DRAFT

Congenital Heart Disease Audit Steering Committee
September 10th 2013 13.30-16.00
Rockefeller G02 UCL

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
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	Julie Sanders	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
National Clinical Audit Service Manager	Nadeem Fazal	NICOR
Apologies		
Chair SCTS Congenital Database Subcommittee	Chuck Mclean	Congenital Heart Surgeon, Royal Hospital for Sick Children, Glasgow
Data Validation Officer	Lin Denne	NICOR

1. **Apologies**
   Apologies were received from Chuck McLean and Lin Denne

2. **Previous minutes and actions**
   2.1. The minutes were agreed as correct and will be published as a PDF version on the portal.
   2.2. Item 5: Unvalidated data for 2012/13 dataset will be available at the end of August/September: 2012/13 validation is complete and data can go up by the end of the month. Contact LD to check if data sufficiently complete to update portal with caveat.
   2.3. Item 7.5 Published data discrepancies. DC updated the group that the 2009/12 funnels are ready to be uploaded onto the portal. In future, both funnels and tables would be updated on an annual basis. The steering group will review all new funnels in June and

uploaded in September. There would not be a period where funnel graphs were not available. **Old versions of the portal will be kept in a separate are of the portal as a resource.**
Action: NF

2.4. Item 4.2 Organisation responsible for publicising the release of the reanalysis of the NHS England report. As this analysis is solely surgical it was agreed that it would be best on this occasion to liaise solely with SCTS. DB has met with the comms department of SCTS and they are happy to support the release of the report when it is ready.

3. NICOR update

3.1. Governance and Review updates

3.1.1. The UCL review is well underway and NICOR staff and clinical leads including RF were asked to complete questionnaires. The panel interviewed John Deanfield and Dick Waite about NICOR and its processes. The first draft of the report is due on September 15th and there will be an opportunity to amend factual errors. The final report is due on October 18th.
JS gave an update on the new NICOR structure (See Appendix xxx). The NICOR Advisory Group remit and membership is to be confirmed and waiting recommendations of the UCL review. The NICOR executive committee meets on a weekly basis. This is the main NICOR decision making group and focuses on the day-to-day functionality of NICOR. The group is attended by chairs of the five NICOR working groups: Informatics and IT; Communications, Risk and Governance, Research Working group and Health technologies working group. The majority of the working groups will meet for the first time this week. The Informatics and IT group will revisit the plans for a new IT platform that was out on hold earlier in the year. The first decision will be either to resurrect the old plans or look at other systems. NICOR is liaising with colleagues working on similar projects in UCL and Denmark.

3.1.2. The Risk and Governance group has been in operation since June and have met several times. The group are looking at risk related issues along the data flows to prioritise areas of work including priority Standard Operating Procedures. SOPs for User registration and Minimum Data Standard were approved in principal at this week's meeting. The aim of the Minimum Data Standard SOP is to improve data quality and will set out the minimum data requirement for each audit. The focus will be on volume and quality and if hospitals do not meet the required standard their results will not be included in reports. Each clinical group will define the minimum data standard which in turn will be included in Terms and Conditions and the MoU that will be set up with each Trust. JS will present the SOP at the Professional Liaison Group. JS suggested that the Congenital Audit could pilot this new approach.

3.1.3. Terms of Reference for all audit groups are on hold until the UCL review recommendations are published.

3.1.4. The contract extension process is well underway. The applications were submitted on August 27th and HQIP will send any queries by 17th September. NICOR will have until September 23rd to respond. A contract extension evaluation meeting is scheduled for October 2nd. The panel will discuss the extension applications with the clinical leads from each of the audit before making a decision on the 2014-16 funding. The congenital slot is from 12-12.45 and up to 4 representatives of the audit, including RF, can attend. JS and TWhi will be there from NICOR. KB is on call but will try and rearrange. Update: KB not required, DC in attendance.

4. Analysis

4.1. PRAiS mediated reanalysis: follow up to the NHS England Report

This was discussed as a closed agenda item at the end of the meeting and was attended by: RF, TS, KE, DC, ON, KB, TW and JS.

