



Minutes

Meeting Name: NCHDA Steering Committee

Date: 14th March 2017

Venue: SCTS Meeting Room 2B, Belfast Waterfront

Time: 10:00am – 12:30pm

Time allocated: 2 1/2 hours	Facilitator's name: Rodney Franklin
Minute Taker: Shenaka Singarayer	No of guests: 14

Persons in attendees (add Initials):		
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 (Skype) (KB)	Paediatric Cardiac Intensivist, Great Ormond Street Hospital
Senior Audit Strategist	David Cunningham (Skype) (DC)	Senior Strategist for National Cardiac Audits, NICOR
BCCA ACHD representative	Kate English (KE)	ACHD Cardiologist, Leeds General Infirmary
NICOR Congenital Audit Developer	Andy Harrison (Skype) (AH)	NICOR
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
Chair SCTS Congenital Sub Committee	Carin Van Doorn (CVD)	Congenital Heart Surgeon, Leeds General Infirmary
NICOR Information Analyst	Jiaqiu Wang (Skype) (JW)	NICOR
NICOR Senior Project Manager	Tracy Whittaker (Skype) (TW)	NICOR
NICOR Project Manager	Sarah Ajayi (Skype) (SA)	NICOR
NICOR Project Coordinator	Shenaka Singarayer (Skype) (SS)	NICOR
Clinical Data Auditor	Lin Denne (LD)	NICOR

Agenda

1. Present and Apologies
2. Minutes of previous meeting – outstanding action points not on Agenda (RF) Paper 2.0
3. NICOR update
 - a. HQIP 2017-22 tender outcome, new NICOR structure, operational changes (TW/RF) Paper 3.0
 - b. ONS and linkage update - (RF/AH/TW)
 - c. PLG update (RF)
4. NCHDA updates
 - a. Validation visits and Papworth (LD)
 - b. Transfer of analyses methodologies, including data cleaning (DC/JW)
 - c. Outlier analysis: same patient multiple same procedures within 30 days (RF/AH/KB)
 - d. Portal upgrade following JW demo (JW/NF)
5. NCHDA 2013-16 Reporting and Press Release
 - a. HQIP changes and new reporting timeline
 - b. Updated 2013-16 report: antenatal diagnosis and related recommendations Paper 5.0
 - c. 'Red Book' for congenital (DB/CvD)
6. Exploratory exercise: 90 Day Outcomes (JW/DC)
 - a. Summary update (RF/JW) Paper 6.0
 - b. Paper update (RF/JW/DC) Paper 6.1
7. Technical update
 - a. Congenital web rollout – update (JS/TW/MS/AH)
 - b. 2017 Dataset changes (RF) Paper 7.0
 - c. Data manual (JS/RF) Paper 7.1
 - d. Data Quality Guidance (TW)
 - e. Algorithm (AH/JS/RF) Paper 7.2
 - f. Fetal database – update (MS/JS/RF)
 - g. Reporting diagnostic catheters - views after CHIG (AT)
8. AOB
 - a. Next meeting dates:
 - June 2017
 - September 2017
 - December 2017

Summary of Discussion:

1. Present and Apologies.

Apologies had been received from Bob Ward(BW), James Chaal (JC) 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 13th December 2016 were agreed.

