**The National Congenital Heart Disease Audit Database**

**Data Quality Audit for**

**CONGENITAL HEART DISEASE**

**For Apr 2017 – Mar 2018**

**The Royal Hospital for Children,**

**Queen Elizabeth University Hospital**

**Glasgow**

**27 September 2018**

*performed by Lin Denne and Dr H Parry*

**Summary**

This validation visit, which has reviewed the congenital cardiac data for the years April – March 2017 -18 has been fully funded by the NHS Scotland.

This visit was supported remotely by the NCHDA clinical audit nurse via a teleconference facility and; on site in person, by Dr H Parry a Locum Consultant in congenital cardiology from Leeds.

Prior to this congenital data review the data return to the NCHDA from the cardiac department of the Royal Hospital for Children at Queen Elizabeth University Campus Glasgow (RHS) indicated that some 552 procedures (300 surgical operations, 158 catheters, 94 others, 10 deaths), had been undertaken during the data collection year of April 2017 to March 2018 in patients aged 16 years or less. As previously reported, procedures in patients aged over 16 years are mostly (but not all) undertaken in Glasgow at the Golden Jubilee National Hospital (GJH) and in Edinburgh at The Royal Infirmary. Whilst NCHDA receive data from GJH and undertake validations at that centre, no data are received from the Edinburgh Royal Infirmary. There is a 1.0WTE position of Information Manager for congenital cardiology based at GJH.

As at all the previous NCHDA visits, there is real time data input by clinicians using Heartsuite at RHS. HeartSuite is available at PCs throughout the congenital cardiac department.

There is a 1.0WTE post for a cardiac information manager at RHS. Since June 2015 it is reported that the role is divided into 2 jobs. There is a permanent 0.75WTE Information Manager (DBM) at RHS. The other is a 0.25 WTE role. 1 specific consultant clinician acts at Audit Lead for this data collection.

As previously reported, local validation of the previous weeks cardiology cases was commenced with the relevant clinicians in September 2007 and now takes place at the weekly MDT meetings. Validation of surgical cases takes place weekly with the consultant surgeons.

**Actions Undertaken since the November 2017 Validation Visit**

1. At the time of this validation visit RHS are utilising HeartSuite 7.6.26. This application is suitable for the NCHDA 2017-18 dataset.
2. The surgical log book and catheter laboratory log book continue to be completed and internally verified regularly. During the audit year the surgical log book was misplaced and some device data was not captured. This had been resolved and the data will be updated.
3. RHS continue to complete additional data checks prior to upload to NCHDA with improved reverse validation procedures to ensure data quality. The inclusion of the primary key did improve these processes, however, this identifier has been removed from some NICOR extracts and this has been difficult and time consuming.
4. Some code changes have impacted on previous procedures but RHS hope all have been resolved with reverse validation.
5. Previous procedures on the database are limited to 12 values per patient record whereas previously this was one comma separated value. This means that the most recent previous procedures are excluded.
6. RHS have noted that the comorbidity field may be recorded incorrectly. This may be due to a disparity in the NCHDA definitions list and the HeartSuite code table.
7. Two patients are missing discharge details and some other data due to the status of current inpatient.
8. Discussions following the second operator query raised at last year’s audit have been resolved. The consultants identified that this information was being recorded to identify the nurse who was in theatre at that time.
9. NCHDA Data Manager is 1.0WTE. at the time of this validation visit.

**Consent for External Validation of Congenital Cardiac Patients Hospital Notes.**

This has been required by NCHDA since 1 April 2007. As previously reported, RHS cardiac department amended their own departmental consent form to accommodate this requirement. Every patient is informed on the consent form that the data relating to their procedure will be submitted to NCHDA and may be externally validated. As reported in January 2013, there have been no refusals by parents/patients or guardians to give this consent reported to NCHDA.

