# UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

## Trust Board Bulletin – 7 July 2011

The following reports are attached to this Bulletin as items for noting, and are circulated to UHL Trust Board members and recipients of public Trust Board papers accordingly:-

- **Briefing on the Bribery Act 2010.** Lead contact point – Mr S Ward, Director of Corporate and Legal Affairs (0116 258 8615) – **paper 1;**

- **Briefing on the BME Symposium.** Lead contact point – Mr M Wightman, Director of Communications and External Relations (0116 258 8615) – **paper 2**;

- **Formal UHL response to the Safe and Sustainable Children's Congenital Heart Services consultation.** Lead contact point – Dr A Tierney, Director of Strategy (contact 0116 204 7991) – **paper 3 (appendices available separately on request)**, and

- **Positive Outcome of a customer service excellence audit.** Lead contact point – Dr A Tierney, Director of Strategy (0116 204 7991) – **paper 4**.

**It is intended that these papers will not be discussed at the formal Trust Board meeting on 7 July 2011, unless members wish to raise specific points on the reports.**

This approach was agreed by the Trust Board on 10 June 2004 (point 7 of paper Q). Any queries should be directed to the specified lead contact point in the first instance. In the event of any further outstanding issues, these may be raised at the Trust Board meeting with the prior agreement of the Chairman.

# UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

**REPORT TO:** **TRUST BOARD**

**DATE:** **7 JULY 2011**

**REPORT BY:** **DIRECTOR OF CORPORATE AND LEGAL AFFAIRS**

**SUBJECT:** **THE BRIBERY ACT 2010**

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**1.** The Director of Corporate and Legal Affairs submitted a report to Trust Board on 2nd June 2011 (bulletin item) on the work in hand to address the implications of the Bribery Act 2010.

**2.** Having obtained external legal advice, the Assistant Director of Corporate and Legal Affairs (Head of Legal Services) is finalising a new Trust 'Anti-corruption and Bribery Policy'. This will be reviewed by the Policy and Guidelines Committee in July 2011 and a further report will be made to the Trust Board on 4th August 2011.

**3.** The Trust Board is invited to receive and note this report.

Stephen Ward
Director of Corporate & Legal Affairs

1 July 2011

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| **To:** | **Trust Board** |
| **From:** | **Mark Wightman** |
| **Date:** | **7 July 2011** |
| **CQC regulation:** | As applicable |

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| **Title:** | Update on the Black and Minority Ethnic (BME) communities symposia programme. |

**Author/Responsible Director:**

Karl Mayes, PPI and Membership Manager / Mark Wightman, Director of Communication and External Relations

**Purpose of the Report:**
To provide the Board with an update on the Trust's recent programme of BME engagement and inform them of actions arising from this.

**The Report is provided to the Board for:**

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| Decision | | Discussion | |
| Assurance | X | Endorsement | |

**Summary / Key Points:**

Since November 2010, the Trust has hosted five BME community engagement events. Two core actions have been agreed by the Trust Executive team;

a) To develop a cultural competence training session
b) To explore the implications of offering greater patient choice in relation to access to same sex practitioners.

This programme of engagement has also informed the development of priorities for the Trust's "Equality Delivery System" (EDS).

**Recommendations:**
See above

**Previously considered at another corporate UHL Committee ?**
The Executive Team have received a report on this programme of engagement and advised on subsequent actions.

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| **Strategic Risk Register**<br>N/A | **Performance KPIs year to date**<br>N/A |

**Resource Implications (eg Financial, HR)**

To be determined

**Assurance Implications**
N/A

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| **Patient and Public Involvement (PPI) Implications**<br>Through this programme the Trust has identified a number of people from diverse communities and organisations who are willing to engage with us in the longer term; some of whom are now considering standing as governors. Moreover, the programme has arguably built confidence among local community groups in the Trust's willingness to listen and respond to their concerns regarding local hospital services. As such, it will support future engagement and involvement. |
| **Equality Impact**<br>The programme has had a positive impact insofar as it has allowed the Trust both to engage with diverse local communities and identify their priorities for service development. It also goes some way to fulfilling the requirements of the Equality Delivery System (EDS) to base the Trust's equality priorities on meaningful engagement. |
| **Information exempt from Disclosure**<br>N/A |
| **Requirement for further review ?**<br><br>A paper reporting on the outcome of actions taken will be presented to the Board later in 2011. |

**Trust Board Bulletin – paper 2**

# UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

**REPORT TO:** **Trust Board**

**REPORT BY:** **Karl Mayes, PPI and Membership Manager**

**DATE:** **7 July 2011**

**SUBJECT:** **BME Communities Health Symposium**

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## 1. Background

On November 2nd 2010, people from local black and minority ethnic (BME) communities were invited to a Health Symposium. The event was held in the Clinical Education Centre at the LGH site; its aims were to;

- Identify BME people's priorities regarding their experience of our services
- Establish an ongoing programme of BME community engagement

The Symposium was well attended (62 participants) and included individuals from a diverse range of backgrounds. There was good representation from voluntary and community groups, as well as professional representation from community development workers, senior UHL staff, NHS equality leads and members of our hospital multi faith chaplaincy. The event was generally well evaluated by participants, many of whom commented on the positive atmosphere generated on the evening, and expressed cautious optimism that the programme of engagement launched by the Symposium would result in positive changes for BME service users. The evaluations reminded us however, that the ultimate success of the event will depend upon such changes actually being implemented.

### Format of the event

Participants were welcomed by the Chairman of the Trust, Mr Martin Hindle, who set out the aims and expectations for the evening. This was followed by a short presentation which provided an overview of recent patient survey results analysed by ethnicity. Participants were then asked to take part in break out sessions where they were invited to;

- identify issues relating to their experience of, and access to UHL services
- agree as a group their top two priorities
- discuss these priorities and suggest remedial actions

Many issues were raised during the evening. However, the priorities identified by the breakout groups clustered around two key themes; communication and cultural competence. These priorities may be further broken down as follows;

### Communication

- Better access to language support
- Improving our communication / written information
- Better access to doctors for inpatients and their families

**Improving the organisation's "cultural competence"**

- Improving engagement between the Trust and BME communities
- Improving cultural awareness / competence among staff
- Better access to same sex healthcare practitioners

These priorities formed the basis of a programme of follow up events, within which each of these themes was explored in greater detail. Subsequent engagement has been good, with several participants returning for all of the follow up meetings. Both this, and the follow up events have been supported by Prakash Panchal, one the of the Trust's Non Executive Directors. The outcomes of these meetings are summarised below.

## 2. Follow up meetings

### a) Access to Same Sex Practitioners

The first follow up meeting, held on December 2nd 2010, was dedicated to a discussion on patients' access to same sex practitioners. 14 people participated in a lively discussion around the topic. Attendance was unfortunately limited at this event by the particularly inclement weather at the time. During the discussion the following points were raised;

- This was widely felt to be an issue that transcended any particular faith group or gender.
- Many participants felt strongly that having a practitioner of the opposite sex significantly compromised a patient's dignity. This is particularly relevant in situations of personal care, and for more intimate procedures.
- Specific mention was made of some patients' discomfort with being seen by male sonographers in our women's services.
- It was pointed out that in many communities, women's contact with non familial males is culturally / socially limited.
- The group acknowledged that the Trust would not always be able to meet requests for same sex practitioners (e.g. in areas with fewer female practitioners, or where a consultant is male). However, there was broad agreement that even where a request could not be met, there was still an expectation that patients should be asked about their preference as part of their routine assessment.
- Most participants noted that this issue had a significant effect on their overall experience of our services.
- Some participants noted that the practitioner's gender isn't always apparent from the appointment letter. As such, they sometimes felt unprepared for an encounter with a practitioner of the opposite gender.
- It was generally agreed that in emergency situations, preserving life at all costs overrode any preference for same sex practitioners.
- One participant argued that honouring a preference for same sex practitioners may support what she referred to as "gender oppression" by some communities and should not be encouraged.
- One or two participants expressed the view that they wanted access to the best professional for the job, regardless of gender.
- It was noted that anxiety about poor access to same sex practitioners had resulted in some women delaying approaching health services, and that this could adversely influence health outcomes.

### Suggested solutions

The group were asked to consider how the Trust should respond to their concerns. The following suggestions were made;

- Preference for same sex practitioners should be recorded as part of the Trust's routine initial assessment. Indeed, many participants suggested that this information should be recorded as part of the patient's referral to the hospital as part of a GP's wider patient needs assessment.
- Patients need to be empowered to ask for same sex practitioners if this is important to them. As such they need greater clarity and information on their rights.
- Choose and book process should be reviewed to capture preference for same sex practitioners
- Staff should be given guidance and training on the significance of this issue to many patients.
- A set of staff guidelines should be drawn up, with the input of community members.

Action to date

This issue was discussed briefly at a meeting of the Executive Team in February and was revisited at an Executive Team meeting in May (see below). The issue was also discussed at a recent Equality and Diversity Board meeting. UHL's Service Equality Manager has agreed to draw up a set of draft guidelines for consideration. These guidelines will be developed with the involvement of UHL staff and Symposium participants.

### b) Communication

A second follow up meeting dedicated to the theme of communication took place on January 25th 2011. 24 participants attended, with discussions covering support for non English speakers and more general issues relating to our written and verbal communication with patients. Prior to the discussion, Deb Baker, the Trust's Service Equality Manager gave an overview of the service provided by PEARL Linguistics, the new interpreting provider that the Trust would be using in future. Participants were then split in to two discussion groups where a range of issues were raised, including;

- The importance of monitoring the uptake of the new provider's service and evaluating the quality of support provided.
- Overall provision of language support was judged to be inadequate, and where not offered, excluded patients and families from participating in their own care and treatment.
- A suggestion that we better utilise our volunteers to provide non clinical language support and befriending to non English speaking patients. This was anticipated to provide a level of social support for patients who often feel anxious and isolated in hospital.
- The need to train staff to recognise the importance of appropriate language support and to dispel misconceptions (for example, if patients speak a little English, do staff assume that they will understand everything?) This was seen as a priority for several participants.
- The need to include a statement about the level of language support a patient could expect in the letters sent to them by the hospital. This also related to the

need for patients and families to be given information about their *rights* in relation to language support.
- Access to our complaints process and to other ways of giving feedback was considered poor for non English speakers.
- The possibility of introducing a "mystery shopper" system to evaluate language support in the Trust.
- There were concerns that the common practice of using relatives as interpreters may breach a patient's confidentiality.
- Most participants agreed that written information needs to be simple and jargon free.
- Some participants felt that staff did not approach non English speakers with a basic level of "common courtesy". As one participant put it, some staff "appear to be unhappy doing their jobs".
- We should understand our patients as customers (the customer is always right!).

Action to date

We have had early discussions with our Volunteer Services manager to explore a role for bilingual volunteers who may act as ward visitors, befriending and providing informal, non-clinical language support for patients. The Service Equality Manager will review training relating not only to language support, but in relation to other communication issues such as communicating with people with disabilities.

**c) Cultural competence and engagement**

During the third follow up meeting, 17 participants met to discuss how the Trust could develop its "cultural competence" and improve engagement with BME communities in the future. The following issues were raised;

- Most participants agreed that culturally competent staff would recognise the significance of cultural difference but remain flexible and responsive to individual needs. In other words, they should be culturally aware, but remain mindful of the dangers of stereotyping and making assumptions. A "one size fits all" approach is not adequate.
- Culture was understood to influence a very wide range of experience, from birth to death. At both ends of this spectrum it was felt that the Trust could do more to support patients from BME communities.
- There was some concern articulated that the NHS can pay lip service to understanding cultural needs, but fall short on delivery.
- Particular examples of "cultural incompetence" were given. These included; poor recognition of important cultural practices relating to birth and preferences to wash, dress and pray before breakfast which were usually precluded by a rigid routine on the wards.

**Suggested solutions**

- Overwhelmingly, effective cultural competence training was seen as the solution to the issues raised. Indeed, most participants argued that cultural competence training should be mandatory for all staff. Some suggested that it be integrated in to any customer service training that the Trust runs. It was agreed that such

training must include an examination of one's own culture and cultural assumptions.
- Some participants suggested a short cultural competence video training tool which should be viewed by all staff in the Trust.
- Training was advocated "from top to bottom" engaging staff at all levels in the Trust.
- Some participants felt that staff should be reprimanded if they were unreasonably inflexible to cultural need.

