ITEM

NHS England

SPECIALISED COMMISSIONING OVERSIGHT GROUP

Title: Update on progress of the new Congenital Heart Disease Review
Clearance: Michael Wilson, Programme Director
Purpose of paper: to provide the members of the Specialised Commissioning Oversight Group with an update on the progress of the new CHD review and the governance process being followed prior to launching a public consultation.
Key issues and recommendations: to note proposals for consulting on new service specifications and standards for congenital heart disease (CHD) services and to consider the implications for specialised commissioners in all parts of NHS England.
Actions required by Committee Members: none

Background

In June 2013 the Secretary of State asked NHS England, as the organisation responsible for commissioning congenital heart services, to undertake a new review, learning from the work of the “Safe and Sustainable” review of children’s congenital heart surgery and taking account of the Judicial Review findings and the report of the IRP.

The review was scoped to include six objectives:

- to develop standards to give improved outcomes, minimal variation and improved patient experience for people with congenital heart disease;
- to analyse the demand for specialist inpatient congenital heart disease care, now and in the future;
- to make recommendations about the 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 congenital heart disease services to inform the commissioning of these services and patient choice; and
- to improve antenatal and neonatal detection rates.

Current status

Working with stakeholders, the review has developed comprehensive service standards covering the whole lifetime pathway of care for CHD patients. The Clinical Reference Group has developed draft specifications aligned to those standards. The proposed new specification for paediatric cardiac services is intended to replace the existing specification. The proposed new specification for adult CHD services is completely new; this area of service is not currently covered by a service specification.

An analysis of current and future CHD activity levels is close to completion.

Next steps

The next steps are to consult on and agree the standards and specifications.

In order to launch the public consultation, the specifications, standards and the associated impact assessments will pass through both programme and specialised commissioning governance. This assures the NHS England board that both the process of developing the materials, and the outputs, have been developed in an open and transparent way and represent the views of all stakeholders. Specific equalities and financial assurance will also be undertaken.

The timeline for these approvals are as follows:

- 22 July: **Programme of Care Board** (to review draft specifications and update on impact assessment progress)
- 29 July: **Programme Board** (approval to apply to POC/CPAG/DCSC and approval of the content of the consultation documents)
- Early August: **Clinical Advisory Panel** (advice to the programme board on the alignment between standards and specifications)
- 12 Aug: **Directly Commissioned Services Committee** (DCSC) (briefing required as final approval by correspondence/chair's action)
- 20 Aug: **Programme of Care Board** (for approval/recommendation to CPAG)
- 1 Sept: **Task and Finish Group of the Board** (briefing and approval to consult, subject to the remaining governance groups)
- 2 Sept: **Clinical Priorities Advisory Group** (for approval to consult)
- 5 Sept: **DCSC** (by correspondence/chair's action)
- 8 Sept: **Programme Board** (final approval to launch consultation)

Consultation

Reflecting the higher than usual interest in this area the consultation on the proposed CHD service specifications and standards differs from NHS England's usual approach in that it is supported by a full suite of consultation materials and a higher level of consultation activity. This will have implications for regional and area teams.

Proposals for consultation activity include:

- At least four regional engagement events during consultation.
- Support (through the provision of materials and advice) for partners (including regional and area teams) and stakeholders to undertake their own consultation activities to ensure greater reach than could be achieved by the programme team alone
- Briefing for local government and Healthwatch
- NHS England attendance at OSCs and HWBBs on request (working with regional and area teams to ensure greater reach than could be achieved by the programme team alone)
- Targeted engagement with adults with CHD; Black, Asian and Minority Ethnic (BAME) groups; CHD patients with learning difficulties; and families who have suffered bereavement/poor outcome.

In order to maximise the impact and reach of consultation the review team is keen to work with colleagues in NHS England regional and area teams to identify how we can collectively encourage and support as many events as possible.

Further Work

The review intends to develop recommendations on the functions & form of the CHD service for the future and to make proposals about the appropriate commissioning & change model.

The review is also facilitating work designed to increase early diagnosis of CHD (both fetal and neonatal).

Final decision making authority on the review's recommendations rests with the full NHS England Board.

The review will then hand over its work to specialised commissioning for implementation and will complete a formal programme close.

Additional information

Attached for information are the following:

- the 'One Year On' paper provided to the NHS England board by the new CHD review Task and Finish Group for background; and
- a set of slides for presentation at the meeting which will cover in more detail the structure of the review programme, the plans for consultation and the opportunity for areas and regional team colleagues.

One Year On: progress of the new congenital heart disease (CHD) review

Executive summary

The review has made progress against all of its objectives. In particular, the development of a single coherent set of standards provides the platform for commissioning an excellent service, and will help determine whether providers are able to meet our requirements. But commissioning an excellent service is not just about the location of surgical units. Our work to date will enable us to describe expectations of the service for the whole lifetime pathway of care; to set out a detailed understanding of current and future demand and the drivers which affect it; to make information readily available on the quality of service; and to improve outcomes by ensuring earlier and better diagnosis.

We had hoped to be consulting on standards by this point, but we have more work to do. The review has managed a constant tension between acting with enough pace to mitigate the risks of “limbo” (whereby investment is withheld, recruitment is difficult, service developments are stalled) versus taking enough time to give all stakeholders the opportunity to shape the future. “Safe and Sustainable” took four years and had a net cost of £6m, but in the end the conclusions were not implemented because of concerns about the process. We are mindful of this and - despite the clamour for a quick solution – have resisted the temptation to take short-cuts in our process, our engagement or in our own internal assurance.