4.1.1. The group reviewed the survival ratio (actual over predicted) chart. Initial analysis highlighted one centre as a positive outlier. The group agreed to follow the outlier policy and review data quality. In the first instance, DC will sense check the data and review data especially discharge status. If results remain the same, RF, TS and DB will formally liaise with the centre.

Update: rapid checking by DC revealed data entry error and on reanalysis, all centres were found to lie within prediction limits. However, this error will require PRAiS recalibration which has been agreed to go ahead in next few weeks, before sending out to the contributing centres.

4.1.2. The group agreed to the format but wanted to make the following changes:

- the legend wording to read 'lower /higher than predicted'.
- Add colour to the central sections of the bar
- The title needs to be appropriate for the lay user (currently it contains technical information that should be removed)
- The legend should avoid use of numbers such as 1 in 40 or 1 in 1000 given the multiple comparisons, since the actual chance of a unit crossing one of these lines give the multiple comparisons is higher than this, therefore these numbers within legends are confusiong. This issue needs to be addressed in the report text.

4.1.3. The group discussed the content and publication of the report and the following was agreed:

- Use NHS England report as a template
- The report will published on the websites of NHS England, SCTS and NICOR
- Analysis will include all operations for the purpose of the report but will limit the centre specific data to UK centres (excluding Republic of Ireland as they have only submitted one year's data.
- Acknowledgment that this is one of several ways of analysing the data and uses an approximate 'binomial' approach to the prediction limits. It was agreed that the methods used for publication must mirror that incorporated into PRAiS. An alternative 'exact' method may be preferable in future and will be explored with the 2010-13 dataset.
- The comments made by David Spiegelhalter need to remain to avoid deriving league tables from the data display plot.
- To include the following reference: "This project/audit is commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP)."

4.2. PRAiS mediated VLAD reports for all centres (KB)

All centres now have PRAiS software for in house monitoring of outcomes using risk adjustment with most up and running. Most centres have contacted CORU and KB asking for in house training and at those sessions came up with comments and feedback. One comment from clinicians has been that the included co morbidities need review, as some require clearer definition and some may need to come out. This has come up since centres became more aware of the importance of co morbidity and its implications for outcome. This is progress in terms of data quality. ON advised that each unit faces range of episodes of varying risk (as is widely recognised given the population of CHD), and that this aspect would be better addressed by the use of exact prediction intervals (rather than

PI with binomial adjustment as is the case at present), as well as the use of individual prediction intervals for each unit (as is already being done). KB commented that the exact PI may weill be the better option (this was already raised by CORU in their report on the April 2013 NICOR report on mortality). This could be addressed at the next iteration of the software.

ON commented that the risk model PRAiS might be more statistically accurate with further work and he might be able to assist with describing limitations or caveats in certain areas. KB commented that limitations and caveats for the risk model are important aspects that need to be included in reports / usages of the model. Further that statistical accuracy is one part of the story but there are many other sources of error such as data quality or coding that may have a greater effect on the validity of analyses.

4.3. Approval for aggregate to go on website

DB approved publication on the Portal of the aggregate data breakdown as originally requested by Alder Hey.

5. Data validation and software solutions.

5.1. Quarterly data submission schedule

5.1.1. TW has liaised with database managers and there have been no objections to submitting data on a quarterly basis. The group discussed feasibility of freezing data on a quarterly basis. DC advised against this as it had been tried within MINAP and data quality was compromised. DC recommended that reports should be viewed as preliminary and centres could continue to submit missed cases until the final annual deadline. The quarterly report would be automated. The reports would support the data validation process especially if it contained information about the number of records rejected and the follow up action taken by NICOR e.g. “emailed unit at 3, 4 and 5 months etc.” PRAIS fields to be part of minimum data standard and should not be classified as fatal (and record rejected) but as a serious error and centres sent a log report.

5.1.2. Every field needs to have a validity check of some sort. Suggested validation rules for weights included entries of weights that are 5 SD from the mean to trigger an error report.

5.1.3. Quarterly data quality reports need to be sent to the clinical audit lead, database manager and surgeon as co-clinical audit lead (if different).

