Feedback from Engagement and Advisory Groups

(January / February 2014 meetings)

Introduction

The new congenital heart disease (CHD) review team held meetings with:

- Providers chaired by Chris Hopson, Chief Executive of the Foundation Trust Network on 15 January 2014 to which Chief Executives (or their nominees) from all providers of CHD services were invited;
- Clinicians chaired by Professor Deirdre Kelly, Professor of Paediatric Hepatology, Birmingham Children's Hospital on 30 January 2014 to which clinicians from all providers of CHD services as well as representatives of other linked specialties were invited; and
- Patients and public chaired by Professor Peter Weissberg, Medical Director at the British Heart Foundation on 10 February 2014 to which a range of national, regional and local charities were invited.

The purpose of the meetings was to provide an opportunity for the new review team to update everyone on its work and progress to date (summarised in John Holden’s weekly blogs) with a particular focus on the standards and some of the areas where there is debate: the ‘knotty issues’. The providers and clinicians meetings were well attended; the patient and public meeting less so. This may have been because of the adverse weather conditions, but may also have been because some invitees did not receive their invitations. The new review team are taking action to ensure that they have the correct contact addresses for all those on the patient and public group.

The new CHD review

- **Overview**

  John Holden summarised the key messages emerging from the groups and outlined the programme objectives. He emphasised the importance of the engagement process and the new review team’s commitment to discussion before, during and after the consultation.

- **Standards**

  Michael Wilson set out the areas covered in the standards work and for each of these identified what is new. He also indicated which areas were contentious and attracted a range of often conflicting views.

- **Analysis**

  In addition to the above, John was able to share a first cut of the analytical work at the Patient and Public meeting.

- **Conflicts of interest**

  In all groups, the new review team reported that the template has been signed off. It is currently being trialled with the aim of sharing with all participants as soon as possible. The team will provide guidance and support to aid completion and once completed, declarations of interest will be posted on the website.

Key issues

There was lively discussion in all three groups. The content of the discussions was specific to the groups. This meant that the providers focused on commissioning, collaboration and working together to influence the way in which services will be provided in the future; the clinicians focused on the knotty issues in the emerging specifications that related to their roles; and the Patient and Public Group plenary highlighted, amongst other things, safety and quality concerns. The respective discussions are reflected in more detail in the accompanying note of the individual meeting. The notes also include Questions and Answers from each session.

Common issues raised in all groups

- Recognition that services have the potential to become better and that the work on standards will play an important role in making this happen
- Importance of recognising and taking account of interdependencies
- Effective communications and supportive relationships across networks and nationally

Common issues raised in the provider and clinicians' groups

- Support for the patient pathway approach, but a recognition that one pathway does not fit all: patients are different
- Importance of networks and teams in delivering high quality services

Issues discussed by one group only

- Pathway and model of care will drive commissioning and will encourage collaboration across centres
- Regional rather than national or local networks are probably the right way to commission
- Need to have adequate funding and clarity of intent and purpose

- Need to get incentives right to move from a good to great service
- Sub-specialisation carries risks and can create unsustainable units
- 1 in 3 rotas were acceptable but 1 in 4 is the ideal (with potentially 1 in 5 for transplant surgeons
- 125 cases per surgeon per annum seemed reasonable as a minimum

Conclusion

The meetings provided an opportunity for participants to hear about the standards and to seek more clarification as needed. As noted above, a number of themes were common discussion points for all groups. The new review team is considering all the points made and will incorporate them into its thinking as it takes work forward. The team will continue to hold meetings with the groups and will consider further ways in which we can improve our communication generally, and in particular, our working with children and young people and Black, Asian and Minority Ethnic (BAME) groups.

Provider Group Meeting

15 January 2014

Introduction

The Chair welcomed attendees and noted apologies from Blackpool Teaching Hospitals NHS Foundation Trust. Notes of the previous meeting were agreed, with a correction to reflect Great Ormond Street Hospital for Children NHS Foundation Trust's attendance at the previous meeting.

Managing conflicts of interest

The Chair explained that the new review team and the Programme Board were keen to err on the side of caution, so that as much information as possible is disclosed.