**Engagement**

The group went on to discuss BME community engagement. The model followed by the Symposium and its subsequent meetings was well received and judged to have been a successful way of developing a more sustained pattern of community engagement. Several participants suggested that the forum that has evolved through this programme continue to meet on a regular basis and that the Trust should continue to seek wider representation on it. A number of participants suggested that the Trust should do more in terms of going out to community groups, to demonstrate a more proactive willingness to engage in community venues. Over the course of the programme participants have consistently reminded us that engagement will only prove valuable if it effects real change that improves the experience of our BME service users.

## 3. Feedback Event

This programme of symposia began with a clear commitment that we would invite participants back to provide feedback on how their input had resulted in action by the Trust. This specifically addressed common community concerns that public sector organisations do not always follow up on the engagement they undertake with communities and that their concerns are not translated in to meaningful action. A concluding feedback event was held on June 7th, and was once more very well attended with 73 participants gathering to hear a summary of the programme to date and the commitments that the Trust has made to act on the issues raised. Participants were also asked to reflect on this model of engagement and to make suggestions about how they wished the Trust to engage in the future. The event was hosted by our Chairman, and included a brief session by Prakash Panchal which encouraged participants to think about the new governor role. Dr Jo Ellins, from Birmingham University was also invited to present some research she has conducted with older BME people in Leicester and Leicestershire. She highlighted the similarities between the outcomes of her research and the issues raised during the Symposium programme.

Participants were invited to consider whether future engagement should continue to specifically focus on the needs of BME communities, or if the Trust should ensure that its engagement with members and the wider public is inclusive and represents the diverse population we serve. Summarising the responses, it was clear that participants would like to see both a more inclusive approach to engagement and continued engagement with BME communities. In particular, some respondents argued that the needs of *specific* communities warranted greater attention by the Trust as opposed to a focus on BME communities as a general category.

## 4. Actions arising from the programme

In May 2011, a paper summarising the engagement to date was taken to the Trust's Executive Team. The team were asked to consider the issues raised throughout the programme and to provide a steer on how the Trust should respond. At this meeting, two clear actions were agreed. Firstly, the PPI and Membership Manager and the Service Equality Manager were asked to devise a training session to promote "cultural competence". It was suggested that the Executive Team be the first recipients of this training. In later discussions with the Director of Corporate and Legal Affairs, it was agreed that both the Executive Team and the Trust's wider senior leadership team be early recipients of this training. Secondly, it was agreed that the Service Equality Manager undertake some scoping work to assess the potential operational, financial and workforce implications of offering greater patient choice in relation to access to same sex practitioners. This work is to focus on a specific area of the Trust in the first instance. A further progress report and proposed development plans will be presented to the Executive Team later in the year.

Since work began on this programme of Symposia, a new "Equality Delivery System" (EDS) has been introduced to the NHS, and the Trust has opted to become an early adopter of this. The EDS requires the Trust to identify its equality priorities through "meaningful engagement" with local people. As such, the priorities that have been raised through these Symposia will also come to shape the Trust's new equality work programme.

## 5. Summary

From our engagement to date, it is apparent that community groups feel we could do more as a Trust to understand and respond to their cultural and religious needs and requirements. There is clearly a desire to see more training in this area across all grades of staff and to encourage a more flexible and sensitive approach to the needs of individuals and their families. A number of participants have suggested a more active and formal role for volunteers to provide social and language support to patients. Another recurrent theme was the need to inform patients of their rights regarding language support and of the level of service they should be able to expect. Perhaps the most challenging outcome from this process was a clear and widely shared desire to exercise greater choice in the gender of one's health practitioner; particularly for more intimate procedures and for personal care.

The Symposium, with its follow up meetings, has thus far proved to be a successful model of engaging with local BME community representatives. The programme has been well received and evaluated by participants and has allowed the Trust to identify local community priorities and explore some of the detail behind them. The process has encouraged participants to come up with solutions to the issues they have raised and has allowed the Trust to establish the beginnings of a dialogue which we hope will continue long after this particular programme concludes. As such, it has proved to be a positive step towards building better relations with our diverse local communities. Any future engagement will seek to build on this positive start, and include wider representation from communities that did not participate in this initial programme.

## 5. Risk

The outcome of any good engagement is empathy, but this must be coupled with the will to reflect this understanding in the way in which we provide services. Having begun a successful programme of engagement with local BME communities, we must now deliver on some of the priority areas discussed above. Through this process we have listened to community concerns and identified priority areas for action. However, if we cannot demonstrate that we are responding and improving outcomes in these areas we will run the risk of jeopardising any future engagement.

**University Hospitals of Leicester NHS Trust**

# Formal Response to the Safe and Sustainable Children's Congenital Heart Services Consultation

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## Introduction

The University Hospitals of Leicester NHS Trust (UHL) welcomes the opportunity to respond to the "Safe and Sustainable - Children's Congenital Heart Services in England" - Consultation Document. We have engaged widely with patients, staff and the public as well as voluntary and statutory bodies.

Respondents voiced an overwhelming consensus that Option A is the best fit to deliver the recommendations and findings of the review, not only for the Midlands, but also for the whole of the UK.

None of the other options were considered to deliver sustainability or deliverability and a key theme throughout has been the capacity of Birmingham Children's Hospital to deliver what is required in Options B, C and D. It is clear to us that our stakeholders share our analysis of the inadequacies and risks of single centre provision of care for the 11 million population of the Midlands.

We do agree that higher volumes of surgery in bigger centres with increased capacity and resourcing can only improve the care that we can provide our paediatric heart surgery patients. We acknowledge the case for each surgical centre undertaking a minimum of 400 surgical procedures per year with 4 surgeons. Without this, surgeons may continue to work onerous rotas or have insufficient cases to maintain their surgical skills.

We would however caveat this with the suggestion that there comes a point where 'critical mass' ceases to be a benefit and can become a risk. For example if a centre were allowed to become so large and the network so dependent on the centre that even a temporary suspension of surgery, as a result of say infection control issues, would destabilise the national provision of surgery and have a very detrimental effect on patients and parents. This risk is larger in those centres that have to deal with a large, seasonally variable non-cardiac case load.

The Trust supports the conclusions drawn that all current centres meet the quality standards and that all centres are within 95% of the top scoring centre.

We were particularly encouraged to hear Sir Ian Kennedy endorse this at the launch of the consultation process. This being the case we conclude that if all centres are performing well in terms of quality and safety the emphasis naturally falls on the questions of family access and sustainability.

Despite the reassurances given by Sir Ian Kennedy we have been concerned by the message from other centres, visiting panel members and the media undermining the quality of our service. This has been a very difficult message for families and staff closely connected with our centre to hear. It does not reflect their personal experience. In order to address this issue we have dedicated part of our response to highlighting areas where we feel that we were underscored on quality and outlining improvements that we have made since the expert panel assessment. The remainder of our response outlines risks and mitigations to engaging widely with the review process, our rationale for supporting Option A and objections to the other options. We conclude with a section on new opportunities for enhancing the centre's profile in the future.

## 1. Quality Scoring

We agree with the quality standards developed by the Safe and Sustainable Steering Group and continue to work towards meeting them in full through our expansion plans and collaboration with centres across the East Midlands network. Quality is not static in time; it can both deteriorate and improve, as is evidenced by our progress in areas that we were reported as weak in the Kennedy panel assessment. We believe our quality score if measured now would be significantly higher.

It is our understanding that Option B was included in the final configuration as a result of "emerging local intelligence" regarding altered patient flows. UHL would strongly urge the Safe and Sustainable Team to equally take into account the current altered quality performance of the East Midlands Congenital Heart Centre. Importantly, this not only includes progress achieved since the review, but also areas where we felt that we were significantly underscored in the original.

### a) Original underscoring

We feel very strongly that our concerns regarding what we viewed as inaccuracies in the expert panel report were not responded to by the Safe and Sustainable Team.

If the Team does not agree with our concerns or the evidence that we have provided, we request that a full response is provided to the Trust.

*Co-location*

We have listened to the concerns raised by the expert panel with regard to the co-location of interdependent services and clarified the existing arrangements which comply with the standards outlined in "Commissioning Safe and Sustainable Specialised Paediatric Services; A Framework of Critical Inter-Dependencies" (2008).

We are very concerned that we have been underscored by the assessment panel on this standard. We have almost identical co-location arrangements as Newcastle but the assessment report comments for Newcastle and Leicester were significantly different. This inconsistency will need rectifying before any decisions are taken where co-location is material.

The Trust's understanding of co-location as described in "Commissioning Safe and Sustainable Specialised Paediatric Services; A Framework of Critical Inter-Dependencies" (2008) is

"location on the same hospital site or

location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site. These would be reinforced through formal links such as:

- consultant job plans; and
- consultant on-call rotas".

Specifically, the Children's and Neonatal Services within UHL are co-located between the Glenfield and Leicester Royal Infirmary sites which are 3 miles apart (approximately 11 minutes travel time). This compares with 2.8 miles between the Children's services at the Royal Victoria Infirmary and Freeman Hospitals in Newcastle (approximately 10 minutes travel time).

The arrangements for individual specialities are:

- We have 24/7 cardiac surgical and intensive care consultant cover
- We have ENT airways cover
- We have specialised paediatric anaesthesia on site 24/7 on-call (1:4)
- We have 24/7 on-call cover (1:5) from paediatric surgeons who all work full time in the speciality and perform regular surgery on neonates and children.

- The paediatric neurology team provide a full day-time service to the children's cardiology department and are fully involved in any child who has suspected neurological problems. Ultrasound, CT and MRI are available 24/7. A paediatric neurology on-call rota (1:4) is currently under development and will cover paediatric cardiology and intensive care services.

- The dedicated team of 4 paediatric respiratory physicians provide a full day-time service to the children's cardiology department as required. Care of children with long-term ventilation needs is shared between the two specialities. The children's long-term ventilation clinic is run from the EMCHC out-patient department.

- There are strong relationships between the neonatal unit based at the LRI and the children's cardiology service. The paediatric cardiologists run joint clinics with the fetal medicine experts at the LRI and there is excellent dialogue between the neonatologists and cardiologists with real time image sharing.

- The paediatric intensive care team has extensive expertise in acute paediatric renal failure through its experience with ECMO patients, but for any chronic renal problems UHL has an arrangement with the regional renal paediatric team in Nottingham for whom EMCHC provides expert cardiological support.

- Clinical haematology works closely with the paediatric cardiology service in the management of children and adults with congenital heart disease requiring anti-coagulation therapy.

*Transition*

We were underscored for our transitional arrangements which we hope can be corrected by recognition of the following:

- a designated cardiac liaison nurse dedicated to transition across the network (Mary McCann)

- protocols which were presented as evidence to the expert panel

- paediatric and adult cardiac liaison nurses who share office accommodation and work closely together both at the centre and in the network hospitals

- paediatric and adult congenital cardiologists who share facilities, M&M meetings, MDT meetings and collaborate in the transition of individual patients/families

*Follow-up*

The Trust believes that there was a misunderstanding regarding patients being brought back to Glenfield for out-patient appointments. We run a substantial number of peripheral clinics in Nottingham (weekly), Derby (weekly), Mansfield (monthly), Kettering (monthly), Grantham (monthly), Peterborough (monthly) and Lincoln (monthly). The numbers seen in these clinics for 2010-11 are included in the capacity review submitted to Paul Larsen (NCG/Safe and Sustainable Review Team).

*Clinical Psychology*

The review reported that there was no clinical psychology support. We would like to reassure the review that EMCHC has a long-standing arrangement with the clinical psychology consultants within the dedicated paediatric service based at the Children's Hospital (LRI).

*Registrar cover for PICU*

The review reported that there was insufficient registrar cover for PICU. We would like to reassure the review that PICU has had an 8 person specialist registrar rota for several years, which rarely has any gaps.

*Nursing staffing and recruitment*

There have been no nursing vacancies within the paediatric cardiac nursing establishments for more than 3 months in the last 5 years. There are a mix of full and part-time staff working in PICU; many of the latter chose to augment their hours when the unit is busy rather than commit to a full time contract. We believe that this may have been mistaken as the Trust being reliant on overtime.

Detailed responses to the expert panel assessment are attached in Appendix 1 for reference.

**b) Improvements since assessment**

Our Assessment did highlight some areas where we needed to be better and we have listened and acted upon this.

*Network*

We already have a network, but it needed strengthening. We have met and discussed with lead clinicians from all around the network. As a group we have

agreed that we will work to provide the highest quality services, centred on the child and their family both locally and centrally.

