

Joint City / County Health Scrutiny Committee

Tuesday, 14 March 2017 at 10:15

County Hall, County Hall, West Bridgford, Nottingham, NG2 7QP

AGENDA

- | | | |
|---|--|--------------|
| 1 | Minutes of the meeting held on 7 Feb 2017 | 3 - 6 |
| 2 | Apologies for Absence | |
| 3 | Declarations of Interests by Members and Officers:- (see note below)
(a) Disclosable Pecuniary Interests
(b) Private Interests (pecuniary and non-pecuniary) | |
| 4 | Sustainability and Transformation Plan Governance Arrangements | 7 - 22 |
| 5 | Congenital Heart Disease | 23 - 188 |
| 6 | Nottingham University Hospitals NHS Service Review | 189 -
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| 8 | Work Programme | 237 -
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Notes

- (1) Members of the public wishing to inspect "Background Papers" referred to in the reports on the agenda or Schedule 12A of the Local Government Act

should contact:-

Customer Services Centre 0300 500 80 80

- (2) Persons making a declaration of interest should have regard to the Code of Conduct and the Council's Procedure Rules. Those declaring must indicate the nature of their interest and the reasons for the declaration.

Councillors or Officers requiring clarification on whether to make a declaration of interest are invited to contact Julie Brailsford (Tel. 0115 977 4694) or a colleague in Democratic Services prior to the meeting.

- (3) Councillors are reminded that Committee and Sub-Committee papers, with the exception of those which contain Exempt or Confidential Information, may be recycled.
- (4) A pre-meeting for Committee Members will be held at 9.45 am on the day of the meeting.
- (5) This agenda and its associated reports are available to view online via an online calendar - <http://www.nottinghamshire.gov.uk/dms/Meetings.aspx>

MINUTES

**JOINT HEALTH SCRUTINY COMMITTEE
7 February 2017 at 10.15am**

Nottinghamshire County Councillors

Councillor Parry Tsimbiridis (Chair)
Councillor Joyce Bosnjak
Councillor Kay Cutts MBE
Councillor Richard Butler
Councillor John Clarke
Councillor John Handley
Councillor Colleen Harwood
Councillor Jacky Williams

Nottingham City Councillors

Councillor A Peach (Vice-Chair)
Councillor M Bryan
A Councillor E Campbell
Councillor C Jones
Councillor G Klein
Councillor B Parbutt
A Councillor C Tansley
A Councillor M Watson

Officers

David Ebbage - Nottinghamshire County Council
Martin Gately - Nottinghamshire County Council
Jane Garrard - Nottingham City Council

Also in attendance

Officers

Dr Agnes Belenscak - Screening & Immunisation Lead
Hazel Buchanan - Director of Operations
Dr James Hopkinson - Clinical Lead
Sarah Mayfield - Screening & Immunisation Lead, Public Health England
Sam Walters - Chief Officer, Nottingham North & East CCG

MINUTES

The minutes of the last meeting held on 10th January 2017, having been circulated to all Members, were taken as read and were confirmed and signed by the Chair.

APOLOGIES

Apologies were received from Councillor Watson and Councillor Campbell.

DECLARATIONS OF INTEREST

Councillor Ginny Klein declared a private interest in Item 5 – Nottingham University Hospitals NHS Trust Service Reviews as she uses a number of the services involved.

CHILDHOOD IMMUNISATION AND VACCINATION IN NOTTINGHAM & NOTTINGHAMSHIRE

Sarah Mayfield, Screening & Immunisation Lead, Public Health England updated the Committee on childhood immunisation and vaccination.

She highlighted the following points in her report:-

- 95.8% of children received a three dose course of DTaP/IPV/Hib, also known as 5-in-1 vaccine, by their 1st birthday in 2015-16. This is above the World Health Organisation (WHO) target of 95% and higher than the England average of 93.6% and East Midlands average of 95.6%.
- 89.7% of children received the first dose of Mumps, Measles and Rubella (MMR) vaccination by their 2nd birthday in 2015-16. This is below the World Health Organisation target of 95% and below the England average of 91.9% and the East Midlands average of 94.1%.
- A decrease in MMR 2 uptake has been observed for the past few years and is below WHO target. This is also the case for 5y DTaP/IPV/Hib% Booster (pre-school booster)
- MMR will be used by the Screening and Immunisation Team as an indicator of poor GP practice performance. Practices will be identified and targeted by their local CCG primary care managers to identify any issues that could be causing the poor uptake of MMR.
- Work with Nottingham City and Nottingham County Local Authorities has helped to increase awareness and promote uptake on the Childhood Flu Programme. Communication plans and links with children's services have helped to achieve this. Both Local authorities are members of the NHS England Flu Planning Group.
- The School Age Flu Programme data shows higher uptake rates for both City and County. Currently the data covers Year 1 and 2 age children. Next year the data will also cover Years 3 & 4.
- Nottinghamshire overall is performing very well in some of the routine vaccinations. The main concerns are with rotavirus, MMR and the pre-school booster. Work will commence with Local Authorities and CCGs to look in to practice level data for MMR2, as this will act as a good indicator of practice immunisation performance.

- Work continues with CCGs and Local Authorities promoting the offer of flu vaccinations to children. Once the final data is collated for flu vaccination uptake, the Screening and Immunisation Team can review the uptake and start to plan for next year's programme, learning from this year's programme.

Overall the service is doing really well, at a stable level and there has been an increase with the numbers at intake level. The service requires a significant amount of stakeholder engagement.

The Chair thanked Sarah Mayfield for her attendance at the meeting.

NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST SERVICE REVIEWS

Hazel Buchanan, Director of Operations and representatives from CCGs briefed Members on the review of services and service changes at Nottingham University Hospitals (NUH) being undertaken by Nottingham North and East Clinical Commissioning Group.

During the report, the following points emerged:

- Over 30 services were reviewed, 5 were seen to have no changes, 16 were decided to stay with NUH and 8 services were under consideration to either partially or fully be provided within the community.
- The 8 services to potential change were: Chronic Fatigue Syndrome, Back Pain and Pain Management, Renal Home Visiting, Motor Neurone Disease, Geriatric Day Care/Medicine, Neuro Assessment/Brain Injury, Dietetics, and Orthoptics.
- Many engagement activities were carried out including local surveys, focus groups with users and carers, one to one meetings with service users and carers.
- Where the proposal has been to move the service into the community, details of the proposed changes was included on Nottinghamshire CCG web sites and were available for people to comment on.
- Where services are staying with NUH, CCGs are working closely with the relevant clinicians, managers and service users on plans for 2017/18.
- For those services that may be going to procurement, it was expected this process will start in February and to be finalised following the review of engagement feedback.
- Nottingham City CCG are going out to tender for the MCP contract which will commence on 1st April 2018. Services decommissioned from NUH will be directly awarded to existing community providers on a short term basis to enable the CCG to align timescales.
- CCGs will develop plans with NUH and the new providers, where relevant on exit strategies to ensure that, existing and new patients continue to access services as per their patient journey and appropriate handovers are managed with clinicians.

During discussion and answering questions, the following points were raised:

- Members were concerned with the lack of information that came with the meeting papers, half a page for each service was not enough to decide whether they could class these changes as substantial.
- Concerns were raised with the length of time it has taken for the Nottingham North and East CCG to come to the Committee to inform members about these service changes, as the formal engagement was last August. This was down to looking at all services on a one by one basis. All services which have been reviewed are very different, the main priority is that the service provider may change into a different location, but the standard of care and support will remain the same.
- Some of the services are already being delivered in the community, the CCG are trying to mirror that across the County with other services and across other CCG's.
- The overall number of patients who potentially could be affected within the 8 services could be quite low as most patients may already receive community care.
- There is no definitive figure to how many people have been engaged with. They have reached out in many different ways which has brought in great feedback but the CCG's have had to reach out for people to engage with them.
- Members agreed that a smaller meeting would be arranged to go the process for bringing substantial variations to the committee. Further details on the proposed changes would be brought to the March meeting for Members to decide whether the service changes or decommissioning represents a substantial variation of service.

RESOLVED

That Members agreed for another meeting to be arranged and for the report to be brought back to the March committee.

WORK PROGRAMME

Members noted the Work Programme

The meeting closed at 11.50am.

Chairman

JOINT CITY AND COUNTY HEALTH SCRUTINY COMMITTEE
14 MARCH 2017
SUSTAINABILITY AND TRANSFORMATION PLAN – GOVERNANCE ARRANGEMENTS
REPORT OF CORPORATE DIRECTOR FOR STRATEGY AND RESOURCES (CITY COUNCIL)

1. Purpose

- 1.1 To receive an update on the Nottinghamshire Sustainability and Transformation Plan with a particular focus on the governance arrangements.

2. Action required

- 2.1 The Committee is asked to:
 - a) review and comment on the proposed governance arrangements for the Nottinghamshire Sustainability and Transformation Plan; and
 - b) consider the role for health scrutiny councillors, and specifically the Joint Health Scrutiny Committee in relation to the Sustainability and Transformation Plan.

3. Background information

- 3.1 The Nottinghamshire Sustainability and Transformation Plan (STP) was published on 24 November 2016. In December David Pearson, STP Lead, attended a meeting of this Committee to discuss a report updating on development of the STP to date.
- 3.2 At that meeting the Committee heard that the consultation period on the STP had been extended to mid February 2017. The Committee requested that the consultation findings and information on how those findings are influencing the Plan are brought back to the Committee. This has been scheduled for the Committee's meeting in April.
- 3.3 In December the Committee discussed the development of governance arrangements for the STP including the role for health scrutiny and Elected Members more generally and asked that the governance proposals be brought back to the Committee.
- 3.4 The Committee needs to consider its role in relation to the STP going forward and how it wishes to engage with development and delivery of

the Plan. The Committee has a statutory role in relation to substantial developments and/or variations in health services but also a wider power to scrutinise the planning, provision or operation in health services in the area.

4. List of attached information

5. Background papers, other than published works or those disclosing exempt or confidential information

5.1 None

6. Published documents referred to in compiling this report

6.1 Reports to and minutes of meetings of the Joint Health Scrutiny Committee held on 14 June and 13 December 2016.

6.2 Nottinghamshire Sustainability and Transformation Plan 2016-2021

7. Wards affected

7.1 All

8. Contact information

Jane Garrard, Senior Governance Officer, Nottingham City Council
Tel: 0115 8764315
Email: jane.garrard@nottinghamcity.gov.uk

STP Leadership Board

Governance

1. Introduction

- 1.1 Across Nottingham and Nottinghamshire, health and social care organisations including partners in the community and voluntary sector, have come together to produce a draft five-year plan known as the Sustainability and Transformation Plan (STP). The plan looks at how we can best improve the quality of care, the health and wellbeing of local people, and the finances of local services.
- 1.2 It is the first time that local authorities (city, county, borough and district) and the NHS (commissioning organisations and providers of services), along with partner organisations, have come together in this way to consider the over-arching whole care needs of everyone in this area. While individual organisations are used to being responsible for their own particular geographical area and care remit (e.g. primary health care, care in hospitals, or social care for example) and have worked in partnership with others at a local scale, the STP is requiring leaders, teams and organisations to think and act bigger.
- 1.3 In working at a larger scale and with a wider set of partners, it is important that roles and responsibilities for individuals and organisations are clear, that structures, processes and lines of reporting are aligned, and that duplication of effort is reduced wherever possible.
- 1.4 This paper sets out the governance arrangements for the STP. As a plan the STP has no statutory basis - all the responsibilities are retained within the individual organisations that make up the partnership. These individual organisations will continue to be governed by their own governing boards or accountability frameworks. The basis for the partnership is that each organisation has a duty to maximise the benefits for the public through taking a broader perspective than just that of their own individual organisation.
- 1.5 The STP proposals are therefore recommendations that will need to be approved by the board of each partner. As a member of the partnership it is expected that organisations align their decision making with other STP members so proposals can be implemented consistently and coherently.

2. Aims of the STP

- 2.1 We have established six aims in order to reach our aspirations and overcome our challenges:
- 2.2 Organise care around individuals and populations - not organisations - and deliver the right type of care based on people's needs. For example:
- 2.2.1 Help those who are largely well today (most of the population) stay well through prevention and health education and manage minor issues themselves in so far as it is possible
 - 2.2.2 Help those with complex or advanced long-term conditions that need professional expertise and support to be as enabled as possible to manage their own care, to have an identified system to escalate care quickly in the event of exacerbations, and to have regular monitoring to identify changes in their health and social care needs as early as possible

- 2.3 Help people remain independent through prevention programmes and offering proactive rather than reactive care, which will also reduce avoidable demand for health and care services
- 2.4 Support and provide care for people at home and in the community as much as possible - which implies shifting resources into those settings - and ensure that hospital, care home beds, and supported housing are available for people who need them
- 2.5 Work in multi-disciplinary teams across organisational boundaries to deliver integrated care as simply and effectively as possible
- 2.6 Minimise inappropriate variations in access, quality, and cost, and deliver care and support as efficiently as possible so that we can maximise the proportion of our budget that we spend on improving health and wellbeing
- 2.7 Maximise the social value that health and social care can add to our communities.

3. Citizens

- 3.1 We must be clear with citizens how we will engage with them to deliver the plan and what it means for them. Citizens want to know that they can get high quality health and social care at the right time and in the right place to meet their needs.
- 3.2 The STP will *assure* citizens that we are driving standards and consistency in outcomes across our whole area, that we are listening to their needs, and delivering best practice and efficiency. The programmes within the STP will *involve* citizens in the local design and delivery of the plans to meet their needs. Services will be delivered in a way that best meet local community needs.

4. Core principles for governance

- 4.1 Through the STP governance arrangements we want to:
 - 4.1.1 *Establish a mutually accountable system with independent challenge*
 - 4.1.2 *Be clear on where risk is owned and managed*
 - 4.1.3 *Transform care through leaders working together*

a) Establish a mutually accountable system with independent challenge

- 4.2 At the STP level, organisational leaders need to ensure they are mutually accountable to each other as well as being mutually supportive. They need to learn, share and provide independent challenge to each other. Leaders need to be the interface between the STP Leadership Board and their own organisations and governing boards.
- 4.3 This will require strong systems leadership – these key individuals have responsibility for managing the public purse across the area, for meeting key national targets, and for ensuring their own organisational strategies and plans align to the STP objectives of improving people's health and wellbeing, care and quality of services, and finance and efficiency.

b) Be clear on where risk is owned and managed

- 4.4 Individual organisations and the two 'transformation boards' (areas of health and care planning covering Mid Nottinghamshire and Greater Nottingham including the city) will continue to manage their own individual risks. Some of these risks may be managed at

the STP level if that is in the best interests of the overall system. The STP Leadership Board will keep track of risks, key metrics and milestones.

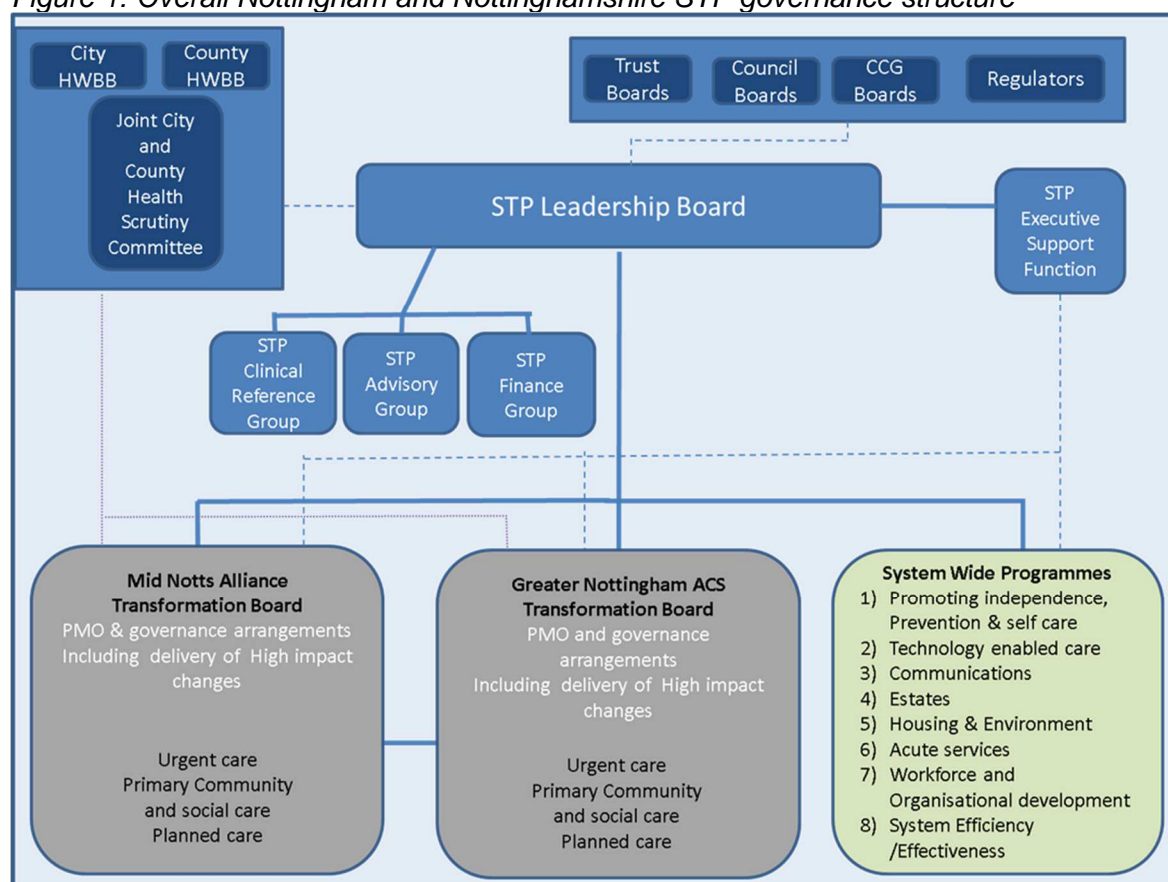
c) Transform care through leaders working together

4.5 The STP seeks to ensure that the location of where a citizen lives should not dictate the quality of service received or the impact on that citizen's health and wellbeing. We have to act as one system for our population, providing evidence-based services and ensuring consistent outcomes. Leaders have to work together within this one system for the greater good. Our governance will underpin this approach.

5. Governance structure

5.1 The STP governance structure is set out in figure one.

Figure 1: Overall Nottingham and Nottinghamshire STP governance structure



5.2 Key features of this approach are:

5.2.1 The STP Leadership Board is where chief executives and accountable officers will hold the implementation teams to account, challenge each other to put system before organisation, ensure services are of a similar high standard across the area, and share best practice across Nottingham and Nottinghamshire. STP Leadership Board membership includes the STP accountable lead, accountable officers from all clinical commissioning group (CCGs) areas, chief executives from NHS trusts and foundation trusts, chief executives of Nottinghamshire County Council, Nottingham City Council, a clinical representative from each of the Transformation Boards, the Chair of the Clinical Reference Group, and leads of high impact and supporting themes and

enablers not otherwise on the Leadership Board. In the event of not being able to attend a meeting, a substitute will be sent

- 5.2.2 There are two major transformation partnerships within our area – overseen by the Mid Notts Alliance Transformation Board and the Greater Nottingham ‘Accountable Care System’ Transformation Board. These boards will lead the implementation of three of the high impact changes and have a lead role in implementing the STP in their areas. These two partnerships host a number of ‘vanguard’ sites chosen by NHS England to find innovative solutions to health challenges; they commission the majority of services in their area; and have established provider alliances to provide those services. The transformation boards will be held to account directly by the STP Leadership Board on all aspects of the plan delivery
- 5.2.3 There is a portfolio of system-wide high impact themes, supporting themes and enabler workstreams; these programmes will have an independent programme management structure and develop system-wide implementation plans or where appropriate develop models, specifications and standards for implementation by the two transformation boards
- 5.2.4 Programme management support will be provided within the programmes rather than at STP Leadership Board level
- 5.2.5 Individual organisation level boards will contribute and approve a range of matters relating to their organisation’s contribution to the STP. They retain the powers and responsibilities for delivering the STP
- 5.2.6 Local democratic oversight is through the councils, primarily through Lead Members and relevant Committees. Overview and Scrutiny arrangements will be undertaken through Joint Health Scrutiny arrangements which are in place
- 5.2.7 Health and Wellbeing Boards will receive regular updates on progress in delivering the STP
- 5.2.8 Citizen involvement is a key aspect of the two transformation programmes and also takes places within various projects/programmes of the STP. A separate Citizen Advisory Group at STP Leadership Board level is being considered for the future but is not currently in the governance arrangements
- 5.2.9 An STP Clinical Reference Group will be represented on the STP Leadership Board to provide senior clinical/ social care advice and to ensure on-going clinical/social care contribution and leadership to STP strategy development and implementation
- 5.2.10 An STP Advisory Group will ensure that wider stakeholders are kept engaged and involved in the development of the STP and can provide advice and recommendations to the STP Leadership Board. The group will include representatives of key partner organisations and associates and representatives from Healthwatch, and key professional bodies
- 5.2.11 An STP Finance Group will provide financial expertise and assistance to support the STP Leadership Board in delivering their objectives and ensure alignment with organisational financial plans

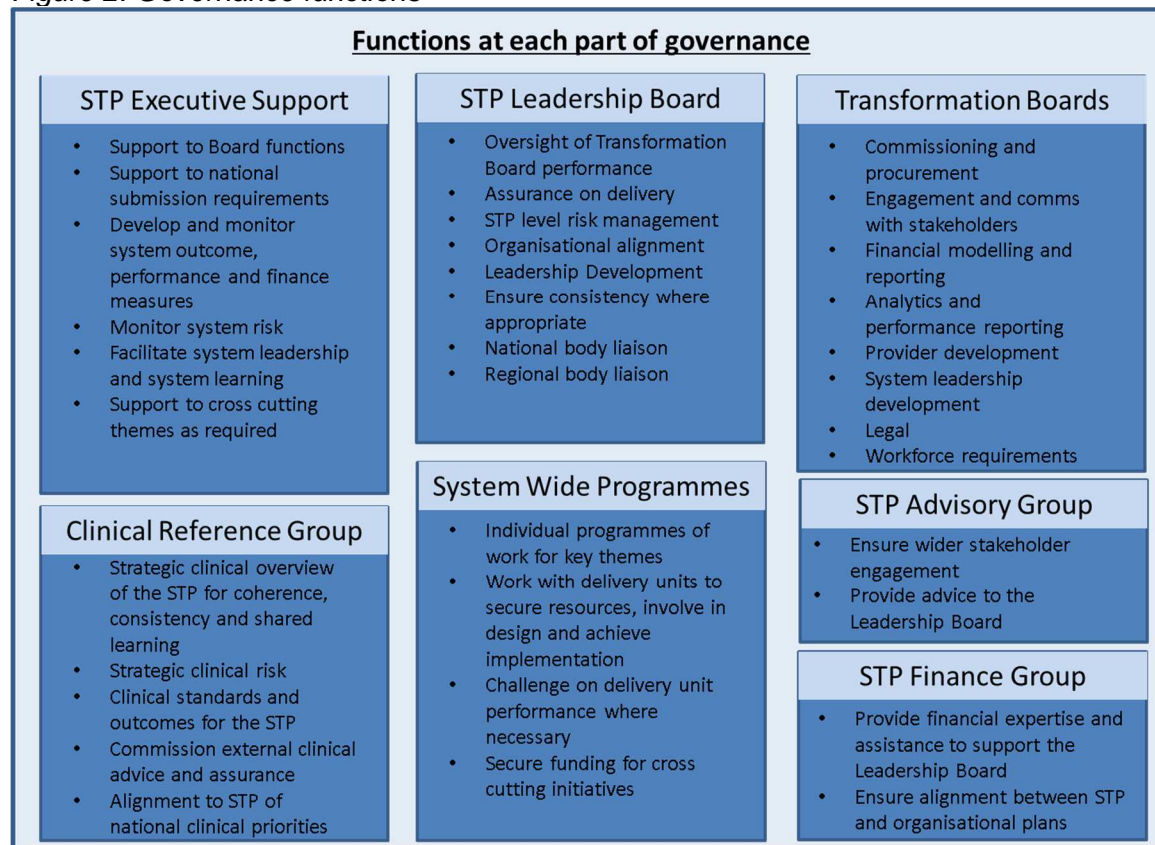
5.3 The STP Executive Support Function has been established to support the role and responsibilities of the STP Leadership Board. The role of this function is to:

- 5.3.1 Co-ordinate production of documents to support national STP submission requirements
- 5.3.2 Support the STP Leadership Board in preparing papers and ensuring that Board actions are followed through in accordance with Board expectations
- 5.3.3 Work with programmes to develop an annual STP performance and outcomes framework summarising key objectives, deliverables and performance
- 5.3.4 Monitor delivery and provide routine performance reports to the STP Leadership Board evidencing progress against the performance and outcomes framework including exception reports
- 5.3.5 Investigate issues highlighted by performance monitoring
- 5.3.6 Undertake support activities as instructed by the STP Leadership Board to ensure that system-wide programmes are delivered
- 5.3.7 Monitor system risks and hold the system risk log
- 5.3.8 Support system leadership development
- 5.3.9 Provide support to the Clinical Reference Group to develop their annual work plan
- 5.3.10 Maintain and develop the wider communications and engagement plan for stakeholders
- 5.3.11 Ensure financial monitoring of delivery against plan and alignment with contract assumptions.

6. Summary of functions

6.1 Each part of the governance structure is required to undertake specific roles and responsibilities. It is critical that these do not overlap. See figure two below.

Figure 2: Governance functions



7. Review of governance arrangements

- 7.1 The role and full expectations of STPs is still under national development - the governance structure will be reviewed at six-monthly intervals or where necessary to reflect any changes to functions.

Appendix 1

Transition arrangements

Transition arrangements are required to take us from the current state to a point where all the programmes are fully up and running. This will help assure NHS England and NHS Improvement and support delivery of the financial benefits outlined in the STP. The table below outlines the transition phase activities and year one operation of the STP.

Table 1: Transition functions to April 2017 and year one of the STP

	Transition phase from now to April 2017	Purpose
a.	Develop and agree readiness self-assessment process for individual programmes to identify governance and capacity	To understand current status and readiness of existing programmes and new workstreams, and resources needed
b.	Undertake peer review of readiness assessments	To ensure consistency and alignment of work where this is possible. Not all schemes will require full time support for all roles
c.	Use additional support from management consultancy to review capacity and readiness across the system to deliver agreed actions	To understand current system capacity to undertake change management roles required against existing capacity and system risk to delivery
d.	Assure individual programmes plans meet critical must do's for 2017-18 against the three 'gaps' (identified in the <i>NHS Five Year Forward View</i>)	To provide clarity on priorities and owners
e.	Ensure alignment of interdependencies/cross cutting themes like 'Making Every Contact Count'	To ensure we have no gaps and accountability is clear
f.	Support the STP Leadership Board to understand alignment between contract outcomes and individual control totals with STP assumptions and agree any further action amendment to STP financial plan	To track viability of STP financial plan and provide assurance to area local boards
g.	Develop an overview programme plan which aligns the individual programme actions/owners with the STP submission (sign off by the STP Leadership Board)	To provide assurance to the STP Leadership Board and hold the system to account for delivery
h.	Continue to manage communications and engagement in relation to the draft plan, supporting stakeholders with their awareness and understanding, and identification of any changes requiring formal consultation	To ensure full and proper communications and engagement. Will require significant ongoing resource
i.	Develop monitoring/reporting approach with delivery units and programmes	
j.	Assure organisational two-year operational plans are consistent with the STP and assumptions	

	2017-18	Purpose
a.	Agree timeframe for each programme to move to full autonomy and steady state reporting based on readiness assessment and delivery	To devolve responsibilities from the STP Leadership Board to the programmes which can provide necessary assurance
b.	Monitor delivery and provide assurance in relation to the delivery of the portfolio of programmes and milestones for 2017-18	To develop reporting structure and refine to move toward steady state model of performance and outcomes framework
c.	Test reporting processes and refine to ensure effectiveness and 'lean' approach	

TERMS OF REFERENCE January 2017

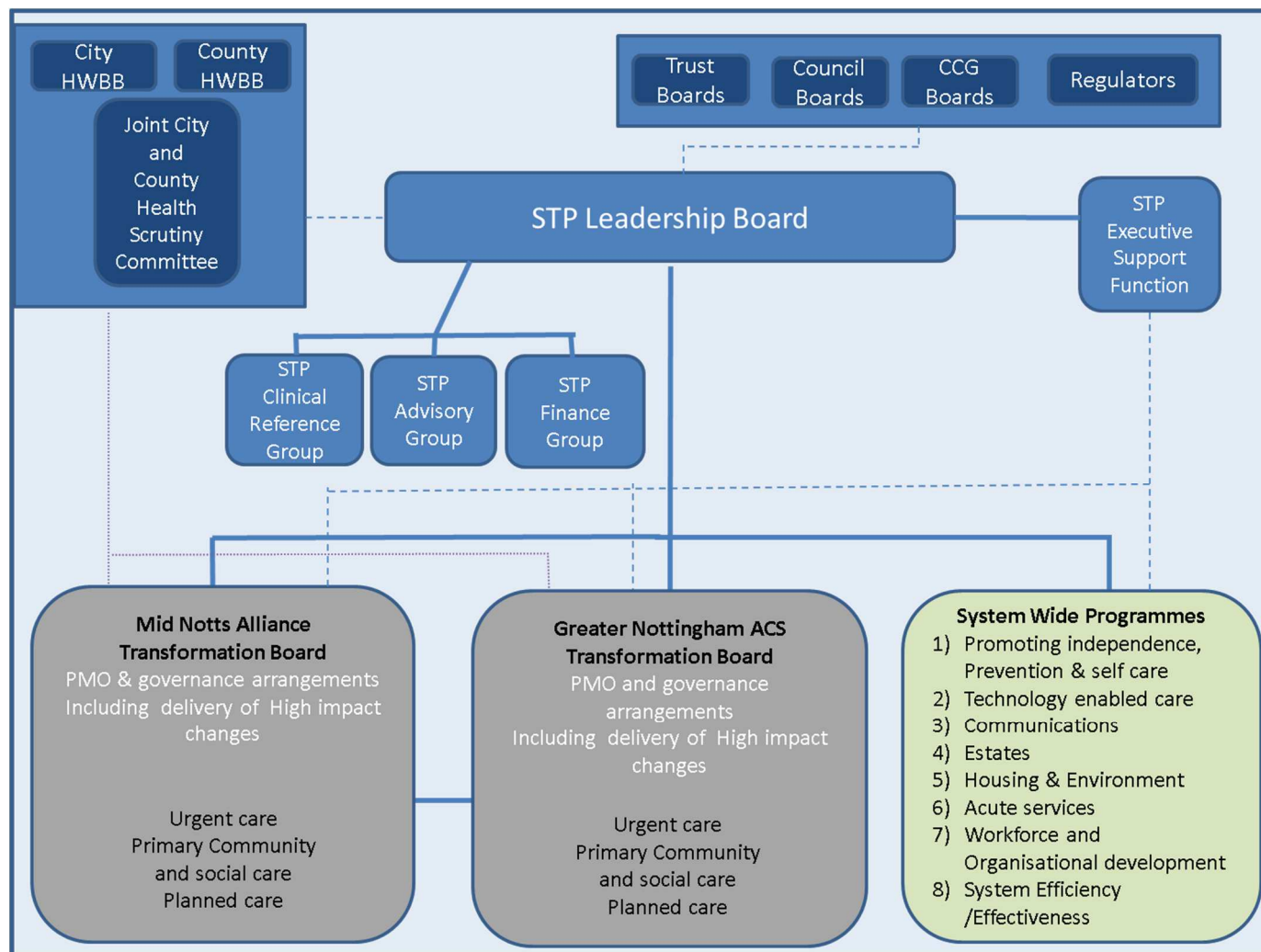
NAME OF GROUP:	STP Leadership Board														
PURPOSE	<p>The STP Leadership Board will provide system leadership and oversight to assure successful delivery of the objectives and outcomes agreed in the Nottingham and Nottinghamshire STP.</p> <p>They will hold the Transformation Boards and workstreams to account for the delivery of the plans, review and monitor progress against the STP objectives and outcomes, challenge each other to put system before organisation, ensure services are of a similar high standard across the area, and share best practice across Nottingham and Nottinghamshire.</p> <p>The Leadership Board will ensure it engages with local Health and Wellbeing Boards and boards of partner organisations within the health, local government, voluntary and independent sectors and meets the requirements of NHSE and arm's-length bodies.</p> <p>Individual organisations and the two 'transformation boards' (areas of health and care planning covering Mid Nottinghamshire and Greater Nottingham including the city) will continue to manage their own individual risks.</p> <p>The Leadership Board will consider and manage system risks level if this is in the best interests of the overall system.</p> <p>The members of the Leadership Board will work to ensure their own organisations' senior teams and Board/Executive bodies are regularly briefed and supportive of the proposed strategic changes and committed to working in partnership to deliver those changes.</p>														
MEMBERSHIP	<p>Chair: STP Lead Nottinghamshire County Council</p> <p>Members:</p> <table border="1"> <tr> <td>Chief Officer</td><td>West and Rushcliffe CCG</td></tr> <tr> <td>Chief Executive</td><td>Nottingham City Council</td></tr> <tr> <td>Chief Executive</td><td>Nottinghamshire Healthcare NHS FT</td></tr> <tr> <td>Chief Executive</td><td>Nottingham University Hospitals Trust</td></tr> <tr> <td>Chief Executive</td><td>Nottinghamshire County Council</td></tr> <tr> <td>Chief Executive (Lead for Housing and Environment)</td><td>Mansfield District Council</td></tr> <tr> <td>Chief Officer</td><td>Nottingham City CCG</td></tr> </table>	Chief Officer	West and Rushcliffe CCG	Chief Executive	Nottingham City Council	Chief Executive	Nottinghamshire Healthcare NHS FT	Chief Executive	Nottingham University Hospitals Trust	Chief Executive	Nottinghamshire County Council	Chief Executive (Lead for Housing and Environment)	Mansfield District Council	Chief Officer	Nottingham City CCG
Chief Officer	West and Rushcliffe CCG														
Chief Executive	Nottingham City Council														
Chief Executive	Nottinghamshire Healthcare NHS FT														
Chief Executive	Nottingham University Hospitals Trust														
Chief Executive	Nottinghamshire County Council														
Chief Executive (Lead for Housing and Environment)	Mansfield District Council														
Chief Officer	Nottingham City CCG														

	Chief Officer	Mid-Notts CCG's
	Chief Officer	Nottingham North East CCG
	Director of Public Health (Lead of Prevention, Independence and self-care workstream)	Nottinghamshire County Council
	Chief Executive (Lead of Future proof workforce and organisational development workstream)	Nottingham City Care Partnership
	Clinical Representatives	Mid Notts and Greater Notts Transformation Board
	Chair STP Clinical Reference Group	
	<p>In attendance:</p> <ul style="list-style-type: none"> • STP Director • Chair of Finance Directors Group/STP Finance Lead • Directors of Transformation for Mid Nottinghamshire and Greater Nottingham 	
PROGRAMME STRUCTURE	See Annex 1.	
RESPONSIBILITIES	<ul style="list-style-type: none"> • Act as a network of leaders ensuring the citizen is at the heart of all activities to continue to develop and deliver the Nottingham and Nottinghamshire Sustainability and Transformation Plan (N&NSTP) Programme working together to manage challenges or constraints to ensure successful delivery; • Lead productive relationships and dialogue between senior leaders in the health and social care system. This will include working closely with: <ul style="list-style-type: none"> ◦ Elected Councillors ensuring decisions are taken through Local Authority due processes; ◦ Local MPs to ensure they are well-briefed and understand and support, wherever possible, the need for major service and system change, together with the consequences of these for the residents they serve; • Work together provide assurance to the NHSE/NHSI in relation to the delivery of the plan, supporting individual partners where issues relate to the need to put system before organisation; • Provide collective leadership to assure delivery of the objectives and outcomes agreed in the STP for Nottingham and Nottinghamshire ensuring organisational support to the teams leading implementation for the system and assure that the critical dependences of the delivery of the STP are effectively managed; • Agree and engage with the organisational development of system leadership behaviours, capacity and skills to support successful delivery of the plan; • Agree with the Transformation Boards and system wide 	

	<p>programmes an annual STP performance and outcomes framework summarising key objectives, deliverables and performance;</p> <ul style="list-style-type: none"> • Monitor the delivery of the STP financial plan and assure alignment with organisational plans, agreeing actions to mitigate risks and develop contingencies where appropriate. Consider approaches to manage system financial risk including agreement of approach to 'system control totals'; • Receive and agree any actions arising from the routine performance reports evidencing progress against the performance and outcomes framework including exception reports; • Receive reports and escalations from the Clinical Reference Group in relation to the strategic clinical overview of the STP, clinical interdependencies and assessment of strategic clinical risks; • Request the Clinical Reference Group to provide expert external clinical advice/assurance as requested to resolve or manage any clinical issues escalated to them; • Assure a co-ordinated approach to citizen, staff, organisation, and wider stakeholder communications and engagement in the delivery of the 5-year strategy advising on the development and delivery of the strategic communications and engagement plan for stakeholders; • Monitor system risks and hold the system risk log, assuring that critical risks associated with the implementation programme are identified, assessed and managed.
FREQUENCY OF MEETINGS	The Board will meet formally on a monthly basis to conduct its business.
REQUIRED ATTENDANCE:	It is expected that members will prioritise these meeting and make themselves available exceptionally where this is not possible a Deputy may attend of sufficient seniority to support delivery in a timely manner and to have delegated authority to make decisions on behalf of their organisation or role on the Board in accordance with the objectives set out in the Terms of Reference for this Board. For Local Authority representatives this will be in accordance with the due political process.
ROLE OF THE EXECUTIVE LEADERS ON THE LEADERSHIP BOARD	<p>The Chief Executives/Chief Officers who are members of the Leadership Board are accountable for contributing and taking personal responsibility for the development of the STP and making decisions on behalf of their organisations where appropriate. They are responsible for keeping their organisational board or equivalent updated on the progress of the STP and will take key items for approval ensuring timely decision making does not delay the work of the STP delivery.</p> <p>Members will escalate to the Leadership Board any organisational strategic objectives or organisational requirements by arms lengths bodies which may jeopardise the delivery of the STP, whilst making efforts to minimise the risks of major unintended consequences for other partners across the system and to avoid</p>

	<p>any major 'surprises'.</p> <p>They will also take responsibility of leading key programmes of work as the Executive Sponsors on behalf of the Leadership Board ensuring the continued development of the STP priority themes and that the objective of ensuring objective of ensuring services are of a similar high standard across the area, and best practice is shared across Nottingham and Nottinghamshire.</p>
QUORUM:	The meeting will quorate when 70% of members are present.
REPORTING PROCEDURES:	<p>The STP Leadership Board will provide a regular communication to partner organisation boards or equivalent and the Health and Wellbeing Boards.</p> <p>The STP Leadership Board will receive regular reports on progress against the agreed performance and outcomes framework and exception and escalation reports from the transformation boards and system wide programmes.</p> <p>The STP Leadership Board will receive reports and appropriate escalations from the Clinical Reference Group.</p> <p>The STP Leadership Board will receive reports and advice from the Advisory Group.</p>
SERVICING:	<p>The Leadership Board will be serviced by the Executive Support Team.</p> <ul style="list-style-type: none"> • Draft agendas will be agreed with the Chair and circulated to Board members to contribute items; • Agreed items for the agenda, to be sent to the STP Team, with the relevant paperwork, up to 3 working days before each meeting; • The Chair agreeing the final agenda; • Papers will be circulated 2 working days before each meeting; • Additional items for the agenda will be taken by exception with the knowledge and agreement of the Chair in advance of the meeting commencing; • The draft minutes of each meeting will be circulated within 2 working days of the meeting being held and will be approved at the following meeting.
REVIEW DATE :	These Terms of Reference will be reviewed on a quarterly basis to ensure continued fitness for purpose in the light of potential changes to the expectations of national requirements or local issue.
DATE APPROVED :	31 January 2017

Annex 1 –



JOINT CITY AND COUNTY HEALTH SCRUTINY COMMITTEE
14 MARCH 2017
CONSULTATION ON PROPOSALS FOR CONGENITAL HEART DISEASE SERVICES
REPORT OF CORPORATE DIRECTOR FOR STRATEGY AND RESOURCES (CITY COUNCIL)

1. Purpose

- 1.1 To consider proposals for congenital heart disease services with a particular focus on the implications for Nottingham and Nottinghamshire residents.

2. Action required

- 2.1 The Committee is asked to:
 - a) confirm that the proposal that surgery and interventional cardiology for children and adults (Level 1 services) would cease at the University Hospitals of Leicester NHS Trust is a substantial variation/ development of services for Nottingham and Nottinghamshire residents;
 - b) consider the information available regarding proposals for congenital heart disease services with a specific focus on the implications for Nottingham and Nottinghamshire residents; and
 - c) either provide comments or decide to seek further information/ have further discussion before submitting comments to NHS England prior to the consultation closing on 5 June 2017.

3. Background information

- 3.1 In September 2016 the Committee was informed that NHS England had announced proposals about the future provision of congenital heart disease services and that this included a proposal to cease surgery and interventional cardiology for children and adults at University Hospitals of Leicester NHS Trust (UHL). This is the provider to which the majority of Nottingham and Nottinghamshire patients requiring these services are referred to.
- 3.2 The Committee was asked to decide whether it considered the transfer of congenital heart disease surgical and interventional cardiology services from University Hospitals Leicester to appropriate alternative

hospitals to be a substantial development or variation to services for Nottingham and Nottinghamshire residents. At that time the Committee felt that it needed further information on both the proposals and the consultation process, which was not then available.

- 3.3 Public consultation on the proposals was launched on 9 February 2017 to run until 5 June 2017. During the consultation period NHS England will be attending a range of events including 3 face to face events (one in Leicester on 9 March) and 3 webinars. A consultation document has been produced and an online survey is available on the NHS England website. Consultation responses will be collated by an independent company and the analysis published in due course. NHS England has stated that in coming to a decision it will consider the responses to the consultation and will adjust its proposals if it considers it appropriate to do so. A final decision will be taken by the NHS England Board.
- 3.4 Copies of the following documents published as part of the consultation process are attached:
 - a) Proposals to implement standards for congenital heart disease services for children and adults in England – Consultation Document
 - b) Equalities and Health Inequalities Impact Assessment
 - c) NHS England Provider Impact Assessment Report
- 3.5 The consultation document sets out the background to the proposals, the case for change and how the proposals were developed; details of the proposals being consulted on; engagement and involvement on the proposals, including the consultation questions; and a summary of the impact assessments carried out.
- 3.6 The consultation document confirms that NHS England is consulting on the proposal that surgical and interventional cardiology for children and adults (Level 1 services) would cease at the University Hospitals of Leicester NHS Trust. It states that children and adults who would currently be most likely to receive surgery and/or interventional cardiology at University Hospitals of Leicester would be likely to choose to receive their care at either Birmingham Children's Hospital NHS Foundation Trust or University Hospitals Birmingham NHS Foundation Trust and that some current Leicester patients would be likely to choose to receive care from Leeds Teaching Hospitals NHS Trust, if this was closer for them than Birmingham. Details of the proposal relating to University Hospitals Leicester (UHL) can be found on pages 17-19 of the consultation document (attached at Appendix 1). The Impact Assessment says that from 2014/15 data it is predicted that 26 adults and 230 children who previously received treatment at UHL would be affected by the changes to Level 1 services (this would include some patients from Nottingham and Nottinghamshire).
- 3.7 An Equalities and Health Impact Assessment has been carried out and is attached at Appendix 2. This includes an assessment of geographical

issues. A Provider Impact Assessment Report has also been carried out and is attached at Appendix 3. An assessment of the specific issues relating to UHL can be found from page 14 onwards in the report, including the impact on other services such as paediatric intensive care and Extracorporeal Membrane Oxygenation (ECMO); impact on workforce; and impact on finances. It is stated that if Level 2 medical services continue to be provided by the Trust then the impacts will be reduced.

- 3.8 As part of the consultation NHS England will be attending this meeting to discuss the proposals with the Committee and receive any comments that the Committee wishes to make at this stage (similar meetings are scheduled with other health scrutiny committees). This is an opportunity for the Committee to ask questions and seek any clarification required both about the process and the proposals themselves. Following this the Committee may wish to submit comments as part of the consultation. This could either take place at this meeting or at a future date before the consultation period ends on 5 June 2017.
- 3.9 As part of the evidence gathering process for this, the Committee has asked local trusts and clinical commissioning groups if they would like to provide any information to the Committee regarding their assessment of the implications of the proposals for Nottingham and Nottinghamshire residents. A presentation from University Hospitals of Leicester is included with the papers.
- 3.10 Health scrutiny committees in other areas of the East Midlands are also considering the proposed changes and have meetings with NHS England scheduled to discuss the impact of the proposed changes on residents in their area.
- 3.11 Changes are also proposed to the provision of Level 2 specialist medical care (including that specialist medical care and interventional cardiology should cease at Nottingham University Hospitals NHS Trust). Those changes are not part of this formal public consultation but the consultation document states that NHS England will be offering the opportunity for people to discuss those proposals.

4. List of attached information

Appendix 1: Proposals to implement standards for congenital heart disease services for children and adults in England – Consultation Document

Appendix 2: Equalities and Health Inequalities Impact Assessment

Appendix 3: NHS England Provider Impact Assessment Report

Appendix 4: Presentation from University Hospitals of Leicester

5. Background papers, other than published works or those disclosing exempt or confidential information

5.1 None

6. Published documents referred to in compiling this report

6.1 Report to and minutes of meeting of the Joint Health Scrutiny Committee held on 13 September 2016

NHS England news “Congenital Heart Disease: NHS England takes action to deliver consistent and high quality services now and for the future” www.england.nhs.uk 08/07/16

7. Wards affected

7.1 All

8. Contact information

Jane Garrard, Senior Governance Officer, Nottingham City Council
Tel: 0115 8764315
Email: jane.garrard@nottinghamcity.gov.uk

Proposals to implement standards for congenital heart disease services for children and adults in England - Consultation Document



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Document Purpose	Consultations
Document Name	Proposals to implement standards for congenital heart disease for children and adults in England - Consultation Document
Author	NHS England
Publication Date	09 February 2017
Target Audience	CCG Clinical Leaders, CCG Accountable Officers, Foundation Trust CEs, Medical Directors, Directors of Nursing, NHS England Regional Directors, NHS England Directors of Commissioning Operations, NHS Trust CEs, Public; Patients; Families; Carers; Patient Group representatives; charities
Additional Circulation List	All NHS England Employees, Directors of HR, Directors of Finance, Communications Leads
Description	NHS England is consulting on its proposals to implement national standards for congenital heart disease services for children and adults. This document sets out the background and context for our proposals; explains the proposals in more detail, including their potential impact, if implemented; and how you can get involved in consultation.
Cross Reference	N/A
Superseded Docs (if applicable)	N/A
Action Required	N/A
Timing / Deadlines (if applicable)	Consultation runs from 9 February to 5 June 2017
Contact Details for further information	Michael Wilson Programme Director Congenital Heart Disease Programme NHS England Skipton House 80 London Road SE1 6LH www.engage.england.nhs.uk

Document Status

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

Consultation Document

First published: 9 February 2017

Prepared by: Specialised Commissioning, NHS England

Classification: OFFICIAL

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Foreword

In July 2016, NHS England published a set of proposals regarding the future commissioning of congenital heart disease (CHD) services for children and adults. They describe the actions which we, as commissioners, propose to take in order to ensure a consistent standard of care for CHD patients across the country, for now and for the future.

We propose to do this by implementing national service standards at every hospital that provides CHD services. The effect of our proposals, if implemented, will be that some hospitals will carry out more CHD surgery and catheter procedures, while others, which do not meet the relevant standards, will stop doing this work.

The standards describe services of the highest possible quality. They were developed by patients, and their families and carers, by surgeons and other specialist doctors and nurses, and were formally agreed by the NHS England Board in 2015. We acknowledged then that implementation of them would be a challenge for some hospitals. We also recognised that it might subsequently prove necessary to make tough choices when considering how to put them into practice.

The guiding principle for our work has always been ‘patients come first’. That principle remains at the forefront of our thinking today. It was patients, and their families/carers and representatives, as well as clinicians in the field, who told us – consistently – that the standards were only worth something if they were actually acted upon and met.

Now is the time for decisive action. We have an opportunity to future-proof CHD services, by ensuring that the standards are met. This will enable services to better cope with an increasing number of complex cases and make best use of advances in technology. We must not squander this opportunity. Equally, however, we must ensure that our commissioning decisions are informed by the views of patients and their families and carers, by clinicians and other hospital staff, and by other stakeholders.

