Congenital CCAD Steering Committee
June 25th 2013 13.30-16.00
Boardroom
NICOR
170 Tottenham Court Road

Agenda

Role – representation	Name	Title - place of work
NICOR Congenital Clinical Lead – Chair	Rodney Franklin	Paediatric Cardiologist, Royal Brompton Hospital
President BCCA	Tony Salmon	Paediatric & Adult Congenital Cardiologist, Southampton
Chair SCTS Congenital Database Subcommittee	Chuck Mclean	Congenital Heart Surgeon, Royal Hospital for Sick Children, Glasgow
Lead for Research and Outcomes	Kate Brown	Paediatric Cardiac Intensivist, GOSH
BCCA ACHD representative	Kate English	ACHD Cardiologist, Leeds General Infirmary
National Lead for Congenital Database Managers	Thomas Witter (TW)	Database Manager, Evelina Children's Hospital
NICOR Chief Op Officer	Dick Waite	COO NICOR Audits
Senior Audit Strategist	David Cunningham	Senior Strategist for National Cardiac Audits, NICOR
NICOR Congenital Project Manager	Tracy Whittaker (TWh)	NICOR
NICOR Senior Analyst	Owen Nicholas	NICOR
NICOR Congenital Audit Developer	Andy Harrison	NICOR
Data Validation Officer	Lin Denne	NICOR
National Clinical Audit Service Manager	Nadeem Fazal	NICOR
Apologies		
NICOR Senior Information Analyst	Emmanouil Lazarides	NICOR
Chair SCTS Congenital Subcommittee	David Barron	Congenital Heart Surgeon, Birmingham Children's Hospital

1. **Apologies**
   Apologies were received from David Barron and Emmanouil Lazarides

2. **Previous minutes and actions**
   2.1. The minutes from the Extraordinary Steering group meeting (May 7th) were agreed. The

group also agreed that all published meeting documents should be in a PDF format.
Action: AH

2.2. Item 5: Unvalidated data for the 2012-13 dataset will be available at the end of August/September 2013 for publication on the Portal as part of the Transparency agenda). The final deadline for submitting data is mid-August and LD will notify all centres. The deadlines also needs to be added to the portal and NICOR website
Action: LD & AH

2.3. DC reminded the group that the Steering Group approved data going to ON via chairman's actions.

3. Minutes and actions from the Extraordinary Stakeholders meeting

3.1. The minutes were signed off subject to the following amendments:

- Inclusion of a full list of attendees and represented centres.
- Item 6.1 - change the term 'performance' to 'outcomes'.

3.2. Item 5.2: "It was also suggested that it would be worth agreeing the criteria for future PRAiS updates". The criteria for recalibrating PRAiS are currently every 3-5 years. There needs to be stability for at least 3 years unless research into areas such as comorbidity require an earlier recalibration or analysis change within the PRAiS software. There is an unknown element to this at the moment as CORU have not seen the cleaned data for 2009/12. If there is a pressing need to revisit the model then a decision to recalibrate earlier will be taken. It is not clear whether the research work on deprivation and ethnicity will impact on the need to recalibrate.

3.3. Item 7.2: "The audit also needs a clear vision of its direction over the next five years". A project plan for the next few years needs to be developed.
Action: to be discussed at next SG meeting

4. Date of the stakeholders meeting

4.1. The group agreed to have additional stakeholder meetings throughout the year to align with key events e.g. launch of new datasets, recalibrated PRAiS or Centre level analyses. There would now be two meetings: 1) Biannual meeting strictly restricted to audit leads and database managers. The next biannual meeting will be scheduled for the Autumn. RF/TWh will identify a suitable date; this could be linked to the BCCA annual meeting. 2) An annual meeting where a full range of stakeholders would be invited, including patient groups. NICOR have suggested inviting the Press for at least part of the meeting to highlight achievements over the preceding year. DW confirmed that NICOR are supportive of this approach and this would involve the new NICOR Communications Committee.