Michael Wilson informed attendees that the policy had been signed off and that the template has been agreed by the Programme Board. The new review team intends to publish all declarations on its website. Before the template is circulated widely, the team will test the process with the Programme Board and team members.

Presentations

- **Feedback**

  In his presentation, John Holden summarised the key messages emerging from the groups. **These are in the accompanying slides.** He outlined the programme objectives and emphasised the importance of the engagement process, and the new review team's commitment to discussion before, during and after the consultation.

- **Standards**

  Michael Wilson then presented a summary of the standards work identifying the areas covered, what they are aiming to achieve and some of the key challenges/knotty issues. **These are in the accompanying slides**. Questions were taken during the presentations and are at Annex A.

Plenary discussion

A plenary discussion followed in which the following key themes were raised:

Commissioning

- Pathway and model of care will drive commissioning and will encourage collaboration across centres
- Pathway is a positive step forward– it incentivises joined up conversations
- Need to compare with e.g. cancer pathway approach
- Small alliance contract – huge risk. By extension doing at scale over larger geography is very difficult. Therefore regional rather than national or local networks are probably the right way to commission
- Need network to be sufficiently large to be sustainable but small enough to manage
- Commissioners need to ensure adequate funding and to have clarity of intent and purpose
- Very important to get interaction between provider and commissioner right
- Need to find right incentives to move from a good to great service e.g. financial; organisational; patient outcomes
- What are conditions for success? Commissioners driving through competitive tender may not be the route to success but it could sometimes be effective e.g. complex epilepsy service
- Need to recognise that some services are stronger; others would be vulnerable in competitive tendering exercise
- Tariff an obstacle to sub-specialisation. Need a ‘national model’ or change HRG

Collaboration

- Collaboration feels intuitively right but need to have clear commissioner expectations that collaboration is good organisational behaviour
- Need to look at what the Operational Delivery Network model offers to future arrangements and collaborative working
- Look at relationships across boundaries (SCNs)
- Strong relationships already exist between some clinicians in some centres on a 1 to 1 basis – how do organisations emulate this regionally and nationally?
- Local networks could work but may or may not be best for population
- Children’s cardiac services have not had a good history of network working – Units have worked individually – not had drive for centralised governance agenda around outcomes
- Can/ will providers collaborate? One of the dynamics is “15-30” (from NHS Planning guidance) which may drive organisations to be more reticent – key concern

Co-creation

- Guiding principle - providers to co-design networks’ organisation/provision - risk of NHS England making unilateral decisions if providers do not respond constructively
- Set out blueprint for the future with a stepped approach
- Need to discuss with colleagues in units

At the end of the discussion, the Chair suggested having a meeting of the provider group without the new review team present and this was welcomed by the group. The aim will be to have a provider-only session at the beginning or end of one of the future meetings (i.e. 18 March 2014 or 21 May 2014).

Feedback

The group also fed back that they had found the meeting useful but felt that they needed reassurance that there will be consistency checking and 'congruency' across the whole of specialised commissioning. The Chair agreed to feed this back to the Programme Board of which he is a member.

Future meetings

The agendas for future meetings had been circulated and the Chair asked whether the provider group were happy with the suggested agendas:

18 March 2014	Standards, analytical work, dashboards
21 May 2014	Workforce training, model of care

The group felt that it would be useful to speak about potential models of care alongside standards. (*Safe and Sustainable* looked at surgical centres and cardiology centres etc).

In the new review:

- What models are on offer?
- What options are still on the table?
- Will models drive standards?
- Are we talking about a homogenous model or sub-specialisation?
- Which things ought to be specified?
- Which things can be left for local approaches?

Joint meeting of the three engagement and advisory groups

The clinicians', patient and public and provider groups all expressed a wish to have a joint meeting. The date is to be finalised, but is likely to be mid/late May 2014.

Questions and Answers

Scope

Q. Will the new review team be looking only at the congenital heart disease workforce?

A. We will need to look at this when we come to it. We have identified in our work with the standards group so far that there needs to be clinical psychologist input and that we do not have national cover. There may be other parts of the workforce that may be impacted. But this is likely to emerge in discussions about structures.

