Health Overview and Scrutiny Committee **19th December 2012**

Report of the Assistant Director Governance and ICT

Update Report:
Review of Children's Congenital Heart Services in England
Proposed Changes to Adult Cardiology Services across the Region

Summary

1. This report provides Members with an update on the outcomes of the Review of Children's Congenital Heart Services in England, the proposed changes and the work undertaken by the regionally formed Joint Health Overview and Scrutiny Committee (Joint HOSC) around this. It also gives an update on the continuing work of the Joint HOSC, around the implementation phase of the review.

2. Councillor Funnell is the current York representative on this Committee, with Councillor Doughty acting as substitute.

3. The report also informs Members of a forthcoming national consultation on services for adults living with congenital heart disease and asks Members to approve the formation of a further Joint HOSC to consider the proposals and implications for Yorkshire and the Humber patients arising from the review of NHS services.

Background

Review of Children's Congenital Heart Services in England

4. In March 2011, a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) (Joint HOSC) was formed to consider the proposed changes to Children's Congenital Heart Services in England (including the reconfiguration options and future location of surgical centres) and to respond to the formal consultation.

5. The Joint HOSC submitted its formal response to the consultation on 5 October 2011 and subsequently issued a formal report to the Joint Committee of Primary Care Trusts (JCPCT), as the appropriate decision-making body, on 10 October 2011.

6. All reports, including the formal response of the Joint HOSC and the final decision of the JCPCT on the reconfiguration options and future location of surgical centres (taken on 4th July 2012) can be found via the link below:

   http://democracy.leeds.gov.uk/ieListMeetings.aspx?CId=793&Year=2012

7. This link contains all papers considered by the Joint HOSC from its first meeting through to the formal response submitted by the Joint HOSC to the JCPCT. It also contains all papers related to the continuing work of the Joint HOSC up to the present day. The volume of papers is vast and it is, unfortunately, not practicable to reproduce these as part of this report, as they run to several thousand pages.

8. In brief the JCPCT, at its meeting on 4th July 2012, agreed consultation 'Option B' for implementation. They also agreed the designation of congenital heart networks should be led by the following surgical centres.

   - Newcastle Upon Tyne Hospitals NHS Foundation Trust
   - Alder Hey Children's Hospital NHS Foundation Trust
   - Birmingham Children's Hospital NHS Foundation Trust
   - University Hospitals of Bristol NHS Foundation Trust
   - Southampton University Hospitals NHS Foundation Trust
   - Great Ormond Street Hospital for Children NHS Foundation Trust
   - Guy's and St Thomas' NHS Foundation Trust

9. This means that children's cardiac surgical services and interventional cardiology services would no longer be available in Leeds.

10. At its meeting on 24 July 2012, the Joint HOSC considered the JCPCT's decision, the associated decision-making business case, alongside the JCPCT's formal response to the Joint HOSC's previous [October 2011] report. At that meeting, the Joint HOSC agreed to refer the JCPCT's decision to the Secretary of State for Health – on the basis of that decision not being in the interest of the local NHS.

11. In October 2012 the Secretary of State for Health commissioned the Independent Reconfiguration Panel (IRP) to undertake a full review into the decision made by the JCPCT.

This was following referrals from Lincolnshire County Council's Health Scrutiny Committee and Leicester, Leicestershire and Rutland's Joint Health Overview and Scrutiny Committee.

12. It should be noted that since the Secretary of State's announcement to commission a full review by the IRP, the JCPCT has stated that it will work closely with the IRP to assist them to in whatever way possible. The JCPCT has also expressed concerns around delaying the implementation process and that planning for implementation will continue with the professional associations.

13. At its meeting on 16 November 2012, the Joint HOSC considered a draft report to support the referral of the JCPCT's decision to the Secretary of State for Health and made the following resolutions:

(a) That, subject to the amendments identified and discussed at the meeting, the report be agreed in support of the Committee's previous decision to refer the matter to the Secretary of State for Health (minute 59 refers) – on the basis of the decision of the Joint Committee of Primary Care Trusts not being in the best interest of local health services across Yorkshire and the Humber, nor the children and families they serve.

(b) That, following the amendments, the Joint Committee's final report be issued to the Secretary of State for Health, as soon as practicable.

