



Minutes

Meeting Name: NCHDA Steering Committee

Date: 13th December 2016

Venue: NICOR Boardroom

Time: 12.30-3.30pm

Time allocated: 3 hours	Facilitator's name: Rodney Franklin
Minute Taker: Shenaka Singarayer	No of guests: 17

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 (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 (Skype) (KE)	ACHD Cardiologist, Leeds General Infirmary
NICOR Congenital Audit Developer	Andy Harrison (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
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
Clinical Data Auditor	Lin Denne (LD)	NICOR
Patient and public representative	Bob Ward (BW)	
HQIP Associate Director for Quality and Development	Kirsten Windfuhr (KW)	HQIP
HQIP Project Manager	Tasneem Hoosain (TH)	HQIP

Agenda

1. Present and Apologies (RF)
2. Minutes of previous meeting – outstanding action points (RF) Paper 2.0
3. NICOR update
 - a. HQIP 2017-22 tender (JC)
 - b. ONS update (JC)
 - c. New staff - Data Manager and Java Developer (TW/SA)
 - d. PLG update (RF)
4. NCHDA updates
 - a. Feedback from validations visits and Papworth issues (LD)
 - b. Data extraction, Data cleaning and analysis (AH/DC/JW)
 - c. Data analysis – Feedback on dry run: (DC/ JW)
 - d. Outlier analysis: same pt. multiple procedures. NACSA feedback + solution. (SA/TW/AH) Paper 4.0
 - e. Potential Outlier Paed Pacing (ALL) Paper 4.1
5. NCHDA 2013-16 Report and Press Release
 - a. 2013-16 report and press release: HQIP suggestions (RF) Papers 5.0/5.1
 - b. Report publication - Plan B (ALL)
 - c. Updating Portal post September demo (SA/JW/TW)
6. Exploratory exercise: 90 Day Outcomes (JW/DC) Paper 6.0
7. Technical: Dataset - Algorithm
 - a. Changes and UAT testing - NCHDA (AH/JS)
 - b. Changes and UAT testing - Fetal (MS/JS/RF/AH)
 - c. Disparity of codes between HeartSuite and Lotus Notes (DC/AH/JW/JS)
 - d. Algorithm (AH/JS/RF) Paper 7.0
 - e. 2017 Dataset changes (RF/JS) Paper 7.1
 - f. Data manual (JS/RF) Paper 7.2
 - g. Data Quality Guidance (TW)
 - h. How to report diagnostic catheters (AT/All)
8. AOB
 - a. Bob Ward – Tiny Tickers enquiry – wider implications for reporting (BW/SA/DC) Paper 7.3
 - b. 'Blue Book' for congenital (DB/CvD) Paper 8.0
 - c. Contributors Day (LD/RF)
 - d. Next meeting dates.

Summary of Discussion:

1. Present and Apologies.
Apologies had been received from Carin Van Doorn(CVD)
2. Minutes of previous meeting – outstanding action points
Draft minutes of the previous meeting held on 12th September were agreed as correct.

