Draft national standards and service specifications for congenital heart disease services: draft equality analysis

Equality and diversity are at the heart of NHS England’s values. Throughout the development of the policies and processes cited in this document, we have given due regard to the need to:

- reduce health inequalities in access and outcomes of healthcare services, integrate services where this may reduce health inequalities;
- eliminate discrimination, harassment and victimisation; and
- advance equality of opportunity and foster good relations between people who share a relevant protected characteristic (as cited in the Equality Act 2010) and those who do not share it.

What are the intended outcomes of this work?

Congenital heart disease is a term for a range of birth defects that affect the normal workings of the heart. The treatment for congenital heart disease depends on the defect. Mild defects, such as an atrial septal defect (a hole in the heart), often do not need to be treated, as they may improve on their own and may not cause any further problems, or will just need regular monitoring by a cardiologist.

If the defect is significant and is causing problems, surgery (or sometimes a less invasive procedure) may be required. Modern surgical techniques can often restore most or all of the heart’s normal function.

However, people with congenital heart disease often do need treatment over their life and therefore require specialist review during childhood and adulthood. This is because people with complex heart problems can develop further problems with their heart rhythm or valves over time.

The new Congenital Heart Disease review

The new Congenital Heart Disease (CHD) review (“the review”) was set up in June 2013 to consider the whole lifetime pathway of care for people with CHD to achieve:

- the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives;
- tackling variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care; and
- great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home.
The development of national standards to be applied through a national service specification is at the heart of the review’s approach. This reflects the views of stakeholders from across the spectrum and is recognised in the review’s objectives.

The review’s six objectives:

1. to develop standards to give improved outcomes, minimal variation and improved patient experience for people with CHD;
2. to analyse demand for specialist inpatient CHD care, now and in the future;
3. to make recommendations on function, form and capacity of services needed to meet that demand, taking account of accessibility and health impact;
4. to make recommendations on the commissioning and change management approach including an assessment of workforce and training needs;
5. to establish a system for the provision of information about the performance of CHD services to inform the commissioning of these services and patient choice; and
6. to improve antenatal and neonatal detection rates.

Draft service standards and specifications
We are consulting on draft standards and specifications for CHD services for children and adults (there is currently a set of standards and a service specification in place for children’s services but standards only exist in draft form for adults).

This equality analysis sets out the evidence we have considered as we have worked with others to develop these standards.

Draft standards
The draft standards cover the following:

- the network approach;
- staffing and skills;
- facilities;
- interdependencies;
- training and education;
- organisation, governance and audit;
- research;
- communication with patients;
- transition;
- pregnancy and contraception;
- fetal diagnosis;
- palliative care and bereavement; and
- dentistry.

We are producing standards and specifications which will enable commissioners to describe and commission an excellent service, within the available resource, and which
will help ensure that services are all meeting the same criteria and in doing this, reduce inequalities in CHD service provision and outcomes.

While some standards could have a bearing on how/where services are delivered (insofar as they make proposals as to surgeon numbers, caseloads and mixes, interdependencies and sub-specialisation), there is no predetermined outcome about the configuration of provider units. We await responses from the consultation to inform the final form of the standards, and the future consideration of the subsequent shape of services.

Scope of this equality analysis
It is important to stress that the work on objectives 2-6 above is not the subject of the current consultation or this equality analysis, but our future work will be informed by what we hear in consultation.

Future thinking on, for example, function, form and capacity will be subject to the equality duty, in so far as it relates to the configuration of services to meet demand. We will consider feedback to this consultation, alongside future evidence and where appropriate, further equality analyses would be produced. Furthermore, as the sole national Commissioner, NHS England will need to ensure monitoring of the duty as part of contract management with service providers.

We hope that this draft equality analysis will demonstrate the information that has informed our thinking so far, and provide an opportunity for stakeholders, and the general public alike, to share this and to enhance their own understanding and ours, by:

- considering and commenting on the evidence we have included, and
- helping us to fill in the gaps.

Who will be affected by this work?
It is estimated that across England and Wales between 5 and 9 in every 1,000 pregnancies, or 1 in every 110 to 200, have some form of CHD. This includes pregnancies which lead to live or still births, those which die before birth and those which are terminated. This is based on information collected by the British Isles Network of Congenital Anomaly Registers (BINOCAR\(^1\)) and cited by the British Heart Foundation\(^2\), which currently only covers 36% of births in England and Wales. In 2011, the average for the six geographical areas covered is 6.1 per 1000 births, but this ranges from 4.5 in one area to 9.1 in another. BINOCAR does not cover key areas such as London. Some academic literature (which varies in scope) also suggests rates of around 5 to 8 per 1000\(^3\).

