Congenital Steering Committee
June 10th 2014 1.00-16.00
Cruciform Foyer 101, Seminar Room 1

Minutes

Role – representation	Name	Title - place of work
NICOR Congenital Clinical Lead – Chair	Rodney Franklin	Paediatric Cardiologist, Royal Brompton Hospital
Chair SCTS Congenital Database Subcommittee	Chuck Mclean	Congenital Heart Surgeon, Royal Hospital for Sick Children, Glasgow
President BCCA	Rob Martin	Bristol Royal Hospital for Children
Chair SCTS Congenital Sub-Committee	David Barron	Birmingham children's hospital
BCCA ACHD representative	Kate English	ACHD Cardiologist, Leeds General Infirmary
NICOR Chief Op Officer	Julie Sanders	COO NICOR Audits
Senior Audit Strategist (t/c)	David Cunningham	Senior Strategist for National Cardiac Audits, NICOR
NICOR Project Manager (Congenital)	Tracy Whittaker(TWh)	NICOR
NICOR Congenital Audit Developer	Andy Harrison	NICOR
National Clinical Audit Service Manager	Nadeem Fazal	NICOR
NICOR Senior Analyst	Owen Nicholas	NICOR

Apologies

Kate Brown, Thomas Witter, Lin Denne,

1. **Previous minutes and actions:**

1.1. The SC minutes were agreed as an accurate record of the meeting.

3a. TWh gave an update on the NICOR Open day which was well attended. There was much interest in the programme of audits and how this fits with other NHS work. Feedback on graphs and charts was very constructive and a number of attendees expressed an interest in becoming more involved with the audits which we are following up. Carol Porteous, the NICOR Patient & Public Engagement Coordinator will be producing a report which TWh will circulate when available.

4: CM to circulate Scottish policy on dealing with death data without ONS to the steering group: CM has circulated the policy to RF who will now circulate to the committee.

Action: RF

1.2. The Stakeholder minutes were agreed as an accurate record of the meeting.

The SC agreed it was unnecessary to have more than one stakeholder meeting a year and this will take place each year on the Monday preceding the March annual

SCTS meeting.

2. Terms of Reference (ToR)

2.1. The group agreed to the ToR with the following amendments:

- An additional interventionalist is required as chosen by the BCCA. RM will consider and inform SC before the next SC meeting.
  Action: RM
  Update: BCCA Council asked Dr Andy Tometzki from Bristol Children's Hospital to be a member of the SC in this role at their 24.06.14 meeting. He has agreed.

- Patient representative: The SC thought it more appropriate to have a lay representative rather than a patient or family member on the steering committee but would support the NICOR policy of recruiting a patient and/or family representative.

3. Annual analysis update:

3.1. Update on publication of procedure funnels (RF)

3.1.1. Feedback about the funnels highlighted the following:

- Names: there needs to be naming consistency as specific hospitals and their abbreviations are not always clear. It was agreed to go with the following convention within reports: [name of town], [name of hospital.].
- DC reminded the SC of the chances of a false positive outlier (see 3.3.2 below). The SC asked that a statement be provided alongside the funnels to add this extra information. DC and CMc offered to draft a statement. In addition, all agreed to review the portal text with reference to the Funnels before publication on June 30th, sending comments to TW.
  Action: DC/CMc to draft statement
  Update: Publication delayed until late August due to decision to publish all 2010-13 analyses together, i.e. inclusive of aggregate PRAiS related analysis too. Further delay due to ON time availability.

