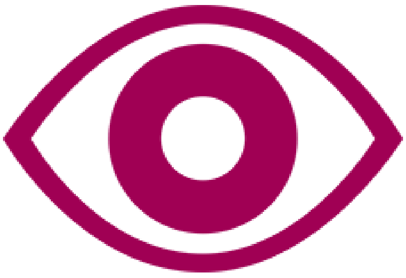
Appendix A

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



**NHS England INFORMATION READER BOX**

| **Directorate** | | |
|---|---|---|
| Medical | **Commissioning Operations** | Patients and Information |
| Nursing | Trans. & Corp. Ops. | Commissioning Strategy |
| Finance | | |

| **Publications Gateway Reference:** | **06374** |
|---|---|
| **Document Purpose** | Consultations |
| **Document Name** | Proposals to implement standards for congenital heart disease for children and adults in England - Consultation Document |
| **Author** | NHS England |
| **Publication Date** | 09 February 2017 |
| **Target Audience** | CCG Clinical Leaders, CCG Accountable Officers, Foundation Trust CEs , Medical Directors, Directors of Nursing, NHS England Regional Directors, NHS England Directors of Commissioning Operations, NHS Trust CEs, Public; Patients; Families; Carers; Patient Group representatives; charities |
| **Additional Circulation List** | All NHS England Employees, Directors of HR, Directors of Finance, Communications Leads |
| **Description** | NHS England is consulting on its proposals to implement national standards for congenital heart disease services for children and adults. This document sets out the background and context for our proposals; explains the proposals in more detail, including their potential impact, if implemented; and how you can get involved in consultation. |
| **Cross Reference** | N/A |
| **Superseded Docs** (if applicable) | N/A |
| **Action Required** | N/A |
| **Timing / Deadlines** (if applicable) | **Consultation runs from 9 February to 5 June 2017** |
| **Contact Details for further information** | Michael Wilson<br>Programme Director Congenital Heart Disease Programme<br>NHS England<br>Skipton House<br>80 London Road<br>SE1 6LH<br>www.engage.england.nhs.uk |

## Document Status

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

## Consultation Document

First published:  9 February 2017

Prepared by: Specialised Commissioning, NHS England

Classification: OFFICIAL

# Contents

# Foreword

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

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

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

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

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

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

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

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

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

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

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

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

## Background and context

> "Sixteen years is a long time to wait. We have lost key consultant staff to posts abroad during that time, as they were not convinced that we were ever going to grasp this nettle. This is our last opportunity to make change happen. If we don't grasp this opportunity now, we have to accept that 'adequate' is good enough".
>
> **Professor Huon Gray**
> **Consultant Cardiologist, University Hospital Southampton NHS Foundation Trust, and National Clinical Director for Heart Disease, NHS England**

1. Congenital heart disease (CHD) refers to a heart condition or defect that develops in the womb, before a baby is born. There are many different forms of CHD, some more minor than others. Some people with CHD do not require any form of surgery or interventional procedure in the treatment of their condition; others require surgery before, or immediately after, birth. Thanks to advances in early diagnosis and medical advances, most babies born with CHD grow up to be adults, living full and active lives. CHD is common. It is estimated that between 5 and 9 in every 1000 babies born in the UK is born with CHD – this is around 5,500 to 6,300 babies each year. These figures will continue to increase if birth rates continue to rise, which leads to an increase in the number of operations and interventional procedures carried out on CHD patients each year.

2. Many congenital heart disease services work together in networks, so that neighbouring hospitals have good systems for referring patients, and for passing information back and forth. Networks help local services to work closely with specialist centres, to ensure that patients receive the care they need in a setting with the right skills and facilities, as close to home as possible.

3. Services are based around a three-tiered model of care with specialist surgical centres (Level 1) managing the most highly complex diagnostics and care, including all surgery and interventional cardiology. At the next level are specialist cardiology centres (Level 2), which provide the same level of specialist medical care as Level 1, but do not provide surgery or interventional cardiology (except for one, specific minor procedure – atrial septal defect (ASD) closures, more commonly known as 'hole in the heart' – at selected hospitals treating adults. These Level 2 hospitals focus on diagnosis, plus ongoing care and management of CHD. At Level 3 will be local cardiology services, which are services in local hospitals run by general paediatricians/cardiologists with a special interest in CHD. They will provide initial diagnosis and ongoing monitoring and care, including joint outpatient clinics with specialists from Level 1 and 2 hospitals. These services are commissioned by local Clinical Commissioning Groups (CCGs), and not by

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

4. Anybody who is familiar with the history of these services will know that publication of NHS England's proposals in the summer of 2016 represented the latest milestone in a very long journey, stretching back 16 years, to the publication of the report of a public inquiry into concerns about the care of children receiving complex cardiac surgery at Bristol Royal Infirmary. This was followed by the Safe and Sustainable review, launched by the Department of Health, in 2008. This review set out recommendations for a CHD service based on networks; with clinical standards for all hospitals designated to provide heart surgery for children, and a reduction in the number of NHS hospitals in England providing that heart surgery. Ultimately, these recommendations were not implemented, following intervention with the Secretary of State.

5. We know, from talking to stakeholders, that the failure to implement the recommendations of previous reviews has created uncertainty for patients and staff, and concerns raised during these, and other enquiries, have remained. However, despite the fact that previous reviews have not resulted in a coordinated programme of change, progress has been made. Outcomes for CHD surgery and interventional procedures across England are good, and compare well with other countries. We also know, from talking to patients and their families and carers in particular, that the quality of CHD care delivered in hospitals is very good. We have heard many, many positive stories about individual patient experiences, and recognise that each of those personal testimonies carries real weight, and shapes how people feel about the NHS service which has cared for, or saved the life of, their loved ones.