Action No./ Meeting date	Action	Owner	Status
13/12/2016 Action 8	<u>Outlier process in Scotland, NI and RoI</u> Nothing further to report and waiting further updates from both in due course. Update: CMc sent update from Scotland 8 June 2017.	RF	Open
13/12/2016 Action 10	<u>Letter to centres on need for quarterly returns:</u> Reporting deadlines have been published on the website for now.	TW	Open
13/12/2016 Action 11	<u>NICOR to update software to allow data on patient death to be entered, along with cause of death field, independent of procedural data:</u> This is in progress and awaits move to web based data submission during summer 2017.	AH/JW /DC	Open
13/12/2016 Action 16	Reporting 90 day outcomes: The summary has been drafted and awaiting the final sign-off. This has been signed off.	RF	Closed
13/12/2016 Action 19	<u>Analysis of Infectious Endocarditis data:</u> RF said this to be moved March or June 2017 meeting. Action Open. In view of lack of resources and not an HQIP deliverable, should be moved to an area to be explored when EUD NCHDA related work begins in the future. Closed from SC Agenda and moved to RC if/ when reconvened.	RF	Closed
13/12/2016 Action 5, & 13	<u>NCHDA Gant Chart progress document:</u> SA to circulate the current chart to the SC once completed.	SA	Open
13/12/2016 Action 8:	<u>Duplication of EP data entries between NCHDA and Cardiac Rhythm Audit, especially ACHD patients.</u> RF agreed to sit with CRM clinical lead (Francis Murgatroyd) to work this out with AH to discuss implications. Still ongoing and priority with Domain harmonisation work in new contract.	RF and AH, FM	Open
13/12/2016 Actions 9,7c, 10 and 12	<u>Algorithm and new categories, including Stent Redilation, Nikaidoh and Aortopexy:</u> On agenda. New procedures ready to launch with 2014-17 analyses and new algorithm.	RF	Closed
13/12/2016 Action 11	<u>How best to report Diagnostic Catheters:</u> feedback from Congenital Heart Interventional Group from AT suggests no breakdown required. RF said that we should revisit once we have 3 years of data and can examine mortality and morbidity outcomes to see if there are subcategories worth highlighting (such as emergent procedures vs elective).	RF	Open when 2017-2018 data cycle analysed
13/12/2016 4(d)	Outlier analysis: same patient multiple procedures. NACSA feedback + solution- to repeat again for next year. Discussion was generated after the meeting, but still in progress: re in situations with procedure combinations.	DC/AH /JW	Open
13/12/2016 4(e)	Potential Outlier Paed Pacing- SA to send letter after further checking of data is correct and respond. Golden Jubilee have confirmed their data: non-outlier.	SA	Closed
13/12/2016 5	Report fetal detection maps. TW to change map colours of the NCHDA report: This is in progress. Now complete.	SA/TW	Closed
13/12/2016 6	<u>Exploratory exercise:</u> 90 Day Outcomes to write this up: A draft to be produced and submitted to the exec committee along with a timeline.	SA	Open
13/12/2016 7(b)	<u>Fetal dataset changes and UAT testing – NCHDA-</u> to be rolled out end of Jan. Testing still ongoing but near finalised. Hope for going live Spring 2017.	AH, JS,AS, MS	Open
13/12/2016 7(c)	Disparity of codes between HeartSuite and Lotus Notes- AH to make sure DC and AH working on the same extract and finalise it – still in progress	JS/AH/ DC	Open
13/12/2016 7(e)	2017 Dataset changes. Sent out on to all centres 1 st March 2017	AH/SA	Closed

13/12/2016 7(f)	<u>Data Manual</u> : A draft has recently been submitted to the steering committee for comment. SA has asked JS to confirm what is else needs to be added or amended. Final amendments near completion.	JS	Open
13/12/2016 7(g)	<u>Data Quality Guidance</u> This is currently on hold until 2014-17 analysis plan decided.	TW &SA	Open

3. NICOR update

a. HQIP 2017-22 tender outcome, new NICOR structure, operational changes (TW/RF)

TW providing NICOR update on James Chaal's COO behalf. NICOR Transition date to Barts now been extended to 1st July 2017 due to Information Governance which needs to be completed by Barts. There are six working groups between Barts, UCL and NICOR for the planning of the move. There will be a 22% + 10% contingency reduction in funding. This needs to map to the deliverables and unclear how this will be divided between the 6 Domains. Additional 20% penalty clause if we do not deliver to time and quality.

