	10	1	11
UHL only fails on one standard which it will achieve by 2018/19	7	4	11
Need to consider impact on childs education from travelling to a centre in another region	5	5	10
How do you intend to support parents and carers when they are far away from home	6	4	10
Plans would restrict patient choice	5	5	10
NHSE should apply the same flexibility (Newcastle fails co-location and surgical numbers BUT has transplant service) and common sense to all sites which offer a specialist service	7	2	9
Changes need to be managed to reduce further uncertainty and instability	9	0	9
Need to consider travel impact of children with other disabilities / behaviour	6	3	9
Number of attendees to public meetings were limited / insufficient public meetings	4	4	8
Welcome emphasis on managed clinical networks, with a focus on improved outcomes and access, and care being delivered as close to home as possible	8	0	8
Publish travel data used	6	2	8
Royal Brompton provides CHD services to 8,000 adults and 4,500 children - a major part of the network capacity	7	1	8
Concern about ACHD facility in Manchester - need for rapid contingency plan	5	2	7
Committed to supporting delivery of CHD services	7	0	7
Provide a date for the decision to be made by	6	1	7
Failure to recognise patient expertise in the consultation	7	0	7
Concerns around the impact on patient transport	4	2	6
Conflict of interest - Prof Huon Gray and Dr Trevor Richens from Southampton Hospital are working in a	4	1	5

Type of Respondent	Politicians & Stakeholders	Public	Total
Total Respondents	50	29	79
national capacity for NHSE - need assurance			
None of the centres meet all the standards	3	2	5
NHSE should support these centres to achieve the standards	2	3	5
Brompton and UHL will not have the facility to offer level 2 services if level 1 is decommissioned	4	1	5
UHL meets / will meet co-location standard (proposal to move paediatric cardiac Level 1 services to Infirmary site)	2	2	4
Insufficient ability to answer questions in the survey	2	2	4
Concern about special treatment of Southampton - not meeting number standards and unlikely to do so	4	0	4
Standards are challenging and high quality and need to be met within set time frames	4	0	4
Consider poor public transport particularly in rural areas	4	0	4
Deal with issues in Bristol where children have died	0	4	4
Support commissioning of level 2 services in Manchester and Leicester	4	0	4
Concerns about engagement with BME communities / special schools in the consultation - translation has taken place	3	0	3
NHSE should hold talks over UHL growth plan which includes large catchment area	3	0	3
Reference to John Radcliffe Hospital in Oxford is irrelevant to UHL	3	0	3
Insufficient impact (on other services) assessment undertaken	3	0	3
Standards were not developed for the purpose of deciding closures	2	1	3
Manchester / Liverpool / Blackpool are excellent - provide a centre in North West	0	3	3
No address provided to respond to the consultation / online access not suitable for all	1	1	2
Inability to respond to consultations during Purdah	2	0	2
Leeds THT confident they can manage the additional capacity	2	0	2
Cases are being transferred away from UHL	2	0	2
Reassurance that timescales are feasible	1	1	2
NHSE will not permit supporting teams of gastroenterologists and general surgeons to work across more than one site, but will permit congenital cardiac surgeons to do so (e.g. between GOS and Bart's)	2	0	2

Type of Respondent	Politicians & Stakeholders	Public	Total
Total Respondents	50	29	79
Need as many specialist outreach clinics as possible to provide care close to home	1	1	2
Brompton was able to provide specialist services during the Grenfell fire disaster	2	0	2
North West congenital heart specialised services to all be located in Liverpool	2	0	2
Support the standards relating to the minimum surgical number of cases to be performed by individual surgeons	2	0	2
Unclear what level 2 services will look like	2	0	2
Will Trust be reimbursed for staff redundancy costs / TUPE	1	1	2
Consultation confusion caused instability leading to crisis in North West	1	1	2
Would affect a world leading research provider in a post Brexit economy	2	0	2
Leeds meets co-location with Leeds General Infirmary	1	0	1
Assured that the derogation process is transparent and fair	1	0	1
Consider the effect on already overstretched ambulance service	0	1	1
There would be two children's CHD (level 1) surgical centres in Birmingham	0	1	1
Request that consideration be given to allocating national funding to the network arrangement in Bristol	1	0	1
Consider flexibility of nursing hours to enable more surgical procedures	0	1	1
Need to consider telemedicine and pulse oximeters (for example) to reduce visits to hospital	1	0	1
Patients will travel for a better service / outcome	1	0	1
Have submitted a costed and workable expansion plan to increase our capacity and throughput for adult and paediatric CHD surgery / interventions and level 2 services if other providers are decommissioned	1	0	1
Support the co-location standard	1	0	1
Will work with Great Ormond Street Hospital NHS Foundation Trust and Guys and St Thomas' NHS Foundation Trust collaboratively if NHSE were to de-commission surgical services from the Royal Brompton site	1	0	1
Newcastle currently looking at options and costs to see how co-location can be achieved	1	0	1
New build at Newcastle is likely to take longer than the 2 year extension - need reassurance	1	0	1
Funding to support recruitment of additional specialist cardiology staff in order that the level 1 and 2 standards can be met	1	0	1

Type of Respondent	Politicians & Stakeholders	Public	Total
Total Respondents	50	29	79
Some interventional procedures e.g. ASD closures, should remain in Manchester	1	0	1
Pregnancy service in Manchester meets level 1 and co-located model - not so in Liverpool. Any move to Liverpool would need assurance on safety	1	0	1
What is the basis for the network of children's heart provision	1	0	1
Safe and Sustainable Review of Children's Heart Services" will not enable the provision of safe, sustainable and accessible services	1	0	1
Congenital cardiac surgery and interventional cardiology should only be provided by specialist teams large enough to sustain a comprehensive range of interventions, round the clock care, training and research	1	0	1
Safe and sustainable left too many questions about sustainability unanswered and to be dealt with as implementation risks	1	0	1
Review of children's and adult services should be combined	1	0	1
Patients should receive congenital heart surgery and interventional cardiology from teams with at least four full-time consultant congenital heart surgeons and appropriate numbers of other specialist staff to sustain a comprehensive range of interventions, round the clock care, training and research.	1	0	1
Before further considering options for change, the detailed work on the clinical model and associated service standards for the whole pathway of care must be completed to demonstrate the benefits for patients and how services will be delivered across each network	1	0	1
For the current service and any proposed options for change, the function, form, activities and location of specialist surgical centres, children's cardiology centres, district children's cardiology services, outreach clinics and retrieval services must be modelled and affordability retested.	1	0	1
NHS England should ensure that a clear programme of action is implemented to improve antenatal detection rates to the highest possible standard across England.	1	0	1
Further capacity analysis, including for paediatric intensive care units, should consider recent and predicted increases in activity, and patient flows.	1	0	1
NHS England must establish a systematic, transparent, authoritative and continuous stream of data and information about the performance of congenital heart services. These data and information should be available to the public and include performance on service standards, mortality and morbidity.	1	0	1
NHS England and the relevant professional associations should put in place the means to continuously review	1	0	1

Type of Respondent	Politicians & Stakeholders	Public	Total
Total Respondents	50	29	79
the pattern of activity and optimize outcomes for the more rare, innovative and complex procedures.			
NHS England should reflect on the criticisms of the JCPCT's assessment of quality and learn the lessons to avoid similar situations in its future commissioning of specialist services.	1	0	1
More detailed and accurate models of how patients will use services under options for change are required to inform a robust assessment of accessibility and the health impact of options so that potential mitigation can be properly considered.	1	0	1
Decisions about the future of cardiothoracic transplant and respiratory ECMO should be contingent on the final proposals for congenital heart services.	1	0	1
NHS England should assure itself that any wider implications for other services of final proposals are fully assessed and considered within a strategic framework for the provision of specialised services.	1	0	1
NHS England should develop a strategic framework for commissioning that reflects both the complex interdependencies between specialised services provision and population needs.	1	0	1
NHS England must ensure that any process leading to the final decision on these services properly involves all stakeholders throughout in the necessary work, reflecting their priorities and feedback in designing a comprehensive model of care to be implemented and the consequent service changes required.	1	0	1
NHS England should use the lessons from this review and create with its partners a more resource and time effective process for achieving genuine involvement and engagement in its commissioning of specialist services.	1	0	1
NHSE should either bring forward proposals for reconfiguration again or adopt a more standards-driven process that engages providers more directly in the managed evolution of services to be delivered	1	0	1

Letter and Email Response by Hospital / Area

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
Effect on PICU (review needed) / bed capacity if centres close / network capacity / foetal / respiratory / ECMO	1	0	25	1	1	1	22	51
Would create substantial additional costs in other areas / funding for provider network and staffing	0	0	19	2	0	2	21	44
World renowned heart disease hospital / centre of excellence / Research / and should be retained	2	0	15	0	0	1	26	44
Unnecessary risk to patient safety	1	0	18	1	3	0	18	41
Adverse effect of travel on patient and family	0	0	28	0	3	0	8	39
Judge against excellent clinical outcomes and CQC results	1	0	20	0	1	1	12	35
Glenfield (UHL) is a world class centre of excellence / ECMO / mobile ECMO and should not be decommissioned	1	0	33	0	0	0	0	34
Could result in loss of specialist staff / resource	2	0	14	0	1	0	14	31
May affect the viability of providing other services	0	0	6	0	1	0	17	24
Every region should have a level 1 centre	0	0	20	0	2	0	0	22
Royal Brompton meets co-location with Chelsea and Westminster Hospital	2	0	0	0	0	0	18	20
Need to consider the increase in CHD and long term capacity needs when proposing closing surgical centres	1	0	10	2	0	0	7	20
Co-location is not clinically essential	0	0	5	0	0	1	12	18
Process is not transparent - not all documents have been made available / decisions to close taken before consultation	1	0	8	0	1	0	8	18
Poor evidence of cost savings and no cost benefit analysis undertaken	0	0	4	1	0	1	11	17
Consider the financial impact of travel and subsistence / deprived communities / reimburse	1	0	13	0	1	0	2	17

