CCAD Annual Contributors'meeting

Jan 18th 2008

Royal College of Surgeons

35-43 Lincoln's Inn Fields
London WC2A 3PE

MEETING SUMMARY

Present: John Gibbs (Chair/Leeds). Lin Denne (CCAD), Nadeem Fazal (CCAD), Bill Brawn (BCCA & Birmingham), Bruce Keogh (SCTS), Sheila Shribman (DH), Sue Dodd (DH), Anne Keatley-Clarke (CHF), Elizabeth Bruce (CHF), Archana Dodhia (CHF), Vashti Poole (Gift), Paula Banda (GUCH), Rodney Franklin (Brompton), Philip Kimberley (Brompton), Kevin Roman (Southampton), Rafael Guerrero (Leeds), Lindsay Cawte (Evelina), John Simpson (Evelina/Guy's), David Anderson (Evelina/Guy's), Heather Whatnall (Glenfield), Magdi Tofeig (Glenfield), Chris Greengrass (Glenfield), Oliver Stumper (Birmingham), John Stickley (Birmingham), Nilima Malaiya (Manchester/Liverpool), Mahadevan (Manchester MRI), John Richards (Manchester MRI), Asif Hasan (Freeman), David Crossland (Freeman), Shela Jameson (Freeman), Obed Onuzo (Cardiff), Steve Westaby (Oxford), Nicky Manning (Oxford), Kate Grebenik (Oxford), Colin Evans (Oxford), Yvonne Glackin (GOS), Miles Curtis (UCL), Victor Tsang (GOS/UCL), Kate Brown (GOS), Ian Sullivan (GOS), Andrew Parry (Bristol), Fiona Walker (UCL), Andrew Sands (Belfast), Dennis Gladstone (Belfast), Kenny Macarthur (Glasgow), Alan Houston (Glasgow), Chuck McLean (Glasgow), Trevor Richens (Glasgow), Lorraine Leask (Glasgow).

Apologies: Roger Boyle, David Cunningham, Andrew Harrison, B Sethia.

JG reported the sad death of Dr Raphael Balcon early this week. Raphael was a key founder of CCAD and his huge contribution to the setting up of the national cardiac audit programs was greatly appreciated.

Public Portal

JG reported that the portal had been updated at Christmas following refinement of the procedure algorithms in November and improvements in data completeness and quality. Individual checking of a sample of over 1500 procedures from Birmingham and Glasgow had suggested greatly improved accuracy of procedure allocation with no evident errors, although the complexity of the EU coding and the many permutations of codes submitted for each procedure would make it unlikely that we have reached perfection. The Glasgow representatives were concerned that the algorithms used to allocate procedures was hard to understand. CCAD accept this and will try to improve on our explanation of its application (Action: DC/LD/JG). The

updated funnel plots were completed only this week. Whilst it is reassuring that there are still no centres at the "red line" alarm confidence limit of 99.95%, we now have a handful of results for specific procedures where a few centres are lying at or just beyond the green (98% confidence limit) line for some procedures (ASD repair, AVSD repair, partial AVSD repair, tetralogy repair, truncus repair and Norwood 1). For these specific procedures the number of deaths at the centres in question were very small – ranging from 2 to 7 deaths over the 5 year period of 2000-2005 used to create the funnel plots. It is likely that there are be good clinical explanations for these deaths, but each centre will be informed by CCAD as well as by the SCTS and BCCA of their position on the funnel plot so that the deaths can be carefully audited. Feedback to the SCTS/BCCA via the respective Trusts' medical directors will be expected. The centres' results for those specific procedures will be marked with an orange flag which will be removed once a 2 year period of survival within the 98% confidence limits has been achieved. Bruce Keogh commented that we should not over react to these findings and pointed out that if we had not found some potential outliers questions could be raised about our chosen warning levels for requesting detailed investigation of the causes of potential increased mortality. The funnel plots which include these results will be updated on the Portal once the centres in question have been informed of the above results.