The next steps in this work are to consult on and agree the standards and specification, complete the analytical work, and develop the functions & form and commissioning & change model. At that point we will be able to make recommendations to the NHS England Board. We expect that by the end of the 2014/15 financial year this will cease to be a dedicated “task and finish” project, and implementation will be mainstreamed as part of NHS England’s wider commissioning of specialised services.

Introduction – an “implementable solution within a year”

In June 2013 the Secretary of State announced that he accepted the recommendations of the Independent Reconfiguration Panel (IRP), and was therefore setting aside the outcome of the “Safe and Sustainable” review of children’s congenital heart surgery. The work had been led by a committee, acting on behalf of all primary care trusts, which no longer existed. He therefore asked NHS England, as the organisation now responsible for commissioning these services, to undertake a new review, learning the lessons of experience to date, including Judicial Review findings and the report of the IRP.

The Board of NHS England, meeting in public in July 2013, discussed the issue (see link to paper). It was recognised that the new review was a vital opportunity to secure lasting improvements for some of the most vulnerable NHS patients. Reviewing such a high profile and sensitive service would be seen as a test of the way in which the emergent NHS England conducted itself, and our commitment to patient and public engagement, clinical leadership in every aspect of our work, and evidence-based decision making. The

Board recognised the difficulties of conducting the review in a climate where trust had broken down and relationships needed to be rebuilt, but was nonetheless concerned about the risks to the congenital heart service due to continuing uncertainty and "limbo". Therefore the Board set an ambition that there should be an "implementable solution within a year". We have now reached the one year anniversary of the Board's challenge, and this paper describes the progress that has been made and what remains to be done.

Overall approach – six objectives

Stakeholders – especially patient groups and clinicians - told us from the start that to have any kind of constructive dialogue, we should "take closure off the table". In other words, we must find a way to discuss the issues without pre-supposing that some units must cease to provide services. Many told us that the threat of closure had led to an adversarial approach during the previous review, both in terms of engagement in the review, and even in the way that surgical centres behaved towards each other, to the detriment of patients. More positively, many stakeholders told us that the key to a successful outcome would be to build consensus around a set of standards, but that the standards should not be "fudged" – i.e. they should objectively describe the optimal model of care, without regard for the current service arrangements.

At the same time, it became apparent to us that we needed a comprehensive understanding of historic activity, and the current and anticipated volume of services. Alongside a new set of standards for the whole pathway care - from fetal through children and adults - this would help us to understand the capacity requirements and the cost implications. Analysis of the historic data could help us to identify any relationship between the way services are organised and the outcomes for patients. In turn, the standards and capacity requirements would allow us to start to describe the functions and form of a congenital heart disease service for all patients in England, including issues not dealt with by the standards like access and geographical distribution. Taking all these points together, we were satisfied that we could legitimately "take closure off the table". We considered that in the absence of compelling, prima facie evidence that closing units was the only way to secure high quality services for the future, that the new review should have an open mind, develop standards of care and follow the evidence as it emerged. Once we had agreed the standards, examined the data and other evidence, and considered functions & form, only then could we have a meaningful dialogue with potential providers about how to meet our requirements, and whether any reconfiguration would be necessary.

NHS England is a commissioning organisation and this strategic review is the front end of a commissioning process – defining the need, and considering the options. Provider organisations told us they wanted to understand and to help shape the approach to commissioning and change – any reconfiguration resulting from the review would affect all those involved and have implications for workforce, teaching, and of course for interdependent clinical services. Even if reconfiguration were not required, it was highly likely that providers would need to make changes to be compliant, and to network effectively.

Finally, patient and public stakeholders, strongly endorsed by clinicians, told us they wanted better real time information to understand how the service was faring, to provide a quality safeguard and to inform patient choice. They argued that current data was overlyfocused on one metric, for “30 day mortality” (i.e. post-operative survival), which showed that in the past decade (since the Kennedy Inquiry at Bristol in 2000) surgical outcomes had levelled up significantly so that across England these outcomes were now world-leading. But mortality is not the only indicator of good care, and does not reveal enough about other outcomes. They also told us that a really good service does not begin at the point that surgery takes place; it begins with early and accurate detection and diagnosis, through improved rates of antenatal detection, supplemented by improved neonatal detection.

In January 2014 our Board was asked to consider and agree a set of six objectives for the review, which captured all of these different strands of work (see link to paper). Progress against the six objectives would be the measure by which we could demonstrate progress against the Board’s ambition for an “implementable solution”.

The following six objectives were agreed:

> **Objective 1:** to develop standards to give improved outcomes, minimal variation and improved patient experience for people with congenital heart disease;
>
> **Objective 2:** to analyse the demand for specialist inpatient congenital heart disease care, now and in the future;
>
> **Objective 3:** to make recommendations about the function, form and capacity of services needed to meet that demand and meet quality standards, taking account of accessibility and health impact;
>
> **Objective 4:** to make recommendations on the commissioning and change management approach including an assessment of workforce and training needs;
>
> **Objective 5:** to establish a system for the provision of information about the performance of congenital heart disease services to inform the commissioning of these services and patient choice; and
>
> **Objective 6:** to improve antenatal and neonatal detection rates.

