New Congenital Heart Disease Review

NHS England

Clinicians' Group Meeting

2 June 2014

1. Welcome, apologies, note of the last meeting and declarations of interest

The chair welcomed everyone, and especially the following new members:

- Dr Michael Burch: Great Ormond Street Hospital for Children NHS Foundation Trust
- Dimopoulos Konstantinos: Royal Brompton and Harefield NHS Foundation Trust
- Aisling Carroll: University Hospital Southampton NHS Foundation Trust
- Dr Simon McDonald: University Hospitals of Leicester NHS Trust
- P Venugopalan: PECSIG (Paediatricians with Expertise in Cardiology Special Interest Group)
- Gurleen Sharland, Julia Grace, Trevor Richens and Graham Stuart (joined for the table discussions on standards): Congenital Heart Services CRG

A full list of attendees can be found at Annex A.

The notes of the last meeting were agreed. Michael Wilson, Programme Director, asked attendees to complete their declarations of interest forms and send them to him as soon as possible.

2. Update and overview

John Holden thanked everyone for their continued support as we could not make progress without it.

He acknowledged that the work of the new review, whilst strategic, was more focused than the broader specialised services review currently underway and would need to be closely aligned with the outputs of the wider review as we moved into implementation.

It is a year since the Secretary of State announced that NHS England should carry out a fresh review. The NHS England Board set a one-year ambition for an implementable solution when it met in July 2013. The process needed more time to be comprehensive and we needed to re-build relationships. The public consultation on standards will now not begin until after the summer as there are specific governance/assurance requirements.

Trust visits

Professor Kelly fed back some high level impressions from the Trust visits. She reiterated that the review will report back on *themes and what we heard whilst on the Trust visits* and will not provide specific feedback on individual Trusts. Twelve visits have been completed and the Team are considering visiting 2-3 ACHD centres.

She confirmed what a privilege it had been to visit the Units and thanked everyone for being so welcoming. She highlighted the good work that is going on in all the Trusts. It was clear that there many different ways of working which is acceptable as long as they meet the standards and outcomes are good.

She summarised a few of the challenges which had been raised:

- Many units commented on the difficulties with paediatric intensive care unit (PICU) capacity and retrieval. Mark Darowski (Chair of the Paediatric Intensive Care Clinical Reference Group (CRG)) confirmed that there is a good specification for retrieval however there was still an issue for less dependent patients (below PICU level).
- Workforce:
    - more psychologists would be advantageous;
    - specialist nurses are essential for maintaining a cohesive service and were much appreciated by patients and their family; and
    - services are dependent on scientists and that difficulties may arise because of recent changes in training.
- Scrutiny of Surgical Results

  Many units highlighted the difficulties of being under continuous scrutiny and how small changes in mortality in specific cases had a detrimental influence on their overall results.

    - The recent breakdown in relationships had made it difficult for units to work together.
    - Many families spoke about concerns with local services, particularly with A&E and inpatient paediatrics.
- All patients and families hold the teams in the specialist centres in high esteem.

3. Standards and service specification focus groups

Topics suggested by group members for discussion prior to the meeting:

- Transplantation
- Interventional activity outside adult specialist surgery centres (SSCs)

Graham Stuart, Trevor Richens, Gurleen Sharland and Julia Grace who had been at the CRG meeting running parallel to the Clinicians' Group joined the meeting to help facilitate the smaller group discussions. The suggestions from CRG were:

- Networks: funding and geography
- Surgery: numbers and counting issues
- Tier 2: surgery/intervention sustainability
- Staffing: can we get enough?, training and recruitment - especially scientists

- Interdependencies: neurosurgery
- Tier 3: funding and commissioning

Four discussion groups were agreed:

- Tier 1 and tier 2: Activity outside adult speciality surgical centres
- Networks: what makes a network?
- Transplantation
- Obstetrics and co-location

Feedback

Tier 1 and tier 2: Activity outside SSCs

A subgroup considered that the limitations on interventional cardiology in tier 2 centres for adults with congenital heart disease (ACHD) were too inflexible and that there was the potential for these units to do more. This standard is different for ACHD because adult cardiologists with experience work outside SSCs but this is not the case for paediatric CHD. It was noted that the majority of adult atrial septal defect (ASD) closure is currently undertaken outside specialist surgical centres and that the results are good.