Slides provided for an overview of the new NICOR structure – NICOR to become National Cardiac Audit Programme (NCAP) as one audit with 6 clinical domains (previous Audits, inclusive of NCHDA). The new tender bid is focussed on HQIP deliverable domain data requirements and QI (although NHSE and CRG still want QA too). All other data uses will be within Extended Use of Data (EUD) remit, although how this will work remains unclear.

IT platform to move to a new flexible system aim to upgrade by April 2018

Bart's team will help NCAP meet their deliverables.

TW described the NCAP Stakeholder Board, which will hold quarterly meetings and include some societies representation: SCTS President and BCS President (PLG Chair), but not BCCA or CHD. Also NHSE, HQIP representation. Remit to sign off strategic plans and objectives of NCAP.

In response to the question about the future of steering and research committees, TW explained that these will no longer be supported by NICOR in terms of admin and hosting meetings at NICOR [this clarified later]. RF will represent views of SC at monthly NCAP Operational & Methodology (NOM) Group meetings. Update: at PLG meeting in May, Sarah Clarke (BCS President) agreed to explore hosting SC meetings at BCS, possibly with admin support, for all 6 Domains. This has yet to be confirmed. It is not clear if NICOR will be represented at such meetings either in person or via telecon.

TW also highlighted that research will not be part of the audit deliverables and Research Committees to be subsumed into EUD Management Group (chaired by JD), although how this will work at Domain level remains unclear.

b. ONS and linkage update - (RF/AH/TW)

AH confirmed that he received the files last week and they are with NICOR for the analyst JW to work.

TW confirmed that JW to do the analyses in the next couple of weeks, RF to add in the quality improvement sections. The team aim to produce a near complete draft before the end of May to get to HQIP.

TW informed that all data sharing agreements need to be signed off before the transfer to Barts.

c. PLG update (RF)

RF said that it was not entirely clear where PLG will sit within new NCAP structure.

4. NCHDA updates

a. Validation visits and Papworth (LD)

LD said there were Information Governance issues which were largely resolved and unique to Papworth in terms of their concerns, probably due to unfamiliarity with validation site visits and previous track record.

RF said that validation visits will not be financed for this coming year. Tw confirmed that the new budget does not cover validation visits as the budget has been broken down by clinical domains. TW offered to take the views and comments of the steering committee to The NICOR Executive committee meeting tomorrow, as this was their executive decision.

RF said letter would be coming to NICOR from CRG/SCTS/BCCA to ask that site visits be retained, given their importance for NHSE Review and Quality Dashboard. Also that no robust and tested alternative was available but that the SC has always been keen to explore alternative methodologies. Update: This was sent 19 Mar 2017 and receipt acknowledged soon after, but no reply received to date (10 June 2017).

RF said ideally validation visits should continue and be covered by HQIP. RF gave LD the go ahead to plan some of the site visits. TW confirmed that wasn't the message the Exec had made, as the decision was that there was no funding dedicated for this purpose. Update May-10th June 2017: all paediatric and most major ACHD sites have agreed to fund the site visits, amounting to approximately £60K of income, covering LD total salary. However TW/JC informed RF/LD 6 June 2017 that despite this, NICOR would still not sanction site visits as 'this decision is the most appropriate for the programme as a whole.' TW asked for all site visits after 9th June be cancelled.

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

This was reported as almost complete by SA, although there are currently a few anomalies that need checking before the transfer of data analyses can be completed.

c. Outlier analysis: same patient multiple same procedures within 30 days and Funnel plots for Specific Procedures (RF/AH/KB).