Range of services covered by the review

Our Board had already decided, in July 2013, that the new review should encompass both adults and children’s services, recognising that in practice they were inextricably linked, through shared staff including surgeons. Stakeholders – especially clinicians - told us this “child and adult” approach was essential, but it was a significant departure from “Safe and Sustainable”, which had been asked to look at children’s services only. This meant that without doing anything else, our work was already much broader in scope than the previous review. And there were more detailed questions of scope to be answered, for example whether and how to take account of interdependencies between services. It was important to get the balance right before asking the Clinical Advisory Panel (Chaired by Professor Sir Michael Rawlins) to consider and advise on the review’s scope, because too broad a scope would make the review undeliverable; too narrow might mean that important dependencies were overlooked. Therefore we consulted our stakeholders for comment, and through this process we formally agreed the scope of our work on standards.

Similarly, one of the most powerful messages we heard from our early meetings with patient groups was that the CHD service sometimes failed patients and families at their lowest ebb, when there was a poor outcome, or during palliative care, or following bereavement. This was about treating people with compassion and dignity, rather than a question of the technical skills of the clinicians involved. So, almost from our first meeting with patients, we decided that there should be a dedicated chapter in our new standards to deal with palliative care and bereavement. And throughout the standards there are references to the importance of open, honest communication. Finally, we have been clear that NHS England's focus is on commissioning services for the population normally resident in England. However, congenital heart surgery for patients resident in Wales invariably takes place in England, and so we have been factoring this in to our work, and considering where appropriate the relatively smaller cross-border flows with the other devolved administrations.

Openness, engagement and decision making

We began our work in June 2013 by meeting the national patients' charities, to get an overall perspective on the challenge. This immediately triggered concerns amongst local charities and patient support groups that their views were not being sought and would not be respected by the national charities. It was clear that relationships between some of the charities and patient groups had been left strained following the “Safe and Sustainable” process.

Our early meetings with stakeholders were focused on giving everyone a chance to say what they felt about the recent history and their hopes for the future. This was essential to the constructive working relationship we have now, based on a programme of regular engagement events with three different groups each chaired by an independent representative of the group concerned. (Patient and Public Group chaired by Professor Peter Weissberg, Medical Director at the British Heart Foundation; Clinicians' Group chaired by Professor Deirdre Kelly, Consultant Paediatric Hepatologist at Birmingham Children's Hospital NHS Foundation Trust; and Provider Group chaired by Chris Hopson, Chief Executive of the Foundation Trust Network). We have sought to involve every constituency in these groups – every charity and patient support group, clinicians and managers from every hospital delivering specialist congenital heart care, and every linked speciality. We make sure that we offer all three groups a broadly similar programme so that there is consistent and comprehensive sharing of information, but we also adapt the agendas to reflect whatever those groups wish to discuss. Every meeting has its own character. All are robust in their debates and appropriately challenging to NHS England. They never allow us to forget that these are real issues that need to be resolved.

For local government and Healthwatch representatives we have held a national plenary meeting (in Birmingham) and subsequently an update via WebEx; we have also attended Overview and Scrutiny Committee hearings around the country to explain the work of the review. We have attended two all-party parliamentary briefing sessions, and supported Department of Health ministers to answer numerous Parliamentary Questions. We have also attended various professional conferences – for example the national association of critical care managers. Over the Easter School Holidays in April 2014 we ran nine regional events around the country, specifically designed to hear from children and young people. Over 100 young people and their families told us their stories. And we have just completed a series of visits to every specialist congenital heart unit in the country, led by the chair of our clinicians' engagement and advisory group. As part of these visits we were able to hear from and talk to front-line clinicians, patients and their families and hospital managers, giving us a much richer understanding of their achievements and challenges. There is more work to do – especially to hear from adults with CHD, from black, Asian and minority ethnic groups, from people with learning disabilities and from bereaved families, all of whom have been relatively under-represented in our work to date. But as a result of this extensive engagement we feel we are in a good position to consult on a set of standards, and that there will be no surprises for any of our constituencies.

The IRP report into "Safe and Sustainable" observed that there were perceptions of a lack of openness, and a suspicion that outcomes were pre-determined. The diagram at Figure 1 shows the governance arrangements we have established for this review, and in particular how our decisions are made, and how the different engagement and advisory groups feed in to the decision making process. We have shared this widely so that there is no confusion about the route by which the ultimate decisions are made – in particular, the pre-eminence of the NHS England Board and its "Task and Finish Group" (chaired by Professor Sir Malcolm Grant) dedicated to this project. But for reasons of simplicity and clarity the diagram does not attempt to show the full complexity of the governance arrangements which must be satisfied in order to consult on the new service standards, which require the involvement of a Programme of Care Board; the Specialised Commissioning Oversight Group; the Clinical Priorities Advisory Group; and the Directly Commissioned Services Committee of the main Board. Successfully navigating this governance without undue delay is one of the main challenges we face in consulting on standards in September 2014.

One of the defining features of our work over the last year has been the approach we have taken to openness and transparency. In addition to involving the widest possible range of stakeholders, we have tried to make sure that everything we do is open to scrutiny, with a conflicts of interest declaration being widely rolled out, and a publications policy where the default is always that we publish everything. This is logistically difficult and can create tensions – often we are doing our "thinking out loud", and in public, and we are robustly challenged on ideas which have merely been floated, not finalised. But on balance the approach has been quite liberating. We publish all significant material, whether it is correspondence, agendas, meeting papers or minutes. We produce a blog every fortnight (there have been 25 in the year from June 2013) in which we describe what is happening and what is forthcoming, and we always feedback what we have heard and what we have done about it.

