APPENDIX 2

The new review of Congenital Heart Disease (CHD) in England

Consultation response

Introduction

The purpose of this paper is to set out the views of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) in relation to the proposed Congenital Heart Disease (CHD) Standards and Service Specification, launched for public consultation by NHS England on 15 September 2014.

This response sets out the main observations of the joint committee following a series of meetings, discussions with key stakeholders (including commissioners, service providers and patient representatives) and consideration of a range of information.

Background

The Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – the JHOSC – is a single representative body for the 15 top-tier local authorities across Yorkshire and the Humber. The JHOSC was initially established (in March 2011) to consider the Safe and Sustainable Review of Children's Congenital Cardiac Services in England, the associated proposals and respond to the options presented for public consultation.

The JHOSC previously produced two reports in relation to the Safe and Sustainable Review of Children's Congenital Cardiac Services in England. The first, published in October 2011, was submitted as a formal response to the options presented for public consultation. The second report, published in November 2012, formed the basis of a formal referral to the Secretary of State for Health following a decision on the proposed future model of care and designation of surgical centres in July 2012.

The work, reports and findings of the JHOSC were fundamental to the findings and recommendations of the Independent Reconfiguration Panel (IRP) report (passed to the Secretary of State for Health in April 2013) and subsequently the Secretary of State's decision to halt the Safe and Sustainable Review.

A number of issues raised by the JHOSC's reports remain relevant to the new CHD review and warrant further consideration by NHS England, particularly in relation to the following areas:

- Co-location of services;
- Caseloads;
- Population density;
- Vulnerable groups;
- Travel and access to services;
- The impact on children, families and friends;
- Established congenital cardiac networks; and,
- Adults with congenital cardiac disease.

Specifically, the JHOSC would not wish to see any dilution of the standards around co-location and recognition that the 'gold standard' remains physical co-location on a single site.

The JHOSC's previous reports are available using the following links: October 2011 and November 2012 (and appendices).

Main Observations

Overview

The following details outline the JHOSC's main observations, following a series of meetings, discussions with key stakeholders (including commissioners, service providers and patient representatives) and consideration of a range of information.

To help inform its view of the proposed standards, the JHOSC sought a range of different inputs. Specifically, it had hoped to consider a detailed gap analysis from Leeds Teaching Hospitals NHS Trust – detailing the Trust's level of compliance with the proposed standards and some analysis of the actions required to attain any unmet standards. Despite receiving assurances from the Trust that there was currently a high degree of compliance with the proposed standards, the JHOSC was disappointed that the detailed gap analysis was not available prior to the deadline for consultation responses.

The JHOSC was interested to understand the timescales and implications associated with implementing the agreed standards. When attending the JHOSC meeting, representatives from NHS England described the derogation process – whereby there would be an agreed temporary delay in meeting key service requirements in full, supported by full implementation over a time limited period according to provider capacity and capability. The JHOSC was concerned about the transparency of this process and is keen to ensure it was not used as a mechanism to circumnavigate consultation about potential service reconfiguration in the future.

In early October 2014, NHS England published its commissioning intentions for Specialised Services – which includes some specific comments on CHD services. This presented the clearest information thus far – stating that the form and function of CHD services will be considered over 12 months – commencing in March/ April 2015. Clearly this has implications for the on-going work of the JHOSC and it is important that NHS England fulfils its statutory duty by maintaining a dialogue with the JHOSC as work progresses.

The JHOSC identified a number of specific areas it wished to comment on. These are detailed below.

Stakeholder involvement

In considering stakeholder engagement, it is important to consider and reflect on the following extracts from the report of the Independent Reconfiguration Panel (IRP).

> ***'NHS England must ensure that any process leading to the final decision on these services properly involves all stakeholders throughout in the necessary work, reflecting their priorities and feedback in designing a comprehensive model of care to be implemented and the consequent service changes required.'***
>
> ***'NHS England should use the lessons from this* [Safe and Sustainable] *review and create with its partners a more resource and time effective process for achieving genuine involvement and engagement in its commissioning of specialist services.'***

Regrettably, the JHOSC believes that NHS England fallen short on some aspects of the IRP recommendations – particularly in relation to the involvement, engagement and consultation with Black and Minority Ethnic (BME) communities.

The JHOSC expressed concern regarding NHS England's decision not to translate its consultation documents into other languages (other than Welsh). This led to a rapid re-think and some translation of the consultation booklet took place. However, in this regard, the JHOSC believes the new CHD review has repeated some of the well documented failings of the previous Safe and Sustainable review.