Action 8: Mar 16	<u>Outlier process in Scotland, NI and Rol.</u> RF said that Chuck Mclean had not heard from the Scottish Authorities and there is a process of ongoing consultation between Republic & Northern Ireland. Action Open RF.
Action 10: Mar 16	<u>Letter to centres on need for quarterly returns.</u> TW confirmed letters to centres have not gone out yet, but will be sent in preparation for the next cycle. Action Open SA/TW.
Action 11: Mar 16	<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> AH: this has not been rolled out yet. Will be possible within new web version. To be carried forward. Action Open. AH
Action 16: Mar 16	<u>Reporting 90 day outcomes.</u> On Agenda. Action open. Possibility of writing up for publication (DC/JW/RF/Others).
Action 19: Mar 16	<u>Analysis of Infectious Endocarditis data.</u> RF said this to be moved March or June 2017 meeting. Action Open.
Action 5, & 13: Jun 16	<u>NCHDA Gant Chart progress document.</u> TW to enable SC access to this to allow tracking of progress with HQIP and other deliverables. RF said it would be more helpful if this was sent out on monthly basis to SC by SA/SS t. Action Open SA
Action 8: Jun 16	<u>Duplication of EP data between NCHDA and Cardiac Rhythm Audit, especially ACHD patients.</u> AT said Graham Stewart was off sick so now Mark Walsh is involved who will be working with Olga in Bristol. Aim: single entry of data for both CRM and NCHDA datasets. To continue with Harmonisation between NCHDA and EP datasets where feasible, assuming HQIP bid successful. Still ongoing. Action Open AT & need to engage CRM (FM)
Actions 9, 10 and 12: Jun 16	<u>Algorithm and new categories, including Stent Redilation, Nikaidoh and Aortopexy.</u> On Agenda item no. 7 Action Open
Action 11: Jun 16	<u>How best to report Diagnostic Catheters.</u> On the Agenda. Action open.

3. NICOR update
 - a. HQIP 2017-22 tender
JC provided an update on where NICOR is with HQIP bid and that there have been ongoing exchanges between NICOR and HQIP. JC was optimistic about a final positive outcome very soon.
 - b. ONS update (JC)
DC and JC confirmed that NHS Digital have finally granted data sharing agreement for ONS up to the end of March 2017. JC will have the agreement signed off today and hopes that we should have the data flowing back to NICOR by the 2nd week of January 2017. However, JC also noted that NICOR are still unable to share ONS data with third parties as the Third party data sharing agreement had still not been granted by NHS Digital. RF highlighted that there will need to be a new data sharing agreement from April 2017 and will be annually renewable thereafter.
 - c. New staff - Data Manager and Java Developer
SA mentioned that at NICOR there was a new Data Manager Naufal Sarghini and new Java Developer Serpil Kose

- d. PLG update
RF said there is no update as the last meeting was in September focussing on the HQIP bid with no minutes so far produced. The next PLG meeting scheduled end of January (update: 22 Feb17).

4. NCHDA updates

- a. Feedback from validations visits and Papworth issues
LD said that Papworth have just entered all their visit data, with final surgical cases yesterday, and harvesting and sampling today. They had some coding issues but are working to finalise the diagnostic and procedure coding for submission soon. The validation visits are to continue for the next year in their current format, aiming to increase the automation of data checking and eventually shorten the time taken for onsite visits.
- b. Data extraction, Data cleaning and analysis for 2013-16 data
AH said he had produced an extract for JW and so that parallel Analyses with DC can take place, aiming for JW to become independent with DC sense checking given his clinical expertise.

- c. Data analysis
RF said no change from recent PRAiS re-analysis and final version awaiting ONS data sharing.

- d. Outlier analysis: same patient multiple same procedures within 30 days. NACSA feedback + solution.

There was general discussion on possible options to prevent the same patient dying twice from multiple procedures but moving forward RF said there would need to be new rules and transparency on the website of how the system would work to accommodate the few cases where this occurs.

DC suggested evaluating how many times this had happened, for both alive and deceased patients, and this would help decide best methodology. KB informed about PRAiS method for dealing with this and where censoring occurred. It was agreed that it would probably be helpful to use a similar method, whilst noting where this has occurred on each relevant procedure funnel.
Action: All with RF/DC/KB lead

- e. Potential Outlier Paed Pacing
RF said JW carried out further analysis with a dry run on December 8th. Another potential outlier but likely to be a data quality issue as LD informed that many of such procedures undertaken in operating theatre and therefore coded as surgical when not the case.
Action. SA to send letter to Golden Jubilee to check the data and feedback. Update: CMc (Audit Lead) for GJ and has personally confirmed to RF that this is a data quality issue and many more procedures have been undertaken, suggested that GJ is not outlying.

