

DRAFT RESPONSE TO CONSULTATION ON CONGENITAL HEART DISEASE SERVICES

Introduction to Children's Heart Surgery Fund

The Children's Heart Surgery Fund (CHSF) is a charity providing support to children and adults born with congenital heart defects. Based at the Leeds General Infirmary, CHSF operates across Yorkshire, Humberside and North Lincolnshire. Through donations from the general public and corporate supporters, the Fund provides equipment, resources and assistance to over 400 children receiving open heart surgery every year at the Children's Heart Surgery Unit in Leeds and the 10,000 outpatients treated there. The Charity is overseen by a board of Trustees that includes clinical staff, parents and business leaders.

Since being established in 1988 by a heart surgeon, Duncan Walker, CHSF has awarded around £6 million in grants to the Unit, patients and their families. This has included funding family accommodation exclusively for heart patients. The Charity has also enabled investment in staff training and new equipment and technology. The Fund's donation to the University of Leeds Mechanical Engineering Department led to the creation of Tissue Regenix, a leading developer of medical devices, including replacement heart valves. The latest fundraising campaign, 'Keeping The Beat', is working to raise £500,000 towards a state-of-the-art, hybrid, children's heart theatre at the LGI by 2018.

CHSF aims to support the Leeds Congenital Heart Centre to become a recognised 'World Class' centre of excellence.

CHSF Involvement with the Review

CHSF successfully led the campaign against NHSE proposals to end children's heart surgery at Leeds under the Safe and Sustainable Review. The campaign was supported by hundreds of thousands of patients, their families, staff and members of the public as well as nearly all the regions' MPs and local authorities, many prominent business people and many others.

The broad range of support for the campaign was quite unprecedented and was reflected in the 600,000 signatures gathered for a petition which was presented at 10 Downing Street.

Our case was entirely vindicated when the Independent Reconfiguration Panel produced a highly critical report in May 2013 and the Review was scrapped.

Since then CHSF has worked constructively with the new review with the aim of not just securing the future of the Leeds Unit but bringing certainty to the provision of CHD services in the UK for the sake of patients and staff. Its priorities for the current consultation are to promote best care for patients and support for families.

Introduction of Standards

We welcome the setting of standards to provide bench marks across the CHD service. We also recognise that no units currently meet the standards and that these should be regarded as aspirational. They should not therefore be considered sacrosanct and NHSE should not be determined on their full implementation by a certain date in every unit, especially where this may have damaging consequences including impacts on other services.

The standards and the resulting consultation should be seen in the context that CHD services have vastly changed since the Bristol scandal. Outcomes are immeasurably improved and are now amongst the best in world. Whilst there should always be a drive for improvement, there is no need no need to take any corrective actions which, in themselves may lead to detrimental consequences

. Implementation of the standards should not therefore be a cause of major disruption as this is not necessary. It will only cause further uncertainty, introduce risks, be a distraction for staff and will cost money. This is all at a time when resources are extremely scarce and the NHS has plenty of other areas which have a greater need for significant improvement.

Whilst we recognise that the standards are worthwhile benchmarks, given the current level of outcomes and that there is no specific evidence in the consultation on how the proposals will improve care for patients, we feel this undermines any justification for significant interventions in the current configuration of services.

We are concerned by the potential impact on staff. There is a real danger that the continued disruption and uncertainty that the current proposals create send a signal about CHD services in the UK that deters specialist staff from applying for posts. This could affect all units.

If plans to close centres are implemented we feel that it is a dangerous assumption that specialised staff will move to where the service moves to, especially post-Brexit. Given the current difficulties all units have in recruiting specialist staff and the number who come from overseas, we are fearful of how NHSE would sustain services if some of the overseas staff choose to relocate abroad.

We would not support any proposed service changes resulting in patients receiving care split at two centres (level one and level two) rather than all at the same centre. From all our experience of working with families, we feel this would be disruptive and not good for patients or their families. We cannot see how splitting care in this way would result in a better service, so why do it?

There is a danger that though unsupported by robust clinical evidence, we end up, at least in the short to medium term, with a worse nationwide service than is currently the case.

Above all, units, clinicians and patients want and need stability after all the uncertainty created by the series of reviews carried out over the last few years.

