Our Ref: 1003 45891/2

Your Ref: DPM/055567/6216365

7 September 2012

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**Dear Sirs** 

# R (CHILDREN'S HEART SURGERY FUND) V JOINT COMMITTEE OF PRIMARY CARE TRUSTS

To: The Defendant, Joint Committee of Primary Care Trusts ("JCPCT")

#### 1 The Claimant

Children's Heart Surgery Fund, a registered charity at the Old Nurses Home, Leeds LS1 3EX (Charity Number: 1148359 and Company Number: 08152970). It is a charity which has for the last 22 years raised funds to provide facilities, equipment and training in support of paediatric cardiac surgery in Leeds.

#### 2 Reference details

Our reference details are: 1003 45891/2.

# 3 The details of the matter being challenged

The Claimant challenges the decision of the Defendant dated 4<sup>th</sup> July 2012 whereby the Defendant decided that of 12 options considered in the consultation process, Option B would provide the best quality care. The consequence is that congenital heart networks will be formally structured around Specialist Surgical Centres in Bristol, Birmingham, Liverpool, Newcastle, Southampton and London. The effect of the decision is that the Children's Heart Surgery at Leeds, which is currently the hub of an exemplary network of paediatric cardiac treatment, and which serves a population of in excess of 5 million patients will cease. The Claimant is concerned about the impact this will have on its beneficiaries, namely the children and families of those with congenital heart conditions in the region supported by the Leeds Unit.

### The issue Part 1:

# The Mishandling of the Kennedy Scores

- The Defendant's decision was reached after a consultation process which was conspicuously unfair in two respects. First, by refusing to disclose the scores underlying the Kennedy Panel assessment of quality ("the Kennedy scores") it denied the Claimant, and others, the opportunity to make informed and intelligent consultation responses on the key issue of quality and how the Defendant ought to evaluate quality in the light of such scores. It is the Claimant's case that the fairness of the consultation process, which was supposed to be open and transparent, was plainly vitiated by the refusal to disclose. Such refusal was, on examination of the minutes, demonstrably for no good reason.
- The consequences of this decision were exacerbated by an apparent "self-denying ordinance" (see the minutes referred to below) whereby the JCPCT decided not to look at the Kennedy scores themselves either. This deprived them of the ability to remedy the consequences of the decision by looking at the Kennedy scores themselves. Since the Defendant came to rely on the total of the weighted Kennedy scores (the "Kennedy totals") the decision hinged on the weighted Kennedy scores providing a secure basis for comparing the quality of care delivered at the centres.
- The reason why this mattered was that the weighted Kennedy scores were not fit for the purpose for which they were being put. We will examine this in more detail in Part II but it springs from the fact that the Kennedy scores:
  - (a) had not been prepared for the purposes of comparing one centre with another, and
  - (b) did not consider the question of 'deliverability and achievability';
  - (c) had been subject to a weighting system which disproportionately emphasised certain aspects of the assessment in a way that produced misleading results when used in a comparative process.

The Kennedy weighted totals were put forward to consultees and used by the Panel as a comparative judgement of quality on which it could rely in choosing between centres. It was not.

7 Had the Claimant and the Joint Health Oversight and Scrutiny Committee of the Yorkshire and Humber local authorities ("JHOSC") been able to comment meaningfully on the underlying scores, then it is likely to have made a significant difference to the outcome of the consultation and in particular the decision to choose Option B over Option G (the option which included Leeds but not Newcastle).

### The background to the Claim

The decision in question followed a public consultation described in the Decision Making Business Case ("DMBC") at page 20 as 'the most exhaustive ever undertaken by the NHS in England'. The public consultation ran for four months from 1<sup>st</sup> March to 1<sup>st</sup> July 2011. It was repeatedly emphasised during the consultation (and in the DMBC) that 'it was important that respondents were reassured that the JCPCT had an open mind, that consultation was genuine and that there were no pre-determined outcomes' Indeed in the introduction to the consultation document Professor Sir Bruce Keogh, NHS Medical Director, is quoted as saying:

'I want you to consider whether you think the proposed changes outlined in this document will deliver better care. Are there better solutions? We need an objective debate'.

On 16 February 2011, the JCPCT met in public to discuss and finally to agree the preferred options to be put out to consultation, the Consultation Document, and the form the consultation was to take. Sir Neil McKay, the Chair of the JCPCT, concluded the formal session by saying in words that were quoted by the judge in the Royal Brompton Hospital action:

"let me say categorically, the consultation exercise is what it says on the tin. We are open minded about the outcome, we are prepared to listen to alternative views, as we said on three occasions during the course of the afternoon, and we will move forward with further discussions in the autumn..." [2011] EWHC 2986 (Admin) para 73

The Claimant duly responded to the consultation. At section 2 of its response it set out in clear terms its very real concerns about the lack of transparency in the assessment of quality which had become an issue of key importance in the review:

'Assessment of Safety and Quality

The recommendations put out for public consultation by the Review team, the Joint Committee of Primary Care Trust (JCPCT) on the future configuration of children's heart surgery services were informed by an assessment of each of the existing centres against standards set by Professor Sir lan Kennedy and carried out by the Independent Expert

Panel (IEP). We remain concerned that the assessment failed to assess and score centres on factors which one would normally associate with 'quality' such as clinical outcomes and patient safety, in addition to the specifics highlighted below...

