

Terms of Reference

New Congenital Heart Disease Review

***Joint Health Overview and Scrutiny Committee
(Yorkshire and the Humber)***

December 2013

**THE JOINT HEALTH OVERVIEW AND SCRUTINY COMMITTEE
(YORKSHIRE AND THE HUMBER)**

**INQUIRY INTO THE NEW REVIEW OF CONGENITAL HEART
DISEASE (CHD) SERVICES IN ENGLAND**

TERMS OF REFERENCE

1.0 Introduction

1.1 In March 2011, a Joint Health Overview and Scrutiny Committee (Yorkshire and the Humber) – the JHOSC, was established to consider the emerging proposals from the Safe and Sustainable Review of Children’s Congenital Cardiac Services in England and the options for public consultation agreed by the Joint Committee of Primary Care Trusts (JCPCT).

1.2 The membership for the JHOSC shall made in accordance with the Joint Health Scrutiny Protocol (Yorkshire and the Humber) and drawn from the following constituent local authorities:

- Barnsley MBC
- Calderdale Council
- City of Bradford MDC
- City of York Council
- Doncaster MBC
- East Riding of Yorkshire Council
- Hull City Council
- Kirklees Council
- Leeds City Council (Chair)
- North East Lincolnshire Council
- North Lincolnshire Council
- North Yorkshire County Council
- Rotherham MBC
- Sheffield City Council
- Wakefield Council

1.3 The JHOSC submitted a formal response to the options presented for public consultation in October 2011.

1.4 Following the JCPCT’s decision on the proposed future model of care and designation of surgical centres on 4 July 2012, the JHOSC referred the JCPCT’s decision to the Secretary of State for Health in November 2012. This was subsequently passed to the Independent Reconfiguration Panel (IRP) for consideration and advice.

1.5 The IRP’s findings and recommendations were set out in its report to the Secretary of State for Health at the end of April 2013. A summary of the IRP’s recommendations is attached at Appendix 1.

1.6 On 12 June 2013, an announcement from the Secretary of State for Health accepted the IRP’s report and recommendations in full and called a halt to the Safe and Sustainable Review of Children’s Congenital Cardiac Services in England and asked NHS England – as the new body responsible for commissioning specialised services following the restructuring arrangements across the NHS that came into force from 1 April 2013, to report how it proposed to proceed by the end of July 2013.

- 1.7 NHS England's response to the Secretary of State for Health, which included a report presented to the NHS England Board on 18 July 2013, is attached at Appendix 2.

2.0 Scope of the inquiry

- 2.1 The overall purpose of this inquiry is to consider the arrangements and outcomes associated with the new review of congenital heart disease (CHD) services in England.
- 2.2 As such, specifically in relation (but not limited) to the population of the constituent authorities' areas, the JHOSC may:

Part 1

- Consider the findings and recommendations of the Independent Reconfiguration Panel (IRP) associated with its assessment of the previous Safe and Sustainable review of Children's Congenital Heart Services in England, and make an assessment of the extent to which they have been acted upon as part of the new CHD review;
- Consider and make an assessment of the new CHD review processes and any associated formulation of proposed options for reconfiguration and future service models, presented for public consultation;
- Consider the views and involvement of local service users, patient groups and/or charity organisation as part of the new CHD review;

Part 2

- Examine the projected service improvements arising from the new CHD review and any proposed reconfiguration and future service model including, but not limited to, the basis of projected improvements to patient outcomes and experience;
- Consider the likely impact arising from the new CHD review on patients and their families accessing services in the short, medium and longer- term, particularly in terms of access to services and travel times;
- Consider the health and equality impacts arising from the new CHD review and any associated reconfiguration and future service model proposals and, in particular, the comparison with existing provision and service configuration;
- Consider other potential implications of any reconfiguration options arising from the new CHD review and presented for consultation, including the impact on the local and regional health and general economy.

Part 3

- Formally respond to the findings of the new CHD review and any reconfiguration options or proposed future service models arising from the new CHD review and presented for public consultation.

Part 4

- Consider and maintain an overview of any plans for implementation associated with the agreed future service model and reconfiguration of services arising from the new CHD review.

