

Hampshire County Council Health Overview and Scrutiny Committee Panel – Children’s Heart Surgery Consultation

Oral Evidence Meeting – 26 May 2011

Attendance – HCC Panel

Cllr Pat West (Chairman)
Cllr Liz Fairhurst (Vice Chairman)
Cllr Phryn Dickens
Cllr Pam Mutton
Cllr Dennis Wright (co-opted member)

Cllr Ann Buckley gave apologies.

Also in attendance:

Cllr Ronald Coatsworth, Chairman of Dorset Health Scrutiny Committee
Cllr Bill Batty-Smith, Vice Chairman of Dorset Health Scrutiny Committee
Cllr Margaret Webster, Chairman, Health and Community Wellbeing Scrutiny Panel,
Isle of Wight Council

Introduction:

1. The Chairman of the Panel, Cllr Pat West, welcomed those attending to the meeting and invited the representatives from Southampton University Hospitals Trust (SUHT) to present evidence to the Panel. The representatives were:
 - Dr Iain Macintosh, Paediatric Intensivist and Director of PICU
 - Dr James Gnanapragasam, Clinical Lead, Paediatric Cardiology
 - Mr Mark Hackett, Chief Executive
 - Dr Michael Marsh, Medical Director
 - Mrs Ali Ayres, Director of Communications

SUHT Evidence:

2. Southampton was one of the earliest centres to provide cardiac surgery, starting in the 1970’s. They audited mortality figures from the outset and are able to demonstrate low figures.
3. There are currently 3 surgeons that perform congenital cardiac procedures currently in post and a 4th is due to start 1 July 2011. Southampton have undertaken 340 procedures this past year (10/11). This number compares favourably with the procedure levels reported by other centres in the consultation document, although some do more than this.
4. Southampton provide full congenital cardiology services from foetal diagnosis to children and through to adults.
5. Professor Sir Ian Kennedy undertook an assessment of the centre last year against the agreed quality standards developed by the Safe and Sustainable Steering Group. Southampton scored 513 (84%) out of a possible 610, the second highest scoring centre in the country and the highest scoring centre outside of London.

6. The team flagged that the process for developing the options had not looked at outcome data (e.g. mortality data) although this was available and a handout was provided demonstrating mortality data by centre.
7. It was noted that this data was not adjusted by the complexity of cases. The CCAD database only separates out data on hypoplastic left heart procedures: other complex conditions are collected together under 'miscellaneous' and therefore cannot be singled out for comparison.
8. The SUHT team felt that the review process was moving away from its original focus on quality as the priority, giving primacy to numbers and access to services. Concern was also expressed about the redefinition of quality as assessed by the 2010 Kennedy Review suggesting that all centres were 'above the line' even though there was nearly 20% difference in how highly the centres were individually rated.
9. The SUHT centre is able to offer the full range of maternity, paediatric and GUCH services co-located on a single site. This is not always the case – some centres are stand alone cardiac units. This is particularly pertinent for congenital heart patients as they often have other needs and conditions. The team highlighted the interdependency between services and the importance of co-location. There was a view that this interdependency and co-location of those services has not been given sufficient weight in the options appraisal process.
10. Southampton is also internationally renowned as a research centre. Numerous publications have been based on innovative practice being undertaken in the centre and numerous letters of support have been received by the team from across the international community.
11. Members were referred to page 115 & 116 in the consultation document which rates key factors in each option by a red or a green flag. It was noted that the option including Southampton (B) is green for PICU impact, Quality and Research/Innovation. Each of these factors are flagged as red in each of the other three options.
12. Option B is flagged as red for access but the Southampton team are of the view that the figures in the consultation document are not correct. These are different from those presented in the business case and fail to take account of the access needs of patients on the Isle of Wight. Additionally patients from the Channel Islands are assessed as being an SO postcode.
13. Access under Option C is given as 6.2% but based on the information from the business case this should be 6.8%. This has been highlighted to the review team but their response was that this difference does not make a material difference.
14. Access under Option B is shown as 6.2% but if according to the business case this should in fact be 4.1%. This is much closer to the 3.6% in the other options which are shown as green and the national team had not defined a threshold for scoring an option red or green. This has been raised with the review team, and the response was that the data in the business case was wrong.