We know that if our proposals are implemented, they will have an impact, not just on patients, but on this small number of hospitals, and some of the other services which they deliver, as well as on the staff working in them. We know that some of you are concerned about potentially longer journey times; having to travel greater distances for surgery; the availability of support and accommodation while away from home, and what might happen if there is an emergency. Thankfully, true emergencies in congenital heart disease are incredibly rare, but we recognise your concerns, and have tried to address them later in this document.

This is why we want to hear from you, during this public consultation, so that we can better understand how any changes might affect you and how we might support patients, hospitals and staff, during any future change. Before reading the rest of this consultation document, there are some important points which you might want to consider:

- No decisions about the future commissioning of CHD services have been taken. The proposals published in July were just that – proposals. If you can think of alternative ways in which the standards can be met, then we want to hear from you;
- This is not about saving money. You will already know that money is tight in the NHS, and the NHS has to live within its means. While implementing most of the standards will cost little, or nothing, we expect the overall amount of money spent on CHD care to increase in the future, driven by the growing number of patients living with this condition;
- These proposals are not about closing CHD units. We do not have a fixed number of hospitals providing CHD services in mind. This is about ensuring that every hospital providing a CHD service meets the standards. We have no view about the final number of hospitals which are able to do that;
- This is not about a short-term fix. We are focusing on the long-term resilience and sustainability of CHD services for generations to come.

Finally, we would like to acknowledge the significant time and effort which patients, parents, families, carers, and NHS staff have put into the various pieces of work which have been carried out during the past 16 years, all aimed at improving congenital heart disease services in England. We have all been at this a long time, and we recognise the cloud of uncertainty which hangs over these services as a result.

We need to put an end to this uncertainty, for everybody's sake. So, as you read this document, we hope that you will keep the future long-term stability of these important services in mind, and help us to reach a clear, and long-term, resolution, in the best interests of patients.



Will Huxter
Senior Responsible Officer for
CHD Commissioning and
Implementation Programme &
Regional Director for
Specialised Commissioning



Professor Huon Gray
National Clinical Director for Heart
Disease, NHS England & Consultant
Cardiologist, University Hospital of
Southampton

Background and context

“Sixteen years is a long time to wait. We have lost key consultant staff to posts abroad during that time, as they were not convinced that we were ever going to grasp this nettle. This is our last opportunity to make change happen. If we don’t grasp this opportunity now, we have to accept that ‘adequate’ is good enough”.

Professor Huon Gray

Consultant Cardiologist, University Hospital Southampton NHS Foundation Trust, and National Clinical Director for Heart Disease, NHS England

1. Congenital heart disease (CHD) refers to a heart condition or defect that develops in the womb, before a baby is born. There are many different forms of CHD, some more minor than others. Some people with CHD do not require any form of surgery or interventional procedure in the treatment of their condition; others require surgery before, or immediately after, birth. Thanks to advances in early diagnosis and medical advances, most babies born with CHD grow up to be adults, living full and active lives. CHD is common. It is estimated that between 5 and 9 in every 1000 babies born in the UK is born with CHD – this is around 5,500 to 6,300 babies each year. These figures will continue to increase if birth rates continue to rise, which leads to an increase in the number of operations and interventional procedures carried out on CHD patients each year.
2. Many congenital heart disease services work together in networks, so that neighbouring hospitals have good systems for referring patients, and for passing information back and forth. Networks help local services to work closely with specialist centres, to ensure that patients receive the care they need in a setting with the right skills and facilities, as close to home as possible.
3. Services are based around a three-tiered model of care with specialist surgical centres (Level 1) managing the most highly complex diagnostics and care, including all surgery and interventional cardiology. At the next level are specialist cardiology centres (Level 2), which provide the same level of specialist medical care as Level 1, but do not provide surgery or interventional cardiology (except for one, specific minor procedure – atrial septal defect (ASD) closures, more commonly known as ‘hole in the heart’ – at selected hospitals treating adults. These Level 2 hospitals focus on diagnosis, plus ongoing care and management of CHD. At Level 3 will be local cardiology services, which are services in local hospitals run by general paediatricians/cardiologists with a special interest in CHD. They will provide initial diagnosis and ongoing monitoring and care, including joint outpatient clinics with specialists from Level 1 and 2 hospitals. These services are commissioned by local Clinical Commissioning Groups (CCGs), and not by

NHS England. We are working with CCG commissioners to address the need for a more integrated approach to care across the three tiers.

4. Anybody who is familiar with the history of these services will know that publication of NHS England's proposals in the summer of 2016 represented the latest milestone in a very long journey, stretching back 16 years, to the publication of the report of a public inquiry into concerns about the care of children receiving complex cardiac surgery at Bristol Royal Infirmary. This was followed by the Safe and Sustainable review, launched by the Department of Health, in 2008. This review set out recommendations for a CHD service based on networks; with clinical standards for all hospitals designated to provide heart surgery for children, and a reduction in the number of NHS hospitals in England providing that heart surgery. Ultimately, these recommendations were not implemented, following intervention with the Secretary of State.
5. We know, from talking to stakeholders, that the failure to implement the recommendations of previous reviews has created uncertainty for patients and staff, and concerns raised during these, and other enquiries, have remained. However, despite the fact that previous reviews have not resulted in a coordinated programme of change, progress has been made. Outcomes for CHD surgery and interventional procedures across England are good, and compare well with other countries. We also know, from talking to patients and their families and carers in particular, that the quality of CHD care delivered in hospitals is very good. We have heard many, many positive stories about individual patient experiences, and recognise that each of those personal testimonies carries real weight, and shapes how people feel about the NHS service which has cared for, or saved the life of, their loved ones.
6. When NHS England took on responsibility for the commissioning of CHD services in 2013, we were aware of the impact that previous reviews had had, as described above, and were told by patients, families, doctors and nurses alike, that the best way to deal with these issues was through the development of service standards, setting out how a good CHD service should be set up, organised and run.
7. We worked with the different groups of stakeholders for more than two years, as part of the New Congenital Heart Disease Review, to create a set of quality and service standards that covered the entire patient pathway, from diagnosis, through treatment, and on into care at home and end of life care, to make sure that every child, young person and adult with CHD, in every part of the country, would receive the same high standard of treatment.
8. Surgeons told us how many operations should be done by each surgeon every year in order to maintain the surgeons' skills. Similarly, specialist doctors and nurses told us what medical care should be available by the bedside of a patient in a critical condition. Patient representatives led the work in developing the standards covering communication, facilities and bereavement. Additionally, for the first time ever, the transition from children's

services to adult services was included in the standards, to ensure that care is truly joined up.

9. The standards have never been considered as an end in themselves. They were developed in the full expectation that their implementation at every hospital in the country providing CHD services would be the means by which our work would be delivered, i.e:
 - securing best possible outcomes for all patients – not just reducing the number of deaths, but reducing disability caused by disease, and improving people's quality of life;
 - tackling variation, so that services are consistent in meeting standards, each of them offering 24/7 care, seven days a week, as part of a nationally resilient service;
 - improving patient experience, including provision of better information for patients, plus more consideration of access and support for families when they are away from home.
10. This review has been underpinned by principles of openness and transparency, and a need to engage as widely as possible, bringing patients, families, carers, patient representatives, and clinicians together, in the joint pursuit of an effective and equitable solution, in the interests of patients now, and in the future. Consensus across all groups was achieved on the content of the standards, and it became clear that NHS England, as the sole national commissioner of CHD services had a unique opportunity to drive service improvement, and reduce variation in access and quality, by implementing a set of nationally-agreed standards, governing a truly national service.

The case for change

11. The standards describe how to deliver CHD services of the very highest quality. We believe that implementation of these standards is the only way to ensure that patients are able to access care delivered to the same high standards, regardless of where they are treated. There is currently some variation as to where individual hospitals lie in meeting the standards, so care may vary, depending on where in England you access services.
12. We know, from talking to patients and their families/carers, that some people consider the care that they and their loved ones have experienced at a hospital to be the best there is. We do not wish to detract from that very personal experience, but it is not the same for everyone, and that simply is not fair.
13. Once all hospitals are meeting the standards, we can ensure that patients with CHD will be receiving the same levels of high quality care. For patients, and their families and carers, this means:
 - higher levels of support from specialist nurses and psychologists;

- improved communication and information, so that newly diagnosed patients have a better understanding of their condition; the care provided; treatment options; and how to take part in decisions about their own care;
- better managed transition from children's to adult services;
- improved palliative and end of life care, with specific standards focused on support for bereaved families and carers.

The above were all aspects of care which patients and patient groups told us were important, and are examples of the highest possible quality care, which we think should be available to all CHD patients, regardless of which hospital they attend.

14. For clinicians, and their teams, the broader benefits of meeting the standards will include:

- hospitals caring for people with CHD have the right staffing and skills mix, with no fewer than minimum staffing and activity levels, which support the maintenance of skills and expertise;
- improved resilience and mutual support provided by a networked model of care;
- enhanced opportunities for developing sub-specialisation;
- enhanced training and mentorship; sharing learning and skills; quality assurance and audit;
- elimination of isolated and occasional practice – this is when small volumes of surgery and interventional cardiology are undertaken in hospitals that do not offer specialist expertise in this field.

15. What we have described here are tangible benefits, things that will really make a difference to the care of patients with CHD, and to the teams caring for them. We believe that every patient receiving care for CHD should expect these highest possible standards of care, regardless of where they receive their treatment.

“From my perspective there are three main clinical advantages for having high-volume congenital cardiac surgical centres. Firstly, as an individual surgeon the more I do the better I become. There's lots of evidence for this in other surgical specialties, in particular showing that high volume centres reduce the number of post-operative complications and improving long-term quality of life. This also works for the whole team providing the care: the more the team does, the better they become, and this gives a huge opportunity for people to learn from each other in a large multidisciplinary setting.

And finally, higher surgical volumes enable specialisation in areas such as neonatal, congenital and device treatments. Importantly, these are all important for the next generation of surgeons coming up through the system - they will be less experienced when they become consultants than in the past - and they will need to fit into a large team to nurture them into becoming the surgeons of the future.”

**Mr Martin Kostolony - Head of Clinical Service - Cardiothoracic Surgery,
Great Ormond Street Hospital for Children NHS Foundation Trust**

16. Apart from the benefits achieved by meeting the standards themselves, there are some specific additional benefits associated with implementation of the standards:

1.1 Ending uncertainty

17. The long history of repeated reviews of CHD services has created uncertainty within the specialty, damaging relationships between hospitals; harming recruitment and retention of specialist staff; and reducing the resilience of services. Continued uncertainty affects recruitment and retention of congenital heart disease surgeons, a group in short supply and subject to international demand.
18. The 2014 report on CHD services at Leeds Teaching Hospitals NHS Trust¹ recommended that NHS England should act to dispel the “almost morbid sense of spectatorship and foreboding that hangs over these services”. Clear resolution is now needed to bring the stability the service needs to move forward.

¹ <https://www.england.nhs.uk/wp-content/uploads/2014/.../leeds-review.pdf>

1.2 Ending occasional practice

We have been calling for standards for adult congenital heart disease for many years and it is excellent that this has finally been achieved. Never before have the services for adults been designated and therefore occasional practice has happened. The introduction of these standards has already mainly eliminated that occasional practice and I am confident it will be a thing of the past, providing a much safer level of care and that is what these standards are all about.

Michael Cumper, Vice President, Somerville Foundation

19. Occasional and isolated practice (small volumes of surgery and interventional cardiology undertaken in hospitals without sufficient specialist expertise) has been a big concern, particularly for charities representing adults with CHD.
20. We asked every non-specialist hospital, where the data showed CHD procedures had taken place, to either cease occasional practice or take steps to meet the requirements of the standards, including minimum volume requirements. Most of these hospitals confirmed that the apparent occasional practice was due to coding errors. In other cases the practice had already stopped or steps were being taken to move this activity to an appropriate specialist Level 1 or Level 2 hospital. Some hospitals confirmed that they wished to be considered as specialist medical centres (Level 2), so we assessed them against the relevant standards
21. Occasional practice has largely been addressed through this process. Where the issue has not yet been resolved, it will be followed up by NHS England's regional teams.

1.3 Resilient, sustainable services

“We know that many people are very nervous about how the standards are moved forward, we must acknowledge those fears and support patients and families affected by any change but if we do not start to implement the new standards soon we will start to see a deterioration in the service.

We know that there are a growing number of children with highly complex conditions travelling through care. It is really important to make sure that there is a really strong service for them from the beginning of their lives, through their childhood and into adult services. They deserve nothing less.

Suzie Hutchinson, Chief Executive and Service Lead, Little Hearts Matter

22. Larger hospitals with bigger teams, more effectively networked with other hospitals, will be more resilient, providing an assurance of full 24-hour, seven- day care and a greater ability to cope with challenging events, for example the loss of a surgeon. We know, from talking to clinicians, that they feel best able to carry out their work when they are part of a team. Surgeons need the support of fellow surgeons, to provide cover for annual leave, and to step in when colleagues fall sick. They also need the support of an expert team around them. It is this kind of set-up that builds resilience in a service, and ensures that patients get access to the best possible care when they need it. The only way we can build this resilience is if we implement the standards.
23. The standards are – rightly – challenging, and it was acknowledged by the NHS England Board, when they were adopted, that it would be difficult for all hospitals to meet them, unless changes were made to the way in which those hospitals work. This is why the timeline for meeting some of the standards differs, as it was recognised that meeting some standards would take longer than others. For instance, the co-location of children’s CHD services with other children’s services might require physical changes to a hospital’s structure or layout.
24. Our proposals are described in detail on page 15. If they are implemented, in future, CHD services will only be provided by hospitals which already meet the standards required, or are likely to meet the standards within required timeframes as a result of the improvement plans they are putting in place.

“We fully support these standards. NHS England must ensure that the standards are applied for the benefit of patients, by ensuring that expertise is concentrated where it is most appropriate. The proposals put forward by NHS England in July 2016 should improve patient outcomes and help address variations in care currently provided”.

Royal College of Surgeons and the Society for Cardiothoracic Surgery (SCTS)

Proposals for consultation

25. At the heart of our proposals is our aim that every patient should be confident that their care is being delivered by a hospital that is able to meet the required standards. In order to achieve this, we propose that in future, NHS England will only commission CHD services from hospitals that are able to meet the standards within the required timeframes.
26. Three specific standards are relevant to our proposals:
 - Surgeon working requirements – the number of surgeons at each hospital, and the number of operations they each perform.
 - o The standards require that, for 2016, surgeons work in teams with a minimum of three surgeons, and in teams of at least four surgeons by April 2021. CHD surgeons are each required to carry out no fewer than 125 congenital heart operations a year (the equivalent of about three operations a week), averaged over a three-year period;
 - Service interdependencies, or co-location – the other services CHD patients depend upon, and which need to be on the same hospital site.
 - o The standards require that specialist children’s cardiac services are only delivered in settings where a wider range of other specialist children’s services are also present on the same hospital site. The standards require that certain paediatric specialties are within a 30-minute call to bedside range for April 2016, and co-located on the same site as children’s CHD services by 2019.
 - Interventional cardiology
 - o The standards require that for 2016, interventional cardiologists work in a team of at least three, and by April 2017 in teams of at least four, with the lead interventional cardiologist carrying out a minimum of 100 procedures a year, and all interventional cardiologists doing a minimum of 50 procedures a year.

27. The proposals on which we are consulting are, therefore:

Level 1 (surgical)

Proposal:

Surgery and interventional cardiology for adults would cease at **Central Manchester University Hospitals NHS Foundation Trust**. Central Manchester does not currently undertake surgery for children.

28. The standards require surgeons to be working in teams of three by April 2016, and in teams of four by April 2021. They also require each surgeon to be carrying out a minimum of 125 operations a year. Central Manchester University Hospitals NHS Foundation Trust has only one congenital heart surgeon, carrying out fewer than 125 congenital heart operations a year.

29. Interventional cardiology for adults at Central Manchester University Hospitals NHS Foundation Trust is already performed primarily by interventional cardiologists from Alder Hey Children's Hospital NHS Foundation Trust who travel to Manchester to see patients. Under our proposals, adult patients requiring surgery or interventional cardiology, who currently receive this level of care at Central Manchester University Hospitals NHS Foundation Trust, would be most likely to go to Liverpool Heart and Chest Hospital NHS Foundation Trust for surgery and/or interventional cardiology. All other care, with the exception of surgery and interventional cardiology, would continue to be provided in Manchester.

Proposal:

Surgery and interventional cardiology for children and adults would cease at **Royal Brompton and Harefield NHS Foundation Trust**.

30. The Royal Brompton and Harefield NHS Foundation Trust currently provides surgery and interventional cardiology for children and adults from the Royal Brompton Hospital. The agreed standards require a number of other specified services for children to be co-located by April 2019 on the same hospital site as surgical and interventional cardiology for children are provided from. The Royal Brompton Hospital does not have all of those required paediatric specialties on site, and does not have firm plans to do so. (These services are currently provided to the Royal Brompton's patients by Chelsea and Westminster NHS Foundation Trust). The Royal Brompton is therefore not able to meet that standard.

31. We are continuing to explore two avenues by which the Royal Brompton could continue to provide some, or all, Level 1 services by meeting all of the required standards:
- The hospital trust is exploring ways in which the paediatric co-location standards could be met by the required deadline of April 2019;
 - NHS England has raised with the Royal Brompton Hospital the potential for it to continue to provide Level 1 adult CHD services, including surgery. This would involve the hospital partnering with another Level 1 CHD hospital in London, that meets the required standards and that cares for children and young people. To date, the Royal Brompton Hospital has indicated that it does not support this approach, but it has not said that it would refuse to treat adults alone.
32. If a solution cannot be found then, under our proposals, children and adults who would currently be most likely to undergo CHD surgery and/or interventional cardiology at Royal Brompton and Harefield NHS Foundation Trust would still be able to receive their care in London, but would be most likely to go to Great Ormond Street Hospital for Children NHS Foundation Trust, Bart's Health NHS Trust or Guy's and St Thomas' NHS Foundation Trust if they required surgery and/or interventional procedures.

Proposal:

Surgery and interventional cardiology for children and adults would cease at **University Hospitals of Leicester NHS Trust**.

33. University Hospitals of Leicester NHS Trust performed 326 surgical procedures in 2015/16 which does not meet the minimum number of cases required by the standards. The hospital trust states that it is very close to meeting the requirement for an overall caseload of 375 operations for 2016/17, and has a growth plan in place to reach an overall caseload of 500 operations by 2021. NHS England does not consider these projections to be sound, and needs to see a more robust plan to support delivery of 375 cases now, and 500 cases by 2021. As of mid-January 2017, this plan has not been provided to us by the hospital trust.
34. The CHD service in Leicester lacks the capacity to deliver a full range of services as a fully independent centre, receiving clinical support for complex cases from surgical and cardiology colleagues in Birmingham. It has also transferred cases to Great Ormond Street Hospital for Children NHS Foundation Trust, and to Newcastle Hospitals NHS Foundation Trust. At this point in time, it is difficult to see how the hospital trust will be able to build up its resilience to ensure sustainable services for the future.

35. Similarly, University Hospitals of Leicester NHS Trust is at the margins of having enough interventional cardiology activity for its proposed team of three interventionists to meet the requirements of a lead interventionist carrying out a minimum of 100 procedures a year, and all interventionists doing a minimum of 50 procedures a year. While the hospital meets the April 2016 requirements, we need to see a credible plan which supports the development of a team of four interventionists by April 2017, and the associated activity that goes with that team.
36. Glenfield Hospital, which is part of University Hospitals of Leicester NHS Trust, and which is where the CHD service is located, has access to 24/7 paediatric gastroenterology and paediatric surgery, but does not have either of these services on site. The hospital originally proposed to achieve co-location of relevant paediatric specialties with its paediatric CHD service by 2019, through plans to build a new children's hospital, bringing all children's specialist services together on one site. However, the Trust has since developed an alternative plan that would involve moving paediatric cardiac services to the Leicester Royal Infirmary by 2019. We consider that the Trust's proposal to move paediatric cardiac Level 1 services to the Infirmary site would allow it to achieve full compliance with the co-location requirements, although the Trust would need to ensure that this move is achieved by the required deadline.
37. If we do not receive assurance that the hospital trust will meet the required standards then, under our proposals, children and adults who would currently be most likely to receive surgery and/or interventional cardiology at University Hospitals of Leicester would be likely to choose to receive their care at either Birmingham Children's Hospital NHS Foundation Trust or University Hospitals Birmingham NHS Foundation Trust. Some current Leicester patients would be likely to choose to receive care from Leeds Teaching Hospitals NHS Trust, if this was closer for them than Birmingham.
38. If our proposals are implemented, University Hospitals of Leicester NHS Trust could continue to offer Level 2 specialist medical services to children and adults, and we continue to discuss this option with the hospital trust. If the hospital carried on offering Level 2 CHD services, then the vast majority of patient care would continue to be offered in Leicester, and patients would only be required to travel elsewhere if they required surgery and/or interventional catheters. We continue to discuss this option with University Hospitals of Leicester NHS Trust.
39. It is important to note that change, such as that proposed above, has already taken place in CHD services without any adverse effects on patients. In 2010, Oxford stopped providing CHD surgery following the deaths of a number of babies. The hospital trust was carrying out more than 100 cases a year up until that time. Surgery was moved to Southampton. Surgeons employed at Oxford moved elsewhere, and there was no impact on other members of staff, who were all redeployed elsewhere within the hospital trust. Oxford is now part of a formal children's network, which means that patients can choose either Southampton or a hospital in London for surgery and/or

interventional catheters, but can have all of the rest of their CHD care in Oxford. One of the knock-on effects of the change was that children requiring specialist surgery are now transferred to Southampton, whilst general children's surgery at Oxford has increased, now that it has more capacity.

40. New patients accept referral to Southampton for surgery/interventional catheters as the norm, and, while some patients would prefer that Oxford were still offering Level 1 CHD surgery, the hospital trust Board made it clear that it would not be appropriate for the hospital to continue to provide CHD surgery. We do not use the Oxford illustration in any way to detract from the concerns that you might have about our proposals, but it does demonstrate that change such as this can take place with minimal impact, if well managed.

Surgery and interventional cardiology for adults and children would continue at **Newcastle upon Tyne Hospitals NHS Foundation Trust**.

41. While we are clear that all hospitals providing CHD services must meet the national CHD standards, we have had to propose a time-limited exception, or derogation, in the case of one particular hospital. Newcastle upon Tyne Hospitals NHS Foundation Trust does not meet the 2016 activity requirement and is unlikely to be able to meet the 2021 activity requirement. It also does not meet the 2019 paediatric co-location requirements or currently have a realistic plan to do so by April 2019. The CHD service for both children and adults is located at the Freeman Hospital, which is primarily an adult acute hospital. Relevant children's specialties – paediatric surgery, nephrology and gastroenterology – are located at the Great North Children's Hospital, which is part of the same hospital trust, but is not located on the same site. While the hospital trust meets the co-location requirement for 2016, i.e. bedside access within 30 minutes, it is unlikely to meet the full co-location requirement for 2019 for children's CHD surgery to be on the same site as other children's specialist services.
42. Newcastle upon Tyne Hospitals NHS Foundation Trust has a unique, strategic position in the NHS in England in delivering care for CHD patients with advanced heart failure, including heart transplantation and bridge to transplant. Advanced heart failure amongst people with CHD is increasing as a result of increased life expectancy, and treatment for people with this condition is dependent on CHD surgeons. Adult CHD patients with end stage heart failure have limited access to heart transplantation, and the unit in Newcastle is recognised as delivering more care to this group than other transplant centres nationally. This service is intimately connected to the CHD service and can only be delivered at a hospital providing Level 1 surgical services. No other provider currently has this capability so, while in principle it would be possible to commission these services from an alternative provider, the learning curve would be long and initially outcomes would not be as good.

43. In addition, the hospital trust is one of only two providing paediatric heart transplantation for the UK (the other is Great Ormond Street Hospital for Children NHS Foundation Trust in London).
44. While Newcastle does not meet these required standards now and is unlikely to be able to do so within the required timeframe, its role as one of only two national providers of critical heart transplantation and bridge to transplant services means that we need to consider retaining services at Newcastle despite the fact that it does not meet all the standards at present and is unlikely to do so within the required timeframes. The surgeons who perform CHD operations are the same surgeons carrying out heart transplants. If CHD surgery were moved elsewhere, the transplantation service could not be replaced in the short term without a negative effect on patients. For this reason, we are proposing to retain CHD services at Newcastle upon Tyne Hospitals NHS Foundation Trust.
45. This does not mean that change at Newcastle upon Tyne Hospitals NHS Foundation Trust will not happen in the longer-term. The hospital trust is required to meet the standards in the same way as all of the other Level 1 surgical centres. Timeframes for doing this may differ, but we will be working closely with the hospital trust to ensure that patients receiving CHD care at Newcastle upon Tyne Hospitals NHS Foundation Trust are not compromised in any way.
46. If our proposals were implemented, this would mean that, in future, Level 1 CHD surgical services would 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)
 - **Birmingham 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)
 - **Leeds Teaching Hospitals NHS Trust** (children's and adult services)
 - **Newcastle upon Tyne Hospitals NHS Foundation Trust** (children's and adult services)
 - **University Hospitals Bristol NHS Foundation Trust** (children's and adult services)
 - **University Hospital Southampton NHS Foundation Trust** (children's and adult services)
47. Changes are also proposed to the provision of Level 2 specialist medical CHD care. In most cases, these proposals involve very small numbers of patients who might be impacted by that change. Whilst those changes are not the subject of this formal public consultation, we are very keen to talk to patients, their families/carers, and staff at affected hospitals, to better

understand the impact of any proposed change, and to hear their views about how we might limit that impact. We will be offering opportunities for stakeholders to talk to us about our proposals in relation to Level 2 services during this consultation period, so that we can discuss how we might support them to adjust to any changes in their care. You can find out about events in your area by visiting our [Consultation Hub](#)

48. If implemented, following our engagement with stakeholders, our proposals would result in the following changes at those hospitals that completed Level 2 self-assessments:

Level 2 (specialist medical services)

Proposals:

Specialist medical care and interventional cardiology should cease at **Blackpool Teaching Hospitals NHS Foundation Trust**

Specialist medical care and interventional cardiology should cease at **Imperial College Healthcare NHS Trust**

Specialist medical care and interventional cardiology should cease at **Nottingham University Hospitals NHS Trust**

Specialist medical care and interventional cardiology should cease at **Papworth Hospital NHS Foundation Trust**

Specialist medical care and interventional cardiology should cease at **University Hospital of South Manchester NHS Foundation Trust**

49. We are continuing to work with Papworth Hospital to consider whether it may be possible for the hospital trust to meet the required standards within the timeframes. At mid-January, there was a significant shortfall in terms of meeting the standards and a robust plan to address this had not been developed. Progress is being made, however. If the hospital trust can demonstrate that it is meeting the standards, or has a robust plan to do so, then we will review our proposal that Level 2 CHD services should cease to be provided at Papworth.

50. If our proposals for the hospitals listed above are implemented, this would mean that, in future, Level 2 CHD services would be provided by the following hospitals:

- **Brighton and Sussex University Hospitals NHS Trust** (adult service)
- **Central Manchester University Hospitals NHS Foundation Trust** (children's services)

- **Norfolk & Norwich University Hospitals NHS Foundation Trust** (adult service)
- **Oxford University Hospitals NHS Foundation Trust** (children's and adult services)

51. We continue to explore the potential for the provision of Level 2 specialist medical services at Central Manchester University Hospitals NHS Foundation Trust and University Hospitals of Leicester NHS Trust.

How our proposals were developed

1.4 Meeting the standards

52. The standards were agreed by NHS England's Board in July 2015, following a 12-week period of [public consultation](#). Once agreed, we started to look at how we might put the standards into practice. Patients and their families/carers, and patient representatives, told us early on 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. That message is really important and has influenced our thinking throughout this process.

53. Initially we looked at whether the hospitals themselves, by working more closely together, could find new ways of working that would mean that the standards could be met across the country. However, this did not provide us with a solution that would give us a truly national CHD service.

54. It was decided, therefore, to look at each hospital individually, and ask them to complete a self-assessment to assess their compliance against a specific number of the standards. In deciding on which standards to focus on at this stage, we took advice from senior CHD clinicians, and from NHS England's Quality Surveillance Team, which has particular expertise in peer review. Collectively, the advice was to focus on those standards considered to be most closely and directly linked to measureable outcomes, and to effective systems for monitoring and improving quality and safety. This exercise was launched in January 2016, focusing on 14 specific requirements which covered 24 of the standards relating to children's care, as well as the corresponding adult standards.

55. The standards came into force on 1 April 2016. Each standard has an associated timeline for implementation, some of which are immediate, from April 2016, and some of which are longer. The timelines were set by NHS England's Congenital Heart Services Clinical Reference Group (CRG), which is made up of clinicians, patient representatives, commissioners and other experts, who felt that some of the changes required to meet the standards, such as the co-location of children's CHD services alongside other specialist children's services, could not be made overnight. They were also agreed by the NHS England Board in July 2015.

56. We asked each hospital whether it was able to meet the April 2016 standards. Where hospitals indicated that they could not meet that initial timescale, we set out development requirements to see them achieved by the end of the financial year (end of March 2017). These development requirements are being closely monitored via NHS contracts. We did not set out development requirements for Central Manchester University Hospitals NHS Foundation Trust, even though the hospital's assessment indicated that it was unable to meet the standards now, or in the future, as there was mutual recognition that the hospital would not be able to meet the requirements within the stated timeframe and would instead work with us to achieve any necessary changes in service delivery.

57. We considered two aspects of the standards to be of particular importance in terms of not just service quality, but for ensuring the resilience and safety of CHD services both for now, and for the future:

- Surgeon working requirements – the number of surgeons at each hospital, and the number of operations they each perform.

The standards require that, for 2016, surgeons work in teams with a minimum of three surgeons, and in teams of at least four surgeons by April 2021. CHD surgeons are each required to carry out no fewer than 125 congenital heart operations a year (the equivalent of about three operations a week); and

- Service interdependencies, or co-location – the other services CHD patients depend upon, and which need to be on the same hospital site. The standards require that specialist children's cardiac services are only delivered in settings where a wider range of other specialist children's services are also present on the same hospital site. The standards require that certain paediatric specialties are within a 30-minute call to bedside range for April 2016, and co-located on the same site as children's CHD services by 2019.

“125 really is a minimum number. It equates to three operations a week, per surgeon. Practice makes perfect, and 125 operations a year is considered the minimum to ensure that a newly appointed consultant surgeon acquires the skills they need across the differing surgical techniques. Some of the operations we do only come up once or twice a year, so ideally you would be doing at least four operations per surgeon each week, as that would result in 170-200 operations a year.

A surgeon doing too many, or too few, operations is not good. Either way can result in a poor performance when it matters, either through fatigue or a loss of skills. Individuals will, of course, vary in capability, but 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. Centres need to oversee the distribution of the work fairly, taking account of any specialist skills, to ensure that all surgeons have the opportunity to work at optimum levels.”

Professor David Anderson, Consultant Heart Surgeon and Professor of Children’s Heart Surgery, Guy’s and St Thomas’ NHS Foundation Trust, and President of the British Congenital Cardiac Association (BCCA)

58. Each set of returns from the hospitals was initially evaluated at a regional level by NHS England’s specialised commissioners, and then by a national panel, comprising patient representatives, clinicians, and commissioners, to ensure consistency of approach. The role of the regional and national panels was to assess each hospital’s ability to meet the standards, based on the evidence submitted by that hospital. A [report](#) of the panel’s work, and its assessments, was published by NHS England in July 2016.
59. In summary, the national panel found that as of May 2016, none of the hospitals providing CHD services met all of the standards tested. This was not unexpected, as the standards were aimed at ensuring that all services were brought up to the level of the best of existing practice. They were intended to be stretching, but realistic, and were focused on driving improvement.
60. The panel found that, with respect to Level 1 surgical services:
- Two hospitals – Birmingham Children’s Hospital NHS Foundation Trust and Great Ormond Street Hospital for Children NHS Foundation Trust – were very close to meeting all of the requirements, with robust and credible plans to meet the rest within the required timescale, i.e. end of March 2017. They were rated green/amber;

- Seven hospitals² were likely to meet all of the requirements within the required timescale with development of their plans. They were rated amber;
- Three hospitals were unable to meet the requirements now, and were unlikely to be able to do so within the required timeframe. They were University Hospitals of Leicester NHS Trust, Newcastle Hospitals NHS Foundation Trust, and the Royal Brompton and Harefield NHS Foundation Trust. They were rated amber/red;
- One hospital – Central Manchester University Hospitals NHS Foundation Trust – was not able to meet the requirements now, and was unlikely to be able to do so within the required timeframe. Manchester has fewer than 100 operations annually undertaken by a single surgeon, with interventional cardiology provided on a sessional basis. Appropriate 24/7 surgical or interventional cover is not provided. The national panel considered these arrangements to be a risk, and rated the centre red.³

61. As the national commissioner of congenital heart disease services, it was the responsibility of NHS England to consider the information provided to it by the national panel, and for deciding what action, if any, should be taken on the basis of that information.

62. The Specialised Services Commissioning Committee met at the end of June 2016, and considered the information provided to members by the national panel. The committee recognised that NHS England needed to take action to ensure that CHD patients, wherever they live in the country, have access to the same safe, stable, high quality services.

63. It was proposed that in future, NHS England would only commission CHD services from hospitals that are able to meet the full set of standards within the required timeframes (with the time-limited exception of Newcastle upon Tyne Hospitals NHS Foundation Trust, for the reasons set out in paragraphs 41- 45), and decided that, subject to appropriate public involvement and/or public consultation, a change in service provision would be appropriate. On the basis of the information received, NHS England then published its proposals on 8 July 2016.

Potential impact of implementing our proposals

64. We know, from talking to patients and their families, and carers; to clinicians and other hospital staff, and to other stakeholders, in the run-up to this consultation, that there are concerns about our proposals, and how implementation of them might affect them personally, or their jobs, or services, and the hospitals as a whole. We acknowledge that these are real

² Alder Hey, Leeds, University Hospitals Birmingham, Barts, Guy's & St Thomas', Bristol, and Southampton

³ Individual assessment reports for each of the CHD provider hospitals were published in September 2016 and can be found at <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/chd/applying/>

concerns and we have listened carefully to all those who have spoken, or written to us during the pre-consultation period. We have tried to answer some very challenging questions as openly and honestly as we could.

65. To better understand these issues, we have undertaken a detailed impact assessment, looking at how, if our proposals are implemented, they might be delivered in practice, and to identify the consequences for patients, providers, commissioners and others.
66. All hospitals providing Level 1 and Level 2 CHD services were asked to review their services in light of NHS England's proposals. Their responses were considered first by NHS England's regional teams, and then a national panel was drawn together to review those submissions. The findings of that panel's review are summarised at Appendix B. A full impact assessment has been published alongside this document.

Pre-consultation engagement and involvement

67. Once the proposals were published, in July 2016, we entered a pre-consultation phase, which ran from July, right up until the start of formal consultation in February 2017.
68. The over-riding objective for NHS England during this period was to engage with hospitals providing CHD services – in particular, with those potentially affected by our proposals – to explore what the key issues were for them, in preventing them from meeting the standards, either for delivery in 2016, or the longer-term. Our aim throughout has been to maintain an open dialogue with the providers, so that we could work together to try and find alternative solutions to meeting the standards.

1.5 Engagement activity

69. Since July 2016, our regional and national teams have met regularly with managers and clinical teams at those hospitals currently providing CHD services and, in particular, with those whose current service will be affected if our proposals were to be implemented. As well as these more regular meetings, we also visited nine hospital trusts to talk specifically about our proposals, meeting with clinicians and managers, and touring the CHD facilities, including paediatric critical care and transplant units. Between July 2016 and January 2017 we visited:

- Royal Brompton and Harefield NHS Foundation Trust
- University Hospitals of Leicester NHS Trust
- Guy's and St Thomas' NHS Foundation Trust
- Birmingham Children's Hospital NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Foundation Trust
- Barts Health NHS Trust
- Newcastle Hospitals NHS Foundation Trust
- University Hospitals Birmingham NHS Foundation Trust

70. In addition to talking to the hospital clinicians and managers, we have also taken the opportunity – whenever possible – to meet with staff on the CHD units, as well as with patients, families, carers and patient representatives. We met with patients, carers and patient representatives in Leicester and Newcastle-upon-Tyne, and attended a meeting of the North West Adult Congenital Heart Disease Forum in Liverpool. We will be meeting with patients and their families/carers and representatives in London during the consultation period.
71. We have also met with MPs, particularly those whose constituencies include one of the CHD units potentially most affected by our proposals, and have provided a written briefing about our proposals to all local authorities across England, and attended Overview and Scrutiny Committees and Health and Wellbeing Boards where invited.
72. We have responded to a significant volume of correspondence relating to our proposals for CHD services during this period, assessing and re-assessing information provided by the hospitals; answering Parliamentary correspondence and Freedom of Information requests, as well as more general correspondence from stakeholders associated with the hospitals who wrote to us expressing concerns and/or asking for more information about our proposals.
73. The discussions during the pre-consultation period were dominated by the theme of how an individual hospital might achieve compliance with the standards, as well as the level of impact which our proposals – if implemented - might have on a hospital, as well as on its staff and, most importantly, its patients and their families.

Consultation

1.6 Why are we consulting?

74. We know, from talking to patients, carers, patient representatives, hospital staff, and other stakeholders, that our proposals have caused some concern in certain areas of the country. We have tried, during the pre-consultation period, to address those concerns as best we can. However, we know that many of you remain concerned about what the future might look like in terms of your care, or that of your loved ones, or where you carry out your work.
75. Consultation is not a vote on whether or not our proposals should be implemented. Instead, it provides an opportunity for us to listen to people's views about our proposals, so that we can take them into account before any commissioning decisions are made. We have set out in this document some of the areas where we think our proposals could impact, or which people have told us could be impacted e.g. travel times for patients, and other hospital services. There may be other areas that we have not thought of, or alternative ways of meeting the standards which have not yet been explored. We need to hear about those now.

76. Consultation is open to everyone, not just those who have direct experience of CHD services.
77. The consultation is being run in accordance with [Cabinet Office guidance](#)
78. While our focus is on services for patients who are resident in England, we recognise that there are children and adults living in Wales, Scotland, and Northern Ireland, who use CHD services in England. We have agreed with our colleagues in the devolved nations that they will help support our consultation in making people aware of the consultation and how they can respond to it.
79. It is important that as many people as possible, with an interest in CHD services in England, have opportunity to contribute their views about the future of these important services.

1.7 How can I make my views known?

1.7.1 How to get involved

80. During consultation, there will be a number of opportunities for you to have your say about the future commissioning arrangements for CHD services.
81. Information about the different ways in which you can have your say is available at the NHS England [Consultation Hub](#). Consultation materials are also available here. We will be running a number of face-to-face events during the consultation period, which will enable us to tell you more about our proposals and provide you with an opportunity to ask us questions. We will also support charities, patient groups, clinicians, and provider hospitals to run their own events, and can provide materials to support this activity if required. To find out where, and when, your nearest event is taking place, and how to register to attend, please visit the [Consultation Hub](#)
82. Hard copies of the consultation document and response form can be made available. If you require a hard copy, please email us at england.congenitalheart@nhs.net
83. We will also be holding a number of webinars throughout the consultation period, which will enable you to learn more about our proposals, and ask us questions, without having to travel. Details about all of the forthcoming webinars, and how to join them, are available at the [Consultation Hub](#).

1.7.2 How to let us know your views

This is an opportunity to set the standards for the next generation. It has clearly taken a long time, and a lot of discussion, to get to where we are now.

There is a real opportunity to have standards that have been nationally agreed; that have been agreed by clinicians; by providers; by patient groups; and set up services that will benefit children and adults with congenital heart defects over the coming generations.

Jon Arnold
Chief Executive, Tiny Tickers

84. Consultation will run from Thursday 9 February 2017 to Monday 5 June 2017.

85. The full list of consultation questions can be found at Appendix A. For your response to be included in the analysis of this consultation, you need to ensure that we receive your response no later than 23.59 on Monday 5 June.

86. The online response form is located at our [Consultation Hub](#). Alternatively, you can send your response (whether on a response form, or as a letter) to:

Beverley Smyth
Specialised Commissioning, NHS England
4N08| Quarry House| Quarry Hill | Leeds | LS2 7UE

When you are replying, please let us know whether you are replying as an individual or whether your views represent those of an organisation. If you are replying on behalf of an organisation, please make it clear who the organisation represents and, where appropriate, how the views of the members were collated.

1.8 What happens next?

87. We have asked an independent company - Participate - to collate all of the responses we receive to the consultation and to produce an analysis of what respondents have said. The analysis will be published in due course and will include information about the number, type and other characteristics of the responses, giving us a good picture of the views expressed.

88. In coming to a decision, NHS England will consider the responses to the consultation and will adjust its proposals if we consider it appropriate to do so. We will take into account and balance all the main factors, including affordability, impact on other services, access and patient choice. Our

recommendations will then be considered by the relevant committees before a final decision is taken by the NHS England Board.

Appendix A: Consultation Questions

It is important, before answering the questions in our consultation survey, for you to ensure that you have read all of the information provided about each of the individual CHD provider hospitals potentially affected by our proposals, so that you understand the potential impact of our proposals on those hospitals, and the way in which service delivery might change, should our proposals be implemented.

Meeting the standards

1. In what capacity are you responding to the consultation?

- ☐ Current CHD patient
- ☐ Parent, family member or carer of a current CHD patient
- ☐ Member of the public
- ☐ CHD patient representative organisation
- ☐ Voluntary organisation / charity
- ☐ Clinician
- ☐ NHS provider organisation
- ☐ NHS commissioner
- ☐ Industry
- ☐ Other public body
- ☐ Other

If other – please specify:

2. In which region are you based?

- ☐ Not applicable/regional/national organisation
- ☐ England - North East
- ☐ England - North West
- ☐ England - Yorkshire and The Humber
- ☐ England - East Midlands
- ☐ England - West Midlands
- ☐ England - East of England
- ☐ England - London
- ☐ England - South East
- ☐ England - South West
- ☐ Scotland
- ☐ Wales
- ☐ Northern Ireland

3. 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?

- ☐ Strongly support
- ☐ Tend to support
- ☐ Neither support or oppose
- ☐ Tend to oppose
- ☐ Strongly oppose

4. Please explain your response to question 3.

Three hospital trusts have been assessed as not able to fully meet the standards within set timeframes. NHS England therefore proposes that surgical (level 1) services are no longer commissioned from:

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

5. Can you think of any viable actions that could be taken to support one or more of the trusts to meet the standards within the set timeframes?

Central Manchester University Hospitals NHS Foundation Trust and University Hospitals of Leicester NHS Trust

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?

- ☐ Strongly support
- ☐ Tend to support
- ☐ Neither support or oppose
- ☐ Tend to oppose
- ☐ Strongly oppose

Royal Brompton and Harefield NHS Foundation Trust

6. 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?

- ☐ Strongly support
- ☐ Tend to support
- ☐ Neither support or oppose
- ☐ Tend to oppose
- ☐ Strongly oppose

Newcastle upon Tyne Hospitals NHS Foundation Trust

7. 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?

- ☐ Strongly support
- ☐ Tend to support
- ☐ Neither support or oppose
- ☐ Tend to oppose
- ☐ Strongly oppose

Travel

We know that some patients will have to travel further for the most specialised care including surgery if the proposals to cease to commission surgical (level 1) services from Central Manchester University Hospitals NHS Foundation Trust (adult service); Royal Brompton & Harefield NHS Foundation Trust (services for adults and children); and University Hospitals of Leicester NHS Trust (services for adults and children) are implemented.

8. Do you think our assessment of the impact of our proposals on patient travel is accurate?
- ☐ Yes
 - ☐ No

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

Equalities and health inequalities

We want to make sure we understand how different people will be affected by our proposals so that CHD services are appropriate and accessible to all and meet different people's needs.

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

- ☐ Yes
- ☐ No

10. 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?

Other impacts

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.

11. Do you think our description of the other known impacts is accurate?

☐ Yes

☐ No

12. 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?

Any other comments

13. Do you have any other comments about the proposals?

About you

14. Which age group are you in?

- ☐ Under 18
- ☐ 19 – 29
- ☐ 30 – 39
- ☐ 40-49
- ☐ 50 – 59
- ☐ 60-69
- ☐ 70-79
- ☐ 80+
- ☐ Prefer not to say

15. Please indicate your gender

- ☐ Male
- ☐ Female
- ☐ Intersex
- ☐ Trans
- ☐ Non-binary
- ☐ Prefer not to say

16. Do you consider yourself to have a disability?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

17. Please select what you consider your ethnic origin to be. Ethnicity is distinct from nationality.

White

- ☐ Welsh/English/Scottish/
Northern Irish/British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other White
background

Asian or Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Any other Asian
background

Other ethnic group

- ☐ Chinese
- ☐ Any other ethnic group

Mixed

- ☐ White and Black
Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other mixed
background

Black or Black British

- ☐ Black - Caribbean
- ☐ Black - African
- ☐ Any other Black
background

18. Please indicate your religion or belief

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> No religion | <input type="checkbox"/> Muslim |
| <input type="checkbox"/> Buddhist | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> Christian | <input type="checkbox"/> Atheist |
| <input type="checkbox"/> Hindu | <input type="checkbox"/> Any other religion |
| <input type="checkbox"/> Jewish | <input type="checkbox"/> Rather not say |

19. Please indicate the option which best describes your sexual orientation

- ☐ Heterosexual
- ☐ Gay
- ☐ Lesbian
- ☐ Bisexual
- ☐ Prefer not to say

Appendix B: Summary of Impact Assessment

89. The following section summarises key points from the provider impact assessment, and from the equalities and health inequalities impact assessment. It also summarises the likely financial impact on NHS England if our proposals are implemented. Documents setting out this detail in full have been published alongside this consultation document.

1.9 Impact on patients

90. A particular concern for some patients and their families is that they may face longer journeys to access Level 1 CHD services which will be inconvenient, and, they fear, carry a level of risk.
91. Our clinical advisers on NHS England's Congenital Heart Services Clinical Reference Group and Clinical Advisory Panel tell us that true emergencies are very rare. Thanks to advances in antenatal diagnosis, most congenital heart defects are detected while a baby is still in the womb, which enables the mother to give birth either at, or close to, an appropriate hospital providing CHD surgery to children. Even in those cases where CHD is not detected antenatally, and problems are spotted during or after delivery, surgery will often be planned over a period of a few days. If infants need to be moved from one hospital to another for emergency care, then ambulance services, local hospitals and specialist retrieval teams are well able to ensure that patients are stabilised before and during transfer so that the risks of long journeys are negligible.
92. We understand that patients feel safer having a hospital providing CHD surgery close by, but, given the relatively small number of congenital heart disease surgeons in England, this could never be the case for all patients. By implementing the standards, we are able to ensure that patients will receive their surgery in the best possible environment to achieve a good outcome. This is a delicate balance, but we believe that it outweighs the risk of additional journey time, given that emergencies in CHD patients are so rare.
93. Under the proposed model of care different journeys would only be required when patients need to undergo surgery or an interventional or other catheter procedure, and for some admissions. The CRG has advised that the distance travelled for surgery is less important than the distances travelled regularly for ongoing care.
94. Over the course of a lifetime, a person with CHD receives most of their care in an outpatient setting. This should not be affected by the proposed changes since outpatient care can be provided at hospitals providing Level 2 services, those offering Level 3 services, and in outreach clinics. In fact most patient care, apart from admission for a procedure, the pre-admission clinic, and a single follow-up outpatient visit, can be undertaken by Level 2 hospitals.
95. Where patients require more complex diagnostic tests, for most inpatient admissions and for surgery and almost all interventional cardiology procedures, patients and their families/carers will need to travel to a Level 1

hospital. In general we expect that patients would travel to their next nearest Level 1 hospital. For some patients this would mean a similar journey, for others, a longer journey than they would have at present.

96. Our modelling suggests that the impact on average journey times for patients is relatively modest:

- An increase in the average journey time of 11 minutes for adults who use Central Manchester.
- An increase in the average journey time of 14 minutes for children who use Leicester and 32 minutes for adults.
- Average journey times would stay much the same for patients who use the Royal Brompton, as most patients would be likely to continue to receive their care from one of the two other Level 1 hospitals in London.

97. Some patients would of course have longer journeys. However 90% of patients who would currently use University Hospitals of Leicester will still have a journey time of less than 1 hour and 45 minutes to their nearest surgical hospital and this is similar to the national picture and shorter than in some other parts of the country (for example the South West peninsula). Similarly, 90% of patients who would currently use Central Manchester University Hospitals would have a journey time of 64 minutes or less to their nearest surgical hospital, and, of the patients who would currently use the Royal Brompton Hospital, 90% will have a journey time of 85 minutes or less to their nearest surgical hospital.