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
Need to remove uncertainty around Child and Adult CHD services as soon as possible	2	0	8	1	2	0	4	17
Brompton / Leeds / UHL / Manchester provides lifelong care and transition from child to adult	1	0	2	1	1	0	9	14
There is insufficient evidence that outcomes would improve with surgical centres undertaking 400 – 500 procedures per annum / could lead to unnecessary surgery	1	0	11	1	0	0	1	14
Develop networks of care and links between level 1 and 2 centres	2	1	3	0	2	0	6	14
Concern about special treatment of Newcastle - not meeting standards and unlikely to do so - legal challenge / inconsistency of approach	0	0	10	2	0	0	2	14
Standard should not be applied retrospectively (2016)	1	0	13	0	0	0	0	14
Unfair rejection of UHL growth plan by NHSE	1	0	12	0	0	0	0	13
Unrealistic journey time quoted	0	0	12	0	0	0	0	12
Recognition that Newcastle provides specialist transplant services	2	0	4	2	0	2	1	11
Welcome a set of clinical standards developed from consultation	3	0	4	1	1	0	2	11
NHSE should develop a strategic model, gap analysis against existing structure then detailed implementation plan	2	0	2	0	2	0	5	11
UHL only fails on one standard which it will achieve by 2018/19	1	0	10	0	0	0	0	11
Need to consider impact on childs education from travelling to a centre in another region	0	0	9	0	1	0	0	10

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
How do you intend to support parents and carers when they are far away from home	0	0	10	0	0	0	0	10
Plans would restrict patient choice	1	0	5	0	1	1	2	10
NHSE should apply the same flexibility (Newcastle fails co-location and surgical numbers BUT has transplant service) and common sense to all sites which offer a specialist service	1	0	6	0	0	0	2	9
Changes need to be managed to reduce further uncertainty and instability	2	0	2	1	1	1	2	9
Need to consider travel impact of children with other disabilities / behaviour	0	0	5	0	1	0	3	9
Number of attendees to public meetings were limited / insufficient public meetings	0	0	8	0	0	0	0	8
Welcome emphasis on managed clinical networks, with a focus on improved outcomes and access, and care being delivered as close to home as possible	1	1	1	1	1	0	3	8
Publish travel data used	0	0	8	0	0	0	0	8
Royal Brompton provides CHD services to 8,000 adults and 4,500 children - a major part of the network capacity	1	0	0	0	0	0	7	8
Concern about ACHD facility in Manchester - need for rapid contingency plan	2	0	1	2	2	0	0	7
Committed to supporting delivery of CHD services	1	0	1	0	1	1	3	7
Provide a date for the decision to be made by	2	0	3	0	2	0	0	7
Failure to recognise patient expertise in the consultation	2	0	0	0	0	0	5	7
Concerns around the impact on patient transport	0	0	4	1	0	0	1	6

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
Conflict of interest - Prof Huon Gray and Dr Trevor Richens from Southampton Hospital are working in a national capacity for NHSE - need assurance	0	0	3	0	0	0	2	5
None of the centres meet all the standards	0	0	4	0	0	0	1	5
NHSE should support these centres to achieve the standards	0	0	4	0	0	0	1	5
Brompton and UHL will not have the facility to offer level 2 services if level 1 is decommissioned	1	0	2	0	0	0	2	5
UHL meets / will meet co-location standard (proposal to move paediatric cardiac Level 1 services to Infirmary site)	0	0	4	0	0	0	0	4
Insufficient ability to answer questions in the survey	0	0	3	0	1	0	0	4
Concern about special treatment of Southampton - not meeting number standards and unlikely to do so	0	0	4	0	0	0	0	4
Standards are challenging and high quality and need to be met within set time frames	2	0	0	1	0	0	1	4
Consider poor public transport particularly in rural areas	0	0	4	0	0	0	0	4
Deal with issues in Bristol where children have died	0	0	4	0	0	0	0	4
Support commissioning of level 2 services in Manchester and Leicester	2	0	1	0	1	0	0	4
Concerns about engagement with BME communities / special schools in the consultation - translation has taken place	1	0	1	1	0	0	0	3
NHSE should hold talks over UHL growth plan which includes large catchment area	0	0	3	0	0	0	0	3
Reference to John Radcliffe Hospital in Oxford is irrelevant to UHL	0	0	3	0	0	0	0	3
Insufficient impact (on other services) assessment	0	0	1	0	0	0	2	3

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
undertaken								
Standards were not developed for the purpose of deciding closures	0	0	2	0	0	0	1	3
Manchester / Liverpool / Blackpool are excellent - provide a centre in North West	0	0	0	0	3	0	0	3
No address provided to respond to the consultation / online access not suitable for all	0	0	1	0	0	0	1	2
Inability to respond to consultations during Purdah	0	0	2	0	0	0	0	2
Leeds THT confident they can manage the additional capacity	0	0	0	2	0	0	0	2
Cases are being transferred away from UHL	0	0	2	0	0	0	0	2
Reassurance that timescales are feasible	0	0	0	0	1	0	1	2
NHSE will not permit supporting teams of gastroenterologists and general surgeons to work across more than one site, but will permit congenital cardiac surgeons to do so (e.g. between GOS and Bart's)	0	0	0	0	0	0	2	2
Need as many specialist outreach clinics as possible to provide care close to home	1	0	1	0	0	0	0	2
Brompton was able to provide specialist services during the Grenfell fire disaster	0	0	0	0	0	0	2	2
North West congenital heart specialised services to all be located in Liverpool	1	0	0	0	1	0	0	2
Support the standards relating to the minimum surgical number of cases to be performed by individual surgeons	1	0	0	0	0	1	0	2
Unclear what level 2 services will look like	0	0	0	0	0	1	1	2
Will Trust be reimbursed for staff redundancy costs / Tupe	0	0	1	0	0	0	1	2

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
Consultation confusion caused instability leading to crisis in North West	0	0	0	0	2	0	0	2
Would affect a world leading research provider in a post Brexit economy	0	0	1	0	0	0	1	2
Leeds meets co-location with Leeds General Infirmary	0	0	0	1	0	0	0	1
Assured that the derogation process is transparent and fair	0	0	0	1	0	0	0	1
Consider the effect on already overstretched ambulance service	0	0	1	0	0	0	0	1
There would be two children's CHD (level 1) surgical centres in Birmingham	0	0	1	0	0	0	0	1
Request that consideration be given to allocating national funding to the network arrangement in Bristol	0	1	0	0	0	0	0	1
Consider flexibility of nursing hours to enable more surgical procedures	0	0	1	0	0	0	0	1
Need to consider telemedicine and pulse oximeters (for example) to reduce visits to hospital	1	0	0	0	0	0	0	1
Patients will travel for a better service / outcome	1	0	0	0	0	0	0	1
Have submitted a costed and workable expansion plan to increase our capacity and throughput for adult and paediatric CHD surgery / interventions and level 2 services if other providers are decommissioned	1	0	0	0	0	0	0	1
Support the co-location standard	1	0	0	0	0	0	0	1
Will work with Great Ormond Street Hospital NHS Foundation Trust and Guys and St Thomas' NHS Foundation Trust collaboratively if NHSE were to de-commission surgical services from the Royal Brompton site	1	0	0	0	0	0	0	1

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
Newcastle currently looking at options and costs to see how co-location can be achieved	0	0	0	0	0	1	0	1
New build at Newcastle is likely to take longer than the 2 year extension - need reassurance	0	0	0	0	0	1	0	1
Funding to support recruitment of additional specialist cardiology staff in order that the level 1 and 2 standards can be met	0	0	0	0	1	0	0	1
Some interventional procedures e.g. ASD closures, should remain in Manchester	0	0	0	0	1	0	0	1
Pregnancy service in Manchester meets level 1 and co-located model - not so in Liverpool. Any move to Liverpool would need assurance on safety	0	0	0	0	1	0	0	1
What is the basis for the network of children's heart provision	0	0	1	0	0	0	0	1
Safe and Sustainable Review of Children's Heart Services" will not enable the provision of safe, sustainable and accessible services	1	0	0	0	0	0	0	1
Congenital cardiac surgery and interventional cardiology should only be provided by specialist teams large enough to sustain a comprehensive range of interventions, round the clock care, training and research	1	0	0	0	0	0	0	1
Safe and sustainable left too many questions about sustainability unanswered and to be dealt with as implementation risks	1	0	0	0	0	0	0	1
Review of children's and adult services should be combined	1	0	0	0	0	0	0	1

