

# Minutes of the Meeting of the HEALTH AND COMMUNITY INVOLVEMENT SCRUTINY COMMISSION

Held: THURSDAY, 26 JULY 2012 at 2.00pm

## PRESENT:

# Councillor Cooke (Chair) Councillor Sangster (Vice-Chair)

Councillor Alfonso Councillor Singh
Councillor Naylor Councillor Westley

## Also present:

Councillor Sood – Assistant City Mayor (Health & Community Involvement)

## In attendance:

Mr Eric Charlesworth, Chairman of the Leicester, Leicestershire

and Rutland LINk

Dr Sanjive Nichani, Consultant Paediatric Intensivist, UHL Consultant Paediatric Intensivist, UHL

Mr Giles Peek, Consultant Paediatric Cardiac Surgeon, UHL

Dr Kevin Harris, Medical Director, UHL

\*\* \* \* \* \* \*

## 1. APOLOGIES FOR ABSENCE

Apologies for absence were received from Councillor Gugnani and Councillor Singh had indicated that he would be late attending the meeting due to a prior meeting commitment.

#### 2. INTRODUCTION

As there were no representatives present from Leicestershire County Council

or Rutland County Council, the scheduled Special Urgent Meeting of the Leicestershire, Leicester and Rutland Joint Health Overview and Scrutiny Committee had fallen by default.

#### 3. WELCOME

The Chair welcomed everyone to the scheduled meeting of the Health and Community Involvement Scrutiny Commission at which he had agreed to take an item of urgent business in relation to the Secretary of State's decision in respect of Paediatric Congenital Cardiac Care in Leicester. He proposed to take this item first on the agenda.

The Chair referred to Appendix D of the Overview and Scrutiny of Health – Guidance issued by the Department of Health, a copy of which was circulated at the meeting. Paragraph 8 of the Guidance gave powers to local authority scrutiny committees to report to the Secretary of State for Health on the following grounds:-

- a) where the committee was concerned that consultation on substantial variation or development of services had been inadequate;
- b) where the committee considered that the proposal was not in the interests of the health service.

It was proposed to look at the issue over a period of 2 or 3 scrutiny meetings in the City. Future meetings would hear representations from the Safe and Sustainable Review Team, the Chief Executive of the PCT and from the University Hospital of Leicester which was currently undertaking a review to consider whether there were legal or clinical grounds for challenging the decision. Other relevant parties would also be welcomed in making representations. The Commission would need to arrive at an informed view on the situation by September. It would need to determine whether the process lacked rigour, whether the consultation process had been inadequate or whether the decision was not in the interest of the health service.

The following documents were circulated at the meeting for Members' information:-

- a) Resolution of Leicester City Council on 28 June 2012 in relation to the Adult and Children's Cardiac Services at Glenfield Hospital.
- b) Resolution of Leicestershire County Council's Cabinet on 23 July 2012 on Glenfield Children's Heart Unit.
- c) Report University Hospitals of Leicester NHS Trust to the Public Trust Board on 26 July 2012 giving an update on the Trust's review of the Secretary of State's decision in relation to securing legal advice and a clinical review of the recommendations.

#### 4. DECLARATIONS OF INTEREST

Councillor Alfonso declared an interest in the general business of the meeting, in so far as she had been involved in raising signatures for the petition against the Secretary of State's decision.

Councillor Cooke declared an interest in the general business of the meeting, in so far as his wife was a patient at the Glenfield Hospital.

Councillor Naylor declared an interest in the general business of the meeting, in so far as he had signed the petition and had helped collect signatures for the petition against the Secretary of State's decision and he was a Shadow Governor of the Leicester Partnership NHS.

Although attending the meeting as an observer, Councillor Newcombe declared an interest in the general business of the meeting, in so far as he had signed the petition and his wife and daughter had received treatment at Glenfield Hospital.

Although attending the meeting as an observer, Councillor Sood declared an interest in the general business of the meeting, in so far as she had signed the petition and had been involved in raising signatures for the petition against the Secretary of State's decision.

Councillor Westley declared an interest in the general business of the meeting, in so far as his sister worked in the cardiology unit at Glenfield Hospital and he had been involved in raising signatures for the petition against the Secretary of State's decision.