15. SUHT also drew attention to the proposed catchment area maps, and argued that the long access times in Option B could be due to the way the borders of the networks have been drawn. It was suggested the boundaries have been drawn to enable certain centres to reach 400 procedures, but result in patients being assumed to travel to a certain centre when in fact an alternative centre would be nearer. The example was given of patients from Sheffield (77) – who have been allocated to the Newcastle catchment. If they were allocated to the Liverpool catchment, option B access times would only be longer for 4.1% of patients. Taking these 77 away from Newcastle would not make that centre unviable. With this adjustment, both Liverpool and Newcastle would have between 400 and 500 procedures each.
16. The issue of patient choice was raised relating to the proposed catchment areas in the consultation document. In particular it was noted that current patient flows had not been taken into account and these showed a very different pattern of referral than that presented in the consultation document.
17. Paediatric cardiac surgeons at the Southampton Centre also perform surgery for 'grown up' congenital heart patients however this surgery has not been included in the number of procedures performed per surgeon considered in the consultation document.

Questions

18. Q: Can you provide data on complex procedures?
19. A: Southampton does the full range of procedures, but there are only small numbers of complex cases and there is no published data from other centres to compare outcomes with. Only one complex procedure is audited nationally – hypoplastic left heart.
20. Q: why is the data not there?
21. A: the CCAD database is evolving.
22. Q: Although some parts of Dorset may be theoretically closer to Bristol, in practice it is easier to travel to Southampton. The comparison chart shows there is only a 2% difference in access times between the options. As access was given the lowest weighting and quality the highest weighting, such a small difference in access times should have made this factor irrelevant.
23. A: SUHT agree. Parents at the consultation event that took place near Gatwick who are counted as part of the London catchment indicated that they prefer to come to Southampton. It is concerning that the process has encouraged quibbling over figures, which distracts from the fundamental issues.
24. Travel distance is important if you need to get somewhere quickly, and acknowledge that if access times hadn't been included in the analysis people would have questioned why it had not been considered. However, the way access has been assessed has become unnecessarily mathematical and distorts the outcomes. The method has also been applied unequally, as if Bristol needs to be in all options due to the 4 hour retrieval limit for patients

from Truro, then Southampton needs to be in all options for the same reason for patients from the Isle of Wight.

25. The analysis is based on a theoretical model of patient flows and doesn't take account of actual patients flows as they take place now, and the model does not allow for patient choice.
26. Q: Do all centres do the range of complex cases?
27. A: The only facts available are the returns to CCAD for hypoplastic left heart. Bristol, Leeds and Leicester have provided no data for this procedure.
28. Southampton have had patients referred from other centres with complex needs e.g. from as far away as Liverpool and Ireland. The Southampton team have pioneered work on teenagers where previous operations haven't been successful.
29. SUHT has provided data on current patient flows for consideration by the HOSC.
30. Q: It appears that quality and procedure numbers are the stated priority in this process, what has the effect of the closure of Oxford been, and why has the Isle of Wight been ignored?
31. A: Southampton's procedure numbers have increased from 231 a year to 340 a year as a result of the closure of Oxford. This makes Southampton larger than the other centres being considered for closure.
32. Southampton have not been able to include the figures of patients treated from the Channel Islands, however the hospitals in the north have been able to include patients treated from across the border in Scotland.
33. Q: Do the figures include the patients of military families, as Southampton has a special arrangement to support military families?
34. A: Yes but these are very small number. Southampton primarily works with the Ministry of Defence in moving seriously ill military families children from outside the country to where their parent's unit is based, this involves transporting them all over the country not just in Hampshire. However, this has meant the Southampton team have developed expertise in retrieving seriously ill children by air. Most patients from the Isle of Wight are retrieved by ambulance on the ferry, but in some cases they are taken by air – in those situations the expertise Southampton have developed in air retrieval comes in handy.
35. Q: Regarding retrieval times, could helicopters be used? Road times distort the picture when helicopters could be used to reach patients in remote areas. Ease of access is also important – e.g. whether you have to go through the city centre to get to the hospital or if it is on the outskirts of the city. What is the evidence for the link being made between procedure numbers and quality.
36. A: It is generally agreed that around 100 procedures a year per surgeon is a good number. However, this process is making a distinction between operating on children and adults – the same surgeons operate on both – therefore their

number of procedures per year will be higher than those given (as this process only considers procedures on children). The distinction made between children's and adults congenital heart surgery is therefore artificial. Also many operations require more than 1 surgeon e.g. for complex procedures. This is not taken into account in the assessment of number of procedures performed. The other omission relates to the training of surgeons: approximately 40% of procedures will have a junior surgeon being mentored by a senior colleague. This is not reflected in the assessment of the number of procedures performed.

