APPENDIX 4

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Date 11 October 2013

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Sent by e-mail only

Dear Mr Holden,

Following the request for comments relating to the second meeting of the New Congenital Heart Disease Review: Task and Finish Group, held on 30 September 2013, you will have already received my personal response.

Now, after consulting more widely with other members of the Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – the JHOSC – I am writing in my capacity as Chair of that body and express the deep concern regarding the following matters:

(1) New Congenital Heart Disease Review: Task and Finish Group

Fundamentally, it is important to understand the remit of the Task and Finish Group and the underpinning legislation that has been used to determine and govern its operation.

Specifically, the draft Terms of Reference document makes specific reference to the Task and Finish Group being authorised by the NHS England Board to provide strategic direction on all matters relevant to the new Congenital Heart Disease review. Indeed, from the governance structure (detailed on page 7 of the document) it is clear that the Task and Finish Group is a sub-group of the full NHSE Board. However, the legislation under which the NHS England Board delegated authority to the Task and Finish Group is less clear, along with the supporting legislation that determines and governs the operation of the Task and Finish Group.

Furthermore, it seems curious that the Terms of Reference for the Task and Finish Group should be determined and formally agreed by the Group itself and not the NHS England Board. This point needs to be specifically addressed and explained.

Given the general lack of clarity around governance, I should be grateful if you could set out the legislative framework under which delegated authority has been passed from NHS England to the Task and Finish Group and its various advisory panels/

groups, alongside the associated legislation that should determine the governance arrangements for the said groups.

(2) Openness and transparency

There has been considerable trumpeting in the media about greater openness and transparency in the NHS, and there would be little disagreement about this being a positive step. Few would disagree that a greater level of openness and transparency needs to apply across all levels of the NHS, with NHS England being the standard bearer in this regard. However, I fear that NHS England is still some way off the levels of openness and transparency it so often requires of other NHS organisations. Notwithstanding the details with the recent IRP report, many would perhaps remain shocked by recent examples of NHS England's unreasonable delays and general reluctance to release information requested under the legislation related to the scrutiny of the NHS – including its attempts to determine what is and is not legitimate information for the JHOSC to request. This was a significant issue during the Safe and Sustainable review and unless there is a shift in attitudes and behaviour it will be virtually impossible to adequately hold NHS England to account – with the risk of the new review repeating the mistakes and duplicating some of the failures of the previous arrangements.

(3) Notification of the meeting

As Chair of the JHOSC, I first received notification on 1 October 2013 (17:24hrs) that the meeting of the Task and Finish Group had taken place the preceding day ((Monday) 30 September 2013). Furthermore, it would appear that the first public notification of the meeting was not provided until late afternoon on (Friday) 27 September 2013 – via a blog update.

There are clear benefits associated with using social media, however it is wholly unsatisfactory for this to be the sole mechanism for providing notice of NHS England business and falls well below the standards demanded by the Public Bodies (Admission to Meetings) Act, which I believe requires such meetings to be properly advertised well in advance.

As such, I believe all the decisions must be re-taken:

(a) Once it can be demonstrated that the Task and Finish Group is acting with proper and well-defined authority; and,

(b) After providing sufficient public notice of the meeting and the matters to be considered.

(4) Requests for comments

In providing notification that the meeting of the Task and Finish Group had taken place, NHS England then proceeded to invite comment on the information discussed – including the proposed governance model, terms of reference etc., but making specific reference to the proposed scope and interdependencies: Seeking comments by the end of (Monday) 7 October 2013.

Such timescales are completely unacceptable and fall well below the standards of general stakeholder engagement I would expect from any NHS organisation – let alone NHS England, which should be acting as a national exemplar for other NHS bodies.

It is also worth considering such standards in the context of the previous Safe and Sustainable review and the issues outlined in the IRP report around engagement and listening.

(5) Engagement with Health Overview and Scrutiny bodies

You will no doubt recall your recent attendance at the JHOSC meeting held on 13 September 2013. You will also recall the significant notice provided when inviting NHS England to attend and prepare its contribution to that meeting, plus the public notification and publication of the agenda and reports beforehand. There was also the provision for considering supplementary information that had become available since the public notification had been issued. Unfortunately, the standards displayed by NHS England do not compare favourably with the JHOSC arrangements and have not provided the JHOSC with sufficient notice to formally consider and respond to the information now provided.

