Leicester
City Council

MINUTES OF THE MEETING OF THE
LEICESTERSHIRE, LEICESTER AND RUTLAND JOINT HEALTH SCRUTINY COMMITTEE

Held: TUESDAY, 27 JUNE 2017 at 10.00am

P R E S E N T :

Councillor Cutkelvin – Chair of the Committee
Mr L Breckon CC – Vice Chair of the Committee

Leicester City Council

Councillor Cassidy Councillor Chaplin
Councillor Dempster

Leicestershire County Council

Mrs H Fryer CC Mr T Parton CC
Mrs A J Hack CC Mrs L Richardson CC
Mrs D Taylor CC

Rutland County Council

Councillor Miss G Waller

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34. WELCOME AND INTRODUCTIONS

The Chair welcomed everyone to the meeting and asked those present to introduce themselves.

The Chair reminded everyone that the primary purpose of the meeting was to hear from patients' and stakeholders about their experiences and for them to give their views on NHS England's proposals. The level of frustration expressed by the public in relation to accessing the consultation process was well understood by Members. Although the meeting was open to the public to attend it was not a 'public meeting' as such and only those that had registered to speak would be allowed to do so. It would not be possible, therefore, to hear comments from the other Members of the public who were in attendance at the

meeting. NHS England had arranged a public consultation meeting at Glenfield Hospital for Saturday 1 July 2017 and that would be the opportunity for the public to participate in the process.

The Chair also welcomed Michael Wilson, Programme Director for CHD, NHS England and Catherine O'Connell, Regional Director Specialised Commissioning - Midlands and East who were attending the meeting to hear the submissions by the public and stakeholders.

35. APOLOGIES FOR ABSENCE

Apologies for absence were received from:-

Councillor Corrall	Leicester City Council
Councillor Fonseca	Leicester City Council
Dr S Hill CC	Leicestershire County Council
Councillor Sangster	Leicester City Council
Councillor Stephenson	Rutland County Council

36. DECLARATIONS OF INTEREST

Members were asked to declare any interests they might have in the business on the agenda. No such declarations were made.

37. MINUTES OF PREVIOUS MEETING

RESOLVED:-

That the minutes of the meeting held on 14 March 2017 be confirmed as a correct record.

38. PETITIONS

The Monitoring Officer reported no petitions had been submitted in accordance with the Council's procedures.

39. QUESTIONS, REPRESENTATIONS, STATEMENTS OF CASE

The Monitoring Officer reported that no questions, petitions, or statements of case in accordance with the Council's procedures.

40. CHAIR'S INTRODUCTION

The Chair stated that given there were a number of new members on the Committee and the Programme Director for the CHD was attending his first meeting of the Committee; she felt it would be useful to set the scene and recap on the points raised at the previous meeting of the Committee.

The Chair mentioned the following points:-

NHS England stated that it wasn't for them to mandate to patients where to have surgery at a particular centre and that it was for parents/patients to determine where they wished to receive treatment.

- UHL disputed this stating that it was NHS England's responsibility to organise these services and whilst they did not choose where a patient was treated, these proposals were seeking to determine where they would not be treated.

The outstanding issue with regards to Glenfield hospital's plans from NHS England's perspective related to their ability to reach 375 operations (125 each for 3 surgeons) per year.

- UHL also argued that small adjustments to the catchment area would enable them to meet the required number of operations.

- Members commented that the destabilising effect of the ongoing proposals may also be having a negative effect and would no doubt influence patient choice if they thought the centre may close whilst not realising the high quality of care that they would receive.

- There was anecdotal evidence that people in Northampton were being directed further south when Glenfield was a much closer option.

It was debated as to whether the figure of 125 surgeries had been applied fairly across all CHD sites in the consultation proposals; given that Newcastle, in particular, had been given no time frame within which to reach the standards.

- UHL argued that if it was safe for Newcastle to continue providing Level 1 services whilst providing considerably less surgeries than Glenfield; then why should it be unsustainable for Glenfield to continue with higher levels of surgeries and still also provide the National ECMO service.

- NHS England stated they would revisit Newcastle if they couldn't meet the required number of surgeries in an agreed timeframe; although no timeframe had been agreed. Also, Newcastle were being treated separately, as they also undertook heart transplant services, the only centre to do so one outside of Great Ormond Street Hospital to perform them and it would be unsafe to only have that service on one site.