We will continue to work together on common pathways and communication processes, to avoid duplication of appointments and investigations, and to justifiably boost confidence in local as well as specialist services. We have agreed there will be minimum standards of local provision both of equipment and expertise in our regional hospitals. All hospitals now provide high definition ECHO machines with paediatric probes for the clinics run by the visiting cardiologists. The majority now provide good technician support allowing maximum use of consultant time to review images and consult with the patient/families and local clinical staff.

We have already learnt a lot from our work across the region with the East Midlands Fetal medicine and other groups about what we can gain by working together. This will stand us in good stead as we move forwards.

Clinicians from 'Option A 'expanded' east Midlands network' centres currently serviced by Birmingham, Leeds and London were involved in our ongoing network dialogue and expressed support and willingness to consider Leicester as their specialist cardiac centre in the future should Option A be selected (Appendix 2).

We have clearly documented support from within our current network, for Option A, and also from many of the centres that would join us if Option A goes ahead.

The clear message we are hearing from patients, clinicians, commissioners and statutory bodies is that if option B, or indeed any of the other options goes ahead, there are major concerns over the inadequacies of single centre provision of care for the entire 11 million population of the Midlands. There are already access problems for a number of specialties referring into Birmingham Children's Hospital with longer waiting times for elective surgery and delay in transferring patients who require specialist care. There are huge risks if Birmingham Children's Hospital is unable to take admissions, for instance due to an infectious outbreak, as happened to their cardiology ward earlier this year.

A formal network launch event was held on the 31 May 2011 with facilitation from Mott Macdonald. Details of the outcomes and minutes from that meeting are outlined in Appendix 3.

We are updating and collating protocols, guidelines and pathways to ensure equity of access and equity of quality across the region. We are exploring the possibility of setting up a web-based portal for sharing these across the network.

We recently met with Birmingham Children's Hospital to informally discuss the concept of managed formal networks (they currently have no formal network arrangements). We were able to share our experiences and model of delivering outreach clinics with our Network team of liaison nurses. We also exchanged views on the establishment of parallel East and West Midlands Congenital cardiac networks which might also cross-fertilise for some aspects of education and training as well as sharing best practice.

We need a formal 'governance body' - our network board, and we agreed formal terms of reference and membership for this at the first network meeting at the end of May. Each representative group has agreed to nominate a lead to sit on the network board which will meet formally at the next network meeting in September and quarterly thereafter.

We are looking hard at ways of improving and speeding up the sharing between centres of the complex imaging information we need on our patients. This will improve patient management, reduce further the need for travelling, and avoid duplicate examinations.

We will be meeting up regularly for both business and educational meetings around the entire region. The next one is in Derby in September.

*PICU staffing*

Approval has been given to recruit a PICU NTN trainee as a first step to introducing a full NTN trainee programme.

The regional cardio-thoracic (CT) training programme has approved a 6 month rotational post for a CT trainee; the second trainee is coming towards the end of his rotation in July.

PICU has launched an Advanced Practitioner programme with the first two staff currently undergoing training at the Evelina Hospital. Within the expansion plans there is provision for 5 APs who will augment the middle-grade doctor rotas enhancing both junior doctor training opportunities (they will not be relied on for service provision) and continuity in the care given to PICU patients.

Since the assessment a further PICU bed has been staffed and an additional 2 ward beds. Details of the nurse recruitment opportunities and plans for expansion are attached in Appendix 1.

*Lead nurse*

At the beginning of April we appointed a lead nurse for the network, Elizabeth Aryeetey whose role will develop in accordance with the guidance and job roles developed by the Royal College of Nursing's specialist paediatric cardiac nurses forum.

*Clinical Psychology*

The job description and funding have been agreed for a dedicated 0.5 wte senior (8c) clinical psychologist to be advertised in September. This post will be supported by the children's clinical psychology department at the Leicester Royal Infirmary but will be based in the congenital centre out-patient area with a dedicated office and clinic room. Cross cover will be provided by two senior members of the team.

*Research*

We already had a great track record in ground breaking research (particularly in ECMO and in the genetic causes of congenital heart disease), but we didn't have a formal research strategy or a Research Director. We now have both which have been ratified by the Trusts R&D committee. Mr Lotto is now our Research Director and our first international research fellow starts next month. The research strategy is attached as Appendix 4.

*Age Appropriate facilities & Parent Accommodation*

The plans for the expansion of PICU and the ward have been further developed since the assessment. The new plans incorporate a dedicated state of the art adolescent area with separate recreational facilities, en-suite single rooms and access to a kitchen area for drinks/snacks. This makes a significant change to the quality of our age-appropriate facilities. In addition there will be one area specifically for under 1 year olds. The on-site parent accommodation increases from 5 double and 2 single rooms to 11 double rooms. A separate dining area and sitting room have also been added to the plans. A dedicated flat has been secured within the grounds of the hospital for families who want to spend time away from the ward with siblings and grandparents.

## 2. Engagement

We have significant concerns regarding the lack of engagement with BAME communities throughout the review. For Leicester this is particularly important as the "minority" ethnic groups are soon to become the majority within the city. These groups are not well represented within ANY of the national or local CHD voluntary organisations and charities that have informed the review to date

We are very aware that the structure of the review process has presented limited opportunities to engage meaningfully with the many cultures and subcultures within Leicester and possibly beyond. We have worked with the Safe and Sustainable Team to facilitate attendance at the HIA workshop but have been told by our communities that this is not a forum that people can feel comfortable attending.

To mitigate against the opinions of BAME not being represented our staff have given a considerable amount of their personal time in visiting local cultural events to raise awareness of the review. Weekends have been spent visiting local temples and Muslim festivals such as the Leicester Kidmah where staff spoke with over 2,000 women in one day. Staff and friends within the different communities have helped formerly unrepresented groups to complete the feedback questionnaires as translated sources arrived too late, and many of the Asian speaking women could not read or write.

We have been genuinely surprised to find out how little is known about the review even amongst people whose children or family members have congenital heart disease.

The feedback that we have received is that issues of travel and separation from families are more important than small differences in quality scores. Many people with whom we spoke had very positive views of the Glenfield hospital and the adult cardiac services which had treated family members. This local knowledge of the hospital's reputation appeared very important in informing people about the location of children's cardiac services.

We were surprised to hear that those who had visited Birmingham Children's Hospital appeared to judge the experience by the difficulties in parking, finding the hospital, the cost of parent accommodation and the isolation and difficulties that the women felt in coping without support from the community and family.

## 3. Support for Option A

We commend the analysis undertaken of access and travel times. This has emerged as a strong theme amongst the hard to reach communities with whom the Trust has engaged.

We support the principle of only two centres in London, based on a population of 9 million (Evelina Children's Hospital and Great Ormond Street Hospital for Children).

We strongly agree that Option A is the best fit to deliver the recommendations and findings of the review. It is best not only for the East Midlands, and the entire Midlands, but also for the whole of the UK because:

Option A delivers 400+ cases in each centre with no centre outside of London increasing its activity by more than 200 cases

Option A maintains all nationally designated centres of excellence in their current location. This principle is strongly supported by the Trust for 3 reasons:

1. Expertise in these super-specialised fields develops slowly and the skills are not easily transferred.

2. There is insufficient capacity in any one centre outside of London to increase its paediatric cardiac activity by 200+ cases and take on a further speciality that requires a high level of intensive care support (for example Leicester's ECMO programme occupied 1000 PICU bed days 2010-11).

3. The risks associated with the major upheaval of services required by the review will be compounded by the moving of ECMO

Option A provides the optimum solution for travel and access (The Joint Committee of Primary Care Trusts, p108). In particular we have concerns regarding the rural populations of Lincolnshire and Peterborough post codes (south Lincolnshire), currently serviced by Leicester. Travel times and access for these areas are significantly increased under Options B, C and D. In addition the population growth in the Midlands points to the need for two specialist centres. Options B, C, and D split local flows around the three Lincolnshire hospitals. We request to know if Lincolnshire will be required to have local clinics supported by three centres, Birmingham, London and Leeds. The current level of service (provided by Leicester) has a significant out-reach programme in Lincolnshire which supports many

families who cannot or will not travel the 70+ miles to Leicester. Reproducing this level of service under options other than Option A will be difficult; the travel times of the visiting clinicians will be considerable.

We understand from our conversations with the Head of Service at Birmingham Children's Hospital (BCH), Mr David Barron that their centre currently does little outreach and that there is a perception that this model does not generate income. Thus, bringing patients to the lead centre is currently the preferred option for outpatient follow-up. In addition, BCH currently provides no cardiac liaison nurse presence at peripheral clinics whereas EMCHC sends a nurse to every clinic. This is a service which continually evaluates excellently with families and the hospitals themselves who have included this in the service level agreement.

The East Midlands Congenital Heart Centre is at the heart of the UK transport network, it is right by the M1, in the centre of the country. With a relatively even spread of units around the rest of the country, there is absolutely no doubt that access and travel times are best in this option. The Midlands with a population of >11 million needs 2 surgical centres. (London, after all, with a population of 9 million retains 2 centres in all options).

We strongly support Option A as providing "best value for money", as it is both the highest scoring option and it requires significantly less capital and revenue investment than Option B. Our location, in a modern, green field site, with opportunities to move other services around, means we don't have to build. Even in this very difficult financial climate, this option is genuinely and realistically affordable. UHL has affordable plans to deliver the increase in capacity already underway, signed off and supported by the Trust and two charities.

There is also no doubt in our minds that we can deliver what is asked of us in Option A. We already provide the world's largest ECMO service, and can continue to do so, alongside our expanded congenital heart programme. The other options will severely compromise this. Our building work for our expanded PICU will be complete by April 2012 and the ward expansion by September 2012. Our staff recruitment plans are spread over two years and we are confident that we can deliver the full plan by year 3 following designation.

## 4. Objections to other options

We strongly oppose the configuration of services in Option B which raise concerns regarding patient flows, the capacity of centres to undertake the activity required, and the upheaval of nationally designated services at a time of unprecedented change. We believe that having a single centre in the midlands for a population of 11 million is unsustainable. We also have great concern regarding the provision of adult congenital cardiac services under this option.

*Patient Flows*

UHL will await the analysis of new patient flows in the south before commenting on the sustainability and deliverability of the configuration which includes both Bristol and Southampton. We have some concerns that patients have not always been offered appropriate choices or information in the re-direction of patients from Oxford to Southampton. The 6.2% of families seeing an increase in travel time to the Specialist surgical centre does not reconcile with our families, particularly from a BAME background, according travel times as a major issue of concern.

*Centre Capacity*

We request to see the evidence that Birmingham has the capacity and capability to undertake both an increased cardiac surgical workload and build a new ECMO service, as well as increase its capacity for neurosurgical and renal work, as outlined in a recent Health Care Commission report. We also request to know how involved the Midlands' specialist commissioners have been in testing these assumptions. Within the last 12 months Leicester was asked by the West Midlands' Commissioners to undertake a number of surgical cases from Birmingham Children's Hospital due to difficulties with long waiting lists.

Option B provides a disproportionate increase in demand for the Newcastle surgical programme (255-526 surgical cases per year) which is unlikely to be delivered and sustained. The demographics of the north east (few areas of large conurbation, large areas of sparse rural population with difficult access and travel to Newcastle (particularly in winter) and no neighbouring centres with which to collaborate on recruitment and training) do not favour a large expansion and retention of specialist nurses and other specialist staff.

*ECMO*

The review recommended that nationally designated services should, where possible, remain in their current locations. Under Option B, ECMO services would move to Birmingham, and this poses a significant risk to the outcomes of children requiring ECMO in the 5 years following designation (the detailed assessment of this risk is outlined in Appendix 5)

*PICU*

UHL strongly disagrees with the statement that under Option B the potential impact to paediatric intensive care units would be lessened. The impact of losing paediatric cardiac surgery in Leicester would present a significant risk to the provision of levels 3 and 4 intensive care for children within the East Midlands. The remaining PICU provision at the Leicester Royal Infirmary would not be sustainable without any specialist "elective" service providing a base-line of activity throughout the year.

Activity would be largely seasonal and staff will therefore be unable to practice their specialist skills throughout the year. (The detailed analysis of this risk is outlined in Appendix 6)

*Adult Congenital Heart Disease and High Risk Obstetric Cardiology*

<u>Critical dependence on Co-location</u>

The EMCHC provides lifelong follow up for patients with congenital heart disorders. The surgical team that operate on the paediatric patients also operate on the adults with congenital heart disease (ACHD) and the paediatric cardiologists undertake the majority of cardiac catheterisations in both age ranges. We are not alone in providing this model of care and indeed even the "stand alone" ACHD centres rely exclusively on surgical teams from local paediatric cardiac surgical centres and often on the skills of paediatric interventionists.

