

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



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

Version number: V2

First published: May 2015, Updated: January 2017

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Classification: OFFICIAL

Draft for consultation

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

should the proposed closures go ahead.

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

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

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

Data sources:

Volumes of Surgery : 1314 NICOR

Proportional use of centres : HES data 0607 to 1415

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

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

Data sources:

Volumes of Surgery : 1415 NICOR

Proportional use of centres : HES data 0607 to 1415

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

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

3.3 Proposed changes to providers offering level one services

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

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

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

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

3.4 Proposed changes to providers offering aspects of level two services

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

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

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

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

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

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

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

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

groups.

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

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

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

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

PART B: Equalities Groups and Health Inequalities Groups

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

5.1. Age

5.1.1 Review of literature and data

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

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

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

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

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

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

⁹ Op. cit.

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

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

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

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

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

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

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

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

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

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

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

Young people told us:

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

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

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

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

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

5.1.3 Potential impact of the proposed service changes

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

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

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

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

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

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

Source: NCDR SUS

CYD includes patients aged <19 at date of admission

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

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

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

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

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

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

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

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

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

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

5.2. Disability

5.2.1 Review of literature and data

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

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

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

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

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

Congenital heart disease as a complication of Down's syndrome

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

hospital.

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

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

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

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

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

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

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

Prevalence of Learning Disability as a secondary diagnosis of CHD patients

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

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

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

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

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

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

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

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

Table 5: Inpatient admissions with CHD diagnosis

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

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

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

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

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

- communication with patients; and
- transition.

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

5.2.4 Potential impact of the proposed changes

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

5.3. Gender reassignment

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

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

5.4. Marriage and civil partnership

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

5.5. Pregnancy and maternity

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

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

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

5.5.1 Review of literature and data

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

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

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

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

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

¹⁶ Royal College of Obstetricians and Gynaecologists (2011)

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

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

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

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

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

5.5.3 Potential impact of the proposed changes

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

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

5.5.4 Proposed actions to mitigate the impact of the proposed changes

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

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

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

5.6. Race

5.6.1 Review of literature and data

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

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

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

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

Ethnicity and prevalence

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Source: NCDR SUS 13/14 to 15/16

Selection criteria: primary diagnosis from CHD 'pure' list

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

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

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

Table 7: Inpatient admissions with CHD 2013 to 2014

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

Ethnicity and outcomes

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

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

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

5.6.3 Potential impact of the proposed changes

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

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

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

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

5.6.4 Proposed actions to mitigate the impact of the proposed changes

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

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

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

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

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

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

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

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

5.7. Religion or belief

5.7.1 Review of literature and data

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

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

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

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

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

5.7.3 Potential impact of the proposed changes

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

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

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

5.7.4 Proposed actions to mitigate the impact of the proposed changes

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

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

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

5.8. Sex or gender

5.8.1 Review of literature and data

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

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

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

Source: 2013/14 HES data

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

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

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

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

²³ Source: NICOR

Programme in 2014/15

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

5.8.3 Potential impact of the proposed changes

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

5.8.4 Proposed actions to mitigate the impact of the proposed changes

None

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

None

5.9. Sexual orientation

5.9.1 Review of literature and data

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

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

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

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

5.9.3 Potential impact of the proposed changes

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

5.9.4 Proposed actions to mitigate the impact of the proposed changes

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

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

None

6. Implications of our work

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

6.1. Alcohol and / or drug misusers

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

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

6.2. Asylum seekers and /or refugees

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

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

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

6.3. Carers

6.3.1 Review of literature and data

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

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

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

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

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

communication with families and carers at that time.

We have developed specific standards on:

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

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

6.3.3 Potential impact of the proposed changes

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

6.3.4 Proposed actions to mitigate the impact of the proposed changes

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

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

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

6.4. Ex-service personnel / veterans

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

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

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

6.6. Gypsies, Roma and travellers

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

6.7. Homeless people and rough sleepers

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

6.8. Those who have experienced human trafficking or modern slavery

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

6.9. Those living with mental health issues

6.9.1 Review of literature and data

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

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

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

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

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

6.9.3 Potential impact of the proposed changes

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

6.9.4 Proposed actions to mitigate the impact of the proposed changes

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

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

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

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

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

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

6.10. Sex workers

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

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

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

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

6.12.1 Review of literature and data

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

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

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

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

6.12.3 Potential impact of the proposed changes

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

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

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

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

6.12.4 Proposed actions to mitigate the impact of the proposed changes

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

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

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

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

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

Draft for consultation

7.1 Geographical variation

7.1.1 Review of literature and data

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

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

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

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

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

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

Relative activity across the country

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

Table 9: Variation in CHD relative activity

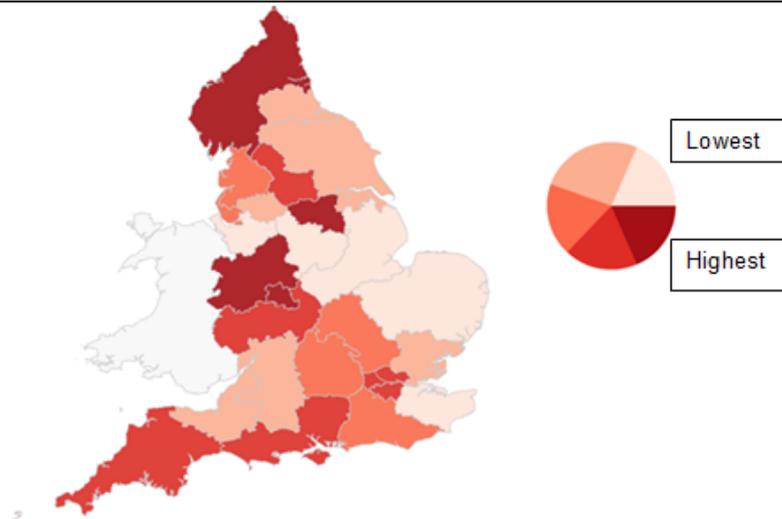
Area Team of patient residence	% of all specialist inpatient episodes	Specialist inpatient episodes per 100,000 (0-18) population	Specialist inpatient episodes per 100,000 (19+) population
Durham, Darlington and Tees	2%	58.3	4.2
Cumbria, Northumberland, Tyne and Wear	4%	69.9	4.4
Lancashire	3%	61.3	6.3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

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

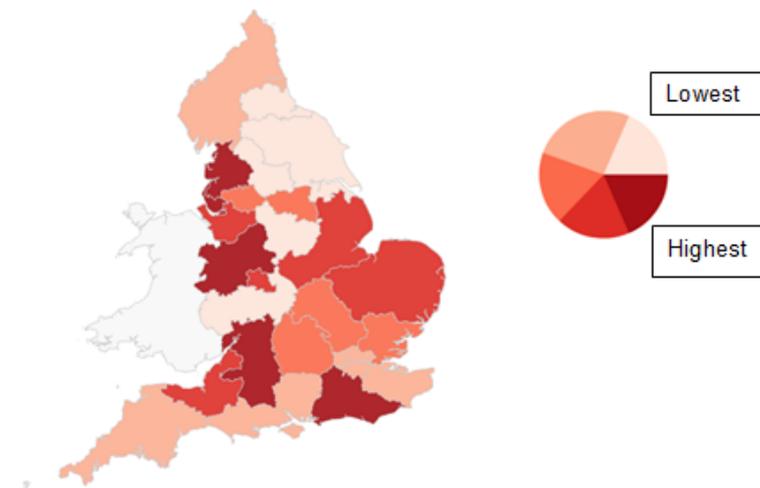
The HES data in table 9 indicates that there is considerable variation across the country in terms of relative activity. The episodes per 100,000 population (age 0-18) show some differences from Kent and Medway at 45.2 to Birmingham and the Black Country at 79.8. In the case of adult services, the episodes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

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

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



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



Impact of the proposed service changes on volumes of surgery

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

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

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

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

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

Data sources:
 Volumes of Surgery : 1314 NICOR
 Proportional use of centres : HES data 0607 to 1415

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

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

Data sources:
 Volumes of Surgery : 1415 NICOR
 Proportional use of centres : HES data 0607 to 1415