6. When NHS England took on responsibility for the commissioning of CHD services in 2013, we were aware of the impact that previous reviews had had, as described above, and were told by patients, families, doctors and nurses alike, that the best way to deal with these issues was through the development of service standards, setting out how a good CHD service should be set up, organised and run.

7. We worked with the different groups of stakeholders for more than two years, as part of the New Congenital Heart Disease Review, to create a set of quality and service standards that covered the entire patient pathway, from diagnosis, through treatment, and on into care at home and end of life care, to make sure that every child, young person and adult with CHD, in every part of the country, would receive the same high standard of treatment.

8. Surgeons told us how many operations should be done by each surgeon every year in order to maintain the surgeons' skills. Similarly, specialist doctors and nurses told us what medical care should be available by the bedside of a patient in a critical condition. Patient representatives led the work in developing the standards covering communication, facilities and bereavement. Additionally, for the first time ever, the transition from children's

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

9. The standards have never been considered as an end in themselves. They were developed in the full expectation that their implementation at every hospital in the country providing CHD services would be the means by which our work would be delivered, i.e:

    - securing best possible outcomes for all patients – not just reducing the number of deaths, but reducing disability caused by disease, and improving people's quality of life;
    - tackling variation, so that services are consistent in meeting standards, each of them offering 24/7 care, seven days a week, as part of a nationally resilient service;
    - improving patient experience, including provision of better information for patients, plus more consideration of access and support for families when they are away from home.

10. This review has been underpinned by principles of openness and transparency, and a need to engage as widely as possible, bringing patients, families, carers, patient representatives, and clinicians together, in the joint pursuit of an effective and equitable solution, in the interests of patients now, and in the future. Consensus across all groups was achieved on the content of the standards, and it became clear that NHS England, as the sole national commissioner of CHD services had a unique opportunity to drive service improvement, and reduce variation in access and quality, by implementing a set of nationally-agreed standards, governing a truly national service.

## The case for change

11. The standards describe how to deliver CHD services of the very highest quality. We believe that implementation of these standards is the only way to ensure that patients are able to access care delivered to the same high standards, regardless of where they are treated. There is currently some variation as to where individual hospitals lie in meeting the standards, so care may vary, depending on where in England you access services.

12. We know, from talking to patients and their families/carers, that some people consider the care that they and their loved ones have experienced at a hospital to be the best there is. We do not wish to detract from that very personal experience, but it is not the same for everyone, and that simply is not fair.

13. Once all hospitals are meeting the standards, we can ensure that patients with CHD will be receiving the same levels of high quality care. For patients, and their families and carers, this means:

    - higher levels of support from specialist nurses and psychologists;

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

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

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

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

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

> "From my perspective there are three main clinical advantages for having high-volume congenital cardiac surgical centres. Firstly, as an individual surgeon the more I do the better I become. There's lots of evidence for this in other surgical specialties, in particular showing that high volume centres reduce the number of post-operative complications and improving long-term quality of life. This also works for the whole team providing the care: the more the team does, the better they become, and this gives a huge opportunity for people to learn from each other in a large multidisciplinary setting.
>
> And finally, higher surgical volumes enable specialisation in areas such as neonatal, congenital and device treatments. Importantly, these are all important for the next generation of surgeons coming up through the system - they will be less experienced when they become consultants than in the past - and they will need to fit into a large team to nurture them into becoming the surgeons of the future."
>
> **Mr Martin Kostolony - Head of Clinical Service - Cardiothoracic Surgery, Great Ormond Street Hospital for Children NHS Foundation Trust**

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

## 1.1 Ending uncertainty

17. The long history of repeated reviews of CHD services has created uncertainty within the specialty, damaging relationships between hospitals; harming recruitment and retention of specialist staff; and reducing the resilience of services. Continued uncertainty affects recruitment and retention of congenital heart disease surgeons, a group in short supply and subject to international demand.
18. The 2014 report on CHD services at Leeds Teaching Hospitals NHS Trust[1] recommended that NHS England should act to dispel the "almost morbid sense of spectatorship and foreboding that hangs over these services". Clear resolution is now needed to bring the stability the service needs to move forward.

---

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

## 1.2 Ending occasional practice

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

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

## 1.3 Resilient, sustainable services

> “We know that many people are very nervous about how the standards are moved forward, we must acknowledge those fears and support patients and families affected by any change but if we do not start to implement the new standards soon we will start to see a deterioration in the service.
>
> We know that there are a growing number of children with highly complex conditions travelling through care. It is really important to make sure that there is a really strong service for them from the beginning of their lives, through their childhood and into adult services. They deserve nothing less.
>
> **Suzie Hutchinson, Chief Executive and Service Lead, Little Hearts Matter**

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

24. Our proposals are described in detail on page 15. If they are implemented, in future, CHD services will only be provided by hospitals which already meet the standards required, or are likely to meet the standards within required timeframes as a result of the improvement plans they are putting in place.

> "We fully support these standards. NHS England must ensure that the standards are applied for the benefit of patients, by ensuring that expertise is concentrated where it is most appropriate. The proposals put forward by NHS England in July 2016 should improve patient outcomes and help address variations in care currently provided".
>
> **Royal College of Surgeons and the Society for Cardiothoracic Surgery (SCTS)**

## Proposals for consultation

25. At the heart of our proposals is our aim that every patient should be confident that their care is being delivered by a hospital that is able to meet the required standards. In order to achieve this, we propose that in future, NHS England will only commission CHD services from hospitals that are able to meet the standards within the required timeframes.

