



Congenital Steering Committee

March 13th 2012 13.30 – 16.00

NICOR

170 Tottenham Court Road

Attendees:	
John Gibbs	Chair
Rodney Franklin	Vice Chair, Consultant Paediatric Cardiologist at Royal Brompton Hospital
Kate Brown	Consultant Intensivist GOS, Research & Outcomes Lead
David Cunningham	Senior Strategist for National Cardiac Audits
Andrew Harrison (AHar)	Developer NICOR
Nadeem Fazal	National Clinical Audit Service Manager
Tracy Whittaker (TWh)	Project Manager NICOR
Apologies	
Tony Salmon/ (BCCA)	Paediatric and Adult Congenital Cardiology University Hospital Southampton
Lin Denne	Data validator
Chuck McLean	Cardiac Surgeon, Royal Hospital for Sick Children, Yorkhill, Glasgow (representing SCTS)
Kate English	Cardiologist, Leeds General Infirmary (BCCA, ACHD)
Thomas Witter (TW)	Surgical Data Manager Guys and St Thomas
Lynne Walker	Programme Manager NICOR
Zoe Fearnley	CEO (NICOR)

1. TOR approval

1.1. The points raised at the previous meeting were discussed. It was agreed that the steering group should avoid increasing in size as this may impact on productivity. Instead the group felt that the more productive option would be to co-opt members as required.

1.2. All agreed that the data manager role was crucial. TWh is due to move to Dublin from July 2013 and a replacement is needed. Unfortunately the previous database managers group led by Phil Kimberley (Brompton) is no longer running and it was



agreed John Stickley (Birmingham) be approached as he is already enthusiastic to join. **Update:** SG subsequently informed that revitalised DBM group would hold election to choose a replacement.

Action: RF

- 1.3. Remove Alan Magee from the draft Terms of Reference as he is not a member of the Steering Group.
- 1.4. Lay representation: JG has written to each of the societies asking that they propose suitable contacts or a process along the lines that they themselves will employ for lay representation. No reply has been received as yet.

Action: TWh to update the ToR to align with NICOR format and content

2. CCAD name

JG proposed that the congenital audit appropriate the CCAD acronym for the Congenital Cardiac Audit Database. The group agreed and JG will raise at the NICOR Operational Meeting on 14/03/2013. **Update:** the name is in use by some other audits but the request will be kept in mind as NICOR derived names supplant CCAD term in the future.

3. Dr Foster

- 3.1. At the last research meeting (18/12/2013), members rejected two applications submitted by Dr Aylin on the basis of poor methodology in dealing with double counting (Application 1 and aggregate data) and 2) access to patient ID (Record level data). Offers to discuss this further have not been taken up. Dr Aylin has written and complained to MPs, particularly the Member for a Leicester constituency, and there has been dialogue between the DH, HQIP and NICOR. Mark Davies from the NHS IC was supportive because of the small numbers involved for many CHD procedures
- 3.2. KB has written to all Parent groups requesting views in writing about the use of risk adjustment for audits, specifically whether they had view on this being done by Congenital NICOR (CCAD) or by other groups too (eg Dr Foster). KB asked that they feed back in writing to the NICOR director and to the chair of the steering committee. Tiny Tickers and Heartline have responded and are supportive of the NICOR decisions. Parent groups felt that NICOR is the preferred single source of CHD outcome data.

4. PRAIS and SMRs

5. Censorship for SMRs – assigning death to a procedure

6. Timing of SMR calculations – additional stakeholders meeting required

Items 4, 5 and 6 were discussed together.

- 6.1. DC presented slides comparing different risk adjusted models. DC highlighted that the way death is assigned alters the findings. If there are multiple procedures, patients' could be recorded as having died several times. In other approaches, the most recent procedure is allocated the death; or the highest ranking in terms of risk



would be allocated the outcome. KB reported that the PRAIS software takes all operations into account.

