Congenital CCAD stakeholder's meeting
Jan 30th 2013 10.30 – 15.30
Royal College of Surgeons
35-43 Lincoln's Inn Fields
London WC2A 3PE

MINUTES

Present: John Gibbs (chair); Rodney Franklin (Brompton & Nicor); Andy Harrison, Nadeem Fazal, Lin Denne, Emmanouil Lazarides, David Cunningham (Nicor); Kate Brown (GOS and Nicor); Miles Curtis (Heart Hospital), Rhian Brimmell (Evelina); Niki Walker, Man Chin Mo, Claire Fenwick (Glasgow Golden Jubilee), Jose Velasquez (Bristol), Irene Arenillas (Imperial); Brodie Knight, Ray Samson (RHSC Glasgow); Andre Ring (Harley St Clinic); Lars Nolke, Sara Cullen (OLCHC Dublin); Joe Evrell, Amy Bahat, Oliver Stumper (Birmingham); Demetris Taliotis, Attilio Lotto (Glenfield); Katie King, Carolyne Boyes, Trevor Richens (Southampton); John Richards (Manchester RI); Elizabeth Orchard (Oxford); Hazel Greig-Midllane (Heartline); Lee Ferguson (Freeman); Juliet Jaikumar, Kirsty Bolter, Christoph Kiesewetter (GSTT); Philip Kimberley, Maria Sereto (Brompton); Rita Butler, Christopher Austin, Brian Grant (Belfast); Anne Keatley-Clarke (CHF); Julie Wootton (Maxappeal), Helena Gardiner (Brompton); Ian Averiss (Tiny Tickers). Raf Guerrero (Alder Hey); Nihal Weerasena (Leeds); Serban Stoica, Andy Tometzki (Bristol); Vicky Banks, Imdad Rahman (GOS); Sheila Jamieson, Ashley Bolton, David Crossland (Newcastle), Orhan Uzun (Cardiff).

Apologies: Roger Boyle, Tracy Whittaker, Chuck McLean, John Thomson, Thomas Witter, Kate English, Jan Burns, Fiona Walker.

Update on Nicor: all the national cardiac audits are now housed at Nicor (170 Tottenham Court Road) along with the other national cardiac audits and alongside the centre for prevention. The Nicor Operational Group (which includes the clinical leads from each of the audits) is co-chaired by Roger Boyle (representing audit) and John Deanfield (representing research & prevention). There is a Nicor Board which deals with financial and governance issues, and a Nicor Research Committee (Kate Brown represents us) whose major function is to promote research and data linkage between the national audits. The Nicor Board has rendered the congenital CCAD Board redundant. Our Steering Committee remains unchanged (JG, RF, David Cunningham, Chuck McLean, Tony Salmon, Kate English (ACHD), Kate Brown, Lin Denne, Nadeem Fazal, Andy Harrison, Thomas Witter (data managers) and Lynne Walker (Nicor). Sadly Thomas Witter, who has been a stalwart of the committee, is leaving. The data managers group will propose a replacement.
Portal update: the public portal has been updated with 2011/12 provisional data, including the latest antenatal diagnosis data (which happily shows a year on year improvement pretty much across the UK). The funnel plots have not yet been updated

but this is imminent. JG reported at the meeting that there were no red liners and that there appeared to be no green liners either. DC pointed out after the meeting (he was not present in the early part) that there are no green liners for the provisional 2011/12 data – but we do not yet know if there are any for the latest 3 years of validated data (it would be unusual if there were none). There were two false positive red liners in the initial analysis of the provisional data – both turned out to be errors, one due to erroneous submission of post infarct VSD closure and one due to a combination of inadequate coding and a glitch in our procedure allocation algorithm which allowed Ross redo to be included in aortic root replacement. That has been corrected.

Dublin joins: we are pleased to welcome Dublin as our first EU data contributor. They fund this themselves. Their first validation visit has been completed. There are some issues of incompatibility – such as a current lack of the ability to track late survival centrally, so for the time being they will be censored from our 1 years survival data.