(c) That, in formalising the Joint Committee's referral, the following areas be drawn to the attention of the Secretary of State for Health, recommending these be incorporated into revised terms of reference for the Independent Reconfiguration Panel's review of the Safe and Sustainable review of children's congenital cardiac services in England:

- *The validity of the Kennedy Panel 'Quality Assessments' in light of recent and/or forthcoming Care Quality Commission reports and/or compliance notices issued to current providers previously assessed by the Kennedy Panel.*

- *The extent to which the JCPCT took account of the IRP's previous advice (endorsed by the Secretary of State for Health) that the JCPCT should give due consideration to comments from the Joint Health Overview and Scrutiny Committee (Yorkshire*

  and the Humber) in relation to the PwC report on assumed patient flows and manageable clinical networks.

- *The implications of an unpopular solution imposed by the JCPCT for patient choice within the NHS.*

- *Issues associated with potential obstetric referral patterns, the impact these may have on patient numbers at the proposed designated surgical centres and to what extent such matters were taken into account within the JCPCT's decision-making processes.*

- *The JCPCT's use of population projections/ estimates to determine potential future demand for services, both in terms of using the most up-to-date information and the lack of consideration of regional variations that may impact on the long term sustainability of specific/ individual surgical centres.*

- *The appropriateness, or otherwise, of the JCPCT' and its supporting secretariat refusing legitimate requests from the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) for access to non-confidential information during its scrutiny inquiry.*

14. The Joint HOSC's report, together with the supporting appendices and the initial report (published in October 2011), are available on Leeds City Council's website using the following links:

November 2012 (Report):
http://www.leeds.gov.uk/docs/Children's%20Cardiac%20Report%20(final)%20-%20November%202012.pdf

November 2012 (Appendices):
http://www.leeds.gov.uk/docs/Children's%20Cardiac%20Report%20(appendices)%20-%20November%202012.pdf

October 2011 (Report & Appendices):
http://www.leeds.gov.uk/docs/Children's%20Cardiac%20Report%20(final)%20-%20October%202011.pdf

15. Copies of the above reports are being distributed to various stakeholders and interested parties, including Members of Parliament (MPs) and all Council Leaders across Yorkshire and the Humber.

Summary of main issues identified by the Joint HOSC

16. There are a number of significant issues highlighted in both of the Joint HOSC's reports (October 2011 and November 2012).

Nonetheless, the overall view is that, as a result of the JCPCT's decision and without the retention of the surgical centre at Leeds Children's Hospital, the overall patient experience for children and families across Yorkshire and the Humber will be significantly worse. The conclusions reached by the Joint HOSC are based on a number of reasons, in particular:

- The range of interdependent surgical services, maternity and neonatal services are not co-located at proposed alternative surgical centres available to Yorkshire and the Humber children and their families;

- The dismantling of the already well-established and very strong cardiac network across Yorkshire and the Humber – and the implications for patients with the proposed Cardiology Centre at Leeds essentially working across multiple networks;

- The current seamless transition between cardiac services for children and adults across Yorkshire and the Humber;

- Considerable additional journey times and travel costs – alongside associated increased accommodation, childcare and living expense costs and increased stress and strain on family life at an already stressful and difficult time;

- The implications of patient choice and the subsequent patient flows – resulting in too onerous caseloads (i.e. overloading) in some surgical centres, with other centres unable to achieve the stated minimum number of 400 surgical procedures.

17. The Joint HOSC remains unconvinced by the adequacy of the Public Consultation conducted by the JCPCT – bearing in mind that the public were supplied with potentially misleading and unreliable information from Professor Kennedy's assessment panel, and unreasonably denied access to other information necessary to make an informed response. The Joint HOSC's reports highlight this issue and also raise concerns around a number of other areas – including the Health Impact Assessments and the sensitivity testing undertaken by the JCPCT.

18. The Joint HOSC believes the above aspects warrant specific and more detailed consideration as part of the review of the JCPCT's decision and associated decision-making processes.

19. The Secretary of State for Health has passed the issues raised by the Joint HOSC to the Independent Reconfiguration Panel (IRP) for initial assessment and requested the outcome to be reported by 7 December 2012. On 10 December 2012, it was confirmed that the IRP had advised the Secretary of State for Health that the Joint HOSC's referral warranted a full review and could form part of the review already commenced by the IRP. The Secretary of State for Health accepted this advice and asked the IRP to report back on its findings by 28 March 2013 (which represents a month extension to the original review timetable).

