National Congenital Heart Disease Audit
Research Committee
June 10th 2014
10.30-12.30
Cruciform Foyer 101
Seminar Room 1

Notes

Attendees:	
Rodney Franklin (chair)	Consultant Paediatric Cardiologist at Royal Brompton Hospital
David Barron	Consultant Congenital Surgeon, Birmingham Children's Hospital, Chair SCTS Congenital Subcommittee
Kate English	Cardiologist, Leeds General Infirmary (BCCA and ACHD)
Chuck McLean (CMcL)	Cardiac Surgeon, Royal Hospital for Sick Children, Yorkhill, Glasgow (representing SCTS)
Serban Stoica	Consultant Cardiac Surgeon University Hospitals Bristol NHS Foundation Trust (SCTS)
Rob Martin	Paediatric Cardiology and Adult Congenital Heart Disease (BCCA President)
Andrew Harrison (AHa)	Developer NICOR
David Cunningham	Senior Strategist for National Cardiac Audits (t/c)
Owen Nicholas	Analyst NICOR
Tracy Whittaker (TWh)	Project Manager NICOR
Apologies:	
Alan Magee	Consultant Paediatric Cardiologist , University Hospital Southampton, BCCA Representative
Thomas Witter (TWi)	Cardiac Data Manager Guys and St Thomas
Andreas Hoschtitzky (AHo) (SCTS)	Consultant Paediatric Cardiac Surgeon Alder Hey Children's Hospital Liverpool UK (SCTS representative)
Kate Brown	Consultant Intensivist, Research & Outcomes Lead

1. **Apologies**
   Alan Magee, Kate Brown, Thomas Witter, Andreas Hoschtitsky

2. **Previous minutes and actions (RF)**
   Paper A
   Section 3.2: It was agreed to amend the wording to reflect that charges are a NICOR policy to be implemented across the audits.
   Action: TW
   Section 3.1: The application to access NCHDA data for a MSc was rejected in December meeting but the RC asked for an update on progress as it had been thought that NICOR may be able to offer supervision on a similar project. Update: Chris Gale, NICOR Research Exec Lead is currently offering supervision on a non-congenital project.
   Action: TW

3. **Updates on in-house/NHS England projects**
   3.1. An update version of the NHS England analysis was summarized by ON. The results show that ethnicity is the only factor of statistical significance and Asian

population 1.2% greater risk than otherwise expected. There was no indication of a relationship between 30 day outcomes and other factors. Each of the factors were discussed in isolation.

3.2. Analysis is based on 2009/12 data and it was agreed that extending analyses to 2010/13 would be informative.

3.3. Ethnicity: The level of missing data from centres was low so DC populated with linkage to HES. There was a discrepancy in DC figures for Asian group (3,000) and ON (1,500). DC and ON agreed to review. It was agreed to describe ethnicity within each unit. The group discussed excluding HSC as this would bias the results due to high number of overseas patients treated. As PRAiS had benchmarked using HSC there was some concern that excluding HSC from the analysis would compromise the validity of the results but ON thought this was not the case.
Action: DC and ON

A more detailed analysis of deprivation and ethnicity is planned for the autumn. This is part of the NICOR in-house research schedule and is a separate piece of work and not part of the NHSE work. ON confirmed that an analytical protocol this work is in draft format and currently with RF and KB for comment.
PRAiS is not due to be updated until Spring 2016 and the RC agreed that CORU should be advised that ethnicity will need to be built into future recalibration.
Action: RF/KB

3.4. Deprivation: There was a high level of missing data and whether the Welsh, Scottish and Republic of O accounted for the 30% missing data reported. DC advised the group on the relative advantages and disadvantages of the two different scoring systems. The Townsend score is designed for use across the UK but DC does not want to use it as it overestimates in urban areas. The group agreed that if deprivation is not an associated factor within England then it is not worth spending time seeking a solution for the other UK countries. It was agreed that the report should be updated to include information on the % of patients included in the analysis, as well as the IMD scores used in analysis.
Action: ON

3.5. Distance. The group agreed that the figures relating to distance looked inaccurate and didn't reflect known information from clinical practice. DC agreed to check but it was also agreed that this would not change the results.
Update: DC found that the distance was out by a factor of 10 and he would update the documentation. The results are the same, i.e. distance is not a discriminating factor to outcome as analysed here.