Progress update against the objectives

- **Objective 1 - standards**

  From the beginning of the review's work, stakeholders told us that the best way to improve services was through clear service standards, uniformly applied. The creation of NHS England as a single national commissioner of specialised services presents an opportunity to drive high standards consistently in a way not open to our predecessors. Under the leadership of Professor Deirdre Kelly and with extensive cooperation from a range of clinical experts and patient representatives, a single coherent set of standards has been developed that describes the whole patient pathway from fetal diagnosis through children's services and adult services including transition and pregnancy. This builds on two discrete sets of pre-existing standards, and a third which was underway; all have been fully reviewed, refreshed and further developed. There is an increased emphasis on good communication with patients and their families and a new section covering end of life care and bereavement. Responding to the challenge set by Professor Sir Bruce Keogh, the standards aim to describe an excellent service, not just best fit with current practice. This has been a lengthy, complex and testing exercise, to harmonise a large number of standards which had previously been organised and expressed in different ways, and grappling with some of the most “knotty” issues. The draft standards will be subject to full public consultation later this year: our target date has slipped from July 2014 to September 2014 and we have been criticised for the delay, which is due to the production of the consultation materials, and the challenge of clearing the internal assurance process referred to above. One issue to be tested in consultation will be the potential trade-offs required if, in meeting the standards at all specialist units, the standards were to be considered unaffordable. Possible approaches could include a longer timetable, commissioning from fewer units (to achieve economies of scale), lowered expectations for those standards associated with higher costs, or focusing on a smaller set of “must do” standards.

The standards, once agreed, will form the basis of NHS England's service specification which we use for contracting. The standards will be challenging and it is not expected that any provider meets all the standards currently. Some of the standards will be developmental, so a timetable for reaching them will be set out. The Clinical Reference Group (CRG) responsible for congenital heart services has worked with the new CHD review team to develop the draft service specification and timetable for developmental standards. Once agreed, the specification will become the basis for NHS England's commissioning of CHD services and all providers will be expected to meet the standards.

In addition to the work described on developing standards for CHD services, the review will work with colleagues from NHS England and the relevant CRGs to develop standards for extra corporeal life support services (including extracorporeal membrane oxygenation) and referral pathways and criteria for CHD patients who could benefit from cardiac transplant.

- **Objective 2 - analysis**

  In order to commission CHD services effectively, NHS England needs to understand the demand for services now and in future. Clinicians and hospitals providing CHD services have told us that they expect the growth in paediatric activity seen over the last ten years to continue in future. The number of adult patients with CHD is now believed to exceed the number of children with CHD for the first time, and the number of adult patients is expected to continue to rise.

  For adult services we have two sources of data available on current inpatient activity, but both are flawed for different reasons. Not all adult activity is reported to the national database run by the National Institute for Cardiovascular Outcomes Research (NICOR), and the generic nature of Hospital Episode Statistics (HES) means it is not easy to distinguish CHD activity from other cardiac services. No comprehensive assessment of expected changes in future years has previously been available for both children and adults. The review's analytical team has worked with clinicians, NICOR and NHS England's lead commissioners from national and area teams to define a set of procedure codes that most accurately describe CHD inpatient activity. Data from the NICOR database and the HES data set are being analysed and compared to give the best understanding possible of current activity as well as trends over the last ten years. By the end of July 2014 we aim to have the first evidence-based projections of activity for children's and adults' services, modelling two different scenarios for growth (population only, and population plus other factors). The emerging analysis already confirms our understanding that beyond those centres providing specialist CHD services, a larger number are involved in providing care for adult patients, mostly undertaking lower numbers of procedures, which raises questions about the incidence of "occasional practice". Our public and patient stakeholders representing adult patients have told us this is a significant concern for them.

- **Objectives 3 and 4 – function, form & capacity and commissioning & change**

  The review will move beyond standard-setting and activity analysis to make recommendations for the shape of the CHD service of the future. It will also consider possible approaches to commissioning those services to ensure that everyone has access to excellent services that meet the service standards, and that occasional practice is eliminated. The preparatory work is already underway, but we cannot pre-judge the outcome of the standards and analytical work. The review is working with colleagues from across NHS England to develop an approach that helps to inform similar work on other specialised services.

  Engagement with our provider leaders' group has highlighted the importance of any change programme taking account of research, training and workforce implications, and the need to have some explicit recognition of the cost of any substantial change. We intend to describe the necessary components of a commissioning approach to facilitate the emergence of regional, collaborative, provider-led solutions, including the potential for the development of formal joint approaches that also meet the necessary requirements of competition and choice.

  The standards will establish some important parameters for future services including the minimum levels of surgical and interventional activity required (because of the requirements for teams of surgeons and interventionists and minimum activity requirements for each of these groups to assure continued competence). This will be taken into account along with considerations of access, changing demand, affordability and other parameters in making these recommendations.

- **Objective 5 – better information**

  The IRP in its review of the work of "Safe and Sustainable" noted that high quality, accessible and understandable information to inform decision making was lacking. The review will therefore ensure that better information is available for commissioners and to inform patient choice.