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
Patients should receive congenital heart surgery and interventional cardiology from teams with at least four full-time consultant congenital heart surgeons and appropriate numbers of other specialist staff to sustain a comprehensive range of interventions, round the clock care, training and research.	1	0	0	0	0	0	0	1
Before further considering options for change, the detailed work on the clinical model and associated service standards for the whole pathway of care must be completed to demonstrate the benefits for patients and how services will be delivered across each network	1	0	0	0	0	0	0	1
For the current service and any proposed options for change, the function, form, activities and location of specialist surgical centres, children's cardiology centres, district children's cardiology services, outreach clinics and retrieval services must be modelled and affordability retested.	1	0	0	0	0	0	0	1
NHS England should ensure that a clear programme of action is implemented to improve antenatal detection rates to the highest possible standard across England.	1	0	0	0	0	0	0	1
Further capacity analysis, including for paediatric intensive care units, should consider recent and predicted increases in activity, and patient flows.	1	0	0	0	0	0	0	1
NHS England must establish a systematic, transparent, authoritative and continuous stream of data and information about the performance of congenital heart services. These data and information should be available to the public and include performance on service standards, mortality and morbidity.	1	0	0	0	0	0	0	1

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
NHS England and the relevant professional associations should put in place the means to continuously review the pattern of activity and optimize outcomes for the more rare, innovative and complex procedures.	1	0	0	0	0	0	0	1
NHS England should reflect on the criticisms of the JCPCT's assessment of quality and learn the lessons to avoid similar situations in its future commissioning of specialist services.	1	0	0	0	0	0	0	1
More detailed and accurate models of how patients will use services under options for change are required to inform a robust assessment of accessibility and the health impact of options so that potential mitigation can be properly considered.	1	0	0	0	0	0	0	1
Decisions about the future of cardiothoracic transplant and respiratory ECMO should be contingent on the final proposals for congenital heart services.	1	0	0	0	0	0	0	1
NHS England should assure itself that any wider implications for other services of final proposals are fully assessed and considered within a strategic framework for the provision of specialised services.	1	0	0	0	0	0	0	1
NHS England should develop a strategic framework for commissioning that reflects both the complex interdependencies between specialised services provision and population needs.	1	0	0	0	0	0	0	1

Hospital / Area	National	Bristol	Glenfield (UHL)	Leeds	Manchester	Newcastle	Royal Brompton	Total
Total Respondents	4	1	38	2	5	2	27	79
NHS England must ensure that any process leading to the final decision on these services properly involves all stakeholders throughout in the necessary work, reflecting their priorities and feedback in designing a comprehensive model of care to be implemented and the consequent service changes required.	1	0	0	0	0	0	0	1
NHS England should use the lessons from this review and create with its partners a more resource and time effective process for achieving genuine involvement and engagement in its commissioning of specialist services.	1	0	0	0	0	0	0	1
NHSE should either bring forward proposals for reconfiguration again or adopt a more standards-driven process that engages providers more directly in the managed evolution of services to be delivered	1	0	0	0	0	0	0	1

Glossary

The following sets out a glossary of acronyms used within this report.

TERM/ACRONYM	DESCRIPTION
ACHD	Adult Congenital Heart Disease
ANAESTHETICS	Procedures that makes a person unable to feel pain
BAME	Black, Asian, Minority Ethnic residents of the UK
CARDIOLOGY	The branch of medicine that deals with diseases and abnormalities of the heart
CHD	Congenital Heart Disease
ECMO	Extra Corporeal Membrane Oxygenation
ELECTROPHYSIOLOGY	The study of the production of electrical activity and the effects of that electrical activity on the body
EXTRACORPOREAL	Outside of the body
EMCHC	East Midlands Congenital Heart Centre
FETAL MEDICINE	Branch of medicine that focuses on managing health concerns of the mother and fetus prior to, during, and shortly after pregnancy
GLENFIELD (UHL)	University Hospitals of Leicester NHS Trust
GOSH	Great Ormond Street Hospital
MANCHESTER	Central Manchester University Hospitals NHS Foundation Trust
NEWCASTLE	Newcastle Upon Tyne Hospitals NHS Foundation Trust
PAEDIATRIC	Branch of medicine dealing with children and their diseases
PICU	Paediatric Intensive Care Unit
PULMONARY HYPERTENSION	A type of high blood pressure that affects the arteries in your lungs and the right side of your heart
RADIOLOGY	A branch of medicine concerned with the use of radiant energy (such as X-rays) or radioactive material in the diagnosis and treatment of disease
RESPIRATORY	Relating to or affecting respiration (breathing) or the organs of respiration
ROYAL BROMPTON	Royal Brompton & Harefield NHS Foundation Trust
VAD	Ventricular assist device - a mechanical pump that takes over the function of the damaged ventricle of the heart and restores normal blood flow

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The Leeds Teaching Hospitals NHS Trust

LEEDS TEACHING HOSPITALS NHS TRUST

Future Commissioning Arrangements for Congenital Heart Disease (CHD) Patients: response to the NHS England (NHSE) Board decision on 30 November

At its meeting on 30 November NHSE Board confirmed the future commissioning arrangements for CHD services in England following a period of public consultation.

The Level 1 Surgical Centre in Leeds

In terms of the service provided by Leeds Teaching Hospital Trust (LTHT) NHSE was satisfied in July 2016 that LTHT was meeting the majority of the national standards and service specifications, or had robust plans in place to meet them within the prescribed timescales. The consultation which was launched in February 2017 was focused primarily on four Level 1 Centres, which had been assessed as unlikely to meet the standards. In effect the meeting on 30 November was the final formal ratification that NHSE would continue to commission CHD services from LTHT.

It has been a challenging nine years for patients, families, staff and supporters of the CHD service in Leeds since NHSE launched the Safe and Sustainable Review of Children's CHD services in England in 2008. We are very grateful for the unwavering support we have received from so many quarters during this period, and it is appropriate to acknowledge the role played by the Joint Health Overview and Scrutiny Committee (JHOSC), Children's Heart Surgery Fund (CHSF) and numerous elected representatives from across Yorkshire and the Humber in securing the future of the centre in Leeds. Our staff have been outstanding and have continued to provide world class treatment and care for our patients throughout this period, as demonstrated by our excellent clinical outcomes and feedback both formally and informally from our patients and their families.

Focusing on the future

Our focus is now very much on the future and there are a number of exciting developments underway. Work has started in November on the children's theatre complex at Leeds General Infirmary, to create a new cardiac operating theatre with state of the art hybrid operating facilities. This will enable surgeons and interventional cardiologists to operate together on the most complex of cases and we are grateful to the Leeds Teaching Hospital Charitable Foundation and CHSF for funding this development.

We have also invested in key personnel to enable us to strengthen our CHD Network across the Yorkshire and Humber. We provide services in partnership with 17 Local Cardiology Centres across

the Yorkshire and Humber, and our aim is to provide care as close to home as possible and to ensure equitable and timely access to the highest quality CHD care for all our patients. Within the last six months we have appointed a Lead Clinician, General Manager and Lead Nurse to take forward this important work across out Network.

We are busy increasing our research and teaching portfolio. We are involved in the training of nursing and medical staff at a national and international level, and our staff are regularly invited to lecture at conferences. In 2017 we organised our first CHD nursing conference and this is to be repeated in 2018.

The decisions relating to other Level 1 Centres

The focus of the decision on 30 November was on the 4 Level 1 centres which were assessed as being unable to meet the standards. These decisions are relevant to LTHT as three out of the four centres border on our own Yorkshire and Humber Network. The decisions were are as follows

- To commission Liverpool Heart and Chest Hospital NHS Foundation Trust to provide Level 1 adult CHD Services in the North West CHD Network.
- To continue to commission University Hospital Leicester NHS Trust to provide Level 1 CHD services conditional on achieving full compliance with the standards in line with their own plan to do so
- To continue to commission Level 1 CHD services from Newcastle upon Tyne Hospitals NHS Foundation Trust until at least 2021. In the meantime NHSE will give further consideration to the commissioning of its advanced heart failure and transplant service and its Level 1 CHD service
- To back the Royal Brompton and Harefield NHS Foundation Trust's ambitious new outline proposal to work with Guy's and St Thomas' hospitals to provide co-located adults and children's CHD services as part of St Thomas' Westminster Bridge Campus

In terms of the situation in the North West, the adult CHD (ACHD) service in Manchester was suspended by the trust in June due to consultant workforce shortages. Since then interim arrangements have been put in place for patients who would normally be seen by the Manchester team to be seen by the clinical teams in Leeds, Newcastle and Birmingham. It is not clear how long it will take for the North West Network to establish its new ACHD arrangements and how long these interim plans will be required. We are in regular dialogue with NHSE about the impacts on the service in Leeds and will keep the situation under review.

Newcastle is one of the smallest providers in England and does not believe it will have enough activity to support a team of four surgeons each performing 125 operations a year as required by the standards from April 2021. There are only two hospitals that do heart transplants on children and it is the main hospital in England for adult transplants, and obviously these services would be lost if Newcastle was decommissioned as a Level 1 Centre. NHSE is therefore taking further time to consider the commissioning position in respect of Newcastle beyond 2021. Again this leaves a degree of uncertainty about the final configuration of CHD services in the north of England.

In summary

In summary we are pleased that the status of the CHD service in Yorkshire and the Humber has been confirmed with the NHSE decision to continue to commission services from the Level 1 Centre in Leeds. We can now focus exclusively on the future and ensuring that we continue to provide world class services for children and adults with CHD across the Yorkshire and Humber for years to come. We are looking forward to working with our partner Trusts across the Network, with CHSF, and our patients and their families to make sure that our services are as responsive as possible. There is still the possibility of further changes in the circumstances of Level 1 Centres around us, which may have relevance for our services in Yorkshire and the Humber, and we obviously need to monitor these and respond appropriately.