Planning and commissioning

Q. Providers are being asked through planning guidance to look at specialist commissioning and the potential to have 15/30 centres. How is the new review team going to ensure that timelines are aligned?

A. NHS England is consulting on specialised services and how they might be delivered. That work sits alongside the new review and it will be important for us to make the links as we move forward. We are working closely with the Director of Direct Commissioning who is a member of the Programme Board for the new review and also with the Specialised Commissioning Lead in order to align our work as much as possible. If 15/30 is what we are heading towards, there is already a concentration of specialist units – it is likely, although we do not know, that many will be on that list.

Q. Providers are looking at 2 and 5 year business plans – we need to ensure that we have alignment

A. The Chair has raised the issue of it being difficult to make 5 year plans unless there was clarity about the 15/30.

Q. Will there be transformation funds for local services?

A. We recognise that there is often a cost of change (double running etc) but that is in the context of the very tight financial situation.

Q. What is the process for developing service models?

A. It is really important that Engagement and Advisory Groups are involved in the discussion. There is not one preferred model and we are keen to have your and others' input in the process.

Q. Will NHS England commission against a few specifications that all providers can achieve or against a more stringent set that only a few can achieve?

A. We intend to set standards which reflect the "ideal", not the lowest common denominator. We want national consistency, not variation, but we will address non-compliance through our commissioning and change model.

Q. Will derogations be considered?

A. There will be different ways in which we can work towards implementing change, and time limited derogations could be part of this.

Q. Will the new specification be in place in time to fit in with the business planning cycle for 2015/16?

A. Some parts of the specification will be in place. Our work on standards and the specification is driven by the desire to have the highest quality service and not by any deadline for potential reconfiguration.

Q. We need to recognise that being aspirational in terms of the service may need changes in the ways things are done and managed. Are the new review team considering affordability and deliverability?

A. We will need an impact assessment for our overall specification, and for any specific change proposals. But we are not yet at the stage of confirming, for example, numbers of clinicians; centres and activity. We will be looking at the information we have; the findings of the independent evidence review we are commissioning; the work we are doing with this group and others; and the consultation to inform our thinking.

Q. Will it be the same process as other service specifications i.e. Put out the specification – test – see if need reconfiguration?

A. That approach is a good starting place, but we shouldn't rule out the possibility of being more radical to make a step change if required. . This could be a test bed for other areas. We may look at a spectrum of approaches.

Reconfiguration

Q. When will work on Objective 3 (function, form, capacity) be completed?

A. Our work on Objective 3 is to a large extent dependent on the outcome of the standards and specification consultation, which we will look at alongside the refreshed data on demand and evidence on different service models.

Data and information

Q. What is the new review team going to do in response to funding for regional CHD registers being withdrawn?

A. We intend to speak to Public Health England (PHE) about the need for a new national registry.

Q. How ambitious are we going to be? Are we looking at international evidence?

A. We want world class services delivered consistently across England. To support this, our review will look at international evidence, for example in the literature review.

Q. Does the new review team have data relating to interdependencies?

A. In addition to clinical advice, we have also asked NICOR and ScHARR to look at this.

Pathways

Q. There are elements of the pathway that will not fall to be commissioned by NHS England – how will these be dealt with?

A. The important thing is to ensure that the whole pathway is based on agreed standards. We will need to look further at commissioning as part of our work under Objective 4 (commissioning and change model).

Networks

Q. We are looking at the network for paediatric and adult congenital heart disease – what about networks with other services e.g. renal?

A. We recognise that networks overlap and will want to encourage working across networks. We would be keen to hear from you about how we can make this work most effectively.

Q. There has been a lot of debate about networks and staffing. Is there going to be a common model or could there be a mix with, for example, sub-specialisation?