4.2. CMc asked which organisation is responsible for publicising the release of the reanalysis of the NHS England report. DW confirmed that NICOR plan to recruit a dedicated Communications Manager but is unlikely to recruit in time for this report. Another option discussed was to involve HQIP, as commissioners for the audit. However, as this analysis is solely surgical it was agreed that it would be best on this occasion to liaise solely with SCTS.
Action: CMc will contact James Roxburgh and DB to discuss.

5. NICOR update

5.1. Governance and Review updates

5.1.1. DW circulated an internal review of NICOR governance that identifies existing, new and proposed plans to improve the current governance structure. There has been a fundamental restructuring including several new working groups. Foremost is the NICOR executive working group that meets on a weekly basis and is a decision making group attended by chairs of the three NICOR working groups (Risk and

Governance, Communications, and Information and technology). The Risk and Governance group are looking at risk related issues along the data flows to prioritise areas of work. The various Terms of Reference are being finalised and will be circulated following sign-off. The structure of the NICOR working groups may change depending on the recommendations of the external NICOR review.

5.1.2. The Governance report refers to quality standards and assessment against standards. There were some concerns over devolved power and that the NICOR executive must recognise that the CHD audit is clinically led and this should not be undermined. DW emphasized that audits can be unique and variable as long as there is a strong evidence base. A Memorandum of Understanding between NICOR and Professional Societies would help establish roles and responsibilities between different organisations. DW gave the new Neuromodulation audit as an example whereby the audit will cover both cardiac and non-cardiac areas, working with different organisations and looking at devolved powers. They are proposing an individual SLA with each stakeholder Trust and a similar arrangement could be applied to the Congenital Audit.

5.1.3. DW highlighted that the CHD audit has three areas it should focus on: the production of an annual public report (see 6.2), the timely submission of complete and high quality data and timely data analysis. DW stated that if there are good reasons for deficiencies in these areas, then these need to be publicly documented. RF noted that previously the audit lacked analytical support and many planned projects, such as 1 year funnel plots, assessment of reoperations and morbidity outcomes, remained unachieved. A reliable risk model with respect to whole centre mortality outcomes has only recently become a reality (PRAiS). Limited resources have meant that the data validation process takes over a year to complete, meaning that published data on the most recent year remains in draft form for up to a further year. This deficiency is understood and the Audit hopes that it can now reduce the validation process by over 6 months. The promise of NICOR resources to achieve this was welcomed (JD personal communication to RF). LD with RF will produce a plan to validate the 2012-13 data on a more rapid timescale, identifying resource needs to take to the NICOR Executive for approval. This process will be helped by the Centres having in-house VLAD data to help monitor data quality as an ongoing live process. The SG confirmed that the CHD Audit would not move away from data validation visits.
Action: LD, RF and TW

5.2. Independent review of NICOR governance - update

The Terms of Reference and membership of the review panel have been agreed. DW confirmed membership as Professor Dawn Oliver, Jon Tomlinson, Charles Knight. The review was due to start this week, so contact has not been made to date. Group members were keen to be involved in the process. CMc proposed that RF should contact the reviews to request interviews, if these were not forthcoming early in the review process.

6. Terms of Reference and Annual Report

6.1. TOR: The CHD Steering and Research Group ToR will need to be updated in line with any recommendations from the NICOR internal and external reviews. Sign off of the TORs will follow, after being discussed at subsequent SG meetings.

6.2. Annual Report (2012 data).

An annual report is required for contractual basis and also to highlight benefits to patient care. Different audits approach reporting in a different way e.g. some just have an annual report. Congenital and ACS have a public portal but in addition ACS also supports publication of the SCTS blue book with considerable external funding. The content of the

report would normally include analyses, research updates and examples of how data has been used to improve patient care. The aim is to publish in December/January each year with respect to previous year's data and analyses.

