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Dear Will

Thank you for your letter dated 14th November. There have been numerous communications between UHL and NHS England recently and your letter appears to be slightly out of order. Your statement that we do not meet the standards appears to be based on the last outcome from the assessment panel, and written before you had sight of our latest response to the self-assessment exercise. I look forward to receiving the panel's assessment of our submission with minutes of the discussions and decisions made. Can you please clarify when the outcome of the latest assessment panel will be available? Can you also clarify when you plan to issue your revised recommendations?

Thank you for answering a number of the questions posed in my letter dated 13th October. I would, however, like to ask for further clarification on the following points (your reference numbers from 14/11/16 letter) and I will supply a commentary where it appears it may be helpful to you.

Point 2 - Risk assessment details - an impact assessment process has commenced, but we have received no details of how and when the results from this are to be published and how that will align to the timings of the public consultation. Can you please clarify these points? In your reply on this point you have emphasised in bold paragraph 98 of the NHSE Board Report. There you acknowledged that:

> **"Our commissioning decisions will need to take into account and balance all the main factors, including affordability, impact on other services, access, and patient choice, and not treat the standards as though they exist in isolation."**

I would like to comment on each of your four "main factors" in order to demonstrate the proposal to cease commissioning congenital cardiac surgery at Glenfield Hospital should be reconsidered:

1. **Affordability:**

   The replacement centres will have to divert resources on a significant scale to finance the replication of our capacity. This is particularly problematic given the unprecedented shortage of capital in the system.

   In addition, in our case you are proposing to cease Level 1 commissioning at UHL, and in effect patients from the south of our region will maintain existing out of area referral patterns to London. From an affordability perspective, it is not reasonable to do this when the London tariff means that each of these cases is costing you, the commissioner, 25% more.

   So the proposal is in conflict with your first main factor.

2. **Impact on other services**

   As you know, your proposals will have an extremely detrimental impact on other services. Leicester is the national home of ECMO. This is where it was first practised in this country, having been financed by our charity. It is still where 50% of the national paediatric and neonatal ECMO is performed and where practically all the national transportation of patients on ECMO is based – so that our staff are regularly used to perform transfers of patients from units such as Southampton or Bristol to centres in London or Newcastle.

   I appreciate that the National Review currently underway is assessing knock-on effects from your proposed decision. However, the decision not to commission congenital cardiac services from our centre will without doubt inflict profound damage on another service which supports the sickest children from all over the country.

   Your proposal therefore clashes directly with your second main factor.

3. **Access**

   A glance at the map shows that it is not reasonable to suppose that you can improve access by closing our centre. We serve a population of over 4 million who live nearer to here than to any other CHD centre and those patients needing CHD will have to travel much further. This is of vital importance for a number of reasons. Firstly, CHD is a lifelong disease: we need to support our patients on the 10,000 days when they do not need surgery, as well as the one day when they do. I know you are proposing that we should remain a Level 2 centre, but how that will work is under great debate, and in our view is not sustainable.

   It also matters massively to the parents of children who need surgery. It is of course trite to say that this is a time of enormous physical and psychological stress to the families as well as these patients, but it is essential that we support them and protect the family dynamic. The parents may well have other calls on their time, having jobs to maintain and other children to support and care for at the same time as they are trying to be with the patient in their days of maximal need. Those who are cared for at Leicester not only have the advantages of proximity, meaning shorter journeys home, they also benefit from our family accommodation that has been paid for by our charity and recently been refurbished. The availability of readily available on-site car parking gives them enormous advantages. Practical access means much more than just proximity.

   The proposal cannot be reconciled with your third main factor.

4. **Patient Choice**

   It is evident that you think that by protecting the current referral pathways offered to the sub 175 surgical cases per annum who do not receive their surgery at EMCHC, you are in some way protecting patient choice. The reality is that you are going to deprive the thousands of patients in our area who currently are treated at EMCHC and are delighted with the quality of their care, of the right to choose to be treated in the hospital of their choice, nearest their home. They feel passionately about this.

   It appears your proposal conflicts with your fourth main factor as well.

Point 3 – We asked NHS England to demonstrate how and by whom the decision not to permit derogation with respect to CHD specialist commissioning was agreed. We have not had a response to this question and would again please request one.