Leeds Teaching Hospitals

December 2017

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CHILDREN'S HEART SURGERY FUND

REPORT TO YORKSHIRE AND THE HUMBER JOINT HOSC MEETING

12th January 2018

Final Assurance for Future of Leeds CHD Unit

CHSF is delighted that following the latest review of Congenital Heart Disease (CHD) services by NHS England (NHSE), all aspects of the Leeds service are described as either meeting all the requirements or will meet them with further development of its plans.

This is final confirmation following the decision made in 2016 to keep commissioning CHD services from Leeds. It puts the Leeds Unit in the same category as most of the other services in England and ahead of some that need to do more to meet the standards. When the assessment was undertaken, no centres met all the standards.

This brings to a close nearly ten years of uncertainty following the launch of the Safe and Sustainable Review in 2008 which considered the future of the CHD services in England. When it reported in 2012 it recommended the closure of the Leeds Unit. The following year the outcome of the Review was scratched by the Secretary of State and a new Review started based on Units having to meet set standards over a period of time.

Over this long period CHSF, and the thousands of patients and family members on whose behalf it works, has been sustained in its campaigning to keep open the Leeds Unit by the enthusiastic support of members of the Joint HOSC along with MPs, Peers, councillors, local government officers and many others from all around Yorkshire and The Humber. This support has meant a huge amount to the charity and to all the patients and their families, as well as all the staff on the Unit and we are very grateful for it.

Potential Impact on Leeds of Outcome for Other Units

The Review confirmed the closure of the Manchester Unit, which has already ceased operating, but granted a reprieve for the one at Leicester which had been threatened with closure. Continued commissioning from Leicester depends on "convincing progress" being made around staffing and co-location. The Trust does not currently have sufficient activity to meet the 2021 staffing standard of four surgeons each performing a minimum of 125 procedures each year. Leicester's plan is that this would be achieved by 2021. It also has a plan to ensure that paediatric CHD services are co-located with other children's services by July 2019.

The Review re-asserted that the Newcastle Unit will stay open based on its specialist provision of paediatric heart transplants until at least March 2021, but further consideration will be given to the future of its CHD and transplant services for the longer term. It is considered that Newcastle is unlikely to meet the 2021 requirement of four surgeons each undertaking at least 125 operations per year. There is an issue with the reliance of the transplant service on one senior surgeon and what might happen after he retires. NHSE said that more information will be requested from the Trust.

The CHD provision at Liverpool is confirmed meaning that that there are three centres covering the North.

With Leicester staying open, there will be less increased activity at Leeds resulting from the Review, although there will still be some from the closure of the Manchester Unit. With some level of uncertainty hanging over Newcastle, and maybe to a lesser extent, Leicester, Leeds may need to look to consider what extra numbers of patients it could take and, if required, how its capacity could be expanded in the future. This might include whether it would be in a position to take on the transplant work currently provided at Newcastle. The only other paediatric heart transplant centre in England is at Great Ormand Street.

Leeds Heart Unit Goes From Strength to Strength

The certainty given to the Leeds Unit has enabled it to focus on its own development.

In 2016/17 there were 422 surgical activities at Leeds which is down on previous years although there is always variability at all centres. Both the Unit and NHSE are confident it will be able to support a team of four surgeons each undertaking at least 125 operations a year from April 2021, which was one of the key standards.

In the table of survival rates for paediatric surgery 2012-15, Leeds had a 97.9% rate which was virtually the average for all centres.

The heart unit is looking at a bright future:

- Construction begins on a revolutionary, new children's heart theatre in January and will be finished in February 2019.

- The Unit will be working with other Local Cardiology Centres across Yorkshire and The Humber to facilitate treating patients as close to their home as possible. The aim is to have equity of access with everyone having care of the highest quality no matter how old they are and where they live.

- A pioneering new procedure is taking place as consultants at the Unit have adapted a procedure used to treat adult heart attack patients to save new born babies with congenital heart disease. The practice of using coronary stents is being used to treat a potentially life-threatening obstruction of flow of blood to the lungs in new born babies. It's now a preferred alternative to heart surgery, and represents the first time a keyhole technique has been proven to give superior results to surgery.

- Patients with more complex surgical needs who previously needed to be referred to London are now being treated at the Unit.

- New staff have been recruited in psychology, and there is an increase in specialist cardiac nurses.

The Children's Heart Surgery Fund Continues To Support the Unit

- We have approved over £400k worth of grants to the Heart Unit this year.

- We have pledged £1.25 million towards the new heart theatre under a campaign called Keeping the Beat (www.chsf.org.uk/keeping-the-beat/). Supporters have raised the majority of a further £500,000 towards equipment and infrastructure and we are almost on target.

- The charity funded one of the consultants, Dr Bentham, to undertake a fellowship year in Boston, USA where he learnt some of the techniques intrinsic to the pioneering stent procedure.

- Dickie Bird has become our most recent Ambassador. He has undertaken ward visits meeting patients, their families and staff giving them all a huge boost. On top of that, he has generously donated £30,000 of his own money towards the Keeping The Beat fund.

- Thanks to generous donations from all our supporters we will be celebrating our 30th anniversary of supporting patients and their families in the new year.

Sharon Coyle
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Children's Heart Surgery Fund

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Report author: Steven Courtney
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Report of Head of Governance and Scrutiny Support

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

Date: 12 January 2018

Subject: The Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber): Summary of activity and the future role

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: Appendix number:	☐ Yes	☒ No

1 Purpose of this report

1.1 The purpose of this report is to present an activity summary of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber), alongside other key events, from January 2011; and provide an opportunity for JHOSC members to consider its future role.

2 Background

2.1 In March 2011, a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – the JHOSC – was established to consider the emerging proposals from the Safe and Sustainable Review of Children's Congenital Cardiac Services in England and the options for public consultation agreed by the Joint Committee of Primary Care Trusts (JCPCT).

2.2 At that time, the terms of reference identified that purpose of the JHOSC's work was to make an assessment of, and where appropriate, make recommendations on the potential options to reconfigure the delivery of Children's Congenital Heart Services in England. It was highlighted that this would specifically include consideration of the:

- Review process and formulation of options presented for consultation;
- Projected improvements in patient outcomes and experience;
- Likely impact on children and their families (in the short, medium and longer-term), in particular in terms of access to services and travel times;
- Views of local service users and/or their representatives;

- Potential implications and impact on the health economy and the economy in general, on a local and regional basis;
- Any other pertinent matters that arise as part of the Committee's inquiry.

2.3 Consideration was also given to the adequacy of the arrangements for consulting on the proposals, which was the subject of an unsuccessful referral to the Secretary of State for Health in October 2011.

2.4 Following the JCPCT's decision on the proposed future model of care and designation of surgical centres on 4 July 2012, in November 2012 the JHOSC referred the JCPCT's decision to the Secretary of State for Health. This was subsequently passed to the Independent Reconfiguration Panel (IRP) for consideration and advice, which was reported to the Secretary of State for Health at the end of April 2013.

2.5 On 12 June 2013, an announcement from the Secretary of State for Health accepted the IRP's report and recommendations in full and called a halt to the Safe and Sustainable review of Children's Congenital Cardiac Services in England.

2.6 A new CHD review, covering the whole lifetime pathway of care, commenced in July 2013 and public consultation on proposed CHD service specifications and draft standards took place between September 2014 and December 2014.

2.7 In mid-2015 NHS England agreed and published the new set of quality standards for all hospitals providing congenital heart disease.

2.8 In February 2017, launched a public consultation on how the agreed quality standards should be implemented. The proposals were considered by the Joint Health Overview and Scrutiny Committee (Yorkshire and Humber) at its meeting on 5 July 2017.

2.9 A summary timeline of the JHOSCs activity and key events is presented at Appendix 1 and details of the JHOSCs Terms of Reference (as amended in December 2013) are presented at Appendix 2.

3 Main issues

3.1 The work of the JHOSC has been undertaken over an extended time period of approximately 7-years. This has exceeded any expectations when the JHOSC was first established in March 2011 and covered the new review of Congenital Cardiac Disease (commenced in July 2013).

3.2 Elsewhere on the agenda, the JHOSC will consider NHS England's decision on the future commissioning arrangements for Congenital Heart Disease Services for Adults and Children in England, which can be summarised by the following recommendations agreed by the NHS England Board at its meeting on 30 November 2017:

1. *Note the results of the consultation;*
2. *Note the assurances that due process has been followed and that it may appropriately proceed to take decisions;*

3. *Agree the recommendations for changes to the provision of level 1 and level 2 adult and paediatric CHD services and the associated implementation schedules; and*
4. *Agree the proposals for full implementation of all the standards, and in particular confirm its support for the recommendations relating to better information, formal CHD networks and peer review.*

3.3 As such, NHS England's new CHD review could essentially be considered to be complete and is summarised by the following extract from the report submitted to the NHS England Board at its meeting on 30 November 2017:

'We have made a series of recommendations for changes to services for people with CHD. Ultimately, the aim of all our work has been to improve the care that patients receive. We believe that if these recommendations are implemented they will mean that, in time, every hospital will be brought up to the level of the very best in every aspect of care. It will mean that every child with CHD receives their care in a hospital that offers a holistic children's environment, with all the facilities and other specialists on site and readily able to contribute to their care. It will mean that all CHD surgeons and interventional cardiologists are doing enough procedures to develop and maintain their skills, and they will be part of teams large enough to provide full 24 hour / seven day care, resilient enough to continue to do so, even if one of the team leaves or is away for some reason. Occasional practice by non-specialists will be a thing of the past. Over time the full range of standards will be implemented with the help of more formal networked working, and including better information, communication and support which patients told us is so important. Commissioners, hospitals and patients alike will have access to a wider range of measures that can tell us all how well services are doing and help inform further improvements.'