A. Sub-specialisation was raised as a potential way of working at our last round of meetings with yourselves and the patient and public group. There was less support among clinicians. We need to hear the clinical concerns and feed these back into the discussion

Item 7.1

Annex B

Attendees at meeting on 15 January 2014

Name	Role	Organisation
Chris Hopson (Chair)	Chief Executive	Foundation Trust Network
Beverley Thorp	Associate Director of Operations	Brighton and Sussex University Hospitals NHS Trust
Darren Banks	Director of Strategic Development	Central Manchester University Hospitals NHS Foundation Trust
Kate Shields	Director of Strategy	University Hospitals of Leicester NHS Trust
Bryan Gill	Consultant, Neonatal Medicine	Leeds Teaching Hospitals NHS Trust
Lynne Willetts	Director of Operations (Division B)	University Hospitals Birmingham NHS Foundation Trust
Robert Burns	Director of Planning and Information	Great Ormond Street Hospital for Children NHS Foundation Trust
Dr Helen Byworth	Head of Contracting	Newcastle upon Tyne Hospitals NHS Foundation Trust
Jane Tomkinson	Chief Executive	Liverpool Heart and Chest Hospital NHS Foundation Trust
Ian Atkinson	Deputy Chief Operating Officer	Alder Hey Children's NHS Foundation Trust
Dr Ian Abbs	Medical Director	Guy's & St. Thomas' NHS Foundation Trust
Ian Barrington	Divisional Director: Women and Children's Services	University Hospitals Bristol NHS Foundation Trust
Stephen Williamson	Divisional Director of Operations	University Hospital Southampton NHS Foundation Trust
Claire Tripp	Director of Operations	Papworth Hospital NHS Foundation Trust
John Holden	Director of System Policy	NHS England
Michael Wilson	Programme Director	NHS England
Jennie Smith	Project Co-ordinator	NHS England
Penny Allsop	Project Manager	NHS England
Caroline Gillespie	Project Manager	NHS England
Julia Grace	Regional Programme of Care Manager – Women's and Children	NHS England
Lisa Marriott	Senior Service Specialist	NHS England
Rachel Lundy	Senior Service Specialist, Women & Children Programme of Care	NHS England

Clinicians' Group Meeting

30 January 2014

Introduction

The Chair welcomed attendees and emphasised the important role the engagement and advisory groups have in informing the new review. Notes of the previous meeting were agreed, with a correction to reflect a point raised about outcome measures and a denominator for outcomes.

The Chair advised that dates of future meetings have been shared to give people as much notice as possible. She also explained that work is underway to finalise her visits to specialist units. The aim of the visits is to meet clinical teams in their units and to understand better how things are working: what is going well and what the challenges are. There will also be an opportunity to meet patients and the public.
The updated terms of reference for the Clinicians' Group were shared and agreed.

Managing conflicts of interest

The Chair explained that the new review team and the Programme Board were keen to err on the side of caution, so that as much information as possible is disclosed.

Michael Wilson informed attendees that the policy had been signed off and that the template has been agreed by the Programme Board. The new review team intends to publish all declarations on its website. Before the template is circulated widely, the team will test the process with the Programme Board and team members.

The team will provide guidance and support to aid completion.

Presentations

- **Feedback**

  In his presentation, John Holden summarised the key messages emerging from the groups. **These are in the accompanying slides.** He outlined the programme objectives and emphasised the importance of the engagement process, and the new review team's commitment to discussion before, during and after the consultation.

- **Standards**

  Michael Wilson then presented a summary of the standards work identifying the areas covered, what they are aiming to achieve and some of the key challenges/knotty issues.
  These are in the accompanying slides.

  Questions were taken during the presentations and are at Annex A.

Table discussions

The meeting divided into smaller groups to discuss the following issues:

Interdependencies

In particular the interdependencies between:

- paediatric congenital heart surgery and other paediatric tertiary and supporting services
- adult congenital heart surgery and other adult tertiary and supporting services
- paediatric congenital heart surgery and adult congenital heart surgery

The group were asked:

- What is the scale of benefit gained in each case by achieving co-location?
- Are there interdependencies that are more significant than others in these services?
- What is the interdependency with neurosurgery?

Feedback

The group recognised the risk of self-interest, i.e. seeking to preserve the status quo in this sort of discussion.

The group felt that the co-location of paediatric congenital heart surgery with other paediatric services and adult congenital heart surgery with other adult tertiary services is ideal, as is the co-location of paediatric and adult congenital heart surgery.

