



National Congenital Heart Disease Audit Steering Committee
June 21 2016
13.15-16.00
Wilkins Garden Room, UCL

Notes

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 (KE)	ACHD Cardiologist, Leeds General Infirmary
NICOR Congenital Audit Developer	Andy Harrison (AH)	NICOR
Chair SCTS Congenital Database Subcommittee	Chuck McLean (CM) (Skype)	Congenital Heart Surgeon, Royal Hospital for Sick Children, Glasgow
President BCCA	David Anderson (DA)	Congenital Heart Surgeon, Evelina London Children's Hospital
BCCA Interventional Representative	Andy Tometzki (AT)	Consultant Paediatric Interventional Cardiologist Bristol Royal Hospital for Children
NICOR Project Manager	Tracy Whittaker (TW)	NICOR
Congenital Database Managers Lead	John Stickley (JS)	Database Manager, Birmingham Children's Hospital
Patient and public representative	Bob Ward (BW)	
Chair SCTS Congenital Sub Committee (from now on)	Carin Van Doorn (CVD)	Congenital Heart Surgeon, Leeds General Infirmary
NICOR Information Analyst	Jiaqiu Wang (JW)	NICOR
NICOR Project Coordinator (minutes)	Kelly O'Brien (KOB)	NICOR

1. Apologies & Introductions

Lin Denne, James Chal and Nadeem Fazal sent apologies. The group welcomed JW to his first meeting since starting work on NCHDA. RF explained that he had taken over from Owen Nicholas who was no longer working on NCHDA.



2. Previous minutes and action log

The minutes were approved as accurate.

There was a discussion arising from the last meeting about the need for a second patient and public representative as a concern had been raised that NCHDA had only one, but AB didn't think that it was mandatory to have a second one.

3. 2012-2015 analyses:

Final Report

Portal update and funnels

DC is in the process of creating the funnel plots now that it was clear that the planned automation of this process by ON had not yet been undertaken. These would then be uploaded to the Portal at the same time as the report is released by AH.

4. 2013-16 analyses

5. NCHDA updates:

5.1. COO Update

5.2. Professional Liaison Group update

The update from the last meeting was not yet available.

5.3. Outlier policy and NHSE expectations:

This had been discussed at length during the Contributors meeting in the morning, but there was a further discussion and there were some strong feelings within the group. There were concerns raised about the makeup of the Quality Surveillance Groups and the reliance on the CRG to make decisions. It was felt that a formal concern should be expressed as ultimately the NCHDA SC has to be sure that there are informed members of the QSG when assessing divergent units. There was reassurance in the morning from NHSE (Ben Parker) that the QSG membership was flexible and would include, in this case, expert congenital cardiology input. There was concern voiced that the NHSE Policy document circulated had not been fully thought through or at least was not transparent on this point. Nor was it clear in explaining what divergence means, the subsequent ramifications for individual units or how these would be publically managed, particularly the likely media attention on statistical outliers.

CVD suggested approaching the Royal College of Surgeons for advice as they have a lot of experience in dealing with outliers, and have established a dedicated professional team to support this.

RF asked CM what parallel processes there were in Scotland as he felt this would be useful to know in advance, should Glasgow be found to be an outlier. It would also be useful to understand processes in NI and Republic of Ireland. **ACTION: CM to find out**



Scottish position on this and clarify processes in Scotland. RF to enquire about NI and Rol processes from their lead clinicians.

KB received an update later during the meeting from Christina Pagel, the PRAiS 2 project lead, who said that the internet launch will involve data already in the public domain, that is after the publication of the 2012-15 report. This is likely to go live onto the website late in May, with terminology and explanations accessible to laypeople, as well as allowing all centres currently running PRAiS1 to download the revised software. This would give the centres the ability to self-analyse their centre's outcomes and be aware of their status ahead of the formal 2013-16 data analysis which DC will undertake in early July 2016. It was emphasised that no data will be published on the website without prior approval from the SC and HQIP.

