CCAD Annual Contributors'meeting

Jan 15th 2009

Royal College of Surgeons

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

MEETING SUMMARY

Present: John Gibbs (Chair/CCAD/Leeds), David Cunningham (CCAD) Lin Denne (CCAD), Nadeem Fazal (CCAD), Bill Brawn (BCCA & Birmingham), Sue Dodd (DH), Anne Keatley-Clarke (CHF), Julie Wooton (CHF), Ian Averiss (Tiny Tickers), Helen Laing (HQIP), Irene Walker (HQIP), Rodney Franklin (Brompton), Maria Sessato (Brompton), Philip Kimberley (Brompton), Kevin Roman (Southampton), Nihal Weerasena (Leeds), Dom Hares (Leeds), Conal Austin (Evelina), Thomas Witter (Evelina), Aaron Bell (Evelina), Joe Omigie (King's), Giles Peek (Glenfield), Mark Duthie (Glenfield), Paul Stafford (Glenfield), John Stickley (Birmingham), Nilima Malaiya (Manchester/Liverpool), John Richards (Manchester MRI), John Richards (Manchester MRI), Ruth Grainger (Liverpool Heart & Chest), Rob Johnson (Liverpool), Asif Hasan (Freeman), Sheila Jameson (Freeman), Neil Wilson (Oxford), Nicky Manning (Oxford), Colin Evans (Oxford), Geralyn Oldham (GOS), Kate Brown (GOS), Vicky Banks (GOS), Andrew Parry (Bristol), Stuart Cross (UCL), Dennis Gladstone (Belfast), Lars Nolke (Dublin), Jan Burns (Glasgow), Mark Danton (Glasgow), Brodie Knight (Glasgow), Trevor Richens (Glasgow), Birute Simkiene (Dendrite), John Payne (Dendrite), Lucy Babey (Southampton), Lucia Katsumbe (Harley St Clinic).

Apologies: Roger Boyle, Sheila Shribman, Andrew Harrison, B Sethia, Chuck McLean.

CCAD administration

Helen Laing from the Health Quality Improvement Partnership gave an update on the recent and planned changes to administration of the National audit projects. HQIP are led by the Academy of Royal Colleges, the College of Nursing and National Voices (patient representation). HQIP have taken over the supervisory role of the Healthcare Commission in audit and administer our funding, the funding ultimately still coming from the DH via NCAPOP (National Clinical Audit and Patient Outcomes Programme). NCAPOP take advice from the NCAAG (National Clinical Audit Advisory Group) who also advise the DH on audit and who are responsible for devising audit policy in England. So none of you will be confused now then (!)

HQIP don't actually run the audit projects. CCAD is presently run by the IC (Information Centre for Health & Social Care). The IC have a contract with HQIP/NCAPOP to continue to run congenital CCAD until April 2010, but the provision of the service after that will be put out to tender later this year. We hope that the contract will be for at least 2 years and possibly 3 to give us some stability.

From CCAD's point of view it's hard not to despair of the endless changes in administration.

Public Portal and data analysis

DC gave an update on how funnel plots are calculated, the statistical reasons for our wide confidence limits, the complexity of the data and its analysis and the problems & expense of tracking life status. Charges for tracking via the ONS in England cost CCAD overall (not just the congenital project) some £82,000 whilst in Scotland it is free. Comment was passed on the absurdity of any national audit having to pay for government data on life status.

DC reminded us of how complex it can be to assign life status to an appropriate procedure when patients have had multiple procedures. This is too labour intensive to do manually, record by record (it's no good just doing it for death, it also has to be done for status = alive or status = reoperated). DC has devised an automated way of doing this, using the procedure allocation algorithm's hierarchy to assign death to the most major procedure the patient has had. There was a consensus that it would be very helpful if centres could be fed back life status, at least those classified as dead, so that every centre can check that the death has been assigned to the appropriate procedure. CCAD will look into ways of doing this. DC pointed out that it is much more manageable and a less daunting prospect for centres to do this on a regular basis rather than wait until a full year's data has been sent

Action: Steering Committee to look into potential mechanisms for feeding back life status for confirmation by centres.

