National Congenital Heart Disease Audit Steering Committee
March 26th 2015 10.30-12.30
c/o SCTS Annual Meeting, Exchange 10 Meeting Room, Manchester Central

Notes

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
Audit & Research Manager	Linda Chadburn (LC)	NICOR
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 (CMc)	Congenital Heart Surgeon, Royal Hospital for Sick Children, Glasgow
NICOR Senior Analyst	Owen Nicholas (ON)	NICOR
BCCA Interventional Representative	Andy Tometzki (AT)	Bristol Royal Hospital for Children
Congenital Database Managers Lead	Thomas Witter (TW)	Database Manager, Evelina Children's Hospital
NICOR Project Manager (Congenital)	Tracy Whittaker (TWh)	NICOR

1. Apologies & Introductions

   Apologies were received from Anthony Bradley, Rob Martin, Nadeem Fazal, Owen Nicholas, Bob Ward (BW) and Gerry Benison.

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2. Previous minutes and action points not arising

   The minutes were accepted as accurate and signed off by the group.

   - 3a: Leaked LGI letter update: LC has completed the investigation and the findings and recommendations are with the NICOR Executive team. No

feedback to SC available at this time.

- 5a: PRAiS mediated aggregate analyses: 2009 – 12 & 2010 – 13. It was agreed by the group that CM & TW should undertake a pilot to make cross references and link with the information held by DC. This action was outstanding but as part of the validation process it was agreed that all centers would be sent a preview of their analysis before the results are published.
  Action: AB/LD/TWh
- 6a: PRAiS mediated aggregate analyses: 2009-12 & 2010-13.
  DC queried how often NICOR should confirm numbers with centres as mismatches accumulate throughout the year. RF advised that centers run the report on a monthly basis to cross check that their input matches that within NICOR. NICOR should only run an overall analysis on an annual basis at data collection year end following the data deadline. It was agreed DC should run this at the end of June 2015 for the 2014-15 dataset and the detail documented on the project plan. Discrepancies would be highlighted to the contributing centres.
  Action: DC and AB/TWh
- DBM Job Description (TW). It was agreed that it was not appropriate for the SC to develop a DBM JD. TW advised that DBM often work on more than one audit and it's up to the Trusts to determine the role. It was agreed that NICOR could make recommendations of desirable requirements.
  Action: TW to produce draft JD with input/ approval by national DBMs for next SC

3. NICOR / NCHDA update (LC)

3.1. Outlier Policy update:

The updated HQIP outlier policy is still with HQIP and RF had submitted a response on behalf of the NCHDA SC via the PLG last summer. A further consultation period had just finished for Consultant Outcomes Publication inclusive of outlier protocols. DB confirmed that some SCTS members are upset by this Consultant Outcomes publication and outlier policy which was nebulous in terms of how the cycle would be closed. There are problems in publishing at individual level and many would prefer the team approach. LC/RF advised that Danny Keenan (HQIP clinical lead) agreed that COP was not suitable for all areas and that NCHDA would be more appropriately fall under the remit of HQIP's Team Outcomes Publication; a draft version for consultation is due out soon from HQIP. DK had confirmed that all audits in the NCPOP audit, including the NCHDA will be part of the COP programme by 2020 but only if relevant. AT emphasized the need to agree formal definitions between adult and paediatrc care. RF confirmed that until the new policy is rolled out the NCHDA is obliged to follow the HQIP 2011 process.

3.2. Professional Liaison Group update:

Danny Keenan (HQIP) had advised the PLG that there is an increasing view that data quality is the responsibility of the hospitals and should be signed off by an organisation's medical director and Chief Executive. The need for external organisations such as NICOR to undertake intensive validation processes may be less likely in the future. However, both RF and LC advised that DK is also supportive

of the current NCHDA validation visits to centres.