- Committee members argued that given the 125 surgeries was not backed by any real scientific evidence for it to be an absolute criteria to provide a resilient service and, given that Newcastle were being given an indefinite time period to meet the required number of surgeries, Leicester should also been given extra time.

If, like Newcastle, they subsequently didn't meet the required number of surgeries in an equal timeframe, then NHS England should review the situation at that time.

- UHL's CHD unit was rated as 'outstanding' by the CQC; the only one in the country and this should not go unrecognised.

- Also, the fact that there were 200 standards, and some were being weighted more than others, felt arbitrary to committee members and they seemed to be chosen to help push a pre-determined decision. The fact that the standards were being implied retrospectively rather than from their approval date in July 2015 was also questioned.

NHS England's proposal would result in an entire region not having CHD surgical services. This would be the only region not to have them and would leave a large geographical gap across the country.

- NHS England suggested that Glenfield could perform Level 2 services as part of the proposals which would still offer a service in the East Midlands
- UHL questioned whether they would be able to perform Level 2 services without a Level 1 service, as they would not have cardiac anaesthetists on site without a Level 1 service and currently no model of what a Level 2 service would look like existed.

The Committee also raised the issue of travel times not being considered properly and the burdens of travel on families seemed nonsensical given there was a service in the East Midlands already providing good outcomes.

The Committee had also been advised of the following prior to the meeting:-

<u>Background Information</u>

NHS England had launched a national consultation on its proposals for the future commissioning of Congenital Heart Disease services on 9 February 2017.

This consultation period was originally intended to end on Monday 5 June, but was subsequently extended to close on Monday 17 July 2017 as a result of the recent Parliamentary Election.

This Joint Committee was the appropriate body to be consulted by NHS England on the proposals in accordance with Regulation 30 of the Local Authority (Public Health and Wellbeing Boards and Health Scrutiny) Regulations 2013. The regulation provided that where the appropriate person (NHS England) had any proposals for a substantial development or variation of a health service in an area they must consult the local authority. Where the

consultation affected more than one local authority in an area, the local authorities were required to appoint a Joint Committee to comment upon the proposal and to require a member or employee of the responsible person to attend its meeting and respond to questions in connection with the consultation.

The Regulation did not prevent constituent Councils of the Joint Committee considering the issues separately; but it was the responsibility of the Joint Committee to formally respond to the consultation process.

The Regulations also provided that a Council may refer a proposal to the Secretary of State where:-

- it was not satisfied that the consultation has been adequate in relation to content or time;

- it was not satisfied with the reasons given for the change in services; or

- it was not satisfied that that the proposal would be in the interests of the health service in its area.

This referral must be made by the full Council unless the Council has delegated the function to a Committee of the Council. Currently, only the City Council had delegated the powers to refer the NHS proposals to the Secretary of State. Leicestershire County Council and Rutland County Council would need to approve any referral at their respective Council meetings.

Supporting Information

The Joint Committee had first met on 29 September 2016 and received the following supporting documents:-

- NHS England's proposals published on 8 July 2016.
- Extracts of decisions taken by Leicester City Council and Leicestershire County Council's Cabinet in response to NHS England's proposals.
- A report from NHS England and a submission from the University Hospitals of Leicester NHS Trust (UHL) submitted to the City Council's Health and Wellbeing Board at their meeting on 18 August 2016, together with the Minutes of the Meeting.
- A report of NHS England and their Assessment of UHL submitted to the Board and updated to reflect the subsequent meeting held with UHL on 16 September 2016 and the revised high level timetable for the consultation and decision making process.
- A letter to the City Council's Deputy City Mayor from NHS England in response to questions asked at the Health and Wellbeing Board.
- Evidence base for new standards & specifications in relation to the 125 cases per surgeon that was requested by the Health and Wellbeing Board.