**Transparency**. The IEP has not released details of its methodology or breakdowns of each centre's scores. When these details were requested by the Joint Health and Overview Scrutiny Committee (Joint HOSC) for Yorkshire and the Humber, the Review team refused on the grounds that they had neither received nor considered such detail. We believe that the refusal to release information on each centre's scoring prevents a true understanding of individual strengths or weaknesses....

...Consistency. Although we cannot know for sure – because the breakdown of assessment scores has never been published – it appears that co-location and population density have been factors in rewarding higher scores to other hospitals but not to Leeds....

...It is notable that the assessment stage of the Review has also received criticism from elsewhere. The judicial review verdict against the JCPCT, for instance, centred on the assessment of Royal Brompton's 'research and innovation' score, whereby the Hospital was automatically scored 'low' for 'research and innovation' because it failed to submit information on the output and quality of its research, even though the reason for this was that such information was never requested'

As noted above, the Claimant was not the only body to request such information. In their consultation response of August 2011 the JHOSC said at §149:

'While the overall assessment scores are publicly available in the consultation document (p.82) and observations (by way of the Independent Expert Panel Report (December 2010)), the detailed breakdown of those assessment scores have not been made publicly available.... ....150. We feel very strongly that information such as this should have been made available for public scrutiny prior to any decision on the future configuration of designated surgical centres and believe it is in the public interest to do so'.

Despite such requests, this information was not disclosed until after the 4<sup>th</sup> July decision had been taken. The only reason that seems to have been given was that the JCPCT themselves had not seen such information and therefore did not consider it needed to be disclosed until after the consultation process. The reasons for the self-denying ordinance seem to be reflected in the minutes of the meeting of JCPCT on 28<sup>th</sup> September 2010, which Sir lan Kennedy attended:

'Ms Claire stated that she did not wish to see the detail; she believed that the experts' interpretation was authoritative. Sir lan Kennedy highlighted the risk of judicial review; the process was undermined if data was provided when experts had been appointed to make a judgment. Ms Llewellyn shared Sir lan Kennedy's concerns. Asked if the detail was disclosable under the Freedom of Information Act, Mr Glyde said he believed it would be, once the process was concluded.'

<sup>&</sup>lt;sup>1</sup> We note that subsequent to that submission, and between the first instance decision and the Court of Appeal, the Royal Brompton's 'research and innovation' score was revisited by the Kennedy Panel and increased to '3' This may be taken as evidence that the Panel would have been receptive to informed criticism.

If this was the reason for non-disclosure, we think it a thoroughly bad one. It was also directly contrary to the transparent process which was supposed to have been undertaken, the expectation of consultees, and it now appears, some members of the JCPCT itself: thus the minutes of 1 September 2010 under the heading 'Options for consultation' record:

'Ms Evans believed that quality was the most important area for consideration in terms of process, given its heavy weighting. She assumed that, during the public consultation, there would be an expectation that the material from the assessment visits would be available for review in order to complete the scoring exercise.'

- This self-denying ordinance also precluded the JCPCT itself from understanding certain features of the Kennedy scores that turned out to be of decisive importance. In any event, even if the JCPCT believed that the experts knew best and did not wish to understand the bases of the assessment because to do so would increase the risk that their own decision would be vulnerable to review by the court, the decision to put consultees into the same position disabled them from making properly informed and intelligent responses to the consultation which would have made a material difference to the outcome.
- July 2012 that, on receipt of the consultation responses, the JCPCT developed further options for consideration, including Option G (an option which had been proposed by Leeds itself), and carried out a number of sensitivity tests purportedly designed to 'test' the evidence for Option B against other options including Option G. However the fairness of that process was undermined by the absence of an intelligent and informed response to the Kennedy Scores by consultees such as the Claimant because these comments turned out to have a formative effect. In minutes of 23<sup>rd</sup> April 2012, Ms Christie of the JCPCT:

'urged that any sensitivity analysis carried out should be in response to specific concerns raised during consultation'.

This comment emphasises both the importance of the comments of consultees and the significance of the refusal to disclose the underlying scores in the Kennedy Panel assessment. The reality was that consultees had been (deliberately) disabled from raising such specific concerns and the JCPCT were disabled from remedying the deficiency for themselves by the self-denying ordinance. The decision of 4<sup>th</sup> July 2012 followed (almost to the letter) the content of the DMBC, which it seems was produced only shortly prior to the decision, albeit reflecting some of the discussions minuted at meetings. It is unclear to us at present when precisely this document (in its final form) was produced for the JCPCT but it is

certainly evident from Jeremy Glyde's comment in the minutes of the 15<sup>th</sup> May 2012 page 10/12 that it was not complete at that date. He said 'the structure of the meeting [on 4<sup>th</sup> July 2012] would follow that of the Business Case which he was writing'.