2.3 In addition, the JHOSC may generally:

- Consider any other pertinent matters that may arise as part of the Committee's inquiry (as agreed by the JHOSC).
- Make any recommendations deemed appropriate in relation to any or all of the above matters.
- Review and scrutinise the effects of the new CHD review on the planning, provision and operation of the health service in the constituent authorities' areas pursuant to Regulation 21 of the Local Authority (Public Health, Health and Wellbeing Boards and Health Scrutiny) Regulations 2013, and make reports and recommendations on such matters pursuant to Regulation 22.
- Act as consultee and discharge the constituent authorities' functions under Regulation 26 in relation to the new CHD review.
- Discharge the constituent authorities' functions under Regulation 26 and Regulation 27.

2.4 As the administering authority, arrangements for the JHOSC shall be in accordance with Leeds City Council's Scrutiny Procedural Rules.

3.0 Desired Outcomes and Measures of Success

3.1 The decision to undertake this inquiry has been based on the JHOSC's previous consideration and reports relating to the Safe and Sustainable Review of Children's Congenital Cardiac Services in England.

3.2 In conducting this inquiry and responding to any future proposals presented for public consultation, the JHOSC wishes to secure high quality, accessible services for patients suffering congenital heart disease (CHD) and their families across Yorkshire and the Humber in the immediate and longer-term.

3.3 It is also important to consider how the JHOSC will deem if its inquiry has been successful in making a difference to local people across Yorkshire and the Humber.

3.4 Some measures of success may be obvious at the initial stages of an inquiry and can be included in these terms of reference. Other

measures of success may become apparent as the inquiry progresses and discussions take place.

3.5 Some initial measures of success are:

- Ensuring the recommendations identified by the Independent Reconfiguration Panel (IRP) have been appropriately acted upon as part of the new CHD review.
- Ensuring the new CHD review processes are rigorous and fit for purpose.
- Ensuring the involvement, engagement and consultation arrangements associated with the new CHD review are appropriate and fit for purpose.
- Ensuring any proposed future service model will deliver improved or enhanced services for patients and families across Yorkshire and the Humber.
- Ensuring any projected service improvements arising from the new CHD review are realistic and have a high prospect for success.

4.0 Comments of the relevant Director and Executive Member

4.1 In line with Leeds City Council's Scrutiny Board Procedure Rule 12.1, the relevant Director(s) and Executive Member(s) shall be consulted on these terms of reference.

5.0 Timetable for the inquiry

5.1 NHS England is currently working toward securing 'an implementable solution' by the end on June 2014. As such, the timetable of this inquiry will broadly reflect NHS England's review timetable.

5.2 The length of the inquiry may be subject to change.

6.0 Submission of evidence

6.1 NHS England is currently working toward securing 'an implementable solution' by the end on June 2014. The timetable of this inquiry and the submission of evidence will broadly reflect NHS England's review timetable.

6.2 The JHOSC will determine the evidence it 'reasonably requires' to discharge its statutory functions and advise those bodies responsible accordingly.

7.0 Witnesses

7.1 The JHOSC will determine those witnesses it may 'reasonably require' and/or may wish to invite to attend its meetings, in order that it may discharge its statutory functions.

7.2 The JHOSC will advise any identified witnesses accordingly.

8.0 Equality and Diversity / Cohesion and Integration

- 8.1 The Equality Improvement Priorities 2011 to 2015 have been developed to ensure Leeds City Council's legal duties are met under the Equality Act 2010. The priorities will help ensure work takes place to reduce disadvantage, discrimination and inequalities of opportunity.
- 8.2 Equality and diversity will be a consideration throughout the inquiry and due regard will be given to equality through the use of evidence, written and verbal, outcomes from consultation and engagement activities.
- 8.3 The JHOSC may engage and involve interested groups and individuals to inform any recommendations.
- 8.4 Where an impact has been identified this will be reflected in any inquiry report and associated recommendations and the body responsible for implementation or delivery should give due regard to equality and diversity, conducting impact assessments where it is deemed appropriate.
- 9.0 Post inquiry report monitoring arrangements**
- 9.1 Following the completion of this inquiry and the publication of any inquiry report and recommendations, the initial response and subsequent progress against such recommendations will be monitored.
- 9.2 Any inquiry report will include information on the arrangements for monitoring the implementation of any recommendations.

