

Congenital CCAD stakeholder's meeting
Jan 28th 2010 10.30 – 15.30
Royal College of Surgeons
Lincoln's Inn Fields
London

MINUTES

Present: John Gibbs (chair), Roger Boyle, Sue Dodd, David Cunningham, Les Hamilton, Shak Qureshi, Rodney Franklin, Martin Elliott, Lin Denne, Andy Harrison, Nadeem Fazal, John Stickley, Joe Evrell, Cecilia Yardley, Joe Omigie, David Crossland, Fidelma Flynn, Conal Austin, Prem Venugopal, Aaron Bell, Nilima Malaiya, Thomas Witter, Chuck McLean, Alan Houston, Ian Averiss, Helena Gardiner, Ellen Kinsey, Colin Evans, Nicky Manning, David Barron, Andy Tometzki, Kate Brown, David Anderson, M Seliato, Philip Kimberley, Lucia Katsumbe, Serban Stoica, Jose Velasquez, Obed Onuzo, John Richards, Hazel Greig-Midlane, Nicola Anderson, Laura Bond, Lindsay Morrison, Miles Curtis, Vicky Banks, GERALYN Oldham, Suzie Hutchinson, Anne Keatley-Clarke, Anne Graham, Sheila Jamieson, Kevin Roman, Lucy Babey, Justin Sanders, Frances Bu'Lock.

Sheila Shribman (along with a number of lesser mortals) sent her apologies.

1. JG gave an update on membership of the steering committee and the project board (the members are listed on the public portal).
2. RB gave an update on the NICOR (National Institute of Clinical Outcomes Research) collaborative bid (which he has led) to take over administration of all the national cardiac audits following the running of the audits being put out to tender. This bid has been strongly supported by the SCTS, BCCA and the CCAD team and in December 09 was provisionally accepted, pending some fine tuning. This will be a major step forward for all the audits and we hope will allow congenital CCAD to achieve many of its current and future aims by allowing us to access analytical skills shared across the audits. NICOR will be housed by UCL and CCAD data storage will probably move from the IC (Information Centre) to DH servers in London. Stakeholders will be kept informed of progress in our newsletters.
3. Progress in 2009

Collaborative projects over the past year have included NICE, revisiting outcomes for some new procedure guidelines such as transcatheter VSD closure); CORU (Clinical Operational Research Unit) at GOS, risk analysis; NSCG (National Specialist Commissioning Group), volumes of work and demographics; GUCH (Grown up Congenital Heart patients association), PREMS; FASP (Fetal Anomaly Screening Program), antenatal diagnosis of infants requiring treatment; W Midlands screening group (screening using oximetry).

2009 saw our first and only outlier (for tetralogy repair). The SCTS was reassured by the local Medical Director that the issue had already been recognized and dealt with, with the approval of the RCS.

Analysis of Fontan/TCPC operations had turned out to be fraught with difficulty, initially due to pooling of results for all ages resulting in one purely adult centre appearing to be an outlier. This was addressed by changing to separate analyses of Fontans in children and adults, but in this process the children had transiently disappeared from the data on the public portal (corrected fairly promptly!). However, the BCCA were still unhappy with the data and was keen to see HLH and non HLH Fontans reported separately. This reanalysis is underway and will result in 3 separate sets of data – those for HLH patients, for non HLH and for over 16s. Time will show if outcomes for HLH prove to be any different from other single pump physiology. Alan Houston had also done some sterling work looking at Glasgow data and had found an old error in our pre 2002 data (some cavopulmonary shunts getting designated as TCPC) as well as some that were being missed due to inclusion of qualifier codes from the long (rather than short) EU codes. The latter have already been corrected.

Individual operator data, available since August 2009 on the “Clinician access” password protected part of the portal was discussed. There were no major suggestions for change in presentation, but many of those present felt that it would be helpful to have a csv download button to allow easier local use of the data.

Action: AH to add a csv download for this data.