5. NCHDA 2013-16 Report and Press Release

2013-16 report and press release: HQIP suggestions

RF said that the publication date for the 2013-2016 report is end of February. This next publication will not include a foreword from HG as time likely to be too short for this given ONS related delays in producing final analyses. Most other HQIP suggestions would be incorporated in 2013-16 report.

BW spoke about changing the map colours. RF asked for TW to change the map colours in a way that best suited a gradation of outcomes.

KW suggested trying to highlight something in the report which demonstrates quality improvement.

Updating Portal post September demo

RF said they are planning on revamping the portal as it's not as user friendly as it could be for the Public. It is currently more geared towards professionals. It was suggested that the Understanding Children's Heart Surgery website could be used as a model. For the reports on the individual 72 procedures.

Action: JW to continue working with this with help from RF/DC/BW/All.

6. Exploratory exercise: 90 Day Outcomes

JW/DC submitted near final draft report on the feasibility of 90 day outcomes reporting for individual procedures, given delays in receiving ONS outcomes due to the coronial process. This was well received and it was clear that this is not currently possible due to an unacceptably high number of misreported deaths (i.e. ONS maintaining live status when known to be dead but in coronial system awaiting the issuing of a death certificate). TW explained that this was a piece of work for NHS England and it was agreed that a brief one page summary be produced for sending to HQIP and NHSE. RF congratulated JW and DC for the work and also suggested that it warranted writing up for Journal publication. Action: Produce A4 summary on 90 day outcomes for HQIP. JW/DC/RF

7. Technical: Dataset – Algorithm

a. Changes and UAT testing - NCHDA

AH said that he made changes to the import routine and that it was finalised last week but found a few interface issues which he is working on with Marion Standing. AH to liaise with JS for final testing and plan to go live by the end of January with full roll out end of March/beginning of April. Action: AH/MS/JC

b. Changes and UAT testing - Fetal

RF said final tweaks needed by MS, RF having sent through recently Next stage to test with Anna Seale (AS), Consultant Fetal Cardiologist at BCH, along with JS help, using live data in segregated area NICOR data area which MS would set up. If all running well, aim for Roll out end of January and full take up by fetal cardiologists April 2017. Action: MS/AH/JS including AS being registered to submit data.

c. Disparity of codes between HeartSuite and Lotus Notes

JS said there is slight difference and there is a bug in the HeartSuite export to do with delimiters (semi-colon between each code description). There will a new export for HeartSuite users soon which hopefully fix this (purely HeartSuite issue). AH and DC to make sure working on the same extract and finalise it.

d. Algorithm

AH: the new algorithm submitted by RF in October has not been tested yet by JS (AH to do). 2013-16 report will not include this algorithm given time constraints and will therefore have to wait until the next cycle for implementation. Test running still required to sense checking the coding. Action: AH to send algorithm extract to JW and JS to test.

e. 2017 Dataset changes.

RF requested document to be sent out by Nov. Will include expanded ethnicity codes using HES breakdown to go live in next cycle. SA/SS to send out asap.

- f. Data manual:
RF to provide feedback of v15 to JS before the New Year.
- g. Data Quality Guidance
The guidance has been updated but still needs to include a data flow and validation process map and a section on how data is cleaned and analysed. This is in progress and a final draft will be sent to the NCHDA SC for final review. Action: TW and SA
- h. How to report diagnostic catheters
This was briefly discussed. AT to take suggestions of breakdown to Congenital Heart Interventional Group meeting early in 2017 for their recommendations on the best breakdown into different subcategorise for reporting in the future. Also if any other data fields or complications that should be considered.

