

Guidance for responding to the CHD public consultation

Please read before starting the survey

This guidance reflects the [views of Royal Brompton & Harefield NHS Foundation Trust's partner charities](#). It is important that your response reflects your true feelings.

Please remember to save your answers as you go, and read over every answer before you move on to the next stage. (You might want to write your answers on a separate document on your computer, and then copy the answers into the relevant boxes on the survey once you are happy with what you have written.)

The text in bold below is taken from the survey; the text not in bold is advice on how you can respond.

If you have access to a printer, you might want to print this guidance out before starting to write your survey answers.

Thank you very much for helping make a difference.

[Click here when you are ready to start the survey \(opens in a new window\)](#)

Meeting the standards (PAGE 1/10)

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

Choose the option that best describes you, or enter another description in the box provided.

2. In which region are you based?

Choose the area you live in from the options provided.

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?

Tick 'Strongly oppose'.

Please explain your response.

- I disagree with this statement because it puts the focus on the standards themselves, instead of on the impact they have on patient care. The standards only mention the resources available at each hospital, they ignore the outcomes achieved.
- For example, NHS England says that the 'co-location' standard is needed to make sure that:
 - 1) Different services involved in CHD care work well together
 - 2) All services can be at the patient's bedside within 30 minutes.

- In the case of Royal Brompton - the CHD service already achieves both of these outcomes.
 - There is no evidence showing that other Trusts that are rated as meeting the co-location standard have better response times, teamwork, care quality or patient outcomes than Royal Brompton.
 - NHS England has not explained specifically what is better at the so-called 'co-located Trusts' that isn't already happening at Royal Brompton.
 - There is no reason to believe that meeting this standard, as defined by NHS England, would make things any better for patients in practice – so it would be wrong for this standard to be the decisive factor in whether or not that service is commissioned.
 - The standards provide good guidelines for the areas to look at in a service, but the decisive factor in whether to commission a service should always be the impact on patients.
 - In any case the question is misleading: NHS England does not propose that, in future, services will only be commissioned from hospitals that are able to meet the full set of standards within the set timeframes – Newcastle will never be able to meet the full set of standards.
- 4. Three hospital trusts have been assessed as not able to fully meet the standards within set timeframes. NHS England proposes that surgical (level 1) services are no longer commissioned from these trusts.**

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?

Royal Brompton does meet the standards. The one standard that is challenged is the co-location standard. I believe the jointly-delivered service with Chelsea and Westminster offers patients the same, if not better, quality of care, than other centres. If there is evidence to show that this is not the case then NHS England should make it available.

Manchester and Leicester (PAGE 2/10)

- 5. This question is about CHD services in Manchester and Leicester. Please ignore and click 'continue' unless you, your loved one or child is treated at the hospital, or you would like to make a comment for other reasons.**

Royal Brompton (PAGE 3/10)

- 6. 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?**

Tick 'Strongly oppose'.

NHS England has not provided space to explain your answer to this question but you can do this at the end of the survey – question 12.

Newcastle (PAGE 4/10)

7. This question is about CHD services in Newcastle, so please ignore and click 'continue' unless you, your loved one or child is treated at the hospital, or you would like to make a comment for other reasons.

Travel (PAGE 5/10)

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

If you would like to answer this question, the response will be personal to you. If Royal Brompton's services are withdrawn, NHS England plans to try to redistribute patients to other centres in London.

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

This question will be personal to each person responding, see above.

Equality and Health inequalities (PAGE 6/10)

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

Tick 'No'

Please describe any other quality or health inequality impacts which you think we should consider.

There will be a devastating impact on the specialist cardiac obstetric service run in conjunction with Chelsea and Westminster Hospital NHSFT, which currently provides services to women with inherited cardiac conditions and other cardiac diseases, and is the UK's leading centre for research in pregnancy and cardiac disease. This should be considered as an impact.

Other impacts (PAGE 7/10)

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

Tick '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?**

Below are impacts that we feel NHS England has not considered. Please mention if you have a personal connection to any of the sections below – for instance if you have used child lung disease services, or children's intensive care.

RESEARCH

Royal Brompton is recognised as the world's leading centre for adult CHD research - this research is crucial for making the advances that will improve the care CHD patients receive in future.

- NHS England's plan for Royal Brompton would close this research unit, meaning patients will not benefit from these advances.

IMPACT ON CHILDREN'S INTENSIVE CARE

- NHS England says that its plans for Royal Brompton will cut the number of 'paediatric intensive care units' (PICUs) that look after the sickest children.
- There is already a shortage of PICU beds in London, forcing very sick children to travel, sometimes hundreds of kilometres around the country to find a bed.
- NHS England says that a 'national PICU review' is looking at this, but that only the "first outputs" – not final plans – will be published before the end of this consultation.
- I feel it would be reckless to go ahead with the CHD plans until there are more solid plans for addressing the likely shortage of PICU beds and highly-trained staff.