Also, in your latest letter, point 3, you state:

> *Standard 2.1 requires a team of at least 3 cardiac surgeons, each of whom must have been the primary operator in a minimum of 125 congenital heart operations per annum as at April 2016,* ***averaged over the previous 3 years*** *(and therefore averaged over that period a minimum of 375 cases per year for the team of surgeons as a whole is required).*

We note the inclusion of the wording 'averaged over the **previous** 3 years'. We strongly dispute the interpretation and implementation of the standard in this way; not least because it is both illogical and inequitable to enforce a standard retrospectively. Moreover, we believe this is the first occasion in which the word 'previous' has been included. Standard B9 (L1) and B10 (L1) both provide an "Implementation Timetable" of immediate for 3 surgeons and within 5 years for 4 surgeons

This was not at any stage of the discussion the intention either of the standards committee or indeed the wider sign off group. This standard is correctly interpreted as running prospectively from the time of implementation (April 2016) and the three years average should therefore be calculated forward from then. EMCHC is on track, as we have demonstrated in our self-assessment submission, to meet this standard as it was proposed.

When we look at the previous documentation, it is clear that NHS England has always approached this on the basis that the three years were to run prospectively from April 2016. As an example, the CRG debate has throughout been on the basis that some centres could or could not meet the standards: if the matter were to be retrospective as your letter now states, the answer would be obvious from the NICOR website when the 2015-16 data was published.

Point 5 - We note that you intend to include 'early outcomes from the national review of PICU, paediatric transport, paediatric surgery, and ECMO 'at the **decision making stage** at the **end of the consultation'.** This is inappropriate. Patients, families and other stakeholders can only tell how they will be affected by this process once they have seen detailed and clear information from the national review. This information needs to be made available for and comprehensively included in the public consultation process. In addition the public should be given time to absorb, comment on and question these outputs. In the meeting on the 16th September, you assured the stakeholders present that the public consultation would be aligned to include this information.

Point 6 – We have seen no clarification of your views as to what services would be provided in a Level 2 centre (paediatric or adult or both) in Leicester, how we would work with at least the 3 main surgical centres you referred to in your proposed 'impact assessment', or how that might align to the current level 2 and Network Standards.

There has not been any public retraction of NHSE's repeated assertions that the statement that 'the majority of specialist cardiology provision would still be provided in Leicester', despite our clarification to you that that this will not be the case.

To reiterate; for paediatric patients, NO inpatient work requiring paediatric cardiac anaesthesia will be possible; this precludes all catheter procedures (diagnostic, intervention and electrophysiology procedures, all non-cardiac surgery on cardiac patients and much imaging). Most of the inpatient work that could be undertaken would be little different from that undertaken in level 3 centres. It is possible that limited diagnostic and minor interventional procedures on adults could be undertaken, but nonetheless most specialist work would need to be re-provided elsewhere. All paediatric ECMO would move elsewhere. This activity totals almost 1000 admissions each year.

This needs to be included in the consultation documentation, along with the outputs of the impact assessments including these facts. This also needs to be informed by the resulting assumptions surrounding level 2 services, but I would challenge how these can be deemed to be accurate without the conclusions from the national review yet to be completed.

Point 7 - I note that you assert that workforce and training are very important to you. Our service nationally already has significant staffing challenges; only 1 surgical trainee applied this year for the 3 training posts, even though the general CTS training course was over-subscribed 500%. EMCHC currently provides around 15% of the UK's congenital cardiology training which would also be lost if the proposals go ahead; re-providing this training will be extremely challenging.

Point 9 – As you state in your blog – 'it is good to talk 'and we would welcome the opportunity to discuss our service with you. We talk with our colleagues from across the country on a regular basis. Indeed our team had the opportunity for in-depth discussions with over 400 senior members of the entire speciality at the Annual Scientific Conference of the BCCA, hosted by EMCHC, last week. We were gratified by the widespread support that we received from colleagues, who clearly felt there were still many unanswered questions in the review process.

Whilst we are more than happy to meet to discuss our service, we believe that it is inappropriate to discuss our role as a Level 2 centre, particularly as our recent submission clearly demonstrates that we are able to meet all of the standards within the designated period, and will therefore presumably not be decommissioned. We must make it clear to you that we regard your proposals as flawed and will continue to contest them vigorously. We have to make this clear to you, as we do to our staff, to protect the growth that our service is demonstrating today. We regularly recruit staff and it is only by assuring them of our determination to protect the service that we are able to maintain it. Ironically, we very recently had nine applicants for our consultant congenital cardiac surgical post, which was extremely encouraging and shows that our resolve and determination is at least recognised within our profession.

Point 10 – We welcome the fact you are working closely with the Midlands and East Regional Specialised Commissioning team. We are concerned however that as the agreed joint approach for assessing the knock on effects was replaced by the impact assessments, Catherine O'Connell may not have the information from our team that she needs. We would

prefer to reinstate the agreed discussions between EMCHC and our regional commissioners as we believe that process would be helpful.