The PLG noted that the draft Outlier policy focuses on both positive and negative outliers. The aim of the positive outlier focus will be to celebrate good practice. CMc raised concerns that positive outliers may be due to data inaccuracies in the same way as negative outliers. The first step for both positive and negative outliers is a review of data accuracy and statistical variability to rule out errors, before considering performance and benchmarking to perceived outcomes above that predicted. There needs to be clear differentiation between data error and performance. DB advised that SCTS is not supportive of publishing positive outliers at face value.

3.3. NCHDA clinical lead post.

LC has sent the final draft of the clinical lead job description to the NICOR executive and is awaiting sign off.

4. NCHDA Patient and Family Day update (LC)

Invites for the NCHDA patient and family day have been circulated to the Children's Heart Federation and all specialist centres to forward onto patients and families. In addition, the flyer will be posted on the NCHDA portal and NICOR website. KB thought a stakeholder perspective could be helpful to the PRAiS2 project and expressed an interest in supporting the event. TW suggested that other stakeholders who use the portal e.g. clinicians and database managers may also like to inform future development. TWh agreed to feed this back to the working group.

Action:TWh

Update: this event has been postponed until later in 2015 with planning meeting held 21.04.15.

5. NCHDA Project Update

5.1. 2011-14 analysis: report & portal update

The final report needs some minor modifications following change in status of one of the procedures (one centre's Green Line found to be due to data error and miscoding). CMc requested time to confirm status of some local cases before the report was finalised.

Action: CMc.

5.2. There was some concern that HQIP had not signed off the revised draft report and this was holding up the reporting process. LC confirmed that HQIP had requested amendments to the Executive summary before initiating the review process but this was due to the technical tone of the initial report and that they felt that the Executive Summary it was not written with sufficient clinical perspective. LC highlighted that HQIP had expedited the process for the NCHDA audit so that the report could be published by the end of March.

Due to purdah restrictions around the forthcoming general election it was not possible to publish after March 30th. The aim is to publish May 8th and to publish all analyses, Funnels and reports on the same day, including an update to all Tables

and the fetal data. Note that the names of the centres on the Portal also need revising to be aligned to the format of the Report.
Action: AB/TWh to send out revised report as soon as available from HQIP/ AH to revise Portal Centre names to align with report.

Post meeting note: *HQIP signed off the report and Executive summary week beginning March 16th.*

5.3. 2012-15 analyses: timeline & plans
Discussed under item 8b.

5.4. Combining Evelina & St Thomas' data
The SC agreed that Evelina & St Thomas' data should be merged with a brief explanation on the Portal.
Action: AH

5.5. IT platform update (AH)
AH has made good progress on web-enabling the front end of the NCHDA database, where lotus notes has been replaced with a web front end. AH is currently working on the import and export routine and the web version will be ready for roll out by June 1st although AH will confirm in due course.TW advised that these need to be compatible with NHS IT systems and Internet Browsers. AH confirmed that the new congenital system has been based on existing web based systems that are known to be compatible.

AH updated the group on a recent visit by the SwedeHeart Team., NICOR envisage transferring all the databases into an open source relational model although the time frame is still to be confirmed. The technologies underpinning the system enable more responsive reporting The Swedish team have offered to support NICOR in this work.

6. Surgical Algorithm changes: shunts, TGA-VSD-Arch obstruction, Norwood/hybrid, PA Band

RF/ DC advised the group of an increase in frequency of patients undergoing TGA, VSD closure and aortic arch repair at the same time. Previously the NCHDA had not reported due to small numbers but has now increased to approximately 50 procedures over 3 years. RF asked DC to look at the results and to feedback to the group to inform a decision on whether the procedure needs to go into a 'bin' or to place in 'low volume' group in PRAiS (probably would be added). There were some concerns that this would impact on the reliability of PRAiS. KB advised that it should be done now whilst PRAiS 2 is in development. The following queries were raised and it agreed that these should be an agenda item for the next meeting:

- Validity of using PRAiS to risk adjust against different time lines e.g. 60 and 90 days.
- Validity of using PRAiS to measure different outcomes

Action: AB/TWh

7. **NHSE Priorities: beyond 30 day mortality reporting**
Not discussed due to time restrictions and to be rescheduled at the next meeting.