In accordance with the Council's new Code of Conduct the interests declared by Members were not Disclosable Pecuniary Interests but were Other Disclosable Interests and for the Scrutiny Commission Members these were not considered so significant that they were likely to prejudice Members judgement of the public interest. Members were, therefore, not required to withdraw from the meeting as a consequence.

#### 5. LEICESTER, LEICESTERSHIRE AND RUTLAND LINKS

Mr Eric Charlesworth, Chairman of the Leicester, Leicestershire and Rutland Joint LINk Paediatric Congenital Cardiac Care Group (PCCC) addressed the meeting. He stated that he represented the three LINks for Leicester, Leicestershire and Rutland and he worked with other LINk bodies that might have citizens who would use the Glenfield facilities.

A copy of letter to MP's and a briefing paper produced by LINk for an MP's meeting with the Health Minister on 17 July 2012 had previously been circulated.

He expressed regret that that there were no representatives from Leicestershire or Rutland present and he had been asked by the Chairman of

the three LINKs to thank Councillor Cooke for his diligence in taking the action to address this matter.

He stated that it was a huge responsibility in hearing the professional concerns and those voiced by patients through the three LINks and that he was the conduit for bringing those views forward. The public wanted outcomes from this process and wanted to know what the Council was doing. He referred to the Leeds Hospital which was undertaking a similar campaign to Glenfield Hospital and stated that these two hospitals were not in competition as they each had their own reasons as to why they should remain part of the overall provision of PCCC. The Glenfield Hospital campaign had attracted interest from 'Look North'. The Leeds Hospital Trust, the Council and the LINks had taken part in a 6 hour webcast scrutiny meeting and the event had attracted such public interest that roads had been closed because of the public attendance and 6,000 signatures had been collected for a petition. He felt that lessons could be learned from their review which had looked at best care based upon factual information without any placard waiving. It was important when looking at emotional and sensitive issues to look at them in a logical manner.

In presenting his evidence to the Scrutiny Commission Mr Charlesworth covered the following points:-

- ➤ There was an alternative course of action that could have been taken and could still be implemented.
- ➤ There was concern at the loss of a world renowned service that would result in the loss of a quality NHS service provision.
- The JCPCT had acknowledged that the loss of other key services was very important, i.e the loss of Brompton's Paediatric Intensive Care Unit. Leicester had experienced a similar loss of key services after the previous consultation on trauma care resulted in the services being transferred to the Queen's Medical Centre at Nottingham.
- MP's of all persuasions from all over the country had expressed equal concerns at the Secretary of State's decision to those expressed locally.
- LINk were grateful to have had a meeting with the Chair of the Scrutiny Commission four days after the decision was taken. Time was of the essence and the review being undertaken by the UHL was not inconsistent with this review.
- LINk questioned whether the decision panel meeting had been conducted properly and he questioned the role of advisors to the panel who later appeared to have sat as part of the panel.
- ➤ The JCPCT had ignored significant facts and should be accountable for that and he welcomed the fact that Catherine Griffiths would be giving evidence to the Scrutiny Commission.
- The Minister would be unlikely to change his decision unless irrefutable facts were put forward.
- ➤ LINk were prepared to give evidence on where they felt the process had been flawed.

- ➤ Following a question, it was stated that the Safe and Sustainable Review Team had not followed their own advice in that consultation had been carried out on 6 options and on the day of the decision had added a further 6 options which had not been consulted upon. It was felt that Glenfield would have come out successfully in 5 of the 6 options.
- ➤ KMPG had been employed to undertake the scoring and the person presenting the options indicated that an 8<sup>th</sup> hospital could be included in the decision without any impact upon the others. The North, South and London each had 2 hospitals within the decision and the Midlands had 1, even though the population was greater than other areas.
- ➤ The last 6 options were discarded in less than 3 hours and there had been no opportunity for the public to comment upon them.
- Option A and I were originally the two favoured ones, Option I was then rejected and Option B was introduced and accepted.

