



The National Congenital Heart Disease Audit

**Procedures for
CONGENITAL HEART DISEASE**

Data Quality Audit for April 2018 to March 2019

Birmingham Children's Hospital NHS Foundation Trust

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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 961 (surgery 373, catheter 404, others 55, [deaths 19 within 30 days]) procedures had been undertaken during the data collection year of 2018/2019 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, 12 catheters and 14 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 teleconference facility and on site in person by Dr Thomas Mukasa, Consultant Congenital Cardiologist from Leicester.

This is the very first validation of data that have been submitted to a new NICOR data platform development referred to as Qreg5.

BCH Overview

There is an overall Cardiac Information Manager at BCH. Since October 2010, there has been a 1.0WTE audit facilitator post for congenital heart disease. 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.

Actions taken since the 2018 Validation Visit

1. The Information Manager at BCH has continued to take an active role in the support some of the analyses programmes for these data.
2. BCH colleagues have played a leading role in the user testing of the Qreg5 data platform for NCHDA developed for NICOR audits
3. BCH routinely review their data collection and validation processes and are undertaking the development of a more streamlined data submission process that will make monthly data submissions possible – to be implemented once the final adjustments to Qreg5 are completed.

Consent for External Validation of Notes.



Since May 2018, the General Data Protection Regulation required that patients are made aware of how their data collected and used. As such, NCHDA now no longer requires a specific consent to examine hospital case notes. If a patient has expressed a wish not to allow their case notes to be examined but others not connected to their care, these wishes will be respected.

Data Quality Indicator

The individual DQI score for BCH is **99%** (99, 99.5, 97.75,) The domain scores are; Demographics 1.0 (1.0, .99, 1.0, Pre Procedure .97 (.99, .99, 96, 96), Procedure .997 (.997, 1.0, .97), and Outcome 1.0 (.98, 1.0, .98).

This represents another excellent DQI score. Well done. There were just 8 discrepancies identified in 920 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
2009	2007-08	98.5%	Sample too small
2010	2008-09	88.75%	92.75%
2011	2009-10	94%	98.25%
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%



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 cath lab log books, indicated that the combined cardiac departments of the Birmingham Children's Hospital have undertaken some 961 (surgery 373, catheter 404, others 55, [deaths 19 within 30 days]) procedures in the data collection year of 2018/2019 on children with congenital heart disease.

The Information Manager and Audit Facilitator, 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 paper bound case notes 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 casenotes 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 are no longer kept at BCH 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 descriptions of procedures in ORMIS do appear to be improving over past years in accuracy in regard to descriptions of procedures performed.
2. 7 submitted records appear to have either blank procedure performed fields or may have discrepant descriptions
3. 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.

19 deceased patients were identified in the data return for 2018-19 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:

- 2 records may have incorrect pre operative weights
- 2 records appear to have incomplete comorbidities
- All dates of death were correct

Casenote Audit

	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
1	Hospital Number	20	20		11	9
2	NHS Number	20	20		11	9
3	Surname	20	20		11	9
4	First Name	20	20		11	9
5	Sex	20	20		11	9
6	DOB	20	20		11	9
7	Ethnicity	20	20		11	9
8	Patient Status	20	20		11	9
9	Postcode	20	20		11	9
10	Pre Procedure Diagnosis	26	26		12	14
11	Previous Procedures	36	39	3 absent	22/25	14
12	Patients Weight at Operation	26	26		12	14
13	Height	24	25	1 incorrect	11	13/14
14	Ante Natal Diagnosis	5	5		3	2
15	Pre Proc Seizures	24	25	1 incorrect	12	1
16	Pre Proc NYHA	1	1		-	1
17	Pre Proc Smoker	1	1		-	1
18	Pre Proc Diabetes	1	1		-	1
19	Hx Pulmonary Dis	1	1		-	1
20	Pre Proc IHD	1	1		-	1
21	Comorbidity Present	25	26	1 incorrect	11/12	14
22	Comorbid Conditions	23	24	1 absent	5/6	17
23	Pre Proc Systemic Ventricular EF	11	11		8	3
24	Pre Proc Sub Pul Ventricular EF	15	15		7	8
25	Pre-proc valve/septal defect/ vessel size	8	8		8	-
26	Consultant	26	26		12	14