17 It is evident that Mr Glyde was selective as to what 'Sensitivity' tests he chose to put into the DMBC, and we note the omission of Sensitivity 7 [see minutes of 23<sup>rd</sup> April 2012 p.10/11) described as

'the only test and combination of sensitivities in which Option B did not rank first in the scores, owing to the impact of weighting all the quality sub-criteria the same. Option G scored highest and Option B scored second highest'.

Later this 'combination' of sensitivity tests was described as 'arbitrary' by the JCPCT and the minutes record one JCPCT member objecting to it on the ground that the two sensitivities (patient choice and sustainability) were not causally related to each other, a point that is difficult to understand. Had, as we suggest, the JCPCT disclosed the underlying scores, informed submissions would have been made in respect of Leeds which would have altered its scoring to 117, just 7 behind Option B. Properly assessed (as sensitivity analysis F shows) Newcastle ought to have scored 236 (it has been wrongly overscored in DMBC with 50 rather than 25), and Leeds 253. This plainly ought to have made a material difference to the JCPCT's considerations.

However one analyses the development of the JCPCT's thinking between the end of the consultation and promulgation of the decision of 4<sup>th</sup> July 2012 and the DMBC that lies behind it, we think it is clear that the JCPCT considered that the consultation process was boiling down to a Leeds vs. Newcastle 'play-off' as early as November 2011 (page 5 of the JCPCT minutes of 17<sup>th</sup> November 2011) and certainly by April 2012 (page 11 of the JCPCT minutes of 23<sup>rd</sup> April 2012). Ms Evans of the JCPCT:

'opined that the Leeds/Newcastle issue was the next major issue for the Committee to address. She suggested the Committee review all the relevant factors for its decision on this point at the following meeting'.

- We are doubtful as to whether that 'review' was in fact carried out at the 15<sup>th</sup> May 2012 meeting, albeit that various sensitivity tests were discussed, and Ms Banks appears to have explained that 'combining sensitivity tests was not a helpful or robust method for testing the original scoring in that it was an arbitrary approach' p.6/12.
- The 'review' on 15<sup>th</sup> May 2012 appears to have culminated in a view that 'there appeared to be no convincing evidence that supported the designation of Leeds over Newcastle', a point

which again we think, underlines the unfairness caused by the refusal to disclose the detailed Kennedy scores. Had such scores been disclosed then the JCPCT would have had before them cogent and reasoned evidence which supported the designation of Leeds over Newcastle both in respect of Quality, Sustainability, and Travel and Access Times. Even in respect of Deliverability (where the JCPCT's main focus seems to have been unduly distracted onto the question of the ability to maintain transplants nationally) the evidence was in Leeds' favour as to its ability to deliver surgical services in the short, medium and long term without negative impact on NHS services.

- In underlining the unfairness in the failure to disclose the detailed Kennedy scores we think it is right to observe the following key points:
  - (a) the Kennedy scoring 'was not a comparative exercise... The panel's role was not to compare or comment critically on centres but to assess them against objective criteria' see Sir Ian Kennedy's witness statement in the Royal Brompton proceedings at §38. Thus in using the Kennedy scores to undertake a comparative exercise, the JCPCT was using them for a purpose for which they were not designed
  - (b) The Kennedy Panel 'had no part in the process of determining the [weighting] multipliers' see Sir Ian Kennedy's witness statement in the Royal Brompton proceedings at §19;
  - (c) The Kennedy Panel did not assess one aspect of 'Quality', namely 'Deliverability and Achievability' see Sir Ian Kennedy's witness statement in the Royal Brompton proceedings at §18. We note that this was 'third in rank' of categories of importance worth some 75 points by itself see at §19 ibid.
  - (d) While the overall Kennedy scores (the score of 401), the weightings which were to be applied (as set out on the self-assessment template) and the narrative observations of the Kennedy Panel on each of the centres were disclosed in the course of consultation, the JCPCT never (despite requests) disclosed the underlying scores which made up the quality assessment. This made meaningful engagement and use of such scores very difficult indeed and deprived consultees of an ability to demonstrate in their responses that the quality scoring:
    - (i) was not reliable for the purpose to which the JCPCT were seeking to put it;
    - (ii) should be re-weighted given the inability of Kennedy to score 'deliverability' a core component of the intended 'quality assessment', and:
    - (iii) should be revisited for the purpose of the configuration exercise.

(e) Given the importance of the Kennedy scores to the configuration assessment, and indeed Sir Ian Kennedy's own insistence that 'the JCPCT should take the differences between the centres' abilities into account when making its decision', this was highly important information. Indeed an excerpt of Sir Ian Kennedy's letter saying this is reproduced in DMBC at p.154:

'The panel is of the view that this report has identified important differences in the extent to which the centres can meet the quality standards in the future; panel members have reflected these differences in their scores and in the report. It is our view that the outcome of the Panel's work would be rendered redundant were the JCPCT to interpret the report's conclusions as finding that there are no material differences across the centres in their ability to meet the quality standards in the future. This interpretation would not be justified. To repeat there are important differences'.

