Congenital CCAD Steering Committee

Sept 23rd 14.00-16.00

The British Cardiovascular Society
9 Fitzroy Square
London W1T 5HW 020 7383 3887

MINUTES

1. Present: John Gibbs (Chair), David Cunningham, Roger Boyle, Sue Dodd, John Thomson, Anne Keatley-Clarke, Nadeem Fazal, Chuck MacLean, James Roxburgh, Andy Harrison, Marion Standing. Apologies: Sheila Shribman, Shak Qureshi (represented by John Thomson, BCCA Secretary), Lin Denne.
2. Report from steering committee
    a. Minimising censorship of data and resulting changes in funnel plots. The Project Board endorsed the Steering Committee's recommendation for a change in censorship of follow up. Our data contributors have frequently raised the issue of the high proportion of life status reported as reoperated/preoperated, due to life status being retained by major procedures. We agreed to change to allocating status of alive, dead or unknown to all procedures unless a further major procedure had taken place within 30 days. DC presented some examples of this simpler approach, illustrating a large increase in number of cases included in the funnel plots (particularly for Fontan procedures). The change in life status allocation had made no discernable difference in outliers although there were, as before and as expected, a few "green liners". This approach will demand caution in

pooling outcomes from multiple procedures as more than one procedure in the same patient may share the same life status.

b. Improvements in timeliness of data analysis & changes to funnel plots. DC and AH had updated the public portal to include 2008/9, despite validation being incomplete for that year. There was a pressing need to be seen to be more up to date following media interest in the Oxford Inquiry. JG had written a brief explanatory note on the home page emphasising that the data for that year was provisional as a few centres had not yet been visited.

c. Progress on freedom from reintervention. The steering committee had drawn up a priority list of procedures for freedom from reintervention, but this work has still not begun due to limited analysts' time.

3. Validation visits

   a. Progress in timing. Lin Denne is trying to move data validation visits to the first 6 months of the year but this is proving difficult with the increased number of visits required to adult centres.

   b. Funding visits outside England. The IC has raised the issue that funding for Northern Ireland and Scotland validation visits is not within their remit (despite us having funded the visits for the last 9 years!). JG will negotiate with HQIP, who are clearly keen (as are the centres involved) to see the visits continue.

   c. Adult congenital heart disease. James Roxburgh, President Elect of the SCTS had asked to attend the meeting because of SCTS concerns that adult congenital cardiac surgery is carried out in small numbers in some centres. Lin Denne had provided very approximate numbers of ACHD surgery and interventions from CCAD data & visits as well as from the limited data available from the SCTS register. There do

appear to be some centres carrying out small numbers of procedures, often shared between several surgeons. The SCTS will investigate further.

4. Collaborative projects
    a. NCEPOD. Our collaboration with NCEPOD's project examining the details of 30 day deaths after surgery or interventional catheterization in children has so far been limited to providing total numbers of deaths to help ensure their complete ascertainment of cases. NCEPOD had asked if local CCAD audit staff could take responsibility for coordinating data collection but JG had replied that this was not within CCAD's gift as these audit staff are employed by individual Trusts.
    b. NICE: new procedure follow up, PFO dataset and tracking outcomes other than survival. With our collaboration on follow up after transcatheter closure of congenital ventricular septal defects NICE published updated advice on perimembraneous VSD closure. NICE had asked if our dataset could be expanded to include specific follow up data for divers, migraineurs and stroke patients. JG had replied that asking cardiologists to provide neurological follow up data was doomed to failure and that such data collection should be collected as part of a prospective trial rather than through national audit.
    c. EU & N American registry links. At the last CCAD open meeting at the RCS there was a much more positive attitude from our data contributors for collaboration with the EU and N American databases, but there remained concern that we had still not been entirely reassured that their data validation was as robust as our own. Nonetheless, we remain keen on the concept of international collaboration. Chuck

MacLean will liaise with these bodies and will update us all at the next RCS CCAD meeting.

5. Oxford inquiry

    a. BCCA suggestion for generic note to be sent with all data released to third parties, explaining complexities and weaknesses of the data and its interpretation. JG had received a letter from the BCCA Council asking that any data sent to third parties should go with a warning about the data complexity. This letter appeared to have been prompted by inappropriate media reporting of the data analyses used by the Oxford inquiry. JG pointed out that a clear explanation of the complexity of the data and its analysis had been included in the Oxford Inquiry report, but had little influence with the Sunday Telegraph! Rather than a generic letter for all data requests JG recommended a tailored approach to each request (which is just what has happened in the past with NICE, NCEPOD and others).

    b. Panel request for CCAD to help identify problems much earlier – pre-validation analyses of standardized mortality ratios. JG has been informed that the Oxford Panel will be making a formal recommendation that CCAD should make data available to all centres to facilitate centres' local data analyses, in particular to facilitate early statistical warnings when mortality rises. The committee unanimously agreed that we should comply with this recommendation, but there was lengthy discussion on how this is best approached. There was unanimous opposition to our publishing overall Standardised Mortality Ratio's (SMR) for each centre because of the lack of case mix risk adjustment compounded by the statistical problems of potential double counting of death and/or survival with our recent change in life status allocation. In the first instance, we agreed that unvalidated survival

analyses should be made available to all data contributors as soon as possible. This would initially involve giving each centre's % survival along with national survival for each procedure, and we would need to update this regularly throughout the year. The committee felt that funnel plots were a more modern way of demonstrating potential outliers than simple standardized mortality ratios for each procedure, and that they have the added advantage of clearly illustrating the volume of procedures as well as "performance". To produce updated funnel plots for all procedures every quarter would be a considerable increase in work for CCAD staff.

