CHILDREN'S HEART SURGERY FUND
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LEEDS CHILDREN'S HEART SURGERY UNIT CLOSURE: A DECISION MADE BY COMMISSIONERS AND NOT FOR PATIENTS

At its decision-making meeting on 4th July, the Joint Committee of PCTs chose Option B as the highest-scoring configuration option, which designates Newcastle as the children's heart surgery unit in the North instead of Leeds. The second highest scoring option was G, which has Leeds instead of Newcastle serving the North. The scoring between B and G was very close.

In his statement on the outcome of the meeting at which the Joint Committee of PCTs reached its final decision following the Safe and Sustainable Review, the Chair, Sir Neil McKay, says: "The needs of children, not the vested interests of hospitals, have been at the heart of this review."

The reality is that the opposite is the case.

The 10 people making the decision, the JCPCT, were ALL commissioners – there was not one clinician or patient representative among them.

PATIENT CHOICE DISREGARDED

- A survey by PriceWaterhouseCooper (PwC) of patients from West and South Yorkshire showed that a majority of people in the major postcode areas (Doncaster, Leeds, Sheffield and Wakefield) there would not choose to travel to Newcastle were Leeds to close. They would rather go west to Liverpool or south to Birmingham or London. This is noted by the analysis:

  "There was more reluctance amongst members of the public to consider travelling to Newcastle as a centre."

  "If the preference of the parents and the public were factored into assumptions of patient flows, they may have implications for projected levels of activity at – in particular – the Newcastle centre".

- When reported at the meeting it was said that these patients, whilst preferring to go somewhere other than Newcastle, would be influenced by referring doctors and the quality of treatment available, with the assumption made that these would point them to Newcastle. No justification was given for this assumption, and there is no reason why these would not point patients instead to Liverpool, Birmingham or London.

- The Review argues that under Option B, if 25% of the forecast caseload from Leeds, Wakefield, Doncaster and Sheffield (the four post codes selected for the survey) chooses to go to Newcastle, the unit there would achieve 403 procedures a year and therefore just scrape past the 400 minimum threshold. But this is the bare minimum of surgical procedures necessary for a safe and sustainable unit. Assuming that even 25% of people in these postcode areas would choose Newcastle is incredibly optimistic and against all the evidence of the survey.

- The assertion was made that this figure could be reached if parents are, and we quote, “properly managed”, they will be persuaded away from their preferred choice of unit and will go to the centre they are told to go to.

- In other words, Newcastle is only viable if a quarter of patients from Yorkshire and Humber and North Lincolnshire are told to go there, whatever their wishes, and all the evidence is that this would be against their wishes. Or in other words, only 75% of patients will be allowed to exercise their choice.

  This is a disgraceful disregard of patient choice and flies in the face of patient choice as enshrined in the NHS constitution.

- Whether the Secretary of State allows this decision to be implemented **will be a first test of the NHS constitution.** This enshrines the right for patients to make choices about their NHS care. Specifically, it reads:

  > *“You have the right to make choices about your NHS care and to information to support these choices.”*

Public Opinion Discounted

- The petition gathered in support of retaining Leeds was signed by 600,000 people, an enormous number for one region. Yet this was counted by the Review as one response. On the other hand, 22,000 text messages received in support of Birmingham were counted as 22,000 separate responses. This is blatantly unfair and was dismissed by the Chair of the JCPCT as “we don't count heads”. In a democracy, it is the heads that are of fundamental importance; this attitude therefore suggests a democratic deficit in this Review.

Co-Location of Children's Services is Essential

- Having all paediatric services on one site was a key recommendation of the Bristol Inquiry and is backed by the British Congenital Cardiac Association, which has said: “It is important that the centres designated to provide paediatric cardiac surgery must be equipped to deal with all of the needs of increasingly complex patients. For these services at each centre to remain sustainable in the long term, **co-location of key clinical services on one site is essential.**”

- In his report following the Bristol Inquiry, Professor Sir Ian Kennedy, in recommendation 178, said: “**Children's acute hospital services should ideally be located in a children's hospital**, which should be physically as close as possible to an acute general hospital. This should be the preferred model for the future.”

- Yet despite Sir Ian's Independent Expert Panel describing the co-location of services on a single site as “optimal”, Sir Ian accepted a watered down definition of co-location (“not limited to that which is immediately adjacent”), which allowed Newcastle to be described

as “co-located”, and Leeds to be closed, despite the Paediatric Intensive Care Society’s assertion that it “would dismiss any suggestion that a service located on another hospital within the same city can be regarded as being equivalent to a service located on the same hospital site.”

Since when does ‘co-location’ mean two miles apart? How can co-location not mean ‘on the same site’? It rather looks like the definition was altered to meet the desired outcome.