  As a first step, we have worked with lead commissioners from regional teams to institute the use of a children's congenital heart "transition dashboard". This was originally specified to manage risks in the period when it was expected that "Safe and Sustainable" would be implemented. Despite implementation not taking place, the transition dashboard still provides a mechanism to test the current health of the system, by collecting specific information on defined aspects of the children's congenital heart services in England. And in line with other specialised services, the

CRG for Congenital Heart Service has developed a quality dashboard covering a range of measures, which will be the enduring approach to real time quality monitoring. Although the quality dashboard has been introduced for 2014/15, it has been agreed that the transition dashboard will remain in situ until further notice.

The review is also working with NICOR to consider how the information it produces can be improved. We will work with them to consider how a wider range of outcomes (beyond mortality) could be reported. We will also work with them to develop ways of presenting the information which would be easier for patients to interpret and allow them to make informed choices.

- **Objective 6 – early detection**

  Abnormalities of the heart are the most common congenital defect and yet rates of diagnosis before and immediately after the baby is born are not as high as they could be. Clinicians tell us that earlier diagnosis can lead to better outcomes throughout a patient's lifetime, more informed choice, better managed births and better experience for families.

  The review has brought together a wide range of stakeholders with an interest in early diagnosis to better understand the reasons for current low antenatal detection rates and to develop plans for addressing these. Early work suggests that better training and support for ultra-sonographers undertaking antenatal scans will be important. We will work with Health Education England (HEE), providers and third sector partners to consider how this, and other potential issues, could be addressed.

  Stakeholders have also told us that the lack of a consistent, national database for recording all congenital defects is a further significant problem. Without this it is not possible to be sure about the rate of antenatal diagnosis. We are in discussion with Public Health England (PHE) who will be developing and implementing a new national database which is expected to be functional by April 2015.

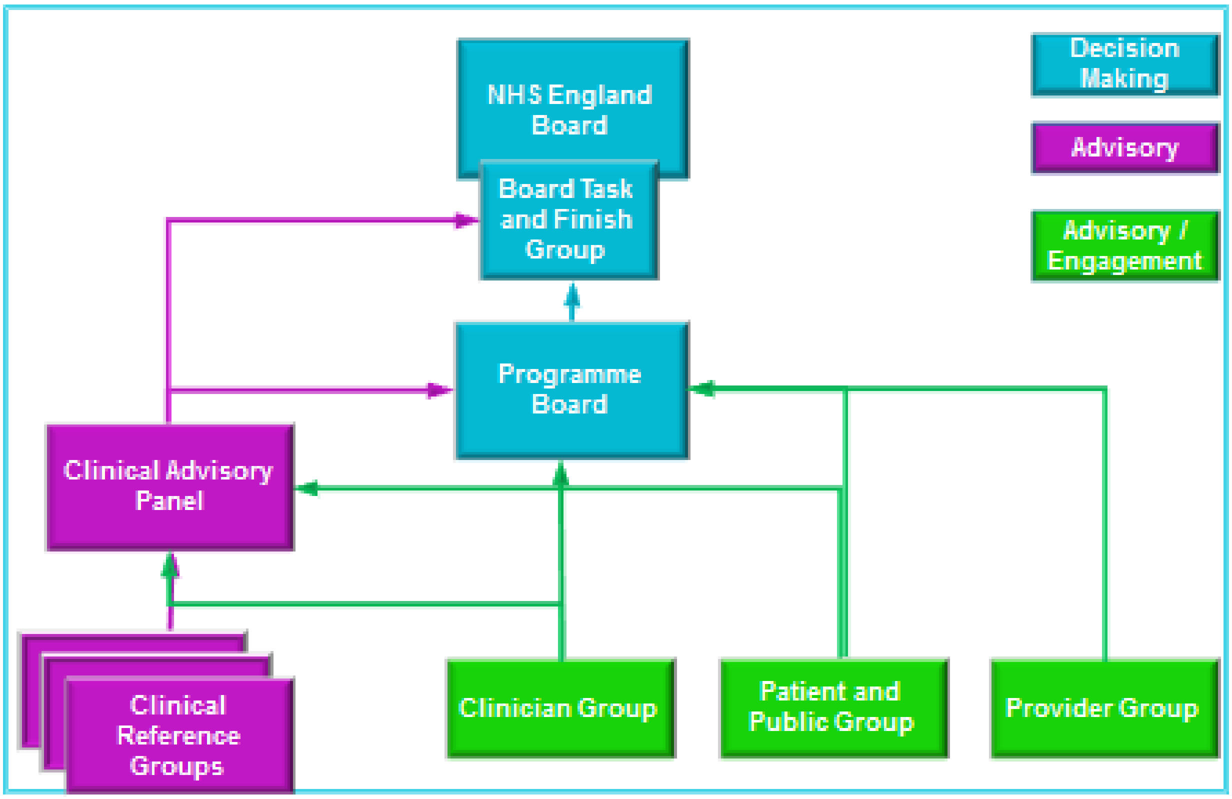
  The National Screening Council (NSC), now part of PHE, recently consulted on the efficiency of pulse oximetry, a simple test to measure oxygen saturation levels in new born infants which can help to identify potential congenital heart problems. The evidence was not conclusive and so the NSC has announced that it will be running a pilot programme to better assess the effectiveness of pulse oximetry and the related implications if it were to be specified as part of the new-born infant physical examination (NIPE). This will help to address longstanding concerns in this area, and the review will stay close to this work as we are very supportive of the evidence-based approach.