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\(^{1}\) 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


There is limited evidence available on how this birth incidence is changing over time, but it is expected to be fairly stable. For a given rate of incidence, as more babies are born, the numbers of babies born with some form of CHD will increase. This, together with people with CHD living longer, means that the number of people living with CHD is increasing.

As well as people with CHD, this work will affect their families and carers, all members of the multidisciplinary clinical teams who support patients with CHD, and hospital managers, 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). These children and their families and carers will also be affected.

Evidence

Our evidence has come from a range of sources. Key sources of evidence for the review in general, and the standards in particular, have been advice from:

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

We have gathered evidence from:

- our patients’ and public, providers’ and clinicians’ engagement and advisory groups;
- the groups that have developed the draft CHD standards;
- the Clinical Advisory Panel;
- visits to 13 Trusts with specialist CHD units where we had the opportunity to meet staff and patients; and
- nine meetings across England with children and young people.


To inform our thinking on standards and the other objectives of the review, we have 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 have also commissioned a systematic literature review; and asked the National Institute for Cardiovascular Outcomes Research (NICOR) to investigate their data.

Systematic literature review (papers since 2003 or earlier if few papers)
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)?

National Institute for Cardiovascular Outcomes Research - 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. Although the final write-up of this work is not yet available, NICOR has kindly supplied a summary of the main findings and these have been incorporated in this paper.

NICOR run 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.

We see the gathering of evidence as part and parcel of our continuing work.

To this end, we propose to hold further engagement and advisory meetings and targeted work with some groups that share protected characteristics: BAME communities; people with learning disabilities and adults with CHD.

In the following sections we consider what impact our proposed standards for congenital heart disease might have on each of the nine protected characteristics:

• Age
• Disability
• Gender reassignment
• Marriage and civil partnership
• Pregnancy and maternity
• Race
• Religion and belief
• Sex
• Sexual orientation

We have also considered carers and geographical variations.
Age

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

Changing CHD population

CHD related episodes by age and as percentage of total (2012/13 HES data)

<table>
<thead>
<tr>
<th>Age band</th>
<th>Age</th>
<th>Episodes</th>
<th>% total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neonate</td>
<td>0 to 30 days</td>
<td>1297</td>
<td>12%</td>
</tr>
<tr>
<td>Infant</td>
<td>30 to 365 days</td>
<td>2318</td>
<td>21%</td>
</tr>
<tr>
<td>Child 1-16</td>
<td>1 to 16 years</td>
<td>4296</td>
<td>39%</td>
</tr>
<tr>
<td>Child 17-18</td>
<td>17 to 18 years</td>
<td>695</td>
<td>6%</td>
</tr>
<tr>
<td>Adult 19-64</td>
<td>19 to 64 years</td>
<td>1856</td>
<td>17%</td>
</tr>
<tr>
<td>Adult 65+</td>
<td>65 years+</td>
<td>600</td>
<td>5%</td>
</tr>
<tr>
<td>Unknown</td>
<td>N/A</td>
<td>25</td>
<td>0%</td>
</tr>
</tbody>
</table>

Note: includes all episodes in NHS England providers for all patients (not just England and Wales)

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 UK. As the birth prevalence of CHD is thought to have remained more stable over this time period, 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 1989.

There is a suggestion from our own analysis 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).

Whereas 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 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.

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For many defects treated in childhood, further problems can develop later in life which then require medical care or further surgery\(^7\).

In *Children and young people: Statistics 2013\(^8\)*, 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\(^9\)’ (page 15).

The report authors go on to highlight the importance of ensuring that facilities are adequate at transition.

**Age and CHD: What we have heard during pre-consultation**

**Increasing need for adult congenital heart disease services**
We have heard that there is a need for increasing capacity in adult congenital heart disease services and that some centres are expanding facilities and recruiting new staff.

**Age-sensitive services**
During pre-consultation, we have heard from patients, families and carers that services need to be age-sensitive and that effective transition is vital. This relates to effective and appropriate communication, but also to the facilities provided.

Young people have told us that they would like more information about sex and relationships and this needs 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.

Our draft 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.