Kennedy assessment, then plainly disclosure of the underlying, detailed scores which culminated in that assessment was necessary as part of a transparent consultation process, particularly given the very strong weighting given to Quality in the configuration assessment. It is the Claimant's case that the JCPCT's refusal to disclose the information underlying the Kennedy total scores which were published, led to unfairness in the process since Leeds and those who supported Leeds' position e.g. the JHOSC, or the Claimant were unable effectively (i) to counter the underlying evidence; and (ii) seek to persuade by submission of

new evidence etc. that the scoring was either unreliable or should be seen in a different light

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given subsequent developments.

If, as stated here, 'material differences across the centres' was an important aspect of the

Furthermore, the JCPCT seems to have accepted that the differences between the centres reflected in the Kennedy scores were important and should influence their decision, but they were also being advised not to try to understand what those differences were. They should take the scores at face value. The evidence is that this is exactly what they did, in as much as the final scores of the different options seem to have been determined by a series of judgements building upon features of the Kennedy scores which were, as we shall see, not fit for that purpose.

After the decision on 4<sup>th</sup> July 2012 was made the scores were finally released. First, on 17<sup>th</sup> July 2012, a set of figures were disclosed which appeared to repeat the previously published totals of 401 for Leeds and 425 for Newcastle, but when one added the respective columns up, Leeds had a score of 414 and Newcastle a score of 421. A similar document was disclosed on 24<sup>th</sup> July 2012. Plainly this was of concern. However by further email, a fresh set of scores were disclosed which reverted to the total figure recorded in the DMBC. We

understand the JCPCT say that this is the correct document and the one 'relied upon' by the JCPCT in reaching their conclusions.

Although it now appears that what was initially disclosed were the underlying figures for Sensitivity A (see DMBC pages 169-171) it seems that the, (it appears inadvertent), disclosure of two sets of figures which produce markedly different results in terms of final outcome underlines why it was appropriate to disclose the underlying figures in the first place in order that informed comment could be made about them, their accuracy, and the effect of the weighting. This was particularly so once it became clear that the Kennedy scores, contrary to the initial indication given in the Self Assessment template and what the centres were told by representatives of the JCPCT, were going to have a direct influence on the configuration assessment scoring. As noted above, the Kennedy Panel had not scored 'Deliverability and Achievability', the scores were not prepared for the purpose of comparing the quality of the centres, and the Kennedy Panel had no say in the 'weightings' that were applied. Had the JHOSC been shown the Kennedy scores they would have made cogent submissions under each of these headings and there is every reason to suppose that the JCPCT would have reached a different view as a result for reasons we will deal with below.

### The Issue Part II:

# What was wrong with the Scores?

- The Kennedy Scores were not produced with the aim of scoring Leeds against Newcastle, or anywhere else. In his witness statement in the Royal Brompton case, Professor Kennedy at paragraphs 11 and 29 said that the Panel did not compare the centres against each other, but "objectively against the [newly devised]<sup>12</sup> Standards". It is not entirely clear what the last phrase meant, but its unfitness for the purposes of the JCPCT when it came to choose between Leeds and Newcastle is demonstrable.
- The change of purpose should have caused the JCPCT to consider the scores with caution when they were invited to rely upon them two years later to make a decisive judgment about the quality of clinical care in one centre as opposed to the other. When Sir Ian Kennedy told the JCPCT that they had not scored the centres against each other, he was pressed by a member of the JCPCT and asked if the weighted rankings were felt to be "intuitively correct"

<sup>&</sup>lt;sup>2</sup> The standards applied had only been existence for some two months and as Sir Ian Kennedy accepted some centres would have had little time to adapt

and he refused to answer as detailed by his witness statement at paragraph 38. Looking at the comments on the centres it is obvious that they were not doing a comparative exercise. There is no attempt to compare the staff or facilities on a numerical basis, and if there had been the results would have appeared very different. The apparent preference for one centre over another in the judgments appears impressionistic, and in some cases the judgments appear simply inaccurate.

We will produce a more detailed analysis subsequently if it proves necessary, but it seems that if the JCPCT had seen the underlying scores in detail they would or should have been gravely concerned. We will now review some of the components of the Kennedy scores to explain why the comparative judgment based upon them was demonstrably unfair.

# 29 Strength of the Network

The Kennedy Panel gave only a narrowly higher weighted score to Leeds in respect of the Network by 41 to 38 or, 48 to 45 in the 25<sup>th</sup> July version. The reality is that Leeds has an exemplary network which has been built up over many years. This includes:

- 17 Outreach locations visited by the Leeds consultants and Specialists
- Cardiac Liasion Nurses
- · Paediatricians with an interest in each DGH
- Locally based staff trained to do ultrasound examinations
- Trained sub-specialists in Grown-Up Congenital Heart Disease ("GUCH") who take part in these visits.

By contrast Newcastle has made little or no progress with any of these and it will be very difficult to support such networks from such a long way off as Newcastle. Newcastle's approach to its Network was repeatedly criticized by the Kennedy Panel on the grounds that it was weak, development plans were incomplete and there was no spirit of collaboration evident.

