NHSE Meeting with stakeholders re: EMCHC

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Context

This paper provides the Trust Board with an update following the recent meeting with NHS England (NHSE) on 16th September 2016. Present at the meeting were:

Dr J Fielden – National Director of Specialised Commissioning / NHSE Dept Medical Director.

Mr W Huxter - Regional Director of Specialised Commissioning (London) and SRO, Congenital Heart Disease Review

Ms C O'Connell – Regional Director of Specialised Commissioning

The UHL team was led by the Chief Executive and included members of the EMCHC clinical team and Executives.

The session began with a closed meeting lasting two hours, followed by a tour of the EMCHC and ended with an open hour long Q&A with stakeholders hosted by the UHL Chairman. The notes from the stakeholder meeting are detailed in Appendix 1.

Summary
NHSE's visit to EMCHC was an opportunity to showcase the extraordinary work that we do; exchange clinician to clinician views and opinions on their proposal and to enable stakeholders to question NHSE on the validity of their plan. In that sense the visit was successful. However we should be clear that at no point during the meetings on the 16th or in subsequent correspondence from NHSE have we heard anything that would indicate that they are prepared to question their assumptions.

Despite this there were some positives; the team showed data which put pay to the myth that Leicester only does the less complex surgical work and looks after relatively less poorly patients. We were also able to challenge their scepticism about our ability to meet the macro co-location standard (i.e. bringing EMCHC across to the Royal) without the need for external capital; essentially we said that this could be funded out of our own capital allocation.

We were also able to reassure them about the micro, sub speciality co-location around gastroenterology cover. Finally we showed NHSE that on *current* surgical volumes, never mind those in 5 years' time, there were sufficient cases locally to sustain 4 surgeons and 500 cases… the rider being that this only worked if the 'nearest centre' model applied.

Given that NHSE's challenge has always been a threefold one; number of cases, overall co-location and sub-speciality co-location, the fact that were able to go some way to offering assurance on two out of three of these issues is significant.

On the downside the core issue of volume / surgeons remains.

In terms of volume and numbers of surgeons, our case is essentially that we are on track to reach 375 / 3 surgeons for 2016/17 but that the only way we can reach 500 cases by 2021 is to repatriate patients to Leicester. In response Dr Fielden said that 'patient choice is sacrosanct' in other words,

he disagrees with our assertion that patients from Northampton and Peterborough postcodes were travelling to GOSH and Southampton on advice from their local clinicians.

As colleagues and stakeholders know we would contend that ending 'patient choice' for the hundreds of patients currently treated in Leicester is a far more significant and damaging intervention from NHSE than the alternative which is for them to intervene and support a change in the current referral patterns from some neighbouring hospitals.

On the matter of consultation NHSE set out an indicative timeline with national consultation on their proposals taking place from mid-December 2016, lasting for 14 weeks. Whilst clarity on their timescales was welcome it would be fair to say that there was some scepticism regarding the feasibility of embarking on a properly informed consultation when the impact of their CHD proposals on Paediatric Intensive Care and ECMO capacity had yet to be understood.

We will continue to engage with NHSE colleagues and our stakeholders as positively and constructively as possible not least because we share a common purpose to do what is right for our patients and their families, now and in the future.

Finally, on behalf of the staff at the EMCHC and the Trust Board we would like to thank those stakeholders who set time aside to meet with NHSE colleagues and in doing so highlighted the depth and breadth of support for the centre.

Recommendations:

The Trust Board are invited to comment on the contents of this paper

For Reference

Edit as appropriate:

1. The following **objectives** were considered when preparing this report:

Safe, high quality, patient centred healthcare	[Yes /No /Not applicable]
Effective, integrated emergency care	[Yes /No /Not applicable]
Consistently meeting national access standards	[Yes /No /Not applicable]
Integrated care in partnership with others	[Yes /No /Not applicable]
Enhanced delivery in research, innovation & ed'	[Yes /No /Not applicable]
A caring, professional, engaged workforce	[Yes /No /Not applicable]
Clinically sustainable services with excellent facilities	[Yes /No /Not applicable]
Financially sustainable NHS organisation	[Yes /No /Not applicable]
Enabled by excellent IM&T	[Yes /No /Not applicable]

2. This matter relates to the following **governance** initiatives:

3. Related **Patient and Public Involvement** actions taken, or to be taken: The Board are aware of the extensive involvement of public and patient stakeholders.