5.4. NICOR update

5.5. Project update

RF had circulated a Gantt chart with estimated timings for next year's report ahead of the meeting and referred the group to this. The data deadline is 2 May as this is when data submission finishes. There had been some pressure from HQIP/NHSE to set the data deadline at the end of April when the data ends but the validation process has been explained to them and they have been more understanding. RF felt that if everything went to plan there was no reason why the report could not be published by end January 2017. Initial analysis of the 2015-16 data (as three year 2013-16 cohort) by DC will be early July 2016 with letters to possible outliers out by end of July for data checking.

5.6. Web enabled platform update

5.7. HES and Life status update.

5.8. NCHDA Patient/Family/Public update.

CM and BW will work on a lay introduction for the web portal. KB asked them to send an email to Christina Pagel as the PRAiS2 Aim 2 project lead explaining and requesting access to the website currently in final stages of development and which focusses on explaining the PRAiS1 whole centre outcome graphic. **ACTION: CM to do this.**

6. NCHDA Data expansion

RF informed the SC that the fetal expansion to the NCHDA dataset had finally been approved and was in advanced development stage led by NF. The hope is that this will go live for web based data entry by fetal cardiologists by June 2016. Each centre had been emailed with details of the dataset fields, requesting comments. There have been very few so far. In addition, a request will be made for names of 1-2 fetal cardiology leads (or fetal Cardiac Nurse Specialist) for data entry so they can be registered with NICOR for data submission. RF advised the group there was a National Fetal Cardiology Group meeting in Leeds on 28 April where he will present details and field questions.

7. 2015-16 Data entry issues

RF said it had been covered in detail with JS earlier at the Contributors meeting and that AH had received requests and feedback as discussed earlier. Of note is that 2015-16 data entry will remain with lotus notes as web based system not yet fully operational. **Action: JS and AH to correspond and probably meet at NICOR to deal with lotus**



note and new web based data entry system

8. NHSE review

8.1. Written guidelines

LD and RF were looking at producing written guidelines for providers, along with JS, as well as exploring ways to speed up the validation process. **Action: LD/JS/RF with draft to SC for next SC meeting in June.**

8.2. 90 day outcomes gap with ONS

this measure was requested by HQIP and they were expecting to see it in the report.

8.3. Reporting > 95% procedural activity

8.4. Updating portal – improving communication

8.5. Adult CHD outcomes

The linked project work had already been discussed in the Contributors and RC meetings that morning.

8.6. Outcomes by diagnosis

Linked to KE presentation in Contributors meeting earlier in the day.

9. Infective Endocarditis Audit

AT advised that there was a recent paper which suggested that there was an increase in IE following NICE guideline changes to prophylaxis guidelines, but it couldn't necessarily say that it was anything to do with dental work.

ACTION: AT to circulate copy of paper if possible.

10. International comparisons

Results cannot directly be compared due to reporting differences at individual procedure level but it should be possible to arrive at an understanding.

11. AOB

- On behalf of the NCHDA SC, RF expressed thanks to David Barron for his contributions over the last 3 years.

12. Next meeting dates

- September 12th venue tbc – **POST MEETNG UPDATE: NICOR Boardroom**
- December 13th - NICOR Boardroom
- March 2017 – as part of SCTS Annual Meeting 2017 in Belfast, either 12 or 13 March

ACTION SUMMARY 15/12/15 (OUTSTANDING)

Number	Action	Owner(s)
01	TW to confirm that GB has been informed that his participation is no longer required. Update 24/03/16 Carry forward	TW