IRP

Independent Reconfiguration Panel

***ADVICE ON
SAFE AND SUSTAINABLE PROPOSALS
FOR CHILDREN'S CONGENITAL HEART SERVICES***

Submitted to the Secretary of State for Health
30 April 2013



Independent Reconfiguration Panel

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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 decision to implement option B (DMBC – 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.

SUMMARY AND RECOMMENDATIONS

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.
- 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.

SUMMARY AND RECOMMENDATIONS

- **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**
- **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.**
- **NHS England should ensure that a clear programme of action is implemented to improve antenatal detection rates to the highest possible standard across England.**
- **Further capacity analysis, including for paediatric intensive care units, should consider recent and predicted increases in activity, and patient flows.**

SUMMARY AND RECOMMENDATIONS

- **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.**
- **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.**
- **NHS England should reflect on the criticisms of the JCPCT's assessment of quality and learn the lessons to avoid similar situations in its future commissioning of specialist services.**
- **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.**
- **Decisions about the future of cardiothoracic transplant and respiratory ECMO should be contingent on the final proposals for congenital heart services.**

SUMMARY AND RECOMMENDATIONS

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

SUMMARY AND RECOMMENDATIONS

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.

SUMMARY AND RECOMMENDATIONS

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.

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31 July 2013

Dear Secretary of State

New review of congenital heart disease (CHD) services

In your letter of 12 June about the “Safe and Sustainable” review, you asked NHS England to report back to you by the end of July setting out how we intend to take the process forwards.

I am pleased to enclose the paper which our Board considered at its meeting in public on 18 July, which sets out our thinking on the nature of the problem and the principles which must underpin our approach. In line with our commitment to transparency, a video recording of the Board’s discussion is also available, at <http://www.england.nhs.uk/2013/07/22/boardvids-180713/>. Annex 1 of the Board paper describes an outline timetable for the work.

We have set ourselves the hugely ambitious challenge of an implementable solution within a year. This does not mean we think the job is easy; on the contrary, it is exceedingly difficult. We have a duty to patients now and to future generations to ensure the best possible quality of care within the available resource. That means best outcomes, a positive patient experience, and consistently high levels of safety.

We do not see this as a competition between providers to find “winners” and “losers”. Instead, we want a single national service which sets high standards for the delivery of care, which are uniformly available to all NHS patients in England, wherever they live. Beyond this aspiration for a national service underpinned by national standards, we do not profess to know yet precisely what the answer is. We are very clear that the Independent Reconfiguration Panel’s (IRP) report requires us, amongst other things, to look at children’s and adults’ services together, to look afresh at the demographic and other relevant data, to describe the entire pathway, and to properly involve all stakeholders throughout the work. So, we need a new process. Although the *Safe and Sustainable* conclusions cannot be implemented, there has nonetheless been some very good work during the past five years, with extensive involvement from clinicians and patient groups, to develop

standards and proposals for networks. As IRP suggests, this work needs to be completed. Once validated it will give us a platform for future work, but it does not in any way require us to reach the same conclusions as the previous process.

As we continue our initial discussions over the next few weeks, and begin to develop a proposition for debate in the autumn, there is bound to be speculation about the “answer” we have in mind. But having promised that we will listen before we act, I can assure you that we have no such prejudice. I welcome your support in reiterating this message.

We are still in an extended period of listening and we regularly publish the notes from our meetings to open the debate as widely as possible. I have established a committee of the Board to give this topic the focus it deserves, and Professor Sir Mike Rawlins will chair a clinical advisory panel to support our medical director Professor Sir Bruce Keogh in obtaining excellent clinical engagement and advice.

