National Congenital Heart Disease Audit Steering Committee
September 22nd 2015,
12.30-15.30
Room G09, 16 Gordon Square, London, WC1H 0AG

Role – representation	Name	Title - place of work
NICOR Congenital Clinical Lead – Chair	Rodney Franklin (RF)	Paediatric Cardiologist, Royal Brompton Hospital
NICOR research & outcomes	Kate Brown (KB)	Paediatric Cardiac Intensivist, Great Ormond Street Hospital
NICOR Chief Operating Officer	James Chal	COO NICOR Audits
Senior Audit Strategist	David Cunningham (Skype) (DC)	Senior Strategist for National Cardiac Audits, NICOR
Data Validation Officer	Lin Denne (LD)	NICOR
BCCA ACHD representative	Kate English (Dial in) (KE)	ACHD Cardiologist, Leeds General Infirmary
NICOR Congenital Audit Developer	Andy Harrison (AH)	NICOR
Chair SCTS Congenital Database Subcommittee	Chuck McLean (CM)	Congenital Heart Surgeon, Royal Hospital for Sick Children, Glasgow
President BCCA	Rob Martin (Dial in) (RM)	Bristol Royal Hospital for Children
NICOR Senior Analyst	Owen Nicholas (ON)	NICOR
Paediatric cardiac intervention	Andy Tometzki (Dial in) (AT)	Bristol Royal Hospital for Children
Congenital Database Managers Lead	John Stickley	Database Manager,
NICOR Project Manager (Congenital)	Tracy Whittaker (TWh)	NICOR

1. **Apologies & Introductions**
   Thomas Witter, David Baron, Nadeem Fazal, Bob Ward, Gerry Bennison

2. **Previous minutes and actions**
   Minutes were agreed as an accurate account of the previous meeting held on June 17th 2015.

3. **Updates:**
   3.1. NICOR update:

TW and JC provided the following update:

- James Chal is the newly appointed NICOR Chief Operating Officer
- Recruitment is underway for several vacancies within the project management team, including the Audit and Research manager. TW will continue to provide Project Management support and will be in post until March 2016 to provide a handover to the new project manager.
- NICOR has now moved to Nomura House, 1 St Martin Le Grand, London.
- The HQIP Contract Review meeting took place on September 16th. The meeting provided an opportunity to discuss progress made and some of the current challenges. Items discussed included the importance of implementing the fetal dataset.

3.2. Professional Liaison Group update:

RF attended the PLG held on 16th September. The key discussion points relevant to NCHDA were:

- The clinical lead job description has been received by the NICOR Executive and is in review. If signed off the jobs will be advertised by the end of the year. RF advised the committee that professional societies propose the audit lead. David Barron is stepping down as the SCTS congenital chair as of next year. CMc was not aware of a reappointment but would confirm.
  Action: CMc.
- John Parkinson (Interim Chief Executive Officer for NICOR) has submitted 'NCAPOP Topic proposal form' (Paper H1) to HQIP. The paper sets out NICORs future strategy and includes information included in the NCHDA 'Fit for Future' paper submitted to the NICOR Executive in July 2015. This will be used to develop the deliverables for 2015/16 as part of the NICOR contract extension as well as demonstrate how the audits continue to be 'fit for the future' in the forthcoming competitive tendering process due to start in 2016.

- HQIP's COP Technical Manual consultation document sets out expectations about responsibilities for data quality including data definitions, missing data and validation. RF highlighted that the NCHDA validation process is seen as the gold standard although it is also recognised the model is too costly for audits that cover a greater number of centers. HQIP's COP Technical Manual document also covers outlier policy although this was not part of the consultation as this has been consulted on previously. The process currently adds 70 working days to the process. RF advised that Simon Ray from BCS has also developed an outlier policy. The BCS process still needs to be finalized and is likely to reflect the HQIP policy. There is an expectation that all audits will report at a consultant level in the future. CMC highlighted that the SCTS is still concerned about the COP programme and Scottish units will continue to be reported at a unit level.
  Action: TW

3.3. HQIP Outlier policy

Covered in the above update.

3.4. Data validation 2014/15

LD provided the following update:

Validation of 2014/15 data:

- The programme of validation visits is on schedule.
- Validation visits at Bristol and Southampton were not completed in terms of case ascertainment due to the number of catheter log books and Adult CHD cases. LD confirmed that they had reviewed cases up until November 2014.

