

CCAD Steering Committee and Project Board

September 15th 11.30 – 13.30

The Board Room
The Heart Hospital
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MINUTES

Present: John Gibbs (chair), Bill Brawn, Les Hamilton, David Cunningham, Rodney Franklin, Martin Elliott, Gruschen Veldtman, Nadeem Fazal, Lin Denne, Andy Harrison, Sue Dodd, Roger Boyle, Anne Keatley-Clarke.

Apologies were received from Sheila Shribman.

Gruschen Veldtman from Southampton was welcomed as the new adult congenital representative.

1. Data analysis issues: Glasgow had pointed out that a PA band was being classified as a simple PA band even when a septectomy was carried out. The committee agreed this was inappropriate and needed to be changed.
Action: RF to check EU short codes related to septectomy and to send to DC/AH for these codes to be added to the exclusion criteria for PA banding

Fontan data analysis: JG & DC had received correspondence from Guys, Birmingham and the BCCA relating to apparent undercounting of Fontan operations. Rather than undercounting, we had changed Fontan analysis to separate it into adults, children who had a Norwood operation (at the request of users who felt they were different) and “ordinary” Fontans. Unfortunately we had not explained this change on the portal, and the separately analysed HLH Fontan data was missed out when the portal was updated. This has already been addressed by DC and the portal should be corrected very soon.
Action: DC/AH to ensure the 3 groups of Fontan data appear on the portal; JG to write brief explanatory text and to reply to BCCA/Guy’s and Birmingham.

AK-C and ME pointed out that parents would wish to see outcomes based upon specific procedures such as HLH. To date we have based our analyses on procedure rather than diagnosis for practical reasons. We agreed we should move forward on this, in line with our plans for publishing actuarial survival plots.

Action: RF to look at permutations of diagnostic and procedure codes which might arise for HLH and forward lists of both to DC. DC to look at analysis of survival based on diagnosis or on procedure, and circulate to steering committee for a decision on which to use on the portal.

Guy's had pointed out that they appear as Evelina in the majority of the portal but that Guy's still appears here & there, potentially causing confusion.

Action: *AH to trawl portal & change all references to Guys to Evelina. JG to check if they want this done for adults as well as children*

2. Delayed data submissions & the CQC: Many centres still send data late, and some are still sending a full year's data in one go, which makes for hard work at CCAD as well as less time to check and correct data. JG had already written to all contributors letting them know that the Care Quality Commission has set a deadline of May for complete data submission for adult cardiac surgery – only 1 month after the end of the financial year. Thinking that a bit harsh just now, we had set deadlines of August 1st this year and July 1st next year. We have received the full years data for 08/09.

Action: *JG to include note in next newsletter reminding all that the 1st June will be strictly adhered to next year.*

3. Definition of “congenital” procedures: JG had received correspondence expressing concerns that adult surgeons were “gaming” with their procedure coding to boost their “congenital” workload in order to comply with the numbers recommended for minimum practice for adult congenital heart disease centre designation. This involved including aortic valve surgery, mitral prolapse surgery and Marfan's related surgery. To nip this in the bud, JG and LH had written a short piece defining what CCAD regard as congenital heart disease procedures. This was circulated to the steering committee for further comment, but is already posted on the public portal, hopefully to be noted by commissioners.

4. Non contributors, CQC health check for Trusts & adult congenital data: Congenital CCAD was added last year to the CQC's list of national audits for their Trust Health check. SD and JG had received correspondence from the CQC after their health check at Sheffield had identified that they carried out congenital cardiac procedures but had not submitted data to congenital CCAD. Sheffield had applied for exemption from CQC measures, claiming that they did not know they should have been sending data. JG had replied to CQC stating that all surgeons had been informed in writing that the SCTS view was that all centres carrying out any congenital procedures should submit their data to us, and that Sheffield cardiologists were also well aware that adult congenital catheter procedures should be sent to us. In their defence Sheffield showed a copy of an email from someone involved with the Heart Failure database (!) at the IC saying that Sheffield did not need to be involved (with no mention of what this response actually referred to). We await the CQC's decision, but the committee were greatly reassured that the process of the Health Check had worked so well from our point of view. There are still a substantial number of non contributing adult centres, which we hope will also be picked up by the CQC.

Action: *SD suggested that involvement with our national audit could be mentioned in the next Bulletin for medical directors.*

5. Timeliness of portal updates, speeding up validation, annual target date for new funnels: The main delay in updating the portal data is the laborious process of validation. LD agreed to look into squeezing all the visits into the first 4 months of the financial year, which could potentially shorten time to

publication by 6 months. We were keen not to compromise on the quality of the validation itself, and still feel complete examination of the theatre and cath lab logbooks is important to ensure complete case ascertainment.

DC has started work on pre-validation funnel plots which would not be placed in the public domain but would be made available to the Project Board for governance purposes, enabling some advance warning for red liners.

