Congenital Steering Committee
Tuesday, September 30th 2014, 12.30-15.00
NICOR, 170 Tottenham Court Road, London W1T 7HA

Minutes

Role – representation	Name	Title - place of work
NICOR Congenital 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 (Congenital)	Anthony Bradley (AB)	NICOR
NICOR research & outcomes	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
Data Validation Officer	Lin Denne (LD)	NICOR
BCCA ACHD representative	Kate English (Dial in) (KE)	ACHD Cardiologist, Leeds General Infirmary
National Clinical Audit Service Manager	Nadeem Fazal (NF)	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 (Dial in) (RM)	Bristol Royal Hospital for Children
NICOR Senior Analyst	Owen Nicholas (ON)	NICOR
NICOR Chief Operating Officer	Julie Sanders (JS)	COO NICOR Audits
BCCA Interventional Congenital Cardiology Rep	Andy Tometzki (Dial in) (AT)	Bristol Royal Hospital for Children
Congenital Database Managers Lead	Thomas Witter (TW)	Database Manager, Evelina Children's Hospital
NICOR Project Manager (Congenital)	Tracy Whittaker (TWh)	NICOR

1. Apologies and introduction:

The group welcomed Linda Chadburn and Anthony Bradley. Linda is the new Audit and Research Manager and Anthony will be replacing Tracy Whittaker as the NCHDA project manager.

2. Previous minutes and actions

It was agreed that the previous meeting's minutes needed a slight rewording within 2.1, under the second bullet point relating to lay representation. It was acknowledged that it needed to be a patient representative. Aside from this minor amendment the group agreed that the minutes reflected an accurate record of the meeting.
Action – TW

3. NICOR update

a. Leaked data – The group discussed the chronology of the events that was circulated at the meeting (Paper B). It was generally accepted that the initial leak could have originated from any of the organisations included within the email trail. RF stressed that it was not the report that had been leaked, only RF's letter to Leeds General Infirmary (LGI).
JS informed the group that the Yorkshire Evening Post were going to run a story concerning the leak and suggesting that it was instigated by LGI, but in the end this did not occur following NICOR's urgent pre-report press release.
RM asked the group as to what restrictions for sharing were put on the letter. RF responded to say that restrictions would be tightened in the future as a result, so that the letter would clearly emphasise its confidential nature. JS said that lessons would be learned and that a full investigation was being undertaken within NICOR.
CM suggested emailing Fragile Hearts to ask who it was that had given them RF's letter; this would be considered only if NICOR's investigation found this to a necessary step.

(Kate English joined the teleconference.)

b. Outlier Policy update – This has yet to be published and in the interim we are still to use the existing 2011 outlier process.
On September 29th, SCTS and NICOR met to discuss respective roles in connection with outliers and JS with DB gave an update. DB found the meeting very helpful and in terms of outliers he would be the first point of contact, escalating it within SCTS if necessary. SCTS are now happy to countersign outlier letters and for products to be badged with professional society logos. RM confirmed that on that basis BCCA would also like to be linked back into the process. DB commented that the NCHDA is duty bound to follow the HQIP policy when it is published although we can add additional steps.

c. PLG report – The Professional liaison group met on 17th September.
    - New job descriptions should be created with clear responsibilities and accountability, with the possibility of funding the leads for their time. JS commented that clinical lead roles within audits can conflict when clinical leads are selected by the Societies and they also have, of necessity, allegiance to NICOR. Job descriptions are to be constructed and rolled out at a time to be established.
    - There has been an amnesty on charges for one year for studies approved by professional societies. John Deanfield has asked clinical leads and professional societies on a mechanism on how to prioritise studies, e.g. quality improvement. This will be limited to three to four extracts and does not include analysis time. RM commented that the BCCA may be able to pay for some analytical time and this will be discussed at the November BCCA Council meeting. KB highlighted that there is still some confusion about the different categories within the current schedule of charges. It was noted that these are available on the NICOR website and the Project Manager should be able to give advice where there is uncertainty.

d. NCHDA Patient & Family Day – An Engagement Day is being proposed and this is likely to take place within the fourth week of November, subject to availability. The aim of the day will be to increase involvement of patients and families and give them the opportunity to discuss the dataset, the portal and understanding their content.

It was discussed that the event needed to be well advertised and suggestions included the Children's Heart Federation and Family Groups associated with each of the specialist centres.
Action – AB & Carol Porteous (CP)

The group were supportive of the aims and objectives that CP had reported in the draft document circulated to the group (Paper C). The aims and objectives would need to be included in any advertisements and highlighted on the day. The day should be designed for both paediatric and adult patients.

