National Congenital Heart Disease Audit Steering Committee
December 15nd 2015,
13.00-15.30
Boardroom, Level 2, 1 St Martin's Le Grand, London EC1A 4NP

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
NICOR Chief Operating Officer	James Chal (JC)	COO NICOR Audits
Senior Audit Strategist	David Cunningham (Skype) (DC)	Senior Strategist for National Cardiac Audits, NICOR
Data Validation Officer	Lin Denne (LD) (Skype)	NICOR
BCCA ACHD representative	Kate English (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	David Anderson (DA)	President-Elect of BCCA, Consultant Cardiologist, Evelina Children's Hospital
NICOR Senior Analyst	Owen Nicholas (ON)	NICOR
NICOR Project Manager (representing Tracy Whittaker)	Anthony Bradley (AB)	NICOR
Congenital Database Managers Lead	John Stickley (JS)	Database Manager
Patient and public representative	Bob Ward (BW)	
Chair SCTS Congenital Sub Committee	David Baron (DB)	Birmingham Children's Hospital
Congenital Database Managers Lead	Thomas Witter (TW)	Database Manager, Evelina Children's Hospital
Project administration	Amber Wyatt	NICOR

1. **Apologies & Introductions**
   Tracy Whittaker and Nadeem Fazal. The group agreed that an additional patient representative was required as the NCHDA had only one patient and family representative for the last 4 meetings. TW to confirm that GB has been informed that he is no longer required given his non-participation for over a year.
   Action: JC/TW

2. **Previous minutes and actions**
   Minutes were agreed as an accurate account of the previous meeting held on September 22nd 2015. (Although noted that AT and KE were present and did not dial in as reported) Minutes to be amended and then posted on NCHDA Portal along with June 2015 minutes and backlog of RC minutes.
   Action: AH/TW

3. **2012-2015 final analyses: PRAiS and procedure funnels**
   3.1. In the absence of an updated HQIP outlier policy, the NCHDA continued to use the 2011 DH outlier policy. RF highlighted that the BCS related document (Maintaining Good Clinical Practice – Handling of Potential Consultant Outliers) was published in November 2015 and had been circulated to SC, noting that it was aimed largely at supporting individual interventionists or surgeons with only a few lines suggesting that 'Team' outcomes may assume similar Societal support.
   3.2. There were no centres who were outliers on overall activity (PRAiS analysis) in the 2012-15 analysis. There were two specific procedure outliers (Evelina London Children's Hospital for Norwood procedure and Liverpool Heart and Chest for surgical ASD closure in adults (1 death).
   3.3. 90 day outcomes. Members had agreed to add as extra column on tables but not to analyse for outlier status due to the lack of a risk model in terms of a PRAiS analysis, and lack of confidence in the accuracy of life status due to ONS coronial reporting of death issues, ruling out 90 day comparative reporting on individual procedures.
   3.4. The audit did not publish provisional figures on the NCDA portal this year as is the usual practice. Given the imminent publication of the report it would no longer be worthwhile publishing provisional data. 2013-16 provisional findings will need to be by end of August 2016 at the latest.
   Action: AH
   3.5. DC agreed to provide a table of all procedures and outcomes to be included in the 2012-15 report.
   Action: DC
   3.6. The group agreed that formal Recommendations should be included for the first time in the NCHDA annual report as requested by HQIP. These would be directed at Specialist Commissioners and provider Chief Executives, Medical Directors and Clinical Leads, and Congenital Cardiology Clinical Audit Teams. The recommendations should focus on participation in the audits, including monitoring participation, providing necessary resources and attention to data quality, importance of MDT input into entering data to ensure accuracy and using the data for monitoring quality of CHD services.

4. **Project updates:**

   4.1. Professional Liaison Group update

   There was an update from the last Professional Liaison Group Meeting held on 14 November 2015. The key discussion points relevant to NCHDA were:

- There was a discussion about the overarching reporting structure, governance arrangements and process for NICOR. John Deanfield (JED) had explained the proposal to set up an Oversight Board for NHS activities performed by NICOR. His hope was that there could be two streams of management in future, the new Oversight Board and the other UCL stream which would cover University academic grants and the industry funding stream.
- JED confirmed that JC was working on the future plans for the 2017-22 HQIP bid. He said that NICOR would need to be creative in finding ways to fund new projects in future as there would be less funding in the new contract.
- There was a discussion about lack of in-house analyst support and delays caused by this. John Parkinson (JP) advised the situation was being addressed but said that the UCL HR process can take up to 6 months.
- Simon Ray from BCS asked the group to review the new BCS Outlier Policy (see 3.1), which provided guidance on the proper response for an individual where there were any concerns, either as an individual or as a member of a wider team. The group agreed the document was very good. David Jenkins suggested that there needed to be liaison with HQIP so the HQIP Outlier Policy didn't contradict the BCS policy. It was also suggested that potentially the BCS policy could be disseminated through NHS England. JP said that NICOR wanted to ensure that individual data and units' data could be used more locally to prevent alarms. It was suggested that following David Spiegelhalter's analysis work he could be approached to provide independent oversight on an ongoing basis. JP had agreed to do this.
- Nadeem Fazal (NF) had circulated an IT update ahead of the meeting. The aim was for BCIS to be the first to be clear of Lotus Notes and using the web platform, before rolling out across all the audits in a phased approach. This was being carried out in parallel with work with a team from UCR in Sweden. An issue was raised about the focus on case ascertainment to the detriment of data quality and it was agreed this should be looked at in more detail.
- JC confirmed that the audit lead job description had been circulated to the NICOR Executive but not formally discussed. SC confirmed that the professional societies would be putting names forward for the roles, and NICOR and the societies would work together in appointing the leads, rather than advertising the positions. Some different models of working were discussed and the issues were carried forward to be discussed at the January PLG meeting.

4.2. NICOR update:

JC provided the following update:

- HQIP contract: the current HQIP contract ends Mar 2016 and NICOR is in the process of agreeing deliverables for the contact extension for 2016/17. NICOR has been notified that the overall HQIP budget has shrunk by 20% and this is expected to be reflected in the NICOR budget. Efficiencies need to be made across the programme of audits and we are working towards a more efficient model of working across teams to deliver support to the audits.
- NICOR is in the process of recruiting to the following posts: project manager, 2 information analysts and a project coordinator. NICOR has also recruited a temporary administrator to support the project management team. NICOR must also work smarter and harmonise work streams across the programme of audits.

- JC confirmed that the clinical audit lead jobs will be advertised on the professional societies' websites for transparency. NICOR will also be setting up a Clinical Audit Lead Group to share best practice amongst the clinical audit leads. John Deanfield is setting up meeting with all Clinical Audit leads to discuss role and responsibilities. RF will be meeting JC and JD In January.
- The group would like reassurance that resources are allocate fairly across the programme as some felt that the NCHDA had been under resourced over the past 12 months, in terms of Project Management time and longer term for the 0.5WTE analyst time the NCHDA is supposed to have. JC confirmed that he was working on the financial report and will provide an update at the next meeting.

4.3. Project update

4.3.1. 15/16 project plan.

TW circulated draft 15/16 project plan for review. The group confirmed that the first harvest of 2015-16 data for outliers would be first week July. Centres will need a breakdown of dates and requirements for checking data quality. RF confirmed that the validation visits would be similar to 2015/16 and to complete by November 2016. JC advised that the validation time frame should be shortened so that reporting could be in line with NHSE requirements. NHSE, NICOR and members of NCHDA professional society representatives are meeting in January to discuss further .JC will confirm date in due course.
Action: JC.
Update: Meeting took place 27/01/16 meeting and agenda item for March NCHDA SC.

4.3.2. Version 5.01 NCHDA dataset issues

The following issues relating to Version 5.01 NCHDA dataset were discussed:

- Devices: A database manager has recommend that NCHDA should follow the format use by NACSA and PCI audits by providing drop down list. SC members agreed to have a list of valves/devices into dataset using NACSA list and be included on 2017-18 data set update depending on data quality of current 2015-16 data.
- Unplanned reoperation within 30 days requires a definition.
  Action: RF

4.3.3. Patient survey

CM and BW agreed to create 'lay version of info for Portal.
Action: CM and BW

4.3.4. 16/17 Analytical time

ON priorities are to look at HES data and automating funnel production. Key priority is to establish ON analytical input and commitment for 2016/17. **Action: JC**

4.4. Web enabled platform update

AH reported that the web enabled platform will be ready for testing in February. TW and JS offered to act as pilot sites for Beta Testing. JS asked AH to distribute the specification for the browser as this will be biggest challenge for centres.
Action: AH

4.5. HES and Life status update.

RF and DC will look to use ICD-10/OPCS coding structures to look at ACHD non submitters via HES analysis. The previous work undertaken by NHSE (Jo Glenwright (JG) with RF input) will be an initial template - NHSE built their CHD report on this work and JG may be able to share final methodology with the NCHDA. RF agreed to contact JG/NHSE.