IMPACT ON CHILDRENS' SPECIALIST RESPIRATORY CARE

- NHS England admits that its plan for Royal Brompton will impact on the Trust's children's specialist respiratory services, but says that it will only look at this in detail once plans CHD services were finalised.
- It is unacceptable for thousands of children with lung diseases such as cystic fibrosis and severe asthma to be considered an after-thought in the planning process.
- This consultation will not be complete until NHS England looks at how ALL patients are affected.
- If the proposals to end congenital heart services at Royal Brompton were adopted, one devastating consequence would be the closure of Royal Brompton's specialist tertiary care children's cystic fibrosis centre. This centre is probably the leading specialist unit in the country and arguably one of the leading centres in the world.
- Although the review identified that the withdrawal of cardiac surgery would result in the closure of the hospital's paediatric intensive care unit, it failed to make any assessment of the impact on other services if the PICU closed. Closure would result in the withdrawal of the specialist paediatric anaesthesia service: the specialist CF centre depends, day in and day out, on that service when treating those who are seriously ill with CF (for example when obtaining venous access for antibiotics using long lines or port-catheters, performing bronchoscopies and inserting feeding tubes).
- If the proposals were implemented, this would be a disaster not just for staff at Royal Brompton's CF centre but for the families and children dependent on CF healthcare provision across London as well as the wider CF community.
- Royal Brompton also has an international reputation for clinical and research work on children with severe problematic asthma. Its clinic of around 130 patients is the largest in the UK, and doctors at the hospital receive referrals from all around the country, from both district general hospitals and other tertiary units (including Alder Hey, Manchester, Bristol, Evelina, Great Ormond Street). They have pioneered diagnosis methods and treatment for these children,

many of whom (around 40%) need complex investigations, particularly bronchoscopy and biopsy under general anaesthesia. Without paediatric anaesthesia and PICU back-up, the clinical teams would be unable to safely use these techniques. This would effectively stop this important national clinical service.

- Similarly, thoracic surgery, along with ear nose and throat surgery and paediatric general surgery (both undertaken jointly with colleagues from Chelsea and Westminster) could no longer be carried out at the Trust.
- The effects on research programmes would also be considerable. Royal Brompton's paediatric respiratory teams undertake groundbreaking research into important areas such as cystic fibrosis, severe asthma and other lung diseases, inflammation of the airways and neuromuscular conditions. The research they undertake can only be carried out at a specialist hospital, where the combination of clinical expertise, the type of patients seen and the numbers of patients seen, provide the necessary conditions. Without a children's intensive care unit and on-site anaesthetists, Royal Brompton hospital will not offer the type of specialist respiratory care it does now and its respiratory consultants say they will therefore have to seek work elsewhere if the research programmes are to continue. As a result, the expert teams that are responsible for both clinical care and research programmes will be broken up and dispersed to other hospitals.

THE IMPACTS OF BECOMING AN “ADULT ONLY” SERVICE

- Royal Brompton's life-long care model would be lost if the Trust only treated adults. NHS England says in its report on CHD standards that many doctors think this life-long care, with child and adult services on the same site, is just as important as the other standards. We also know that the Trust's adult patients value and benefit from this model.
- The Trust's adult CHD research team, which is rated the best in the world in terms of the number and impact of its publications, would suffer greatly if the Trust only treated adults. Royal Brompton's researchers have made it clear that having child and adult services together is a major factor in the team's success, as it improves the quality and quantity of their data and their ability to share ideas between child and adult teams.
- If Royal Brompton became an adult-only centre, its surgeons would perform fewer operations, as most operations CHD surgeons perform are on children. This would mean that the Trust's heart surgeons would have to spend time at another hospital in order to perform 125 operations a year (as NHS England's new standards say they have to). If surgeons are spending most of their time at other hospitals, patients are less likely to see the same surgeon if they need emergency follow-up care in the days after surgery. We know that this care is best carried out by the same surgeon who performed the operation. We also know that patients value having a relationship with one surgeon that they know, and who knows them. It would be a backward step to deny this to patients.
- Both child and adult care at Royal Brompton benefits from the cross-fertilisation of ideas between paediatric and adult services. For instance, stereotaxis (a minimally invasive form of surgery) is not available at any children's hospital in the UK, as its use among children is too infrequent to justify the cost. However, its availability at Royal Brompton for the hospital's adult patients has enabled researchers and clinicians to pioneer its use in some complex paediatric cases, giving children treatment that would not have been possible elsewhere.

- CHD services are criticised for patients getting ‘lost’ as they transition to adult services. A centre like Royal Brompton, where the transition is seamless, results in far fewer teenagers getting lost in the system.

THE COST TO THE NHS AND TAXPAYER

- NHS England has given very little detail about how much these plans will cost, other than mentioning a few areas where several million pounds will need to be spent.
- It is deeply concerning that NHS England has made plans without knowing how much they will cost to implement, at a time when the NHS is already under huge financial pressure.
- Without knowing the full cost, no one can say whether the plans are value for money.
- When new treatments are made available, they are examined by NICE to see whether the benefits patients receive are worth the cost. These plans should not be any different.

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

Below are some other comments that we would like to make. Please add the points you agree with in your own words, and make any other final points you’d like to make. Then click ‘continue’.

- The last review of CHD services – Safe and Sustainable – was criticised for only looking at children’s services. It is for this reason that this review looks at adult services too.
- This review says it wants to cover “the entire patient pathway from diagnosis, through treatment and end of life care”. For most CHD patients these days, diagnosis takes place before birth, and end-of-life care takes place in old age.
- It therefore doesn’t make sense that this review should want to break up one of the largest and most successful joint child and adult services in the country at Royal Brompton, which cares for patients from before they are born right through to older age. Royal Brompton provides continuity for patients in a way that they value.
- It seems irrational to say that children’s gastroenterologists and general surgeons must be based on site, when they are needed as an emergency in less than 1% of cases.
- Outcomes for congenital heart disease surgery in this country are among the best in the world. All the evidence shows that Royal Brompton has some of the best patient outcomes and satisfaction levels in the UK. I do not believe there is a problem and am unclear as to why NHS England appears intent on solving one.

About you (PAGE 8/10)

Please choose the options for questions 15-20 that best describe you.

Almost done (PAGE 9/10)

Enter your email address only if you wish to receive a summary of your response. This is not essential.

Completed! (PAGE 10/10)