Childrens and Adults CHD Engagement

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1 Questions & answers

1.1 Proposals

1.1.1 Why are you closing hospitals?

Our proposals are not to close hospitals. We are proposing that in future we would only commission CHD services that can meet the service standards that were created collaboratively and agreed by the NHS England Board in July 2015. If these proposals are implemented, some hospitals which cannot meet the standards would need to stop providing their current level of CHD services. The proposals can be found by following this link: https://www.engage.england.nhs.uk/consultation/chd/

1.1.2 How can we respond to consultation?

The easiest way to respond to consultation is to follow the link:
https://www.engage.england.nhs.uk/consultation/chd/

Alternatively, you can send your response via the post to Beverley Smyth - Specialised Commissioning, NHS England, 4N08 Quarry House, Quarry Hill, Leeds. LS2 7UE.

If you have any queries please contact us via email at:
england.congenitalheart@nhs.net

1.1.3 Why are some hospitals being treated differently in the proposals?

All hospitals have been assessed against the standards in exactly the same way. We are proposing that in future we would only commission CHD services that can meet the service standards that were created collaboratively and agreed by the NHS England Board in July 2015.

Newcastle is an exception to this because of the importance of its work with patients with advanced heart failure and its role as one of only two transplantation centres nationally.

Newcastle is one of only two centres in the country to provide children's heart transplants (the other being Great Ormond St) for CHD patients. It also provides more heart transplants for adults with CHD than any other centre in the country. These services can only be provided from a CHD surgical centre and NHS England does not consider that it would be possible, in the short term, to commission them from an alternative provider. In light of this, NHS England has proposed that it will continue to commission CHD services from Newcastle in the short term. This does not mean that change will not happen in the longer term. Newcastle is still required to meet the standards. Newcastle has now committed to undertaking an options appraisal with regards to co-location for its paediatric cardiac services.

1.1.4 Are you saying that the services are not safe at the hospitals where you are going to stop doing surgery?

No, outcomes at all hospitals currently providing CHD services are good. We do not have safety concerns about any of these hospitals. However, some of the hospitals are more fragile than others in terms of the number of surgeons they currently employ, and the volume of activity being carried out. This is not sustainable in the long-term for a small number of hospitals, so this exercise is focused more on the longer-term resilience of these hospitals, rather than any current concerns about the care being delivered.

1.1.5 Where will my child receive care from in the future and when will it happen?

No decisions have yet been taken. The NHS England Board will decide, probably later this year, whether change needs to happen.

If changes are made to service provision, they are not expected to begin before April 2018and a transition plan would be put in place for affected patients as is the current practice for patients who move home or wish to transfer to another centre.

Patient choice will ensure patients can choose which centre they would like to attend for their care if their current centre is affected by change.

1.2 Public Consultation

1.2.1 Where can I find out about public consultation events in my area?

A list of the events that are happening (and have already occurred) during public consultation can be found at: https://www.engage.england.nhs.uk/consultation/chd/

1.2.2 Why are you not doing more to meet face-to-face with the public, patients and carers?

By the time consultation closes, we will have attended over 30 meetings all over the country to talk to patients, families, staff, the public and local councillors about the proposals, and to listen to views and answer questions. We have also held webinars and posted webcasts to support those unable to travel or who have commitments that prevent them from attending the events.

1.2.3 Why have you only announced some events recently?

At the beginning of consultation, we announced dates for all the events planned and agreed at that time. As the consultation has gone on, we have agreed a number of new events with local stakeholders: we have agreed to attend some additional local council overview and scrutiny committees; and in a small number of cases, we have agreed revised dates and times for meetings at the request of local stakeholders. The website is kept updated to reflect all the latest information. https://www.engage.england.nhs.uk/consultation/chd/

We are happy to confirm that the dates of all meetings have been announced in advance of those meetings taking place.

