

Response to the JCPCT *Safe and Sustainable* Consultation regarding the future configuration of paediatric cardiac surgery

1 Introduction

- 1.1 Royal Brompton & Harefield NHS FT “Royal Brompton” welcomes this, its first opportunity to contribute directly to the process of deciding what should be done about reorganising Congenital Cardiac Surgery “CCS” as a result of the Safe and Sustainable “S&S” Review.
- 1.2 So far Royal Brompton has only been permitted to challenge the self-evident errors in the proposals through the medium of Judicial Review. In those proceedings we can challenge errors of law, fairness and rationality, but not to advance the Royal Brompton’s view of the best way to go forward. Since Royal Brompton has been a leading national centre of expertise in heart and lung disease (since the NHS was born in 1948) this exclusion seems to be extraordinary.
- 1.3 In this paper we will deal with the problem as follows:

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2 Executive Summary

- 2.1 The proposal to decommission paediatric cardiac surgery at Royal Brompton was conceived for NHS political reasons before the Review started, which is why Royal Brompton experts were not included in the process. In turn, this led to the failure to understand our vertical model of care.
- 2.2 Research carried out for the Review found no evidence that centres doing more than 300 paediatric cardiac surgery cases achieve better results. The double standard of 500 in London and 400 elsewhere defies logic.
- 2.3 Royal Brompton is one of 2 hospitals in the country at which 4 surgeons already handle well over 500 congenital cardiac cases a year and thus achieves all that the professional consensus demands. It is the only centre in the country to have undertaken over 1000 interventions in a year for these diseases.
- 2.4 The 2009 joint Royal Brompton and Great Ormond Street paper proposed the constructive expansion of services into an ambitious joint centre, which is the antithesis of the proposal to remove our paediatric cardiac surgery. This joint paper has been misused and misrepresented by the JCPCT and its advocates.
- 2.5 The vague and unsubstantiated criticism of our research achievements cannot be reconciled with the findings of the HEFCE Assessment Exercise and the NIHR decision to site the cardiovascular Biomedical Research Unit at Royal Brompton.
- 2.6 Our quality as measured by outcomes stands comparison with any other centre. The criticism is so opaque as to be incomprehensible.
- 2.7 The JCPCT process now asserts it did not understand the damage that its proposals would do to the rest of the work of this hospital. We explain the devastating effect it would have on a wide range of clinical outcomes both here and elsewhere.
- 2.8 The 10 axioms we invite the Review to accept as the basis for its future work.

3 The Defective Architecture

3.1 There are two possible explanations for the way the S&S process was set up. The simpler is that the architects of the process had already decided that it would be necessary to sacrifice Royal Brompton in order to quell opposition elsewhere. Two particular pieces of evidence support this idea.

3.1.1 The briefing to the London Specialised Commissioning Group, which was endorsed at its meeting on 26 April, 2010 before any of the assessments took place.

“It is likely that the rest of the country will take a view that London should take its share of the pain of closures and will seek to make one closure in the capital in order to make closures elsewhere more palatable.”¹

So the idea of closing one London centre was embedded in the warp and weft of the process at an early stage for reasons that had nothing to do with clinical outcomes. We hope this will prove to be obsolete in the light of the Minister’s statement to the House of Commons on 8 June, 2011:

Pat Glass

The Minister will have to make some difficult decisions very soon about specialist children's heart provision. In my part of the world, the choice will be between the NHS trusts in Newcastle and Leeds. Can he confirm that those decisions will be based on clinical outcomes, not political expediency?

The Minister of State, Department of Health (Mr Simon Burns):

I can give the hon. Lady a categorical assurance that they will be based on clinical outcomes, not political considerations”²

Certainly we shall take this as encouragement to emphasise issues that bear on clinical outcomes.

3.1.2 The second piece of evidence that Royal Brompton’s fate was settled as far as the architects were concerned is the deliberate exclusion of anyone from Royal Brompton on the Standards Working Group and the Steering Group. This position was adhered to even when the omission was pointed out. Both of the other London centres had one of their senior consultants and another senior consultant closely associated with their work on the Steering Group

- 3.1.3 The alternative explanation is that it was just a mistake, stemming from a failure to understand that there are two completely different ways of approaching the problems faced by patients suffering from Congenital Heart Disease (CHD) and that by excluding anyone from Royal Brompton, the architects were condemning the process to fail to take account of the model of care associated with our type of speciality hospital.
- 3.1.4 Whatever the reason, as a result the authors of the process took two fundamental decisions before approaching the evidence that shaped the final conclusions in a fashion that cannot now be justified. It is worth describing those two decisions and looking at how they led inexorably to the outcome.

3.2 **The Vertical Approach to Congenital Disease**

- 3.2.1 There are two alternative approaches to the treatment of CHD, and neither has been shown to be better than the other. The first is the vertical approach, which has been followed by Royal Brompton since the subject was developed here in the 1950s: this involves concentrating all of the surgical, medical and related specialties interested in cardiac disease in one place, caring for the individual patient from the womb to extreme old age. It enables doctors who care for patients at each stage in their lives to cross-fertilise expertise, using a valuable multi-disciplinary team model.
- 3.2.2 This has enabled Royal Brompton to create a centre of study into cardiac science such as cannot be matched for scale and volume of research anywhere else in the country. This reflects the range of our work, because many of the advances that benefit the modern CHD patient are not made by the congenital surgeons but by a host of other complementary integrated clinicians and scientists who advance our understanding of the disease process as a whole. There are fetal cardiologists who transform the range of options available to patients and help to inform the preparations that surgeons are able to make. There are morphologists, cardiac imaging specialists and electro-physiologists who enhance the surgeon's understanding of the abnormal heart that requires surgery. There are people pioneering medical solutions that will reduce the number of babies who have to undergo surgery at all, such as biochemists interested in stem cells, geneticists pioneering gene therapy or those in more distant fields looking at immunology or metabolomics. Many of them are doing animal studies, although over the last 10 years there has been an increased awareness of the importance of

translational research, in which studies in basic sciences are pursued in close harmony with clinicians. The range of these people can be gauged from the fact that there are not only 103 cardiac and respiratory consultants at Royal Brompton, but that 24 of them also hold senior academic research posts in the National Heart and Lung Institute of Imperial College (the NHLI), the primary academic partner of Royal Brompton.

3.2.3 It is because of the importance of this wider agenda that Imperial College, to which we are affiliated, was found by the latest Research Assessment Exercise to be by far the strongest centre of cardiac research in the country; that is also one of the reasons why the National Institute of Health Research (NIHR) decided to site one of its cardiovascular Biomedical Research Units (BRU) at Royal Brompton Hospital. We will examine how the S&S team handled these points when we look at their handling of the evidence of research.

3.2.4 We also believe strongly that the vertical approach has enormous advantages to the individual patient for a number of reasons. For example:

3.2.4.1 It is easier to achieve better continuity of care if young adults are dealt with in a clinic attended by what is widely seen as the strongest team of Adult Congenital Heart Disease (ACHD) specialists in London, as well as by the paediatricians who have looked after them throughout their lives and who are well-known to them and their families.

3.2.4.2 There are intrinsic advantages in a centre where all the research and clinical care is based on a shared recognition that this is a lifetime condition. This view is shared by other hospitals which have pursued a vertical model in other specialties, such as:

- Royal Marsden Hospital
- Royal National Orthopaedic Hospital
- Moorfields Eye Hospital
- Eastman Dental Hospital

All those hospitals have made major contributions to the development of their specialties by cross-fertilising adult and paediatric medicine and surgery.

- 3.2.4.3 An optimal service for children requires an excellent fetal medicine service. Ours is outstanding, partly because it is integrated with obstetric services across other hospitals in London.
- 3.2.4.4 Optimal management of paediatric CHD demands excellent electrophysiology. This is often treating family disorders as we shall describe, and so needs to be integrated with adult medicine.
- 3.2.5 The alternative horizontal approach believes equally passionately that wherever possible children should be treated in a children's hospital in which all the services that the patient may need are available from dedicated specialist teams of paediatricians. Its adherents – who unsurprisingly dominate thinking at the specialist children's hospitals – are sometimes intolerant of any vertical approach. They believe that there is more to be gained from the co-location under one roof of all the specialists that any sick child might conceivably need, than will be lost by the failure to assemble the greatest concentration of specialists and scientists who are working in cardiovascular science.
- 3.2.6 Neither approach has been shown to be superior, and it may well be that London should rejoice in having world-famous exemplars of both views. However a highly relevant point in this context is that the artificial division in care at the age of 16 is likely to have something to do with one of the major potentially resolvable problems with this disease in this country: most patients nationwide are lost to follow-up, and that many re-present as adults with serious problems as a result. This is not only because the re-location of care at age 16 creates a division in the minds of carers and patients, it is also because the horizontal approach may reflect an attitude that the treatment of the baby's congenital heart problem is a complete work in itself, rather than the beginning of a lifelong process of continuous care. Royal Brompton has over 6,000 adults with CHD under supervision: few other centres have anything like that number.
- 3.2.7 The importance parents attach to this was emphasised to the JCPCT at its meeting on 7 July 2010 by Sir Neil McKay when he reported that

“Parents valued a seamless transition from antenatal to adult services; fragmented pathways should therefore be avoided.”

We shall therefore highlight ways in which Royal Brompton's unmatched strength in fetal and adult cardiology leads to seamless transition and strengthens services to those afflicted by familial conditions. We believe the

vertical model offers unmatched advantages during the difficult time of adolescence when the patient often opts to take less responsibility for his health. The transition within the hospital is staged and occurs at a time that suits the individual patient.

- 3.2.8 However all that needs to be said at this point is that both approaches have made enormous contributions to the advances over the last 50 years and that nothing has happened recently to render either approach obsolete.
- 3.2.9 There is no doubt that the vertical approach should be taken on board in the planning of cardiac services, because the older patients are operated by the same CHD surgeons who treated them as children. This happens in every modern centre of which we are aware, thus when older CHD patients attend the Heart Hospital, the centre attached to University College London Hospitals, they are treated by the CHD surgeons from GOSH.
- 3.2.10 We will now identify the decisions the architects of the S&S made at the outset as a result of this misperception and which led directly to its indefensible conclusions.

