APPENDIX B

Independent Reconfiguration Panel Summary and Recommendations (12 June 2013)

On 12 June 2013, the report of the Independent Reconfiguration Panel on the *Safe and Sustainable* Proposals for Children's Congenital Heart Services was published. The summary and recommendations from the IRP's report are set out below. The Health Scrutiny Committee for Lincolnshire as part of its referral to the Secretary of State referred to the issue of travel and accessibility, which is covered in recommendation 10. For the Committee's reference, the IRP's advice leading to recommendation 10 is also included in this Appendix.

IRP Summary and Recommendations

The Secretary of State for Health asked the IRP to advise whether it is of the opinion that the proposals for change under the *"Safe and Sustainable* Review of Children's Heart Services*"* will enable the provision of safe, sustainable and accessible services and if not why not. Overall, the Panel is of the opinion that the proposals for change, as presented, fall short of achieving this aim.

The Panel's view is that people - children and adults - with congenital heart disease in England and Wales will benefit from services commissioned to national standards for the whole pathway of their care.

The Panel agree that congenital cardiac surgery and interventional cardiology should only be provided by specialist teams large enough to sustain a comprehensive range of interventions, round the clock care, training and research.

However, the Panel has concluded the JCPCT's [Joint Committee of Primary Care Trust's] decision to implement option B (DMBC [Decision Making Business Case] – Recommendation 17) was based on flawed analysis of incomplete proposals and their health impact, leaving too many questions about sustainability unanswered and to be dealt with as implementation risks.

Throughout our review, people told us that being listened to was something they valued. The opportunity to change and improve services is widely recognised and, in taking forward our recommendations, those responsible must continue to listen to legitimate criticisms and respond openly.

We set out below recommendations to enable sustainable improvements for these services and learning for future national commissioning of health services.

- The proposals for children's services are undermined by the lack of co-ordination with the review of adult services. The opportunity must be taken to address the criticism of separate reviews by bringing them together to ensure the best possible services for patients. *[Recommendation 1]*

- Patients should receive congenital heart surgery and interventional cardiology from teams with at least four full-time consultant congenital heart surgeons and

appropriate numbers of other specialist staff to sustain a comprehensive range of interventions, round the clock care, training and research.

[Recommendation 2]

- Before further considering options for change, the detailed work on the clinical model and associated service standards for the whole pathway of care must be completed to demonstrate the benefits for patients and how services will be delivered across each network. *[Recommendation 3]*

- For the current service and any proposed options for change, the function, form, activities and location of specialist surgical centres, children's cardiology centres, district children's cardiology services, outreach clinics and retrieval services must be modelled and affordability retested. *[Recommendation 4]*

- NHS England should ensure that a clear programme of action is implemented to improve antenatal detection rates to the highest possible standard across England. *[Recommendation 5]*

- Further capacity analysis, including for paediatric intensive care units, should consider recent and predicted increases in activity, and patient flows.

[Recommendation 6]

- NHS England must establish a systematic, transparent, authoritative and continuous stream of data and information about the performance of congenital heart services. These data and information should be available to the public and include performance on service standards, mortality and morbidity.

[Recommendation 7]

- NHS England and the relevant professional associations should put in place the means to continuously review the pattern of activity and optimize outcomes for the more rare, innovative and complex procedures. *[Recommendation 8]*

- NHS England should reflect on the criticisms of the Joint Committee of Primary Care Trust's assessment of quality and learn the lessons to avoid similar situations in its future commissioning of specialist services. *[Recommendation 9]*

- More detailed and accurate models of how patients will use services under options for change are required to inform a robust assessment of accessibility and the health impact of options so that potential mitigation can be properly considered. *[Recommendation 10]*

- Decisions about the future of cardiothoracic transplant and respiratory ECMO [Extra-Corporeal Membrane Oxygenation] should be contingent on the final proposals for congenital heart services.

[Recommendation 11]

- NHS England should assure itself that any wider implications for other services of final proposals are fully assessed and considered within a strategic framework for the provision of specialised services.

[Recommendation 12]

- NHS England should develop a strategic framework for commissioning that reflects both the complex interdependencies between specialised services provision and population needs.

[Recommendation 13]

- NHS England must ensure that any process leading to the final decision on these services properly involves all stakeholders throughout in the necessary work, reflecting their priorities and feedback in designing a comprehensive model of care to be implemented and the consequent service changes required.

[Recommendation 14]

- NHS England should use the lessons from this review and create with its partners a more resource and time effective process for achieving genuine involvement and engagement in its commissioning of specialist services.

[Recommendation 15]

The Panel's advice has been produced in the context of changing and peculiar circumstances. Since 1 April 2013, responsibility for commissioning congenital heart services rests with NHS England, which has inherited the original proposals, a judicial review, responsibility for the quality of current services and the potential consequences of the IRP's advice, subject to the Secretary of State's decision.

The Panel's advice sets out what needs to be done to bring about the desired improvements in services in a way that addresses gaps and weaknesses in the original proposals. The Panel's recommendations stand on their own irrespective of any future decision by NHS England regarding the judicial review proceedings. We note that the court's judgment of 27 March 2013 appears congruent to our own advice and that a successful appeal on legal grounds will not, of itself, address the recommendations in this report.

The Panel's advice addresses the weaknesses in the original proposals but it is not a mandate for either the status quo or going back over all the ground in the last five years. There is a case for change that commands wide understanding and support, and there are opportunities to create better services for patients. The challenge for NHS England is to determine how to move forward as quickly and effectively as possible.