c. Outliers in Oxford stats analysis. The Oxford panel had, for reasons related to its specific remit, analysed standardized mortality ratios for each procedure which CCAD report on and had gone on to calculate overall SMRs for each centre over an 8 year period (2000-2008). This had shown Leeds, Guys and Leicester to lie at or beyond the 95th confidence limit. JG had been asked by the Oxford panel to inform the Project Board of these results.

d. Oxford statistician's methodology and CCAD. The committee was concerned that calculation of overall SMRs for each centre was potentially misleading because of varying case mix and lack of risk stratification. There was also concern from the DH, the BCCA and SCTS that publishing SMRs is likely to encourage media publication of league tables. There was unanimous support for continuing to publish funnel plots rather that overall SMRs. JR reported that the SCTS are moving away from pooled outcome reporting in favour of specific procedure reporting because of concerns that uniform risk

stratification in adult cardiac surgery may not be applicable to different procedures.

e. FOI request to South Central SHA for centre specific outcomes. The Sunday Telegraph publication of the Oxford data analyses over an 8 year period going back to 2000 (obtained under the FOI act) has caused a good deal of anxiety. The BCCA, the SCTS and CCAD staff were surprised at the level of interest in the article (particularly from the Safe & Sustainable team) when the data is so clearly out of date and when more contemporary data is published openly by CCAD. Anne Keatley-Clarke pointed out that there is a danger in resisting public access to any data as it encourages public thinking that the profession are trying to hide something.

f. Pre-empting future FOI requests. Legal advice from the IC as well as from the South Central SHA (who commissioned the Oxford Panel) is that the FOI covers just about anything, and that even draft data analyses which are later amended can be obtained unless there is a clear argument that such data is against the public interest (for example possible identification of patients). Other than us all bearing in mind how careful wording should be even in draft documents, there seems no way round the FOI and it is probably best to just assume that FOI requests will come along now and again.

6. Antenatal diagnosis. DC had updated the public portal to include antenatal diagnosis of major cardiac anomalies analysed by both SHA and PCT. There is already evidence in the North of England that this has prompted funding of specialised teaching to improve performance in obstetric centres.
7. Endocarditis. The endocarditis dataset is now included in data validation visits (from this year), with a separate DQI calculated for this dataset. Data quality is

still patchy, but appears to be improving (no doubt stimulated by data validation).

8. NCAAG recommendations on identifying outliers. JG reported that the National Clinical Audit Advisory Group had circulated draft recommendations for detection and management of outliers. These recommendations include the use of 95% confidence limits. JG and DC have both replied that we feel very strongly that 95% limits are inappropriate for the large number of analyses performed by congenital CCAD and would result in large numbers of false positive outliers. A group response to NCAAG is also being sent by NICOR.
9. NICOR. RB gave an update on progress with the NICOR (National Institute of Clinical Outcomes Research) bid to take over administration of the national cardiac audits currently run by the Information Centre. A great deal of work has been involved, the bid has been provisionally accepted by HQIP (the Health Quality Improvement Partnership), negotiations with the IC are at an advanced stage and we hope will be completed by the end of the year. We remain optimistic that the core CCAD team will transfer to NICOR at a UCL site, although the committee were very sorry to hear that Andy Harrison has resigned from his post at CCAD. The committee thanked him for his sterling efforts and wished him well for the future. Marion Standing (CCAD) had been invited to the PB by way of an introduction to proceedings as we hope she will take on some of Andy's congenital CCAD role.
10. Future funding. RB, JG and DC had recently attended a meeting with Bruce Keogh and others to discuss future funding of the National Audits. Central funding cuts are likely to be draconian and there seems little doubt that we will need to fund alternative means of funding. It seems most likely that Trusts will be charged a proportion of procedure tariffs to fund audit. JG was concerned that this could be a very significant bill for the small number of

congenital cardiac centres (as opposed to the very large number of centres sharing the cost of MINAP, for example). There was some reassurance from HQIP that, at least as an interim measure, central funding would continue for some very specialized audits and that it was felt extremely unlikely that congenital CCAD would cease to be funded.

11. Next RCS meeting. The next contributors' meeting will be at the RCS London as usual on Friday 4th February 2011. Agenda to be circulated nearer the time.
12. AOB & date of next meeting
    a) JT reported that some BCCA Council members had asked for better communication from CCAD. We agreed that sending our newsletters (usually 2-3 per year) via the BCCA rather than just via JG's email list may help.
    b) JG had received a request from NICE and from the DH for data on transcatheter pulmonary valve replacement. The PB agreed to these requests and will provide data on the number of procedures carried out at each centre, survival and repeat procedures. The committee also felt that we should add this procedure to our analyses on the public portal.
    c) JG had received several criticisms of our funnel plots contain procedures done at all ages and that risk is almost certainly different in adults and children. DC reported that the funnel plots were becoming very crowded with the increasing number of centres sending adult data. We agreed that adults (over 16) should be analysed separately, although there was some concern about the extra workload for CCAD staff.
    d) The BCCA and SCTS were keen to send a joint letter with CCAD to the Safe & Sustainable program expressing our concern about their response to outdated data published by the Sunday Telegraph. The PB unanimously endorsed the draft letter (which was read out to the committee).

JLG 10/10/2010 jlgibbs@mac.com