National Congenital Heart Disease Audit Steering Committee
June 17th 2015, 13.00-16.00
Boardroom
NICOR, 170 Tottenham Court Road, London, W1T 7HA

Notes

Attendees		
Role – representation	**Name**	**Title - place of work**
NICOR Congenital Clinical Lead – Chair	Rodney Franklin (RF)	Paediatric Cardiologist, Royal Brompton Hospital
Chair SCTS Congenital Sub-Committee	David Barron (DB)	Birmingham Children's 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
Data Validation Officer	Lin Denne (LD)	NICOR
BCCA ACHD representative	Kate English (Skype) (KE)	ACHD Cardiologist, Leeds General Infirmary
Technical Service Manager	Nadeem Fazal	NICOR
NICOR Congenital Audit Developer	Andy Harrison (AH)	NICOR
President BCCA	Rob Martin (RM)	Bristol Royal Hospital for Children
NICOR Senior Analyst	Owen Nicholas (ON)	NICOR
Patient and public representative	Bob Ward	
Congenital Database Managers Lead	Thomas Witter (TW)	Database Manager, Evelina Children's Hospital
NICOR Project Manager (Congenital)	Tracy Whittaker (TWh)	NICOR
Patient and public representative	Gerry Bennison	
Chair SCTS Congenital Database Subcommittee	Chuck McLean (CMc)	Congenital Heart Surgeon, Royal Hospital for Sick Children, Glasgow
BCCA Interventional Representative	Andy Tometzki (AT)	Bristol Royal Hospital for Children

1. **Apologies & Introductions**
   Gerry Bennison, Chuck McLean, Andy Tometzki

2. Previous minutes and actions

Apart from minor changes the minutes were approved.

3. 2013/14 report: outstanding issues

3.1. ASO funnel

The original format of the Arterial Switch Outcomes implied that one centre was an outlier. This was an effect of smoothing the curve and the centre was in fact not an outlier. The SC agreed to publish the two funnel curves (with and without smoothing), along with an explanation circulated in advance of the meeting, taking into account the comments from the SC.

Action: AH to post

3.2. Outlier process text

The original text on the NCHDA portal relating to the outlier process was out of date and required updating. The group agreed that the text should just direct people to the Department of Health Outlier policy.

Action: TWh and AH

3.3. Remote validation 2013/14

TWh updated the group on the remote validation process for 13/14 data. The format signed off by the SC included a break down by specific procedure activity, whilst the format sent to centers was only at an aggregate surgical and interventional level. All centers, including those who had also received a validation visit, were asked to confirm the aggregate figures. All centers except Nottingham, confirmed the numbers. It was agreed that this year's reports should follow the agreed format, inclusive of procedure level breakdown, and be clearly labelled 'remote validation'. The data should only go to the centres not visited.

4. Minimum Data Standard

The current NCHDA minimum data standard id due to be rolled our but needs to be updated to align with the new dataset that was launched in April 2015. The committee agreed the following actions:

4.1. The MDS needs to be updated to the fields shown in the Table. In addition 'unknown' options should be removed from the following fields:

- 3.07 Type of procedure
- 4.03 Discharge status

4.2. The minimum data standard should be distributed to both clinical lead and database managers.

Data field
1.01 Hospital identifier
1.02 Patient Case Record Number
1.06 Patient Date of Birth
1.07 Patient gender
1.10 Patient post code
2.01 Diagnosis
2.02 Previous procedure
2.03 Weight
2.03b Height (cm)
2.04 Antenatal Diagnosis
2.07 Comorbid Conditions
3.01 Date/Time procedure
3.01 b Procedure Urgency
3.01 c Unplanned reoperation or reintervention
3.02 Consultant Responsible for Procedure