The second meeting on 14 March 2017 had received the following documents:-

- The “Proposals to Implement Standards for Congenital Heart Disease Services for Children and Adults in England - Consultation Document”
- Minutes of the Meeting of the Joint Committee held on 29 September 2016 when the Joint Committee considered the proposals in the pre-consultation engagement stage.
- A letter from Will Huxter responding to issues raised by the Joint Committee on 29 September 2017.
- Proposals to implement standards for Congenital Heart Disease Services for Children and Adults in England - Consultation Summary.
- Congenital Heart Disease Equality and Health Inequalities Analysis – Draft for consultation.
- Congenital Heart Disease Provider Impact Assessment: National Panel Report.
- NHS England Congenital Heart Disease Provider Impact Assessment.
- Congenital Heart Disease Consultation – Events List.

The agenda, reports and minutes of the Joint Committee’s meetings referred to above can be found at the following link:-

http://www.cabinet.leicester.gov.uk/ieListMeetings.aspx?CId=420&Year=0

41. UHL'S VIEW ON NHS ENGLAND'S PROPOSALS FOR CONGENITAL HEART DISEASE SERVICES

The Chair welcomed the following representatives of University Hospitals of Leicester NHS Trust (UHL) to the meeting:-

John Adler, Chief Executive.
Dr Aidan Bolger, Consultant Cardiologist & Honorary Senior Lecturer and Head of Service East Midlands Congenital Heart Centre.
Mark Wightman, Director of Communications Integration and Engagement.
Alison Poole, Senior Manager Special Projects.

John Alder thanked the Committee for the opportunity to address the Committee. He stated that UHL were opposed to the proposals in NHS England’s Consultation Documents for the Congenital Heart Disease (CHD) Review; particularly as the Trust had made good progress in meeting the standards required and NHS England had formally acknowledged that the only point of issue was the standard for each surgeon to perform 125 procedures a year. The Trust had submitted a Growth Plan to NHS England, at their request, in May 2017 which had clear and robust plans to meet the target standard specified in standard B10 (L1) and demonstrated that the Trust had already begun to put this plan into place to meet the required target. It was understood that NHS England had been considering the growth plan since it was submitted and had promised a meeting with UHL during the consultation period to discuss it. However, no formal response had been received from NHS England.

Dr Bolger gave a presentation on their current view of the proposals and a copy of the presentation is attached to these minutes.

During the presentation the following points were noted:-

a) The announcement that NHS England were minded to decommission Level 1 services in Leicester was made in July 2016. It was not until February 2017 that the public consultation was launched and in may not be until 2018 that the outcomes will be known. This was having a destabilising effect on those centres put forward for decommissioning.

b) This destabilising effect had already impacted upon Level 1 services in Manchester as the unit had recently closed prematurely at short notice. This was the result of senior staff leaving because of the uncertainty over its future and, as the Trust could no longer provide Level 1 congenital heart services. NHS England has had to form a crisis team to manage the situation externally, calling on other Level 1 providers in the North of England and Queen Elizabeth Hospital in Birmingham to provide care for Manchester's patients. It was of concern that this had been allowed to happen, particularly as NHS England did not have a contingency plan in place for this eventuality during the consultation process. This uncertainty remained and there was still a danger that other centres, such as UHL, could be susceptible to the same pressures. If UHL was forced to close prematurely then patients would be at risk as there were no plans in place to absorb their caseload at short notice.

c) The national picture in relation to CHD services has transformed immensely since the concerns associated with Bristol in the 1980's and 1990's. At that time, Bristol had a 30 day post-operation mortality rate of 28% in those under a year of age compared to the national average of 14% and Leicester's 13%. In 2015-16, the national mortality rate was 2% for all children's heart surgery compared to Leicester's 0.6%. The number of CHD centres in the UK had reduced from 17 in 1991 to the current 12 centres and there was now far more regulation, governance and audit in place to monitor safety and outcomes than in 1991, when there was very little overview.

d) After a self-assessment exercise in early 2016, UHL were informed that they were non-compliant with 8 out of 14 "core standards". NHS England's "minded" decision was based on this analysis. After UHL challenged this position, further discussions took place with NHS England, after which NHS England revised UHL's compliance to 13 out of 14. Despite this, it didn't alter NHS England's "minded" decision to decommission Level Services from UHL. According to NHS England, UHL failed to achieve the surgical activity standard by April 1st 2016. The standard refers to a centre having a team of three surgeons undertaking 125 operations per year (i.e. 375), averaged over three years. UHL objected to NHS England's retrospective application of this standard. They pointed to the fact that this was never agreed by the

working group of stakeholders who proposed the standards, to the fact that current surgical activity was now significantly higher than the historical data NHS England used and to the fact that the rate of increase in surgical activity will mean that for the current year, (2016-17), 375 operations would be undertaken. UHL also submitted a robust growth plan to NHS England in May 2017 that described how the network would grow in order to reach the 2021 standard of four surgeons/500 cases per year. Despite UHL providing them with a detailed growth plan that described how the 500 cases per year would be achieved, and agreeing to meet them to discuss that plan, NHS England had failed to reply to enquiries from UHL about when, or even if, those discussions would take place.