3.6. Volume: ON described how volume could be approached in two different ways: log linear and doubling volumes. ON applied a log-linear approach as nationally, the policy focus nationally is based on the premise that higher volume better outcome. It was agreed that ON would do both analyses and include a chart with volume (x axis) and associated risk (y axis).
Action: ON

3.7. Weekend: The group agreed that a comparison of weekday and weekend/out of hours outcomes is not possible at the moment due to limitations of the dataset. This needs to be considered when the dataset is reviewed over the summer.
Action: RF

3.8. NHS England report: a high level report is required this week which TW will discuss with Jo Glenwright.
Action: TW

4. Terms of Reference

The draft Terms of Reference were reviewed and the following points discussed:

4.1. Qualification of membership: The suggested membership roles were agreed with the requests that an additional Interventionalist is included. RF will contact BCCA. It was agreed to save the patient and public representative discussion to the SC. All agreed that a deputy was needed for the RC.

4.2. End of membership: The group raised concerns that Alan Magee had not attended in a while and that according to the draft ToR, is membership should cease. TW agreed to confirm attendance from previous notes and RM agreed to contact AM to discuss.

Action: TW and RM

Update. AM confirmed at BCCA Council that he wanted to continue in this role and would ensure he attends future RC meetings

4.3. Structure of partnerships: A paragraph describing rules of engagement for Committee members is needed in addition to the reference about overarching policies and NOCOR SOP. For example, SC members cannot discuss detail/discussion with stakeholders and colleagues before sign off by the SC. The ToR also needs to state that three representatives of the Research Committee also attend the SC.

Action: TW

5. Data requests (TW)

5.1. 14_CONG_05:

RC responses were supportive although there was a query about providing center specific data. Although pseudonymised the center could be extrapolated by cross referencing with procedure activity published on the portal. TW also suggested that two applications may be needed but the group agreed that one would suffice. The group approved the study.

Action: TW

5.2. The group discussed the potential situation where a research study indicated divergence between centers, especially if centers could be names by cross reference with the portal. The group agreed that this will need to be addressed but it should not restrict data sharing .The group felt that researchers should be duty bound to report any results that indicate divergence of clinical performance or quality assurance issues.TW highlighted that all draft manuscripts should be submitted to the RC but this is difficult to monitor. TW will discuss with JS to see if this is covered within the new Data Sharing policy.

Action: TW

5.3. Ongoing requests: Summary update:

Not covered due to time restrictions

6. Charges

6.1. TW provided summary of the proposed charging structure. NICOR are required to support data sharing process as part of the contractual deliverables but is not included in the current funding which is specifically for audit purpose. To ensure audit resources are not used inappropriately, a charging framework is required to cover the administrative costs. The proposed charges have been discussed at the Research Executive group and the Professional Liaison Group and have not yet been signed off but a decision is due shortly. The group were supportive of the principal that audit finds should not be used to

support research. There were a few queries about the detail and it was agreed to delay the discussion until the SC, where JS would be in attendance.

7. Update from NICOR Research Executive

7.1. TW provided an update on behalf of KB for the NICOR Executive. The main discussion focused on proposal for updating the NICOR data sharing process which included items on a draft charging framework , standardizing the approval process by introduction of an assessment framework, use of one central approval process whereby all applications to go to the Research Executive. Discussions are ongoing and there have been no decisions as yet regarding charges and the central approval process.

8. Project Updates

- Reoperations project (SS)
  Outcomes for valve: AVR data good and ready for publication other elements of the data need further work. SS and DC have liaised about how to get the updated data. DC will provide a translation form that will go to the database manager who will then amend and reimport back into NICOR. In addition, SS will ask centers to check pre 2000 data to update on misclassification . NICOR will send out the emails on behalf of SS.
  Action: SS/TW
- Long term outcomes of Fallot and Switch (AH)
  This was not discussed as AH was not at the meeting.

9. Analyst time (TW)

9.1. In response to recent frustrations about access to analytical time, TW set out the current arrangements within NICOR. ON is contracted for 0.7 WTE within NICOR and currently works on congenital 0.4 WTE. There is no specific budget for each audit so all staff work across the programme of audits and there are currently 3 WTE analysts for 6 HQIP audits. In addition to ON, the NCHDA also has some of DC time to support analytical work. The RC made it clear that they were very supportive of ON but disappointed that he had not been given enough time to deal with NHSE RC work or HQIP deliverables, such as 2009-12 and 2010-13 aggregate PRAiS mediated centre outcome analyses, due to work for other audits.

10. Bypass time

DB reported that the SCTS were still discussing whether Bypass analysis is a useful metric for future publication.

11. Representation at future meetings: KB and KE

It was agreed that there would not be a need to identify deputies for KB and KE as they would only miss one meeting.

12. Next meetings:

NCHDA Research Committee:	September 30th December 2nd March 23rd 2015 (Manchester) June 17th 2015
NCHDA Data Validation Review working group	July 4th 4-5 August 1st 4-5

13. AOB : There was no other business.