7. Data submission, quality and Analyses

7.1. The SG agreed that the CHD Audit should move to compulsory quarterly data uploads from the Centres, using the Adult Cardiac Surgery (ACS) model. It was noted that the final upload needed to tie in with the CQC deadline of May 30th. TWh offered to email the database managers for feedback on quarterly uploads.
Action: TWh

7.2. Additional data quality feedback loops with the Centres will need to be built into Lotus Notes and should also be captured in the project plan.
Action: AH, RF and TWh

7.3. PRAiS mediated reanalysis of 2009-12 data for whole centre outcomes: follow up to the April 8th NHS England report

7.3.1. The outstanding data quality issue from the Centres, which had been holding back PRAiS recalibration and subsequent reanalysis, has been comorbidity data with very wide variation between hospitals. DC presented the recently resubmitted comorbidity data, showing less inter-centre variation, although this was still 13-46%. The most common comorbid conditions were prematurity, preprocedural ventilator support, chromosomal anomalies and pulmonary hypertension.

7.3.2. It had been agreed at the May 22nd Extraordinary Stakeholders meeting that Funnel Plot to be used for the Report would be Option 1 of those proposed by CORU: (Actual (observed) / Expected Survivors) vs Case Volume. KB and Christina Pagel presented a number of graphical options for presenting the funnel plot reanalysis in the Report, now based on recalibrated PRAiS software. These included publishing a series of separate single unit funnel plots and an amalgamation of these plots from all centres, producing a single fuzzy line or spaghetti appearance of all the lines. DW advised that the audit would be open to criticism for using a fuzzy line or multiple lines, as it implies no clear cut measure for identifying outliers.

7.3.3. The group agreed to go with a single unit specific funnel plot on each centre's home page and a combined plot for the Report. The exact nature of the lines was not finalised at the meeting. Subsequent discussions by email and phone have led to a final detailed analysis plan being agreed. This includes two 2-sided Prediction Limits (a term used in preference to Confidence Limits) at 95% and 99.8% and these will be displayed using two extreme lines for centre spread at each of the two PLs. The initial results will be distributed by DC to SG clinicians only, with any outliers being dealt with following the SCTS process. The ensuing report will be co-written by SG with additional help from CORU and Prof David Spiegelhalter.

7.3.4. The meeting also debated using an alternative outcomes display using a Centre specific, risk adjusted survival grid, analogous to the ACS portal – effectively a vertical slice through the unit specific funnels. Although no clear decision at the meeting was reached in this regard, it was agreed during subsequent email exchanges that it would be best to keep the 2009-12 final report looking similar to that of the April one, i.e. a funnel plot. The 2010-13 dataset could be used to look at such alternative displays and these could also be presented to the next stakeholder meeting for discussion.

7.4. NICOR in house analysis plans and research

Not discussed in SG as largely covered in Research Group meeting.

7.5. Published data discrepancies

The group discussed the practicalities of freezing the data for the last 10 years to ensure data on the website and in reports is identical. The audit has received some criticisms as the tables on the portal are live and can change on a daily basis, whilst the funnel plots are updated on annual basis only, meaning that there are sometimes marked discrepancies. It was suggested that the Audit move away from live data updates on the portal but potential implications needed to be thought through. It was agreed to delay a final decision until the next SG meeting. However, at subsequent discussion it was agreed that the 2009-12 procedure specific Funnels would be re-run using the updated centre data inputs (previous run at beginning of year) and there would be a freeze on Portal data updates thereafter at least until the next SG meeting.
Action: DC and AH

7.6. In House VLAD analyses at Centres. In the new distribution of PRAiSv2 software each centre will be able to generate a snapshot of their current mortality outcome with respect to that expected, using display Option 3 (Expected-observed deaths vs Case Volume) of those distributed by CORU as an inverse Funnel or Trumpet display. This will enable the centre to respond to external queries over outcomes, as well as dovetailing with the commissioning dashboard and NHS England expectations of Centre responsiveness.

8. Data requests: not discussed in SG as covered in Research Group meeting

9. Data validation and software solutions
This item was not covered and will be rescheduled for the September meeting

10. Future plans: not discussed as such but see 3.3.

11. AOB: None.

12. Date of next meeting: 10th September 2013 13.30 – 16.00. Venue: Foster Court 216, Gower Street WC1E 6BT.