#### 30 Staffing and Activity

Both centres were given the same weighted score, 73 points, in respect of staffing and activity. The numbers of staff are quantifiable and the conclusion that they are equivalent is unsustainable.

Category of Staff	<u>Leeds</u>	<u>Newcastle</u>
PCCS (Congenital Cardiac Surgeons)	3	2
PCC (Paediatric cardiologists)	6.5	4
GUCH Specialist Consultants	3.5	0
Fetal Cardiologists	1	0
Psychologist	1	0
Specialist Cardiac Nurses	8	0
Transition Nurse	1	0
Specialist Congenital Echo Sonographers	4	1
Intensive Care Consultants	6	2
		<b>⊷</b>
Total:	<u>34</u>	<u>9</u>

- 31 Self-evidently there are far more specialist staff in these categories at present in Leeds than in Newcastle. Again, we do not seek to say more than that any reasonable observer would expect the larger centre to be favoured in the scores if they had been put on a comparative basis. The realisation that such disparity is not reflected in the scores would have caused the JCPCT to have asked what Sir Ian Kennedy meant by saying that they were being scored against their ability to meet the standards when they assessed them equally. If the Claimant had seen the scores they would have pointed out forcefully that they were not fit for the purpose of determining the quality now or in the future.
- 32 The argument would have gone further than simply calling that component of the Kennedy scores into question. These staff often will not follow the work, either because they cannot for family reasons or because of personal disinclination. The British Congenital Cardiac Association ("BCCA") has reported that there will be a 40% loss to the profession when centres close, and there are only 3 national training numbers in PCCS and PCC, enough to replace retirees, but not enough to replenish a massive and sudden shortfall. Clinicians from Leeds will describe their own career plans and the reasons why they would not move to Newcastle.
- It is impossible to believe that the JCPCT would not have wanted to reconsider the matter if they had seen the breakdown and been aware of the true position on a comparative basis. Similarly, if the Panel had been comparing the staffing of the two centres against each other, our client cannot accept that they would have given them the same score. They

acknowledged that Newcastle had only 2 surgeons and gaps in the workforce and rota and concerns over the quality of training. There were "insufficient staff in PICU for there to be a consultant led service." The clear inference is that they simply did not think it was as good as Leeds, where there were three surgeons with plans to recruit a fourth; the six consultant intensivists looking after the two PICUs and during out of hours, one consultant covered both (since they are across the corridor this is hardly surprising).

Whatever the merits of the Kennedy scores when looked at in isolation, in respect of staffing it was not fit for the purpose of reaching a view that Newcastle would be equally able to meet the standard in the future. One of the problems is that neither the consultees nor the JCPCT could tell what the Kennedy Panel meant when it said that the staffing of the two centres were equally able to meet the standard. They may have been comparing it with the existing workload, which would have been a poor basis for predicting their ability to handle much larger numbers in the future. They may have been impressed by proposals to recruit but, if so, the JCPCT would no doubt have wanted to evaluate the realisability of those plans, since the Kennedy Panel had rightly disqualified themselves from making such an evaluation. There is no way of knowing.

### 35 <u>Facilities and Capacity</u>

<u>Facilities</u>		<u>Leeds</u>	<u>Newcastle</u>
Dedicated Paediatric Theatres		2	1
Catheter Labs			
	Adult/Shared	5	3
	Paediatric Dedicated	1	0
Beds			
	Paediatric Intensive Care (PICU)	8	2
	Ward	26	12

Given the remarkable disparity in Leeds' favour described above, if the JCPCT had been shown the breakdown of the scores they would or should have raised serious questions about the fact that Newcastle was given a higher weighted score, 56 compared to 42 in the 25<sup>th</sup> July version of the breakdown, and 48 to 36 in the 17<sup>th</sup> July version. Whether judged by the number of staff or the facilities available, Leeds was streets ahead and yet given a lower

score. Sir Ian Kennedy is clearly right when he says that the Panel was not trying to compare the two centres.

We say it goes further than raising questions about the validity of the Kennedy scores and their weighting as a basis for evaluating on a comparative basis the facilities of the respective institutions. What is now proposed is to shoehorn a larger service and facility into a smaller hospital: for any decision-maker contemplating the merger of a service, that is an ambitious and unusual proposal. Self-evidently, the loss of the larger facility will be much harder to replace and the larger the new arrival the more difficult it will be to prepare for it. If the JCPCT had realised what was proposed, or if our client had realised that this assessment of the available facilities was what was being treated as a component of the assessment of Quality, they would have suggested that the weighting given to Quality (39) should have been reduced by comparison with, for example, the weighting given to Access and Travel Times (14) and that given to Sustainability (25).

As a result of the self-denying ordinance the JCPCT disabled themselves from appreciating these facts. As a result of their refusal to share the Kennedy scores with consultees, they disabled our client and others from helping them by pointing these things out.

