

National Congenital Heart Disease Audit Steering Committee
NICOR Boardroom,
1 St Martin's Le Grand
London EC1A 4NP
September 12th 2016
13.00 – 16.00

Notes

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
Senior Audit Strategist	David Cunningham (Skype) (DC)	Senior Strategist for National Cardiac Audits, NICOR
BCCA ACHD representative	Kate English (KE)	ACHD Cardiologist, Leeds General Infirmary
SCTS Congenital Audit Lead	David Baron (DB)	Birmingham Children's Hospital
BCCA Interventional Representative	Andy Tometzki (AT)	Consultant Paediatric Interventional Cardiologist Bristol Royal Hospital for Children
Congenital Database Managers Lead	John Stickley (JS)	Database Manager, Birmingham Children's Hospital
HQIP Associate Director for Quality and Development	Kirsten Windfuhr (KW)	HQIP
HQIP Project Manager	Tasneem Hoosain (TH)	HQIP
Patient and public representative	Bob Ward (BW)	
Chair SCTS Congenital Sub Committee	Carin Van Doorn (CVD)	Congenital Heart Surgeon, Leeds General Infirmary
NICOR Project Manager	Tracy Whittaker (TW) (Skype)	NICOR
NICOR National Clinical Audit Services Manager	Nadeem Fazal (NF)	NICOR
Clinical Data	Lin Denne	NICOR
NICOR Congenital Audit Developer	Andy Harrison (AH)	NICOR
NICOR Information Analyst	Jiaqiu Wang (JW)	NICOR
NICOR Project Manager	Sarah Ajayi (SA)	NICOR
NICOR Project Coordinator (minutes)	Shenaka Singarayer (SS)	NICOR



1. Apologies & Introductions

Apologies had been received from David Anderson and James Chal.

2. Previous minutes and action log

Papers 2.1,2.22.3

Draft minutes of the previous meeting held on 21st of June were agreed as correct.

Actions from last meetings not discussed as part of Agenda (See action log for full update)

ID	Action point
Action 8 Dec 2015	<u>Identifying ACHD non-submitting centres using HES data.</u> RF will be part of the EnRICHeD project and can therefore be closed with respect to a NCHDA-NICOR action. However some feedback from other NICOR Audits will be explored to identify centres in the meantime. Closed.
Action 8 March 2016	<u>Outlier process in Scotland, NI and RoI.</u> Chuck Mclean has had no response from his letter of enquiry to Scottish Authorities sent August 2016. RF sent similar enquiry to Republic & Northern Ireland. Paul Oslizlok (RoI) and Frank Casey (NI) replied that they have no policy or protocol for outliers, and no official HQIP-type document to work from. PO and FC had said that a pan Ireland document is needed and they will take forward in due course, informing NCHDA when completed. Open.
Action 10: March 2016	<u>Letter to centres on need for quarterly returns.</u> TW confirmed letters had not been sent. RF recommended that these should be sent as a reminder to Audit Leads copying MDs about need for quarterly data submissions, our minimum requirement. LD confirmed 25% of the centres submit quarterly. Going forward, SA will receive monthly report from LD on which centres have submitted. Open.
Action 11 March 2016	<u>NICOR to update software to allow data on patient death to be entered, along with cause of death field, independent of procedural data.</u> AH: this has not been rolled out yet. Will be possible with focus on including in new web version. To be carried forward. Open.
Action 16 March 2016	<u>Reporting 90 day outcomes.</u> On Agenda. Open.
Action 19 March 2016	Analysis of Infectious Endocarditis data. RF: to be moved to Dec or March 2017 meeting. Open.
Action 21 March 2016	<u>Need for Republic of Ireland map for antenatal data reporting.</u> DC does not have software for this and recommends Andrew Hughes Public Heath England to implement. TW/SA to action. Update: completed Oct 2016. Closed.
Action 2 June 2016	<u>Positive outliers reporting.</u> KW said that the last word from Danny Keenan is that recommendations on actions to be taken with respect to positive outliers is on hold, therefore action can be closed at present. KW will check with Michael Wilson and DK and let NCHDA know if this not the case. Closed.
Actions 1 and 3 June 2016	<u>PRAiS2 Child Heart Surgery Information website.</u> RF: Positive feedback about the website nationally has been received. The site will be updated with the latest PRAiS2 analysis due to be published with NCHDA annual report 19 Dec 2016, and each subsequent publication of PRAiS analysis (annually or even quarterly if available). Closed.
Action 5, & 13 June	TW sent Gantt chart with papers for meeting if not agreeable she will change it. TW to look at the possibility of setting up a shared version of a NCHDA Gant Chart