1.2.4 How do I book onto the events?

Only a few of the events have required people to book a place. These are meetings where a high level of interest has been anticipated and we need to be sure that we would not exceed the capacity of the rooms booked, for health and safety reasons, and as importantly to make sure that everyone has had a chance to participate. Meetings that require booking are clearly marked on the website, with instructions for booking provided: https://www.engage.england.nhs.uk/consultation/chd/

If you have any queries about attending events, please contact england.congenitalheart@nhs.net

1.2.5 Where can I see recordings of the Leicester and London public events?

The recordings can be found here:

- Leicester: https://www.youtube.com/watch?v=AcidnxC6Jek
- London: https://www.youtube.com/watch?v=VI8FBU-b1Q0

1.2.6 Are public events minuted?

We take notes of the themes discussed and questions raised but not detailed minutes. The role of the meetings is to raise awareness of the consultation proposals and answer questions. They are not our main way of gathering views on the proposals – this is done via the consultation on our website: https://www.engage.england.nhs.uk/consultation/chd/

1.3 Cost & benefits

1.3.1 How much has this and previous reviews for CHD cost?

NHS England spent £808,039 between August 2015 and January 2017 developing its proposals for implementing the new standards for children and adults with congenital heart disease, including preparing for and launching the consultation. This expenditure comprises £423,533 of pay and £384,506 of non-pay related costs.

At this stage, NHS England expects to spend around £85,000 on the national public consultation. There is likely to be further expenditure on venue hire and travel costs. Every effort is being made to minimise costs while delivering an effective consultation that meets best practice and legal requirements. The full costs of consultation will not be known until after the close of consultation.

1.3.2 Why are you trying to fix something that is not broken?

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 by the Secretary of State.

Stakeholders have told us 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.

Outcomes for CHD surgery and interventional procedures across England are good, and compare well with other countries. We know, from talking to patients and their families and carers in particular, that the quality of CHD care delivered in hospitals is also good, but could be better.

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, 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.

NHS England has been working with expert clinicians; patients; and Trust executives since 2013 to devise and agree a new set of standards for the treatment of congenital heart disease (CHD). The aim of these standards is to secure the best outcomes for all patients, including:

- improved opportunities for survivors to lead better lives;
- tackling variation in services, particularly to ensure resilient 24-hour, seven days a week care; and
- improved patient experience.

NHS England acknowledges that, while it may be possible to achieve good outcomes without meeting all of these standards, centres that meet the standards are the ones where commissioners, acting on behalf of patients, have the greatest assurance that good outcomes will be consistently achieved; offering high quality care for all patients wherever they may present.

1.3.3 Is this just a cost-saving exercise?

No. These plans are not about making cuts – they are about making services better and more consistent for patients both now and into the future. We expect spending on CHD services to continue to rise, as more and more people are – thankfully – living longer with CHD.

1.3.4 Can centres continue if they meet the standards?

Yes, if hospitals can show they can consistently meet the standards in the future to provide sustainable services.

NHS England continues to work with all the hospitals to support delivery of the standards. Robust and sustainable plans will need to be provided for all CHD services.

1.3.5 How long have the hospitals got to implement the standards and get it right?

The timelines for implementation of each of the standards were explicit in the consultation on the standards, as agreed by the NHS England Board in July 2015. The standards cover a wider range of subjects than previous standards, reflecting the views of patients and their families/carers about what matters to them. These standards began in April 2016.

We assessed hospitals against certain key standards in 2016. At the time of the assessment, none of the providers of level 1 and level 2 services met all the standards assessed. However, NHS England is satisfied that each Trust where service change has not been proposed has a robust plan in place to meet the standards within required timescales.

1.3.6 How will you be sure the hospitals will be ready to receive the work from those losing the patient care?

The hospitals that would be taking on additional patients, if our proposals are implemented, have confirmed that they would be able to manage the increase in activity. In those circumstances, we would work with hospitals affected to develop detailed plans for any changes that are made and to manage the transition.

1.3.7 Why can’t you just say that patients should be referred to Manchester, Leicester, Newcastle and the Royal Brompton, so that they meet the standards and everyone gets care close to home?