- As anyone who has visited the Leeds Unit will see, it is very common for sick children to have multiple problems requiring the attention, sometimes the very urgent attention, of other paediatric specialists. At Leeds these are all on one site. At Newcastle the heart surgery unit is a stand-alone unit two miles away from other paediatric facilities located in the Royal Victoria Infirmary in the city centre. Two miles may not seem much, but it means a specialist responding to a call to attend a patient at the heart unit having to get to their car, get across the city centre, perhaps in rush hour, park and get to the patient. That could be a considerable time.

- In practice, the patients are often seen by the specialist at the end of their busy day as they come from their main hospital.

- How can this be considered as being the equivalent of having all the specialists on one site, available to come down a corridor or up some stairs, when needed? The co-location of services is deemed important for a good reason. Newcastle is the only unit designated last week by JCPCT that is not co-located.

- Moreover, Leeds has the ideal customer service model in that not only are all associated medical services under one roof, but also the maternity services are on site, so mothers with high-risk pregnancies can deliver and have transfers delivered immediately to neonatal unit under same roof.

What this means is that by forcing them to go to Newcastle, Yorkshire and Humber and North Lincolnshire children and families are being asked to accept a lower standard of services than they currently have.

- Because of this, clinicians at Leeds will be reluctant to refer patients to Newcastle, further undermining the probability that it will achieve the required 400 procedures.

NEWCASTLE IS UNSUSTAINABLE

- Allowing for patient choice and without the flow of patients from the populous areas of Yorkshire as evidenced by the traffic flows survey by PwC, it is clear that Newcastle would not meet the minimum 400 surgical procedures threshold.

- In 2010/11, Leeds delivered 336 surgical procedures whilst Newcastle delivered only 271, some of which would have been on patients from Northern Ireland who are referred to Newcastle but could just as easily be referred to Leeds. Moreover, without the disruption caused by this Review, Leeds would have been able to recruit a fourth surgeon and make the 400 threshold already.

It would be strange indeed for a centre that is close to achieving the required number of procedures to be closed in favour of one that is well behind.

Serving the Local Community

- The Review has been inconsistent on the question of whether population density matters when deciding where the future surgical centres should be. The consultation document accepted the principle that it matters in the case of Birmingham:

  "The Birmingham centre should remain in all options because of the high number of referrals it gets due to the large population in its immediate catchment area."

- But it doesn't appear to have applied to Leeds, which serves a regional population of 5.5 million, which is double that of Newcastle and the Northeast of England at 2.6m. Moreover, 2008-based projections suggest that the Yorkshire and Humber region could have 6.2 million residents by 2030 - 16.5% more than in 2010. This increase is higher than the projected 14.4% population increase in England as a whole. By contrast, the Northeast population is projected to increase by only 8.2%, half that of Yorkshire and well below the national rate.

- This result flies in the face of logical health planning which is for services to be based according to where the population lies. With far more people living closer to Leeds than Newcastle, it makes little sense moving clinicians and surgery away from major population centres. **Doctors should travel to where the patients are, rather than the other way round**; a sentiment shared by the British Congenital Cardiac Association (BCCA):

  "Where possible, the location of units providing paediatric cardiac surgery should reflect the distribution of the population to minimise disruption and strain on families."

- In assessing travel times, it is a nonsense that the children's heart surgery unit at Glasgow was excluded from being taken into consideration. Scotland is not yet an independent country and the unit is easily accessible for many English based patients who currently use Newcastle. No account was taken of this in assessing travel times were Newcastle to close. There is already a small amount of cross-border patient flow, with the Galashiels postcode area using Newcastle; moreover, Glasgow currently has a low number of surgical procedures. There is, therefore, no reason in principal or in practice why patients in the Northeast could not use Glasgow.

Health Impact

- According to the Health Impact Assessment, Options G and I were the only two that would induce the fewest negative impacts. **So it is admitted that the chosen Option B, will have more negative impacts than the second highest, which is G.**

- It was noted that Option B would have a very detrimental effect on paediatric intensive care in Yorkshire and the Humber, whereas Option G would have only a slight detrimental effect on intensive care in the North East.

- The Health Impact Assessment was not made available before the consultation and was only released at the decision-making meeting.

Access is a Quality Issue

- In the arbitrary scoring system used by Safe and Sustainable (see below), 'travel and access' was weighted at less than half that of quality. What this fails to take into account is that for the parents of sick children, being able to be with their children is a massive

contribution to the quality of the service they are receiving. For many parents, it is difficult enough to manage to be with their children in hospital given that they will often have other children that need taking care of, they and/or their partners may have work obligations and the expense involved in travelling and other costs.

- Forcing patients to have to go to Newcastle will be a massive detriment to the quality of service and this should have been more fully reflected in the scoring used.

