Clinician Group Meeting, 22 November 2013

Introduction

The clinician group of the new congenital heart disease review met for the first time on 22 November 2013. The clinician group comprises one clinician (nominated by the organisation's Chief Executive) from:

- every English provider trust identified as providing any congenital heart surgery or cardiology intervention or with a specialist congenital cardiology centre
- Welsh, Scottish and Northern Irish hospitals providing specialist congenital heart services
- relevant professional colleges and societies covering the main clinical professions and specialist groups involved in delivering care for congenital heart disease.

A list of those attending the meeting is enclosed as a table at the end of this report.

The group is chaired by Professor Deirdre Kelly, Professor of Paediatric Hepatology at Birmingham Children's Hospital.

In her welcome, Professor Kelly told attendees that the new review is different because it covers the whole patient pathway so the group includes attendees from every part of the pathway. The new process is building on good work from the previous review and will bring together the surgical standards from safe and sustainable, ACHD, and the new paediatric standards from Clinical Implementation Advisory Group (CIAG).

Professor Kelly stressed that the review must focus on what's best for patients in 2014 and beyond. In forming its views, the group must focus on patients and their families and not on their own units. She said that she was looking forward to working with the group to achieve first class services.

The remit of the group would be to advise on all clinical aspects of the review. As the group's Chair she will take the group's views to the programme board and Clinical Advisory Panel.

Presentation

John Holden welcomed participants to the meeting and emphasised the importance of their contribution to ongoing thinking. He acknowledged the need for more notice of meeting times. He gave an update on the work of the review but emphasised that the update should not contain surprises/new material. He noted that the aim was to build on work done to date particularly in those areas that were controversial or perhaps not fully worked through in the previous work. He identified the different strands of work:

- alignment of three different sets of standards dealing with any ambiguity and ensuring that they reflect the model of optimum care;

- analysis using latest data focusing in the first instance on specialist inpatient care and later on other aspects of the service and other interdependent services;
- using the analysis to enable modelling of functions and form to meet capacity requirements;
- commissioning and change model – looking at how NHS England will commission for change ensuring that service specifications translate into practical improvements for patients;
- making sure information is provided that is understandable to all and is timely; and
- early diagnosis that will lead to better and less variable ante-natal detection rates.

John Holden emphasised that the new review team are committed to making the process as open as possible. He also noted that the current timescale for this work is heroic given a number of factors including local Government elections, and that the team will let people know if there are changes.

Key Points – raised by the group

- Need to explain simply and persuasively the case for change.
- Support for the scope of the review and bringing adults' and children's standards together, including the additional focus on fetal part of the pathway in addition to the other parts that are not the surgical episode. Too much focus on the surgery. Patients need to get the right care in the right place. Surgery needs to fit around that not the other way.
- Support for not going "back to square one" on standards which are largely uncontentious. Discussions at BCCA meeting suggested universal acceptance of the proposed adult standards. Many of the clinical standards for paediatrics have been accepted so members do not want to start on any new standards. There is agreement that a minimum number of surgeons per centre needs to be set as well as the number of operations per surgeon.
- Concern that any proposals for change might not survive the inevitable challenges/objections?
- The need to make rapid progress – surgeons in some centres are under great pressure and yet delivering great results – this is not sustainable
- A clear plan is needed for implementation and an appropriate tariff; training and workforce planning;
- Appointing new CHD surgeons would be a great achievement because there are not trainees coming through and there are similar concerns about the nursing workforce.
- Need to look at how training and workforce planning feed into this network way of working

- Junior staffing and training is a problem. Larger units including those that are combined adult and child have an advantage in scale for rotas.
- How to “future proof” the service?
- Need to ensure that clinicians are involved in the development of outcome measures. These should go beyond mortality - morbidity is a better measure of unit competence. Some peer review of centres could be helpful. The denominator for outcomes data should be the fetus diagnosed at 30 weeks rather than those who arrive in the specialist service.
- Support for the pathway to include prenatal care; antenatal detection ‘is abysmal and needs to be improved’
- A recognition that this review might be a step towards achieving a world class service but may not provide all the answers. An ongoing process would be needed with providers working together collaboratively to deliver the solution rather than the previous review that tried to get there in one step.
- All want a world class service and we should bear that in mind.
- In managing conflicts of interest it would be important to include vested interests so that statements could be seen in light of what people do and where they come from. Everyone has vested interests.
- Need to be sure that loudest noise is not from those with most strongly held views / vested interests
- Varying experiences of communication to date – there are improvements to be made
- Don't want us to duck the difficult issues or ditch standards because of the difficult issues. Decision must be firm. Concerned about the potential impact of general election - not just timing but also the outcome.
- Group (and work generally) needs to have more input from beyond just the medical profession.
- Objectives very broad and need to see these translated into specifics
- Don't want distorted catchments to prop up units
- There was no agreement on whether there should be specialisation between centres
- Co-location was controversial. But the standards for CHD can't be separated from standards for intensive care and transport. From an anaesthetic perspective need information about all aspects of their care. That's much harder when services not co-located or at least very close by.

Sir Bruce Keogh also addressed the group. He recognised that the past process impinged on the sense of confidence, but asked the group to put aside their views about Safe and Sustainable. In the new review there are no preconceived ideas. For him the new review is about ambition - the opportunity to be the best in the world. Changing things to make them better for those who use the service and for those who deliver the service. People expect ever higher standards. His view was that together we could deliver them. The people in the room needed to tell us how. There may be a variety of possible solutions. NHS England was open to consider them and needed the group to understand the problem and propose solutions. As the single commissioner of this service, NHS England would then be able to help them to do it.