3.3 The Error of Team Selection

- 3.3.1 The first decision which disabled the JCPCT Steering Group from giving due weight to the value to the vertical approach was that it included no advisors from the only vertical London centre. It may or may not be the case that the architects of the review had already decided that “Royal Brompton Must Go” for NHS political reasons long before the Steering Group was selected, but by choosing London representatives exclusively affiliated with London’s children’s hospitals they disabled the Review from giving a fair appreciation of the vertical approach. It is true that some of the centres outside London are both vertical and horizontal, in the sense that they treat children and adults for a wide range of conditions, but none of them has the concentration of broad science on cardiovascular disease from womb to old age that the Royal Brompton has assembled.
- 3.3.2 We have alleged in our court proceedings that the exclusion of anyone from Royal Brompton made the Steering Group process into a “stitch-up”. This is because the Steering Group included a surgeon who is Co-Medical Director at GOSH, a physician who leads at the Evelina and a DGH paediatrician who also works closely with the Evelina team. It is futile to pretend and feign

innocence that their institutions did not have a significant vested interest in knocking the Royal Brompton out: the visionary 2009 paper which was signed off by the Boards of both GOSH and RB&HFT, and on which S&S members have just recently purported to rely, notes that GOSH makes a loss of £400,000 pa from paediatric cardiac surgery and respiratory services, whilst the Royal Brompton makes a surplus of £3.7m from this work. The transfer of the Royal Brompton cases would be an enormous fiscal boost to GOSH and Evelina when both are being challenged at a time of NHS fiscal stringency. Furthermore the professional and research status of these organisations and their leading members would be enormously enhanced if the only real professional peer in London were taken out of the equation. The failure of the architects of the S&S process to appreciate this, if that is what happened, is remarkable indeed.

- 3.3.3 When a Royal Brompton physician wrote to the Chair of the SG and suggested that his Brompton colleague should be included because they needed someone to comment particularly on issues of research, the SG decided this was unnecessary. The Chair, perhaps with more optimism than confidence

“Reminded the group that members of the Steering Group had been invited to represent their professional associations and not their individual centres”³

The informality of that arrangement is highlighted by the fact that none of the SG Minutes contains the customary Declaration of Interests with which most medical or corporate governance meetings on such matters now commence.

- 3.3.4 However the simpler point is that the absence of any advisors who could point out the value of the vertical approach to the problems of CHD meant that an argument which has been won by neither side during 30 years of professional debate was abruptly determined by the pen of a public sector official. Not only was Royal Brompton not represented at any of the meetings where its future was to be determined on the advice of its competitors, nor was the vertical approach to CHD on which it has built a world reputation over the last 60 years.

3.4 **Children do Grow Up**

- 3.4.1 The second mistake was to deal with children in isolation. The reason for this was put forward in the facile and unsupported assertion that “*you have to*

draw the line somewhere.” As we shall see this has proved catastrophic: by dealing with children in isolation the S&S review will have left too few cases for a separate system for Adult Congenital Heart Disease to be established that meets its own criteria. It is not entirely clear where responsibility for this decision lies. At the meeting of the JCPCT Steering Group on 15 July 2010, Mr Jeremy Glyde of the National Commissioning Group (NCG) referred to the public disquiet about this decision and the suggestion that it had been imposed on the Group.⁴ He reminded the Group that it was a decision that had been taken by the Group itself at its first meeting. He pointed out that this was an issue of collective responsibility, as though anxious to ensure that responsibility for this decision was confined within the Steering Group. The Minutes of the first meeting in 2008 suggest Mr Glyde was right,⁵ although no reason was given and no debate on the point is recorded. In reality, both the title and original composition of the Steering Group make it clear that it was set up to consider paediatric rather than congenital disease and so the members who acquiesced in this position were playing parts allocated to them by an external scriptwriter. Mr Glyde was supported by Mr Leslie Hamilton, who said there had been an expectation that adult services would be co-located with paediatric services, which certainly does not appear in the Minutes of the first meeting and reveals that the closure of Royal Brompton’s ACHD surgery was also envisaged by the Steering Group from its first meeting, before any evidence was assembled.

- 3.4.2 By picking off the children first and dealing with them in isolation S&S will determine the provision for adult services before they begin to consider it, because no ACHD centre can reach an appropriate number of cases without travelling distances that S&S have deemed acceptable. The same propositions that we shall consider more closely in the next section, about needing 4 surgeons for sustainable cross cover and each needing to do 125 operations to maintain their skills, apply just as strongly to those who treat these children after the age of 16 and S&S says that the NHS should espouse “the same principles of safety, sustainability and good quality outcomes”⁶ Yet according to CCAD data there are only 350 ACHD operations performed each year in London and S&S estimate there are about 858 cases a year nationally spread between 21 centres.⁷ If separated from the children, the NHS would be unable to support two ACHD centres in the country, achieving what it calls the “magic number” of 500 cases per annum.⁸

3.4.3 The authors of the separate adult version of the S&S Review, which is supposed to start work soon, may legitimately complain that this being set up incorrectly. The quotation from Mr Hamilton in 3.4.1 above – that there was an unrecorded expectation that ACHD would be co-located with children’s surgery, appears to suggest that they intend to revert to a model such as the Royal Brompton, albeit with the adult cases being tagged on to a nearby adult hospital which the paediatric surgeons will visit. This is the model used for example at GOSH and the Evelina, where older patients are operated on at the Heart Hospital and Guy’s respectively: it involves accepting the disadvantages implicit in the surgeon having commitments at another hospital at a time the patient is recovering from surgery.

3.5 The Numerical Misdirection

3.5.1 The view that small units have worse outcomes became embodied in the professional consciousness after the Bristol Inquiry in the 1990s. At Bristol two surgeons were performing between 130 and 140 CHD operations a year.⁹ The John Radcliffe Hospital at Oxford more recently had two surgeons sharing 108 operations and the results were judged to be so poor that the service had been suspended. Thus the case for closing Oxford and redistributing its cases was strongly based on two premises – that it was too small and its results were not good enough. However the case for going further has not been established with any confidence.

3.5.2 The question of how large a centre should be for an optimal service has been debated internationally for over 10 years. The consensus that very small centres have poor outcomes has triggered a debate about how large a centre should be for optimal outcomes. The S&S website shows that the National Specialised Commissioning Group (NSCG) commissioned a specific literature review in 2009 from Public Health Resource Unit in 2009.¹⁰ This reported as follows:

3.5.2.1 There was no clear evidence on the point;

3.5.2.2 The Monro report in 2003¹¹ had suggested 300 cases per annum;

3.5.2.3 The European Association of Cardiothoracic Surgeons, also in 2003 had suggested 250 cases per annum;¹²

3.5.2.4 A study by Welke in 2009¹³ after reviewing the results of 32,000 cases had suggested there was an optimal figure of between 200 and 300 cases a year;

3.5.2.5 Each surgeon should do 3 operations a week to avoid the dangers of “occasional surgery,” that entails 126 cases per surgeon per annum.

3.5.3 That is as far as the data could take them. There is no evidence that supports the proposition that centres larger than 300 cases per annum have any advantages. Nevertheless, the two fundamental propositions, reasonably accepted by the S&S team, were:

3.5.3.1 A centre needs 4 surgeons for purposes of providing 24/7 cover, managing holidays and succession issues. We agree and S&S found that the Royal Brompton is one of only two centres with four surgeons.

3.5.3.2 That each surgeon should on average do a minimum of 126 congenital operations a year.

This leads directly to what S&S described in its publicity material as the “Magic Number” of 500 cases per year.¹⁴ As we say, there is a sort of professional consensus around that aspiration.

3.5.4 However as S&S admits in its Business Case, it has never before been suggested that they all need to be paediatric cases. The consensus professional advice on which S&S drew, particularly from the European Association acknowledges that the same surgeons also operate on adults suffering from these lesions, so that a substantial part of the work of most congenital surgeons will in practice be made up of such cases. As a result the 4 surgeons should handle 500 congenital cases a year, of which 400 should be paediatric:

“...it is not stated that these 126 procedures per surgeon must all be in paediatric cardiac surgery; they could include procedures for adults with congenital heart disease. The *SAFE AND SUSTAINABLE* review has used 500 paediatric procedures per unit as the optimal figure and set the minimum number at 400 paediatric procedures per unit which provide each of the surgeons with 100 paediatric cardiac surgery procedures per year as a minimum (in addition to any adult congenital surgical caseload).”¹⁵

S&S Business Case p28

- 3.5.5 So that is where the 400/500 figure came from: the S&S team have taken a widely shared professional consensus view that there should ideally be 4 surgeons doing 500 congenital cases per year of which 400 should be paediatric. Unfortunately they have then applied the higher figure to the purely paediatric part of the problem, a proposal for which they have no authority in any previous professional consensus. It is also ungrounded in the professional review of the evidence that S&S itself commissioned. No reference or justification for it is offered anywhere in the S&S Business Case or the Minutes of their meetings. There has never been any warrant, based on either evidence or consensus for saying that there is any advantage in all of the 500 patients who undergo surgery for their CHD at each centre being aged under 16.
- 3.5.6 Having adopted the target of 500 paediatric cases, they have left the two figures of 400 and 500 behind, as though they have forgotten where they came from. Now they are used to create a double standard, 500 for London and 400 for the centres outside. The individual surgeon must perform 126 paediatric operations a year in London, but just 100 will do if he works elsewhere.
- 3.5.7 As a result of its insistence on considering children in isolation, S&S underestimated the throughput of centres which follow the vertical model. Thus they have reached the indefensible position of condemning a centre such as Royal Brompton which has reached all three thresholds for the last two years. There are four surgeons, they do perform 500 congenital cases a year, of which 400 are paediatric. They did this not only in the year under review but subsequently as well:

Table 1:
Royal Brompton Hospital Congenital Surgery Operations 2009-2011¹⁶

		<u>NHS</u>	<u>0/seas</u>	<u>Private UK</u>	<u>Total</u>
2009/10	Adults	104	10	20	134
	Children	<u>330</u>	<u>59</u>	<u>23</u>	<u>412</u>
	Total	434	69	43	546
2010/11	Adults	118	13	7	138
	Children	<u>379</u>	<u>39</u>	<u>13</u>	<u>431</u>
	Total	493	52	20	565

- 3.5.8 If a more flexible approach had been embraced which acknowledged the contribution ACHD cases make to the sustaining of surgical skills as well as

the need to cater for these patients properly, S&S would have realised that it could achieve 500 cases per annum without closing so many centres, with the consequent disruption of teams and services and increased need for patients to travel.

3.5.9 Since the Royal Brompton has been more successful at dealing with ACHD than anywhere else in London it does far more ACHD procedures. Royal Brompton is by far the largest centre in London, with our surgeons doing 138 of the 347 cases recorded by CCAD in 2010/11, more than twice the total for the next largest centre.

3.5.10 As a result our exclusion distorted the numbers to our detriment and led directly to the failure of S&S to give credit to what Royal Brompton is achieving more generally. Because no other centre does anything like 138 ACHD cases, this error distorted the comparison between centres.

