**The National Congenital Heart Disease Audit Database**

**Data Quality Audit**

**for**

**Apr 2017 - Mar 2018**

**Royal Brompton & Harefield NHS Foundation Trust**

**12 and 13 June 2018**

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**Summary**

Prior to this validation visit, the data return to NCHDA from Royal Brompton & Harefield NHS Foundation Trust (RBH) for the data collection year 2017/18 indicated that some 1413 procedures (713 surgery, 429 catheterisations, 271 others, 17 deaths) had been undertaken in children and adults with congenital heart disease. These procedures take place at both Royal Brompton and Harefield Hospitals.

This validation visit was fully funded by the Royal Brompton & Harefield NHS Foundation Trust.

As reported at all previous visits, data were input to the Dendrite information system by consultant and junior medical staff. This system is ‘web enabled’ and is called INTELLECT. Computer terminals are available in a variety of different clinical locations including operating theatres and catheter laboratories and real time data input is expected. There is one single dedicated 1.0WTE Quality and Safety Lead post for Congenital Heart Disease on the RBH site. This post was vacant at the time of this validation visit.

The Reviewers again recognise that the Trust is well advanced in its move towards full electronic records and fully support and encourage this process, noting that systems must continue to be in place to ensure complete and accurate identification of patients for submission to NCHDA. RBH have moved from ‘paper lite’ to mostly being paper free at this visit in June 2018.

The Quality and Safety Team at the Trust had printed off the relevant documents from the ePR that held the data that was to be audited and highlighted many of these data items*.* Therefore, it was easy to find the majority of data required. Access to the ePR was also provided in case the Reviewers wished to scrutinise any other documents.

**Consent for External Validation of Notes.**

As previously reported, since February 2011, this centre has started to use a modified version of their generic patient registration form to include a clause to accommodate consent for external case note validation. This page had been printed for each of the records seen on the day. The Validation Team are again grateful to the Medical Director of the Trust for giving permission to review any case note that did not appear to have any consent for external review contained in it.

**Feedback on Actions Implemented following the last NCHDA Validation Visits in 2017**

* The current post of 1.0WTE dedicated congenital cardiac data and outcomes manager (vacated in early June 2018) is currently being recruited.
* SOPs / ‘data collection rules’ are available on the Quality & Safety shared folder but have not been updated recently.  These will be updated when the new data collection manger (as above) is in post.
* Junior Drs are being encouraged to volunteer to participate in external audit visits
* The Trust continues to submit data to the NCHDA every month two weeks in arrears

**Data Quality Indicator**

The DQI for the Trust is calculated to be **99%** (99.25, 99.25, 99,at previous visits). The Domain scores for this visit are; (with previous years in parentheses) Demographics 1.0 (1.0, 1.0, 1.0), Pre Procedure .99 (.99 .99 .995), Procedure .98 (.98, 99 1.0) and Outcome .99 (.99, .99 .98). This DQI demonstrates again a consistently high standard of data collection and validation within the Trust.

As well as the overall DQI for each centre, the DQI for surgery and catheters is being calculated. On review of the DQI when the cases were split into their surgery and catheter groups the scores are:

|  |  |  |  |
| --- | --- | --- | --- |
| **Year of visit** | **Data year being validated** | **Surgery** | **Therapeutic Catheter Interventions** |
| **2009** | 07/08 | 98.25% | 97% |
| **2010** | 08/09 | 98% | 96% |
| **2011** | 09/10 | 97.25% | 99.5% |
| **2012** | 10/11 | 97.75% | 98% |
| **2013(i)** | 11/12 | 99.75% | 98.25% |
| **2013(ii)** | 12/13 | 97.86% | 96.43% |
| **2014** | 13/14 | 99.25% | 96.25% |
| **2015** | 14/15 | 98.75% | 97.75% |
| **2016** | 15/16 | 99.5% | 98.75% |
| **2017** | 16/17 | 99.25% | 98.75% |
| **2018** | 17/18 | 98% | 99.25% |

The body of this report is drawn from answers given on the NICOR pre-visit Questionnaire (PVQ).

**Introduction**

Prior to this validation visit, the data return to NCHDA from Royal Brompton & Harefield NHS Foundation Trust for the data collection year 2017/18 indicated that some 1412 procedures (713 surgery, 428 catheterisations, 271 others, 17 deaths) had been undertaken in children and adults with congenital heart disease, of which 20 cases were randomly selected for the case note review. These procedures take place at both Royal Brompton and Harefield Hospitals

The NICOR Data Auditor and one external consultant in adult congenital heart disease undertook the site audit.