37. Q: Are you happy that 4 surgeons doing 340 procedures between them is an appropriate level?
38. A: the evidence on thresholds isn't strong. Southampton supports the idea that change is needed to improve quality, however SUHT is of the view that it would not be good to have centres that were too big – quality may go down and patients would lack the personal experience they receive at a centre the size of Southampton.
39. The 2 centres that scored highest in the Kennedy assessments have relatively low procedure levels, the common factor is that both have good PICU's.
40. The handout shared by the SUHT team at the meeting provided an indication on PICU mortality.
41. Human factors also affect quality, numbers alone won't replicate quality – teamwork takes years to develop.
42. It was noted that 340 procedures is a temporary figure, in future SUHT expects to be doing 0 or over 400!
43. The lowest scoring centre was excluded in all the options. The range in the remaining centres scores is quite broad (between 66% and 88%) , however the review team are now saying all remaining centres are 'above the bar' and therefore equal. This doesn't make sense when they have been scored and some have scored better than others.
44. Q: the mortality data provided only goes up to 2008, why is this?
45. A: there is a lag in publication of the figures as they need to be verified, however figures are now available for 09/10.
46. Q: At the visit, members received the impression that for parents, having someone to contact once out of hospital (mainly the cardiac liaison nurse) was highly valued – Southampton is clearly strong on this and could be using this as an argument in their favour.
47. A: SUHT is of the view that quality is made up of safety, experience and outcomes. The patient experience is vital as is the ethos of a centre providing care. If SUHT grew in future it would seek to maintain its current ethos. The Kennedy scores are probably the best way to compare centres as these assessments took a range of factors into account.

48. Q: SUHT clearly has expertise in undertaking complex procedures, what would happen to this expertise if SUHT ceased providing this type of surgery?
49. A: The surgeons concerned have indicated that they would have to think carefully about their future and that their future may not be in this country. Bristol does not currently publish any data on complex procedures.
50. Q: How would your rating change if SUHT were re-assessed now?
51. A: The team anticipates that it would increase as the work from Oxford and supporting clinical networks have developed significantly. The work from Oxford has been managed within current resources and with no impact on quality.
52. **SUHT Evidence on PICU:** Southampton has the lowest standardised PICU mortality of all the centres being considered in this process.
53. SUHT are concerned that their PICU will be adversely affected if cardiac surgery is taken away. The issue of the volume of a centre's PICU admissions has not been given sufficient weight. SUHT PICU admissions will drop by 39% without cardiac patients and cardiac patients account for 44% of PICU bed days. The SUHT team could not understand how the case is being made for centres to undertake certain volumes of procedures in order to provide quality in cardiac surgery, and yet the impact of reduced volumes on the quality of a centre's PICU is not considered a significant issue. Half of patients that have renal replacement at SUHT are cardiac patients – so without cardiac patients the number of these procedures undertaken will be significantly reduced. The Wessex PIC Forum has formally written to the Safe and Sustainable team setting out its concerns about the implications for PICU services across the South Central and South East Coast areas should children's heart surgery cease at SUHT.
54. At present the PICU at SUHT has 13 beds each of which is staffed by a nurse 24/7. If 1 bed is blocked for some time – only 1/13th of their capacity is out of action. If they reduce to 7 beds due to a reduction in cardiac patients – one bed will take 1/7th of their capacity up which is significantly more. Larger PICUs mean it is easier to deal with the peaks and troughs in demand. Last year no patients were sent out of catchment due to a lack of PICU beds. 6 years ago 10's of patients had to be moved elsewhere (there were only 7 PICU beds in SUHT at that time).
55. SUHT have a designated ambulance that can be staffed with specialists in order to retrieve seriously ill children when required. Sufficient resource is required to do this and not leave the PICU itself under-staffed. SUHT currently benefits from using trainees that help provide an extra resource – it is expected that if they lose the cardiac patients they would lose national training status. This would be a significant concern for the unit. The impact on staffing that results from this possible change, coupled with a reduction in capacity if cardiac patients were relocated could mean that the retrieval team would not be able to continue to operate. This would mean that PICU patients would have to be retrieved by staff travelling from either Bristol or London. This has significant implications for all PICU services across the current network.

56. The options comparison table in the consultation doc (page 115) gives retrieval as green across all options. Bristol is in all options due to being the only centre that can retrieve patients from Truro in under 4 hours, however the omission of the Isle of Wight is material and needs to be addressed. With reduced ferry times at night, it can take 5 hours to get to London from the Isle of Wight. At present helicopter retrieval is only used rarely – only once in 6 years. Helicopter retrieval is not ideal as this limits the team of people able to attend and the equipment that can be transported. If Southampton's PICU capacity reduced – other critically ill patients (not just cardiac patients) may need to be retrieved from the Isle of Wight to other surgical centres.
57. If the option to retrieve by helicopter had been taken into account – centres would have been included in options purely based on quality, and Southampton may have featured more often. If road travel times are being used – road and ferry times from the Isle of Wight should be taken into account which would mean Southampton would be required in all options to meet the retrieval criteria.
58. The Isle of Wight issue was communicated to the Paediatric Intensive Care President on 23 March. It was acknowledged this was an issue, however to date this has not been publicly acknowledged by the review team.
59. The options appraisal arguably fails on three counts 1) creating a Southampton versus Bristol dichotomy based on theoretical catchment procedure numbers that can be challenged, 2) giving priority to Bristol based on flawed retrieval times information, 3) not admitting that the model needs revising now that it has come to light that the Isle of Wight retrieval time was disregarded.
60. The SUHT team has written to the PIC president about the omission of the retrieval times from the Isle of Wight.

