OFFICE OF LIZ KENDALL MP

HOUSE OF COMMONS

LONDON SW1A 0AA

IRP Secretariat
6th Floor,
157-197 Buckingham Palace Road
London
SW1W 9SP

4th December 2012

To the IRP Secretariat

Re: IRP review into Safe and Sustainable

Thank you for your email of the 16th November in relation to the abovementioned review.

We have long understood and fully support the need for reform of children's heart surgery. The evidence has been clear since the findings of the Bristol Royal infirmary inquiry 10 years ago that services need to change.

In supporting the calls for change, we need to ensure that every child gets the very best standard of care, both now and in the future. It is to this end that proper consideration needs to be given to the clinical case for retaining services at Glenfield Hospital in Leicester.

We are pleased that the Independent Reconfiguration Panel (IRP) is conducting a review into the conclusions of the Safe and Sustainable Review. As part of this process, we want to highlight three particular clinical points relating to Glenfield as we remain concerned that these were not adequately considered as the Joint Committee of Primary Care Trusts drew up their most recent conclusions:

(i) The impact of transferring Glenfield's children's Extra Corporeal Membrane Oxygenation (ECMO) service
(ii) Potential capacity issues at Birmingham under the proposed configuration
(iii) Evidence which shows that Glenfield has the lowest standard mortality rates out of all of the UK's centres.

ECMO

Glenfield is recognised internationally as a centre of excellence, providing clinical leadership and learning both in this country and abroad.

It has one of the largest ECMO services in the world with the longest experience in the UK, having been established in 1989. Glenfield's unit is the only one to provide care for patients of all ages. This was crucial during the last H1N1 flu pandemic as Leicester was able to 'flex' its service to treat up to 10 adults simultaneously, whilst training other adult centres, co-ordinating the national service by triaging patients, and providing the majority of the patient transport.

Glenfield is also the only unit in the country to provide a mobile ECMO service for children, which is vital in retrieving patients and taking them to the most appropriate centre for their care.

Outcomes for ECMO patients at Glenfield are significantly better than elsewhere. Independently validated data from the UK Paediatric Intensive Care Unit database (PICANET) show survival rates are at least 50% higher at Glenfield. This difference in mortality is maintained even when the severity of illness treated at Glenfield are taken into account.

Data from the international register – provided by the Extracorporeal Life Support Organisation (ELSO) – supports the good outcomes in Leicester. This shows that crude mortality rates in Glenfield are 19% but in other centres are nearly twice as high, at 35%.

Despite this evidence, on 13th July 2012 the former Secretary of State for Health Andrew Lansley, having accepted the advice of the Advisory Group for National Specialised Services, designated Birmingham Children's Hospital as a nationally commissioned provider of ECMO services for children with respiratory failure – in place of the existing unit at Glenfield Hospital, Leicester.

In his letter to you of 22nd October, the new Secretary of State for Health Jeremy Hunt MP states that the decision taken by the former Secretary of State "regarding the removal of the Extracorporeal Membrane Oxygenation equipment from Glenfield to Birmingham should not form part of the [IRP's new independent] review as this decision was not taken by the Joint Committee of Primary Care Trusts".

We are extremely concerned that the IRP will not be able to consider the future of children's heart surgery services and children's ECMO services together. The two services are intimately linked as they are provided by the same teams of staff and led by the same expert clinicians. Not considering ECMO and heart services together is to fundamentally misunderstand the issue at hand, and relying on an earlier decision process, which failed to consider these two services together, will make no sense to our constituents, patients and families, the staff working at Glenfield, and the international ECMO community.

Moving Glenfield's children's ECMO services is not simply a matter of moving equipment. The skills and expertise of staff, including experience built up through of years of team working, is vital to achieving high quality standards of care. 80% of the staff at Glenfield's unit say they are "not at all likely" to move to Birmingham. Crucially, none of the unit's ECMO specialists say they are able to consider working in Birmingham.

Moving Glenfield's children's ECMO service will therefore result in the loss of vital skills and expertise. Leading clinicians strongly argue that it will take 8 to 10 years before the service will be brought back up to the same excellent standards of clinical care currently being provided, posing very real risks to children's lives in the meantime.

The Parliamentary Under-Secretary of State at the Department of Health acknowledged the link between ECMO and Children's Heart surgery during the recent debate on children's heart surgery on 22nd October.

"Decisions about ECMO for children at Leicester being moved to Birmingham follow from the decision to transfer heart surgery to Birmingham. In other words, it was a consequence of the JCPCT's decision."

The Minister went on to say:

"If the IRP wants another full review of all that has happened—it effectively calls into question the whole process, and so on—it obviously flows from that that the ECMO children's service at Leicester must be retained in that event, because it flows from the JCPCT's decision about where to have the specialist children's heart services."

We would therefore ask you to clarify as a matter of urgency whether the IRP's review will fully consider the future of these two services together.

Capacity at Birmingham Children's Hospital

New evidence has come to light which raises serious questions about the facts underpinning the reconfiguration models in the Safe and Sustainable review and the capacity of Birmingham Children's Hospital to meet increases in demand.

The original national projections for demand for paediatric heart surgery used by the JCPCT were based on Dr Martin Ashton-Key's analysis of the 2006/07 validated Central Cardiac Audit Database (CCAD) data, which was the latest available validated data at the time. Dr Ashton-Key's projections suggested that demand would remain fairly stable, and the estimated paediatric cardiac surgery activity in 2025 would be 3990 cases.

However, validated CCAD data is now available for three more years (to 2009-10) and this new information shows that demand is increasing significantly faster than previously projected. According to this new data, the paediatric cardiac surgery caseload is now set to rise from 3739 in 2010-11 to 5422 in 2025 - 1,356 more than the estimate used by the JCPCT in the Safe and Sustainable review.