98. We do, however, recognise that it is difficult for families to support patients in hospital at some distance from home. This is a problem faced by many families already, not just in CHD services, but in many other specialist services, which tend to be provided in a smaller number of hospitals across the country. Because of this, and based on the advice of patients and families, a number of standards were developed to make life easier in this situation - providing better information about where to eat and sleep; better facilities to prepare meals; provision of Wi-Fi; ensuring parking is easily accessible and parking charges affordable; and providing overnight accommodation for parents and carers.

99. Our equalities impact assessment showed that three groups of patients would potentially be more affected by the proposed changes:

- children and young people with CHD because most surgical and interventional procedures (around 7 in 10) occur in children and young people;
- people with CHD and learning disability (LD) because there is a higher likelihood of learning disability amongst people with CHD and people with learning disabilities and especially people with autistic spectrum disorder cope best when things are familiar, so changing settings and changing staff is more of an issue; and

- people of Asian ethnicity with CHD because people who are of Asian ethnicity have a higher incidence of CHD, and may be more likely to have more severe forms of the disease.

100. We will make available materials in different formats to assist people who are part of these groups to participate in the consultation, and will be talking directly to these groups during consultation so that we can better understand the potential impacts of our proposals and any steps we could take to minimise these.

1.10 Impact on CHD services

101. We have modelled the way in which patient flows may change if the proposals are implemented. The modelling assumes that a patient will go to their next nearest surgical hospital. There are clearly limitations to this approach which mean that the results should be treated as a guide rather than an exact representation of what will happen:

Hospital	Additional Operations	% increase
Birmingham - Children's Hospital	180	36%
University Hospitals Birmingham	45	45%
Liverpool Heart and Chest	90	N/A⁴
Leeds - General Infirmary	50	10%
Guy's and St Thomas'	200	40%
Great Ormond Street	220	31%
Barts	85	110%
Southampton	20	5%

102. Under this modelling, there would be little or no change to activity at Newcastle, Alder Hey or Bristol.

103. NHS England is working with the hospitals listed above to ensure that they would be ready and able to manage any increase in activity if the proposals are implemented. In each case we have received an assurance that if the changes go ahead, the hospital would increase its capacity – facilities, equipment, staffing – as necessary to be able to take the extra patients without any fall in service quality or rise in waiting times.

104. The aim of our proposals is to ensure that every provider that we commission to deliver CHD services meets the agreed standards. The standards were set to reflect the best evidence, expert advice and the

⁴ Liverpool Heart and Chest Hospital does not currently undertake CHD surgery.

experience of patients and families about what makes for the best services. We believe that making the changes we have proposed will ensure that no matter where they live, patients and their families will receive excellent care.

105. Services will also be more resilient and sustainable for the future. Under present arrangements services in some hospitals receive significant levels of support from other hospitals. Without this support, at best, these hospitals would not be able to offer their patients a full range of CHD services.
106. Bigger hospitals are generally more resilient. The provision of consistent care at all times of day and night throughout the year is more assured. Bigger teams are better able to cope when one of their number is unavailable or leaves. They are also better able to support the full range of surgical procedures and the development of very specialised practice.

1.11 Impact on other services

1.11.1 Impact on other services: Paediatric Intensive Care

107. Our assessment shows that if our proposals are implemented there will be an impact on paediatric intensive care (PIC) at University Hospitals of Leicester NHS Trust and the Royal Brompton and Harefield NHS Foundation Trust. The proposals affect only adult services at Central Manchester University Hospitals NHS Foundation Trust.

1.11.1.1 University Hospitals of Leicester: Paediatric Intensive Care

108. University Hospitals of Leicester has two paediatric intensive care units (PICUs), one at the Leicester Royal Infirmary and one at Glenfield Hospital (which supports CHD services). While we cannot pre-empt the decisions that NHS England will make on CHD services, or the findings and recommendations of its [Paediatric Critical Care & Specialised Surgery for Children Service Review](#), at this point we expect that Leicester would still provide PICU care for the East Midlands if our proposals are implemented, even if it no longer provides Level 1 cardiac surgery for children. This would be through a single PICU at the Royal Infirmary. We understand that, even if our proposals are not implemented and Leicester continues to provide Level 1 children's cardiac surgery, it plans to move this service from Glenfield to the Infirmary, which would be likely to lead to the closure at the Glenfield anyway (and a corresponding increase in capacity of PICU at the Infirmary). Accordingly, the future of the PICU at Glenfield is uncertain, whether or not NHS England's proposals on CHD are implemented, whereas the provision of the PICU at the Infirmary would be unaffected by the implementation of the proposals. The hospital trust does not share this assessment.

1.11.1.2 Royal Brompton: Paediatric Intensive Care

109. The Royal Brompton's PICU is largely dependent on the hospital's CHD service for children, because CHD accounts for 86% of the admissions. The hospital trust considers that its PICU would no longer be viable if the proposals are implemented, because paediatric cardiac patients are a large

proportion of its work and it would not have enough other patients to stay open. The national panel accepted that this was an accurate assessment. If the PICU at the Royal Brompton were to close, this would be expected to have an effect on their paediatric respiratory services, the only other clinical service for children offered by the Trust (see below).

1.11.1.3 Paediatric Intensive Care: wider implications

110. In order to ensure that there is still sufficient PICU capacity for CHD patients, NHS England will work with the other hospitals where increased paediatric cardiac surgery would be expected if our proposals are implemented (Birmingham Children's Hospital, Great Ormond Street, Leeds General Infirmary, St Thomas' - Evelina Hospital) to undertake the necessary planning and preparation to manage any increase in PICU capacity that would be needed for CHD patients.
111. If our proposals are implemented, there may also be an effect on the wider regional and national PIC system. NHS England has accelerated its Paediatric Critical Care & Specialised Surgery for Children Service Review, which will consider paediatric intensive care provision and paediatric transport. The critical care review aims to bring forward initial work looking at where paediatric critical care capacity is likely to be needed in future, with the first outputs coming through early in 2017. When the Board takes its decisions on the CHD proposals, it will therefore be able to take into account the impact on PIC for CHD patients in the wider regional and national context. The Paediatric Critical Care & Specialised Surgery for Children Service Review will then be able to pick up and deal with any wider implications for changes in PIC consequent upon the proposed CHD changes, as it considers the required capacity and distribution of PICU across the country as a whole.

1.11.2 Impact on other services: Extracorporeal Membrane Oxygenation (ECMO)

112. Extracorporeal Membrane Oxygenation (ECMO) is a technique that provides cardiac and/or respiratory support for very sick patients. When we use ECMO to support the lungs, supporting individuals with severe, potentially reversible respiratory failure, it is called 'respiratory ECMO'. When it is used to support the heart, it is called 'cardiac ECMO'.

1.11.2.1 Leicester: ECMO

113. Leicester provides cardiac and respiratory ECMO for children and is at present the only provider commissioned to offer mobile ECMO (which allows children to be transferred between hospitals on ECMO). It also provides cardiac and respiratory ECMO for adults. If our proposals were to be implemented, Leicester would no longer be able to provide cardiac or respiratory ECMO for children or mobile ECMO for children. Taken together this would affect around 55 children a year. It would no longer provide cardiac ECMO for adults with CHD. We would expect that Leicester could continue to provide adult respiratory ECMO, in a similar way to other hospitals

where services are supported by adult cardiac surgery services (not congenital cardiac).

1.11.2.2 Royal Brompton: ECMO

114. The Royal Brompton provides cardiac ECMO for children and cardiac and respiratory ECMO for adults. If our proposals were to be implemented, Royal Brompton would no longer be able to provide cardiac ECMO for children. This would affect around 15 children a year. It would no longer provide cardiac ECMO for adults with CHD. Adult respiratory ECMO provision at the Royal Brompton is the subject of a separate current procurement being undertaken by NHS England.

1.11.2.3 Central Manchester: ECMO

115. Central Manchester provides cardiac ECMO for adults with CHD. If our proposals were to be implemented, Central Manchester would no longer be able to provide cardiac ECMO for adults with CHD.

1.11.2.4 ECMO: wider implications

116. NHS England will work with the other hospitals, where increased paediatric cardiac surgery would be expected, if our proposals are implemented, (Birmingham Children's Hospital, Great Ormond Street, Leeds General Infirmary, and St Thomas' - Evelina Hospital) to undertake the necessary planning and preparation to manage any increase in paediatric cardiac ECMO capacity that would be needed for CHD patients.
117. If our proposals are implemented, there may also be a wider regional and national effect on ECMO services. NHS England has accelerated its Paediatric Critical Care & Specialised Surgery for Children Service Review, which will consider paediatric ECMO. When the NHS England Board makes its decision about the CHD proposals, it should, therefore, have greater clarity about the impact on ECMO for CHD patients in the wider regional and national context. The Paediatric Critical Care & Specialised Surgery for Children Service Review will then be able to pick up and address any wider implications for changes in children's ECMO services, as a consequence of the proposed CHD changes, as it considers the required capacity and distribution of children's ECMO across the country as a whole. We will re-commission appropriate levels of children's respiratory ECMO and mobile ECMO from an appropriate number of providers in the light of the recommendations of that review.

1.11.3 Impact on other services: Specialist paediatric respiratory services

118. As outlined above, the Royal Brompton considers it likely that its PICU would no longer be viable if our proposals are implemented, because paediatric cardiac patients are a large proportion of its work and it might not have enough other patients to stay open. The national panel accepted that this was an accurate assessment. The hospital trust considers that this would have a serious detrimental effect on children's respiratory services which also use the PICU.

119. The national panel considered that there would be an impact on paediatric respiratory services, if paediatric cardiac services and PICU were no longer provided by the Royal Brompton. NHS England's work focusses on congenital heart disease and has not examined paediatric respiratory services. The membership of the panel reflects that focus. Given this, it would not have been appropriate for the panel to undertake detailed assessment of this impact.

120. If a decision is taken that results in closure of the PICU at the Royal Brompton Hospital, NHS England will work with the hospital trust to understand and manage the impact on paediatric respiratory services. This could require a local service change process with further public engagement, potentially including full public consultation. There are alternative providers of specialist paediatric respiratory services in London.

1.12 Workforce Impact

1.12.1 Provider organisations where level 1 services would be provided under the proposals: workforce impact

121. The panel considered that hospitals that would gain more patients if the proposals were to be implemented were well placed to be able to expand their capacity to be able to provide that care. The recruitment of the necessary workforce for this increased activity was seen as potentially challenging for a number of these hospitals. Specifically, the recruitment of the PICU nurses necessary for the additional beds which would be required. The hospitals gaining significant activity believed that although challenging they had a good record of recruiting staff and would be able to recruit the necessary staff as long as they were given sufficient time prior to these proposals being implemented.

1.12.2 Provider organisations where level 1 services would no longer be provided under the proposals: workforce impact

122. Under our proposals some hospitals would no longer provide level 1 CHD services. In some cases this is likely to also affect the future of other linked services. For the staff delivering these services the potential implications include:

- employees being redeployed into other roles;
- the transfer of the contracts of employment of employees from one organisation to another;
- changes to the volume of work carried out by employees (either through increases or decreases in patient activity within the Trust they work for);
- employees working within the service being made redundant; and
- changes to the future workforce requirements to deliver the CHD standards and service specifications across the commissioned centres.

123. One of the key challenges both to current CHD services and to any future configuration is ensuring that there are sufficient staff with the necessary skills and experience to undertake this work across the country.
124. NHS England will work with provider organisations to ensure that staff are supported through any change process and redundancies are avoided wherever possible.
125. The national panel noted that experience at other hospitals where level 1 services have ceased – Edinburgh, Cardiff and Oxford – was that the majority of staff did not transfer to alternative providers of these services, but there were virtually no redundancies, with most staff being redeployed internally. It is reasonable to expect that many staff would seek to take up alternative roles within the relevant hospital trusts, rather than moving to another hospital. However, the panel noted that certain staff, such as CHD surgeons, would look to move to a Level 1 CHD hospital.

1.12.2.1 Impact on workforce at the Royal Brompton Hospital

126. The Royal Brompton identified approximately 430 WTE staff that it considered would be affected by the proposals, including those working as part of their CHD service, paediatric respiratory, paediatric intensive care and other services which will be impacted to a lesser extent. The hospital trust has estimated the cost of redundancies to be approximately £13.5m.
127. The panel was not able to take a view on the likelihood of all these staff being significantly impacted by the proposed changes; however, it was acknowledged that there would be a significant impact on the Royal Brompton's workforce, if the proposals were to be implemented. The panel noted that this impact would be reduced, were the Royal Brompton to continue providing adult-only Level 1.
128. NHS England has reviewed the hospital trust's assessment of the potential level of redundancy. Given that we expect that most patients using the Royal Brompton would transfer to alternative hospitals within three miles of the Royal Brompton with the scope for redeployment that would result, NHS England has a materially different view of possible redundancy costs. Internal redeployment is also likely to make a significant contribution to avoiding redundancy. We estimate that the costs could however be up to £1 – 1.5m. This estimate is highly sensitive to the degree to which staff can be redeployed.

1.12.2.2 Impact on workforce at University Hospitals of Leicester

129. University Hospitals of Leicester identified 153 WTE staff that would be directly affected by the proposals, including administrative and clerical staff, estates and ancillary, medical and dental and nursing and midwifery staff that work solely for East Midlands Congenital Cardiac Service. In addition to the staff directly affected, the hospital trust has also identified other roles, such as those working in theatres, imaging, outpatient care, catheter labs and intensive care that would be indirectly affected. University Hospitals of

Leicester considers it likely that many of its staff would prefer to take up posts elsewhere in the hospital trust if possible.

130. The panel was not able to take a view on the likelihood of all these staff being significantly impacted by the proposed changes; however, it was acknowledged that there would be a significant impact on the hospital trust's workforce, if the proposals were to be implemented. The panel noted that this impact would be reduced, were University Hospitals of Leicester to continue providing Level 2 specialist medical services.
131. NHS England considers it probable that most at risk staff will be redeployed and that therefore the costs of redundancy will be mitigated. We estimate that the costs could however be up to £1m. This estimate is highly sensitive to the degree to which staff can be redeployed.

1.12.2.3 Impact on workforce at Central Manchester University Hospitals

132. The hospital trust did not respond to the request to provide information on the potential impact of the proposals. The panel considered it likely that the impact on staff at Central Manchester University Hospitals would be considerably less than the other two hospitals as the scale of service reduction would be much smaller. Where staff are affected, close working between Central Manchester University Hospitals, Alder Hey Children's Hospital and Liverpool Heart and Chest Hospital should enable Central Manchester to ensure that staff are appropriately supported and that clear plans are made to enable staff who wish to transfer to a Level 1 hospital to do so.

1.13 Financial Impact

1.13.1 Provider organisations where level 1 services would be provided under the proposals: finance impact

1.13.1.1 Confirmation that revenue costs of implementing standards should be covered by increasing income for increasing activity

133. Trusts are paid for CHD services through tariff, which ensures that the money received is linked to patient activity. It is likely that there will be some economies of scale for providers linked with providing a higher volume of activity. As such the trusts which would gain activity under these proposals are confident of being able to fund this expansion through the income which would be associated with this extra activity.
134. The financial assessment undertaken in 2015 at the time the Board agreed the standards showed that additional income to hospital trusts resulting from growth in activity would be sufficient to fund the implementation of the standards. Growth predictions have been refreshed and continue to provide assurance that implementation of the standards will be affordable for providers.

1.13.1.2 Assessment of capital requirements at hospitals that would take additional patients under the proposals and the sources of this capital

135. NHS England asked hospitals providing CHD services whether there would be any capital implications if they were required to take additional patients if our proposals are implemented. NHS England has confirmed that no specific central funds will be made available.
136. Two hospital trusts indicated that they would need to source capital funds to accommodate additional activity: University Hospitals Birmingham (£4M) and Great Ormond Street (£6M). In both of these cases it is expected that the provider would be able to source the capital funding from existing allocations and/or charitable funds. This is being confirmed with NHS Improvement. No other provider indicated any requirement for capital funding, and the risk around capital funding requirement is minimal at this stage.

1.13.2 Provider organisations where level 1 services would no longer be provided under the proposals: finance impact

137. NHS England has assessed for each of the hospitals where it is proposed that level 1 congenital cardiac surgery is no longer provided what proportion of their income comes from caring for patients with congenital heart disease.

1.13.2.1 Impact on finances at Leicester

138. The overall contract value for specialised services at Leicester is approximately £234m. NHS England estimates that the financial effect of the proposed changes would be a reduction in income of around £14m (rather than the £19-20m estimate provided by the hospital trust). This is partly explained by a difference in view on the impact of the proposals on PICU. The hospital trust's estimate is based on an assumption that it would no longer be able to provide PICU services. The panel considered that there was no reason why PICU services could not continue at the Infirmary site even if the PICU currently located at the Glenfield site needed to close.
139. The loss of income to the hospital trust would, on the panel's assessment, represent between 1.6% and 2.2% of the hospital trust's total income, and between 6% and 8% of their total specialised services income. Some of this loss of income could be reduced if University Hospitals of Leicester continued to provide Level 2 specialist medical services. The loss of income to the hospital trust would also, to some extent, be offset by the reduction in the costs of providing the service.

1.13.2.2 Impact on finances at Central Manchester

140. The overall contract value for specialised services at Central Manchester is approximately £348m. The hospital trust did not respond to the request to provide information on the potential impact of the proposals. NHS England estimates that the financial effect of the proposed changes would be

around £1m. The loss of income to the hospital trust would therefore represent approximately 0.3% of their total specialised services income.

141. Some of this loss of income could be reduced if Central Manchester University Hospitals continued to provide Level 2 adult CHD services. The loss of income to the hospital trust would also, to some extent, be offset by a reduction in costs.

1.13.2.3 Impact on finances at the Royal Brompton:

142. The overall contract value for specialised services at Royal Brompton is approximately £226m. NHS England estimates that the financial effect of the proposed changes would be around £35m excluding the impact on paediatric respiratory services. The hospital trust's estimate of a £47m loss in income when paediatric respiratory services are taken into account appears to be broadly in line with NHS England's own estimate. The hospital trust estimates that the loss resulting from these proposals would be approximately 13% of its total income and 21% of its total specialised services income, which represents a significant financial and business challenge. The scale of loss reflects the impact on PICU and the potential impact on paediatric respiratory services.
143. Some of this loss of income could be reduced if the Royal Brompton continued to provide adult-only Level 1 surgical services, in partnership with a Level 1 paediatric hospital. Whilst adult Level 2 services to be provided at RBH would lessen the financial impact of the proposals on the Royal Brompton to a limited degree the vast majority of its CHD income relates to inpatient activity linked to a surgical or interventional procedure and therefore the Royal Brompton have identified just over £3m income from CHD activity not relating to surgery or catheter interventions. However, this almost totally related to paediatric services and as such if the Royal Brompton were to only offer adult Level 2 services, it is unlikely this would provide significant income to the Trust
144. The loss of income to the hospital trust would, to some extent, be offset by a reduction in costs. Data supplied by the Royal Brompton indicates that its provision of CHD services results in an overall net loss, and therefore although the loss of income is significant it may be that in the long term no longer providing these services is in the best financial interest of the hospital trust. The Royal Brompton has, however, stated that owing to the stranded costs associated with this service they estimate an adverse impact of over £7m per year to its bottom line if these proposals are implemented. The financial impact of the changes could be reduced if the Royal Brompton provided Level 1 services for adults.
145. We note that the Royal Brompton is an active partner in the North West London Sustainability and Transformation Planning process and has identified a number of potential areas for partnership working which could potentially contribute to the mitigation of any financial losses if our proposals are implemented.

1.13.2.4 Finance impact: NHS England

146. The cost of the CHD service to NHS England has been estimated at £175m pa (based on 2013/14 figures). Activity is projected to increase whether or not the new standards are implemented. As a result, we forecast that – in today's prices - by 2025/26 expenditure on CHD services will be between £186m and £207m depending on the level of activity growth. We therefore expect that the challenge for us as commissioners will be in meeting the costs of activity growth rather than any costs arising from meeting the standards, or costs arising from the proposed changes. There are no current plans to reduce the CHD budget (per capita or overall).
147. As commissioners of CHD services we pay hospitals for the majority of these services using the national tariff (price) per unit of activity. Were we to change the number of centres where care is provided, this would therefore have no impact on our expenditure on patient care. NHS England finance experts have advised that it is logical to assume that an improvement to clinical outcomes and the clinical, operational and administrative efficiency and geographical/estates consolidation that would result from implementation of our proposals should lead to reduction in unit cost of this service for providers.

Equalities and Health Inequalities

148. The CHD standards are intended to ensure that everyone with CHD gets the best possible care within available resources. Earlier analysis and engagement indicated that any proposed service change may differentially impact some Black and Ethnic Minority (BME) patients (those of Asian ethnicity), and those with a learning disability. In addition, services for CHD are of particular interest to children, and to the families and carers of children. We will be carrying out specific engagement activities with these groups during the consultation period.
149. We asked hospitals providing CHD services about any equalities or health inequalities as a consequence of our proposals being implemented. All responses submitted by the hospitals can be found in the Equalities and Health Inequalities Impact Assessment which has been published alongside this document.

1.14 Age

150. Our analysis shows that there has been an increase in demand for adult CHD care. More children now benefit from advances in treatment for CHD, and are therefore reaching adulthood. As more people survive with this condition, it is likely that the service will move from one that is centred on children, to one that is, in addition, treating a growing number of young people and adults. This has consequences for the way in which services are planned and delivered.

151. Most surgery and interventional cardiology for CHD happens early in life so our proposals, if implemented, will affect where care for children and young people will be delivered and will therefore impact children and young people. We will be talking directly to children and young people during the consultation period, and have also developed an Easy Read version of the consultation document to help younger children better understand our proposals.

1.15 Disability

152. Children and adults with CHD are at an increased risk of developing further difficulties. Many children with CHD experience delays in their development, for instance, taking longer to walk or talk. Some children will have a learning disability. Around 50% of children with Down's Syndrome have a congenital heart defect and around 60% of those children will require treatment in hospital.
153. Change for people with learning disabilities or on the autistic spectrum is more difficult. Any service change for this population can be more difficult and needs to be managed well. This is not unique to the CHD proposed service change; however careful consideration should be given to the management of change for these patients. The particular concern has been around the practical elements of change like travelling to a new location, and patients being treated by clinical teams in a location that they are not familiar with. For example, people with learning disabilities who allow clinicians that they know to work with them are more likely than people without learning disabilities to refuse the same treatment in an unfamiliar surrounding by unfamiliar people.
154. During consultation we will make special arrangements to gather the views of people with learning disabilities and their families and carers. We have also produced an Easy Read version of this consultation document to help parents and carers explain the proposals to people with learning disabilities. As part of our consultation we are asking people about the impact implementation of the proposals would have on people with learning disabilities and their families and carers and also for advice on dealing with any concerns.

1.16 Gender reassignment

155. We have not identified any specific evidence relating to gender reassignment (including transgender) and CHD. The standards and service specifications do not alter access or delivery of these services to people with this protected characteristic.

1.17 Marriage and civil partnership

156. We have not identified any specific evidence relating to marriage and civil partnership and CHD. (We do not think it appropriate or justified to assume that people who are married or in a civil partnership are more likely to be the parents or carers or in a family with a person with CHD). The standards and service specifications do not alter access or delivery of these services to people with this protected characteristic.

1.18 Pregnancy and maternity

157. Two distinct groups in this category may be affected by the proposed changes.

- Women with CHD who are pregnant
- Women who are pregnant carrying a baby with CHD

158. In both cases most maternity care is delivered through local maternity services at a hospital close to the woman's home. Arrangements will be made for the delivery of the baby that take account of the needs of both mother and child. This may be at the local obstetric unit or at an obstetric centre at or close to the specialist surgical centre. For some women, if the proposals are implemented it will mean that delivery will take place at an obstetric unit further from home

159. We believe that the proposed standards will have a positive impact on the experience and outcomes of women with CHD who are considering pregnancy, are pregnant or are receiving maternity care and on women who are pregnant carrying a baby with CHD. For the first time services will be nationally commissioned using common service specifications.

1.19 Race

160. Ethnicity is known to relate to the prevalence of certain diseases. The relationship between ethnicity and CHD is complex and may be confounded by cultural and religious factors. Research dating back to the 1980s⁵ and 1990s⁶ demonstrated higher prevalence among Asian communities in various UK cities including Manchester and Leeds, and in the West Midlands.

161. We looked at the recorded ethnicity of CHD patients at the three affected level 1 hospitals. All three trusts have a higher prevalence of South Asian patients than the average for the population and higher than the CHD patient group at other level 1 CHD hospitals:

⁵ Gatrad AR, Reap AP, Watson GH Consanguinity and complex cardiac anomalies with situs ambiguous, *Arch. Dis Child* 1984; 59: 242-5

⁶ Sadiq M, Stumper O, Wright JGC, de Giovanni JV, Billingham C, Silove ED Influence of ethnic origin on the pattern of congenital heart defects in the first year of life *Br Heart J* 1995; 73: 173-176

- CMFT has the highest prevalence of Asian population of the three providers that will be impacted by the service change at 15.9% compared to the average of 11.2% of all hospital trusts.
- UHL has a prevalence of 12.6% compared to the average of 11.2% of all hospital trusts.
- Royal Brompton has a prevalence of 12.1% compared to the average of 11.2% of all hospital trusts.

The data above shows that the changes will affect more people of Asian origin than the general population because of the higher incidence of CHD amongst people of Asian origin.

It is not straightforward to assess whether the proposed changes will affect people of Asian ethnicity differently from other groups. Implementation of the standards will ensure that everyone benefits from services provided to a consistent standard across the country. The consultation process will enable us to better understand the impact of the proposed changes by engaging with BME groups, and we will make special arrangements to gather the views of people of Asian ethnicity with CHD during the consultation period. We have produced a summary version of this consultation document in a number of Asian languages and the full document can be translated on request. We heard that religion and belief and culture could make it difficult for some people to engage with us in an open forum, and will therefore ensure that there are opportunities for people to engage with us on a one-to-one basis, via telephone interview, during the consultation period.

1.20 Religion or belief

162. We do not have any evidence that shows a particular impact of the proposed changes on people of differing religions and beliefs. It is envisaged that hospitals that would be expected to provide care for more patients, under our proposals, will review ethnic, religious and cultural mix of patient information in light of the standards and feedback of the communications, engagement and the independent consultation report

1.21 Sex or gender

163. We do not anticipate that the proposed changes will have a differential impact either by sex or gender of patient or carer.

1.22 Sexual orientation

164. We do not anticipate that the proposed changes will have a differential impact depending on sexual orientation.

1.23 Asylum seekers and/or refugees

165. We have not identified any specific evidence relating to asylum seekers and or refugees and CHD. Access to healthcare, understanding of the English health system and communication difficulties and cultural differences may be

relevant differences for asylum seekers and refugees but would not be specific to CHD services or the proposed changes.

1.24 Carers

166. We have heard how important it is for parents and carers to be supported, particularly when they are away from home. They told us about difficulties with finding their way around new hospitals, finding accommodation and eating balanced meals. They also told us about problems with car parking. These effects may be amplified if parents and carers have to travel to a new hospital. We also heard about the importance of having support for end of life for both children and adults. This means having identified support structures that encourage and enable open and honest communication with families and carers at that time. We have developed specific standards to address these issues.

Consultation will seek views from families and carers as well as from people with CHD. The consultation questions include open ended questions where families and carers will have the opportunity to share their experiences and concerns. This may include families and carers who would have compounded impacts of the proposed service changes.

1.25 Those living with mental health issues

167. In addition to medical problems, people living longer with CHD face psychological, sociological and behaviour challenges⁷. Since people with CHD are surviving longer into adulthood, the increasing population of adults with CHD also means there will be an increasing percentage of adult CHD patients that have mental health issues such as anxiety and depression.

168. We do not have any data to understand the percentage of people with mental health issues and CHD that would be impacted by the changes. However, we have heard during the 2016 preliminary stakeholder engagement that people with mental health issues may be differentially impacted by the proposed service changes. This will need further exploration during the consultation to understand the specific impact.

1.26 Other groups

169. We have not identified any specific evidence relating to the following groups and CHD:

- Alcohol and/or drug misusers
- Ex-service personnel/veterans
- Those who have experienced Female Genital Mutilation (FGM)
- Gypsies, Roma and travellers
- Homeless people and rough sleepers

⁷ [Int J Cardiol.](#) 2013 Dec 5;170 (1):49-53. doi: 10.1016/j.ijcard.2013.10.003. Epub 2013 Oct 11.

- Sex workers
- Trans people or other members of the non-binary community

Glossary

Adult Congenital Heart Disease	ACHD	This is also known as “grown-up congenital heart disease”, or “GUCH”.
Atrial Septal Defect	ASD	Most common type of ‘hole in the heart’
Bridge to heart transplant		The use of a ventricular assist device (VAD), or other form of circulatory assistance, to support the pumping action of a failing heart until a donor heart becomes available for transplantation. The technique is known as ‘bridge to transplant’.
Cardiologist		A doctor who specialises in investigating and treating diseases affecting the heart and some blood vessels.
Cardiothoracic:		Conditions affecting organs within the thorax, such as the heart, lungs and oesophagus.
Clinical Commissioning Groups	CCG	Groups of GP practices responsible for buying the majority of hospital and community-based health services for patients within their local communities
Clinical Reference Group	CRG	Groups of clinicians, patient representatives, commissioners and other experts, covering the full range of specialised clinical services, (such as cardiac), and providing clinical advice in support of NHS England’s direct commissioning function.
Clinician		Any health professional who is directly involved in the care and treatment of patients, for example, nurses, doctors, therapists, and midwives.
Co-location / service interdependencies		The other services required to provide optimum care of the whole patient, particularly when their conditions are complex or complications arise, and which need to be on the same hospital site.
Commissioning:		The process of buying health services, involving the assessment and understanding of a population’s health needs; the planning of services to meet those needs; securing services on a defined budget, and then monitoring of the services. Commissioning in the NHS in England is managed locally by CCGs, and nationally by NHS England.
Congenital Heart Disease	CHD	Refers to a range of birth defects that

		affect the normal workings of the heart.
Consultant		A senior doctor who is a specialist in a particular area of medicine
Diagnostics		Medical tests used to identify a medical condition or disease.
Extracorporeal Membrane Oxygenation	ECMO	A complex technique that provides cardiac and/or respiratory support for very sick patients
Gastroenterology		Area of medical specialism which deals with disorders of the abdomen, particularly the stomach and intestines.
Interventional cardiology		Various non-surgical procedures for treating cardiovascular disease, such as coronary angioplasty (inserting a tube with a balloon on the end to treat a narrowing or blockage in an coronary artery) or cardiac valve intervention.
Nephrology		Area of medical specialisation that deals with the physiology and diseases of the kidneys.
NHS England Board		The Board is the senior decision-making structure in NHS England and consists of a Chair and eight non-executive directors and four voting executive directors.
NHS England Clinical Advisory Panel	CAP	A group of experienced clinicians that is part of the CHD Review's governance structure.
Paediatric		A branch of medicine providing care for infants and children.
Paediatric Critical Care and Specialised Surgery for Children service review		NHS England national service review which will consider the provision of paediatric Intensive Care and paediatric transport in England
Paediatric Intensive Care	PIC	A highly specialist hospital ward that provides sick children with the highest level of medical care.
Referral		Sending a patient to a specialist, or between specialists, for expert care.
Service Standards		Sets out how NHS services should be set up, organised and run
Specialist		A clinician whose work is concentrated on a particular area of medicine.
Stakeholder		All individuals, parties or organisations with a particular interest in the organisation and delivery of particular clinical services, etc.
Sub-specialisation		Surgeons and cardiologists train generally in their specialty and, at the end of their training, will qualify as a

		consultant. Many will then sub-specialise in an area of particular expertise. These areas are known as sub-specialties.
Surgeon		A clinician who is qualified to practice surgery.
Time limited derogation		NHS England will put in place time limited exceptions (or derogations) allowing hospitals to continue providing essential quality services for their patients whilst working to meet more rigorous service specifications.
Whole time equivalent	WTE	A measure of staffing that takes account of both full time and part time workers.

Congenital Heart Disease Equality and Health Inequalities analysis – Draft for consultation



**National Standards and Service Specifications for Congenital Heart Disease
Equality and Health Inequalities analysis – Draft for consultation**

Version number: V2

First published: May 2015, Updated: January 2017

Prepared by: Congenital Heart Disease Programme Team

Classification: OFFICIAL

Draft for consultation

PART A: General Information
1. Title of the project, programme or work:
Congenital Heart Disease Equality and Health Inequalities Analysis
2. What are the intended outcomes?
<p>This review is an extension of the equality and health inequality impact assessment conducted in May 2015 on the standards by:</p> <ul style="list-style-type: none"> • Refreshing the Equality Impact Assessment conducted in 2015 with new available data; and • Undertaking an equality impact assessment on the proposals to cease the commissioning of level one and level two services at particular centres. We will consider whether the proposals would have a differential impact on any group with protected characteristics. <p>The National CHD Programme Team intends to review the Equality Impact Assessment periodically to ensure that ongoing feedback is included.</p>
3. Who will be affected by this project, programme or work?
<p>The following section addresses (i) who will be affected by the CHD service review and (ii) who would be affected by the proposed service changes.</p> <p>3.1 Who will be affected by the CHD service review</p> <p>It is estimated that across England and Wales between 5 and 9 in every 1,000 pregnancies are associated with some form of congenital heart disease (CHD) based on information collected by the British Isles Network of Congenital Anomaly Registers (BINOCAR¹). It is noted that the number of babies born with CHD will increase if the total numbers of babies being born continues to rise². Future birth rates are very difficult to predict. In their 'principal' projections, the Office of National Statistics (ONS) predicts that birth rates will fall over the next 10 years rates. But under their 'high' projections, ONS recognises that birth rates could rise.³</p> <p>Because of improvements in treatment, people with CHD can now expect to live longer than ever before. Between 1979-1983 and 2004-2008, the number of deaths from CHD in children under 15 years fell by 83% in the UK⁴. As a result, the number of people living with CHD is rising. This means that in the future we are likely to see the service moving from one that has been centred on children, to one that is treating a growing number of young people and adults. Advances in paediatric cardiology, intensive care medicine, and cardiac surgery mean that the number of children with</p>

¹ Table 1.1 and 5.1, "Congenital Anomaly Statistics 2011, England and Wales", BINOCAR, September 2013, found at: http://www.binocar.org/content/Annual%20report%202011_FINAL_040913.pdf

² ONS Population Estimates 2002-2010 available at: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-269171>

³ ONS Population projection 2012-2037 available at: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-318453>

⁴ Mortality with congenital heart defects in England and Wales, 1959-2009: exploring technological change through period and birth cohort analysis Knowles RL, Bull C, Wren C, Dezateux C (2012) Arch Dis Child, 2012 Oct; 97(10): 861-5

congenital heart disease (CHD) surviving into adulthood continues to increase. Hence, adults will constitute an ever-growing population⁵, who will continue to have (often complex) health needs. For many congenital defects treated in childhood, further problems can develop later in life that require medical care or further surgery⁶. As well as people with CHD, this work will affect: their families and carers; all members of the multidisciplinary teams who support patients with CHD; and hospitals, in particular those with specialist CHD units. Paediatric cardiac services also care for children with acquired and inherited cardiac diseases (although CHD accounts for most of their work).

The standards and specifications produced will ensure that services are provided to a consistent standard across the country and by doing so will reduce inequalities in CHD service provision and optimise outcomes.

3.2 Who would be affected by the CHD proposed service changes?

Patients who are currently receiving treatment in providers offering level 1 or 2 services, whose level of provision may be decommissioned would be impacted by the proposed service changes as at least some of their care would be transferred to another provider. The families and carers of patients with CHD affected by the changes would also be affected. Future patients and their families and carers who would have been treated at those centres and who will now be treated at a different centre will also be affected.

If level 1 services cease at the three centres proposed it is possible that level 2 services may continue (this is one aspect being explored in consultation). If this were to be the case the majority of care for those patients could continue to be provided at their existing centre except for any operations or cardiology interventions, and one pre-procedure and one post-procedure outpatient appointment.

We have outlined the providers that would be impacted by the proposed service change in section 3.3.

The next round of consultation is proposed to take place in December 2016 through to March 2017 and will be focused on understanding the impact of the proposed service changes. NHS England will not make a final decision until the consultation has concluded and the responses analysed.

The aim of the proposed service change is to provide a better service overall by ensuring that every patient receives their care from a centre that is able to meet the service standards and specifications. We do not anticipate that there should be a negative impact on the quality of services provided by centres that remain in operation: the principal impact will come from the reduction in the number of centres with the result that some patients will live further from their centre of choice. However, in the period during which change may be happening, there may also be transitional effects that may impact some patients more than others (most obviously, patients receiving treatment from centres that may cease providing the services they currently receive).

Patients who are currently at centres that will see increased volumes due to the proposed decommissioning of services may also be impacted. To understand the estimated volumes of CHD surgery per year moving to other providers if the suggested services are suspended two options have been modelled in table 1 and 2.

- In both scenarios a majority of patients from the Royal Brompton would attend Great Ormond Street Hospital should the proposed closures go ahead.
- In both scenarios a majority of patients from CMFT would attend Liverpool Heart and Chest

⁵ *Delivery of care for adult patients with congenital heart disease in Europe: results from the Euro Heart Survey*, Moons et al (2006) European Heart Journal 27, 1324–1330

⁶ *Care and Treatment for congenital heart defects* (2011) American Heart Association
<http://heart.org/HEARTORG/Conditions/CongenitalHeartDefects>

should the proposed closures go ahead.

- In both scenarios a majority of patients from UHL would attend University Hospitals Birmingham should the proposed closures go ahead.

Table 1: Scenario 1 of estimated volumes of CHD surgery/ year moving to other providers

Receiving Trust	Patients/year From Royal Brompton			Patients/Year From CMFT			Patients/year From UHL			Grand Total		
	Adult	Paeds	Total	Adult	Paeds	Total	Adult	Paeds	Total	Adult	Paeds	Total
ALDER HEY CHILDREN'S NHS FOUNDATION TRUST		1	1		-	-		8	8	-	9	9
BARTS HEALTH NHS FOUNDATION TRUST	77		77		-	-	1		1	78	-	78
BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST		5	5		-	-		174	174	-	179	179
GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST		228	228		-	-		4	4	-	232	232
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	30	173	203		-	-		4	4	30	177	207
LEEDS TEACHING HOSPITALS NHS TRUST	1	-	1	4	-	4	10	37	47	15	37	52
LIVERPOOL HEART AND CHEST NHS FOUNDATION TRUST	1		1	96	-	96	-		-	97	-	97
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST		-	-		-	-		-	-	-	-	-
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	6	11	17		-	-		1	1	6	12	18
UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST	2		2		-	-	49		49	51	-	51
UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST	3	2	5		-	-		2	2	3	4	7
Total	120	420	540	100	-	100	60	230	290	280	650	930

Data sources:

Volumes of Surgery : 1314 NICOR

Proportional use of centres : HES data 0607 to 1415

Table 2: Scenario 2 of estimated volumes of CHD surgery/ year moving to other providers

Receiving Trust	Patients/year From Royal Brompton			Patients/Year From CMFT			Patients/year From UHL			Grand Total		
	Adult	Paeds	Total	Adult	Paeds	Total	Adult	Paeds	Total	Adult	Paeds	Total
ALDER HEY CHILDREN'S NHS FOUNDATION TRUST		1	1		-	-		8	8	-	9	9
BARTS HEALTH NHS FOUNDATION TRUST	90		90		-	-	1		1	91	-	91
BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST		4	4		-	-		174	174	-	178	178
GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST		201	201		-	-		4	4	-	205	205
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	36	153	189		-	-		4	4	36	157	193
LEEDS TEACHING HOSPITALS NHS TRUST	1		1	4	-	4	8	37	45	13	37	50
LIVERPOOL HEART AND CHEST NHS FOUNDATION TRUST	1		1	85	-	85	-		-	86	-	86
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST		-	-		-	-		-	-	-	-	-
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	7	9	16		-	-		1	1	7	10	17
UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST	3		3		-	-	37		37	40	-	40
UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST	4	2	6		-	-		2	2	4	4	8
Total	142	370	512	89	-	89	46	230	276	277	600	877

Data sources:

Volumes of Surgery : 1415 NICOR

Proportional use of centres : HES data 0607 to 1415

Providers have also been asked to assess the impact on their services as a result of the proposed closures. From this information we understand the patient choice has not been factored into the modelling of where patients will go should the decommissioning of centres go ahead. Rather, the model looks at proposed new catchment areas. The impact on time travel is analysed in section 8.

The equality impact assessment aims to understand whether there will be a differential impact on any group with protected characteristics as a result of the proposed service change. The consultation will also provide a more detailed perspective on the impact of the proposed changes on patients.

3.3 Proposed changes to providers offering level one services

NHS England is currently minded to make changes at centres that provide level 1 (surgical) services:

- Surgery and interventional cardiology for adults should **cease** at Central Manchester University Hospitals NHS Foundation Trust (CMFT). CMFT does not undertake surgery in children.
- Surgery and interventional cardiology for adults and children should **cease** at Royal Brompton & Harefield NHS Foundation Trust.
- Surgery and interventional cardiology for children and adults and children should **cease** at University Hospitals of Leicester NHS Trust.

This means that the following centres would continue to provide level 1 services:

- Alder Hey Children's Hospital NHS Foundation Trust (children's services)
- Liverpool Heart and Chest Hospital NHS Foundation Trust (adult service)
- Birmingham Children's Hospital NHS Foundation Trust (children's services)
- University Hospitals Birmingham NHS Foundation Trust (adult service)
- Great Ormond Street Hospital for Children NHS Foundation Trust (children's services)
- Barts Health NHS Trust (adult service)
- Guy's and St Thomas' NHS Foundation Trust (children's and adult services)
- Leeds Teaching Hospitals NHS Trust (children's and adult services)
- Newcastle Hospitals NHS Foundation Trust (children's and adult services)
- University Hospitals Bristol NHS Foundation Trust (children's and adult services)
- University Hospital Southampton NHS Foundation Trust (children's and adult services)

3.4 Proposed changes to providers offering aspects of level two services

The following changes are proposed at centres that provide level 2 (medical) services

- Specialist medical care and interventional cardiology should **cease** at Blackpool Teaching Hospitals NHS Foundation Trust
- Specialist medical care and interventional cardiology should **cease** at Imperial College Healthcare NHS Trust
- Specialist medical care and interventional cardiology should **cease** at Nottingham University Hospitals NHS Trust
- Specialist medical care and interventional cardiology should **cease** at Papworth Hospital NHS Foundation Trust
- Specialist medical care and interventional cardiology have **already ceased** at University Hospital of South Manchester NHS Foundation Trust based on the recommendations of the Review.

This means that the following centres would continue to provide level 2 services:

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

NHS England is discussing the potential for the provision of level 2 medical services at hospitals where level 1 care would cease. The National CHD team is interested in the support for this approach and will test this as part of the consultation. This possibility relates to:

- Central Manchester University Hospitals NHS Foundation Trust (adult service)
- Royal Brompton & Harefield NHS Foundation Trust (children's and adult services)
- University Hospitals of Leicester NHS Trust (children's and adult services)

4. Which groups protected by the Equality Act 2010 and/ or groups that face health inequalities are very likely to be affected by this work?

The proposed standards are intended to ensure that everyone with CHD gets the best possible care within the available resources. Earlier analysis and engagement, has indicated that the impact of the proposed service change may differentially impact some Black and Minority Ethnic (BME) patients (those of Asian ethnicity) and those with a learning disability. In addition, services for CHD are of particular interest to children and the families and carers of children. We hope to build our understanding of the nature of the impact through the proposed December 2016 – March 2017 consultation. Therefore, the consultation considers the impact of the proposed changes on these

groups.

We do not believe that the work would undermine compliance with the Public Sector Equality Duty or section 11 of the Children Act 2004 which requires NHS England to make arrangements for ensuring that its functions are discharged having regard to the need to safeguard and promote the welfare of children; and that any services provided by another person pursuant to arrangements made by NHS England are provided having regard to that need.

4.1 Summary of response from providers regarding equality and inequality impact as a result of the proposals

The CHD Implementation Programme team asked providers to supply information about any equalities or inequalities consequences of the proposals. A number of hospitals responded to the request, however most centres did not identify any significant equality or health inequalities impacts associated with the proposals.

One centre stated that the reduction in services available in the East Midlands may create a geographical inequality in their ability access CHD care. Another centre suggested that a greater number of economically disadvantaged patients would find it harder to access outpatient clinics. All the responses submitted by the centres were considered in more detail and the analysis can be seen in section 7.1 (geographic variation).

PART B: Equalities Groups and Health Inequalities Groups

5. Impact of this work for the equality groups listed below.

5.1. Age

5.1.1 Review of literature and data

Mortality from CHD has decreased over the past 30 years; between 1979-1983 and 2004-2008, absolute numbers of deaths from CHD in children under 15 years declined by 83% in the UK⁷. As the birth prevalence of CHD is thought to have remained more stable over this time period⁸, it can be inferred that a large part of this decline in mortality is due to improved survival. Knowles *et al.* found that while deaths rates in the first year of life have been reducing throughout the period studied, drops in mortality in all age groups has only been observed for birth cohorts originating after 1989⁹.

There is a suggestion from our own analysis (table 3) and what we have heard that there has been an increase in demand for adult congenital heart disease care, not just among people in their twenties (i.e. birth cohorts originating after 1989).

Table 3: CHD related episodes by age and as percentage of total (2013/14 HES data)

Age band	Age	Episodes	% total
Neonate	0 to 30 days	1081	11%

⁷ *Mortality with congenital heart defects in England and Wales, 1959-2009: exploring technological change through period and birth cohort analysis* Knowles RL, Bull C, Wren C, Dezateux C (2012) Arch Dis Child, 2012 Oct; 97(10): 861-5

⁸ *Temporal variability in birth prevalence of cardiovascular malformations* Wren C, Richmond S, Donaldson L (2000). Heart; 83: 414-9

⁹ Op. cit.

Infant	31 to 364 days	1930	20%
Child 1 -15	1 to 15 years	3741	38%
Child 16-18	16 to 18 years	815	8%
Adult 19-64	19 to 64 years	1654	17%
Adult 65+	65 years+	588	6%

Note: includes all episodes with a procedure (excluding electrophysiology) in NHS England providers for all patients resident in England.

In the past, mortality rates were higher in the early days and months, now more children in the UK with CHD benefit from advances in paediatric cardiac surgery and intensive care, and receive treatment and reach adulthood. The greatest decline in deaths from congenital heart disease has occurred in those aged less than one year.

This means that in the future, as more people survive, we are likely to see the service moving from one that is centred around children to one that is in addition treating a growing number of young people and adults, who will continue to have (often complex) health needs. This has consequences for the way in which services are delivered and what sort of services are delivered, for both children and young people (and their different needs and expectations) through to transition for young people into adult services.

For many congenital defects treated in childhood, further problems can develop later in life which then requires medical care or further surgery¹⁰.

In *Children and young people: Statistics 2013*¹¹, the British Heart Foundation notes: 'Treatment of adults with congenital heart disease is relatively new as more children with congenital heart defects receive treatment and reach adulthood. As a result of the success of paediatric cardiology and cardiac surgery over the last four decades, it is thought that more adults with congenital heart disease will require medical care than children'¹² (page 15). The report authors go on to highlight the importance of ensuring that facilities are adequate at transition.

5.1.2 What we heard during pre-consultation and consultation during the CHD Review Programme in 2014/15

¹⁰ *Care and Treatment for congenital heart defects* (2011) American Heart Association
<http://heart.org/HEARTORG/Conditions/CongenitalHeartDefects>

¹¹ *Children and young people: Statistics 2013* (2013) Townsend N, Bhatnagar P, Wickramasinghe K, Williams J, Vujcich D, Rayner M, British Heart Foundation: London

¹² *Task force on the management of grown up congenital heart disease of the European Society of Cardiology* (2003) European Heart Journal; 24: 1035-1084

Typically we hear most from the families of children and young people with CHD. However, we have made efforts to ensure that we hear directly from children and young people with CHD themselves (and from adults with CHD too). We will continue to do so in this consultation. In creating the standards we took the time to listen to children and young people and what mattered most to them. We learned that their concerns were different from those of their parents or those who run services.