Data validation visits and Endocarditis data: LD gave an update on the last year's visits and a summary of data quality. DQIs are almost universally lower in the centres who only carry out adult procedures, although they are improving gradually. There is most room for improvement in Cerebral Performance Category, duration of postoperative ventilation and comorbidities. The importance of accurate recording of comorbidities for risk adjustment was emphasised. We need more volunteers for data validation visits and are pleased to involve trainees. DQIs for endocarditis data are still below par and it often proves difficult to validate data – it is important to note that consent is required for validators to see the medical records. We hope that the BCS supported voluntary registry for endocarditis might be of help in improving our data collection – it is clear that microbiologists have the best data on IE and we should try to include them in our data acquisition.

Process for outliers: JG had received a few emails suggesting that the process for outliers is unclear. It isn't. The process is summarised on the public portal. We notify any red liner centre (and their medical director), HQIP (Health Quality improvement Partnership) and the Presidents (or their representatives of the SCTS and BCCA. The role of the professional societies is purely one of giving advice and support – they have no regulatory role. The only body (other than the local MD) with a remit to take action for outliers is the Care Quality Commission (who are informed via HQIP).

Access to individual operator data: we have improved access to the password protected "Clinician Access" part of the portal, with users able to update their passwords on line rather than having to call the helpdesk. We hope this will make data presentation for revalidation much easier – we are keen to hear ideas for how we can improve this further.

Access to CCAD data: all data requests must now be accompanied by a properly completed Nicor data request form (downloadable from the Nicor site). Any application should be made with particular attention to issues of patient confidentiality – we are not allowed to pass on date of birth or date of death for instance! Requests which include centre identification should include justification for that identification. A summary of the data requests received in the last year was given – we plan to list these of the website, including giving public access to the data request forms. In all, three requests for data have been received from Dr Foster, all of which were rejected for a variety of reasons including concerns about their proposed methodology.

Standardised Mortality Ratios, Risk adjustment and Variable Adjusted Life Displays: Kate Brown summarised our collaborative research with CORU (Clinical

operational Research unit) at UCL over the last couple of years and the work has been published in 2012. The complex partial risk adjustment model (PRAiS) has been validated and, taking into account diagnoses as well as procedures, comorbidities, other risk factors and real mortality data from CCAD appears to be more robust than any previous model. Whilst it was emphasised that there can never be "perfect" risk adjustment in such a complex field, there was unanimous support for this work and for implementing it in our data analyses. It is clear that if Nicor do not publish such data it will be done far less well by others. There was unanimous support from the delegates at the meeting (including the Childrens' Heart Federation, Maxappeal and Heartline) for us to proceed with implementing PRAiS and publishing centre specific SMRs. The parents' support groups as well as the other stakeholders present were all very much opposed to outcome data being released by different sources and strongly support the concept of a single trusted source (Nicor) endorsed by the professional societies, the DH and other stakeholders.
CORUs work on PRAiS has also allowed them to develop risk adjusted variable life display software which allows local regular monitoring of trends in survival. Kate Brown presented this work, which was unanimously supported and was felt to be invaluable as it offers a much more timely way of centres monitoring trends than Nicor can currently offer. The original funding for PRAis (from NIHR) has been used, so we are left with the problem of funding the software to be provided to each centre. The estimated cost (which would include some training) is about £3,000 per centre. Nicor is not able to fund this. There is a possibility of some funding from the S&S process, but this is not definite and it remains possible that each centre may have to fund it themselves.
Paediatric cardiac "dashboard" for commissioners: some members of the Nicor congenital team, Roger Boyle and John Deanfield had met with representatives of the NHS specialist commissioning group (on 29th Jan). They plan a publicly accessible source of outcome data for paediatric cardiac procedures but strangely had not contacted Nicor! Happily they will continue to liaise with us and, we hope, will choose Nicor as the platform for this data if we can engineer linkage to other data sources such as SSI (surgical site infections) data. Also happily they were dissuaded from publishing non risk adjusted cardiac centres' mortality!
Transparency agenda and individual operator data: the government appear determined that healthcare data should be in the public domain, and Bruce Keogh has stated publicly that individual operator data on outcomes will be made available to the public. There was acceptance by those present that this is going to happen, and a unanimous view that if it is going to happen, Nicor should do it rather than allow others to do it far less well. Whilst there was not a single objection raised to us proceeding with this, it was noted that there was a rather disappointing number of surgeons present. It was agreed that Nicor should proceed with individual operator outcome analysis (with PRAiS employed for the children), but that the results would be discussed with the surgical community and the SCTS. Chuck McLean will be asked to coordinate a meeting of congenital cardiac surgeons to discuss this further. DC demonstrated that data cleaning is necessary even for apparently simple data like this – with some operators being listed under slightly different names, initials etc. It was agreed that we should change the dataset to include GMC number for the consultant responsible for the procedure and for each of the operators, to minimise the need for repeated data cleaning.
EPCC and international collaboration update: RF gave an update of European Coding; it is hoped that software companies will incorporate the latest update