They considered that the flexibility offered by the standard on electrophysiology was more appropriate - this requires that electrophysiology may be undertaken outside a SSC if the patients are discussed at the multidisciplinary team (MDT) meeting. The group considered that this flexibility should be replicated for other forms of intervention/diagnostic catheters outside the surgical centre as long as they were performed as part of the network and patients were discussed at an MDT meeting. This might include ASD and patent foramen ovale (PFO) closure. They also recommended that arrangements for ASDs and PFOs should be consistent to reduce the risk of gaming. It was agreed that as a minimum British Cardiovascular Society (BCS) standards must be met including numbers of interventionists and numbers of procedures undertaken by each. The proposed tier 2 ACHD standards would also need to be met.

Any procedures carried out on adults in tier 2 or 3 must have cardiothoracic surgery on site.

There was concern that the surgical cover might not be adequate as general adult cardiovascular surgeons become more sub-specialist and might not have the skills. They also suggested a revision to the standard.

Networks

A subgroup considered the question of whether network boundaries should be managed or should emerge as a result of competition and choice. The group considered that unless boundaries were managed it would continue to damage relationships.

They considered that managed boundary networks would be more efficient and would drive costs down. The group therefore advised a more formal statement about this issue.

The group considered how boundaries could be set in a managed scenario (closest, shortest journey time) and how commissioners could enforce these arrangements, for example by not paying for activity where the boundaries were not respected.

Other members of the Clinicians' Group considered that patient choice must be allowed which implied competition.

The managed boundary model proposed led to units that would be similarly sized. Some considered that there was a case for at least some units to be larger. Others argued that if units all had to undertake at least 500 cases this meant that the decision not to have bigger units had in effect been taken.

Experience from trauma networks was that managed network boundaries had been effective and well accepted.

Michael suggested that this should be a question for consultation and that coming up with answer needed to be part of what was done for objective 3.

It was noted that it is stated in the standards that referrers need to explain why they are recommending a certain centre and what choices are available for patients/families.

Transplant

A sub-group considered the approach to transplant taken in the standards and agreed it was sufficient.

Adults requiring transplant range from simple procedures that can be done in any of the transplant centres to complex patients who can only be done where there is special expertise. Most of these complex indications are done in Newcastle. In the future we can expect more complex adult demand – and a second centre may be required. There will also be a continued rise in the use of mechanical assist devices both as bridge to transplant and, in time, as destination therapy.

Future planning would also need to cover heart and lung transplant and not just heart transplant as demand for these procedures could be expected to rise.

The group identified a problem in applying the CHD standards to Newcastle as the centre is in a sparsely populated region where there are not sufficient patients to meet the CHD activity requirements. The group advised that a super-network and intelligent commissioning would be needed to preserve the transplant service.

It was proposed that there should be a minor change in wording to differentiate between referral of simple rather than complex patients:

The proposed adult standard (A2) which stated that *"each specialist ACHD centre must demonstrate formal working relationships with a cardiothoracic transplant centre staffed by transplant surgeons with a congenital practice"* has been modified to read *"each specialist ACHD centre must demonstrate formal working relationships with cardiothoracic transplant centres, including one staffed by transplant surgeons with a congenital practice".*

Obstetric standards

The group made some changes removing ambiguity and clarifying the standards.

Co-location

One member suggested that the co-location standards had been set in a collegiate way 'to make sure that everyone can meet them' and there was not enough ambition.

As mortality improves, morbidity will become much more important.