e) UHL had demonstrated unequivocally to NHS England that 500 operations per year are undertaken on patients from this region already with many having to travel outside the region to receive specialist care. NHS England had undertaken its own analysis of activity in the region and agreed with UHL's conclusions. UHL, therefore, stated that the issue was not one of a centre situated in a small geographical area with a small population of patients, as is found elsewhere in the country where there is no threat of decommissioning, but one of improving access to care for a large and populous region.

f) In addition to activity growth from existing network partners, UHL had been working with Chesterfield, Peterborough and Northampton hospitals who had expressed clear support for the continuance of CHD services in Leicester and the desire to explore network relationships in the future. These new referral pathways would accelerate the surgical activity in Leicester so that the target of 500 operations per year by 2021 would be comfortably achieved. However, critically, the fact that it was now a year since NHS England had announced that it was minded to decommission Level 1 services in Leicester and the fact that NHS England had still not decided when it would finally make a decision on future commissioning had created such instability and uncertainty that providers up and down the country were struggling to move forward with developing care pathways for paediatric and adult congenital heart services.

g) UHL had also held informal discussions with clinicians in Milton Keynes and Warwickshire Hospitals who were currently outside Leicester's Network but which were geographically close and had short journey times. There was interest in exploring network membership further. Any referrals from these centres had not been included in the UHL's Growth Plan adding further confidence to UHL's firm belief that they will reach the required target for operations in the required time.

h) UHL felt that there should be much more consistency with respect to the approach NHS England was taking. For example, UHL had asked NHS England to consider its world leading ECMO programme in the same light as the cardiac transplant service in Newcastle. NHS England had

stated that ECMO was subject to a separate review as it was not in the terms of reference for the congenital heart review and yet heart transplantation was not in the terms of reference for the congenital review but was given due consideration. That included an open-ended derogation on achieving the surgical activity target and co-location of paediatric cardiac services with all other children's services with respect to the Newcastle service. As another example, UHL had been required to submit a detailed Growth Plan to NHS England to demonstrate their ability to reach 500 operations per year by 2021. Other centres for whom this target is equally challenging, but who were not earmarked for decommissioning, had not been asked to provide anywhere near this level of detail. Through Freedom of Information requests, UHL was aware that at least one other centre had stated in its impact assessment that they would achieve the 500 target only by other centres closing. This was felt to be inequitable. Many patients would have to travel further than their nearest centre for this to be achieved, something highlighted by the Independent Reconfiguration Panel (IRP) that reviewed the Safe and Sustainable decision as being highly undesirable.

i) UHL had demonstrated the largest sustained percentage growth in operations for CHD services over the last 8 years compared to other Level 1 centres where the number of operations has remained static or declined in the same period.

j) UHL's provision of regional and local PICU and regional and national ECMO services should have received equal consideration to Newcastle's heart transplant services. The PICU and ECMO provision should have been part of the CHD Services Review from the outset as had been recommended by the IRP in their report to the Secretary of State for Health in 2013 on the matter of the Safe and Sustainable Review.

k) UHL questioned the ability of other centres to cope with the additional workload that would result from decommissioning in Leicester. Consideration seemed to have only been given to cardiac surgery whereas PICU capacity, catheter interventions ("key hole" procedures), non-cardiac surgery, ECMO, obstetric cardiology (the care of expectant mums with heart conditions), education, training and research seemed to have been given far too little attention; if any at all. The point was made that many of the complex patients need outpatient review in the Level 1 centres and the NHS England model that describes outpatient review in a Level 1 centre only on a single occasion before surgery and a single occasion after surgery just was not accurate. UHL expressed concern that waiting lists in other Level 1 centres were already under pressure and moving patients out of the East Midlands would make this worse. Patients from the East Midlands were therefore likely to have to wait longer for operations and catheter procedures than they do now and by default so would patients in the receiving centres. This must be seen as a risk to implementing the current proposals. UHL also stated that the surgical activity data sent to other Level 1 centres to test their

capacity expansion plans was years out of date, again adding significant and unnecessary risks to implementation.

