National Congenital Heart Disease Audit

Steering Group: 10 March 2014, 12.45-14.45

Soutre Room, SCTS Annual Meeting, International Conference Centre, Edinburgh

In attendance

Forname	Surname	Role	Organisation
Kate	Brown	NICOR research & outcomes lead	GOSH
Rebecca	Cosgriff (mins)	Audit project manager	NICOR
Lin	Denne	Data validation officer	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
Julie	Sanders (Skype)	COO	NICOR
Thomas	Witter	Congenital database managers' lead	EVH

1. Apologies — **Action**

Apologies were received from David Barron, David Cunningham, Owen Nicholas and Tracy Whittaker.

2. Previous minutes and actions

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

7. Annual report

KB has submitted some comments and additional material to TWh.

Action: TW is to incorporate amends and circulate to the group. — **TWh**

9.1.NHS England initiatives

HQIP are happy for Scotland and/or Northern Ireland to be included in the audit, but cannot provide funding for any additional support (e.g. validation visits) required.

JS reported that HQIP have approached the Scottish Health Board, which has turned down the offer of an official agreement at national level. NICOR could pursue a separate agreement if desired, but funding would need to be provided by Scotland.

CM stated that clarification is required regarding the correspondence that has taken place between HQIP and the Scottish Health Board.

Action: JS is to ask for more detail about prior correspondence at a meeting with HQIP on Thursday and report back to CM to ensure appropriate people are involved in discussions. — **JS**

All other actions are covered on the main agenda.

3. NICOR update

a. Governance and internal and external review updates

Governance

RF talked the steering group through the new organisational structure. The audit has been called 'National Audit of Congenital Heart Disease Procedures' by HQIP in the new contract negotiations. RF stated that due to also including endocarditis patients the use of procedures in the title would be inaccurate. TW will ensure this is changed on the new contract.

There was some confusion about the roles of the NICOR Research Executive and the NICOR Research Working Group (RWG).

JS explained that the RWG is responsible for the day to day running of research activity at NICOR; such as revising the data sharing policy and application form. The Research Executive is primarily responsible for approving data applications that have been escalated from individual audit research groups or involve data linkage.

The ToR and membership of the Research Executive is currently under review and will be communicated when finalised.

The membership of the Professional Liaison Group (PLG) was discussed, with CM stating that a congenital surgeon should be represented.
RF explained that congenital surgery is represented via the audit leads and specialist society members (SCTS President in this case), with JS adding that the chair can invite additional members for specific agenda items where necessary.

Internal and external review

RF provided an update to the steering group regarding the internal and external reviews of NICOR following the Leeds data release in March 2013.

Following internal review and subsequent governance changes, all NICOR staff and audit steering groups were invited to complete a questionnaire by an external UCL review panel. The subsequent report, which was made available in December 2013, highlighted 13 key areas for development:

1. *External communications*
   Including recruitment of a dedicated Communications Manager, use of social media, and revision of the NICOR website.
   CM queried whether any clinicians will be present at the PPI open day, as parent and patient groups involved in the Congenital Audit tend to be very vocal and potentially very critical. JS stated that congenital clinical queries relating to Bristol will be addressed at a different session so as not to detract the focus from the aims of the day. However, if it is clear that there is a need for a more wide ranging PPI for the Congenital Audit, this will be organised at a subsequent event with SC clinician involvement.

   The current advertising strategy for the Open day may not reach congenital patients' families. An advert should be placed through the Children's Heart Federation and the BCCA website.

   Action: TWh is to pursue congenital advertising in collaboration with Carol Porteous. **TWh**

2. *Internal communications*
   The effectiveness of new meeting structure in improving this will be assessed
3. *Consistency between audits where appropriate*
4. *Relationship with specialist societies to be formalised with MoUs*
5. *Managing outliers process to be consistent, simple and efficient*
6. *NICORs roles and purpose need to be defined and developed*
7. *ICS and UCL context*
8. *Governance arrangements to be included at staff inductions*
9. *Data provision*
   Including development of a diagram outlining who is responsible for the quality of data at any given point, to be published on the NICOR website.

   KB stated that care needs to be taken when allocating responsibility for sense checking data supplied by third parties, such as ONS and HES.
10. *Data points*
11. *Analytics/statistics; more staff to be recruited*
12. *Responsibility of hospitals to be formalised with MoUs*
13. *IT Systems to be redeveloped under the Informatics and IT working group*
    RF queries the current state of play with the new IT platform. JS explained that in the short term lotus notes data are being exported into SQL for analytical purposes, and all audits will be web enabled by the end of 2014. In the longer term an options appraisal a new IT platform will be undertaken

b. NICOR Risk and Governance: Outlier Policy

RF outlined the congenital outlier policy that has been in place up to now; which triggers different levels of action depending upon the extent to which data is outlying.

The draft proposed NICOR Outlier policy was then discussed. Concerns were raised about the lack of differentiation between varying levels of outlying data.