**Data Quality Indicator Scores (DQI)**

The overall DQI for the hospital is calculated to be (with previous years in parentheses) **99.5%** (99.25, 99.25, 98.5), with domain scores Demographics 1.0 (1.0 1.0 1.0) Pre Procedure 1.0 (.99, .99, .98) Procedure 1.0 (.99, .98, .96) and Outcome .98 (.99, 1.0, 1.0).

Also, for this visit, a separate DQI calculation is being made for surgery and catheter procedures where there is a minimum of 5 records in either group at the case note validation.

The scores for RHS are:

|  |  |  |  |
| --- | --- | --- | --- |
| **Year of Visit** | **Data Years reviewed** | **Surgery DQI** | **Catheters DQI** |
| **2010** | 07-08 | 99% | 97% |
| **2011** | 08-09 | 95.25% | 91.5% |
| **2011** | 09-10 | 95.25% | 95.5% |
| **2012** | 10-11 | 95% | 92% |
| **2013(i)** | 11-12 | 96% | 97% |
| **2013(ii)** | 12-13 | 99% | 99% |
| **2014** | 13-14 | 97.5% | 99.5% |
| **2015** | 14-15 | 99.5% | 96.5% |
| **2016** | 15-16 | 98.75% | 99.25% |
| **2017** | 16-17 | 99.25% | 99.75% |
| **2018** | 17-18 | 99.5% | 100% |

The NCHDA pre visit Questionnaire was completed and returned prior to the validation visit. This confirmed that there are good processes and procedures in place in regard to:

Data Security and Management

Validation and Quality Assurance

Training in Data Management

Information Governance Training

There are identified accountable person/people for NCHDA data quality and information validity

Data Submissions are Timely and Accurate.

**Introduction**

The data return to NCHDA from the cardiac department of the Royal Hospital for Children Glasgow indicated that some 552 procedures (300 surgical operations, 158 catheters, 94 others, 10 deaths) had been undertaken in the data collection year 2017/2018 of which 20 records were selected for review.

As stated above, 20 sets of patient notes were requested for review (the Sample), a further 10 sets (the Reserves) were selected as a reserve in case any of the first 20 were unavailable on the day.

On the day 20 sets were made available (19 Samples, 1 Reserves) covering 26 procedures, (16 operations and 10 catheters).

The accuracy of the NCHDA data return was then checked against each set of notes to enable the Data Quality Indicator (DQI) to be scored.

**Review of case notes**

The Validation Team would again like to thank the Data Manager for the meticulous attention to detail in printing the relevant pages from the ePR during a very challenging period. This was of great assistance to the independent external clinician who was on site. The following observations during the case note audit;

1. The admission summary sheets that were seen were again found to be very helpful
2. The PICU/BADGER reports were generally very helpful and almost always recorded the date of extubation but not the exact time.
3. As previously reported, perfusion sheets were seen for almost all surgical patients.
4. The cardiac catheter sheets were fairly easy to locate and the data required for NCHDA were easy to identify.
5. It was noted that the discharge proforma appear to be prefilled prior to the actual discharge date

**Review of the Catheter and Theatre Log Books**

As previously reported, bound bespoke log books to record activity in both the cath labs and operating theatres were reinstated 2012 at RHS following a trial without them. The HeartSuite activity log is validated against the hospitals theatre management log OPERA and these books. OPERA is an all in one booking, scheduling and intraoperative data collection system. OPERA was not found to be such a comprehensive and accurate log of procedures as the bound log books and HeartSuite at earlier validation visits.

It was noted on several occasions in the hand written log book that the name of the operation performed did not always appear to accurately describe the actual procedure.

1. 0 surgical procedures were identified that may have been missed from the congenital submission
2. No other surgical queries were identified.

