NHS England
Congenital Heart Disease
Public Consultation
Report
October 2017

Participate Ltd. Charles House, Princes Court, Beam Heath Way, Nantwich, Cheshire CW5 6PQ
Tel: 0845 094 8191 Email: info@participate.uk.com Web: www.participate.uk.com
ParticipateUK
@ParticipateUK
Co. Reg. 06313232 VAT Registration No. 933 8827 88

Document Control Sheet

Client	NHS England
Document Title	Congenital Heart Disease Consultation Report
Version	06
Status	Final
Client Ref:	
Author	Louise Bradley & John Poole
Date	October 2017
Further copies from	info@participate.uk.com

Document History			
Version	**Date**	**Author**	**Comments**
01	31st July 2017	Participate	Summary of other responses to add and update qual frequency tables
02	August	Participate	Qual tables updated
03	29th August	Participate	Meeting notes, young people's survey and main findings added
04	6th September	Participate	Other elements added acronyms expanded
05	7th September	Participate	Glossary added
06	16th September	Participate	Updated summary of findings
07	2nd October	Participate	More detail added in summary of findings

Contents

Introduction

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

Context

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

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

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

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

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

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

Consultation Methodology

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

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

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

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

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

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

Approach to Analysis

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

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

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

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

Standardised Responses

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

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

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

Summary of Findings

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

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

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

PROPOSAL TO ONLY COMMISSION FROM PROVIDERS ABLE TO MEET THE STANDARDS

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Survey Data Feedback

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

Q1 In what capacity are you responding?

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

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

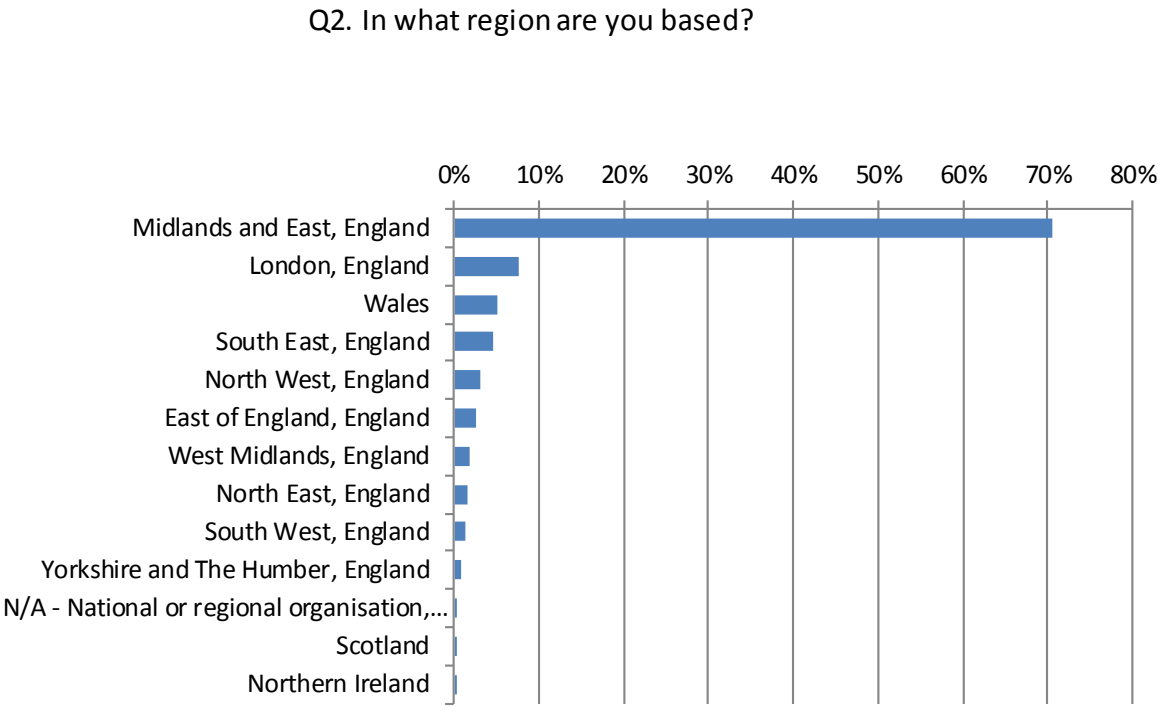
It is apparent that the majority of the responses are from members of the public and those categorised as 'other'. Data has been analysed according to how respondents self-categorised, although some respondents categorising as "other" would fit into different specified categories.

