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

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Consultation Summary

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Summary

1.1 Introduction

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

2. We propose to do this by implementing consistent national service standards at every hospital that provides CHD services. The standards cover the entire patient pathway from diagnosis, through treatment, and on into care at home and end of life care. The effect of our proposals, if implemented, will be that some hospitals will carry out more CHD surgery and catheter procedures, while others, which are not meeting the relevant standards, will stop doing this work.

3. This means that those patients who would currently be likely to receive surgery and/or interventional catheter procedures at a hospital where we are proposing to stop that activity will, in future, be likely to receive that surgery and/or catheter procedure at a different hospital. For some patients this will mean travelling further for surgery/catheter procedures, and for one appointment both pre, and post-surgery. However, most follow-up appointments, and ongoing monitoring and care can still be done closer to home.

4. What will also change is the level of care which all CHD patients can expect in the future. If we implement the national standards in full in every hospital providing CHD services across England, we will be able to ensure that every patient receiving treatment for CHD will be getting care delivered to the same high standards, regardless of which hospital they are attending. This means consistent and equitable high quality treatment for all.

1.2 Background

5. The national CHD standards were developed in the wake of a series of reviews and enquiries, starting with a public inquiry into concerns about the care of children receiving complex cardiac surgery at Bristol Royal Infirmary, published in 2001.

6. The standards were developed by people with a direct interest in CHD services – patients, families, carers and patient representatives – in collaboration with those delivering the services – the surgeons, cardiologists, specialist nurses, and others. Consensus across all groups was achieved, and the standards were approved by NHS England's Board in July 2015. It was 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 standards which would govern a truly national service.

7. The standards describe how to deliver CHD services of the very highest quality. They are – rightly – challenging, and it was acknowledged by the NHS England Board that it would be difficult for all hospitals to meet them, unless changes were made to the way in which they work. The timeline for meeting some of the standards differs, as it was recognised that it would take longer to meet some of them, such as the co-location of children's CHD services with other children's specialist services, which might require physical changes to a hospital's structure or layout.

8. Once all hospitals are meeting the standards, all patients with CHD will be receiving care of the highest possible quality. This means that they, and their families/carers, will get higher levels of support from specialist nurses and psychologists; improved information and communication, so they will have a better understanding of their condition and treatment options; and a better managed transition from children's to adult services. Clinicians and other specialist staff will be working in an environment which has the right staffing levels and skills, which means the service is resilient and better able to cope with sickness and holiday/emergency cover. They will also have more opportunities for training and sharing learning, and surgeons will have more opportunity to practice and maintain their skills, because they are carrying out more operations and interventional procedures.

9. We think all of these elements make a real difference to patients, and to their families and carers, and to health outcomes, as well as benefitting the teams caring for them. We believe that every patient with CHD should have access to care delivered at the same high standards, regardless of where they receive their treatment.

1.3 Meeting the standards

10. Once the standards had been agreed, we first looked at whether hospitals currently providing CHD services could work together, in networks, to deliver services which met the required standards. This approach did not provide a national solution to meeting the standards. We therefore asked the hospitals to complete a self-assessment, to assess compliance against a specific number of the standards. We took clinical advice about which standards we should ask the hospitals to look at, and opted for 14 requirements in total, which were those most closely linked to measureable outcomes and to improving safety and quality.

11. 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.

1.4 Proposals for consultation

12. The information submitted by the hospitals was considered by a national panel, which included patient representatives, clinicians and commissioners. The panel assessed each hospital's ability to meet the standards and found that at the time none of them met all of the standards tested. This was not unexpected, as the standards were expected to 'stretch' the hospitals, and bring all services in all hospitals consistently up to the level of best practice.

13. The majority of the hospitals were either very close to meeting the requirements, or were considered to be likely to meet them within the required timescales, with further development of their plans. They were rated green/amber, or amber.

    - Three of the hospitals - University Hospitals of Leicester NHS Trust, Newcastle upon Tyne Hospitals NHS Foundation Trust, and the Royal Brompton and Harefield NHS Foundation Trust - were unable to meet the requirements for April 2016, and were considered unlikely to be able to do so within the required timeframe. 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.

14. 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 timeframe. 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.

15. In practice, this means that, in future, if our proposals are agreed:

- Surgery and interventional cardiology for adults would cease at Central Manchester University Hospitals NHS Foundation Trust, and patients requiring such procedures would be most likely to go to Liverpool Heart and Chest Hospital NHS Foundation Trust. Patients requiring all other forms of treatment, i.e. anything other than surgery and/or interventional cardiology may still be able to receive their care in Manchester. We continue to discuss this option with the hospital trust.
- Surgery and interventional cardiology for children and adults would cease at Royal Brompton and Harefield NHS Foundation Trust, and patients requiring such procedures would be most likely to continue to receive their care in London, at Great Ormond Street for Children NHS Foundation Trust, Bart's Health NHS Trust, or Guy's and St Thomas' NHS Foundation Trust. There is a possibility that the hospital trust might continue to provide surgery and interventional cardiology for adults only. This option remains open for discussion.
- Surgery and interventional cardiology for children and adults would cease at University Hospitals of Leicester NHS Trust, and patients requiring such procedures would be most likely to receive their care at either Birmingham Children's Hospital NHS Foundation Trust, University Hospitals Birmingham NHS Foundation Trust, or Leeds Teaching Hospitals NHS Trust, as closer for some patients than Birmingham. There is a possibility that the hospital trust might continue to provide CHD services for children and adults other than surgery and interventional cardiology. This option remains open for discussion.