- In assessing the Review evidence the feeling was that the Committee members were not giving enough weight to the fact that these are not just heart patients, but above all are children and therefore different priorities apply. It did not help that of the three clinical advisers to the JCPCT at the decision-making meeting on 4th July, only one specialised in paediatrics.

DECISION AGAINST HEALTH SECRETARY'S CRITERIA

- The Secretary of State said last year in a speech to the King's Fund that his stated aim for the NHS is: "no decision about me, without me". For the parents of sick children in Yorkshire and Humber, this is very much a decision made "about us, but without us."

SECRETARY OF STATE'S TESTS FOR RECONFIGURATION

- In a speech to the NHS Confederation on 21st June, the Secretary of State for Health referred to the four tests stipulated for redesigning services:

    - **clear clinical benefits** - All centres are deemed to meet the required standard but the Health Impact Assessment said that Option G had fewer negative impacts than the option chosen

    - **clinician support** - There is no evidence of this decision having the support of clinicians, indeed most have given their support to retaining Leeds and are concerned about the lower standard of services at Newcastle with not being co-located. This decision also flies in the face of all best practice health care planning and goes against both the BCCA and Bristol Inquiry's definitions of co-location.

    - **views of the public** - 600,000 people signed a petition against closing Leeds and MPs, patients and the public in the region have made it clear that that they want Leeds to stay open

    - **will it support patient choice?** - The survey undertaken of patients in West and South Yorkshire clearly demonstrates patients would not choose to travel to Newcastle

- In the same statement, the Secretary of State pointed to positive changes to cardiac and stroke services that mean patients can get the care they need as quickly as possible. It cannot make sense then to force large patient numbers to travel for two or three hours to Newcastle when they could have a much shorter journey to Leeds.

    Andrew Lansley said: "If they [plans to change services] don't meet the four tests, the service change shouldn't happen." If the Secretary of State is to be consistent, he cannot accept the decision of the JCPCT which clearly fails all of his tests.

FAULTS AT THE DECISION MAKING MEETING

NHS PROCEDURES NOT FOLLOWED - THE DECISION WAS ALREADY MADE

- No papers were circulated in advance of the meeting on 4th July and there were none available to those attending. This is against the Department of Health Guidance Document 'Code of Practice on Openness in the NHS' (August 2003). Paragraph 2.1 of which states:

  "NHS Trusts and PCTs are required to hold their board meetings in public. An agenda, papers, the accounts and the annual report must be publicly available at least 7 days in advance of the meeting. Provision must be made for questions and comments to be put by the public."

- The agenda was only released on Friday, 29th June at around 17:40hrs (outside normal office hours).

- The 'Decision Making Business Case' document containing all the recommendations the JCPCT was being asked to approve, was not available until after the decision had been reached. Although it was stated that the decision was being made at the meeting, the fact that the Business Case was handed out within minutes of the decision having been made demonstrates that the meeting was basically a sham as the decision had been made prior to 4th July.

- During the meeting, JCPCT members kept referring to recommendations and pages in the document, which no-one else attending had sight of.

- In view of this, the JCPCT should now disclose all the agendas, reports and minutes for all the private meetings of the JCPCT that must have preceded the 4th July meeting.

LACK OF ACCOUNTABILITY

- Although the meeting was held in public, no-one was allowed to ask any questions or seek any clarification from the decision makers, other than three medical advisers who formed part of the panel on the stage.

- No advance notice was given of a call by the chair at the start of the meeting for those attending to make a statement. This allowed for no preparation. As it transpired, this was a totally pointless exercise given that the decision had been taken and it only served to further antagonise representatives of patients' families and clinicians attending, creating as it did an illusion of democracy and accountability.

- One of the three key, influential clinical advisers to the JCPCT present at the meeting was a heart surgeon at Newcastle, one of the hospitals in the Review; a fact that was not revealed when declarations of interest were asked for at the meeting.

- The Committee members did not challenge any of the evidence presented and indeed a number of them stated several times that such arguments had already been well rehearsed - which for a decision that they alleged was to be made in the meeting, is highly suspicious but confirms our contention that the meeting to make the decision was a sham.

- IPSOS MORI reported back that in the public consultation that less than half of the respondents agreed that some centres needed to close in order to ensure safe and sustainable services for the future. Despite this, the panel asked Leslie Hamilton, one of the clinical advisers, what he thought and he advised that not closing centres was not an option. They agreed with him and dismissed the evidence from the public consultation, although used it when it suited them.

Newcastle's Transplant Services a Key Factor

- A key factor in the decision making process which favoured retaining Newcastle was that it performs transplants and there was no capacity at the other transplant centre, Birmingham, for this to be conducted there. This was confirmed when one of the members, Teresa Moss (Director of the NHS' National Specialised Commissioning Team and Birmingham consultant) presented evidence to the panel in the form of a letter from the CEO of Birmingham's Children's Hospital claiming that Birmingham would not have the capacity to take both ECMO services from Leicester and transplant surgery from Newcastle, should both close. Birmingham, like all units have stated in public what their maximum capacity would be. It stated 800.