Questions:

61. Q: The potential impact on PICU beds is a concern, has this been raised with the review team?
62. A: The response given was that the impact on PICU would be addressed in the implementation phase. However, SUHT argue that the number of PICU patients affected (that may need to go elsewhere as a result of reduced capacity) is probably more than the number of cardiac patients calculated as having increased access times under the proposals. This has not been factored in to the option appraisal process.
63. Q: How many staff working with Southampton are from the Oxford centre that ceased surgery?
64. A: This information could be provided – noted would be cardiologists not surgeons.
65. Q: As SUHT is currently a research centre, would this research capacity be moving under these proposals?

66. A: This has not been considered, and would potentially be a big impact. Southampton has been very successful in attracting international calibre staff and is able to recruit patients for research. Both would be at risk if cardiac surgery removed. The implications for training in particular is an issue that needs to be carefully considered This could be a significant impact as SUHT is a teaching hospital linked to a University.
67. It was noted that the ambulance used for retrieval is provided by a charity, so SUHT are not reliant on SCAS releasing one of their ambulances for this purpose.
68. Q: Was the accommodation provision at Heart Beat House taken into account in the assessment of centres?
69. A: This was considered by the Kennedy panel. However the impact on Heart Beat House of de-designation has not been taken into account.
70. **Closing statement:** There is enough work across the South of England and London to sustain 4 centres, it just depends on how the lines are drawn e.g. parts of the South East are currently considered to flow into London that could come to Southampton instead e.g. 160 patients from Surrey and 86 in West Sussex. Southampton would only need another 60 to reach the 400 threshold. The way the information is presented in the document makes it appear that only Southampton or Bristol are required for the South, this is not a true reflection. Activity could be distributed differently to support the 4 best centres across the South and the Chief Executive was exploring how this could most effectively be achieved.
71. SUHT has the fifth largest PICU in the country at present, this would be reduced if cardiac surgery were removed and the existing retrieval network put at risk. Option B is really the only choice and the best choice. The consultation document is misleading, Southampton ought to be in all the options due to the retrieval issues for the Isle of Wight. There could be an 'option 5' that makes more sensible catchments in the South. The north of the country is a separate issue and those in the north are entitled to consider what is best for them, and this could be addressed separately.
72. SUHT support fewer larger centres, but does not support mediocrity. The true test of the best option should be the one that provides for the highest quality service.
73. Southampton has attracted surgeons from all over the world. The reds against Option B are not really red when you look more closely.
74. The Panel may wish to consider contacting Professor Ted Baker and Ian Jenkins of the PIC Society regarding co-location and how this has been assessed in the proposals.

Patients Views

Sam Prior – Families of Ocean Ward

75. Sam explained that her son has hypoplastic left heart syndrome, which was diagnosed at the Princess Anne hospital (on the same site as Southampton

General) at a routine scan. She was invited to see the lead cardiologist a couple of days later. She was shown around the ward before he was born and found this reassuring. Her son's first surgery as at 4 days old, it was an 8 hour procedure and resulted in 3 or 4 days stay in PICU, and about a month in hospital. There are other complications with a baby with congenital heart problems e.g. it was hard to breastfeed. He had a 2nd operation at 2 months old – this was an unplanned stage. The 3rd operation was at 5 months. Over the past 10 years she has been very satisfied with the quality of the services offered at Southampton. Although her son has needed 2 other non cardiac procedures the specialists involved were comfortable to do these procedures due to the fact that there was cardiac surgery back up at Southampton in-case of emergency.

76. Not all units can treat hypoplastic left heart – Southampton has published its performance in performing this procedure and is able to demonstrate the quality of the care it provides. The failure of the consultation document to acknowledged where complex procedures are performed is a significant gap.
77. Sam has been involved in meetings related to this review for the past 18 months. She doesn't agree with the information provided in the consultation document and believes it gives an unfair presentation of Southampton. She is concerned that this mis-informs people who don't know the true local situation.
78. Sam related an example where a clinician had reported receiving pressure to refer patients to another centre and expressed concern that the process is encouraging rivalry between the centres.
79. Her son has a view on the consultation, however patients views are not being taken into account very well. They are clear that quality not distance travelled is the over-riding priority.
80. The patient flows assumed by the consultation document were misleading and did not represent actual flows. This is a flaw.