Conclusion and next steps

The review has taken seriously the Boards' ambition for an implementable solution to be delivered within one year. Early work with stakeholders made clear that the scope of the review needed to be wider than originally envisaged and that a new approach would need to be developed, retaining what was useful from earlier processes (e.g. the work on standards for children's surgical centres) but with no pre-conceptions about a particular "answer". The review also needed to rebuild trust, and this has been successful because in large part it was not rushed. In the year since we were asked to take on this challenge, NHS England has invested significant time and effort in working with public and patients (and their representatives), clinicians from provider organisations and national bodies, and provider leaders. We have been very open in our processes and maintained a constant account of what we are doing, publishing all relevant documentation at every step of the way. Taken together, these factors have made it hard to meet the ambitious timeline originally envisaged.

Good progress has however been made on all of the review's objectives, especially in the development of standards for the whole lifetime pathway. Plans are well advanced to consult on these standards, but there remain significant risks, and our current expectation is that consultation could commence in September 2014, subject to approval by NHS England's internal assurances processes. This could then mean that the review would be able to make recommendations to the NHS England Board on all six objectives at the end of the financial year.

Figure 1: Decision making, advice and engagement

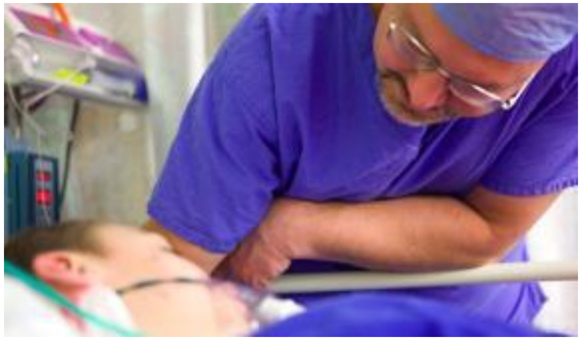


New Congenital Heart Disease Review

NHS England

Update to the Specialised Commissioning Oversight Group

July 2014



Michael Wilson
Programme Director

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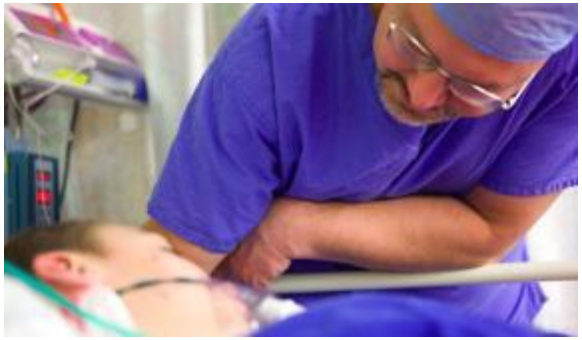
Background



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The Challenge

- The best outcomes
- Consistently meeting standards
- The best patient experience
- Standards driven
- No pre-conceived answers
- The health of the service
- Delivery at pace vs. inclusivity
- Scope

Scope of review

a) Improving the quality of care for people with suspected or diagnosed congenital heart disease (CHD) along the whole patient pathway

b) The review covers all care for CHD commissioned by the NHS for people living in England

c) Conditions which aren't CHD but receive services wholly or mainly from CHD pathway – won't set standards for these conditions but full involvement in review

d) Services which aren't CHD-specific but often used by CHD patients - review won't set their standards but full involvement and consideration of dependencies