26. Three specific standards are relevant to our proposals:

- Surgeon working requirements – the number of surgeons at each hospital, and the number of operations they each perform.
    - The standards require that, for 2016, surgeons work in teams with a minimum of three surgeons, and in teams of at least four surgeons by April 2021. CHD surgeons are each required to carry out no fewer than 125 congenital heart operations a year (the equivalent of about three operations a week), averaged over a three-year period;

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

- Interventional cardiology
    - The standards require that for 2016, interventional cardiologists work in a team of at least three, and by April 2017 in teams of at least four, with the lead interventional cardiologist carrying out a minimum of 100 procedures a year, and all interventional cardiologists doing a minimum of 50 procedures a year.

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

**Level 1 (surgical)**

Proposal:

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

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

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

Proposal:

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

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

31. We are continuing to explore two avenues by which the Royal Brompton could continue to provide some, or all, Level 1 services by meeting all of the required standards:

- The hospital trust is exploring ways in which the paediatric co-location standards could be met by the required deadline of April 2019;
- NHS England has raised with the Royal Brompton Hospital the potential for it to continue to provide Level 1 adult CHD services, including surgery. This would involve the hospital partnering with another Level 1 CHD hospital in London, that meets the required standards and that cares for children and young people. To date, the Royal Brompton Hospital has indicated that it does not support this approach, but it has not said that it would refuse to treat adults alone.

32. If a solution cannot be found then, under our proposals, children and adults who would currently be most likely to undergo CHD surgery and/or interventional cardiology at Royal Brompton and Harefield NHS Foundation Trust would still be able to receive their care in London, but would be most likely to go to Great Ormond Street Hospital for Children NHS Foundation Trust, Bart's Health NHS Trust or Guy's and St Thomas' NHS Foundation Trust if they required surgery and/or interventional procedures.

Proposal:

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

33. University Hospitals of Leicester NHS Trust performed 326 surgical procedures in 2015/16 which does not meet the minimum number of cases required by the standards. The hospital trust states that it is very close to meeting the requirement for an overall caseload of 375 operations for 2016/17, and has a growth plan in place to reach an overall caseload of 500 operations by 2021. NHS England does not consider these projections to be sound, and needs to see a more robust plan to support delivery of 375 cases now, and 500 cases by 2021. As of mid-January 2017, this plan has not been provided to us by the hospital trust.

34. The CHD service in Leicester lacks the capacity to deliver a full range of services as a fully independent centre, receiving clinical support for complex cases from surgical and cardiology colleagues in Birmingham. It has also transferred cases to Great Ormond Street Hospital for Children NHS Foundation Trust, and to Newcastle Hospitals NHS Foundation Trust. At this point in time, it is difficult to see how the hospital trust will be able to build up its resilience to ensure sustainable services for the future.

35. Similarly, University Hospitals of Leicester NHS Trust is at the margins of having enough interventional cardiology activity for its proposed team of three interventionists to meet the requirements of a lead interventionist carrying out a minimum of 100 procedures a year, and all interventionists doing a minimum of 50 procedures a year. While the hospital meets the April 2016 requirements, we need to see a credible plan which supports the development of a team of four interventionists by April 2017, and the associated activity that goes with that team.

36. Glenfield Hospital, which is part of University Hospitals of Leicester NHS Trust, and which is where the CHD service is located, has access to 24/7 paediatric gastroenterology and paediatric surgery, but does not have either of these services on site. The hospital originally proposed to achieve co-location of relevant paediatric specialties with its paediatric CHD service by 2019, through plans to build a new children’s hospital, bringing all children’s specialist services together on one site. However, the Trust has since developed an alternative plan that would involve moving paediatric cardiac services to the Leicester Royal Infirmary by 2019. We consider that the Trust’s proposal to move paediatric cardiac Level 1 services to the Infirmary site would allow it to achieve full compliance with the co-location requirements, although the Trust would need to ensure that this move is achieved by the required deadline.

37. If we do not receive assurance that the hospital trust will meet the required standards then, under our proposals, children and adults who would currently be most likely to receive surgery and/or interventional cardiology at University Hospitals of Leicester would be likely to choose to receive their care at either Birmingham Children’s Hospital NHS Foundation Trust or University Hospitals Birmingham NHS Foundation Trust. Some current Leicester patients would be likely to choose to receive care from Leeds Teaching Hospitals NHS Trust, if this was closer for them than Birmingham.

38. If our proposals are implemented, University Hospitals of Leicester NHS Trust could continue to offer Level 2 specialist medical services to children and adults, and we continue to discuss this option with the hospital trust. If the hospital carried on offering Level 2 CHD services, then the vast majority of patient care would continue to be offered in Leicester, and patients would only be required to travel elsewhere if they required surgery and/or interventional catheters. We continue to discuss this option with University Hospitals of Leicester NHS Trust.

39. It is important to note that change, such as that proposed above, has already taken place in CHD services without any adverse effects on patients. In 2010, Oxford stopped providing CHD surgery following the deaths of a number of babies. The hospital trust was carrying out more than 100 cases a year up until that time. Surgery was moved to Southampton. Surgeons employed at Oxford moved elsewhere, and there was no impact on other members of staff, who were all redeployed elsewhere within the hospital trust. Oxford is now part of a formal children’s network, which means that patients can choose either Southampton or a hospital in London for surgery and/or

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

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

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

41. While we are clear that all hospitals providing CHD services must meet the national CHD standards, we have had to propose a time-limited exception, or derogation, in the case of one particular hospital. Newcastle upon Tyne Hospitals NHS Foundation Trust does not meet the 2016 activity requirement and is unlikely to be able to meet the 2021 activity requirement. It also does not meet the 2019 paediatric co-location requirements or currently have a realistic plan to do so by April 2019. The CHD service for both children and adults is located at the Freeman Hospital, which is primarily an adult acute hospital. Relevant children's specialties – paediatric surgery, nephrology and gastroenterology – are located at the Great North Children's Hospital, which is part of the same hospital trust, but is not located on the same site. While the hospital trust meets the co-location requirement for 2016, i.e. bedside access within 30 minutes, it is unlikely to meet the full co-location requirement for 2019 for children's CHD surgery to be on the same site as other children's specialist services.

