Children's Heart Services: Member Briefing

Introduction

1. The purpose of this document is to highlight key issues for members of the Review Panel considering the proposed changes to the configuration of Children's Congenital Heart Services in the UK.

2. Across England 11 centres currently provide surgical services for children with congenital heart problems. Often these children will require a high level of care from birth through to adulthood. Developments in heart surgery, and more recently interventional cardiology procedures, has meant that the outcomes for these children have improved significantly, and since the 1980's 85% of these children have reached adulthood.

3. In South Central there were two hospitals providing paediatric cardiac surgery services up until February 2010 when the Oxford Radcliffe suspended their service. Southampton General Hospital also provides this service and has been supporting Oxford and Thames Valley patients from this date operating on over 110 children in 2010/11.

4. It was announced last October that the Oxford Radcliffe would not be included in any of the options for paediatric cardiac surgery centres in the future. However, the decision to do this is also part of the consultation.

5. As the consultation document runs to nearly 250 pages a summary has been produced to sit alongside this briefing.

Clinical Evidence

6. The generation of the current consultation is rooted in the review of children's heart surgery undertaken by Sir Ian Kennedy in 2001 and the subsequent Paediatric and Congenital Heart Services Review Group (Monro) report in 2003. Both these reviews recommended that standards should be set regarding minimum numbers of surgical procedures to be performed by hospitals undertaking paediatric cardiac surgery.

7. The 'Monro' report noted the lack of evidence to inform the setting of volume thresholds at hospital, procedure or surgeon level. The report suggested a minimum volume of 300 paediatric cardiac procedures per annum based on an unreferenced American study. In the absence of clear evidence, four operating sessions per centre per week and a surgeon volume of 40-50 open-heart procedures per year were suggested as a consensus view. The European Association of Cardio-Thoracic Surgery recommendations (2003) proposed an optimum activity level per centre of over 250 patients operated per year. This included all congenital cardiac surgery in adults as well as children.

8. The 2001 Kennedy Report included the following recommendations relating to surgical volume:

> 193. With regard to paediatric cardiac surgery, the standards should stipulate the minimum number of procedures which must be performed in a hospital over a given period of time in order to have the best opportunity of achieving good outcomes for children. This service must not be undertaken in hospitals which do not meet the minimum number of procedures. **Considerations of ease of access to a hospital should not be taken into account in determining whether PCS should be undertaken at that hospital** (bold authors)**.**
>
> 194. With regard to those surgeons who undertake paediatric cardiac surgery, although not stipulating the number of operating sessions sufficient to maintain competence, it may be that four sessions a week should be the minimum number required. Agreement on this should be reached as a matter of urgency after appropriate consultation.
>
> 195. With regard to the very particular circumstances of open-heart surgery on very young children (including neo-nates and infants), we stipulate that the following standard should apply unless, within six months of the publication of this Report, this standard is varied by the DoH having taken the advice of relevant experts: there must, **in any unit providing open-heart surgery on very young children, be two surgeons trained in paediatric surgery who must each undertake between 40 and 50 open-heart operations a year (**bold authors)**.**
>
> 197. **Surgical services for children with very rare congenital heart conditions or involving procedures undertaken very rarely, should only be performed in a maximum of two units, validated as such on the advice of experts** (bold authors). Such arrangements should be subject to periodic review.
>
> 198. An investigation should be conducted as a matter of urgency to ensure that PCS is not currently being carried out where the low volume of patients or other factors make it unsafe to perform such surgery.

9. A literature review of the available evidence undertaken in support of the 'Safe and Sustainable' review found that

> 'Whilst confirming the association between volume and outcome in paediatric cardiac surgery, the papers reviewed do not provide sufficient evidence to make firm recommendations regarding the cut off point for minimum volume of activity for paediatric cardiac procedures overall or for specific high complexity procedures at either institutional or surgeon level. Neither is it possible to stratify optimal volume by age of the patient'.

10. Despite these findings the Safe and Sustainable review team have set minimum threshold for the number of paediatric congenital heart operations that centres and individual surgeons need to carry out each year. Professional consensus about this threshold appears to have been reached at a meeting in October 2009 It is not known how complex or rare conditions have been taken into account in setting these thresholds. There is reference in the consultation document to the need to address the risk of 'occasional practice' in surgical procedures but this is not defined.

11. Interdependencies with nationally commissioned paediatric services, such as heart transplants, are given prominence by the Safe and Sustainable review team but it is not clear what the basis is for including these services in the business case or the development of the options. Evidence relating to paediatric congenital heart services and adults (including young people) in the literature review are referred to only generally in the consultation document, despite the importance of transition from one service to another highlighted in the quality standards.

12. Professor Sir Ian Kennedy reviewed each of the 11 centres providing paediatric heart surgery in 2010, assessing them against the agreed national quality stardards. The ranking of each centre against these standards can be found on page 6 of the summary document. Southampton General was rated as providing the country's highest quality service outside London, and training, patient information and innovation were described as "exemplary."