As such, there can be no doubt that the decisions made with regard to paediatric cardiac surgery will have profound and far-reaching effects on the national provision

of care for adults with CHD. All centres failing to retain paediatric cardiac surgery will lose ACHD surgery and intervention. This will have significant consequences for the local and regional populations that these centres serve and will have important knock-on effects for surviving centres that will have to cater for a sudden increase in work load.

Despite the critical dependency of ACHD services on paediatric surgery and cardiology, the national impact on ACHD services has not been considered by Safe and Sustainable. That we are likely to be facing the prospect of a reduction in surgical/interventional centres caring for adults with CHD at a time when this population is rapidly expanding raises the stakes considerably. We specifically highlighted this omission to the Panel at the Leicester public meeting in June 2010, again on the Panel's visit to EMCHC, and would like to ask that further consideration is given to ACHD services by Safe and Sustainable in their further deliberations.

East Midlands Congenital Heart Centre Perspective

EMCHC has a rapidly growing ACHD service and has been instrumental in the development of an extensive ACHD network throughout the East Midlands. We saw 451 new patients with ACHD in the Glenfield clinic alone in the last 12 months, an increase of 97% on 2008-9 figures. Our joint network clinics are expanding at a similar rate. With an estimated 7000 patients with moderate or complex ACHD in our region there is considerable work to do but after recognising these trends, the network is taking a proactive approach to management. Network clinic frequency is increasing across sites and new clinics are being brought in to the network. Restructuring of ACHD care at Glenfield has seen recruitment at consultant, registrar and liaison nurse levels within the last 18 months and inpatient care pathways have been stream-lined.

In addition, a regional high risk obstetric cardiology service has been developed to cater for expectant mothers with ACHD, cardiomyopathy, coronary artery disease and rhythm disorders. In its first year the service saw over 120 women from around the region, the highest risk cases coming forward for delivery at Glenfield Hospital and Leicester Royal Infirmary. Again this service is critically inter-dependent on co-

location with a tertiary congenital cardiac centre and the loss of these services to the region would have a considerable impact on the care of these patients.

Conclusion

We hope that Safe and Sustainable recognise that the future of ACHD care and high risk obstetric cardiology is critically inter-dependent on co-location with paediatric cardiac surgery and consider this in future decision making. We consider that the issues concerning access and travel, quality, deliverability, sustainability and affordability should equally apply to our patients beyond the age of 16 years as they do below this age and believe that we are in an exceptionally strong position to deliver safe and sustainable ACHD care under Option A.

Further information concerning ACHD care and the high risk obstetric cardiology service is given in Appendix 7.

*Options C&D*

We do not consider that reducing the numbers of surgical centres to 6 is deliverable or sustainable due to the impact on nationally commissioned services, increased travel times and failure to achieve or sustain the levels of activity required by Birmingham and Newcastle in option C and Leeds in Option D. A 6 centre option carries greater risk to a disruption in service nationally should one centre close temporarily as a result of safety concerns (example, Oxford) or a sudden increase in PICU demand (example, H1N1 pandemic).

## 4. New opportunities

*Tracheal Surgery*

As part of the expansion of the paediatric congenital cardiac services in Leicester, the University Hospitals of Leicester is exploring areas in which it can further develop its portfolio of services. The Trust believes it is in a strong position to develop a bid for the national tracheal surgical programme currently provided by Great Ormond Street Hospital.

Background

Children with tracheal and airway problems present with 'acute on chronic' insufficiency which, at its most severe, manifests as ventilator-dependent respiratory failure.

Paediatric Tracheal and Airway Management within UHL

The University Hospitals Leicester has developed a strong clinical interest in children with tracheal and airway problems as a consequence of managing a large cohort of children with 'acute on chronic' insufficiency due to upper airway abnormalities. Over the last 3 years, the service has managed 25 children with trachea-bronchial problems. All have received invasive ventilator support via tracheostomy. Several have been considered for 'airway stenting' with one patient treated at Great Ormond Street. All these children have been fully investigated and diagnosed in Leicester using multi-modal techniques including 'virtual CT bronchoscopy' and 'bronchography' to determine opening pressure and functional airway anatomy.

The service is recognised to be large with significant expertise; a comparable sized nearby paediatric centre (Queens Medical Centre, Nottingham) has only managed one patient in this period.

Capability to Provide Tracheal Surgery

The service at UHL comprises of senior consultants based in the departments of Paediatric Cardiothoracic Surgery, Paediatric Ear, Nose and Throat Surgery, Paediatric Respiratory Medicine and Transitional Care and Paediatric Radiology. A cadre of dedicated specialist respiratory nurses and respiratory technicians support day to day management of our patients. The delivery of the service is based on a multi-disciplinary team approach. The collocation of the world's largest ECMO unit with a paediatric cardio-thoracic surgical service undertaking the full range of cardiac surgical operations alongside major thoracic tumour resections in children makes our unit ideally placed to safely provide tracheal surgery. Sustainability of the service is ensured by the presence of two surgeons trained at GOS who both regularly undertake both cardiac and thoracic surgery as well as ECMO.

The range of expertise within our service as a result of managing patients over a long period of time makes us a realistic and viable proposition as a centre which would offer assessment and treatment of children with tracheal and airway problems.

## Conclusion

The University Hospitals of Leicester NHS Trust has engaged widely with stakeholders across the current and potential future East Midlands network in putting together this response. This document represents the views and concerns that have been voiced. We believe that the dedication, passion and exceptional organisational skills of the East Midlands' Congenital Heart Centre staff is reflected in their achievement of engaging large sections of the local population (including hard to reach groups), ensuring that this response is reflective of the views of all users and potential users of children's congenital heart services in the Midlands.

As outlined in the introduction respondents voiced an overwhelming consensus that Option A is the best fit to deliver the recommendations and findings of the review. We have heard major concerns expressed regarding the capacity of Birmingham and Newcastle to deliver both congenital cardiac surgery and ECMO if the East Midlands Congenital Heart Centre closes.

We have been told repeatedly that the Midlands requires a two centre model and that the consequence of losing congenital cardiac surgery and ECMO in Leicester will present real risks to PICU provision across the midlands and beyond. Our stakeholders say that disrupting the nationally designated ECMO service and relocating it from Leicester (the major deliverer of care and training for neonates, children and adults) will have major negative consequences at a time of unprecedented upheaval to paediatric cardiac services.

We have made the case for a revaluation of our quality score based on our belief that we were underscored originally and have made substantial improvement in some areas of the quality standards since the assessment was undertaken. In particular we have addressed the issue of consultant cover in PICU, clarified our co-location arrangements, formalised our research strategy and established a network model that has received support and engagement from clinicians in the existing and expanded East Midlands Network.

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Appendix 1 Detailed Responses to the Kennedy Panel Assessment

Appendix 2 Network Communication Document

Appendix 3 Network Invite & Minutes

Appendix 4 Research Strategy

Appendix 5 Impact of ECMO relocation

Appendix 6 Impact on East Midlands Paediatric Intensive Care Provision

Appendix 7 Impact on ACHD

Appendix 1 Detailed Responses to the Kennedy Panel Assessment

**Leadership and Strategic vision (Leicester)**

| | **Gaps in Compliance** | **Current Position** |
|---|---|---|
| **Aims, Business Strategy and Strategy Priorities** | The business case contained a large number of assumptions, especially with regard to financial planning. | In response to this concern, the business case has been remodelled according to expected activity under the expanded network of Option A. Clinical, logistical and financial considerations have been scrutinised in detail and the resulting new and revised business case has been endorsed by the Divisional management team, the East Midlands' Specialised Commissioning Group, the Trust's Commercial Executive (chaired by the Director of Finance) and the Trust Board. It was signed off by the Trust Board on 21 June, 2011 and is attached to the Capacity Review update submitted to Paul Larsen. |
| **IT and Estates Strategy** | Whilst the Estates Strategy is robust, it maintains a split site approach with critically interdependent services on a different site to the paediatric cardiac surgery service. | With respect, we disagree with this conclusion. The critically interdependent services meet the criteria outlined in the standards, "Commissioning safe and sustainable specialised paediatric services: a framework of critical inter-dependencies" (2008).<br><br>Co-location in this context was defined as meaning:<br>"location on the same hospital site; or location in other neighbouring hospitals if specialist opinion and intervention were available within the same parameters as if services were on the same site. These would be reinforced through formal links such as consultant job plans and consultant on-call rotas" (p8).<br><br>The critically interdependent services of paediatric cardiology, paediatric cardiac anaesthesia and paediatric intensive care are all on the Glenfield site with 24/7 on-call arrangements specific to this site and commitments confirmed within respective job plans. |

| | Gaps in Compliance | Current Position |
|---|---|---|
| **IT and Estates Strategy**<br><br>**(continued)** | | The critically inter-dependent services of paediatric surgery and ENT (airway management) are sited 10 minutes (3 miles) from the Glenfield Hospital site. Out-of-hours consultants are all able to reach the hospital within 20 minutes (often less).<br><br>There are very strong relationships, established over 20 years, between departments and consultants across the UHL Hospitals. Any neonate or child with urgent/emergent surgical problems is seen within 10-20 minutes. Surgery, if required, is undertaken in the paediatric cardiac theatre or emergency theatre at the Glenfield Hospital. This service is also provided for neonates/children on ECMO.<br><br>The Trust is confident that the current co-location of all its children's services is both SAFE and SUSTAINABLE. Governance arrangements for all children's services is ensured by shared protocols, documentation, membership of decision-making boards, incident reporting and complaints, risk strategies (including medicines management) and professional accountability. The Lead Nurse for the children's cardiac network is accountability to the Lead Nurse for Children's Services in UHL and the Paediatric Intensive Care Consultants are accountable to the Medical Director of the Trust through the Clinical Director of Children's Services. |
| **Main Stakeholder Groups** | The Trust did not demonstrate a strong relationship with its commissioners; however it had a strong relationship with the clinical referrers. | We were surprised by this impression. The Trust has received considerable support and has an excellent relationship with the East Midlands' Specialist Commissioning Group (EMSCG). As part of the assessment process, the Trust presented a letter of support from Kate Caston, the then Director of EMSCG. EMSCG is now formally represented on the East Midland Congenital Heart Centre Programme Board (strategic planning), chaired by UHL Director of Strategy. We consider that we have an exceptionally strong and productive relationship with EMSCG. |

| | **Gaps in Compliance** | **Current Position** |
|---|---|---|
| **Main Stakeholder Groups**<br><br>**(continued)** | The panel felt that the main stakeholder groups, including parents had not been made fully aware of the implications of the Trusts submission if successful (i.e. implications of increased activity and staffing, impact to other services and management of a larger network). | EMCHC has worked closely with parent groups such as Heartlink and Keepthebeat to allow a full understanding of the implications of increased activity and staffing and the likely changes associated with becoming a larger specialist centre and network. Out stakeholder groups have welcomed the proposed expansion to services so that more patients, in the expanded network, may benefit from the Glenfield approach. They are ready to rise to the challenges that will result in higher activity. |
| **Critical Success Factors for Delivering Plans** | The panel felt that the Trust had not fully taken on board the implications of the gap in PICU service provision.<br><br>The Trust had not taken a proactive stance in identifying where their increased activity would come from and the panel felt that there were too many assumptions that the Trust would receive these referrals "by default".<br><br>The panel did not see evidence that the Trust had considered how they could manage an increase in activity to 500 procedures per year. | In light of this concern the Trust has reassessed the PICU service provision and funded an additional 2 consultant Intensivist posts (1:5 rota in place since 01 June 2011). This ensures 24/7 consultant on-call for the paediatric cardiac surgical site and a consultant resident for complex surgical patients such as stage 1 Norwood.<br><br>We trust that the Panel understands the sensitivities of approaching hospitals that lie in the network of other paediatric cardiac centres that may close as a result of this process. We do not want the Panel to interpret this as passive or lacking ambition but rather professional respect. Since the publication of the Report the Trust has modelled the new East Midlands network outlined in Option A and has undertaken extensive engagement with clinicians in the new centres.<br><br>We are surprised at this conclusion. The Panel will be aware that the Trust has secured major funding from Thomas Cook Travel which will allow expansion of PICU from 8 to 12 beds (out to tender, completing February 2012). Additional secured Trust investment will see the expansion of the paediatric cardiology ward from 13 to 24 beds including a dedicated 4 room adolescent unit with lounge. Parent accommodation adjacent to the ward will increase from space for 12 in 7 rooms to 20 in 11 rooms (scheduled completion end 2012). In light of the report findings the Trust has reviewed and revised its business plan to accommodate 450 cases (Option A network estimates 420). |