# 39 Age Appropriate Care

Leeds was given a marginal win 31 to 29, or 26 to 25. Yet Leeds has a new Children's Hospital supported by a psychologists and paediatric cardiac nurses. Its facilities include a school and play teachers on the wards. Newcastle delivers its surgery in an adult hospital. Leeds has a nurse with an interest in transition, "but no robust plans for a dedicated Transition Nurse to facilitate the transition to adult care," according to the Kennedy Panel; we shall produce evidence to show that the Kennedy Panel had got hold of the wrong end of the stick about transitional care, but for the purpose of this comparison we note only that Newcastle has less staff working with transition cases, partly because it has no cardcarrying trained sub-specialists in Adult Congenital Heart Disease (ACHD). The Kennedy view of the problem was arbitrary because it was prohibited from considering ACHD but purported to pass judgement on Transition. Leeds has separate accommodation for adolescents and the gap in compliance identified was that it did not have separate recreational facilities for them. Leeds has a dedicated 8 bed cardiac PICU across the corridor from the rest of the regional PICU which contains another 8 beds, bringing with it the advantages of scale of having 16 PICU beds together. Newcastle's PICU consists of a few paediatric beds on the end of the adult ward. Self-evidently, the Kennedy Panel were simply

not comparing the two centres or scoring them against each other, which is why the use of the scores for a purpose for which they were not intended was fraught with hazard, hazards of which the JCPCT remained wholly unaware until after they had taken their decision.

#### 40 Inter-dependent services

Given that the Leeds Unit is to be located in an enormous hospital dedicated to maternity and children as from next year, whilst Newcastle is in an adult cardiology hospital with no interdependent services, it is hard to see how Newcastle could get 80% of Leeds's score, 4 where Leeds got 5.

- This highlights another concern. Even if the scores had been fairly prepared for comparative purposes of many centres across the country, once the decision came down to a straight choice between Leeds and Newcastle, one might have expected a sensible decision maker to compare the two centres more closely, as proposed by Ms Evans paragraph 18 above. This did not happen. Newcastle may have done better than for example Leicester, which failed the Baker co-location tests, and on that account been given a moderate score. But when it came to a straight choice between Newcastle and Leeds the difference should have been much greater on this heading as it should have been in respect of Networks.
- We are not sure of the detail of the process, but we think that what happened is that the Kennedy Panel were asked to re-score this issue to reflect the points made by consultees about co-location and they refused to do so. As a result, the scores remained the same but the Safe and Sustainable staff did a sensitivity test, which involved re-weighting the Kennedy consensus scores. The result took Leeds up from 62 to 114. Newcastle's score was also increased, from 48 to 88, but none of this mattered because the JCPCT were not troubled with the detail or reliability of the underlying scores when used on a comparative basis, still less were consultees given the opportunity of commenting on the results of such purported 'sensitivity' analyses

#### 43 <u>Information and Choices</u>

Leeds scored a narrow win, 31 to 27, or 26 to 23. Again, this is hardly reflective of the gulf between the centres by 2012.

- Information is thought to refer to the arrangements for counselling patients. With its psychologist, Nurse Specialists and the Patient Representative on the Network Group, Leeds reflects the results of steady work over more than a decade. Newcastle has none of these things as Sir Ian Kennedy noted in his report at page 29 of Appendix K1.
- During the two years since the Kennedy Panel visited the centres, the PwC Report has 45 become available. This showed that the parents would not go to Newcastle voluntarily, and the DMBC proposed to railroad them into going to Newcastle on the basis of a report that 96% of referring doctors said that they would refer in accordance with commissioning arrangements. This proposition is ambiguous: the referring doctors may have meant no more than that they would refer to one of the 6 or 7 hospitals ear-marked to continue doing this work. It seems as if the JCPCT supposed that the 96% meant that they would do as they were told, acting as advocates for what was proposed by the JCPCT. Thus the paediatricians in Sheffield would all persuade their parents and patients to travel the 130 miles to Newcastle, when they may have meant that they would refer to Liverpool which is only 72 miles or Birmingham which is 90 miles away. The DMBC seem to have interpreted this ambiguous proposition in a counter-intuitive fashion, one which would require the referrers to persuade parents to put their choice aside, This is an approach which might be thought to cut sharply across the grain of the 'patient choice' agenda which the Safe and Sustainable review was supposed to be championing should have resulted in Newcastle getting a lower score on choices...
- Thus the Kennedy score would or should have been recognised as rendered obsolete by the PWC analysis, if the JCPCT had seen the breakdown.

#### 47 Other Matters

The Secretariat recognised that the list of clinical matters did not provide an exhaustive means of assessing the centres and they added two additional sections and asked the Kennedy Panel to score them, even though they had nothing to do with matters clinical. The first section was called Leadership and Vision. It included various things including IT and Estates Strategy, where the qualifications of the Kennedy Panel seem ill suited. Overall it is on this heading that Newcastle won, and on which the judgment of quality came to depend. Again, had there been more transparency about the process, it is hard to believe that

consultees would not have pointed out, or the JCPCT would have failed to recognise, that the weighted assessment had moved a long way from a reliable "quality of service" assessment and that a weighting of 39 was not appropriate.

