National Congenital Heart Disease Audit Steering Committee
Steering Group: 10 March 2014, 12.45-14.45
Soutre Room, SCTS Annual Meeting
International Conference Centre,
Edinburgh
Notes

In attendance

Forname	Surname	Role	Organisation
Kate	Brown	NICOR research & outcomes lead	GOSH
Rebecca	Cosgriff (mins)(BC)	Audit project manager	NICOR
Kate	English	BCCA ACHD rep	LGI
Rodney	Franklin (chair)	NICOR congenital lead	RBH
Robin	Martin	BCCA president	BRHC
Chuck	McLean	SCTS congenital database subcommittee chair	RHSCG
Thomas	Witter	Congenital database managers' lead	EVH
Serban	Stoica	SCTS representative	UHBristol
Andreas	Hoschtitzky	SCTS representative	AHCH

1. Apologies — **Action**

Apologies were received from David Barron, David Cunningham, Alan Magee, Owen Nicholas, Emmanoul Lazaridis, and Tracy Whittaker.

2. Previous minutes and actions

The minutes were agreed to be an accurate record of the meeting.

3a. Research applications

13-Cong-03: Gaining Andrew Jones' GOSH data request HQIP approval took six weeks.

BC stated that HQIP holds monthly sign off meetings for data applications; a timetable has been circulated within NICOR to all project managers. Urgent requests can be fast-tracked if a clear rationale (e.g. upcoming conference) can be provided as to why it must be prioritised.

Action: TWh to disseminate HQIP approvals timetable to the Research Committee. — **TWh**

Action: DC to confirm that this project did not require S251 approval, and that the data have been released. — **DC**

3. Data requests

3.1 Research Requests

The group reviewed the congenital data requests spreadsheet.

KB requested a correction to 09-CGG-1: the PI is Victor Tsang, not Christina Pagel (although CP is involved).

Action: TWh to amend the spreadsheet accordingly. **TWh**

14-CONG-01: Dr Paul Clift
This request has been signed off, and data has been issued.

14-CONG-02: Lee Ferguson
KB stated that the linkage required that this project needs will require REC ethical and HRA approvals. A £5k charge will be issued by NICOR as this is a complex project; this fee can be factored into the research grant, as already suggested in the application form. This project is approved, provided evidence of appropriate approvals can be supplied prior to data release.

14-CONG-03: Kate Brown
This project has been approved. A grant in place to pay a 5k charge for this linkage project.

14-CONG-04: Frances Bu-Lock
RF has amended this application on FB-L's behalf as it was incomplete on submission. Confusion arose as the applicant was attempting to complete a research form for a service evaluation project.

The group pointed out that this analysis is being carried out by NHS England at CCG level already.

To avoid duplication, and potential issues with providing postcode data of more relevance to other units, the RC felt it best for NICOR to conduct this analysis and publish it on the NICOR website with a quick turnaround.

RF

Action: RF to contact the applicant to provide an update.

Masters application form: Helen Christmas
This application has been circulated to the group; it intends to look at social deprivation in a similar way to the on-going NHS England work.

Life status at one year is not a feasible outcome measure as PRAiS is not configured for this. This would be a very challenging project and the application shows lack of understanding of the methodological issues related to the inherent complexities in CHD and related procedures. These concerns need to be fed back in a constructive manner. **RF**

Action: RF to contact the applicant to discuss the group's concerns, and to note the pre-existing NHS England work on deprivation and ethnicity, as well as KB Infant Surveillance Project which is looking at 1 year outcomes.

To avoid duplication of future research applications, all past and on-going research applications should be listed on the NICOR website and/or congenital portal, including related NHSE research. **TWh**
Action: TWh is to add current and past research applications to the NICOR website **TWh**

Antenatal diagnosis project: Rodney and Helena Gardiner
This project has been completed and published in Heart.
Action: RF to send TWh the paperwork so that this can be added to the **RF**

website as an audit publication.

3.2 Charges

The following statement has been issued by NICOR:

"*The existing NICOR policy is that all extracts should be charged £5K, unless it is requested from a participating hospital for their centre data. To date, this has only been implemented by MINAP and a few congenital studies. It is necessary to ensure standardisation, and fairness, across the audits so all studies will be charged £5,000 and £5,000 for linkage. The charge for annual updates will be £1,000. We are currently reviewing the charging policy and will devise a tiering system to reflect the types of applications we are receiving. Any suggestions from anyone would be most welcome."*

John Gibbs has submitted a statement that recommends NICOR data applications are judged on their merits and only charged if the project is complex or commercial.

RF stated that there is unhappiness with the current charging regime of £5K for all in other audits, such as CRM.

JS has reported that implementation of the aforementioned charging structure is a requirement of the NICOR research lead, but also that there are proposals for a tiered structure.

KB reported that the charging policy has not been discussed at the research committee.

RM voiced concern that charging units for data will stifle research and good will, and TW suggested that units may cut NICOR out of the process and gain data direct from one another. Charges must be sensible and proportionate.

CM stated that there needs to be a clear and fair algorithmic rule; with all costs justifiable. Indeed, some requests may warrant a charge of more than £5k.

The group asked for a clear breakdown of costs relating to the £5k fee, and where the funds would be allocated, as analytical resource is already funded and projects will not be given additional statistical support in return for generating research applications.

