

Recommendations of the Independent Reconfiguration Panel

This report explains how the new congenital heart disease review has sought to learn lessons from the Safe and Sustainable review and specifically the recommendations raised by the Independent Reconfiguration (IRP).

Background

The Safe and Sustainable review was established in 2008 to consider 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.

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.

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 IRP to consider the JCPCT findings.

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". 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. The IRP did, however, 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. The IRP report included fifteen specific recommendations which should be considered as part of any further review of Congenital Heart Services.

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".

The New Congenital Heart Disease Review

Following this decision NHS England launched a new review of congenital heart disease services which was designed to take into account the recommendations made in the IRP report and produce an implementable solution. The review considers the whole lifetime pathway and its aims are:

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- 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 variations so that services across the country consistently meet demanding performance standards and are able to offer resilient 24/7 care; and
- improving patient experience, including how information is provided to patients and their families, and consideration of access and support for families when they have to be away from home.

On Monday 15 September 2014, NHS England launched its twelve week consultation on draft standards and service specifications for congenital heart disease services. This will run until 5pm on 8 December 2014. The standards and service specifications are draft which means that no decisions have been made.

Recommendations

Throughout this review, NHS England have been mindful of the concerns which the IRP raised in their report on the Safe and Sustainable review. This review is not a continuation of the Safe and Sustainable review but rather a new review by a wholly new and different organisation with different governance arrangements and a different approach. However, it remained important to learn from the experience of the Safe and Sustainable review. The key messages of the IRP report revolve around five key areas which we have taken into account throughout the review. A brief summary of the concerns and key actions we have taken are included below:

1. Scope

(This section refers to recommendations 1, 3, 5, 7 and 11 from the IRP report)

A number of the recommendations in the IRP report referred to the scope of the Safe and Sustainable review and ensuring that any future work covered all of the necessary areas. One key area of concern for the IRP was the separation of children's services and adult services. The new review has included both adult and children's services in its review and produced draft standards and service specifications for both. In order to ensure that the review had an appropriate scope six objectives were agreed which cover the key areas required to review CHD services including those recommended by the IRP in their report. The objectives of the review are:

- To develop standards to give improved outcomes, minimal variation and improved patient experience.
- To analyse demand for specialist inpatient CHD care, now and in the future.
- To make recommendations on function, form and capacity of services needed to meet that demand and meet quality standards, taking account of accessibility and health impact.
- To make recommendations on the commissioning and change management approach including an assessment of workforce and training needs.
- To establish a system for the provision of information about the performance of CHD services to inform the commissioning of these services and patient choice.
- To improve antenatal and neonatal detection rates.

A paper on Scope and Interdependencies was also submitted to the Board Task and Finish Group in October 2013 to provide assurances that an appropriate scope was in place for the review: <http://www.england.nhs.uk/wp-content/uploads/2013/10/item9.pdf>

2. Proposed Standards and Model of Care

(This section refers to recommendations 2, 3, 5, 8 and 13 from the IRP report)

The IRP report included some recommendations which related specifically to the proposed standards and model of care. For example there were recommendations

relating to the size of surgical teams and sub-specialisation. The new congenital heart disease review has set out proposals covering the whole pathway of care and in doing so we have given fresh consideration to all areas of the standards. As part of this process we commissioned a fresh examination of published evidence and listened to the views of clinicians and patients, who are experts by experience. This is a key element of the work of the review as noted by the Chair of the Clinical Advisory Panel Professor Sir Michael Rawlins:

“In my experience, the amount of quantitative scientific evidence available to guide us in deciding how best to organise health services is often much less than we would like. In these circumstances we rely heavily on the views of experts, both specialist clinicians and those who are expert because of their experience of using the services in question. The views of experts, while qualitative rather than quantitative, are also valid and an important source of evidence in our deliberations.”

As a result, the proposed standards and model of care reflect the expert advice we have received in all areas including those specifically highlighted in the IRP report.

Another area of concern related to the complex interdependencies between existing specialised services provision and population needs. NHS England has established a tiered clinical assurance process made up of Clinical Reference Groups, Programme of Care Boards and Clinical Priorities Advisory Groups to ensure that proposals for individual services are always considered in the wider context of other related services, and the impact each may have on the other. This structure has been used to ensure that due consideration is given to how any proposals would affect other services.

3. Managing Change

(This section refers to recommendations 4, 6, 9, 10 and 12 from the IRP report)

The IRP recommended that in any future work effective processes were put in place for managing any change to CHD services which occurred as a result of the review. We are currently in the process of consulting on models of care, standards and service specifications and no changes to services have been proposed. We have performed an activity analysis to help us review capacity and any predicted increases in activity.

Following standards and service specifications being agreed, the next step would be a commissioning process. Changes to services, were they to be needed would flow from this commissioning process. We will prepare a business case for commissioning the service against the standards and service specifications once these have been agreed, but no proposals are being made at this time for changes to the current services or the location of any service provision. Further activity analysis, financial assessments and processes for managing any change will be developed according to the changes, if any, which occur as a result of this process.

During 2015/16 NHS England expects to agree new service specifications for paediatric cardiac and adult congenital heart disease (ACHD) services. In year we expect to run a commissioning process designed to ensure that from April 2016 all services meet the applicable service specification (noting that the different standards have identified specific timetables). Providers will be expected to work together in responding to NHS England's commissioning process and to maintain good working relationships in the interests of patients. Providers will be encouraged to use 2015/16 to self-assess against the new standards, in shadow form, and to develop action plans to address any areas of concern. Throughout this period more detailed impact assessments and processes for managing any proposed change will need to be developed.