16. Newcastle upon Tyne Hospitals NHS Foundation Trust was also given an amber/red rating, in the same category as both University Hospitals of Leicester NHS Trust and Royal Brompton and Harefield NHS Foundation Trust. However, Newcastle has a unique role in delivering care for CHD patients with advanced heart failure including heart transplant and bridge to transplant and this could not be replaced in the short term without a negative effect on patients. On balance therefore our present view is that it is better to continue to commission level 1 CHD services from Newcastle. CHD surgery and the transplant programme involve the same surgeons so the two are tied up together.

17. 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 to ensure that patients receiving CHD care at

Newcastle upon Tyne Hospitals NHS Foundation Trust are not compromised in any way.

1.5 What would be the benefit of implementing these proposals?

18. We believe that implementation of the national standards for CHD is the only way to ensure that patients are able to access the highest possible quality care, regardless of where they are treated. There is currently some variation in terms of where hospitals are in meeting the standards so care may vary, depending on where in England you access services.

19. The NHS has been trying to improve care for CHD patients for almost 20 years and, while we have learned much from previous reviews and enquiries, we know that there remains a cloud of uncertainty hanging over these services which has damaged relationships between hospitals; harmed the recruitment of staff; and reduced the resilience of these services. We need to create a stable, resilient and sustainable national CHD service for the future, by introducing certainty and consistency of approach across the country.

1.6 Potential impact of implementing our proposals

20. We know, from talking to patients and their families/carers, clinicians, and other hospital staff, that there are concerns about our proposals and how implementation of them might affect them personally, or their jobs, or other services in the hospitals affected. We acknowledge these concerns, which is why we are holding a full public consultation, so that we can talk to you in more detail about our proposals, and learn more from you about how you think implementation of the standards might impact you, your family, or where you work. It is important to note that, even if our proposals are implemented, change will not take place until early 2018, and we will be working closely with all hospitals involved to ensure that patient care is not interrupted or unduly affected.

21. We know, from talking to people during the pre-consultation period, that patients, in particular, are concerned about where their care will take place in the future. If our proposals are implemented, journey times will increase for some people when they need to attend their new hospital for surgery or a catheter procedure. We expect the average rise in journey times to be fairly small, although we know for some patients it will be more substantial. While we acknowledge that this extra journey length will be difficult for some, we think that patients will ultimately benefit from being treated at a hospital which is meeting the national standards in full.

22. Fortunately, the vast majority of admissions to hospital for CHD surgery are planned, and there are very few true emergency admissions for CHD patients. Even in those cases where CHD has not been diagnosed in the womb, and surgery is required soon after birth, that operation will be planned over a period of a few days, and newborns are stabilised and transported to a surgical centre by expert and highly skilled children's transport teams. The same goes for adult patients.

23. We also know that there is concern about the impact of our proposals on other hospital services, such as paediatric intensive care, and on the wider hospitals and their staff. Formal impact assessments, which set out what implementation of our proposals might mean for each of the hospitals affected, have been carried out as part of our planning for public consultation.

1.7 How can I make my views known?

24. During consultation there will be a number of opportunities for you to have your say about the future of CHD services. We want to hear from anybody with an interest in these important services, and have set out a number of questions which we want to ask you about our proposals. The answers to these questions will be independently analysed, and will be considered by the NHS England Board before a decision is made.

25. We will be holding a number of events, such as public meetings, webinars and Twitter chats, so there will be lots of different ways for you to ask us questions, and hear more about our proposals.

26. The consultation questions, and all other information about this public consultation, can be found at our Consultation Hub. The consultation questions are attached at Appendix A for ease of reference. If you would prefer to send us your responses to consultation by post, please answer the questions on the form attached, and post it back to us at:

    CHD Consultation
    c/o Beverley Smyth (Specialised Commissioning)
    NHS England
    4N08| Quarry House| Quarry Hill | Leeds | LS2 7UE

27. If you cannot find the information you are looking for, or have any other questions relating to this consultation, please contact us at england.congenitalheart@nhs.net

Appendix A – Consultation questions

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	☐Muslim
☐Buddhist	☐Sikh
☐Christian	☐Atheist
☐Hindu	☐Any other religion
☐Jewish	☐Rather not say

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

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