Antenatal diagnosis data and the presentation of our limited data (only for infants requiring invasive treatment other than ASD or PDA closure) were discussed, along with plans to update our data analysis to include PCTs rather than just SHAs, and to include the latest year’s data as well as the previous 5 years’ data to give some idea on recently improved performance. This met with approval and there was a unanimous view that all PCTs/SHAs should aspire to the best practice apparent in London.

Action: DC/AH to complete PCT analyses and update portal

4. Technical update (DC)

Work continues on our collaborative project with CORU to look at risk adjustment. Our instinct tells us that rather than persisting with consensus based adjustment for perceived risk or perceived complexity we should now be looking

at our 10 years of real data to come up with some real risk adjustment. This effort has been very much restricted by our limited analytical resources and we hope will bear fruit once the new NICOR alliance is up and running. For the time being we continue to report on survival for the 48 procedures currently analysed.

5. Executive & annual reports

We published a brief executive report on congenital CCAD (see portal) last autumn, describing the scope and aims of the project, largely for managerial and commissioning use. HQIP and the CQC have suggested that we should produce a formal annual report. We plan to do this by developing a downloadable version of the public portal contents, which we hope will satisfy their request. Publishing a formal paper report each year (like the adult cardiac surgery blue book) would be very time consuming and expensive.

Action: AH/DC to develop a downloadable version of the data analyses on the public portal

6. Timeliness of publication

We have been criticized over the timeliness of publication of our data. Whilst there are good reasons behind this (data validation and delayed publication to allow reporting of 1 year outcomes), we will strive to improve on this over the coming year. In the first instance we will try to concentrate the data validation visits within the first half of the financial year, and we also hope that the move to NICOR may speed up our annual data analyses.

7. Data validation

Lin Denne gave an update on the validation visits, data quality and consent issues. The visits have shown that appropriate consent is not filed in the records in a variable number of cases. In one centre this was such a problem that 80 sets of notes had to be sent for before 20 were found with documented consent. We are optimistic this will improve in the next round of visits and most centres had introduced new ways of ensuring that consent is taken and filed.

Alan Houston presented the results of local audit of Glasgow data in comparison with the portal data, identifying both local and central issues. Most importantly (other than the early Fontan data) he found undercounting of tetralogy repairs on the portal, which appears to be due to children who have previously been shunted remaining in the shunt follow up data rather than defaulting into the tetralogy repair follow up data. This clearly needs our attention, and it was felt wise for the steering committee to revisit all categorisation of reoperations to ensure they are delegated to the correct procedure "bin". Alan was thanked for his efforts and others were encouraged to engage in similar local audits to help us improve our analytical accuracy.

Action: JG to convene steering committee meeting to deal with this and to recheck all our algorithms.

8. Endocarditis

Collection of data relating to endocarditis started in April 2008, but data submission has been patchy so far. This data will be included in the present round of data validation visits, but will be given a separate data quality indicator.

Part of the difficulty has been persuading software companies to include the IE dataset, but this situation is, we understand, improving. Centres were urged to keep collecting data even if data submission will be delayed (numbers should be small, so hopefully not too much work involved). It would seem sensible to keep a paper log of endocarditis admissions to aid in case ascertainment at the validation visits. **Please note** that consent is necessary for these patients if CCAD are to be able to access their records at our validation visits.

9. Pacing & ablation

Last year we decided that we did not necessarily need this data submitting to congenital CCAD as it should be sent to the CRM database, with which we can link via the NHS number. However, it was pointed out that the CRM database is voluntary and is not validated. This issue will be discussed by the steering committee, but JG's preference is to play safe and send the data to us anyway. There has been concern that CRM's paediatric data in particular is incomplete.

10. Hybrid procedures

The new category of hybrid procedures (defined as procedures jointly undertaken by both a surgeon and a cardiologist) had been added to our data categories in April 2009. We have yet to validate this data, but recognize the potential for double counting if the procedures appear in both the surgical and catheter data outputs. Some concern was raised that these procedures currently are planned to appear as primary responsibility of the surgeon involved, but DC assured the group that, as we know the two consultants involved, that it was possible to list both surgeon and cardiologist when we come to analyse the data so that responsibility will be shared.