The Glasgow representatives asked if there could be a wider group than the Steering Committee making decisions on what data should be in the public domain and how it should be analysed. JG felt that the steering committee must be kept to a manageable size if it is to remain efficient, and that there were many openly available routes for individuals or groups to contact CCAD to give their views and ideas. The view of the delegates at the annual contributors' meetings at the RCS has always been that one meeting a year was sufficient and the consensus today confirmed that. JG reminded all that contact could be made with the CCAD office at the Information Centre, to JG or DC directly, to Lin Denne and CCAD staff at validation visits and also via either the BCCA or the SCTS, and that we would invariably listen and respond to received views. JG felt that the current CCAD arrangements and single "all comer" annual meeting at the RCS should stand, but that CCAD would have no objection whatever to additional user groups being formed and sending their views to CCAD.
Bill Brawn and Bruce Keogh felt that identification of potential outliers on the funnel plots should be seen as a stimulus for learning and improvement, Bill suggesting that the BCCA and SCTS should form a group dedicated to detailed review of all deaths such that we might learn more about the causes and potential avoidability. This met with unanimous support. JG reminded all that CCAD's responsibility lies with collecting, validating and analysing data but no more, and that it was indeed most appropriate that investigation of deaths should be carried out by the SCTS & BCCA.
Action: BB & BK.
JG felt that our consent process for validation should be sufficient to allow BCCA/SCTS detailed audit of deaths to go ahead, but agreed to write to Dick Waite of the Healthcare Commission so that this can be checked with PIAG (Patient Information Advisory Group). *Action: JG.*

The Children's Heart Federation representatives made a plea for the Portal's ergonomics to improve as well as the text explanations to be made more easily understood by the public. Whilst JG pointed out that it is hard to portray analysis of outcomes from 48 procedures carried out in 13 centres in a very simple manner, there

was wide consensus from all present that more could be done to improve the Portal appearance, navigability and intelligibility. *Action: DC/JG/all CCAD staff, with CHF).*

Future improvements

Further improvement in central tracking of deaths remains more complex than it should be, with less than satisfactory % confirmation of life status at 1 year post procedure. Linkage with the ONS is not free and stretches the project budget. DC is currently exploring potential for us to get free life status via the new direct link between HES and the ONS, which is looking promising but will only improve matters in England. DC is also working on improving tracking via the Scottish Register. We feel that 1 year confirmed life status is not yet adequate to allow us to reliably plot 1 year funnel plots, but we remain optimistic that we will be able to do so in the not too distant future. John Stickley asked if it was possible for centres to confirm late life status themselves but JG was not able to answer that and will seek advice. It goes without saying that central tracking should prove most reliable, but this will never work with foreign national patients where "manual" confirmation would be of help.
Action: DC/JG to look into potential mechanism for life status confirmation by centres.

BK commented that the DH are keen to see audit projects developing more sophisticated outcome measures rather than such crude measures as mortality. There was wise support for doing this, with work already starting (see below) on freedom from reintervention analysis. BK pointed out that from the patient's point of view there were many other, if less important. Outcome measures such as timely communication with health professionals and clear and appropriate mechanisms for post procedure care. We had been hoping to strengthen our links with Bruce's previous department – the Institute of Clinical outcomes based at UCL – to improve and increase the analyses of our data (such as UK and centre specific actuarial survival curves). BK reported that the Institute will survive, along with its funding, and there should be opportunities for us to make use of their analytical expertise once his replacement has been appointed.

Data validation visits

Lin Denne gave an overview of the validation visits, including making a plea for more clinical volunteers to join her on the visits. We are happy for the more senior SpRs (surgeons and cardiologists) to do this. Most centres' data quality indexes had improved slightly in the last year, the overall average DQI being 92%. The data fields still causing trouble are second operator name and the fields relating to neurological status pre and post procedure. JG stressed the importance of improving this particular data as neurological damage is an extremely important outcome measure for our patients. Although procedure coding seems to have improved greatly, there remain serious concerns over the accuracy of some pre-procedure diagnosis codes. These have been discussed many times over the years; it is obvious that diagnosis for many of our patients changes and we have always asked for up to date diagnosis codes for each procedure. For instance, for a pulmonary artery reconstruction after tetralogy repair, the pre-procedure diagnosis becomes repaired tetralogy, pulmonary artery stenosis – the diagnosis is no longer tetralogy. It is of particular importance to get this right as we are moving towards analysis of some procedures specifically taking into account the pre-procedure diagnosis. How this is managed will vary with different

local software, but one simple answer is to recode diagnosis at every procedure. Each centre will need to liaise closely with their software developers to ensure accurate data export for this field. Lin will try to include samples of diagnoses at future validation visits, time allowing.

Lin reported that consent procedures for data submission & validation are now established in all centres. Some are using a specific consent form whilst awaiting changes to their Trust's generic consent form. During the validation visits it sometimes appears that consent documentation was not always perfect – an important issue for centres to address. With the consent processes in place, we anticipate the current validation visits continuing on an annual basis.

Adult congenital data

After years of encouragement we are pleased that in the last year we have seven new centres recruited who are sending us adult congenital intervention and/or surgery data (Brighton, Cardiff, Liverpool CTC, Manchester Royal, St George's London, Nottingham and Walsgrave. At present these centres who only carry out relatively small numbers of procedures have not been included in the validation visits and only some have introduced the consent process to allow visits to occur – Lin has now visited Manchester RI and we plan a visit to Liverpool CTC in the coming year. We continue to encourage adult units to obtain consent and we hope to be expanding our adult validation visits as consent processes are introduced in more adult centres.

