



National Congenital Heart Disease Audit Steering Committee
Tuesday, December 2nd 2014, 12.30-15.00
Meeting Room 1, NICOR, 170 Tottenham Court Road, London W1T 7HA

Minutes

Role – representation	Name	Title - place of work
NICOR NCHDA Clinical Lead – Chair	Rodney Franklin (RF)	Paediatric Cardiologist, Royal Brompton Hospital
Chair SCTS Congenital Sub-Committee	David Barron (Dial in) (DB)	Birmingham Children’s Hospital
NICOR Project Manager (NCHDA)	Anthony Bradley (AB)	NICOR
NCHDA research & outcomes Lead	Kate Brown (KB)	Paediatric Cardiac Intensivist, Great Ormond Street Hospital
Audit & Research Manager	Linda Chadburn (LC)	NICOR
Senior Audit Strategist	David Cunningham (Skype) (DC)	Senior Strategist for National Cardiac Audits, NICOR
Clinical Data Auditor	Lin Denne (LD)	NICOR
NICOR Congenital Audit Developer	Andy Harrison (AH)	NICOR
Chair SCTS Congenital Database Subcommittee	Chuck McLean (CM)	Congenital Heart Surgeon, Royal Hospital for Sick Children, Glasgow
President BCCA	Rob Martin (RM)	Bristol Royal Hospital for Children
Patient and Public Engagement Coordinator	Carol Porteous (CP)	NICOR
BCCA Interventional Congenital Cardiology Rep	Andy Tometzki (Dial in) (AT)	Bristol Royal Hospital for Children
Lay representative	Bob Ward (BW)	Lay representative
Congenital Database Managers Lead	Thomas Witter (TW)	Database Manager, Evelina Children's Hospital

1. Apologies and introduction:

Kate English, Nadeem Fazal, Owen Nicholas, Julie Sanders

2. Previous minutes and actions

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

3. NICOR/NCHDA update



It was noted that JS had stepped down as COO. The SC thanked JS for her work and strong support for the NCHDA during her time as COO, and were pleased to note that there will be some transition with JS working 2 days/week at NICOR in the New Year.

a) 'Leaked' LGI letter update

LC gave a brief update on the investigation on the leaked LGI letter. However the details of the investigation were unable to be broadcast within the meeting. But it was relayed to the group that it was not thought to be due to a data breach from within NICOR itself.

b) Outlier Policy update

LC informed the group that NICOR are still awaiting the outlier policy from HQIP.

c) PLG update

There was no update from the Patient Liaison Group.

4. **NCHDA Patient and Family Day update**

CP informed the group that funding had been applied for through the Beacon bursary. We will find out in January whether or not the application is successful. However, the day will go ahead regardless of whether or not the funding application is successful. The date proposed for the day was 19th February. However, it was pointed out by RF that this falls on a half term week and suggested considering a revised date, if initial enquiries from parents found this a problem. CP said the date can be moved although room availability could be an issue.

CP pointed out that a description of the day will be worked on after Christmas and that the day will be advertised across a number of platforms.

5. **NCHDA Project update**

a) PRAiS mediated aggregate analyses: 2009 – 12 & 2010 – 13

CM highlighted that as DC uses the PRAiS methodology, is there a way to check whether or not the figures he has matches with that of the units? This should be undertaken to serve as a safety measure.

Action: It was agreed by the group that CM & TW should undertake a pilot to make cross references and link with the information held by DC.

b) 2011-14 analyses: timeline & plans

The results had been distributed before the meeting. Of note was that all units across the UK and Rol performed well and at a level that remains at a very high standard, comparing well to outcomes published in Europe and North America. There were no outlier units in the aggregate PRAiS mediated analysis. There were three Green line outliers for individual operations and letters to the two centres were due to go out soon. A report back would then be due in mid-January. Early indications suggest that



one centre in fact is not an outlier due to a data error, whilst the other centre had already instigated remedial actions.

There was a disquiet on the SC about the purported date of when the 2011 - 14 report should be published. LC informed the group that HQIP needed two months' notice of any report being published. It was felt within the committee that if the report was ready and data had been validated, HQIP and NHSE should be informed of the wish to publish as soon as possible (probably by February). The SC were unhappy that the NCHDA were being criticised for delays in publishing by NHSE and HQIP yet it was going to take 2 months for HQIP ratification with no clarity as to the HQIP process. RF felt that it would be better to work within the regulations and honour the two month period of notice that HQIP requires, rather than publish independently. However NICOR should make it clear to all parties why there was a delay in publication. The NCHDA team should be proud of having worked to new deadlines such that publication was likely to be possible only 8 months after data submission deadlines, including site validation visits to all Paediatric Specialist centres and the major ACHD ones. This is 9 months earlier than the 2010-13 dataset.

c) Portal

AH said that the portal will be given a makeover after the patient day to ensure that the attendees of the day are given an opportunity to have some input within the re-development.

d) Life Status

CM submitted an important document recommending specific processes for the recording and tracking of life status for those countries without the NHS unique identifier number, particularly Scotland, NI and RoI. This should work for Scotland and might be possible in NI too. DC said he would look into this and make relevant comments to the group. The SC thanked CM for advancing this process.

Action DC

6. Data validation: subcommittee report

a) Site and Remote validation issues 2013/14 data

LD informed the committee that Great Ormond Street had still not provided any data, Leeds General Infirmary have provided data for one quarter but have recently lost their data manager. Birmingham, Queen Elizabeth Hospital has submitted data for surgery but nothing for cardiology at the time of the meeting. There is currently no data manager at Queen Elizabeth hospital, DB was asked by RF if he could help sort out this particular issue locally.

It was discussed that a suitable job description should be constructed for the DBM role.

Action: TW to investigate the provision of a National JD for DBM appointments detailing NHCDA DBM related requirements

TW asked if there was a Standard Operating Procedure for minimum data standard. LC said that there is a draft SOP and this would be implemented in January.



- b) Data validation 2014/15 onwards: not discussed in detail due to lack of time but for the moment it was agreed that the same format of site visits used for the 2013-14 should be planned for 2014-15.

7. Dataset changes

- a) Generic
- b) ACHD
- c) Catheter
- d) Fetal Proposal

These had been previously circulated and agreed. No new changes.

The fetal expansion of the NCHDA dataset business case submitted by RF with DC help, still requires in house NICOR costing and would then be presented back to the NICOR Executive, asap and hopefully before Xmas.

8. Stakeholders Meeting: Manchester 26th March 2015

AB to circulate all stakeholders details of the date, time and location in next 1-2 weeks.

9. AOB

It was noted that AAB's participation in the meeting as Project Manager was less than ideal as he tried to take minutes by hand throughout.

Action: AB to organise for the SC and RC meetings to be recorded in the future

10. Dates of next meetings:

Thursday 26th March 2015 (Manchester SCTS including Stakeholders meeting)

Wednesday 17th June (NICOR)

Date TBC September 2015 (NICOR)