The National Congenital Heart Disease Audit

Procedures for CONGENITAL HEART DISEASE

Data Quality Audit for April 2019 to March 2020

Birmingham Children's Hospital NHS Foundation Trust

2 September 2020

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Summary

Prior to this validation visit the Congenital NICOR data return from the Birmingham Children's Hospital NHS Foundation Trust (BCH) indicated that some 984 (surgery 444, catheter 503, others 37, [deaths 13 within 30 days]) procedures had been undertaken during the data collection year of 2019/2020 on children with congenital heart disease.

20 sets of case notes are randomly selected from the BCH submission (the Sample) with a further 10 randomly selected as reserves. 7 case notes were used from the reserve list to replace those unavailable in the sample. A combined total of 26 procedures were reviewed, 11 catheters and 15 operations.

The HeartSuite information system continues to be used at Birmingham Children's Hospital to collect and manage all congenital cardiac data.

This validation visit has been fully funded by the Birmingham Women's and Children's NHS Foundation NHS Trust. This visit was supported remotely by the NCHDA clinical audit nurse via a Zoom and MS Teams video conference facility and on site in person by Dr D Cullington, Consultant Congenital Cardiologist from Liverpool.

BCH Overview

There is an overall Cardiac Information Manager at BCH. At the time of this visit, this post was vacant the audit facilitator had been covering the position. There has been a 1.0WTE audit facilitator post for congenital heart disease at BCH since October 2010. There is a further 1.0WTE post within the cardiac information department that provides support for a number of audits and registries as well as NCHDA. The post of audit facilitator is currently vacant awaiting recruitment. BCH do however have a Research Nurse part time (18.5 hours per week) who assists in this Audit.

Actions taken since the 2019 Validation Visit

1. The Information Manager at BCH post has been reappointed following retirement of the previous occupant.
2. BCH have updated their SOPs for this data registries to support the change in post holder and role definitions.

Data Quality Indicator

The individual DQI score for BCH is **99%** (99, 99, 99.5,) The domain scores are; Demographics 1.0 (1.0, 1.0, .99), Pre Procedure .985 (.97, .99, .99), Procedure 1.0 (.997, .997, 1.0), and Outcome .97 (1.0, .98, 1.0).

This represents another excellent DQI score. Well done. There were just 7 discrepancies identified in 897 variables.

Separate DQI for Surgery and Catheters

Since the 2009 cycle of visits commenced, as well as the overall DQI for each centre, the DQI for surgery and catheters is being calculated. It is recommended that a minimum number of 5 procedures in either group are required for the differential DQI calculation.

DQI	Data Year Reviewed	Surgery	Catheters
2012	2010-11	94.5%	98.75%
2013	2011-12	95.75%	94.25%
2014(i)	2012-13	98%	98%
2014(ii)	2013-14	96.75%	97%
2015	2014-15	98.5%	98%
2016	2015-16	98.75%	96.75%
2017	2016-17	100%	99.5%
2018	2017-18	98.75%	99%
2019	2018-19	99.5%	98.5%
2020	2019-20	99%	99%

Congenital NICOR 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 is or are identified accountable person/people for NCHDA data quality and information validity
Data Submissions are Timely and Accurate.

Introduction

The NCHDA data return, prior to checking the theatre and catheter lab log books, indicated that the combined cardiac departments of the Birmingham Children's Hospital have undertaken some 984 (surgery 444, catheter 503, others 37, [deaths 13 within 30 days]) procedures in the data collection year of 2019/2020 on children with congenital heart disease.

The Information Manager in collaboration with colleagues completed the pre visit self assessment questionnaire at BCH.

20 sets of notes were requested at BCH, and 20 sets of mixed paper bound case notes and screen shots from a local digital ePR screen were made available on the day (7 were required from the Reserve List). 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.

The Congenital Data Auditor for the NCHDA undertook the visit remotely with an external Consultant Congenital Cardiology physically present at BCH.

Review of notes

1. The notes had again been meticulously prepared by the Congenital Audit Team
2. The relevant clinical records were highlighted in the case notes and therefore very easy to find
3. The NHS number was always easily available on the individual patients labels.
4. Documentation of ventricular function was sometimes difficult to find and it was noted that a variety of adjectives were sometimes used to describe the findings instead of approximate percentage of performance.

Review of Log Books for Operating Rooms and Cardiac Catheter

Paper log books have not been kept kept at BCH for over a decade and have been replaced by Operating Room Information System (ORMIS) in both the cath labs and operating theatres. A spreadsheet of all cases ordered by date for the period under review was provided on a screen for the visiting clinician to review.

The findings were:

1. The accuracy of descriptions of procedures in ORMIS do appear to be improving over past years.
2. 0 records were identified that may be suitable for inclusion in NCHDA

Validation of Dates of Death and Procedure Coding of Deceased Patients

This commenced with the validation of the 2014/15 data. The NCHDA 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.

BCH identify out of hospital deaths either from the local information system as its updated and/or from running regular queries on the NHSE Strategic Tracking System. For non NHS patients or patients from Scotland or N Ireland, the Information Team liaise with those colleagues as required.

13 deceased patients were identified in the data return for 2019-20 who had died within 30 days of their therapeutic procedure. The PRAiS sensitive fields were reviewed for each of the patients and the findings were:

- All dates of death were correct
- No data discrepancies were identified.