Discussion with Scrutiny Commission Members ensued and the following points were raised:-

- ➤ LINk were thanked for their presentation.
- ➤ It appeared that the views of world-wide experts had been ignored.
- Moving the Paediatric Congenital Cardiac Care unit to Birmingham Children's Hospital would result in increased local mortality rates among children requiring treatment.
- The focus should be on what Glenfield had achieved over the last 20 years and there was a need to invest in the future particularly with the current growth in local population rates.
- ➤ A Member had been present at Glenfield when the Secretary of State had visited the PCCC unit and had praised the unit for having a world-wide reputation and for its part in providing vital services across the East Midlands. The Member also had close experience of a friend's child requiring treatment as a premature baby and who was now living a healthy life as a 10 year old.
- ➤ There was concern that there were currently 50 beds in Glenfield and 50 beds in Birmingham and if the services transferred to Birmingham patients could be put at risk as not all patients may be able to be treated in the future.

The Chair invited comments and questions from the members of the public who were present. The following issue was mentioned:-

➤ Option B had been favoured on the predication that Mr Markus Hall, Leading Paediatric Heart Surgeon at Southampton Hospital would be leading the unit forward in the future. He had now left the hospital and the question was raised as to how significant this could now be in terms of the reason for the original decision.

## 6. UNIVERSITY HOSPITAL LEICESTER (UHL)

The representatives of the University Hospital Leicester (UHL) thanked the Scrutiny Commission for the opportunity to present evidence to them. Dr Nichani had previously submitted a briefing paper on the grounds for challenging the decision of the Joint Committee for Primary Care Trusts (JCPCT) on the 4 July 2021.

During the process the following points were made:-

- > The Safe and Sustainability principles were generally supported.
- ➤ The focus of the Safe and Sustainability Review had been too narrow and had focused too much on the criterion of 400 cases with 4 surgeons.
- ➤ Due to the focus above there was no consideration of the clinical risk to the Extracorporeal Membrane Oxygenation (ECMO) Unit.
- Although the Leicester Hospitals are 3 miles apart the national results are reported as one unit and there is a rotation of staff between the two hospitals.
- ➤ The focus of the review had been on tertiary levels of care and no account was taken of quartertiary levels of care provision.
- No adequate consultation had been carried out on whether ECMO could be moved safely. It had been deemed to be moved to Birmingham Children's Hospital but no contact had been made with Glenfield to discuss the implications of this.
- No health impact assessment had been carried out on the effect upon the ECMO Unit.
- There had been no engagement with the ECMO community in the UK or world-wide about the proposed transfer of the Unit.
- ➤ The independent expert for ECMO, Dr Palmer from Sweden, had written to the Secretary of State to indicate his opposition to moving the ECMO Unit to Birmingham on the grounds that the survival rate would reduce by 10% over 5 years while the new Unit was established. This represented the loss of approximately 50 lives over the five year period.
- ➤ It could take 5-20 years after moving an ECMO Unit to rebuild the skills and expertise and until the previous levels of these were achieved there would be an increase in morbidity rates. This had been borne out by the Extracorporeal Life Support Organization Committee (ELSO) that draws upon the expertise and services of ECMO specialists world-wide.
- ➤ The Safe and Sustainability Review had not placed enough emphasis on the views of world experts.
- ➤ It had been stated in Parliament that the Secretary of State had taken a hurried decision.
- ➤ The ECMO Unit represented the quartertiary level of care which is the highest form of Intensive Care possible.
- There were currently 3 neonatal and paediatric ECMO Units in the country at Great Ormond Street Hospital, Newcastle and Glenfield. The treatment at Glenfield represented approximately