Young people told us:

- They want doctors and nurses to talk to them and not just to mum and dad; to be honest; and to communicate in a way that is appropriate for the individual taking account of their age and any disabilities.
- Even very young children quickly become expert on their condition and this needs to be acknowledged.
- They want to understand what's going to happen but not be scared by it.
- They want better information on living with CHD as a young person including on sex, drugs, alcohol, relationships, contraception, the possibility of children – and this needs to be away from parents completely.
- They would like there to be more specialist nurses, psychologists, counsellors.
- Getting to know and being known by hospital staff makes hospital life easier so keeping the same consultant/surgeon is very important.
- They would really like Wi-Fi as they are dependent on devices to keep in touch with the outside world.
- They want facilities including entertainment and play for all the different age groups.
- Everyone wants to improve transition so that the move from children's to adults' services is smoother; and transition needs to be individualised - there can't be an age limit – each patient is different – some should move early, others late, others never; and
- While they are in hospital children and young people want to maintain some level of normality, for example eating with their family, exercising/playing sports, seeing friends; keeping up with school; and having access to social media/internet/online resources.

Many of these concerns are directly addressed by the standards. We believe that our proposals to ensure that every patient can be confident that they will receive their care from a centre that meets the standards will have a very positive impact for children and young people.

In consultation in 2014/15, we heard that there is a need for increasing capacity in adult congenital heart disease services and that some centres were expanding facilities and recruiting new staff. We heard from patients, families and carers that services needed to be age-sensitive and that effective transition was vital. This related to effective and appropriate communication, but also to the facilities provided.

Young people told us that they would like more information about the implication of CHD on sex and relationships. They also recommended that this needed to be away from parents, since many teenagers are uncomfortable speaking about this in front of their parents, some didn't even don't like the idea of speaking with their regular doctors.

During consultation we spoke with individuals as well as organisations; this included: children, young people and adults, including service users' families and carers. Information provided during consultation guided us to review elements such as transition and collocation of services to support families who have multiple generations with congenital heart disease that require treatment.

5.1.3 Potential impact of the proposed service changes

We know that most surgery and cardiological interventions for CHD happen in early life. Because the proposals particularly affect where this sort of care will be delivered, children and young people (and

their families and carers) will be more affected than adults with CHD.

They can be expected both to gain more (the changes particularly focus on assurance that centres are able to meet the activity volumes required for best practice by surgeons and interventional cardiologists, and on the interdependencies required for children's cardiac services) and also to be more affected by change and by different journeys to the level 1 CHD centre when needed. Some children and their families will live further away from centres that will be continuing to make provision than they do from a centre that may cease provision. Some journey times will increase. Some families may find it harder to visit a child who is receiving in-patient care.

To understand the breakdown of children and young people and adults that would be impacted by the proposed changes we looked at the prevalence of children and young people (CYP) who were admitted to the Royal Brompton, Central Manchester Foundation Trust and University Hospitals of Leicester NHS Trust over a three year period (2013/14 to 2014/16). From table 4 we can see that there more CYP admitted than adults with the prevalence being 59%, 57% and 75% respectively.

Table 4: Inpatient admissions with CHD diagnosis 2013/14 to 2015/16

Inpatient Admissions with CHD diagnosis 13/14 to 15/16									
Provider	#patients (3yrs)	#patients (1yrs)	total admissions	#CYP	%CYP	#Asian	%Asian	#LD	%LD
RT3: Royal Brompton & Harefield NHS Foundation Trust	3,672	1,224	4,939	722	59%	8	1%	0	0.03%
RW3: Central Manchester University Hospitals NHS Foundation Trust	1,158	386	1,416	219	57%	55	14%	0	0.1%
RWE: University Hospitals of Leicester NHS Trust	1,217	406	1,584	304	75%	43	11%	1	0.2%

Source: NCDR SUS

CYD includes patients aged <19 at date of admission

Section 8 provides detailed information about the impact of travel. Children who currently receive treatment at Leicester and Royal Brompton would be impacted by the proposed changes. Average time travel would increase by 14 minutes for children who attend Leicester and 2 minutes for children use the Royal Brompton.

5.1.4 Proposed actions to mitigate the impact of the proposed service changes

The proposed standards emphasise, in several places, the importance of open, honest communication in ways that are appropriate to the patient's needs. In addition we have also developed specific standards on:

- communication with patients;
- transition; and
- pregnancy and contraception.

The standards specifically address a number of age related life course elements including birth, transition from paediatric to adult services, recognition of the increasing number of adults living with CHD and end of life.

We have commissioned the development of a survey to measure patient reported experience. The questions to be asked have been guided by the concerns of patients and their families including children and young people. This will mean that from next year we will be directly measuring and reporting on the experience of children and young people and will be able to track and address any changes that arise as a result of the proposed changes if they are agreed.

5.1.5 Implications for the 2016/17 consultation on the propose service change as part of the CHD Commissioning and Implementation Programme

During consultation we will make special arrangements to gather the views of children and young

people. We have also produced an EasyRead version of this consultation document to help parents and carers explain the proposals to children.

As part of our consultation we are asking people about the impact implementation of the proposals would have on children and young people and also for advice on dealing with any concerns. This will include gathering qualitative evidence on the impact on young people through open ended questions.

5.2. Disability

5.2.1 Review of literature and data

Children and adults with congenital heart disease are at an increased risk of developing further difficulties. Many children with congenital heart disease experience delays in their development. For example, they may take longer to start walking or talking. They may also have lifelong problems with physical coordination.

Some children with congenital heart disease also have learning disabilities, which are thought to be caused by a poor oxygen supply during early life, which affects the development of the brain.

Natural intelligence is usually unaffected, but some children often perform well below the academic level they would be expected to reach. This is because of problems such as:

- impaired memory;
- problems expressing themselves using language;
- problems understanding the language of others;
- low attention span and difficulty concentrating;
- poor planning abilities; and
- poor impulse control – acting rashly without thinking about the possible consequences.

Recent research has found that children who have had surgery for transposition of the great arteries have significant problems related to a concept known as theory of mind (TOM). TOM is the ability to understand other people's mental states and recognise that they may differ from your own. In other words, to recognise that everyone has their own set of desires, intentions, beliefs, emotions, perspective, likes and dislikes. In simple terms, TOM is the ability to see the world through another person's eyes. An inability to recognise other people's mental states can lead to problems with social interaction and behaviour in later life.

Congenital heart disease as a complication of Down's syndrome

Around 50% of children with Down's syndrome have a congenital heart defect and around 60% of children with Down's syndrome who are born with a heart defect require treatment in

hospital.

Septal defects account for 9 out of 10 cases of congenital heart disease in people with Down's syndrome. (A septal defect is a hole inside one of the walls that separate the four chambers of the heart, often referred to as a 'hole in the heart').

Less common but serious types of congenital heart disease in people with Down's syndrome include:

- tetralogy of Fallot (accounts for 6% of cases); and
- patent ductus arteriosus (accounts for around 4% of cases).

As noted above in relation to age, it is possible that in complex congenital heart disease cases, further problems (which could include a disability) will develop later in life that will require medical care or further surgery¹³.

Congenital heart disease as a complication of 22q11 Deletion Syndrome (22q11DS)

22q11DS is a deletion of 1.5 to 3Mb on the long (q) arm of chromosome 22. It is the most common autosomal deletion in humans. The prevalence is 1 in 2 to 4000, and at least 1 in 6000. In the UK and Ireland, of a population of 66 million, approximately 150 to 200 infants are born each year with 22q11DS. Between 50 and 85% of individuals with 22q11DS have congenital heart disease¹⁴.

Therefore people with Down's Syndrome and 22q11DS may be more affected by the proposed service changes.

Prevalence of Learning Disability as a secondary diagnosis of CHD patients

The incidence of learning disability is 2.9% amongst children in England and Wales and 2.17% amongst adults¹⁵. We cannot make an exact estimate of the number of people with CHD who also have LD, but based on the evidence quoted above we can assume that it will be more than found in the general population. Using the incidence of learning disability we calculated the number of adults

¹³ *Care and Treatment for congenital heart defects* (2011) American Heart Association

<http://heart.org/HEARTORG/Conditions/CongenitalHeartDefects>

¹⁴ *Consensus Document on 22q11 Deletion Syndrome* Max Appeal

http://www.maxappeal.org.uk/downloads/Consensus_Document_on_22q11_Deletion_Syndrome.pdf

¹⁵ *People with Learning Disabilities in England*, Public Health England, 2013

http://www.improvinghealthandlives.org.uk/securefiles/161107_1231/People%20with%20learning%20disabilities%20in%20England%202013.pdf

and children with a learning disability that may be impacted by the proposed service change in each provider in table 5.

Table 5: Inpatient admissions with CHD diagnosis

Inpatient Admissions with CHD diagnosis 13/14 to 15/16, and pro rata NICOR 1415											
Provider	Group	#patients (3yrs)	total admissions	Patients/year	#Asian	%Asian	#LD	%LD	NICOR 1415	Est Asian patients/year	Est LD/year
RT3: Royal Brompton & Harefield NHS Foundation Trust	Adults	1,506	1,621	502	61	12.1%	11	2.17%	142	2	-
	Paeds	2,166	3,318	722	87	12.1%	21	2.90%	370	-	<1
RW3: Central Manchester University Hospitals NHS Foundation Trust	Adults	502	565	167	27	15.9%	4	2.17%	89	6	-
	Paeds	656	851	219	35	15.9%	6	2.90%	-	-	<1
RWE: University Hospitals of Leicester NHS Trust	Adults	305	352	102	13	12.6%	2	2.17%	46	3	<1
	Paeds	912	1,232	304	38	12.6%	9	2.90%	230	27	<1
Source: NCDR SUS											
CYP includes patients aged < 19 at date of admission											
#Patients and total admissions includes records where Ethnic category is 'Not Stated', 'Not Known' and NULL											

Note: refer to appendix 2 for the list of diagnosis used in the learning disability calculation

5.2.2 What we heard during pre-consultation and consultation during the CHD Review Programme in 2014/15

We heard about the importance of ensuring the standards respect the needs of people with disabilities.

We have proposed standards that address the needs of all patients and have included particular standards that relate to learning disability, for example in relation to:

- communication with patients; and
- transition.

We heard about the difficulties that individuals and carers have when caring for someone with a disability and CHD during consultation. For example the relation to the actual and perceived age of the individual with a learning disability; the need for staff to be trained in caring for those with specific special needs and the importance of the carer in this role. (Relating to the Carers Act 2014)

5.2.4 Potential impact of the proposed changes

Change for people with learning disabilities or on the autistic spectrum is more difficult. Any service change for this population can be more difficult and needs to be managed well. This is not unique to the CHD proposed service change; however careful consideration should be given to the management of change for these patients.

We asked charities that work with people with both CHD and learning disabilities about the potential impact of our proposals on people with learning disabilities. They told us that:

- People with learning disabilities and especially people with autistic spectrum disorder cope best when things are familiar, so changing settings and changing staff is more of an issue. 60% of those with any form of Q22 deletion will have an anxiety disorder of some kind, and this makes change and new experiences (as well as everyday experiences) particularly traumatic.
- We will need to be able to let patients and their families / carers know what is going to happen very clearly including the practical details.
- Travel for people using wheelchairs or supportive aids is difficult. Children with autistic spectrum disorders often can't use public transport easily. So the issue of access and travel needs extra attention and support for people with learning disabilities and their families / carers
- The impact of a cancellation on a family of a learning disabled patient can be huge – so capacity at centres taking additional patients will need to be sufficient that cancellations can be minimised.
- Care and attention needs to be paid to any successful change and transition - visits with familiar staff to new units, new staff coming to meet a patient on familiar ground, arranging for visits prior to surgery or interventions to see where things will happen, what the ward looks like etc. can help.
- Discharge needs better planning and organisation so that travel doesn't mean that patients are arriving at their destination very late at night, and out of their regular schedule.
- Parents and carers need to be included in the planning each patient's needs.

The particular concern has been around the practical elements of change like travelling to a new location, and patients being treated by clinical teams in a location that they are not familiar with. People with learning disabilities allow clinicians that they know to work with them and may refuse the same treatment in an unfamiliar surrounding by unfamiliar people.

- If our proposals are agreed we will ensure that these concerns are addressed in the planning and preparation for any changes that follow.

The proposed service changes may also result in patients receiving care split at two centres (level one and level two) rather than all at the same centre. This may be disruptive for all patients and especially those with a learning disability. Clinical team should be encouraged to communicate to make the transition as smooth as possible. We anticipate that the network model of care will encourage good communication between clinical teams. It is also expected that the regional networks will work in a coordinated manner to ensure equality and standardisation of care throughout the NHS.

The standards address the particular needs of people with learning disability for example in requiring appropriate facilities, appropriate communication and individualised transition to adult services. There is also a requirement to work with the learning disability team and for CHD health professionals to include training on meeting the needs of people with learning disability in their continuing professional development. Many other aspects of the standards will have a positive effect on the experience of people with learning disability and their families.

5.2.5 Proposed actions to mitigate the impact of the proposed service changes

Consideration has been given to the 'target audience' for documents and information, and whether proactive publication in any alternative languages and / or formats is appropriate.

Documents and information published by NHS England, as well as corporate correspondence, should be as accessible as possible to as many people as possible as stated by the [NHS England Accessible Information Standard](#). This does not mean that multiple formats or versions of every document should always be produced; rather that accessibility should be built into the development of 'standard' versions and consideration should be given to the most appropriate approach to alternative language and format provision as part of preparing for publication. - *Therefore, information can be made available in formats, such as easy read or large print, and may be available in alternative languages, upon request.*

Previously we listened and responded to this in consultation; producing easy read material; offering different forms of media, as well as face-to-face at consultation events; translating material and being available to answer queries via email or phone. We will continue to do this for the proposed December 2016 consultation.

From preliminary conversations with stakeholders we found that ensuring there is a learning disability team in Trusts is crucial. Reasonable adjustments are also already being made at providers across the country. This may include scheduling patients with a learning disability during the beginning or end of the day when the hospital is quieter. It is important that best practice is shared between trusts and that clinical teams are communicating the needs of patients. We believe that the network model will encourage communication between centres which is especially important for vulnerable groups.

We will also encourage providers to communicate with parents, carers and patients about the changes and what practical implications will arise. This would help lessen concerns and enable enough time to make alternative arrangements. When service change does happen the National CHD Team should seek to assure patients that communication will be smooth and that patients will have change managed well.

Standards around family support, transportation and accommodation will become even more important for patients that are moved to new centres. The implementation of the standards will also take into account capacity at units in order to minimise cancellations.

5.2.6 Implications for the 2016/17 consultation on the propose service change as part of the CHD Commissioning and Implementation Programme

The consultation should specifically consider the impact on people with learning disabilities and understand the best way to create continuity for people with learning disabilities. This will aim to minimise the disruption of change and make the transition period smoother.

During consultation we will make special arrangements to gather the views of people with learning disabilities and their families and carers. We have also produced an EasyRead version of this consultation document to help parents and carers explain the proposals to people with learning disabilities. As part of our consultation we are asking people about the impact implementation of the proposals would have on people with learning disabilities and their families and carers and also for advice on dealing with any concerns.

5.3. Gender reassignment

We have not identified any specific evidence relating to gender reassignment (including

transgender) and CHD. Additionally we have not heard anything on this topic in pre-consultation or consultation. The standards and service specifications do not alter access or delivery of these services to people with this protected characteristic.

5.4. Marriage and civil partnership

We have not identified any specific evidence relating to marriage and civil partnership and CHD. Additionally we have heard nothing on this topic both pre-consultation and during consultation. (We do not think it appropriate or justified to assume that people who are married or in a civil partnership are more likely to be the parents or carers or in a family with a person with CHD). The standards and service specifications do not alter access or delivery of these services to people with this protected characteristic.

5.5. Pregnancy and maternity

Two distinct groups in this category may be affected by the proposed changes.

- Women with CHD who are pregnant
- Women who are pregnant carrying a baby with CHD

In both cases most maternity care is delivered through local maternity services at a hospital close to the woman's home. Arrangements will be made for the delivery of the baby that take account of the needs of both mother and child. This may be at the local obstetric unit or at an obstetric centre at or close to the specialist surgical centre. These requirements are described in the standards in sections J and K.

5.5.1 Review of literature and data

While cardiac disease is a leading cause of maternal death in pregnancy¹⁶ there is evidence that this is acquired rather than congenital heart disease and outcomes for pregnant women with CHD are good.

The Royal College of Obstetricians and Gynaecologists (RCOG) published a Good Practice guideline in 2011 which noted that pregnancy carries increased risks for women with congenital heart disease and particular efforts should be made to prevent any unwanted pregnancies. In particular teenage girls with congenital heart disease should have access to a specialist who can advise on contraception and later in life on preconception counselling. RCOG also noted the importance of ensuring that women with CHD:

- who go to their GP or midwife for advice are referred promptly to an appropriate high-risk pregnancy and heart disease team; see a cardiologist to establish how well the heart is working; and discuss how pregnancy may impact their health.
- who want to become pregnant or who are pregnant visit their obstetrician and ideally should talk to them jointly with a cardiologist.

5.5.2 What we heard during pre-consultation and consultation during the CHD Review Programme in 2014/15

We heard choices in care delivery are offered and these choices must be clearly defined and shared, including positive and negative outcomes, support in both circumstances must be offered. We heard

¹⁶ Royal College of Obstetricians and Gynaecologists (2011)

that there is a possibility that increased fetal diagnoses could in some cases increase terminations and reduce activity. But in other cases, it could increase the chance of survival and increase activity.

We also heard that as a consequence of better care for people with congenital heart disease, more are going on to have their own children. This means that it is very important that there are close links between maternity services and Adult Congenital Heart Disease services, and that deliveries are planned for safety.

We heard comments on the standards relating to maternity care for women with CHD – for example the specific request for earlier diagnosis; the wording of the standards in relation to choice, options and access to procedures and care how such services would be implemented and monitored.

In 2014/15, we undertook a separate piece of work to improve fetal diagnosis of congenital heart disease. An implementation project group commenced to ensure early diagnosis and improved standards of detection, with partner organisations such as Health Education England, Public Health England, societies and charities. We developed specific standards on:

- pregnancy and contraception (section J); and
- fetal diagnosis (section k).

5.5.3 Potential impact of the proposed changes

We believe that the proposed standards will have a positive impact on the experience and outcomes of women with CHD who are considering pregnancy, are pregnant or are receiving maternity care and on women who are pregnant carrying a baby with CHD. For the first time services will be nationally commissioned using common service specifications.

For some women, if the proposals are implemented it will mean that delivery will take place at an obstetric unit further from home. These issues are dealt with in section 8.1 below.

5.5.4 Proposed actions to mitigate the impact of the proposed changes

We believe the standards published in 2014/15 that specifically consider maternity and pregnancy mitigate any impact of the proposed standards. We do not think that the proposed service changes for 2016/17 will impact pregnancy and maternity.

5.5.5 Implications for the 2016/17 consultation on the propose service change as part of the CHD Commissioning and Implementation Programme

Pregnancy and maternity do not have implications on the 2016/17 consultation.

5.6. Race

5.6.1 Review of literature and data

Ethnicity is known to relate to the prevalence of certain diseases. The relationship between ethnicity and CHD is complex and may be confounded by cultural and religious factors.

We looked at hospital activity data in comparison to the population to see whether some ethnic groups receive a greater than expected level of hospital care.

The data (appendix 2) appears to show higher levels of inpatient activity for congenital heart disease amongst BME groups than would be expected on a strict population basis amongst children, but not

amongst adults. This data does not tell us whether the incidence of CHD is higher in these groups – higher levels of inpatient activity may reflect a similar incidence but a greater proportion of serious disease, or may reflect other factors leading to higher admission rates.

Ethnicity and prevalence

Research dating back to the 1980s¹⁷ and 1990s¹⁸ demonstrated higher prevalence among Asian communities in various UK cities including Manchester and Leeds, and in the West Midlands.

Research conducted at the Birmingham Children's Hospital indicates there is a higher prevalence of Asian infants with congenital heart disease. The prevalence for Asian infants is estimated to be 9.45 per 1000 and 4.56 per 1000 for non-Asian infants. The difference between these two groups is highly statistically significant¹⁹.

In the 1980s research links were made between CHD and consanguinity in the Asian Muslim population. More recently in *Consanguinity and the risk of congenital heart disease*, (2012)²⁰ found that the majority of studies support the view that consanguinity increases prevalence of CHD, but found only three population-based studies controlled for potential socio-demographic confounding. The results suggested that the risk for CHD is increased in consanguineous unions in the studied populations, principally at first cousin level and closer.

For more precise risk estimates a better understanding of the underlying disease factors is needed. It has been suggested that we should consider whether and how to raise awareness of the risk of CHD within these communities. This is discussed in more detail under proposed actions in section 5.6.4.

The national census 2011²¹ shows that 7.5% of the population of England and Wales has Asian ethnicity including Indian 2.5%, Pakistani 2%, Bangladeshi 1.5% and white and Asian 0.6%. Based on the evidence already presented we would expect that there would be a higher proportion of people with Asian ethnicity amongst CHD patients.

We looked at the recorded ethnicity of CHD patients at the three affected level 1 centres. From the data in table 6, we can see that all three trusts have a higher prevalence of South Asian patients than the average for the population and higher than the CHD patient group at other level 1 CHD hospitals.

- CMFT has the highest prevalence of the three providers that will be impacted by the service change at 15.9% compared to the average of 11.2%.
- UHL has a prevalence of 12.6% compared to the average of 11.2%.
- Royal Brompton has a prevalence of 12.1% compared to the average of 11.2%.

Table 6: Ethnicity prevalence in CMFT, Leicester and Royal Brompton

¹⁷ Gatrad AR, Reap AP, Watson GH Consanguinity and complex cardiac anomalies with situs ambiguous, *Arch.Dis Child* 1984; 59: 242-5

¹⁸ Sadiq M, Stumper O, Wright JGC, de Giovanni JV, Billingham C, Silove ED Influence of ethnic origin on the pattern of congenital heart defects in the first year of life *Br Heart J* 1995; 73: 173-176

¹⁹ Sadiq M, Stumper O, Wright JGC, de Giovanni JV, Billingham C, Silove ED Influence of ethnic origin on the pattern of congenital heart defects in the first year of life *Br Heart J* 1995; 73: 173-176

²⁰ *Am J Med Genet A*. 2012 May;158A(5):1236-41. doi: 10.1002/ajmg.a.35272. Epub 2012 Apr 9.

²¹ Ethnicity and National Identity in England and Wales, ONS 2011

<http://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11>

RW3: Central Manchester University Hospitals NHS Foundation Trust	RWE: University Hospitals of Leicester NHS Trust	RT3: Royal Brompton & Harefield NHS Foundation Trust	All Trusts Grand total	Ethnic Category_
70.6%	75.8%	72.6%	74.1%	A: British
0.8%	0.3%	2.4%	0.5%	B: Irish
2.6%	3.6%	4.8%	4.7%	C: Any other white background
0.9%	1.4%	0.4%	0.8%	D: White and black Caribbean
0.7%	0.1%	0.0%	0.4%	E: White and black African
0.6%	0.4%	0.4%	0.7%	F: White and Asian
1.3%	1.0%	0.4%	0.9%	G: Any other mixed background
15.9%	12.6%	12.1%	11.2%	H: Asian
0.7%	0.6%	0.8%	0.7%	M: Caribbean
2.6%	0.9%	3.2%	2.2%	N: African
0.5%	0.9%	0.0%	0.9%	P: Any other black background
0.7%	0.3%	0.8%	0.6%	R: Chinese
2.2%	2.1%	2.0%	2.3%	S: Any other ethnic group

Source: NCDR SUS 13/14 to 15/16

Selection criteria: primary diagnosis from CHD 'pure' list

'Not known' and 'Not stated' excluded (4672 of 26605 records)

Furthermore we looked at inpatient admissions for people with a CHD diagnosis for Royal Brompton, CMFT and UHL to determine the number of patients from Asian groups that would be impacted by the proposed service change.

From Table 7, we can see that CMFT has the largest Asian patient population and therefore the proposals would have the largest impact on Asian patients at CMFT

Table 7: Inpatient admissions with CHD 2013 to 2014

Inpatient Admissions with CHD diagnosis 13/14 to 15/16, and pro rata NICOR 1415											
Provider	Group	#patients (3yrs)	total admissions	Patients/year	#Asian	%Asian	#LD	%LD	NICOR 1415 Est Asian patients/year Est LD/year		
RT3: Royal Brompton & Harefield NHS Foundation Trust	Adults	1,506	1,621	502	61	12.1%	11	2.17%	142	2	-
	Paeds	2,166	3,318	722	87	12.1%	21	2.90%	370	-	<1
RW3: Central Manchester University Hospitals NHS Foundation Trust	Adults	502	565	167	27	15.9%	4	2.17%	89	6	-
	Paeds	656	851	219	35	15.9%	6	2.90%	-	-	<1
RWE: University Hospitals of Leicester NHS Trust	Adults	305	352	102	13	12.6%	2	2.17%	46	3	<1
	Paeds	912	1,232	304	38	12.6%	9	2.90%	230	27	<1
Source: NICOR SUS											
CYP includes patients aged < 19 at date of admission											
#Patients and total admissions includes records where Ethnic category is 'Not Stated', 'Not Known' and NULL											

Ethnicity and outcomes

We asked NICOR to examine whether there was any link between ethnicity and the 30-day outcome after paediatric surgery. The NICOR²² analysis showed that Asian ethnicity is associated with poorer outcomes (30-day post-operative mortality). This association does not prove that Asian ethnicity causes poorer outcomes. Other factors beyond simple ethnicity may play a factor in this finding, such as deprivation and a higher incidence of consanguinity which is associated with more complex congenital heart disease and therefore less good outcomes. More work will be needed to understand this association.

5.6.2 What we heard during pre-consultation and consultation during the CHD Review Programme in 2014/15

During the 2014/15 pre-consultation we heard that BME groups would need to be contacted to ensure that they were aware and engaged within the process. We made every effort to ensure that this happened.

5.6.3 Potential impact of the proposed changes

The data above shows that the changes will affect more people of Asian origin than the general population because of the higher incidence of CHD amongst people of Asian origin.

It is not straightforward to assess whether the proposed changes will affect people of Asian ethnicity differently from other groups. Implementation of the standards will ensure that everyone benefits from services provided to a consistent standard across the country.

Language barriers can cause challenges when being offered or receiving treatment.

The consultation process will enable us to better understand the impact of the proposed changes by engaging with BME groups.

5.6.4 Proposed actions to mitigate the impact of the proposed changes

Language barriers can cause challenges when being offered or receiving treatment. Support for people for whom English is not their first language is addressed in the standards:

H8(L1): Specialist Children's Surgical Centres must demonstrate that arrangements are in place for parents and carers, children and young people to be given an agreed, written

²² (Sonya Crowe, Kate L. Brown, Christina Pagel, Nagarajan Muthialu, David Cunningham, John Gibbs, Catherine Bull, Rodney Franklin, Martin Utley, Victor T. Tsang, **Development of a diagnosis- and procedure-based risk model for 30-day outcome after paediatric cardiac surgery**, The Journal of Thoracic and Cardiovascular Surgery, Volume 145, Issue 5, May 2013, Pages 1270-1278, ISSN 0022-5223, <http://dx.doi.org/10.1016/j.jtcvs.2012.06.023>)

management plan in a language they can understand, that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.

H18(L1): Copies of all correspondence for GP and local centres must be copied to the parent/carer/young person (as appropriate) in plain language to retain in the patient's personal record in accordance with national guidance.

H16(L1): Where patients do not have English as their first language, or have other communication difficulties such as deafness or learning difficulties, they must be provided with interpreters/advocates where practical, or use of alternative arrangements such as telephone translation services and learning disability 'passports' which define their communication needs.

5.6.5 Implications for the 2016/17 consultation on the propose service change as part of the CHD Commissioning and Implementation Programme

During consultation we will make special arrangements to gather the views of people of Asian ethnicity with CHD. We have produced a summary version of this consultation document in a number of Asian languages and the full document can be translated on request. As part of our consultation we are asking people about the impact implementation of the proposals would have on people of Asian ethnicity with CHD and also for advice on dealing with any concerns.

5.7. Religion or belief

5.7.1 Review of literature and data

Please refer to section 5.6 for information on CHD and consanguineous unions.

5.7.2 What we heard during pre-consultation and consultation during the CHD Review Programme in 2014/15

We heard that religion and belief and culture could make it difficult for some people to engage with us in an open forum.

During the 2014/15 consultation, we heard that when a fetal diagnosis is made, how the options of terminating or continuing the pregnancy are delivered, can be difficult if a patient has religious beliefs, or their culture pre-disposes them to not entering discussion on such matters.

We also heard that sometimes parental accommodation is unsuitable for Muslim women because of the possibility of contact with men, for example in shared communal areas such as kitchens. This issue is not specific to CHD services and is not tackled by the new standards. There is no evidence that this would become a greater issue if our proposals were to be implemented.

5.7.3 Potential impact of the proposed changes

We do not have any evidence that shows a particular impact of the proposed changes on people of differing religions and beliefs.

The standards recognise the need for communication and information giving to be culturally sensitive.

It is envisaged that hospitals that would be expected to provide care for more patients, under our proposals, will review ethnic, religious and cultural mix of patient information in light of the standards and feedback of the communications, engagement and the independent consultation report.

5.7.4 Proposed actions to mitigate the impact of the proposed changes

The impact on people of different ethnicity (which may be linked to religion and culture or with different beliefs) will be explored further during the consultation. We will explain the method of doing this in section 5.7.5.

5.7.5 Implications for the 2016/17 consultation on the proposed service change as part of the CHD Commissioning and Implementation Programme

As part of our consultation we are asking people about the impact implementation of the proposals would have on groups protected characteristics and also for advice on dealing with any concerns

5.8. Sex or gender

5.8.1 Review of literature and data

Data was reviewed to identify if there was any specific correlation between gender and hospital episodes relating to CHD.

Table 8: CHD-related episodes by gender and as percentage of total

Gender	%	%
Paediatric cardiac	Episodes	Patients
Male	55	54
Female	45	46
ACHD	Episodes	Patients
Male	47	47
Female	53	53

Source: 2013/14 HES data

Note: includes all episodes with a procedure (excluding electrophysiology) in NHS England providers for all patients resident in England.

From table 8 we can see that in terms of activity levels, there are more episodes for males than females in paediatric cardiac procedures but more episodes for females than males in adulthood.

In terms of outcomes, there is no evidence that outcomes differ by gender – based on analysis by NICOR – no statistical association between 30-day mortality and patient gender has been identified²³. However, *Children and young people: Statistics 2013* (2013) notes that in children under five years of age, 3.5% of all deaths in boys and 4.8% of all deaths in girls are from congenital heart disease.

5.8.2 What we heard during pre-consultation and consultation during the CHD Review

²³ Source: NICOR

Programme in 2014/15

During consultation we spoke with both genders and received comments only in relation to pregnancy and maternity as already discussed within the paper.

5.8.3 Potential impact of the proposed changes

We do not anticipate that the proposed changes will differentially impact this pregnancy and maternity.

5.8.4 Proposed actions to mitigate the impact of the proposed changes

None

5.8.5 Implications for the 2016/17 consultation on the propose service change as part of the CHD Commissioning and Implementation Programme

None

5.9. Sexual orientation

5.9.1 Review of literature and data

We have not identified any specific evidence relating to sexual orientation and CHD.

5.9.2 What we heard during pre-consultation and consultation during the CHD Review Programme in 2014/15

Young people have told us that they would like more information about sex and relationships and this need to be away from parents – many teenagers are uncomfortable speaking about any of these things in front of their parents and some don't even like the idea of speaking with their regular doctors.

We did not hear specific concerns on sexual orientation during the consultation. However, we believe that the standards will have a positive impact on the experience and outcomes of children and adults with differing sexual orientation who have CHD.

5.9.3 Potential impact of the proposed changes

We do not anticipate that the proposed changes will have a differential impact depending on sexual orientation.

5.9.4 Proposed actions to mitigate the impact of the proposed changes

Our standards emphasise, in several places, the importance of open, honest communication in ways that are appropriate to the patient's needs.

5.9.5 Implications for the 2016/17 consultation on the propose service change as part of the CHD Commissioning and Implementation Programme

None

6. Implications of our work

Implications for our work has been included in discussion of each of the protected characteristic groups

6.1. Alcohol and / or drug misusers

One study found that rates of substance abuse among patients with CHD are either comparable or lower than comparable samples of similarly aged peers.²⁴

We do not believe that the proposed service change will have a differential impact on patients who are alcohol and/ or drug misusers.

6.2. Asylum seekers and /or refugees

We have not identified any specific evidence relating to asylum seekers and or refugees and CHD.

Access to healthcare, understanding of the English health system and communication difficulties and cultural differences may be relevant differences for asylum seekers and refugees but would not be specific to CHD services or the proposed changes.

We will ensure if the proposals are approved that enhanced communication and support is available for any patients and families with CHD who are refugees/asylum seekers.

6.3. Carers

6.3.1 Review of literature and data

It will be important to ensure that parents and carers of children and adults with CHD have access to the information and any psychological support they might need.

6.3.2 What we heard during pre-consultation and consultation during the CHD Review Programme in 2014/15

We heard how important it is for parents and carers to be supported, particularly when they are away from home. They told us about difficulties with finding their way round new hospitals, finding accommodation and eating balanced meals. They also told us about problems with car parking. These effects may be amplified if parents and carers have to travel to a new centre.

We also heard the importance of having support for end of life for both children and adults. This means having identified support structures that encourage and enable open and honest

²⁴ [Congenit Heart Dis.](#) 2008 Jan-Feb;3(1):16-25. doi: 10.1111/j.1747-0803.2007.00161.x.

communication with families and carers at that time.

We have developed specific standards on:

- facilities; and
- palliative care and bereavement
- networks and integration of care provision
- support groups.

The difficulties for carers were identified e.g. juggling family responsibilities while caring for an individual with CHD; being able to participate in the care of the individual while they are in hospital.

6.3.3 Potential impact of the proposed changes

We aim to understand the impact of the proposed changes on carers through the consultation process.

6.3.4 Proposed actions to mitigate the impact of the proposed changes

It has been proposed that level one centre(s) consider whether the number of hotel facilities available for carers reflects the volume of care they provide.

6.3.5 Implications for the 2016/17 consultation on the proposed service change as part of the CHD Commissioning and Implementation Programme

Consultation will seek views from families and carers as well as from people with CHD. The consultation questions include open ended questions where families and carers will have the opportunity to share their experiences and concerns. This may include families and carers who would have compounded impacts of the proposed service changes. This would include parents and carers with disabilities, from particular religious observations and some characteristics that are not protected but would bear considering, e.g. single carers, those on low income.

6.4. Ex-service personnel / veterans

We have not identified any specific evidence relating to ex-service personnel or veterans and CHD

6.5. Those who have experienced Female Genital Mutilation (FGM)

We have not identified any specific evidence relating to those who have experienced FGM and CHD.

6.6. Gypsies, Roma and travellers

We have not identified any specific evidence relating to Gypsies, Roma and travellers and CHD.

6.7. Homeless people and rough sleepers

We have not identified any specific evidence relating to homeless people and rough sleepers and CHD.

6.8. Those who have experienced human trafficking or modern slavery

We have not identified any specific evidence relating to those who have experienced human trafficking or modern slavery and CHD.

6.9. Those living with mental health issues

6.9.1 Review of literature and data

In addition to medical problems, people living longer with CHD face psychological, sociological and behaviour challenges²⁵. Since people with CHD are surviving longer into adulthood, the increasing population of adults with CHD also means there will be an increasing percentage of adult CHD patients that have mental health issues such as anxiety and depression.

Some studies show that female patients and patients with complex forms of CHD are more prone to worse psychological adjustment and to psychopathology. Patients with complex forms of CHD need regular care, which restricts social contact with peers and family and regular social integration. Furthermore, patients who had undergone surgery showed worse quality of life as they often have long hospital stays, during which social activities are restricted, making it more difficult for them to develop a good social support network²⁶.

Evidence highlights the importance of multi-disciplinary teams with specialised follow up to manage these complex patients²⁷. The multi-disciplinary team may include clinical psychologists or councillors to help patients living with CHD transition into adulthood. It is important to highlight the need for social support as it plays a crucial role in buffering stress and promoting patients' adjustment.

6.9.2 What we heard during pre-consultation and consultation during the CHD Review Programme in 2014/15

People with mental health conditions and CHD were not covered explicitly in the pre-consultation and consultation on the standards.

6.9.3 Potential impact of the proposed changes

We do not have any data to understand the percentage of people with mental health issues and CHD that would be impacted by the changes. However, we have heard during the 2016 preliminary stakeholder engagement that people with mental health issues may be differentially impacted by the proposed service changes. This will need further exploration to understand the specific impact during the consultation.

6.9.4 Proposed actions to mitigate the impact of the proposed changes

The consultation will help inform any proposed actions to mitigate the impact.

6.9.5 Implications for the 2016/17 consultation on the proposed service change as part of the

²⁵ [Int J Cardiol.](#) 2013 Dec 5;170 (1):49-53. doi: 10.1016/j.ijcard.2013.10.003. Epub 2013 Oct 11.

²⁶ *Revista Portuguesa de Cardiologia, Volume 32, Issue 9, September 2013, Pages 657-664*

²⁷ [Eur J Cardiothorac Surg.](#) 2009 Jul;36(1):105-11; discussion 111. doi: 10.1016/j.ejcts.2009.03.023. Epub 2009 May 12

CHD Commissioning and Implementation Programme

The consultation process should help us gather more information about the nature of the impact on people with mental health issues.

6.10. Sex workers

We have not identified any specific evidence relating sex workers and CHD

6.11. Trans people or other members of the non-binary community

We have not identified any specific evidence relating to Trans people or other members of the non-binary community and CHD

6.12. The overlapping impact on different groups who face health inequalities

6.12.1 Review of literature and data

A study in Sweden has found that deprived areas have higher rates of CHD by 23%²⁸. Level of deprivation may influence risk of CHD through a number of general mechanisms, including unfavourable health-related behaviours of women during pregnancy. However, the association did not seem to be independent of individual- and family-level characteristics.

We have not identified any specific literature around CHD and the compounded impact on carers or people from a disadvantaged social economic standing.

6.12.2 What we heard during pre-consultation and consultation on the standards

This was not covered in the pre-consultation and consultation on the standards.

6.12.3 Potential impact of the proposed changes

The proposed changes may have a compounded impact on several groups:

- carers of vulnerable people such as those with a learning disability or from BME groups;
- travel for people using wheelchairs or supportive aids can be more difficult; and
- carers of people from a disadvantaged social economic standing.

We have heard that carers might find the changes difficult as they will have to manage the impact on vulnerable people. We have heard the concern that some carers may not be willing to travel further to visit patients in hospital. This may lead to social isolation and make vulnerable people less likely to want to travel. Confounding factors such as poverty would also make travel more difficult.

The consultation process should help us gather more information about the overlapping impact of carers and social economic status on people with CHD.

6.12.4 Proposed actions to mitigate the impact of the proposed changes

²⁸ *Int J Behav Med.* 2016 February; 23(1): 112–120. doi:10.1007/s12529-015-9488-9
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4808140/pdf/nihms766685.pdf>

The consultation will help inform any proposed actions to mitigate the impact.

6.12.5 Implications for the 2016/17 consultation on the propose service change as part of the CHD Commissioning and Implementation Programme

The consultation process should help us gather more information about the nature of the impact on health inequalities.

7. Other groups that face health inequalities that we have identified.

Draft for consultation

7.1 Geographical variation

7.1.1 Review of literature and data

The analysis on geographical variation was structured to understand two factors: activity and time travelled to a different centre under the proposed new structure. To understand these factors we conducted the following analysis:

First, relative activity was calculated to understand the number of patients who would be impacted by the proposed service change.

- CHD-related episodes by area to understand whether there could be quality issues by geography;
- Mapping of relative activity by geography to determine relative activity in each area; and
- Modelling the estimated volume of CHD surgery per year moving to other providers if suggested services are suspended.

Second, to understand the time travelled by patients as a result of the new proposed catchment areas we calculated the time patients would have to travel as a result of the new catchments. This was done in two steps:

- Impact of the proposed service changes on provider catchment area
- Time travel analysis as a result of the proposed service change on surgical patients

We then used this information to understand the impact of the proposed changes on travel time.

Relative activity across the country

While not a protected characteristic, we have looked at CHD-related episodes (specialist inpatient activity) by area as percentage of total, and episodes per head of population (2013/4 HES data). This was done to test whether there could be geographic quality issues.

Table 9: Variation in CHD relative activity

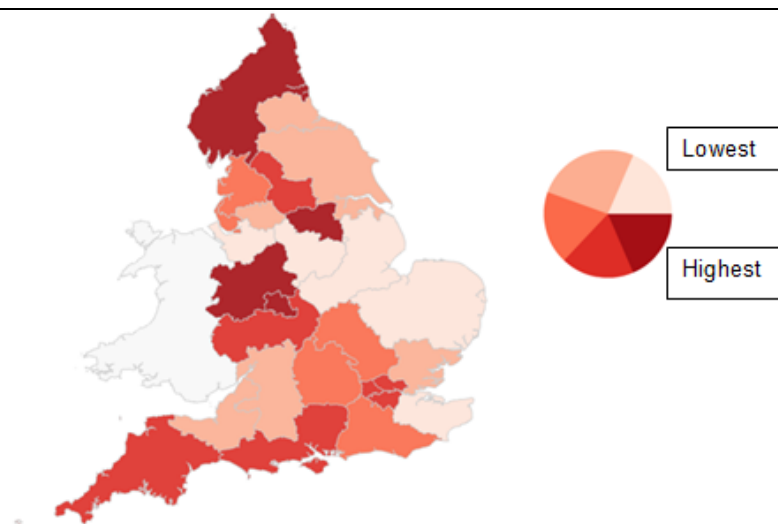
Area Team of patient residence	% of all specialist inpatient episodes	Specialist inpatient episodes per 100,000 (0-18) population	Specialist inpatient episodes per 100,000 (19+) population
Durham, Darlington and Tees	2%	58.3	4.2
Cumbria, Northumberland, Tyne and Wear	4%	69.9	4.4
Lancashire	3%	61.3	6.3
Greater Manchester	5%	57.0	5.5
Cheshire, Warrington and Wirral	2%	50.9	5.9
Merseyside	3%	59.0	11.5
West Yorkshire	5%	69.0	3.9
South Yorkshire and Bassetlaw	3%	73.4	5.0
North Yorkshire and Humber	2%	54.7	2.8
Leicestershire and Lincolnshire	3%	50.5	5.7
Hertfordshire and The South Midlands	5%	61.0	5.4
Derbyshire and Nottinghamshire	3%	52.2	4.3
Birmingham and The Black Country	6%	79.8	6.2
Shropshire and Staffordshire	3%	74.0	7.1
Arden, Herefordshire and Worcestershire	3%	66.0	3.5
East Anglia	4%	51.7	5.8
Essex	3%	58.5	5.2
London	17%	69.3	4.9
Kent and Medway	3%	45.2	4.7
Surrey and Sussex	5%	58.9	7.0
Thames Valley	4%	60.2	5.5
Wessex	5%	67.0	4.9
Bath, Gloucestershire, Swindon and Wiltshire	3%	57.4	8.0
Bristol, North Somerset, Somerset and South Gloucestershire	2%	54.8	5.7
Devon, Cornwall and Isles Of Scilly	3%	62.9	4.4

Note: includes all episodes with a procedure (excluding electrophysiology) in NHS England providers for all patients resident in England.

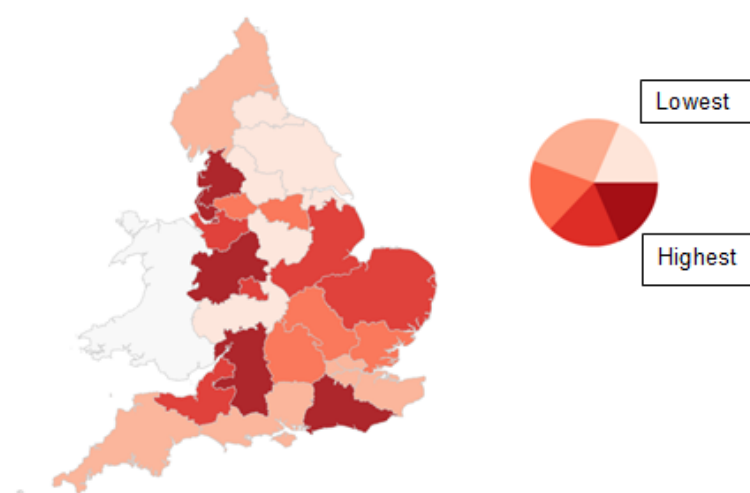
The HES data in table 9 indicates that there is considerable variation across the country in terms of relative activity. The episodes per 100,000 population (age 0-18) show some differences from Kent and Medway at 45.2 to Birmingham and the Black Country at 79.8. In the case of adult services, the episodes per 100,000 population show differences from North Yorkshire and Humber at 2.8 to Merseyside at 11.5.

This is demonstrated in the maps (image 1 and 2); the darker the colour the higher the relative activity in that area. The reasons for this variation are unclear.

Image 1: Paediatric specialist inpatient episodes per 100,000 population, by Area Team



ACHD (19+) 2013/14 HES specialist inpatient episodes per 100,000 population, by Area Team of patient residence (activity per head so controlled for different population sizes)



Impact of the proposed service changes on volumes of surgery

We have modelled two scenarios, one with 2013/14 NICOR data and one with 14/15 NICOR data to understand the potential volumes of CHD surgery moving to other providers if suggested services are suspended. This analysis will help build an understanding of the number of patients that would be impacted in each geography by the service change.

From the 2014/15 data we can predict that the following number of patients would be impacted by the changes to level one services:

- 142 adults and 370 children who previously received treatment at the Royal Brompton;
- 89 adults who previously received treatment at CMFT; and
- 26 adults and 230 children who previously received treatment at UHL.

Table 10: Estimated volumes of CHD surgery per year moving to other providers if suggested services are suspended (using 2013/14 NICOR data)

Receiving Trust	Patients/year From Royal Brom			Patients/Year From CMFT			Patients/year From UHL			Grand Total		
	Adult	Paeds	Total	Adult	Paeds	Total	Adult	Paeds	Total	Adult	Paeds	Total
ALDER HEY CHILDREN'S NHS FOUNDATION TRUST		1	1		-	-		8	8	-	9	9
BARTS HEALTH NHS FOUNDATION TRUST	77		77		-	-	1		1	78	-	78
BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST		5	5		-	-		174	174	-	179	179
GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST		228	228		-	-		4	4	-	232	232
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	30	173	203		-	-		4	4	30	177	207
LEEDS TEACHING HOSPITALS NHS TRUST	1	-	1	4	-	4	10	37	47	15	37	52
LIVERPOOL HEART AND CHEST NHS FOUNDATION TRUST	1		1	96	-	96	-		-	97	-	97
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST		-	-		-	-		-	-	-	-	-
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	6	11	17		-	-		1	1	6	12	18
UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST	2		2		-	-	49		49	51	-	51
UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST	3	2	5		-	-		2	2	3	4	7
Total	120	420	540	100	-	100	60	230	290	280	650	930

Data sources:

Volumes of Surgery : 1314 NICOR

Proportional use of centres : HES data 0607 to 1415

Table 11: Estimated volumes of CHD surgery per year moving to other providers if suggested services are suspended (using 2014/15 NICOR data)

Receiving Trust	Patients/year From Royal Brom			Patients/Year From CMFT			Patients/year From UHL			Grand Total		
	Adult	Paeds	Total	Adult	Paeds	Total	Adult	Paeds	Total	Adult	Paeds	Total
ALDER HEY CHILDREN'S NHS FOUNDATION TRUST		1	1		-	-		8	8	-	9	9
BARTS HEALTH NHS FOUNDATION TRUST	90		90		-	-	1		1	91	-	91
BIRMINGHAM CHILDREN'S HOSPITAL NHS FOUNDATION TRUST		4	4		-	-		174	174	-	178	178
GREAT ORMOND STREET HOSPITAL FOR CHILDREN NHS FOUNDATION TRUST		201	201		-	-		4	4	-	205	205
GUY'S AND ST THOMAS' NHS FOUNDATION TRUST	36	153	189		-	-	-	4	4	36	157	193
LEEDS TEACHING HOSPITALS NHS TRUST	1		1	4	-	4	8	37	45	13	37	50
LIVERPOOL HEART AND CHEST NHS FOUNDATION TRUST	1		1	85	-	85	-		-	86	-	86
THE NEWCASTLE UPON TYNE HOSPITALS NHS FOUNDATION TRUST		-	-		-	-		-	-	-	-	-
UNIVERSITY HOSPITAL SOUTHAMPTON NHS FOUNDATION TRUST	7	9	16		-	-		1	1	7	10	17
UNIVERSITY HOSPITALS BIRMINGHAM NHS FOUNDATION TRUST	3		3		-	-	37		37	40	-	40
UNIVERSITY HOSPITALS BRISTOL NHS FOUNDATION TRUST	4	2	6		-	-		2	2	4	4	8
Total	142	370	512	89	-	89	46	230	276	277	600	877

Data sources:

Volumes of Surgery : 1415 NICOR

Proportional use of centres : HES data 0607 to 1415

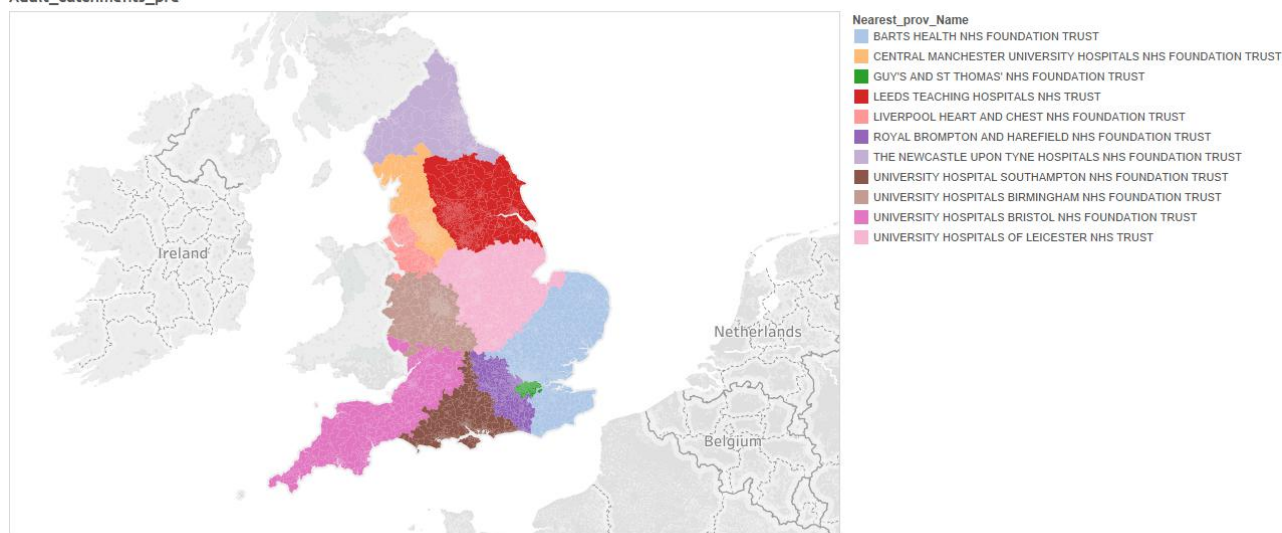
Impact of the proposed service changes on provider catchment area

The two maps (image 2 and 3) show the proposed catchment areas change for adult and paediatric CHD services. Both the adult and paediatric catchment areas have become larger as a result of the proposed service change.