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

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

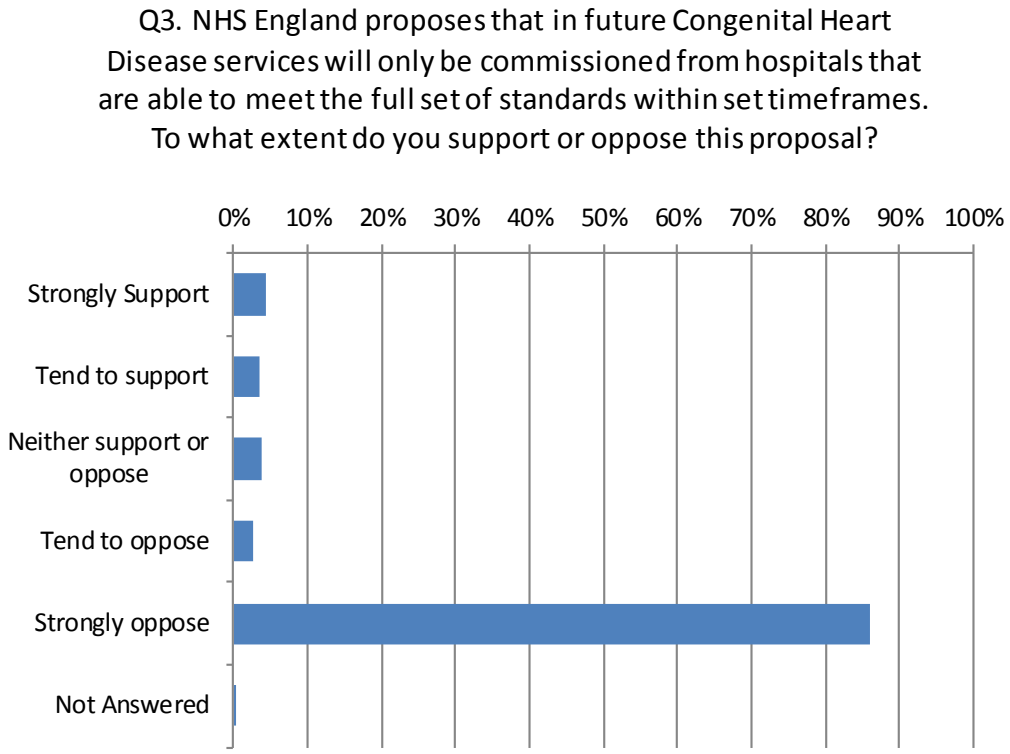
It should also be noted that the responses categorised as 'NHS Provider' are not necessarily the response that represents the views of that organisation, as they are mixed with personal/individual responses from staff who work for that particular provider.

Q2 – In what region are you based?