Joint rotas and the need to minimise losses to follow up at transition mean that paediatric congenital heart surgery and adult congenital heart surgery need to be in close proximity if not co-located.

The important issues are response time and time to bedside, and the ability to do neurosurgery on site if needed.

The group considered the patient pathway and the need to ensure that the clinical team available is appropriate to the needs of the individual patient. In some cases the assessment will take place in outpatients with a cardiologist; but in other cases, the whole team will need to be available and this needs a hospital setting. There was discussion of circumstances where it might be appropriate for the surgeon to go to the patient in another setting, rather than require the patient to attend a particular unit.

The important issue is not always co-location, but rather excellent and timely communications and information sharing between specialties as part of a networked approach is essential.

Sub-specialisation

The new review team explained that this issue had been raised by both of the other engagement and advisory groups (Providers, and Patient & Public) as an important aspect of this work.

The current wording in the proposed standards is:

- *Consultant interventionalist cardiologists and surgeons must only undertake procedures for which they have the appropriate competence. In other cases, either the support of a competent second operator must be obtained within the network or another Specialist Surgical Centre (SSC) or the patient must be referred to an alternative SSC where a surgeon has appropriate skills. Out of hours arrangements must take these requirements into account.*
- *Arrangements must be in place in each SSC both for consultant interventional cardiologists and for congenital cardiac surgeons to operate together on complex or rare cases, within compliant rotas.*
- *SSCs and networks must work together to support national, regional and network collaborative arrangements that facilitate joint operating, mentorship and centre to centre referrals.*

The group were asked:

- Do you agree with the approach of not designating sub-specialist centres?
- Will the proposed standards ensure that all patients are cared for by the most appropriate surgeon for their needs?

The group noted that as posed, the questions rely too much on individual cardiologists and surgeons and do not focus on the need for competent teams supervised through effective networks.

The emphasis needs to be on networks that monitor themselves through feedback and peer review and become a mechanism to share good and new practice that can be rolled out more widely across centres. In terms of improving practice, the data needs to focus on morbidity as well as mortality.

The group felt that all centres should be able to do all procedures and that there should be no further sub-specialisation as this creates unsustainable units. At the same time, surgeons and units needed to recognise their own limitations – for example, some of the surgeons working with adult patients with congenital heart disease are not specialists in congenital heart disease.

There was general agreement that the emphasis needs to be on networks that monitor themselves through feedback and peer review and become a mechanism to share good and new practice that can be rolled out more widely across centres. In terms of improving practice, the data needs to focus on morbidity as well as mortality.

The service should support the free movement of surgeons to mentor and work alongside other surgeons for difficult cases and the managed introduction of new techniques.

Surgeon activity

a) Surgeon numbers

This discussion was prefaced by discussion of the need for surgeons to work in teams to ensure:

- Availability of a range of skills and concentration of expertise
- Resilient 24/7/365 clinical cover with appropriate work/life balance
- Clinical governance and support, training and research

The current wording in the proposed standard is:

A consultant congenital cardiac surgeon must not participate in an on-call rota more frequent than 1 in 4 (requiring a minimum of four surgeons). In centres with three surgeons, there will be the potential for commissioners to agree a 1 in 3 rota for a defined period while working towards a 1 in 4 rota.

The group were asked:

- Do you agree that ideally surgeons should work in teams of at least 4? Why?

b) Surgical volumes

This discussion was prefaced by discussion of the need for surgeons to operate regularly to maintain their skills. This is especially important in congenital heart disease because of the range and complexity of procedures undertaken.

The current wording in the proposed standard is:

Congenital cardiac surgeons must be the primary operator in a minimum of 125 congenital heart operations per year (in adults and/or paediatrics), averaged over a three year period.

And to aid definitions and counting it has been agreed:

- Only auditable cases may be counted, as defined by submission to NICOR
- Where a senior surgeon is mentoring a second consultant for complex cases or training a new appointment both could count the procedure, as long as the 'junior' consultant is the first operator. This would provide recognition of the work done in the area of mentorship and succession planning. However, in the situation of a more junior consultant assisting a senior consultant, only the primary operator would count the case.

The group were asked:

- Do you agree with the standard?
- Is any further guidance needed on counting?
- Should the standards also set a minimum volume for centres?