4 The Flawed Aspiration: how many centres do we need?

4.1 S&S estimates that the number of paediatric cases this year is about 3,600 and that it will rise over the next 14 years to 3,990.¹⁷ S&S also estimates that there are a further 858 ACHD cases this year and that that figure is also rising. If the aspiration to avoid the unacceptable loss to follow up is accepted and acted upon, it may be anticipated that the ACHD figure will rise more rapidly. It seems reasonable to say that the NHS has to plan to cater for 5,000 CHD cases per annum of which 4,000 will be paediatric.

4.2 Balancing the problems of transport and economies of scale, the consensus advice on which S&S has relied would seem to suggest that the country could justify 9 or 10 centres if it is to comply with the 4 x 126 formulation across the country.

4.3 Anything more radical would seem to depend on a quite different proposition, a desire to create an equivalent centre of excellence able to rival Boston Children's Hospital – which now deals with 1100 cases a year - or the other 5 North American centres that deal with over 700 cases per annum. These are world-famous institutions doing great work; they have magnificent teams, ample resources and they are very large. However there is no evidence that the connection between these propositions is that the success and the brand are due to the size.

4.4 On the contrary, what has really happened over a period of decades is that hospitals like Boston, Philadelphia and Toronto have built up and supported a stable team of outstanding doctors and researchers. This has created a remarkable "brand" which has acted like a magnet for other doctors and researchers and patients. It has also

attracted money from industry and research funders anxious to be associated with this success. The size is the consequence of the success in other areas, the success has not been conferred in a top-down fashion as a consequence of the size. Indeed an article in the New England Journal¹⁸ this month looking at a wide range of operations (not including CHD) failed to find any convincing benefits of large scale institutions.

4.5 If the S&S team wish to emulate the Boston model, as we proposed in the 2009 paper that we will discuss in section 5 below, we suggest that they should do the following things:

4.5.1 Conserve and cherish the existing great brands. We believe that the Brompton has a distinctive brand in cardiac surgery like nowhere else in this country. We do not say that it is “better” than GOSH or Evelina , but it is different and it has a unique value. Its success can be measured by the numerous honorary fellows that are here, the doctors in training who come here at their own expense or sponsored by their governments to study and return to lead their institutions. The value of this process is indicated by their predecessors and other graduates of our training system who are now leading major institutions all over the world. Quite apart from the doctors who are leading other centres in this country, our former trainees include:

- Andrew Reddington, Professor and medical director at the The Hospital for Sick Children, Toronto
- Daniel Penny, Chief of Cardiology at Texas Children's Hospital
- Maurice Leung, Professor at the University of Hong Kong
- Lara Shekerdeman, Chief of Critical Care at Texas Children's Hospital
- Jochen Weil, Professor at the University of Hamburg
- Michael Cheung, Acting Director Cardiology, Royal Children's Hospital, Melbourne
- Kai Chou Lai, Chief of Electrophysiology at University of Sydney
- Tom Trail Professor of ACHD at Johns Hopkins, Baltimore, USA
- Katya de Groote, Paediatric Cardiologist, University Hospital Gent, Belgium
- Mayi Al-Sayed, Professor of Paediatric Cardiology, Cairo, Egypt

These alumni amongst many others form an international confraternity that refer bright young doctors between the centres to experience the way in which the profession is moving forward.

- 4.5.2 Recognise that if there is to be a radical change in organisation, it will require enormous resources and should be timed when these are available. At a time when all NHS organisations are short of funds and likely to remain so for some years to come, it would be folly to incur avoidable expenditure in pursuit of speculative long-term benefits.
- 4.6 At any time, a decision to close a great institution, to disrupt a team that has been assembled over decades involves certain harm and uncertain benefit. It is precisely the opposite course of what has yielded so much in the great institutions of North America. First there is the problem of persuading the surgeons and professors with international reputations who are used to working in a given way in a specific environment that they should move and adapt to a new institution where they know they will be newcomers. Some of them will seize the opportunity, but many will feel they are too old to start again in someone else's hospital, especially in such a high risk and pressurised occupation as paediatric cardiac surgery. A survey carried out by the BCCA during the S&S process¹⁹ reported this month that if their units were to close, only 27% of CHD cardiologists and 60% of PCCS surgeons would in fact move to another UK centre – the rest would do something else or retire. This represents a substantial loss: the proposition that there is an army of younger, brighter, better trained surgeons waiting to step into the shoes of senior consultants is not something that will appeal to anyone familiar with what has happened to medical training in recent years and the present recruitment problems in cardiac surgery.
- 4.7 If it is difficult to transfer the leaders, it is even harder to reassemble their teams. The clinical work pursued by these hospitals depends upon a myriad of partnerships. The surgeon needs the highly expert team of anaesthetists, perfusionists, nurses and the rest of those who look after the patient in theatre. The patient's safety also depends upon the cardiologists and investigative specialists who work up the case before they go to theatre, as well as the team who take over at the conclusion of the operation and manage the child safely through the PICU. Up to 100 people will look after one patient and an optimal outcome depends upon them all playing their part. The transfer of that team is highly unlikely to be achieved, even if the extra resources that would be needed were available.
- 4.8 The same is true of research. Successful partnerships are built upon far more than proximity. The researchers have to know what their colleagues are interested in

pursuing and where there are promising lines of shared interest. This knowledge and the inclination to work together often develop over many years. Moving part of a team will involve certain loss, and any compensating gains will be uncertain and slow to emerge.

4.9 In the face of this proposed disruption, the onus must be on the would-be innovators to justify their radical proposals. Before you start dismantling successful teams on this sort of scale, you have to be able to describe the alternative you will create and to demonstrate how and why it will be an improvement. Whereas in the 2009 proposal (described in para 5.1 below) there was a clear explanation of how and why the new shared centre would be structured, the presently suggested S&S version of the JCPCT offers no description of how or why there might be an improvement beyond a bold and unsubstantiated assumption that bigger is necessarily better.

4.10 Even if the proposition that England would be better-off with only seven centres is established, it does not follow that London should not have three of them.

4.10.1 The argument against having three centres in London is based on the proposition that it would require 40% of the patients to travel to London and that this is unfair and London-Centric. This is vulnerable to the principal objection that it is dependent on the requirement of 500 *paediatric* cases per centre, which is not supported by the professional consensus or the evidence – see above. If the team settles for the “magic number” of 500 cases based on 4 surgeons doing 126 cases, then three centres will carry 30% or 33% of the total CHD workload depending on whether there were 9 or 10 in total.

4.10.2 However, almost 40% of the cases do flow naturally into London. The maps S&S are presenting in order to justify consideration of Southampton at the expense of the Royal Brompton show patients from Oxfordshire, Hertfordshire and other counties just west and north of London being diverted away to Southampton.²⁰ Some of them may well travel past the Royal Brompton.

4.10.3 The contortions in which the Steering Group has engaged to justify the proposition are as evident as they are ungainly. For example:

4.10.3.1 They debated solving the Oxford problem by requiring the Brompton to move there, but then recognised that London patients would be reluctant to travel to Oxford. This rather overlooked the incongruity of disrupting a centre doing over 500 cases a year to support one doing 108.²¹

4.10.3.2 The double standard we have referred to above implicit in the words

“a minimum of 400 and preferably 500”

meaning that places such as Leicester, Southampton and Bristol will be judged satisfactory on a total of 400 cases, whilst the Royal Brompton, which already has 4 surgeons doing 430 paediatric and 168 adult cases a year as well as the capacity to expand, and which is the most productive centre in the country if catheter interventions are included in the assessment, will be closed for being too small!

5 The Mistakes made in the Assessment

Having been set up to fail to do justice to both the Royal Brompton and the approach it represents, S&S stumbled through the process and made a series of demonstrable errors in its handling of the evidence about clinical outcomes, which as the Minister of Health has now made clear should determine this issue. We will in this section review the specific and identifiable mistakes that have paved the way to what threatens to be a disaster for patients lasting decades.

5.1 The Dream Abused – the Misuse of the 2009 Paper

5.1.1 The Royal Brompton has for some years recognised that there would be value in a visionary new shared centre for heart and lung disease within which both approaches could flourish. We do recognise that there would be advantages of scale – there are disadvantages as well, but on balance we agree that a new centre, properly resourced in which we all pooled our assets would be to the benefit of all our patients. This was described in the 2009 paper approved as an outline by the Boards of both GOSH and Royal Brompton.²²

5.1.2 This has been misrepresented by S&S as an agreement that the Paediatric surgery at the Royal Brompton should close and all the work be transferred to GOSH. Thus when asked to explain the S&S process at the Emirates Stadium, Mr Leslie Hamilton, one of the Steering Group members, referred to the 2009 paper on six occasions, in response to every question he was asked. He asserted that Royal Brompton had agreed to a proposal to move paediatric cardiac surgery in 2009 and professed not to understand what the fuss was about now. This is a misrepresentation of the facts.

5.1.3 The case for creating an innovative new Centre is set out at paragraph 9.3.1 of the 2009 paper:

“The working group agreed that a single site option with improved patient care and family facilities, and staff working conditions would be the ideal. Further, it was recommended that the joint respiratory facility should end up in WC1 and not SW3. Although RB&H would lose co-location adult links (clinical, academic) it would gain easy access to non-respiratory paediatric specialists”.²³

5.1.4 These words appeared in the context of a carefully planned and financed joint project run by the teams from both hospitals. The words above appeared under the heading “Phase 3” and was to follow *Phases 1* and *2* which were described in paragraph 9.1 and Appendix 10. The coming together was to be preceded by a number of steps which were to involve an enormously ambitious new centre to be built by the Royal Brompton and GOSH and jointly owned. Appendix 10 paragraph 2 recognised that:

“any relocation of cardiac services would require inpatient respiratory services to similarly relocate”.²⁴

And a single site would be the ideal only so long as

“there were no compromises to patient standards”.²⁵

Amongst the long list of things Appendix 10 agreed would be necessary before this could happen were the provision of:

- **20 CF (*Cystic Fibrosis*) cubicles and 20 other respiratory beds**
- **Segregated 8-roomed CF clinics (4 per week) and at least 10 respiratory clinics per week**
- **Dedicated Sleep Unit of 6-8 beds**
- **Day Case Unit to handle up to 500 /year**²⁶

5.1.5 S&S omit any reference to these awkward details in what is a startling example of quotation out of context. The original proposal was summarised in the crucial paragraph 6.4 of the Report:

“An evolutionary approach will be adopted, building on the current collaborative ways of working, transitioning gradually to a single organisation and eventually to a single site, subject to the availability of appropriate space and related funding.”²⁷

- 5.1.6 In other words, the 2009 paper described an ambition of both institutions working together to promote all of their relevant services in a new properly funded, single site, world-leading centre in which cardiac and respiratory services would relocate after exhaustive preparations. This would enable both teams to be preserved, it would build on the shared brands of the Royal Brompton Hospital and Great Ormond Street. We identified a careful process that would be necessary before respiratory and cardiac services, joined at the hip, could be moved together to a new centre.
- 5.1.7 This is almost the antithesis of the smash and grab raid which is now proposed by the JCPCT whereby the paediatric cardiac surgery is to be torn out of the Brompton and distributed between two other centres, rendering the interventional cardiology, the respiratory medicine and ACHD services at Royal Brompton non-viable and with it the potential fiscal viability of the hospital.