Adult

Image 2: Adult catchments before the proposed service change

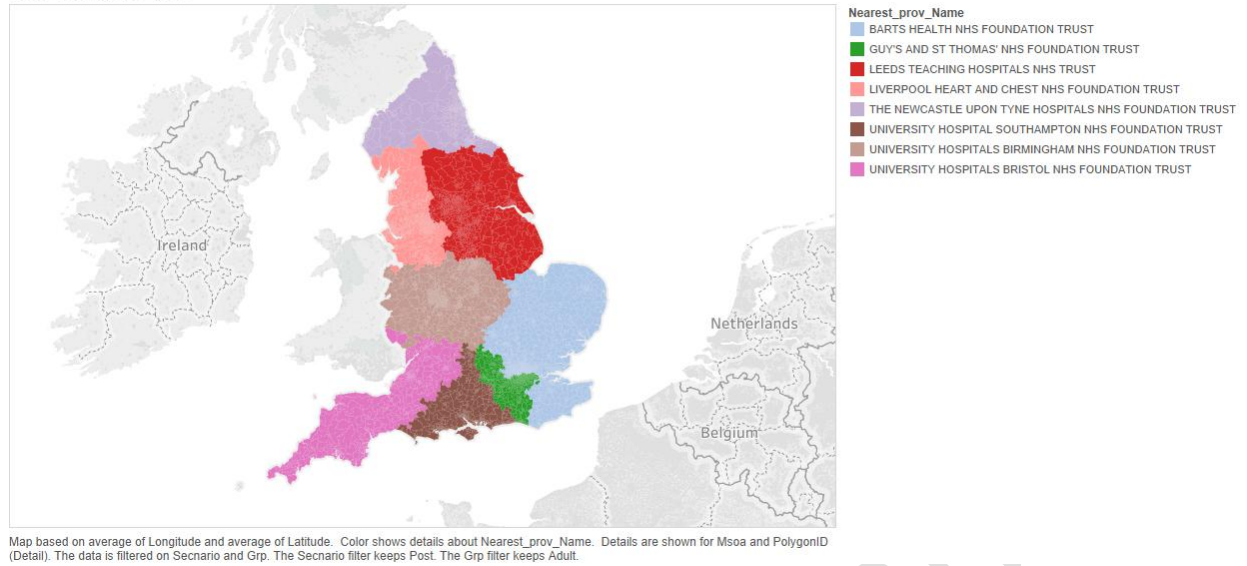
Adult_catchments_pre



Map based on average of Longitude and average of Latitude. Color shows details about Nearest_prov_Name. Details are shown for Msoa and PolygonID (Detail). The data is filtered on Scenario and Grp. The Scenario filter keeps Pre. The Grp filter keeps Adult.

Image 3: Adult catchments after the proposed service change

Adult_catchments_post



Paediatric

Image 4: Paediatric catchments before the proposed service change

Paeds_catchments_pre

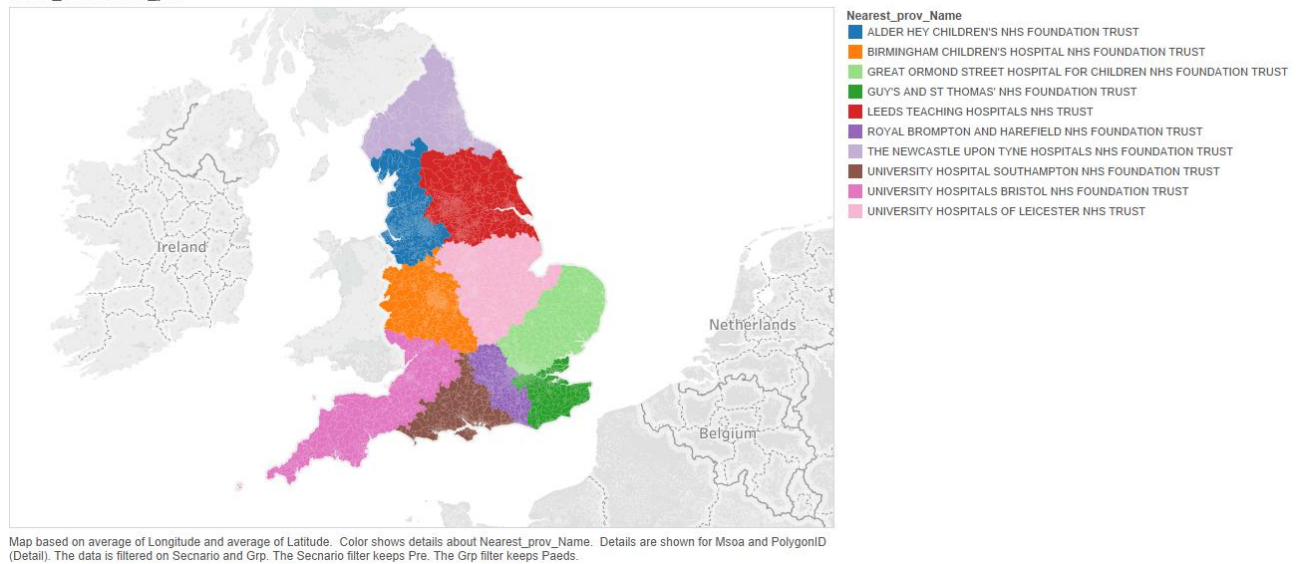
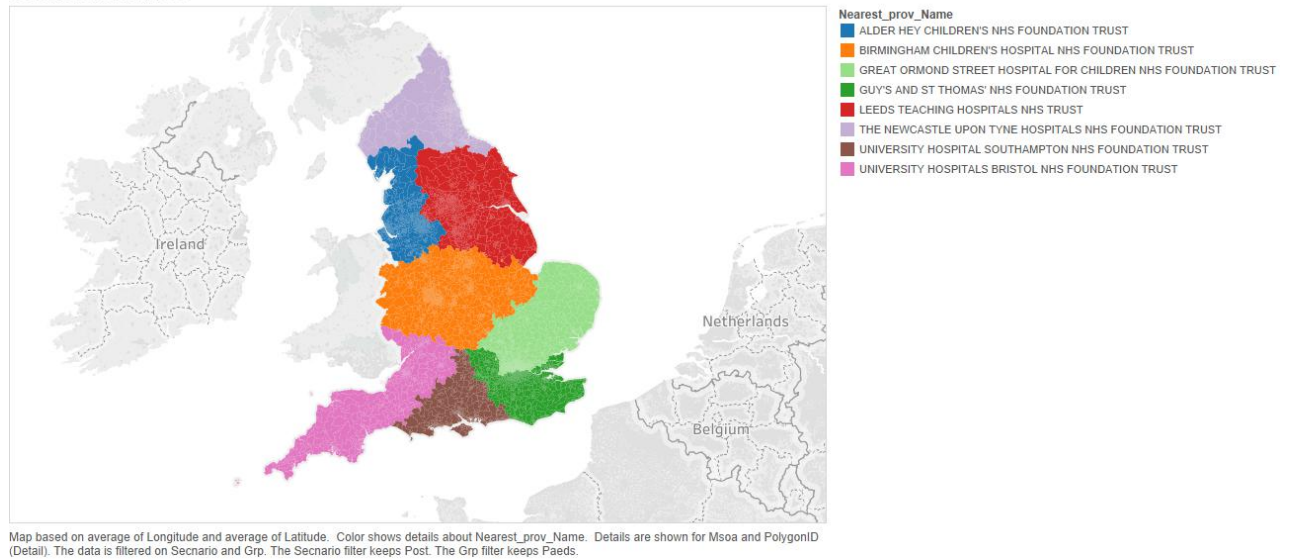


Image 5: Paediatric catchments after the proposed service change

Paeds_catchments_post



To understand the impact of the new catchment areas on patients we have conducted travel time analysis.

Time travel analysis as a result of the proposed service change on surgical patients

The table 12 and 13 show the median and maximum time travel before and after the proposed decommissioning. From the analysis it can be determined that while journey times will increase for some people when they need to attend their level 1 centres, especially for those living close to the hospitals whose services are changing. We expect the average change in travel times will not significantly increase as a result of new catchment areas, although a small number of patients will experience a significant increase. Our modelling suggests an average increase of:

- 14 minutes for children who use Leicester and 32 minutes for adults;
- 11 minutes for adults who use Manchester; and
- 2 minutes for children and a reduction in one minute for adults who use the Royal Brompton.

Table 12: Median and maximum travel times before decommissioning

Patients going to	Median Travel time	Max travel time for 90% of patients
CMFT Adults	00:29:05	00:59:19
Royal Brompton Adults	00:47:50	01:43:40
UHL Adults	00:41:10	01:18:28
Adults National pre decommissioning	00:41:18	01:25:55
Royal Brompton Paeds	00:43:00	01:37:19
UHL Paeds	00:45:40	01:54:46
Paeds National pre decommissioning	00:43:41	01:53:27

Table 13: Median and maximum travel times after decommissioning

Patients previously going to	Median Travel time	Max travel time for 90% of patients
CMFT Adults	00:40:06	01:04:18
Royal Brompton Adults	00:46:15	01:22:35
UHL Adults	01:13:18	01:44:19
Adults National post decommissioning	00:49:30	01:25:33
Royal Brompton Paeds	00:45:15	01:24:42
UHL Paeds	00:59:01	01:41:04
Paeds National post decommissioning	00:45:34	01:50:24

Note: The calculations in the table 'Before Decommissioning' are based on data which include a number of patients who travelled very long distances (from out of logical catchment) to the three centres. In the 'after decommissioning' data these have been redirected to their nearest provider. While patients previously very close to the decommissioned services would have to travel further to an alternative centre (and hence increase average travel times) mathematically the redirection of the patients travelling long distances reduces the estimated maximum travel time for 90%. These estimated reductions are marginal (22 seconds for adults and circa 3 minutes for paediatrics).

7.1.2 What we heard during pre-consultation and consultation during the CHD Review Programme in 2014/15

The evidence we have received in relation to geographical variation has been limited. Where geography has been raised it has been in relation to how services are delivered now and how they might be delivered in the future. The focus has been on whether existing units will meet the standards and what it means to staff and patients if not; and travel times now and in the future.

During consultation we heard that people were concerned that depending on where you live you may have a CHD service on your doorstep, or it could potentially be 2-3 hours' drive away. However we have also heard that the main impact of the changing centres is not the time travel, rather the aspect of change and patients and families having to adjust to travelling to new centres. This was discussed earlier under disability.

7.1.3 Potential impact of the proposed changes

We recognise that it is more difficult for families to support patients in hospital at some distance from home and that this is a common problem already. Based on the advice of patients and families, a number of standards were developed to make life easier in this situation.

NHS Choices has guidance on claiming or getting travel costs refunded under the Healthcare Travel Costs Scheme. This scheme can help with travel costs if three conditions are met: meeting the eligibility criteria of the NHS Low Income Scheme, having a referral from a health care professional, and the appointment is separate to when the referral was made. The schemes can apply to children, dependents and carers.

The scheme and conditions are explained in detail on the NHS Choices webpage:
<http://www.nhs.uk/nhsengland/healthcosts/pages/travelcosts.aspx>

7.1.4 Proposed actions to mitigate the impact of the proposed changes

To make this situation easier for patients, carers and families we have developed standards – for better information about where to park, eat and sleep; better facilities to prepare meals; providing Wi-Fi; ensuring parking charges are affordable; and providing overnight accommodation for parents and carers.

7.1.5 Implications for the 2016/17 consultation on the propose service change as part of the CHD Commissioning and Implementation Programme

The consultation will specifically ask about the impact of longer journeys and seek suggestions for dealing with any concerns.

Draft for consultation

PART C: Promoting integrated services and working with partners
Short explanatory notes: Integrated services and reducing health inequalities.
<p>8. How can this work increase integrated services and reduce health inequalities?</p> <p>We believe that implementing the standards will have a positive impact on the experience and outcomes of all children, young people and adults with CHD. We have given full consideration to the health outcomes, experiences and access to health care services to different population groups. All of which has been evidenced previously in this document.</p> <p>For the first time services will be nationally commissioned and regionally delivered using common service specifications across all ages. As the sole National Commissioner, NHS England will need to ensure monitoring of the duty as part of contract management with service providers.</p> <p>The first set of standards - category A – The Network Approach, will help to integrate CHD services. We are proposing that across the country services should be organised according to a three tier model (level 1, 2 and 3), with clear roles and responsibilities for each tier. Networks will help local services to work closely with specialist centres, to ensure that patients receive the care they need in a setting with the right skills and facilities, as close to home as possible</p>
PART D: Engagement and involvement
<p>9. Engagement and involvement activities already undertaken.</p> <p>A three month consultation on the proposed standards and specifications for CHD services for children and adults ran until the 8th December 2014 (there was already a set of standards and a service specification in place for children's services but standards only existed in draft form for adults).</p> <p>The consultation was an open process, enabling groups, organisations and individuals to respond. Information captured was reviewed on an individual basis, enabling all information to be captured and thereby avoiding the creation of a voting process on what the majority said.</p> <p>The review team visited twelve locations across the country, to provide information through a variety of media forms and enable people to discuss face-to-face their concerns, worries or queries.</p> <p>People were able to fill in their responses on-line, by post and could seek help in completion of a response if required. Translated material was available, with further translations available on request. This included 'easy' read to support those who may have disabilities and for those that wanted a version that was easy to read, providing the essentials of the consultation material. This version was tested with appropriate charities and support groups.</p> <p>Support in ensuring widespread communication of the consultation was sought by the review team from groups who had mechanisms already established to reach those groups classed as 'hard to reach'.</p> <p>The communication and engagement report contains further detail on consultation and the independent report on consultation prepared by 'Dialogue by Design' provides further information on the numbers of responses, the type of response and their origin.</p> <p>The proposed standards were central to our engagement and involvement work from the outset and informed the development of the draft service specifications. We sought to address any gaps in evidence across all protected characteristics during the engagement process of</p>

developing these standards, testing all our work, with experts and service users (particularly through our engagement and advisory groups - clinicians, patients and the public and provider and organisation representatives).

As well as regular meetings of formal engagement and advisory groups, we have visited all the specialist units; these visits were led by Professor Deirdre Kelly, previously Chair of the Clinician Group. During these visits, members of the new CHD review team had an opportunity to speak to clinical staff, patients and their families and carers. Nine dedicated events for children and young people were held around the country.

The CHD Commissioning and Implementation Programme continues to adopt an approach of openness and transparency and all the previous CHD review programme papers are published on the NHS England Congenital Heart Disease Review website and included within John Holden's blog.

The CHD Commissioning and Implementation updates are now provided through Will Huxter's blog.

10. Which stakeholders and equalities and health inclusion groups were involved?

During 2015, we worked with a wide range of stakeholders to develop the proposed standards. These included:

- children and young people with CHD along with their families and carers;
- adults with CHD and their families and carers;
- groups representing people with CHD;
- clinicians and other members of the multidisciplinary team;
- providers; and
- local authorities and Healthwatch.

During the proposed December 2016 to March 2017 consultation we will focus on patients that are residents in England. Whilst we recognise that there are patients living in Wales, Scotland and Northern Ireland who use CHD services in England, we have agreed with colleagues in other countries that they will make people aware of the consultation. We will welcome all responses. We have specifically designed questions to understand the impact of the proposed changes on vulnerable groups or people with protected characteristics.

11. Key information from the engagement and involvement activities undertaken.

During the 2015 pre-consultation we gathered evidence from stakeholders on:

- the network approach;
- level two specialist cardiology centres;
- level three local cardiology centres and local hospitals;
- staffing and skills;
- facilities;
- interdependencies;
- training and education;
- organisation, governance and audit;
- research;
- transition;
- pregnancy and contraception;
- fetal diagnosis;
- palliative care and bereavement;

- dental; and
- any other issues.

A full report detailing the information gathered at these events and concerns expressed by stakeholders is available on the NHS England (<https://www.england.nhs.uk/wp-content/uploads/2014/07/chd-cap-6.pdf>). Stakeholders were broadly supportive on the new standards and service specifications as they will increase the quality of care within the available resources.

12. Stakeholders were not broadly supportive but we need to go ahead.

N/A

13. Further engagement and involvement activities planned.

Another round of consultation will potentially start during the week of 12 December 2016 and run for 14 weeks, with additional time added in recognition of Christmas and New Year holidays; and therefore ending 19 March, 2017.

The purpose of the consultation is to understand the various perspectives on the changes to level one services that were set out in the July announcement. These changes will be set in the context of NHS England's whole programme of work in this field.

The consultation document will provide a rationale for the proposal in respect of each centre, summarising the case for change and pointing to the more detailed analysis where relevant. The rationale will include:

- Impact on service quality
- Impact on patients, including transport
- Transition plans
- Impact on health inequalities
- Impact on groups sharing a protected characteristic
- Impact on patient choice
- Cost implications

In the proposed consultation December 2016 to March 2017 we seek to understand the impact of the proposals on each local health economy. This includes the proposal to cease commissioning some level one and level two centres as indicated previously. During the consultation we will be keen to understand:

- whether patients support the proposals that every patient is able to receive a service that is able to meet the standards;
- whether patients support the proposed new commissioning models;
- whether patients agree that the implementation of the service will reduce health inequalities;
- whether patients think implementation of the proposal would have an impact on any group sharing a protected characteristic that has not already been considered;
- whether the proposals relating to paediatric services will safeguard and promote the welfare of children;
- whether the proposals promote and safeguard the welfare of children;
- whether patients have any suggestions for dealing with concerns; and
- and whether there are any suggestions that would help us make sure that the proposed changes are agreed happen as smoothly as possible for patients and their families.

Question time events

In the three cities where most change is proposed an event will be organised following the 'Question Time' format with an independent facilitator. Questions should be pre-submitted to the facilitator. The events should be ticketed to ensure that the size of audience can be matched to the capacity of the venue, with free registration taking place on the NHS England events system. For these to be successful we will need to work closely with campaigners, charities, providers and democratically elected representatives to ensure a representative panel and audience. It will also be important to ensure that all parties work together to ensure that large numbers of people without tickets do not attend.

WebEx Seminars

Web enabled seminars will be offered and provide an important tool in reaching targeted audiences.

Targeted engagement

Targeted engagement will be used to elicit the views of groups known to be more affected by CHD including people with learning disabilities and their families and carers; people of Asian origin (this work would be inclusive of people for whom English was not their first language); children and young people. We will work with relevant charities and support groups in undertaking this engagement, and where necessary engage specialist agencies to undertake work on our behalf.

PART E: Monitoring and Evaluation

14. In relation to equalities and reducing health inequalities, please summarise the most important monitoring and evaluation activities undertaken in relation to this work

Stakeholder Engagement

Evidence to support the review of CHD services has come from a range of sources. Key sources of evidence for the review in general, and the standards in particular, have been advised from:

- patients;
- clinicians;
- provider leaders;
- academics and other experts; and
- the wider public through correspondence and responses to our blog.

During 2014/15 we gathered evidence from:

- our patients and public, providers' and clinicians' engagement and advisory groups;
- the groups that have developed the CHD standards;
- the Clinical Advisory Panel;
- a formal review of academic literature undertaken by ScHARR (see below);
- visits to 13 Trusts with specialist CHD units where we had the opportunity to meet staff and patients;
- nine meetings across England with children and young people;
- twelve consultation events;
- consultation responses.

An independent report was commissioned by NHS England and written by Dialogue by Design

entitled 'Consultation on draft standards and service specifications for congenital heart disease services' published on the 2nd March 2015.

This enabled us to understand and take account of the views of a much wider range of stakeholders.

Furthermore, the CHD team is proposing to conduct another round of engagement from December 2016 to March 2017 to understand the patient perspective on the proposed service change.

Literature Review

A report that summarises some of the evidence is available at on the NHS England (<https://www.england.nhs.uk/wp-content/uploads/2014/07/chd-cap-6.pdf>). This paper summarises views expressed during the 2014/15 pre-consultation period. In particular it reflects views from the CHD review's children and young people events, visits to CHD services across England and Wales, discussions with the CHD review's three engagement and advisory groups and discussions at the CHD Clinical Reference Group.

In 2014/15, to inform our thinking on standards and the other objectives of the CHD Review Programme, we put in place other pieces of work to gather evidence. This has been done in parallel with the work of the review's lead analyst who has been progressing work on Objective 2 (including interrogating Hospital Episodes Statistics (HES) data).

We also commissioned a systematic literature review; and asked the National Institute for Cardiovascular Outcomes Research (NICOR) to investigate their data.

The independent systematic literature review, undertaken by The University of Sheffield, School of Health and Related Research (SchARR) on our behalf, aimed to understand how organisational factors may affect patient outcomes focusing on:

- What is the current evidence for the relationship between institutional and surgeon volume and patient outcomes, and how is the relationship influenced by complexity of procedure and by patient case mix?
- How are patient outcomes influenced by proximity to/co-location with other specialist clinical services (e.g. co-location of services such as specialist paediatric intensive care)?

During the 2016 refresh of the equality impact assessment new research was conducted on the protected characteristics to understand if new studies have been conducted. During this process, our thinking was tested with a few key stakeholders, prior to wider consultation. The data collected from consultation will be analysed by an independent firm experienced in the analysis of consultation.

Data analysis

The National Institute for Cardiovascular Outcomes Research (NICOR) was asked to examine its data and to advise on what this showed about service factors that could influence outcomes. NICOR ran the Congenital Heart Disease Audit using patient information collected by the Central Cardiac Audit Database (CCAD). We asked them to consider whether the information collected could be used to further understand the relationship between certain organisational or patient factors and patient outcomes. NICOR have helped us understand better the association between 30-day mortality rates in relation to ethnicity and social deprivation.

Further data analysis has been conducted to understand the projected impact of ceasing to commission some level one and level two centres. This work has been summarised in the section B and C.

15. Please identify the main data sets and sources that you have drawn on in relation to this work. Which key reports or data sets have you drawn on?

Covered in the section 16

16. Important equalities or health inequalities data gaps or gaps in relation to evaluation.

In relation to this work have you identified any:

- important equalities or health inequalities data gaps or
- gaps in relation to monitoring and evaluation?

Yes

No

No – we will explore some factors in more details such as travel that may have an impact on inequalities.

17. Planned action to address important equalities or health inequalities data gaps or gaps in relation to evaluation.

We have taken action to ensure that the consultation process is accessible to as many people as possible and has a wide reach. We have done this through the following steps:

- Consultation document is available through the consultation hub website.
- Hard copies of the documents will be distributed to charities and patient support groups.
- The consultation documents will be emailed to all stakeholders and available at all events.
- Translated versions of the consultation document and other materials will be made available on request.
- An easy read version of consultation document will be available. While principally developed to support the participation of people with learning disabilities this version may also be helpful for younger children and for people for whom English is not their first language.
- Foreign language summary of consultation proposals have been translated into most common non-English languages and Welsh.
- Video summary of consultation proposals is available via the consultation hub website and will be shown at events.
- Talking head videos support key aspects of the proposals and the standards underpinning them. These will be available through the consultation hub website and

will be shown at events.

- The standards available on NHS England website.
- A report of national panel and detailed centre reports will also be available on NHS England website.

Throughout the CHD Review Programme in 2014/15 we heard that work is needed to develop the information provided to both patients and commissioners about the performance of congenital heart disease services. The primary outcome measure used to monitor congenital heart services is 30 day postoperative mortality measured over a three year rolling period. As survival rates improve there is a need to develop other quality measures and pay more attention to adult congenital heart services. The CHD team has recommended the following actions to improve the quality of data.

Adult data recommendations

- NICOR to publish a non-risk adjusted report on whole centre adult mortality alongside their paediatric mortality reports
- NICOR to begin developing case mix adjusted reporting on the outcomes of adult interventions

Process recommendations

- NICOR to implement a web based system for providers to submit their data
- NICOR to provide written guidance to providers to include information on responsibilities, data submission, reporting and what will happen if alert/warning limits are breached
- Health Quality Improvement Partnerships to update their policy on the detection and management of outliers to include a step to inform the Accountable Commissioner for the Congenital Heart Services Clinical Reference Group (CHS CRG) and the HQIP contract manager of any outliers
- NHS England to develop a consistent process for responding to any outliers

Communication of information recommendations

- NICOR to produce their annual report on paediatric and adult mortality within six months of the end of the year it has reported
- NICOR to report both paediatric and adult risk adjusted mortality on a quarterly basis
- NICOR to improve the design and publication of audit data, with specific targeted communication for; Patients/Public, Providers (Clinical Teams/Units), Commissioners and Trust Boards. This will also include the establishment of a communication strategy for informing stakeholders when reports have been published
- The Clinical Operational Research Unit (CORU) to complete its project to develop, test, and disseminate online resources for families and carers affected by congenital heart disease in children, the public and the media to facilitate appropriate interpretation of published mortality data following paediatric cardiac surgery
- The CHS CRG to review the outcome of the CORU project looking at disseminating online resources to determine if it provides any learning regarding how to better communicate information on congenital heart disease outcomes

Expanded mortality data

- NICOR to report on 90 day mortality alongside 30 day mortality
- NICOR to review the 56 procedures against which mortality information is provided to ensure as many as possible are included within this list
- NICOR to report outcomes by diagnosis as well as procedure
- The CHS CRG information sub-group to add measures to the dashboard relating to out of hospital mortality for high risk procedures
- The CHS CRG to review the outcome of the CORU project looking at long term

outcomes to determine if it provides any learning regarding how to report on longer term outcomes by diagnosis.

Quality

- To improve the information on quality of care, NHS England has established the Transition Dashboard and the Quality Dashboards across congenital heart services.
- Public Health England has also established the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) which started having national coverage in April 2016. This will include all patients diagnosed with congenital heart disease and may provide a useful way of recording any presenting information on long term quality of care.

Morbidities

- The CHS CRG information sub-group will develop a meaningful way of reporting surgical complications via the Quality Dashboard.
- Information will be collected and analysed on ten morbidities. These have been agreed by a panel of clinicians and patient representatives to establish whether or not these provide useful and comparable information. Upon completion of the projects the CHS CRG will review the findings to determine whether these indicators should be reported on nationally by the Quality Dashboard or NCHDA.

Long term outcomes

- The Clinical Operational Research Unit is looking at long term outcomes, this and developing metrics relating to monitoring them. This information should enable patients to better understand the long term impacts of specific conditions and reveal variation in long term outcomes.

Service measures

- NICOR has also been commissioned to identify a small number of Clinical Service Quality Measures (CSQMs) for congenital heart disease which can be used by commissioners and patients to provide a high level view of areas of concern at any of the specialist centres

Dashboards

- NHS England has commissioned the development of a portal which will enable NHS staff to access the dashboard information and submit data to it. Following this a Quality Surveillance Portal will be established as a public facing portal where dashboard information can be viewed by members of the public

Patient Experience

- Metrics which report on patients' experience of care are seen as an important marker of the quality of the service and help to establish that the patient is at the centre not just of the care they receive but of the way the quality of their care is measured
- The expansion of patient centred outcome measures (PCOMS) may provide congenital heart disease with an opportunity to collect information on patient outcomes in a different way.
- Procure a service to develop paediatric PREMS surveys, validate the existing adult survey, create a web based portal for completing the surveys and provide ongoing analysis to centres of the results of these surveys. Explore whether the PREMS survey will capture information about protected characteristics.

PART F: Summary analysis and recommended action		
18. Contributing to the first PSED equality aim.		
Can this work contribute to eliminating discrimination, harassment or victimisation?		
Yes	No	Do not know
If yes please explain how, in a few short sentences		
The standards state that providers should ensure that facilities meet the appropriate requirements of the Equality Act 2010.		
19. Contributing to the second PSED equality aim.		
Can this policy or piece of work contribute to advancing equality of opportunity? Please circle as appropriate.		
Yes	No	Do not know
If yes please explain how, in a few short sentences		
<p>All groups should benefit since the standards state that the Networks should form seamless pathways of care for patients. It is expected that the networks will work in a coordinated manner to ensure equality and standardisation of care throughout the NHS, eliminating regional variation that might have an indirect negative effect on equality and opportunity.</p> <p>The standards should also ensure a better and more consistent service for people with CHD, hence improvement in their health and wellbeing. This also means they can participate more in public life and therefore the standards could have a secondary impact of advancing equality of opportunity.</p>		
20. Contributing to the third PSED equality aim.		
Can this policy or piece of work contribute to fostering good relations between groups? Please circle as appropriate.		
Yes	No	Do not know
If yes please explain how, in a few short sentences		
This work can contribute to fostering good relationship between groups through the network model. Good communication is encouraged through the standards and will be important in providing a good service in the network model.		
21. Contributing to reducing inequalities in access to health services.		
Can this policy or piece of work contribute to reducing inequalities in access to health services?		
Yes	No	Do not know
If yes which groups should benefit and how and/or might any group lose out?		

<p>All groups should benefit since that the Networks should form seamless pathways of care for patients. There will be regular collaboration to ensure equality and consistency of care throughout the health service. Furthermore, it is expected that the networks will work in a coordinated manner to ensure equality and standardisation of care throughout the NHS.</p>				
<p>22. Contributing to reducing inequalities in health outcomes.</p> <p>Can this work contribute to reducing inequalities in health outcomes?</p>				
Yes		No		Do not know
<p>If yes which groups should benefit and how and/or might any group lose out?</p>				
<p>All groups should benefit since the standards state that the Networks should form seamless pathways of care for patients separate Congenital Heart Networks will not work independently of each other. There will be regular collaboration to ensure equality of care throughout the health service. Furthermore, it is expected that the networks will work in a coordinated manner to ensure equality and standardisation of care throughout the NHS.</p>				
<p>23. Contributing to the PSED and reducing health inequalities.</p> <p>How will the policy or piece of work contribute to the achieving the PSED and reducing health inequalities in access and outcomes? Please describe below in a few short sentences.</p>				
<p>Implementation of the standards and service specifications by all providers is expected to contribute to improvements in health inequalities and public health outcomes. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.</p>				
<p>24. Agreed or recommended actions.</p> <p>What actions are proposed to address any key concerns identified in this Equality and Health Inequalities Analysis (EHIA) and / or to ensure that the work contributes to the reducing unlawful discrimination / acts, advancing equality of opportunity, fostering good relations and / or reducing health inequalities? Is there a need to review the EHI analysis at a later stage?</p>				
<p>The consultation will provide qualitative information on the impact of the proposed standards and any concerns relating to the equality and health inequalities. This will be taken into account by the NHS England board in reaching its final decisions.</p>				
Action	Public Sector Equality Duty	Health Inequality	By when	By whom
PART G: Record keeping				
25.1. Date draft circulated to E&HIU:	25/10/2016			
25.1. Date draft EHIA completed:	28/10/2016			
25.2: Date final EHIA produced:	04/01/17			
25.3. Date signed off by Director:				

25.4: Date EHIA published:		
25.5: Review date:		
26. Details of the person completing this EHIA		
Name	Post held	E-mail address
Sophie Solti	Senior Policy Manager	Sophie.solti@nhs.net
27: Name of the responsible Director		
Name:	Directorate:	
Michael Wilson	Specialised Commissioning	

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NHS England Congenital Heart Disease Provider Impact Assessment



NHS England Congenital Heart Disease Provider Impact Assessment

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1 Introduction

1. In July 2015, NHS England Board agreed the proposed CHD standards and service specifications relating to three levels of CHD service provision that had been collaboratively developed with and agreed by all stakeholders. A 'go-live' date for commissioning of the standards and the service specification was agreed for April 2016.
2. Starting in April 2015 NHS England supported an initial provider-led process to consider how they might work together in order to meet the standards. On 9 October 2015 submissions from networks were received by NHS England and assessed. Overall it was considered that this work had not produced an acceptable solution, in the best interests of patients, and nor was it likely to do so even if the providers were given more time. NHS England concluded that developing a nationally coherent delivery model would require it to provide significant support and direction¹.
3. Between January and April 2016 existing providers of CHD services were assessed against key selected standards by a national commissioner led panel with clinician and patient/public representation. The panel's role was to assess each hospital's ability to meet the selected standards, based on the evidence submitted by the Trust. The panel was not responsible for deciding what action to take as a result of that assessment. That responsibility sits with NHS England as the single national commissioner of CHD services.
4. This assessment² demonstrated that some providers met most of the standards and were likely to be able to meet the remainder by April 2017, and that others should be able to meet the requirements with further development of their plans. NHS England has since been working with those providers as they progress towards full compliance. Other hospitals were not meeting or likely to meet all of the relevant standards within the required timescales. Some presented a clinical and governance risk. Since then, we have been working with them to look for ways to bring them into full compliance. This has not (so far) been possible. The panel's assessment was considered by NHS England's Specialised Services Commissioning Committee (SSCC), at the end of June 2016. SSCC recognised that the status quo could not continue and that NHS England needed to ensure that patients, wherever they lived in the country, had access to safe, stable, high quality services. SSCC also recognised that achieving this within the current arrangement of services would be problematic.

¹ The full report of this work is available here: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/chd/quick-links/>

² The full report of this assessment is available here: <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/chd/>

5. SSCC determined that, subject to appropriate public involvement and/or consultation, a change in service provision was appropriate. As a result it was proposed that in future NHS England would only commission CHD services from hospitals that are able to meet the standards within the required timeframes.
6. As a result proposals for service change were announced on 8 July 2016. Subject to public consultation, if implemented, our proposals would mean that in future CHD level 1 (surgical) services in England would 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)
 - **Birmingham 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)
 - **Leeds Teaching Hospitals NHS Trust** (children's and adult services)
 - **Newcastle Hospitals NHS Foundation Trust** (children's and adult services)
 - **University Hospitals Bristol NHS Foundation Trust** (children's and adult services)
 - **University Hospital Southampton NHS Foundation Trust** (children's and adult services)
7. If implemented, our proposals would result in the following changes at hospitals that currently provide level 1 (surgical) CHD services:
 - Surgery and interventional cardiology for adults should cease at **Central Manchester University Hospitals NHS Foundation Trust (CMFT)**. CMFT does not undertake surgery in children.
 - Surgery and interventional cardiology for children and adults should cease at **Royal Brompton & Harefield NHS Foundation Trust**.
 - Surgery and interventional cardiology for children and adults should cease at **University Hospitals of Leicester NHS Trust**.
8. Changes are also proposed to the provision of level 2 specialist medical CHD care. While not the subject of the forthcoming consultation they will be

described in our consultation materials and stakeholders invited to provide us with their views. We will also be conducting specific further engagement with patients and others who would be affected by implementation of the proposals

9. If implemented, our proposals would mean that in future level 2 (specialist medical) CHD services in England would be provided by the following hospitals:
 - **Brighton and Sussex University Hospitals NHS Trust** (adult service)
 - **Central Manchester University Hospitals NHS Foundation Trust** (children's services)
 - **Norfolk & Norwich University Hospitals NHS Foundation Trust** (adult service)
 - **Oxford University Hospitals NHS Foundation Trust** (children's and adult services)
10. NHS England is exploring the potential for the provision of level 2 medical services at hospitals where level 1 care would cease. We are interested in the degree of support for this approach and will test this as part of the consultation. This possibility relates to:
 - **Central Manchester University Hospitals NHS Foundation Trust** (adult service)
 - **Royal Brompton & Harefield NHS Foundation Trust** (adult service)
 - **University Hospitals of Leicester NHS Trust** (children's and adult services)
11. NHS England has also raised with the Royal Brompton the potential for it to continue to provide level 1 adult CHD services, including surgery, by partnering with another level 1 CHD centre in London that is able to provide care for children and young people with CHD that meets the required standards. . To date, the Royal Brompton Hospital has indicated that it does not support this approach, but it has not said that they would refuse to treat adults alone. NHS England believes that it has sufficient merits to be explored further. The Royal Brompton is also exploring with partners ways in which it could achieve compliance with the standard for paediatric co-location, but to date no plan and timetable for this to be achieved have been shared with NHS England.
12. If implemented, our proposals would result in the following changes at hospitals that currently provide level 2 specialist medical CHD care (subject to further local engagement as appropriate).
 - Specialist medical care and interventional cardiology would cease at **Blackpool Teaching Hospitals NHS Foundation Trust**
 - Specialist medical care and interventional cardiology would cease at **Imperial College Healthcare NHS Trust**

- Specialist medical care and interventional cardiology would cease at **Nottingham University Hospitals NHS Trust**
 - Specialist medical care and interventional cardiology would cease at **Papworth Hospital NHS Foundation Trust**
 - Specialist medical care and interventional cardiology would cease at **University Hospital of South Manchester NHS Foundation Trust**
13. NHS England is continuing discussions with Papworth Hospital NHS Foundation Trust about its plans to meet the requirements to continue to provide specialist medical care and interventional cardiology. If the Trust can demonstrate that it now either meets the standards or has a robust plan to do so, NHS England will review its proposal that L2 CHD services should cease to be provided.

2 Part One: The impact assessment

14. NHS England has undertaken a detailed impact assessment considering the impact on patients and their families, on CHD services and other clinical services, on provider organisations including financial implications. This paper reports NHS England's assessment of the impact on providers of CHD services as at January 2017.
15. All level 1 and level 2 CHD providers were asked to review their services in light of NHS England's proposals.
16. The data received was considered first by specialised commissioning teams from the relevant NHS England region during the period 10-15 November 2016. This allowed for a review of both sets of data and for consideration of any wider regional implications.
17. The impacts were then considered by a national panel drawn together to review the submissions, to moderate the regional assessments and to take a national overview. The national panel met on 18 November 2016. A separate report from the panel has been published alongside this NHS England report.
18. The panel's role was to assess the likely impact of NHS England's proposals on each hospital and its services. The panel was not responsible for deciding what action to take as a result of that assessment. That responsibility sits with NHS England as the single national commissioner of CHD services.
19. Since the panel completed its assessment, NHS England has continued to maintain a dialogue with the affected hospitals as a result of which new or revised information has been provided and further analyses undertaken.
20. This report takes account of the panel's assessment and recommendations as well as NHS England's subsequent work. It reports NHS England's pre-

consultation assessment of the impact of its proposals on provider organisations. It should be read in conjunction with the national panel report.

2.1 The impact at centres which, under the proposals, would not continue to be commissioned as Level 1 CHD centres

2.1.1 Royal Brompton

21. Under the proposals the Royal Brompton would no longer perform surgical or interventional cardiology on people with CHD. The panel considered that the scale of this change was especially significant to the Royal Brompton's provision of paediatric services but the impact on the organisation and on patients could be reduced if it provided adult only level 1 services.

2.1.1.1 Impact on other services: Paediatric Intensive Care and Extracorporeal Membrane Oxygenation (ECMO)

22. The Royal Brompton's PICU is largely dependent on their paediatric CHD service, because CHD accounts for 86% of the admissions. The Trust considers that its PICU would no longer be viable if the proposals are implemented, because paediatric cardiac patients are a large proportion of its work and it would not have enough other patients to stay open. The national panel accepted that this was an accurate assessment. If the PICU at the Royal Brompton were to close, this would be expected to have an effect on their paediatric respiratory services, the only other clinical service for children offered by the Trust. NHS England accepts the panel's view.
23. The Royal Brompton provides cardiac ECMO for children and cardiac and respiratory ECMO for adults. If our proposals were to be implemented, Royal Brompton would no longer be able to provide cardiac ECMO for children. This would affect around 15 children a year. It would no longer provide cardiac ECMO for adults with CHD. Adult respiratory ECMO provision at the Royal Brompton is the subject of a separate current procurement being undertaken by NHS England.
24. There are close links between paediatric cardiac services and PIC and children's ECMO services. As a result, our proposals will have an impact on both. The effects, both on paediatric cardiac patients, and any wider impact on PIC and ECMO services nationally, can be managed, as described below, and should not preclude NHS England proceeding to consult on its proposals.

2.1.1.2 Impact on other services: Specialist paediatric respiratory services

25. The particular circumstances at the Royal Brompton where paediatric cardiac and paediatric respiratory are the only children's services offered mean that our

proposals will have an impact on their paediatric respiratory service because of the effect on their PICU.

26. The national panel considered that there would be an impact on paediatric respiratory services, if paediatric cardiac services and PICU were no longer provided by the Royal Brompton. NHS England's work focusses on congenital heart disease and has not examined paediatric respiratory services. The membership of the panel reflected that focus. Given this, it would not have been appropriate for the panel to undertake detailed assessment of this impact.
27. If a decision is taken that results in PICU closure at the Royal Brompton, NHS England will work with the Trust to manage the impact on paediatric respiratory services. This could require a local service change process with further public engagement, potentially including full public consultation. There are alternative providers of specialist paediatric respiratory services in London. This should not preclude NHS England proceeding to consult on its proposals.

2.1.1.3 Impact on finances

28. The overall contract value for specialised services at Royal Brompton is approximately £226m. NHS England estimates that the financial effect of the proposed changes would be around £35m excluding the impact on paediatric respiratory services. The Trust's estimate of a £47m loss in income when paediatric respiratory services are taken into account appears to be broadly in line with NHS England's own estimate. The Trust estimates that the loss resulting from these proposals would be approximately 13% of the Trust's total income and 21% of its total specialised services income, which represents a significant financial and business challenge. The scale of loss reflects the impact on PICU and the potential impact on paediatric respiratory services.
29. The loss of income to the Trust would, to some extent, be offset by a reduction in costs. The Trust stated that owing to the stranded costs associated with this service they estimate an adverse impact of over £7m per year to the Trust's bottom line if these proposals are implemented. Data supplied by the Royal Brompton indicates that its provision of CHD services results in an overall net loss, and therefore although the loss of income is significant it may be that, depending on the stranded costs, in the long term no longer providing these services is in the best financial interest of the Trust.
30. The financial impact of the changes could be reduced if the Royal Brompton provided level 1 adult services.
31. We note that Royal Brompton is an active partner in the North West London Sustainability and Transformation Planning process and has identified a number of potential areas for partnership working which could potentially contribute to the mitigation of any financial losses if our proposals are implemented.

32. While there would be an impact on the income of The Royal Brompton, this could be partially offset by other forms of service provision. This should not preclude NHS England proceeding to consult on its proposals.

2.1.1.4 Impact on workforce

33. In further correspondence with NHS England following the panel's assessment, The Royal Brompton identified approximately 430 WTE staff that it considered would be affected by the proposals, including those working as part of their CHD service, paediatric respiratory, paediatric intensive care and other services which will be impacted to a lesser extent. The Trust has estimated the cost of redundancies to be approximately £13.5m.
34. The panel was not able to take a view on the likelihood of all the staff identified by the Royal Brompton being significantly impacted by the proposed changes. However, it was acknowledged that there would be a significant impact on the Royal Brompton's workforce, if the proposals were to be implemented. The panel noted that this impact would be reduced, were the Royal Brompton to continue providing adult only level 1 services.
35. NHS England has reviewed the Trust's assessment of the potential level of redundancy. Given that we expect that most patients using the Royal Brompton would transfer to alternative providers within 3 miles of the Royal Brompton with the scope for redeployment that would result, NHS England has a materially different view of possible redundancy costs. Internal redeployment is also likely to make a significant contribution to avoiding redundancy. We estimate that the costs could however be up to £1 – 1.5m. This estimate is highly sensitive to the degree to which staff can be redeployed.

Estimate of Redundancy at RBH - Redeployment at 90%		
Service	WTE	Estimate of Redundancy Costs
Adult CHD	3.86	£149,865
Long Term Ventilation (LTV)	0.00	£0
Morphology Unit	0.00	£0
Paediatric CHD	15.62	£461,919
Paediatric Intensive Care	12.24	£345,346
Paediatric Respiratory	0.00	£0
Primary Dyskinesia Ciliary (PCD)	0.00	£0
Grand Total	31.71	£957,130

Estimate of Redundancy at RBH - Redeployment at 85%

Service	WTE	Estimate of Redundancy Costs
Adult CHD	5.79	£224,797
Long Term Ventilation (LTV)	0.00	£0
Morphology Unit	0.00	£0
Paediatric CHD	23.43	£692,879
Paediatric Intensive Care	18.35	£518,019
Paediatric Respiratory	0.00	£0
Primary Dyskinesia Ciliary (PCD)	0.00	£0
Grand Total	47.57	£1,435,694

36. Experience from previous CHD service changes shows that a number of staff, perhaps most, would prefer to be re-deployed within their current Trust, though in some cases staff may transfer in accordance with TUPE regulations
37. However, we do not expect that it will be viable for the Royal Brompton to continue to provide PICU if our proposals are implemented so there would be little or no opportunity for internal redeployment of PICU specialist staff.
38. There is no experience of such changes within London but it is reasonable to suppose that more staff would consider transferring with the patients because the distances involved are so small and the impact on staff would therefore be lower. Additional PICU staff especially nurses will be needed by those Trusts delivering more activity if our proposals are implemented and we would expect TUPE to apply.
39. Previous experience suggests there will be relatively few redundancies but with such large numbers of staff potentially affected by the changes, some redundancies cannot be ruled out. NHS England will encourage providers to minimise redundancies by supporting staff to transfer with the patients or by redeploying them internally. This should not preclude NHS England proceeding to consult on its proposals.

2.1.2 University Hospitals Leicester (UHL)

40. Under the proposals the UHL would no longer perform surgical or interventional cardiology on people with CHD. The panel considered that the scale of this change was not as significant as at the Royal Brompton due to the greater number of services which UHL provide. The panel also noted that the impact on the organisation and on patients could be reduced if it provided level 2 services.

2.1.2.1 Impact on other services: Paediatric Intensive Care and Extracorporeal Membrane Oxygenation (ECMO)

41. UHL has two paediatric intensive care units (PICUs), one at the Leicester Royal Infirmary and one at Glenfield (which supports CHD services).
42. The panel accepted that the proposals would make the PICU at the Glenfield Hospital unviable but did not accept that they would result in the cessation of PICU services at Leicester Royal Infirmary.
43. While we cannot pre-empt the decisions that NHS England will make on CHD services, or the findings and recommendations of its Paediatric Critical Care & Specialised Surgery for Children Service Review, at this point we expect Leicester would still provide PICU care for the East Midlands if our proposals are implemented, even if it no longer provides level 1 paediatric cardiac surgery. This would be through a single PICU at the Royal Infirmary.
44. If Leicester continues to provide level 1 paediatric cardiac surgery it plans to move this service from Glenfield to the Infirmary, so the future of the PICU at Glenfield is in question whether or not NHS England's proposals on CHD are agreed.
45. UHL provides cardiac and respiratory ECMO for children and is at the present the only provider commissioned to offer mobile ECMO (which allows children to be transferred between hospitals on ECMO). It also provides cardiac and respiratory ECMO for adults. If our proposals were to be implemented, Leicester would no longer be able to provide cardiac or respiratory ECMO for children or mobile ECMO for children. Taken together this would affect around 55 children a year. It would no longer provide cardiac ECMO for adults with CHD. We would expect that Leicester could continue to provide adult respiratory ECMO, in a similar way to other hospitals where services are supported by adult cardiac surgery services (not congenital cardiac).
46. There are close links between paediatric cardiac services and PIC and children's ECMO services. As a result our proposals will have an impact on both. The effects, both on paediatric cardiac patients, and on the wider national service, can be managed, as described below, and should not preclude NHS England proceeding to consult on its proposals.