13. Concluding the 2010 review process Professor Kennedy commented:

> 'During the current assessment process I and my colleagues on the panel found many examples of commendably high commitment and dedication by talented NHS staff delivering congenital heart services. But we found exemplary practice to be the exception rather than the rule. Mediocrity must not be our benchmark for the future'.

The Options for Consultation

14. The options for consultation were developed by applying the following weightings

    - Quality (39)
    - Sustainability (25)
    - Deliverability (22)
    - Access and travel times (14)

15. Feedback from parents supported this approach with priority given to survival and quality of life. Other areas of concern included:

    - Accommodation for families
    - Childcare
    - Cost of travel
    - Time off work and impact on families

16. The distance to hospital was the least important priority.

17. Subsequent iterations of the 'scoring' process undertaken by the Safe and Sustainable review team give particular emphasis to access and retrieval times over quality. It is not clear what the basis was for making these additional to the weighting process.

18. As a consequence of this process Southampton is included in just one of the four options being proposed (see page 4 of the summary document). Geography (in terms of access and retrieval times) and an allocation of the number of cases by post code to hit activity thresholds appear to have taken precedence in the appraisal process. Option B – the "quality" option with those centres scoring the highest in the 2010 Kennedy panel visits- is the only option to include Southampton General.

19. The following centres are in all the options:

    - Birmingham – is the second largest conurbation after London and one of the largest surgical units.
    - Liverpool – based on 2 centres for the north, one of which must be Liverpool.
    - Evelina and Great Ormond Street – London only needs two centres and these are named as the preferred centres for London. Already achieving the minimum numbers.
    - Bristol – needed owing to geography and achievement of the 3 hour target for PICU retrieval.

20. In essence this results in a case of either Leeds or Newcastle and Southampton or Leicester needing to cease to do surgery.

21. Option A (includes the 5 hospitals above plus Leicester and Newcastle) was found to be the highest scoring potential option as judged by the Safe and Sustainable Review assessment process but not the preferred option.

22. Option B (includes the 5 hospitals above plus Southampton and Newcastle) scored well and could have scored higher pending the outcome of the debate about future patient flows, and because it minimises the adverse risk of configuration to national PICU.

23. Based on a strict application of patients travelling to their nearest centre the Bristol and Southampton centres are mutually exclusive because there are not enough patients in South Central England, South West England and South Wales.

24. The 2010 Kennedy report noted that it was not clear how Southampton can capture/increase demand outside of its current catchment area and there was concern about insufficient demand in the catchment area to meet the threshold set by the Safe and Sustainable review (400 paediatric open heart procedures a year undertaken by 4 surgeons).

25. Southampton and the Oxford Radcliffe have now established a close working relationship, with Southampton operating on paediatric patients that would previously have been treated at the Radcliffe. The Kennedy report subsequently acknowledged this partnership and the fact that it has enabled Southampton to demonstrate that it does have the capacity to take on additional workload.

26. Both hospitals feel strongly that their continued partnership would ensure that children and families in the areas they serve receive high quality treatment, and that it is in the best interests of patients that services are preserved as locally as possible. This view is supported by the South Central Strategic Health Authority.

Local Considerations

27. Southampton General was rated as providing the country's highest quality service outside London. The following areas were identified as exemplary practice

    - Management of paediatric intensive care
    - Supporting parents with information and choice
    - Training and innovation

28. Surgical numbers have increased significantly in the past year owing to the cessation of surgery in Oxford. The Hospital is close to achieving the minimum number of cases required (400) in 2010/11

29. This summer the Trust will have the required 4 surgeons to meet the service standards.

Emerging South Central Congenital Heart Network

30. Since March when surgery was suspended in Oxford, Southampton has undertaken the majority of cases, from the start there have been joint management teams. Oxford catheters cases are now done in Southampton by the Oxford team.

31. The Southampton/Oxford joint working is fully aligned with the proposed model of care.

32. There is full support from the Executive Teams of Southampton and Oxford.

Consultation Process

33. Consultation is focussing on the following areas;

    - the new national standards that have been developed,
    - the suggested new approach in providing children's congenital heart services
    - the proposed options for reconfiguration.
    - New systems for measuring quality

34. Hampshire HOSC has already written to the national Specialist Commissioning team setting out concerns about the complexity of the consultation document and the response form. Additionally the public meetings in our area are already oversubscribed and the HOSC request for a further meeting has thus far been declined.

35. This matter is currently being pursued with the national team.

Key Lines of Inquiry Issues to be considered

36. Taking the above into account members will wish to understand the following:

Evidence Base

37. Whilst the literature review supporting this work found an association between greater volume and outcome it was clear that specific thresholds for procedures undertaken on a unit or individual surgeon basis were not considered appropriate. Additionally it looks at these services across adult and children's services. The thresholds outlined in the consultation document are only based on children's heart surgery. It is not clear how this picture would change if congenital heart services were looked at across the board or if some hospitals (such as those providing an integrated adult/child congenital heart service) have been disadvantaged by this focus.

38. There seems to be professional consensus but no evidence base underpinning the thresholds set for surgical procedures for children's heart services.