42. Newcastle upon Tyne Hospitals NHS Foundation Trust has a unique, strategic position in the NHS in England in delivering care for CHD patients with advanced heart failure, including heart transplantation and bridge to transplant. Advanced heart failure amongst people with CHD is increasing as a result of increased life expectancy, and treatment for people with this condition is dependent on CHD surgeons. Adult CHD patients with end stage heart failure have limited access to heart transplantation, and the unit in Newcastle is recognised as delivering more care to this group than other transplant centres nationally. This service is intimately connected to the CHD service and can only be delivered at a hospital providing Level 1 surgical services. No other provider currently has this capability so, while in principle it would be possible to commission these services from an alternative provider, the learning curve would be long and initially outcomes would not be as good.

43. In addition, the hospital trust is one of only two providing paediatric heart transplantation for the UK (the other is Great Ormond Street Hospital for Children NHS Foundation Trust in London).

44. While Newcastle does not meet these required standards now and is unlikely to be able to do so within the required timeframe, its role as one of only two national providers of critical heart transplantation and bridge to transplant services means that we need to consider retaining services at Newcastle despite the fact that it does not meet all the standards at present and is unlikely to do so within the required timeframes. The surgeons who perform CHD operations are the same surgeons carrying out heart transplants. If CHD surgery were moved elsewhere, the transplantation service could not be replaced in the short term without a negative effect on patients. For this reason, we are proposing to retain CHD services at Newcastle upon Tyne Hospitals NHS Foundation Trust.

45. This does not mean that change at Newcastle upon Tyne Hospitals NHS Foundation Trust will not happen in the longer-term. The hospital trust is required to meet the standards in the same way as all of the other Level 1 surgical centres. Timeframes for doing this may differ, but we will be working closely with the hospital trust to ensure that patients receiving CHD care at Newcastle upon Tyne Hospitals NHS Foundation Trust are not compromised in any way.

46. If our proposals were implemented, this would mean that, in future, Level 1 CHD surgical services would be provided by the following hospitals:

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

47. Changes are also proposed to the provision of Level 2 specialist medical CHD care. In most cases, these proposals involve very small numbers of patients who might be impacted by that change. Whilst those changes are not the subject of this formal public consultation, we are very keen to talk to patients, their families/carers, and staff at affected hospitals, to better

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

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

### Level 2 (specialist medical services)

Proposals:

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

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

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

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

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

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

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

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

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

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

# How our proposals were developed

## 1.4 Meeting the standards

52. The standards were agreed by NHS England's Board in July 2015, following a 12-week period of public consultation. Once agreed, we started to look at how we might put the standards into practice. Patients and their families/carers, and patient representatives, told us early on that, while it was a good thing to have standards, they only really mattered if we ensured that they were met. Otherwise, they were a waste of time. That message is really important and has influenced our thinking throughout this process.

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

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

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

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

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

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

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

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

> “125 really is a minimum number. It equates to three operations a week, per surgeon. Practice makes perfect, and 125 operations a year is considered the minimum to ensure that a newly appointed consultant surgeon acquires the skills they need across the differing surgical techniques. Some of the operations we do only come up once or twice a year, so ideally you would be doing at least four operations per surgeon each week, as that would result in 170-200 operations a year.
>
> A surgeon doing too many, or too few, operations is not good. Either way can result in a poor performance when it matters, either through fatigue or a loss of skills. Individuals will, of course, vary in capability, but we must set a minimum standard in order to ensure that a surgeon has an acceptable level of skill refined and maintained through regular practice. Centres need to oversee the distribution of the work fairly, taking account of any specialist skills, to ensure that all surgeons have the opportunity to work at optimum levels.”
>
> **Professor David Anderson, Consultant Heart Surgeon and Professor of Children’s Heart Surgery, Guy’s and St Thomas’ NHS Foundation Trust, and President of the British Congenital Cardiac Association (BCCA)**

58. Each set of returns from the hospitals was initially evaluated at a regional level by NHS England’s specialised commissioners, and then by a national panel, comprising patient representatives, clinicians, and commissioners, to ensure consistency of approach. The role of the regional and national panels was to assess each hospital’s ability to meet the standards, based on the evidence submitted by that hospital. A report of the panel’s work, and its assessments, was published by NHS England in July 2016.

59. In summary, the national panel found that as of May 2016, none of the hospitals providing CHD services met all of the standards tested. This was not unexpected, as the standards were aimed at ensuring that all services were brought up to the level of the best of existing practice. They were intended to be stretching, but realistic, and were focused on driving improvement.

60. The panel found that, with respect to Level 1 surgical services:

    - Two hospitals – Birmingham Children’s Hospital NHS Foundation Trust and Great Ormond Street Hospital for Children NHS Foundation Trust – were very close to meeting all of the requirements, with robust and credible plans to meet the rest within the required timescale, i.e. end of March 2017. They were rated green/amber;

- Seven hospitals[2]were likely to meet all of the requirements within the required timescale with development of their plans. They were rated amber;
- Three hospitals were unable to meet the requirements now, and were unlikely to be able to do so within the required timeframe. They were University Hospitals of Leicester NHS Trust, Newcastle Hospitals NHS Foundation Trust, and the Royal Brompton and Harefield NHS Foundation Trust. They were rated amber/red;
- One hospital – Central Manchester University Hospitals NHS Foundation Trust – was not able to meet the requirements now, and was unlikely to be able to do so within the required timeframe. Manchester has fewer than 100 operations annually undertaken by a single surgeon, with interventional cardiology provided on a sessional basis. Appropriate 24/7 surgical or interventional cover is not provided. The national panel considered these arrangements to be a risk, and rated the centre red.[3]

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

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

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

## Potential impact of implementing our proposals

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

---

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

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

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

65. To better understand these issues, we have undertaken a detailed impact assessment, looking at how, if our proposals are implemented, they might be delivered in practice, and to identify the consequences for patients, providers, commissioners and others.