Further discussion and agreement about a suitable approach is still needed on this. Update: the method to use has been finalised:

- a. All duplicate procedures for the same patient within 30 days of the initial procedure, alive and dead, are not shown on the plots themselves and are not included in the analyses as two procedures, thus avoiding dying twice (censored as final life status for the 2 procedures) – same as PRAIS.
- b. The totals in the top/initial tables above the Funnels for numbers of these procedures would not be altered and so reflect actual activity for surgical/catheter numbers.
- c. Where there are duplicates in the funnels, an additional line of text, linked by an asterisk to the centre in question, would state that an additional censored procedure took place within 30 days and which is not visible on the Funnel, such as 'An additional procedure on the same patient within 30 days of the first procedure is not included in this funnel plot or in the funnel plot analysis, so as to avoid counting this patient as alive or dead twice within the analysis of life status at 30 days following the procedure. Activity numbers attributable to the centre include both procedures.'
- d. If a patient has a procedure towards the end of March then life status at 30 days extends to April (next analysis year) the procedure and outcome remain as being counted within the year that the procedure was done.

e. If a patient has a procedure in March and then a second same procedure within 30 days but in April (next analysis year), then the end life status stays linked to the initial procedure in the first year, but only the first procedure is counted in overall procedure activity for that year. No asterisk is therefore required as activity and funnel numbers will be the same. When analysing for next cycle, it is just the second procedure which appears in activity numbers, and life status then shifts in effect to the second procedure as the only one occurring in this later three year analysis.

d. Portal upgrade following JW demo (JW/NF)

RF/TW presented the new interface to the group and responded to comments. This is still in progress and developments will continue to be shared when they are made. Going live now expected summer 2017 after further testing (JS/TW/AH).

5. NCHDA 2013-16 Report and Press Release

a. HQIP changes and new reporting timeline

TW explained that the current SRP has recently been revised and now includes extra processes, one of which is for any publication be subject to a full review and being signed off by BK.

b. Updated 2013-16 report: antenatal diagnosis and related recommendations

RF will add to the Recommendations, emphasising QI. The analysis will be updated and report be subject to a full review by HQIP and BK, following HQIP timeline.

Potential outlier might affect the new timelines, but the correct processes and procedures will be followed if this occurs.

c. 'Red Book' for congenital (DB/CvD)

DB confirmed that its generation had been put on hold. TW also said that the work would need to be guaranteed by Barts when NICOR switches over to Barts

6. Exploratory exercise: 90 Day Outcomes

a. Summary update (RF/JW)

RF confirmed he signed off in the December and just needs minor tweaking to be done.

b. Paper update (RF/JW/DC)

JW and SA have discussed a timeline for this and it was agreed that this would need to be submitted to the NICOR exec as a piece of work that might be carried over to Barts.

7. Technical: Dataset – Algorithm

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

This has now been rolled out and is currently being tested by TW. Not due to go live now until Summer 2017.

- b. 2017 Dataset changes (RF)
RF said he needed to update the EPC coding but not for 2017-18 data collection. It would be sent out by October 2017 for implementation April 2018-19 cycle.
- c. Data manual (JS/RF)
JS said the Data manual is not quite complete as they need additional information on the SP algorithm and PRAiS analysis. JS to complete asap.
- d. Data Quality Guidance (TW)
TW confirmed that the Data quality guidance was on hold until we put the analysis plan in and then it will be ready to go.
- e. Algorithm (AH/JS/RF)
JS said that RF needs to align the algorithm with PRAiS before we can roll out another algorithm. This will be ready for initial analyses of SPs in Summer 2017.
- f. Fetal database – update (MS/JS/RF)
RF said Anna Seal and JS had tested in Birmingham but still not ready to roll out. Aiming for Spring 2017.
- g. Reporting diagnostic catheters - views after CHIG (AT)
RF said it had already been covered in detail early on in the meeting (see above action points).

8. AOB

- a. Next meeting dates: SA/SS to send out doodle poll for next meetings.
 - June 2017
 - September 2017
 - December 2017

1. Summary of Action Points

Meeting date	Action No.	Action	Owner	Status
14/03/2017	5b	RF will add to the Recommendations, emphasising QI. The analyses will be updated and report be subject to a full review by HQIP and BK, following HQIP timeline.	RF/All	Open
14/03/2017	4a	TW to take the views and comments of the steering committee to The NICOR Executive committee re: validation visits.	TW	Open
14/03/2017		Send out doodle poll for next meetings.	SA/SS	Open