2016	progress document that the Steering group can all access. TW said the people wanted to have live access to a version that allows joint updates and o keep track of NHS deliverables. TW said this can be done by setting up honorary contract to have access to UCL's shared drive. TW expressed that this may be possible to set up with RF in the first instance, then consider additional contributors depending how complicated. TW said it can be sent on a weekly or monthly basis. RF said it would be helpful to be sent out on monthly basis either from TW/SA coming from the Audit. Action SATW
Action 6: June 2016	<u>AH to work on ensuring previous procedures allow duplicates of same procedure on different dates.</u> AH said he is ready to go live and that the history table will be updated with current data entered by hospitals. Funnels represent a snapshot. The Funnel will be reanalysed and finalised by November and published Funnels will all match each other. Open
Action 8: June 2016	<u>Duplication of EP data between NCHDA and Cardiac Rhythm Audit, especially ACHD patients.</u> AT to set up telecom to discuss: Graham Stewart (Bristol) /AT/RF. JS also to meet with a colleague Olga as this issue is relevant to all Data managers and discuss with AT what can be done internally in Bristol as a starting point. Aim: single entry of data for both CRM and NCHDA datasets. Harmonisation agenda within NICOR should help, assuming HQIP bid successful. Bring forward to Dec 2016 SC. Open
Actions 9, 10 and 12 June 2016	<u>Algorithm and new categories, including Stent Redilation, Nikaidoh and Aortopexy.</u> RF to update the algorithms in next couple of weeks, sending to AH, as per decisions in June with new categories and codes, including EP ones. After testing for errors and sense checking new categories to see if valid to report new proposed categories with JS/DC/JW, 2013 -16 data to use this and additional funnels to be generated by JW. Open.
Action 11	<u>How best to report Diagnostic Catheters.</u> To be brought to Dec 16 meeting. Open.
Action 14 June 2016	<u>Life Status new category: death subject to coroner's inquest.</u> This will be added to dataset from April 2017 and go into Data Manual as a new outcome if it's known. It will not disappear until ONS provide life status following the issuing of a death certificate. Closed (added to Manual and dataset by JS).
Action 15 June 2016	<u>PRAiS2 Understanding Children's Heart Surgery Outcomes website link from NCHDA portal.</u> AH said link to new information website from the main portal has been done. Closed.

2.1 PFO closure (Action 20)

RF to look at PFO closures with DC and assess whether bypass time coded for these patients and whether procedures miscoded when it was in fact an ASD. Results sent to SC showed vast majority did not have a bypass time figure. RF and DC had agreed therefore to reallocate all those without bypass times to transcatheter closures as they would not have had surgery. The few patients with a bypass were early era and the numbers did not justify any further action (highly unlikely to have had surgery to close just a PFO). **Closed.**



3. 2013-16 analyses and publication

3.1. PRAiS2 update

- **Validation check**

RF confirmed that the recently released PRAiS 2 model, using PRAiS v3 software, was used for the initial analysis of the NCHDA 13-16 data in July, and that there were no potential outliers. There are two centres with much higher survival than predicted. RF said KW had confirmed that for the moment there will be no actions with respect to units performing at this level.

RF said that ideally there should be a learning process in place to enable centres with exemplary results to pass on aspects of care judged to contribute to their higher than predicted outcomes. This is dependent upon HQIP and NHS England to provide guidelines in the future.

3.2. Specific procedures table and funnels

- **Validation check**

It was confirmed that the initial 2013-16 funnels were sent to the SC in July 2016 and for the first time used the same control limits as PRAiS software at 2 and 3 standard deviations.

Emerging issue: Outlier: same patient & multiple procedures

Three potential negative outliers were identified. There was a data error arising from two procedures at two centres, where a single patient had been counted twice. The patient had undergone the same procedure twice within a 30 day period: mitral valve replacement in one case, pulmonary arterial stenting in the other. There was a similar issue in the 2012-15 analysis.