11. Adult congenital

Thanks largely to Lin's efforts, we have had 4 new ACHD recruits in the last year with another 3 requests to join in the last month. This will be helped by the CQC having made involvement in congenital CCAD a specific requirement for the Trust "health check". There was a section on this in the National Medical Director's Bulletin this month, so there can be no excuses pleading ignorance. It is encouraging that this process actually worked when the CQC visited Sheffield and the Chief Exec was asked to explain why the Trust chose not to be involved in National audit. Some centres have sent in small numbers of cases but we still believe all submitting centres should have data validation visits.

Shak Qureshi, in his role as BCCA President, is chairing a joint committee with BCIS and BCS addressing governance issues and ACHD interventions. We hope that the final document will be approved shortly – we are assured that it will state that involvement in national audit will be deemed mandatory.

We still have no adult congenital data from Scotland, but we are assured that things will change in 2010.....

12. Developments for 2010

We still have many plans unfulfilled – in particular actuarial survival plots,

freedom from reintervention for specific conditions and have still not found the time to look more closely at how useful our data on cerebral performance might be. We remain optimistic that NICOR will improve things, and might even be a panacea for our aspirations.

13. Other data

ECMO, cardiac & non cardiac.

We had one request to collect all data on ECMO (including respiratory cases), which we declined! Respiratory ECMO data is already collected nationally by the specialist ECMO centres. We still feel it is useful to have data on cardiac ECMO whether it is for post or pre-op support in the cardiac cases. We have yet to decide how we can usefully analyse this data – the steering committee have it on the list of “to dos”.

Complications/morbidity

The EU codes for complications were added to the dataset last year (see website) but there is still divided opinion on which parameters are really useful surrogates for quality of care. We are being pressed by HQIP, CQC and the NCAAG to expand our outcome measures. There is still a majority feeling that chest drains and pericardial drainage are unlikely to prove valuable outcome measures, but complications such as wound infection serious enough to warrant further surgical intervention are important. The SCTS has recently published its views on significant morbidities, which the steering committee will consider.

PROMS & PREMS

Rodney Franklin gave a brief update on work in London developing a QOL questionnaire for older children. JG reported that NICOR have had contact with Picker International (a non profit organization aiming to improve patient information and outcomes) who have expressed interest in all the national cardiac audits. It is possible they might provide an element of independence in analysis of patient questionnaires. We will keep our stakeholders informed. The GUCH PA has developed patient experience questionnaires for inpatients and outpatients and have offered to administer the questionnaires to any ACHD centre interested. CCAD have agreed to publish the results of the questionnaires on our public portal, and we remain in touch with the organisation.

14. New ideas & AOB

We have always felt a little uncomfortable that a substantial proportion (up to 40% in some centres) of activity is not analysed by us at present – purely because of small numbers rendering statistical analysis inappropriate. DC reported that the highest volumes of procedures other than our currently analysed 48 procedures are ablation, septostomy, pacing and ICDs. We all felt that analysing septostomy would be unlikely to prove fruitful (but worthy of consideration) but we did feel that it would be useful for us all to know outcomes after ablation etc. The steering committee will consider these issues and report back.

International collaboration

We have discussed this matter many times. In the past our stakeholders have felt very reluctant to send our validated data to be included in EU and North American data which is unvalidated. The attitude of all present had changed dramatically at today's meeting because EACTS have now introduced validation systems for some centres. There was unanimous support on this occasion for us to collaborate with these international databases, providing any differences in validation protocols are made clear.

Action: JG to seek Project Board approval for anonymised sharing of UK data with EACTS and the STS of North America.

15. Next meeting: RCS, ideally in early Feb 2011 to avoid the STS congenital meeting.