We are absolutely committed to achieve the service change required for these very vulnerable patients. We will exploit the full potential of NHS England as the sole national commissioner, and do so in a way that properly engages all interested parties, but at sufficient pace to mitigate the risks of further delay.
Yours sincerely



Professor Sir Malcolm Grant
Chair

BOARD PAPER - NHS ENGLAND

<p>Title: New review of congenital heart services</p>
<p>Clearance: Bill McCarthy, National Director: Policy</p>
<p>Purpose of paper:</p> <ul style="list-style-type: none"> • To describe the challenge facing NHS England in improving congenital heart disease services • To outline early thinking on the way forward
<p>Key issues and recommendations:</p> <p>On 12 June 2013 the Secretary of State announced in Parliament that the safe and sustainable proposals for children’s congenital heart services could not go ahead in their current form. He went on to say that “it is right we continue with this process, albeit in a different way”.</p> <p>NHS England is the body responsible for commissioning specialised congenital heart services and for taking forward the process.</p> <p>A new review is being established to consider the whole lifetime pathway of care for people with congenital heart disease (CHD), to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources.</p>
<p>Actions required by Board Members:</p> <ul style="list-style-type: none"> • To note the proposals for conducting a review of congenital heart disease services

New review of congenital heart services

Summary

Following the outcome of judicial review, the report by the Independent Reconfiguration Panel (IRP) and the Secretary of State's announcements relating to the safe and sustainable review of children's congenital heart services, NHS England is now the responsible body for taking forward the process. A new review is now being established to consider the whole lifetime pathway of care for people with congenital heart disease (CHD).

The ambition of this review is to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources:

- the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
- tackling variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care
- great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home

We recognise that continued uncertainty is a risk to the service and unsettling for patients. We must therefore set ourselves the target of delivering the new review at pace. But we know that speed cannot be an excuse for imposing a top down solution or for running a process where people feel excluded from the real discussions, so we will be setting ourselves the additional challenge of achieving new levels of transparency and the highest levels of genuine participation. We know that this will need a new approach. We want to make sure that as well as mobilising NHS England's resources from right across the organisation, that we also work closely with partners and stakeholders to design the way forward.

By the end of September we will have established the new programme, co-designed a process for the work going forward and undertaken initial work on how to secure high quality resilient services.

By June 2014 working closely with stakeholders, we will have developed, tested and revised a proposition, undertaken work to identify a preferred approach to implementation, and completed the necessary preparatory work.

Background

1. Around eight out of every 1,000 babies have some form of congenital heart disease (CHD) – around 5,800 babies in 2011. The number of children born with CHD is expected to rise, as the birth rate rises. As technology and expertise continue to develop, it is possible to do more than ever before to improve their lives, so that more children with CHD are surviving to adulthood.
2. NHS cardiac surgery for children is currently provided by 10 hospitals in England. Specialist paediatric cardiology is also provided by a further three centres. Around 3,700 paediatric surgical procedures and 2,000 paediatric interventional cardiology procedures are carried out each year.

3. A recommendation for the concentration of medical and nursing expertise in a smaller number of centres of excellence was made as far back as 2001, in the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary. Since that time, there have been major improvements in outcomes, so that analysis of risk adjusted mortality for 2009-12, published this year by the National Institute for Cardiovascular Outcomes Research (NICOR), shows that no surgical unit has a mortality rate significantly above the "expected" rate, and on this evidence (for example, mortality rates alone) services are currently "safe".
4. For adults, around 850 surgical procedures and 1,600 interventional cardiology procedures are carried out each year and reported to NICOR by 25 hospitals in England, however a further 10 hospitals have undertaken procedures in recent years but not provided data to NICOR.