2.1.2.2 Impact on finances

47. The overall contract value for specialised services at UHL is approximately £234m. NHS England estimates that the financial effect of the proposed changes would be a reduction of income around £14m (rather than the £19-20m estimate provided by the Trust). This is partly explained by a difference in view on the impact of the proposals on PICU. UHL's estimate is based on an assumption that it would no longer be able to provide PICU services. The panel

considered that there was no reason why PICU services could not continue at the Infirmary site even if the PICU currently located on the Glenfield site needed to close.

48. The loss of income to the Trust would therefore represent between 1.6% and 2.2% of the Trust's total income and between 6% and 8% of their total specialised services income.
49. The panel viewed the potential financial loss to UHL as less significant than that at the Royal Brompton due to the projected income which would be lost being smaller and the higher overall income of the Trust. Some of this loss of income could be reduced if UHL continued to provide Level 2 services. The loss of income to the Trust would also, to some extent, be offset by a reduction in costs.
50. While there would be an impact on the income of UHL, this could be partially offset by other forms of service provision. This should not preclude NHS England proceeding to consult on its proposals.

2.1.2.3 Impact on workforce

51. Leicester identified 153 WTE staff that would be directly affected by the proposals, including administrative and clerical staff, estates and ancillary, medical and dental and nursing and midwifery staff that work solely for East Midlands Congenital Cardiac Service. In addition to the staff directly affected, the Trust has also identified other roles, such as those working in theatres, imaging, outpatient care, catheter labs and intensive care that would be indirectly affected. Leicester considers it likely that many of its staff would prefer to take up posts elsewhere in the Trust if possible.
52. The panel was not able to take a view on the likelihood of all these staff being significantly impacted by the proposed changes; however, it was acknowledged that there would be a significant impact on the Leicester's workforce, if the proposals were to be implemented. The panel noted that this impact would be reduced, were Leicester to continue providing level 2 services.
53. NHS England considers it probable that most at risk staff will be redeployed and that therefore the costs of redundancy will be mitigated. We estimate that the costs could however be up to £1m. This estimate is highly sensitive to the degree to which staff can be redeployed.
54. Experience from previous CHD service changes shows that a number of staff, perhaps most, would prefer to be re-deployed within their current Trust, though in some cases staff may transfer in accordance with TUPE regulations
55. Previous experience suggests there will be relatively few redundancies but with such large numbers of staff potentially affected by the changes, some

redundancies cannot be ruled out. NHS England will encourage providers to minimise redundancies by supporting staff to transfer with the patients or by redeploying them internally. This should not preclude NHS England proceeding to consult on its proposals.

2.1.3 Central Manchester Foundation Trust (CMFT)

56. Under the proposals the CMFT would no longer perform surgical or interventional cardiology on adults with CHD. The panel considered that the scale of this change was considerably less than at the other Level 1 centres no longer being commissioned due to the significantly lower number of surgical or interventional procedures which are undertaken at CMFT. The panel also noted that this impact will be reduced if CMFT continue to provide level 2 services as part of the overall CHD service provision in the North West.

2.1.3.1 Impact on other services: Paediatric Intensive Care and Extracorporeal Membrane Oxygenation (ECMO)

57. The proposals would have no effect on PICU provision in Manchester as CMFT does not provide level 1 CHD services.
58. CMFT provides cardiac ECMO for adults with CHD. If our proposals were to be implemented, Central Manchester would no longer be able to provide cardiac ECMO for adults with CHD. It does not provide paediatric ECMO.
59. These proposals would have no significant impact on any other services within the Trust.

2.1.3.2 Impact on finances

60. The Trust did not respond to the request to provide information on the potential impact of the proposals.
61. The overall contract value for specialised services at Central Manchester is approximately £348m. NHS England estimates that the financial effect of the proposed changes would be around £1m.
62. The loss of income to the Trust would therefore represent approximately 0.1% of the Trust's total income and approximately 0.3% of their total specialised services income.
63. The panel viewed the potential financial loss to CMFT as much less significant due to the overall income they currently receive for level 1 CHD services being much lower than other centres which would lose activity as a result of these proposals. The panel considered that the financial impact of the changes will be offset by the establishment of a new model for the delivery of CHD services in the North West. The impact on CMFT as a Trust would be very limited, as it has only been undertaking a relatively low volume of CHD surgical activity.

64. The financial impact of this change is therefore not likely to have a significant impact on the Trust. Some of this loss of income could be reduced if Central Manchester continued to provide level 2 adult CHD services. The loss of income to the Trust would also, to some extent, be offset by a reduction in costs.
65. While there would be an impact on the income of Central Manchester, this could be partially offset by other forms of service provision. This should not preclude NHS England proceeding to consult on its proposals.

2.1.3.3 Impact on workforce

66. The Trust did not respond to the request to provide information on the potential impact of the proposals.
67. The panel considered it likely that the impact on staff at CMFT would be considerably less than the other two centres as the scale of service reduction would be much smaller. Where staff are affected, close working between CMFT, Alder Hey Children's Hospital and Liverpool Heart and Chest should enable CMFT to ensure that staff are appropriately supported and that clear plans are made to enable staff who wish to transfer to a Level 1 centre to do so.
68. Previous experience suggests there will be relatively few redundancies and because of the small scale of the services that are affected, the number of staff affected is expected to be commensurately small. NHS England will encourage providers to minimise redundancies by supporting staff to transfer with the patients or by redeploying them internally. This should not preclude NHS England proceeding to consult on its proposals.

2.1.4 Paediatric Intensive Care: wider implications

69. In order to ensure that there is still sufficient PICU capacity for CHD patients, NHS England will work with the other hospitals where increased paediatric cardiac surgery would be expected if our proposals are implemented (Birmingham Children's Hospital, Great Ormond Street, Leeds General Infirmary, St Thomas' - Evelina Hospital) to undertake the necessary planning and preparation to manage any increase in PICU capacity that would be needed for CHD patients.
70. If our proposals are implemented, there may also be an effect on the wider regional and national PIC system. NHS England has accelerated its review of Paediatric Critical Care & Specialised Surgery in Children, which will consider paediatric intensive care provision and paediatric transport. The critical care review aims to carry out initial work looking at where paediatric critical care capacity is likely to be needed in future, with the first outputs coming through early in 2017. When the Board takes its decisions on the CHD proposals, it should therefore have greater clarity around the impact on PIC for CHD patients

in the wider regional and national context. The Paediatric Critical Care & Specialised Surgery in Children Service Review will then be able to pick up and deal with any wider implications for changes in PIC consequent upon the proposed CHD changes, as it considers the required capacity and distribution of PICU across the country as a whole.

2.1.5 Paediatric ECMO: wider implications

71. NHS England will work with the other hospitals, where increased paediatric cardiac and adult congenital surgery would be expected, if our proposals are implemented, (Birmingham Children's Hospital, Great Ormond Street, Leeds General Infirmary and St Thomas' - Evelina Hospital) to undertake the necessary planning and preparation to manage any increase in paediatric cardiac ECMO capacity that would be needed for CHD patients.
72. If our proposals are implemented, there may also be a wider regional and national effect on ECMO services. NHS England has accelerated its Paediatric Critical Care & Specialised Surgery for Children Service Review, which will consider paediatric ECMO. When the Board takes its decisions on the CHD proposals, it should therefore have greater clarity around emerging thinking from the national review, which is likely to be ongoing at the time of the Board's decision. The Paediatric Critical Care & Specialised Surgery for Children Service Review will then be able to pick up and deal with any wider implications for changes in children's ECMO consequent upon the proposed CHD changes, as it considers the required capacity and distribution of children's ECMO across the country as a whole.

2.1.6 Summary

73. There would be a significant impact at each of the Trusts where it was proposed that current level 1 services should cease, if our proposals are implemented. The scale of these is not considered such that it should prevent NHS England from proceeding to consult on its proposals.
74. The proposals can be implemented and that the risks identified can be reduced or mitigated through ongoing work with Trusts.
75. Whilst the financial impact of these proposals is likely to be material for the Royal Brompton and UHL they are not considered sufficient to threaten the viability of the Trusts or their ability to continue to provide a wide range of services.
76. Detailed planning of the changes and an appropriate implementation timetable will be important for effective management of the changes needed.

2.2 The impact at centres which, under the proposals, would continue to be commissioned as Level 1 CHD centres

2.2.1 Confirmation that revenue costs of implementing standards should be covered by increasing income for increasing activity

77. Trusts are paid for CHD services through tariff, which ensures that the money received is linked to patient activity.
78. It is likely that there will be some economies of scale for providers linked with providing a higher volume of activity. As such the trusts which would gain activity under these proposals are confident of being able to fund this expansion through the income which would be associated with this extra activity.
79. The financial assessment undertaken in 2015 at the time the Board agreed the standards showed that additional income to Trusts resulting from growth in activity would be sufficient to fund the implementation of the standards.
80. Growth predictions have been refreshed and continue to provide assurance that implementation of the standards will be affordable for providers.

2.2.2 Assessment of capital requirements at hospitals that would take additional patients under the proposals and the sources of this capital

81. NHS England asked providers whether there would be any capital implications if they were required to take additional patients if our proposals are implemented. NHS England has confirmed that no specific central funds will be made available.
82. Two providers indicated that they would need to source capital funds to accommodate additional activity: University Hospitals Birmingham (£4M) and Great Ormond Street (£6M). In both of these cases it is expected that the provider would be able to source the capital funding from existing allocations and/or charitable funds. This is being confirmed with NHS Improvement.
83. No other provider indicated any requirement for capital funding.
84. The risk around capital funding requirement is minimal.

2.2.3 Provider organisations where level 1 services would be provided under the proposals: workforce impact

85. The panel considered that centres that would gain more patients if the proposals were to be implemented were well placed to be able to expand their capacity to be able to provide that care. The recruitment of the necessary workforce for this increased activity was seen as potentially challenging for a number of these centres. Specifically, the recruitment of the PICU nurses necessary for the additional beds which would be required. The centres gaining significant activity believed that although challenging they had a good record of

recruiting staff and would be able to recruit the necessary staff as long as they were given sufficient time prior to these proposals being implemented.

2.2.4 The impact at centres which, under the proposals, would continue to be commissioned as Level 1 CHD centres

2.2.4.1 Alder Hey Children's Hospital

86. No significant increase in surgical activity is expected at Alder Hey as a result of the proposals. The direct impact on Alder Hey will therefore be minimal.
87. However, under the proposals Alder Hey will form a joint level 1 centre with Liverpool Heart and Chest Hospital (which does not currently offer a level 1 adult CHD service) with a single surgical team. NHS England accepts the panel's recommendations that Alder Hey would therefore need to act as the senior partner in the transition of Level 1 services from CMFT to Liverpool Heart and Chest in order to provide assurance for the continuation of the service at CMFT and support LHCH in the development of its service.

2.2.4.2 Barts Health

88. The proposals are likely to result in increased activity at Barts. While the number of patients involved is relatively small this still represents a doubling of activity for Barts. The panel considered this scale of increase to be a significant challenge for Barts. Other factors noted by the panel as contributing to the risk posed by this change were:
 - Barts only took on responsibility for delivering Level 1 CHD services for adults at the new Barts Heart Centre in 2015, following comprehensive reorganisation of cardiac services across North Central and North Central London between UCLH and Barts.
 - Barts is currently in financial special measures.
 - Barts had not clearly demonstrated that it had quantified the additional staff it would require.
89. As such the panel considered there to be a moderate risk associated with its ability to provide Level 1 CHD services for the increased number of patients envisaged under these proposals. The panel considered the most significant risk associated with Barts increasing its capacity to be in relation to the additional workforce they would require.
90. Barts is part of a joint level 1 centre with Great Ormond Street Hospital with a single surgical team. NHS England accepts the panel's recommendations that Great Ormond Street should act as the senior partner in the scaling up of Level 1 services at Barts in order to provide assurance of the development of its service.

91. NHS England recognises that it will have an important role to play in supporting implementation if the proposals are agreed. This is described in more detail in section 3.7 below.
92. We note that Barts Health NHS Trust is in Special Measures. Some adult CHD activity is expected to transfer to Barts Health from Royal Brompton if our proposals are implemented. The proposed expansion of CHD activity at Barts will bring a positive contribution to the Trust bottom line by increasing income by greater use of an existing facility.
93. There is available capacity in the PFI-financed Cardiac Centre on the St Bartholomew's site. Further development of cardiac services is in line with the Trust's strategic aims.

2.2.4.3 Birmingham Children's Hospital

94. The proposals are likely to result in significantly increased activity at Birmingham Children's Hospital. While the number of patients involved is relatively large this represents a more modest proportional increase in activity for Birmingham Children's of 36%.
95. Birmingham Children's Hospital is confident of its ability to increase its capacity sufficiently to provide the extra activity required under these proposals. The panel considered that it had provided very good evidence of having understood the scale of what would be required and of plans to increase capacity.
96. Birmingham Children's Hospital identified that in order to provide the extra activity required by these proposals it would need additional PICU and ward beds. It has identified a number of options for providing this additional capacity and is currently in the process of appraising these options. It is confident it would have this additional capacity in place by early 2018 but notes the significant challenge there will be in recruiting the necessary PICU nurses for this expansion.
97. The panel did not consider there to be any significant risks associated with Birmingham Children's Hospital increasing their capacity to meet the activity required by the proposals but did note the challenges associated with the recruitment of staff, most notably PICU nurses, and the need for sufficient lead in time.

2.2.4.4 Great Ormond Street Hospital

98. The proposals are likely to result in significantly increased activity at Great Ormond Street Hospital. While the number of patients involved is relatively large this represents a more modest proportional increase in activity for Great Ormond Street of 31%.

99. Great Ormond Street Hospital is confident of its ability to increase capacity sufficiently to provide the extra activity required under these proposals. The panel considered that they had provided good evidence of having understood the scale of what would be required of them and of their plans to increase capacity.
100. Great Ormond Street identified that in order to provide the extra activity required by these proposals they would need additional PICU beds. It plans on providing this additional capacity through its new “Premier Inn Clinical Building” which will be completed in September 2017. If Great Ormond Street is required to provide extra capacity prior to this, it stated it would be able to utilise vacant capacity on its current PICU and NICU in the short term.
101. The panel did not consider there to be any significant risks associated with Great Ormond Street increasing their capacity to meet the activity required by the proposals, but did note the challenges associated with the recruitment of staff, most notably PICU nurses, and the need for sufficient lead in time.
102. Great Ormond Street is part of a joint level 1 centre with Barts. NHS England accepts the panel’s recommendations that Great Ormond Street would need to act as the senior partner in the scaling up of Level 1 services at Barts in order to provide assurance of the development of its service.

2.2.4.5 Guy’s and St Thomas’ Hospitals NHS Foundation Trust

103. The proposals are likely to result in significantly increased activity at Guy’s and St Thomas’. While the number of patients involved is relatively large this represents a more modest proportional increase in activity for Guy’s and St Thomas’ of 40%.
104. Guy’s and St Thomas’ is confident of its ability to increase its capacity sufficiently to provide the extra activity required under these proposals. The panel considered that it had provided good evidence of having understood the scale of what would be required of it and of their plans to increase capacity.
105. Guy’s and St Thomas’ identified a need for both additional ward and PICU capacity in order to provide the additional activity modelled under these procedures. It has not identified the number of additional PICU and ward beds required because it is confident that the extra capacity to be provided under its planned expansion scheme will be sufficient. This will provide up to eleven ward beds and up to ten PICU beds by December 2017.
106. The panel noted that as the surgical work undertaken by Guy’s and St Thomas’ on behalf of Northern Ireland moves to Dublin (currently expected to happen at the end of 2017) this would free up capacity.

107. The panel did not consider there to be any significant risks associated with Guy's and St Thomas' absorbing the activity required by NHS England's proposals. However, the panel did note that the most significant risk related to the workforce implications of the proposals on Guy's and St Thomas' and its ability to recruit the appropriate staff, most notably PICU nurses.

2.2.4.6 Leeds Teaching Hospitals

108. The proposals are likely to result in increased activity at Leeds Teaching Hospitals. The number of patients involved is relatively modest and represents a small proportional increase in activity for Leeds of 10%.
109. Leeds Teaching Hospitals is confident of their ability to increase its capacity sufficiently to provide the extra activity required under these proposals. The panel considered that it had provided good evidence of having understood the scale of what would be required of it and of their plans to increase capacity.
110. Whilst the panel had some concerns relating to its ability to increase capacity in their cardiac ward, PICU and theatre they did not consider that these posed a significant risk to their ability to provide services for these additional patients.

2.2.4.7 Liverpool Heart and Chest Hospital

111. Liverpool Heart and Chest Hospital (LHCH) currently provides level 2 CHD services. Liverpool Heart and Chest does not currently have a level 1 adult CHD service. Under the proposals LHCH would begin performing Level 1 services including surgery and interventional cardiology on adults for the first time³. This will mean a significant change in the cohort of patients and activity levels.
112. The panel considered the scale and nature of this change to be a significant challenge for LHCH and the most significant risk amongst hospitals gaining activity as a result of the proposals.
113. Liverpool Heart and Chest Hospital would be providing adult Level 1 CHD services for the first time having previously been a level 2 centre. As a result of this it will not simply be doing more of the activity it has already been undertaking (as is the case with other centres gaining activity) but rather starting to undertake a type of activity it has not previously done. This increases the risks.
114. In addition, the panel was concerned that Liverpool Heart and Chest Hospital had not clearly quantified the additional capacity and workforce it would require to provide this additional activity in its submission. Therefore it could not provide

³ Although Liverpool Heart and Chest has reported CHD surgical procedures to NICOR, most of the procedures concerned were either aortic surgery (patients referred to an aortic specialist surgeon including referrals from CHD surgeons) or cases that do not require a CHD surgeon (based on the definitions of adult CHD surgery established before NHS England's work in this area).

convincing assurances about how and when this would be provided. These risks were seen as more significant due to Liverpool Heart and Chest Hospital's current breaching of referral to treatment waiting times (RTT) specifically in relation to cardiac surgery.

115. Under the proposals LHCH will form a joint level 1 centre with Alder Hey. NHS England accepts the panel's recommendations that Alder Hey would therefore need to act as the senior partner in the transition of Level 1 services from CMFT to Liverpool Heart and Chest in order to provide assurance for the continuation of the service at CMFT and support LHCH in the development of its service.
116. Managing the risk of this change will require close working between CMFT, Alder Hey Children's Hospital and Liverpool Heart and Chest Hospital to ensure that they have a clear understanding of the activity LHCH will be required to undertake and the systems, facilities, staffing and capacity needed to manage this activity.
117. NHS England recognises that it will have an important role to play in supporting implementation if the proposals are agreed. This is described in more detail in section 3.7 below.

2.2.4.8 Newcastle Hospitals

118. No significant increase in surgical activity is expected at Newcastle as a result of the proposals. The impact on Newcastle will therefore be minimal.
119. While noting that this meant that proposals posed a minimal risk at Newcastle, the panel considered that real risks did arise because Newcastle does not meet the 2016 activity requirement and is unlikely to be able to meet the 2021 activity requirement. It also does not meet the 2019 paediatric co-location requirements or have a realistic plan to do so by April 2019.
120. The panel considered that if Newcastle could not meet the standards, a clear plan would be needed either to move the advanced heart failure service, or deliver it under a different model. A phased, planned transition supported by the Newcastle team would be required if the service needed to move. This would minimise the risks.
121. The panel also considered that succession planning would be an issue for the service in Newcastle.
122. NHS England notes the panel's concerns. However Newcastle has a unique role in delivering care for CHD patients with advanced heart failure including heart transplant and bridge to transplant and that this could not be replaced in the short term without a negative effect on patients. On balance therefore our present view is that it is better to continue to commission level 1 CHD services from Newcastle.

123. This does not mean that change at Newcastle Hospitals NHS Foundation Trust will not happen in the longer-term. The hospital trust is required to meet the standards in the same way as all of the other Level 1 surgical centres. Timeframes for doing this may differ, but we will be working closely with the hospital to ensure that patients receiving CHD care at Newcastle Hospitals NHS Foundation Trust are not compromised in any way.
124. NHS England notes the panel's recommendation that these shortfalls could not be ignored and that if there was to be derogation, the issues needed to be resolved by the end of the period of derogation. If this proposal is implemented we will work with Newcastle to ensure progress is made towards meeting the standards and to ensure the service is sustainable and resilient. We will take expert advice on the best possible development plans; and mitigations in the circumstances and support their implementation. These arrangements will be time limited and subject to further review by 2021.
125. The panel recommended that NHS England would need to undertake specific work on the future of advanced heart failure services in England, to ensure their ongoing provision and resilience. If this were to result in the development of an alternative model for advanced heart failure services for CHD patients then a review of the long term future of Level 1 CHD services in Newcastle would also be enabled.
126. NHS England notes the panel's recommendation that there should be a review of the future of advanced heart failure services in England. If our proposals are agreed, this recommendation will be further considered.
127. NHS England recognises that it will have an important role to play in supporting implementation if the proposals are agreed. This is described in more detail in section 3.7 below.

2.2.4.9 University Hospitals Birmingham

128. The proposals are likely to result in increased activity at University Hospitals Birmingham (UHB). The number of patients involved is relatively modest although this represents a 40% increase in activity for UHB.
129. University Hospitals Birmingham (UHB) is confident of their ability to increase their capacity sufficiently to provide the extra activity required under these proposals. The panel considered that UHB had provided good evidence of having understood the scale of what would be required of them and of their plans to increase capacity.
130. The panel did not consider that there was any significant risk associated with UHB absorbing this additional activity.

131. Due to the size of its overall adult cardiac service including ITU provision the level of activity it would absorb as a result of the proposed changes is not considered to be significant, and the panel was therefore confident that any transition of activity would be able to be undertaken in a timely manner.

2.2.4.10 University Hospitals Bristol

132. No significant increase in surgical activity is expected at Bristol as a result of the proposals. The impact on Bristol will therefore be minimal.

2.2.4.11 University Hospital Southampton

133. The modelling of patient flows which NHS England produced did not envisage significant activity flowing to Southampton as a result of these proposals.
134. The proposals are likely to result in increased activity at Southampton. The number of patients involved is relatively modest and represents a small proportional increase in activity for Southampton of 5%.
135. Southampton is confident of their ability to increase its capacity sufficiently to provide the extra activity required by the standards.
136. The panel did not consider that there was any significant risk associated with Southampton absorbing this additional activity.
137. The panel considered that it had provided good evidence of having understood the scale of what would be required and of its plans to increase capacity. Work is already underway to expand PICU.

2.2.5 Conclusion

138. The panel considered that centres that would gain more patients if the proposals were to be implemented were well placed to be able to expand their capacity to be able to provide that care.
139. All the centres which would gain additional activity under the proposals indicated that they were able to increase capacity in order to meet this increased demand.
140. Detailed planning of the changes and an appropriate implementation timetable were considered important for effective management of the changes needed.
141. The recruitment of the necessary workforce for this increased activity was seen as potentially challenging for a number of these centres. Specifically, the recruitment of the PICU nurses necessary for the additional beds which would be required. The centres gaining significant activity believed that although challenging they had a good record of recruiting staff and would be able to recruit the necessary staff as long as they were given sufficient time prior to these proposals being implemented.

142. All centres are confident of their ability to provide high quality CHD services to these additional patients and the risks which remain largely relate to ensuring that sufficient lead in time is given to any changes and that the detailed work of understanding the precise nature of any changes and thus the specific requirements on these centres has been undertaken prior to these proposals being implemented.
143. A higher level of support will be needed for the changes proposed at Liverpool Heart and Chest, Barts and for Newcastle as it works towards meeting the standards.
144. NHS England recognises that it will have an important role to play in supporting implementation if the proposals are agreed. This is described in more detail in section 3.7 below.

3 Response to National Panel recommendations

145. The national panel made a number of recommendations to NHS England. Most relate to the planning and preparation for change if a decision is taken to implement the proposals.

3.1 Workforce

146. NHS England recognises the importance of employing Trusts supporting current staff during a period of uncertainty.
147. Sufficient experienced staff within the service is vital key to good patient outcomes across the care pathway and therefore were these proposals to be implemented significant work would be required to ensure every effort was made to retain experienced staff, and ensure that every Level 1 centre maintained a highly skilled and experienced workforce.
148. NHS England would support TUPE and/or COSOP arrangements to enable staff affected by change to transfer their employment to other Level 1 centres requiring their skills.
149. A priority will be the development of a framework across organisations to ensure the best possible outcome for staff. The national panel advised that all units are resourceful and where there is a shortfall in the staff available they were confident they will continue to find ways to recruit the necessary staff, including international recruitment where necessary.

3.2 The resilience of surgical teams

150. NHS England accepts the panel's recommendation that if the proposals are implemented, each centre's implementation planning must ensure that appropriately robust surgical teams are in place with clear succession plans.

3.3 Managing patient flows

151. We have modelled the way in which patient flows may change if the proposals are implemented. The modelling assumes that a patient will go to their next nearest centre, calculated as car journey time. The results of this modelling are intended as a guide rather than an exact representation of what will happen.
152. During planning and preparation for implementation, NHS England recognises that further modelling may be required to explore different assumptions, for example if CHD referrals align with referrals for other specialised paediatric services.

3.4 Communication

153. NHS England will continue to offer open communication on its work on CHD services, seeking to support patients in understanding the proposals, the staged approach to meeting the standards and the timetable for implementation if the proposals are agreed.

3.5 PICU and ECMO

154. NHS England notes the panel's support for the national paediatric critical care and children's surgery review. This review will consider the overall requirement for PICU beds in future across the country and for all patient groups, the appropriate model of children's ECMO provision and the appropriate number of providers, the case for minimum activity levels and the appropriate number of mobile ECMO providers.

3.6 Advanced heart failure

155. NHS England acknowledges the panel's recommendation that NHS England should undertake specific work on the future of advanced heart failure services in England.
156. If our proposals are agreed, this recommendation will be further considered.

3.7 Support

157. NHS England accepts the panel's recommendation that, if our proposals are implemented, centres will need to collaborate to ensure close working between centres to support the safe transition of services. The changes proposed will take some time to implement.
158. NHS England remains committed to promoting collaborative working and will continue to work with providers to facilitate these conversations, including the development of network protocols.
159. In addition to this, once final decisions have been made, NHS England will make money available to pump prime the formation of networks, in line with the approach to other Operational Delivery Networks for specialised services.
160. If a decision to move services is made, work would begin to turn those 'agreements in principle' into firm plans. Clinicians at all the affected centres will be involved in developing plans for how the service would work in the future.
161. NHS England recognises that it will have an important role to play in supporting implementation if the proposals are agreed.
162. The current CHD Implementation and Commissioning Programme Board will oversee implementation. Membership of the group will be reviewed and refreshed to reflect the different nature of the implementation challenge. This would allow the inclusion of representatives from affected provider organisations if appropriate. The programme board reports to the national Specialised Commissioning Oversight Group (SCOG) which in turn reports to the Specialised Services Commissioning Committee, a sub-committee of the NHS England Board.
163. The work will continue to be supported by a national programme team with programme management, communications and engagement, information and analytical capabilities. The programme will continue to receive dedicated resources, as part of the national specialised commissioning programme budget.
164. The programme board will continue to identify and manage risks and escalate these to SCOG in line with organisational policy.
165. The programme board will oversee the implementation process to make sure that:
 - the process is carried out carefully and thoroughly;

- there is a strong link between the plans of those hospitals that would cease to provide level 1 services and those hospitals that would expand their provision;
 - that no change happens until there is enough capacity at the new hospital, including overnight accommodation and other facilities for families;
 - that staff and patient representatives from the hospitals concerned are included in the planning process;
 - there is frequent and clear communication so that everyone knows what to expect and how it will affect them; and
 - service quality and waiting times are closely monitored and managed.
166. NHS England's regional teams are represented on the programme board either by the Regional Director for Specialised Commissioning or the Regional Clinical Director for Specialised Commissioning.
167. Regional teams will continue to manage NHS England's relationships with the affected hospitals. This will include working closely with providers to support the development of:
- Locally appropriate care model including consideration of the role of level 2 care
 - Capacity planning and development
 - Transition planning
 - Implementation of 'staff affected by change' policies across affected organisations including action to minimise redundancies; there will be no reduction in the number of specialist staff required to deliver services
 - Workforce planning and development
 - Staff communication plans
 - Patient communication plans
 - Local media management
168. Patients and their families have told us that changes to where their care is provided and to the staff providing their care can be unsettling, so we will ask the hospitals involved to look carefully at how this process is managed if our proposals are implemented. We think the pattern set out in the standards for transition from children's to adult services may be helpful as this offers an opportunity to visit the new centre and meet the new staff in advance of the change happening. We will also ask them to maximise continuity in care so that as much as possible can remain familiar. If level 2 care continues to be provided at hospitals that no longer provide level 1 services many aspects of patient care will continue as before and patients would experience a high degree of continuity.

169. We will ask for special attention to be paid to people with learning disabilities and their families because we know that change can be particularly difficult for this group.
170. All providers of CHD care are contractually required to meet NHS England's service standards by the CHD service specifications (Paediatric Cardiac E05/S/a and Adult CHD E05/S/b). Where a provider did not meet one or more of the standards, but we considered that they would be able to in future, we have agreed with them an improvement plan with an agreed timetable, and this plan has been made binding through a contract variation. Delivery against these plans will be monitored by commissioners in regular performance management meetings. The NHS England CHD Programme Board will receive regular reports of delivery against plan in order to ensure that there is a national understanding of progress.

3.8 Level 2 services and the impact of the end of Commissioning through Evaluation for Patent Foramen Ovale (PFO)

171. Following the end of Commissioning through Evaluation for PFO closures we will monitor interventional activity at Brighton and Oxford to determine whether these centres are able to continue performing these procedures.
172. If these centres are not able to perform ASD catheter closures they may still choose to provide level 2 CHD services in the same way as Norfolk and Norwich Hospital.

4 Part Two: Further assessment against the standards

4.1 Introduction

173. NHS England's initial assessment of compliance against the specifications and standards focussed on the standards that came into effect in April 2016.
174. Where the panel considered that the evidence did not show that providers met the 2016 standards their assessment also took account whether providers were likely to be able to meet the elements of the interdependency/co-location requirements that come into effect in 2019 or the surgical standards that come into effect in 2021.
175. NHS England has always been clear that the implementation date specified by the standard does not indicate that NHS England will not consider whether the standard has been met until this time. On the contrary, NHS England will require hospitals either to show that they meet the required standards at the go-live date or that they have robust plans in place to do so, where necessary supported by appropriate mitigations to deal with the shortfall in the interim.⁴ In addition, our letters to providers at the start of the self-assessment process clearly stated that if a provider does not meet the specification and is unlikely to be able to do so, we would need to discuss future service provisions.
176. However, as we had not explicitly asked providers about their plans to comply with these future standards we wrote to the Royal Brompton and UHL and offered them the opportunity to submit additional information to the National Panel on their ability to meet these requirements.
177. Assessment of the additional information submitted by UHL and the Royal Brompton in respect of standards with a future implementation date was undertaken by the national panel at the same time as the Impact Assessment.

4.1.1 Paediatric interdependency requirements

178. The standards state that by 2019 the following specialties or facilities must be located on the same hospital site as Specialist Children's Surgical Centres. They must function as part of the multidisciplinary team. In addition, consultants from the following services must be able to provide emergency bedside care (call to bedside within 30 minutes).
- Paediatric Cardiology;
 - Paediatric Airway Team capable of complex airway management (composition of the team will vary between institutions);

⁴ <https://www.england.nhs.uk/wp-content/uploads/2015/07/Item-4-CHD-Report.pdf>

- Paediatric Intensive Care Unit (PICU);
- High Dependency beds;
- Specialised paediatric cardiac anaesthesia;
- Perioperative extracorporeal life support (Non-nationally designated extracorporeal membrane oxygenation (ECMO));
- Paediatric Surgery;
- Paediatric Nephrology/Renal Replacement Therapy;
- Paediatric Gastroenterology.

4.1.2 Surgeon minimum activity levels and surgical team size

179. The standards state that congenital cardiac surgeons must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three-year period. Only auditable cases may be counted, as defined by submission to the National Institute for Cardiovascular Outcomes (NICOR). They must work in teams of three by April 2016 and teams of four by April 2021.

4.2 University Hospitals Leicester (UHL)

4.2.1 Paediatric interdependency requirements

180. UHL stated that all paediatric specialist services, including paediatric cardiac services, will be co-located at Leicester Royal Infirmary by 2019 and they will therefore be fully compliant with the co-location requirements. This plan no longer depends on the building of a new children's hospital.
181. The panel considered that UHL's proposal to move paediatric cardiac Level 1 services to the Infirmary site would allow it to achieve full compliance with the requirements. However, the panel considered that UHL needed to set out their plans in more detail to be fully reassuring that this move could and would be achieved by the required deadline.
182. UHL provided assurances that the project will not require external capital funding, as it will be funded using a combination of the Trust's Capital Resource Limit and charitable donations. It will be designed as part of (but is not dependent upon) the wider Children's Hospital Project, to ensure the integration of paediatric services to create a defined Children's Hospital in Leicester.

4.2.2 Surgeon minimum activity levels and surgical team size

183. UHL's surgical activity in 15/16 was 326 procedures. 16/17 activity data was not available to the panel.

184. UHL submitted a surgical growth plan which they consider would result in them achieving the minimum level of activity required to ensure four surgeons are each able to perform a minimum of 125 procedures per year by 2021.
185. The projected increase in activity depends on population growth, technical advances, and changes to patient flows. NHS England has repeatedly stated that it has no intention of mandating patient flows and as such the panel remained unconvinced that the changes to patient flow required to achieve the necessary growth are likely to occur.
186. UHL reported that they have successfully established a complete lifetime referral pathway with Kettering General Hospital and had positive discussions with two other network hospitals to establish lifetime referral pathways. UHL suggested additional surgical cases from these partners as demonstrated in the table below:

Table 4: UHL estimated additional future referrals

Year	Partner 1	Partner 2	Partner 3
2016/17	0	0	0
2017/18	4	6	4
2018/19	8	11	7
2019/20	11	17	11
2020/21	15	22	14

187. To date these arrangements have not been established and as such UHL do not expect to see any additional activity from these until 2017/18.
188. UHL did not provide any evidence of formal agreements having been established or any basis for its assertions over the amount of additional activity they would receive from these networks.
189. The changes to referral pathways described by UHL were not considered sufficient to bring about the level of growth required for them to meet the 2021 requirements. In order for these requirements to be met their activity would need to increase by 53% from 2015/16 levels in five years, when the previous five years have only resulted in a total growth of 24%.
190. Applying national predicted growth rates to UHL surgical activity, and factoring in the additional referrals cited above (though evidence for these has not been provided) NHS England has estimated that UHL's surgical activity in 2020/21 will be more than 20% below the minimum requirement of 500 operations and 4 surgeons. As a result, some if not all surgeons would be undertaking fewer than the minimum of 125 cases per surgeon per year.
191. UHL's growth estimate assumes growth will continue at the rate seen at UHL between 2014 and 2016 as well as technical advances and changes in its

network. The basis for these assumptions and their impact within UHL's modelling is not well explained

192. The panel considered it likely that UHL would reach activity levels sufficient to support a team of three surgeons each undertaking 125 operations per year but that it was not clear when this would happen. The Trust's own most recent estimate was that this would be achieved by 2017/18.
193. The panel considered that UHL had not provided sufficient evidence to provide confidence that it would achieve the minimum surgical activity requirements by 2021.

4.2.3 Summary

194. Following the Trust's latest submission the panel considered that:

- UHL had demonstrated that it could meet the April 2019 co-location requirement though more detailed plans were required to be fully reassuring;
- UHL had not demonstrated that it met the April 2016 requirement of three surgeons each performing a minimum of 125 procedures per year;
- While UHL had not provided sufficient information to know when the April 2016 requirement would be met, it was likely that this requirement would be met; and
- UHL had not set out a convincing plan as to how they will meet the April 2021 requirements of four surgeons each performing a minimum of 125 procedures per year.

195. NHS England accepted this assessment.

4.3 Royal Brompton Hospital (RBH)

4.3.1 Paediatric interdependency requirements

196. RBH has previously demonstrated that it meets all of the co-location requirements with the exception of paediatric surgery and gastroenterology.
197. RBH did not provide any additional information or evidence as to how they plan to meet the 2019 requirements to co-locate their paediatric CHD service with other key specialties.
198. They stated that although they do not have paediatric surgery or paediatric gastroenterology co-located on site they provide these services through their partnership with Chelsea and Westminster who participate in MDTs and ward rounds and provide out of hours cover as required.

199. RBH stated that it did not consider that 2019 requirements should be a part of this assessment process or that decisions should be made on the basis of these.

4.3.2 Summary

200. Following the Trust's latest submission the panel considered that:

- RBH had not demonstrated that it could meet the April 2019 co-location requirement for paediatric gastroenterology or paediatric surgery

201. NHS England accepted this assessment.

5 Conclusion

202. The panel did not consider that any of the potential impacts or risks identified through this process was sufficient to require the proposals to be altered.

203. The panel was confident that those centres required to provide additional Level 1 services were these proposals to be implemented would be able to provide sufficient capacity for this.

204. The panel concluded that the additional evidence submitted did not alter their original assessment of the three trusts (CMFT – Red; UHL – Red/Amber; RBH – Red/Amber).

205. The panel considered that while the proposals would have a material impact on the trusts no longer providing Level 1 services, especially the Royal Brompton and Leicester, it did not consider it to be likely that these would be sufficient to threaten either their continued viability or their continued ability to provide a wide range of specialised services.

6 Next steps

206. This is a high level impact assessment intended to identify the risks associated with the proposals as they currently are and test the plausibility of the proposals, to inform NHS England's assurance processes prior to the launch of public consultation. Whilst there remain a number of unknowns relating to the implementation of these proposals as well as a number of risks which will require managing, there is nothing highlighted within this document which seems likely to make the proposals unviable.

207. No commissioning decisions have yet been made, as the public consultation is pending and therefore it is not appropriate to produce a detailed implementation plan at this stage. This will be produced once decisions have been taken by the

Board of NHS England, following the completion of public consultation. Throughout the consultation period and beyond we will continue to work with providers to understand the impact of the changes which are being proposed and refine the impact assessment we have completed to date.

Draft for consultation

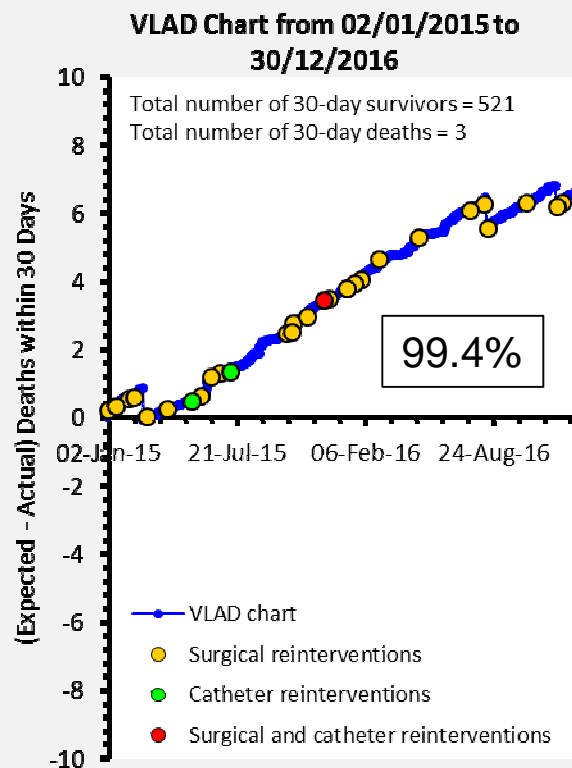
University Hospitals of Leicester

Nottingham and Nottinghamshire Joint Health Scrutiny Committee



Better than expected surgical survival

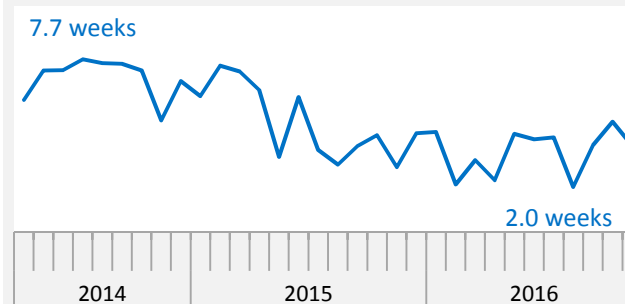
Risk-adjusted survival following paediatric surgery is statistically better than expected for the previous 2 years.



National average (PRAiS 2012-15) = 98%

4 weeks

average waiting time for
paediatric surgery in 2016



Lower rates of:

- Surgical cancellations
- Complications
- Catheter re-interventions

Specialised Services Quality Dashboards



Statistically lower rates compared with other Level 1 congenital heart centres in Q1 of 2016-17 according to our Specialised Quality Dashboards.

99%

Recommendation rate
from our Friends and
Family test

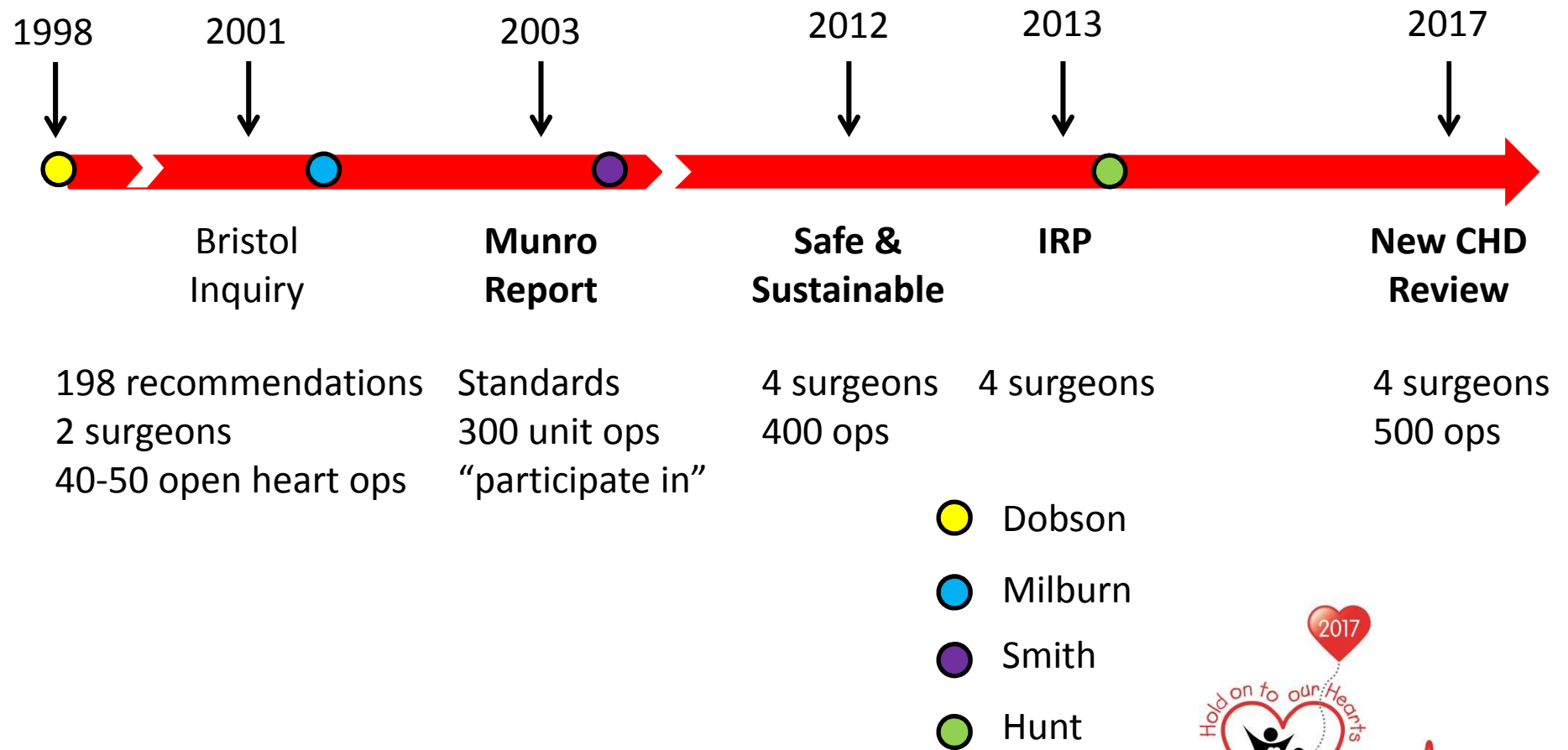


434 /436 respondents
would recommend
our services to their
family and friends.