RF said to avoid a repeat of this scenario of deaths being counted more than once for the same patient undergoing the same procedure in a 30 day period, NCHDA analysis could go back to the original approach of reporting outcomes for the patient, such that the patient would be censored from the funnel at each subsequent procedure in the three year period, entering into a new funnel, meaning that the numbers in the funnels may not reflect the actual numbers of patients undergoing that procedure. The group were against moving away from the current Procedure based reporting (without such censorship), believing that it was better to avoid inaccurate numbers within the funnels given previous public criticism. An explanation would therefore be provided on the Portal to explain that certain procedures included the same patient more than once (whether survived or deceased). In the long term the group agreed to give greater consideration to this issue and offer an approach/solution that ensures it is accounted for when calculating the funnels. This may also help avoid needlessly going through the potential outlier process.

SA/TW to contact NACSA to ask what process if any is in place for such a scenario in adult cardiac surgery.

This leaves one outlier: bidirectional Glenn (BDG) procedures in Glasgow. TW said that the centre's Audit Lead and DB still required some data clarification with NICOR to ensure accuracy. DC and LD will liaise with Glasgow to clear this up. Assuming

the outlier status remains, then Glasgow will produce a report. The outlier protocol to be followed would be the same as in previous years involving the BCCA and SCTS (HQIP 2011 guidance) as only NHSE centres would follow the new pathway, formally informing commissioners and NHSE via the Quality Assurance Team.

Action: SA/TW to check with NACSA on how they deal with repetition of same procedure within same year or 30 day period.

Action: LD and DC: Two potential outliers, and one has been confirmed and going through the process.

Action: LD and DC: to confirm Glasgow data with centre re: BDG outlier status.

Action: RF to contact SCTS to find out what they have in place regarding dealing with specific procedures.

3.3. Validation progress update

LD reported having three more English sites to do on site visits and has volunteers in place to help. These will be followed by Ireland and Scotland centres.

LD reported that the data quality for the new fields was very good. Only one centre had dropped their DQI due to issues with entering device details. New guidance on codes relating to devices is required and will be provided in Dataset Manual which JS is finalising.

Papworth are now submitting data and will include retrospective data from 2013. RF asked LD to visit the centre when possible, before April 2017 to ensure quality of their data submissions. LD happy to go, most cases are catheter interventions.

Action: LD

3.4. Activity tables: Separation of Transcatheter and EP procedures

NHSE has requested activity tables be divided up in this way for future NCHDA reports, so as to help with calculating interventional catheter procedure numbers for each centre for future commissioning against NHSE CHD Standards.

DC had already done this as an urgent NHSE request in June for 14-15 data. AT reported that NHSE requirements per operator may not be achieved even though centre level activity may be high.

It was agreed that future reports and the Portal should have this additional breakdown of non-surgical activity.

Action: DC and JW: provision of 2013-16 data for NCHDA report with division of transcatheter and EP interventions

3.5. Suggestions for additional Recommendations

A draft 13/16 report was distributed as part of the papers. The groups agreed the following changes to the recommendations section:

- Updates:
 - Inclusion of Papworth data
 - Reference to PRAiS2 and new PRAiS v3 software
 - Link to Children's Heart Information Website
 - Outlier policy to align with NHSE

- Reference to linking NCHDA and fetal screening data and objective to improve antenatal diagnosis.
- Antenatal diagnosis maps to be upgraded.
- Table 2 - centres to be alphabetically ordered
- NHSE requested antenatal figures to go 100%: to be changed
- Brief update moving to PRAiS2 – **Action: KB**

Action: TW, RF, JW, LD- Above actions now **Closed**

- Additional recommendation: dedicated staff for audits 1WTE data manager and 1WTE data assistant per centre per 300 cases
- Participation: Inclusion of PCI reported PFO closures based on PCI survey: **Action: TW. Closed**

4. NCHDA Updates

4.1. NICOR update (NICOR TW)

4.1.1. HQIP tender

The proposal for funding was submitted in August and Barts/NICOR have been invited to a clarification meeting on October 12th.