4. Results of any **Equality Impact Assessment**, relating to this matter: [Insert here]

5. Scheduled date for the **next paper** on this topic: November 2016

6. Executive Summaries should not exceed **1 page**. [My paper does comply]

7. Papers should not exceed **7 pages.** [My paper does comply]

UNIVERSITY HOSPITALS OF LEICESTER NHS TRUST

STAKEHOLDER Q&A MEETING WITH NHS ENGLAND (NHSE) RE: CHILDREN'S HEARTS SURGERY (EMCHC), HELD ON FRIDAY 16 SEPTEMBER 2016 AT 2PM IN ROOMS 2 & 3, CLINICAL EDUCATION CENTRE, GLENFIELD HOSPITAL

UHL representatives:-
Mr K Singh – Trust Chairman (chairing the meeting)
Mr J Adler – Chief Executive
Mr M Wightman – Director of Marketing and Communications

In attendance
Ms T Jones – Deputy Director of Communications
Ms A Poole – EMCHC Project Manager
Ms H Stokes – Senior Trust Administrator

NHSE representatives (up to and including note 2.4)
Dr J Fielden – Director of Specialised Commissioning
Mr W Huxter - Regional Director of Specialised Commissioning (London) and SRO, Congenital Heart Disease Review
Dr C O'Connell – Regional Director of Specialised Commissioning
Ms J Stringer – Communications Lead

1. Introduction:-

1.1 The Trust Chairman thanked all those attending this session, and introduced his UHL and NHSE colleagues. Dr J Fielden, Director of Specialised Commissioning NHSE advised that the congenital heart disease review was now in the 'pre-consultation' phase, during which NHSE would be working with organisations, staff and stakeholders to verify the information available ahead of formal consultation. That formal consultation was now envisaged to start in mid-December 2016, due partly to the extensive pre-consultation requested. He reiterated that no firm decisions had been made at this stage and that NHSE was in "listening mode". The emphasis was on providing the right treatment at the right time in the right place, rather than focusing on closing services. NHSE also thanked the UHL clinical team for the discussion session held earlier today.

1.2 NHSE also considered that it was "extremely likely" that the medical aspects of paediatric cardiology would remain at UHL Leicester, with only the surgical aspects currently under review. NHSE would also review the key interdependencies in detail. NHSE further noted that the key issue was how to deliver the agreed standards both now and in the future.

1.3 The meeting was then opened up to questions from attendees, which included stakeholders, members of the public, patients' relatives, staff, and local MPs. These questions and the NHSE response are shown in the table below. **Please note that this is not a verbatim transcript of the questions or answers.**