The JHOSC has significant concerns more generally regarding the involvement and engagement of Black and Minority Ethnic (BME) communities – in particular Pakistani and South Asian communities, where the prevalence of CHD is known to be proportionally higher than in other communities. Regardless of the approach around translating consultation documents, as 'known' service users, the JHOSC believes NHS England should have had more general regard for the active involvement and engagement of BME communities (as part of the established sub-group structure) throughout the development of proposed service standards and the new CHD process in general.

There was also concern regarding the ownership of the consultation process, with NHS England seemingly leaving the local charity to organise local events across the region. With limited notification around the commencement of the 12-week consultation period, this provided very limited opportunity in terms of planning and delivering such events. It is likely this was replicated elsewhere in England.

The JHOSC was also concerned to hear that Embrace (the regional, dedicated neonatal and paediatric transport service) had not been asked to participate in any specific groups or workstreams of the new CHD review. Again, the JHOSC does not believe this adequately reflects the recommendations of the IRP.

Implications of the proposed standards

In terms of implications of the proposed standards, the JHOSC believes the following extract from the IRP's report is an important consideration:

> ***'…the Panel has concluded the JCPCT's decision to implement option B (DMBC – Recommendation 17) was based on flawed analysis of incomplete proposals and their health impact, leaving too many questions about sustainability unanswered and to be dealt with as implementation risks.'***

The JHOSC believes that in considering the proposed standards, it is equally important to consider the likely impact and implications of implementing and achieving those standards: It is difficult to whole-heartedly support proposals when the potential impact remains unclear and uncertain.

The JHOSC heard that, from a patient transport perspective, the proposed specifications and standards do not raise any issues and that the patient transport provider currently meets the service specification and standards (as drafted). However, the JHOSC was also advised that a re-assessment against the standards would be required should there be any changes to the current configuration and provision of services across Yorkshire and the Humber. This supports the JHOSC's view that while the majority of proposed standards might be seen as helping achieve

the aims of the review, it is equally important to consider any impacts associated with implementation before unreservedly endorsing any proposals.

The JHOSC also heard and supports the view that there is insufficient evidence that outcomes will improve with surgical centres undertaking 400 – 500 procedures per annum. This issue was also discussed in the IRP report. The JHOSC is concerned that standards relating to minimum levels of procedures and/or surgeons will lead to closure of some existing centres sometime in the relatively near future. However, with the current rate of increase in the population of adult patients with congenital heart disease (due to better survival rates etc.), there is concern that any closure of surgical centres in the short-term would most likely lead to problems with national capacity in the longer-term. This supports and reinforces the JHOSCs previous view that surgical centres in both Leeds and Newcastle should be retained in order to meet the needs of a growing cohort of service users.

In relation to the discussions on derogation, there appeared to be some confusion – and certainly a lack of clarity – about how this might be applied to the implementation of the agreed standards. For example, the standard relating to the number of surgeons required at a surgical centre was identified as an 'immediate standard', whereas evidence from Leeds Teaching Hospitals NHS Trust suggested there would be a 3-year window to recruit a fourth surgeon.

There has been considerable debate regarding the number of surgeons necessary for a sustainable surgical centre. This debate has continued from the previous Safe and Sustainable Review through to the new CHD review. While it could be argued that a minimum of four surgeons might be preferable, there seems to be little evidence to support this as a fundamental requirement. Furthermore, the JHOSC heard the availability of specialist cardiac surgeons remained a national issue and had been adversely affected by the Safe and Sustainable Review. The JHOSC seriously questions whether four surgeons per surgical centre is realistic and achievable, and believes this is likely to be a key issue during the implementation phase of the review and beyond. In light of this remaining an issue for some considerable time, the JHOSC's view is that the standards should require a minimum of three surgeons per surgical centre.

The JHOSC also has some general concerns regarding those standards relating to staffing and particular roles – specifically where providers are not able to directly control the availability of suitably qualified staff. There is clearly likely to be a time lag between individuals undertaking the necessary training and being able to work within a clinical environment.