The number of patients is not the only issue behind our proposals. And even where this is important, we recognise that there is a mix of reasons why people attend different centres, including reputation, geography, patient choice and the recommendation of the referring clinician. Any changes to patient flows would need to be agreed between the hospitals concerned, the referring doctors, and representatives of the patients affected. As commissioners, we do not propose to mandate changes to patient flows: referral pathways are most appropriately decided between doctors and their patients.

1.3.8 How much will it cost to implement the proposals?

Implementing most of the standards will cost little, or nothing.

There would be some additional cost to those hospitals taking on an increase in activity, should our proposals be implemented. If hospitals need to provide care to more patients, this will be paid for by the tariff system under which hospitals are paid for the care they provide.

NHS England asked providers whether there would be any capital implications if they were required to take additional patients if our proposals are implemented. Two providers 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. No other provider indicated any requirement for capital funding

The financial impact of our proposals is set out in detail in the impact assessments for individual hospitals which can be found at https://www.engage.england.nhs.uk/consultation/chd/

1.4 Research

1.4.1 The Royal Brompton makes an important contribution to research which in turn feeds through into better patient care. Won’t that be lost if NHS England’s proposals are implemented?

The proposed changes would, if implemented, result in some disruption to the current arrangements, but we do not consider that the contribution of the Royal Brompton's specialists will be completely lost. It is very much part of our aim to try to retain specialists within CHD services, and we would expect that researchers currently based at the Royal Brompton would continue their research, albeit at a new institution. Other centres already have an important focus on research, and active involvement in research is required by the standards.

We have asked the Royal Brompton to explore the potential for offering an adult only level 1 CHD service in partnership with another centre. Were this to be taken forward, it would mean that the Royal Brompton’s research in adult patients with CHD would be able to continue alongside the care they offered.

Finally we should note that NHS England's focus has been on improving direct patient care. That is not to say that research is unimportant and the NHS England Board will take into account the potential impact on research in reaching its commissioning decisions. This is something that NHS England is keen to hear more about in response to the consultation.

1.5 Travel Times

1.5.1 The CHD proposal will mean that I will need to receive care from a different centre, how have you calculated the travel times?

We have calculated travel times for patients potentially affected by the proposals. We can’t give open access to the model itself as the model includes Hospital Episodes Statistics (HES) data which is patient specific, and we cannot share this for information governance and confidentiality reasons. But here is the explanation of our method.

We calculated the travel times by looking at all the patients admitted for surgery relating to CHD in England between 2006/07 and 2014/15. We looked at where those patients lived and calculated their journey time to their current level 1 centre. We then calculated their journey time to their nearest centre if our proposals were to be implemented. From these figures we calculated average (median) journey times and the maximum travel time experienced by 90% of patients. We then compared journey times for the current arrangement of services and if our proposals are implemented (i.e. without level 1 services in Manchester, Leicester and at the Royal Brompton in London). Our calculations are based on transport by car, not by public transport.

- Patient locations were based on the MSOA of residence rather than their actual address. Super Output Areas are a geography used by government for statistical comparison. Middle Layer Super Output Areas (MSOAs) have an average population size of 7,500. We used MSOAs rather than actual addresses because of information governance restrictions on the use of patient identifiable data.
- Information on admissions was taken from the HES dataset (Hospital Episode Statistics: the NHS standard data source for information about hospital activity). We used HES because this gave us both the means to identify hospital activity as related to CHD (using procedure and diagnosis codes) and the means to derive the MSOA in which the patients were resident.
- The journey times used in the calculations were from Google Maps (using the Google Maps API - Application Programming Interface).

In considering these journey time calculations it is worth remembering that not all patients currently receive their care from their closest centre. So when looking at how journey times would change if our proposals are implemented, those patients currently using a centre that is not their closest would, in our calculations, see a reduced travel time if that centre ceased providing L1 care, because we assume they would in future go to their nearest centre. And those patients living near a centre that could cease providing L1 care, but who currently travel elsewhere for their care, would be modelled as having no change in their journey time, because we assume that they would not change centre.