	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
27	Date of Procedure + Time start	26	26		12	14
28	Proc Urgency	26	26		12	14
29	Unplanned Proc	26	26		12	14
30	Single Operator	3	3		3	-
31	Operator 1	26	26		12	14
32	Operator 1 Grade	23	23		12	14
33	Operator 2	23	23		9	14
34	Operator 2 Grade	26	26		9	14
35	Procedure Type	25	26	1 incorrect	11/12	14
36	Sternotomy Sequence	12	12		-	12
37	Operation Performed	26	26		12	14
38	Sizing balloon used for septal defect	1	1		1	-
39	No of stents or coils	4	4		4	-
40	Device Manufacturer	11	11		9	2
41	Device Model	12	12		10	2
42	Device Ser No	12	12		10	2
43	Device Size	12	12		10	2
44	Total Bypass Time	14	14		-	14
45	XClamp Time,	13	13		-	13
46	Total Arrest	8	8		-	8
47	Cath Proc Time,	12	12		12	-
48	Cath Fluro Time,	12	12		12	-
49	Cath Fluro Dose,	12	12		12	-



	Parameter	Total Score	Total No	Comments	Scores for Cardiology & Surgery	
					C	S
50	Duration of Post Op Intubation	12	12		-	12
51	Post Procedure Seizures	26	26		14	12
52	Post Proc Complications	5	5		1	4
53	Date of Discharge	26	26		14	12
54	Date of Death	-	-		-	-
55	Attribution of Death	-	-		-	-
56	Status at Discharge	26	26		14	12
57	Discharge Destination	26	26		14	12



Data Quality Indicator Assessment:

The Overall Trust DQI = 99%

Cardiology DQI = 98.5%

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	
<u>Demographics</u> Hospital Number, NHS Number, Surname, First Name, DOB, Sex, Ethnicity, Postcode, Patient Status,	Overall 1.0	
	Card 1.0	Surg 1.0
<u>Pre Procedure</u> 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 .97	
	Card .95	Surg .98
<u>Procedure</u> 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 .997	
	Card .99	Surg 1.0
<u>Outcome</u> Duration of Post Op Intubation, Post Procedure Seizures, Date of Discharge, Date of Death, Status at Discharge, Discharge Destination. Post Procedure Complications.	Overall 1.0	
	Card 1.0	Surg 1.0



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

DOMAIN.	Score 2019	Score 2018	Score 2017	Score 2016
<u>Demographic</u>	1.0	.99	1.0	1.0
<u>Pre Procedure</u>	.97	.99	.96	.96
<u>Procedure</u>	.997	1.0	.97	1.0
<u>Outcome</u>	1.0	1.0	1.0	.98



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 8 discrepancies in 920 variables. The Validation Team would particularly like to recognise the level of conscientiousness displayed by the Congenital Audit Facilitators and their colleagues in preparing the hospital notes and various printed sheets so meticulously.

The Reviewers would also like to thank BCH for being the first centre to undergo their NCHDA validation using data submitted to the new Qreg5 data platform commissioned by NICOR. This proved to be a very good validation of the ease of use of this new system for this purpose and clearly identified several otherwise unrecognised technical problems. Technical errors were identified relating to the sequential coding for diagnoses, previous procedures and procedures performed. Other technical errors related to the recording of comorbidities and number of stents implanted. None of these technical issues have been allowed to impinge on the DQI score.

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 impossible to clearly identify exactly what catheter procedure had actually been performed in some of the entries and therefore to validate numbers and details of cardiac catheterisations performed in particular.

Within the review of the deceased patients data there were there were a very small number of queries as documented elsewhere in this report.

Recommendations

1. It is 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. If not already in place, it is recommended that Standard Operating Protocols are devised for the data collection, to include detailed guidance on and exactly who is responsible for each of the following;
 - 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 ACH 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 Auditors, but for all staff in the Department who may be involved with data input. 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, 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.