5.2 The Perverse decision to Ignore Overseas Private Patients

- 5.2.1 Because of its international reputation as a world-leading centre, the Royal Brompton has attracted a large proportion of private patients and paying patients from a number of sources overseas. These are plainly a valuable resource: it is often overlooked that revenues from private patients make a valuable contribution to NHS trusts' overall income streams, money which is then reinvested back into NHS services. It may or may not be true that they are not in the long term as reliable a source of income as NHS patients, but they show no signs of slowing up and they are part of the demand that the service as a whole wishes to meet. Over the 8 years since 2003 the volume of our patients coming from overseas has been fairly stable. It has fluctuated between 58 cases in 2004/05 and 80 cases in 2006/07. It is not, incidentally, true that they all come from countries such as Greece that are economically challenged.
- 5.2.2 S&S decided to ignore the overseas paying patients who come to the Royal Brompton, so that its "magic number" of 500 refers only to UK patients, as though overseas private patients did not count as valid clinical cases within the total of 126 patients managed by each of 4 surgeons!
- 5.2.3 The exclusion is flawed because the S&S was concerned to assess capacity rather than marketing achievement: the overseas patients are characteristically more complicated – the simplest procedures, such as the

closures of the patent ductus, are more likely to be done in their countries of origin. More will be re-operations, which are characteristically more challenging and absorb more theatre and PICU time. Thus if the overseas patients did stop coming, they would free up more spare capacity and mean the Brompton was able to do even more cases. There is some evidence of this in Table 1: the slight diminution in private and overseas cases in 2010 was associated with an increase in total cases in the year.

5.3 The Perverse Research Assessment

- 5.3.1 When the NHS was founded in 1948 a single specialty hospital was designated as the Postgraduate Teaching Hospital for each of 12 subjects. These hospitals, run by their Preserved Boards of Governors were designated by the Minister of Health as the postgraduate centres of excellence for each specialty. What has become the Royal Brompton was thus designated as the national centre for cardiac disease by the Minister of Health in SI 1948 No 979 under powers created by the NHS Act 1946. London University established a national centre of academic research to partner each of the hospitals. Thus, Great Ormond Street was established as the Postgraduate Teaching Hospital for the single speciality of paediatrics and the Institute of Child Health was established by London University as its research partner. What became the Royal Brompton Hospital was designated as the Postgraduate Teaching Hospital for cardiology and chest medicine and surgery and the National Heart & Lung Institute (NHLI) was established across the road as its research partner.
- 5.3.2 Over the course of the next 60 years this partnership has pioneered the development of many aspects of cardiac science as well as congenital heart disease. The result is an enormously wide range of research which informs every aspect of paediatric cardiac surgery. The NHLI now boasts 28 Imperial College professors, all specialising in some aspect of cardiovascular medicine; some of them are pure scientists but many of them hold shared appointments as clinicians at the Royal Brompton.
- 5.3.3 The S&S team have no particular skill in assessing the quality of research, being a mixed specialty group of people. Indeed it was the absence of anyone there with an express brief to represent the interests of research that Dr Macrae pointed out when he suggested they should co-opt Dr Piers Daubeney, a Reader in Paediatric Cardiology to the SG in 2009. It is thus

surprising that the Committee should have taken upon itself the task of reassessing the quality of research nationwide and ignored the work of the Higher Education Funding Council for England (HEFCE) in its Research Assessment Exercise (RAE) which was published in 2008. This was an enormous and rigorous attempt by the academic community nationwide to grade every university for the purposes of planning the future work of HEFCE in deciding where to distribute funding for future research. It commands general respect for its rigour and fairness, even amongst the disappointed centres. Since this will determine how a large amount of research money was distributed over the next 10 years it was fiercely competitive and every university put forward those whom it thought were doing the best work and they were then graded by their peers.

2008 Research Assessment Exercise

Unit of Assessment : 01 Cardiovascular Medicine

Number of submissions: 13

	FTE Category A staff submitted	Overall quality profile (percentage of research activity at each quality level)				
		4*	3*	2*	1*	unclassified
University of Birmingham	25.70	5	35	60	0	0
University of Bristol	20.00	10	45	45	0	0
University of Cambridge	14.00	35	50	10	5	0
Imperial College London	64.27	20	45	30	5	0
King's College London	32.40	20	60	20	0	0
University of Leeds	30.00	5	40	55	0	0
University of Leicester	21.00	10	45	40	5	0
University of Manchester	24.20	15	60	25	0	0
University of Oxford	18.60	45	40	15	0	0
St George's Hospital Medical School	16.86	5	45	40	5	5
University of Sheffield	22.00	0	25	65	10	0
University of Glasgow	50.60	15	50	30	5	0
Cardiff University	19.40	5	35	40	20	0

Table 2: HEFCE National RAE of the quality of research in cardiovascular medicine. Source HEFCE Website.

5.3.4 It is remarkable that Imperial College, of which the NHLI is located and the Royal Brompton provide the cardiological component, was found to have more cardiology researchers doing 4* work, that is work of

“Quality that is world-leading in terms of originality, significance and rigour “

than any other two Centres in England put together. It is astonishing that the Panel should have ignored this when reaching a radically different view. To

reject such an authoritative conclusion reached after such an exhaustive process looks brave if not idiosyncratic; to fail to refer to the HEFCE's RAE when doing so looks ill-informed.

- 5.3.5 At the same time as HEFCE was recognising the pre-eminence of Imperial College's academic research, the NHS National Institute of Health Research (NIHR) had to decide where to site two of its Biomedical Research Units in cardiovascular and respiratory medicine. This is the Department of Health's equivalent recognition of excellence and two were placed in the Royal Brompton Hospital. It is only a small component of the research being carried out at the Brompton and the NHLI – but as a recognition of excellence in research by the NHS it is unequalled. Here at least the S&S team did recognise the presence of the BRU, but they disregarded it on the basis that:

“The Trust has a good track record with clinical research however the panel felt this has recently slipped and the research undertaken by the two BRUs at the Trust is not relevant to paediatric cardiac surgery...The panel did not feel that there were explicit plans for research undertaken by the BRUs to include research relevant paediatric cardiac surgery”²⁸

This sort of value-judgement is hard to counter but the breadth and volume of publications undertaken by Royal Brompton is hard to reconcile with such a proposition (<http://www.rbht.nhs.uk/research/projects/publications/> and <http://www.rbht.nhs.uk/research/projects/>). More cogently HEFCE found that the scale of the work being done here dwarfs that at other centres.

- 5.3.6 It is true that one of the two BRUs is less likely to be directly relevant to cardiac surgery since it is concerned with respiratory medicine. However even here we may note that primary ciliary dyskinesia, a respiratory condition, is also associated with complex congenital heart disease (an association first described at this institution) and there are ongoing joint projects which might sit in either BRU. The same is true of acute lung injury after cardiac surgery, in which Dr Nazima Pathan is leading an important project.
- 5.3.7 Nevertheless, we do accept that the majority of research work in cardiovascular medicine undertaken by the NIHR and the majority of work undertaken by the cardiovascular BRU do not deal with the subject of paediatric cardiac surgery narrowly defined. But what S&S overlooked, inexplicably, is:

- 5.3.7.1 The BRU means that the DoH NIHR, in its way as respected as HEFCE, although not setting out to do the same thing, has given

Royal Brompton a similar vote of confidence in the quality of its research;

5.3.7.2 That the future best interests of patients suffering from these diseases will be served by supporting a broad base of research into cardiovascular science, not by concentrating narrowly on surgical research. The damage that will be done to research as a result of this decision will impact on future generations.

5.3.8 In fact research being carried on here over the next five years will pioneer new treatments for heart disease using gene therapy, stem cells, tissue engineering and mechanical and electrical devices. We are also working on cardiovascular genetics in close synergy with advanced cardiac imaging and cardiac positron emission tomography (PET). We expect that this will lead to a stream of discoveries about new mechanisms of heart disease and new treatment modalities for them. The imaging technologies will also be used to develop new techniques for delivering novel treatments, such as stem cells. It may be that the Panel decided to ignore work being done at the NHLI on the grounds that it is not taking place in the Trust, if so this is difficult to understand.

5.3.9 Work being carried on at Royal Brompton which is not being carried out by cardiac surgeons includes studies of the following:

- The incidence and nature of specific congenital diseases in this country and abroad which have elicited risk factors for poor outcome from surgery.
- An enormous research study into the association of assisted conception and congenital heart disease.
- The use of clopidogrel to prevent post operative thrombotic disease in paediatric surgery.
- The use of Ivabradine which slows the heart rate in patients with congenital heart disease.
- Studies of connexins, which are proteins composing the junctions between heart muscle cells and may be responsible for impaired cell to cell communication and hence the development of congenital cardiac abnormalities.

- World-leading work is being carried out at Royal Brompton Hospital into cardiac electrophysiology and cardiac morphology studying the structure of the heart will help to reduce the dangers of surgery.
- We are unique in having two Readers in Fetal Cardiology and their present projects, in addition to the description of structural defects at a time when the fetal heart is tiny include
 - Studying fetal ECGs and arrhythmias,
 - Studying perinatal adaptation of the fetus with CHD
 - Investigating biochemical markers in CHD and 3D-fetal echocardiography.
 - The development of normative data.

The contribution of the Brompton to the clinical care of the fetus with CHD, like its work in teaching sonographers and other professionals to recognise f-CHD with the aim of improving prenatal detection rates does not appear to have been taken into account at any point when S&S 'graded' the Royal Brompton against other centres in the UK.

- 5.3.10 None of this is research into paediatric cardiac surgery per se, but, crucially, these are studies are likely to benefit the service offered to such patients over the next 10 years and they are crucially dependent on the clinical work with patients going on around them. The proposition that Royal Brompton is not an outstanding international centre of research simply does not stand comparison with the objective evidence, and the proposition that none of this will benefit patients with CHD is similarly unsupportable.

5.4 **The Flawed approach to Quality**

It is very difficult to understand how S&S has reached its conclusion in assessing the quality element of different Centres. The view that was reached does not stand comparison with the objective data which shows for example that Royal Brompton's mortality data stands comparison with other speciality centres elsewhere. Certainly none of the documentation that we have seen enables us to understand what the Panel mean by quality or the respects in which the other London centres were found to be better than Royal Brompton.