| | Gaps in Compliance | Current Position |
|---|---|---|
| **Main Internal and External Factors upon which Successful Delivery is Dependent upon** | The Trust had not fully considered external factors and the demand plans were heavily dependent on inheriting referrals "by default" from other centres. | The Trust has recognised the importance of gaining the support of centres that are potential partners and sources of referral in the network outlined in Option A. It has proactively engaged with fetal medicine consultants, obstetricians, general paediatricians, paediatricians with expertise in cardiology, intensivists and cardiologists with an interest in ACHD. |
| **Main Constraints and Risks** | The panel felt that the split site was a significant risk, and this has not been sufficiently addressed in the estates strategy.<br><br>The Trust recognised the challenge in recruiting the necessary number of nurses. | The Trust has evidenced its compliance with the co-location standards as outlined above<br><br>The Trust has recruited to a further PICU bed since the assessment, plans to complete recruitment to a further bed by the end of the 2011 and to the expanded PICU and ward thereafter. |

| | Gaps in Compliance | Current Position |
|---|---|---|
| **High Level Strategic and Operational Benefits** | The panel felt that the Trust had over-emphasised the importance of the paediatric cardiac surgery service and this was because of the reputational impact of retaining this service. | The Trust recognises the importance of the EMCHC to providing care for patients with congenital heart disease across the region and is proud to provide a comprehensive service for patients of all ages with congenital heart disease. The Trust recognises the domino effect on Specialist Children's services that may ensue if cardiac surgery is lost from the Trust. As such, the Trust does not feel that the importance of paediatric cardiac surgery has been over-inflated. |
| **Opportunities for Innovative Working** | The Trust did not demonstrate how it collaborated with the network in developing new ways of working.<br><br>The panel felt that that Trust's implementation of PACS and foetal cardiology screening was good, but standard practice and therefore did not demonstrate innovative working. | The East Midlands Congenital Cardiac Network has been launched with one of its key objectives to develop real time image sharing. |

**Strength of Network (Leicester)**

| | Gaps in Compliance | Current Position |
|---|---|---|
| **Current achievement against the core standards A1, A2, A5, A7, A8, A13, A24, A25 and B3** | The panel felt that the Trust has adopted a top down, hub and spoke model to networking instead of a collaborative approach.<br><br>Patients are generally brought back to Glenfield Hospital instead of having outpatient appointments in the network | The Trust has taken on board the criticism of a top down approach to the network and has had a very positive response to the collaborative approach adopted through the formal launch of the East Midlands congenital network. Under its constitution, clinicians throughout the network of various disciplines will be invited to hold positions of responsibility on the network board.<br><br>There seems to have been a misunderstanding regarding patients being brought back to Glenfield for out-patient appointments. We run a substantial number of peripheral clinics in Nottingham (weekly), Derby (weekly), Mansfield (monthly), Kettering (monthly), Grantham (monthly), Peterborough (monthly) and Lincoln (monthly). |
| **Development plans/ risks to meeting standards A1, A2, A5, A7, A8, A13, A24, A25 and B3 (if not all ready achieving)** | The Trust did not articulate any risks or mitigation to plans.<br><br>The panel felt that the clinicians did not demonstrate that they see themselves in a clinical leadership role. | In recognition of this, the Trust has identified risks and mitigations in relation to the final outcome of the Review and these have been incorporated into the EMCHC's business plan.<br><br>In response to the panel's observations, the EMCHC has now developed a leadership framework with lead clinicians for each major division of service including intervention, foetal cardiology, education, research and ACHD. |

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| | **Gaps in Compliance** | **Current Position** |
| **Impact on standards A1, A2, A5, A7, A8, A13, A24, A25 and B3 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased** | The panel had concerns about the sustainability of off-site services including paediatric general surgery.<br><br>The Trust had not demonstrated that it had sufficiently modelled the number of clinical staff that would be required within the network if activity increased to 400+ procedures a year. | Please see response to provision of critical inter-dependent services above.<br><br>The Trust has remodelled its workforce planning and increased provision for cardiologists, paediatricians with expertise in cardiology, cardiac liaison nurses, consultants in intensive care, catheter lab and theatre staff, physiotherapists and pharmacists. These are detailed in the capacity plans submitted as part of the consultation process. |

**Staffing and Activity (Leicester)**

| | Gaps in Compliance | Current Position |
|---|---|---|
| **Current achievement against the core standards C4, C5, C6, C7, C9, C11 and F2** | The Trust employs 2 full time surgeons and 1 locum surgeon.<br><br>The Trust does not meet the minimum activity thresholds. | The Trust employs 3 full time surgeons and agreed funding for a 4th when activity increases.<br><br>The Trust performs the numbers of cases generated from its current catchments' population and has built the capacity and network links to increase this to over 400 cases from the extended network described in Option A. |
| **Development plans/ risks to meeting standards C4, C5, C6, C7, C9, C11 and F2**<br><br>**(if not all ready achieving)** | The Trust did not demonstrate robust thinking around how activity could be increased. The panel did not receive a sufficient explanation of the basis for assumptions nor around the identification of risks.<br><br>The panel felt that the Trust was over-confident in its ability to meet the challenge of recruiting the large numbers of nursing staff required to meet current capacity requirements. Risks had not been sufficiently identified. | The Trust has approached and discussed referral pathways and collaborative arrangements with its extended network under Option A; Coventry/Warwick, Sheffield, Doncaster, Grimsby and Scunthorpe. It has received positive assurance from ALL of these centres that they would be happy to refer to Leicester in the event that Option A becomes the model of reconfiguration. The Trust has also made approaches to the paediatrician with an interest in cardiology in Northampton.<br><br>The Trust recognises that there is a risk that the Northampton clinician will continue to refer to London even under the model of Option A but it continues to pursue dialogue with him as well as invited to participate in the weekly MDT. The feedback from parents in the area is that they wish to be offered a choice between Leicester and London.<br><br>The Trust has concerns regarding the inconsistencies with regard to the panel's comments on nurse recruitment. The assessment panel did not highlight significant concerns regarding the recruitment plans for expansion in Newcastle despite reporting that it had CURRENT vacancies. Leicester has NO current vacancies and demonstrated an excellent |

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| | | track record of recruitment. |
| | **Gaps in Compliance** | **Current Position** |
| **Development plans/ risks to meeting standards C4, C5, C6, C7, C9, C11 and F2**<br><br>**(continued)** | The Trust appears dependent on overtime to sustain an appropriate level of nursing cover. | The Trust has a robust plan to recruit nursing staff both to PICU and the ward. It has continued to recruit to PICU throughout the review period, increasing PICU capacity by an additional bed and the ward by 2 beds. The Trust HR and Director of Nursing are involved in developing a recruitment strategy to launch at the point that it becomes clear that the unit is to be designated as a specialist cardiac centre. As a large Trust with neonatal services, large adult ICU services and community paediatric services there is a large pool of experienced staff to attract to posts. Recruitment from newly qualified nurses will also be strongly encouraged.<br><br>Both PICU and the ward have excellent feedback from the University and students regarding the quality of their experience during placements. The demand for post-graduate positions in these two areas has been consistently higher than the available vacancies. In the last year the unit has attracted recruits from Birmingham, Alder Hey and Manchester as well as two local adult ICU nurses and one neonatal nurse. During the period of "limbo" between consultation and designation the Trust has committed to continuing recruitment at the level of one PICU/year.<br><br>At the time of the assessment visit the unit had stepped up to the challenge of supporting the adult ECMO programme to deliver a service to the H1N1 pandemic which was achieved by staff undertaking a substantial amount of over-time. This is not the normal practice of the unit, although a proportion of staff work part-time and increase their hours at times of peak activity to allow them greater flexibility. |

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| | | From 1st June 2011 the PICU consultant rotas between Glenfield and LRI have been split allowing dedicated rotas on each site. Additional resources have been allocated for two new consultant posts at Glenfield. |
| | **Gaps in Compliance** | **Current Position** |
| | The panel felt that PICU may not be sustainable because consultants had to cover both PICUs; there is no sufficient throughput of SpRs | PICU has an 8 person SpR rota with no gaps and therefore we are unclear why there was criticism of SpR cover on PICU. If this comment referred specifically to ICU trainees then we are pleased to confirm that Deanery approval has been given to recruit a PICU NTN trainee as a first step to introducing a full ICU NTN trainee programme.<br><br>Furthermore, the recent PICU launch of an Advanced Practitioner programme is another exciting development. The first two staff are currently undergoing training at the Evelina Children's Hospital. Within the expansion plans there is provision for 5 APs who will augment the middle-grade doctor rotas, enhancing both junior doctor training opportunities (they will not be relied on for service provision) and continuity of care for PICU patients. |
| **Impact on standards C4, C5, C6, C7, C9, C11 and F2 if activity increases to**<br><br>**400 procedures per year and any additional development that** | The Trust did not demonstrate robust thinking around how activity could be increased.<br><br>It was not sufficiently clear how a caseload of 500+ procedures a year could be met and sustained.<br><br>The panel expressed serious | The Trust's activity and expanded network plans are described above and in Appendix 3.<br><br>As above, the network that the Trust is exploring will deliver over 400 cases and should this increase over time there is capacity within the Trust's plans to take on further activity. The PICU and ward expansion of beds and recruitment of an additional surgeon, intensivists, nurses and Advanced Practitioners, as described above has been planned around the expanded activity under Option A and has already begun in earnest to improve existing |

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| **would be necessary if activity increased** | concerns over the long term sustainability of PICU as there were no robust plans to recruit more PICU consultants. | services at current activity levels.<br><br>Please see the statements above on PICU bed expansion, division of Glenfield and Leicester Royal Infirmary on-call rotas and the recruitment of 2 additional PICU consultants. |

**Interdependent Services (Leicester)**

| | Gaps in Compliance | Current Position |
|---|---|---|
| **Current achievement against the core standards C12-21, C64 and C65** | Although all interdependent services were delivered either on the same site as the paediatric cardiac surgery services or on another site in the same hospital trust, the panel had concerns that the other site may not be close enough to be regarded as being co-located.<br><br>There were serious concerns that ENT was not on the same site as the paediatric cardiac surgery service as this is deemed a critical service. | We are concerned that there are inconsistencies in the reporting from different centres. Newcastle, for example, is considered compliant in meeting co-location standards for critically inter-dependent services and Leicester is not. There is no significant difference in the distance and travel times between co-located sites in these two centres (as defined in "Commissioning safe and sustainable specialised paediatric services: a framework of critical inter-dependencies," 2008).<br><br>We do consider ENT to be co-located, see above and below. |
| **Development plans/ risks to meeting standards C12-21, C64 and C65 (if not all ready achieving)** | There are no plans to co-locate ENT on the same site as paediatric cardiac surgery service. | ENT surgery meets the co-location standards as described above. ENT surgeons are available within the same parameters 24/7, proving the same service as a single site centre. |

| | Gaps in Compliance | Current Position |
|---|---|---|
| **Impact on standards C12-21, C64 and C65 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased** | The Trust has not identified any need to move services to enhance co-location. | The Trust meets the co-location standards as described above. |

**Facilities and Capacity (Leicester)**

| | Gaps in Compliance | Current Position |
|---|---|---|
| **Current achievement against the core standards C64, C65 and F6** | The current nursing workforce appears to be coping well; however this is dependent on overtime and good will.<br><br>There was limited evidence of sufficient paediatric nursing and consultant cover in PICU. | The Unit is proud of its committed and experienced nursing workforce which has been built up over many years. It has an excellent retention record and success in recruiting to an expanded PICU and ward base.<br><br>The unit has addressed the consultant cover for PICU by recruiting to an 8th consultant post and securing funding for 2 additional posts. It has already attracted a highly experienced recruit to the 9th Intensivist post and is confident that it will recruit to the 10th post within the next 6 months. In the interim, locum cover has been secured to provide independent rotas on Glenfield and Royal Infirmary sites respectively. |
| **Development plans/ risks to meeting standards C64, C65 and F6 (if not all ready achieving)** | The panel recognise the challenge in recruiting such a large number of nurses, and there are no plans to increase the PICU workforce capacity. | The number of nurses required has fallen since the assessment as recruitment has been successful and retention (even through this period of uncertainty) has remained excellent. The nursing workforce has been complemented by additional medical staff and in the expansion plan, physiotherapists, pharmacists and ECHO technicians. |
| **Impact on standards C64, C65 and F6 if activity increases to 400 procedures per year** | The concerns over PICU capacity remain. | Please see comments concerning PICU new build above. |