Duplicate records have become a problem for all audits, not just us. The problem arises mainly as a result of a centre correcting a patient's records and resubmitting the data rather than changing existing data on line via Lotus Notes. At poresent the unique identifier for a record is it's full date field (ie date + time) but many centres only submit a date, making it difficult to automatically detect whether a patient has genuinely had 2 procedures on a given date or not. GOS had suggested we add a new field to the dataset – a unique procedure identifier. Whilst all agreed this would be helpful (perhaps we should have done it 9 years ago!), it would cause trouble getting all the software manufacturers to do this and rewrite their CCAD export routines. For the time being it was decided to see if the increased awareness of the problem after this discussion will result in a reduction in the number of duplicates.

JG reported that the portal had been updated just before Christmas, with updating of the funnel plots. The delay in updating the funnels was partly due to lack of in house resources, but also to a long wait for centres to clean their poor quality NHS number data and resubmit. Following JG's letter to all centres last summer pointing out that our high proportion of untrackable patients was due to a lack of NHS numbers, all but two centres have now responded – with a huge reduction in missing numbers and an increase in trackability to around 87%. Even though the deadline for resubmitting data has expired, we are still keen that the 2 remaining naughty centres will comply.

The updated funnel plots did not reveal any new centres at the green line and there are still no red liners to date.

Data validation visits and consent

Lin Denne gave a review of the last year's validation visits and made a plea for more clinical volunteers to help with the visits. She reminded us that PIAG's deadline of last April to have a consent process in place for data validation would have an important potential impact on the coming round of validation of 07/08 data. Lin will be checking the medical records for evidence of consent and if none is apparent she

will be unable to use those records. The proportion of records which do not contain evidence of consent will appear in the visit report. One centre claimed that their Caldicott guardian had said that the standard hospital consent form was sufficient for our purposes. CCAD do not accept that a local Caldicott guardian has authority to contradict the Healthcare Commission and PIAG, who have told us very plainly that specific consent is required for data to be inspected by personnel who do not have any direct role in a patient's healthcare provision.
Lin reported that overall our DQI (data quality index) for 06/07 had remained unchanged since 05/06 at 92%. The main culprits for the 8% missing or incorrect data were duration of post-operative ventilation, PCPC (paediatric cerebral performance score) and post procedure seizures. There was debate as to whether ventilation duration should be abandoned, with no majority view apparent. Nonetheless, the SCTS feel strongly that this is a useful surrogate for morbidity and were keen we should try to improve rather than abandon its collection. All centres were encouraged to discuss this with their Picanet colleagues to try to improve our DQI in this domain. One or two delegates felt we should abandon collecting PCPC but JG and the CHF feel very strongly that this very simple measure of brain function should be collected as procedure related neurological damage is a very major issue and simply cannot be ignored.
Action: CCAD to circulate all centres with a list of each centre's DQIs for these domains to stimulate improvement.

Pacing and ablation
The CRM (Cardiac Rhythm Management) database has now come under the auspices of CCAD. This means we can link to CRM records using the NHS number, so it is no longer essential that pacing and ablation is submitted to both CRM and congenital CCAD – one data submission will do (we understand that this is likely to be almost all to CRM).

Pulmonary hypertension
Simon Gibbs, of the National pulmonary hypertension service, kindly came to give an update on the national PHT dataset and its collection. The dataset has been considerably simplified and is now being sent to CCAD by the specialist PHT centres. The data storage and analysis is funded by the PHT patient association at present, an application to HQIP having been unsuccessful. The funding arrangements are for only two years, so an alternative means of supporting the project will be required from 2011. The dataset includes children and adults with congenital heart disease, so will provide valuable outcome data for our patients and will allow linkage via the NHS number for those who have had interventions for congenital heart disease.

Progress with planned developments
At last year's meeting there was agreement to proceed with a number of new developments including making a start on actuarial survival plots for each of the 48 procedures analysed as well as freedom from reintervention. We have not made much progress on these two aspects of data analysis due to a lack of analytical resources within CCAD. We hope to make some progress over the coming year, hopefully by forging a much closer relationship with NICOR (the National Institute of Clinical Outcomes Research) if our bid for additional funding from HQIP is successful.
We've made progress with the ergonomics of the public portal with help from the CHF – in particular we have improved on our "plain English" and the explanations of the data and the funnel plots.
We've made progress with our collaboration with NICE and are working with them to revisit their early IPG (Interventional Procedure Guidance) on transcatheter VSD

closure with our offer of providing basic statistics on the procedure as well as tracking of survival and reintervention.
We have also made progress with individual operator results (as agreed last year), with a pilot version of Leeds data on line via Lotus Notes going live at the beginning of January. This will be accessible to all centres within a few weeks, with each centre being able to see each of its own operators' survival statistics for each procedure undertaken. Once we have feedback from centres on the presentation of the data we plan to make this available via a password secure part of the portal, avoiding the need to use Notes for access. We hope this data will be useful for local Trust appraisal and governance and will also make it much easier for individual operators to check their data on line.