5.5 At the moment we are quite unable to understand how the Panel have reached their assessment of Quality. We have requested an explanation repeatedly but as of June 28th 2011, we have met with obstinate resistance. We have called for the raw data relating to the assessments of the other centres and hope that when these are forthcoming, as of course they will eventually have to be through the Freedom of Information Act and the process of disclosure in our application for Judicial Review, they will be taken into consideration as part of this consultation.

5.6 **The Misunderstood Co-Location**

5.6.1 The strongest argument of those who believe in a horizontal approach is that any other specialist services that a child might need will be available on site from a dedicated team already there. Great Ormond Street Hospital (GOSH) understandably believes that it has unequalled strength in this direction. Evelina Children's Hospital believes that it combines the best of both worlds since it has adult medicine available from the adjacent Guy's & St Thomas' Hospital whilst having a large range of paediatric specialists available within the Evelina Children's Hospital itself. In fact there are good grounds for concluding that all three hospitals have to make compromises and that the compromises made by the Royal Brompton are no less advantageous to patients than those made elsewhere.

5.6.2 First, the importance of respiratory medicine to these children cannot be over stated. A significant proportion of children being treated for cardiac disease also need the attention of respiratory physicians and vice versa. Royal Brompton has the strongest respiratory team in London led by Professor Andrew Bush and indeed that team is relied upon by the Evelina Children's Hospital to assist with some of their cardiac surgical cases.

5.6.3 By contrast, Royal Brompton enjoys an advantageous relationship with the Chelsea & Westminster Hospital ("C&W") in the form of fixed Service Level Agreements (SLAs). C&W is 10 minutes' walk from Royal Brompton, less time than it takes to cross the campus at many a larger hospital and certainly less time than it takes to reach, for example, the Evelina from Guy's or Lewisham Hospital, the Freeman Hospital from the Royal Victoria Infirmary in Newcastle or Leeds General Infirmary from St James's Hospital in Leeds. All of these intra-Trust journeys are far longer than the distance between C&W and the Brompton. Furthermore, Royal Brompton has two priceless advantages arising from its SLA with C&W. The first is that the attending

doctor is always a Consultant and second, once they have reached Royal Brompton it is a matter of moments to reach the relevant ward and obtain whatever support is needed.

- 5.6.4 Where such compromises have to be made, a fair assessment will inevitably revert to the standards for co-location laid down by the Baker Report. There is no question but that our arrangements mean that we meet those requirements handsomely.

6 The damage that will be done to clinical outcomes

The most puzzling proposition in the S&S Review was contained in the sentences:

“It is proposed that the Royal Brompton Hospital has scored lower than the Evelina Children’s Hospital due to the application of the sub criterion ‘the negative impact for the provision of paediatric care and other inter dependent services is kept to a minimum’ as the PICU at the Royal Brompton Hospital exists predominantly to support cardiac surgery the exclusion of this unit from potential configuration options presents limited risk to local and national PICU provision.”²⁹

This remarkable sentence makes the classic mistake of attempting to judge the effect of an action by looking at what is being taken away, rather than attempting to assess the viability of what will be left behind. Of course it is true that since 10 of the 12 beds in the Royal Brompton PICU are devoted to CHD surgery, only two other beds would be affected; but that adds nothing to the analysis of the problem and makes no attempt to assess the extent of the other services that will be compromised. We are glad that the S&S team should have belatedly set up a working party to assess this, but since this has happened after proposals were formulated on which the public has been consulted, it is hard to see how it can feed into the consultation process or how the working party can do anything other than attempt to make excuses for what has been done.

The reality is that the proposal to withdraw paediatric cardiac surgery from Royal Brompton Hospital will call in question the Trust’s professional and fiscal viability. The oversight plainly reflects the fact that Royal Brompton alone of the hospitals in London was unrepresented on the S&S Steering Group. Even so, the indifference to the damage that will be done to clinical outcomes for a broad cohort of respiratory and cardiac patients beggars belief.

6.1 The Damage to other Paediatric Services

The devastating effect on other paediatric services that will result from these proposals has been spelled out in detail in the paper submitted to your expert panel by our Chief Executive and we attach a copy [Annex 1].

6.2 The Financial Damage

- 6.2.1 According to our latest annual accounts to 31 March this year, the turnover of the Trust is about £284 million.³⁰ The surplus before meeting our public capital dividend obligation is about £10 million.
- 6.2.2 According to the 2009 paper agreed by both Trust Boards, our income from paediatric services including cardiac surgery was then about £28 million.³¹ The direct costs that we incurred in delivering this service were £17 million and the indirect costs were £7.1 million. We made an estimated net surplus from this work of £3.7 million for reinvestment in services. It is worth noting that today's equivalent of this surplus will under these proposals become available to other centres whose representatives were on the Steering Group. It would be naïve to conclude that this fact escaped the attention of those representatives. GOSH was noted by the 2009 paper to have a deficit from this work of £0.4 million. The financial incentive for others to take over this work is self-evident.
- 6.2.3 However, what we want to concentrate on in this document is the damage it would do to our business model if a total income of £32 million (the value of our paediatric services revenues for the year to 31 March 2011) was stripped from our turnover and the only savings that we made would be the related direct costs. This would certainly imperil the Trust's financial standing with its Foundation Trust regulator, Monitor. This has already been recognised by the bank with which we were negotiating a working capital borrowing facility: the bank withdrew from the process, expressing concerns about the financial impact on the Trust of losing our paediatric service. We have since been able to make other borrowing arrangements but only at an additional cost of some £200,000 a year. So the S&S Review has already caused us financial damage because private bankers can see the harm it will do to our Trust.

6.3 The Damage to the Vertical Model for dealing with Familial Conditions

The Consultation Document is based on the premise that the future model for the delivery of paediatric services can be determined in isolation to the future model for delivery of adult services. This is fallacious because it overlooks the importance of the Royal Brompton approach for various specific groups of patients. We will dwell on this because the composition of the Steering Group has resulted in these important matters not being considered – as far as we can see they were never discussed. Many cardiac

electrophysiological conditions are inherited, and parents and other family members of such children may all be at risk of sudden death. The Royal Brompton model of vertical care enables the whole family to be assessed together. Organisations such as CRY and SADS demand centres that can provide comprehensive care for all affected family members.

- 6.3.1 The service needs to be based around the family, and in a dedicated family multidisciplinary clinic, where all members can be seen during the same visit, under the same roof and where the complex physical and psychological issues and family dynamics can be addressed. The family needs to be confident that at a very stressful and traumatic time, there will be *seamless care across age groups* to all those affected, as Professor Qureshi is quoted as saying in the Consultation Document.³² They will not want to keep going over the same complex and potentially painful case history with a succession of new and different medical advisors. All members of the family will want to know that the team dealing with them is fully conversant with both the individual case history and the picture of the family as a whole.
- 6.3.2 Many affected children are in the adolescent age group and need care from their teenage years to young adult life. A joint service facilitates a seamless transition from paediatric to young adult and then full adult services and it doesn't make sense to be assessed at 15 years in one hospital to find you need to move to a different hospital and set of doctors the next year.
- 6.3.3 Children with rhythm abnormalities may require an implanted device such as a pacemaker or an implantable defibrillator as part of their management. Worldwide, such devices are much more commonly used in adult patients. Children with rhythm problems also require electrophysiological treatment and ablation. A joint adult and paediatric service is better placed to provide optimum world class management for these children as they can use the extensive experience gained from the adult patients to best serve these children and provide ground breaking treatment. The Safe and Sustainable process has not considered that around the country many adult trained electrophysiologists perform ablations on children. The result of closing centres would be that you would not leave an adequate number of operators for the children requiring ablation. Without children, centres catering for adults would be less able to sustain an electrophysiology service because volumes would be reduced.

- 6.3.4 The service at the Brompton for arrhythmia care in children is one of the largest in the UK, running dedicated inherited cardiac disease and paediatric arrhythmia clinics and seeing over 1500 patients per year.

6.4 The Damage to Adult Congenital Cardiology

Royal Brompton Hospital appointed the first Consultant the country in ACHD in 1988. This reinforced our philosophy that CHD a disease which is rarely cured by the initial surgery and the patients suffering from it need to be supervised throughout their lives. The removal of paediatric cardiac surgery and interventional cardiology will undermine this seamless approach and destroy the cross fertilisation which has proved so valuable. It will also immediately weaken the ACHD programme because over 70% of new attendees to ACHD clinics every year are graduates from our own paediatric service.

- 6.4.1 We have already pointed out that there will not be a critical mass of ACHD patients coming to surgery in sufficient numbers to support a safe and sustainable team of four surgeons who are not practising occasional surgery. The arithmetic that the S&S team have found to be so beguiling when dealing with small children applies just as strongly to the cohort of patients they have thus far ignored. That will be a fundamental weakness in those teams performing ACHD in the future: the Royal Brompton's team will be diminished so that it resembles those at other centres. Our 138 operations last year viewed in isolation could be handled by one surgeon, but a team of one cannot provide safe out of hours, sick leave, holiday or study leave cover; he cannot train a successor. He is neither safe nor sustainable. If we appointed one colleague we would not resolve those issues satisfactorily and by reducing the two to 65 operations a year we would enter the dangers of occasional surgery.
- 6.4.2 The damage that this will involve can be seen by comparing what happens at the Royal Brompton with what happens at other centres. At the Royal Brompton Hospital the team consists of four Consultants who specialise in ACHD. The paediatric cardiologists who come to the ACHD clinics are those who have treated the patients in the past and who are treating their successors. There is thus a clinical cross fertilisation as well as mutual support for their research.
- 6.4.3 The ACHD team at the Royal Brompton Hospital is an internationally renowned centre of excellence. At any one time there are 7 or 8 overseas

research fellows – doctors who have come from abroad either at their own expense or sponsored by their own Governments, in order to experience what the world famous team at Royal Brompton Hospital has to offer. There have so far been 80 such International Fellows who have contributed not only to the treatment of our patients but also to the advancement of learning. The S&S team seem to have proceeded on the footing that the ACHD team at Royal Brompton might be undermined by losing a few recruits each year as they graduate on their 16th birthday, but that otherwise things will carry on much as they are for a decade or so. The reality is that the business model of the ACHD team will be fatally flawed as soon as this is introduced. For example:-

- 6.4.3.1 The loss of the paediatric cardiologists will immediately diminish the quality of the Multi Disciplinary Team meetings that consider ACHD cases;
- 6.4.3.2 The loss of 70% of their new referrals each year would impoverish the research and the clinical work of the team.
- 6.4.3.3 The loss of the paediatric ACHD surgeons will mean that they will be immediately unable to maintain a cadre of up to date skilled surgeons that matches the 4 x 126 criteria set by S&S for children and which we believe holds true for adults for the same reasons.