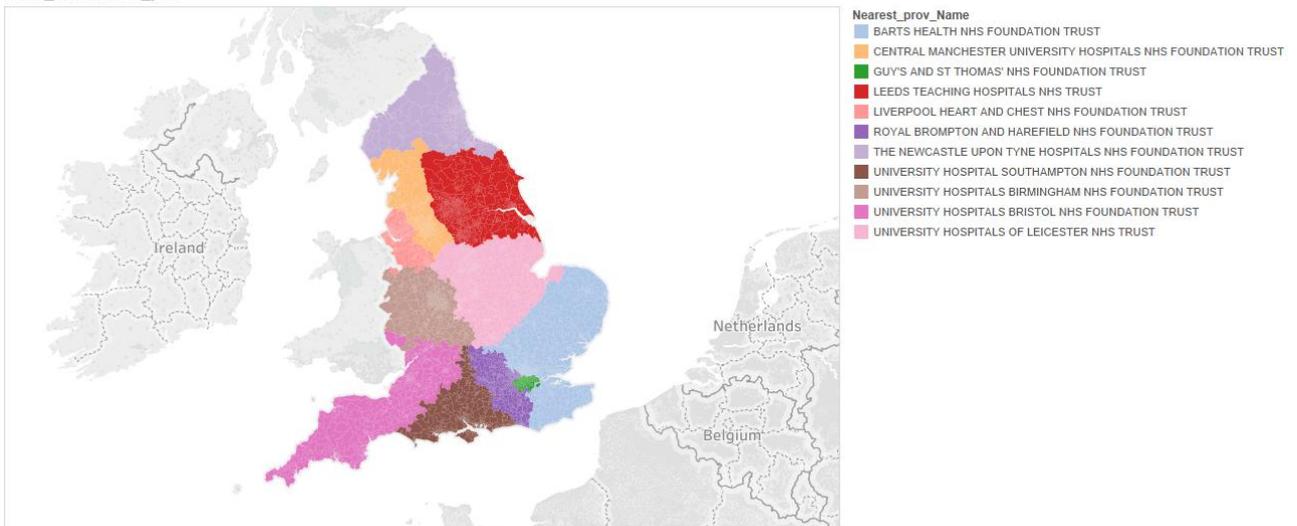
Impact of the proposed service changes on provider catchment area