Action for outliers and investigating deaths
Les Hamilton (for SCTS) and Bill Brawn (for BCCA) had agreed a simplified approach to potential outliers. Earlier plans for a "traffic light" system on the portal as an alert to green or red liners were abandoned after last year's meeting as we all felt that the green and red lines alone were sufficient. Centres reaching the green line (98% confidence limit) would receive a letter from the CCAD project Board letting them know that they had reached the green line. Local action and investigation would then be a matter for the local clinicians and Medical Director. DC emphasised that the number of deaths required to reach the green line was very small in some cases, and that even using the 98% confidence limit there was a 16% probability that reaching the green line should happen just by chance. However, a chance arrival at the red line (99.95 confidence limit) is extremely unlikely and in these circumstances a letter from the CCAD Project Board would be followed by an offer from the SCTS and BCCA to visit the centre to investigate. This process is explained on the portal alongside the funnel plots.
Last year, at Bill Brawn's suggestion, there was strong support for development of a mechanism for a detailed look at all deaths after treatment for congenital heart disease. Les Hamilton reported the excellent news that an application to NCEPOD (National Confidential Enquiry into Post Operative Deaths) has been successful. NCEPOD carry out projects for a limited period of time (usually 2 years), so if we feel an ongoing need for looking at all deaths we'll need to revisit this in 2011.

Infectious endocarditis data
The updated dataset, which includes the addition of data fields for endocarditis as well as the new option to identify hybrid procedures is now posted on the public portal. So far, it appears that the only centres with local databases updated to include the dataset and automated export facilities are the Brompton and Leeds. All centres were encouraged to keep a paper log of endocarditis cases as well as to put pressure on their software providers to include the new dataset. The IE dataset will be included in validation visits from April 2010.
Action: ALL

Adult congenital data
After years of encouragement we are pleased that in the last 18 months we have nine new centres recruited who are now sending us adult congenital intervention and/or surgery data. At present these centres who only carry out relatively small numbers of procedures have not been included in the validation visits but we now plan to visit all centres who submit data. We continue to encourage adult units to obtain consent to allow visits to take place. It is disappointing that there are still a substantial number of centres who are known to carry out adult procedures who have made no attempt to send data to CCAD – HES data (admittedly unlikely to be very accurate for

congenital disease) suggests that there are almost twice as many PFO closures carried out than are submitted to CCAD, despite NICE's recommendation for data to be sent to us.

New proposals

The DH is encouraging national audits to include PROMS (Patient Reported Outcome Measures) as indicators of quality of care. Anne Keatley-Clarke gave a brief overview of PROMS, which have already been used in some specialties such as hip and knee replacement. Many have used straightforward measurements of pain and mobility, and some have concentrated on assessment of QOL. Unfortunately we do not have any obvious simple metrics for PROMS in treatment of congenital heart disease and assessment of QOL is not only very time consuming and complex in children, it is also very difficult to interpret in the context of outcome of treatment. In addition, it is clear that patients and parents are often very reluctant to criticise doctors looking after them or their children. The CHF have previously carried out a patient satisfaction survey and Michael Cumper of GUCHPA is currently leading a survey of patient opinions on quality of care for adults with congenital heart disease. Some aspects of these surveys may prove useful in developing PROMS for our specialty. We were agreed that procedure specific measures of outcome would be ideal. The CHF emphasised that neurological outcomes should be high on the agenda, and thought that parents reported neurological outcomes would likely be even more important than pre-discharge cerebral performance scoring.

Andre Parry suggested that waiting list times and cancellations should be part of the assessment of quality of care.

Bill Brawn suggested that ECMO for cardiac patients warranted analysis. We should have data on such cases as the procedure should be coded.

Action: JG & steering Committee to have further discussions on PROMS with the CHF. Steering committee to look at what data we have on ECMO and how it might be analysed.

AOB

Philip Kimberley (Brompton) is organising a conference for national audit database managers. For further info contact Philip at P.Kimberley@rbht.nhs.uk

JLG 18/1/2009
jlgibbs@mac.com