It is envisaged that the day won't be used to discuss specific issues and it is hoped that this won't take over the day. CM suggested that any personal or specific issues should be raised in advance and not be brought up on the day.
It was agreed that there should be clinical involvement on the day and that anyone wishing to be involved or have any ideas would be welcome.
Action – CP to circulate details soon

4. Project Update

a. PRAiS mediated aggregate analyses: 2010-13

b. 2010-13 Funnels – RF updated the group on a current issue (reported 28/9/2014) whereby four, 30 day deaths during this period had not been included in the current analysis. Whilst the new policy of hospital death trumping ONS status had been agreed at the March 2014 SC meeting in Edinburgh, it had not been implemented within the analysis methodology. This issue emerged following a reanalysis of the data as part of a process to try and align the portal and funnels patient numbers ahead of publication.
DC said he believed that this had not been fully implemented due to developer issues. JS said this was not the case and the developer work on this had not been completed.

c. Annual report and press release – The Congenital Annual Report was published on 25th September and to date NICOR has received one query.

d. Portal – RF provided a summary of the events that led to the decision to change the layout of the portal with a division between the Funnels and the Tables for the 2010-13 cohort. When DC took an extract of the data in July, the tables were not updated at the same time. This July's extract produced Funnels which were later sent to HQIP and had been used when assessing outlier status. When taking a further extract in September to produce aligned Funnels and Tables, it was apparent that many hospitals had updated data in the interim, leading to differences in the new Funnels from the July extract. This September's reanalysis, which also included deaths in the latest ONS tracking extract (still using the old life status methodology), identified 1 confirmed and 1 potential specific procedure outlier (later proved not be an outlier). The confirmed centre has not been notified of the outlier status as yet but a process will follow led by JS, in this case in consultation with NHSE and the centre concerned. To avoid delaying publication, the decision was made to publish as planned with the July extract Funnels and use the September extract for the Tables,

acknowledging that the two would not add up as planned. To make this distinction clearer, it was agreed that the two outcomes (Funnels and Tables) would be displayed on the Portal under separate tabs, with clear statements to explain the differences in extract dates. The current situation is a short term fix and, on publication of 2011/14 data, the outcomes will revert back to the original layout. When funnels are updated with 2013/14 data, the tables will be updated and the refreshed page will remain unpublished until the funnels are published too. In terms of next steps, NICOR will have a debrief session on the process and ways to ensure this does not happen again.

e. 2011 – 14 analyses: timeline & plans – Not discussed due to time constraints.

5. Data validation: subcommittee report

a. Remote validation 2013/14 data – As part of the process to streamline the validation process, low volume adult centres will not receive a validation visit. Instead, a remote methodology will be used similar to one used by the Adult Cardiac Surgery and PCI audits. In these audits, analysis is distributed to the centres and centres are given 2-3 weeks to confirm accuracy. A mockup of the analysis (Paper D), based on counts of procedures and deaths, was circulated ahead of the meeting.

b. Data validation 2014/15 onwards – not discussed due to time limitations

6. Dataset changes

a. **Generic** – Not discussed due to time limitations but previously agreed changes fields were not in dispute.

b. **ACHD** – Not discussed due to time limitations and KE unable to stay on call. Previously agreed field additions were also not in dispute. A plan to have these ratified by the ACHD wider senior Consultant community had already been agreed.

c. Catheter

- AT raised concerns about the some of the proposed increase in diagnostic data items, the feasibility of local data collection and whether data could be validated. There is a need to be clear on the reasons for collecting specific data and how it will meaningfully help the assessment of postprocedural outcomes, particularly complications. Wherever possible, data points need to be mapped to the new NHSE Standards. DC said that the dataset needs to be finalised by October 17th. Suppliers need six months lead in time to implement the changes. RF suggested a **teleconference to finalize dataset changes week beginning 13/10/2014.**
- Surgical dataset: It was agreed to add one more field to be called Complications with approximately six sub-categories. It was also agreed to keep bypass and cross-clamp fields in for now.
- JS advised the group that any changes also need to reflect future strategic directions. The current contract ends in March 2016 and the audit will be up for competitive tender in 2015. By this time, the audit needs to be in a good position to demonstrate that a strategy for quality improvement was already in place.

d. **Fetal**

- RF has been collaborating with NHSE, Public Health England and Dr Gurleen Sharland (GS; Lead Fetal Cardiologist at Evelina) to develop a fetal dataset that will capture fetal outcomes, which would then link to the current post-natal procedural dataset using the mother's NHS number, post code and date of birth. Additional data

fields will be Reason for fetal scan, extracardiac and genetic comorbidities and fetal outcome (termination, in utero demise and live birth with compassionate care or an interventional procedure). It had also been agreed to target specific lesions only at this stage (HLHS, TGA, AVSD, Fallot, Pulmonary Atresia, functionally UVH). This would be a major step forward in achieving the long term aim of the NCHDA of monitoring outcomes based on the patient's diagnosis, rather than solely post procedural outcomes.

- GS with RF are currently drafting a proposal to take to BCCA in November. There may be additional NHSE/PHE funding for expansion of the fetal dataset and its linkage to postnatal neonatal and infant procedure based outcomes. As this is not in the current scope of the audit it will need to be approved by NICOR Exec initially before submitting to HQIP. AB/TW will then draft a proposal based on the BCCA proposal.
  Action: RF/GS, AB/TW

7. AOB

LD highlighted that at the end of quarter 2, 6 centres have still not submitted for quarter 1. All 6 have been contacted and 5 have responded with only Bristol not to have made a formal response. However it was pointed out that this is due to a new data manager being in post.

8. Dates of next meetings:

Tuesday 2nd December 2014 (NICOR)
Monday 23rd March 2015 (Manchester SCTS including Stakeholders meeting)
Wednesday 17th June (NICOR)
Date TBC September 2015 (NICOR)