20 sets of notes were requested (the Sample). A list of 10 records (the Reserves) was also supplied in case any of the Sample were unavailable. On the day of the validation no Sample case notes were required.The accuracy of the NCHDA data return was then checked against each set of notes in order to calculate the Data Quality Indicator (DQI).

**Review of notes**

Of the 20 patient’s case notes that were reviewed, there were a total of 23 procedures (18 catheters, 5 operations).

1. As previously, the notes were very tidy print outs from the ePR, and meticulously prepared for the visit
2. The NHS Number was present in all notes and is included on the patients’ identity label.
3. Perfusion records were seen in all the case notes of bypass patients
4. Of the surgical case notes reviewed, it was noted that all had a typed surgical summary. This is a commendable practice and tremendously aided the data review.

**Theatre & Catheter Lab Records and Review of the Catheter Laboratory Log Books**

As previously reported ICIP is the electronic theatre management system in place at both Royal Brompton & Harefield Hospitals. Extracts were made available from both sites.

1. There were 2 queries raised from the surgery records submitted to NCHDA
2. There were 10 queries raised from the cath lab records
3. 1 submitted surgical record appears to have an error in it
4. 1 surgical record was identified that should be removed
5. 31 surgical records were not validated in the electronic surgical activity log that was provided

Across both sites, the radiologists use a customised electronic data collection tool (Radiology Information System or RIS) in the catheterisation laboratories. This has been adapted for the collection of all catheter intervention and diagnostic data, rather than just for radiology. Infoflex is a database that is used in the cath labs to collect information on electrophysiology activity and PACEnet is a data base used in the cath labs to collect information on all pacing procedures. COGNOS is the software used to extract data and run reports. The only congenital catheter interventions taking place at Harefield site are some closures of PFOs in adults. This activity is easily picked up from the COGNOS reports.

On the day however, it was not clear exactly where the electronic activity data offered for this part of the review originated. Therefore it is possible that there is incomplete case ascertainment.

1. 2  submitted catheter records appeared to have errors in them
2. 28 submitted catheter records were not validated in the electronic records provided.
3. As noted previously, the descriptions of procedures in the cath lab activity record did not always accurately portray exactly what had actually taken place or whether the patient had a diagnosis of congenital heart disease.
4. When reviewing the pacing activity records it was sometimes quite difficult to know whether or not a patient having a procedure had congenital heart disease or not.

As noted previously it is of great assistance when reviewing these documents if a single consistent approach to identifying NCHDA procedures within log books (electronic or hand written) that can be used across both hospital sites.

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

Commencing with the validation of the 2013/14 data, the National Congenital Heart Disease Audit wish to verify any dates of death of deceased patients notified to them from the hospital under 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 is asked for permission to undertake this review. The Validation Team are grateful to the MD of the Royal Brompton and Harefield NHS Foundation Trust for giving this permission. 17 post procedural deaths were submitted in the data for the year 2017/18.

All data on the deceased patients was readily available and concise. All patients were discussed in the local mortality meetings and a summary of the findings were available for review. All of the cases were very complex and were investigated fully at local level. A further example of very good clinical and audit practice at the Royal Brompton & Harefield NHS Foundation Trust.

1. All dates of death were correct.
2. The preoperative weights for these procedures did not appear to be easily or readily available in the ePR.
3. 1 preoperative weight could not be validated

The Pre Visit Questionnaire was completed and returned prior to the validation visit and confirms that there are appropriate measures in place in respect of;

Security and Confidentiality (Data Management)

Coverage (Data Management)

Quality Assurance of Data (internally and externally)