Source of question	Question/comments	NHSE response (where provided/ needed)
Leicester Mercury Patients' Panel	After the "debacle" of Safe and Sustainable, what steps are being taken to ensure appropriate patient and public involvement (PPI) in the consultation and in the actual issues ?	NHSE recognised the process challenges re: Safe and Sustainable. Part of the reason for the slippage on the formal consultation is to enable this pre-consultation phase. The clinical reference groups on the clinical panel have very strong PPI input, to help craft the consultation questions. NHSE is keen not to let Christmas constrain the consultation period.
Leicester Mercury Patients' Panel (points raised later in the session)	Do the standards compare the casemix between units or are they reliant only on numbers ?	
	NHSE's blog originally said in July 2016 that consultation would only be undertaken 'if appropriate' ?	NHSE confirm that it was always intended to consult re: EMCHC. Non-consultation would only apply in the case of providers with fewer than 10 cases.
Deputy Mayor of Leicester	What analysis will NHSE do of the interdependencies and will that analysis be published as part of the consultation ? Local Government would be expected to do this.	Knowing those interdependencies (and their relative criticality) is crucial. In parallel to the congenital heart disease review NHSE is therefore accelerating national service reviews of PICU, paediatric surgery, ECMO and paediatric transport to assess national as well as local interdependencies. At the session held earlier on 16.9.16 with the UHL clinical team, it had been agreed to share further information in order to arrive at a common understanding of the regional impact and interdependencies.
Deputy Mayor of Leicester (point raised later in the session)	125 operations per surgeon per year is arbitrary, feel – what research or evidence backs up this figure ? Will NHSE publish the notes of its discussions on these figures ? The public needs to understand the evidence, and Leicester might want to review the evidence used. "Arbitrary" is quoted in one of NHSE's own documents.	125 is the minimum figure – this is based on evidence and clinical opinion. NHSE feel that the reasons behind this are already in the public domain.
Staff/stakeholder	Outcomes and quality have improved over the last 15 years and NHSE are causing the only uncertainty. "Doing Something" has become an obsession.	NHSE acknowledge that some units – cited as Great Ormond Street and Birmingham Children's Hospital – are outstanding but NHSE need to look at sustainability going forward. This is linked to numbers (patients and surgeons) and NHSE feel that UHL does not currently meet the 2016 standard and either will not or is unlikely to meet 2019-20 standards. Co-location is also an issue. *UHL's Chief Executive then advised that the Trust has proposed a way of achieving the numbers and the issue is now whether NHSE will agree. He further advised that co-location had been discussed at that morning's clinical meeting with NHSE, with a further exchange of information now planned between UHL and NHSE on that issue.*
	2 paediatric centres won't meet the requirement for co-location of adult and	NHSE reiterate the 30-minute requirement.

	paediatric services – how is this being reconciled ?	
Staff/stakeholder (points raised later in the session)	Are paediatric transplant services in England being reviewed ?	No.
	Why is a worldclass ECMO service being reviewed and not paediatric transplant services ? They are all interlinked.	
	What will it take for NHSE to work with UHL on meeting the standards?	That is the process being undertaken now, similarly for Brompton and Manchester. No final decision has yet been made.
Healthwatch	What has changed since the 2015 decision not to close EMCHC – why is it now earmarked for closure. EMCHC is a facility of outstanding quality and it seems 'stupid' to put patients and families to all this trouble.	NHSE consider that UHL is well short of the 375 cases number, and the standard of 375 and 500 is the number deemed by clinical colleagues nationally as necessary for sustainability. 4 surgeons are needed. Based on the information provided by UHL, NHSE does not believe that these figures will be achieved, nor co-location. NHSE acknowledge that further information has been provided today however. The upheaval is only for 300 cases, and there is a need to really delve into the critical interdependencies and understand the impact on PICU and other domino effects. NHSE cannot see PICU **not** remaining at Leicester.
Healthwatch (points raised later in the session)	What weighting will be given to the consultation outcome ? Asking people for views on interdependencies is a very complex issue. If the public opinion is to keep EMCHC open, will it still close ? Is consultation just a 'sham' and a waste of money ? Is the clinical view more important than public opinion ?	The consultation is neither a sham nor a waste of money. NHSE can have a pre-consultation discussion with UHL about the numbers but the issue is that the Trust either meets or does not meet the standards. The consultation will be a national exercise, so the reasons for the decisions do matter. The point of the consultation is to reach a decision by the standards could be met.
MP Leicester West	There are 500 cases in the EM region but not all come to UHL. In an issue not related to patient choice, it is felt that there are some historic referral patterns in place involving referrals to outside of the region and there is a need for Commissioners to commission appropriately. Will NHSE look at those historic referral patterns ? NICOR data shows good outcomes for EMCHC.	Clinical choice is often linked to historic relationships. NHSE cannot dictate or override patient choice. It is not for NHSE to change referral practices, and NHSE notes work by UHL with neighbouring Trusts on this. NHSE comment that some patients are choosing to go to centres with 'better outcomes'.
	Which services does NHSE want to be co-located and which is the Trust planning to co-locate ?	NHSE confirm that this was discussed earlier with clinicians. Subspecialty co-location requirements relate to paediatric gastroenterology, interventional radiology and vascular surgical services. *UHL's Chief Executive advised that the overall co-location of children's services was being delivered through the children's hospital development – the Trust had confirmed to NHSE earlier that morning that the EMCHC element of this could be delivered within the timescale. Although some further clarification was needed on certain subspecialty issues, UHL could not see a problem with any of the co-location*