Suzie Hutchinson – **Little Hearts Matter**

81. Little Hearts Matter is a national organisation, therefore they are unbiased towards any particular centre. They don't want the process to stop – it has taken over a decade to reach this point after the Bristol Inquiry. There is an issue with the travel times used and other inaccuracies in the document, but this should not halt the process. Nobody wants a 'mediocre' service to be the result of the consultation. Informally it was reported that LHM would quality of service as the basis for making a decision and would therefore be likely to support Option B.
82. Individuals will normally support the centre they are used to going to, but looking nationally, the only way to ensure a good standard of care for all is to go for centres that are the highest quality – which means option B. There is more to quality than mortality- morbidity and quality of life are also important. There should be nationally recognised standards on quality. Children should be sent to centres where they can be treated safely.

Michael Cumper – **Grown Up Congenital Heart Patients Association**

83. Michael informed the Panel that he took part in the Monroe review and has had congenital heart disease for 48 years. He stressed that GUCH patients are different to adults that develop heart disease. They have grown up with the condition and will often have other pre-existing conditions. This can mean the physical look of ‘the plumbing’ and other patient needs is different to a condition resulting from illness or lifestyle developed later in life.
84. The likelihood of survival past the age of 16 for congenital heart patients has hugely improved since the 70’s. Now the number of GUCH patients is larger than the number of children with congenital heart problems. GUCH are the worst catered for of cardiac patients. Agree with LHM that we need to continue this process – to not do something (e.g. allow the status quo to continue) can be negative – occasional practice must be stopped. Oxford was not an example of occasional practice, but it was a centre which has been stopped from undertaking surgery which was considered not up to standard, like those who do occasional practice.
85. This consultation is based on paediatric procedures. However, there is no such thing as a paediatric congenital heart surgeon – the same surgeons operate on children and GUCH patients. This process will determine which centres offer GUCH in future, but GUCH patients have not been taken into account in the process. The excuse is that GUCH will be looked at afterwards, but by then it will be too late – by default only those centres designated for paediatric heart surgery will be able to operate on GUCH patients.
86. There is a concern that cardiologists are unlikely to want to work somewhere where there is no surgery.
87. It is important to stop Paediatric Cardiac surgery happening where it shouldn’t – a point also raised by a previous speaker. The most important issue is to decide on the basis of quality.

Questions:

88. Q: could the centres that remain cope with GUCH patients?
89. A: at present all centres have more than they can cope with. GUCH also has sub specialities and complexity – this process could end up closing centres that offer a GUCH speciality – this needs to be taken into account, to ensure this expertise will be available in any new configuration. This process needs to conclude, however it is essential that the right option is agreed. Quality is the most important priority so it is surprising that 2nd best in the country is only in 1 option.
90. Q: How can we get to the best solution?
91. A: LHM have drawn up additional standards to submit to the consultation. Standards are a good place to start to achieve a gold standard service. The concern is how these measures are applied. Other countries have undertaken a similar process and make big cuts. This process has set unit against unit, which isn’t helpful when ideally centres need to work together.

92. The GUCH Patients Association have had 2 meetings with Patricia Hamilton, but the request to consider GUCH issues has fallen on deaf ears. There is a concern that the review has not looked sufficiently at what happens next in each scenario and the impact on GUCH needs have not been taken into account. The GUCH Patients Association feel it is important to give feedback about their preferred option of those offered, this must include consideration of the impact on GUCH of each option.
93. Sam noted that she is concerned that GUCH is not being considered, as her son will become a GUCH one day and she would like to know suitable arrangements will be in place for that stage of his life.
94. Despite these concerns GUCH PA do not want to delay the process any further and put people at risk of having surgery at poor centres. It should have been just a 'congenital heart' review not a 'paediatric congenital heart' review. The patients pathway should be considered from conception to death, not split into stages.
95. Sam was concerned that a member of the steering group ruled out additional options being considered in a TV interview, and that it was said that all four options were equal, when she doesn't consider they are. The suggestion that all units could provide equal level of service in future ignores existing differences and that it would be easier for a centre that is good already to develop. She is of the view that the results of the Kennedy assessments are not being used properly in this process, and that the risks to PICU have not been given sufficient weight. There is a suggestion that options C&D are not viable, therefore it is a choice of A or B. Some centres in option A will struggle with PICU provision according to Kennedy. Numbers of procedures are easy to fix – improving quality of PICU etc is not easy to fix. Catchment areas could be nationally re-configured to share out the numbers among 4 centres in the south.
96. Historically, London pulls in patients from a large area e.g. London cardiologists do outreach work in Portsmouth. However, this historical situation can be changed and unnecessary travel could be avoided with some patients coming to Southampton that currently go to London.
97. Q: The document lists the panel members and out of 43 it appears there was only 1 independent patient advocate, would more presence from patient representatives have been preferable?
98. A: There were in fact 2. GUCH PA have not been involved because they have been told that the review is not considering GUCH. Ann Kimberly Clark represents the Children's Heart Federation – this is an umbrella organisation that is supposed to represent all the other heart organisations. There is concern that she has to represent a range of organisations views, therefore some views may not be represented how those organisations would like. However it was noted that other organisations had fed in directly to the review through other less formal routes.
99. It was suggested that the implementation stage would benefit from greater patient representation.