l) UHL raised the prospect of a shortage in human resources, particularly PICU nurses as a serious concern with respect to the transfer of surgical services to another centre. Indeed it was highlighted that Birmingham Children's Hospital had already expressed their concerns over recruiting sufficient staff to accommodate the increase workload in the event of UHL ceasing to provide Level 1 services. It was stated that the issue at hand was not whether other centres could build a hospital big enough to accommodate all the patients from the East Midlands with congenital heart conditions but whether they should.

The Chair thanked UHL for their presentation and commented that this was a regional issue and not just a local issue to Leicester. There was a great deal of concern across the East Midlands about the current proposals.

The Chair offered the representatives of NHS England the opportunity to comment upon the points raised by UHL. The representatives indicated that they did not wish to comment as they were attending the meeting to hear the views put forward by the public and stakeholders.

The Chair then asked Members to refrain from asking questions until the Committee had heard the representations and submissions from patients and stakeholders as there may be some duplication of questions arising from UHL's presentation and representations and submissions still to be heard.

42. REPRESENTATIONS FROM THE PATIENTS, PATIENTS' GROUPS AND OTHER STAKEHOLDERS

The Chair stated that the Commission had previously invited members of the public, patients groups and other stakeholders to submit their views on NHS England's proposals for Congenital Heart Disease Services. A number of individuals and stakeholders had registered their interest to address the Committee and had submitted written submissions.

Leicester University had been invited to attend the meeting and although Professor Philip Baker, Pro-Vice Chancellor and Head of College Medicine, Biological Sciences and Psychology was unable to attend, he had submitted a representation on behalf of the University. A copy of the letter is attached at Appendix A to these minutes.

Lincolnshire Health Scrutiny Committee had submitted their response to NHS England's Consultation on the Congenital Heart Disease Review and a copy of their submission is at Appendix B to these minutes.

The Chair stated that the primary purpose of people presenting their submission was for the Committee to hear at first hand the views being expressed and, as such there, would be no opportunity for members of the Committee to ask questions on the submissions. Representatives of NHS

England were present but they would not be asked to respond to the submissions. They would, however, consider the submissions as part of the consultation process.

The Chair stated that each person would be given 5 minutes to present their submission and it would be published with the minutes of the meeting unless the person presenting the submission indicated they did not wish it to be made public. The submissions could also be included as part of the Committee's evidence to the Consultation process. All those who were intending to make a presentation to the Committee were then asked to indicate if they wished their submission to remain private. No such indications were received and the Chair confirmed that all the submissions would be published with the minutes of the meeting.

The Chair then invited the following patients and stakeholders to address the Committee for a maximum period of 5 minutes each:-

a) Shirley Barnes, a parent of child with a congenital heart disease. A copy of the submission is attached as Appendix C to these minutes.

b) Olivia Barnes, a parent of child with a congenital heart disease. A copy of the submission is attached as Appendix D to these minutes.

c) Jess Whitehouse, a parent of child with a congenital heart disease. A copy of the submission is attached as Appendix E to these minutes.

d) Dr Sally Ruane, Health Policy Research Unit, DeMonfort University. A copy of the submission is attached as Appendix F to these minutes.

e) Katy Weatley, Leicester Mercury Patient Panel. A copy of the submission is attached as Appendix G to these minutes

f) Karen Chouhan, Chair of Healthwatch Leicester, representing Healthwatch Leicestershire and Healthwatch Rutland. A copy of the submission is attached as Appendix H to these minutes.

g) Eric Charlesworth submitted a question, a copy of which is attached as Appendix I to these minutes.

   Mr Charlesworth commented that a number of questions previously asked at public meetings had not received a response from NHS England. It was important that the public were given the answers or, if not, an explanations as to why the questions have not been answered. He was also concerned that the PICU and ECMO review proposals were only made public on the previous Friday and he questioned how this could realistically be incorporated in the CHD Review at this stage, which was not in keeping with the previous IRP finding on this issue.