This predicted increase in the surgical caseload could be further exacerbated by the substantial increases in the number of nought to four-year-olds in the Midlands and London. The Office for National Statistics published data in October last year which shows additional population growth that was not factored into the Safe and Sustainable Review, with the 0-4 population in the East Midlands set to grow by 11%, in the West Midlands by 9%, and in London by 12% by 2025. The same age group is anticipated to remain static or decrease in the South and the North East.

The new figures on both the number of surgery cases and the wider population cause real concern about whether Birmingham will be able to cope with the corresponding increase in its caseload. This is exacerbated by the fact that Birmingham's caseload will further increase because of the closure of Northern Ireland's children's heart surgery services.

The Safe and Sustainable review proposes an all-Ireland framework, with Northern Ireland cases going to Dublin. However, this will take several years to establish and, in the meantime, a significant and increasing number of babies will continue to travel to Birmingham.

We understand that the combined factors of Glenfield closing, the likely increase in surgical activity, the increase in population, in particular among the nought to fours, and the increase in cases coming from Northern Ireland have led to Birmingham Children's Hospital itself having concerns about whether it has the capacity to cope with all the extra cases.

We understand that the hospital has analysed the caseload and produced an internal paper concluding that it would have to perform one thousand cases a year, which is at the very limit of what the Safe and Sustainable review panel says is a safe number.

These concerns come in the context of previous issues with Capacity at Birmingham. In response to the Healthcare Commission's concerns regarding the then high numbers of cancelled operations due to ICU capacity Birmingham, the Trust announced, in March 2010, the expansion of 11 extra ICU beds, taking the hospital's capacity to 33.

We urge the IRP to look at whether Birmingham Children's Hospital did produce an internal paper on its capacity, and to assess all such evidence in its review.

Mortality

The IRP will no doubt be aware of the distinguished career of Professor Brian Jarman, who is currently head of the respected Dr Foster Unit at Imperial Collage London. As well as being a former President of the British Medical Association and world renowned clinical expert, Professor Jarman sat on the panel for the Bristol Royal Infirmary Inquiry between 1999 and 2001.

Professor Jarman has produced an analysis of Standardised Mortality Ratios (SMRs) across the eleven paediatric heart surgery centres currently under review, which can be found at www.brianjarman.com. He examined children under five having open heart

surgery, excluding transplants, over two time periods: the six years between April 2006 and March 2012 and the four years between April 2008 and March 2012.

This found that Glenfield Hospital had the lowest SMR of all eleven paediatric heart surgery centres in the four year analysis. Indeed, between April 2008 and March 2012, Glenfield's SMR was just 12.4 according to Professor Jarman's analysis. This is a stark contrast to Birmingham Children's Hospital's SMR of 104.4 and is significantly lower than the England national figure, defined as 100. A similar pattern is seen with the data for the six years between April 2006 and March 2012.

Before putting his findings in the public domain, Professor Jarman emailed the data to the NHS Medical Director, Professor Sir Bruce Keogh, on 27th May 2011 and again on the 24th October 2012. Professor Jarman has not yet received a response to these emails.

Leslie Hamilton, Deputy Chairman of the Safe and Sustainable steering group has subsequently told local media that:

"Caseloads [in Professor Jarman's report] are too low to make meaningful comparisons across hospitals and a significant number of procedures are not included in the validated data.

"Furthermore, the data provides no reliable way of reflecting case complexity, disadvantaging units that regularly perform more high-risk surgical procedures."

Professor Jarman notes in his research that the procedure groups he used are based on those used for the Bristol Royal Infirmary Inquiry and that current caseloads will have changed. Whilst the Dr Foster Unit model does make extensive adjustments for a wide range of factors, Professor Jarman points out that Central Cardiac Audit Database (CCAD) data may give a better model, which possibly includes additional procedures and a more up-to-date case mix.

With this in mind, Professor Jarman's Unit at Imperial College had previously requested the CCAD data used in the JCPCT's analysis from the Healthcare Quality Improvement Partnership (HQIP) but the request was declined. The HQIP considered that releasing the data didn't 'demonstrate value to patients.' We understand that Professor Jarman's Unit has reapplied to HQIP for the data.

We strongly disagree with the view expressed by HQIP and urge the IRP to press for the CCAD data to be released to Professor Jarman. Furthermore, we urge for representatives of the IRP to meet with Professor Jarman and to fully consider and respond to his input as part of the current review.

In conclusion, we firmly believe that there is a strong clinical case to retain services at Glenfield and that this demands a full and proper reconsideration of the evidence, including that outlined above.

Liz Kendall MP and Nicky Morgan MP have already written to Lord Bernard Ribeiro requesting a meeting and we'd be keen to set this up in Westminster at his earliest convenience, bringing together MPs from across Leicestershire and the East Midlands.

We look forward to hearing from you as a matter of urgency.

Yours sincerely,

Liz Kendall MP
MP for Leicester West

Nicky Morgan MP
MP for Loughborough

Graham Allen MP
Leicester South

Jonathan Ashworth MP
MP for Leicester South

Andrew Bridgen MP for
MP for North West
Leicestershire

Vernon Coaker MP
MP for Gedling

Lilian Greenwood MP
MP for Nottingham South

Philip Hollobone MP
MP for Kettering

Pauline Latham MP
MP for Mid Derbyshire

John Mann MP
MP for Bassetlaw

Karl McCartney MP
MP for Lincoln

David Tredinnick MP
MP for Bosworth

Heather Wheeler MP
MP for South Derbyshire

Chris Williamson MP
MP for Derby North

Keith Vaz MP
MP for Leicester East

Tim Stevens
Bishop of Leicester

Lord Willy Bach
Lord of Lutterworth