

**Congenital Steering Committee**  
**September 18<sup>th</sup> 2012 13.30 – 16.00**  
**NICOR**  
**170 Tottenham Court Road**  
**Agenda**

<b>Attendees:</b>	
John Gibbs	Chair
Rodney Franklin	Vice Chair, Consultant Paediatric Cardiologist at Royal Brompton Hospital
Kate Brown	Consultant Intensivist GOS, Research & Outcomes Lead
Thomas Witter (TWi)	Surgical Data Manager Guys and St Thomas
Kate English	Cardiologist, Leeds General Infirmary (BCCA, ACHD)
Chuck McLean	Cardiac Surgeon, Royal Hospital for Sick Children, Yorkhill, Glasgow (representing SCTS)
David Cunningham	Senior Strategist for National Cardiac Audits
Lynne Walker	Programme Manager NICOR
Andrew Harrison,	Developer NICOR
Nadeem Fazal	National Clinical Audit Service Manager
Lin Denne	Data validator
Tracy Whittaker (TWh)	Project Manager NICOR
<b>Apologies</b>	
Tony Salmon/ (BCCA)	Paediatric and Adult Congenital Cardiology University Hospital Southampton
Alan Magee	Paediatric cardiologist, Royal Brompton & Harefield NHS Foundation Trust

**1. NICOR update**

1.1. Work is underway to develop a new IT platform that will house all of the cardiac audits. The high level design has been approved and signed off. Stakeholders and clinical leads are represented on a management committee to provide input on functionality and performance. It should be possible to provide screen shots and updates at the 2013 stakeholders meeting. TWi felt this would be a good time to drive data quality.

**2. Report from NICOR research group**

KB gave an update on the NICOR research group meeting:

2.1. At a NICOR level the research priority focuses on linkage projects and that will determine access to analytical resources. That said, they are also keen to pursue international collaboration so it would be worth KB

highlighting any international collaborative work.

- 2.2. NICOR also has a policy that NICOR data is acknowledged within any publication. This is stated in the NICOR data application form. The exact form of the wording has not been finalized but it is hoped that the term 'NICOR' and the name of the audit would be picked up by search engines.

### **3. Congenital Research Group Update**

- 3.1. Freedom from reintervention and actuarial survival work is ongoing and JG currently contacting sites about data quality
- 3.2. DC is looking at two separate outcome measures: neurological assessment and stroke.
- 3.3. Serban Stoica (Bristol) is looking at the CCAD data to develop a morbidity metric
- 3.4. CORU work is progressing well and a draft article submitted for peer review. The work has highlighted the problem of data quality.

### **4. Mechanisms for data error and detection**

- 4.1. CORI work highlighted poor quality diagnosis vs procedures. There are some issues surrounding data quality but a number of solutions have been identified. For example, AH and NF described some technical facilities such as pop up screens and automated reports that feedback data quality to local clinicians and data managers. AH and NF will review facilities in existing data bases and feedback to the group.
- 4.2. LD raises awareness of data quality at each site visit especially for diagnosis fields. LD also reported that some of the problems may be caused by third party suppliers. For example, solutions to a problem reported by one site are not always rolled out to other sites. This seems to be a problem with HeartSuite. There are also compatibility issues with some bespoke systems (e.g. Alder Hey).
- 4.3. JG will include a section on data quality in the next newsletter.

### **5. Fetal update**

- 5.1. DC distributed antenatal analysis which is also available on the congenital website. It was agreed that this work would also be included in the annual report. JG and NF have been working on a final draft of the annual report which is near completion.

**Action: JG**

### **6. Data analysis and censorship**

- 6.1. As an indirect of Dr Foster work, analysis with censorship has been abandoned as there is a risk of double counting. This raises issues of data requests and how to avoid future problems.