Finance and affordability

In considering finance and affordability, the JHOSC again reflected on elements from the IRP report and recommendations – as follows:

> ***'For the current service and any proposed options for change, the function, form, activities and location of specialist surgical centres, children's cardiology centres, district children's cardiology services, outreach clinics and retrieval services must be modelled and affordability retested.'***

The JHOSC is concerned at the level of available detail and the robustness of financial modelling undertaken prior to consultation. The JHOSC heard from NHS England that

there was no funding identified to assist with the implementation of the proposed standards. Indeed, NHS England's financial assessment concludes that any additional costs associated with providers implementing the new standards should be met through the national tariff – with greater income generated through increased activity, rather than an increase in the rate of tariff. It is suggested that the national tariff includes an element for investment, which is reinforced in Part 4 of the consultation document (pages 50-52).

This raised a number of specific issues and concerns for the JHOSC, as follows:

(a) The evidence from NHS England appears to be odds with feedback from other stakeholders. The JHOSC heard from the Chief Executive of Leeds Teaching Hospitals NHS Trust, who stated that the availability of resources was an important issue and some of the draft standards required significant investment. It was anticipated this would necessitate discussions with commissioners about any necessary additional investment (a particular example raised was around funding for a hybrid theatre). As such, much greater clarity is needed around the financial impact and affordability of the standards, and specifically how additional costs will be met.

(b) The JHOSC has previously considered the historical levels of funding/ investment for specialised services across England. This showed that historical funding across Yorkshire and the Humber was relatively low in comparison to most other areas of the country. The legacy of such historical spending patterns is likely to have led to a lower level of investment in specific areas across service providers. As such, there is likely to be different affordability gaps across different providers. The JHOSC understands that similar concerns were raised in the joint network meeting (summarised in Appendix 2). This further supports the need for greater clarity around the financial impact and affordability of the standards, and how additional costs will be met.

(c) Another specific consideration regarding affordability relates to the ability of individual providers to generate (or borrow) capital for investment. This ability can also be directly influenced by the 'Foundation Trust (FT) status' of individual providers. Additional freedoms and flexibilities around resources are often cited as significant benefit of FT status. Therefore, the financial implications of meeting the proposed standards are likely to be directly influenced by the FT status of individual providers. The JHOSC believes that NHS England (as the service commissioner) has a duty to consider the needs of the population – first and foremost – and this again supports the need for greater clarity around the financial impact and affordability of the standards.

The JHOSC was also advised that resource issues had been highlighted at the Providers Group meetings and were an issue across different units. It was also stated that the financial modelling was unclear. It is clearly important that NHS England clarifies issues associated with resources and implementation.

Networks

The importance and strength of network arrangements is a key feature of the new CHD review – as it was under the previous Safe and Sustainable review. In its previous reports, the JHOSC was pleased to be able to highlight the strength of the network across Yorkshire and the Humber. However, the JHOSC was disappointed to learn that since NHS England formed in April 2013, the dedicated managerial support for the network ceased to exist. The JHOSC understands the network had previously

been funded by a collaborative funding arrangement between Primary Care Trusts (PCTs) across Yorkshire and the Humber. This is particularly disappointing given the following comments and observations in the IRP report:

> ***'…the establishment of a formal network board would be the driver for developing the congenital heart network in the north of England and that clinical colleagues from the existing Yorkshire and Humber network would be key to its development.'***

The JHOSC recognised that the previous Safe and sustainable Review had created tensions between existing surgical centres. In the North of England, despite the suggestions that relationships were improving, the JHOSC believes tensions between Leeds and Newcastle remain. Relationships have certainly not been helped by the on-going and protracted review of services at Leeds Teaching Hospitals NHS Trust, following the temporary suspension of services in March/ April 2013. While that review has now been concluded, repairing the damaged relationship between Leeds and Newcastle is likely to take some considerable time. This is particularly pertinent when considering the central role of networks – particularly in terms of the development of a network of surgical centres.

It should be noted that the JHOSC has maintained an overview of the review of services at Leeds Teaching Hospitals NHS Trust, following the temporary suspension of services in March/ April 2013. The JHOSC aims to produce a report setting out its observations of the process and any recommendations for improvement in early 2015.

Additional information

Some specific information provided to the JHOSC is attached at Appendix 1 (Feedback from a joint network meeting) and Appendix 2 (Feedback from local engagement events organised by Children's Heart Surgery Fund (CHSF)). While it is envisaged this feedback will be provided directly as part of other consultation responses, it is attached and repeated here for completeness.

Summary

In general, the JHOSC recognises and welcomes NHS England's more open and transparent approach in relation to the new CHD review. However, a number of concerns remain (as detailed above) and it is hoped these will be taken into account and addressed as the review moves forward.