3.4 The details in this report and the associated attachments are presented to the JHOSC to provide an opportunity for members of the JHOSC to formally review its work and consider its future role.

4 Recommendations

4.1 The Joint Committee is asked to consider the details set out this report and consider the future role of the JHOSC.

5 Background papers[1]

5.1 None used

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

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APPENDIX 1

Review of Congenital Heart Disease in England

Timeline (from January 2011)

Event	Date
Regional Health Scrutiny Network meeting, supported by Centre for Public Scrutiny (CfPS) including a discussion around Safe and Sustainable Review of Children's Congenital Cardiac Surgery Services and the establishment of a Joint Scrutiny Committee to consider the proposals and respond to any consultation. Chaired by Cllr Mark Dobson.	January 2011
Joint Committee of Primary Care Trusts (JCPCT) agrees outline business case and basis for public consultation	February 2011
Public consultation around the future of Children's Congenital Heart Services in England launched	March 2011
Joint Health Overview and Scrutiny Committee (Yorkshire and Humber) (Joint HOSC) formally established	March 2011
New JHOSC Chair appointed (Cllr Mulherin)	May 2011
Consultation period for HOSCs extended to October 2011	June 2011
Public consultation on proposals closes	July 2011
Royal Brompton and Harefield NHS Foundation Trust granted a judicial review on options for consultation	July 2011
JHOSC submits consultation response	October 2011
Consultation period for HOSCs closes	October 2011
JHOSC submits formal report to JCPCT	October 2011
JHOSC refers matter to Secretary of State on basis of inadequate consultation	October 2011
Judicial review finds in favour of Royal Brompton and Harefield NHS Foundation Trust	November 2011
JCPCT lodges appeal against judicial review ruling	November 2011
JHOSC referral passed to the Independent Reconfiguration Panel (IRP) for initial advice	December 2011

APPENDIX 1

Event	Date
JCPCT granted leave to appeal against judicial review	January 2012
Secretary of State for Health accepts IRP initial assessment of JHOSC referral. No full review undertaken	February 2012
Court of Appeal hearing	March 2012
Judicial Review ruling over-turned on appeal	April 2012
JHOSC Statement: Testing the assumptions around patient flows and manageable clinical networks	April 2012
New JHOSC Chair appointed (Cllr Illingworth)	May 2012
JCPCT decision-making meeting	July 2012
JHOSC agrees (in principal) to formally refer the JCPCT decision to the Secretary of State for Health	July 2012
Children's Heart Surgery Fund (CHSF) commences proceedings against JCPCT decision. Action brought by Save Our Surgery Ltd.	September 2012
Secretary of State for Health announce full IRP review of JCPCT decision	October 2012
JHOSC finalise referral to Secretary of State for Health, which is incorporated into full review	November 2012
IRP meeting with JHOSC	January 2013
Judicial Review hearing	February 2013
High Court ruling finds in favour of Save Our Surgery Ltd. and states JCPCT decision unlawful and fundamentally flawed	March 2013
Temporary suspension of Children's Cardiac Surgery at LTHT (following visit from Sir Bruce Keogh)	March 2013
Rapid review of services at LTHT. Report considered by risk summit and decision to recommence Children's Cardiac Surgery at LTHT	April 2013

APPENDIX 1

Event	Date
NHS England announces second stage review of Children's Cardiac Surgery Services at LTHT. Review to include 3 elements: • Mortality review; • Parental/ family concerns; • Professional concerns (from other units)	April 2013
NHS England announce decision to appeal against the High Court ruling	April 2013
IRP report issued to Secretary of State for Health	April 2013
Secretary of State for Health accepts IRP report, findings and recommendations in full and 'halts' Safe & Sustainable review	June 2013
NHS England submit proposals for undertaking a new review covering congenital heart services to both children and adults.	July 2013
New Congenital Heart Disease (CHD) review commences. Target date for completion June 2014	July 2013
JHOSC agrees revised / new Terms of Reference	December 2013
NHS England publishes elements of the second stage review of Children's Cardiac Surgery Services at LTHT, covering: • Mortality review; and, • Parental/ family concerns (published as 'Family Experience')	March 2014
NHS England advise JHOSC that third element of second stage review (i.e. covering professional concerns (from other units)) to be completed and published mid-May 2014	April 2014
New JHOSC Chair appointed (Cllr Coupar)	May 2014
NHS England report **best case scenario** for consultation launch on standards as mid/late September 2014.	June 2014
Public consultation around proposed CHD service standards and specifications commences.	September 2014
JHOSC advised that third element of second stage review (i.e. covering professional concerns (from other units)) to be completed and published November 2014	October 2014

APPENDIX 1

Event	Date
NHSE publishes third element of second stage review (i.e. covering professional concerns (from other units)) and overarching report.	October 2014
JHOSC considers third element of second stage review (i.e. covering professional concerns (from other units)) and overarching report.	November 2014
JHOSC considers proposed CHD service standards and specifications and input of stakeholders.	November 2014
JHOSC submits its response to the proposed CHD service standards and specifications	December 2014
Public consultation around proposed CHD service standards and specifications closes.	December 2014
New JHOSC Chair appointed (Cllr Gruen)	May 2015
NHSE agree the proposed model of care, and desirable standards and service specifications.	July 2015
NHS England publishes proposed actions to ensure hospital trusts providing CHD services complied with the agreed standards – subject to any necessary public consultation.	July 2016
NHSE launches public consultation on implementing new standards for CHD services in England (due to close 9 June 2017).	February 2017
General Election announced.	April 2017
New JHOSC Chair appointed (Cllr Hayden)	May 2017
NHSE extend consultation period (due to General Election and 'purdah' period) to 17 June 2017.	May 2017
JHOSC meets to consider proposals and submits response.	June 2017
NHSE decision on future delivery of CHD services (30 November 2017).	November 2017
JHOSC review of NHSE decision and local implications (planned meeting 12 January 2018)	January 2018