4.1.2. Recruitment

There has been a number of new recruits within NICOR. Within the project management team there are two new project managers, three project coordinators, one patient and public engagement coordinator and one Communications Coordinator. Within the technical and analytical team NICOR is recruiting staff to support the audits and to develop the new IT platform based on the Swedeheart system. Sarah Ajayi and Shenaka Singarayer will be the new Project Manager and Coordinator for NCHDA working an equivalent 1WTE on the audit. The handover is in process with the view of formally taking over early October.

4.1.3. ONS life status.

The NICOR and NHS Digital data sharing agreement has expired and the new process for extending is taking longer than expected due to new processes within NHS digital. This may have an impact on publication date if delays continue into November. HQIP is working with NICOR to support the process.

4.2. Professional Liaison Group update (RF)

The last Professional Liaison Group meeting in July was focused on the HQIP bid. Nothing further to report.

4.3. Project update including NHS E deliverables (TW)

4.3.1. Progress update

Circulated papers gave an overview of progress to date. The group would like an overview update each month.

Action: SA



Agreed data quality threshold and data validation visits to be discussed in December 2016. RF suggested that in the future some centres could be visited every other year to shorten timescales, but this should also involve societal agreement. LD advised that the visits should continue as they are for one more year just to ensure data quality continues to improve, with a view to possibly changing the process thereafter.

Action: SA/SS to include December agenda

There was discussion on definition of year end in relation to reporting within 9 months. Is it March 31st or data submission deadline which is 1st May. KW said that she would seek advice and confirm HQIP view. The SC view was strongly that this should be from data submission deadline as no validation could begin until after this date.

Action: KW

Adult risk model: RF and KE have submitted a proposal to NHIR with CORU (EnRICHed). In the meantime it was agreed to continue with the plan to adopt an interim approach in the absence of a validated risk model based on the US Society of Thoracic Surgeons STAT score. RF to send JW the Jeff Jacobs paper for JW to develop methodology and take forward work that ON had previously been tasked with.

Action: RF, KE and JW

4.3.2. 90 day outcomes 'gap' with ONS (JW/DC)

Work is underway and result will be presented at the December meeting.

4.3.3. Updating portal: Demonstration (JW)

The demonstration was delayed until after the meeting due to time limitations within the meeting. Initial SC comments were very favourable.

4.3.4. Outcomes by diagnosis/ Fetal dataset / NCARDS

-Outcomes by Diagnosis:

-Fetal dataset: the work has been delayed at the UAT phase and awaiting feedback from RF and JS as additional dataset items and fields are required to meet National Fetal Cardiology Group needs:

Action: RF, JS and Gurleen Sharland /Anna Seale via telecom. Once completed, NICOR to finalise and ready for UAT phase before BCCA meeting 23-24 November.

4.4. Technical update (AH)

4.4.1. Web enabled platform (Action 17, June 2016):

Last part to be done is the import tool. JS said it will be good to have user acceptance test before going live.

AH mentioned it should be ready for testing beginning November. AH /JS testing main update on the front end has been done. Update to import routine will require couple weeks work followed by user acceptance testing before goes lives.

NF said Marion made changes from last meeting and best to run lotus notes to the end of this cycle. NF confirmed that once full testing completed it will be rolled out early November. The work has been delayed at the UAT phase and awaiting feedback from JS. A face-to-face meeting is likely required so that all parties can view the database

and make suggested changes.

4.4.2. Technical issues (JS/AH)

Restructure the way the database is, drop downs need to be addressed, changes to the dataset for the referring hospital, ability to record data in excel.

4.5. NCHDA Patient/Family/Public update (BW)

No update.

5. Data Quality Guidelines

5.1. Data Manual (JS)

Draft version of the guidance was circulated ahead of the meeting and specific changes were discussed. RF and JS will continue to work on the detail

Action: RF and JS

5.2. Overall Data Quality guidance (TW)

A number of changes were made to the draft by RF. SC members asked to send any amendments to TW.

Action: ALL

6. Reduction in data validation timeline

It was agreed to add this to the December agenda

Action: RF and SA

7. AOB

6.1 Blue book for NCHDA (CVD/DB)

DB provided an overview and confirmed the society has agreed to fund it for next years' cycle.

Action: DB to take forward with SCTS and NCHDA in due course.

8. Dates of next meetings:

- December 13th 2016 1-4 NICOR Boardroom
- March 13-14 Belfast part of SCTS meeting exact date and location tbc