It is disappointing that there are still a good number of centres who are known to carry out adult procedures who have made no attempt to send data to CCAD – just some examples being Edinburgh, Glasgow, Hull and Sheffield. JG reported that there is ongoing work between the BCCA, the BCS and BCIS to agree upon governance guidance for adult congenital therapeutic catheterisation, which should progress in the coming months. Involvement in National audit will of course feature strongly in that guidance.

Mahadevan suggested that we need to improve coding for comorbidities for adult congenital patients, a good point as the paediatric EU codes for comorbidity do not include smoking, lung disease and the like.

Action: RF to consider expanding EU codes to cope with adult comorbidity.

Individual operator results

After the annual lengthy discussion on this subject there was unanimous approval that CCAD should analyse operator specific survival for each of the 48 procedures currently analysed on a centre specific basis, but that this data should NOT be on the public portal. It was agreed by all that it would be useful for individual consultants and their colleagues to be able to see their operator specific results at the click of a mouse. This will be implemented in a secure manner with password protection so that all consultants in each centre will be able to see their own and their immediate colleagues results, but they will not (at least for the time being) be able to see individual operator results at other centres. The Glasgow representatives were nervous that the Freedom of Information Act might force this data into the public domain, but others felt that the FOI already allows any individual or body to request this data now – regardless of whether it is held by CCAD or individual Trusts.

Action: DC and team to develop this facility.

Freedom from reintervention
JG showed some illustrations of our first venture into freedom from reintervention curves. It is clear that even for "simple" procedures such as isolated VSD repair or transcatheter ASD closure the data is more complex than it initially appears – the explanation for a slow decline in freedom from reintervention even for these procedures is likely to be due to some patients with complex disease undergoing these procedures – ie the underlying diagnoses not being as straightforward as VSD or ASD. Further analyses will be done taking pre procedure diagnosis into account.

Hybrid procedures
NICE had contacted CCAD asking us to consider collecting audit data on hybrid procedures – in particular he hybrid procedure for initial palliation for hypoplastic left heart syndrome. All present agreed this seemed appropriate. A new procedure category "Hybrid procedure" will be added to the current categories of bypass, non bypass, catheter . thoracic, other. Local centres will need to ensure that data export software is appropriately revised to include this group of procedures.
Action: DC/CCAD staff to make necessary central changes and to circulate a revised data export guide to known software developers.

Infectious endocarditis data
It is widespread knowledge, following the public consultation on the imminent NICE guidelines for endocarditis prophylaxis, that big changes to recommendations on preventative measures are to be made. There has understandably been concern amongst patients, parents and healthcare professionals that we do not have a mechanism for collecting reliable data on endocarditis and that this will be of particular importance if we change our practice. Whilst it will not be possible to compare prospective data in the future with data from past practice (there isn't such past data in existence), all agreed that national collection of data seems wise. JG had looked into making IE a notifiable disease, but this proves to be a very lengthy process involving a change in statute. It seems unlikely that it would be realistic to set up a completely new national audit of IE across the NHS, but it should be possible for us to implement data collection on IE in children (and rather less reliably in adults with congenital heart disease) as part of CCAD's current processes. This will mean a new approach, involving another new category of treatment (see hybrid procedures above) but will also mean collection of additional data specific to endocarditis.
JG suggested a small additional dataset (reduced in size after initial consultation with the CCAD steering committee), which was approved by all present. As well as data already collected for other procedures – demographics, admission & discharge dates and life status), the new fields will include: date of diagnosis, IE episode sequence, Blood culture results, Site of infection, Pre- IE diagnosis, Dental Rx received or required, Date of last dental Rx, Antibiotic cover?, Invasive procedure prior to IE, Antibiotic course within 1 month of IE diagnosis. The new Endocarditis data set will be posted on the website. Data collection will start on April 1st 2008, so prompt action by software developers will be necessary.
Action: DC and CCAD technical staff.

Pulmonary hypertension
JG reported that CCAD has been approached by the National Pulmonary Hypertension group which is chaired by Dr Simon Gibbs (Hammersmith). NSCAG already insist on a very large dataset for PHT treatment, and there are imminent plans

for CCAD to host this data, but funded by the PH association rather than this becoming part of the national cardiac audits. The PH group are keen that we get involved. After some deliberation, those present at the meeting felt that we could not offer much extra value to the research data collected in the NSGAC dataset, but that we would keep an open mind about specific audit aims in PHT if they were identified in the future.

AOB
There was no other business. Next meeting will be planned for similar date in 2009.

JLG 23/1/2008