Action: RF, JG and DC

4.6. NCHDA Patient and family Day update

Following the low number of response to the patient survey, AH looked at user figures for the NCHDA portal. AH – half people spend less than 10 secs on page, only 43 out of 2000 spent more than 30 minutes. CM and BW to help create a lay version of info for Portal.

5. Data validation

Covered in item 4.3.1

6. NHSE review (objective 5 paper)

NHSE review Option 5 paper was circulated ahead of the meeting

6.1. 2015/16 data analyses

90 day and additional coverage. See above. Until the concerns on ONS reporting of life status are resolved, this will not be possible but should be kept under review.

6.2. Adult CHD outcomes

Work on developing an adult risk model is dependent on the availability of data from the new dataset fields introduced in April 2015, which won't be available until July 2016. The NCHDA research committee have set up a working group to 1) review interim approaches and 2) plan development of risk modelling work when data is available. The first meeting has been arranged for late January 2016 (KE,ON,RF).

6.3. Antenatal outcomes

Expansion of the fetal dataset will be key to outcome by diagnosis. RF reported that Tiny Tickers may still be able to help fund the development of the dataset. JC agreed to look at current resources with the view to implementing the fetal extension in April 2016.

7. Infective endocarditis audit.

DC agreed to undertake initial analyses of IE data to review the value of data collection. Depending on outcome, the IE dataset may be dropped from April 2016 onwards. Decision regarding continuation of IE data collection to be agreed at NCHDA SC March meeting. TW to add to agenda.

Action: TW

8. Data sharing NCARDS

The group were notified that NCARDS has submitted an application for PID NCHDA data via the NCHDA research committee. The group agreed in principle but had a number of queries regarding the application and RF will liaise with Michelle Griffin to discuss.

Action: RF

9. International comparisons

Item was postponed until March or June meeting due to time constraints.

10. AOB

On behalf of the NCHDA SC, RF expressed sincere thanks to Thomas W for his contribution to the audit over the last 5 years.

11. Next meeting

- March 15th SCTS Meeting, ICC Birmingham.
- June 21st venue tbc
- September 12th venue tbc
- December 13th venue tbc

ACTION SUMMARY

Number	Action	Owner(s)
01	The group agreed that an additional patient representative was required as the NCHDA had had only one patient and family representative for the last 4 meetings. TW to confirm that GB has been informed that his participation is no longer required.	JC/TW
02	2015-16 provisional data for procedures and Tables for the NCHDA portal should be uploaded by end August 2016.	AH
03	NHSE, NICOR and members of NCHDA professional society representatives are meeting in January to discuss shortening time frame for deliverables so that reporting could be in line with NHSE requirements .JC will confirm date in due course. **Update: Meeting took place 27/01/16 meeting and agenda item for March NCHDA SC.**	JC
04	Version 5.01 NCHDA dataset **-** Unplanned reoperation within 30 days requires a definition.	RF
05	CM and BW agreed to create 'lay version of Patient Survey info for NCHDA Portal.	CM/BW
06	ON priorities are to look at HES data and automating funnel production. Key priority is to establish ON analytical input and commitment for 2016/17.	JC
07	JS asked AH to distribute the specification for the browser for the web enabled platform as this will be biggest challenge for centres.	AH
08	RF and DC will look to use ICD-10/OPCS coding structures to look at ACHD non submitters via HES analysis. The previous work undertaken by NHSE (Jo Glenwright with RF input) will support this work. RF agreed to contact JG/NHSE to ask if JG can share the final methodology with the NCHDA.	RF/JG/DC
09	DC agreed to provide a table of all procedures and outcomes to be included in the 2012-15 Annual report.	DC
10	Decision regarding continuation of Infective Endocarditis data collection to be agreed at NCHDA SC March meeting. DC to do initial analyses of data collected to date to inform decision. TW to add to agenda.	DC/ TW
11	RF to liaise with Michelle Griffin to discuss NCARDS PID data sharing application.	RF