The Chair thanked everyone for their contributions and submissions, which provided a valuable insight to the effect of the proposals on patients.

The Chair then invited questions from the members of the Committee. The following comments/statements and questions were received (these have been grouped into general themes for ease of reference). NHS England responded to some the comments/statements and questions and these are shown below each themed area.

GENERAL

a) It was disappointing that NHS England had not responded to the questions asked by the public and patients at previous public meetings. It was important that the members of the public were given an explanation why these questions had not been answered. A Member had been unable to find NHS England's Q&A on the website during the meeting which indicated the difficulties the public were having in accessing the information. There was frustration that, in common with other NHS consultations on the STP and health care in general, it was impossible to receive forthright answers to questions asked during the process; which added to the concerns over openness and transparency. It was felt important that NHS England should demonstrate at the forthcoming public meeting how to access this link and that show that the questions had been answered. It was not reasonable to expect that patients and families who were already under stress should have to make tortuous searches to find the answers they were seeking.

b) NHS England should publish its risk analysis to patients in areas where they were proposing to close a Level 1 centre, particularly in relation to the vulnerable groups already identified by NHS England.

c) It was worrying that some centres were being allowed to continue as Level 1 centres based upon an assumption that they would achieve the 125 operations per surgeon simply by other Level 1 centres closing. This was inequitable in relation to how UHL, in particular, were being treated and raised grounds for judicial review in relation to the process used for carrying out the review and the consultation, particularly the disparity of treatment between UHL and Newcastle, the poor travel modelling and the assertion that 125 operations per surgeon was an essential requirement to provide a safe and sustainable service in the future. There were also concerns over questions relating to the transparency and conflicts of interest of some of those involved in the process of putting forward the proposals in the review who were working in Trusts that would benefit from the proposals.

d) The uncertainty of the timeline for the review and the taking of the final decision was considered detrimental and damaging to the current provision of services as it created uncertainty and worry for those staff and their families working in the current centres put forward for closure. It was also considered that it was unsettling for patients and families and caused additional anxiety at a time of extreme stress for them. This uncertainty had already led to the early closure of Manchester Level 1

services.

e) There was enough evidence already to indicate that the proposal to cease Level 1 services at UHL was not sustainable and that the proposal should be dropped now. Services had previously been regionalised and the outcomes at Glenfield were excellent compared to other units. It was the only centre between Newcastle and London on the eastern side of the country and if it closed it would disadvantage patients in the East Midlands for ever more.

f)

g) NHS England had still not put forward an EIA in relation to specific individual vulnerable groups, such as people of south Asian origin, and this was of particular concern as there were large numbers of this vulnerable group in the east midlands generally and in Leicester in particular. The proposals did not make sense in proposing to close a Level 1 centre in Leicester when there was such a large identified vulnerable group in the region.

h) The personal accounts submitted to the meeting by parents and the patient panel had emphatically demonstrated families faced difficult situations over long periods of time and it was clear that the proposals would only add to these difficulties.

i) There were concerns at the previous meeting that if UHL did not provide Level 1 services they would not be able to provide Level 2 services. NHS England had indicated that they would discuss the issue with UHL and they were asked if any progress had been made.

j) It was still not clear why an excellent unit such as UHL with low mortality outcomes was being put forward for closure. Given the predicted growth rates in the region, it was questioned how the larger centres would cope with the additional demand from the areas where centres were closed in addition to the increased demand from their own catchment areas, particularly when these large centres had been fairly static in terms of the number of operations for some years. It was also questioned how the larger centres would recruit the additional specialised staff required to meet the increased demands. There were concerns that waiting times for operations in the larger centres could increase as a result of these proposals, particularly if they could not recruit sufficient numbers of staff, and this could also impact upon mortality rates.

k) When the review started it was expected that the decision would be made by 30 November 2017 but there had been no indication when the decision would now be made as a result of suspending the consultation during the general election period. It was also unknown who or which body would be involved in making the final decision, and this further added to concerns over transparency.

NHS England's Response

Michael Wilson thanked Members for the invitation to attend the meeting and hear the contributions made by parents and stakeholders. He stated that the prime purpose of NHS England's attendance was to note the contributions to the meeting and to relay these back to NHS England.