- Option B, which includes Leicester closing, requires Birmingham to take 611 patients for surgery. Given that Newcastle performs fewer than 10 transplants a year, it is difficult to understand how doing 621 operations is beyond their stated capacity of 800.

- This also ignores, and contradicts, a statement from the JCPCT chair that services are about "people, not buildings". Heart transplant could be undertaken at Leeds. Leeds already performs liver and kidney transplants on children and so has all the resources for post-operative transplant care. This was a fallacious argument, again designed to get the desired end result.

Opaque and Arbitrary Scoring Methodology

- There were 12 options for re-configuration of the Units considered. KPMG had been commissioned to score these using a weighting formula of the 4 categories (Access, Quality, Deliverability and Sustainability). The decision of the weighting (14 for 'access and travel times' and 39 for 'quality') was completely arbitrary and no explanation was given for their calculation. They were not informed by the public consultation, but played a decisive role in the end result.

- Scores were allocated to 4 bands and these 1-4 points were then multiplied by the weighting so giving a table of final scores. The result was that Option B (the "Newcastle" option) scored 286 points, while option G (the "Leeds" option) was the runner up, scoring 239 points. This meant that a small number of extra points could mean a higher band with significant impact on the calculation not merited by the marginal difference. Why could not the raw scores have been used as this would have been more accurate?

Impact on Adult Surgery

- The Committee confirmed that it did not have a legal right to make a decision about adult congenital surgery but then acknowledged that the outcome of their decision regarding Children's Congenital Surgery would have a major impact on the outcome of the future Adult review, as the surgeons are usually the same surgeons. We have argued this point all along and therefore that the reviews should run alongside each other.

FLAWS IN THE PROCESS BEFORE 4TH JULY

- The Safe and Sustainable clinical steering group who advised the decision makers throughout the review did not have medical representation from Leeds, Leicester or the Royal Brompton - the 3 centres that have now been closed.

- Professor Sir Ian Kennedy's Independent Expert Panel report that was used to determine the final decision was never released in full to provider units before it was put out on public record. This is highly unusual and indeed the report contains factual inaccuracies.

- The IEP scoring and weighting criteria have never been shared with the hospitals involved nor with patients and parents. We are advised that there are 300 subscores. These must be released so that the reasons for differences in the overall league table Sir Ian produced are clear, transparent and open to scrutiny. This is despite FOI requests from parents and patients.

- The notes from the public consultation meetings held in 10 locations around England have never been made available despite requests for these. These meetings were recorded and had journalists in attendance, so it is exceptionally concerning that parents who took part have been refused access to the notes.

- Quality domains in the Prof Kennedy report failed to assess vital aspects of quality. The NHS has standard quality domains which include patient experience, clinical effectiveness and clinical outcomes. The Kennedy review did not assess or score these at any point in the review.

- The parents' view on the Safe and Sustainable Steering Group was represented by the Children's Heart Federation (CHF). As well as stating in the media which centres they thought should be designated prior to any assessment of the units, Anne Keatley-Clarke, the chief executive of the CHF, continued to brief against Leeds. This included making totally unfounded allegations about the Unit's surgical outcomes in the media, causing significant distress to the parents and staff. These allegations were investigated by the CQC and found to be totally unfounded.

CONCLUSION

- All the elected representatives of patients and their families are fully behind the Leeds Unit, and yet the unelected decision-makers have ignored the will of the people. Commissioners have a duty to commission services on behalf of the public – we feel they have not properly upheld this duty.

- We believe the patients of Yorkshire and Humber will now be left with a worse service than they currently receive, which goes against the entire principle of the review. Patients will now be asked to travel further, at greater cost and disruption to families, to a centre that is not their closest, that is the only designated unit that is not part of a children's hospital, and which does not have gold standard co-location.

- Parents' choices of where their children receive life-saving surgery should not be "managed" to suit a business case that isn't viable otherwise.

- What was clear from the 4th July meeting was that the evidence has all been made to fit the desire by commissioners for Newcastle to remain open because of its specialist treatments. It is clear that NHS politics has taken precedence over the rights and needs of patients which is the fear we have expressed all along.

- Health planning should be based on population size and density, future growth projections, and improving the model of service delivery for patients and their families. Leeds has the ideal customer/patient service delivery model for the future, as recommended by Sir Ian Kennedy in the Bristol Inquiry, and the BCCA. This is because it has maternity services, a neonatal unit and children's heart services all under one roof.

- **The conclusion cannot fail to be drawn that the decision was made in advance to designate Newcastle instead of Leeds for NHS managerial and health political reasons.**