2015/16 data entry

- LD warned that centres are struggling to complete the new dataset, largely due to software issues which are slowly being resolved by the companies concerned, particularly HeartSuite.
- The main centre of concern was Belfast as they hadn't had a HeartSuite upgrade in 3 years due to in house IT issues.
- Southampton no longer has a dedicated data manager and has not run a PRAiS analysis since May. One other centre has not been able to submit for 2015-16.
- Variation in IT skills and an understanding of how to do batch uploads mean that data entry is time consuming in some centres.
- LD agreed to email all centres to confirm expected dates for submission of Q1 and then Q2 data.
  Action: LD

3.5. NCHDA Project update

- Independent Review of Children's Cardiac Services in Bristol is underway and has contacted NICOR to provide information relating to the data submission of 3 individual patients. NICOR has responded and submitted a report and related communications to the review on 15/9/2015.
- Work is well underway to web-enable the lotus notes application. The database will be rolled out before Christmas and an implementation plan will be developed and sent to centres.
- Following sign off from the NCHDA steering committee, the Minimum Data Standard is now ready to roll out this week.
- TW will continue to provide project management support for the audit and will be on hand until March 2016 to provide an extended handovers period for the new project manager. This is likely to be an existing NICOR project Manager.
- Data validation review. The data validation working group met 17/7/2015 and agreed the options. These have been included in a paper covered in Agenda Item 5.
- Technical update
  AH confirmed that the data for the circulated funnels was based on the live data. Once a cut off date for data submission and corrections, AH

will freeze the data in the portal ready for publication in January 2016. This will ensure the activity tables are aligned with analysis underpinning the 2012/15 funnels. The draft funnels will need to be updated as required if data changes.

3.6. HES and Life Status update

DC confirmed that ONS life status was last updated in July 2015. HES data: DC informed that it looks like NICOR will finally have access to HES data in the near future.

4. 2012-2015 initial analyses:

4.1. PRAiS, Funnels & Activity

4.1.1. PRAiS analysis: Analysis based on unvalidated data indicates there are no negative outliers with respect to death at 30 days following an operation. There are 2 positive 'alert' outliers and one positive 'alarm'. The process for notifying and reviewing positive outliers needs to be agreed to both confirm and learn from these centres. NHSE and HQIP advise that these need to be scrutinized to the same level as negative outliers. However, the likelihood of positive 'alerts' is 25% and it agreed that no action required with respect to these 2 centres, apart from noting in report. Positive 'alarm' is much less likely at 1.35%. The SC agreed to maintain the current standard deviation limits as these followed the guidance set out in the HQIP reporting guidance. A discussion on how to manage this centre in terms of data checking was discussed, noting the difficulty as analysis is with respect to all centre activity. One way would be to check for casemix complexity trends between centres over last few years and see if any centres were becoming more risk averse to improve outcomes and not choosing to operate on the highest risk patients. DC agreed to look at this. In addition it was agreed to seek guidance from HQIP and SCTS on this matter. It was also agreed that the Annual Report should certainly note this very positive outcome but that this should not be overly celebratory given that some children were still not surviving CHD operations.

Action: 1. DC: to undertake case mix analysis and look at the trend over the last 5 years. 2. To seek guidance from SCTS / HQIP on how to manage positive outliers at 'alarm level'. DB/TW

4.1.2. There was also a discussion about recalibrating PRAiS given the overall trend of lower mortality. It was agreed that this should wait until the PRAiS2 study was completed as the resulting upgrade to PRAiS would have better weighting of relevant comorbidities and risk factors. This would be a better time to recalibrate with recent outcomes as a baseline and would likely be within the next 2 years.

4.1.3. Specific procedures: There are two paediatric centres that are outliers for single specific procedures and one ACHD centre. Centres needs to be notified that preliminary analysis shows an alert and for

centres to check data. The outlier process will be initiated and RF will notify centres and TW will draft letters. Centres will need to confirm data accuracy by November for a final analysis.
Action: TW and RF

ON highlighted that the number of outliers is low. By chance alone, one alarm would be expected every 4 years. DC advised that the specific procedure analyses are not risk adjusted and may explain the low outlier rates. In North America and Europe, the STS/EACTS database has moved towards adding supplementary potentially confounding diagnosis factors to the analysis of outcomes after specific procedures, such as intramural coronary arterial course as a factor for the arterial switch procedure.

4.1.4. Activity Reports

- DC has circulated 2014/15 activity reports for all hospitals to confirm activity and life status.

4.2. 90 day outcomes

The group discussed the validity of publishing 90 day outcomes in this current reporting period. DC reported that 25% of congenital cases are subject to coroner's inquest and the time frame from inquest to ONS can vary between 6 weeks and 2 years. In 2013-14 there were 91 discrepancies likely to bias the results. This would be a matter of public concern especially if ONS know about inquests but seem unable to pass this information onto NICOR. It may be possible for hospitals to update if they become aware but this is not reliable e.g. an interstage post-Norwood baby that dies at home. DC agreed to continue negotiations with ONS to provide information on inquest cases. If there is no change then the group will escalate through HQIP. It was agreed that 90 day risk adjusted outcomes will not be possible until ONS highlight the cases that have gone to inquest but an interim measure would be to simply include a 90 day column in the tables.