**For the 2017/2018 Cath Lab logbook review,**

1. 4 submitted catheter records may have data errors in them

**Validation of Deceased Patients Diagnostic and Procedure Coding**

Commencing with the validation of the 2014/15 data, the National Congenital Heart Disease Audit wish to verify any dates of death of deceased patients included in the year under review. The diagnosis and procedure coding will also be validated. The requirement for patient/parent/guardian consent to review the case notes is the same as for the congenital procedures review. In cases where it is unclear if this consent has been obtained during life, the Medical Director or CEO is asked for permission to undertake this review. The Validation Team are grateful to the MD of RHS for giving this permission.

It is noted that under the General Data Protection Regulation of May 2018, it is likely that the data of deceased patients may no longer require consent for case note review.

10 patients were identified to have died following cardiac procedures during 2017/18. 8 of these deaths are reported to have occurred within 30 days of either a surgical or interventional catheter procedure. These 8 case notes were made available for this review.

* All dates of death appear to be correct.
* There appears to be discrepancies on 2 comorbidity records

**Casenote Audit**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Parameter** | **Total Score** | **Total No** | **Comments** | **Scores for Cardiology & Surgery** | |
|  |  | | | | **C** | **S** |
| 1 | Hospital Number | 20 | 20 |  | 9 | 11 |
| 2 | NHS Number | 20 | 20 |  | 9 | 11 |
| 3 | Surname | 20 | 20 |  | 9 | 11 |
| 4 | First Name | 20 | 20 |  | 9 | 11 |
| 5 | Sex | 20 | 20 |  | 9 | 11 |
| 6 | DOB | 20 | 20 |  | 9 | 11 |
| 7 | Ethnicity | 20 | 20 |  | 9 | 11 |
| 8 | Patient Status | 20 | 20 |  | 9 | 11 |
| 9 | Postcode | 20 | 20 |  | 9 | 11 |
| 10 | Pre Procedure  Diagnosis | 26 | 26 |  | 10 | 16 |
| 11 | Previous Procedures | 27 | 27 |  | 11 | 16 |
| 12 | Patients Weight at  Operation | 26 | 26 |  | 10 | 16 |
| 13 | Height | 24 | 24 |  | 8 | 16 |
| 14 | Ante Natal Diagnosis | 2 | 2 |  | 1 | 1 |
| 15 | Pre Proc Seizures | 26 | 26 |  | 10 | 16 |
| 16 | Pre Proc NYHA | - | - |  | - | - |
| 17 | Pre Proc Smoker | - | - |  | - | - |
| 18 | Pre Proc Diabetes | - | - |  | - | - |
| 19 | Hx Pulmonary Dis | - | - |  | - | - |
| 20 | Pre Proc IHD | - | - |  | - | - |
| 21 | Comorbidity Present | 26 | 26 |  | 10 | 16 |
| 22 | Comorbid Conditions | 26 | 26 |  | 14 | 12 |
| 23 | Pre Proc Systemic Ventricular EF | 26 | 26 |  | 10 | 16 |
| 24 | Pre Proc Sub Pul Ventricular EF | 22 | 22 |  | 8 | 13 |
| 25 | Pre-proc valve/septal defect/ vessel size | 2 | 2 |  | 2 | - |
| 26 | Consultant | 26 | 26 |  | 10 | 16 |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Parameter** | **Total Score** | **Total No** | **Comments** | **Scores for Cardiology & Surgery** | |
|  |  |  |  |  | **C** | **S** |
| 27 | Date of Procedure + Time Start | 26 | 26 |  | 10 | 16 |
| 28 | Proc Urgency | 26 | 26 |  | 10 | 16 |
| 29 | Unplanned Proc | 26 | 26 |  | 10 | 16 |
| 30 | Single Operator | 7 | 7 |  | 7 | - |
| 31 | Operator 1 | 26 | 26 |  | 10 | 16 |
| 32 | Operator 1 Grade | 26 | 26 |  | 10 | 16 |
| 33 | Operator 2 | 19 | 19 |  | 3 | 16 |
| 34 | Operator 2 Grade | 19 | 19 |  | 3 | 16 |
| 35 | Procedure Type | 26 | 26 |  | 10 | 16 |
| 36 | Sternotomy Sequence | 13 | 13 |  | - | 13 |
| 37 | Operation Performed | 26 | 26 |  | 10 | 16 |
| 38 | Sizing balloon used for septal defect | 1 | 1 |  | 1 | - |
| 39 | No of stents or coils | 2 | 2 |  | 2 | - |
| 40 | Device Manufacturer | 7 | 7 |  | 2 | 5 |
| 41 | Device Model | 8 | 8 |  | 2 | 6 |
| 42 | Device Ser No | 9 | 9 |  | 2 | 7 |
| 43 | Device Size | 7 | 7 |  | 2 | 5 |
| 44 | Total Bypass Time | 12 | 12 |  | - | 12 |
| 45 | XClamp Time, | 10 | 10 |  | - | 10 |
| 46 | Total Arrest | 1 | 1 |  | - | 1 |
| 47 | Cath Proc Time, | 10 | 10 |  | 10 | - |
| 48 | Cath Fluro Time, | 10 | 10 |  | 10 | - |
| 49 | Cath Fluro Dose, | 10 | 10 |  | 10 | - |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Parameter** | **Total Score** | **Total No** | **Comments** | **Scores for Cardiology & Surgery** | |
|  |  |  |  |  | **C** | **S** |
| 50 | Duration of Post Op Intubation | 5 | 7 | 2 incorrect | - | 5/7 |
| 51 | Post Procedure Seizures | 26 | 26 |  | 10 | 16 |
| 52 | Post Proc Complications | 6 | 6 |  | 0 | 6 |
| 53 | Date of Discharge | 26 | 26 |  | 10 | 16 |
| 54 | Date of Death | 1 | 1 |  | - | 1 |
| 55 | Attribution of Death | 1 | 1 |  | - | 1 |
| 56 | Status at Discharge | 26 | 26 |  | 10 | 16 |
| 57 | Discharge Destination | 26 | 26 |  | 10 | 16 |