- 6.2. There is a pressure to publish overall unit SMRs in the light of the recent issues surrounding the Dr Aylin data requests. The aim would be to publish 3 year funnel plots. Single year funnels would be available only to individual centres.
- 6.3. It was agreed that an additional meeting with the Societies and the stakeholders would be useful. The purpose of the meeting would be to discuss presentation and publication of centre specific SMRs. Political management of the current issues should not rush the publication of these to ensure that they are accurate and centres have time to see and comment on the findings before they are published. This could coincide with access to the PRAiS derived VLAD software, although the funding of this software still requires confirmation.

Post meeting update: RF proposed that this meeting should be appended to AEPC meeting at the Hilton London Metropole in London (Paddington) May 22-25th 2013.

Action: RF to investigate with AEPC organising committee

Action: RF and JG to confirm any decision on funding implementation of PRAiS related VLADs in for all UK centres. **Update:** funding will be provided by S&S

7. Individual operator outcomes

- 7.1. This is to be put on hold until the centre specific data is published. SCTS and BCIS have, or in the process, of publishing operator level data so NICOR will have experience of the process and can support the centres.

8. Algorithms for recently added procedures (transact PVR, ICD, duct stenting, RVOT stenting).

- 8.1. DC will look at adding these procedures to the procedure specific analyses and publishing them on the Portal with accompanying funnel plots. Descriptions will need to be written in due course.

9. Publishing Cerebral Performance Category Score outcomes

- 9.1. The group agreed to write a short descriptive paper for Heart and to publish on the portal and website. The report would be based on aggregate, not centre level data, as it is the change and improvement that is important.
- 9.2. KB and RF suggested this would be a good piece of work for a research fellow. NICOR could do the in-house analysis and somebody with the clinical knowledge to write the report, for example trainee clinicians.
- 9.3. It was anticipated that at some point in the future there would be sufficient activity to offer clinical trainees 3 month research placement contracts within NICOR. RF requested that this should be discussed in more detail at the next meeting.

Action: TW

10. Publishing a list of minor procedures



10.1. Minor procedures tend to be removed from analyses. This can cause some confusion when results don't tally. An explanation of what is removed needs to be provided on the website and portal.

Action: RF to write a descriptive paragraph and AH will upload onto the portal. SMR findings will also need descriptive information about the data included in the analysis before any publication of the results.

11. Cause of death

11.1. This was also discussed under AOB at the earlier research meeting. DC provided an update on the linkage work on accessing stroke data. MRIS has provided fact and cause of death and HES episodes. DC will discuss at the next meeting

12. Commissioners dashboard

12.1. This whole Clinical Reference Group (CRG) process has been put on hold until there is more clarity about the requirements (email from Graham Stewart – Chair of Congenital Cardiology CRG). RF has been assured by Graham Stewart that a place will be reserved in the work group for the Congenital NICOR chair and that there was no need to reapply as had been requested for other regional representatives.

13. Device specific data

13.1. The dataset will need to be updated to capture device data. The following three fields need to be added: manufacturer; model and serial number. Suppliers normally require 6 months' notice when changing or adding fields to the database.

14. Executive and annual reports

14.1. The group agreed to draft a 2012 public report based on the previous executive summaries but with additional focus on improvements and research activity such as the CORU work. TWh will circulate a draft for comment ahead of the next meeting.

Action: TWh

15. AOB and date of next meeting.

15.1. RF reported some discrepancies between documentation on the congenital portal e.g. REF values differ.

Action: AH

15.2. EL updated the group on future analytic resources. This year the analysis will be undertaken in-house as it is with MINAP, Heart failure, CRM and PCI. It is anticipated that future analysis will be generated on an automatic basis in the future.

15.3. Date of next meeting: Scheduled for 25 June 2013 but extraordinary meeting required: **May 7th NICOR Meeting Room 1 from 12.30 – 2.30pm.**