In early October 2014, NHS England published its commissioning intentions for Specialised Services. This included some specific comments around CHD services – stating that the form and function of CHD services will be considered over 12 months – commencing in March/ April 2015. Clearly this has implications for the on-going work of the JHOSC and it is important that NHS England fulfils its statutory duty by maintaining a dialogue with the JHOSC as work progresses.

The JHOSC will consider whether it wishes NHS England to provide a specific response to the issues identified in this paper.

Cllr Debra Coupar (Chair)
Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber)

APPENDIX 2

Appendix 1

Report to the Joint Health Overview and Scrutiny Committee (JHOSC) for Yorkshire and the Humber – 28 November 2014

Feedback from a joint network meeting

At the JHOSC meeting on 3 November 2014, members heard that a clinical network meeting was due to consider the proposed service specifications and draft standards at a meeting on 10 November 2014.

It should be noted that minutes from the network meeting are not routinely taken, as they tend to be more educational type meetings with presentations and discussion. It should also be noted that, prior to the NHS England being founded in April 2013, a formal network board existed and was supported through a collective of Yorkshire and Humber Primary Care Trusts.

The Network meeting was joint meeting between the Leeds Network and the Leicester Network. The Trusts represented at the meeting included:

- LTHT
- Leicester University Hospital Trust
- Nottingham Children's Hospital
- Sheffield Children's Hospital
- York Hospital
- Chesterfield District General Hospital
- Hull Hospital

Based on feedback from Leeds Teaching Hospitals NHS Trust's lead cardiologist, Dr Elspeth Brown, the points below set out the main areas of discussion/ outcomes from that meeting:

- Generally it was felt the standards were sensible and described a good service.

- There were concerns that there is no evidence for 400 or 500 cases per centre (as discussed in the IRP report) and this standard would at present lead to centres having to close. There was concern that with the current rate of increase in the population of adult patients with congenital heart disease (due to better survival) closure of centres now would lead to problems with national capacity in the future.

- The new standards define a network structure with a network manager and administrative support. The description of the network represents an Operational Delivery Network and it should be funded as such.

- Historical funding for specialised services was discussed and it was felt that historic differences in funding should be recognised as part of any implementation.

Report to the Joint Health Overview and Scrutiny Committee (JHOSC) for Yorkshire and the Humber – 28 November 2014

Feedback from local engagement events organised by Children's Heart Surgery Fund (CHSF)

The most discussed issues so far have concerned **staffing and skills**, **the network approach**, **transition**, **communication with parents**, and **fetal diagnosis**.

These subjects seemed to prompt many personal stories, mostly being around the lack of understanding at regional hospitals. Nearly all patients said once they arrive at Leeds they were dealt with professionally and appropriately. In contrast, they felt very vulnerable at local centres due to lack of cardiac knowledge. Parents also expressed concern about referral times.

Parents said they wanted an instant referral, stating 3-7 days was too long as the bad news is hard enough to bare and not knowing the severity of the unborn baby's condition is deeply distressing from the point of knowing there is a problem.

Transition

This is a real issue for patients. Attendees have stated they felt the leap from children's services at the young age of 16 to the adult service is a leap too far.

To be put on a ward with patients who are non-congenital and a lot older than them, they felt was not only inappropriate, but also depressing.

The Network Approach

Families were quite keen to ask for re-assurance regarding the current support they receive whereby the Leeds staff visit them in the peripheral clinics for follow up appointments.

Families have spoken about how they have valued this service and would hope it would continue as Leeds for some people is just too far.

Staffing and Skills

We also received a considerable amount of questioning about the need for **4** surgeons performing 125 operations.

Some parents felt the most important issue was a surgeon's capabilities and most people seemed to think performing a reasonable amount of surgery with varied case mix was more important than the stipulated 125 number of procedures.

Many of the attendees at the Leeds meeting had done some fact finding and were quite clued up on the fact surgeons in other countries perform fewer operations, yet have very good outcomes.

People also commented on the fact we don't have an abundance of heart surgeons in this country therefore this standard is a hard one to reach considering the lack of available surgeons in this field of medicine.

Fetal Diagnosis.

This is the point where people are genuinely traumatised and had very vivid memories about the way they were treated. In fact many of the attendees talked about the 'post trauma' they felt once there child's condition had been stabilised through an operation or some sort of intervention.

Lots of people talked about the need for training in this area, and how surprised they were that this has not been readily available in some centres.

They also welcomed the use of pulse oximetry which is being trialled at the moment.