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

Adult

Image 2: Adult catchments before the proposed service change

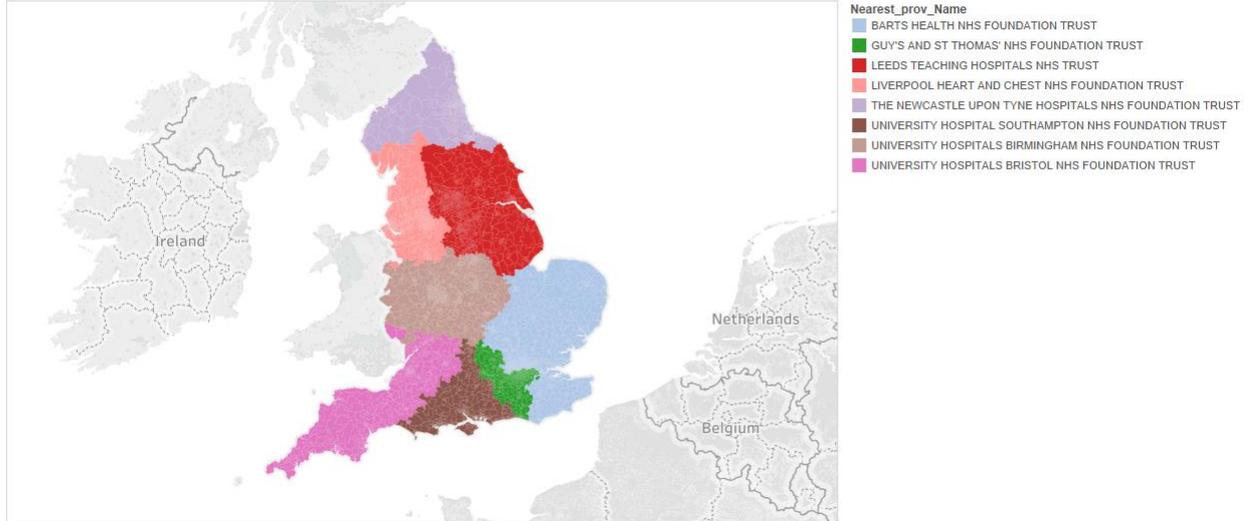
Adult_catchments_pre



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

Image 3: Adult catchments after the proposed service change

Adult_catchments_post

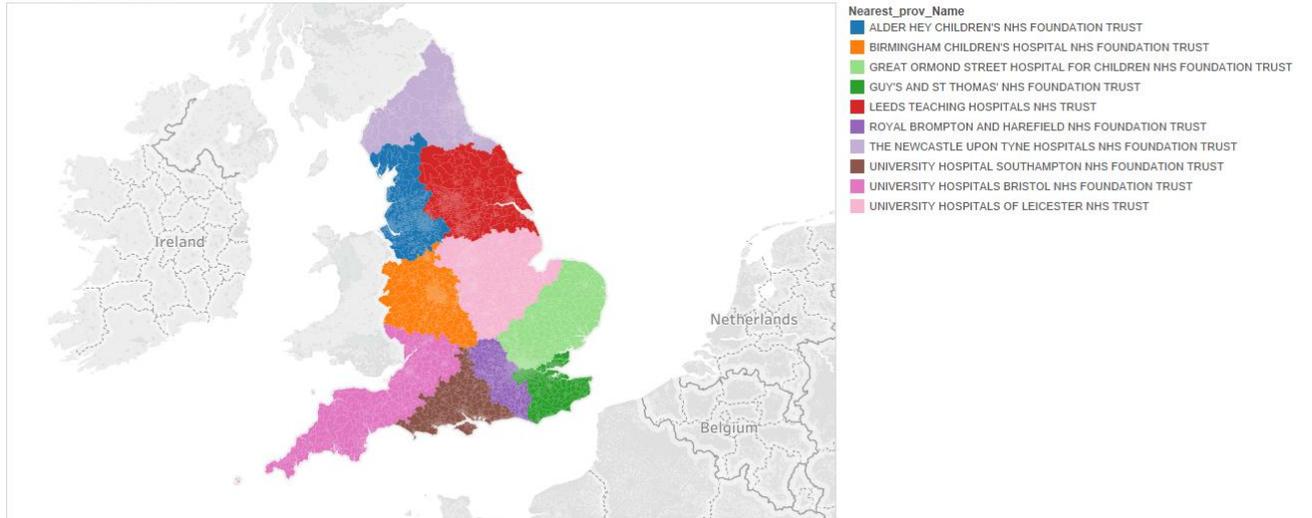


Map based on average of Longitude and average of Latitude. Color shows details about Nearest_prov_Name. Details are shown for Msoa and PolygonID (Detail). The data is filtered on Secnario and Grp. The Secnario filter keeps Post. The Grp filter keeps Adult.