20. However, it should be noted that it is not clear whether or not the IRP's terms of reference will be revised to reflect the points identified by the Joint HOSC.

Other matters for consideration

21. It should also be noted that at a further meeting of the Joint HOSC on 3 December 2012, Members considered a range of further information and agreed to forward these to the Secretary of State for Health for consideration and inclusion within the IRP's current review. The details included:

a) Spending patterns for Nationally Commissioned Services – which may have influenced the JCPCT's decision;

b) Membership and attendance details of the JCPCT and various supporting/ advisory bodies – which the Joint HOSC believes warrant further and more detailed examination, in terms of the governance and general transparency arrangements associated with the review; and,

c) A transport impact assessment produced by a Lead Clinician at Leeds Teaching Hospitals NHS Trust (LTHT).

22. These details are in the process of being referred to the Secretary of State for consideration in line with the Joint HOSC's resolutions.

Implementation Phase of the Review

23. At a meeting of the Joint HOSC on 24th July 2012 it was agreed that the Terms of Reference for the Committee be changed to cover the implementation stage of the review so that the work of the Committee could continue and their views be expressed.

24. At its meeting on 16 November 2012, the Joint HOSC identified some concerns regarding the implementation phase of the review and the implementation plan presented at the meeting.

National Review on Adult Congenital Heart Disease

25. The national NHS Specialised Commissioning Team is proposing to review services for Adults with Congenital Heart Disease (ACHD). This is a separate review to the Safe and Sustainable review of Children's Congenital Cardiac Services. There is a proposed national consultation on ACHD due to start in the Summer/Autumn 2013.

26. As part of its work, it should be noted that the Joint HOSC identified specific concerns regarding the separate consideration of congenital cardiac services for children and adults. These were identified in the Joint HOSC's response to the national consultation submitted to the JCPCT in October 2011 and the relevant extracts are detailed below:

'We are aware that the minimum number of surgical procedures, within designated centres and those undertaken by individual surgeons, are a cornerstone to the proposals put forward. We note the rationale behind the minimum numbers, but remain to be convinced by the clinical evidence used to support the number of procedures presented in the proposals.

We understand that the NHS is reviewing the provision of congenital cardiac services via two separate but related reviews and that the process for the designation of adult congenital services will proceed in 2011. This will include reference to the separate standards that have been developed by a separate expert group which were published in 2009. In preparing this report, it should be noted that we have not sought to consider these service standards.

As previously stated, we have been advised that in Leeds the same surgeons treat children and adults on the same site and there is continuity of care for patients from childhood through into adulthood. We also understand that elsewhere in the country; other surgeons also treat both children and adult congenital cardiac patients.

We received evidence that Adult congenital heart surgery is currently spread across 21 hospitals, many without the expertise and regular experience of operating on congenital heart problems. This is clearly not safe or sustainable.

We understand that when reviewing any service, it is necessary to define the scope of the review.
We also understand that this can be a complex exercise in itself. Nonetheless, we believe that the consideration of children's and adult's congenital cardiac services as two separate reviews is too simplistic an approach and represents an artificial separation of existing clinical practice.

We firmly believe that on a similar basis to the sustainability issues put forward in the children's congenital cardiac services consultation document, and ***by considering adult congenital services separately, the outcome from the children's congenital cardiac services review will almost certainly pre-determine the outcome of the adult's services review.***

Adult congenital heart patients at the Leeds Centre have also made their views clear that they feel disenfranchised by the fact that their service is not being consulted upon jointly with the children's service in this review.

Furthermore, by considering the number of paediatric and adult cardiac surgical procedures in totality, we believe this provides a completely different landscape and, in our view, would significantly affect the number of surgical centres required across the country. We learnt that there were 859 adult congenital heart surgical procedures carried out across the country last year. Enough to justify retaining another two centres if the suggested minimum number of 400 surgical procedures is applied.

As previously stated, we understand that with three surgeons in post, 392 surgical procedures (adults and children combined) were undertaken last year at the current surgical centre in Leeds.