3.1.2. The SC reviewed the report submitted by Bristol in response to the outlier letter. It was a comprehensive response but more detail was felt to be needed on what actions had been taken locally. JS highlighted that from a NICOR perspective, one of our requirements is to support local improvement, one way would be to provide guidance and advice on how to use the data including what to do in the event of an outlier being detected locally. A template setting out the information required in a response report would be useful e.g. local actions in response to the findings, how many operators involved, conclusions of mortality meeting, etc). Consideration also needs to be given to the key roles that should be involved in writing and sign off the report.
Action: DB/CMc/RM to produce draft of requirements for response to potential outlier status by Specialist Centre

3.1.3. The group discussed what happens to the reports that are submitted to the SC. RF confirmed that for centres meeting the green line, copies are kept by NICOR and the professional societies. The NICOR Professional Liaison Group has agreed that letters should be sent jointly from NICOR and involved professional society(ies). Following a teleconference with SCTS members, JS reported that TG felt it was inappropriate to be a cosignatory on outlier letters if not part of the process. At that time he felt that the SCTS needed to be involved earlier in the discussions regarding congenital outliers if they were going to be signing the letter. However, at the end of the teleconference the consensus agreement was that the SCTS with BCCA would sign off the NICOR letter but

also send their own separate one.
Update: in the end NICOR alone is currently signing letters pending further discussions between SCTS & NICOR scheduled for 29 Sept 2014.

3.1.4. JS highlighted that as part of the data validation, consideration would be given to a remote method for data validation whenever this was possible. For example, in adult cardiac surgery, centres are sent 3 iterations of analysis and then sign off. Consideration will be given to adopting a similar approach within NCHDA, particularly for ACHD centres. The main concern for paediatric centres is for case ascertainment which should be 100% nationally, whilst we know that ACHD is at best 80% due to non-submission by several centres.

3.1.5. As part of HQIP SRP all published reports and analyses need to be submitted to HQIP for review. TW will circulate a publication work plan to the committee. Following the advice of JS, the group agreed that a press release is required. TW will draft and circulate to the groups for review and sign off by the end of the week.
Action: TW & then All

3.1.6. All centres should be notified that the results have been published. CMc suggested that all centres should receive a letter from the SC that can be circulated to everyone in local teams and he had previously emailed a draft. The letter should provide information on the number of procedures undertaken over the last three years and in general should have a positive tone given the very few outlier centres for individual procedures.
Action: TW/RF/CMc

3.2. Summary report

3.2.1. There was some discussion around the name of the audit. The group would like to be referred to as National Congenital Heart Disease Audit, as is in NICOR documentation such as the NICOR structure diagram sent to PLG and others over the last year. This name has already had wide usage amongst stakeholders. JS however thought that it might need to be in line with the HQIP contract, although this had not been discussed with the SC. JS agreed to raise the issue with HQIP.
Action: JS

3.2.2. The following changes were agreed:

- Further work is needed on the introduction to give it a more positive spin. CMc agreed to update the section.
  Acton: CMc/RF
- Note that the term ‘procedures’ covers transcatheter interventions, rhythm related interventions and surgical operations.
- Provide the number of surgical, transcatheter and rhythm related intervention procedures for the UK and RoI.
- Use the term predicted survival rates instead of mortality or expected survival rates
- Remove section on quarterly updates and change to annual updates with Tables and Funnels frozen for the year, unless found to erroneous. This needs to be explained.
- In the Research section: include all authors on the references.
- Provide an update on dataset changes
- Refer to Lin as Clinical Data Auditor.

3.3. PRAiS mediated reanalysis: 2009-12 and 2010-13 dataset (ON)

3.3.1. ON provided a preliminary summary report of the 2009-12 analysis. ON will update the report with funnel plots using methodology agreed in September 2013 and additional text. Analysis shows there are no outlier units at 2 sided 95% level (97.5% green warning line, 99.9% red alert line).