8. AOB

- a. Bob Ward – Tiny Tickers enquiry – wider implications for reporting
The need for publishing fetal data with denominator was emphasised for each region to better be able to compare regions, noting the number of potential patients in each area. This had been done previously but somehow dropped in most recent reports. Reporting by postcode areas would not make sense as too much variation in where patients live with their maternity unit, especially in the SE. The expanded fetal dataset would be the best way forward longer term to identify obstetric units most in need of improvement and additional training. Meanwhile NCHDA to consider publishing data on the diagnosis by region of a couple of key lesions, such as HLHS and TGA. Action: RF with DC/JW
- b. 'Red Book' for congenital
Anthony Bradley (AB) joined the meeting and explained that NICOR has been commissioned to produce a revised version of the SCTS Blue Book. The funding will include a 'Red book' for an NCHDA report which AB will be working with David Barron to produce. AB shared his progress on this work and explained that he had contacted SCTS so as to produce a timetable for the work. The work will be in stages and the SCTS are hoping that it can be launched at their Annual Conference in March 2017. Action: DB (with CvD) to provide AB with a list outlining planned content.
- c. Contributors Day
RF confirmed this will be Tues March 14th in Belfast at SCTS Annual Meeting in the afternoon. Action: LD/JS with SS to send email confirmation to DBMs and Audit leads asap. Action: SA/SS to liaise with SCTS organisers (Isabelle Ferner) for Logistics at Belfast conference centre
- d. Next meeting date
RF confirmed that there will be a Steering Committee meeting on the morning of Tuesday March 14th at the Belfast annual SCTS meeting.

9. Summary of Action Points

Meeting date	Action No.	Action	Owner	Status
Mar 16	Action 8: Mar 16	Outlier process in Scotland, NI and Rol. Still waiting feedback from CM and FC (NI)-Rol.	RF	Open
Mar 16	Action 10	Letter to centres on need for quarterly returns.	TW	Open
Mar 16	Action 11	NICOR to update software to allow data on patient death to be entered, along with cause of death field, independent of procedural data.	AH/JW	Open
Mar 16	Action 16	Reporting 90 day outcomes. Update: Final report agreed.	JW/DC	Open
Mar 16	Action 19	Analysis of Infectious Endocarditis data	RF	Open
Jun 2016	Action 5,13	NCHDA Gant Chart progress document: regular sending to SC	SA	Open
Jun 2016	Action 8	Duplication of EP data between NCHDA and Cardiac Rhythm Audit, especially ACHD patients.	AT/RF	Open
Jun 2016	Actions 9, 10 and 12	Algorithm and new categories. New algorithm produced and awaiting testing.	RF/AH/ JS/JW	Open
Jun 2016	Action 11	How best to report Diagnostic Catheters.	AT/RF	Open
13/12/2016	4(d)	Outlier analysis: same patient multiple procedures. NACSA feedback + solution - to repeat again for next year	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	SA	Open
13/12/2016	5	TW to change map colours for fetal part of NCHDA report	SA	Open
13/12/2016	5	2013-16 report: awaiting ONS data and final analyses	SA	Open
13/12/2016	6	Exploratory exercise: 90 Day Outcomes: final write up for NHSE and possibly fuller analysis as paper.	SA	Open
13/12/2016	7(b)	Changes and UAT testing – NCHDA- to be rolled out end of Jan	AH, JS,AS	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.	JS/AH/DC	Open
13/12/2016	7(d)	Algorithm - Action: AH to send algorithm extract to JW and JS to test.	AH, JW ,JS	Open
13/12/2016	7(e)	2017 Dataset change document: to be sent out asap to DBMs and Audit leads	SA/SS to LD	Open
13/12/2016	7(f)	Data Manual: finalise for sending to DBMs/Audit leads	RF/JS	Open
13/12/2016	7(g)	Data Quality Guidance: to complete for sending to SC	TW &SA	Open
13/12/2016	8(c)	Fetal NCHDA report to include denominators as previously. Also to look at publish regional outcomes by specific CHD diagnoses (e.g. HLHS, TGA + IVS).	DC/JEW/RF	Open
13/12/2016	8(b)	Congenital 'Red Book': Action: DB/CvD to provide AB with a list outlining planned content.	DB/CvD	Open
13/12/2016	8(c)	NICOR to work out Logistics with Belfast conference centre for next steering committee	SS/ SA	Open