While all members of the JHOSC remain grateful for your attendance and contribution to the discussion at the meeting on 13 September 2013, I would also make specific reference to the following two aspects from that meeting:

(a) You asked the JHOSC to give you (NHS England) a fair hearing – requesting that NHS England be judged and held to account for its actions and not the actions of its predecessors (namely those involved and responsible for the Safe and Sustainable Review). The JHOSC noted your request and agreed it was appropriate to look forward and judge NHS England on how the new review moved forward and was conducted.

As such, it seems appropriate that NHS England should be held to account for its recent failures in this regard and provide a response to the concerns raised.

(b) You will no doubt recall the discussion around 'scope' of the new review, with specific reference to standards of care and provision of services for neonates. At that point, you were reluctant to enter into detailed discussion on scope as it had not yet been determined. In light of the current request, this seems to have been a significant opportunity missed – i.e. to directly engage with a stakeholder group representing over 5 million people across Yorkshire and the Humber. You also failed to give any indication of the timescales for agreeing the scope, and made no reference to the (at that point) forthcoming meetings of the Task and Finish Group or the Clinical Advisory Panel meetings – at which scope would be considered and largely determined.

Given your role in the new review, it is hard to believe you were unaware of the proposals to consider and discuss the scope of the new review at these meetings, or indeed the thinking or discussions (at that time) of what would or would not form the scope of the new review. Again, it seems appropriate NHS England should be held to account for its failures in this regard and provide a response to the concerns raised.

In expressing the above concerns, it is worth emphasising that the JHOSC had hoped and expected much better of NHS England – particularly given the early stage of the new review and the statements made at the recent JHOSC meeting. In this regard, I

think it is worth specifically highlighting the following points raised at the JHOSC meeting and detailed in the draft minutes:

- Concerns over potential bias at such an early stage in the new review: It would be important to maintain an overview of such matters going forward.
- The importance of NHS England maintaining a close dialogue with all stakeholders.
- The need to avoid mistakes and learn the lessons from the previous review that produced a situation of 'winners and losers'.
- The new review needed to be undertaken in a robust manner in order to establish credibility and maintain the confidence of all stakeholders.
- Concerns regarding the proposed timescales of the new review.

As set out in the report to the NHS England Board meeting in July 2013, the new review of CHD is likely to set the benchmark and blueprint for reviewing other specialised services. As such, it is vitally important that NHS England works to the highest possible standards from the outset.

As such, I would like NHS England to provide sufficient assurance to the JHOSC of much better general standards of operation moving forward, including a response to each of the issues identified above.

Comments of the reports/ papers considered by the Task and Finish Group

Notwithstanding the misgivings outlined above, and despite not having the opportunity to have face-to-face discussions with other JHOSC members, please see the following points in relation to specific agenda items from the recent Task and Finish Group meeting.

Item 2 – Notes of meeting of Board CHD sub group – 29 July 2013

Recognising these notes formed part of the agenda papers presented to the JHOSC on 13 September 2013, I should be grateful if you could:

(a) Confirm/ explain the relationship between the new review and the 'Call to Action' along with the need to 'reconcile' the two.

(b) Explain in more detail the 'specialised commissioning approach' to be adopted and provide assurance that this is not an attempt to work around the requirements of the NHS to work and engage with local authority health scrutiny bodies around substantial variation and/or development of services.

Item 3- Action Log

No specific comments at this time.

Item 4 – Terms of reference

Notwithstanding the general points about governance arrangements detailed above, it is worth highlighting the following points:

(a) There is limited reference to the specific outcomes from the judicial review and the IRP recommendations (which were accepted in full by the Secretary of State for Health). As the body responsible for overseeing the new review, it would not seem

unreasonable for NHS England to reflect the specific points highlighted through the judicial review and IRP review processes the specific points/ considerations for the new review, to be repeated in the terms of reference document.

(b) Furthermore, looking at the governance structure (detailed on page 7 of the document) it is clear that the Task and Finish Group is a sub-group of the full NHSE Board. Again, it would not seem unreasonable to expect the Terms of reference to be determined and formally agreed by that Board and not the Group itself.

The draft document makes reference to Phase 3 of the review (preparation for implementation) – without any reference to Phases 1 and 2 and what these might consist of. This is particularly relevant as the document also details that the Group will meet (as a minimum) at the end of each phase of the programme (review). Please provide details of all anticipated phases of the review, including likely timescales and the anticipated outcomes from each phase of the review.

