



# Minutes

Meeting Name: NCHDA Steering Committee

Date: 20<sup>th</sup> June 2017

Venue: NICOR head office

Time: 2:15pm – 4:45pm

Time allocated: 2 1/2 hours	Facilitator's name: Rodney Franklin
Minute Taker: Shenaka Singarayer	No of guests: 15

Persons in attendees		
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
BCCA ACHD representative	Kate English(Skype) (KE)	ACHD Cardiologist, Leeds General Infirmary
President BCCA	David Anderson (DA)	President-Elect BCCA, Consultant Cardiologist, Evelina Children's Hospital
BCCA Interventional Representative	Andy Tometzki (AT)	Consultant Paediatric Interventional Cardiologist
SCTS Congenital Audit Lead	David Barron (DB)	Birmingham Children's Hospital
Congenital Database Managers Lead	John Stickley (JS)	Database Manager, Birmingham Children's Hospital
Patient and public representative	Bob Ward	
Chair SCTS Congenital Sub Committee	Carin Van Doorn (Skype) (CVD)	Congenital Heart Surgeon, Leeds General Infirmary
NICOR Chief Operating Officer	James Chal (JC)	NICOR
NICOR Congenital Audit Developer	Andy Harrison (AH)	NICOR
NICOR Information Analyst	Jiaqiu Wang (JW)	NICOR
NICOR Senior Project Manager	Tracy Whittaker (TW)	NICOR
NICOR Project Manager	Sarah Ajayi (SA)	NICOR
NICOR Project Coordinator	Shenaka Singarayer (SS)	NICOR

## AGENDA

1. Present and Apologies
2. Minutes of previous meeting: outstanding action points not on Agenda (RF) Paper 2.0
3. NICOR update Paper 3.0
  - a. Latest NICOR structure, operational changes (TW/RF)
  - b. ONS and linkage update – new 2017-18 agreement (TW/AH)
  - c. PLG update and future SC meetings (RF/TW)
4. NCHDA 2013-16 Report and Press Release Paper 4.0 and 4.1
  - a. Response to latest feedback from NHSE/BK/HQIP
  - b. Final sign off time line and further actions required
  - c. Portal update on 13 July 2017 (SA/AH)
5. NCHDA updates
  - a. Validation visits 2017-18 (LD/TW/All)
  - b. Transfer of analyses methodologies, including data cleaning (SA/JW)
  - c. Portal upgrade plans (JW/NF)
  - d. ACHD report project and use of STS risk stratification model (JW/KE/SA/RF)
6. Technical update Paper 6.1
  - a. Congenital web rollout – update (JS/MS/AH)
  - b. Data manual (JS)
  - c. Data Quality Guidance (TW)
  - d. Fetal database – update (MS/JS/RF)
7. AOB Paper 7.0
  - a. Life Status issues in Scotland (RF/CMc paper)
  - b. Next meeting dates.  
September 2017  
December 2017

## Summary of Discussion:

1. Present and Apologies.  
Apologies had been received from Lin Denne (LD), Kirsten Windfuhr (KW) and Tasneem Hoosain (TH)
2. Minutes of previous meeting – outstanding action points not on Agenda (RF)  
Draft minutes of the previous meeting held on 14<sup>th</sup> March 2017 were agreed with slight modification to look at the 90 day summary report and sign off minutes.

### 3. NICOR update

#### a. Latest NICOR structure, operational changes (TW/RF)

JC said the National Cardiac Audit (NCAP) had been signed off by HQIP to start on the 1<sup>st</sup> July 2017 with Barts NHS Trust. One condition of the tender is that Barts holds the contract.

JC outlined the next three years that NCAP will be headed by the NOM (NCAP Operational and Methodological Group) and a senior Lecturer to provide methodological and strategic input.

Delivery group to provide programme management and support the whole program. There will be Staff supporting the domain working group only for NCAP issues to be fed in and out of the NOM. Also that the societies will represent themselves but along with stakeholders will provide input. RF said the PLG will continue as far as we are aware.

TW said the all the governance has been revised for this structure and has now been signed off.

The stakeholder board will set the strategy and the role of the NOM is to design operational objectives around that and for working group to implement that, the terms of reference still needs to worked out and the domain working group is still part Steering group (rebranded) but is purely focused on the HQIP deliverables operational side. There will be one Programme wide Annual report with six domains. TW also confirmed that the SC/DWG can have meetings but very few will be administered by NICOR.

#### b. ONS and linkage update – new 2017-18 agreement (TW/AH)

JC gave an update on the status of the ONS contract and said that the contract extension was until the end of June and will continue when NICOR moves to Barts. The next extension is being renegotiated with an initial focus on the HQIP deliverables, and the hope is that this will be extended to include having ONS life status data for Research and data applications from third parties as was the case up until 1.5 years ago. There was a suggestion that ONS may be reluctant to provide this for Extended Use Data as they would prefer researchers to apply directly to ONS who would provide this data only after a fee has been paid.

#### c. Professional Liaison Group (PLG) update (RF)

In the NICOR update JC talked through the new NICOR structure and operational changes. The PLG and patient liaison groups are not currently represented in the structure but both will remain active.