promptly. He also (in Chuck McLean's absence) gave an update on our proposed international collaboration with the European and North American registries. Plans for a pilot comparison of 1 year's data (restricted to European & US centres who have undergone data validation) will, hopefully, be finalised over the next few months.
Late outcome data: DC and JG summarised our provisional work on actuarial survival and reintervention for switch (for simple TGA) and for tetralogy repair. Data cleaning was proving to be very time consuming and we had concluded that this work requires a dedicated research fellow. Andreas Hoschtitzky is leading this on behalf of the research group and is preparing a grant application to BHF. Other procedures to prioritise for long term outcome analysis were discussed, with agreement that (in the first instance) it is best to focus on procedures which (ideally) should not require reintervention. The research group had suggested isolated coarctation repair, coarctation stenting, VSD repair, and partial and complete AVSD repair. An additional suggestion of the Ross operation was suggested. Suggestions welcome.
Adult congenital update: JG gave a brief update in the absence of Kate English. Little has changed in the last year, with some centres carrying out congenital procedures (mostly catheter interventions rather than surgery) without sending us any data. It appears that BCIS still regard PFO and ASD closure as their domain, and are even considering setting up their own database for these procedures. Nicor's meeting with commissioners suggested that commissioners wish to have a single source of audit data. It is likely that the new commissioning process will help to improve our adult data submission as well as to concentrate congenital procedure data in one place.
Data collection and analysis changes: this year four new procedures will be added to the specific procedure outcomes shown on the public portal – ICD implants, transcatheter pulmonbary valve implants, right ventricular outflow stenting and ductal stenting.

Suggestions for change
Neurological outcomes: as data quality for CPC has improved a great deal over the years we agreed it was time to take a provisional look at these, with a view to publishing percentages of patients with each specific procedure whose post procedure CPC score had deteriorated from the pre-procedure CPC score. Whilst all accepted this data is difficult to interpret and it is unlikely that there will be sufficient numbers to allow comparison between centres, there was general support for data on the portal to show clearly that there is a risk of brain damage for many procedures. It was agreed that the Nicor team should proceed with this analysis and that, prior to adding the data to the website, the analyses would be circulated to stakeholders for their comments.
Cause of death: in recent months Nicor has been granted access to centrally recorded cause of death. For some extraordinary reason this has been deemed by bureaucrats to be sensitive information, so Nicor will not be permitted to pass the data to outside bodies or the public. However, we plan in house analysis of the data in the hope that we will have better information on cardiac and non cardiac death.
Wound infections: are an obviously important outcome measure, but such data is very complex to collect. It is clear that this data is collected by SSI departments in every Trust. We are optimistic that, alongside our work with commissioners, we may be able to obtain this data by record linkage. This will be investigated.
Device specific data: after last year's media interest in the lack of device specific procedure we had hoped that we might be offered some funding to collect such data, but JG's inquiries were met with encouragement but no money. It would be a major

(and expensive) task to maintain a central database of all implantable devices. But DC informed the group that simple multivalue data fields containing manufacturer, model number and serial number would allow individual devices to be identified and tracked. There was unanimous approval for us to add these data fields to the dataset, albeit with the realistic expectation that it will probably take some time for data quality to reach our current levels for other fields. The possibility of collecting this data locally by bar code was raised, but those with experience said that this can prove very difficult as some manufacturers place different types of product identifiers on different parts of device packaging.
AOB: there was a suggestion that we should consider changing from procedure based outcomes to diagnosis based outcomes. This has been considered many times over the last 17 years but it would be a huge task which would need to involve every hospital in the land and still appears to be beyond our resources. One day?
This was JG's last stakeholders meeting as he is being put out to full pasture in March. Happily for the future of the audit Rodney Franklin is bravely taking over as clinical lead. He and Julie Wootton kindly thanked JG for his efforts.

Next meeting: same place early 2014, but possibly an interim meeting to discuss analysis of individual operator data.

31/1/2013
jlgibbs@mac.com