Steven Courtney
Principal Scrutiny Adviser, Leeds City Council

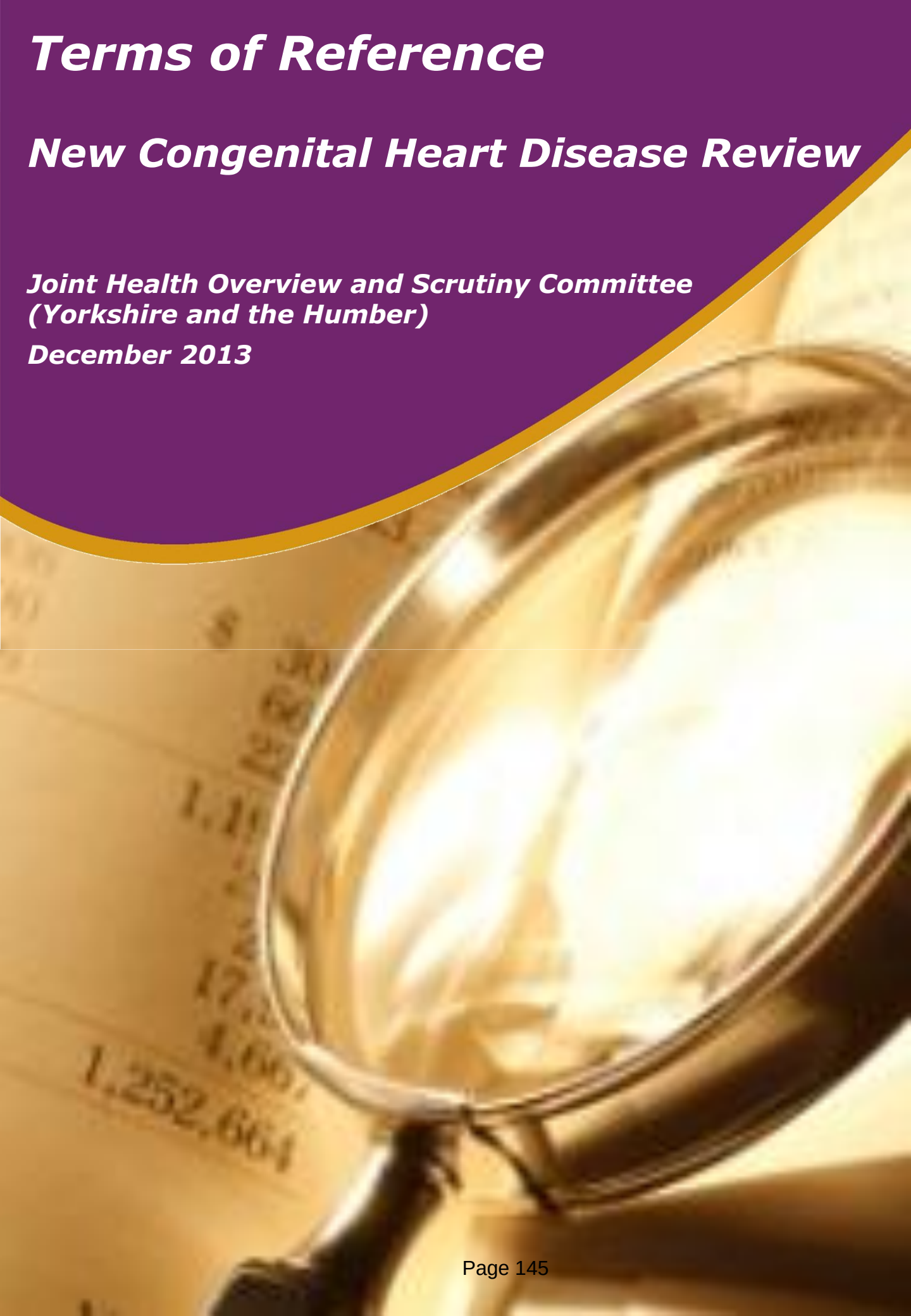
December 2017

Terms of Reference

New Congenital Heart Disease Review

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

December 2013



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

INQUIRY INTO THE NEW REVIEW OF CONGENITAL HEART DISEASE (CHD) SERVICES IN ENGLAND

TERMS OF REFERENCE

1.0 Introduction

1.1 In March 2011, a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – the JHOSC, was established to consider the emerging proposals from the Safe and Sustainable Review of Children's Congenital Cardiac Services in England and the options for public consultation agreed by the Joint Committee of Primary Care Trusts (JCPCT).

1.2 The membership for the JHOSC shall made in accordance with the Joint Health Scrutiny Protocol (Yorkshire and the Humber) and drawn from the following constituent local authorities:

- Barnsley MBC
- Calderdale Council
- City of Bradford MDC
- City of York Council
- Doncaster MBC
- East Riding of Yorkshire Council
- Hull City Council
- Kirklees Council
- Leeds City Council (Chair)
- North East Lincolnshire Council
- North Lincolnshire Council
- North Yorkshire County Council
- Rotherham MBC
- Sheffield City Council
- Wakefield Council

1.3 The JHOSC submitted a formal response to the options presented for public consultation in October 2011.

1.4 Following the JCPCT's decision on the proposed future model of care and designation of surgical centres on 4 July 2012, the JHOSC referred the JCPCT's decision to the Secretary of State for Health in November 2012. This was subsequently passed to the Independent Reconfiguration Panel (IRP) for consideration and advice.

1.5 The IRP's findings and recommendations were set out in its report to the Secretary of State for Health at the end of April 2013. A summary of the IRP's recommendations is attached at Appendix 1.

1.6 On 12 June 2013, an announcement from the Secretary of State for Health accepted the IRP's report and recommendations in full and called a halt to the Safe and Sustainable Review of Children's Congenital Cardiac Services in England and asked NHS England – as the new body responsible for commissioning specialised services following the restructuring arrangements across the NHS that came into force from 1 April 2013, to report how it proposed to proceed by the end of July 2013.

1.7 NHS England's response to the Secretary of State for Health, which included a report presented to the NHS England Board on 18 July 2013, is attached at Appendix 2.

2.0 Scope of the inquiry

2.1 The overall purpose of this inquiry is to consider the arrangements and outcomes associated with the new review of congenial heart disease (CHD) services in England.

2.2 As such, specifically in relation (but not limited) to the population of the constituent authorities' areas, the JHOSC may:

Part 1

- Consider the findings and recommendations of the Independent Reconfiguration Panel (IRP) associated with its assessment of the previous Safe and Sustainable review of Children's Congenital Heart Services in England, and make an assessment of the extent to which they have been acted upon as part of the new CHD review;

- Consider and make an assessment of the new CHD review processes and any associated formulation of proposed options for reconfiguration and future service models, presented for public consultation;

- Consider the views and involvement of local service users, patient groups and/or charity organisation as part of the new CHD review;

Part 2

- Examine the projected service improvements arising from the new CHD review and any proposed reconfiguration and future service model including, but not limited to, the basis of projected improvements to patient outcomes and experience;

- Consider the likely impact arising from the new CHD review on patients and their families accessing services in the short, medium and longer- term, particularly in terms of access to services and travel times;

- Consider the health and equality impacts arising from the new CHD review and any associated reconfiguration and future service model proposals and, in particular, the comparison with existing provision and service configuration;

- Consider other potential implications of any reconfiguration options arising from the new CHD review and presented for consultation, including the impact on the local and regional health and general economy.

Part 3

- Formally respond to the findings of the new CHD review and any reconfiguration options or proposed future service models arising from the new CHD review and presented for public consultation.

Part 4

- Consider and maintain an overview of any plans for implementation associated with the agreed future service model and reconfiguration of services arising from the new CHD review.

2.3 In addition, the JHOSC may generally:

- Consider any other pertinent matters that may arise as part of the Committee's inquiry (as agreed by the JHOSC).

- Make any recommendations deemed appropriate in relation to any or all of the above matters.

- Review and scrutinise the effects of the new CHD review on the planning, provision and operation of the health service in the constituent authorities' areas pursuant to Regulation 21 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013, and make reports and recommendations on such matters pursuant to Regulation 22.

- Act as consultee and discharge the constituent authorities' functions under Regulation 26 in relation to the new CHD review.

- Discharge the constituent authorities' functions under Regulation 26 and Regulation 27.

2.4 As the administering authority, arrangements for the JHOSC shall be in accordance with Leeds City Council's Scrutiny Procedural Rules.

3.0 Desired Outcomes and Measures of Success

3.1 The decision to undertake this inquiry has been based on the JHOSC's previous consideration and reports relating to the Safe and Sustainable Review of Children's Congenital Cardiac Services in England.

3.2 In conducting this inquiry and responding to any future proposals presented for public consultation, the JHOSC wishes to secure high quality, accessible services for patients suffering congenital heart disease (CHD) and their families across Yorkshire and the Humber in the immediate and longer-term.

3.3 It is also important to consider how the JHOSC will deem if its inquiry has been successful in making a difference to local people across Yorkshire and the Humber.

3.4 Some measures of success may be obvious at the initial stages of an inquiry and can be included in these terms of reference. Other

measures of success may become apparent as the inquiry progresses and discussions take place.

3.5 Some initial measures of success are:

- Ensuring the recommendations identified by the Independent Reconfiguration Panel (IRP) have been appropriately acted upon as part of the new CHD review.
- Ensuring the new CHD review processes are rigorous and fit for purpose.
- Ensuring the involvement, engagement and consultation arrangements associated with the new CHD review are appropriate and fit for purpose.
- Ensuring any proposed future service model will deliver improved or enhanced services for patients and families across Yorkshire and the Humber.
- Ensuring any projected service improvements arising from the new CHD review are realistic and have a high prospect for success.

4.0 Comments of the relevant Director and Executive Member

4.1 In line with Leeds City Council's Scrutiny Board Procedure Rule 12.1, the relevant Director(s) and Executive Member(s) shall be consulted on these terms of reference.

5.0 Timetable for the inquiry

5.1 NHS England is currently working toward securing 'an implementable solution' by the end on June 2014. As such, the timetable of this inquiry will broadly reflect NHS England's review timetable.

5.2 The length of the inquiry may be subject to change.

6.0 Submission of evidence

6.1 NHS England is currently working toward securing 'an implementable solution' by the end on June 2014. The timetable of this inquiry and the submission of evidence will broadly reflect NHS England's review timetable.

6.2 The JHOSC will determine the evidence it 'reasonably requires' to discharge its statutory functions and advise those bodies responsible accordingly.

7.0 Witnesses

7.1 The JHOSC will determine those witnesses it may 'reasonably require' and/or may wish to invite to attend its meetings, in order that it may discharge its statutory functions.

7.2 The JHOSC will advise any identified witnesses accordingly.

8.0 Equality and Diversity / Cohesion and Integration

8.1 The Equality Improvement Priorities 2011 to 2015 have been developed to ensure Leeds City Council's legal duties are met under the Equality Act 2010. The priorities will help ensure work takes place to reduce disadvantage, discrimination and inequalities of opportunity.

8.2 Equality and diversity will be a consideration throughout the inquiry and due regard will be given to equality through the use of evidence, written and verbal, outcomes from consultation and engagement activities.

8.3 The JHOSC may engage and involve interested groups and individuals to inform any recommendations.

8.4 Where an impact has been identified this will be reflected in any inquiry report and associated recommendations and the body responsible for implementation or delivery should give due regard to equality and diversity, conducting impact assessments where it is deemed appropriate.

9.0 Post inquiry report monitoring arrangements

9.1 Following the completion of this inquiry and the publication of any inquiry report and recommendations, the initial response and subsequent progress against such recommendations will be monitored.

9.2 Any inquiry report will include information on the arrangements for monitoring the implementation of any recommendations.

IRP

Independent Reconfiguration Panel

ADVICE ON

SAFE AND SUSTAINABLE *PROPOSALS*

FOR CHILDREN'S CONGENITAL HEART SERVICES

Submitted to the Secretary of State for Health

30 April 2013

IRP

Independent Reconfiguration Panel

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SUMMARY AND RECOMMENDATIONS

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

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

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

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

SUMMARY AND RECOMMENDATIONS

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

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

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

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

SUMMARY AND RECOMMENDATIONS

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

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

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

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

SUMMARY AND RECOMMENDATIONS

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

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

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

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

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

SUMMARY AND RECOMMENDATIONS

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

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

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

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

SUMMARY AND RECOMMENDATIONS

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

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

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

SUMMARY AND RECOMMENDATIONS

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

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Rt Hon Jeremy Hunt MP
Secretary of State for Health
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31 July 2013

Dear Secretary of State

New review of congenital heart disease (CHD) services

In your letter of 12 June about the "Safe and Sustainable" review, you asked NHS England to report back to you by the end of July setting out how we intend to take the process forwards.