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

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



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

Q4. Please explain your response to question 3

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

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

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

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

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

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

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

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

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

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

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

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

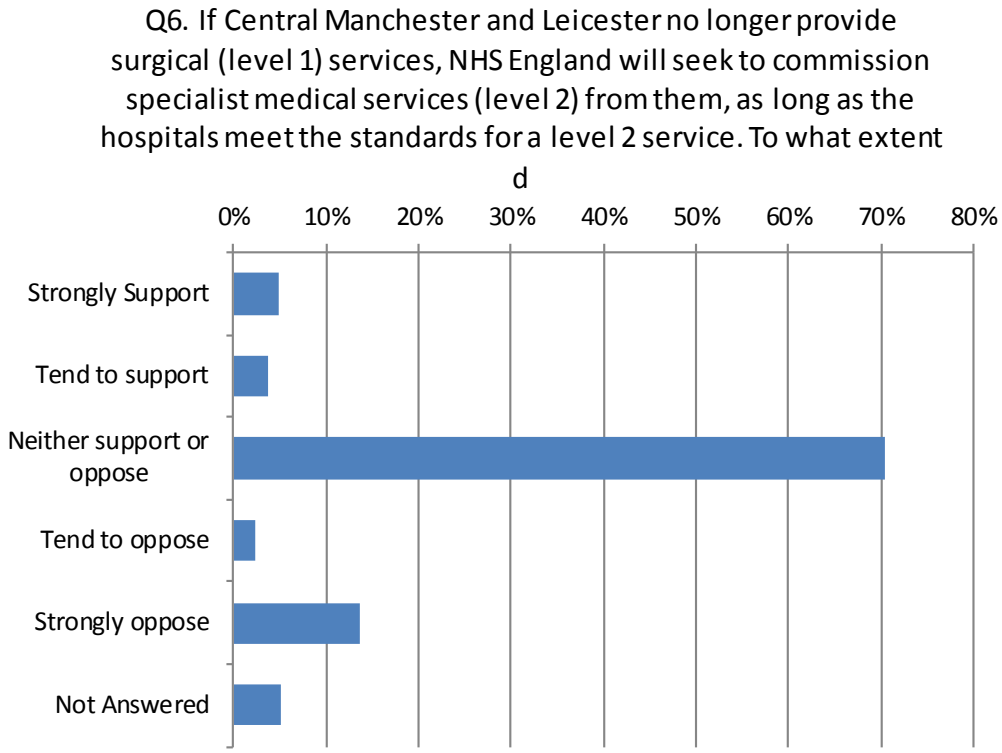
In terms of feedback from the London area in relation to Royal Brompton & Harefield NHS Foundation Trust, the most common themes include: the co-location standard is challenged as by working in partnership it meets all standards; there is a call to re-assess the validity of the standards against clinical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

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

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

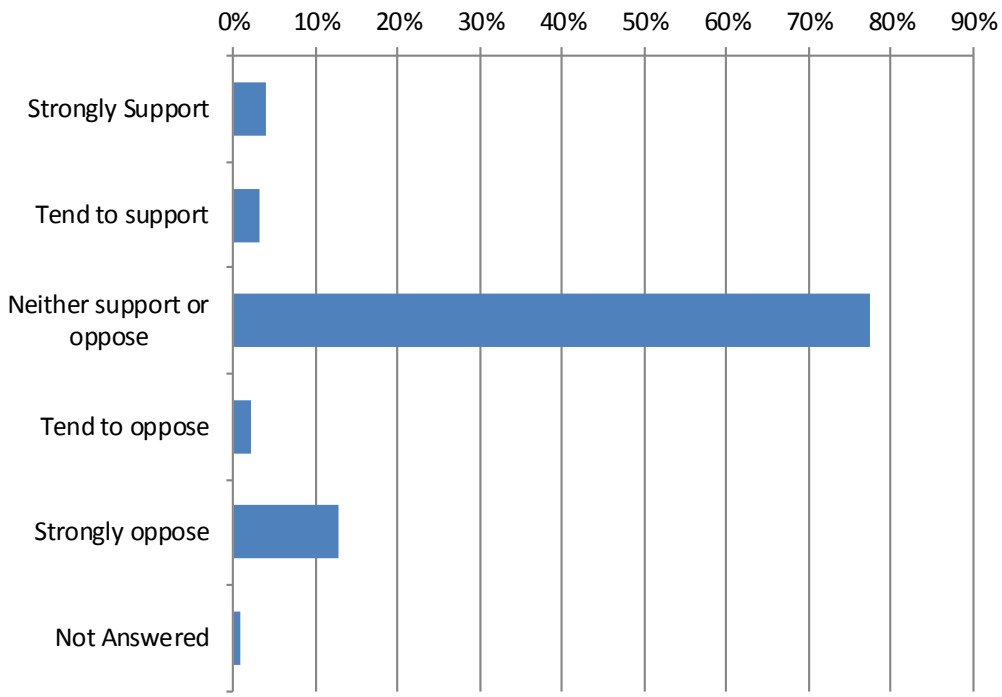
It should be noted that there is commonality of themes across all regions in terms of focusing upon patient outcomes, sharing resources and training local staff.