The safe and sustainable review

5. The safe and sustainable review was established in 2008, with a view to reconfiguring surgical services for children with CHD. Taking into consideration concerns that surgeons and resources may be spread too thinly across the centres, the review considered whether expertise would be better concentrated in fewer sites.
6. At the end of the four year programme, in July 2012, a joint committee of Primary Care Trusts (JCPCT) made a series of decisions on the future of children's congenital heart services in England, covering:
 - the development of congenital heart networks,
 - service standards,
 - improving the collection, reporting and analysis of outcome data, and
 - the configuration of surgical services, which would have reduced the number of centres providing children's heart surgery from ten to seven, with surgery ceasing at Leeds, Leicester and the Royal Brompton.
7. The decision regarding configuration resulted in two separate challenges: a judicial review (JR), and referrals to the Secretary of State, who in turn asked the Independent Reconfiguration Panel (IRP) to consider the JCPCT findings.
8. The JR was decided on 7 March 2013, when the High Court declared that both the consultation process and the decision making process of the JCPCT were unlawful and quashed the decision to reconfigure surgical services. The judgement was based on a narrow point of process and the Court recognised "the compelling and urgent clinical case for the reform of existing paediatric congenital cardiac services" stating that the judgment should not be "construed as advocating a need to return to the start of the consultation process". Following legal advice, NHS England initially sought leave to appeal this decision but - in the light of the IRP's report and the Secretary of State's response (see below) - has since withdrawn this request.
9. The IRP were of the view that children and adults with CHD in England and Wales would benefit from services commissioned to national standards for the whole pathway of their care. They agreed 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 IRP concluded that the JCPCT's decisions were 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".

Addressing the IRP findings

10. On 12 June 2013 the Secretary of State announced in Parliament that he accepted the IRP's advice, and that "the [Safe and Sustainable] proposals cannot go ahead in their current form". He went on to say that "it is right we continue with this process, albeit in a different way" and that "NHS England now must move forward on the basis of these clear recommendations".
11. The IRP's report highlighted the need to align the review of children's CHD services with ongoing work to consider the provision of adults' CHD services. Since the same surgeons operate on the same patients at different times in their lives, there are considerable dependencies between adults' and children's services, especially in the availability of surgical teams to provide 24/7 cover.
12. The IRP were also concerned that while the Safe and Sustainable process received 75,000 responses to its public consultation, some stakeholders were nonetheless left feeling that their views were not fully heard or understood, or that they were not given all the information they needed to contribute fully. This in turn created, for some, the perception of a pre-determined outcome.
13. The IRP's report called for NHS England to develop a strategic framework for commissioning that reflects the complex interdependencies between specialised services provision and population need as a context within which any decisions about congenital heart services should be taken.
14. Importantly, neither the Courts, nor SofS nor IRP have questioned the need for change to ensure the resilience, sustainability and excellence of these services.

The challenge for NHS England

15. The challenge for NHS England is how to ensure that services for people with congenital heart disease are provided in a way that achieves the highest possible quality, within the available resources, now and for future generations:
 - Securing the best outcomes for all patients, not just lowest mortality but reduced disability and an improved opportunity for survivors to lead better lives.
 - Tackling variation so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care
 - Delivering great patient experience, which includes how information is provided to patients and their families, considerations of access and support for families when they have to be away from home
16. To do this, we need to develop a process which is as transparent and inclusive as it can be, particularly in the use of evidence and data. Almost as important as the thoroughness of our work will be the need to be seen to be engaging as widely as possible, bringing patients, clinicians and their representatives together

in the joint pursuit of an effective and equitable solution, in the interests of all service users now and in the future. What we do for CHD services will in some ways be seen as a template for whether and how NHS England undertakes other major service change in future.

17. It is widely acknowledged that the uncertainty which has been caused by recent developments is one of the greatest risks to the current delivery of the service. Patients and families are now unsure about precisely where and how they will receive treatment. Surgical centres are hamstrung in their planning, and recruitment and retention is made more difficult by the lack of a clear service model. This in turn creates a risk that the safety and quality of services may not be able to be maintained, that service levels could reduce or there could be unplanned closure(s). Charities, clinicians and other stakeholders gave a huge commitment to support change; many say they are demoralised, frustrated, exhausted and angry. Some doubt that there is the will to make the necessary changes happen.
18. These concerns need to be addressed as part of the new process. To support this measures designed to give commissioners early warning of any emerging concerns at units providing children's congenital heart services will be rolled out across the country, (and to adapt it to include adult services) accepting that it is still a developmental approach, and used as the basis of regular conversations between area teams and providers. A system will be established to ensure that aggregated information is regularly provided to the board committee.
19. In the light of all this, NHS England must bring forward an implementable solution within a year, ie by the end of June 2014. Given the complexity of the issues, the enlarged scope (children AND adults), the legitimate but differing views of stakeholders, and the need to build as much consensus wherever possible (in circumstances where some of the relationships have been badly bruised) this is a demanding but important ambition. We simply cannot re-run the previous process and hope to achieve a different outcome in a quarter of the time.
20. Instead, we must find ways to do this differently. As the sole national commissioner of specialised services NHS England has an opportunity not open to our predecessors. This creates a significant opportunity to drive service improvement including reduced variation in access and quality. We can focus on national standards for a national service, commissioned through a single model which enables us to drive change in the interests of patients.