I am pleased to enclose the paper which our Board considered at its meeting in public on 18 July, which sets out our thinking on the nature of the problem and the principles which must underpin our approach. In line with our commitment to transparency, a video recording of the Board's discussion is also available, at http://www.england.nhs.uk/2013/07/22/boardvids-180713/. Annex 1 of the Board paper describes an outline timetable for the work.

We have set ourselves the hugely ambitious challenge of an implementable solution within a year. This does not mean we think the job is easy; on the contrary, it is exceedingly difficult. We have a duty to patients now and to future generations to ensure the best possible quality of care within the available resource. That means best outcomes, a positive patient experience, and consistently high levels of safety.

We do not see this as a competition between providers to find "winners" and "losers". Instead, we want a single national service which sets high standards for the delivery of care, which are uniformly available to all NHS patients in England, wherever they live. Beyond this aspiration for a national service underpinned by national standards, we do not profess to know yet precisely what the answer is. We are very clear that the Independent Reconfiguration Panel's (IRP) report requires us, amongst other things, to look at children's and adults' services together, to look afresh at the demographic and other relevant data, to describe the entire pathway, and to properly involve all stakeholders throughout the work. So, we need a new process. Although the *Safe and Sustainable* conclusions cannot be implemented, there has nonetheless been some very good work during the past five years, with extensive involvement from clinicians and patient groups, to develop

standards and proposals for networks. As IRP suggests, this work needs to be completed. Once validated it will give us a platform for future work, but it does not in any way require us to reach the same conclusions as the previous process.

As we continue our initial discussions over the next few weeks, and begin to develop a proposition for debate in the autumn, there is bound to be speculation about the “answer” we have in mind. But having promised that we will listen before we act, I can assure you that we have no such prejudice. I welcome your support in reiterating this message.

We are still in an extended period of listening and we regularly publish the notes from our meetings to open the debate as widely as possible. I have established a committee of the Board to give this topic the focus it deserves, and Professor Sir Mike Rawlins will chair a clinical advisory panel to support our medical director Professor Sir Bruce Keogh in obtaining excellent clinical engagement and advice.

We are absolutely committed to achieve the service change required for these very vulnerable patients. We will exploit the full potential of NHS England as the sole national commissioner, and do so in a way that properly engages all interested parties, but at sufficient pace to mitigate the risks of further delay.
Yours sincerely

Professor Sir Malcolm Grant
Chair

NHSE180713

BOARD PAPER - NHS ENGLAND

Title: New review of congenital heart services

Clearance: Bill McCarthy, National Director: Policy

Purpose of paper:

- To describe the challenge facing NHS England in improving congenital heart disease services
- To outline early thinking on the way forward

Key issues and recommendations:

On 12 June 2013 the Secretary of State announced in Parliament that the safe and sustainable proposals for children's congenital heart services could not go ahead in their current form. He went on to say that "it is right we continue with this process, albeit in a different way".

NHS England is the body responsible for commissioning specialised congenital heart services and for taking forward the process.

A new review is being established to consider the whole lifetime pathway of care for people with congenital heart disease (CHD), to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources.

Actions required by Board Members:

- To note the proposals for conducting a review of congenital heart disease services

New review of congenital heart services

Summary

Following the outcome of judicial review, the report by the Independent Reconfiguration Panel (IRP) and the Secretary of State's announcements relating to the safe and sustainable review of children's congenital heart services, NHS England is now the responsible body for taking forward the process. A new review is now being established to consider the whole lifetime pathway of care for people with congenital heart disease (CHD).

The ambition of this review is to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources:

- the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
- tackling variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care
- great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home

We recognise that continued uncertainty is a risk to the service and unsettling for patients. We must therefore set ourselves the target of delivering the new review at pace. But we know that speed cannot be an excuse for imposing a top down solution or for running a process where people feel excluded from the real discussions, so we will be setting ourselves the additional challenge of achieving new levels of transparency and the highest levels of genuine participation. We know that this will need a new approach. We want to make sure that as well as mobilising NHS England's resources from right across the organisation, that we also work closely with partners and stakeholders to design the way forward.

By the end of September we will have established the new programme, co-designed a process for the work going forward and undertaken initial work on how to secure high quality resilient services.

By June 2014 working closely with stakeholders, we will have developed, tested and revised a proposition, undertaken work to identify a preferred approach to implementation, and completed the necessary preparatory work.

Background

1. Around eight out of every 1,000 babies have some form of congenital heart disease (CHD) – around 5,800 babies in 2011. The number of children born with CHD is expected to rise, as the birth rate rises. As technology and expertise continue to develop, it is possible to do more than ever before to improve their lives, so that more children with CHD are surviving to adulthood.
2. NHS cardiac surgery for children is currently provided by 10 hospitals in England. Specialist paediatric cardiology is also provided by a further three centres. Around 3,700 paediatric surgical procedures and 2,000 paediatric interventional cardiology procedures are carried out each year.

3. A recommendation for the concentration of medical and nursing expertise in a smaller number of centres of excellence was made as far back as 2001, in the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary. Since that time, there have been major improvements in outcomes, so that analysis of risk adjusted mortality for 2009-12, published this year by the National Institute for Cardiovascular Outcomes Research (NICOR), shows that no surgical unit has a mortality rate significantly above the "expected" rate, and on this evidence (for example, mortality rates alone) services are currently "safe".

4. For adults, around 850 surgical procedures and 1,600 interventional cardiology procedures are carried out each year and reported to NICOR by 25 hospitals in England, however a further 10 hospitals have undertaken procedures in recent years but not provided data to NICOR.

The safe and sustainable review

5. The safe and sustainable review was established in 2008, with a view to reconfiguring surgical services for children with CHD. Taking into consideration concerns that surgeons and resources may be spread too thinly across the centres, the review considered whether expertise would be better concentrated in fewer sites.

6. At the end of the four year programme, in July 2012, a joint committee of Primary Care Trusts (JCPCT) made a series of decisions on the future of children's congenital heart services in England, covering:
   - the development of congenital heart networks,
   - service standards,
   - improving the collection, reporting and analysis of outcome data, and
   - the configuration of surgical services, which would have reduced the number of centres providing children's heart surgery from ten to seven, with surgery ceasing at Leeds, Leicester and the Royal Brompton.

7. The decision regarding configuration resulted in two separate challenges: a judicial review (JR), and referrals to the Secretary of State, who in turn asked the Independent Reconfiguration Panel (IRP) to consider the JCPCT findings.

8. The JR was decided on 7 March 2013, when the High Court declared that both the consultation process and the decision making process of the JCPCT were unlawful and quashed the decision to reconfigure surgical services. The judgement was based on a narrow point of process and the Court recognised "the compelling and urgent clinical case for the reform of existing paediatric congenital cardiac services" stating that the judgment should not be "construed as advocating a need to return to the start of the consultation process". Following legal advice, NHS England initially sought leave to appeal this decision but - in the light of the IRP's report and the Secretary of State's response (see below) - has since withdrawn this request.

9. The IRP were of the view that children and adults with CHD in England and Wales would benefit from services commissioned to national standards for the whole pathway of their care. They agreed that congenital cardiac surgery and interventional cardiology should only be provided by specialist teams large

enough to sustain a comprehensive range of interventions, round the clock care, training and research. However, the IRP concluded that the JCPCT's decisions were based on "flawed analysis of incomplete proposals and their health impact, leaving too many questions about sustainability unanswered and to be dealt with as implementation risks".

Addressing the IRP findings

10. On 12 June 2013 the Secretary of State announced in Parliament that he accepted the IRP's advice, and that "the [Safe and Sustainable] proposals cannot go ahead in their current form". He went on to say that "it is right we continue with this process, albeit in a different way" and that "NHS England now must move forward on the basis of these clear recommendations".

11. The IRP's report highlighted the need to align the review of children's CHD services with ongoing work to consider the provision of adults' CHD services. Since the same surgeons operate on the same patients at different times in their lives, there are considerable dependencies between adults' and children's services, especially in the availability of surgical teams to provide 24/7 cover.

12. The IRP were also concerned that the while the Safe and Sustainable process received 75,000 responses to its public consultation, some stakeholders were nonetheless left feeling that their views were not fully heard or understood, or that they were not given all the information they needed to contribute fully. This in turn created, for some, the perception of a pre-determined outcome.

13. The IRP's report called for NHS England to develop a strategic framework for commissioning that reflects the complex interdependencies between specialised services provision and population need as a context within which any decisions about congenital heart services should be taken.

14. Importantly, neither the Courts, nor SofS nor IRP have questioned the need for change to ensure the resilience, sustainability and excellence of these services.