		requirements.
MP Leicester West (these points raised later in the session)	People feel very frustrated by the 'minded to' announcement particularly before NHSE has assessed the PICU/ECMO impact – such an announcement could be a self-fulfilling prophecy. It will not be easy to move ECMO, and why move such a world-class service anyway ?	
	There is a clear issue around referrals and the question of patient choice. Can NHSE look into this ? eg to assess whether the out of area referrals are due to clinician preferences and not patient choice ?	
	Have applied for a Parliamentary debate on this issue and is raising these issues with the Minister of State for the Department of Health. This is a cross-party effort.	
Parent/service user	Feel closure will negatively impact on the patient choice of those patients who wish to come to UHL but can't if it is closed. Many patients already travel to EMCHC through choice.	The size of the units and their through-flow is crucial to high quality outcomes. Globally, units are being concentrated and NHSE feel that EM patients would have to travel relatively short distances for an alternative service provider if EMCHC was closed [later clarified as relating to average travel times].
Health and Wellbeing Board	The standards are just numbers, not a guarantee of quality. When did the standards become a reason for closure ? Why is NHSE prepared to work with other centres who don't currently meet the standards but not with UHL ? What does Leicester have to do to convince NHSE ?	NHSE advise that the information received so far was being assessed but no final decision had yet been made ahead of the pre-consultation and formal consultation stages. NHSE was working with all centres not currently meeting the standards (eg discussions with the Royal Brompton on 14.9.16). NHSE feel it is evident that specialist medical cardiology will remain at UHL – it is just the surgical aspect which would move. The debate is how the standards can be met, and all centres are being judged against those standards.
Stakeholder (CCG)	Leicester's hospitals have been under-resourced historically, since 2003-04 – does NHSE take no responsibility for this ? The NHS brand in Leicestershire has been damaged by these repeated reviews into children's heart surgery. There is an excellent service in Leicester. The Safe and Sustainable process was completely flawed. Are Leicester and the EM not seen as priorities ? Non-UHL referrals are not the result of patient choice. Travel times to other centres	NHSE advise it was not in place in 2003-04 and doesn't know the background to the assertion. Investment levels will always be debated. This specific review process now is not related to money, it is about meeting the standards. It is not NHSE's intention to damage the NHS but the standards must be applied and implemented. NHSE is trying to ensure a correct, inclusive process but within the time limits.
Stakeholder (CCG) (points raised later in the session)	The first consultation was totally flawed. The public feel that NHSE wants to get rid of the Leicester service come what may. NHSE is undermining the service constantly. Feel the service should be given a 3-year breathing space to meet the standards. The position is not fair on Leicester.	NHSE do not agree. Delay would not create clarity. NHSE reiterate that no final decision has been made.
Parent/service user	This originally felt like an inclusive process	NHSE advised that it has to announce what