6.5 The Damage to Fetal Cardiology

- 6.5.1 This is at the opposite end of ACHD in the Royal Brompton vertical model. We have 5 Consultants (2 full time Readers and three who also do paediatrics) who provide prenatal assessment of fetal congenital heart disease (f-CHD). Royal Brompton is one of the largest service providers in this area in the UK and our team approach has secured an international reputation. We were pioneers in introducing first trimester assessment of the fetal heart in clinical practice. By comparison, the Evelina has one full time specialist fetal cardiologist and GOSH as a Children's Hospital, understandably does not have a single full time fetal cardiologist on its staff.
- 6.5.2 The team involves not only paediatric cardiologists but also cardiac surgeons, cardiac nurse specialists and clinical psychologists working at the Royal Brompton and Harefield sites. We work with fetal medicine specialists, obstetricians, midwives, clinical geneticists, neonatologists and paediatric pathologists in fetal medicine units across London. We take our expertise to the units where f-CHD presents and thus optimise prenatal care and the care of the newborn affected with a critical cardiac lesion. As a multidisciplinary team, we deliver quality service throughout pregnancy so that we prepare families for the arrival of their baby who will be treated by the same team they got to know during pregnancy.
- 6.5.3 The contribution of Royal Brompton to the clinical care of the fetus with CHD, to teaching sonographers and other professionals to recognise f-CHD with the aim to improve prenatal detection rates and the growing research activities in this area do not appear to have been taken into account when S&S 'graded' the Royal Brompton against other centres in the UK. Our loss would have an impact on the quality of fetal cardiology far beyond the walls of this hospital. Similarly the work of our fetal cardiologists is not confined to describing structural defects, it also includes all the areas of research we described in section 5.3.10
- 6.5.4 If Royal Brompton paediatric cardiac surgery closes, this will undoubtedly disrupt a model that is known worldwide for its quality of clinical service. The S&S negative impact on this service will unquestionably impact on the research work that Brompton Fetal Cardiology has developed over the last 15 years.

6.6 **The Impact on the work of the Chelsea and Westminster Hospital**

Our work is closely integrated with the Chelsea and Westminster Hospital. Many of their patients utilise our operative facilities and PICU. We can see no evidence that this has been understood and taken account of by the S&S review. A sensible review would have to quantify this damage and consider how the necessary compensations would be reached.

6.7 **The Loss of the Hospital**

For the reasons we have described above, we believe this proposal could potentially destroy Royal Brompton. If so, the consequential damage would include the whole of the adult cardiac and respiratory services of the Trust. The Business Model of the organisation simply could not withstand the impact of these proposals which have been crafted by our competitors so as to exclude any option under which Royal Brompton would continue, despite having the largest caseload of CHD procedures according to the Central Cardiac Audit Database (nowhere else does over 1,000 procedures per annum, taking operations and catheters together). It is this that made us take the unprecedented and regrettable step of instructing lawyers to sue the JCPCT: our duty was and is to our patients and our work and we believe we were left with no alternative when a detailed and carefully planned process from which we had been deliberately excluded came up with a series of options for public consultation, not one of which included the continuation at Royal Brompton Hospital. Nothing we have learned at any of the public meetings has changed our minds.

7 **The Way Forward**

7.1 The S&S proposal is a devastating blow that will be equally damaging to the financial, clinical and the research business plans of the Royal Brompton & Harefield NHS Foundation Trust. It will be wholly destructive and as such represents the antithesis of the joint plan of 2009 to create a world-leading joint centre for paediatric heart and lung disease. It will directly destroy a wide range of services delivered to the paediatric cardiac surgery patients and the interventional cardiology patients; it will render the services to the paediatric respiratory patients and the adult congenital patients unsafe and unsustainable. All of these services can be rebuilt elsewhere eventually, but only after causing harm that will damage the interests of patients for a decade or more. Even if the experts who lead the teams may agree to be re-employed elsewhere, all of them depend upon the highly skilled, coherently integrated teams that they lead. Many

of these team members will be unable to move for family reasons, for professional reasons or because at a time of stringency there simply will not be enough money in the system to rebuild the centres in the fashion that would be necessary, even if the space can be found within the competing institutions.

- 7.2 It is evident that the S&S team either failed to understand this because they ruthlessly excluded anyone from Royal Brompton Hospital from their counsels, or because the destruction of Royal Brompton Hospital was anticipated from the outset and before the evidence was considered at all. There are those who cynically believe that it was part of a deliberate plot to destroy this independent successful Foundation Trust to access the value of our real estate, so that it will be available to support less successful NHS bodies. Whatever the truth of the matter, this is the destruction of a tradition of excellence which has been built up over 150 years. It will be a tragedy for countless patients in the future.
- 7.3 We hope that those who have read this will realise not only why we have been forced to go to court, but why we are confident of succeeding. However this is an argument that can only be resolved by the NHS and we do urge our colleagues even at this late hour to realise that the proposal that has been put forward is miscalculated and ill-advised. We cannot suppose that the NHS really wanted to do this amount of damage to one of the world leading institutions which has contributed so much to the interests of patients.
- 7.4 Royal Brompton Hospital is a recognised national centre of excellence, which has been built up over many decades. It has a world famous reputation that once lost could never be regained. Its loss would be a disastrous setback, not only for countless patients in the future, but also for the art and science of cardiac surgery, cardiology and respiratory medicine.

8 Our Axioms

We conclude with ten axioms that we suggest should guide your further deliberations:

- 8.1 Any decision to withdraw a clinical service should be taken on the basis of evidence or a broadly-shared professional consensus about what may be expected to produce the best clinical outcome for patients over the foreseeable future.
- 8.2 We will only deal with part of the problem faced by patients suffering from congenital heart disease if we deal with children in isolation, and such a piecemeal approach will

have a devastating effect on fetal services and those required by children when they reach 16 if it does not consider their interests.

- 8.3 The only professional consensus that has been articulated before the S&S process is for 4 surgeons x 126 cases leading to 500 cases of CHD operations per institution per annum, of which 400 should be on children.
- 8.4 There is no evidence-based or theoretical advantage in handling 500 paediatric cases a year in one centre, and it will do harm if that centre is imposed in a top down fashion rather than being allowed to develop organically, capitalising on what has already been achieved as a result of investment over decades.
- 8.5 There is no basis for the pretence that the 400/500 aspiration justified a double standard for centres in London and outside.
- 8.6 London fully justifies three paediatric cardiac surgery centres and the only contrary argument is the NHS political one that we quoted in paragraph 3.1.1 above.
- 8.7 Further reorganisations beyond those necessary to deliver the 400/500 objective should reflect specific opportunities to deliver improved clinical outcomes for patients.
- 8.8 No unnecessary reorganisations can be justified in a time of financial stringency because the cost will divert scarce resources from patient care.
- 8.9 There is no evidence of countervailing benefit to justify the damaging disruption of clinical services.
- 8.10 Any sensible plan to reorganise services must take careful account of the damage that it will do to other aspects of the National Health Service.

The future lies in two or more of the three London centres jointly collaborating to create a pan-London/National centre of excellence. This was the basis of the 2009 joint Royal Brompton and Great Ormond Street initiative. The Royal Brompton & Harefield NHS Foundation Trust remains committed to these principles.

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For the attention of the expert Panel advising the JCPCT:

**“A SUMMARY OF CONCERNS RELATING TO THE IMPACT OF THE JCPCT’S
PROPOSALS ON ALL OTHER PAEDIATRIC SERVICES OPERATED BY THE ROYAL
BROMPTON & HAREFIELD NHS FOUNDATION TRUST”**

Submitted on behalf of the Board of the Royal Brompton & Harefield NHS Foundation
Trust,

June 23rd 2011



Robert J. Bell,
Chief Executive

1. Preliminary remarks to our Summary

- 1.1 In a letter dated 2nd June, Sir Neil McKay has kindly invited the Board of our Trust to lay out its concerns as to the impact of the JCPCT's proposals - that the Royal Brompton Hospital (RBH) should cease providing paediatric cardiac surgery - on all other paediatric services carried out at RBH.
- 1.2 Although Sir Neil's letter refers to 'other paediatric services', the Terms of Reference (ToR) for the Panel to whom this Summary has been submitted however identify only two types of services, namely '*diagnostic bronchoscopy*' and '*paediatric respiratory services*'. The stated rationale for this is that these were 'the services identified at risk by RBH'. The ToR also states that "*the RBH did not submit any detailed evidence to the JCPCT about the services during the review process during 2010 and 2011*".
- 1.3 In response to this, we ask that the Panel should be aware that throughout the review process our Trust has consistently indicated that a very broad range of services would be subject to the impact of the proposals of the JCPCT:
- At the end of March 2010, in a paper submitted to the London Specialised Commissioning Group (LSCG), a senior member of which subsequently sat on the Steering Group / 'expert clinical group' that advised the JCPCT, we pointed out that:
 - "*Reconfiguration around surgery at two sites would cause the relocation or severe undermining of all RB&H's inpatient paediatrics, including paediatric intensive care, paediatric thoracic surgery, paediatric long-term ventilation and paediatric respiratory medicine*"; and that a likely consequence of this "*would be to force the GUCH programme at RB&H – the largest in the UK - to wind down*".
 - In May 2010, our formal submission to the Kennedy review stated that:
 - "*The removal of paediatric cardiac services would render the PICU completely unworkable, in turn removing an essential underpinning for our paediatric respiratory services for patients with diseases such as cystic fibrosis and DMD [Duchenne Muscular Dystrophy]. These are widely recognised as one of the leading set of services in the UK, if not Europe: the impact on patients (as well as on the Trust's long-term financial health and reputation) would be hugely detrimental*".
 - On the 3rd June 2010, we received from the National Specialist Commissioning Group (NSCG) on "Safe & Sustainability" letterhead a summary prepared by the LSCG commenting on our formal submission to the Kennedy review, one of which comments stated that:
 - "*Commissioners are aware that the loss of the PCCS service would significantly undermine much of the rest of the Trust's paediatric services, most significantly PICU*".
 - On the 11th March 2011, in a letter following a meeting with Sir Neil McKay, the Trust's Chief Executive and its Chairman stated that:
 - "*The inter-relationship of the services...was, in effect a house of cards. If Paediatric Cardiac Surgery went, Paediatric Intensive Care Unit (PICU) would cease to be viable, and that would impair our Respiratory Services, since they also depended upon the availability of PICU. We explained to you that Interventional Cardiology Services also depended upon there being a PICU and the availability of Cardiac Surgery so that Paediatric Cardiology as we practice it would also be imperilled...[and]...that the Adult Congenital Heart Disease (ACHD) service depended upon the inter-relationship and joint sharing of the same surgeons with [the] Paediatric Congenital Cardiac Surgery service.*"

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- 1.4 We respectfully suggest to the Panel that the premise upon which the scope of services for the Terms of Reference (ToR) is based – ie *'diagnostic bronchoscopy'* and *'paediatric respiratory services'* because these were *'the services identified at risk by RBH'* - is incorrect; and that the contention within the ToR that *'RBH did not submit any detailed evidence to the JCPCT about the services'* is wholly misplaced.
- 1.5 Consequently we have described in section 2 below three sets of services directly impacted by the JCPCT's proposals which however lie outside the ToR. In deference to Sir Neil's request that our Summary should focus on the Panel's Terms of Reference, we have abbreviated these descriptions so as to ensure that the main body of this Summary (section 3 & onwards) relates to services within the ToR.