5.2. Data Validation visits: timetable and changes

The audit has been criticised for the current data cycle which currently takes 12/18 months if Adult Congenital Centres are included. LD cannot complete the visit to the required standard within a shorter time frame and will require additional support. NICOR has agreed to fund additional support and it has been agreed that TW would be seconded for 3 days per week until the end of December 2013 to help with the visits. **Action: JS to liaise with Evelina to enable TW to be seconded.**

5.3. Data validation approaches

JS proposed that this would be a good opportunity to review the current validation process. Additional funding would not be available in subsequent years so different approach needs to be identified. Publication needs to be quicker and approaches from other audits could inform the process. A data validation meeting was held on September 4th attended by RF, TW, LD, NF, JS and TWh. The main focus was to agree a strategy for 2012/13 data but future approaches were also discussed. For example, the ACS audit publishes data 6 months after the data deadline. It was recognised that the congenital audit is more complex but that a lot more could be done within the database to support the validation

process. DB queried whether ACS also has access to HES to measure case ascertainment as that is a key function of the validation visits. ACS does not use HES and validation rests with centres. Other audits, such as Heart Failure, use HES as a denominator. The PCI audit uses an aggregate survey based on figures pulled from the cath lab system. If additional processes are in place and working well then perhaps data validation visits could occur less frequently. KE volunteered Leeds as a pilot site.

6. Comorbidity codes and definitions

6.1. RF and TW have been working on the comorbity codes and definitions and now at the stage for pruning down which will require a face-to-face meeting. Examples include Timing e.g. if pre-op renal then definition including the time frame such as 1 week/1 year. The STS congenital database have a definition set based on that published by the MultiSocietal Database Committee (Cardiology in the Young supplement, 2008), that may be suitable and may also help with the international mapping work. RF and KB will meet in the first instance to discuss.
Action: RF

6.2. Additional Comorbidity fields need to be included in the dataset to force completion of fields. TWi proposed a new field 'Comorbidity present – Y/N.' DC also reminded the group that 3 additional fields for devices had previously been agreed at stakeholders meeting. Both changes were approved. DC highlighted that dataset changes need to be agreed before the end of December to be implemented from April 2014. Other dataset changes will also depend on the work on comorbidities.
Action: DC

7. Revision to EPCC codes.

7.1. DC highlighted the need to map the various codes used within the database. There are approximately 1600 short codes and over 10,000 long codes which may have contaminated the submissions by some centres or entered the Ref Vals in error. DC will take extract from Ref Vals and compare. There are some quirks in the mapping, e.g. in cardiac intervention and ductal stent. DC will review and RF offered to help.
Action: DC

7.2. Hybrid patients will probably need their own funnel plot. DC offered to bring new funnels to the December meeting as well as a breakdown of everything in that group to establish whether contributors are submitting in the right way. There will be an educational aspect on how best to code procedures which should be calrified to centres via DBMs.

8. Annual Report

Publication of an annual report is a HQIP contractual requirement that is outstanding. The current plan is to publish in early January and the group discussed whether the report should be a celebratory report covering the last 10 years or focus specifically on 2011 data. There were concerns about time pressures given the NHS England Report and ongoing work commitments of the group, making a 10 year report more challenging given the time frame. To start the process, TW will pull together a structure and send to the SG for comment.
Action: TWh

9. Stakeholders meeting

At the last stakeholder meeting, the possibility of holding 6 monthly database manager and lead clinician meetings was discussed. It had been thought that an autumn meeting could be held in Edinburgh to coincide with the SCTS meeting but surgical attendance was anticipated to be low. Another suggestion was to hold a March meeting at the SCTS meeting in Edinburgh.

DB and TS offered to liaise with the societies to see if this is feasible. KE suggested consulting the users via Survey monkey to see what would work for them.
Action: TWh

John Deanfield (NICOR director) is keen to continue with an annual stakeholders meeting but with a different approach, suggesting a series of speakers rather than feedback sessions. Potential speakers include Bruce Keogh, Martin Utley and David Spiegelhalter. This is likely to be Spring 2014 and to be focussed on the 2010-13 dataset rather than the problems there have been with the 2009-12 analyses.

10. **AOB:** None.

11. **Dates of future meetings:**
    Tuesday 10th December 2013 13.30 – 16.00. Venue: tbc
    10/11/12th March – date tbc
    Tuesday 10th June - venue tbc