6. Antenatal diagnosis: initial responses to portal data and next action
JG had received very positive feedback from Tiny Tickers (fetal cardiac charity) and from FASP (the Fetal Anomaly Screening Program). However, there were a couple of initially hostile emails from centres disappointed to appear to have poor performance because they were tarred with the brush of overall SHA data. These centres (and some SHAs and commissioners) are keen that we move on quickly to PCT specific rather than SHA specific data alone.
JG had also received a letter from the BCCA Council expressing their concerns that we are using our data to indicate performance when the data only relates to infants requiring treatment, and that the data was likely to be misinterpreted as representing all antenatal cardiac screening. JG read the introductory text from the web page to the committee, whose view (like that of Tiny Tickers) was that it would be very hard to misinterpret what we had reported. Nonetheless, the committee asked AK-C if she would ask the CHF team to scrutinize the web page carefully and suggest any improvements in plain English.
Action: AK-C to get her team at CHF to look at text on portal and feed back to JG.
JG to reply to BCCA letter.
7. Individual operator data and the Portal: on target for 1st October, in password protected part of portal. JG agreed with the BCCA view that it would make local data checking much easier if we could show operators what codes they had submitted for each case and what procedure we had allocated the case to. DC said this could be done on Lotus Notes, but there are difficulties with operator access to Notes locally. DC also said that such additional data could very much slow down portal access speed. AH felt this would be difficult to do on the portal without patient identifiers. JG suggested just a date of procedure without other identifiers, which would allow the centre but nobody else to identify the patient. DC agreed to investigate ways of doing this.
Action: DC/AH to look at ways of feeding back individual case procedure allocation to users.
8. Actuarial survival plots: no progress.
Action: JG to resend to DC list of procedures where actuarial plots would be useful. DC to circulate plots to steering committee members for approval/comment prior to them being added to the portal.
9. Endocarditis: to date only 6 centres have submitted IE data with a total of 46 cases. LD reported that Heartsuite has now added the IE dataset to its software.
Action: JG to remind contributors to send IE data.
10. ACHD progress: dealt with in 2&3 above.

11. PROMS and patient support groups: JG has been in contact again with Michael Cumper of GUCH PA. GUCH have developed patient questionnaires (partly outcomes, partly patient satisfaction but not specific quality metrics) for outpatient and inpatients. So far The Heart Hospital has completed the OPD survey, and has given GUCH permission for CCAD to publish the results. JG suggested this would be a good step towards PROMS and has offered to publish all centres' GUCH survey results on the CCAD portal. Hopefully this would encourage more centres to take up the survey (Leeds just about to). ME and RF reported that other groups in the UK and N America are looking at paediatric PROMS and suggested we might get a speaker too update us on that work at a future contributors' meeting.
12. First red liner – update on process: Our process appears to have worked well. LH wrote to the Leeds Medical Director on behalf of the SCTS asking for a response to the poor survival results. The MD replied (after a surprisingly long delay) that the problem had already been identified locally almost 3 years earlier and that the RCS rapid response team had visited and that a change in local concentration of expertise had resulted in a reduction in mortality. The SCTS were content that no further action was required.
13. Executive report: JG and NF had written an updated executive report on the audit at the request of HQIP, which we think will be sent to SHAs to heighten awareness of the audit. The report is currently with the design department for cosmetic attention and will then be posted on the portal.
14. Annual report format: HQIP has also asked for an annual report, and seemed happy for us to develop a downloadable version of the contents of the portal rather than go to the lengths of printing a specific paper report along the lines of the adult blue book.
Action: NF/AH to develop downloadable, printer friendly version of portal contents.
15. Risk adjustment: progress and update on collaboration with CORU: little to report. Main cause of delay is that this requires our diagnostic (as opposed to procedure) coding to be cleaned – a process which we have not needed to do to date. RF and DC have been working on this and will liaise with CORU when the cleaning is done.
16. Relationship with NICOR and tender for admin of CCAD: RB updated the committee on the administration of the cardiac audits being put out to tender, with the likely outcome that we will no longer be managed by the Information Centre. Tenders have been requested and the deadline for submission is mid October. NICOR (National Institute for Clinical Outcome Research) is based at UCL at present and is putting together a group bid for the audits, with the support of BCC, SCTS, BCS and BCIS.
17. Date for next contributors' meeting at RCS: Thursday 28th Jan 2010.
18. AOB: JG raised the issue of incomplete consent processes which have become apparent at the validation visits. Lack of consent filed in the records prevents

the visitors from looking at the records. Presence of consent will feature in the data quality report for each centre from this year.

19. BB, on behalf of the BCCA, suggested that we ask a data manager to join the steering committee. The committee agreed this may be helpful. **Action: JG to write to Philip Kimberley (Brompton), who is the lead for the data managers, to ask for a nomination.**

20. Date of next meeting: TBA.