The challenge for NHS England

15. The challenge for NHS England is how to ensure that services for people with congenital heart disease are provided in a way that achieves the highest possible quality, within the available resources, now and for future generations:

    - Securing the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
    - Tackling variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care
    - Delivering great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home

16. To do this, we need to develop a process which is as transparent and inclusive as it can be, particularly in the use of evidence and data. Almost as important as the thoroughness of our work will be the need to be seen to be engaging as widely as possible, bringing patients, clinicians and their representatives together

in the joint pursuit of an effective and equitable solution, in the interests of all service users now and in the future. What we do for CHD services will in some ways be seen as a template for whether and how NHS England undertakes other major service change in future.

17. It is widely acknowledged that the uncertainty which has been caused by recent developments is one of the greatest risks to the current delivery of the service. Patients and families are now unsure about precisely where and how they will receive treatment. Surgical centres are hamstrung in their planning, and recruitment and retention is made more difficult by the lack of a clear service model. This in turn creates a risk that the safety and quality of services may not be able to be maintained, that service levels could reduce or there could be unplanned closure(s). Charities, clinicians and other stakeholders gave a huge commitment to support change; many say they are demoralised, frustrated, exhausted and angry. Some doubt that there is the will to make the necessary changes happen.

18. These concerns need to be addressed as part of the new process. To support this measures designed to give commissioners early warning of any emerging concerns at units providing children's congenital heart services will be rolled out across the country, (and to adapt it to include adult services) accepting that it is still a developmental approach, and used as the basis of regular conversations between area teams and providers. A system will be established to ensure that aggregated information is regularly provided to the board committee.

19. In the light of all this, NHS England must bring forward an implementable solution within a year, ie by the end of June 2014. Given the complexity of the issues, the enlarged scope (children AND adults), the legitimate but differing views of stakeholders, and the need to build as much consensus wherever possible (in circumstances where some of the relationships have been badly bruised) this is a demanding but important ambition. We simply cannot re-run the previous process and hope to achieve a different outcome in a quarter of the time.

20. Instead, we must find ways to do this differently. As the sole national commissioner of specialised services NHS England has an opportunity not open to our predecessors. This creates a significant opportunity to drive service improvement including reduced variation in access and quality. We can focus on national standards for a national service, commissioned through a single model which enables us to drive change in the interests of patients.

Principles / Approach

21. We propose the following principles and approach:

- **Patients come first**: the new review must have patients and their families at its heart, with a relentless focus on the best outcomes now and for the future. That aim over-rides organisational boundaries.
- **Retaining what was good from earlier work**: although the JCPCT's decision on configuration of children's congenital heart services has been overturned, much else was developed as part of that process and the subsequent implementation programme including a model of care, service standards, and well-developed thinking about network working. Similarly standards for adult services have also been developed and are ready for

formal consultation. This work has had extensive clinical and patient input and has the potential to be applicable to whatever service configuration is decided. Therefore NHS England must work with stakeholders to determine how much of this work can be retained.

- **Transparency and participation**: NHS England is committed to openness, transparency and participation. We should work with user, clinical and organisational stakeholders to ensure that we develop an approach to take the work forward that is true to those values. Our work should be grounded in standards, rigour, honesty and transparency.
- **Evidence**: the IRP reflected criticism of the way in which Safe and Sustainable used evidence to support its conclusions. The new review will need to be clear about the nature and limitations of the available evidence, and about any intention to rely on expert opinion in the absence of evidence. Notwithstanding the comment above about "retaining what was good", we must have no preconceived notions about the outcome. Wherever there is an assumption it must be made explicit, and justified.

22. We have not attempted to develop a full plan describing how the work will be taken forward, because we want to take time to understand from stakeholders what was good and should be retained from the previous process and what did not work well. We believe however that it is likely that a standards driven process – developing, testing, adopting and applying best practice standards for every part of the pathway – has much to commend it, and we will be testing this with stakeholders.

Governance

23. The Board has established a committee which will provide formal governance of this work. The committee is chaired by Sir Malcolm Grant, Board Chairman, and includes Margaret Casely-Hayford and Ed Smith (non-executive directors), Sir Bruce Keogh (Medical Director), and Bill McCarthy (National Director for Policy). To support the committee, arrangements will be put in place for clinical, organisational and service user representation.

24. Bill McCarthy is the senior responsible officer for this work. John Holden (Director of System Policy) will co-ordinate the work within NHS England and ensure the full involvement of the many different stakeholders.

Stakeholder engagement and communications

25. We are drawing up a stakeholder engagement plan, based on how these stakeholders tell us they wish to be involved, and identifying the different groups, their preferred channels of communication and the key messages throughout the process. For example we know that some of the existing surgical centres have well established patient groups and using these channels may be one way to reach the majority of those most directly affected. For patients, families and their representatives we have sought expert external help from three charities - National Voices, Involve and Centre for Public Scrutiny (CFPS) – to help us design and implement effective and appropriate engagement. They can also

help us manage our risks (eg CFPS are experienced in working with oversight and scrutiny committees and can help us better understand the local government dimension). Due to their limited size these bodies are unable to be directly involved in the work but all have agreed to act in a mentoring capacity. For clinicians, Sir Bruce is convening a clinical advisory panel which will guide him throughout the process and will help design broader clinical engagement and address specific issues which may arise. He has identified the need for some international perspective on this work and will take some soundings from his international peers to determine how best international advice is provided.

26. Our communications will be as open and as often as possible – we have already initiated a fortnightly blog on the NHS England website where we will trail forthcoming meetings and provide a summary of recent progress and discussions. With the support of the NHS England Director of Communications and his team, we are also considering the potential for dedicated web pages, or other IT applications which allow documents and other information to be freely exchanged. We want to give anyone who is interested a simple and easy to use way to find out what is going on and to become involved. We will use social media as appropriate – and if our stakeholders find it helpful – to discuss and share information. We are also considering how we can address the needs of those who do not have access to the internet or do not use English as a first language.

Resources

27. We need to take this opportunity to review the resourcing of this work. It will be important to ensure that it is a priority for the whole organisation and that the resources of the whole organisation are appropriately mobilised to support the work. The cost of dedicated programme management and administrative support will be met from recycling funds previously reserved for the Safe and Sustainable process. The estimated annual cost of this support is £500k.

Conclusion

28. As the body responsible for commissioning specialised congenital heart services, NHS England is setting out ambitious plans to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources. To achieve this, a new Congenital Heart review is being established to consider the whole lifetime pathway of care for people with CHD. The Board is asked to consider and comment on the proposed approach.

Bill McCarthy

National Director: Policy

July 2013

Annex 1: Programme Plan

Our indicative timetable is follows:

Phase 1 – up to October 2013

Co-design a process for the work going forward

- Take advice from external experts to help shape listening exercise *[done]*
- Review previous stakeholder input in order not to lose what has already been achieved; and check its continuing relevance with stakeholders *[under way]*
- Begin communications as per stakeholders preferences, eg blog, shared resources on webpage/sharepoint *[under way]*
- Agree approaches to participation, identify preferred communications channels

Establish the programme

- Establish governance, advisory and stakeholder arrangements *[under way]*
- Develop programme plan, update Board, secure agreement, update Secretary of State *[under way]*
- Identify resources *[underway]*

Initial work on how to achieve programme aims of higher quality services

- Agree with stakeholders what should be taken forward from previous processes
- Complete work on proposed paediatric cardiology standards *[underway]*
- Bring together adult and children's standards and agree process for approval and adoption *[underway]*
- Develop proposals for testing/implementing formal network arrangements *[underway]*
- Work with stakeholders to identify any fixed points and how these would influence service design. This is likely to include (but not be limited to) discussion of the provision of transplant services, the need for children's heart surgery and other tertiary paediatrics to be provided on the same site, and the need for children's and adults' surgery (and interventional cardiology) to be provided in close proximity
- Develop a "proposition" – not a list of sites, but a straw man of what a high quality and sustainable service looks like for adults and children, unconstrained by current configuration – the optimal model
- Consider and weigh, with legal advice, possible approaches for a managed process to translate these fixed points into firm proposals for structuring services, test with stakeholders, outline agreed process
- Establish the required capacity of the service in future years
- Set an ambitious timeline to have completed the work and be ready to implement.

Phase 2 – up to February 2014

Develop, test and revise the proposition

- Using multiple channels, including local and national clinically led events, engage on the clinical appropriateness and user acceptability of the proposition

- Benchmark existing provision against the proposition – considering access as well as service quality
- Test any emerging alternative proposals
- Review dependencies – eg for children, neonatal and paediatric intensive care (PICU) and retrieval services, extracorporeal membrane oxygenation (ECMO). While the IRP recommended that decisions about the future of transplant services and respiratory ECMO should be contingent on final proposals for congenital heart services, in practice the level of interdependency may mean that they need to be considered together
- Weigh alternative implementation approaches: early thinking suggests that some fixed points could constitute 'hurdle criteria' for potential providers within a commissioner led standards driven approach, however alternative approaches need to be considered including option appraisal and designation and provider led regional solutions.
- Agree revised proposition with clinical and patient groups

Phase 3 – up to June 2014

Preparation for implementation

Work in this phase will of course be dependent on the nature of the proposition developed and the measure of agreement with that approach.

- If the solution is for a national plan in which current centres continue/cease to provide surgery, then – subject to legal advice - there may need to be further full formal consultation. This could take the timeline for implementation beyond one year.
- If the solution is a commissioning approach to enforce a set of national standards which invites providers to cooperate to provide the service, any consultation could be undertaken sub-nationally as part of the development of tenders. Assuming local resolution and provider cooperation, the focus of this period would be on developing the tender exercise.

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