The group noted that surgeon numbers and surgical volumes are inextricably linked.

Surgeon numbers: While important, the group felt that the number of surgeons is a less important determinant of quality than the number of cases per surgeon. The group felt that 1 in 2 on call rotas were unacceptable; 1 in 3 was acceptable (and that if there was a choice for a 400 procedure unit between 3 surgeons achieving 125 cases and 4 surgeons not achieving 125 cases, the former is preferable; but that 1 in 4 should be the minimum that all units aim for, not least because 1 in 3 is 1 in 2 for 30 weeks of the year, and would lead to a better work/life balance. On-call is not usually onerous except in transplant centres, where a 1 in 5 (or better) may be appropriate.

Surgical volume: The group considered that 125 cases per surgeon seemed reasonable as the absolute minimum to ensure quality.

The group questioned whether there needed to be a measure of competency as well as a measure for numbers and volumes.

Future meetings

- Monday 7 April 2014 13:30 – 17:00
- Monday 2 June 2014 13:30 – 17:00

Joint meeting of the three engagement and advisory groups

The clinicians', patient and public and provider groups have all expressed a wish to have a joint meeting. The date is to be finalised, but is likely to be mid/late May 2014.

Questions and Answers

Consultation

Q. Does the consultation have to be 3 months?

A. Yes. We recognise that Cabinet Office guidance is that consultation periods can vary, depending on the consultation. However, with a consultation like this one, we want to ensure that we allow maximum time for all interested parties to respond. We also recognise that anything less than 12 weeks in this case may be challenged.

Q. How will we ensure that we have the best services if we are potentially thinking about having commissioning derogations?

A. We will all be working to the same standards, but we need to recognise that not all units will meet every aspect of the standards in the short term. We will need to consider the need for temporary flexibility so that all units have the opportunity to develop in order to meet the standards.

Annex B

Attendees at meeting on 30 January 2014

Name	Chair and Enablers
Professor Deirdre Kelly	Professor of Paediatric Hepatology and Chair, new CHD review Clinicians' Group
Tony Salmon	Chair, new Congenital Heart Disease review Standards group
Professor John Deanfield	Chair, Adult Congenital Heart Disease, Standards group
David Anderson	British Congenital Cardiac Association

Clinician in attendance	Organisations
Prem Venugopal	Alder Hey Children's NHS Foundation Trust
Mark Spence	Belfast Health and Social Care Trust
Oliver Stumper	Birmingham Children's Hospital NHS Foundation Trust
Joseph Zacharias	Blackpool Teaching Hospitals NHS Foundation Trust
Rachel James	Brighton and Sussex University Hospitals NHS Trust
Dirk Wilson	Cardiff and Vale University Health Board
Daniel Keenan	Central Manchester University Hospitals NHS Foundation Trust
Andrew Taylor	Great Ormond Street Hospital for Children NHS Foundation Trust
Owen Miller	Guy's and St Thomas' NHS Foundation Trust
Carin Van Doorn	Leeds Teaching Hospitals NHS Trust
Glenn Russell	Liverpool Heart and Chest Hospital NHS Foundation Trust
Apologies	Newcastle upon Tyne Hospitals NHS Foundation Trust
Elizabeth Orchard	Oxford University Hospitals NHS Trust
Lorna Swan	Royal Brompton and Harefield NHS Foundation Trust
Laurence O'Toole	Sheffield Teaching Hospitals NHS Foundation Trust
Fiona Walker	University College London Hospitals NHS Foundation Trust
James Gnanapragasam	University Hospital Southampton NHS Foundation Trust
Sara Thorne	University Hospitals Birmingham NHS Foundation Trust
Andrew Parry Alison Hayes	University Hospitals Bristol NHS Foundation Trust
Aidan Bolger	University Hospitals of Leicester NHS Trust