Although NHS England were not attending to specifically respond to comments made at the meeting it was felt helpful to make the following responses:-

a) NHS England had received UHL's growth plan and were considering it and a response would be sent to UHL. This issue had now been passed to John Stewart, Acting Director of Specialised Commissioning NHS who was the new Programme Director for the CHD Review.

b) NHS England aimed to respond to all FOI enquiries within the 20 day target but this was not always possible.

c) NHS England had updated the information on the Q&A area of the website to take into account questions raised during the consultation. If anyone did not feel their question had been answered they should contact the Review Team and Mr Wilson would make sure that the question was answered.

d) The NHS England Board would take the final decision in the light of the responses to the consultation responses.

e) The concerns surrounding the 125 cases per surgeon were noted but NHS England believed they had set out the basis for the figure of 125 cases in the documentation when standards were agreed. NHS England believed the figure to be a fair representation based upon the recommendations of surgeons working in this particular speciality and they also felt that they had provided an explanation of the evidence they had used.

f) The EIA and Impact Assessment had been published as part of the review and consultation and it was unclear to them what was meant by the comments that they had not been published. It would be helpful if the specific details could be made known to NHS England after the meeting.

g) The frustrations about straight answers to questions were understood and NHS England needed to make sure that the link to the Q&As was more easily accessible. NHS England intended to answer the questions asked even though the answers may not always be what the questioner wanted to hear.

h) The NHS Board, in making the final decision, would need to consider whether the proposals were appropriate and whether any changes

outweighed the cost of those changes, including the question of having no Level I services within the East Midlands in the future.

i) It was expected that those centres taking on increased workloads as a result of the proposals would need more staff. NHS England would want to work with staff in Level 1 centres that would close to have the opportunity to transfer to another Level 1 centre that would have additional workloads. However, it was recognised that not all staff would want to move and, therefore, a good number of the additional staff required by a Level 1 centre with increased workloads would have to be recruited by that centre.

j) The modelling for the Review for the growth in numbers was most affected by the numbers of births rather than the overall number of people in an area. UHL's growth plan took into account their view of the growth in the population in the East Midlands and NHS England's work had also taken into account how the demand for CHD services would change in response to changes in population.

k) It was not possible to indicate with any certainty when the final decision would be made; it could be late in 2017 or early in 2018. The volume of responses to the consultation had been high and NHS England needed time to analyse these and assess what they indicated in relation to the proposals.

<u>UHL's Comments</u>

a) It was not UHL's desire to become embroiled in a legal dispute with NHS England through the courts as both bodies were part of the wider NHS system. However, UHL had taken legal advice on the proposals and were of the view that there was significant scope for challenge in relation to what was expected of public bodies and the process of how they should do it.

b) If UHL were a Level 2 centre as a result of the proposals, they would be the only Level 2 centre in the country that did not have a Level 1 centre in their region. The other Level 2 centres in the country were Cardiff, who were in a partnership with Bristol, Oxford were in partnership with Southampton and Edinburgh with Glasgow. This would mean that UHL would need to create a partnership and a network with Level 1 centres outside of the region. This network would include Birmingham Children's Hospital, Queen Elizabeth Hospital Birmingham for adult patients and also Leeds. It was also likely to include one or more centres in London. This model for providing Level 2 services and care was untested as it did not exist anywhere else in the country.

c) The idea that a Level 2 centre is a Level 1 centre without surgery was erroneous. It had been suggested that a Level 2 would undertake the simpler catheter interventions for example. The existing Level 2 centres at Cardiff, Oxford or Edinburgh did not undertake the catheter

intervention in children as they don't have the surgical expertise in the centre to intervene should there be any complications from the procedure. UHL would not wish to undertake keyhole procedures if there was no the surgical expertise available as this would not be safe for the patient if they had to be transferred to another Level 1 centre many miles away.

d) Existing Level 1centres also saw patients from Level 2 centres because they had the specialist equipment for specific imaging or scanning techniques that were required for Level 2 patients. Level 1 specialist services and equipment were also required for Outpatients as they often need to undergo further tests on the day of their appointment provided by a Level 1 centre. UHL felt that NHS England were unaware of these practicalities and the current proposals would mean that even more patients would be required to travel out of the region to attend a Level 1 centre.