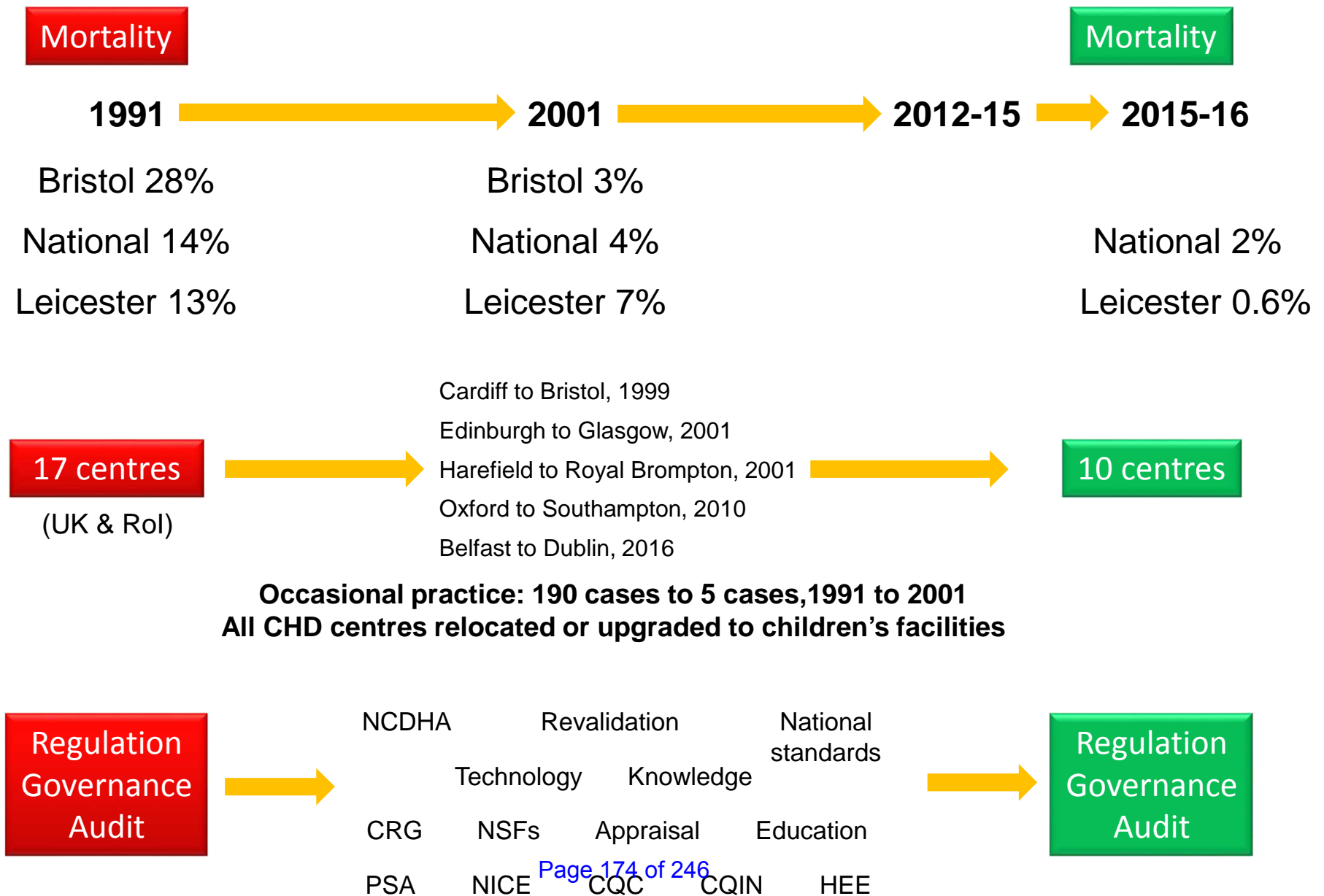
(Jan 16 – Nov 16),



Timeline of Reviews



A profession transformed



The Report of the Independent Review of Children's Cardiac Services in Bristol

Eleanor Grey QC, Professor Sir Ian Kennedy

June 2016

“There is a fundamental difference between the circumstances revealed by the Bristol Public Inquiry...and the situation now”

**The work of the National Congenital Heart Disease Audit
“should ensure that such a situation would now not go undetected”.**

UHL compliance with 14 key standards

Criteria	Compliance
1.1 Surgery and catheter procedures to take place in a Specialist Surgical Centre	Compliant
1.2 Network MDT discussions for rare, complex and innovative procedures	Compliant
1.3 Age-appropriate care environments	Compliant
2.1 Surgeons to be primary operator in 125 procedures each year (3-year average), 4 surgeons by 2021	Plan not approved
2.2 Cardiologist to be primary operator for 50 procedures each year (lead cardiologist = 100) each year (3-year average)	Plan
3.1 Surgical rotas should be no more than 1 in 3	Compliant
3.2 Interventional cardiologist rotas should be no more than 1 in 3	Compliant
3.3 Cardiologist rotas should be no more than 1 in 4	Compliant
3.4 A consultant ward round occurs daily	Compliant
3.5 Patients and their families can access support and advice at any time	Compliant
3.6 Network medical staff can access expert CHD advice at any time	Compliant
4.1 Co-location of key specialities and facilities (call-to-bedside within 30 mins)	Plan
4.2 Key specialities to function as a multidisciplinary team	Compliant
5.1 Participate in national audits, use current risk adjustment models and learn from adverse incidents	Compliant

NHS England's numbers game

Case numbers – 3 Surgeons

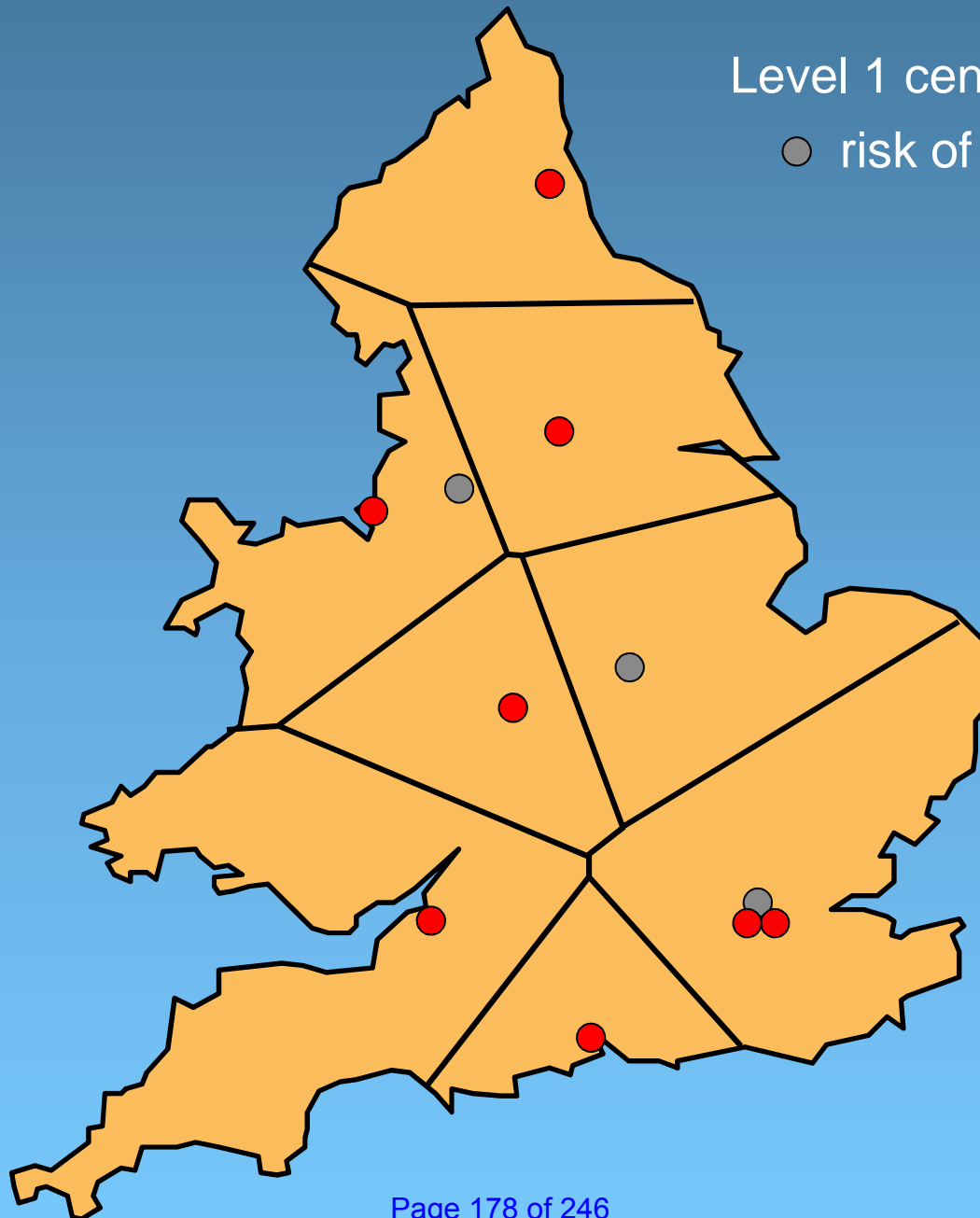
- Standard 2.1 requires each surgeon to perform 125 cases pa and the unit to achieve 375 cases per year, averaged over three years
- NHSE are counting this retrospectively rather than from standards implementation in April 2016 thereby predetermining the outcome
- If counted from this year onwards (as intended), we expect to be compliant with this standard by March 2019 as required

Case numbers – 4 Surgeons

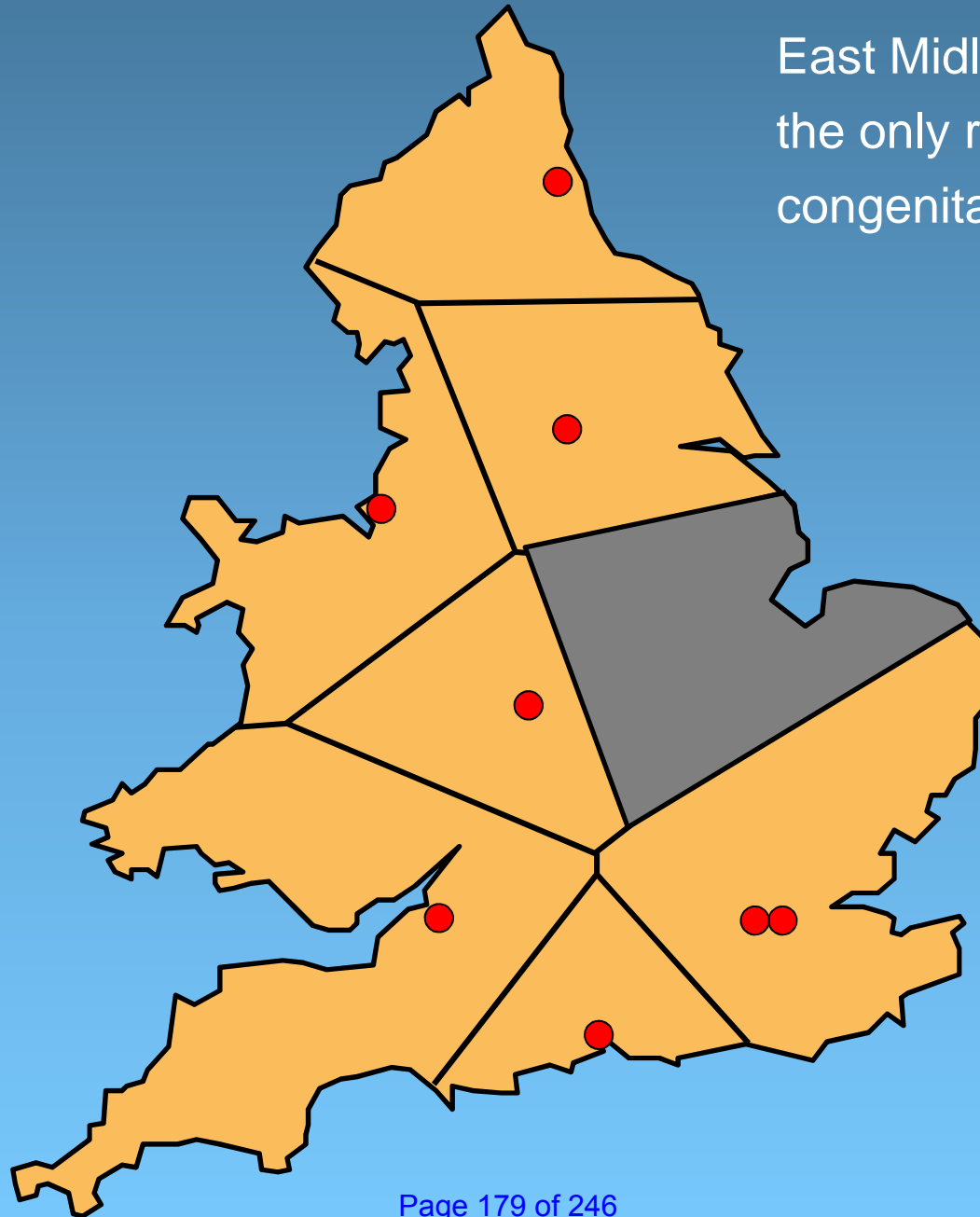
- by 2021 teams should have 4 surgeons all performing 125 cases pa i.e. a total of 500 cases
- We have submitted a network development plan that clearly demonstrates how we can meet this standard
- NHSE have refused to consider our proposal as a potential solution

Level 1 centres in England

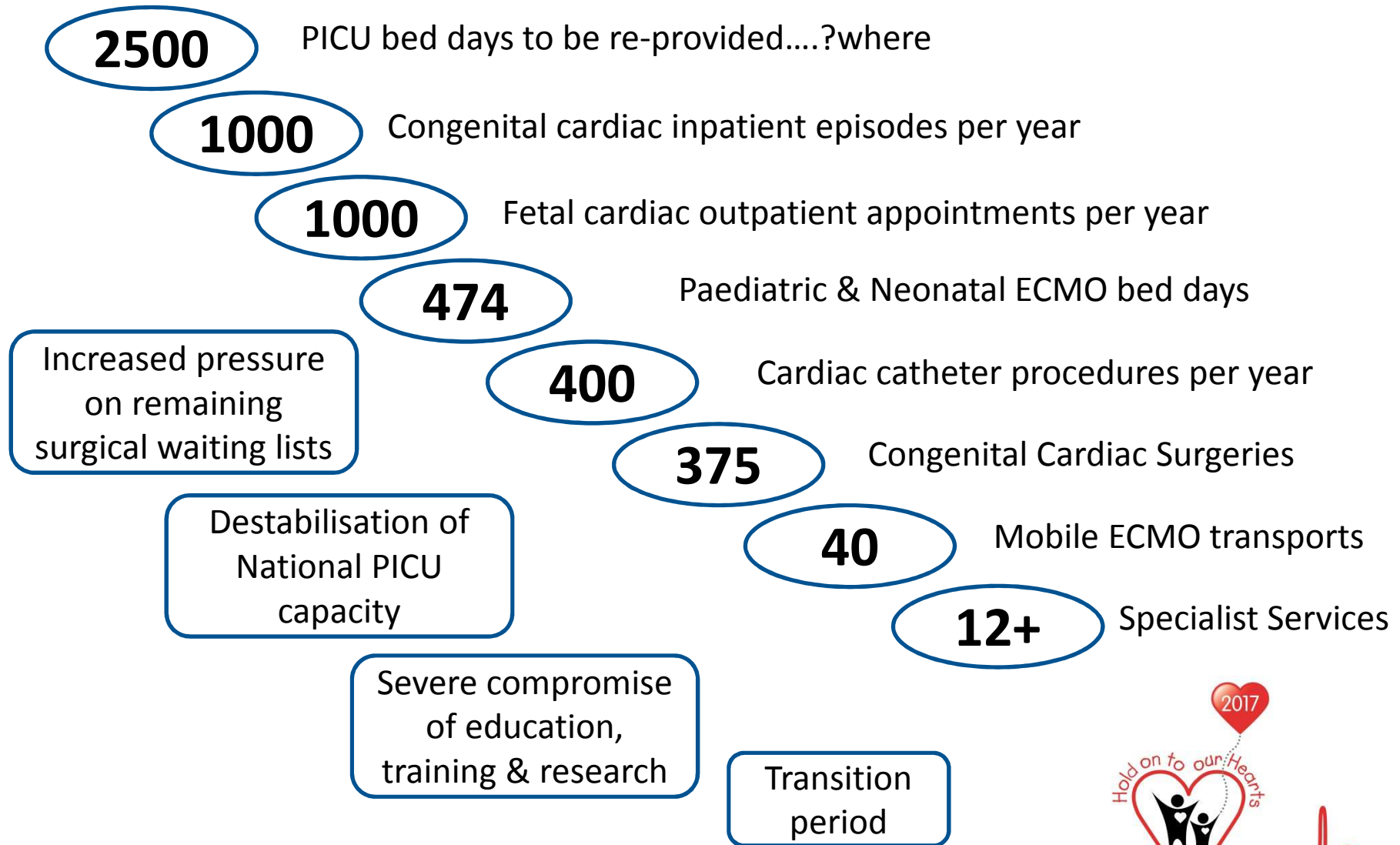
● risk of closure



East Midlands would be
the only region without a
congenital heart centre



Likely patient impacts ...



Likely patient impacts ...

- Travel times
- Cost
- Ease of access
- Increased waiting lists
- Disruption of patient-clinician relationships
- Uncertainty and anxiety

 Healthcare inequality

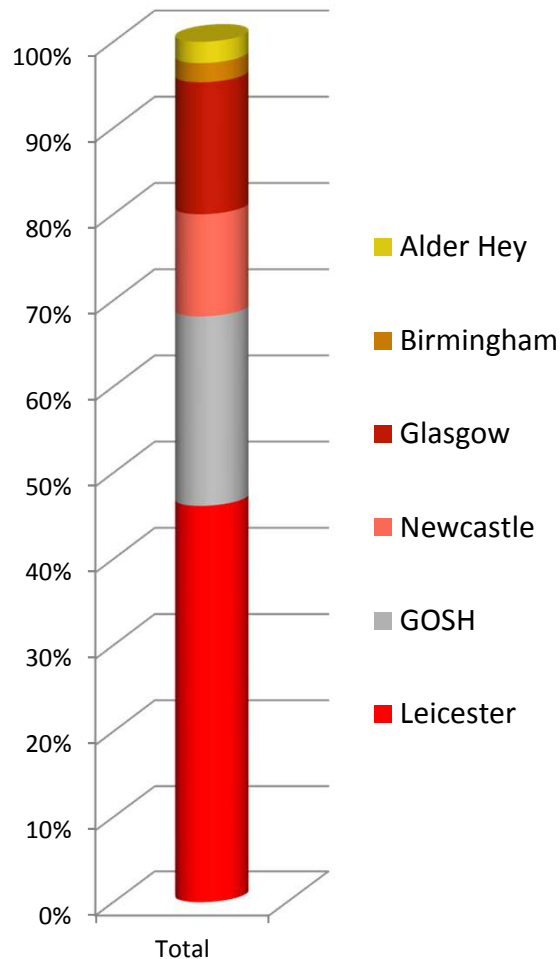
Given the harm, costs and illogicality of NHSE's proposal, we shouldn't be asking whether Birmingham Children's Hospital can accommodate patients from the East Midlands but rather, *should it*.



ECMO Activity

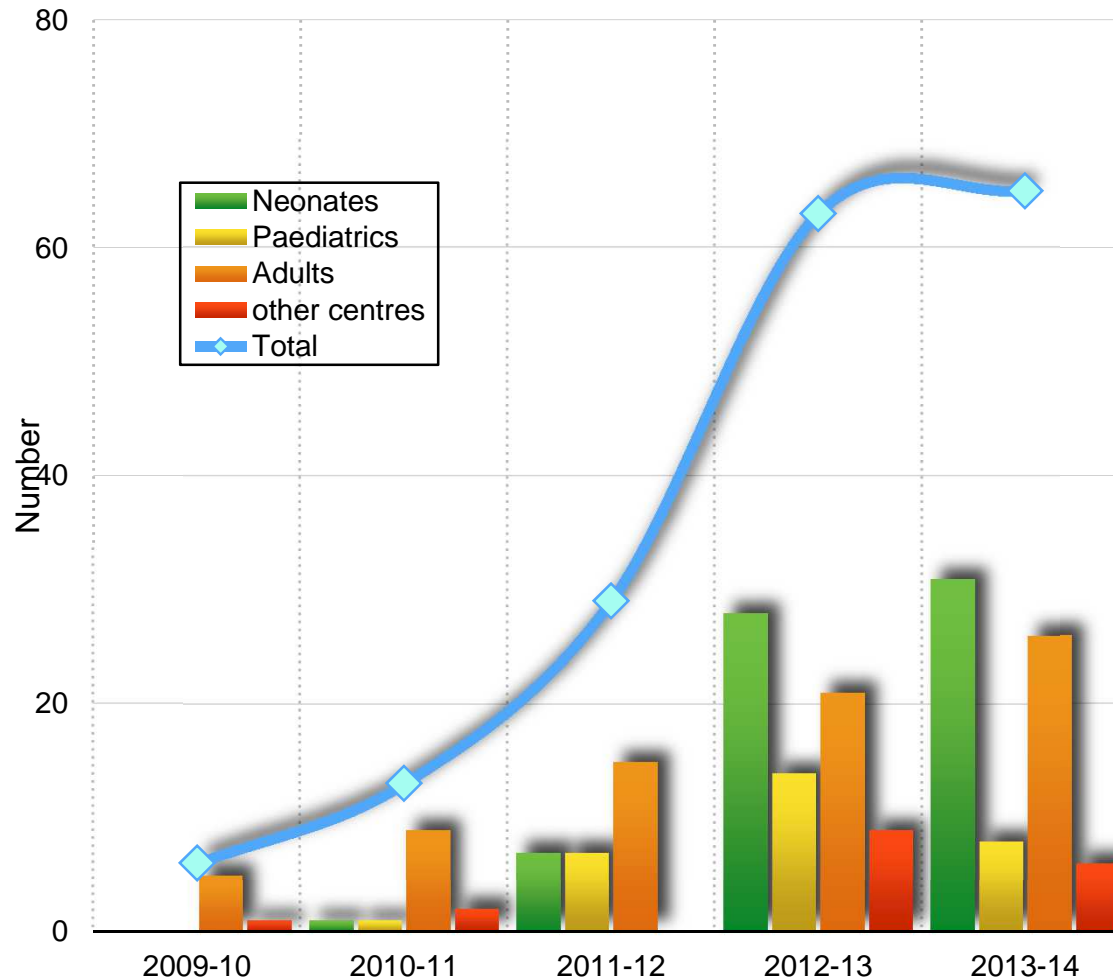
World Leading ECMO Centre

- ECMO Commenced in 1989 funded by our Heart Link Charity
- Second centre globally to treat more than 2000 patients
- Accounts for nearly 50% of UK Respiratory Paediatric activity
- Only UK 24/7 mobile service



Combined UK Respiratory Neonatal & Paediatric Data (2012-2015)

Numbers of mobile ECMO cases



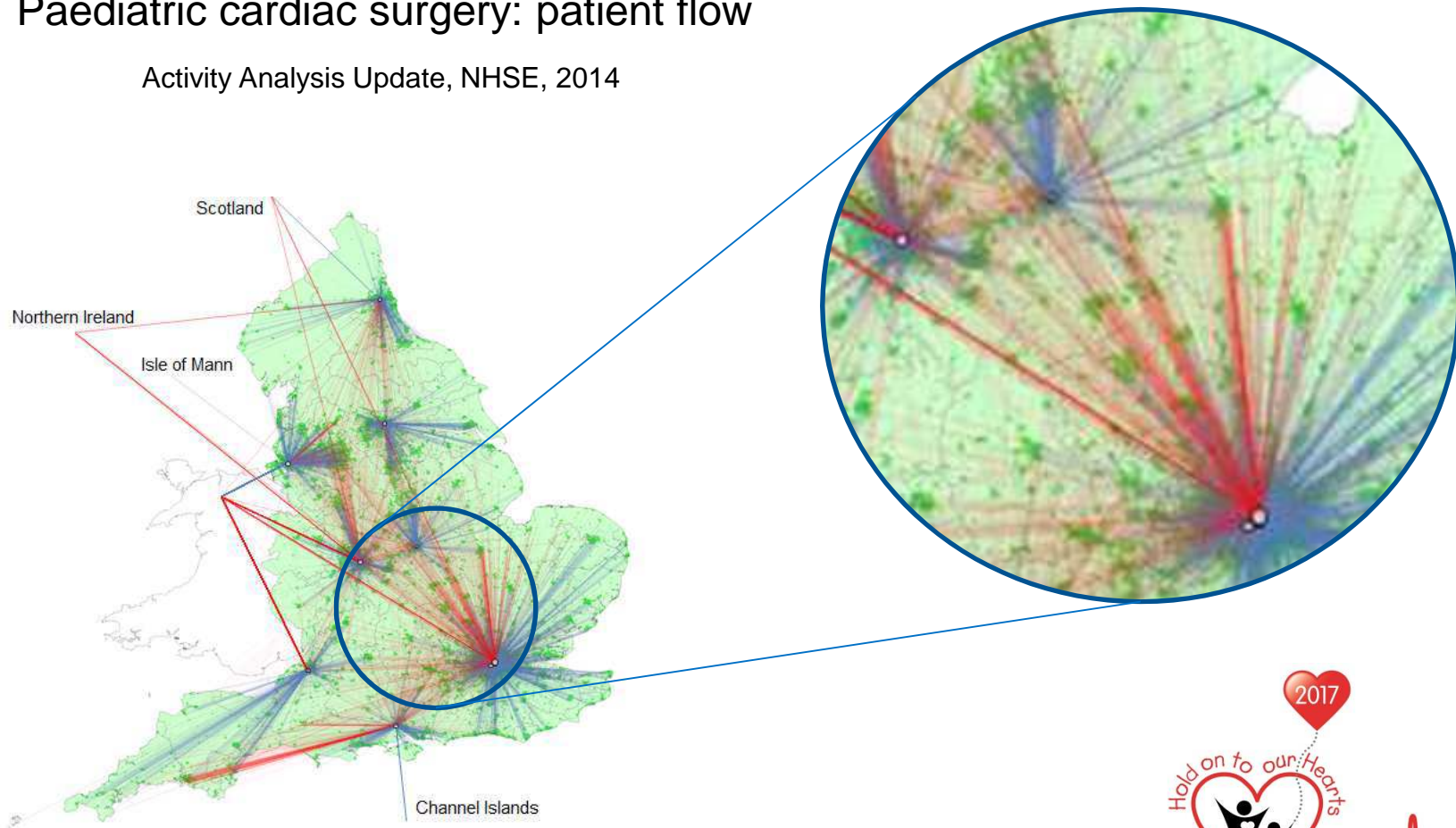
The EMCHC ECMO team dominate the provision across Paediatrics and Adults – the other centres do not have the expertise to manage the additional demand if EMCHC were to close .



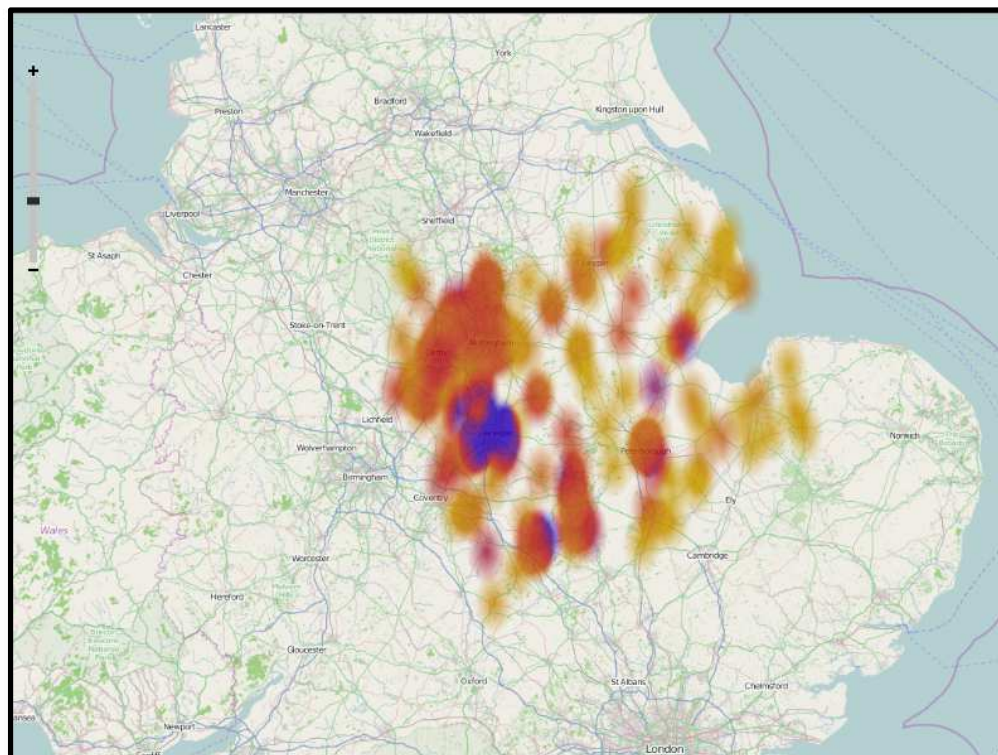
The simple solution: East Midlands patients treated closest to home

Paediatric cardiac surgery: patient flow

Activity Analysis Update, NHSE, 2014



The simple solution: East Midlands patients treated closest to home

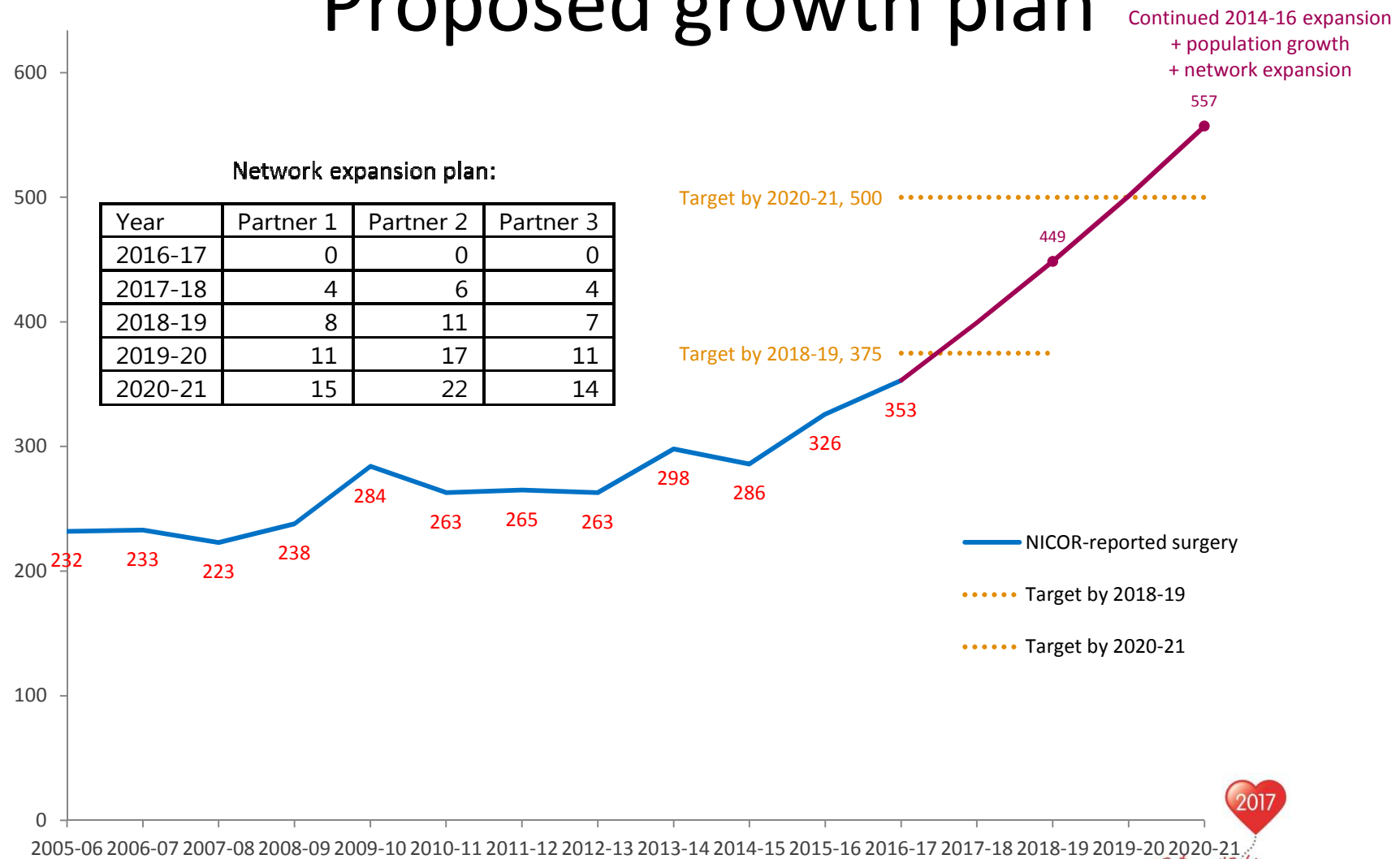


NICOR data 2014-16: 502 operations per year

2017



Proposed growth plan



Summary

- UK CHD surgery already transformed and results now world leading, including in Leicester
- Current process disproportionate, costly and disruptive
- NHS time & resources could be focussed where there is pressing clinical need
- Geographical balance of CHD provision severely threatened by NHSE plans and specifically to the detriment of the East Midlands population
- Any concerns about centre size resolved by adopting our simple proposal to allow East Midlands patients to stay in their region for treatment
- Our proposal should be supported by NHSE, not ignored

14 March 2017

Agenda Item: 6

REPORT OF THE CHAIRMAN OF JOINT CITY AND COUNTY HEALTH SCRUTINY COMMITTEE

NOTTINGHAM UNIVERSITY HOSPITALS NHS TRUST SERVICE REVIEWS

Purpose of the Report

1. To provide the Joint Health Committee with an initial briefing on the review of services and service changes at Nottingham University Hospitals (NUH) being undertaken by Nottingham North and East Clinical Commissioning Group.

Information and Advice

2. Further to the attendance by the commissioners at the last meeting of the Joint Health Scrutiny Committee on 7th February, Nottingham North and East commissioners return to this meeting to provide further details on a range of changes: Pain, Neuro Services, Dietetics, Geriatric Day Care/Medicine Day Care/Complex Rehabilitation, Renal Conservative Management, Chronic Fatigue Syndrome and Motor Neurone Disease.
3. The CCG has indicated that none of the changes are likely to amount to a substantial variation of service. Engagement rather than formal consultation has taken place in relation to these services
4. Hazel Buchanan, Director of Operations at Nottingham North and East CCG (and colleagues) will attend this meeting of the Joint Health Scrutiny Committee to brief Members and answer questions.
5. A full briefing covering all of the areas that are subject to change is attached as an appendix to this report.
6. Members may wish to make a determination as to whether any of the areas of change described are, or may be, substantial variations of service.

RECOMMENDATION

That the Joint City and County Health Scrutiny Committee:

- 1) Consider and comment on the information provided

- 2) Form a view on whether or not any of the service changes or decommissioning described represents a substantial variation of service
- 3) Schedule further consideration, as appropriate, with a view to determining if the changes are in the interests of the local health service

Councillor Parry Tsimbiridis

Chairman of Joint City and County Health Scrutiny Committee

For any enquiries about this report please contact: Martin Gately – 0115 9772826

Background Papers

Nil

Electoral Division(s) and Member(s) Affected

All



**NOTTINGHAM NORTH AND EAST CCG
RUSHCLIFFE CCG
NOTTINGHAM WEST CCG**

NUH Service Review

Joint Health Overview and Scrutiny
Committee – March 2017

This paper provides an overview of consideration that was taken in establishing plans for patient and public engagement along with whether a service change was substantial.

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1. Introduction

CCGs have a duty to act efficiently, effectively and economically and in order to do this, we are continually reviewing and planning services to meet the needs of the local population and to secure value for money. The Nottingham University Hospitals NHS Trust (NUH) service reviews are an element of this. This programme included reviews of 30 separate services and has been carried out to ascertain whether they are being provided to a specification, in the most appropriate setting and whether they are delivering best value for money. For some services, the reviews highlighted that specifications, information on patient outcomes and activity was not available.

This paper outlines the detail for south Nottinghamshire for those services where it was proposed that they were moved into a community setting. The paper includes criteria considered in relation to whether a proposal was deemed to be a substantial variation and a summary of the service user, carer, public and clinical engagement carried out. The paper also includes timescales and any plans for transition.

Proposals were agreed in the NHS Nottingham North and East, Rushcliffe and Nottingham West Governing Bodies on the 10 February 2017. The outcomes of the decisions are included for each service listed in section 2.

1.1 Establishing whether a service change is substantial.

The planning for patient and public engagement, along with whether a service change was substantial, is based on the proportionality of a service and the nature of the proposal. To do this, the CCG balances its duty to make arrangements to involve with its duty to act efficiently, effectively and economically. In relation to the NUH service review, decisions on the nature and extent of public involvement were considered for each service independently in order to take account of specific circumstances and proportionality.

Generally, in order to assess whether a service is substantial, the following criteria will usually be taken into consideration:

Access – in terms of level of inconvenience, reduction or increase in service due to change of location or opening times

Patient Outcomes – impact on patient outcomes, speed of recovery, impact on ability to lead a full life, impact on person's health, level of comfort

Service Delivery – changes in physical environment, impact on how other services are delivered, impact on system

No. of Patients – patient numbers, proportion of population affected

Cost – cost of existing service, level of savings, impact on system

A decision that a proposed change is substantial may be dependent on one area only, or a combination of criteria.

It is not possible to assign specific parameters to define substantial within each of the criteria, however a key element for consideration is the impact on patient outcomes. Proportionality is assessed against the impact on the patient as well as the breadth and type of services commissioned and the size of the service.

1.2 Engagement

For all services engagement was carried out with clinicians, patients/service users, carers and the general public. It was not possible to contact service users directly through NUH and therefore the CCGs reached out through Practice Patient Groups, CCG web-sites, Facebook, Twitter, self-help groups, voluntary sector organisations, libraries, Surestart Centres, post offices.

For all services, it is not possible to determine a percentage of service users who responded for one or more reasons as follows: The CCG is unable to hold personal details; the number of service users is not always known; CCGs do not have access to the lists of service users.

Engagement plans were informed by legal advice and adhered to the statutory requirements of CCGs. In some cases, engagement is ongoing and this is outlined below.

The Equality Impact Assessments can be found in appendix 1 and demographics in appendix 2.

2. Service Changes

2.1 Pain

The Governing Bodies approved the decision to procure a new service, adhering to NICE guidance. The procurement of the service will address fragmentation and provide equity in care across Greater Nottingham. Patient and clinical feedback has been considered in relation to the final specification and has impacted on the commissioning decision and how transition is managed from the existing to new service.

2.1.1 Overview of Proposal

As part of establishing the specification, an evidenced based review of the clinical and cost effectiveness of interventions currently used was conducted by Public Health colleagues and in conjunction with the Core Standards for Pain Management in the UK (Faculty of Pain Medicine Oct 2015), NICE guidance and SIGN (Scottish Intercollegiate Guidelines Network) guidance. This provided a clear way forward to define the proposal in order to improve the consistency and quality of services for patients across the area.

More specifically, in relation to the service itself it was proposed that care be delivered through a three level system:

Level One

Primary care services from GPs, community pharmacists, community psychological therapies, pain self-help organisations/groups and community based physical and psychological therapies.

Level Two

Community based services offering a multi-disciplinary team approach to pain management including specialist physical and psychological therapies, evidence based interventions such as exercise programmes and access to self-help resources.

The Level Two service will consist of a multi-disciplinary team that can assess all referrals, and manage patient's physical, psychological and social needs associated with pain.

It will ensure patients experiencing chronic pain are appropriately managed in a community environment. Patients requiring secondary care can be referred into an appropriate hospital setting when they need specialist interventions and will then be

transferred back to a community setting (if necessary) once Level Three intervention is complete. Injections will be provided in line with NICE guidance and it will be patient choice with respect to whether they go to the hospital or to a community provider to have their injections.

Level Three

Secondary care service for patients requiring surgery or procedures that require an acute care setting. Referrals to this service must be in line with the agreed service pathway

The use of a “never discharged but not followed up” policy will be adopted to enable long term follow up of patients at set points as agreed with the patient. This enables the patient to self-refer back into the service directly when agreed changes in their condition are noted or if the patient/carer/family need to seek advice to assist in self-management.

All patients will have a comprehensive treatment plan. This will enable colleagues across services to talk to the patient regarding their care plan using common language that everyone understands.

For times of crises, the treatment plan will include a clear explanation of the circumstances where it is expected that patients will need to access services, including how to manage flare ups and how the pain services can help in these situations as opposed to patients having to make a decision whether to contact their GP practice or attend Emergency Departments.

Reducing the fragmentation of the current pathway for patients with chronic pain and ensuring more standardisation in the treatment of patients will reduce duplicating or overlapping service provision and the consequent extra payment for the same or similar service. Therefore, it is in keeping with our duty to act effectively, efficiently and economically ensuring value for money.

2.1.2 Assessment of Substantial

Access - Patient choice for locations will increase with the implementation of a community service. Services will be less fragmented. Patients will continue to receive psychological, physical, social support through the service. Services will be in different locations.

Patient Outcomes - Outcomes and patient experience will be at minimal, the same as existing service in relation to impact on a person's health, ability to lead the same quality of life. Service will be delivered in line with NICE guidance – evidence based and outcomes. Therefore, our expectation is that outcomes and experience will improve through services that are patient centred, rather than organisational centred, with ease of access and an evidenced based specification.

Service Delivery - Service model is based on current service delivery and will not impact on range of services or manner of delivery. Same services as currently available will be provided. An additional step of Cognitive Behavioural Therapy will be available for patients. Removal of duplication. Elements of care that need to be provided in a hospital setting will continue to do so. It is not expected that there will be a detrimental impact on other services as a result of the proposal.

Number of Patients – 483 patients access pain management team. 2714 patients per year access the back pain service. (This is the total number and so more than those that will be accessing the newly commissioned service)

Cost – Total cost of services at NUH is £798k

Summary – the change was agreed as not being substantial as patient outcomes will remain the same or improve due to clear levels of care, treatment plans and crisis management. The proposal outlined that patients will receive the same care that they currently receive. Size of service is proportionately small.

2.1.3 Service User, Carer and Public Engagement

Engagement was carried out in two stages in order to both inform the proposal and to receive feedback on the proposal itself and commissioning intentions.

Stage 1 - The first stage of engagement included national patient experience and outcomes, existing local feedback received over the past year (in relation to engagement and patient experience feedback), specific focus groups and patient surveys. 60 patient surveys were completed and 33 people attended focus groups, 20 of whom were patients or carers. The demographics in relation to the survey are included in appendix two.

Service users were asked the following questions:

What would a good pain service feel like?

What mattered to you most throughout your treatment/whilst using the service?

How easy is it to access current services?

What is the follow up care like for this service?

A summary of the feedback related to the importance of a personal/tailored service, the importance of the service in providing freedom from pain and improved quality of life, continuum of care is important taking into consideration the physical and psychological effects of pain, importance of staff who are sympathetic and understand patient needs, importance of knowledgeable staff, importance of service supporting independence and control for individual patients.

Stage 2 – A summary of the proposal was provided for people to comment on. The proposal considered feedback from stage 1. People could comment through the web-site, by email, telephone or in writing. 65 responses were received.

A summary of the feedback is as follows:

Substantial concerns on not having access to injections

Services allow individuals to maintain activities of daily living

All areas of therapy need to be together

Concerns on how equipment will be accessible in and across different community venues

Stage 3 – Focus groups are being held with service users who currently have injections in order to understand more fully their physical, psychological and social needs relevant to service delivery.

2.1.4 Clinical Engagement

At the time of developing the proposal, it was not possible to meet with NUH clinicians. However, robust clinical engagement was sought by involving the following:

- Asking local providers, including NUH to nominate clinicians who could be involved with the work
- The Clinical Senate circulating their wider membership to ask for people who would be prepared to support the reviews
- Approaching key individuals or organisations relevant for the service e.g. Local Optometrist Committee, Chartered Society of Physiotherapy, specialist advisors

- Clinical engagement events were held for some service areas

During stage 2 outlined above, all clinical feedback was considered as part of the decision making process. Consultants and staff within the service provided direct feedback.

A summary of clinical feedback highlighted the experience required for the team, this cohort of patients are vulnerable with physical, psychological and social difficulties, chronic and lasting pain is complex and context sensitive, evidence based management is required that differs from other conditions and requires specialist skills.

2.1.5 Next Steps and Transition

Following consideration of the feedback alongside other criteria, a decision was made to commission a community based service in line with NICE guidance. The service is currently out to tender with the requirement that the new service will be live 15 July 2017. There will be a mobilisation period and how this is managed will depend on the outcome of the procurement process. Any risks will be managed through the mobilisation and transition period. As part of the mobilisation, clinical reviews will be carried out where relevant with existing service users and in order to manage the transition to treatment in line with NICE guidance.

2.2 Neuro Services

The Governing Bodies approved the decision to continue to commission the brain injury and neuro assessment services from NUH. Discussions will be held with NUH on how best to remove duplication and gain efficiencies i.e. through feedback it was highlighted that there is a cohort of patients who are accessing neuro services should be accessing other rehabilitation services. Patient and clinical feedback has been considered in relation to the final specification and has impacted on the commissioning decision to leave the service at NUH.

2.2.1 Overview of Proposal

There are 3 services provided at NUH which serve very similar patient groups:

- Neuro assessment service – this provides outpatient services for patients who have a neurological diagnosis, are under the care of a consultant physician and have specific treatment goals. Specifically the service provides assessment of clinical and psychological needs, identifies and treats or manages problems, and helps co-ordination of services to achieve an integrated, seamless and cost-efficient plan to achieve rehabilitation goals and care.
- Brain injury service – this provides an outpatient service for patients who have had a documented Glasgow Coma Scale Score of 12 or less for at least 30 minutes which requires admission to hospital, and a definite, documented, traumatic brain injury. Specifically it provides interdisciplinary assessment and treatment to patients who present with complex physical and/or cognitive deficits resulting from neurological conditions and who require on-going therapy. Patients are offered an appointment for an initial assessment which results in the patient's goals/focus for neuro rehabilitation and professionals required being identified
- Neuro re-ablement - this service is designed to rehabilitate and enable patients for a wide range of conditions following their admission to hospital. Specifically it facilitates complex discharges and promote earlier discharges , provides rehabilitation in the patient's home, and provides specialist neurological rehabilitation for a wide range of conditions

The proposal was to commission a community based neuro rehabilitation service with the aim of providing the same services and patient outcomes that are currently provided.

The proposal aims to provide a high quality, equitable specialist community neuro-rehabilitation service to reduce the impact of both physical and psychological impairments, maximise independence, reduce mortality and prevent avoidable complications.

The proposed service includes assessment of patients who are referred and confirmation through a multi-disciplinary team whether the patient requires interventions for 16 weeks in relation to a long-term neurological condition or 12 to 14 months for a traumatic or acquired brain injury.

It is proposed that where clinically appropriate for the service, patients will commence on a 16 week or 12 to 14 month community treatment and rehabilitation programme provided by a multi-disciplinary team.

It was proposed that the service provides each patient with a senior expert clinician as their case manager who will oversee the delivery of the plan

It was proposed that by bringing together services that are currently delivered separately there is opportunity to review the overall staffing levels and skill mix whilst still ensuring high quality services are delivered. The aim is that patients will receive intensive but time limited rehabilitation after which they will be referred to community services for the continuation of the rehabilitation programme if required.

2.2.2 Assessment of Substantial

Access – Access would be through a community hub. The proposal included care in the community and in people's own homes.

Patient Outcomes - Outcomes and patient experience will be the same as existing service in relation to the impact on a person's health, flexibility, rehabilitation.

Service Delivery - Service model is based on current service delivery and will not impact on range of services or manner of delivery. Same services as currently available will be provided. It is not expected that there will be a detrimental impact on other services as a result of the proposal.

Number of Patients – Traumatic brain injury is 35-40 new referrals per year. Neuro assessment is 276 referrals per year.

Cost – Total cost of services at NUH is £411k

Summary – the change was agreed as not being substantial as patient outcomes will remain the same or improve due to clear levels of care, treatment plans and crisis management. The proposal outlined that patients will receive the same care that they currently receive. Size of service is proportionately small.

2.2.3 Service User, Carer and Public Engagement

Engagement was carried out in two stages in order to both inform the proposal and to receive feedback on the proposal itself and commissioning intentions.

Stage 1 - The first stage of engagement included national patient experience and outcomes, existing local feedback received over the past year (in relation to engagement and patient experience feedback), specific focus groups, one to one interviews and patient surveys. 40 patient surveys were completed and 19 people attended focus groups and/or were interviewed on a one to one basis. Demographic details in relation to the survey are included in appendix 2.

Service users were asked the following questions:

What would a good neuro service (brain injury, assessment, reablement) feel like?

What mattered to you most throughout your treatment/whilst using the service?
What would you like to change in relation to neuro services?
How easy is it to access current services?
What is the follow up care like for this service?

A summary of the feedback related to the need for immediate and ongoing aftercare following a brain injury, the importance and need for an understanding of their condition and its impact, services need to be linked to community and voluntary sector support for when an individual returns home, lack of knowledge by both general and health professionals on the needs of people with brain injuries, social aspects of care are very important, peer groups are very important.

Stage 2 – A summary of the proposal was provided for people to comment on. The proposal considered feedback from stage 1. People could comment through the web-site, by email, telephone or in writing. 150 responses were received. Two further focus groups were held and 70 people attended these. A petition was also started and comments from this were considered as part of the feedback (the petition related to CCGs stopping brain injury services which was not part of the proposal).

A summary of the feedback is as follows:

The service must recognise patient needs and how an individual is responding to care – flexibility in care plans
The proposal does not reflect the differences in care required for traumatic brain injury vs long term condition
The services requires specialist skills and equipment
The proposal needs to reflect how the service gives people their life back
Continuity of care is very important in relation to how quickly an individual recovers

2.2.4 Clinical Engagement

At the time of developing the proposal, it was not possible to meet with NUH clinicians. However, robust clinical engagement was sought by involving the following:

- Asking local providers, including NUH to nominate clinicians who could be involved with the work
- The Clinical Senate circulating their wider membership to ask for people who would be prepared to support the reviews
- Approaching key individuals or organisations relevant for the service e.g. Local Optometrist Committee, Chartered Society of Physiotherapy, specialist advisors
- Clinical engagement events were held for some service areas

During stage 2 outlined above, all clinical feedback was considered as part of the decision making process. Consultants and staff within the service provided direct feedback.

A summary of the clinical feedback included concerns that the specification did not take into consideration reablement and the needs of patients with traumatic brain injuries versus long term conditions, highlighted that there is a need for flexibility in length and intensity in treatment, working from one base is beneficial to facilitate inter-disciplinary working, including access to equipment.

2.2.5 Next Steps and Transition

Following consideration of the feedback alongside other criteria, a decision was made to keep the neuro services at NUH. This has had positive responses from patients and clinicians.

Commissioners are working with NUH on the structure and design of the services going forward from July onwards. Any risks will be identified through this mobilisation process.

2.3 Dietetics

The Governing Bodies approved the decision to continue to procure new integrated dietetics services. This includes notice being provided to both NUH and Health Partnerships. The procurement of an integrated service will allow for a structured and consistent approach across south Nottinghamshire. Patient and clinical feedback on the proposal related to concerns on ongoing dietetic care for certain conditions. This has been updated and is reflected in the revised specification and included as part of the invitation to tender.

2.3.1 Overview of Proposal

Nottingham University Hospitals (NUH) provides a Dietetics Outpatients service which treats adults and children. The aim of the service is to treat the nutritional consequences of disease through a variety of nutritional interventions. For many of the pathways, patients are seen as part of the multidisciplinary team (MDT) clinic and are generally seen on the same day as the Consultant and other members of the team. In other cases, where a dietitian does not sit in the MDT clinic, referrals are managed in a stand-alone clinic or when they come to NUH for their treatment. The service also offers telephone contacts to appropriate patients.