As mentioned previously, the notification of the Group's meeting and publication of its agenda and reports has fallen well below the standards expected of a publically funded body. In addition, while the terms of reference sets out that the agenda and papers '…will be published on the NHS England website in advance of the meeting', it provides no indication of timescales. For any local authority body meeting in public, a minimum of 5 clear working days' notice is required – meaning a meeting on 30 September 2013, would require the agenda to be published no later than 20 September 2013 – and not 27 September 2013 as has been the case in this instance.

The document also makes reference to a 'procedural rules document'; however a search of the NHS England website does not appear to reveal any such document. Please provide a copy of the document and detail its status/ official standing – including where and when it was agreed and where it is publically available.

<u>Item 5 – Scope and interdependencies</u>

It is difficult to comment on scope without discussion the potential implications of including or excluding specific elements/ areas. As such and as previously mentioned, if NHS England is serious in its desire to seek the views of all stakeholders, perhaps it would have been helpful to have engaged in a more detailed discussion in this regard at the JHOSC meeting on 13 September 2013.

That said, based on the limited information available I would make the following observations on behalf of the Joint HOSC:

(a) Both the outcome of the judicial review and the IRP review identified a number of matters that NHS England should consider as part of any subsequent review process. To date, NHS England has not provided a definitive response to such outcomes in general and specifically the recommendations submitted by the IRP. The draft Terms of Reference also makes little reference to such matters. As such, I should be grateful if NHS England could provide a full response to the IRP report and recommendations – setting out in detail how each recommendation will be taken forward as part of the new review.

(b) There are concerns that service areas such as neonatal, paediatric and adult intensive care unit services and local maternity services are currently deemed to be outside the

scope of the review. Such matters were intrinsic elements of the Safe and Sustainable Review and are referenced within the associated standards documents.

(c) The issue and consideration of co-location of services should be a fundamental element of the new review, as previously outlined in the JHOSC's reports. The matter of co-location is also highlighted in the IRP report. The JHOSC has not been provided with any evidence (or details of any expert judgement) to suggest its previously stated position should not remain the case and believes co-location should remain a significant consideration as part of the review. Again, co-location of services is referenced within the associated standards documents.

(d) It also seems illogical to exclude transport and retrieval services as part of a national service review that aims to deliver a national service to national standards. Transport and retrieval services will be vital elements of the service into the future – particularly if the outcome of the review results in fewer surgical centres. There will need to be clear and consistent standards for transfers and retrievals.

(e) In terms of the areas 'to be determined', there are clear links with a number of service areas – particularly those previously referred to as Nationally Commissioned Services under the Safe and Sustainable review. The view of the JHOSC at that time was that too much emphasis was placed on such services and the focus of the review should be on those areas which deliver and maintain clinical benefits to the largest number of patients. This may result in the need for some subsequent and/or difficult decisions around other service areas, however the JHOSC has not been provided with any evidence (or details of any expert judgement) to suggest its previously stated position should not remain the case.

(f) One of the main findings of the IRP's review was that too many unanswered questions remained as part of the implementation phase. It is vital that the new review does not repeat that mistake.

As previously stated, the JHOSC has not had the benefit of being able to fully consider any changing circumstances and/or the implications of including or excluding specific areas from the scope of the new review. It should be recognised this is the case and, as such, the comments above should not prejudice any future consideration of such matters.

<u>Item 6 – Proposed governance and decision-making arrangements</u>

In general, due to concerns regarding how the previous Safe and Sustainable Review established and used various advisory bodies, it is essential to be explicit about the precise scope, terms of reference and membership of the groups detailed in the document. The need for openness is referenced in the 'Supplementary Publication Scheme' document, but not all terms of reference documents and membership details are available. I am specifically referring to the following groups:

- Patient and Public Group
- Provider Group
- Clinician Group
- (Some) Clinical Reference Groups – currently information about individual CRGs is (at best) inconstant and not up-to-date.

I believe to be truly open and transparent, it is also essential that details of meeting dates, agendas, reports and minutes of meetings for all the groups listed (and indeed any additional groups subsequently established) are made available throughout the review. In this regard, I

should be grateful if you could immediately provide any details currently available and make further/future information regularly and routinely available through the dedicated web-pages for the new review.