66. All hospitals providing Level 1 and Level 2 CHD services were asked to review their services in light of NHS England's proposals. Their responses were considered first by NHS England's regional teams, and then a national panel was drawn together to review those submissions. The findings of that panel's review are summarised at Appendix B. A full impact assessment has been published alongside this document.

## Pre-consultation engagement and involvement

67. Once the proposals were published, in July 2016, we entered a pre-consultation phase, which ran from July, right up until the start of formal consultation in February 2017.

68. The over-riding objective for NHS England during this period was to engage with hospitals providing CHD services – in particular, with those potentially affected by our proposals – to explore what the key issues were for them, in preventing them from meeting the standards, either for delivery in 2016, or the longer-term. Our aim throughout has been to maintain an open dialogue with the providers, so that we could work together to try and find alternative solutions to meeting the standards.

### 1.5 Engagement activity

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

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

70. In addition to talking to the hospital clinicians and managers, we have also taken the opportunity – whenever possible – to meet with staff on the CHD units, as well as with patients, families, carers and patient representatives. We met with patients, carers and patient representatives in Leicester and Newcastle-upon-Tyne, and attended a meeting of the North West Adult Congenital Heart Disease Forum in Liverpool. We will be meeting with patients and their families/carers and representatives in London during the consultation period.

71. We have also met with MPs, particularly those whose constituencies include one of the CHD units potentially most affected by our proposals, and have provided a written briefing about our proposals to all local authorities across England, and attended Overview and Scrutiny Committees and Health and Wellbeing Boards where invited.

72. We have responded to a significant volume of correspondence relating to our proposals for CHD services during this period, assessing and re-assessing information provided by the hospitals; answering Parliamentary correspondence and Freedom of Information requests, as well as more general correspondence from stakeholders associated with the hospitals who wrote to us expressing concerns and/or asking for more information about our proposals.

73. The discussions during the pre-consultation period were dominated by the theme of how an individual hospital might achieve compliance with the standards, as well as the level of impact which our proposals – if implemented - might have on a hospital, as well as on its staff and, most importantly, its patients and their families.

## Consultation

### 1.6 Why are we consulting?

74. We know, from talking to patients, carers, patient representatives, hospital staff, and other stakeholders, that our proposals have caused some concern in certain areas of the country. We have tried, during the pre-consultation period, to address those concerns as best we can. However, we know that many of you remain concerned about what the future might look like in terms of your care, or that of your loved ones, or where you carry out your work.

75. Consultation is not a vote on whether or not our proposals should be implemented. Instead, it provides an opportunity for us to listen to people's views about our proposals, so that we can take them into account before any commissioning decisions are made. We have set out in this document some of the areas where we think our proposals could impact, or which people have told us could be impacted e.g. travel times for patients, and other hospital services. There may be other areas that we have not thought of, or alternative ways of meeting the standards which have not yet been explored. We need to hear about those now.

76. Consultation is open to everyone, not just those who have direct experience of CHD services.

77. The consultation is being run in accordance with Cabinet Office guidance

78. While our focus is on services for patients who are resident in England, we recognise that there are children and adults living in Wales, Scotland, and Northern Ireland, who use CHD services in England. We have agreed with our colleagues in the devolved nations that they will help support our consultation in making people aware of the consultation and how they can respond to it.

79. It is important that as many people as possible, with an interest in CHD services in England, have opportunity to contribute their views about the future of these important services.

## 1.7 How can I make my views known?

### 1.7.1 How to get involved

80. During consultation, there will be a number of opportunities for you to have your say about the future commissioning arrangements for CHD services.

81. Information about the different ways in which you can have your say is available at the NHS England Consultation Hub. Consultation materials are also available here. We will be running a number of face-to-face events during the consultation period, which will enable us to tell you more about our proposals and provide you with an opportunity to ask us questions. We will also support charities, patient groups, clinicians, and provider hospitals to run their own events, and can provide materials to support this activity if required. To find out where, and when, your nearest event is taking place, and how to register to attend, please visit the Consultation Hub

82. Hard copies of the consultation document and response form can be made available. If you require a hard copy, please email us at england.congenitalheart@nhs.net

83. We will also be holding a number of webinars throughout the consultation period, which will enable you to learn more about our proposals, and ask us questions, without having to travel. Details about all of the forthcoming webinars, and how to join them, are available at the Consultation Hub.

### 1.7.2 How to let us know your views

> This is an opportunity to set the standards for the next generation. It has clearly taken a long time, and a lot of discussion, to get to where we are now.
>
> There is a real opportunity to have standards that have been nationally agreed; that have been agreed by clinicians; by providers; by patient groups; and set up services that will benefit children and adults with congenital heart defects over the coming generations.
>
> **Jon Arnold**
> **Chief Executive, Tiny Tickers**

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

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

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

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

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

## 1.8 What happens next?

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

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

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

# Appendix A: Consultation Questions

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

### Meeting the standards

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

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

If other – please specify:

____________________________________________________________

**2.** In which region are you based?

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

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

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

4. Please explain your response to question 3.

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

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

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

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

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

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

### Royal Brompton and Harefield NHS Foundation Trust

6. The Royal Brompton could meet the standards for providing surgical (level 1) services for adults by working in partnership with another hospital that provides surgical (level 1) services for children. As an alternative to decommissioning the adult services, NHS England would like to support this way of working.

   To what extent do you support or oppose the proposal that the Royal Brompton provide an adult only (level 1) service?