Other issues

One member stated that reducing the number of cases/surgeon from 125 to 100 would make little difference to the surgeons but might make the networks viable.

One member stated that it is incorrect to count all surgical cases as equal - some are much more complex especially in adults.

4. Preparing for consultation

Michael Wilson, Programme Director, gave an overview of the standards and then an explanation of what we are doing to prepare for consultation. The standards and specification will subject to consultation at the same time.

There is a plan to procure independent analysis of the consultation responses.

There was concern raised about the process for moving from the outcome of consultation on the standards to any necessary decision about the number of units. Michael reiterated that the consultation is about the standards. The new review was separately considering future demand and capacity as one of the other objectives, and this would help direct advice on the appropriate size, and number of units and the network model.

It is not yet clear how congenital heart services will be commissioned which will impact on how the units and networks will be set up.

One member stated that the last process had been disappointing. Michael highlighted that this time we are consulting on the standards – asking whether you think the review has got it right. We aim to reflect all the different views expressed about the standards then decide on the final standards.

Whilst we are not consulting on the number of centres the consultation document needs to be specific about number of centres, operations and surgeons.

In discussion, it was noted that the number of surgical procedures per surgeon and number of surgeons would effectively determine the maximum number of units. This will be part of the consultation based on the advice from the Professional Societies.

5. Date and time of next meeting

The Clinicians’ Group will next meet in late September/early October 2014.

Date for the joint meeting of all three engagement and advisory groups will be the 25 July 2014: location tbc.

Annex A

Attendance

Chair	
Chair of the new Congenital Heart Disease review's Clinicians' Group and Professor of Paediatric Hepatology	Professor Deirdre Kelly

Organisation	**Name**
Birmingham Children's Hospital NHS Foundation Trust	Oliver Stumper
Blackpool Teaching Hospitals NHS Foundation Trust	Mr J Zacharias
Great Ormond Street Hospital for Children NHS Foundation Trust	Dr Michael Burch
Guy's and St Thomas' NHS Foundation Trust	Dr Owen Miller
Newcastle upon Tyne Hospitals NHS Foundation Trust	Mr Asif Hasan
Oxford University Hospitals NHS Trust	Elizabeth Orchard
Papworth Hospital NHS Foundation Trust	Dr Clive Lewis
Royal Brompton and Harefield NHS Foundation Trust	Dimopoulos Konstantinos
Sheffield Teaching Hospitals NHS Foundation Trust	Laurence O'Toole
University Hospital Southampton NHS Foundation Trust	Aisling Carroll
University Hospitals Bristol NHS Foundation Trust	Dr Alison Hayes
University Hospitals of Leicester NHS Trust	Dr Simon McDonald

Medical Associations and Royal Colleges	**Name**
Association of Cardiothoracic Anaesthetists	Dr Ravi Gill
British Cardiovascular Society	David Hildick-Smith
British Maternal & Fetal Medicine Society	Sarah Vause
British Psychological Society	Emma Twigg
Cardiothoracic Advisory Group	Nick Banner
Extracorporeal Life Support Association (ELSO)	Mr Giles J Peek
Fetal Anomaly Screening Programme	Pranav Pandya
PICS	Peter Marc-Fortune
PECSIG	P Venugopalan
Royal College of Nursing	Collette Cochran

Clinical Reference Groups	
Adult Critical Care CRG	Dr Jane Eddleston
Congenital Heart Services CRG	Trevor Richens
Congenital Heart Services CRG	Dr Graham Stuart
Congenital Heart Services CRG	Gurleen Sharland
Congenital Heart Services CRG	Julia Grace
Heart & lung Transplantation CRG	Professor John Dark
Paediatric Intensive Care CRG	Mark Darowski

NHS England Representatives	
Programme Director,	Michael Wilson
Director of System Policy	John Holden
Project manager	Jane Docherty
Project Co-ordinator	Jennie Smith