**We believe that the standards will have a positive impact on the experience and outcomes of all children and adults with CHD. For the first time services will be nationally commissioned using common service specifications across all ages.**

*We welcome more information/evidence.*

\(^7\) *Care and Treatment for congenital heart defects* (2011) American Heart Association
http://heart.org/HEARTORG/Conditions/CongenitalHeartDefects


Disability

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

Children and adults with congenital heart disease are at an increased risk of developing further problems. 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 difficulties. These 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 surgery\textsuperscript{10}.

Disability and CHD: What we have heard during pre-consultation

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 believe that the standards will have a positive impact on the experience and outcomes of all children and adults with CHD, a number of whom have a disability. For the first time services will be nationally commissioned using common service specifications across all ages.

\textit{We welcome more information/evidence.}

Gender reassignment (including transgender)

\textit{The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.}

We have not identified any specific evidence relating to gender reassignment (including transgender) and CHD.

\textit{We welcome more information/evidence.}

Marriage and civil partnership

\textit{The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.}

We have not identified any specific evidence relating to marriage and civil partnership and CHD.

\textit{We welcome more information/evidence.}

\textsuperscript{10} Care and Treatment for congenital heart defects (2011) American Heart Association
http://heart.org/HEARTORG/Conditions/CongenitalHeartDefects
Pregnancy and maternity

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

Cardiac disease is a leading cause of maternal death in pregnancy\(^{11}\).

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 and 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.

Fetal diagnosis

We are undertaking separate work (Objective 6) to improve fetal diagnosis of congenital heart disease.

Pregnancy and maternity and CHD: What we have heard during consultation

We have heard 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 have 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 ACHD services, and that deliveries are planned for safety.

We have developed specific standards on:
- pregnancy and contraception; and
- fetal diagnosis.

We believe that the proposed standards alongside our work to improve antenatal and neonatal detection rates (Objective 6) 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. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

\(^{11}\) Royal College of Obstetricians and Gynaecologists (2011)
Race

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

CHD related episodes by ethnicity and as percentage of total (2012/3 HES data)

<table>
<thead>
<tr>
<th>Ethnicity (%)</th>
<th>Specialist inpatient Episodes</th>
<th>Specialist inpatient Patients</th>
<th>ONS 2011 Census</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paediatric cardiac</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>66%</td>
<td>66%</td>
<td>79%</td>
</tr>
<tr>
<td>Black</td>
<td>4%</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>White and Black</td>
<td>2%</td>
<td>1%</td>
<td>N/A</td>
</tr>
<tr>
<td>Asian</td>
<td>10%</td>
<td>10%</td>
<td>9%</td>
</tr>
<tr>
<td>White and Asian</td>
<td>1%</td>
<td>1%</td>
<td>N/A</td>
</tr>
<tr>
<td>Chinese and other</td>
<td>3%</td>
<td>3%</td>
<td>1%</td>
</tr>
<tr>
<td>Any other mixed</td>
<td>1%</td>
<td>1%</td>
<td>6%</td>
</tr>
<tr>
<td>Not Known</td>
<td>4%</td>
<td>4%</td>
<td>N/A</td>
</tr>
<tr>
<td>Not Stated</td>
<td>10%</td>
<td>11%</td>
<td>N/A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity (%)</th>
<th>Specialist inpatient Episodes</th>
<th>Specialist inpatient Patients</th>
<th>ONS 2011 Census</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACHD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>79%</td>
<td>79%</td>
<td>88%</td>
</tr>
<tr>
<td>Black</td>
<td>2%</td>
<td>2%</td>
<td>3%</td>
</tr>
<tr>
<td>White and Black</td>
<td>0%</td>
<td>0%</td>
<td>N/A</td>
</tr>
<tr>
<td>Asian</td>
<td>5%</td>
<td>5%</td>
<td>7%</td>
</tr>
<tr>
<td>White and Asian</td>
<td>0%</td>
<td>0%</td>
<td>N/A</td>
</tr>
<tr>
<td>Chinese and other</td>
<td>2%</td>
<td>2%</td>
<td>1%</td>
</tr>
<tr>
<td>Any other mixed</td>
<td>0%</td>
<td>0%</td>
<td>2%</td>
</tr>
<tr>
<td>Not Known</td>
<td>5%</td>
<td>5%</td>
<td>N/A</td>
</tr>
<tr>
<td>Not Stated</td>
<td>7%</td>
<td>7%</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Note: ONS 2011 census do not use the same ethnic groups as HES so not directly comparable but give some sense of how the ethnic mix of activity for specialist inpatient CHD care compares to the general population of England and Wales.

The HES data above indicates that the majority of CHD episodes are among those patients classified as white, followed by those patients classified as Asian.