Name	Medical Associations and Royal Colleges
Ravi Gill	Association of Cardiothoracic Anaesthetists
David Anderson	British Congenital Cardiac Association
Martin Lowe	British Heart Rhythm Society
Sarah Vause	British Maternal & Fetal Medicine Society
Emma Twigg	British Psychological Society
Nick Banner	Cardiothoracic Advisory Group
Eithne Polke	CATS – PICS ATG
Giles Peek	Extracorporeal Life Support Organization (ELSO)
Annette McHugh	Fetal Anomaly Screening programme
Pran Pandya	
Jeff Perring	PICS
Collette Cochran Sheena Vernon	Royal College of Nursing
David Howe	Royal College of Obstetricians and Gynaecologists
Andrew Mclean	Society for Cardiothoracic Surgery

Name	Clinical Reference Groups
Jane Eddleston	Adult Critical Care CRG
Trevor Richens	Congenital Heart Services CRG
Graham Stuart	
John Dark	Heart & Lung Transplantation CRG
Neil Marlow	Neonatal Critical Care CRG
Andy Petros	Paediatric Intensive Care CRG

Name	NHS England Representatives
Michael Wilson	Programme Director
John Holden	Director of System Policy
Jane Docherty	Project Manager
Jennie Smith	Project Administrator

Patient and Public Group Meeting

10 February 2014

Introduction

The Chair welcomed attendees and noted that a number of people had not been able to attend. It was thought that this might have been because of the adverse weather conditions, but the new review team undertook to revisit its contacts list to ensure that those who were expected, but not present, had received details about the meeting.

The Chair explained that the purpose of the meeting was to provide an update on work to date, set out the direction of travel and to hear from the group about their concerns and views.

Managing conflicts of interest

The Chair explained that the new review team and the Programme Board were keen to err on the side of caution, so that as much information as possible is disclosed.

Michael Wilson informed attendees that the policy had been signed off and that the template has been agreed by the Programme Board. The new review team intends to publish all declarations on its website. Before the template is circulated widely, the team will test the process with the Programme Board and team members.

The team will provide guidance and support to aid completion.

Presentations

- **Feedback**

  In his presentation, John Holden summarised the key messages emerging from the groups. **These are in the accompanying slides.** He outlined the programme objectives and emphasised the importance of the engagement process, and the new review team's commitment to discussion before, during and after the consultation.

- **Standards**

  Michael Wilson then presented a summary of the standards work identifying the areas covered, what they are aiming to achieve and some of the key challenges/knotty issues. **These are in the accompanying slides**.
  Questions were taken during the presentations and are at Annex A.
  Michael Wilson asked the group to let the new review team know if there was any relevant material which could be used to inform the analytical work.

- **Evidence**

  John Holden presented the latest work from Joanna Glenwright who leads on the analytical work.

Group discussion

At the beginning of the event some members of the group wanted to discuss current concerns about quality and safety in surgical units. They felt that there were issues within units and possibly this was due to a lack of investment in services because people were waiting for the outcome of this review and that this posed a risk to current service provision.

It was suggested that an unacceptable number of operations were being cancelled at short notice, causing distress to patients and families. But other group members argued that there is always a risk, in any health system, that surgical capacity will be required to perform more clinically urgent work.

Members of the group advised that they had raised issues relating to safety both with NHS England and the Secretary of State for Health and not seen a response commensurate with the concern being raised.

Acknowledging the strength of feeling in the room and the concerns raised, the new review team undertook to arrange a meeting at which those responsible for quality and safety could come together with the group to discuss the issues. This would most likely include a representative from the Care Quality Commission (given their responsibility for essential levels of safety and quality.

Other areas that were raised for potential inclusion in the standards were:

- transport and retrieval services (Embrace was raised as an example of best practice);
- co-location of antenatal care;
- the need to ensure that we have the right care in the right place and that services fit around children and not vice versa;
- interdependencies and response times, and the need for robust agreements between hospitals;
- effective communications between clinicians across networks and nationally; and
- recognition that there is not one pathway - that patients are different and so are their pathways.

The group noted that it would be important to prioritise implementation of the standards.

Feedback

Members of the group thanked the new review team for their work to date and suggested the following items for future discussion:

- Antenatal screening.
- Neonatal detection.
- Impact of early diagnosis.

Future meetings

The next meeting scheduled for 27 March 2014 will be used to discuss – alongside other issues – some of the current safety and quality issues raised in this meeting.