#### The Issue PART III:

# Would it have made any difference? Almost certainly.

- The points that we have already made are in our submission dispositive of the proposition that the court should quash the decision. Unnecessary though it may be, we go further and submit that the arguments in favour of the proposition that a properly advised JCPCT would have decided in favour of Leeds are overwhelming for reasons that can be stated shortly.
- The population of the Yorkshire area is about double that of the North East. There are about of 5.2 million compared to 2.6 million so that the balance of convenience for patients must point to Leeds on this ground alone. Furthermore the Leeds area is growing faster than the North East so that that position will become even worse over 10 years.
- Dr Mark Darowski produced a Population Distance Indicator ("PDI" charting the distance travelled x number of people) which provided a practical illustration of the implications for users of the service. It is not clear whether the JCPCT ever saw this or understood its implications. We should be grateful if you would tell us.
- The way in which the information was handled suggests that the JCPCT looked at this through the wrong end of the telescope: by concentrating on those who had operations they thought that relatively small numbers were involved and failed to take account of the proportion of the 10,000 people who use the Leeds PCCS service every year who would either have to travel much further or experience a less specialist service.
- All we say at this point is that those who knew nothing else about the problem would assume the reasonable decision maker would choose Leeds on this ground alone, unless all other things were very unequal indeed. When planning a service for the future, most things are dynamic and changeable: the senior surgeons in both centres will retire within a few years, the facilities will wear out and investment can change most things. The two points that are immutable are the location of the patients and the ability to recruit the staff, mostly from the local population but, in the case of the high fliers, by persuading them to migrate. We say that this is another reason why consultees and the JCPCT would have been unlikely to

agree to such a massive weighting being given to quality (39) as opposed to access and travel times (14), if they had realised that it provided such a fragile basis for comparing the centres. The advantages of placing a centre close to 5.2 rather than 2.6 million people are obvious, overwhelming and enduring.

# 53 Vulnerable Groups

It is clear that the JCPCT were properly mindful of their obligations under the Equality Act 2010 and the heavy preponderance of vulnerable groups in the Leeds area who are dependent on these services. Here we note the fact that it would have been expected to lead to a location in Leeds rather than Newcastle as a result of the policy embodied in the statutory duty.

We do not want to labour the point, because we know that the JCPCT is very familiar with it, but in essence, the South Asian population of Yorkshire have a higher demand for children's heart surgery services. We remain concerned as to whether there is a potential for indirect discrimination as a consequence of the JCPCT decision if the scales between Leeds and Newcastle are finely balanced, but for the purpose of this argument we simply note that the JCPCT would rightly have been inclined towards Leeds.

# 55 Poverty and attempts to alleviate hardship

The Health Impact Assessment of Mott MacDonald recognises that the BAME population will be disproportionately impacted by the decision to close Leeds. It notes that for many BAME families for whom English is not their first language, the requirement to use new routes or modes of transport could present particular challenges. The DMBC at page 77 suggests that implementation should consider "practical mitigation" such as: financial assistance with additional travel costs and car parking; affordable overnight accommodation and personal transport from very remote areas. This raised the question of the equity in creating special privileges for this group of patients when using their assigned surgical centre, as opposed to conferring such privileges on the basis of need. It is further evidence that the JCPCT were concerned and would have been likely to choose Leeds if all other matters were equal.

#### Legal Principles

At the heart of a public law challenge to a decision reached after extensive consultation is the question of whether the process was unfair: 'so unfair it was unlawful' -see Devon County Council v. Secretary of State for Communities and Local Government [2010] EWHC

1456 (Admin) at 70 per Ouseley J. That test is satisfied. We think 'clearly or radically wrong' – see R(Greenpeace) v Secretary of State for Trade and Industry[2007] EWHC 311 (Admin) at 63, probably puts the bar too high, but if that is the bar, it was clearly crossed in the present case by the self-denying ordinance and the failure to disclose highly important information in response to requests.

- The requirements of lawful consultation are often distilled into the well known *Gunning*<sup>3</sup> criteria viz.:
  - (i) Consultation must take place when the proposal is still at a formative stage;
  - (ii) Sufficient reasons must be put forward for the proposal to allow intelligent consideration and response;
  - (iii) Adequate time must be given for consideration and response;
  - (iv) The product of consultation must be conscientiously taken into

account.

In Lord Woolf's judgment in *R v. North East Devon Health Authority ex parte Coughlan* [2001] QB 213 the general statement of principle is set out at paragraph 108:

"108. ... To be proper, consultation must be undertaken at a time when proposals are still at a formative stage; it must include sufficient reasons for particular proposals to allow those consulted to give intelligent consideration and an intelligent response; adequate time must be given for this purpose; and the product of consultation must be conscientiously taken into account when the ultimate decision is taken ....