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



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

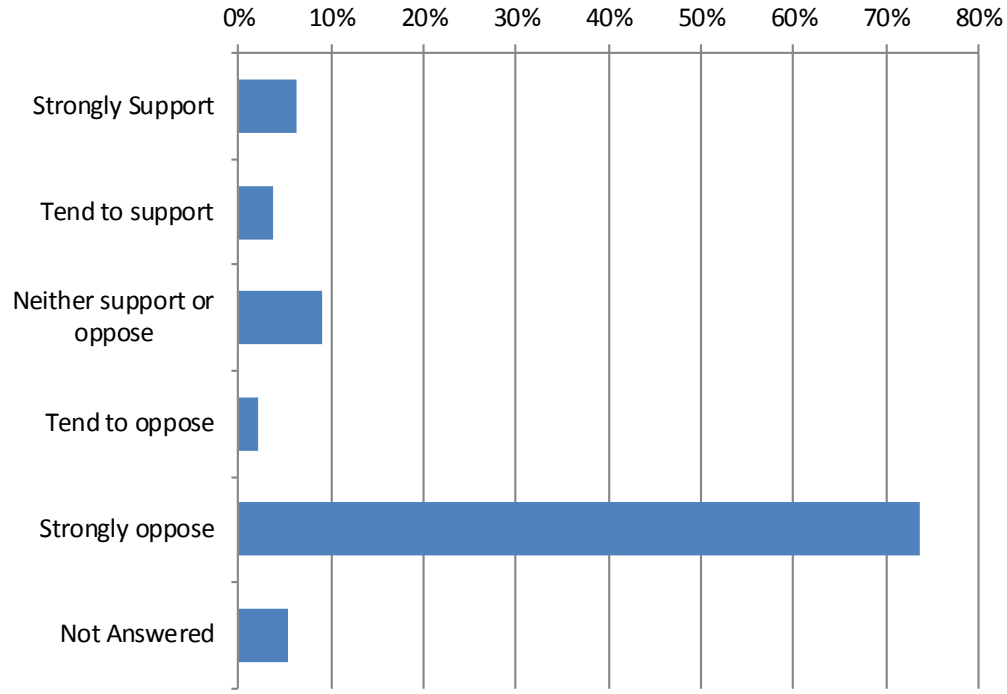
Q7 - The Royal Brompton could meet the standards for providing surgical (level 1) services for adults by working in partnership with another hospital that provides surgical (level 1) services for children. As an alternative to decommissioning the adult services, NHS England would like to support this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