A number of issues were raised in the meeting

Issue: It's been said that closures would be cost neutral. Reconfiguration has an unavoidable cost (double running etc) – any expectation of "cost neutrality" is unrealistic and would therefore be unacceptable

NHS England Response: The new review has not said cost neutral but we simply don't know what changes may be required or know what the costs of any changes might be. Decisions will be made on the plans for improvement that there are. So we need a plan and then we'll cost it and look at the money. There is bound to be a need for double running costs to support any change. But the financial climate is tougher than it has been in the past – there is minimal growth, so Clinical Reference Groups will also be asked to look for opportunities to make savings.

Issue: Where and when will this group see and be able to comment on the standards?

NHS England Response: The group will be able to comment on the standards before consultation.

Issue: If you have to make difficult decisions, how will you do that in a way that avoids possible challenge.

NHS England Response: No-one can give a guarantee that in the event of making difficult decisions possible challenge can be avoided. This group and the discussions are part of our approach to mitigate that risk.

Issue: Why are we doing this, why are we here?

Contributions from the group:

- We have come a long way. Our outcomes are good. There is no other country with surgical outcomes in the public domain. But there is an expanding population and increasing complexity of clinical practice. The previous review was damaging to what we have already achieved. Concerned that there is political pressure to deliver too quickly and jeopardise outcomes that are already very good in this country. There is

evidence shows that competition is a good thing for outcomes. Don't want to be part of something that spends more but doesn't achieve anything. Will people listen?

- Few long standing surgeons are still working. And that's because of the stress on surgeons. It is difficult for smaller centres because there is so little room for error. Surgeon's lives are under pressure to deliver excellence. This is unsustainable. A 1 in 2 rota is not acceptable. And 1 in 3 is 1 in 2 for 30 weeks of the year. Larger centres are fortunate in this respect. We are waiting for this to be sorted out.
- The process needs to be about quality and not just about mortality. Sub-specialisation, practice elsewhere in the world will have an influence.

NHS England Response: An ambition to be the best in the world. To achieve a safe resilient service that is sustainable into the future and eliminates variation across the country. To address issues of occasional practice.

Terms of Reference

The Chair introduced draft Terms of Reference which were deliberately concise and concentrated.

It was agreed that:

- The relationship with the Clinical Advisory Panel (CAP) should clarified and show that CAP needs to be responsive to this group and there should be the opportunity for this group to comment on what the CAP recommends. Need to see transparently that views of the group are taken to the CAP and programme board.
- A quorum was not needed.
- The group would meet every two months (with more than 6 weeks' notice to be given).

Attendees at meeting on 22 November 2013

Name	Organisation
Professor David Anderson	British Congenital Cardiac Association
Dr Nick Banner	Cardiothoracic Advisory Group
Dr Aidan Bolger	University Hospitals of Leicester NHS Trust
Professor John Dark	Heart & Lung Transplantation Clinical Reference Group
Dr Mark Darowski	Paediatric Intensive Care Clinical Reference Group
Dr Jane Eddleston	Adult Critical Care Clinical Reference Group
Professor M Gatzoulis	Royal Brompton and Harefield NHS Foundation Trust
Dr Ravi Gill	Association of Cardiothoracic Anaesthetists
Dr James Gnanapragasam	University Hospital Southampton NHS Foundation Trust
Mr Asif Hasan	Newcastle Freeman Hospital
Dr Alison Hays	University Hospitals Bristol NHS Foundation Trust
Professor Daniel Keenan	Cardiac Surgery Clinical Reference Group
King's College Hospital	Represented by Guys and St Thomas Trust FT
Dr Clive Lewis	Papworth Hospital NHS Foundation Trust
Dr Jim McLenachan	Complex Invasive Cardiology Clinical Reference Group
Dr Owen Miller	Guy's and St Thomas' NHS Foundation Trust
Dr Cathy Nelson-Peircy	Specialised Maternity Services Clinical Reference Group
Dr Elizabeth Orchard	Oxford University Hospitals NHS Trust
Dr Laurence O'Toole	Sheffield Teaching Hospitals NHS Foundation Trust
Dr Vicky Parish	Brighton and Sussex University Hospitals NHS Trust
Giles J Peek	Extracorporeal Life Support Association (ELSO)
Eithne Polke	Children's Acute Transport Service (CATS)
Dr Trevor Richens	Congenital Heart Services Clinical Reference Group
Dr Glenn Russell	Liverpool Heart and Chest Hospital NHS Foundation Trust
Richard Smith	Royal College of Obstetricians and Gynaecologists and
	Fetal Medicine Clinical Reference Group
Dr Mark Spence	Belfast Health and Social Care Trust
Prof. Terence Stephenson	Royal College of Paediatrics and Child Health
Professor Andrew Taylor	Great Ormond Street Hospital for Children NHS FT
Dr Sara Thorne	University Hospitals Birmingham NHS Foundation Trust
Miss Carin Van-Doorn	Leeds Teaching Hospitals NHS Trust
Dr Sarah Vause	British Maternal & Fetal Medicine Society
Dr Prem Venugopal	Alder Hey Children's NHS Foundation Trust
Dr Dirk Wilson	Cardiff and Vale University Health Board
Mr J Zacharias	Blackpool, Fylde and Wyre Hospitals NHS Foundation Trust