4. Stakeholder Involvement

(This section refers to recommendations 14 and 15 from the IRP report)

The IRP recommended that in any future work processes are established to enable the effective engagement of stakeholders throughout the review of CHD services.

NHS England has developed and consulted on a wide range of proposals for specialised services and has sought to develop cost effective standard processes for stakeholder engagement in this work through its clinical reference groups, their wider stakeholder groups and public consultation. Throughout this review we have considered each case on its merits to make judgements about whether anything beyond that standard approach may be needed, taking into account the high degree of public interest and concern.

The new congenital heart review established formal groups to ensure that appropriate stakeholders were involved throughout the process. This included the establishment of the following groups:

- The Clinical Advisory Panel – The Clinical Advisory Panel has been convened to provide a full range of clinical advice and recommendations on all aspects of the new congenital heart disease review to the NHS England National Medical Director and to the NHS England Board, the Board Task and Finish Group and the Programme Board. The constitution of the Panel ensures a broad and strategic perspective, from across a wide range of specialties as well as an international perspective, allowing the review to benefit from expertise, not limited only to congenital heart disease, but the broader system and the challenges of delivering clinical services.
- The Clinicians' Engagement and Advisory Group – This group consists of representatives from all of the trusts that our data suggested performed any surgical or interventional work on people with CHD. In addition, medical associations, clinical reference groups and Royal Colleges who had an interest in congenital heart disease were also invited to send representatives.
- The Patient and Public Engagement and Advisory Group – This group consists of representatives from national charities, local charities and patient and public support groups.
- The Provider Engagement and Advisory Group - This group consists of management representatives from all of the trusts that our data suggested performed any surgical or interventional work on people with CHD.

The engagement and advisory groups were designed to engage with as many stakeholders as possible and as a result any group who has requested to be represented on one of these groups has been accepted. These groups play a key part in the governance and engagement arrangements for the new congenital heart disease review. A summary of the governance arrangements for the review can be found here:

<http://www.england.nhs.uk/wp-content/uploads/2014/08/cpag-governance-paper.pdf>

In addition to these formal arrangements we have made significant efforts to engage with a wider range of stakeholders through visits to provider units, children and young people events and events for local government, MPs and peers. A summary of these additional arrangements can be found here:

<http://www.england.nhs.uk/wp-content/uploads/2014/08/cpag-engagement-paper.pdf>

This commitment to stakeholder involvement continues throughout the consultation period during which the review team will be hosting a number of open consultation events which will be suitable for all audiences. The events are designed to help those

who attend to learn about and understand the standards and the changes these could mean to services. The events will be of an 'exhibition style' which will include panel displays, audio-visual materials, and team members to talk to.

5. Transparency

(Whilst this section does not refer to specific recommendations it was a common concern raised throughout the report)

The IRP recommended that in any future work steps should be taken to address the apparent lack of transparency over some elements of the Safe and Sustainable review, including the processes for making decisions. In an attempt to ensure that the new review was transparent the new congenital heart disease review has sought to take steps to make as much information available as possible.

Throughout the review we have published all the agendas, papers and minutes from the key groups involved in the review as well as their terms of references including membership lists. We have required each of our members to complete declaration of interest forms which have also been published on the NHS England website.

<http://www.england.nhs.uk/ourwork/qual-clin-lead/chd/dec-of-int/>

We have both published and distributed draft versions of key documents including the standards, service specifications and consultation documents to ensure that as many interested parties are aware of the progress of the review throughout.

A key element of this transparency has been John Holden's fortnightly blog (<http://www.england.nhs.uk/tag/john-holden/>) which is used to highlight key documents, papers and meeting minutes as well as informing people of the current progress of the review.

6. Consultation

(Whilst this section does not refer to specific recommendations it was a common concern raised throughout the report)

The IRP highlighted issues with the consultation activity of the Safe and Sustainable review which we have been mindful of when planning the consultation approach we are currently taking. There was a concern that the consultation document was overly long and that the process for responding was too complex and limited. We have limited the length of our consultation document and have limited the response form to 12 open questions which can be completed using an online form or on paper.

There was also a concern that consultation activities had not been appropriately prepared for the number of people wishing to attend and that the communication plan did not pay sufficient attention to the need to engage with BAME communities. We have planned to hold 12 open drop in consultation events held over a number of hours to improve accessibility. We have asked provider trusts and patient and public groups to help promote these events. In addition to this we have specifically asked trusts located in areas with large BAME communities and groups such as the Race Equality Foundation to help us engage with these groups. We would appreciate any help which local councils could give us to further engage with these communities.

The report also stated that there was a perception that different weighting was given to different responses resulting in a feeling that views of certain groups, for example parents of children with CHD, were not valued. We have actively sought the views of parents throughout our review and have engaged an external organisation, Dialogue by

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Design, to provide an independent analysis of the formal engagement responses we receive.

Conclusion

In the design and operation of the review we have been mindful of the IRP's recommendations and sought to learn the lessons from the Safe and Sustainable review. It is worth noting that not all of the recommendations are relevant at this stage of NHS England's work due to the different approach this review is taking.