Training for Data collection, handling and Information Governance

Communications

Accountability

Health Records Management

Timeliness

Completeness and Validity

Accuracy

**Case Note Audit**:

Patient’s notes were audited covering 18 catheter interventions and 5 operations.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Parameter** | **Total Score** | **Total No** | **Comments** | **Scores for Cardiology & Surgery** | |
|  |  | | | | **C** | **S** |
| 1 | Hospital Number | 20 | 20 |  | 16 | 4 |
| 2 | NHS Number | 20 | 20 |  | 16 | 4 |
| 3 | Surname | 20 | 20 |  | 16 | 4 |
| 4 | First Name | 20 | 20 |  | 16 | 4 |
| 5 | Sex | 20 | 20 |  | 16 | 4 |
| 6 | DOB | 20 | 20 |  | 16 | 4 |
| 7 | Ethnicity | 20 | 20 |  | 16 | 4 |
| 8 | Patient Status | 20 | 20 |  | 16 | 4 |
| 9 | Postcode | 20 | 20 |  | 16 | 4 |
| 10 | Pre Procedure  Diagnosis | 23 | 23 |  | 18 | 5 |
| 11 | Previous Procedures | 39 | 39 |  | 38 | 1 |
| 12 | Patients Weight at  Operation | 22 | 23 | 1 incorrect | 17/18 | 5 |
| 13 | Height | 23 | 23 |  | 18 | 5 |
| 14 | Ante Natal Diagnosis | 1 | 1 |  | 1 | - |
| 15 | Pre Proc Seizures | 23 | 23 |  | 18 | 5 |
| 16 | Pre Proc NYHA | 10 | 10 |  | 8 | 2 |
| 17 | Pre Proc Smoker | 9 | 10 | 1 incorrect | 8 | ½ |
| 18 | Pre Proc Diabetes | 10 | 10 |  | 8 | 2 |
| 19 | Hx Pulmonary Dis | 10 | 10 |  | 8 | 2 |
| 20 | Pre Proc IHD | 9 | 10 | 1 incorrect | 8 | ½ |
| 21 | Comorbidity Present | 7 | 7 |  | 7 | - |
| 22 | Comorbid Conditions | 15 | 15 |  | 12 | 3 |
| 23 | Pre Proc Systemic Ventricular EF | 23 | 23 |  | 18 | 5 |
| 24 | Pre Proc Sub Pul Ventricular EF | 23 | 23 |  | 18 | 5 |
| 25 | Pre-proc valve/septal defect/ vessel size | 7 | 7 |  | 7 | - |
| 26 | Consultant | 23 | 23 |  | 18 | 5 |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Parameter** | **Total Score** | **Total No** | **Comments** | **Scores for Cardiology & Surgery** | |
|  |  |  |  |  | **C** | **S** |
| 27 | Date of Procedure + Time Start | 23 | 23 |  | 18 | 5 |
| 28 | Proc Urgency | 23 | 23 |  | 18 | 5 |
| 29 | Unplanned Proc | 0 | 0 |  | 0 | 0 |
| 30 | Single Operator | 4 | 4 |  | 4 | - |
| 31 | Operator 1 | 23 | 23 |  | 18 | 5 |
| 32 | Operator 1 Grade | 23 | 23 |  | 18 | 5 |
| 33 | Operator 2 | 18 | 18 |  | 13 | 5 |
| 34 | Operator 2 Grade | 18 | 18 |  | 13 | 5 |
| 35 | Procedure Type | 23 | 23 |  | 18 | 5 |
| 36 | Sternotomy Sequence | 5 | 5 |  | - | 5 |
| 37 | Operation Performed | 23 | 23 |  | 18 | 5 |
| 38 | Sizing balloon used for septal defect | 4 | 4 |  | 4 | - |
| 39 | No of stents or coils | 11 | 11 |  | 11 | - |
| 40 | Device Manufacturer | 14 | 14 |  | 13 | 1 |
| 41 | Device Model | 16 | 16 |  | 15 | 1 |
| 42 | Device Ser No | 16 | 16 |  | 15 | 1 |
| 43 | Device Size | 11 | 11 |  | 10 | 1 |
| 44 | Total Bypass Time | 5 | 5 |  | - | 5 |
| 45 | XClamp Time, | 5 | 5 |  | - | 5 |
| 46 | Total Arrest | 0 | 0 |  | - | 0 |
| 47 | Cath Proc Time, | 13 | 18 | 5 incorrect | 13/18 | - |
| 48 | Cath Fluro Time, | 18 | 18 |  | 18 | - |
| 49 | Cath Fluro Dose, | 18 | 18 |  | 18 | - |