1.5.2 I'm worried about longer journeys - what will happen in an emergency?

Our clinical advisors (doctors from all of the centres providing CHD care) tell us that true emergencies in CHD are – thankfully – very rare. Thanks to advances in antenatal diagnosis, most congenital heart defects are detected in the womb, which enables the mother to give birth either at, or close to, an appropriate hospital providing CHD surgery for children. Even in those cases where CHD is only spotted during, or after delivery, surgery will often be planned over a period of days. If infants need to be moved from one hospital to another for emergency care, then ambulance services, local hospitals and specialist retrieval transport teams are able to ensure that patients are stabilised before and during transfer, so the risks of long journeys are negligible.

Access and proximity to care is an understandable concern. We have heard that the distance travelled for surgery is less important than travelling for ongoing care. We are working to strengthen local care so that as much care as possible can be delivered closer to home. We will also consider whether some hospitals should continue to provide specialist medical care for CHD patients even if surgery and interventional cardiology move elsewhere.

We acknowledge that travel will be difficult for some people, especially those who live in more remote areas, with limited public transport options. We have had to balance this with the need to ensure that all patients with CHD have access to high quality care, which meets the required standards. We want to ensure that access to these important services is fair and equitable, and that no patient receives sub-standard care, simply because of where they live.

We anticipate that longer journeys to a surgical centre will only be required for an outpatient appointment, before and after surgery, and for the surgery itself. This means that most of the care received by people with CHD can be at a Level 2 hospital. This is why we are working to strengthen local care as much as possible, to ensure that patients, and their families/carers are only required to travel further afield when absolutely necessary.

The standards address a number of areas that patients and families told us could be improved to make life more manageable when a patient is in hospital. This includes things like access to free wifi, overnight accommodation and facilities for meal preparation.

1.6 Other services & resources

1.6.1 How can any decision be made for the CHD service without the output of the review of ECMO and PICU?

We have taken great care to ensure that our consultation document and associated materials provide a comprehensive explanation of what is proposed, the reasons for the proposals and the likely impact of those proposals. This includes an explanation of the impact on PICU and ECMO services at the centres where change is proposed, including gaining an assurance that the capacity required for those affected is provided at the centres where they would be likely to go in future.

The CHD review has assessed the potential impact of the proposed changes on PIC and ECMO services and gained an assurance that the PIC and ECMO capacity required for CHD patients can be re-provided at the centres where those patients would be likely to go if the proposals are implemented. NHS England has accelerated the review of paediatric critical care and specialised surgery in children in order to support alignment between the two. The paediatric critical care review will need to deal with any wider implications for changes in PIC and ECMO consequent upon the proposed CHD changes as it considers the required capacity and distribution of PICU and ECMO across the country as a whole.

We expect early findings from the critical care review, including an examination of capacity and demand for paediatric intensive care across the country, to be available during the coming weeks, which means that it can be taken into account by the NHS England Board when it makes its decisions about the future of congenital heart disease services.

1.6.2 Where can I find out any information on PICU and ECMO?

More information about the Paediatric Critical Care and Specialised Surgery for Children review can be found here:

https://www.england.nhs.uk/2016/10/child-specialised-services/

1.6.3 University Hospitals of Leicester NHS Trust (UHL) are the only Trust offering mobile ECMO - how can you replace that?

While UHL is the only Trust at present commissioned to provide a mobile ECMO service in England, they have successfully demonstrated that it is possible to offer a safe and high quality service across a wide geographical area. We are confident that we would be able to procure one or more providers to deliver the service currently commissioned from UHL if that service ceases.

1.6.4 The cystic fibrosis and paediatric respiratory services will be affected with the CHD service changing at the Royal Brompton, how is this being reviewed?

We have worked with the Royal Brompton, and all other affected providers, to assess the likely impact on CHD and other services should our proposals for change be implemented. The impact assessments, which have been published, cover both the providers which would no longer be commissioned to provide surgical services, and those which would be commissioned to provide additional surgical services.