### 4. NCHDA 2013-16 Report and Press Release

a. The 2013-16 report currently is with NHS England, Bruce Keogh and Simon Stevens with a response awaited. HQIP feedback has been acceptable with no further changes required, as we understand it. Update: BK, NHSE, SS all satisfied with report. But numbers missing and incorrect in Appendix Table 1 which need reworking. Initial aim of July 13 publication not possible and further date of September 14<sup>th</sup> given. Due to analyst handover issues and new Countable Procedures agreement with NHSE (now including VADs, primary ECMO, lung transplant, etc.), as well as need for long term utility, JS with JW have written a new R code for Activity Algorithm (independent of Specific Procedure Algorithm and PRAiS internal algorithm). This took much of the summer but is successfully in place and Table 1 (now in 3 parts) completed with revised Tables 2, 4-6 in main report. No changes to recommendations or key points in the Report. Unfortunately Sept 14<sup>th</sup> date deemed not viable as HQIP / NHSE insisting on full repeat 2 month review process. Therefore next scheduled date for publication is Nov 2017.

#### b. Final sign off time line and further actions required

SA said in principle NHS England are happy with the report, press release and key messages.

#### c. Portal update on 13 July 2017 (SA/AH)

SA mentioned about explanation on the portal with regards to the duplicates and the SP funnel plots that is the same patient having the same procedure in a 30 day period, alive or dead. RF said he had

written out was agreed upon in the previous minutes and how to deal with duplicates. RF said the analysis excluding the patient and an asterisk is to be included for a particular funnel to indicate that a patient who had two procedures who survived or died from same centre was present. This means total procedure numbers include the two procedures but the Funnel does not and survival is based on patients. . AH confirmed that he will implement this and the Portal should be ready to be updated with new 2013-16 SP funnels at the time the report is published. SA said on the portal that the text needs to describe this generically in the Funnel methodology, acknowledging duplicate cases for two procedures within same 30 day period.

RF said we need to get formula correct with regards to the EP and Intervention split so they are Separate (previously combined), as agreed with NHSE.

SA mention about PRAiS for the children's heart surgery website (CORU developed). RF said this was were part of the whole process with PRAiS and the website is to be updated each year we produce the report by NCHDA passing on the new PRAiS data so the website graphics and verbiage can be updated. RF said they will not update their site until we publish the NHCDA Annual report.

AH confirmed any contents changes portal is fine as there is no cut off period do but any more analysis or new codes changes would be trickier to do.

RF asked it would be useful for the team to look at the portal if any changes need updating before the new dataset rolled out next year.SA said she is tasked to update portal to match the report.

## 5. NCHDA updates

### a. Validation visits (LD)

JC said the NCAP will no longer be funding validation visits from July 1<sup>st</sup> 2017. This was initially due to the limited funding, but this is still not possible even though all centres are offering to fully fund their own visits and despite letters of concern about this from the BCCA, SCTS, CRG and Children's and Congenital Heart Forum (patient group). The NCHDA SC strongly favours that they continue with a transition phase until a robust remote methodology can be tested, on the basis that the visits are funded for up to three years by the centres. JC said that Validation plans for funding by the centres are limited for NCAP at an HR level. NICOR cannot legally employ anyone for the validation once transferred from UCL to Barts nor employ anyone outside of NCAP mechanism, as apparently not part of the HQIP deliverables.

LD said that Dublin has access issues, and that OLS and GOS tend to over code things like Fallot Repairs, both centres tend to submit individual codes for each aspect of Fallot repair and/or an overall Fallot repair code .She will follow with them after NICOR's transition to Barts on the 2<sup>nd</sup> July.

### b. Transfer of analyses methodologies, including data cleaning (SA/JW)

SA gave an update on the process. JS mentioned that he has debugged the algorithm and that they will implement the new specific procedures and they will run in tandem. See above update.

### c. Portal upgrade plans (JW/NF)

RF said the Portal upgrade in process looking at rolling in out next year rather than this year.

### d. ACHD report project and use of STS risk stratification model (JW/KE/SA/RF)

RF said risk stratification model to work on it and look at it again by Christmas.

6. Technical: Update

a. Congenital web rollout – update (JS/MS/AH)

RF said implementing the last few changes. JS to test next week and roll out to some centres. JS confirmed he should be free to test. No data input to date whilst centres await this before submitting.

b. Data manual (JS)

JS to update the data manual – near completion.

c. Data Quality Guidance (TW)

On hold until the move to Barts.

d. Fetal database – update (MS/JS/RF)

RF said Marion unable to implement the last few things. RF confirmed to carry out with the testing. JS to test in the next week or so and rollout to some centres. Fetal to roll out in July and start encouraging centres to complete. RF said JS will send to guidelines to all centres.

7. AOB

a. Life Status issues in Scotland (RF/CMc paper): for information.

b. AT mentioned that his tenure was coming to an end he suggested that Jamie Bentham be considered to take his place as BCCA Interventional Cardiology rep. Update: BCCA have asked that AT continue pro temp whilst NICOR shift to new contract and until clarity over the future of SC.

c. Next meeting dates.

September 2017

December 2017

1. Summary of Action Points

Meeting date	Action No.	Action	Owner	Status
20/03/2017	5b	RF will add to the Recommendations, emphasising Fetal QI. The analyses will be updated and report be subject to a full review by HQIP and BK, following HQIP timeline. Completed early June 2017	RF/All	Closed
20/06/2017	4a	TW to take the views and comments of the steering committee to The NICOR Executive committee re: validation visits.	TW	Open
20/06/2017		Send out doodle poll for next meetings.	SA/SS	Open
20/06/2017	6b	JS to make changes to the Data manual	JS	Open
20/06/2017		SA to update the portal	SA	Open