Ethnicity and prevalence

Research dating back to the 1980s and 1990s demonstrated higher prevalence among Asian communities in various UK cities including Manchester and Leeds, and in the West Midlands. 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 defects in the first year of life Br Heart J 1995; 73: 173-176
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disease, (2012)\textsuperscript{14} JT Shieh \textit{et al.} undertook a systematic review of consanguinity in CHD, focusing on non-syndromic disease, with the methodologies and results from studies of different ethnic populations compared. They 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.

\textbf{Ethnicity and outcomes}

We asked NICOR to see whether there was any link between ethnicity and the 30-day outcome after paediatric surgery. NICOR have used a 2009-12 dataset and a Partial Risk Adjustment in Surgery (PRAiS) model\textsuperscript{15} recalibrated to evaluate the candidate risk factors for ethnicity. The PRAiS model assigns risk of death by 30 days after the first surgical operation (29 different specific procedures) in 30-day episodes of surgical management. NICOR’s analysis of data from 13 paediatric surgery centres (12,186 episodes of care in paediatric heart surgery during April 2009 to March 2012 inclusive) showed that Asian ethnicity is associated with poorer outcomes (30-day post-operative mortality). This is a statistically significant finding. Other categories of ethnicity (Black, Chinese and Other) did not have statistically different risk from the Caucasian category.

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.

\textbf{Race and CHD: What we have heard during pre-consultation}

We believe that the standards will have a positive impact on the experience and outcomes of children and adults from ethnic minorities with CHD. For the first time services will be nationally commissioned using common service specifications.

\textit{We welcome more information/evidence.}


Religion or belief

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

We have not identified any specific literature relating to religion or belief and CHD.

Religion or belief and CHD: What we have heard during pre-consultation

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

We welcome more information/evidence.

Sex

The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.

CHD-related episodes by gender and as percentage of total (2012/13 HES data)

<table>
<thead>
<tr>
<th>Gender</th>
<th>%</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paediatric cardiac</td>
<td>Episodes</td>
<td>Patients</td>
</tr>
<tr>
<td>Male</td>
<td>56</td>
<td>55</td>
</tr>
<tr>
<td>Female</td>
<td>44</td>
<td>45</td>
</tr>
<tr>
<td>ACHD</td>
<td>Episodes</td>
<td>Patients</td>
</tr>
<tr>
<td>Male</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Female</td>
<td>50</td>
<td>50</td>
</tr>
</tbody>
</table>

In terms of activity levels the HES data above shows that there are more episodes for males than females in paediatric cardiac procedures but the number evens out 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 identified\(^\text{16}\). 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.

We have not identified any specific literature relating to gender and CHD.

Gender and CHD: What we have heard during pre-consultation

We did not identify any key messages about gender.

\(^{16}\) Source: NICOR
We believe that the standards will have a positive impact on the experience and outcomes of children and adults of both sexes with CHD. For the first time services will be nationally commissioned using common service specifications.

*We welcome more information/evidence.*

**Sexual orientation**

*The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.*

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

**Sexual orientation and CHD: What we have heard during pre-consultation**

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

*We welcome more information/evidence.*

**Carers**

*The draft standards are intended to ensure that everyone with CHD gets the best possible care within the available resource.*

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

**Carers and CHD: What we have heard during pre-consultation**

In addition, we have heard how important it is for parents and carers to be supported, particularly when they are away from home. They have told us about difficulties with finding their way round new hospitals, finding accommodation and eating balanced meals. They have also told us about problems with car parking.

We have also heard how important it is to have support for end of life and poor outcomes. This means having identified support structures that encourage and enable open and honest communication with families and carers at that time.

We have developed specific standards on:

- facilities; and
- palliative care and bereavement.
We believe that the standards will have a positive impact on the experience and outcomes for families and carers, ensuring that they are recognised and appropriately supported in their care of children and adults with CHD. For the first time services will be nationally commissioned using common service specifications.

We welcome more information/evidence.