Please note, in terms of the earlier comments regarding the timing of information relating to the Task and Finish Group meetings being made available – these also apply to the various groups detailed in the documents.

Having reviewed the various draft documents, we also have reservations regarding the Clinical Advisory Panel insofar as the frequency of meetings is concerned – specifically regarding the use of email to seek advice. Please provide assurance of the processes that will govern such practice and provide the necessary levels of openness and transparency to ensure such advice is properly debated, recorded and made publically available (in its entirety).

You will be aware of the concerns raised by Children's Heart Surgery Fund (CHSF) and echoed by the JHOSC regarding the membership (and associated appointments process) of the Congenital Heart Services Clinical Reference Group (CRG). At the time of writing, I understand that responses to those concerns and/or assurances from NHS England have not yet been provided. I would urge NHS England to address this matter urgently and provide the JHOSC with details of its response to the concerns raised.

Furthermore, given the statutory nature of the local authority health scrutiny function, it is disappointing not to see any specific reference to NHS England's responsibilities in this regard detailed in the documents provided. NHS England should give specific consideration to its responsibilities associated with local authority health scrutiny.

Item 7 – Proposed stakeholder participation and engagement arrangements

The comments in terms of local and national government are noted. However, I would again remind you of local government's statutory health scrutiny function – most often delegated to overview and scrutiny committees. NHS England should also be reminded of the clear consensus, at the meeting on 13 September 2013, for the JHOSC to maintain an overview of the new review and respond at appropriate times to any consultations. Revised terms of reference are currently being drafted to reflect this position.

Item 8 – Developing the proposition

The paper sets out some useful information and the JHOSC would welcome the opportunity to discuss this in more detail: It would be useful to do this within the context of understanding the discussion from the meeting and therefore the minutes will be extremely useful.

In addition, I believe it is also worthwhile highlighting some of the points discussed at the recent JHOSC meeting – particularly in relation to the use and development of outcome data, likely to be key considerations in a national review seeking, in part, to address variations across the country.

As discussed at the JHOSC meeting, external factors that might reasonably be expected to affect surgical outcomes include:

- Ethnicity
- Social class

- Travelling distances
- Size of cardiac surgical unit
- Historic NHS spending patterns
- Co-located and interdependent services

This is not intended to be an exhaustive list, nor is it intended to replace those clinical factors (such as the patient's age and weight) which have already been identified as key variables. However, having established the PRAiS system for partial risk adjustment in cardiac surgery, it is essential for NHS England should attempt to identify the most important and influential factors that determine outcomes. Failing to take account of specific variables without analysis of the available data and/or a well-reasoned judgements for not doing so will not positively affect the credibility of the new review.

Item 9 – Highlight Report

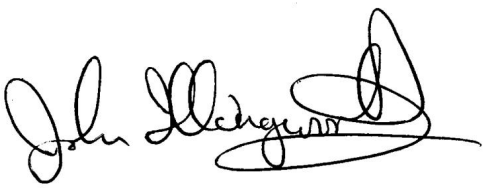
This provides a useful summary of progress but it would be helpful to have fuller details of the future meeting dates of all the various groups detailed in the governance papers.

In summary

At the JHOSC meeting on 13 September 2013, it was stated that the ambitious timescales for undertaking the review did not provide an excuse for a top-down review process. Unfortunately, the nature of this current engagement very much feels like just that. As such, given there has been no opportunity for a collective discussion with other JHOSC members I would again wish to record the dissatisfaction regarding the timescales and the totally unsatisfactory nature that comments have been requested. On behalf of the JHOSC I reserve the right to provide any additional comments following any future consideration and discussion of these matters by the JHOSC.

I look forward to a detailed response on the specific issues raised in the near future.

Yours sincerely



Councillor John Illingworth
Chair, Joint Health Overview and Scrutiny Committee, Yorkshire and the Humber

cc: All Members of the JHOSC (Yorkshire and the Humber)
All Members of Parliament (Yorkshire and the Humber)
All Yorkshire and Humber Local Authority Leaders
Cllr Lisa Mulherin, Executive Member for Health and Wellbeing, Leeds City Council
Tom Riordan, Chief Executive – Leeds City Council
Andy Buck, Director – NHS England (West Yorkshire Area Team)
Tim Gilling, Deputy Executive Director – Centre for Public Scrutiny

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