- 80% of the activity in current neonatal and paediatric activity in England and Wales and often took patients from Great Ormond Street Hospital and Newcastle as they had limited capacity. Patients were also admitted from abroad.
- ➤ Glenfield ECMO Unit was originally funded through public subscription and was now the largest in the country that was nationally commissioned to provide its service. PCT's were top sliced to fund nationally commissioned services.
- ➤ Equipment had been provided at Glenfield through public donations and subscriptions.
- ➤ The unit was also one of the largest in the world with one of the longest experiences having started in 1989. It was the only unit that could treat all age groups.
- If the Unit moved it was highly unlikely that the expertise attached to it would move to Birmingham. Moving an ECMO Unit was similar to moving a small village. There were currently 80 ECMO specialist nurses at Glenfield. Most were female and second wage earners so the likelihood of them transferring to Birmingham was very low. This meant that the current specialist nursing skills built up over the last 20 years would be lost and it would take time for new nurses to be trained and acquire the current level of expertise.
- ➤ The Unit needed 7 highly trained staff to support 1 patient per day. If there were no heart and lung operations being carried out at the site there would be an immediate loss of specialist support to ECMO.
- Mr Peek was the only UK ECMO doctor on the ELSO World-wide Steering Committee and he was also Chair of the Euro ELSO Steering Committee. No consultation had been carried out with him on moving the Unit and the question of due diligence arose as the same process had not been applied to the ECMO Unit as had been applied to the Paediatric Congenital Coronary Care service.
- > The Glenfield ECMO Unit was the largest Unit in the world and had the best results in the world.
- Statistics had been collected for 10,000 ITU cases. In the 10 years up to 2012 there were 1,500 ECMO treatments in the UK for children and infants, approximately a third of these were at Glenfield.
- ➤ The crude mortality rate at Glenfield was 20% compared to 34% for other centres this represented a loss of 62 lives in other centres compared to the Glenfield success rate.
- ➤ There was no reason to think that patients at Glenfield were less sick than elsewhere and yet the outcomes at Glenfield were 50% better than other centres.
- ➤ ELSO data showed that of the 12,069 ECMO children and infant cases world-wide, 435 had been at Glenfield. Overall Glenfield had a crude mortality rate of 19% compared to 35% in centres world-wide.

- ➤ The Glenfield ECMO Unit was the only one in the country to provide a mobile ECMO care when the patient was too ill to be moved. Patients usually referred for ECMO had an 80% chance of dying. Some were too sick to be moved and the Glenfield team had mobile incubator facilities to treat a patient on site before moving them to a hospital based ECMO Unit. Glenfield have been successfully doing this for 3 years and often took these patients to Great Ormond Street and Newcastle Hospitals.
- ➤ Birmingham Children's Hospital's results for cardiac ECMO are not as good as Leicester's. The national survival rate in this instance was 50% whereas Leicester had a 60% success rate.
- Leaving ECMO at Glenfield without a paediatric cardiac team would not be possible as the two services needed the same team of experts to function.
- Glenfield was the training centre for the rest of the world as well as nationally. Doctors have already been trained from America, Australia, India, Italy, South Africa and Japan.
- ➤ It was important to see and recognise the value of the Glenfield ECMO Unit in its national context as well as the local one.
- Newcastle Hospital were given points in the Review for the use of a Heart Assist Device for heart patients and yet Glenfield had not been given any points for their Mobile ECMO and Ground breaking Circuit and teaching and training.
- ➤ The review looked at out dated figures for Glenfield. Glenfield ECMO Unit treated large numbers of patients during the swine flu epidemic which reduced children cases to 38. This underrepresented approximately 100 cases in a normal year.
- Options A/B or I were proposed to the JCPCT and the clinicians felt that AB was the best option. KPMG strongly advised the JCPCT to look seriously at Option A/B and given a 7.1% rise in population growth, this would give the right number of cases for the Safe and Sustainability criterion.

The Chair invited comments from the public and the following issues were raised:-

- ➤ A parent of a child patient at Glenfield stated that he felt that what was missing from the process was what people and patients actually wanted. The Child Heart Foundation had sent out over 5,000 questionnaires and 1,000 had been returned. He had not received one and his impression was that those returned were from areas where the services were relatively safe.
- ➤ The scoring system was changed at the last meeting of the Safe and Sustainability Review and it was felt that the public had been misled for 2 ½ years as a result.
- It was felt that there were flaws in the consultation process and that the population increase locally had been overlooked.
- Infant mortality was likely to increase locally as a result of moving the PCCC to Birmingham.

The Chair thanked everyone for their attendance and contribution to the meeting.

#### AGREED:

- that in accordance with Appendix D of the Overview and Scrutiny of Health Guidance issued by the Department of Health, there was sufficient evidence to indicate that the Scrutiny Commission could submit a report to the Secretary of State upon his decision in relation to Paediatric Congenital Coronary Care in Leicester, and
- 2) that it would be prudent to write to the Secretary of State to inform him that the Scrutiny Commission were undertaking a review and a report would be submitted when it was completed.

## 7. REMAINDER OF THE AGENDA

The Chair indicated that the remainder of the agenda would be considered at a future date.

#### 8. CLOSE OF MEETING

The meeting closed at 3.30 pm