Geographical variation

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 (2012/3 HES data)

<table>
<thead>
<tr>
<th>Area Team of patient residence</th>
<th>% of all specialist inpatient episodes</th>
<th>Specialist inpatient episodes per 100,000 (0-18) population</th>
<th>Specialist inpatient episodes per 100,000 (19+) population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Durham, Darlington and Tees</td>
<td>2%</td>
<td>60.0</td>
<td>4.9</td>
</tr>
<tr>
<td>Cumbria, Northumberland, Tyne and Wear</td>
<td>3%</td>
<td>69.0</td>
<td>3.9</td>
</tr>
<tr>
<td>Lancashire</td>
<td>3%</td>
<td>67.3</td>
<td>5.4</td>
</tr>
<tr>
<td>Greater Manchester</td>
<td>5%</td>
<td>63.1</td>
<td>6.3</td>
</tr>
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<td>Cheshire, Warrington and Wirral</td>
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</tr>
<tr>
<td>Merseyside</td>
<td>3%</td>
<td>72.4</td>
<td>10.5</td>
</tr>
<tr>
<td>West Yorkshire</td>
<td>4%</td>
<td>69.9</td>
<td>6.6</td>
</tr>
<tr>
<td>South Yorkshire and Bassetlaw</td>
<td>2%</td>
<td>59.8</td>
<td>3.4</td>
</tr>
<tr>
<td>North Yorkshire and Humber</td>
<td>2%</td>
<td>54.8</td>
<td>4.3</td>
</tr>
<tr>
<td>Leicestershire and Lincolnshire</td>
<td>3%</td>
<td>69.9</td>
<td>5.8</td>
</tr>
<tr>
<td>Hertfordshire and The South Midlands</td>
<td>5%</td>
<td>67.8</td>
<td>5.3</td>
</tr>
<tr>
<td>Derbyshire and Nottinghamshire</td>
<td>3%</td>
<td>59.7</td>
<td>5.1</td>
</tr>
<tr>
<td>Birmingham and The Black Country</td>
<td>6%</td>
<td>86.6</td>
<td>4.8</td>
</tr>
<tr>
<td>Shropshire and Staffordshire</td>
<td>3%</td>
<td>69.5</td>
<td>6.7</td>
</tr>
<tr>
<td>Arden, Herefordshire and Worcestershire</td>
<td>3%</td>
<td>72.2</td>
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<tr>
<td>East Anglia</td>
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<td>55.4</td>
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<tr>
<td>Essex</td>
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<td>59.5</td>
<td>3.9</td>
</tr>
<tr>
<td>London</td>
<td>16%</td>
<td>70.8</td>
<td>5.4</td>
</tr>
<tr>
<td>Kent and Medway</td>
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<td>53.7</td>
<td>4.5</td>
</tr>
<tr>
<td>Surrey and Sussex</td>
<td>4%</td>
<td>59.4</td>
<td>6.0</td>
</tr>
<tr>
<td>Thames Valley</td>
<td>3%</td>
<td>56.5</td>
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</tr>
<tr>
<td>Wessex</td>
<td>4%</td>
<td>59.5</td>
<td>4.6</td>
</tr>
<tr>
<td>Bath, Gloucestershire, Swindon and Wiltshire</td>
<td>3%</td>
<td>59.8</td>
<td>8.8</td>
</tr>
<tr>
<td>Bristol, North Somerset, Somerset and South Gloucestershire</td>
<td>3%</td>
<td>63.9</td>
<td>6.9</td>
</tr>
<tr>
<td>Devon, Cornwall and Isles Of Scilly</td>
<td>3%</td>
<td>60.1</td>
<td>6.6</td>
</tr>
</tbody>
</table>
The HES data above indicates that activity is fairly evenly spread across the country with the exception of London which has a much larger population, and Birmingham and Greater Manchester who are also slightly higher. However, once we account for different populations in each area we can see there is much more variation across the country in terms of relative activity. The episodes per 100,000 population show some differences from Wales at 52.6 and Kent and Medway at 53.7 to Merseyside at 72.4 to Birmingham and the Black Country at 86.6 (all paediatric services). In the case of adult services, the episodes per 100,000 population show differences from Wales at 2 and Essex at 3.9 to Bath, Gloucestershire, Swindon and Wiltshire at 8.8 and Merseyside at 10.5. This is demonstrated in the maps below; the darker the colour the higher the relative activity in that area.

Paediatric (0-18) 2012/13 HES specialist inpatient episodes per 100,000 population, by Area Team of patient residence (activity per head so controlled for different population sizes)
Geographical variation and CHD: What we have heard during pre-consultation

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.

We have noted the feedback we have received during pre-consultation on the concerns about how services will be delivered in the future, and will use this to inform our thinking in relation to future work on Objectives 3, 4 and 5.