**Age Appropriate Care (Leicester)**

| | Gaps in Compliance | Current Position |
|---|---|---|
| **Current achievement against the core standards D1- D8** | There is no transition nurse within the network.<br><br>There is no clinical psychologist.<br><br>The panel felt that facilities for adolescents were weak, as they were given a choice of either adult or children's wards and neither of these are appropriate for adolescents. The alternative is a cubicle, which the panel deemed as insufficient. | We respectfully point out that this is factually incorrect. There is a designated transition nurse for the network (Mary McCann) who has been in post for 6 years.<br><br>The centre receives Clinical Psychology support from the dedicated paediatric service based at the Children's Hospital (LRI). In the development plan this is augmented to a 0.5 WTE senior (Band 8c) post dedicated to paediatric cardiology but with peer support and cover from colleagues based at the LRI. The advertisement for this post will be placed in September 2011.<br><br>As described above, this deficiency has been recognised and the ward expansion plan includes a four bedded adolescent unit (all single en-suite rooms) with recreational areas. This is scheduled for completion in 2012. |
| **Development plans/ risks to meeting standards D1- D8 (if not all ready achieving)** | There are no plans to recruit a transition nurse for the network, and the Trust did not recognise the need for such a post. | As stated above, this conclusion is incorrect. |

**Information and Choice (Leicester)**

| | Gaps in Compliance | Current position |
|---|---|---|
| **Current achievement against the core standards E1- E14** | The Trust did not use hand held records and there is no dedicated parent forum.<br><br>There is no clinical psychologist. | The Trust works in close collaboration with its main parent support group, Heartlink, who run a dedicated parent only forum on a monthly basis. This regular meeting is also used as an opportunity for parents to discuss issues and concerns with nursing, medical staff and management. These structures have been in place for many years.<br><br>There is clinical psychology support as described above and this will be greatly enhanced by the end of the year with a new senior appointment to the service. |
| **Impact on standards E1-E14 if activity increases to 400 procedures per year and any additional development that would be necessary if activity increased** | The Trust did not feel that they needed to make any changes to how parents and children received information if activity increased to 400 + procedures per year.<br><br>The Trust did not sufficiently explain how they would disseminate information to parents within a larger network. | The Trust plan to appoint an additional 3 cardiac liaison nurses in line with the increased activity allowing first class communication between hospital, patients and parents by local visits, educational events and improvements to written literature.<br><br>Since the assessment visit the service has developed its own website (www.eastmidlandscongenitalheart.nhs.uk/) and is planning interactive forums for both parents and adolescents thereby enhancing communication across the extended network. |

**Ensuring Excellent Care (Leicester)**

| | **Gaps in Compliance** | **Current Position** |
|---|---|---|
| **Current achievement against the core standards G1, G4 and G12** | The Trust does not demonstrate a formal research strategy. | The Trust now has a formal research strategy for the EMCHC which has been endorsed by the Trust's Research and Development Board. |
| **Development plans/ risks to meeting standards G1, G4 and G12 (if not all ready achieving)** | Limited evidence of the development of a formal strategy.<br><br>The panel was not confident that the Trust had considered how the research strategy would be rolled out across the network. | Please see above |
| **Impact on standards G1, G4 and G12 if activity increases to 400 procedures per year** | The panel expressed concerns that the research strategy did not contain sufficient detail and was not robust. | Please see above |

**Summary**

By taking account all of the above we feel that we've addressed the large majority of concerns. We are certain that our quality score has been enhanced considerably and we would now compare with the higher scoring centres in the original report.

Appendix 2 Network Communication

| **Referring Centre (inc. all in UHL Network for Option A)** | **Name of Lead Referring Clinician/s** | **UHL Lead Contact** | **Response (ie: which option do they support, any feedback etc)** |
|---|---|---|---|
| Nottingham | Pradip Thakker (Paediatrician with Expertise)<br>Lucy Kean (Head of Service, Fetal Medicine)<br>Steve Wardle (Head of Service, Neonates)<br>Stephanie Smith ( Head of Service, Paediatrics ) | Dr Frances Bu'Lock<br>Elizabeth Aryeetey | Support Option A.<br><br>Clinicians have indicated that they will be making a formal joint / separate response to the S&S review panel |
| Derby | Janet Ashworth (Fetal)<br>Gitika Joshi (Paediatrician with Expertise)<br>Jon McIntyre (Head of Service, Paediatrics) | Dr Demetris Taliotis<br>Elizabeth Aryeetey | Support Option A<br><br>Not keen to have single site surgery for Midlands as distances, time and bed availability at BCH insufficiently robust. |
| Mansfield | Helena Clements (Head of Service, Paediatrics),<br>Vibert Noble, Link Paediatrician<br><br>Sue Ward (Obstetrician) | Dr Suhair Shebani<br>Elizabeth Aryeetey | Support Option A.<br><br>Recreating enhanced outpatient service with MDTs. |
| Peterborough | Tim Jones, Diana Yong (Paediatricians)<br>Shirley Steele & Michael Lumb (Obstetricians) | Abdul Duke<br>Frances Bu'Lock | Paediatricians very happy with their existing arrangement, being able to refer both to GOSH and ourselves. GOSH who also do a weekly clinic<br><br>They are concerned about the impact on PICU and services other than ours. |

| **Referring Centre (inc. all in UHL Network for Option A)** | **Name of Lead Referring Clinician/s** | **UHL Lead Contact** | **Response (ie: which option do they support, any feedback etc)** |
|---|---|---|---|
| Peterborough<br><br>(continued) | | | Their links with GOSH are very strong.<br><br>The obstetric team have a very long standing relationship with the fetal team at GOSH; this seemed to be a major issue, in so far as they did not wish to upset a system that worked very well for them. |
| Kettering | Paul Wood, Sunil Doshi & Rukhsana Iqbal (Obstetricians)<br>Margaret Grier (Specialist midwife)<br>Patti Rao & Nagarajan Nandakumar (Nanda) (Paediatricians)<br>Harsha Bilolokar (Head of Service) | Abdul Duke<br>Frances Bu'Lock | Dr Bilolokar came to network meeting.<br><br>Paediatricians support Option A. Obstetricians still refer to Oxford but significant numbers being referred onward to Leicester for surgery |
| Lincoln | Alastair Scammell (AS) (Paediatrician)<br>Sudakhar Rao (Neonatologist)<br>George Gough & colleagues (Obstetrician)<br>Richard Andrews (ACHD) | Frances Bu'Lock<br>Elizabeth Aryeetey | Strongly support Option A.<br><br>Would like telelink; AS has money for kit |
| Grantham | Clinics staffed from Boston. No inpatients | n/a | n/a |
| Boston | Margaret Crawford (MC) & Dr Hanumara (Paediatricians)<br><br>Sunny Ikhena (Obstetrician) | Frances Bu'Lock<br>Mary McCann | Strongly support Option A.<br><br>MC came to network meeting. Would like more clinics. |

| **Referring Centre (inc. all in UHL Network for Option A)** | **Name of Lead Referring Clinician/s** | **UHL Lead Contact** | **Response (ie: which option do they support, any feedback etc)** |
|---|---|---|---|
| Sheffield | Roobin Jokhi, Dilly Anunmba & Saurab Ghandhi (Fetal Medicine)<br><br>Simon Clarke and Poros Bustani (Neonatologists)<br><br>Carrie McKenzie (Link Paediatrician)<br><br>Dr Stephen Hancock transport lead for EMBRACE and Intensivist at Sheffield Children's Hospital<br><br>Jeff Povey Director of PICU and Alison Hollett GM for PICU, Embrace and HDU | France Bu'Lock<br>Sanjiv Nichani<br>Elizabeth Aryeetey | Currently look to Leeds but happy to shift practice to Leicester if Option A goes ahead. Good discussion with fetal medicine team about outreach 'hub' and also telemedicine. Would prefer Option A to anything except Option D and acknowledge the other problems with Option D. Concerned not to lose ECMO.<br><br>Carrie McKenzie also happy to work with us in Option A, would need weekly clinics as per Derby and Nottingham. & significant support for their PICU. She does not scan but has one Sonographer and 24/7 radiologists who do. Possibility of telemedicine to cover PICU would be an advance on current situation. Their outreach currently provided as a 'private contract' between the Trust and Dr John Thomson from Leeds.<br><br>EMBRACE and Intensivist at SCH, Jeff Povey Director of PICU and Alison Hollett GM for PICU, Embrace and HDU agree in principle that they will send patients to us instead of Newcastle. |

| **Referring Centre (inc. all in UHL Network for Option A)** | **Name of Lead Referring Clinician/s** | **UHL Lead Contact** | **Response (ie: which option do they support, any feedback etc)** |
|---|---|---|---|
| Doncaster<br><br>(& Rotherham) | Dr Kurien (Paediatrician)<br>Dr Losil Sidra (Fetal medicine)<br>Dr Nigel Brooks (Neonatologist)<br>(Sue Rutter Obstetrician in Rotherham) | SN | Positive about Leeds network but would be happy to engage with Leicester if Option A goes ahead.<br><br>If Leeds closes Doncaster patients will be referred to Leicester rather than Newcastle. Yorkshire commissioners are reported to be aware and are on board.<br><br>Obstetricians have a good relationship with Leeds but are happy to engage with Leicester if Leeds closes. |
| Chesterfield | Heather Durward (PEC) | Frances Bu'Lock<br>Elizabeth Aryeetey | Heather attended the network meeting.<br><br>Positive about Leeds network but would be happy to engage with Leicester if Option A goes ahead. |
| Scunthorpe & Grimsby (Goole) | Pauline Adiotomre (Link Paediatrician, Grimsby)<br>Sandeep Kapoor (Lead Paediatrician, Scunthorpe) | Frances Bu'Lcok<br>Carmel Hunt | Unable to attend a network meeting. Currently reasonably happy with Leeds but have some working relationships with EMCHC already. Frances and Carmel attended a meeting in Grimsby on 28 June. |

| **Referring Centre (inc. all in UHL Network for Option A)** | **Name of Lead Referring Clinician/s** | **UHL Lead Contact** | **Response (ie: which option do they support, any feedback etc)** |
|---|---|---|---|
| Scunthorpe & Grimsby (Goole)<br><br>(continued) | | | Happy to engage with Leicester if Option A goes ahead and supportive of the network proposals and models discussed. |
| Nuneaton | Richard de Boer (Paediatrician /Neonatologist) | Frances Bu'Lock<br>Sanjiv Nichani | Support Option A. Clinicians strongly support retaining 2 centres in the Midlands.<br><br>George Elliot clinicians have requested joint clinics with EMCHC and Warwick as soon as possible. |
| Warwick | Ajay Upponi (PEC) | Frances Bu'Lock<br>Sanjiv Nichani | Support Option A. Clinicians strongly support retaining 2 centres in the Midlands.<br><br>Clinicians reported disappointment with local commissioners who have signed up to Option B.<br><br>Requested joint clinics with EMCHC and Warwick. |
| Coventry | Andy Coe & Ashok Acharya<br>(Paediatrician /Neonatologist)<br>Mina Rajimwale (PEC) | Frances Bu'Lock<br>Sanjiv Nichani<br>Attilio Lotto | Support Option A. Clinicians strongly support retaining 2 centres in the Midlands.<br><br>Clinicians reported disappointment with local commissioners who have signed up to Option B. |

| **Referring Centre (inc. all in UHL Network for Option A)** | **Name of Lead Referring Clinician/s** | **UHL Lead Contact** | **Response (ie: which option do they support, any feedback etc)** |
|---|---|---|---|
| Coventry<br><br>(continued) | No real obstetric contacts…. Although there has been some discussion re fetal outreach which we could support | | |
| Northampton | Nick Barnes (PEC)<br>W Davies (Obstetrician) | Giles Peek<br>Frances Bu'Lock | Good service from GOSH. Would be prepared to consider swap if Option A goes ahead and convinced that would get equivalent / better service.<br><br>Wishes to visit us for MDT etc… date not yet finalised.<br><br>Runs quite an 'independent' service with good focus.<br><br>Fetal currently still to Oxford. Gentle trickle of referrals back from Oxford. |

Appendix 3 Network Invite and Minutes

East Midlands
Congenital Heart Centre

Dear Colleague

We would like to invite you to join us at **2pm on 31st May 2011** for a discussion about the creation of a formal East Midlands Congenital Cardiac Network. This will be held in the **Clinical Education Centre**, Glenfield Hospital Leicester.

