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Congenital CCAD stakeholder's meeting
Feb 4th 2011 10.30 – 15.30
Royal College of Surgeons

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

MINUTES

Present: John Gibbs (chair & Leeds), David Cunningham (CCAD), Rodney Franklin (CCAD & Brompton), Sue Dodd (DH Heart team), Lin Denne (CCAD), Nadeem Fazal (CCAD), Marion Standing (CCAD), Chuck McLean (CCAD & Glasgow), Shak Qureshi (BCCA & Evelina), Thomas Witter (CCAD & Evelina), David Anderson (Evelina), Irene Arenillas (Hammersmith & Imperial), Miles Curtis (UCH), Debbie Evans (Cardiff), Obed Onuzo (Cardiff), Jean Beamer (Alder Hey), Christine Daniels (Alder Hey), Anne Keatley-Clarke (CHF), Julie Wooton (CHF & Max Appeal), Colin Evans (Oxford), Nicky Manning (Oxford), Nilima Malaiya (Manchester RI), John Richards (Manchester RI), Paul Arnold (Liverpool Heart & Chest), Jayde Archer (Harley St Clinic), Katie Hill (Southampton), Sheila Jamieson (Newcastle), Kevin Roman (Southampton), Prem Venugopal (Alder Hey), Nelson Alphonso (Alder Hey), Rafael Guerrero (Leeds), Attilio Lotto (Glenfield), Alison Hayes (Bristol), Andrew Sands (Belfast), Anne Graham (Belfast), Phil Kimberley (Brompton), Maria Serrato (Brompton), Alan Magee (Brompton), Oliver Stumper (Birmingham), Kate Brown (GOS), Martin Utley (CORU), Ian Averiss (Tiny Tickers), Helena Gardiner (Brompton/Charlotte's), John Stickley (Birmingham) Amy Bahat (Birmingham) Alison Hayes (Bristol), Jose Velasquez (Bristol), Vicky Banks (GOS), Imdad Rahman (GOS), Serban Stoica (Bristol), Aidan Bolger (Glenfield), Elizabeth Aryeetey (Glenfield).

Apologies: Roger Boyle, Sheila Shribman, a number of lesser mortals.

1. JG gave an update on the membership of the Steering Committee and the Project Board, along with a summary of the funding difficulties facing most national audits. Additional/alternative sources of funding have been suggested for some audits such as a mandatory fee derived from existing NHS tariffs, grants from industry, a levy on implantable devices, and charging all third parties for data. The group found none of these particularly attractive. Informal advice from HQIP is that our funding should not be at immediate risk as we are relatively high profile at present.

2. Sue Dodd gave an update on progress of our move from the IC (Information Centre) to NICOR (National Institute of Clinical Outcomes Research) at UCL. There have been bureaucratic delays, but the move (including transfer of our core CCAD staff) should be completed by April. The CCAD team feel this is a major step forward and should increase our resources and allow us to be much more in control of our budget.

3. What's happened in 2010

1.Outliers: there were the expected few "green liners" but no "red liners" in the 2006-9 data analyses.

2.Individual operator data: JG reported that improvements are on the way for the individual operator data views, both in Lotus Notes and via the Clinician

Access part of the portal. In particular, we will be adding NHS number (visible only to the relevant centre) to the view, along with the procedure allocated by CCAD along with the coding string submitted by the centre. This should help centres with their local data validation and should help to stimulate further improvements to the allocation algorithms.

3.FOI requests: JG suggested we should reconsider placing individual operator data in the public domain because this data can be obtained via the FOI by anyone. If the data was published by us we would have more control over it's format and it's context and would be likely to forestall FOI requests (which are very time consuming to deal with). Although there was more support for this than when it was discussed last year, there was still strong opposition from some delegates who felt it would result in protective practice, that the data would be misinterpreted and that it would be a very threatening process for new consultants. It was agreed that we would revisit the question next year, but that there was not sufficient support to proceed with publication at the moment. Of note that the CHF agreed with JG that we should be moving towards this in a controlled manner!

4. Antenatal diagnosis: the dust has settled over our initial antenatal data analysis by SHA, helped by publication of the latest year's data as well as the latest 5 years, as well as analysis by PCT, along with a more understanding relationship with FASP. JG reported that funding for training had improved in Yorkshire & Humberside following the publication of the data.

4.Data collection & analysis changes

1.Removing censorship: JG reported that, after numerous complaints about "undercounting" of procedures (almost all explained by censorship due to a procedure losing its follow up status), the Steering Committee had unanimously decided to make major changes in the data analyses to remove censorship. This results in each procedure having a follow up status of alive, dead or unknown, regardless of further procedures undertaken before or after. This is statistically valid providing it is clear what the analysis relates to, and that no attempt to combine survival from multiple groups of procedures is made (this would result in double counting of deaths). DC presented examples of how this changes the data analyses – adding considerably to numbers in some funnel plots, thereby tightening confidence limits and resulting in fewer green liners. No new red liners resulted from the new analyses. The new methodology, although a little unconventional, met with general approval. A clear explanation of the change in analysis and its inherent dangers will be posted on the public portal.