Paediatric

Image 4: Paediatric catchments before the proposed service change

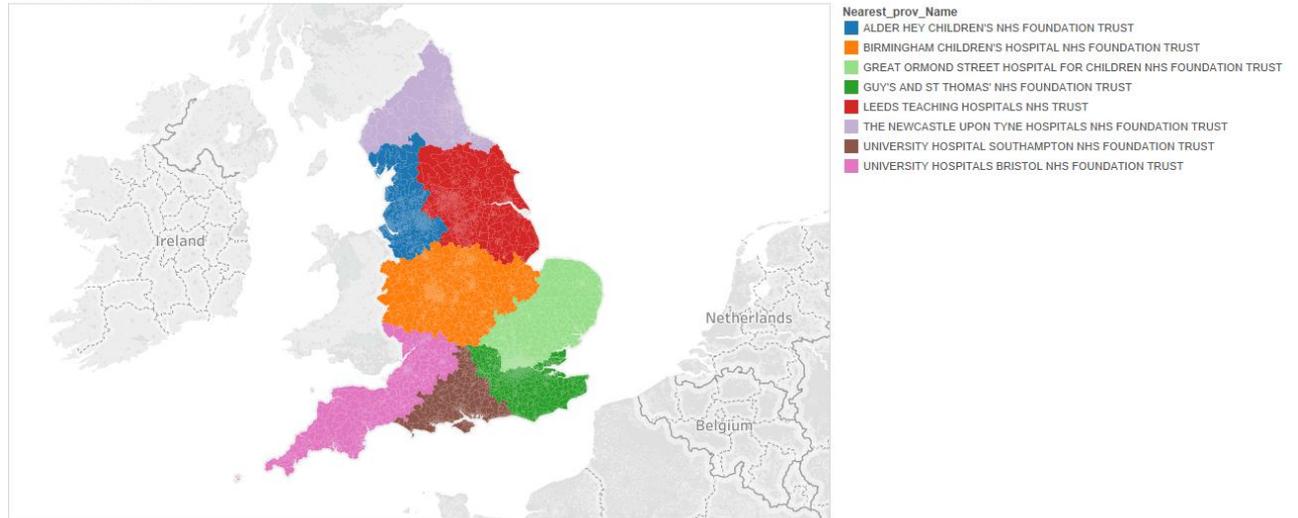
Paeds_catchments_pre



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

Image 5: Paediatric catchments after the proposed service change

Paeds_catchments_post



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

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

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

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

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

Table 12: Median and maximum travel times before decommissioning

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

Table 13: Median and maximum travel times after decommissioning

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

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

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

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

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

7.1.3 Potential impact of the proposed changes

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

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

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

7.1.4 Proposed actions to mitigate the impact of the proposed changes

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

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

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

Draft for consultation

PART C: Promoting integrated services and working with partners

Short explanatory notes: Integrated services and reducing health inequalities.

8. How can this work increase integrated services and reduce health inequalities?

We believe that implementing the standards will have a positive impact on the experience and outcomes of all children, young people and adults with CHD. We have given full consideration to the health outcomes, experiences and access to health care services to different population groups. All of which has been evidenced previously in this document.

For the first time services will be nationally commissioned and regionally delivered using common service specifications across all ages. As the sole National Commissioner, NHS England will need to ensure monitoring of the duty as part of contract management with service providers.

The first set of standards - category A – The Network Approach, will help to integrate CHD services. We are proposing that across the country services should be organised according to a three tier model (level 1, 2 and 3), with clear roles and responsibilities for each tier. Networks will help local services to work closely with specialist centres, to ensure that patients receive the care they need in a setting with the right skills and facilities, as close to home as possible

PART D: Engagement and involvement

9. Engagement and involvement activities already undertaken.

A three month consultation on the proposed standards and specifications for CHD services for children and adults ran until the 8th December 2014 (there was already a set of standards and a service specification in place for children's services but standards only existed in draft form for adults).

The consultation was an open process, enabling groups, organisations and individuals to respond. Information captured was reviewed on an individual basis, enabling all information to be captured and thereby avoiding the creation of a voting process on what the majority said.

The review team visited twelve locations across the country, to provide information through a variety of media forms and enable people to discuss face-to-face their concerns, worries or queries.

People were able to fill in their responses on-line, by post and could seek help in completion of a response if required. Translated material was available, with further translations available on request. This included 'easy' read to support those who may have disabilities and for those that wanted a version that was easy to read, providing the essentials of the consultation material. This version was tested with appropriate charities and support groups.

Support in ensuring widespread communication of the consultation was sought by the review team from groups who had mechanisms already established to reach those groups classed as 'hard to reach'.

The communication and engagement report contains further detail on consultation and the independent report on consultation prepared by 'Dialogue by Design' provides further information on the numbers of responses, the type of response and their origin.

The proposed standards were central to our engagement and involvement work from the outset and informed the development of the draft service specifications. We sought to address any gaps in evidence across all protected characteristics during the engagement process of

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

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

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

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

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

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

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

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

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

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

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

- dental; and
- any other issues.

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

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

N/A

13. Further engagement and involvement activities planned.

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

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

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

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

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

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

Question time events

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

WebEx Seminars

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

Targeted engagement

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

PART E: Monitoring and Evaluation

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

Stakeholder Engagement

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

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

During 2014/15 we gathered evidence from:

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

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

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

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

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

Literature Review

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

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

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

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

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

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

Data analysis

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

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

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

Covered in the section 16

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

In relation to this work have you identified any:

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

Yes

No

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

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

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

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

will be shown at events.

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

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

Adult data recommendations

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

Process recommendations

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

Communication of information recommendations

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

Expanded mortality data

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

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

Quality

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

Morbidities

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

Long term outcomes

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

Service measures

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

Dashboards

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

Patient Experience

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

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

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

25.4: Date EHIA published:		
25.5. Review date:		
26. Details of the person completing this EHIA		
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27: Name of the responsible Director		
Name:	Directorate:	
Michael Wilson	Specialised Commissioning	

Draft for consultation

Draft for consultation