Data Quality Indicator Assessment:

The Overall Trust DQI = 99.5% Cardiology DQI = 100% Surgery DQI = 99.5%

This DQI is based upon the domain scoring below. The methodology for this DQI is provided in the paper The CCAD Audit – An Introduction to the Process.

|  |  |  |
| --- | --- | --- |
| **DOMAIN** | **DOMAIN**  **Score** | |
| **Demographics**  Hospital Number, NHS Number, Surname, First Name, DOB, Sex, Ethnicity, Postcode, Patient Status, | **Overall 1.0**. | |
| **Card**  1.0. | **Surg**  1.0 |
| **Pre Procedure**  Pre procedure Diagnosis, Selected Previous Procedures, Patient Weight at Operation, Consultant, Antenatal Diagnosis, Pre Procedure Seizures, Comorbid Conditions,  Height, Pre Procedure NYHA, Pre Procedure Smoker, Pre Procedure Diabetes, Previous Pulmonary Disease, Pre Procedure Ischaemic Heart Disease, Comorbidity Present, Pre Procedure Systemic Ventricular Ejection Fraction, Pre Procedure Sub Pulmonary Ejection Fraction, Pre Procedure valve/septal defect/vessel size,  Note, the scores for his domain are affected by the selected previous procedure and pre procedure diagnosis | **Overall 1.0** | |
| **Card**  1.0 | **Surg**  1.0 |
| **Procedure**  Date of procedure, Operator 1, Operator 2 Cardiopulmonary Bypass used, Operator 1 grade, Operator 2 grade, Operation performed, Sternotomy sequence, Bypass Time, CircArrest, XClamp Time, Cath Proc Time, Cath Fluro Time, Cath Fluro Dose,  Time Start, Procedure Urgency, Unplanned Procedure, Single Operator, Sizing Balloon Used, No of Stents/Coils, Device Mfr, Device Model, Device Ser No, Device Size, | **Overall** 1.0 | |
| **Card**  1.0 | **Surg**  1.0 |
| **Outcome**  Duration of Post Op Intubation, Post Procedure Seizures, Date of Discharge, Date of Death, Status at Discharge, Discharge Destination.  Post Procedure Complications. | **Overall** .98 | |
| **Card**  1.0 | **Surg**  .97 |