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

### Newcastle upon Tyne Hospitals NHS Foundation Trust

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

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

### Travel

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

8. Do you think our assessment of the impact of our proposals on patient travel is accurate?

   ☐ Yes
   ☐ No

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

**Equalities and health inequalities**

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

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

☐ Yes

☐ No

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

### Other impacts

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

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

    ☐ Yes

    ☐ No

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

## Any other comments

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

## About you

14. Which age group are you in?

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

15. Please indicate your gender

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

16. Do you consider yourself to have a disability?

☐ Yes
☐ No
☐ Prefer not to say

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

**White**

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

**Asian or Asian British**

☐Indian
☐Pakistani
☐Bangladeshi
☐Any other Asian background

**Other ethnic group**

☐Chinese
☐Any other ethnic group

**Mixed**

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

**Black or Black British**

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

18. Please indicate your religion or belief

☐No religion
☐Buddhist
☐Christian
☐Hindu
☐Jewish
☐Muslim
☐Sikh
☐Atheist
☐Any other religion
☐Rather not say

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

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

# Appendix B: Summary of Impact Assessment

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

## 1.9 Impact on patients

90. A particular concern for some patients and their families is that they may face longer journeys to access Level 1 CHD services which will be inconvenient, and, they fear, carry a level of risk.

91. Our clinical advisers on NHS England's Congenital Heart Services Clinical Reference Group and Clinical Advisory Panel tell us that true emergencies are very rare. Thanks to advances in antenatal diagnosis, most congenital heart defects are detected while a baby is still in the womb, which enables the mother to give birth either at, or close to, an appropriate hospital providing CHD surgery to children. Even in those cases where CHD is not detected antenatally, and problems are spotted during or after delivery, surgery will often be planned over a period of a few days. If infants need to be moved from one hospital to another for emergency care, then ambulance services, local hospitals and specialist retrieval teams are well able to ensure that patients are stabilised before and during transfer so that the risks of long journeys are negligible.

92. We understand that patients feel safer having a hospital providing CHD surgery close by, but, given the relatively small number of congenital heart disease surgeons in England, this could never be the case for all patients. By implementing the standards, we are able to ensure that patients will receive their surgery in the best possible environment to achieve a good outcome. This is a delicate balance, but we believe that it outweighs the risk of additional journey time, given that emergencies in CHD patients are so rare.

93. Under the proposed model of care different journeys would only be required when patients need to undergo surgery or an interventional or other catheter procedure, and for some admissions. The CRG has advised that the distance travelled for surgery is less important than the distances travelled regularly for ongoing care.

94. Over the course of a lifetime, a person with CHD receives most of their care in an outpatient setting. This should not be affected by the proposed changes since outpatient care can be provided at hospitals providing Level 2 services, those offering Level 3 services, and in outreach clinics. In fact most patient care, apart from admission for a procedure, the pre-admission clinic, and a single follow-up outpatient visit, can be undertaken by Level 2 hospitals.

95. Where patients require more complex diagnostic tests, for most inpatient admissions and for surgery and almost all interventional cardiology procedures, patients and their families/carers will need to travel to a Level 1

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

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

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

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

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

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

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

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

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

## 1.10 Impact on CHD services

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

| Hospital | Additional Operations | % increase |
|---|---|---|
| **Birmingham - Children's Hospital** | **180** | **36%** |
| **University Hospitals Birmingham** | **45** | **45%** |
| **Liverpool Heart and Chest** | **90** | **N/A**[4] |
| **Leeds - General Infirmary** | **50** | **10%** |
| **Guy's and St Thomas'** | **200** | **40%** |
| **Great Ormond Street** | **220** | **31%** |
| **Barts** | **85** | **110%** |
| **Southampton** | **20** | **5%** |

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

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

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

---

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

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

105. Services will also be more resilient and sustainable for the future. Under present arrangements services in some hospitals receive significant levels of support from other hospitals. Without this support, at best, these hospitals would not be able to offer their patients a full range of CHD services.

106. Bigger hospitals are generally more resilient. The provision of consistent care at all times of day and night throughout the year is more assured. Bigger teams are better able to cope when one of their number is unavailable or leaves. They are also better able to support the full range of surgical procedures and the development of very specialised practice.

## 1.11 Impact on other services

### 1.11.1 Impact on other services: Paediatric Intensive Care

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

#### *1.11.1.1 University Hospitals of Leicester: Paediatric Intensive Care*

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

#### *1.11.1.2 Royal Brompton: Paediatric Intensive Care*

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

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

#### 1.11.1.3 Paediatric Intensive Care: wider implications

110. In order to ensure that there is still sufficient PICU capacity for CHD patients, NHS England will work with the other hospitals where increased paediatric cardiac surgery would be expected if our proposals are implemented (Birmingham Children's Hospital, Great Ormond Street, Leeds General Infirmary, St Thomas' - Evelina Hospital) to undertake the necessary planning and preparation to manage any increase in PICU capacity that would be needed for CHD patients.

111. If our proposals are implemented, there may also be an effect on the wider regional and national PIC system. NHS England has accelerated its Paediatric Critical Care & Specialised Surgery for Children Service Review, which will consider paediatric intensive care provision and paediatric transport. The critical care review aims to bring forward initial work looking at where paediatric critical care capacity is likely to be needed in future, with the first outputs coming through early in 2017. When the Board takes its decisions on the CHD proposals, it will therefore be able to take into account the impact on PIC for CHD patients in the wider regional and national context. The Paediatric Critical Care & Specialised Surgery for Children Service Review will then be able to pick up and deal with any wider implications for changes in PIC consequent upon the proposed CHD changes, as it considers the required capacity and distribution of PICU across the country as a whole.