Although we have not been provided with any detailed projections, we are advised that the adult population requiring cardiac surgery in the future is likely to rise significantly in the coming years and, at some point in the future, may actually rise higher than the number of surgical procedures undertaken on children. This is in part due to the advances in this field of medicine and the increase in survival rates for children into adulthood.

As such, simply by continuing to treat patient numbers arising in Yorkshire and the Humber, we would question whether in reality there are indeed any sustainability issues around the surgical centre in Leeds. Similar considerations may also be true for other areas.

We understand that similar concerns around the exclusion of the number of adult procedures have been raised by other professional bodies. We understand that concerns have been raised both in terms of absolute patient numbers and also around pre-determination. Such concerns appear to remain unaddressed.

Recommendation 5:
Adult cardiac services and the overall number of congenital cardiac surgical procedures carried out should be considered within the scope of this review and used to help determine the future configuration of surgical centres. As a minimum there should be a moratorium on any decision to designate children's cardiac surgical centres until the review of the adult congenital cardiac services is completed and the two can be considered together.'

27. These concerns were reinforced in the Joint HOSC's second report (November 2012).

28. Nonetheless, in anticipation of a national consultation in the Summer/Autumn of 2013 on proposals for ACHD services, the Committee may like to give consideration to establishing a further regional Joint HOSC – on the basis that the proposals are likely to represent a substantial variation/development of services across several local authority boundaries. Specific Terms of Reference are yet to be drafted and will need to be agreed by the relevant Joint HOSC (if established), but the overall purpose of such a Joint HOSC would be to specifically consider and respond to any proposals put forward.

29. Any such arrangements to establish a Joint HOSC would need to be in line with the agreed Joint Health Scrutiny Protocol.

Consultation

30. Consultation has taken place throughout the Joint HOSC's review. Details of all those consulted can be found in the papers associated with the review and these can be accessed via the link at Paragraph 6 of this report.

Options

31. Members are asked to note the updates contained within this report; more specifically they are asked to confirm whether they agree to the establishment of a further regional Joint HOSC to consider and respond

to any proposals put forward into the proposed national review of services for Adults with Congenital Heart Disease.

Analysis

32. The Joint Health OSC and subsequently the review into children's congenital cardiac services have been and continues to be administered by Leeds City Council. The Joint HOSC is formed with representatives from across the Yorkshire and Humber Region. Analysis of all the information received as part of the review is contained within the papers they have produced. Members are asked to note the continuing work of the Joint HOSC and direct any comments they might wish to make to the Chair of this Committee so that they can be fed back to the Joint HOSC.

33. In addition to this the Committee are, today, asked to give consideration to whether they agree to the establishment of a further regional Joint HOSC to consider and respond to any proposals put forward into the proposed national review of services for Adults with Congenital Heart Disease.

34. In principle, this would seem to be a sensible way forward. However, Members should note that once the consultation document is available they will need to initially agree whether they think the proposals constitute a substantial variation to service. However, notwithstanding this, and to enable the region to prepare for administering another Joint HOSC, it would be pertinent to consider nominating the Chair, with Vice-Chair acting as substitute, to any Joint HOSC formed.

Dependent on the number of authorities involved in the review there may be further places available, however these will need to be in line with the Regional Joint Health Scrutiny Protocol.

Council Plan

35. This report details the work of the Joint HOSC in relation to a national consultation regarding the provision of Children's Congenital Cardiac Services and the decisions taken thereafter. It is not directly linked to the five priorities the Council has set.

Implications

36. **Financial** - There are no direct financial implications linked to the recommendations in this report.

37. **Human Resources** – There are no known Human Resources implications linked to the recommendations in this report.

38. There are no known other implications associated with the recommendations within this report.

Risk Management

39. There are no risks associated with the recommendations within this report.

Recommendations

40. Members are asked to:

- Note the update in this report
- Agree to nominate the Chair (with Vice-Chair acting as substitute) to any further Joint HOSC established to consider the proposed review into Adults with Congenital Heart Disease.

Reason: To keep the Committee informed of the work of the Joint HOSC.

Contact Details

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Report Approved ✓ **Date** *07.12.12*

Specialist Implications Officer(s) None

Wards Affected: **All** ✓

For further information please contact the author of the report

Background Papers:

All background papers are available via the link at Paragraph 6 to this report.

Annexes

None