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

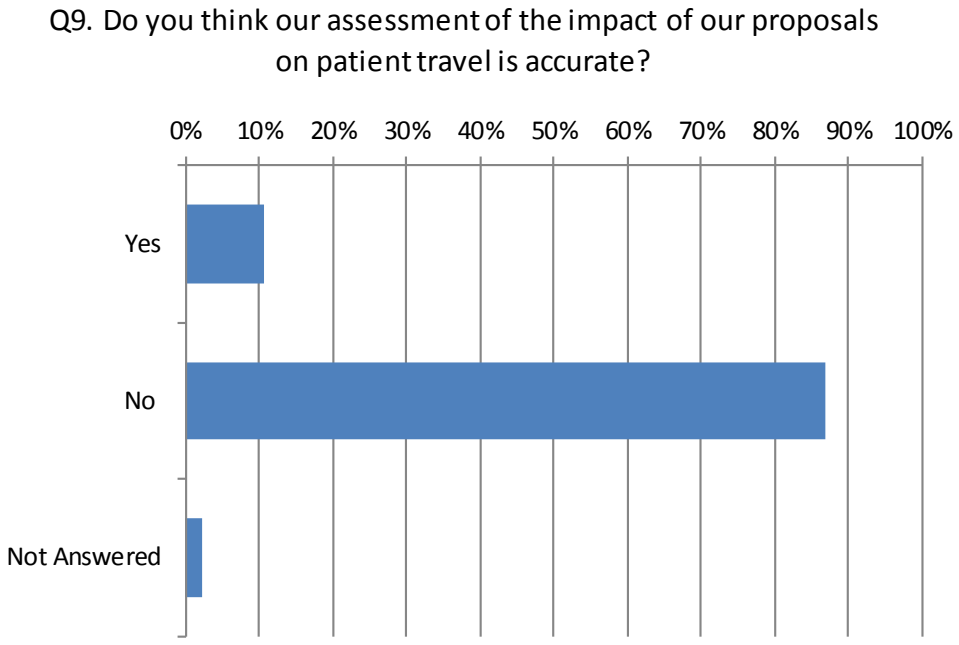
Q8 - NHS England is proposing to continue to commission surgical (level 1) services from Newcastle Upon Tyne Hospitals NHS Foundation Trust, whilst working with them to deliver the standards within a different timeframe. To what extent do you support or oppose this proposal?

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



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

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



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

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

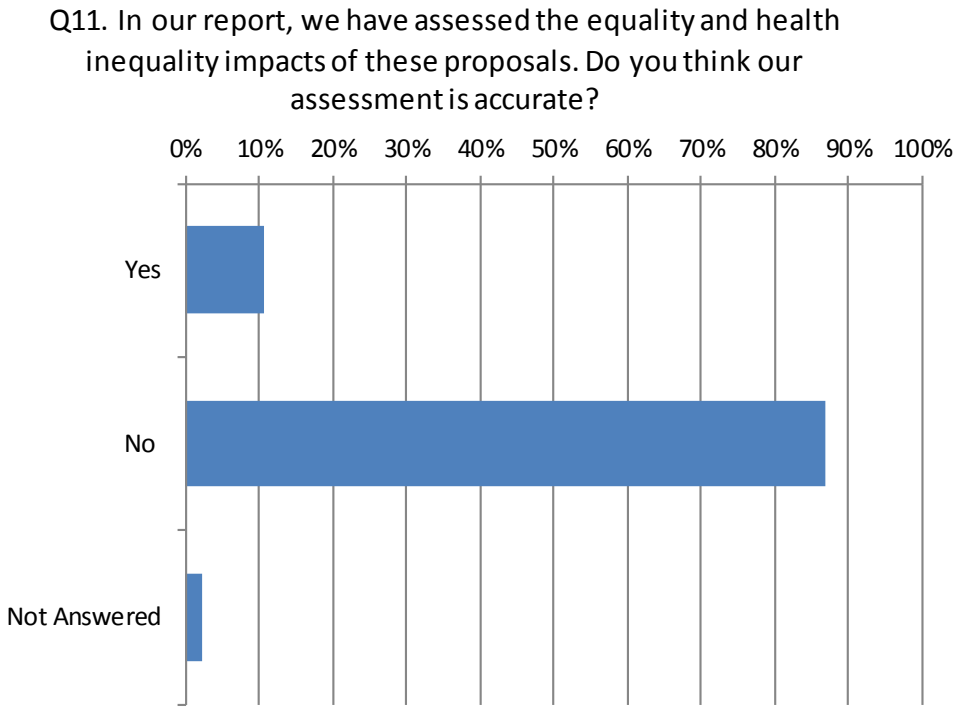
Table 8 - What more might be done to avoid, reduce or compensate for longer journeys where these occur?	
Response	**Total**
Publish travel data to allow all to analyse / look at different times	**37%**
Travel times based on car - what about public transport.	**29%**
Keep existing units open and save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