Principles / Approach

21. We propose the following principles and approach:
 - **Patients come first:** the new review must have patients and their families at its heart, with a relentless focus on the best outcomes now and for the future. That aim over-rides organisational boundaries.
 - **Retaining what was good from earlier work:** although the JCPCT's decision on configuration of children's congenital heart services has been overturned, much else was developed as part of that process and the subsequent implementation programme including a model of care, service standards, and well-developed thinking about network working. Similarly standards for adult services have also been developed and are ready for

formal consultation. This work has had extensive clinical and patient input and has the potential to be applicable to whatever service configuration is decided. Therefore NHS England must work with stakeholders to determine how much of this work can be retained.

- **Transparency and participation:** NHS England is committed to openness, transparency and participation. We should work with user, clinical and organisational stakeholders to ensure that we develop an approach to take the work forward that is true to those values. Our work should be grounded in standards, rigour, honesty and transparency.
- **Evidence:** the IRP reflected criticism of the way in which Safe and Sustainable used evidence to support its conclusions. The new review will need to be clear about the nature and limitations of the available evidence, and about any intention to rely on expert opinion in the absence of evidence. Notwithstanding the comment above about “retaining what was good”, we must have no preconceived notions about the outcome. Wherever there is an assumption it must be made explicit, and justified.

22. We have not attempted to develop a full plan describing how the work will be taken forward, because we want to take time to understand from stakeholders what was good and should be retained from the previous process and what did not work well. We believe however that it is likely that a standards driven process – developing, testing, adopting and applying best practice standards for every part of the pathway – has much to commend it, and we will be testing this with stakeholders.

Governance

23. The Board has established a committee which will provide formal governance of this work. The committee is chaired by Sir Malcolm Grant, Board Chairman, and includes Margaret Casely-Hayford and Ed Smith (non-executive directors), Sir Bruce Keogh (Medical Director), and Bill McCarthy (National Director for Policy). To support the committee, arrangements will be put in place for clinical, organisational and service user representation.
24. Bill McCarthy is the senior responsible officer for this work. John Holden (Director of System Policy) will co-ordinate the work within NHS England and ensure the full involvement of the many different stakeholders.

Stakeholder engagement and communications

25. We are drawing up a stakeholder engagement plan, based on how these stakeholders tell us they wish to be involved, and identifying the different groups, their preferred channels of communication and the key messages throughout the process. For example we know that some of the existing surgical centres have well established patient groups and using these channels may be one way to reach the majority of those most directly affected. For patients, families and their representatives we have sought expert external help from three charities - National Voices, Involve and Centre for Public Scrutiny (CFPS) – to help us design and implement effective and appropriate engagement. They can also

help us manage our risks (eg CFPS are experienced in working with oversight and scrutiny committees and can help us better understand the local government dimension). Due to their limited size these bodies are unable to be directly involved in the work but all have agreed to act in a mentoring capacity. For clinicians, Sir Bruce is convening a clinical advisory panel which will guide him throughout the process and will help design broader clinical engagement and address specific issues which may arise. He has identified the need for some international perspective on this work and will take some soundings from his international peers to determine how best international advice is provided.

26. Our communications will be as open and as often as possible – we have already initiated a fortnightly blog on the NHS England website where we will trail forthcoming meetings and provide a summary of recent progress and discussions. With the support of the NHS England Director of Communications and his team, we are also considering the potential for dedicated web pages, or other IT applications which allow documents and other information to be freely exchanged. We want to give anyone who is interested a simple and easy to use way to find out what is going on and to become involved. We will use social media as appropriate – and if our stakeholders find it helpful – to discuss and share information. We are also considering how we can address the needs of those who do not have access to the internet or do not use English as a first language.