Joint meeting of the three engagement and advisory groups

The clinicians', patient and public and provider groups have all expressed a wish to have a joint meeting. The date is to be finalised, but is likely to be mid/late May 2014.

Questions and Answers

Data

Q. **How will we get accurate measures since NICOR only collect information on children who have had surgery?**

A. We are looking at ways of addressing this e.g. through a national anomaly register introduced by Public Health England. We may also be able to get information from the Paediatric Intensive Care Audit Network (PICANet) and directly from clinicians.

Q. **What is being done to ensure safety and quality now? Operations are being cancelled. It does not feel like concerns are being addressed**

A. We recognise that there are cancellations on the day for adults as well as children. In part this is due to capacity, throughput and the ability to flex. There is a system of quality regulation in place and at a local level where concerns are raised; CQC and the Chief Inspector of Hospitals have a key role to play alongside NHS England regional and area teams. We have heard the concerns raised in the room today.

Q. **Is the new review team liaising with Scotland, Wales and Northern Ireland?**

A. Yes. There are clinicians from Scotland and Wales on the Standards group and the Wales Cardiology Service to the Clinicians' Group. Added to this, the analytical work will take account of cross-border flows.

Q. **What is the new review team doing to ensure that the information collected on the NHS dashboard is robust?**

A. The dashboard is one tool we have to ensure that we are collecting comprehensive, consistent information. As the single national commissioner for these services, NHS England can look at what is being collected and ask for other information to be collected as appropriate.

Q. **Will NHS England suggest to Ministers that they attach targets to these services and so get additional funding?**

A. NHS England is legally responsible for delivering congenital heart disease services. We are already investing £12-13 billion in specialised services. We need now to look at how we can make service improvement within the available resource. The cost of change may incur some additional costs, but there is also evidence that quality improvement can reduce costs.

Q. Who are the Clinical Reference Group (CRG) stakeholders?

A. The process is underway and successful candidates maybe known by the end of February 2014.

Q. How will you engage with the Patient and Public Group during the pre-consultation phase?

A. We consider that all our work to date is part of the overall engagement. We are looking at how best to engage with the Patient and Public Group and our other Engagement and Advisory Groups when we consult with the CRG external stakeholders and will keep you posted.

Q. Will derogations be considered and if so what does this mean?

A. We may consider derogations to enable us to draw up contracts with services that do not yet meet all the standards. Any derogation would be time-limited.

Q. Will the standards be used to close units?

A. The purpose of developing the standards is to ensure that NHS England commissions a consistently high quality of care for all patients nationally. Once the standards have been agreed we will be working with service providers to achieve compliance, including phased approaches. Regardless of capacity and demand, if a provider does not meet the standards and it seems unlikely that they ever will, then this raises the question of whether it is appropriate to continue to commission the service.

Item 7.3

Annex B

Attendees at meeting on 10 February 2014

Attendee	Organisation
Professor Peter Weissberg (Chair)	British Heart Foundation
Maura Gillespie	British Heart Foundation
Mike Knapton	British Heart Foundation
Anne Keatley-Clarke	Children's Heart Federation
Rohini Simbodyal	Children's Heart Federation
Sharon Cheng	Children's Heart Surgery Fund
Lois Brown	Children's Heart Surgery Fund
Chris Stringfellow	Down's Heart Group
Penny Green	Down's Heart Group
Hazel Greig-Midlane	Heartline Families
Adam Tansey	KEEPTHEBEAT
Robyn Lotto	KEEPTHEBEAT
Peter Turner	Little Hearts Matter
Suzie Hutchinson	Little Hearts Matter
Julie Wootton	Max Appeal!
Bob Ward	Save our Surgery
Trudy Nickels	The Brompton Fountain
Caroline Mutton	The Brompton Fountain
John Richardson	The Somerville Foundation
Jon Arnold	Tony Tickers
Caroline Langridge	Young Hearts

NHS England representatives	Role
John Holden	Director of System Policy
Michael Wilson	Programme Director
Jane Docherty	Project Manager
Claire McDonald	Engagement Advisor
Lauren Phillips	Programme Development Manager
Jennie Smith	Project Administrator