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

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

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

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



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

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

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

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

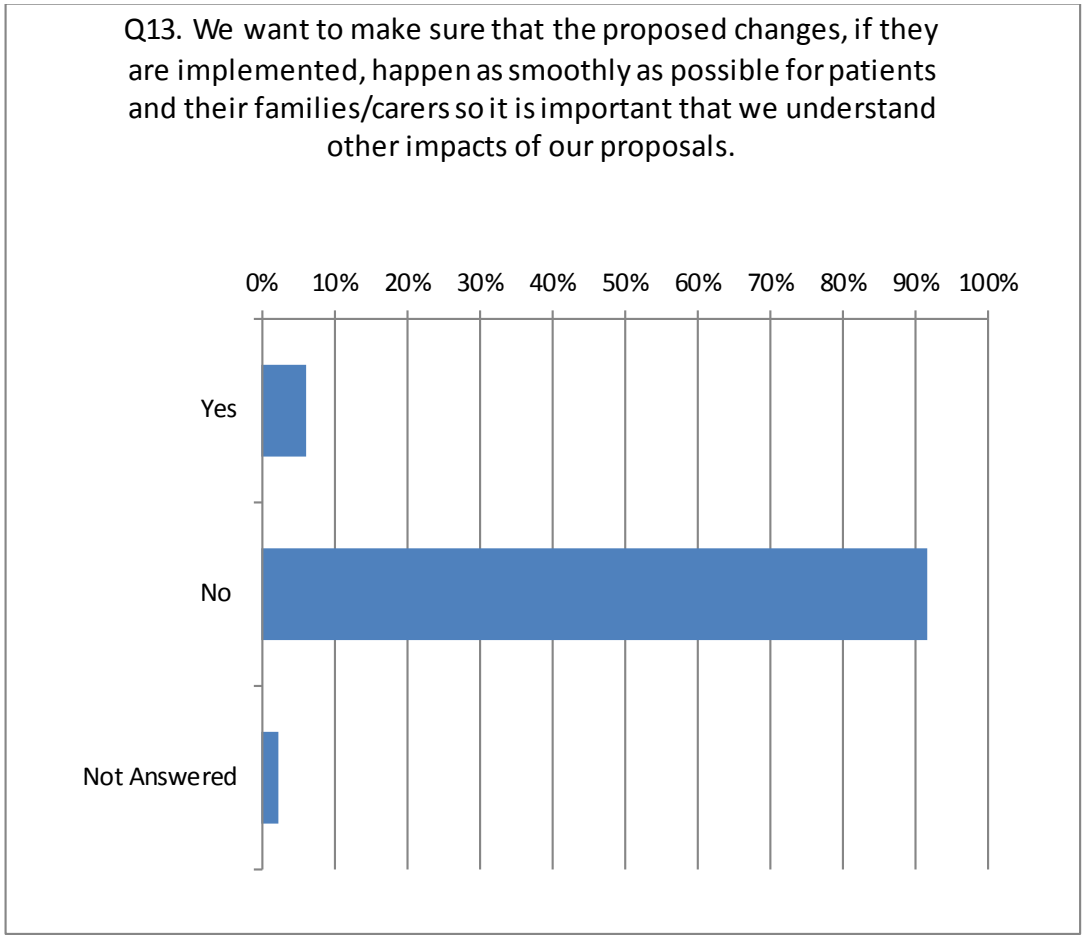
A lack of public transport and the impact of rural locations were particularly asked to be considered by respondents from the Midlands/East region and from Wales, this was not a strong theme for the London region.