After some discussion, the group agreed that a £5k flat rate and would request that it is not implemented at this stage. A tiered algorithmic approach is required and a flat rate should not be arbitrarily imposed due to a historic policy document. In the interim, each project will be judged on its merits and forewarned that a fee may be payable.

CM stated that the definition of 'service evaluation' needs to be clarified. KB agreed; service evaluation projects won't be charged but it is not clear how these are categorised.

3.3 FOI

As DC was not in attendance, this item was not discussed in detail. An FOI request has been received from Bob Ward; which has been dealt with by UCL as per policy. Update: In fact this request is for a breakdown of procedures by 2 digit postcodes and is therefore virtually identical to that requested by Dr

Bu'lock and clarification on what will be provided to Bob Ward is needed as it would be logical to provide Dr Bu'lock with the same data.

3.4 Spreadsheet
This item was covered under 3.1

3.5 Bypass time
This item is to be carried over to the next meeting, as DC and DB were not in attendance. Action points from the last RC should be revisited by DB and ON who have action points on this. **DB/ON**

4. Update from NICOR Research meeting
KB reported that the last meeting was cancelled. There is nothing of specific congenital interest to report. It was clarified that Chris Gale is the chair of this group.

5. Project updates
5.1 Reoperations project (SS)
This project is almost complete. Two abstracts from the aortic valve project have been shown at conferences.

The project has a third component; to compare surgical and balloon valvotomy, which will be published. However, some operations pre-date CCAD. The group advised that this could be resolved by converting this project to a multi institutional venture, using local records to ascertain the pre-CCAD outcomes.

KB advised that written confirmation from CAG that ethical approval is not required must be gained; this assurance can be shown to participating centres, and used when submitting papers for publication.

RF stated that, for NICOR to carry out the linkage and avoid PID being supplied to SS, an application must be submitted and a charge may be incurred by NICOR.

SS went on to describe that a coronary anomalies project has generated interesting preliminary results, but follow up and life status is missing for around 20% of patients (usually this is closer to 10%). RF recommended verifying with DC that recent ONS issues have not affected this dataset. Life status data for the dataset may need to be re-sent as missing data may have reduced. The aortic project may also be affected.

KB raised that there is a NICOR acknowledgement that needs to be added to all research papers based on NICOR data. TWh can supply the form of words.

5.2 Long term outcomes of Fallot and Switch (AH)
Some progress has been made but this project is not yet completed. KB stated that this project may not require ethics approval as reoperations at other units can be identified by NICOR and pseudonymised prior to data release.

5.3 Diagnosis based outcomes as a current project (KB)
An update on this project will be provided at the next meeting.

6. **Updates on in-house/NHS England projects**

RF presented slides provided by ON relating to the on-going NHS England projects.

One year outcomes need to be removed from the analysis plans as these have not been agreed.

The new draft analytical protocol for ethnicity and deprivation has not been sent to RF and KB as the slides state (as far as they are aware).
Action: ON is to send RF and KB the 'draft analytical protocol' with an update on the status of this project so this can be finished by the end of April as agreed with NHSE. — ON

It was noted that ON has yet to put in application forms for the NHSE work and this must be a priority (immediately after ON's look at the PRAiS recalibration data submission to CORU).
This must then have approval from the Congenital RC.
Action: ON to submit a research applications for the NHS England work — ON

The group were concerned that John Holden's NHS England blog has a linked paper entitled Update on Analytical Work, which includes predictions of CHD activity based on NICOR derived activity, but also includes a section on planned further Outcome Analyses by NICOR. In this it is stated that analyses relating 30 day mortality to Ethnicity, Deprivation, Volume of Procedures by Unit and Procedure & Complexity would all be delivered by 30 April 2014. This schedule had not been agreed by the RC and only Ethnicity and Deprivation were likely to be ready by then and had had approval (Dec 2013 RC). Further the document states that analyses later than April 2014 which had been agreed (tick next to each), were Volume of procedures by Surgeon, Patient proximity to surgical unit and Timing of procedures. The first was very much not agreed by the RC or SCTS and the RC confirmed that this would only ever be agreed if the SCTS stated that they were happy for theis analysis to go ahead.

Action: RF to contact NHSE to state that only deprivation and ethnicity analysis will be achieved by the end of April 2014. **Update**: JG said that she had written the above following a teleconversation with TWh, DC and ON and her impression was that this had been agreed. She however said it was down as 'a proposal', despite the ticks. RF made it clear that there was no agreement that for surgeon specific analysis of any kind, including by number of surgeons in the unit (a separate suggestion). RF emphasised, as had the RC, that this was because surgical procedures undertaken for CHD was a team activity, with crucial input from intensive care doctors, paediatric cardiologists and anaesthetists, more so than in adult acquired surgical practice. Therefore such analyses would only be possible if the SCTS gave permission for this. JG confirmed she understood this and would discuss internally with NHSE colleagues. — RF

CM proposed that NHSE could link with PICANET/HES to ascertain whether CHD patients are dying without treatment. Update: RF confirmed that JG had said that assessment of non-procedure based activity was part of the NHSE plan and he is helping with related coding interrogation of HES at this stage related to procedures but this would progress to non-procedural activity in due course.

7. ACHD updates
Due to time constraints this item was not discussed.

8. PICANET
This item is to be discussed at the next meeting.

9. AOB
None