	but now feels very closed. Why was the July 2016 'minded to' announcement made ? Is that standard wording for such announcements ? That announcement actually started the domino effect because the units/staff/parents were now uncertain and insecure. Natural referral patterns were being changed and the effect on the quality of life for patients and their families was being changed for ever. Was it normal practice to announce an intention before doing the consultation ?	it is consulting on – the announcement is not meant to imply a decision, hence the period of pre-consultation now to judge the true domino effect. NSHE wishes to get the process done quickly but allow 'enough time'.
	The impact on patients and their families of this announcement was very significant. If all regions received fair referrals and travelled equally, then the outcome of the review would be different. Clinicians must feel able to refer through a logical and natural route. People are being sent where they don't need to go. Patients must be given a choice not herded down a particular clinical preference.	NHSE recognised the impact on patients and the need to have the right information.
	People move once they think the service will close. Is this the 'NHS way' – eg announcing a minded decision, then pre-consultation, then consultation, with a decision taken over months.	A period is needed to assess the information. The length of the consultation tends to depend on the level of agreement. NHSE wants to work constructively with the Trust.
Staff	NHSE's July 2016 announcement said it would work with Newcastle – are Newcastle's transplant patients more important than UHL's ECMO patients ? How will other centres take on UHL's ECMO work ? Bristol, Leeds, Birmingham, Barts and Guys are all being supported by NHSE but not Leicester – why not ?	Transplant patients are not more important than ECMO patients. The other centres mentioned are much closer to meeting the standards than UHL. ECMO interdependencies will be linked in to the review – other centres do already do ECMO and NHSE are looking at the national provision picture.
Stakeholder (group)	UHL has the only ECMO centre which retrieves patients. Also, UHL's ECMO was originally funded by HeartLink, not by Government.	UHL is right be proud of the ECMO service. UHL has highlighted the critical interdependency of ECMO, and NHSE reiterates its view that paediatric medical cardiology and PICU will remain in Leicester.
Stakeholder (other Trust)	Reassures UHL that clinicians at their Trust are still operating a 'business as usual' approach with EMCHC.	
	What are the plans to manage capacity for patients needing surgery if EMCHC closes, and how will these be communicated to other providers ? Birmingham do not have capacity. Also concerned by PICU capacity issues.	PICU capacity nationally is being reviewed through the accelerated service review. With regard to EMCHC capacity, UHL has links to Birmingham. Although the final decision is still being consulted upon, there is a need to explore a managed transition process too (contracting guidance will also reflect this). Consultation due mid-December 2016 for 12-14 weeks with a view to a decision in late Spring/early Summer 2017. The process will therefore take a certain amount of time and it is not possible to provide a specific timescale. Additional capacity will be put into the system if the decision is taken to close EMCHC but this cannot yet be planned as the decision has not been made.

Public	Will an independent panel formulate the consultation questions ? What assurance is there that the consultation process will be genuine ?	The pre-consultation phase will be used to get the questions right. NHSE will take independent advice as for all national consultation exercises. The patient voice will also be heard, and will review the questions. NHSE acknowledge that it is hard to obtain completely independent advice – however the panel is independently chaired and all conflicts of interest are declared.
Staff	If children's heart surgery is removed from UHL, will MRI/CT/catheter patients still be able to be treated ? eg what about the knock-on effects for other treatments ?	NHSE reiterates its view that medical cardiology is likely to remain, but the exact other services which would still be in place depends on the outcome of the formal consultation and the composition of the clinical teams
Stakeholder (group)	Catheterisation procedures can only be done in tier 1 surgical centres? If so, how can UHL continue to do them if EMCHC closes ? The service won't be sustainable.	NHSE advise that for level 2 centres, it depends on the links to other centres and services.
Staff	What guarantees are there that proper consideration will be given to Leicester ? Feel that NHSE's body language says 'closure'.	The consultation process will take place before any final decision.

2. Closing remarks

2.1 NHSE thanked all speakers for their clarity and passion, and reiterated that it was committed to working with Leicester on quality services now and for the future.

2.2 The Trust Chairman thanked NHSE colleagues for attending the meeting, and noted the very significant level of passion expressed by public attendees during the Q&A session. He confirmed that he had written to the Secretary of State for Health expressing his hope that the consultation would be open-minded and clear. The Trust Chairman noted that comments at today's Q&A session had indicated some considerable level of scepticism about the process, and he emphasised the need therefore for NHSE to give clear messages about the remit of the consultation exercise and to show appropriate care when developing and communicating the consultation questions. Although the consultation was a national one, there was a uniquely diverse demography in Leicester and the Chairman noted the need to take appropriate account of access issues. He requested explicitly that the national consultation contain specific chapters for each centre.

2.3 It was vital to avoid any perception that the consultation was a predetermined decision, and the Trust Chairman also emphasised that the current uncertainty helped nobody, particularly not patients. It was evident that the original April 2017 timescale was not now realistic

The meeting closed at 4.30pm