2. Impact of the JCPCT proposals on services outside the Panel's terms of reference

- 2.1 The impact of these proposals extends in particular to three other adult and paediatric cardiac services of national and international standing that operate at RBH.
- 2.2 Paediatric Interventional Cardiology – the Trust is one of the largest centres in the UK providing electrophysiological interventions to paediatric patients with arrhythmias. These patients get ready access to technologies, expertise and equipment (eg magnetic navigation, device implantation) that exist as a result of a larger set of adult electrophysiology services, yet these interventions cannot be performed without paediatric anaesthesia and the back-up of a PICU. One important group of patients that would be affected would be those with Inherited Cardiac Diseases (ICDs), such as Hypertrophic Cardiomyopathy and Long-QT Syndrome. We believe that RBH is probably the only one of all the centres in the UK that has a fully comprehensive service for both adults and children, enabling it to diagnose and treat patients of all ages within the same family at the same time. This capability would be rendered useless if there was no access to paediatric intensive care and anaesthesia.
- 2.3 Adult Congenital Heart Disease (ACHD): RBH has the largest adult congenital heart disease population in the UK with more than 6,000 patients. The 'Brompton model' of vertical integration to treat the patient throughout all stages of his / her life is recognised internationally. It is this vertical model of care that determines that our four congenital surgeons operate on both adults and children, and that each achieves a level of more than 145 procedures each per year. If however they are no longer able to operate on children, the average number of procedures drops to 40, a clearly unsustainable level of activity. From a non-surgical perspective, some 70-80% of new patients entering RBH's ACHD patient cohort transition seamlessly from paediatric care (one of the key reasons why our population of 6,000 patients is the largest in the UK). Without this flow, the wider ACHD service will wind down inevitably and become unviable.
- 2.4 Pulmonary Hypertension: RBH is one of nine specialist pulmonary hypertension (PHT) centres in the UK, with a designated focus on patients with congenital cardiac abnormalities. Consequently 50-60% of these PHT patients – principally those with Eisenmenger Syndrome – arrive at RBH through the ACHD service and its clinics. Without the ACHD service feeding into it, our PHT service would lack the critical mass to remain viable.

3. Paediatric Respiratory Medicine at RBH – an introduction

- 3.1 The paediatric respiratory medicine unit is the largest clinical and academic unit of its kind in the UK, and arguably the only one of a size to compete internationally in both areas. With recent appointments, we comprise three full time and one part time NHS consultants, one Professor, one Reader and two Senior Lecturers, with three specialist registrars and three clinical fellows. The multidisciplinary team includes four specialist cystic fibrosis nurses (two home care full-time equivalents), two whole time equivalent specialist asthma nurses, a research nurse funded by the Medicines for Children Research Network, four physiotherapists (two home care job-share), two dieticians, two clinical psychologists and a specialist pharmacist. There are three physiologists, two for sleep and one for primary ciliary dyskinesia. We are an integral resource for the Technology Dependent Children's team, headed by Dr. Gillian Halley, which is staffed by a consultant, a respiratory advanced practitioner, two clinical nurse specialists, and a physiotherapy respiratory specialist. These teams have been built up over a number of years, and have developed ways of working closely together that enable the transfer of techniques developed by one team to all the others. Examples of this include the introduction of NIV (Non-invasive ventilation) to cardiac patients, and the development of common best practices in pain management and sedation. This combination of a critical mass of cross-disease / cross-functional expertise and proven working inter-relationships would be broken up in the event of the decommissioning of paediatric intensive care and anaesthesia at RBH, and its benefits wholly lost. We cannot identify any other single unit in London which can house this size a team in its entirety. It should be noted that despite the size of the team, on a per capita basis the CF (Cystic Fibrosis) Trust has identified us as having fewer staff members per CF patient than most other units.
- 3.2 The scale of our activities has been increasing steadily over the last five years, with over 1,200 patients generating 1,600 in-patient spells and over 4,800 outpatient consultations per annum. During the recent CF Trust accreditation visit, the unacceptably long waiting times for admission were highlighted, as a result of which we propose to open 14 new CF beds. We are also building a dedicated sleep laboratory, which will grow the number of sleep studies we can offer from 780 to c.1,100 per year as well as increasing their level of sophistication, and which will also be a major resource for Dr Halley's team. We know of no unit in London which can offer us in matched facilities. In addition to our in-house workload, we run Consultant delivered, shared care outreach clinics in 19 District General Hospitals across the South-East of England.

4. The essential role of paediatric intensive care and paediatric anaesthesia

- 4.1 It is impossible to look after sick children, or children with complex respiratory problems, without access to paediatric anaesthesia and paediatric intensive care. We know of no unit of comparable size or expertise anywhere in the world which would try to function without these specialities. The importance of these specialities to the various divisions will be highlighted in section 5.
- 4.2 Paediatric intensive care: the JCPCT recognises that the proposed decommissioning of Paediatric Cardiac Surgery at Royal Brompton will lead to closure of the Paediatric Intensive Care Unit. However they clearly have not considered the effect on other services of the closure of the PICU. Our admission figures for April 2010 – March 2011 show that of 615 receiving intensive care, 498 had heart disease as a primary cause of admission. Of these cases 436 admissions followed cardiac

surgery, the balance being children admitted following cardiac catheterisation, following electrophysiological procedures and both internal and external non-surgical cardiac cases such as cardiomyopathy and arrhythmia. In the same year the PICU also cared for 63 children with lung disease including 30 undergoing thoracic surgery (mainly for cancer), and the majority in support of our complex tertiary respiratory practice. Finally 32 children were admitted to the PICU following paediatric non-cardiac surgery. These children all had serious underlying heart or lung disease and needed major general surgical or ENT procedures. Our ENT and general paediatric surgical colleagues from other centres are an intrinsic part of our extended team, and have dedicated operating sessions in the Trust. They choose to undertake such procedures on complex cases at RBH because of the co-location of skilled speciality paediatrics (cardiology, paediatric respiratory medicine), paediatric anaesthesia and paediatric intensive care on the RBH site. In summary therefore, the closure of the PICU will displace not only 436 surgical children, but 179 other cases disrupting care pathways in children's cardiology, electrophysiology, paediatric pulmonology, paediatric thoracic surgery and paediatric general surgery.

4.3 Paediatric anaesthesia: Every paediatric cardiac surgeon, procedural cardiologist and bronchoscopist works hand in hand with a consultant paediatric anaesthetist and extended paediatric team. The volume of cases is just as important for the paediatric anaesthetist as for the paediatric cardiac surgeon. RBH provides 24/7 cover with anaesthetists dedicated to the paediatric service. Information drawn from the RBH Operating Theatre Information System shows that a total of 931 anaesthetics were undertaken for children under 16 years of age between April 2010 and March 2011. Of these cases 462 were paediatric cardiac surgery-related, 251 were respiratory (bronchoscopies), the balance being thoracic surgery, paediatric non-cardiac surgery and dental cases. In 2010 (data from Catheter Laboratory Database via Dr S. Jaggar), 440 anaesthetics were administered to children in the cardiac catheter and electrophysiology labs. Virtually all of this work requires the availability of an intensive care bed as either the planned post-procedural destination, or as a backup. The residual paediatric anaesthetic workload if cardiac surgery, cardiac catheterisation and other specialist surgery requiring PICU post-procedure were to disappear, as it will with the decommissioning of paediatric cardiac surgery and the closure of the PICU, the residual volume of paediatric cases would be insufficient to maintain a safe paediatric anaesthetic service on-site. This would further degrade the Trust's ability to provide acute care.

5. The wider impact of the close of the PICU and paediatric anaesthesia on other services

5.1 Clinical work – investigation of children with respiratory disorders: the most commonly performed invasive investigation is fiberoptic bronchoscopy (around 250 per year, which, although no National database exists, is probably more than any other unit in the UK). Although some units perform this procedure under sedation, it is the unanimous view of the paediatricians and anaesthetists that the very sick population of children we see are best served by general anaesthesia. Although unexpected admission after bronchoscopy to PICU is uncommon due to the experience of our theatre and anaesthesia teams, it would be quite unjustified to imperil the life of a child by performing bronchoscopy under anything but optimal conditions. Without paediatric anaesthesia and PICU we would be totally unable to investigate many children who are referred to us. Modern scanners for the most part do not require children to be anaesthetised, but in particular for small children adequate

scanning requires them to be anaesthetised. Again, this would be impossible if our paediatric anaesthetic service disappeared.

- 5.2 Clinical work – Cystic Fibrosis: We have the largest paediatric CF clinic in Europe (320 children) and the only larger clinic is Adult CF at Brompton (550 adults). Co-location with adult services allows seamless transition in this as in all other respiratory diseases. We are the only unit south of Liverpool able to offer a diagnostic electrophysiology service (nasal potential difference), and receive referrals from throughout the south of England, Wales and Ireland for this investigation, while also training investigators from CF units throughout Europe. A small number predictably require bronchoscopy (to determine whether occult infection is being missed in a child who is doing badly) and surgery (implantation of vascular access devices, feeding tube insertion). No specialist CF unit anywhere would try to function without offering these facilities, not least because the CF Trust would never accredit such a unit. We believe that the other main centre (Great Ormond Street Hospital) in London for paediatric CF has no spare capacity, having imposed upon itself a cap of a maximum of 200 patients.
- 5.3 Clinical work – Primary ciliary dyskinesia (PCD): Royal Brompton is one of only three centres which are centrally funded to offer diagnostic services for this condition. Typically more than 300 children are tested each year, with the numbers having risen steadily. We follow up 140 children with PCD through 6 specialist multidisciplinary clinics with audiology and ENT input, by far the largest group being followed up in the UK. In addition we have four annual transition clinics to stream around 16-24 patients a year into the adult PCD service here at RBH, which combined with the paediatric service constitutes the largest cohort of PCD patients in Europe. We are currently applying for NCG funding to develop further and expand the PCD management service to further improve the quality of care: having passed successfully through the preliminary bid process we are now in the final application process. If the bid is successful, we will then have the largest PCD clinic in the world with a service that runs 'from cradle to grave'. Children with PCD have very similar surgical and PICU requirements as those with cystic fibrosis: consequently this service would be rendered wholly inoperable by the loss of paediatric anaesthesia and intensive care.
- 5.4 Clinical work – Severe asthma: This service attracts quaternary referrals from all over the UK, and beyond to Europe, amounting in total to around 130 patients. We have shown that a specialist multidisciplinary assessment obviates the need for invasive investigation in more than half the referrals, and recent unpublished data shows that the benefits extend out to two years post-assessment. This leads to reduced morbidity in the children, and a reduction in NHS costs. However, a substantial remainder of these children require invasive investigation including bronchoscopy, which would be impossible without PICU and paediatric anaesthesia. We are leading on the UK-wide database, and also interacting with the GA2LEN network as part of the Europe-wide initiatives to set up randomised controlled trials of treatment. We are the only unit in the UK conducting controlled trials of the efficacy of steroid sparing agents for children with severe asthma, including omalizumab (monoclonal anti-IgE antibody), subcutaneous terbutaline, and other agents such as methotrexate and ciclosporin.
- 5.5 Clinical work – Technology dependent children: These patients fall into two categories.
- Firstly, in conjunction with the adult unit, we look after 220 children who use non-invasive nasal mask ventilators just at night, mainly because of muscle weakness, the largest such group in the UK. These children suffer acute deteriorations requiring PICU,

and their successful weaning requires the specialist skills of the physiotherapists. It would be ludicrous for their PICU care to be off-site, away from the physiotherapists whose skills are pivotal to a successful outcome