ISSUES RELATING TO STANDARDS

a) The points made by Sally Ruane in relation to the lack of published evidence to support the selection of 125 operations per surgeon as being a definitive figure needed to be addressed and fully evidenced by NHS England; rather than rely on a figure arrived at by the consensus of specialist clinicians, many of whom would benefit from these proposals.

b) Few studies had been carried out and their findings differed and offered contradicting viewpoints. One study suggested 250 operations per centre was a recommended level of activity. Other studies showed that small centres could perform better than large centres and also that centres of equal size could perform differently. These studies demonstrated that the evidence was mixed and complex and that there were many factors that contributed to good outcomes. The outcomes of these studies suggested that focussing solely on the number of operations was not the best approach to providing a high quality service.

c) The focus should be on the mortality rates of Level 1 centres as this was evidence of good outcomes for patients. It was difficult to understand how a well performing centre such as UHL with mortality rates better than most was being proposed for closure.

ISSUES RELATING TO TRAVEL

a) NHS England had not sufficiently considered the impact of travel of for severely ill children and the effect this could have on the mental wellbeing of parents, other family members and close relatives. Mental health was a crucial aspect of the whole process. The focus should be on the patient and the family and the care and support that is given to the family and not on the number of operations carried per surgeon. It had been expressed many times that UHL gave excellent care and support and these proposals were putting more stress on people who

are already under stress.

b) There was still concern that the proposals did not adequately consider the impact of people in outlying areas such as Boston having to travel long distances many times during the duration of their care.

c) The impact of the proposals upon other members of family, children parents and grandparents needed to be fully considered as they could cause life changing effects to the family. It could not be assumed that the immediate family would be on hand to provide support at a time of stress and crisis. Not all families lived close by to their relatives and the proposals did not seem to consider its impact on the increased costs to families in maintaining the household, extra travel and accommodation away from home. It was vitality important that children were not disadvantaged by choices which not of their not of their making and the proposals should also take into account their impact upon the social aspects of family and extended family life.

The Chair echoed members thanks to the parents and stakeholders for attending and giving the Committee their representations. The representations clearly demonstrated that the issue was not simply a number game or about the number of procedures as quality of care was much broader than that. The patient experience was integral to the whole process and should be recognised and all the representations had emphasised that the consistency and continuity of care was essential and that the support the staff that UHL provided was far beyond that which could be expected and they were almost part of the extended family and support network. The importance of having care as close to home was important for families especially on the impact for other family members attending local children. It was important that normal family life was maintained as far possible for all family members whilst coping with the demands placed upon them from caring for a child with CHD. The emotional needs of the child and the family also needed to be considered; none more so than where a child also had other special needs.

The views expressed at the meeting would be incorporated into the Committee's submission to the consultation process. There was obvious frustration expressed by both the public and Members with the whole consultation process and the particular concerns over its equity and fairness. The overall impression from the Committee's meetings on this issue has been that NHS England had been put in the position of defending the proposals, which Members feel were indefensible for the reasons put forward. This process had not been helped by a new Programme Director being appointed part way through the consultation process and, whilst that was not the fault of NHS England, they now needed to undertake considerable work to reassure the public about the process.

AGREED:-

That the members of the public and the various stakeholders be thanked for their submissions and that NHS England take the views expressed at the meeting in account as part of the

consultation process and when considering the final decision.

43. NEXT STEPS IN RESPONSE TO THE CONSULTATION PROCESS

The Chair commented that based on the discussions of this and previous meetings a response to NHS England's consultation would be prepared. The consultation response would be shared with the constituent Council's for comment prior to it being submitted before the deadline on 17 July.

The Chair also commented that the City Council would be writing to the Secretary of State expressing concerns in relation to the inequality of the proposals and the way in which the standards had been determined and applied in the consultation process. The proposals were also not considered to be in the best interests of health services in Leicester and the wider region. The letter would also indicate that, because of those concerns, a referral would be made to the Secretary of State in the future should Level 1 services no longer be commissioned from UHL.

44. ANY OTHER URGENT BUSINESS

There were no items of Any Other Urgent Business to be discussed.

45. CLOSE OF MEETING

The Chair declared the meeting closed at 7.47 pm.