The Royal Brompton told us that because of the impact on its PICU there would also be an effect on its paediatric respiratory services if the proposals are implemented. NHS England's national panel acknowledged that this was likely to be the case but has asked for expert advice on assessing the impact. NHS England is in the process of obtaining that advice. Whatever the outcome of this, the assessment of the impact on the Royal Brompton’s paediatric respiratory services will be taken into account by the Board of NHS England when it makes its decisions.

1.6.5 Won’t the proposals affect staff if services move?

NHS England expects that if our proposals for change are implemented, redundancies would be minimal. Experience at other centres where level 1 CHD services have previously ceased was that there were virtually no redundancies.

However, with such large numbers of staff potentially affected, some redundancies cannot be ruled out.

Hospital employees who care for patients with congenital heart disease do an excellent job and have essential skills which we do not want to lose from the NHS. In the event that our proposals are implemented, we will work with all of the affected hospitals to ensure that staff are supported through the change, and any redundancies are kept to an absolute minimum.

1.6.6 How will NHS England support staff in the affected hospitals?

The staff at hospitals providing CHD services are employed by the individual hospital trust, so any changes, if implemented, which might affect staff would be managed by that hospital trust. As well as the protections provided in law, for example TUPE, we will work with any hospital trusts affected to ensure that staff are supported, if our proposals were to be implemented. We will wish to retain the skills and experience of the staff in affected trusts through opportunities in providers which will undertake more activity under our proposals.

1.7 Multidisciplinary team (MDT) working

1.7.1 Why do services need to be co-located as my child got the best care and the services were not on the same 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. This determines what medical care is available by the bedside for a child in a critical condition, which is important because many children with CHD have multiple medical needs. However, while this responsiveness is one important element behind the co-location requirement, it is not the only one. NHS England's clinical advisers consider that co-location with specialised paediatric services is also important because it allows much closer working relationships to develop between paediatric cardiology specialists and the wider specialised paediatrics team. Delivering these services effectively requires the input of the wider paediatric multidisciplinary team, and the interaction between these teams on a daily basis, when co-located, was considered by NHS England's clinical advisers to be of significant benefit to patients. This way of working brings paediatric cardiac care into line with expectations in other specialist children’s services, because most other specialist paediatric services have moved to a paediatric environment, including liver transplantation; bone marrow transplant; stem cell/cancer therapy; and gastroenterology. This follows the accepted international norm and is why the standard requires co-location on the same hospital site, not just the ability to get to bedside within 30 minutes of call. NHS England's clinical advisers have said that in their view it was not safe to care for children with complex conditions and co-morbidities (a high proportion of whom will need input from other specialties) in settings where other paediatric services were not on site. Having all tertiary specialties on one site means neither the child nor the specialist has to travel with the potential compromises involved in the care environment, access to the full team and equipment and timeliness of advice and intervention.

We should note here that it is not the fact that these services are not co-located now that has led to our proposals but rather that hospitals have not developed a robust plan to address this shortfall.

No decisions have yet been taken, and these questions are at the heart of NHS England's consultation, and we want to hear views in response to these proposals.

1.8 Standards and outcomes

1.8.1 What are the standards for the CHD service?

The paediatric and adult standards can be found here https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/chd-spec-standards-2016.pdf

The standards encompass the whole patient pathway, each set of standards is subdivided into categories A to M outlined below:
A – The Network Approach
B – Staffing and skills
C – Facilities
D – Interdependencies
E – Training and education
F – Organisation, governance and audit
G – Research
H – Communication with patients
I – Transition
J – Pregnancy and contraception
K – Fetal diagnosis
L – Palliative care and bereavement
M – Dental

1.8.2 Who agreed the standards?

The NHS England Board agreed the standards in July 2015 following public consultation.

1.8.3 Why are you not consulting on the standards?

The standards were consulted on prior to the NHS England Board decision. Consultation ran from 15 September to 8 December 2014.

1.8.4 I have been told the standards are changing, is this true?

No, the standards have not changed from when they were agreed by the NHS England Board decision in July 2015.