*We welcome more information.*

**Engagement and Involvement**

Over the past 12 months we have been working with a wide range of stakeholders to develop the current draft standards. We have worked with and spoken to:

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

As well as regular meetings of formal engagement and advisory groups, we have undertaken visits to all specialist units, led by Professor Deirdre Kelly, Chair of the Clinician Group. During these visits, members of the new CHD review team had an opportunity to speak to clinical staff, and patients and their families. We also ran nine dedicated events for children and young people around the country.
The draft standards have been central to our engagement and involvement work from the outset and have informed the development of the draft service specifications. For the past year we have been working with experts to develop the draft standards, and then testing them out with our engagement and advisory groups and a wider audience.

We have adopted an approach of openness and transparency and all our papers are published on the NHS England Congenital Heart Disease Review website and John Holden’s blog. Blog 23 contained the then-current version of the standards and so was open to everyone to see.

Launch of the consultation is the next step in the process and our work on engagement and involvement is ongoing. We plan to arrange four further regional visits during consultation and to do some targeted work with the stakeholders with an interest in the following protected characteristics:

- Age (specifically adults with CHD, with whom we have had less contact than children and young people)
- Disability (in particular, learning disability)
- Race

**Summary of analysis**

The evidence and engagement activity considered above has highlighted ways in which, subject to consultation and final agreement, our standards can help improve the way in which services are delivered to all those with CHD, including those in protected groups.

This is particularly so in relation to:

- Age
- Disability
- Pregnancy and maternity
- Race

The links between the standards and their impact on other protected groups is not so obvious. We hope to better understand how the standards might be used to support other protected groups through focused activities during the consultation – and also increase our understanding of the needs of adults with congenital heart disease.

The standards and the service specifications will, once agreed, set the framework through which CHD services will be delivered. It will be important for providers to ensure that they have regard to the equality duty in the provision of these CHD services.

**Eliminating discrimination, harassment and victimisation**

The draft standards apply to CHD services for children and adults – we currently only have agreed standards and a service specification for CHD services for children. The new draft
standards will ensure that everyone with CHD gets the best possible care whatever their age, thereby improving the consistency of our approach with adults.

Advancing equality of opportunity

The draft standards apply to CHD services wherever they are delivered in the country. They apply to all services (levels 1, 2 and 3). The draft standards will help ensure that all services are working to the same aims – and that people with CHD can receive a consistently high quality service.

Promoting good relations between groups

The standards will provide a consistent approach for all those with CHD in protected groups.

Our work to date has also enabled us to identify some areas that are common to all groups (and not solely applicable to CHD services) and improvements in these areas will benefit all:

- Effective communications
- Information sharing between professionals
- Transition

Evidence-based decision making

Our engagement and involvement to date has been invaluable in enabling us to develop the current draft standards and to hear from a wide range of people. It has at the same time allowed us to develop our thinking in relation to protected groups and to identify some gaps in relation to our understanding of whether people with CHD in some protected groups have a voice and are being heard.

Our work with children and young people and meeting patients and families at the hospitals we visited gave us a particular insight into issues around age (specifically children and young people, and the transition into adult services) disability, pregnancy and maternity, and race.

It has highlighted issues relating to three protected groups that would benefit from further consideration and research:

- How CHD services will develop to meet changing needs as the number of adults with CHD exceeds the number of children with CHD.
- The reason for the prevalence of CHD in some Asian communities and poorer outcomes at 30 days after first surgical procedure.
- How CHD services can best be developed to meet the needs of patients with a disability, in particular learning disability.
We are also keen during consultation to hear from people who can provide further evidence to inform our thinking in relation to those protected groups not mentioned above.

Sharing this draft equality analysis
As part of our assurance, this draft analysis will be shared with our programme board, the Specialised Commissioning Oversight Group, Programme of Care Board for Women and Children, the Clinical Priorities Advisory Group and the Directly Commissioned Services Committee.

The draft equality analysis will form part of the reference document that will accompany the consultation document, draft standards and service specifications.

As such it will be included in our communications and engagement activity at launch. We will send it to our engagement and advisory groups, our Clinical Advisory Panel and blog followers.

<table>
<thead>
<tr>
<th>For your records</th>
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</thead>
<tbody>
<tr>
<td>Name of person(s) who carried out this draft analysis:</td>
<td>Penny Allsop</td>
</tr>
<tr>
<td>Name of Sponsor Director:</td>
<td>John Holden, Director of System Policy</td>
</tr>
<tr>
<td>Date analysis was completed:</td>
<td>July 2014</td>
</tr>
<tr>
<td>Review date:</td>
<td>TBC post-consultation</td>
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