Point 11 - A combined review of PICU/ECMO/Surgery/transport has been announced, the first meeting of which was on December 1st 2016. However, can you please clarify:

a. The programme timescale:
    i. ensures the review fully aligns with the proposed public consultation
    ii. includes the ability for the findings to be reviewed as part of the CHD public consultation,
    iii. Allows for its completion and full consultation before any final decisions are taken by NHS England.
b. Details of governance arrangements, including decision-making processes and publication of minutes, reports etc.
c. Arrangements for the involvement of all affected organisations (including UHL)

We note the membership of the review panel, and note that there is no ECMO coordinator. As the review will need to consider both fixed ECMO and mobile ECMO we are concerned that without the inclusion of such specialised expertise, a full understanding of the requirements for ECMO will be difficult.

We would like to offer the services of Ms Gail Faulkner to the review panel. Gail is the longest standing ECMO coordinator in the UK, from the centre that has delivered the second highest number of ECMO procedures in the world, the only centre in the UK that provides mobile ECMO, and is renowned for the training in ECMO across the UK and internationally. Please let us know if you would like Gail to join the group.

Point 17 – Whilst we acknowledge that the summary assessments of other centres are available for review, the detail behind these assessments is not in the public domain. Please explain how you justify commissioning proposals that see centres achieving the surgical activity standard only by closing other centres, and how you decided which centres fell into which commissioning category. Equally, we would be interested to learn how these centres justified how they would achieve the 2021 activity standard based on their existing network activity whilst not knowing that centres were to be closed.

Point 21 – We remain extremely disappointed at the implicit negative connotations and critical view behind this point in your response, despite your assurances to the contrary. In the modern context every patient should receive optimal treatment within the limits of the service. Whilst you as commissioners appear to seek to use the specialist skills of one centre as a weapon against another centre, our doctors are co-operating with each other across the country.

a) EP

We are concerned about the erroneous information regarding provision of paediatric Electrophysiology (EP) services in Leicester and would like to know from whom you have received this information? All paediatric EP is and always has been provided at Leicester. Indeed there have been a number of occasions when Leicester has also provided electrophysiology to cover service gaps at other centres. We currently have a jointly funded

and appointed consultant post with Birmingham Children's Hospital and all EP procedures for both children and adults on EMCHC patients are performed at Glenfield Hospital.

b) Referrals Elsewhere

The detail you have requested on cases referred elsewhere suggests that you believe our clinical and surgical expertise to be lacking. We strongly refute this assumption and refer you to the current surgical outcomes of our surgical team and the significant improvements in overall service with the current EMCHC team. You will have seen our VLAD scores and excellent record of surgical mortality.

As we stated in our previous response, your own standards A3(L1) , A4(L1) and clinical best practice expect , and indeed require, clinicians to seek peer advice and support, and every Level 1 centre across the UK will send patients to other centres when capacity dictates or when it is clinically appropriate to do so. Indeed this is something most valued by parent and patient groups alike. We would refer you again to the recent Bristol Review

Unfortunately, the five bullet points request data that cannot be interpreted without comparative data from all the other current level 1 centres.

We can provide data about the provenance of patients we have treated. I will ask our teams to do this for you and I suggest that whilst we do so, you ask the other centres to help you with a similar exercise. That way you will get a complete – or nearly complete - understanding of the complex patterns of referrals that work to the benefit of our patients as a result of the professionalism and co-operation of doctors and the wider teams across the service.

As stated in point 9, we will gladly consider a meeting as you suggest in your covering letter. If you could please clarify the agenda, NHS England attendees and objective of the meeting we will ensure the appropriate team is available.

Point 26 – please find attached the programme to illustrate the anticipated timings for the move of the EMCHC service from Glenfield Hospital to be co-located with all relevant services, in full compliance to the standards. I have to say that I find your continued doubts about our ability to achieve the co-location standard particularly puzzling. The co-location scheme is a modest one by our standards and we carry out similar schemes every year as part of our internal capital programme.

We hope that this continued dialogue is helpful to you. In essence, the only significant issue between us now relates to surgical numbers. From the very start of this review (and before that), we have proposed a perfectly workable solution to this which would achieve the sustainability which we all seek, maintain reasonable access for a large section of the English population and avoid what would be a destabilising period of unnecessary change. We would once again urge you to grasp the opportunity that this solution offers and not to proceed to formal consultation on the basis of your current proposals.

Yours sincerely

John Adler
Chief Executive

cc: Jonathan Fielden