100. **Follow up:** Sam reported that in the pre consultation business case it indicated the 400 procedures threshold could include GUCH patients, but in the consultation document this was changed to be children only.
101. There were no questions about GUCH in the 2010 Kennedy assessments. If surgeons are doing 125 children's procedures in addition to GUCH patients this could adversely impact on quality.
102. Q: what difference would the GUCH figures make?
103. A: The data is not published. Attempts to get the numbers over the past 2 months have not been successful. This information is relevant to the 400 procedures threshold which originated from the idea that undertaking around 100 procedures a year per surgeon is good to keep up to date. A surgeon may be doing 100, but if only 60 are children this will not be considered good enough.
104. Q: Are there concerns regarding retrieval from the Isle of Wight
105. A: Foetal diagnosis needs to be good – then the parents have choice and can plan the surgery required. It's easier to move a pregnant mother than a baby. Ignoring the Isle of Wight is appalling. Helicopter's cannot be used in bad weather. Getting the team to a child is the most important aspect – to stabilise the patient. Southampton have a very good retrieval team, which makes a big difference.
106. It was noted that travel times from Wales were considered even though the review is of English services.
107. Q: have you ever been unable to contact the unit or had planned care cancelled? And do GUCH have a 'liaison nurse' type contact?
108. A: The liaison nurses at Southampton have been there for years, and cover long hours. There is open access to ring the ward 24/7. Sam said the relationship with liaison nurse is very good e.g. she went to her son's school to explain the needs of a cardiac child to the teachers.
109. Sam reported that the NCAT report noted that a unit is only as good as the team in it – this is true of Southampton which has a good team. None of her son's surgery was cancelled. A routine catheter procedure was cancelled once. Other units have long waiting lists. There is a concern that this would be worse if big hospitals took on even greater numbers.
110. Southampton does have GUCH liaison nurses and these are very important. There are 2 at Southampton. They were under threat 5 years ago, but GUCH PA put up a fight to save them which was successful.
111. Q: this situation obviously has an impact on the whole family, would the strain be increased if you had to travel further?
112. A: yes. It is expensive to stay at hospital. Parents can apply to the Family Fund for financial assistance, but local support is also important e.g. heart beat

house. A family moved from Reading to Southampton so their child could be treated at Southampton. They were initially treated in London but found this traumatic e.g. having to take the child on the tube to get home 6 days after surgery. A 6 day stay in London cost £700. They are concerned now that Southampton is under threat.

113. Some families who have experience of both Southampton and London prefer Southampton because of the quality of the team and the way this shapes the experience of patients and their families. The option appraisal process hasn't given much profile to the patient experience – being a name not a number and having continuity of staff contact is important. There are examples where cases have been turned away from other centres e.g. high risk procedures, but Southampton will often take them on. The team does not turn people away.
114. Q: in what circumstances might people be turned away?
115. A: some units can't do certain procedures, in which case they will refer the patient on. However, referral patterns often reflect historic practice rather than quality of outcomes – often based on who knows who rather than anything else.
116. It was suggested that some centres have recently been performing complex procedures that they would not normally undertake – due to concern that it may be held against them in this process – but that this was not being reported for audit purposes on CCAD .
117. Q: Is it correct that most patients only require surgery once?
118. A: yes, approximately 80%, though they may also require interventional cardiology. Complex cases may comprise 10-15% of patients but 50% of the workload of centres due to longer hospital stays etc. This has not been taken into account.
119. Q: could there be a '5th option' and if so how can we get there?
120. A: to pick up by email.