3.02c Single Operator Procedure
3.03 First Operator
3.05 First Assistant
3.07 Type of Procedure
3.08 Sternotomy sequence
3.09 Operation performed
3.10 Total bypass time
3.11 Total bypass cross clamp time
3.12 Total circulatory arrest time
3.13 Catheter procedure duration
3.14 Total fluoroscopy time
3.15 Total fluoroscopy dose
4.01 Date of Discharge
4.03 Discharge status
4.07 Duration of post-operative intubation
4.08 Post-operative complications
7.04 Catheterisation complication severity rating
5.01 Device manufacturer
5.02 Device model
5.03 Device serial number
5.04 Device size
6.01 Pre-procedure NYHA status
7.01 Pre-procedural valve or septal defect or vessel size
7.02 Sizing balloon used for septal defect closure
7.03 Number of stents or coils
7.04 Catheterisation complication severity rating
7.05 Catheterisation complications

5. NCHDA Project Update:

5.1. Professional Liaison Group update (RF)

The last Professional Liaison Group meeting was held on 19/5/2015. NCHDA representatives at this meeting were RM with apologies from RF. HQIP will continue to fund the NICOR Audits until 2017 but there will be a tendering process for continued funding thereafter. To this end, John Deanfield, John Parkinson and Jess Tudor-Williams distributed 'NICOR Fit for Future' document which documents the need for each Audit to provide a strategic vision for the future to inform the tendering process. Following discussion at the PLG about key points, all clinical leads were asked to work with their respective steering committees to develop a strategic paper for the next PLG meeting using a template provided, focusing specifically on patient safety, QI, QA, NICE quality standards and where appropriate PROMs information and post market surveillance. RM noted that a major point in the paper was on device tracking and potentially generating income from sources other than HQIP. RM did not think that the NCHDA should not be overly concerned about its future given the stated backing of NHSE for the Audit and its incorporation into specialist commissioning metrics. TWh advised that Jess Tudor-Williams expected a draft response by 19th June and that this was an important opportunity for the audit. RF said this was duly noted and asked members to read the papers and send any comments to TWh within the week. RF asked TWh to collate responses as a priority.

Action: TWh

5.2. Project update

5.2.1. The NCHDA work plan was circulated ahead of the meeting for information. This provided an updated against the NCHDA deliverables and highlighting areas of risk.

5.2.2. TW has highlighted that NCHDA data will be used for CQUINS (commissioning for quality and innovation payments) as from April 2015. The man concerns raised were that NCHDA

data may be required ahead of data validation and publication. For example, 14/15 data was requested in April 2015. TWh reported that NICOR has not been formally approached and will look into this.
Action: TWh

5.3. Technical update
AH reported that dataset version 5.0 went live in April but has been superseded by 5.1 and these updates are in progress. The portal has been updated with the new tables and funnels following publication of the 11/14 data. However the Fetal pages still need to be published with new Tables inclusive of patient numbers.

5.4. HES and Life Status update
DC reported that the life status file is due to be sent to HSCIC July 1st. Delays is accessing HES data continues but approval for HES linked data has been approved. DC has also signed the Data Sharing Agreement so NICOR should receive the data within 4 weeks.

5.5. RF chairmanship is due for renewal in April 2016 and the process of reelection will need to be initiated soon. However guidance on this and a possible contract of engagement is still awaited from NICOR.
Action: LC/JTW

6. Data validation:

6.1. Data validation 2014/15
LD updated the team on the current data validation schedule. The majority of visits have been scheduled, although Glasgow to be finalized for the Autumn. DC advised that outliers will be identified much earlier as centers will be sent draft aggregate analyses earlier in the process. Centers will be given 4 weeks to check and confirm accuracy of results including number of procedures. In other words validation and initial analyses will run in parallel this year so that any outliers can be identified and processed earlier than previous years.

The SC agreed that future reports should also include a list of hospitals undertaking congenital procedures but not submitting data to the NCHDA. The group agreed to identify potential sources including PCI aggregate survey, HES and adult cardiac surgery audit.