Resources

27. We need to take this opportunity to review the resourcing of this work. It will be important to ensure that it is a priority for the whole organisation and that the resources of the whole organisation are appropriately mobilised to support the work. The cost of dedicated programme management and administrative support will be met from recycling funds previously reserved for the Safe and Sustainable process. The estimated annual cost of this support is £500k.

Conclusion

28. As the body responsible for commissioning specialised congenital heart services, NHS England is setting out ambitious plans to ensure that services for people with CHD are provided in a way that achieves the highest possible quality within the available resources. To achieve this, a new Congenital Heart review is being established to consider the whole lifetime pathway of care for people with CHD. The Board is asked to consider and comment on the proposed approach.

Bill McCarthy

National Director: Policy

July 2013

Annex 1: Programme Plan

Our indicative timetable is follows:

Phase 1 – up to October 2013

Co-design a process for the work going forward

- Take advice from external experts to help shape listening exercise *[done]*
- Review previous stakeholder input in order not to lose what has already been achieved; and check its continuing relevance with stakeholders *[under way]*
- Begin communications as per stakeholders preferences, eg blog, shared resources on webpage/sharepoint *[under way]*
- Agree approaches to participation, identify preferred communications channels

Establish the programme

- Establish governance, advisory and stakeholder arrangements *[under way]*
- Develop programme plan, update Board, secure agreement, update Secretary of State *[under way]*
- Identify resources *[underway]*

Initial work on how to achieve programme aims of higher quality services

- Agree with stakeholders what should be taken forward from previous processes
- Complete work on proposed paediatric cardiology standards *[underway]*
- Bring together adult and children's standards and agree process for approval and adoption *[underway]*
- Develop proposals for testing/implementing formal network arrangements *[underway]*
- Work with stakeholders to identify any fixed points and how these would influence service design. This is likely to include (but not be limited to) discussion of the provision of transplant services, the need for children's heart surgery and other tertiary paediatrics to be provided on the same site, and the need for children's and adults' surgery (and interventional cardiology) to be provided in close proximity
- Develop a "proposition" – not a list of sites, but a straw man of what a high quality and sustainable service looks like for adults and children, unconstrained by current configuration – the optimal model
- Consider and weigh, with legal advice, possible approaches for a managed process to translate these fixed points into firm proposals for structuring services, test with stakeholders, outline agreed process
- Establish the required capacity of the service in future years
- Set an ambitious timeline to have completed the work and be ready to implement.

Phase 2 – up to February 2014

Develop, test and revise the proposition

- Using multiple channels, including local and national clinically led events, engage on the clinical appropriateness and user acceptability of the proposition

- Benchmark existing provision against the proposition – considering access as well as service quality
- Test any emerging alternative proposals
- Review dependencies – eg for children, neonatal and paediatric intensive care (PICU) and retrieval services, extracorporeal membrane oxygenation (ECMO). While the IRP recommended that decisions about the future of transplant services and respiratory ECMO should be contingent on final proposals for congenital heart services, in practice the level of interdependency may mean that they need to be considered together
- Weigh alternative implementation approaches: early thinking suggests that some fixed points could constitute 'hurdle criteria' for potential providers within a commissioner led standards driven approach, however alternative approaches need to be considered including option appraisal and designation and provider led regional solutions.
- Agree revised proposition with clinical and patient groups

Phase 3 – up to June 2014

Preparation for implementation

Work in this phase will of course be dependent on the nature of the proposition developed and the measure of agreement with that approach.

- If the solution is for a national plan in which current centres continue/cease to provide surgery, then – subject to legal advice - there may need to be further full formal consultation. This could take the timeline for implementation beyond one year.
- If the solution is a commissioning approach to enforce a set of national standards which invites providers to cooperate to provide the service, any consultation could be undertaken sub-nationally as part of the development of tenders. Assuming local resolution and provider cooperation, the focus of this period would be on developing the tender exercise.

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