Specialised Commissioning Group

Simon Jupp – South Central Specialised Commissioning Group Director

Teresa Warr – South Central Specialised Commissioning Group Head of Service Development

121. The South Central Specialised Commissioning Group commission services for rare conditions on behalf of PCT's. There are 10 such commissioning groups across the country. There is also a national specialised commissioning group who commission services for the rarest conditions. The Safe and Sustainable Review team is part of the national specialised commissioning group – they are the secretariat for this review.
122. The Joint Committee of Primary Care Trusts will make the final decision on the configuration options. The JCPCT is made up of the 10 Chairs of each SCG

across the country. The SCG chair's are PCT Chief Executive's, and many are becoming the Chief Executive for their local cluster of PCTs. The Hampshire PCT Chief Exec Debbie Fleming is the SCSCG Chair and therefore sits on the JCPCT.

Questions

123. Q: How can HOSCs link with the JCPCT?
124. A: Can make representations to them. They have not attended any scrutiny meetings to date. Believe they have not been formally asked.
125. The JCPCT met once in public – 16 Feb 2011 – when the options for consultation were agreed. This was their last meeting. Their next meeting is scheduled for late July, however this meeting is not due to be in public. The date of the next meeting would be provided together with confirmation the meetings to be held in public.
126. Q: What is the accountability of the JCPCT to PCT's, the public and HOSC's?
127. A: not aware the request for attendance at this meeting went to the JCPCT
128. Q: how is the JCPCT clinically advised?
129. A: The steering group developed the standards. Page 139 of the consultation doc indicates how clinical advice is provided to the JCPCT is through the steering group.
130. Q: are there clinical and patient representatives on the JCPCT?
131. A: There are various representatives on the steering group. Page 151 lists the JCPCT members – it is chaired by the East of England SCG as there is no current surgical centre in that area. Patricia Hamilton and Leslie Hamilton are the Chair and Vice Chair of the Steering Group and they sit on the JCPCT to provide the link between the two.
132. Q: The panel at the public consultation event were not the decision makers and couldn't answer the questions being asked.
133. A: The JCPCT are accountable to PCTs – they have delegated authority, they don't need to go back to PCT Boards to ratify their decision. There could be a view that a decision of this magnitude should have local input through PCT Boards, but at present this does not need to happen.
134. HOSCs are being encouraged to respond to the public consultation by 1st July, however the impact assessments will also be shared with HOSCs as well as the Ipsos Mori assessment of consultation response (expected in August). HOSCs can then add any additional comments up to 5th October. These will be taken into account when the decision is taken (expected in November) by the JCPCT. The decision will be shared with HOSCs.
135. Q: will there be opportunity to challenge the decision?

136. A: would expect stakeholders to be able to provide feedback.
137. Q: How are the issues raised regarding the postcode allocation and the Isle of Wight being addressed?
138. A: SCSCG commission by PCT not by postcode, the catchment maps don't acknowledge hospitals and how they refer. There is a meeting today where this is being discussed – Price Waterhouse Coopers have been commissioned to test the current and assumed patient flows. SCSCG is working with SUHT regarding patient flows and the implications of the options.
139. It was acknowledged by Safe and Sustainable at the public consultation event that leaving out the Isle of Wight was a mistake. Including the Isle of Wight is likely to make a material difference – this has been investigated over the past 8 weeks. A paper on this has been prepared. A press statement is likely in the next few days on this. The Chair of the JCPCT wanted to speak to the SUHT Chief Executive first.
140. The Channel Island patient numbers were put in with the SO postcodes.
141. The numbers of children requiring paediatric heart surgery from the Isle of Wight Channel Islands are as follows:
142. Isle of Wight – 13 patients in 09/10, 9 in 10/11. Guernsey over past 3 years 9,5,5, Jersey over past 3 years 4,4,7 (numbers refer to CCAD verified procedures).
143. Q: Will the JCPCT be making the decision based on the options set out in the consultation document?
144. A: This is the consultation document – there will be a fresh document produced after this process that includes information that has come up during the consultation.
145. Q: distance is least important and yet 2 ½ % difference is given as a negative for option B but quality is rated as green in only one of the four options presented- option B. Both parents and professionals agree this is the most important priority – so seems obvious that option B should be the preferred option, especially as there is a lack of scientific evidence to support procedure number thresholds, and that catchments should be drawn rationally not by postcode.
146. A: 4 surgeons is important to provide cover, but agree the procedure threshold is not defined. The level of complexity a centre is able to cope with is important. Nationally there are a number of processes feeding in to the decision including work testing the viability of the postcode allocation, HR issues, capability of centres to develop etc.
147. It must be remembered that the process is also consulting on the proposed model of care – this is key – it is important to respond about this as well not just the centres issue. Keeping centres that are de- designated as cardiology centres has been demonstrated by the Oxford and Southampton network.