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

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

#### 1.11.2.1 Leicester: ECMO

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

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

#### 1.11.2.2 Royal Brompton: ECMO

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

#### 1.11.2.3 Central Manchester: ECMO

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

#### 1.11.2.4 ECMO: wider implications

116. NHS England will work with the other hospitals, where increased paediatric cardiac surgery would be expected, if our proposals are implemented, (Birmingham Children’s Hospital, Great Ormond Street, Leeds General Infirmary, and St Thomas’ - Evelina Hospital) to undertake the necessary planning and preparation to manage any increase in paediatric cardiac ECMO capacity that would be needed for CHD patients.

117. If our proposals are implemented, there may also be a wider regional and national effect on ECMO services. NHS England has accelerated its Paediatric Critical Care & Specialised Surgery for Children Service Review, which will consider paediatric ECMO. When the NHS England Board makes its decision about the CHD proposals, it should, therefore, have greater clarity about the impact on ECMO for CHD patients in the wider regional and national context. The Paediatric Critical Care & Specialised Surgery for Children Service Review will then be able to pick up and address any wider implications for changes in children’s ECMO services, as a consequence of the proposed CHD changes, as it considers the required capacity and distribution of children’s ECMO across the country as a whole. We will re-commission appropriate levels of children’s respiratory ECMO and mobile ECMO from an appropriate number of providers in the light of the recommendations of that review.

### 1.11.3 Impact on other services: Specialist paediatric respiratory services

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

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

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

## 1.12 Workforce Impact

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

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

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

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

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

123. One of the key challenges both to current CHD services and to any future configuration is ensuring that there are sufficient staff with the necessary skills and experience to undertake this work across the country.

124. NHS England will work with provider organisations to ensure that staff are supported through any change process and redundancies are avoided wherever possible.

125. The national panel noted that experience at other hospitals where level 1 services have ceased – Edinburgh, Cardiff and Oxford – was that the majority of staff did not transfer to alternative providers of these services, but there were virtually no redundancies, with most staff being redeployed internally. It is reasonable to expect that many staff would seek to take up alternative roles within the relevant hospital trusts, rather than moving to another hospital. However, the panel noted that certain staff, such as CHD surgeons, would look to move to a Level 1 CHD hospital.

#### 1.12.2.1 Impact on workforce at the Royal Brompton Hospital

126. The Royal Brompton identified approximately 430 WTE staff that it considered would be affected by the proposals, including those working as part of their CHD service, paediatric respiratory, paediatric intensive care and other services which will be impacted to a lesser extent. The hospital trust has estimated the cost of redundancies to be approximately £13.5m.

127. The panel was not able to take a view on the likelihood of all these staff being significantly impacted by the proposed changes; however, it was acknowledged that there would be a significant impact on the Royal Brompton's workforce, if the proposals were to be implemented. The panel noted that this impact would be reduced, were the Royal Brompton to continue providing adult-only Level 1.

128. NHS England has reviewed the hospital trust's assessment of the potential level of redundancy. Given that we expect that most patients using the Royal Brompton would transfer to alternative hospitals within three miles of the Royal Brompton with the scope for redeployment that would result, NHS England has a materially different view of possible redundancy costs. Internal redeployment is also likely to make a significant contribution to avoiding redundancy. We estimate that the costs could however be up to £1 – 1.5m. This estimate is highly sensitive to the degree to which staff can be redeployed.

#### 1.12.2.2 Impact on workforce at University Hospitals of Leicester

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

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

130. The panel was not able to take a view on the likelihood of all these staff being significantly impacted by the proposed changes; however, it was acknowledged that there would be a significant impact on the hospital trust's workforce, if the proposals were to be implemented. The panel noted that this impact would be reduced, were University Hospitals of Leicester to continue providing Level 2 specialist medical services.

131. NHS England considers it probable that most at risk staff will be redeployed and that therefore the costs of redundancy will be mitigated. We estimate that the costs could however be up to £1m. This estimate is highly sensitive to the degree to which staff can be redeployed.

#### 1.12.2.3 Impact on workforce at Central Manchester University Hospitals

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

## 1.13 Financial Impact

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

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

133. Trusts are paid for CHD services through tariff, which ensures that the money received is linked to patient activity. It is likely that there will be some economies of scale for providers linked with providing a higher volume of activity. As such the trusts which would gain activity under these proposals are confident of being able to fund this expansion through the income which would be associated with this extra activity.

134. The financial assessment undertaken in 2015 at the time the Board agreed the standards showed that additional income to hospital trusts resulting from growth in activity would be sufficient to fund the implementation of the standards. Growth predictions have been refreshed and continue to provide assurance that implementation of the standards will be affordable for providers.

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

135. NHS England asked hospitals providing CHD services whether there would be any capital implications if they were required to take additional patients if our proposals are implemented. NHS England has confirmed that no specific central funds will be made available.

136. Two hospital trusts indicated that they would need to source capital funds to accommodate additional activity: University Hospitals Birmingham (£4M) and Great Ormond Street (£6M). In both of these cases it is expected that the provider would be able to source the capital funding from existing allocations and/or charitable funds. This is being confirmed with NHS Improvement. No other provider indicated any requirement for capital funding, and the risk around capital funding requirement is minimal at this stage.

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

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

##### 1.13.2.1 Impact on finances at Leicester

138. The overall contract value for specialised services at Leicester is approximately £234m. NHS England estimates that the financial effect of the proposed changes would be a reduction in income of around £14m (rather than the £19-20m estimate provided by the hospital trust). This is partly explained by a difference in view on the impact of the proposals on PICU. The hospital trust's estimate is based on an assumption that it would no longer be able to provide PICU services. The panel considered that there was no reason why PICU services could not continue at the Infirmary site even if the PICU currently located at the Glenfield site needed to close.