- The second group of patients (c.150) are children with tracheostomies, who have a much higher level of dependency, and for whom the Children's Long Term Ventilation (LTV) Service is unique in offering specialist clinical support across boundaries from hospital to home throughout London and the South East. The multidisciplinary team provides an outreach service to all London paediatric intensive care units as well as premature baby units, local hospitals, hospices, children's centres and the community. Our education and training programme is available to all hospital and community professionals with a module for parents and carers to support delivery of safer care at home.

The LTV clinical pathway is patient centred and won the NHS London Innovator Award in November 2009. Dr Halley's team has also received NHS London Regional Innovation Fund in 2010 and was selected against stiff competition to receive a second round of funding in 2011 to support diffusion of an initiative that has attracted the attention of government ministers including Secretary of State for Health, Andrew Lansley, and Lord Howe. Dr Halley is working with colleagues within the Department of Health to support care closer to home for this population and to redesign a commissioning model that matches the clinical pathway in order to deliver cost savings to the NHS as well as better quality of care for patients and their families.

It is vital that the team maintain advanced skills by working within the tertiary centre. Children referred from other regional centres are admitted to PICU for specialist respiratory evaluation including setting up portable ventilation and carrying out investigations including bronchoscopy. This inpatient assessment is often critical in evaluating medical stability and technology dependence which in turn supports local teams in their management and risk assessment. Building on the home nursing and physiotherapy care programme that RBH pioneered for Cystic Fibrosis, the LTV team is not just delivering an inpatient service but follows the entire patient pathway to ensure that care in the community is as safe as it can be. This service is in keeping with the NHS directive for care closer to home in long term conditions, as well as with the message delivered by David Nicholson to the NHS Innovation Expo 2011 in which he emphasised the importance of breaking down the barriers between hospital and community care.

5.6 Clinical work – Empyema: We look after 40-50 cases of empyema per year, and insert all chest drains under general anaesthesia. This is a very safe and humane way to carry out this procedure in children. Due to intensive medical management only a minority (c. 3%) of these children require open surgery and admission to PICU. It is not always possible to predict in advance which patients will require PICU recovery but it is essential that this option is available to all on-site. During the winter when beds are scarce in London, District General Hospitals often find it difficult to find a bed for a child with empyema, resulting in delay to starting the urgent treatment they require. As a consequence we frequently admit patients from as far afield as East Kent, Essex and West Sussex. The decommissioning of paediatric anaesthesia and intensive care at RBH will put even greater pressure on the other 3-4 centres in the South-East of the UK who deal with this condition.

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- 5.7 Clinical work - overlap with paediatric surgery: We receive frequent referrals for assessment of interstitial lung disease, usually mandating a surgical lung biopsy, requiring anaesthesia and PICU back-up because these children are very sick. Other surgical work includes removal of endobronchial foreign bodies, resection of metastatic cancer, and lung resection for congenital lung malformations. The intensive care and anaesthetic requirements for these procedures are the same.
- 5.8 Clinical work - transition to adult services: A major strength of the clinical service at RBH is the seamless transition to adult care. There are established transition pathways for all major conditions, including cystic fibrosis, primary ciliary dyskinesia, neuromuscular diseases, bronchiectasis, asthma and sleep disorders. As we have both adult and paediatric services on site which allows a seamless transition from paediatric to adult care. A particularly good exemplar is paediatric non-invasive ventilation, where paediatric outpatient clinics for initiation of non-invasive ventilation are attended by a team member (usually the Consultant physiotherapist in sleep and ventilation) who covers both paediatric and adult services. There are also combined paediatric ventilation clinics staffed by a paediatrician, paediatric neurologist and consultant physician with an interest in ventilatory support. This enables a unique working environment that assists in the transition of teenagers into the adult service within a team that is well known to them and their families. Being located on one site means that the patient and their family come to know the health care team, which allows stability of provision of care during the transition period. This is of significant benefit to patients and their families at a time when the child is taking on responsibility for their own health care. The difficulties of transition are often compounded by the need of the teenager to adjust to new clinical teams and a new hospital. Neuromuscular disease is a long term condition, which requires an understanding of the different issues that occur during life. The team members involved in the provision of ventilatory support or surveillance are well placed to provide that support as the patient with a lifelong or life limiting condition copes with the demands of adult life. Furthermore, this arrangement, as well as being highly beneficial to the patients, allows for economies of scale, and obviates the duplication of expertise, equipment and facilities where paediatric and adult services are on separate sites. The decommissioning of paediatric intensive care and anaesthesia would negate the benefits of this model of transition for long term care and would remove an important choice for patients and their families. Space precludes detailed discussion of our other transition pathways.

6. The impact of the JCPCT's proposals on RBH's academic and teaching & training work

- 6.1 The Department has always been very Research active, not merely in purely paediatric projects, but also jointly with adult medicine. Examples of the latter, which would be completely disrupted if the Department were to be compelled to move or redistributed between disparate centres, include the GABRIEL consortium (€11 million), U-BIOPRED (Professor Bush being the lead for Paediatrics for the total grant, €24.5 million) and the Gene Therapy funding (£40m total, RBH's share being £17.5m). We receive regular grant support from the Wellcome Foundation, Asthma UK, the CF Trust, and the British Lung Foundation. Professor Bush is a Principal Investigator in the MRC Asthma UK centre for Allergic Mechanisms in Asthma (Imperial College and Guys/Kings/St Thomas's Hospitals), and is a Senior Investigator of the NIHR. He has been cited more than 9,000 times, which places him among the top 10 respiratory scientists in Europe. Dr Jane Davies is co-Principal Investigator with Dr Di Bilton in the European CF clinical trial network centre based at RBH, which is one of only 4 CF centres in the

UK to have been admitted, none of the others being in the south. Dr Davies also sits on the Medicines for Children Research Network Respiratory and CF Clinical Studies Group, the European CF Diagnostic Network and the European CF Standardisation Committee. She is the clinical lead for the UK CF Gene Therapy Consortium, which is shortly to start the largest ever trial of gene therapy for children and adults with CF. In close collaboration with the adult service, we are involved in phase 3 trials of novel small molecule drugs targeting CFTR, acting as a referral centre for all other south of England centres. More than 120 peer review papers (2005 to end-2010) have been produced, as well as numerous invited chapters and books edited. All consultants and academics lecture all over the world, usually giving more than 100 invited lectures per year.

6.2 Teaching and Training: We are part of the National Grid training scheme and the London rotation is usually the most popular. In the past 20 years, more than 50 junior doctors who received training in the Department have been appointed to senior positions. Nearly two thirds have been appointed to Teaching or Postgraduate hospitals, or University positions. In the same time period, 24 MD, MD(Res) and PhD theses have been awarded to Research Fellows in the Department. Currently three PhD and five MD(Res) students are actively researching and four MD(Res) students are writing up. In 2011, Professor Bush was given the Rector's award and medal for excellence in Research Supervision. Other training activities include the CF Shared Care Study Days for our shared care clinics, and the Bronchoscopy Course (alternate years) which attracts trainees from all over the world. This is the only course of its kind in the UK.

6.3 Public service: Professor Bush is co-Editor in Chief of Thorax, the top-ranked respiratory journal outside the UK, the first paediatrician to hold this post, and co-Editor of Kendig's Textbook of Respiratory Paediatrics, the major book in the field. He is past Head of the Paediatric Assembly of the European Respiratory Society 2005-8), Charles West Lecturer of the Royal College of Physicians (2007), Jonxis medallist (2008, University of Groningen) and has been visiting professor in the USA on five occasions. He was the CIPP Presidents awardee, 2010, for "*Outstanding achievement in Pediatric Respiratory Science and for contributions to the improvement of global care of children with pulmonary diseases*". Dr Ian Balfour-Lynn is past president of the British Paediatric Respiratory Society (and a current Vice-President), a member of the British Thoracic Society Specialist Advisory Group for cystic fibrosis and also for home oxygen, a member of the CF Trust Medical Advisory Committee and Chair of CF Trust Standards of Care Committee, the Associate Editor (Respiratory) Archives of Disease in Childhood, a member of the Editorial Board of Paediatric Pulmonology, and an Associate Editor of the Paediatric Respiratory Reviews. Dr Jane Davies sits on the Medicines for Children Research Network Respiratory Group; Dr Mark Rosenthal is Chairman of Paediatrics for the NHS Information Centre; Dr Claire Hogg is a founder and Board/Scientific Advisory Board member of the Ciliopathies Alliance UK; and Dr Seajal Saglani is Chair Elect of the European Respiratory Society's Lung Science conference, the first Paediatrician to hold this post.

7. Summary

Paediatric Respiratory Medicine at RBH is a very large thriving unit, clinically and research active to a level that arguably cannot be rivalled anywhere else in the UK, and prominent in teaching and in training. There is no single space in London to re-locate it. This would mean that this concentration and critical mass of expertise and knowledge would, in being broken up, be to a

very great extent dissipated. This is inevitable if paediatric anaesthesia and intensive care, without which it cannot function, were to be removed from RBH. In addition, a broad set of both paediatric and adult cardiac services, for which RBH is one of the leading centres in the UK, would be also be rendered inoperable by the absence of paediatric anaesthesia and intensive care that would result from the JCPCT's proposals.