1.8.5 The outcomes for the hospitals that may stop surgery are good, why are you planning to stop the services?

Outcomes at all hospitals currently providing CHD services are good. This is about ensuring high quality, consistency and sustainability for the future through common standards. These standards were agreed by clinicians, other experts and patient and public voice representatives as being the best way to make sure every patient can benefit from the same excellent care, regardless of where they access it.

The standards cover the entire pathway of care, from diagnosis, through treatment, and on into care at home at end of life care. Once all hospitals are meeting the standards, we can ensure that all patients with CHD will be receiving high quality care. 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 and treatment options; plus a better managed transition between children’s and adult services. Patients and patient groups told us that these were important aspects of care, so this is not just about making sure that the surgery is of the highest possible quality, it’s about the entire pathway.

1.8.6 How will the outcomes be measured in the future and who will monitor these?

It is widely acknowledged that while important, 30 day mortality is a very limited and narrow measure of outcome. NHS England has a much broader focus on improving quality and reducing variation.

We have worked with the Clinical Reference Group to develop a new dashboard that includes a wide range of new measures designed to monitor the quality of care and the health of services. We expect peer review, required by the standards, to be introduced in 2018/19 to bring a rolling programme of attention on the full range of standards. And we are working with NICOR – the organisation that runs the national audit of CHD services on our behalf – to encourage the publication of a wider range of measures.

1.8.7 What options do the services have if they cannot meet the standards for level 1?

In some cases, hospitals may appropriately provide level 2 care, if they are able to meet the required standards, and if this is in the interests of patients. They could also offer level 3 services and / or host outreach clinics with specialists from their network level 1 centre.

We have also asked the Royal Brompton to explore the potential for offering a continued adult CHD service at level 1 including surgery by working in partnership with a commissioned children’s surgical centre, with a joint surgical team across the two. This would be similar to the arrangements between Great Ormond Street and

Barts. This possibility is included in our consultation document and we are asking for views.

1.8.8 What is NHS England doing to prevent congenital heart disease?

Very little is known about the causes of CHD, so there is no guaranteed way of preventing its occurrence. Public Health England has established the National Congenital Anomaly and Rare Disease registration Service (NCARDS). We expect that this comprehensive database will in time support epidemiological research that will help identify modifiable risk factors. The first reports from NCARDS are expected in 2019.

1.8.9 What happens if the new model fails?

If the proposals are implemented, detailed plans will be developed before any planned changes take place. Services will be monitored (for example using the dashboard described above) to ensure that quality and outcomes across the whole patient pathway are maintained. Although the changes will be locally delivered, there will also be national oversight of the whole programme to identify and manage any emerging problems.

Networks will monitor have a key role in supporting implementation of the standards and sharing good practice to ensure that services keep improving.

1.9 Decision-making

1.9.1 When will the decision be made on the CHD service and by whom?

The NHS England's decision-making timetable will follow the end of public consultation on congenital heart disease services.

Decisions will be taken at a meeting of the Board of NHS England, held in public. NHS England will make its decisions having reviewed the consultation responses. At this stage, we anticipate a very high volume of responses to the consultation, including detailed written comments and questions. These will all be analysed by the independent external company engaged by NHS England, prior to decision-making by NHS England.

1.9.2 How will you ensure that equality is achieved?

An Equality Impact Assessment (EIA) has been undertaken and can be found here: https://www.engage.england.nhs.uk/consultation/chd/

The EIA will be reviewed following public consultation to ensure that any perceived inequalities are considered. Profiling of parents and carers has been put to the programme already.

1.10 What impact will the election have on the consultation

The calling of a general election means that NHS England as a public institution entered the pre-election period on midnight of Friday 21st April. This means that, in line with the requirements of Cabinet Office guidance for the public bodies, while the consultation will continue and the materials will remain upon the NHS England website and responses will still be received, NHS England will not hold any events or attend meetings before the election has been completed.

The events that had been scheduled to take place will be reorganised for after 8th June. The event details will be posted on the consultation web pages as they are arranged.

The consultation will be extended to the 17th July to enable us to reschedule the events and enable those attending to respond to the consultation.