This DQI is based upon the domain scoring below. The methodology for this DQI is provided in the paper The NCHDA – An Introduction to the Process.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Domain** | **2018**  **17-18** | **2017**  **16-17** | **2016**  **15-16** | **2015**  **14-15** |
| **Demographics** | 1.0 | 1.0 | 1.0 | 1.0 |
| **Pre Procedure** | 1.0 | .99 | .99 | .98 |
| **Procedure** | 1.0 | .99 | .98 | .96 |
| **Outcome** | .98 | .99 | 1.0 | 1.0 |

**Conclusions**

On the whole the NCHDA data was accurate, well documented in the hospital electronic notes, and good quality.

The DQI score has again been maintained above 99% which is excellent and demonstrates that there continue to be robust methods and processes for clinical audit data quality maintenance and data collection at RHS. There were just 2 data errors or omissions in 906 variables.

The Reviewers would again like to commend the dedication and conscientiousness of the DBM who has worked very many extra hours to ensure that only good quality complete data were submitted for the year 2017/2018. There have been a number of technical challenges with the NCHDA database also during this data collection period, in particular the move to a web based system.

The bound operating theatre log books, as previously reported, are very well kept, being very neat and a concise record of activity. As previously reported, it was noted that on occasions the name of procedure performed appeared to be taken from the operating list for the day rather than completed at the end of the procedure with the precise description of the operation that had occurred. At times the descriptions of procedures in the cath labs appeared to be a little vague and imprecise.

**Validation of Deceased Patients Diagnostic and Procedure Coding**

The congenital data manager at RHS receives data on all cardiac deaths in Scotland on a quarterly report. This enables prompt identification of any out of hospital deaths that may have occurred.

There were two minor discrepancies identified in the data of the deceased patients case note review.

**Recommendations (as in 2014-17 and updated in 2018)**

1. If not already in place, it is recommended that Standard Operating Protocols are devised for the congenital data collection, to include detailed guidance on and exactly **who** is responsible for each of the following;
   1. Ensuring each patient/parent/guardian is given full appropriate information on informed consent for collection of, submission and external validation of NCHDA data in line with the GDPR. Information should include detail on how their data are securely recorded, stored, where this information is shared and who with. And op out explained to patients/carers.
   2. Input of the data for each diagnostic and therapeutic procedure at which point of the service delivery and it what time frame
   3. Ensuring the diagnosis reconciles with the procedure performed.
   4. Ensuring that radiation dosage is recorded in CG/cm2
   5. Validity checking, completeness and the time intervals for feedback to responsible clinicians on this with a clear time scale and line of responsibility for rectifying any omissions or errors in both surgery and cardiology disciplines
   6. Leading the local review (and how frequently and in which forum for both disciplines)
   7. Monthly running of PRAiS analysis and checking of congenital algorithm analysis
   8. Making timely submissions (monthly is recommended, quarterly is mandatory) and
   9. Timely reverse validation at RHS against an acknowledged ‘gold standard’ record of activity and procedures performed.
   10. Reviewing/Updating all of the SOPs at timely intervals
2. As previously recommended, consider developing a standard discharge summary style for use throughout the cardiac department. Such a document should logically list all NCHDA pertinent information to that in-patient episode and previous interventions or operations.
3. To continue to develop training not only for the Cardiac Information Managers, but all staff who may be involved with data management. This should involve visiting other centres who return data to NCHDA and sharing ideas and experience