NHS ENGLAND CONSULTATION ON THE FUTURE OF CONGENITAL HEART DISEASE SERVICES

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Appendix: Easy Read Consultation Document (Proposals to implement standards for congenital heart disease services for children and adults in England)

Why Close The Leading Congenital Heart And Lung Unit In The UK?

NHS England is proposing to stop commissioning Congenital Heart Disease (CHD) services from Royal Brompton & Harefield NHS Foundation Trust. This is the largest CHD service in the country and the proposal will affect some 14,000 heart and lung patients.

The Unit has among the best patient outcomes of any in the UK and the cardiology service as a whole (including at Harefield Hospital) has among the highest patient satisfaction ratings of any in the country. At a time when the NHS is struggling for resources, why is it going ahead with a plan to spend millions of pounds closing the UK's largest congenital heart unit, with an outstanding record, when there is no evidence to show closure will improve services?

An Unnecessary, Costly Review

NHS England (NHSE) has launched a consultation on its plans to close the congenital heart disease (CHD) services at Royal Brompton & Harefield NHS Foundation Trust (RBH). The consultation follows a report by NHSE which established a set of standards to be achieved by hospitals providing these services despite the UK's CHD services being considered to be among the best in the world.

This plan will cost the NHS millions of pounds to provide the capacity to treat the 14,000 Royal Brompton patients affected. Even if other Trusts do have funds available, spending them on this plan prevents their use on other, arguably higher priority, areas, such as A&E and improving mental health services. The NHS has more serious problems to address than an unnecessary re-structuring of CHD care, for which there is no evidence to show any resulting improvement in patient care.

Despite requests, NHS England has provided no cost-benefit analysis of their proposals. At a public consultation on 7 March 2017, NHS England's national clinical director for heart disease, Professor Huon Gray, admitted there was "no scientific evidence" to back the decision to withdraw congenital heart disease services from Royal Brompton Hospital.

Risks to Patient Care

NHSE proposes to close two other CHD units as well as Royal Brompton. This will involve a large transfer of services and patients. NHSE admits there are staffing risks with the plan. They have warned that hospitals face a "significant challenge" in providing enough staff to meet the capacity for the 900 operations needing to be found elsewhere as a result of the Units closing.

Example: NHSE proposes that some 85 operations a year are transferred to Barts from Royal Brompton. This represents a huge 110% increase in their level of activity and that Trust is in financial special measures. Not surprisingly, the impact assessment said this would be a "significant challenge" for them.

Impact on Hillingdon and Harefield Hospitals

Some of the services that would be affected include:

- The children's CHD outpatient clinic at Harefield Hospital will end, meaning journeys of a further 20 miles into central London for children and their families (either SW1 or WC1).
- The fetal echo outreach service offered by Royal Brompton to pregnant women at Hillingdon would end, meaning journeys into London for this group of patients.
- Clinical networks would be destroyed. In the words of one paediatrician at Hillingdon: "I cannot emphasise enough the personal relationships that have developed between the fetal, cardiology, obstetric and paediatric consultants. Women and their babies get personalised care as a result of the ease of access to specialist opinions. Only last week, through close working, teams at Royal Brompton and Hillingdon agreed a care plan so a baby could be delivered at Hillingdon despite complex congenital cardiac anomaly."
- The loss of 24 paediatric critical care beds in North West London (NWL) is likely to reduce access to PICU beds, and have an impact on winter (and spring) pressures, making it more likely that critically ill children will have further to travel.
- Without CHD services, we lose the essential infrastructure for specialist services like children's cystic fibrosis and (adult) pulmonary hypertension. This would have a serious impact on many patients including the cystic fibrosis children who have shared care with Hillingdon.
- Harefield Hospital cannot be immune to the effects of the financial damage that the plans will inflict on the Trust – redundancy costs alone are estimated to be a potential £13.5m, with recurring losses of between £5m and £7m per annum from lost services.

Loss of Child To Adult Care

Royal Brompton's teams have developed an international reputation for tailoring the individual transition from paediatric to adult care in a seamless, coordinated process. With the latest evidence showing that congenital heart disease patients now need most treatment during their adult years, the best chance of improving care for them is to focus on the whole pathway from fetal diagnosis to adult care. This approach will be lost if Royal Brompton's unit is closed.

NHSE's final report on the review acknowledged that some clinicians felt that "the link between paediatric CHD and adult CHD services is more important than the link between paediatric CHD and other specialist paediatric services". This advice was rejected against the recommendation of the clinician group without any evidence given.