6.2. Data validation: 2015/16 onwards
Data validation working group meetings resumed on 5th June 2015. One of the actions from the meeting was to assess data analytical processes and opportunities for reducing the timeline from the data submission deadline to publication. A paper was circulated ahead of the SC meeting and members asked to consider various questions in relation to the NICOR data flow. TW advised NHS E had a clear directive to produce service level markers for all services by 2020 and that quarterly reporting and timely validation will be a key component of this approach. RF advised that this should be discussed at the next data validation meeting on July 17th 2015.
Action: TW to add to the agenda

6.3. Potential opportunities for reducing validation timeline (All)
Covered in 6.2

7. Fetal proposal
RF updated the group on the fetal dataset expansion plans. At this point in time, funding had not been identified. RF had requested that NICOR aim to absorb the cost of the work within the current resource allocation but so far this has not been approved for 2014/15 due to current workload. RF and Gurleen Sharland will also submit the proposal to a charitable organisation in the hope that some additional funding towards the work could be obtained (specifically not the UCL surcharge). RF clarified that the data will be supplied by fetal cardiologists who are all members of the specialist centre congenital cardiology team, although their fetal cardiology activity may be located at nearby Fetal Medicine Units.

8. NHSE request

The NCHDA has been approached by NHS E with a list of areas they want to priotize. NHS England is awaiting feedback and RF had asked the group for comments on the draft NICOR response.

8.1. NICOR will publish a non-risk adjusted report on adult mortality alongside their paediatric mortality reports. The proposed timeline was September 2016 as a full year of validated data would be required to begin to develop an adult risk model, following roll out of the necessary dates fields in April 2015. At the NCHDA research Committee Serban Stoica suggested that EuroSCORE could be used as an initial basis for the model. Bristol and Evelina double submit adult cases to both NCHDA and NACSA, within which EuroSCORE is a requirement, so that any required additional data fields would be present at these centres.

8.2. NICOR will begin reporting on 90 day mortality alongside 30 day mortality. KB advised that it would be problematic to generate 90 day outcomes within PRAiS as this has not been validated for this timeframe. In addition, within each 90 day episode there was a higher chance that additional procedures (elective or non-elective) might take place. These issues would need to be resolved before 90 day model could be applied. If one year outcomes are to be produced this will need to be done via diagnosis and not procedure. However RF tabled initial procedure specific Funnel curves which may be an initial step towards this NHSE goal. It is also clear that family support groups are keen to be move beyond solely reporting comparative 30 day mortality outcomes, as some complex patients may survive beyond this time but still die during their hospital stay. RF asked for this to be discussed further at the September SC meeting.
Action: TWh to add to Agenda

8.3. G2: Page 2 pacemakers. Draw up a shortlist and sign off in September.
Action: TWh add to agenda. 20-30% of cases do not go into a procedure bin. TGA-VSD 60-70 cases agreed in 2014. Need to relook at the algorhythm, could change miscellaneous to categories.

9. NCHDA Patient and Family Day update

The final draft of the survey was signed off and will be distributed after the meeting BW offered to help.

10. AOB

10.1. Linking datasets with the European Congenital Heart Surgeons Association. The SC and SCTS congenital group had previously given approval to pilot a linkage between the ECHSA database and NCHDA, but that any publication would be limited to comparisons with those ECHSA centres who had previously undergone validation (about 20% of centres). DC had undertaken some initial aggregate analyses (procedure specific NCHDA vs ECHSA centres; not individual centres), which were circulated ahead of the meeting to the SC clinicians. There was insufficient time to discuss these, except that RF noted that NCHDA centres performed very well. This will be discussed further at a future SC meeting.
Action: To be discussed at Sept or Dec SC.

10.2. LD highlighted that only 4 clinicians came to the contributors meeting in March. LD was concerned that clinicians may be missing the meeting invite. It was agreed that the date should be circulated now so dates were in diaries.

10.3. LD highlighted a situation where ACHD patients died through perinatal complications during a congenital cardiology intervention undertaken as an emergency during pregnancy. it was agreed that this should be considered as an addition to the complications list during the next revision of the dataset, noting however that this is a very rare event.

10.4. TW is stepping down as the database manager at the December meeting as tenure is coming to an end. There is currently one definite and 3 possible nominees and election will take place in due course.

11. Dates of next meetings:

September 8th 2015 1-4 (venue tbc)
December 15th 2015 1-4 (venue tbc)
March 14th 2016 Birmingham ICC