

CCAD Steering Committee

Sept 21st 14.00--17.00

Selwyn College

Cambridge

Agenda

Present: John Gibbs (chair), Chuck McLean (SCTS), Shak Qureshi (BCCA), Rodney Franklin, Gruschen Veldtman, Kate Brown, Lin Denne, Andy Harrison.

Apologies: David Cunningham, Thomas Witter.

1. We were pleased to welcome Kate Brown, who has joined the steering committee in place of Martin Elliott.
2. **Nicor update:** the CCAD team are now housed in UCL premises on Tottenham Court Road, with plans to move further down the road later this year to a permanent home along with John Deanfield's prevention research team (some disquiet over suitability of office facilities though). Management of the audits is now formally removed from the Information Centre and resides with NICOR, although the data servers (housed in Harrogate) at present remain the property of the IC and we have to pay them accordingly. There are plans for NICOR to either take over the server contracts or to resite new servers at UCL (either option being much cheaper in the long run).
3. **Latest data analyses:** the long delay in updating the portal has been due to an error in the data provided via the IC from ONS, with wrong dates of death in some cases. This took many months to sort (outside our control) but has now been fixed and tested. Initial data analysis for 2009/10 had shown a single red liner (Belfast, for tetralogy repair) and 5 green liners. JG had informed all the centres involved and their medical directors. Local investigation is underway at each centre and there will be a re-audit of Belfast's data. This has prompted refinement of the "alert" process at the SCTS and BCCA and a formal

statement is in the pipeline. Local audit of each of the green liners has identified coding problems – a duplicate record of a death in one case, wrong coding in some others and a couple of glitches in our procedure algorithm. We are making minor changes to the algorithm to correct these errors (eg we had not anticipated a VSD repair with pulmonary vein stenosis repair – it was included in the VSD repairs). As a result of centres checking their data there will be fewer green liners when the data goes live.

4. **Latest antenatal data:** DC's update of the antenatal diagnosis map shows a substantial improvement in the percentage of major congenital cardiac anomalies detected antenatally in many areas of the country. The map and latest data will be uploaded onto the portal (with luck) by the end of November.
5. **Procedure algorithms:** some minor changes to the procedure algorithms are underway after feedback from local centres (particularly after some green lines prompted some to take a detailed look at their coding). The two procedures most affected were VSD repair and PA banding (some complex cases were being included that should not have been). These problems are getting increasingly infrequent as more centres are bothering to feed back to us – helped by the procedure binning & original coding being available on line via Lotus Notes.
6. **ECMO and transplantation:** some ECMO centres had objected that the procedure counts provided by CCAD to Safe & Sustainable did not include their ECMO workload. The committee still feel that ECMO for respiratory failure is not our domain and that this data is already collected and analysed by others for the purposes of specialized commissioning. We maintain, therefore, our current position of collecting “cardiac” ECMO only. Although

transplantation data is also collected by others, we feel it is important for long term outcome analysis for heart transplantation in congenital heart disease to be sent to us.

7. **Cause of death definitions:** RF plans to add a simple list of cause of death codes to the EPCC short list. We continue to explore how we might reliably change from all cause mortality reporting to cardiac mortality, but this is not straightforward! An update will be given at the next stakeholders meeting.
8. **Wound infection data access:** several committee members had investigated how SSI (Surgical Site Infection) is recorded at their centres, in the hope that we might adopt a generic approach to importing post op infection data from other databases. It seems that practice varies from centre to centre
9. **Target date for 1 year survival funnels,** for actuarial survival plots, for reintervention and neuro outcomes analyses: deferred in the absence of David Cunningham (dates will depend upon recruitment of new analysts at NICOR, which is in hand).
10. **CORU collaboration:** our collaborative research with the Clinical operational Research Unit at UCL, led by Kate Brown and Martin Utley is forging ahead. Kate presented their initial work on risk adjustment taking into account diagnosis as well as procedure. The risk model allowed a far greater number of procedures to be allocated to a procedure group. Kate will give an update at the next stakeholders meeting.
11. **Future of Project Board:** JG reported that our Project Board membership has been reduced following the abolition of the National Director posts as we have known them. The committee supported the suggestion that we should encourage NICOR to create a governance committee for all the cardiac audits

and that in future we should be part of that rather than have our own separate Project Board. *Action: JG to discuss with NICOR Board.*

12. **International collaboration:** JG and Chuck McLean met with the STS and EACTS database teams to discuss data sharing. There has been considerable progress in validation programs in North America and in some centres in Europe, such that we felt it appropriate to strengthen our international collaboration. In the first instance we agreed an anonymised pilot comparison of a small number of specific procedures with STS and EACTS data (excluding centres who have not been included in the EU validation process). The pilot will include only children (under 16) and will be restricted to the 8 current STS “benchmark” procedures. No data will go into the public domain until we have shared the pilot results with our UK centres. Our provisional assessment is that UK results will compare very favourably with those from other countries. Chuck will elaborate at the next stakeholders meeting.
13. **Date of next meeting:** TBA, probably December. The next stakeholders meeting will be at RCS London as usual, on February 29th.