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Parameter** | **Total Score** | **Total No** | **Comments** | **Scores for Cardiology & Surgery** | |
|  |  |  |  |  | **C** | **S** |
| 50 | Duration of Post Op Intubation | 3 | 4 |  | - | 3/4 |
| 51 | Post Procedure Seizures | 23 | 23 |  | 18 | 5 |
| 52 | Post Proc Complications | 2 | 2 |  | - | 2 |
| 53 | Date of Discharge | 23 | 23 |  | 18 | 5 |
| 54 | Date of Death | - | - |  | - | - |
| 55 | Attribution of Death | - | - |  | - | - |
| 56 | Status at Discharge | 23 | 23 |  | 18 | 5 |
| 57 | Discharge Destination | 23 | 23 |  | 18 | 5 |

Data Quality Indicator Assessment:

The Overall Trust DQI =99% Cardiology DQI =99.25% Surgery DQI = 98%

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 .99** | |
| **Card**  .996 | **Surg**  .96 |
| **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** .98 | |
| **Card**  .98 | **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** .99 | |
| **Card**  1.0 | **Surg**  .96 |

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

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **DOMAIN** | **2018**  **June**  **17/18** | **2017**  **May**  **16/17** | **2016**  **Oct**  **15/16** | **2015**  **Oct**  **14/15** |
| **Demographics** | 1.0 | 1.0 | 1.0 | 1.0 |
| **Pre Procedure** | .99 | .99 | .99 | .955 |
| **Procedure** | .98 | .98 | .99 | 1.0 |
| **Outcome** | .99 | .99 | .99 | .98 |

**Conclusions**

There were considerable technical challenges during the data collection year of 2017/18. The final dataset was not released until 10 March 2018 and the web enabled database to which these data were to be submitted was also not available until that date. The Validation Team would like to commend the Quality and Safety Team not only for the attention to detail in the preparation of the case notes, which greatly enhanced this part of the Review, but for managing singlehandedly the timely data collection, quality management and then submission of these data for the largest Congenital NHS Centre in the UK. It is also recognised that a large number of extra hours had been invested by the previous Quality and Safety Lead to ensure that the data that were submitted were complete and accurate prior to submission to NCHDA.

On the whole the NCHDA data were very well documented, high quality and were appropriately recorded in the electronic printouts seen at this validation visit. However, as mentioned in previous validation reports, the precise descriptions of the procedures performed and whether or not it was for congenital heart disease were often not recorded but this is improving slowly year on year. The overall quality of the electronic notes and data submission is to be commended. The PICU discharge summaries and the inpatient discharge letters were of great help during the Review.

The availability of electronic theatre and catheter lab registries is very useful and expedites the time needed to perform this task. The Reviewers were informed that NCHDA patients are flagged within the system and would recommend that robust procedures are in place to check the reliability of this flagging system as the Trust moves forward with electronic records. However, as stated above it was often not clear to the Reviewers whether or not a procedure was being performed for congenital heart disease.

The Reviewers are delighted to report that RBH, as one of the largest congenital centres in the UK that has maintained an excellent standard of data quality >5 years, and there is a 1.0WTE member of staff to support this data collection alongside the role of Data Quality Lead for Congenital heart disease. The high standards of data quality may well be compromised without at least 2.0 WTE to support not only the NCHDA, but also the various related NHSE monthly and quarterly activity analyses and ‘dashboard’ requests.

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

Just 1 query was raised with these data and all of the dates of death were found to be correct.

**Recommendations (as in 2017)**

1. To continue to strive to meet the New Congenital Heart Disease Review (NHSE July 2015) recommendation B32(L1) that each Specialist Surgical Centre must have a minimum of 1.0 WTE dedicated paediatric cardiac surgery/cardiology data collection manager, with at least 1.0 WTE assistant, responsible for audit and database submissions in accordance with necessary timescales. This is further underpinned by The Report of the Independent Review of Childrens Cardiac Services in Bristol (June 2016 Grey, Kennedy 1.22(2) and Ch17) These should fulfil dedicated roles to meet the growing demands of the NCHDA data collection and NHSE with no other ‘add on’ parts.
2. It is recommended that the Standard Operating Protocols for this data collection are regularly reviewed to ensure ongoing consistently good data standards. .
3. It is recommended to maintain the scheduled monthly submissions to NCHDA. More frequent submissions are welcomed but are not mandatory.
4. It is recommended that all staff involved with managing and collecting NCHDA data undertake an annual visit to another congenital centre to observe the validation processes and practices and share experiences with colleagues.