Leeds

It is predicted under the two scenarios put forward in the consultation that the impact of the proposed reconfiguration on the Leeds unit is that it will gain 13-15 adults and 37 children for CHD surgery per year.

The number of patients involved represents about a 10% increase in activity for Leeds. We are satisfied that the expressed confidence of the Trust in their ability to increase their capacity to provide the extra activity required is justified.

Manchester, Leicester and Royal Brompton

Implementation of the standards should not come at the expense of existing good practice, as recognised by clinicians and borne out by positive outcomes, being dismantled. This is especially the case where removal of commissioning will cause major disruption, staffing difficulties, extra costs and hardship for patients and their families.

Closure of units should only happen where there is case backed by evidence to support the view that care standards and outcomes would be improved for patients by the closure of that unit.

Also, to be taken into account should be any significant knock on effects on other services provided by a unit that may affect patients from around the country. This includes research facilities and outcomes from which all providers and patients ultimately benefit. We are therefore particularly concerned by the proposed closure of the unit at the Royal Brompton which we are led to believe would lead to the closure of their adult CHD research facility. This is world renowned and all providers ultimately benefit from its work.

Given this, we would suggest that there is little or no evidence to support the need to close Royal Brompton and Leicester. Their closure would cause major disruption and as long as they continue to have satisfactory outcomes, they should remain open. Unless there is a problem with them, why incur unnecessary expense, take risks with staffing and cause uncertainty for staff and anxiety for patients by closing them?

Closure could still go ahead at Central Manchester, as it appears it could do so without significant disruption and without local opposition.

Newcastle

Given that the consultation recognises that Newcastle is unlikely to meet the activity requirement by 2021 or the co-location requirement by 2019, the retention of CHD services there is illogical given NHSE's position regarding implementation of the standards and undermines the whole case relating to the reasons for closing other units.

The Panel considering the impact assessment noted that real risks did arise with Newcastle not meeting the activity requirement and that if it could not meet the standards, a clear plan would be needed either to move the advanced heart failure service or deliver it under a different model. It said a phased, planned transition supported by the Newcastle team would be required if the service needed to move. The panel recommended that NHSE would need to undertake specific work on the future of advanced heart failure services in England to ensure their ongoing provision and resilience.

NHSE noted the Panel's concerns and recommendation and replied that if the proposals are agreed, this recommendation will be further considered. It says that any mitigation arrangements will be time limited and subject to further review by 2021.

This is creating further uncertainty. It is recognised in the consultation that change will need to happen at Newcastle in the long term and that it will be required to meet the standards in the same way as other units

NHSE knows full well that it is impossible to see how the standards relating to activity can ever be met by Newcastle given the limited geographic area served by the unit and taking account of the relative proximity of units at Glasgow and Leeds.

It will also be aware of concern over the future of Newcastle with questions about succession planning following the imminent retirement of a leading surgeon and plans being made to establish a heart transplant programme for children in Ireland which would end cases being sent to Newcastle.

It is accepted in the consultation that: "in principle it would be possible to commission these services from an alternative provider, the learning curve would be long."

To prevent any further delays, it would be sensible to look at other models to recreate transplant services elsewhere. Ideally this would be at a more geographically central unit given that the only other hospital providing this service is in London. Given that there would need to be a relatively long transition period, this is all the more reason to start the process now. With the appropriate transition period, this need not in any way adversely affect outcomes for patients. Indeed, delaying dealing with the issue is more likely to lead to a situation where there is a more urgent need to replace the service with greater inherent risks for patients.

We note that the consultation recognises the huge improvement in outcomes for children with CHD to the extent that many more now reach adulthood.

Our experience supports the conclusion that as more people with CHD survive childhood, we are likely to see the service moving from one that is centred around children to one that is in addition treating a growing number of young people and adults who will continue to have (often complex) health needs. This has consequences for the way in which services are delivered and what sort of services are delivered, for both children and young people through to transition for young people into adult services. For many congenital defects treated in childhood, further problems can develop later in life which then require medical care or further surgery. **The British Heart Foundation** notes: 'Treatment of adults with congenital heart disease is relatively new as more children with congenital heart defects receive treatment and reach adulthood. As a result of the success of paediatric cardiology and cardiac surgery over the last four decades, it is thought that more adults with congenital heart disease will require medical care than children'.