8. **Data validation:**

8.1. Site and Remote validation issues 2013/14 data

LD confirmed that all paediatric and associated adult centres had received data validation visits. However it wasn't clear whether remote validation process had happened for several relatively small volume ACHD centres.

Post meeting note: *Remote validation took place between November and December 2014. DC prepared a spreadsheet of activity counts and 30 day death counts that were sent to the centres. LD confirmed that these had been sent between end of November/early December and all but Nottingham responded confirming accuracy.*

8.2. Data validation 2014/15 onwards

LD provided an update of the validation visits. The current schedule for data validation visits runs into November due to time taken to schedule and undertake the visits as well as accommodate annual leave over the summer months. The NCHDA is required to bring the reporting timeframe to 6 months from end of year (i.e. September) for the 2015/16 reporting period. This will bring the reporting schedule in line with the other national audits. The NCHDA HQIP deliverables support this by gradually reducing the publication time over the interim period. The key deadlines for reporting 2014/15 data are:

- Validation complete by the end of September 2015.
- Draft analyses, report and press release to HQIP by November 2015.
- NCHDA 2014/15 data published by January 2016.

LD thought it would be very difficult to expedite the visits and the schedule any further. Lin also advised that the visits and schedule will likely be longer for 2015/16 data as the dataset is 30% larger and diagnostic catheters and deaths are now included in the validation press.
LC advised that all visits should be completed by HQIP deadline and would liaise with LD after the meeting.

The SC agreed that the process needs further discussion and that the Data Validation working group need to resume the 1-2 monthly meetings. The group would also like to see a work plan and time line for validation 2014/15 data.
Action: AB/TWh

9. **Dataset changes**

9.1. Device related issues

Not discussed due to time restrictions but DC had largely resolved these during email correspondence

9.2. Unique procedure identifier

Not discussed due to time restrictions

9.3. Fetal Proposal

RF shared the proposed costs for the fetal dataset. The group discussed the project and associated costs and the following points were clarified:

- Indirect overheads are a regulatory part of developing costs and cover business activities such as HR and payroll.
- The proposal is part of the NCHDA strategy to develop the audit but there was uncertainty within the NICOR management team whether this is a new piece of work or a dataset extension similar to the IE dataset. The SC clinicians made it clear that in their view this was an extension and not a new database.
- Several organizations have expressed support but so far funding has not been sought. RF would like the project to be absorbed by existing NCHDA resources. LC agreed to take the proposal to the NICOR Executive.
  Action: LC
- RF raised the issue of access to analytical staff and felt that the audit had not received sufficient analytical time from ON due to being committed to other non-NCHDA work since early summer 2014 with no time allocation to the NHCHA. All 2010-10 and 2011-14 data analyses had been performed by DC. RF suggested that the NICOR development costs for the fetal dataset expansion could be funded from the NCHDA analytical time not utilised in 2014-15 to date. LC thought that that both DC and ON had provided analytical support but would look into the detail and clarify resource allocation for the next meeting. RF requested greater transparency and access to the NCHDA financial budget so as to review allocation and use of audit resources.
  Action: LC/TWh

10. NCHDA Audit Lead & DBM Meeting

RF confirmed that the meeting time had changed due to the simultaneous scheduling of the national Congenital Cardiology Clinical Reference Group meeting in Manchester, and was now scheduled from 15.00 – 17.30

11. AOB

There was no other business

12. Dates of next meetings:

Wednesday 17th June NICOR
Tuesday Sept 8th 2015 tbc
Tuesday Dec 15th 2015 tbc
Monday March 14th 2016 SCTS annual meeting