We recognise that we need to improve on what already exists to better serve the needs of our colleagues and patients across the region. In order to do this we need to gather your views, experience and expertise on what currently works well and where there is scope for improvement. We would like to examine referrals and shared care pathways, outreach provision, governance and education, as well as any other issues **you** feel need addressing and we are very keen for your input as to how we can best achieve this together.

We are inviting not only clinical and managerial colleagues from our existing 'catchment area' but also from the much larger 'network' proposed in Option A of the 'Safe and Sustainable' children's cardiac surgical review. It is important that we open this dialogue before final decisions are made around the designation of individual centres as there needs to be an understanding of how these proposed networks will be managed and whether the patient flows can be supported by robust clinical pathways and good relationships between the different groups and specialities of clinicians across the network.

We feel it important to listen to colleagues from fetal medicine, obstetrics, neonatology, paediatrics and also adult cardiology, so if you have knowledge of other colleagues you feel might be willing to join us for this meeting we would be most grateful if you would pass on and circulate this invitation as widely as possible.

We appreciate that you are busy and as such if you are unable to make it to the event we would be happy to talk to you ahead of the meeting and feed your views into the discussion. Alternatively, if you would like us to visit you over the next few weeks, please let us know and we will arrange a convenient time.

Please reply as soon as possible to Margaret King (secretary to Dr Frances Bu'Lock) margaret.king@uhl-tr.nhs.uk or telephone 0116 256 3904 for further information.

**Circulation:** Foetal medicine experts/Obstetricians, Neonatologists, Paediatricians, Paediatricians with expertise in cardiology, Adult cardiologists with expertise in congenital cardiology in Nottingham, Lincolnshire, Derby, Peterborough, Chesterfield, Sheffield, Doncaster, Scunthorpe and Goole, Coventry and Warwickshire.

# East Midlands Congenital Heart Centre Network Event

## 31st May 2011

### Attendees

Gitika Joshi – Neonatologist (Derby), Andy Leslie – Consultant Nurse (Neonates, Leicester), Jon Currington (East Midlands Specialist Commissioning Group), Margaret Ramsey – Obstetrician (Nottingham), Heather Durward – Paediatrician (Chesterfield), Alastair Scammell – Paediatrician (Lincoln), Susan Ward – Obstetrician (Mansfield), Harsha Bilolikar – Paediatrician (Kettering), Lucy Kean – Obstetrician (Nottingham), Ursula Ngwu – Paediatrician (Mansfield), Margaret Crawford – Paediatrician (Boston), Martin Hindle – Chairman, UHL, Helen Mather – Divisional Manager, UHL, Giles Peek – EMCHC Head of Service (surgeon), Attilio Lotto – EMCHC Surgeon, Frances Bu'Lock – EMCHC Cardiologist, Abdul Duke – EMCHC Cardiologist, Demetris Taliotis - EMCHC Cardiologist, Suhair Shebani – EMCHC Cardiologist, Elizabeth Aryeetey – EMCHC Service manager/Lead Nurse

### Facilitator

Andrew Hartshorn, Mott Macdonald

### Agreed Actions

| No | Action | Responsible |
|---|---|---|
| 1 | Contact your colleagues around the region to ask for their views and expressions of interest | All attendees |
| 2 | People who are interested in being on the strategic board or the representative board should put their names forward | Gitika Joshi to collate |
| 3 | A whole day meeting will be held in Derby in 3 months time. Proposed outline agenda will be;<br>AM: Network meeting to move forward<br>Lunch: Strategic Board Meeting<br>PM: Educational session | Giles, Elizabeth and Gitika Joshi |
| 4 | Contact Bernie Stocks at the SHA about the Innovation Fund | Elizabeth |
| 5 | Contact Simon Swift about using the QO website as a temporary website for the network | Elizabeth |
| 6 | Collate current care pathways and protocols which | Frances & Elizabeth |

| | | |
|---|---|---|
| | will then be put on to the temporary website | |
| 7 | Documentation and experiences (good and bad) of clinical networks to be sent to Elizabeth | All attendees & Elizabeth to collate |
| 8 | Take forward image sharing as a project | Strategic Board |

**Minutes**

**Purpose and objectives**

What objectives do people want met by the network?

- Quality
- Appropriate care without duplication
- Communicate freely with transparency and trust
- The definition of quality is the same across the network
- Children needing cardiac services are seen in the right place at the right time by the right person
- Integrated care from pre-natal diagnosis to post-natal treatment/surgery
- Involvement of stakeholders in demonstrating support for paediatric cardiac surgery in the East Midlands
- Clear pathways and commitment from outreach sites
- Governance including information governance
- Issue of information going both ways eg feedback to obstetric services after the baby is born
- Question about IT systems – compatibility
- Network meetings – opportunity to share information and get feedback

How do people aspire to work?

- Use of technology to support working across the region – telemedicine/ real time imaging
- Education role for ECHO

**Vision**

Four key themes emerged:-

- Capability
    - The understanding of the ways of working across the region; what capability does the network have?
- Process
    - What are the processes used across the network?
    - Who decides on the agreed process?
    - Recognised the need for two way communication

- Minimum and absolute standards
    - Agreed the need for defining the minimum and absolute standards
    - Recognised a Network will have more power than individuals in one trust about the recruiting decisions
- Communications
    - Commissioning (early view from EMSCG) – one contract with one body (network) as opposed to a series of contracts across the care pathway

**Scope of the network**

The discussion on scope covered two key themes; patient care and then the scope of the service

Patient & care condition

- All aspects of child care and adults with congenital disease
- Mothers with a foetus diagnosed with a congenital heart defect
- Families with a history of congenital heart defect
- All children with heart disease (not necessarily congenital)

Provision scope

Need to have continuum and linkages with other services/ networks

- Principal of care close to patient home
- Network needs to have capacity to cope with all referrals
    - Need to devolve some responsibility for care to non-specialist cardiac unit
    - Capacity for referrals from elsewhere (e.g given of BCH who could not cope with all the referrals)

Broader points to be discussed;

- What are the capabilities and standards required in this context?
- Recognise the need for honesty and trust in communications
    - The network will be representing each other
    - Practice of sharing data with each other
    - Optimising what can be done and where it can be done in the network

**Operating Principles**

- Integrated care pathway agreed and works across whole network
- Pathway may be variable for different centres due to service & workforce capacity and capability
- There is a need to allow for co-existing pathways and the undiagnosed as well as diagnosed. Whole care needs to be provided
- Need for working groups to lead/coordinate pathways
    - Pathways need to have contact info/
- Recognise the information requirements; additional information to accompany referral to reduce duplication of tests/procedures

**Network set up**

- One of the quality standards set out by the Safe & Sustainable review is strong clinical networks; there is an assumption that there will be some funding available for the development of these networks
- Currently no funding allocated to set up the network
    - Bernie Stocks at EMSHA has an innovation fund which may support the setting up of the network

**Communications**

Two types;

- Broader information/ educational materials
    - Opportunity for a virtual hub with whiteboards
- Specific patient level information
    - Lack of a network wide Real Time Imaging Service;

Current:

- No current framework to host a network website
- EMQO may assist with a temporary site
- Potential opportunity to develop specific solution to meet networks needs
- Potentially network could be a powerful influencer in developing the case for technology such as real time imaging

**Boundaries**

- How wide the boundaries are will influence manpower? Overall, what works best?
- Questions to be discussed include:
    - What makes sense clinically and for the patient
    - Question about pooling resources – funding or workforce
    - Need to actively think about innovation/ re-provision
        - E.g Pull a clinic or service or upgrade it
- Education
    - Two way dialogue
        - M&M/ outcome meetings (4 monthly – equitable in terms of where sited by rotating)
    - Reciprocal meetings
        - Case sharing
        - Contact

**Governance & membership**

Proposed structure

### Representative Board

- All specialities and localities represented
- Sign off authority/ work programme
- Meets once or twice a year
- Each speciality will vote someone as their representative

### Strategic Board

- Maximum 7 people; ideally 4/5
- Meets several times a year
- Rotates membership/ interests

### Working groups

- Progress the work programme e.g developing and agreeing care pathways
- Agreed to rotate around the region for meetings to ensure equity.
- Educational meetings should also be rotated for interest/ speciality

### Remit

- Goals of board
    - Terms of reference/ Standards = mandate
- Collective responsibility for change
    - Working Group representatives
    - Facilitating network of different sized units/ trusts
    - Priority list – agreed work programmes – sent back to people to progress in working groups

Appendix 4

## East Midlands Congenital Heart Centre Research Strategy

### Introduction

The Panel the commended the "substantial amount of research, especially with regard to ECMO" and acknowledged that the "Trust had a strategy for genetic research" but commented on the lack of a formal research strategy. In light of these comments and as part of ongoing efforts to improve research efforts an EMCHC Research Strategy was developed. This has now been endorsed by the Trust's Research and Development Board.

This initiative will form one part of the cardiovascular research effort of University Hospitals of Leicester that has the Biomedical Research Unit of the University of Leicester at its heart (see Figure 1). As such EMCHC research is now recognised as a unique clinical and research entity within the broader UHL research strategy and benefits from the full support and governance structure of the Trust's Research and Development Department.

**EMCHC Research Board**

- Comprises research leads for the various areas of investigation (see below)
- Chaired by EMCHC Director of Research (Mr Attilio Lotto)
- To set research priorities, facilitate collaboration, support grant application, and have responsibility for research governance
- Develop a strategy for research appointments and the supervision of higher degrees
- Formalise a 5 year strategy

**Existing areas of research activity**

*Extra-corporeal membrane oxygenation (ECMO)*

Lead: Mr Giles Peek

Focus: Efficacy of ECMO for cardiac and respiratory failure

Planned activity: (i) pilot study for a larger multi-centre randomised trial on the use of ECMO in post-cardiotomy syndrome, (ii) basic science collaboration with the Cardiovascular Science Department of Leicester University looking at the growth of endothelial cells derived from the extr-corporeal circuits of patients undergoing ECMO.

*Genetics of congenital heart disease*

Lead: Dr Frances Bu'Lock

Focus: Current project, "Do genetic changes cause congenital heart disorders?", a collaboration with University of Nottingham, and funded by the British Heart Foundation

*Adult Congenital Heart Disease*

Lead: Dr Aidan Bolger

Focus: Heart failure in adult congenital heart disease, several British Heart Foundation funded collaborative projects with University College London Hospitals and Great Ormond Street Hospital for Children and active contributor to the Adult Congenital Research Network (ACORN)

*Intensive Care*

Lead: Dr Suneel Pooboni

Focus: Role of procalcitonin in detecting infective states in ECMO patients, a Hearlink funded project on the role of novel inflammatory markers in patients receiving ECMO.

Participating centre in the ChiP Trial, a study examining bllod glucose levels in paediatric patients on ICU

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**Further research opportunities**

- Research leads will be identified for foetal cardiology, catheter intervention and congenital cardiac surgery.

- A research fellow has been appointed from Milan (to commence August 2011) to conduct ECMO research

- Collaborative links are being actively pursued between EMCHC and the Department of Cardiovascular Science of the University of Leicester (molecular genetics, cardiac and vascular biology and cardiovascular peptides in heart disease), the Bristol Heart Institute at Bristol University, the Universities of Milan and Naples and the newly formed Medicine for Children Research Network (MCRN): EAST (part of the NIHR). The latter represents an opportunity for involvement in collaborative efforts across UK congenital cardiac units.

## Conclusion

EMCHC has an excellent track record of research in congenital cardiac disease. With new focus on a co-ordinated programme of study and its broad portfolio of interests it is in an exceptionally strong position to deliver high quality contributions to congenital heart disease research.

Appendix 5

**Impact of ECMO relocation**

Extracorporeal Membrane Oxygenation or ECMO is the use of a modified heart-lung machine to support patients of all ages with severe but potentially reversible failure of the lungs and/or heart.

ECMO is currently provided by a number of UK centres for both respiratory and cardiac support. The nationally designated UK Neonatal and Paediatric respiratory ECMO service is provided between Glasgow, Leicester, Newcastle and Great Ormond Street in London. The only nationally designated centre for adult respiratory ECMO is Leicester. ECMO for paediatric cardiac support is designated in Newcastle and GOS, but as they are often full is often provided in Leicester.