Work to address gaps in the clinical model and associated service standards (Recommendation Three above) is underway and should be brought to a rapid conclusion. In parallel, there are different potential approaches to effect positive change that might be considered. These include whether to bring forward proposals for reconfiguration again or adopt a more standards-driven process that engages providers more directly in the managed evolution of services to be delivered. The critical factor to consider, in the Panel's view, is that engagement of all interested parties is the key to achieving improvements for patients and families without unnecessary delay.

IRP's Report - Extracts Leading to Recommendation 10 on Accessibility

One of the main concerns raised by the health Scrutiny Committee for Lincolnshire was the impact of the Safe and Sustainable Proposals on patients and their families. The IRP's report included the following findings which led to Recommendation 10.

"5.7 **Impact on patients and their families**

"5.7.1 The potential impact of reducing the number of centres was recognized from the outset. The consultation sought views on the issue, based on the proposition that the vast majority of patients needing intervention only go to a surgical centre once and the networks of district services and children's cardiology centres will provide care closer to home. The subsequent analysis of accessibility and health impact assessment proceeded on the basis of these assumptions with no further scrutiny or analysis.

"5.7.2 The Panel found that the assessment that 88 per cent of patients will travel to the surgical centre once was flawed. It was based on incomplete data regarding the number of stays in hospital per child over the period 2000-2010. Almost half of the procedures were missed from the analysis. In addition, the analysis did not assess the experience of the cohort of children who had their first intervention in 2000 by tracking the pattern of treatment over a ten-year period. As a result, the figure understated the number of interventions children have. Finally, no adjustment was made, or caveat stated to account for the fact that a ten-year data set cannot legitimately be used to represent the 16-year childhood experience of patients with CHD. The statement also gave no consideration to the need for patients and families to visit the surgical centre in advance to familiarise themselves with the centre and meet the team.

"5.7.3 The Panel found that the Health Impact Assessment (HIA) used only data on the number of patients undergoing surgery and did not consider the impact on children undergoing interventional cardiology, who similarly would have to travel to the surgical centre under the proposals. This was despite equally robust, validated and detailed data being available for interventional cardiology as there is for cardiac surgery. Around 35 per cent of the patients receiving services at the surgical centre will be attending for interventional cardiology. The assessment, therefore, not only lacks important detail but is also based on flawed analysis of key data. Consequently, the downside impacts are systematically understated and the suggested mitigating impacts have no evidence to underpin them.

"5.7.4 The Panel found that the assessment and scoring of the options on the access criterion was flawed for the same reason and systematically understated the impact and numbers of patients and families affected. The DMBC [Decision Making Business Case] states categorically that it identifies the numbers of patients and families affected and yet the findings are based on an analysis that does not account for a significant proportion of patients.

"5.7.5 The Panel heard from parents and others the same concerns that had been expressed in response to the consultation – that whilst securing the best possible care is paramount, the impact of accessibility in terms of time, costs, and stress is their greatest concern about the proposals. The Panel found a significant mismatch between parents' experiences and concerns and the JCPCT's presentation of accessibility. The JCPCT told the Panel that the primary objective was to reduce the number of surgical centres

and access was the least important factor. The statement that 88 per cent will travel only once was a frequently quoted justification for weighting access as the least important criterion in the options scoring process.

"5.7.6 The absence of detail in the proposals about what services would be provided where outside the seven designated surgical centres exacerbated the concerns of parents. The fact is that the accessibility of the service, and consequently the impact, for large sections of the population of England under the proposals is unknown and the pledge that the proposals will result in care closer to home is unproven. This issue is of particular relevance to the populations most affected in Yorkshire and the Humber and in the east Midlands.

"5.7.7 In the case of the former, this was one element of a previous referral by the Y&H Joint HOSC. The IRP's advice of 13 January 2012 on this issue was that a suitably comprehensive health impact assessment was required to address the concerns raised. The JCPCT appears not to have noted this advice.

"5.7.8 The Panel found that the proposals would have a disproportionate impact on people in Yorkshire and the Humber in terms of increase in travel times and potentially negative impacts on health inequalities due to the areas most affected having high concentrations of vulnerable groups. The Panel also had concerns about the impact on the population in some areas of the Lincolnshire coast for similar reasons.

"5.7.9 The Panel was concerned that the network areas as proposed require some children and their families to travel to the CCC and/or surgical centre that is not the nearest, and in some cases not the second nearest to where they live. In effect the proposed network catchment areas place an excess social cost and burden on some children and families in order to achieve patient flows that generate 400 or more surgical procedures per centre per year. The statement that parents will 'travel to the moon' to access the best care for their children was stated frequently by those supporting the proposals, that is, people are willing to travel further to access a better quality service. However, the Panel found that for some patients and families the proposition is rather different, and they are being asked to travel further in future to a service that offers equal quality to one closer to them. The appropriateness and sustainability of designing a service on this assumption is clearly debatable and the legitimate concerns raised as a result were not addressed in a meaningful way.

"5.7.10 A number of the surgical centres had themselves raised concerns about the sustainability of their proposed networks and the Panel agrees with them. Taking account of population density, geography and transport links there are clear challenges to sustainability for some of the proposed networks.

"5.7.11 The Panel found that the standard of a minimum of 400 paediatric procedures per centre was based on professional opinion of the Steering Group, referencing the research evidence, and was devised before the implications for network boundaries and accessibility had been assessed. And yet the Panel found a complete unwillingness to debate the inevitable trade-offs that are inherent in the proposals between the potential benefits for outcomes of a threshold of 400 paediatric operations and the accessibility of the service to the population it serves.

"5.7.12 The Panel concludes that the JCPCT's decision used a flawed and incomplete analysis of accessibility based on an inadequate health impact assessment. Consequently, the real impacts of the proposals and their potential mitigations were missed."