148. Q: could there be a '5th option'?
149. A: Some people will want to feed in their own views not just the options presented. However, the process should not be drawn out too much – people want it concluded. Perhaps the discussion should not be around a new option but what adjustments are required to option B. The postcode mapping is being tested with clinicians – so this will be considered if 4 centres could be sustained in the south.
150. Q: How will people not from this area understand the issues that are not covered in the consultation document and be able to make an informed choice?
151. A: the world has moved on since the consultation document was developed. The intention is that the information provided during the consultation period will be taken into account in the document developed for the decision meeting.
152. Q: what are the costs of this process?
153. A: quoted press statement saying costs will be published once the process has concluded.
154. Q: why have children's and adults congenital heart disease cases been separated?
155. A: It was children's surgery that has been under review – the pressure to improve is on this area – to include GUCH as well would make the process very big and cumbersome.
156. Q: there is a risk centres will focus on reaching procedure number targets rather than quality?
157. A: when the changes are implemented – will review over time the impact of the changes and the reality of procedure levels and outcomes. Stand by the proposed standards and network model – this is good – Oxford and Southampton working together demonstrates this.
158. Q: is there pressure on people to refer to particular centres?
159. A: a map of existing referral patterns would be useful, and to see how much change would be required under each option.
160. Q: what if patient choice means centres still fall below the threshold?
161. A: it will be important to review the situation during the implementation phase.
162. Q: have GP views been included as per the '4 tests'?
163. A: Safe and Sustainable are satisfied the 4 tests have been met, though GP input has yet to be published.
164. Q: how would you define co-location?

165. A: it is defined by Professor Ted Baker in the framework for critical inter-dependencies report for specialised paediatric services. He thinks that the framework has been included in the standards but considered that these had largely been ignored in developing the options. There are 4 core services required for a paediatric centre – this is picked up in the standards – these should be physically co-located. The Sir Ian Kennedy report identified one service did not meet these criteria. This was raised at the 16 Feb meeting – it was suggested this be looked at during the consultation process. Prof Baker was at the Oxford public consultation event and gave the view that the critical interdependencies had been ignored in developing the options – he had not been asked to assist in applying the framework to the options.
166. Q: do neonates require special treatment and can all centres provide for complex procedures?
167. A: need to raise these issues in consultation response. Each unit submits data to CCAD – the latest is due in June. This will be analysed including by age band and procedure type to input to this process.
168. Q: How can we find out if children have been turned away from centres?
169. A: it should be in the referral data – this data is being looked at in the postcode analysis.
170. Q: why haven't GUCH numbers been provided?
171. A: GUCH numbers are given on page 117. Hospitals do count the number of patients they treat as that is how they get paid. This information is available.
172. Quality was given the highest weighting, but access issues were used to cut down the number of options before quality considerations were applied.
173. Q: How has the expense for families to travel further been evaluated
174. A: the impact assessment should look at impacts like this and suggest mitigation. This report is due before 1st July in initial form with a full version in August (which will be provided to HOSCs).
175. Q: what will happen to centres where services are withdrawn?
176. A: agree this isn't covered much in the document. Oxford is an example of where this has happened. Impact on PICU is a big factor. There are 5 Children's hospitals nationally – they are in all the options – they integrate with maternity hospitals that are separate. In other places like Southampton maternity and adult services are on the same site. Yet other centres are stand alone and not part of a broader paediatric unit. The impact of a reduction in surgery will be different on each type. In some cases the PICU provision is just for cardiac patients. In Southampton the PICU provision is used for other paediatric cases.
177. Q: why was GUCH excluded?

178. A: agree continuity is important. Again there are different layouts – in some set ups children’s and adults surgery is undertaken at different but linked hospitals e.g. Liverpool and Manchester.
179. There is consensus that something needs to be done, we need to seize the opportunity to do something.
180. Q: is the funding available to support services to develop?
181. A: it has been stated that financial aspects are not being taken into account. Page 124 deals with cost issues. This area is only 0.2% of total NHS annual spend. Some costs are expected to be paid for from efficiency savings or economies of scale.
182. Q: what about the cost of losing expertise overseas?
183. A: agree this is a concern, will be a range of staff not just surgeons.
184. Q: will it become mandatory to refer patients to certain centres?
185. A: patients have a choice. However, District General Hospitals will be the key link in the new network model, they will be linked to a surgical centre and would logically refer there.
186. Q: there are a number of large housing developments in the south, has this been taken into account in future patient number projections?
187. A: historically it appears that numbers within the population are fairly static over time. Approx 4 per 1000 born with congenital heart disease. There may be a case for looking at the developments in the south and the impact they could have on these services.
188. **Close:** The Chairman thanked all witnesses for attending and closed the meeting.