39. There is no defined age range for children and the GUCH ('grown ups with congenital heart disease') population in the consultation document but it is assumed that 'GUCH' normally refers to young people between 16 and 18. The figures for GUCH do not seem to be included in the option appraisal process but it not clear why this should be the case. There is reference to GUCH services being subject to a 'formal process to establish which hospitals can meet the agreed GUCH quality standards and meet future demand' but the impact of the current proposals on these

services do not seem to have been assessed- even though they are a key area in the agreed quality standards.

40. Account is taken of some clinical interdependencies but not others (e.g. children with a congenital heart condition often have other conditions). It is not clear how these interdependencies have been weighted or systematically prioritised. In particular the impact of the change on paediatric intensive care unit (PICU) needs to be assessed as 29% of the cases referred to Southampton General PICU are cardiac patients. In some areas it is clear that the proposed reconfiguration will mean that some PICUs will not be sustainable. The impact on other services as a result of this change has not been quantified.

41. In addition to children's congenital heart surgery it is proposed that interventional cardiology is also moved to the surgical centres. There is no information on the consequential impact this may have on other services provided at the hospitals affected or if the number of these interventions that children require are of the same order as suggested for surgery (i.e. 88.4% of children requiring just one visit to the surgical centre).

42. The case for reducing surgical centres is that smaller centres 'come with risks'. These include:

    - An inability to run a safe 24/7 rota.
    - Greater likelihood of the cancellation of planned surgery
    - Difficulty in attracting and retaining the best staff
    - Surgical techniques are not up to date
    - Greater risk of service suspension
    - Greater strain on surgeons.

43. It would be helpful to understand the performance of Southampton General in relation to the above.

Quality of Service

44. Parents and professionals both give priority to quality of service and access or distance to a facility the lowest priority. The option appraisal process seems to turn this on its head and give greatest weight to geography to support access and retrieval times. This would appear to run counter to the principles set out in the documentation.

45. It is not clear how patients from the Isle of Wight or the Channel Islands have been considered as part of this process This is a significant omission.

46. Travel is assessed by road times from the centre of post code areas. No consideration is given to air ambulances, which are frequently called on for when there are difficulties in retrieving trauma patients for example. No

consideration has been given to the fact that Southampton General will shortly have a helipad.

47. The case was strongly made in the assessment of specialist burns services for a single centre for the most severely injured patients. The basis for this argument was the quality of care it would be possible to provide in such a unit. For our population this centre is Swansea or London. Geographical location was considered secondary to quality when making this decision. Whilst the clinical considerations will be different the issues of retrieval and travel are the same whichever direction a patient's journey takes. It is not apparent why this is acceptable for one service but not another.

48. The figures for children's heart services in Scotland and Northern Ireland (273 and 73 cases respectively in 2006/07) are significantly below the figures set for England. Does this mean that these centres are providing a suboptimal service?

49. It is now over a decade since the original Kennedy report yet there is still no published data on outcomes and mortality, although the CCAD system is an acknowledged world lead in beginning to make this information available. Similarly there has been little progress in establishing clinical networks that are able to exercise the leadership necessary to facilitate to changes required. The pre-consultation business case states that:

> 'It is well recognised that clinical networks thrive best when there is mutual professional respect and trust, encouragement of a learning environment: supported by organsiations…….Developing this climate when there are complex changes to take forward that affect NHS staff and patients as well as organisations will require significant leadership and sensitivity.'

50. Members will wish to understand how the current process, which is basically setting unit against unit and community against community, is going to support this process and deliver the original objectives of the Kennedy report from 2001.

Case mix and complexity

51. Although the original Kennedy report states that there should be just 2 centres nationally caring for the most complex or rarest heart conditions there is no reference to this in the consultation document or the pre-consultation business case. The assumption seems to be that all cases are of equal complexity and as such can readily be dealt with by the centres identified without the need for referrals between centres. It would be helpful to have specific confirmation that all centres will be able to deal with all cases equally effectively and where there is evidence to support this.

52. How would the network ensure that activity thresholds do not create a scenario where achieving the numbers takes precedence over the quality of care?

Choice versus postcode

53. The consultation document states that some parents may decide that their child should be treated at a different hospital – even if this means that they are travelling further. This is evidenced by the patients' flows for Southampton General in the last year which includes patients from both the south west and south east catchment areas. The assumptions about thresholds are based only on numbers in postcode areas. It seems counter-intuitive for the document to be suggesting that a service, independently assessed as being of high quality, should close in order to meet an post code threshold that is not actually evidence based. Parents can and will exercise choice and have already indicated that quality of care **not** the distance travelled is their priority.

54. Guidance issued on service reconfiguration in July 2010 highlights the need for commissioners to consider how 'the proposed service reconfiguration affects choice of provider, setting and intervention'. The expectation is that in meeting the 'choice test' commissioners will make a strong case 'for the quality of the proposed service and improvements in the patient experience'. The consultation document makes reference to the importance of choice but does not appear to develop this in terms the way in which the options are developed. This Guidance also makes reference to the need for informal advice from the Co-operation and Competition Panel on the implications of the reconfiguration plans for patient choice.

55. Equally primary care and hospital catchment areas do not conform rigidly to postcodes as set out in the document. It is not clear how this has been taken into account in the current set of options.