The service accepts referrals for the following conditions/ reasons renal, diabetes, obesity, cancer, HIV, Cystic Fibrosis, Gastroenterology conditions (e.g. Coeliac Disease), Paediatrics specific conditions (Metabolic, Allergy, Failure to thrive).

In addition to the NUH dietetics service, there is also a community dietetic service provided by Community Health Partnerships. They may see patients for similar conditions and provide community based clinics, group sessions and home visits.

Due to the nature of long term conditions managed by the Dietetics Outpatient team, service users may vary between requiring specialist management within secondary care, and when more stable could be managed within the community setting, closer to home.

At present, it is difficult to flow between the two services and settings. Therefore the proposal is for a single provider (or group of providers working together) to provide an integrated dietetic service to deliver all non-inpatients dietetics.

The proposal is for an integrated dietetic service with the aim that it will provide the following:

- A structured and consistent approach to dietetic management through multidisciplinary working, promoting effective and integrated working relationships with the clinicians within the acute setting, community services and Primary Care.
- The aim that the most appropriate clinician, setting and intervention are identified and offered at the outset of treatment. This is reviewed during the patients care and is adjusted as clinically appropriate.
- A movement towards specialist staff delivering services closer to home and up-skilling of community staff to see a more complex case mix.
- A broader offer of delivery methods, to include group sessions, improved access to self-care information and greater use of technology.

2.3.2 Assessment of Substantial

Access – Service provision will continue to be community and hospital based. Access will be improved through clearer patient journeys and removal of duplication of services across providers.

Patient Outcomes - Outcomes and patient experience will be the same as existing services, if not improved through a clearer patient journey and removal of fragmentation. Therefore, our expectation is that outcomes and experience will improve through services that are patient centred, rather than organisational centred

Service Delivery - Service model is based on current service delivery and will not impact on range of services or manner of delivery. Duplication will be removed and specialist skills will be maintained within an integrated service. It is not expected that there will be a detrimental impact on other services as a result of the proposal.

Number of Patients – Not available – contacts over a year were 133 for the community service and 3638 for the acute service.

Cost – Total cost of services is £584k

Summary – the change was agreed as not being substantial as patient outcomes will remain the same due to the proposal using the same service model as is currently provided. Services will be provided in the most appropriate clinical setting ie community or hospital based and in the majority of **circumstances** this will be the same as current arrangement.

2.3.3 Service User, Carer and Public Engagement

Engagement was carried out in two stages in order to both inform the proposal and to receive feedback on the proposal itself and commissioning intentions.

Stage 1 - The first stage of engagement included existing local feedback received over the past year (in relation to both engagement and patient experience feedback), patient surveys and one to one discussions. 10 people commented on dietetics.

Service users were asked the following questions:

What would a good dietetics service feel like?
What mattered to you most whilst using the service?
What would you like to change in relation to dietetic services?
How easy is it to access current services?

A summary of the feedback related to patients lacking confidence about their condition, referrals being refused/rejected and the patient being sent back to their GP – resulting in patients not being seen by any of the dietetics services commissioned. Lack of clarity from the services as to which patients they are treating resulting in service not working well and pathways not being clear, better education and information of dietary needs are needed.

Stage 2 – A summary of the proposal was provided for people to comment on. The proposal considered feedback from stage 1. People could comment through the web-site, by email, telephone or in writing. 52 responses were received.

A summary of the feedback is as follows:

Assurance that support will continue for babies/children with PKU, including during periods of illness.

Concerns as to whether the service will have specialist knowledge around certain conditions
To have specialist knowledge including of renal patients.

Will patients still be able to access specialist dietetics information when they are at the hospital for other treatments i.e. dialysis.

2.3.4 Clinical Engagement

At the time of developing the proposal, it was not possible to meet with NUH clinicians. However, robust clinical engagement was sought by involving the following:

- Asking local providers, including NUH to nominate clinicians who could be involved with the work
- The Clinical Senate circulating their wider membership to ask for people who would be prepared to support the reviews
- Approaching key individuals or organisations relevant for the service e.g. Local Optometrist Committee, Chartered Society of Physiotherapy, specialist advisors
- Clinical engagement events were held for some service areas

During stage 2 outlined above, all clinical feedback was considered as part of the decision making process. Consultants and staff within the service provided direct feedback.

A summary of clinical feedback highlighted the risk of fragmentation, concerns that inpatient dietetics will be de-stabilised due to a shortage of clinical skills, an erosion of skilled workforce in the system, for patients with chronic kidney disease a close link between the consultant and dietetics will need to be maintained, clinical risk due to communication required with different dieticians across the system.

2.3.5 Next Steps and Transition

The service is currently out to tender with the requirement that the new service will be live 15 July 2017. Since announcing the decision, further feedback has been received in relation to the alignment with specialised services which are commissioned by NHS England. There will be a mobilisation period and how this is managed will depend on the outcome of the procurement process. Any risks will be managed through the mobilisation and transition period.

2.4 Complex Rehabilitation/Medicine Day Care/Geriatric Day Care

The Governing Bodies approved the decision to move the service into the community as part of integrated rehabilitation services. This will provide greater access for patients and alignment with other relevant services in particular falls and stroke. Patient and clinical feedback related predominantly to concerns on the removal of a service for patients with Parkinson's. As a result, a specific annex is being written to ensure that Parkinson's patients continue to receive the same level of care.

2.4.1 Overview of Proposal

The Nottingham University Hospitals Rehabilitation Unit (NUHRU) provides specialised comprehensive, multidisciplinary assessment and individualised treatment programmes to meet the goals and needs of frail older out-patients whose needs are too complex to be provided for effectively in community i.e. complex falls patients, early complex stroke patients, Parkinson's Disease patients and complex geriatric patients. Patients are discussed at a multidisciplinary team (MDT) meeting, and a goal-oriented, individualised care plan produced.

The proposal is that the service will be provided in either a community location with specialised equipment or in the home environment.

Referral criteria will remain the same, along with a focus on complex falls and complex neurological conditions including Parkinson's Disease.

It was proposed to deliver rehabilitation for this cohort of patients with the aim of services being integrated. The aim of the proposal is to provide rehabilitation following a multi-disciplinary

team approach with physiotherapy, occupational therapy and social care being provided by a community service. The proposal includes medical review of complex patients within a multi-disciplinary team environment and the aim is that this would also include a community geriatrician service and where complex investigations are needed, these would be requested through secondary care (for example, tilt table testing and imaging). It is proposed that close links with primary care on prescribing and medicines management would support the service model and support for nursing services such as continence care and dietetics support would be provided through community services.

The delivery model will exclude stroke patients where those stroke patients will be cared for by the specialist stroke community service.

2.4.2 Assessment of Substantial

Access – Service provision will be provided in a community setting and integrated with existing services. Therefore services should be more accessible for patients.

Patient Outcomes - Outcomes and patient experience will be the same as existing services, if not improved through the integration with existing services. Therefore, our expectation is that outcomes and experience will improve through services that are patient centred, rather than organisational centred, with ease of access and an evidenced based specification

Service Delivery - Service model is based on current service delivery and will not impact on range of services or manner of delivery. Patients currently accessing the service who have had a fall will be managed through the specific falls services. Patients with Parkinson's will have the same service within existing rehabilitation services. Duplication will be removed and specialist skills will be maintained within an integrated service. It is not expected that there will be a detrimental impact on other services as a result of the proposal.

Number of Patients – 421 patients referred into the service.

Cost – Total cost of service is £1.1m

Summary – the change was agreed as not being substantial as patient outcomes will remain the same due to the proposal using the same service model as is currently provided. Services for patients accessing complex rehab are already provided in the community in relation to falls and stroke. Parkinson's patients will continue to receive the same service in a community setting. The cost of the service will reduce considerably however care to patients will be the same if not improved.

2.4.3 Service User, Carer and Public Engagement

Engagement was carried out in two stages in order to both inform the proposal and to receive feedback on the proposal itself and commissioning intentions.

Stage 1 - The first stage of engagement included existing local feedback received over the past year (in relation to both engagement and patient experience feedback), detail from a national survey on rehab for Parkinson's patients, NHS England patient feedback in commissioning guidance for rehabilitation, interviews with patients at the NUH rehabilitation unit, patient feedback in relation to falls services. Seven responses were received on the survey and eleven patients were interviewed on a one to one basis. Demographic details are included in appendix 2.

Service users were asked the following questions:

What would a good service feel like?
What mattered to you most whilst using the service?
What would you like to change in relation to services?
How easy is it to access current services?

A summary of the feedback included positive patient experience, the service feels more important being provided in a hospital. However, the majority of patients felt that the service did not need to be provided in a hospital. Patients want personalised care which is tailored to them as individuals. A small number of patients saw a doctor. Can see an improvement through the physiotherapy. The service includes the social side i.e. a day out for a half hour appointment. The service can be difficult to access due to attending for a day/half day.

Stage 2 – A summary of the proposal was provided for people to comment on. The proposal considered feedback from stage 1. People could comment through the web-site, by email, telephone or in writing. 39 responses were received.

A summary of the feedback predominantly related to patients with Parkinson's and concerns that the proposal did not cover the current service received. Peer and social support is important, how will community services have the specialist equipment, group exercise is very beneficial, will this compromise patient treatment resulting in more use of drugs.

For this service there will be a stage three for engagement which will cover Parkinson's specifically.

Stage 3 – Two focus groups are being held to discuss the annex for patients with Parkinson's. These are being co-ordinated with the support of Parkinson's UK.

2.4.4 Clinical Engagement

At the time of developing the proposal, it was not possible to meet with NUH clinicians. However, robust clinical engagement was sought by involving the following:

- Asking local providers, including NUH to nominate clinicians who could be involved with the work
- The Clinical Senate circulating their wider membership to ask for people who would be prepared to support the reviews
- Approaching key individuals or organisations relevant for the service e.g. Local Optometrist Committee, Chartered Society of Physiotherapy, specialist advisors
- Clinical engagement events were held for some service areas

During stage 2 outlined above, all clinical feedback was considered as part of the decision making process. Consultants and staff within the service provided direct feedback.

A summary of clinical feedback highlighted the medical and rehab needs of complex patients and concerns as to whether these had been fully considered as part of the proposal, this is a group of patients requiring regular, multi-disciplinary assessment and treatment, concerns on the capability to safely manage heavy equipment in the community.

2.4.5 Next Steps and Transition

Mobilisation will be carried out between March and June with the transfer to community services taking place in July. Mobilisation includes further service user, carer and public engagement in order to inform the appendix to the contract. Mobilisation will also include meetings between providers in order to discuss the services and transition in detail. This will include any relevant discussions on staff. Discussions to date have not identified any risks.

2.5 Renal Conservative Management

The Governing Bodies approved the decision to continue with the service at NUH and to commission as part of an overall renal service covering home dialysis and renal conservative management. This was as a result of the specialist knowledge required for the service, recognising also that through the review efficiencies were identified.

2.5.1 Overview of Proposal

End of life support through the Conservative Management Home Visiting Service for end stage renal disease. The current service provides advanced care planning, symptom management, practical nursing care, facilitates end of life care and discusses preferred place of care and death.

There are currently other dedicated end of life services provided in the community and therefore the proposal was to move this service to the community with the aim of fully integrated care. It was proposed that this could allow for a greater emphasis on patient outcomes and how to meet these and improved patient and carer experience. The proposed change takes into consideration the removal of duplication in services and as a result, could provide better value for money.

The proposal outlines a case management approach:

Principles include:

- 24 hour nursing care within their own home due to long term chronic disease or as a result of an acute episode of ill health;
- Ongoing case management or rehabilitation as a result of a long term condition(s) or complex needs from multiple conditions.
- Adherence to and provision of evidence of compliance with the NICE quality standard for End of life for adults.

The proposal was that the service will continue to be provided in a patient's own home and the aim of the new model is care co-ordination across other relevant community services.

2.5.2 Assessment of Substantial

Access – Service provision would be the same in that the majority of care would be provided in the patient's own home.

Patient Outcomes - Outcomes and patient experience would be the same as the existing service.

Service Delivery - Service model is based on current service delivery and will not impact on range of services or manner of delivery. Patients would receive the same care predominantly in their own homes. Specialist skills would be the same with access to very specialist knowledge remaining at NUH.

Number of Patients – 77 referrals in one year.

Cost – Total annual cost of service is £31k.

Summary – the change was agreed as not being substantial as patient outcomes will remain the same due to the proposal using the same service model as is currently provided. Service provision would also remain in patient's own home.

2.5.3 Service User, Carer and Public Engagement

Engagement was carried out in two stages in order to both inform the proposal and to receive feedback on the proposal itself and commissioning intentions.

Stage 1 – Due to the specialist nature of the service it was very difficult to reach out to service users and NUH were unable to provide access to patients currently in the service. Previous engagement on end of life services was used to inform the proposal.

Stage 2 - Two comments were received, again reflecting the very specialist nature of the service. The concern was that the proposal focused predominantly on end of life when the service provided a wider spectrum of care. Patients could be with the service for as long as five years.

2.5.4 Clinical Engagement

At the time of developing the proposal, it was not possible to meet with NUH clinicians. However, robust clinical engagement was sought by involving the following:

- Asking local providers, including NUH to nominate clinicians who could be involved with the work
- The Clinical Senate circulating their wider membership to ask for people who would be prepared to support the reviews
- Approaching key individuals or organisations relevant for the service e.g. Local Optometrist Committee, Chartered Society of Physiotherapy, specialist advisors
- Clinical engagement events were held for some service areas

During stage 2 outlined above, all clinical feedback was considered as part of the decision making process. Consultants and staff within the service provided direct feedback.

A summary of clinical feedback highlighted that the service supported complex renal patients requiring specialist skills, provides a specialised system management for patients who are not suitable or do not wish to go on dialysis, end of life is only a small part of the service, if decommissioned NUH would not be able to offer ad hoc telephone advice.

2.5.5 Next Steps and Transition

Commissioners are working with NUH on the structure and design of the services going forward from July onwards. Any risks will be identified through this mobilisation process.

2.6 Chronic Fatigue Syndrome (CFS) Service

The Governing Bodies approved the decision to move the service into the community, ensuring that specialist knowledge on CFS was maintained. The service will be provided in line with NICE guidance and will be part of the pain service which is being procured. Patient engagement emphasised the importance of specialist CFS knowledge as well as peer support for patients.

2.6.1 Overview of Proposal

The current service at Nottingham University Hospitals (NUH) assesses and helps those patients diagnosed with mild to moderate Chronic Fatigue Syndrome (CFS). The service supports patients to develop appropriate strategies for managing their symptoms and improving their quality of life. Patients begin with a therapist or consultant assessment. Patients can be discharged at this point with advice, or they can receive one or more of the following interventions:

- 6-8 individual sessions with an occupational therapist
- 9 week group programme led by appropriate therapists
- 10 -12 individual Cognitive Behavioural Therapy (CBT) or Psychology sessions

The National Institute for Clinical Excellence (NICE) has published guidelines for CFS management which recommend the following:

- Patients and therapists working together
- Cognitive Behavioural Therapy
- Graded Exercise Therapy

NICE highlights that these are the interventions for which there is the clearest evidence of benefit. In addition the guidelines advise that CFS services should provide support if symptoms worsen during treatment and should develop a plan to manage relapses.

It is proposed that this service provides evidence based interventions only, as identified by NICE. The proposal is that a community based service will provide the following:

- Be delivered by a multi-disciplinary team which will include appropriate CFS specialists that can triage all referrals and manage patient's physical, psychological and social needs
- Act as a single point of access for patients with chronic pain or CFS providing a simpler patient journey
- Provide a holistic assessment and management approach for patients with chronic pain or CFS as early as possible in the pathway
- Support patients living with chronic pain or CFS and their nominated carers to:
 - manage their own condition and make decisions about self-care and treatment
 - allow them to live as independently as possible continue care and support (where appropriate) learnt through the service post discharge
- Provide appropriate access points for patients and carers following discharge to support in the management of flare ups and avoid re-entry into the service where possible

As part of the proposal, the group therapy that is currently provided will not continue. It is proposed that this service could be integrated into existing community based physio and rehab services. In order to ensure the specialist skills for CFS continue in the community the specification will include the requirement that clinicians have the competencies required to work with CFS patients.

2.6.2 Assessment of Substantial

Access – Service provision will be provided in a community setting and integrated with existing services. Therefore services should be more accessible for patients.

Patient Outcomes - Outcomes and patient experience will be the same as existing services, if not improved through the integration with existing services. Therefore, our expectation is that outcomes and experience will improve through services that are patient centred, rather than organisational centred, with ease of access and an evidenced based specification

Service Delivery - Service model is based on current service delivery and in line with NICE guidance. Duplication will be removed and specialist skills will be maintained within an integrated service. It is not expected that there will be a detrimental impact on other services as a result of the proposal.

Number of Patients – Number of patients is not available. Over one year there were 77 visits with a consultant, 158 attendances at the CBT course, 449 attendances at group therapy, 251 individual therapy courses and 125 therapy assessments.

Cost – Total annual cost of the service is £135k.

Summary – the change was agreed as not being substantial as patient outcomes will remain the and the proposal is in line with NICE guidance providing evidenced base care. Specialist CFS knowledge will be retained and accessibility will include various community settings.

2.6.3 Service User, Carer and Patient Engagement

Stage 1 - The first stage of engagement included existing local feedback received over the past year (in relation to both engagement and patient experience feedback), review of patients feedback in relation to the NICE guidance, focus groups held with patients, patient survey. Demographic details in relation to the survey are included in appendix 2. 18 responses were received via the online survey and 20 people attended focus groups.

Service users were asked the following questions:

What would a good service feel like?
What mattered to you most whilst using the service?
What would you like to change in relation to services?
How easy is it to access current services?

A summary of the feedback included the need for services to have an understanding of CFS (so they can validate, recognise and believe those that are ill), clinicians to have an understanding of the individual, being listened to by caring and empathetic practitioners, GPs to have a better awareness of NICE recommendations, up-to-date treatment methods, capability to support patients at different stages so that patient can “re-programme” themselves, access to a multidisciplinary team is beneficial, flexibility in service delivery, option of group and individual sessions, support for carers is required.

Stage 2 – A summary of the proposal was provided for people to comment on. The proposal considered feedback from stage 1. People could comment through the web-site, by email, telephone or in writing. 16 responses were received.

A summary of the feedback predominantly related to accessibility of the service and the need for flexibility. Group therapy is beneficial in managing the condition. The service does require clinicians with specialist knowledge of CFS. Service users have mixed views on graded exercise therapy. Patients welcome the opportunity to talk to other people with CFS, in particular to discuss their coping mechanisms and how they’ve been able to “re-programme” themselves.

2.6.4 Clinical Engagement

At the time of developing the proposal, it was not possible to meet with NUH clinicians. However, robust clinical engagement was sought by involving the following:

- Asking local providers, including NUH to nominate clinicians who could be involved with the work
- The Clinical Senate circulating their wider membership to ask for people who would be prepared to support the reviews
- Approaching key individuals or organisations relevant for the service e.g. Local Optometrist Committee, Chartered Society of Physiotherapy, specialist advisors
- Clinical engagement events were held for some service areas

During stage 2 outlined above, all clinical feedback was considered as part of the decision making process. Consultants and staff within the service provided direct feedback.

A summary of clinical feedback highlighted concerns on the discontinuation of group therapy and the feeling that NICE guidance is out of date.

2.6.5 Next Steps and Transition

The service is currently out to tender as part of the pain service with the requirement that the new service will be live 15 July 2017. There will be a mobilisation period and how this is managed will depend on the outcome of the procurement process. Any risks will be managed through the mobilisation and transition period. In order to support group therapy going forward, CCGs are working with self-help Nottingham to establish specific CFS groups.

2.7 Motor Neurone Disease (MND) Home Visiting Service

The Governing Bodies approved the decision to move the service from NUH into existing community services. A specific annex to the contract for the provider of community services will ensure that the specialist skills are available to care for patients with MND. Patient feedback emphasised the complexity of disease and the need for multi-disciplinary care which can be provided more effectively through an integrated community service.

2.7.1 Overview of Proposal

The MND Care Co-ordinator provides home visits which include a holistic health, psychosocial and physical review. The main emphasis being on MND symptom management control.

In reviewing this service the proposal took into consideration the view that there is duplication with services provided in the community. It was proposed that if the service was moved out of the acute setting this could allow for improved integration of care and as a result a greater emphasis on patient outcomes.

It was proposed that care will still be provided in a patient's home as required. The proposal is to maintain the current principles of crisis management, rehabilitation, self-management. The following care is provided under the existing service and it is proposed that it will continue with the new service:

- Assessment of oxygen saturation levels
- Swallow assessment
- Nutrition assessment
- Activities of daily living assessment
- Discussion regarding Do Not Resuscitate
- Discuss advance decision to refuse treatment (and put this in place)
- Facilitate end of life care with community teams and GP
- Discuss preferred place of care and death

The proposal included care co-ordination across other relevant community services. It is proposed that links with the acute neurology team will remain.

2.7.2 Assessment of Substantial

Access – Service provision will be provided in a home environment and provide greater integration with existing community services. Therefore services should be more accessible for patients.

Patient Outcomes - Outcomes and patient experience will be the same as existing services, if not improved through the integration with existing services. Therefore, our expectation is that outcomes and experience will improve through services that are patient centred, rather than organisational centred.

Service Delivery - Service model is based on current service delivery with access to the same specialist skills. It is not expected that there will be a detrimental impact on other services as a result of the proposal.

Number of Patients – 17 referrals and 27 contacts over one year.

Cost – Total annual cost of the service is £62k.

Summary – the change was agreed as not being substantial as patient outcomes will remain the same. Access to specialist services will remain, along with care in a patient's own home. Service is very small and therefore, would be beneficial to be part of an integrated service.

2.7.3 Service User, Carer and Public Engagement

Engagement was carried out in two stages in order to both inform the proposal and to receive feedback on the proposal itself and commissioning intentions.

Stage 1 – Due to the specialist nature of the service it was very difficult to reach out to service users and NUH were unable to provide access to patients currently in the service. MND Nottinghamshire asked patients and carers to complete a survey and provided feedback. A national survey on improving MND care was used as well as existing feedback. Demographic details in relation to the CCG survey are included in appendix 2. Four people responded to the online survey. To put this in context, the number of contacts with MND patients recorded in 2015/16 by NUH was 27.

A summary of the feedback included that services can be provided in the community – mobility can be a big problem for MND patients so care in the community is beneficial if it's accessible. Patients with MND have a high regard for the care centre at Queen's Medical Centre with treatment being very personalised to individual patients. Individuals need good access to a range of specialists. Individuals feel it takes too long to get a diagnosis.

Stage 2 - Three comments were received, reflecting the small numbers of patients with this condition. Feedback highlighted that there needs to be the right capacity and capability ensuring skills and expertise to meet the complex needs of patients with MND. Patients need access to a wide range of support and care. Services need to be able to respond and implement care plans quickly and be able to meet the needs relevant to the degenerative nature of the disease.

Stage 3 – Further engagement will be carried out with carers and service users in order to ensure that all factors are considered as part of future service delivery..

2.7.4 Clinical Engagement

At the time of developing the proposal, it was not possible to meet with NUH clinicians. However, robust clinical engagement was sought by involving the following:

- Asking local providers, including NUH to nominate clinicians who could be involved with the work
- The Clinical Senate circulating their wider membership to ask for people who would be prepared to support the reviews
- Approaching key individuals or organisations relevant for the service e.g. Local Optometrist Committee, Chartered Society of Physiotherapy, specialist advisors
- Clinical engagement events were held for some service areas

During stage 2 outlined above, all clinical feedback was considered as part of the decision making process. Consultants and staff within the service provided direct feedback.

A summary of clinical feedback highlighted that a specialist rather than a generic approach to care co-ordination is required, community teams need to work in close partnership with acute sector for integrated pathway, the service must be able to meet NICE quality standards.

2.7.5 Next Steps and Transition

Mobilisation will be carried out between March and June with the transfer to community services taking place in July. Mobilisation includes further service user, carer and public engagement in order to inform the appendix to the contract. Mobilisation will also include meetings between providers in order to discuss the services and transition in detail. This will include any relevant discussions on staff. Discussions to date have not identified any risks.

3. Conclusion

Patient, service user, public and clinical feedback has informed decisions throughout the process of the NUH service review. Activities have been proportionate and have met statutory responsibilities. Out of 30 services reviewed, five are moving to the community and three of these are out to procurement. Therefore, the overall programme has not had a detrimental impact on other services and/or the system. The five services are Pain, Chronic Fatigue Syndrome, Dietetics, Motor Neurone Disease Home Visiting, Complex Rehab. The programme of work has been a positive step forward and is an example of good commissioning, with the outcome that commissioners and NUH have greater clarity on the services which are now supported by evidenced based specifications.

When considering the services individually against criteria including access, service delivery, patient outcomes, number of patients and cost they are not considered to be substantial or significant. Patient and public engagement has been central to informing the specifications and the commissioning decisions and this has been carried out proportionately to the changes.

Appendix 1 – Equality Impact Assessments

1. Pain Services

No negative impacts on the protected characteristics were identified. There were no concerns identified for other minority populations (eg travellers, sex workers, single parents, those on low income) who may be disadvantaged by the policy or service's operation, or who may receive unequal treatment. The proposal does not directly/indirectly discriminate against any section of the community.

	Negative Impact	Positive Impact	Neutral Impact	Reason(s)
Age			X	The service to be commissioned will continue to provide services with community settings. Therefore this will not adversely impact any group inequitably on the basis of age. The wider implications of this decision to the patient-group as a whole (regardless of Age), are considered within the relevant Quality Impact Assessment.
Disability – including physical, sensory or mental		X		The service to be commissioned will continue to provide services with community settings. Therefore this may positively impact on the basis of disability due to service potentially being provided closer to home. The wider implications of this decision to the patient-group as a whole (including those with Disabilities), are considered within the relevant Quality Impact Assessment.
Gender - including transgender and issues relating to pregnancy and maternity			X	The service to be commissioned will continue to provide services with community settings. This will not adversely impact any group inequitably on the basis of gender. The wider implications of this decision to the patient-group as a whole (regardless of Gender), are considered within the relevant Quality Impact Assessment.
Race/Ethnicity			X	The service to be commissioned will continue to provide services with community settings. This will not adversely impact any group inequitably on the basis of race or ethnicity. The wider implications of this decision to the patient-group as a whole (regardless of race or ethnicity), are considered within the relevant Quality Impact Assessment.
Religion or Belief			X	The service to be commissioned will continue to provide services with community settings. This will not adversely impact any group inequitably on the basis of religion or belief. The wider implications of this decision to the patient-group as a whole (regardless of religion or belief), are considered within the relevant Quality Impact Assessment.
Sexual Orientation – including issues relating to marriage and civil partnerships			X	The service to be commissioned will continue to provide services with community settings. This will not adversely impact any group inequitably on the basis of sexual orientation. The wider implications of this decision to the

				patient-group as a whole (regardless of sexual orientation), are considered within the relevant Quality Impact Assessment.
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2. Neuro Services

No negative impacts on the protected characteristics were identified. There were no concerns identified for other minority populations (eg travellers, sex workers, single parents, those on low income) who may be disadvantaged by the policy or service's operation, or who may receive unequal treatment. The proposal does not directly/indirectly discriminate against any section of the community.

	Negative Impact	Positive Impact	Neutral Impact	Reason(s)
Age			X	The service will cover patients over the age of 16 registered with all CCGs within the NUH consortia. Patients under the age of 16 will be seen within paediatrics and remain under a consultant. There is no impact to specific age groups.
Disability – including physical, sensory or mental		X		We would expect the provider to be able to support the following groups: <ul style="list-style-type: none"> • mobility impaired • physically impaired • citizens with 1 or more long term condition • deaf/hearing impaired • blind/partially sighted • speech impairment • learning disability • citizens with a mental health condition The provider should also have access to translators and people who are able to use sign language. The new specification requires treatments to be delivered in the home as well as in NUH facilities. This enables the provider to meet any additional needs the patient may have, in their own environment. All staff would be appropriately trained to support patients with this long term condition.
Gender - including transgender and issues relating to pregnancy and maternity		X		The provider is expected to have undertaken the necessary training and knowledge to understand these protected characteristics, and is expected not to discriminate or disadvantage any patients based on this characteristic.
Race/Ethnicity		X		The service is not targeted towards any specific race; patients are referred by healthcare professionals (predominantly secondary care) based on the referral criteria outlined in the service specification, which does not indicate any specific race requirements.
Religion or Belief		X		The provider is expected to be sensitive to patients religious and belief needs by supporting them with their preferences e.g. providing female staff for female patients.
Sexual Orientation – including issues relating to marriage and civil partnerships		X		The provider is expected to have undertaken the necessary training and knowledge to understand this characteristic, and is expected not to discriminate or disadvantage any patients based on this characteristic. Spouses and partners will be supported by the provider of this service and appropriately trained to support the patient at home.

3. Dietetics

No negative impacts on the protected characteristics were identified. There were no concerns identified for other minority populations (eg travellers, sex workers, single parents, those on low income) who may be disadvantaged by the policy or service's operation, or who may receive unequal treatment. The proposal does not directly/indirectly discriminate against any section of the community.

	Negative Impact	Positive Impact	Neutral Impact	Reason
Age			X	Neutral impact - The service will continue to be delivered, however the setting may be different.
Disability – including physical, sensory or mental		X		Positive impact - The service will continue to be delivered, however were possible, the service will be delivered from accessible community locations.
Gender – including trans* and issues relating to pregnancy and maternity			X	Neutral impact - The service will continue to be delivered, however the setting may be different.
Race/Ethnicity			X	Neutral impact - The service will continue to be delivered, however the setting may be different.
Religion or Belief			X	Neutral impact - The service will continue to be delivered, however the setting may be different.
Sexual Orientation - including issues relating to marriage and civil partnerships			X	Neutral impact - The service will continue to be delivered, however the setting may be different.

4. Complex Rehab/Medicine Day Care/Geriatric Day Care

No negative impacts on the protected characteristics were identified. There were no concerns identified for other minority populations (eg travellers, sex workers, single parents, those on low income) who may be disadvantaged by the policy or service's operation, or who may receive unequal treatment. The proposal does not directly/indirectly discriminate against any section of the community.

	Negative Impact	Positive Impact	Neutral Impact	Reason(s)
Age			X	Patients are still entitled to receive alternative community care.
Disability – including physical, sensory or mental		X		The location of more community services will benefit those who find difficulty in travelling.
Gender - including transgender and issues relating to pregnancy and maternity			X	Patients are still entitled to receive alternative community care.
Race/Ethnicity			X	Patients are still entitled to receive alternative community care.
Religion or Belief			X	Patients are still entitled to receive alternative community care.
Sexual Orientation – including issues relating to marriage and civil partnerships			X	Patients are still entitled to receive alternative community care.

5. Renal Conservative Management

No negative impacts on the protected characteristics were identified. There were no concerns identified for other minority populations (eg travellers, sex workers, single parents, those on low income) who may be disadvantaged by the policy or service's operation, or who may receive unequal treatment. The proposal does not directly/indirectly discriminate against any section of the community.

	Negative Impact	Positive Impact	Neutral Impact	Reason(s)
Age			X	The service will be delivered via an alternative pathway in the community. There is no impact to specific age groups.
Disability – including physical, sensory or mental		X		As the service will be decommissioned and patients managed along an alternative community pathway, there is potential for a negative impact on patients with renal failure as they will be managed by general community services rather than clinicians specialising in the management of renal failure. However it was felt that the service is inequitable as patients with other progressive/palliative conditions are already seen by general community services. In addition to this clinical feedback from an existing end of life community service has confirmed that this cohort of patients does not have needs that are over and above what can be managed in the community.
Gender - including transgender and issues relating to pregnancy and maternity			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to specific genders.
Race/Ethnicity			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to this protected group.
Religion or Belief			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to this protected group.
Sexual Orientation – including issues relating to marriage and civil partnerships			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to this protected group.

6. CFS

A negative impact was identified for patients with CFS/ME and this is mitigated through the commissioning of the service in line with NICE guidance. Also, through the transition, assurance will be gained that staff have specific training relevant to CFS/ME. No other negative impacts on the protected characteristics were identified. There were no concerns identified for other minority populations (eg travellers, sex workers, single parents, those on low income) who may be disadvantaged by the policy or service's operation, or who may receive unequal treatment. The proposal does not directly/indirectly discriminate against any section of the community.

	Negative Impact	Positive Impact	Neutral Impact	Reason
Age			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to specific age groups.
Disability – including physical, sensory or mental	X			As the service will be re-commissioned and patients managed utilising a reduced number of interventions, there is potential for a negative impact on CFS/ME patients.
Gender – including trans* and issues			X	Neutral impact - The service will be delivered via an alternative

relating to pregnancy and maternity				pathway. There is no impact to specific genders.
Race/Ethnicity			X	Neutral impact - The service will be delivered via an alternative pathway. There is no impact to this protected group.
Religion or Belief			X	Neutral impact - The service will be delivered via an alternative pathway. There is no impact to this protected group.
Sexual Orientation - including issues relating to marriage and civil partnerships			X	Neutral impact - The service will be delivered via an alternative pathway. There is no impact to this protected group.

7. Motor Neurone Home Visiting Service

A negative impact was identified in relation to patients with MND and this has been mitigated with inclusion of an appendix to the existing contract with the community provider to ensure that staff have the required skill levels. Further engagement is being carried out to support this. No other negative impacts on the protected characteristics were identified. There were no concerns identified for other minority populations (eg travellers, sex workers, single parents, those on low income) who may be disadvantaged by the policy or service's operation, or who may receive unequal treatment. The proposal does not directly/indirectly discriminate against any section of the community.

	Negative Impact	Positive Impact	Neutral Impact	Reason
Age			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to specific age groups.
Disability – including physical, sensory or mental	X			As the service will be decommissioned and patients managed along an alternative community pathway, there is potential for a negative impact on MND patients as they will be managed by general community services rather than clinicians specialising in the management of MND. Although it was felt that the service is inequitable as there is no similar service for people with other progressive conditions
Gender – including trans* and issues relating to pregnancy and maternity			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to specific genders.
Race/Ethnicity			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to this protected group.
Religion or Belief			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to this protected group.
Sexual Orientation - including issues relating to marriage and civil partnerships			X	Neutral impact - The service will be delivered via an alternative pathway in the community. There is no impact to this protected group.

Appendix 2 – Survey Demographics

Gender (7% skipped)

- Male – 35.59%
- Female – 64.41%

Is your gender the same as it was at birth? (40% skipped)

- Yes - 99.13%
- No – 0%
- Prefer not to say - 0.87%

Ethnic origin (13% skipped)

Answer Choices	Responses
White British	89.16%
White Irish	0.00%
Any other White background (including Traveller)	2.41%
White & Black Caribbean	1.20%
White & Black African	0.60%
White & Asian	0.00%
Other mixed	1.20%
Asian/Asian British Indian	1.20%
Asian/Asian British Pakistani	0.60%
Asian/Asian British Bangladeshi	0.00%
Asian/Asian British other	0.00%
Black or Black British Africa	0.60%
Black or Black British Caribbean	0.60%
Black or Black British other	0.60%
Other ethnic group	1.81%
Total	

Age (8% skipped)

Answer Choices	Responses
0-17	0.00%
18-30	6.25%
31-65	56.25%
65 and over	37.50%
Total	

Do you consider yourself to have a disability? (11% skipped)

Answer Choices	Responses	
Yes	25.88%	44
No	40.59%	69
Prefer not to say	3.53%	6
If yes, please specify	30.00%	51
Total		170

Sexual orientation (25% skipped)

Answer Choices	Responses
Heterosexual	79.86%
Gay	1.39%
Lesbian	0.69%
Bisexual	3.47%
Prefer not to say	14.58%
Total	

Religion or belief (15% skipped)

Answer Choices	Responses
No religion	22.16%
Bahai	0.60%
Christian	62.28%
Jain	0.00%
Jewish	0.60%
Hindu	0.60%
Muslim	1.80%
Sikh	0.00%
Prefer not to say	6.59%
Other (please specify)	5.39%
Total	

Marital/ civil partnership status (7% skipped)

Answer Choices	Responses
Single	15.82% 28
Married	63.84% 113
Civil Partnership	2.26% 4
Divorced	6.21% 11
Separated	2.26% 4
Widowed	6.21% 11
Prefer not to say	3.39% 6
Total	177

Are you currently pregnant? (22% skipped)

- Yes - 1.34%
- No - 97.32%
- Prefer not to say - 1.34%

14 March 2017**Agenda Item: 7****REPORT OF THE CHAIRMAN OF JOINT CITY AND COUNTY HEALTH
SCRUTINY COMMITTEE****NOTTINGHAM UNIVERSITY HOSPITALS CLEANING CONTRACT****Purpose of the Report**

1. To introduce the latest information regarding the cleaning contract at Nottingham University Hospitals (NUH).

Information and Advice

2. The Joint Health Committee regularly receives information regarding cleaning services at NUH.
3. In late July 2016, NUH issued a statement indicating that there had been some early signs of improvement from Carillion in some of the areas which required urgent attention, including the availability of cleaning materials and linen. Carillion also introduced a new 'bank' to cover unexpected staff absences and have adapted some working practices so that services are more responsive to the needs of NUH wards and clinical areas. NUH satisfaction levels are based on the 'lived' experience of patients and staff, and this indicates that there remains much work to do to ensure the consistent delivery of the necessary standards across all services. At the same time, Carillion reactively stated that it was committed to providing a high standard of service to the Trust, and wishes to work closely with the Trust to tackle any identified problems. Carillion will continue to monitor clinical teams' experience of their services.
4. In August 2016, Unison issued a statement saying it believes that Carillion was failing to deliver on cleaning services. In response, NUH issued a statement that the Trust Board requires urgent improvements from Carillion in response to declining cleanliness standards and inconsistent standards across a range of services including linen provision, availability of equipment and portering. It reported that there had been no general increase in infections over the period standards of cleanliness have deteriorated. The Trust Board is monitoring Carillion's performance monthly and is considering the future of the contract with Carillion.
5. Information on standards of cleanliness was last brought before the Joint Health Committee on 13 September 2016, when Members heard that the contract with Carillion did include financial sanctions and that monitoring cleaning was using up the valuable time of nursing staff. Members were concerned that there was no particular evidence that contracted out cleaning was any better than in-house cleaning – particularly with regard to managing cleaning staff.

6. Members were reassured by NUH that there would be improvement from Carillion within a reasonable timescale. Members also heard that Carillion hold similar contracts with other healthcare providers and these have also experienced problems.
7. In November 2016, NUH issued a statement that NUH and Carillion are jointly exploring a managed exit from the Carillion contract. The managed exit from the contract was mutually agreed in January 2017. Core Environment and Facilities services will be back under NUH management by 1 April 2017.
8. A presentation from Nottingham University Hospitals (NUH) is attached as an appendix to this report.
9. Peter Homa, Chief Executive of NUH will attend the Joint Health Committee to deliver the presentation and answer questions.

RECOMMENDATION

- 1) That the Joint City and County Health Scrutiny Committee consider and comment on the information provided.

Councillor Parry Tsimbiridis

Chairman of Joint City and County Health Scrutiny Committee

For any enquiries about this report please contact: Martin Gately – 0115 9772826

Background Papers

Nil

Electoral Division(s) and Member(s) Affected

All

Improving Estates & Facilities services for patients and staff

NUH

Peter Homa
Chief Executive

February 2017

Agenda

- Carillion
- Car parking
- Discussion

Carillion: background

- Carillion awarded a 5-year contract to run Estates and Facilities services at NUH in April 2014 following a competitive process
- Circa 1,500 Carillion staff
- NUH Contract Management Team

Inconsistent standards

- Cleanliness audits (internal & external) showed deterioration early 2016 after initial improvement
- Patients & staff raised growing concerns cleaning & wider services provided by Carillion
- Independent cleaning assessment commissioned by NUH concluded unacceptable standards (October 2016)

Managed contract exit

- NUH Board required significant changes to the arrangements with Carillion to improve standards
- January 2017: NUH and Carillion mutually agreed to a managed exit from the core aspects of the E&F contract
- Core E&F services will come back under NUH management by 1 April 2017

Next steps

- Cleaning improvements & safe transfer of staff and services: immediate priority
- Recruitment exercise underway to address staffing gaps
- Carillion staff will transfer to NUH by April
- Comprehensive improvement plan under development

Car parking improvements

- Car parking & traffic management will remain under Carillion's management
- Carillion will invest significant capital to improve car parking infrastructure and traffic management
- Car parking enforcement to be introduced Spring 2017 – to tackle inconsiderate parking (includes monitoring appropriate use of parking for disabled)

Dedicated tram entrance

- Over 2,200 passengers daily use QMC tram stop
- Opens end of July 2017
- Patient/volunteer involvement





Discussion

14 March 2017

Agenda Item: 8

REPORT OF THE CHAIRMAN OF JOINT CITY AND COUNTY HEALTH SCRUTINY COMMITTEE

WORK PROGRAMME

Purpose of the Report

1. To introduce the Joint City and County Health Scrutiny Committee work programme.

Information and Advice

2. The Joint City and County Health Scrutiny Committee is responsible for scrutinising decisions made by NHS organisations, and reviewing other issues which impact on services provided by trusts which are accessed by both City and County residents.
3. The work programme for 2016-17 is attached as an appendix for information.
4. Quality Accounts – this year, due to time constraints, it is anticipated that consideration of Quality Accounts will take place at a single study group meeting for each relevant provider Trust/organisation. Lead officers are currently setting up these meetings.

RECOMMENDATION

- 1) That the Joint City and County Health Scrutiny Committee note the content of the work programme for 2016-17 and dates for future meetings.

Councillor Parry Tsimbiridis
Chairman of Joint City and County Health Scrutiny Committee

For any enquiries about this report please contact: Martin Gately – 0115 9772826

Background Papers

Nil

Electoral Division(s) and Member(s) Affected

All

Joint Health Scrutiny Committee 2016/17 Work Programme

<p>12 July 2016</p>	<ul style="list-style-type: none"> <p>Transforming care for people with learning disabilities and/or autism spectrum disorders in Nottingham and Nottinghamshire – outcomes of consultation and progress against key deliverables To consider the consultation process and findings and if/how proposals are changing to reflect those findings; and progress against the key deliverables to be completed by June 2016 (Nottingham City CCG lead)</p> <p>The Willows Medical Centre, Carlton To review action taken by Nottingham North and East Clinical Commissioning Group to ensure that all patients in the Carlton area have access to good quality GP services during the temporary closure of The Willows Medical Centre; and in the future. (Nottingham North and East CCG)</p> <p>Work Programme To consider the 2016/17 Work Programme</p>
<p>13 September 2016</p>	<ul style="list-style-type: none"> <p>Environment, Waste and Cleanliness at Nottingham University Hospitals To review progress in improving the environment, waste management and cleanliness at Nottingham University Hospitals sites (Nottingham University Hospitals)</p> <p>Defence and National Rehabilitation Centre (Stanford Hall) To examine the development of services for trauma rehabilitation (Nottingham University Hospitals)</p>

	<ul style="list-style-type: none"> • Future of Congenital Heart Disease Services To consider NHS England's recent announcement about the future of congenital heart disease services, including changes to the commissioning of services at the East Midlands Congenital Heart Centre at Glenfield Hospital, Leicester. • Work Programme To consider the 2016/17 Work Programme
11 October 2016	<ul style="list-style-type: none"> • Nottingham University Hospitals and Sherwood Forest Hospitals Trust Merger – Progress Update (Nottingham University Hospitals) • Community Child and Adolescent Mental Health Services (CAMHS) (Nottinghamshire Healthcare Trust/ commissioners/ local authority public health) • Rampton Hospital/Psychologically Informed Planned Environments (PIPES) To receive information on the operation of PIPES in prisons (NHS England) • The Willows Medical Centre, Carlton To consider changes to services following the resignation from Dr Nyatsuro in relation to his GP practice contract (Nottingham North and East CCG) • Work Programme To consider the 2016/17 Work Programme

<p>8 November 2016</p>	<ul style="list-style-type: none"> East Midlands Clinical Senate and Strategic Clinical Networks To receive the EMCSSCN Annual Report and updates on other recent developments (EMCSSCN) NUH Emergency Department Targets To receive briefing on Accident and Emergency performance (NUH) NUH Planning for Winter Pressures To receive briefing on NUH's plans to cope with winter pressures 2016/17 (and also whole system briefing from commissioners and social care partners). (NUH) Work Programme To consider the 2016/17 Work Programme
<p>13 December 2016</p>	<ul style="list-style-type: none"> Environment, Waste and Cleanliness at Nottingham University Hospitals To review progress in improving the environment, waste management and cleanliness at Nottingham University Hospitals sites (NUH) Daybrook Dental Practice Report Findings An update further to the conclusion of recent proceedings (NHS England) Sustainability and Transformation Plan To receive information about the STP, including an outline of the Plan, governance and plans for delivery, plans

	<p>for consultation and engagement; and information about any anticipated substantial developments or changes to services.</p> <p>(STP Team)</p> <ul style="list-style-type: none"> • Work Programme To consider the 2016/17 Work Programme
10 January 2017	<ul style="list-style-type: none"> • Winter Pressures - EMAS Evidence gathering as part of an ongoing review of winter planning • NUH – Research and Innovation Update Briefing on new developments • NUH – Technology in Care Briefing on new developments • Work Programme To consider the 2016/17 Work Programme
7 February 2017	<ul style="list-style-type: none"> • Uptake of Child Immunisation Programmes To consider the latest performance in uptake and how uptake rates are being improved (NHS England/ Local Authority Public Health) • Nottingham University Hospitals NHS Trust Service Reviews To receive information about the local commissioning changes across a variety of services further to service reviews undertaken by the CCG. (Nottingham North and East CCG)

	<ul style="list-style-type: none"> • Work Programme To consider the 2016/17 Work Programme
14 March 2017	<ul style="list-style-type: none"> • Congenital Heart Disease To consider a potential substantial variation of service NHS England • NUH Service Review Further details on proposed service changes from Nottingham North and East CCG. • Sustainability and Transformation Plan Governance Arrangements To consider proposed governance arrangements for development and delivery of the Sustainability and Transformation Plan and to give consideration to the role for health scrutiny STP Team • NUH/Carillion Contract To provide an update on the position with the cleaning services contract at NUH NUH • Work Programme To consider the 2016/17 Work Programme
18 April 2017	<ul style="list-style-type: none"> • Urgent Care Resilience To review progress in developing resilience within the urgent care system, including the delivery of services during winter 2016/17 and how effectively winter pressures were dealt with. • GP service capacity in Carlton area To take a strategic overview of GP capacity and any pressures on service provision in the Carlton area and,

	<p>where appropriate, work taking place to ensure access to good quality GP services for all residents in the area</p> <p>(Nottingham North and East CCG/ Nottingham City CCG) (Nottingham City CCG/ NUH)</p> <ul style="list-style-type: none"> Sustainability and Transformation Plan To review the findings from initial consultation and engagement on the Sustainability and Transformation Plan and if/ how the Plan is developing to take these findings into account. (STP Team) Integrated Community Children and Young People's Healthcare Programme To review the implementation and impact of the new service model. (ICCYPH Programme Manager, commissioners, Nottinghamshire Healthcare Trust) Work Programme To consider the 2016/17 Work Programme
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To schedule:

- Progress against JHSC recommendation that “that the City and County Councils work with their partners, for example Marketing Nottingham and Nottinghamshire to support Health Education East Midlands to promote the East Midlands as a place for health professionals and students to train and work”
- Integrated Community Children and Young People's Healthcare Programme – review of implementation and outcomes from service changes
- Procurement of Patient Transport Service, including development of service specification - awaiting confirmation of procurement timings
- Evaluation of Urgent and Emergency Care Vanguard (primary care at the ‘front door’)
- Integrated Urgent Care
- Strategic Health Plans for the South of the County
- Evaluation of GP Access pilots

- STP Governance Proposals
- Healthwatch Report – Experiences of Mental Health Crisis

Study Groups:

- Quality Accounts

Visits:

- Nottingham University Hospitals sites

Other meetings:

- NUH (Peter Homa)
- NHCT (Ruth Hawkins)
- EMAS (Greg Cox) (informal meeting with East Midlands Health Scrutiny Chairs to consider EMAS response to CQC inspection)

Items for 2017/18 Work Programme:

May/ June

- Nottinghamshire Healthcare Trust Transformational Plans for Children and Young People – CAMHS and Perinatal Mental Health Services update (to include workforce issues, development of Education Centre and financial position)

NHS 111 (align with publication of NHS 111 Annual Report)

Visit to new CAMHS and Perinatal Services Site (spring 2018)