The ECMO unit at Glenfield Hospital in Leicester is the oldest in the UK, being operational since 1989. It is currently one of the largest units in the world and has treated over 1582 patients to date. Glenfield usually treats the majority of ECMO cases in the UK, often treating more patients each year than all of the other units combined. It has taken many years to build up the expertise and manpower required to deliver this level of service fig 1, 2 & 3. We have 91 highly trained ECMO specialist nurses. We are the leading unit in the UK in terms of ECMO training courses offering 5 courses per year. These courses are attended by nurses, perfusionists and doctors from all over the world as well as being used to train the ECMO teams from Alder Hey Children's Hospital, Wythenshawe Hospital, Royal Brompton, Aberdeen Royal Infirmary and Birmingham Childrens Hospital. Indeed the Birmingham Children's Hospital and Alder Hey Children's Hospital teams not only receive their ECMO course training and clinical preceptorships in Leicester, but they also continue to work regularly in the Leicester unit to maintain their skills. Since September 2007 we have trained 43 nurses from Birmingham Children's Hospital. Since April 2010 we have trained 15 nurses from Alder Hey Children's Hospital.

The Leicester ECMO team is the only team in the UK that can provide a mobile ECMO retrieval service, the team travel to the referring hospital and establish the patient on ECMO before returning to Glenfield. We also provide an ECMO transfer service to move patients who are on ECMO in another cardiac unit such as BCH who require transplantation in either Freeman Hospital: Newcastle or Great Ormond Street Hospital.

In the last 16 years we have done over 40 mobile ECMO transfers including 34 patients who were cannulated emergently in the referring hospital.

The Leicester ECMO team were the first team in the UK to use Partial Liquid Ventilation, Poly-methyl pentene oxygenators, Levitronix pump for ECMO, ¼" Levitronix pedi-vas pump for both ECMO and VAD, Kendall, Origen and Avalon VVDL ECMO cannulae. Members of our team are frequently asked to act as opinion leaders by academic bodies, health care planners and industry. We are also frequently invited to lecture all around the world. There has been a Leicester presence on the ELSO steering committee since 1995.

Two of the five randomised controlled trials of ECMO versus conventional treatment in the world scientific literature are from Leicester (UK Collaborative Neonatal ECMO trial, Principle Investigator David Field & CESAR, Principle Investigator Giles Peek), as well as countless case series, case reports and review articles.

The ECMO service in Leicester is lead by two consultants, one is also an adult cardiac surgeon and is close to retirement and the other is also a congenital heart surgeon. If the children's cardiac surgical service at Glenfield were to close the ECMO service would be unsustainable. In order to provide the current level of service in other hospitals approximately 100 ECMO specialist nurses will need to be trained, this will take approximately 5 years in the current environment where they could be trained in Leicester, but could take much longer and be more costly if this facility were not available. The additional beds required to support this level of ECMO provision has not been allowed for in the expansion plans under option B, C or D. In addition to the capacity issues the clinical teams in these hypothetical new ECMO centres will be lead by consultants who would not have undergone formal training in ECMO, will have little experience and will take several years to obtain similar results to those obtained currently in Leicester.

In conclusion, designation of any option other than A is likely to result in approximately 150 babies, children and adults per year who will be unable to receive ECMO. The majority of these patients will die; this situation is likely to last for a minimum of 5 years after closure of Leicester, assuming that another training solution for the emerging ECMO teams can be found.

Appendix 6

**Impact on East Midlands Paediatric Intensive Care Provision**

*Background*

The review consultation document states (p105) that the review team have assessed the risk to paediatric intensive care units following their proposed reorganisation. They conclude that losing paediatric cardiac surgery in Leicester represents limited risk to local and national paediatric intensive care provision, but that redesignation of units in Bristol, Leeds or Southampton represents a higher risk. We believe that this analysis is incorrect.

*Current situation*

Paediatric intensive care services are provided in one unit on a single site in Southampton; one unit on two sites in Leicester; two units on one site in Leeds; and Newcastle has three units on three sites. In the case of Southampton, Leeds and Leicester the consultant staff work on both cardiothoracic and general PICUs, and these are effectively considered as a single unit.

The activity of each centre is shown in the table (data from PICANET for year 2009):

| Centre | Leicester | Southampton | Leeds | Newcastle |
|---|---|---|---|---|
| Total Cases | 785 | 740 | 802 | 896 |
| Cardiac cases | 313 | 214 | 311 | 267 |
| % cardiac[1] | 40 | 29 | 39 | 30 |
| % cardiac[2] | n/a | 29 | 39 | n/a |
| ECMO | 51 | 1 | 0 | 20 |
| Non-Cardiac/ECMO[1] | **421** | **525** | **491** | **609** |

[1] Arithmetic [2] from Children's Congenital Heart Surgery consultation document for cross reference

*Assessment*

Taking the paediatric intensive care provision in each city as a whole, it is clear that the unit in Leicester is most at risk, no longer meeting lead paediatric intensive care unit status as defined in the Paediatric Intensive Care Society Standards 2010.

*Consequences*

Reduction and possible closure of intensive care facilities in the East Midlands would have a number of adverse consequences:

- General PICU patients from Leicestershire would need to travel elsewhere. The nearest unit in Nottingham is often full, and patients would need to be transferred to Birmingham, Sheffield, Leeds or Cambridge.

- Nottingham PICU does not currently offer a retrieval service. Options which redesignate Leicester PICU would likely mean that there would be no retrieval service for paediatric patients in the East Midlands.

- 86 non cardiac/ECMO patients were admitted to Leicester PICU from the West Midlands in 2010. These patients would need to be accommodated in Birmingham Children's Hospital or transferred out of region. We are not aware that the BCH business plan includes these patients.

- Sub specialty services currently provided in Leicester including paediatric surgery, paediatric respiratory medicine, and paediatric ENT would be under threat.

*Conclusion*

The adverse impact upon the paediatric intensive care provision in the East Midlands should be considered as a risk under options B, C and D.

The effect on Birmingham Children's Hospital of a reduction in PICU capacity in the East Midlands should be considered in consideration of options B and C.

Appendix 7

**Impact on adult congenital cardiology in the East Midlands**

***Background***

Because around 85% of those born with congenital heart disease survive into adulthood, and because significant numbers born with congenital heart disease are not diagnosed until adulthood, there are substantially more adults than children with congenital heart disease. Most born with congenital heart disease require life long follow up and many require surgery and catheter intervention in adulthood either for the first time or for late complications.

All centres in England offering surgery and catheter intervention for adults with congenital heart disease (ACHD) do so either as integrated units offering lifetime follow up of congenital heart disease, (such as the East Midlands Congenital Heart Centre in Leicester), or have a partnering children's hospital within the same city. In both models, the provision of safe and sustainable services for ACHD is critically dependent on the existence of local paediatric cardiac services as surgeons, cardiologists and technical staff provide care across the age ranges.

***The ACHD service in the East Midlands Congenital Heart Network***

In order to adapt to the changing patient demographic the EMCHC has invested heavily in order to provide a first class service for adults with CHD. Together with consultant colleagues in the regions' hospitals we have developed an extensive ACHD network across the East Midlands. Joint ACHD clinics currently operate in four centres outside Leicester with two more due to start this year.

Annual ACHD outpatient visits now total almost 3300 in the existing network. With respect to Glenfield figures this represents an increase of 9% on last year's figures and 16% versus 2008-9. The investment in ACHD services in-house at Glenfield has also seen an increase in new ACHD referrals in the last year of 62% compared to the previous 12 months and is up 97% on two years ago (Table 1). With an expanding and ageing ACHD population the number of surgical and catheter cases will increase significantly from current annual figures of 50-60 and 100-120 cases respectively.

These numbers are set to increase significantly as the planned network expansion continues and the scale of need is illustrated by the 2009 report by the National Specialised Commissioning Group, "Designation of Specialist Service Providers for

GUCH/ACHD". Here, the Group state that the estimated prevalence of ACHD in the East Midlands is 13 000, 7000 of whom are expected to have moderate or complex conditions requiring regular follow up in specialist clinics.

| ACHD Outpatient Activity | 2008-9 | 2009-10 | 2010-11 |
|---|---|---|---|
| **All ACHD outpatient visits**<br><br>Glenfield<br><br>East Midlands Network | 2346<br><br>- | 2502 (6.2%)<br><br>- | 2720 (8.7%)<br><br>3283 |
| **New ACDH outpatient visits, Glenfield** | 229 | 278 (21.4%) | 451 (62.2%) |

Table 1: ACHD outpatient visit trends over the last three years with percentage changes versus the previous year's figures in parentheses

***East Midlands high risk obstetric cardiology service***

The obstetric department of the United Hospitals of Leicester is one of the country's busiest, seeing the delivery of around 11 000 babies per annum. Responding to local and regional needs for the care of pregnant women with complex cardiac conditions, a high risk obstetric cardiology service was established at Leicester Royal Infirmary in May 2010. The team comprises an ACHD cardiologist, two foetal/maternal medicine obstetricians, obstetric anaesthetists, midwives and nurses.

In its first year the service cared for 126 pregnant women, 43% of whom had ACHD (Figure 1). Referrals were taken from across the East Midlands with the highest risk cases delivering at the Royal Infirmary or Glenfield Hospital. Again, this regional high risk pregnancy service is critically dependent on the provision of congenital heart services on the Glenfield site.

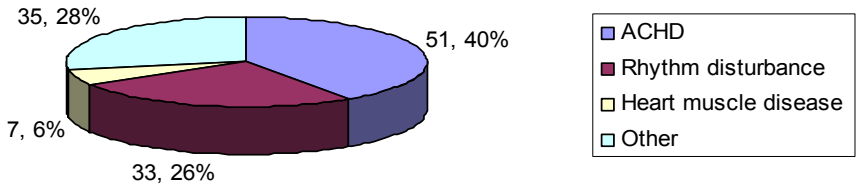


Figure 1: Expectant mothers with ACHD comprise the largest single group attending the joint obstetric cardiology clinic

***Conclusions***

The ACHD service at Glenfield Hospital, the high risk obstetric cardiology service at Leicester Royal Infirmary and the provision of both services to the wider network are critically dependent on the continuing provision of paediatric cardiac surgery at the EMCHC. As such, the arguments we have set out supporting the continued and expanded paediatric cardiac surgical programme at Glenfield Hospital apply equally to our region's ACHD and obstetric cardiology services.

The Safe and Sustainable review has considered the provision of paediatric cardiac surgery in isolation but we consider that the issues concerning access and travel, quality, deliverability, sustainability and affordability should equally apply to our patients beyond the age of 16 years as they do below this age. We can and are delivering these services now and would welcome the chance to extend our reach under Option A. Account should be taken of the impact at local and regional levels if these services are lost to the East Midlands and equally, the impact on any centre left to take on the adult congenital population if Option A isn't chosen.

We therefore believe that the provision of care for adults with CHD should be considered crucial to the Safe and Sustainable process and be recognised as such. Option A is the highest scoring and highest ranking option for paediatric cardiac surgery and we believe it is also the option that will allow the provision of the safest and most sustainable services for the care of adult patients with congenital heart conditions.

Dear Colleagues,

We are extremely pleased to announce that The Glenfield and Leicester General Hospital Facilities' Departments have successfully retained the Customer Services Excellence (CSE) award for another year.

The Facilities Departments at the Glenfield Hospital have held the Charter Mark for excellence in Customer Care for twelve years. Four years ago the Leicester General Hospital successfully joined us in gaining the Charter Mark award which then became the Customer Services Excellence (CSE) award.

Last year we went through a transition assessment and we successfully gained the new award.

This year, on Friday 3 June 2011, it was our first maintenance assessment to check that we are keeping up our standards and to look for any further improvements we may have made during the last year.

The CSE has five criterion containing fifty-seven elements and we were fully compliant in two criterions and now have only four "partial compliance" in the remaining elements. This is an improvement on last year.

More importantly we have no "non-compliances" at all.

We will be continually assessed over the next four years covering all fifty-seven elements and we will be working towards becoming fully compliant in all five criterions.

The team would like to take this opportunity to thank Facilities and Clinical colleagues for their support in meeting with the assessor and for submitting strong evidence documentation and for all the facilities staff and colleagues, spoken to on the assessors "walk about"

The team would also like to thank all the people that took time out of their busy schedules to attend the Q&A lunch time sessions.

The Assessor said that we should all be very proud of our sustained and continued success in not only maintaining but improving our standards during a very challenging year.

Please pass on our thanks to all of your teams' contributions.

Kind Regards

Gaye Page, John Willett and Peter Summers