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		11	15
11	Previous Procedures	51	55	4 absent	21	31/34
12	Patients Weight at Operation	26	26		11	15
13	Height	26	26		11	15
14	Ante Natal Diagnosis	5	5		3	2
15	Pre Proc Seizures	26	26		11	15
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		11	15
22	Comorbid Conditions	18	18		7	11
23	Pre Proc Systemic Ventricular EF	26	26		11	15
24	Pre Proc Sub Pul Ventricular EF	19	19		10	9
25	Pre-proc valve/septal defect/ vessel size	-	-		-	-
26	Consultant	26	26		11	15

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
27	Date of Procedure + Time start	26	26		11	15
28	Proc Urgency	26	26		11	15
29	Unplanned Proc	-	-		-	-
30	Single Operator	-	-		-	-
31	Operator 1	26	26		11	15
32	Operator 1 Grade	26	26		11	15
33	Operator 2	26	26		11	15
34	Operator 2 Grade	26	26		11	15
35	Procedure Type	26	26		11	15
36	Sternotomy Sequence	14	14		-	14
37	Operation Performed	26	26		11	15
38	Sizing balloon used for septal defect	-	-		-	-
39	No of stents or coils	1	1		1	-
40	Device Manufacturer	8	8		4	4
41	Device Model	8	8		4	4
42	Device Ser No	8	8		4	4
43	Device Size	6	6		4	2
44	Total Bypass Time	13	13		-	13
45	XClamp Time,	12	12		-	12
46	Total Arrest	0	0		-	5
47	Cath Proc Time,	11	11		11	-
48	Cath Fluro Time,	11	11		11	-
49	Cath Fluro Dose,	11	11		11	-

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
50	Duration of Post Op Intubation	10	11	1 incorrect	-	10/11
51	Post Procedure Seizures	26	26		11	15
52	Post Proc Complications	3	3		2	1
53	Date of Discharge	24	26	2 incorrect	9/11	15
54	Date of Death	-	-		-	-
55	Attribution of Death	-	-		-	-
56	Status at Discharge	26	26		11	15
57	Discharge Destination	26	26		11	15

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Data Quality Indicator Assessment:

The Overall Trust DQI = 99% Cardiology DQI = 99% Surgery DQI = .99%

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 .985**	
	Card 1.0	**Surg** .975
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** .97	
	Card .96	**Surg** .99

DOMAIN.	Score 2020	Score 2019	Score 2018	Score 2017
Demographic	1.0	1.0	.99	1.0
Pre Procedure	.985	.97	.99	.96
Procedure	1.0	.997	1.0	.97
Outcome	.97	1.0	1.0	1.0

Conclusions

On the whole the NCHDA data were of very good quality. The Data Quality Indicator (DQI) has remained at 99% and this is another excellent score. This also further demonstrates that there are robust processes in place to ensure good quality data standards are maintained.

It is very clear that BCH NHS Trust consider the matter of collecting good quality, accurate and validated information about patient procedural activity to be of the highest importance and this has become embedded within the culture in the Cardiac Department. There were just 7 discrepancies in 897 variables. The Validation Team would particularly like to recognise the level of conscientiousness displayed by the Audit Facilitator who was covering the role of Cardiac Information Manager and colleagues in preparing the hospital notes and various printed sheets so meticulously. This is a very large task to perform in particular when there is no assistant data manager currently in post to assist.

It has been noted that subsequent to this visit that the Audit Facilitator has been appointed into the role of Cardiac Information Manager.

It is reported that clinicians input much of the NCHDA data to HeartSuite in the first instance. However it is not always clear that colleagues are always involved in reverse validating their own data.

As previously reported, the standard and accuracy of the information recorded in ORMIS for surgery appears to continue to improve since the 2014 visit, however it is still a little poor in places for the catheter procedures. It was a little difficult at times to clearly identify exactly what catheter procedure had actually been performed in some of the entries.

Within the review of the deceased patients data there were no discrepancies identified.

Recommendations

1. It is a recommended that in line with the New Congenital Heart Disease Review (NHSE July 2015) recommendation B32(L1) that there should be consideration given to ensuring that 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 are in post.
2. It is recommended that Standard Operating Protocols for the data collection, to include detailed guidance on and exactly who is responsible for each of the following be regularly reviewed to ensure they fit the correct purpose. IE;
    i. Ensuring each patient/parent/guardian is given appropriate information in relation to how their data are recorded, stored and who it is shared with in line with GDPR 2018.
    ii. Input of congenital patients NCHDA required dataset items and at which point of service delivery
    iii. Encouraging every responsible clinician or allied professional to input complete data for each operation, diagnostic or catheter intervention at the point of the service delivery from admission to discharge and to own their data.
    iv. Recording the knife to skin time for all surgical procedures where it can be validated (ie perfusion or anaesthetic record).
    v. Validity checking and 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
    vi. Reverse validation of the data submitted to NCHDA by responsible clinicians in conjunction with the Data/Audit Managers at least monthly.
    vii. Running the PRAiS (Paediatric Risk Analysis in Surgery) analysis tool monthly. This will inform the quarterly NHSE Dashboard reports.
    viii. Ensuring that dates of death are reported for any BCH patient who has previously had a record submitted to the NCHDA
    ix. Leading the local review (and how frequently and in which forum for both disciplines)
    x. Making timely submissions (monthly is recommended where possible) and
    xi. Including details of manufacturer, model and serial numbers of all implantable devices the procedure record for each patient.

3. In liaison with the person responsible for staff training and development in the Trust, regular training should be provided not only for the NCHDA Data Managers, but for all staff in the Department who may be involved with data input and validation. This should include regular Quality Assurance and Governance training and visits to other centres who are involved in NCHDA data collection and submission.
4. As previously recommended, to 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.

5. All trainees (ST6 and above) should be encouraged to volunteer to participate in a NCHDA site validation visit as an external colleague to gain insights to the importance of maintaining good standards in data collection and quality management.