3.3.2. The SC discussed current confidence limits. DC reminded the group that the risk of a spurious false positive is higher as the number of centres decreases. The audit uses 98% and 99.5% confidence intervals for the funnel plots to generate roughly a 1:40 and 1:1000 risk of a false positive. However HQIP 'recommend' using $p<0.05$ (2 sd), which even if we only look for negative performance (one sided test) has a 22-59% risk of a false positive with so few centres. We have therefore used a two sided 95% prediction limit within the NHSE report. The committee agreed to use the two limits within the funnel plots (99% and 99.9%) and 3 limits within the tables in the NHSE reports (95%, 99% and 99.9%). For published analyses it was agreed these need to be consistent across all analyses e.g. PRAiS and Specific procedures. It was agreed to continue with the current levels but to include a statement that states the risk of false positive outliers at each confidence level.
Update: this decision was superseded and only 2 levels published following HQIP guidance at 2 and 3 SDs (2 sided 95% & 99.9%).

3.3.3. JS reminded the group of the HQIP outlier policy advised on using 95% confidence level. The current outlier policy is out for consultation and there is an HQIP workshop meeting on June 30th to discuss. Guidance may change and the audit will need to comply with the guidance in next year's analyses. This is a HQIP meeting and all clinical leads are expected to be invited. JS is attending and all agreed it was important to have a statistician at the meeting.

3.3.4. The next stage is to provide 2010-13 aggregate analysis. ON reminded the group of 2013 discussion with David Spiegelhalter about factors taken/not taken into account by the PRAiS model. There is now an opportunity to think about future approaches. All agreed that consistency was important especially when both analyses are going to be published as part of the same report. ON will undertake 2010/13 analysis using PRAiS but will also review alternative methods for subsequent aggregate analyses in due course.
Update: DC performed both 2009-12 & 2010-13 analyses

3.4. Antenatal diagnosis

The analysis provided by DC was well received were happy for it to be uploaded onto the portal, once an explanatory text had been signed off by the SC (email consultation).
Action: KE/DC

4. NICOR update

4.1. HQIP: JS has contacted HQIP to identify the internal process and key personnel involved on the Standard Reporting Process and will update in due course.

4.2. Contract review: HQIP have reduced the contract review meetings to twice a year which are scheduled for July 17th 2014 and January 14th 2015. RF is unavailable in July and a clinical representative is needed. The SC clinical members offered to look at their availability.
Action: RF
Update: CMc agreed to be there and represented the NCHDA

5. Project update

5.1. Data validation:

5.1.1. **2013/14 schedule of visits and update**

Apart from a couple of centres, the schedule of validation visits for all paediatric centres will be completed by October. Analysis will take place in December. LD had reported that centres had worked to meet the revised schedule and she wanted to express thanks for their help and cooperation.

5.1.2. **Validating date of death**

RF confirmed the following position relating to hospital and ONS mortality status. Previously ONS 'alive' status supplanted hospital death status but we now know that delays in coroner inquests can lead to discrepancies. From March 2014, the hospital reported 'death' will not be superseded by ONS 'alive' status and any discrepancies will be investigated.

As a result Validating Date of Death is now required as part of the data validation visits. RF and LD have proposed that this could be provided by a discharge summary. Rhian highlighted occasional cases where the specialist centre won't know about the death for some time; e.g. transferred to a different centre. TWh is supportive of validating this data item but would like more formal guidance on the process. In addition it was agreed that the procedure and diagnosis would be checked for all deceased patients using a discharge summary or similar (the notes themselves do not need to be checked). This is to ensure that the data submitted has been correctly coded by the centres before submission, i.e. not just a crosscheck that data submitted has been correctly received by NICOR. This exercise is aimed at minimising false positive outliers being identified, which turn out to be due to erroneous coding by the centre or an algorithm issue at NICOR (as happened to three centres this year). This will require parent/patient consent as should occur for all patients to enable validation; when missing the centre's MD may be required to sign a disclaimer allowing this patient level data to be checked.
Action: RF/LD to email centres to this effect.

5.1.3. **Data validation working group update (TW):** TW will circulate the minutes as there was insufficient time to cover this item.