2.New analyses: the delegates endorsed the Steering Committee's suggestion to add ablation, AICDs, transcath PVR, and combined shunt + TAPVD repair (the latter because of its very high risk) to the current specific analyses. JG forgot to add that the steering committee had also thought it would be useful to add heart transplantation to the analyses.

3. Executive annual reports: the previously downloadable, printable version of the executive report has been temporarily removed from the portal, hopefully to return in the Spring when it has been updated to reflect the new changes above.

4. Timeliness of publication & data submission: we are still striving to bring most of the validation visits into the first half of the financial year in order to

shorten our time to publication. JG emphasised that we are under great pressure to improve on timeliness (HQIP, CQC etc) and that a strict deadline for the full year's data submission has been set for May 31st for all centres. This gives a full 2 months after the end of the financial year to get data sent. Data received after this are unlikely to be included in the year's analyses. On behalf of the BCCA Shak Qureshi asked that we should try to give centres at least a month's notice prior to publication if they were green or red liners, and that we should continue to actively notify centres for green lining, not just red.

5.Data validation visits, consent and data quality: Lin Denne gave an overview of the year's validation visits, the DQIs and how they had changed in the last year, highlighting that data quality appears better in centres with a mixed paediatric and adult congenital practice. Duration of ventilation remains the poorest field for paediatric centres with Cerebral Performance Category (we think we should remove the "P" for paediatric from this) not far behind. For adult centres CPC, weight, antenatal diagnosis, fluoroscopy data and second operator identity remain weakest. Lin reminded all of the importance of consent for the validation process – lack of consent was a major issue at some adult centres.
Lin also gave an update on endocarditis data, reminding us that consent is essential for validation of these cases too. Only 15 of the 23 centres sending us audit data had submitted IE data. There is clearly a lot of room for improvement. Poorest quality data was for diagnosis, dental treatment and date of diagnosis (if not originally diagnosed at the specialist centre).

6.Progress with risk adjustment: Martin Utley (CORU) and Kate Brown (GOS) gave an update on our collaborative work assessing risk stratification (funded by NIHR). 10 years' data is being used, with an initial assessment of data quality across the years (obviously much better in more recent years) for the 44,000 odd patients included. Martin gave an update of the difficulties involved, including the changing nature of risk models with time. Factors such as procedure, procedure complexity, age, weight, diagnoses, comorbidities and multiple procedures are included. The project is funded until September 2011; Martin and Kate will give us an update next year.

7.International collaboration: at last year's RCS meeting delegates were much more favourably inclined towards international collaboration, but we still had very limited information on validation protocols employed by the STS and EACTS. Chuck McLean is following this up and gave us some feedback from the US and EU audit projects. However, we still have limited information on the exact validation protocols. There was support from the delegates to gently move ahead with this, but we felt the steering committee should consider carefully these organisations' precise validation processes and only send some pilot data once we are content that appropriate validation is taking place and we can compare like with like.

8.Developments for 2011: JG reported that we are behind schedule with our work on actuarial survival and reintervention. We believe in fairies and firmly believe that our move to NICOR will get these analyses off the ground. We plan, in the first instance, to look at reintervention after VSD repair, switch for simple TGA, AVSD repair, coarctation repair, coarctation angioplasty, coarctation stenting

and transcath ASD closure. We remain optimistic that a preliminary report on this will be available later in the year. We also hope to analyse our data on Cerebral Performance Category changes in the coming year.

9. Suggestions for change. Those received include:
Adding a new data field to identify “Emergency” procedures, which was thought to be very difficult to define and interpret, so got the thumbs down.
Adding a new data field for cause of death – met with wide support but is not as straightforward as it sounds. Nonetheless, the steering committee will take this forward, probably by asking all centres to identify a cause of death rather than by central tracking (expensive and not necessarily reliable).
Analysis of results of valve repair based on intention to treat rather than final operation alone. The steering committee will look at this, but gut feeling is that numbers are pretty small at present. Rodney reported that there would be some additional codes for these procedures in the updated short list this year.
Analysis of pulmonary artery angioplasty outcomes – DC says this is a procedure done in reasonable numbers so might be the next addition to our analyses. Steering committee to look at in more detail.
1 year survival funnels (as well as 30 day funnels), which met with general support (the steering committee will consider this in detail and take it forward).

10. AOB & next meeting
Bob Anderson emailed to point out that the information about cardiac units on the public portal were out of date in some cases, even including listing staff who have left. All centres to check their data and update please (email to helpdesk).

JG reported that he had received a draft version of the S&S committee’s recommendations for improvement in audit. There were some specific suggestions for expanding our reported outcome measures (we have been planning that for years anyway), to make it easier for centres to compare their own survival statistics with the national mean (we are working on this already by including % national survival for each procedure on the portal). There are also specific recommendations for each centre (not CCAD) to carry out regular statistical analyses of their survivals using CUSUM plots or VLAD plots as used by the Oxford review panel statistician. Martin Utley (CORU, m.utley@ucl.ac.uk) informed the meeting that his unit has produced a simple guide to such analyses and will be happy to send the guide to any interested parties.

Next meeting: same venue, early 2012.

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