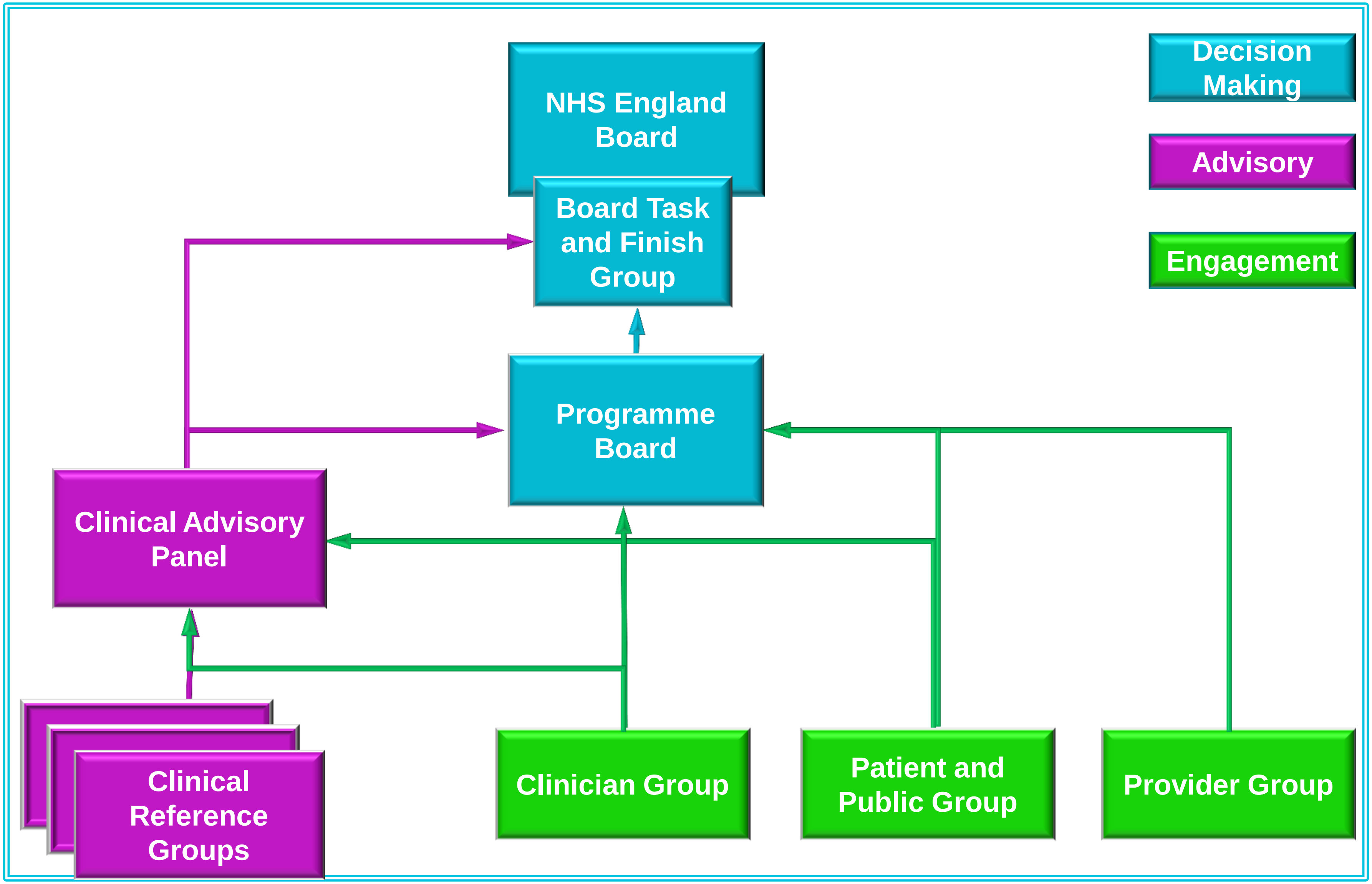
Services which are explicitly out of scope of this review are:

- Adults with inherited heart disease;
- Adult respiratory ECMO;
- Local maternity services; and
- Pulmonary hypertension services.

Objectives… we aim to

- Develop standards to improve outcomes, minimise variation & improve patient experience
- Analyse demand for specialist inpatient care now and in future
- Make recommendations about function form and capacity of services to met demand and quality standard, taking account of accessibility and health impact
- Make recommendations on commissioning and change management approach including workforce and training needs
- Establish a system for provision of information about performance to inform commissioning and patient choice
- Improve antenatal and neonatal detection rates