An issue similar to that in the present case was considered in *R(Eisai) v. National Institute of Clinical Excellence* [2008] EWCA Civ 43 in which the unfairness complained of was the failure to disclose a fully executable document which could be analysed and responded to by the Claimant. After reciting the relevant principles, Richards LJ concluded that the non-disclosure was unfair notwithstanding the very large quantity of information that had been disclosed by NICE as part the consultation. The reason for the unfairness stated at §65 by Richards LJ was that:

'It does place consultees (or at least a sub-set of them, since it is mainly the pharmaceutical companies which are likely to be affected by this in practice) at a significant disadvantage in challenging the reliability of the model. In that respect it limits their ability to make an intelligent response on something that is central to the appraisal process. The reasons put forward for refusal to release the fully executable version are in part unsound and are

<sup>&</sup>lt;sup>3</sup> R v. Brent London BC, ex p. Gunning (1985) 84 LGR 168

in any event of insufficient weight to justify NICE's position.' (emphasis emboldened)

# **Summary submissions**

- We think that the reasoning we have emphasised in *Eisai v NICE* can be applied to the present case. The information underlying the scores was significant, non-disclosure of the information limited effective and intelligent response, and the issue was central to the consultation process. The reasons for non-disclosure, as given in the minutes by Sir Ian Kennedy (fear of judicial review), are entirely unsound, particularly in a process which was supposed to be fair and transparent.
- In this regard we note how in the JCPCT minutes of 11 January 2011, as the configuration criteria were being developed, the issue is discussed and importance of the reliability of the Kennedy scoring highlighted:

'Ms Evans asked how the network quality issue would feature in the scoring. Mr Reed highlighted this was linked to the broader issue of the reliability of the Kennedy scoring on future service planning'

- Thus, it seems to us that 'the *reliability of the Kennedy scoring*' on the priority issue of 'Quality' was always an issue that required informed and intelligent response during the consultation process.
- The point is brought into sharper focus when it is recalled that the Kennedy panel had no say in the weightings to be applied, nor sought to compare one hospital against the other, but rather simply scored each location against newly developed standards with which each institution had had little time to adapt. The point is clear from the following extract from the minutes of the 11<sup>th</sup> January 2011 meeting:-

'The Chair asked whether the Panel's scores were intended to be relative. Sir lan answered that the Panel had not scored centres against each other, but in isolation and on their own merits. There had been no discussion of weighting and percentage difference. Ms Christie explained that understanding the difference in scores was important and asked whether the weighted ranking was intuitively felt to be correct by the Panel. Sir lan explained that it was beyond the role of the Panel to discuss intuition or move beyond the objective results...

...Sir lan's view was that all centres, apart from Oxford, which was an outlier, were acceptable against the standards.... and warned that, the more subjective factors were considered, the greater the risk of challenge and judicial review'

The self-denying ordinance of the JCPCT meant that they did not scrutinise the composition of the Kennedy scores themselves and so had no opportunity of evaluating them. Despite

what they were told by Sir Ian Kennedy himself, the JCPCT acted on the assumption that the Kennedy Panel had produced a robust comparative scoring of the centres on the basis of which they could produce a judgment of the quality of the surgical and medical services delivered. They were wrong and by insisting on not disclosing the Kennedy scores they prevented consultees from rescuing them from their error.

In summary, the failure of the JCPCT to disclose the underlying scores – which would have prompted an informed submission about weighting and the reliability of the overall Kennedy scoring of quality and their use for purposes beyond that for which they had been prepared (i.e. for comparative purposes), particularly in view of the Kennedy Panel's conclusion that it could not assess deliverability and achievability, was a material flaw in the consultation process which rendered the consultation process (and its subsequent product) unfair. The decision of the 4<sup>th</sup> July 2012 ought to be quashed.

# The details of the action that the Defendant is expected to take

The Defendant is expected to confirm forthwith that:

(i) It will agree to a quashing of the decision of 4<sup>th</sup> July 2012.

# 67 The details of the legal advisors, if any, dealing with this claim

The Claimant's legal advisors are Hempsons Solicitors.

# 68 Interested Parties

None

# 69 The details of information sought

None.

#### 70 The details of any documents that are considered relevant and necessary

We await the minutes of the JCPCT meeting of 4 July 2012.

# 71 The address for reply and service of court documents

The address for reply is Hempsons, Hempsons House, 40 Villiers Street, London WC2N 6NJ (DX 138411 Charing Cross 1)

#### 72 Proposed reply date

We request a reply within 14 days after which we intend to issue proceedings for judicial review. In the light of the detailed content of the letter above we consider that you will

recognise the claim is arguable and that permission for judicial review is likely to be granted. In such circumstances we invite you to:

- (ii) Consent to/not oppose the grant of permission
- (iii) agree to a protective costs order in favour of the Claimant, limiting the Claimant's exposure to adverse costs, with a reciprocal costs cap on the Claimant's recoverable costs.
- (iv) agree that the case is suitable for an expedited hearing in the Administrative Court, time estimate 2 days, to be heard if at all possible by the end of the Michaelmas term.

We look forward to hearing from you.

Yours faithfully,

#### **HEMPSONS**

d: 020 7484 7606 df: 0207 839 8212

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