### **7. Outcome measures**

- 7.1. Outcome measures other than death are being explored. DC is looking at the use of freedom of intervention, neurological status data and early reoperation within 30 days. Plans are also in place to link congenital data with HES stoke data. There is also a growing call from parent groups to

include neurological assessment.

**Action: DC to circulate his preliminary analysis of cerebral performance category**

## **8. CQuins for commissioners**

CQuins (care quality indicators) are being demanded in future by commissioners. The CQuins for congenital heart disease procedures include %mortality per 1000 live births - data which is undefinable, undeliverable and plain nonsense. CCAD has not been asked for advice or input!

## **9. Data request from Dr Foster**

9.1. The second request for data has been rejected on the basis of lack of ethical consent, confidentiality issues and poor methodology.

## **10. Adult congenital update**

10.1. Data is slowly improving and is expected to improve as the number of operating centers reduces and clarity over the definition of congenital heart surgery improves.

## **11. Ireland North and South**

11.1. Mortality linkage continues to be an ongoing in Ireland as they have unique identifiers but cannot link this with mortality data. Northern Ireland and Scotland have therefore not been included in initial long term outcome analyses. There are also ongoing information governance issues about sending PID between different EU countries. Despite a national policy, the Information Commissioner in Ireland refuses to give permission for hospitals to submit date of birth to the audit. One approach would be to include mortality data in clinical consent forms.

**Action: JG to write to RB**

11.2. The group discussed current consent forms and it was agreed that the sustainability of the audit was dependent on 100% consent. The process and content needs to be reviewed and extended to cover audit, research and life status. Within the audit, consent forms only cover purpose of validation. This will be an item on the agenda for the next steering group before reporting back to the societies for feedback. This will also need to be published in the newsletter.

**Action: CMc**

11.3. LD thanked TWi for his support in helping Dublin to participate in the audit.

11.4. It was agreed that access to the congenital portal would be more user friendly if there was a standalone link on the left hand side of the NICOR website.

**Action: TW**

## **12. Linkage to HES for PFO follow up**

DC will update the group at the next meeting

### 13. Lay representation

13.1. The group debated the mechanism for lay representation. BCCA and SCTS Councils have been asked for their views. There are plans for lay representation on the imminent NICOR governance board and it may be that this representative would also give lay advice to congenital CCAD.

**Action: TS and CMcL to discuss with respective Councils**

13.2. The group discussed the role of the Steering group, the NICOR Executive Board and its members. CMcL highlighted the importance of transparency and clarity over roles and responsibilities, particularly given the high profile nature of the plans for analysing freedom from re-intervention. JG agreed this was important. The remit of the research group was covered in its Terms of Reference.

**Action: TW to circulate the Research Group Terms of Reference.**

### 14. Succession plan

JG is due to retire at the end of the year. RF will be the new Chair of the Congenital Steering group from February 2013 although JG will continue to provide support until April 2013. RF will represent the Congenital Audit at the NICOR Executive meeting. LW will update the NICOR Executive membership and Invite RF to the next meeting.

**Action: LW**

### 15. Stakeholders meeting 2013

The group agreed that the stakeholders meeting should continue at the Royal College. JG to ask RCS for room availability for January 29<sup>th</sup> or 30<sup>th</sup>.

**Action: JG to confirm**

### 16. AOB

16.1. Funding for the clinical lead position was discussed following a request from the Brompton for a contribution towards RF's time when he takes over the role. JG had anticipated this and had included costing for 1PA per week in the original budget for congenital CCAD in the NICOR bid **Action: JG to write to Zoe Fearnley**

16.2. LD is in the process of reviewing validation fees for sites in Scotland and Ireland. The group agreed to an increase of 3.2% of the current fees.

16.3. Some Trusts are commissioning services from private hospitals to reduce waiting times. LD queried how these cases should be coded.

**Action: LD to discuss with DC.**

### 17. Date of next meeting

Tuesday December 18<sup>th</sup>, Meeting room 1, 170 Tottenham Court Road 13.30 – 15.00