RB queried how often the congenital outlier process will be carried out and RF stated that it would be annual, following data validation visits. It would supplement more regular local validation using PRAiS mediated VLAD plots. It remains important that units are given sufficient notice prior to analysis being published, and that any outlier process has been acted upon in advance of public publication.

The group felt that the phrase ‘case to answer’ might be too emotive, which JS stated she would take into consideration as PCI has raised a similar concern. However this phraseology reflects the national DoH/HQIP Guidance on the Identification and Management of Outliers. JS emphasised that the document is in effect an early draft and was due to be discussed at the PLG on March 12th.

TW suggested that database managers should be contacted in the first instance, as well as clinical and governance leads, to investigate outlying data. This should help to ensure a prompt and informed response.

The group preferred the term ‘potential outlier’ to be used throughout the

outlier process. **JS**

Action: JS is to consider the suggestions of the steering group for incorporation into future drafts of the NICOR outlier process.

c. Terms of reference

This is a standing agenda item due for discussion once the TOR format had been agreed and standardised for all the Audits. **Action:** TWh to add to agenda for next meeting in June 2014. **TWh**

d. HQIP deliverables

The HQIP contractual deliverables for 2014-2016 have been seen previously by the Steering group, and have now been officially signed off between HQIP and NICOR.

RF highlighted that a timeline for delivery of Consultant Level Outcomes was down to be devised by April 2015. From the Congenital Audit's standpoint this could only be agreed with Societal backing which is not forthcoming at present, particularly the SCTS as CHD surgery requires a collaborative approach with important contributions from anaesthetists, intensivists and cardiologists. This is much more the case than for Adult surgery. A debate therefore will need to take place between the Specialist Societies and HQIP in relation to this in due course.

RF sought confirmation that a Project Plan would be devised by TWh by Apriland will include a detailed plan for implementation of required portal development.

A feasibility assessment on utilising HES data to estimate case ascertainment will be complete by September 2014.

4. Analysis

Previously ONS has been used by the Congenital Audit as a 'gold standard', which has superseded hospital entered mortality data where discrepancies have occurred. In line with other NICOR audits, this policy has now been reversed. RF outlined the reasons for this to the steering group.

In November 2013 it was detected that an issue with new ONS software caused an error in mortality data that led to over 100 mortalities from October 2011 going undetected.

There is no implication for data prior to October 2011. The recalibration of the PRAiS model in summer 2013 may have been slightly affected, but this will be remedied when the recalibration is repeated over the next month.

In addition to this, it came to light that ONS does not record mortality until any ensuing inquest has been concluded. Inquests occur in around 15% of congenital mortality cases and can take up over a year to resolve. This has led to deceased patients being recorded as alive.

LD raised a third issue; that of lack of consent to look at the medical notes of a deceased patient; which would lead to the case not being reported. RF stated that cases such as these would require escalation to the Medical

Director of the centre concerned so that permission can be granted.

CM suggested that a quality control warning should be issued where mortality data is missing.

Action: CM to circulate Scottish policy on dealing with death data without ONS to the steering group

CM

5. Dataset changes

Due to delays in signing off a new dataset, implementation in April 2014 is no longer realistic. The group decided that the dataset should be mandatorily implemented from 1 April 2015, but distributed to users ASAP so that hospitals that are able can begin to retrospectively and/or prospectively enter the new fields prior to this date.

New dataset items were detailed and will include GMC code. There will be new data fields specifically for ACHD and arrhythmia related procedures so as to enable linkage to the CRM Audit database: height, systemic LV function, NHYA status, added arrhythmia code and procedure details. In addition other fields and codes will be added, such as Comorbidity (Y/N), emergency procedures (with definition) and operation starting time. Operation finish time will not be collected; return to ward can be gained accurately and avoiding duplication through linkage to the PICANET audit.

6. Data quality

a. Data validation visits: timetable and changes

LD has drawn up a provisional validation visit timetable to commence in May; closer to the data entry deadline than previously. Hospitals will be provided with a smaller choice of validation dates to speed up the process, and the timetable will be disseminated by LD shortly.

b. Review of data validation process

A data validation committee has been established to review the data validation process and make recommendations for a more efficient process.

c. Minimum data standard

This has already been signed off by the steering group and was not discussed further.

7. Review of 2010-13 procedure funnels

It is statistically invalid to publish multiple units in a funnel plot with the same control limits. Therefore the congenital audit is moving away from traditional funnel plot displays to show each unit with its own control limit.

KE voiced concern that the ‘much higher than predicted’ language is potentially problematic.

8. HES linkage

Due to time constraints, this item was not discussed.

9. Interventional procedures and complications/risk adjustment

Due to time constraints, this item was not discussed.

10. Next meetings

a. Stakeholder meeting CiTY (Cardiology in the young) 16 April: NICOR business meeting. Update: it was decided that the Business meeting would no longer be required given the proximity to the Stakeholders meeting (10 March 2014) and PPI Open day. Invitations would go out to patient groups to the earlier joint NICOR-CitY session.

TWh

b. Research and steering group meeting 10 June 2014 NICOR

11. AOB

None