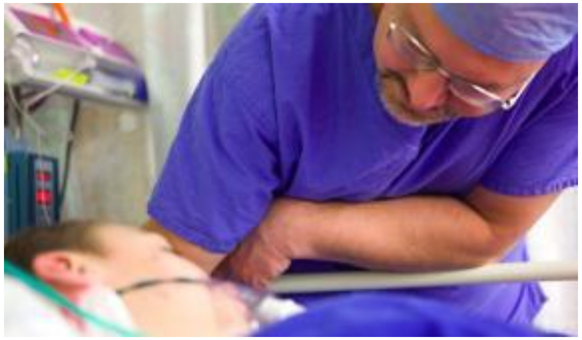
Decision making, advice and engagement



New Congenital Heart Disease Review

NHS England

Preparing for consultation



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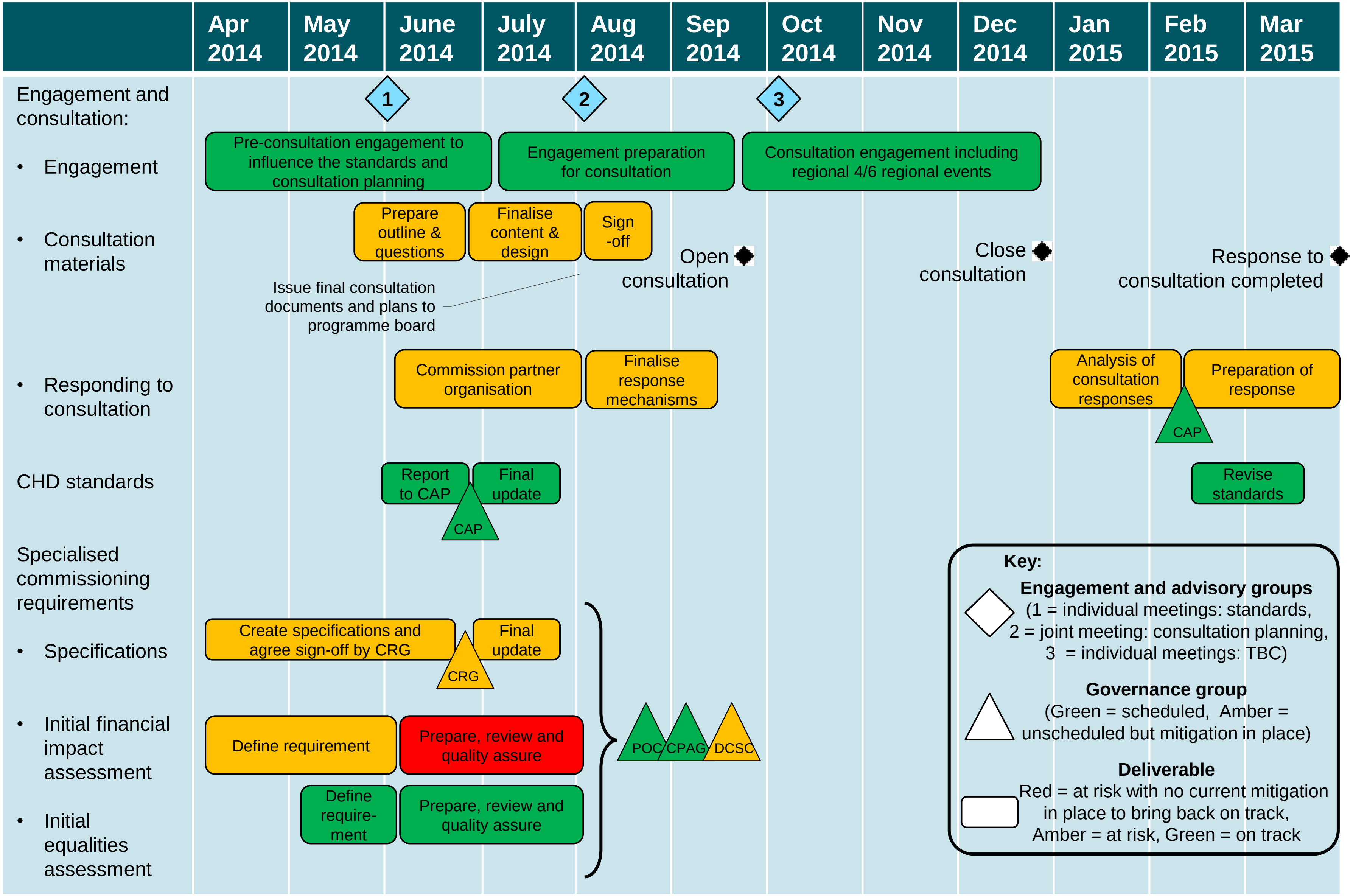
Governance and assurance: feedback from POC and CPAG

We attended both POC and CPAG meetings in April 2014 to seek their feedback on what they need to see to approve the consultation:

Both groups endorsed our approaches to:

1. Assurance, governance and decision making
2. Stakeholder testing – in addition CPAG will need to assure the process of creating the standards and ensure that they were co-produced with our stakeholders
3. Having due regard to the aims of the Equality Act 2010
4. Financial impact assessment

Current expected timetable (June 2014)



Apr 2014 | May 2014 | June 2014 | July 2014 | Aug 2014 | Sep 2014 | Oct 2014 | Nov 2014 | Dec 2014 | Jan 2015 | Feb 2015 | Mar 2015

Engagement and consultation:

1 2 3

- Engagement

Pre-consultation engagement to influence the standards and consultation planning

Engagement preparation for consultation

Consultation engagement including regional 4/6 regional events

- Consultation materials

Prepare outline & questions

Finalise content & design

Sign-off

Issue final consultation documents and plans to programme board

Open ◆ consultation

Close ◆ consultation

Response to ◆ consultation completed

- Responding to consultation

Commission partner organisation

Finalise response mechanisms

Analysis of consultation responses

Preparation of response

CAP

CHD standards

Report to CAP

Final update

CAP

Revise standards

Specialised commissioning requirements

- Specifications

Create specifications and agree sign-off by CRG

Final update

CRG

- Initial financial impact assessment

Define requirement

Prepare, review and quality assure

- Initial equalities assessment

Define require-ment

Prepare, review and quality assure

POC CPAG DCSC

Key:

◇ **Engagement and advisory groups**
(1 = individual meetings: standards,
2 = joint meeting: consultation planning,
3 = individual meetings: TBC)

△ **Governance group**
(Green = scheduled, Amber = unscheduled but mitigation in place)

▭ **Deliverable**
Red = at risk with no current mitigation in place to bring back on track,
Amber = at risk, Green = on track

Consultation materials

Our consultation materials:

- a plain English consultation document
- an audio visual version of the consultation document
- a full reference document
- an easy read consultation document
- draft standards and specifications
- initial financial impact and equality assessments

Communications plan

Ensure all interested parties are aware of consultation notify known stakeholders via:

- NHS England regional and area teams;
- charities and support groups;
- professional associations; and
- provider organisations.

Use national, local and specialist media opportunities to raise awareness.

Develop materials for use by partners including FAQs.

Events

We are planning at least four engagement events during consultation.

We are considering the opportunities for wider engagement, not solely delivered by the review team, but taking into account the roles of the following:

- NHS England regional and area teams
- Charities and support groups
- Professional associations
- Provider organisations

We are planning targeted engagement with adults with CHD; Black, Asian and Minority Ethnic (BAME) groups; CHD patients with learning difficulties and families who have suffered bereavement/poor outcome.

Roles during consultation

During consultation the review team will:

- run engagement events and targeted activities
- respond to questions raised during consultation
- provide supporting materials for national, regional and local events run by others
- respond to requests to speak at events.

To this end, the review team is keen to maximise the impact it can have and is keen to work with colleagues in NHS England regional and area teams to identify how we can collectively encourage and support as many events as possible.

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