Loss of World Leading Heart Disease Research

The Trust is the leading centre of research into adult congenital heart disease (ACHD) in the world. We currently publish more research into ACHD than any other centre internationally. This research saves lives but the team conducting it will be dismantled if the unit closes. Experts say dispersing this team could set ACHD research back ten years.

Destruction of a Leading UK Centre for Respiratory Medicine

Without the volume of patients provided by the CHD services, Royal Brompton's highly regarded paediatric intensive care unit (PICU) will be forced to close. This will mean the loss of nearly a quarter of London's PICU capacity at a time when there is already a shortage. There are regular instances of children having to travel up to 100km to find an intensive care bed, due to none being available in London and the South.

The Trust is the national centre for treating babies and children from around the UK with some of the most severe forms of cystic fibrosis, asthma, muscular dystrophies and other respiratory illnesses. Without the back-up of intensive care, it will be unsafe to undertake the more complex specialist treatments and they will have to stop.

NHSE admits that its plan for Royal Brompton will impact on the Trust's children's specialist respiratory services but has publicly admitted that no risk assessment had been carried out for those patients. It is unacceptable for thousands of children with severe lung diseases to be considered an after-thought in the planning process.

An Irrelevant Reason for Closure

The only reason given by NHSE to end CHD services is the perceived non-compliance with just one of the 470 new standards for CHD care. This is called 'co-location', requiring certain paediatric services to be based in the same building in case they are needed in emergency. The clinical reference group advising on standards defined co-location as an emergency response time within 30 minutes. These views were overruled by a smaller group of advisers when the standards were finalised.

Royal Brompton already ensures that all necessary services are on-site, through a tried and tested partnership with neighbouring Chelsea and Westminster hospital just a short walk away. Doctors are jointly appointed and hold joint team meetings and ward rounds. Fewer than 1% of paediatric CHD patients need these services within 30 minutes and Royal Brompton has a 100% record of attendance when they do. Chelsea and Westminster consultants are within a shorter journey time than doctors at some other 'same site' centres, who have to cross large hospital campuses to see patients.

This partnership has helped the Trust achieve among the best patient outcomes in the country. We challenge NHSE to describe how exactly their plans could produce a service that is more cohesive, more responsive and provides better care than this. NHSE has not explained how co-location would in any way improve patient care at Royal Brompton. Indeed, it admits that there is no evidence showing it has any clinical benefits. The national clinical director for heart disease, Professor Huon Gray, has publicly stated that the decision was not based on evidence.

If co-location ensured better performance, Trusts with co-located services would have better patient outcomes than us. They don't. Professor B Sethia, President of the Royal Society of Medicine and consultant cardiac surgeon: "These proposals are poorly thought out, based on imprecise or no evidence and disregard the excellent outcomes delivered by Royal Brompton Hospital in both adult and paediatric cardiac patients. Furthermore, given the shortage of beds, it is ridiculous to assume that there are the necessary resources for patients to move to other centres for treatment."

Inconsistency

Newcastle's Freeman Hospital will be allowed to continue providing children's heart surgery despite not meeting TWO fundamental standards: co-location and having the required number of surgeons and operations. NHSE states that the Newcastle CHD service works well in practice despite not being co-located on the same site - as does the one at Royal Brompton. Given that NHSE is clearly prepared to have the standards breached, why has equal consideration not been given to the enormous damage that would be caused at Royal Brompton & Harefield should CHD services be withdrawn?

What is Closure Aiming to Achieve?

Given that NHSE has said that there are no concerns over the quality of services provided by Royal Brompton which remain among the best in the country, what problem is the proposal aiming to solve? The closure could only be justified if it is clearly set out how this would lead to a better service for patients. NHSE has admitted that it has no evidence that this will be the case.

It is completely irrational to withdraw a service from 14,000 patients on the basis of one new paediatric standard that affects 1% of children with CHD, treated at the hospital. What is the logic of spending millions of pounds recreating capacity at other centres when it already exists at Royal Brompton?

BACKGROUND DOCUMENTS

- Proposals to implement standards for congenital heart disease services for children and adults in England - Consultation Document: https://www.engage.england.nhs.uk/consultation/chd/supporting_documents/Proposals%20to%20implement%20standards%20for%20congenital%20heart%20disease%20services%20for%20children%20and%20adults%20in%20England%20%20Consultation%20Document.pdf