

**CCAD Congenital Heart Disease  
Project Board Meeting  
Wednesday, 2<sup>nd</sup> July 2008  
13.00-14.30**

**Information Centre for health and social care  
Harmsworth House, London**

**Minutes**

**Attendees:**

John Gibbs (Chair)	JG	CCAD
David Cunningham	DC	CCAD
Linn Denne	LD	CCAD
Nadeem Fazal	NF	CCAD
Sue Dodd	SD	Department of Health
Anne Keatley-Clarke	AKC	Children's Heart Federation
Leslie Hamilton	LH	Society of Cardiothoracic Surgery
Zaki Kramer	ZK	Information Centre for Health & Social Care (minutes)

**1. Apologies**

1.1 Apologies were given for Sheila Shribman, Bill Brawn, Helen Laing (HL) and Martin Old (MO). Roger Boyle attended the Steering Committee and was represented at the Project Board by Sue Dodd.

**2. Minutes of the previous meeting**

2.1 The minutes of the previous meeting were agreed as a true and accurate record.

**3. Management update**

3.1 JG gave a brief management update in place of MO.

3.2 Management of the audit ahs been taken over by the Health Quality Improvement Partnership (HQIP). The national audit will be taken over by a group called the National Clinical Audit Advisory Group (NCAAG) headed up by Nick Black. It is made up of a consortium of the Academy of Medical Royal Colleges including the Royal College of Nurses.

3.3 There has been no contact as of yet with the project team, however the majority of staff at HQIP has yet to be appointed.

- 3.4 Dick Waite, the principal contact at the HealthCare Commission (HCC) has left his post.
- 3.5 Andrew Harrison is due to leave on 1<sup>st</sup> October 2008. This is as a result of the IC's recruitment policy. This action would be greatly detrimental for the future of the audit. This issue was discussed at length by the project board.
- 3.6 It was agreed that a letter would be drafted questioning how the vacant post would be filled and meet the required level of specialisation.

**ACTION JG**

**4. Potential Outliers**

- 4.1 JG gave the board an update regarding potential outliers.
- 4.2 5 centres have hit the "green line." JG gave a breakdown of the 5 centres and why they had potential outliers.
- 4.3 The SCTS and the BCCA have written to each centre asking for a response from their local clinical governance groups.
- 4.4 LH gave the board an update on how the specialist societies would act. JG reiterated that it was not CCAD job to investigate why outliers are occurring. CCAD role is to collect the data.
- 4.5 It was stated that there is also a red line on the funnel plots. There are no centres approaching the red line. LH gave the view from SCTS and BCCA that "green liners" should be alerted to their results but that further action should be a matter for local clinical governance. The SCTS and the BCCA would only become involved if the centres approach the red line.
- 4.6 The private centre involved with the green line was discussed. The centre believes this was due to a simple coding error. The private centre does not have validation visits and have not resubmitted their data. CCAD will offer the centre a validation visit.
- 4.7 The board felt that contributors and the public would appreciate a simple explanation of the SCTS/BCCA process for potential outliers. It was agreed that LH and Bill Brawn would draft a document regarding this issue and where responsibilities lie and that this would be published on the website.

**ACTION LH**

**5. Portal improvement**

- 5.1 JG gave the board an update regarding improvement to the portal.

5.2 It has been decided to amalgamate the data that was on the old CCAD website with the portal data. Everything will now be available on the portal. Andy Harrison will work on this issue.

5.3 Extra tabs will be added to include technical information and minutes of Project Board meetings.

5.4 Andy Harrison, JG and NF will meet with representatives of the children's heart federation later this week and will develop mutual ideas to improve the portal.

## **6. Small numbers and potential disclosures**

6.1 Dr Foster has written to the IC pointing out that numbers are very small for some of the reported procedures, and that they were concerned about potential disclosure for these cases. There is a Department of Health suggestion that reports should not be published on procedures that number less than 5 as patient identification might become possible.

6.2 JG and DC received the full support of the Project Board for their defence of our practice and agreed that we should continue to publish these results. It was unanimously agreed that the risk of disclosure is negligible for centres publishing anonymised data from very large and varied populations from very large geographical areas. It was felt that the granting of consent for CCAD data submission and validation was an additional justification for continued publication.

## **7. Data quality**

7.1 The BBCA council sent JG a letter outlining their concerns regarding the quality of data published on the portal as there is a substantial proportion of patients where we have been unable to centrally track their survival. This has been investigated internally. DC has identified a recent problem for a small proportion of cases with incomplete data return from the ONS. This cohort of patients will be resubmitted to ONS. However, it is clear that the principle reason for the lack of tracking is the failure of centres to send the NHS numbers.

7.2 JG has received numerous letters of support from the council since replying to the letter.

7.3 JG will circulate to all the centres a list of how many NHS numbers are missing from each centre. The Board suggested offering all centres a 3 month period to collect the missing numbers and resubmit their data to CCAD.

7.4 The issue of private patients was discussed. Foreign Nationals do not have an NHS number, so will always appear in the "unknown" section. The Board felt that the only way to improve this aspect of the data quality is to report three stages of survival data rather than two.

7.5 We now plan to report declared discharge status (which accounts for all patients including foreign nationals). The 30 day tracked survival and 1 year survival data will follow, with patients identified as private cases without an NHS number censored. The 30 day and 1 year data will therefore much more closely reflect UK nationals' healthcare demands, and the number of un-traceable patients will be proportionally reduced.

**ACTION: AH/DC**

## **8. Data analyses**

8.1 The Board endorsed the recommendation of the steering committee that heart transplantation, arrhythmia ablation and pacemaker procedure survivals should be added to the portal.

8.2 Differentiating results from the different age groups was discussed. The issue had arisen because one centre who returns purely adult data had appeared to lie on the green line of the funnel plot for Fontan operations. No other procedure appeared to have any obvious relationship between mortality and age over 16. It was agreed that two separate funnel plots for over and under 16s will be published on the portal for the Fontan procedures but not for other procedures.

8.3 JG would like to produce national actuarial survival codes. This will only be possible with increased resources.

8.4 There is the potential to focus on research in partnership with the British Heart Foundation.

## **9. Individual operator results**

9.1 There was unanimous approval for this at this year's contributors' meeting at the RCS on the strict provision that this should be password protected for each centre.

9.2 This has not occurred yet because of a lack of resources.

## **10. Links with NICE**

10.1 NICE are keen to get follow up data on procedures that are published. It was agreed that the project should do everything possible to help NICE with this request.

## **11. Adult Congenital Data**

11.1 There are now more centres currently on board as a result of the hard work by LD.

11.2 The Board felt that all centres sending data should receive validation visits, although there was some concern that some centres have submitted data on very small numbers of patients. JG agreed to write to centres with small numbers pointing out the many difficulties with small numbers (not least from the public's perspective).

## Actions Table

Reference	Action	Responsibility
3.6	It was agreed that a letter would be drafted questioning how the vacant post would be filled and meet the required level of specialisation.	JG
4.7	It was agreed that LH and Bill Brawn would draft a document regarding this issue and where responsibilities lie that would be put onto the website	LH
7.5	We now plan to report declared discharge status (which accounts for all patients including foreign nationals). The 30 day tracked survival and 1 year survival data will follow, with patients identified as private cases without an NHS number censored,	AH/DC

### Date and time of next meeting

- December 2008 tbc