5.2. <u>ONS/HES mortality status</u> (DC):

The suspension of the ONS mortality tracking service continues. DC has tried several times to get this addressed and has been escalated to Bruce Keogh and Huon Gray (National Clinical Director for Heart Disease). JS will find out more on June 11th. The SC was concerned as this is a risk to child safety if survival rates cannot be monitored in a timely manner.

Update: ONS have agreed to resume their tracking service to NICOR.

5.3. Technical development work: NF and AH gave an update on the planned work scheduled over the next 6 months:

- The NCHDA database will be web enabled and work will start, following consultation with the centres with completion by December 2014.

- The congenital portal will be updated to take advantage of the new technology. As part of this work NICOR will host a meeting to seek feedback from families about how they would like to see information presented. A date is yet to be scheduled but is expected to take place in the autumn. CMc asked if the portal could have its own direct link as opposed to the 3-4 steps currently required. The SC agreed that this would be optimal.
  Action AH

- Technical issues: Unique identifiers: a centre has been validating the 2013-14 data and found some cases where diagnoses, procedures and comorbidities have been submitted, but not showing on Lotus Notes or the reverse download. Validating the procedures/diagnoses is difficult as they download in a different order to submission. AH established that this was down to local centres using replica databases. This is now resolved.

- Merging hospital data into Trust data. TWh has requested that Evelina's Children's Hospital data and the ACHD data be merged as CHD activity now all takes place at the St Thomas' site, to give a complete and unified picture of the Trust's congenital activity in one place. There was some support for this approach as some units do have both ACHD and paediatric activity at the same site and report together; e.g. RBH and LGI. However, DC continues to be opposed to this policy given retrospective governance issues for the Trust. DC highlighted that the Unique Identifier issues as one that is compromised by submitting multiple site data under one code. The Committee agreed to give this some thought and this will be discussed at the next SC.
  Update: This has now been resolved in principle. The technical team are checking potential options for merging data.

5.4. Project plan: There was insufficient time to cover this item but TW will circulate a summary report.
Action: TW

5.5. Communication: RF and TW have met to discuss how communication could be improved between NICOR and SC. In addition to including project updates at the SC meetings, TW will distribute highlight reports on a quarterly basis.

6. Specialist commissioning dashboard (RF)
RF has been asked by the Specialist Commissioning Board to complete and submit a form designed to assess the suitability of the NCHDA data for use in dashboards. This requires some background information from NICOR, which TW will complete.
Action: TW

7. Dataset revision

7.1. A number of additional fields need to be added to the dataset to ensure it captures information appropriate for adult cases. Definitions of inclusion/exclusion criteria between NCHDA, PCI and adult cardiac surgery need to be agreed and outcome captured in the new dataset. Changes need to be signed off at the September SC to be implemented by April 1st 2015 as there is a 6 month lead in time for third party suppliers. It was agreed to start the process via email discussion but also to have a face-to-face/Skype meeting(s) to help finalise the draft before submitted to SC, for September sign off. TW will set up a meeting for the end of July.
Action: TW

7.2. There may be a need to modify / remove the specific procedure category of Arterial Shunt due to the heterogeneity of the underlying cardiac anatomy with linked variance in outcomes. It was agreed to discuss this further via email. As part of this DC agreed to look at the various diagnoses and outcomes in further detail. AH asked if PRAiS was developed on all specific procedures, and sought clarification on whether removal of Shunt would impact on the validity of the tool. RF would check with KB.
Action: DC/RF

7.3. Validation rules for the existing and new dataset are required. TW will circulate this along with the NCHDA, PCI and adult cardiac surgery datasets.
Action: TW

8. Representation at future meeting: KB and KE: There will be no need for deputies as both representatives are likely to only miss one meeting.

9. Next meetings:

9.1. NCHDA Steering Committee:

September 30th
December 2nd
March 23rd 201(Manchester)
June 17th 2015

9.2. NCHDA Data Validation Review working group

July 4th 4-5
August 1st 4-5

10. AOB