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

All other themes were common across all regions and included:

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

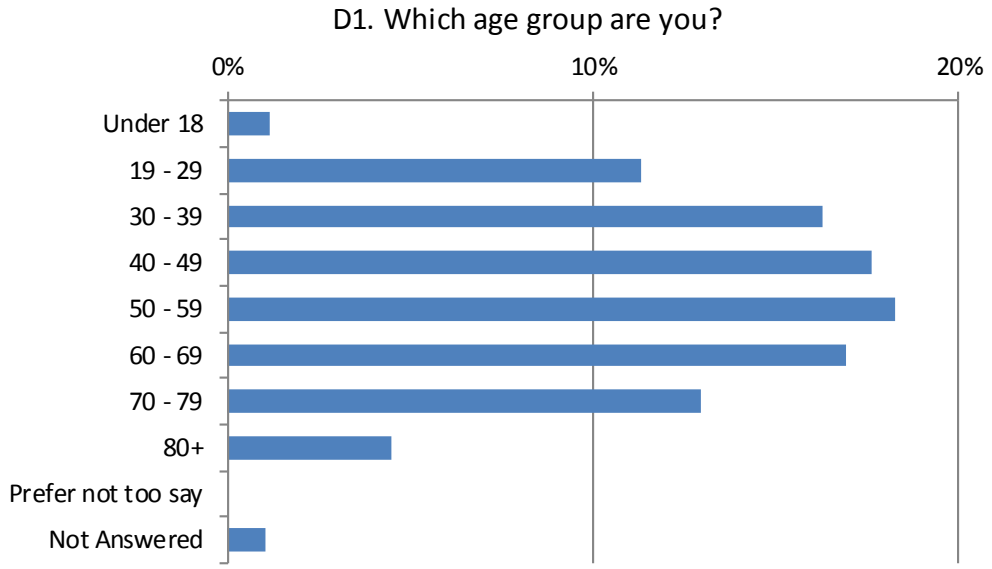
Table 11 – Do you have any other comments?	
Response	**Total**
Specialist knowledge - The assumption that there will be appropriately trained clinical and nursing staff available to deliver this specialist care across all of the units is severely challenged by the fact the majority of ECMO provided by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