02	2015-16 provisional data for procedures and Tables for the NCHDA portal should be uploaded by end August 2016. Update 24/03/16 Carry forward	AH
03	NHSE, NICOR and members of NCHDA professional society representatives are meeting in January to discuss shortening time frame for deliverables so that reporting could be in line with NHSE requirements JC will confirm date in due course. Update: Meeting took place 27/01/16 meeting and agenda item for March NCHDA SC. Update 24/03/16 Carry forward	JC
04	Version 5.01 NCHDA dataset - Unplanned reoperation within 30 days requires a definition: Update 24/03/16 RF has provided a definition from CORU Morbidity Study, which JS will circulate and will be incorporated into dataset Excel	RF
05	CM and BW agreed to create 'lay version of Patient Survey info for NCHDA Portal. Update 24/03/16 Carry forward	CM/BW
06	ON priorities are to look at HES data and automating funnel production. Key priority is to establish ON analytical input and commitment for 2016/17. Update 24/03/16 Carry forward	JC
07	JS asked AH to distribute the specification for the browser for the web enabled platform as this will be biggest challenge for centres. Update 24/03/16 Carry forward	AH
08	RF and DC will look to use ICD-10/OPCS coding structures to look at ACHD non submitters via HES analysis. The previous work undertaken by NHSE (Jo Glenwright with RF input) will support this work. RF agreed to contact JG/NHSE to ask if JG can share the final methodology with the NCHDA. Update 24/03/16 Carry forward	RF/JG/DC
09	DC agreed to provide a table of all procedures and outcomes to be included in the 2012-15 Annual report. Update 24/03/16 Done	DC
10	Decision regarding continuation of Infective Endocarditis data collection to be agreed at NCHDA SC March meeting. DC to do initial analyses of data collected to date to inform decision. TW to add to agenda. Update 124/03/16 Discussed	DC/ TW
11	RF to liaise with Michelle Griffin to discuss NCARDS PID data sharing application. Update 124/03/16 Done and actioned	RF

ACTION SUMMARY 15/03/16 (new actions)

Number	Action	Owner(s)
01	AB/TW to check with JC and confirm whether an additional patient representative is required for the NCHDA or whether one is enough.	AB/TW
02	AB to take issue of publishing deadline for Welsh Assembly election purdah period back to JC and pass on that the SC strongly feel that ideally the report should be published ahead of it, at the beginning of April (deadline 4 April 2016).	AB
03	RF to look at putting a statement on the website ahead of the purdah period if publication not possible.	RF
04	CM to send suggested wording change for page 5 as he has	CM



	some issues with it. This to be done as soon as possible as the aim is to publish soon.	
05	AH to check feasibility of putting in a column next to each procedure to say that a centre has carried out that procedure.	AH
06	AH and DC to discuss outside the meeting with a view to publishing before Monday 4 April. JC to inform on back-up arrangements to enable beginning April work when UCL back from Easter leave but AH still away.	AH/DC/JC
07	AB to get confirmation from JC/HQIP by close of play on Wednesday 16 March as to when the report could be published. Update (24.03.16). HQIP confirmed deadline 4 April 2016 before Welsh assembly election purdah. Still awaiting return of Report from HQIP/NHSE so report can be released in this timeline.	AB
08	CM to find out Scottish process and RF to enquire about Rol and NI policy around outliers.	CM/RF
09	It was agreed that a decision would be made at the SC in June whether to go with PRAiS 2 for the next report. RF/TW to add to June agenda.	RF/TW
10	TW/RF to send letter to Audit Leads, copying MDs about need for quarterly data submissions in accordance with NHSE congenital cardiology quality standards.	TW/RF
11	NICOR to update software to allow data on patient death to be entered, along with cause of death field, independent of procedural data (NF/AH). Letter to then be sent to centres (TW/RF)	NF/AH and TW/RF
12	JS and AH to correspond and probably meet at NICOR to deal with lotus note and new web based data entry system	JS/AH
13	CM to send an email to Christina Pagel as the project lead explaining that he and BW are working on a lay introduction for the web portal and requesting access for them both.	CM
14	LD/JS/RF to draft written guidelines for providers and circulate for approval next SC meeting in June.	LD/JS/RF
15	RF to speak to TW to see what should be done about including 90 day outcomes in the report as some members of the SC felt that it was not feasible to do so. Update: not possible to incorporate in 2012-15 report at this late stage.	RF/TW
16	ON to complete analysis to understand how many patients ONS not reporting in 30-90 day window ('the gap') as requested by NHSE by end May 2016, ahead of June SC meeting.	ON
17	AT to obtain and circulate a copy of the Infective Endocarditis paper he has read which suggests there is an increase.	AT
18	It was agreed that IE data should cease to be collected from April 2016 with no validation of 2014-15 IE data entries, given large increase in validation work for this year. LD/JS to inform centres.	LD/JS
19	Analysis of IE data (over 870 patients) should continue with aim to write up and publish from RC members. DC/RF to lead.	DC/RF
20	RF to look at format of agenda, to do lists and a numbering	RF



	system for papers to make it easier to work with these.	
21	DC to include centres in the Republic of Ireland in the antenatal map.	DC