4.3. Procedures & algorithm

The group briefly reviewed Paper F1 with proposed new procedures to report, alongside the initial 2012-2015 analysis. The SC agreed that the expanded list of procedures were sound but that more should be reviewed.. The following was agreed:

- To again review the frequency of procedures within the 'miscellaneous' group to identify procedures that could be reliably grouped and therefore reported separately.
  Action: RF to work with DC on this and then send out suggestions to SC ahead of next meeting.
- To probably continue to bucket hybrids within miscellaneous as numbers very low overall.

5. Data validation 2015-16: reducing timelines

Paper G, setting out options for validation was discussed. LD advised that data quality in general was very good and the number of deaths and missing cases identified during visits was relatively low. RF highlighted that in Centre PRAiS replaced some of the need for annual validation with respect to whole centre performance, such that the visits acted as a secondary check. However, LD advised this is likely to change following the introduction of the new dataset with significantly more fields to validate. Centres are already struggling to implement the new dataset and are needing support; the visits will be crucial to ensure data entered is reliable. The group agreed to continue with the current validation method until data quality of the new dataset meets the minimum data standard.

However RF requested that, as was happening to some extent this year, that the validation timeline and both PRAiS and procedure specific analyses with funnel production are run in parallel in the summer and be included in the project time line. This would mean that the outlier process could begin up to 3 months earlier than the final validation visits, considerably shortening the overall timeline to annual report production.

The IE dataset as a whole should be a topic for the next SC Agenda in Dec 2015, following an initial analysis of the data held. It seems likely that this sub dataset will be discontinued and therefore will no longer require validation, depending on the results of the Dec 2015 SC discussions.

Action: NICOR (probably DC) to undertake initial analysis of IE data collected to date for presentation at next SC

The group also agreed the length of stay and bypass times should also be reported and that the NCHDA should follow the principle that data should not be included if it's not going to be reported.

6. NCAPOP proposal: CQC-HQIP metrics

The NCAPOP topic proposal was discussed under item 3.2. The CRG-CHD dashboard was not discussed due to lack of time and will be added to Dec 2015 Agenda.

7. Dataset issues

7.1. Fetal proposal

RF and Gurleen Sharland have discussed the fetal dataset with Tiny Tickers and the charity has agreed to look into funding development costs (£31k) but not estate and 'UCL indirect' charges (£26k) . RF had asked Jess Tudor-Williams to consider waiving the UCL costs but this was said not to be possible as it contravened UCL contracting processes. RF asked JC to review as the committee felt that the audit had not received its full allocation of resources over the last year at least, particularly with respect to analysts time. RF asked JC to provide a full breakdown of how NCHDA funding had been used over the last 2 years. LC had agreed to look into this and confirm

whether this information could be disseminated within the group but this was yet to be circulated. JC agreed to follow this up and look into possible ways to cover the costs required to expand the NCHDA dataset to include antenatal data as proposed, noting that this was strongly supported by the BCCA, SCTS, HQIP and PHE.
Action: JC

7.2. Minimum Dataset: confirmation of content

TW circulated the minimum data standard ahead of the meeting. The addition of ethnicity was agreed. The group agreed to leave as it is for now and review next year. Definitions need to be tightened up e.g. height and stent size
Action: TW

8. NCHDA Patient and Family Day update

TW provided an update on findings:

- The number of responses was low despite circulation via patient groups associated with centres and charitable organisations. The group suggested sending the survey to patients and families via Cardiac Specialist Nurses.
  Action: TW
- Raise the internet profile of the NCHDA portal so that it will be picked up via search engines.
- Appearance may be informed by Speigelhalter work and Aim 2 of the PRAiS2 project currently underway at the Clinical Outcome Research Unit of UCL.
- The group agreed to extend the survey to commissioners and centers. This should be added to the NCHDA work plan. TW advised this would be subject to availability of resources.
  Action: TW

9. International comparisons

This was not discussed and will be tabled for the next agenda.

10. AOB

10.1. Membership:

- KE is to stand down as ACHD representative on BCCA council and will be replaced by Dr Aisling Carroll from Southampton. However KE has asked BCCA Council if she can remain as BCCA ACHD NCHDA rep at least for a long handover period given her knowledge of NCHDA and projects which she is involved, particularly developing an ACHD risk stratification model. This should be decided by the next SC meeting in December.
- TW to review the process for recruiting a new patient representative.
  Action: TW

11. Dates of next meetings:

- Tues Dec 15th 2015 1-4 NICOR Offices, 1 St Martin's Le Grand, London.
- Mon March 14th 2016 Birmingham ICC (room and time tbc)
- New potential dates for 2-3rd week of June, Sept and Dec 2016 to be circulated (TW)