139. The loss of income to the hospital trust would, on the panel's assessment, represent between 1.6% and 2.2% of the hospital trust's total income, and between 6% and 8% of their total specialised services income. Some of this loss of income could be reduced if University Hospitals of Leicester continued to provide Level 2 specialist medical services. The loss of income to the hospital trust would also, to some extent, be offset by the reduction in the costs of providing the service.

##### 1.13.2.2 Impact on finances at Central Manchester

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

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

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

### 1.13.2.3 Impact on finances at the Royal Brompton:

142. The overall contract value for specialised services at Royal Brompton is approximately £226m. NHS England estimates that the financial effect of the proposed changes would be around £35m excluding the impact on paediatric respiratory services. The hospital trust's estimate of a £47m loss in income when paediatric respiratory services are taken into account appears to be broadly in line with NHS England's own estimate. The hospital trust estimates that the loss resulting from these proposals would be approximately 13% of its total income and 21% of its total specialised services income, which represents a significant financial and business challenge. The scale of loss reflects the impact on PICU and the potential impact on paediatric respiratory services.

143. Some of this loss of income could be reduced if the Royal Brompton continued to provide adult-only Level 1 surgical services, in partnership with a Level 1 paediatric hospital. Whilst adult Level 2 services to be provided at RBH would lessen the financial impact of the proposals on the Royal Brompton to a limited degree the vast majority of its CHD income relates to inpatient activity linked to a surgical or interventional procedure and therefore the Royal Brompton have identified just over £3m income from CHD activity not relating to surgery or catheter interventions. However, this almost totally related to paediatric services and as such if the Royal Brompton were to only offer adult Level 2 services, it is unlikely this would provide significant income to the Trust

144. The loss of income to the hospital trust would, to some extent, be offset by a reduction in costs. Data supplied by the Royal Brompton indicates that its provision of CHD services results in an overall net loss, and therefore although the loss of income is significant it may be that in the long term no longer providing these services is in the best financial interest of the hospital trust. The Royal Brompton has, however, stated that owing to the stranded costs associated with this service they estimate an adverse impact of over £7m per year to its bottom line if these proposals are implemented. The financial impact of the changes could be reduced if the Royal Brompton provided Level 1 services for adults.

145. We note that the Royal Brompton is an active partner in the North West London Sustainability and Transformation Planning process and has identified a number of potential areas for partnership working which could potentially contribute to the mitigation of any financial losses if our proposals are implemented.

#### 1.13.2.4 Finance impact: NHS England

146. The cost of the CHD service to NHS England has been estimated at £175m pa (based on 2013/14 figures). Activity is projected to increase whether or not the new standards are implemented. As a result, we forecast that – in today's prices - by 2025/26 expenditure on CHD services will be between £186m and £207m depending on the level of activity growth. We therefore expect that the challenge for us as commissioners will be in meeting the costs of activity growth rather than any costs arising from meeting the standards, or costs arising from the proposed changes. There are no current plans to reduce the CHD budget (per capita or overall).

147. As commissioners of CHD services we pay hospitals for the majority of these services using the national tariff (price) per unit of activity. Were we to change the number of centres where care is provided, this would therefore have no impact on our expenditure on patient care. NHS England finance experts have advised that it is logical to assume that an improvement to clinical outcomes and the clinical, operational and administrative efficiency and geographical/estates consolidation that would result from implementation of our proposals should lead to reduction in unit cost of this service for providers.

## Equalities and Health Inequalities

148. The CHD standards are intended to ensure that everyone with CHD gets the best possible care within available resources. Earlier analysis and engagement indicated that any proposed service change may differentially impact some Black and Ethnic Minority (BME) patients (those of Asian ethnicity), and those with a learning disability. In addition, services for CHD are of particular interest to children, and to the families and carers of children. We will be carrying out specific engagement activities with these groups during the consultation period.

149. We asked hospitals providing CHD services about any equalities or health inequalities as a consequence of our proposals being implemented. All responses submitted by the hospitals can be found in the Equalities and Health Inequalities Impact Assessment which has been published alongside this document.

## 1.14 Age

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

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

## 1.15 Disability

152. Children and adults with CHD are at an increased risk of developing further difficulties. Many children with CHD experience delays in their development, for instance, taking longer to walk or talk. Some children will have a learning disability. Around 50% of children with Down's Syndrome have a congenital heart defect and around 60% of those children will require treatment in hospital.

153. Change for people with learning disabilities or on the autistic spectrum is more difficult. Any service change for this population can be more difficult and needs to be managed well. This is not unique to the CHD proposed service change; however careful consideration should be given to the management of change for these patients. The particular concern has been around the practical elements of change like travelling to a new location, and patients being treated by clinical teams in a location that they are not familiar with. For example, people with learning disabilities who allow clinicians that they know to work with them are more likely than people without learning disabilities to refuse the same treatment in an unfamiliar surrounding by unfamiliar people.

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

## 1.16 Gender reassignment

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

## 1.17 Marriage and civil partnership

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

## 1.18 Pregnancy and maternity

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

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

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

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

## 1.19 Race

160. Ethnicity is known to relate to the prevalence of certain diseases. The relationship between ethnicity and CHD is complex and may be confounded by cultural and religious factors. Research dating back to the 1980s[5] and 1990s[6] demonstrated higher prevalence among Asian communities in various UK cities including Manchester and Leeds, and in the West Midlands.

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

---

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

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

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

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

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

## 1.20 Religion or belief

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

## 1.21 Sex or gender

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

## 1.22 Sexual orientation

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

## 1.23 Asylum seekers and/or refugees

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

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

## 1.24 Carers

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

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

## 1.25 Those living with mental health issues

167. In addition to medical problems, people living longer with CHD face psychological, sociological and behaviour challenges[7]. 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 metal health issues such as anxiety and depression.

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

## 1.26 Other groups

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

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

---

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

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

## Glossary

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

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

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