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

Background and context

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

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

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

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

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

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

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

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

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

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

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

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

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

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

The case for change

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

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

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

    - higher levels of support from specialist nurses and psychologists;

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

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

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

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

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

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

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

1.1 Ending uncertainty

17. The long history of repeated reviews of CHD services has created uncertainty within the specialty, damaging relationships between hospitals; harming recruitment and retention of specialist staff; and reducing the resilience of services. Continued uncertainty affects recruitment and retention of congenital heart disease surgeons, a group in short supply and subject to international demand.
18. The 2014 report on CHD services at Leeds Teaching Hospitals NHS 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.

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[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.