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

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

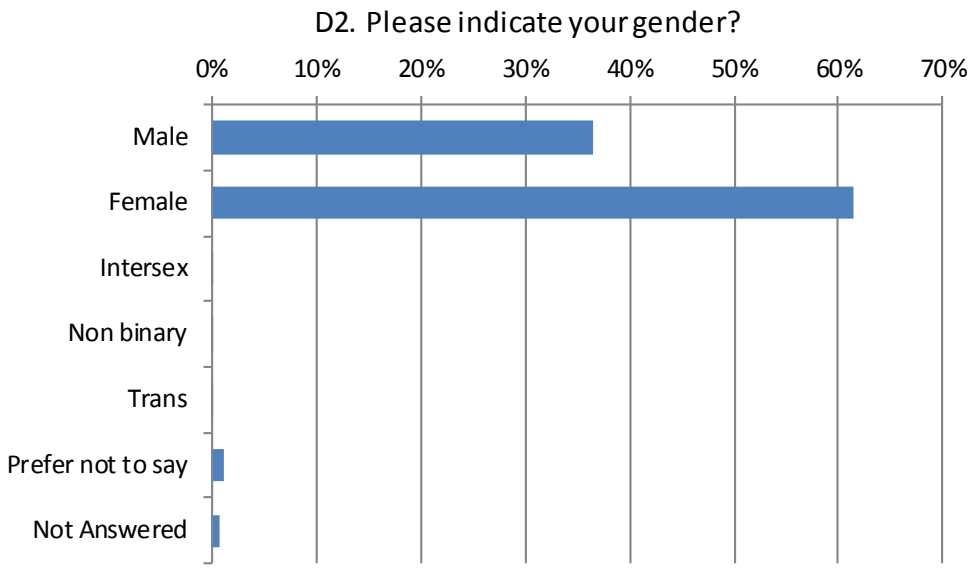
Respondent Profiling

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

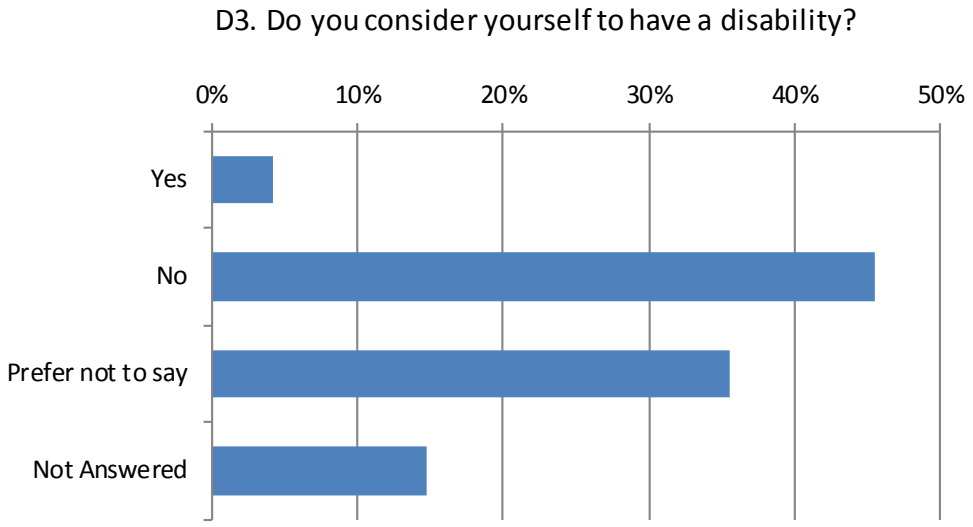


A wide range of age categories are represented in terms of the responses to the survey, including the traditionally harder to reach groups aged 19-29 years old (at 11% of all responses). When interrogating the data further it is apparent that in terms of CHD patients, the age ranges reflect the overall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

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



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



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

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

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

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

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

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

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

Meeting Notes Data

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

Events – Notes from Meetings

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

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

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

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

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

Young People Survey Data

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

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

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

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

Feedback by Stakeholder Category

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

PROPOSAL TO ONLY COMMISSION FROM PROVIDERS ABLE TO MEET THE STANDARDS

Children's Heart Charities

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

Royal Colleges and Specialist Societies

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

Hospital Trusts

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

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

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

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

The NHS in the Devolved Administrations

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

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

Children's Heart Charities

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

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

Respiratory Charities/Organisations

- Need to end this uncertainty.

Royal Colleges and Specialist Societies

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

Hospital Trusts

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

Public representatives (MPs, Councillors, OSCs)

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

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

The NHS in the Devolved Administrations

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

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

Public representatives (MPs, Councillors, OSCs)

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

The NHS in the Devolved Administrations

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

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

Children's Heart Charities

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

Respiratory Charities/Organisations

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

Royal Colleges and Specialist Societies

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

Hospital Trusts

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

Public representatives (MPs, Councillors, OSCs)

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

The NHS in the Devolved Administrations

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

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

Children's Heart Charities

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

Royal Colleges and Specialist Societies

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

Public representatives (MPs, Councillors, OSCs)

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

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

Children's Heart Charities

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

Royal Colleges and Specialist Societies

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

Hospital Trusts

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

Public representatives (MPs, Councillors, OSCs)

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

The NHS in the Devolved Administrations

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

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

Children's Heart Charities

- Financial impact and cost of travel on deprived families

Respiratory Charities/Organisations

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

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

Hospital Trusts

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

Public representatives (MPs, Councillors, OSCs)

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

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

Children's Heart Charities

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

Respiratory Charities/Organisations

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

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

Royal Colleges and Specialist Societies

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

Hospital Trusts

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

Public representatives (MPs, Councillors, OSCs)

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

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

The NHS in the Devolved Administrations

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

Other Responses

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

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

Letter and Email Response by Type of Respondent

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

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

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

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

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

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

Letter and Email Response by Hospital / Area

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

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

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

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

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

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

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

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

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

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

Glossary

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

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